SWDTP Webinar- Analysing qualitative data with diverse co-researcher and advisory input

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1h 2m 46s

JC **Jonathan Chow** 0:03

Hello everybody. Thanks for your patience. Just starting a little bit later than expected, but hopefully we'll catch up. I mean, I hope the sun is nice where you are as well, certainly as in Bristol. But welcome to another session in our webinar series. This time, very excited to share kind of the journey of 1 quite big project. If you've been to some of our previous sessions, obviously you will.

separate projects from separate different researchers. This is not the case this time. But today we're looking at kind of analysing qualitative data where there is kind of diverse co-researcher advisory input. And so

Joining me today, we have Professor Maria Loade, Natalia Kika both from the University of Bath, and Dr. Nina Higson-Sweeney from University of Oxford. We don't have the chat turned on, but we do have the Q&A turned on. So throughout the session, I'd welcome

you to drop your questions in the Q&A box. We will visit all the questions at the end of the presentation, but feel free to just drop questions in throughout the session today. The captions are available, but just be mindful that they are automatically generated.

So without further ado, I am going to now pass over to Natalia to start us off. Over to you, Natalia.

NK **Natalia Kika** 1:45

Thank you, Jonathan. Thanks for having us and thank you everyone for joining us today. So as Jonathan mentioned, we will be talking about analysing qualitative data with diverse core researcher and advisor input and we'll be focusing particularly on participatory qualitative methods

and co-produced research with young people and also parental involvement. So I'm Natalia Kika, I'm a final year Phd researcher at the University of Bath and my Phd programme of work focuses on supporting parents of adolescents with depression and I'm developing A brief online intervention for parents to help them with that. And we have Professor Maria Loz. She is also based at the University of Bath and she

leads the LAMP research group. And her main mission has been to increase access to scalable mental health support for young people. And she is currently running two randomised controlled trials where we are evaluating single session interventions.
for young people in the UK. And we have Dr. Nina Hickson-Sweeney based at the University of Oxford. She is also involved with us at LAMP and at Bath in terms of the single session intervention work. But her main work at Oxford is currently focused on improving help seeking for ethnic minority adolescents with OCD.
So just in terms of a few housekeeping points, so we would really love to hear where you're from and if you have any past experience with participatory research, could also be anything to do with co-production or patient and public involvement. It would just be good to kind of get an idea of your backgrounds.
And as Jonathan said, if you have any questions throughout the session, please just leave them in the Q&A section and we'd love to discuss them with you after our talks.
So the plan for the session is, first of all, to give you a bit of an overview in terms of what participatory research is and the different kind of terms that relate to it. And then Maria will talk about the Can We Connect study, where we had significant participatory input from young people.
Then Nina will talk to us about participatory qualitative methods, specifically in terms of reflexive thematic analysis. And then finally, I will talk about the parental involvement that I have going on in my Phd research.
Oh, sorry everyone. Just give me one second.
Sorry, a bit of, oh, sorry, I will have to show a different set of slides.

JC **Jonathan Chow** 4:34
No worries, Natalia, take your time.

NK **Natalia Kika** 4:34
You.
Sorry, I think something's gone wrong with the live version.
Okay.
Here we are, apologies. So in terms of anything, you may have heard about co-production, you may have heard about PPIE, participatory research, and I think these terms kind of get used interchangeably and sometimes they even get conflated. And I do understand and there are quite a few different terms, but

I think the thing to keep in mind is that they all talk about the different extent to which we can involve the people for whom and about whom we are talking when we do any kind of research. So starting from co-production, this is probably one of the most common terms used in this context.
So this describes the collaborative process of involving researchers, patients, public, any kind of professionals that you might be involving throughout the research process. So all of these stakeholders coming together to bring their input to the table. Co-design, very similar, but usually relating to specific input. So for example, if you have something
like a mental health app or an online intervention or maybe participant facing leaflets and materials. So this is more about collaborating with diverse inputs to design specific research outputs. And then PPI and PPIE, so patient and public involvement, more so referring to the active involvement of patients and the public, so professionals as well, when, for example, designing a new mental health
service. And then in PPIE, the engagement part refers specifically to members of the public and specific patients group also engaging with the wider public. So perhaps sharing output such as blogs or speaking to the media or speaking at events to disseminate the research from their lived experience perspectives.
And then participatory research, which we will be focusing on today, specifically refers to involving the user group, so the population for whom we are trying to do the research and with whom we are doing the research, by having them step into the role of active contributors. So we are
training them and upskilling them in some of the research methods we are using so that they become co-researchers. So they have a very active role throughout each phase of the research process. And similarly to this, participatory action research, which combines participation and action, so also very interactive with
with members of the public as co-researchers. And then involvement, which is something I will be touching on, which is a more general, so more broad term where you are involving members of the public or a specific patient group, but it's more so in a kind of consultant or advisory capacity.
Okay, and I will now pass over to Mireia for the Can We Connect study.

ML **Maria Loades** 7:42
Thanks so much, Natalia.
Now let me see if I get the slide share right.

Okay.
So.
I'm going to briefly walk you through the Can We Connect study and relay the background to it and what we did to set the scene for what Nina will then tell you about in terms of what we did with the data analysis specifically.
Natalia mentioned that our group is the spotlight on adolescent and young adult mood problems group, or LAMP, here at Bath. And our mission generally is to enable all young people to thrive and live their best lives. And really, we aim to do that by improving access
to help for young people with low mood, trying to make help available with as few barriers as possible and as early as possible before something becomes too much of a problem.
I'm doing a quite large funded programme of work that Can We Connect is part of. That's funded by the NIHR and particularly through the Advanced Fellowship Scheme. And my programme of work has kind of three components. First of all, we wanted to
find out where young people look for information and support when they first start to struggle with their mood and with depression symptoms. We wanted to build messaging on a website and we also wanted to test online self-help single session interventions as a
potential scalable solution in this space.
So what Can We Connect is about is really the first three of these components, which is this is the programme of work we did to really find out more about where young people look for mental health support when they first start to struggle. Now, obviously, we already knew some things from prior research before we
conducted this programme of work, and particularly a researcher called Pretorius had done quite a lot of work looking at young people's help seeking for mental health online. They had found that there are various benefits young people to see to help provided online, like
but it's very accessible. They like that it's anonymous and they like that they have a high degree of control over it. But there are also barriers for them when they do seek help online, including that they lack trust in things they find on the internet, that there's a lack of confidentiality, particularly in more like forum or social media spaces. and that they might not recognise the problem they have and therefore not know what to search for or how to search for it.

They also formulate these three potential functions of online information and support for help seekers. So online can provide information about symptoms, can connect them with others like peers or professionals, but can also be an alternative to other sources of help seeking.
So in this context of knowing some already about this, we formulated the Can We Connect study? And what we specifically wanted to find out in Can We Connect was, well, where do young people, and specifically in the UK, look for information when they first start to experience symptoms of depression?
Where do they look for information via the internet and social media and how do they use different platforms for different purposes? And how do they search for information and what are their experiences of what they find?
So what we did was the Can We Connect study. This was semi-structured interviews. We recruited 13 to 18 years old, based in the UK, and we wanted to get as broad a sample as possible. So we didn't require people to necessarily have or declare experience of mental health.
problems. We advertised widely on social media particularly, and we recruited during the summer holidays in 2023 to try to catch young people when they had some time available. And we offered people a 20 pound gift voucher for doing an
online interview with us. In total, we did interview 24 young people and we used various prompts within our interviews, like for example, a small, what we call a case vignette or a little case study really of a young person who's experiencing depression symptoms.
If the young person we were interviewing didn't feel comfortable to disclose their own experience or indeed didn't have lived experience of mental health problems or help seeking, we gave them this concrete so that they could choose how much they brought of themselves in their own experience or how much they talked more in terms of what they thought this case
reference would do. We also embedded what we call think aloud techniques. So once we told them about Sally, who's a 15 year old who's starting to struggle with their mood, we said, we'd like you to show us how you think Sally would search the internet. So got them to screen share with us so that we could see what they were doing.
and then to think out loud about what they thought about what they found, encouraging them to click on things that took their interest and to let us know what they then thought about those resources. So I'm not going to go in detail into our

participants because I think that's of less interest today, but we did have quite a broad and diverse

Sample.

just a few of the prompts we showed young people and some of the things they found included kind of NHS sites and some of the prompts we would then use for things like what do you think about this information? How trustworthy is it? How relevant is it? So this was all from our topic guide. Another thing we showed young people and also several found themselves was

Your minds as an example of a charity provider in the UK. Again, similar prompts we use.

The key that I really want to tell you about is how we involve young people as co-researchers. So this is the participatory research component. So before we...

commenced interviews, but after we got ethical approval, we recruited a young research team. So we recruited 4 young people. They were all 16 to 18 year olds. We reached out through a partner organisation we worked with, Norfolk and Suffolk NHS Foundation Trust.

who have got a large group of people on their community mailing lists. And we offered this opportunity for people in our age range that we were looking for in our samples for 13 to 18 year olds to sign up to be co-researchers over the summer.

in our Can We Connect team. And we got 4 expressions of interest. We onboarded all of those and they all became our young co-researchers. So they were all in the same

age group as our population of interest. We offered them first training and involved them in data collection. Because we'd already got ethical approval, we involved them a bit less in actually conceiving the project, but we did tweak some of the topic guide and so forth.

based on their feedback whilst we were doing the training and getting them inducted to the processes. So they were then involved in all the interviews. So in every single one of the interviews, after our 1 1/2 hour training that we did with them, we

had interviews in pairs. So we always had a research team member together with a young co-researcher and do interviews. There was one interview that for scheduling purposes was done only by a research team member, but 23 of the 24 interviews were done with an interviewer pair. The interviewer pair would always have a pre-meet just to plan how they were going to do the interview. They would then

interview the young person together via teams. We had certain sections of the topic guide that we'd identified the young person pro-researcher would ask, certain that the research team member would ask.
But what was really lovely in the interviews is that in many of the interviews, actually, the young co-researchers were just naturally involved in like helping with the screen shares. Sometimes when we went wrong as the researchers, they were like helpful with problem solving around that. They were far more techie than we were. So it was just brilliant to have them.
And then after each interview finished, there would be a quick debrief between the interviewer pair. And then we had a final debrief meeting on the data collection process at the end of the summer as a research and young co-researcher team.
I think some of the things that really helped facilitate the young co-researchers involvement was working with this partner organisation who already had contacts in the community and some experience of doing this kind of work, and we learned a lot from them. And they set up with each of the young co-researchers honorary contracts, which
Kind of.
set out who was responsible for what, what we could expect from each other, and set out what we would give the young people as a remuneration for their time. And because I had the NIHR funding, within that, we'd been able to cost for vouchers for the young people. We couldn't pay them research assistant salaries, but we could give them vouchers for
and essentially thanking them for the time they spent. So per hour of input, they got a 10 pound voucher. We also loaned one of the young people a laptop where they didn't have access to that themselves to facilitate their involvement. So what we then did is involve them a lot in data analysis and Nina's going to tell you all about that in just a sec. I just wanted to finish off by telling you just a little bit about what we did subsequently. The following summer, we actually invited our young research team members to join us to write a bit of a commentary about our experiences of working together as
young co-researchers and a research team. And we got some additional funding from the public engagement office at the University of Bath, again, to have some research assistant support with that, but also to give our young co-researchers some more vouchers from that. And we've written that up.
as a paper which you can go and read if you're interested. And actually, that's where

this graphic comes from. But really what we did is just all shared together using a very...
a kind of simple, should I say, survey in Qualtrics, with a few semi-structured prompts and some free text boxes about what our experience had been of working together. And then the young co-researchers really analysed that with the research assistant support and wrote up a paper. And what we found was that
both from the young co-researchers perspective, but also from the research team's perspective. There have been huge value to the young people themselves of being co-researchers. They valued that they got connexions with professionals and people in the clinical psychology field, and they valued being really properly involved in work experience. They said other work experience they'd done
had been more like kind of hearing about what people do, but less about actually doing it alongside them. They also highlighted, as did we, the real value that their input brought to the research. Certainly having a young person co-researcher in the room really seemed to set the participants at ease, and I think we got richer data as a result.
but they also made incredibly articulate and insightful contributions to the process from beginning to end. We all agreed that really capitalising on differences is important. We don't all need to know everything, but actually young people understand some things like social media and what it's like to be a young person on social media far better than we do, so they could actually really speak to that in a way that we
Couldn't.
They really did highlight, and I think we thought this was really important too, of having really structured support. So having this process of pre-meets and debriefs, having flexibility and trust and really building a two-way relationship was key. And we also had to balance what we asked of them in terms of their involvement with their real lives. Look, there were people
who were going on holidays in the summer or working part time jobs, studying for exams, they were preparing for UCAS. So there was, you know, a realistic level of what we wanted from them and what they could provide. And we had to really think carefully about what it was fair to ask them to do.
And I think key take home for us was open, transparent and honest communication is key to building trust and enabling the people that are our participants to also be involved as members of our research teams. So on that note, I will stop and turn over

to Nina, who's going to tell you all about what we actually did in terms of involving young people in the data analysis process.

NH **Nina Higson-Sweeney** 22:16

Perfect. All right. So let me just get my slides up and I'm going to trust you all to say something if they end up not working.

Can we see everything perfectly? Maria, I want you to, I want you to nod if you can see it.

Oh, I think you're frozen. Oh, yeah, yeah, I can see. Perfect. Okay, let's get going. So perfect introductions from Natalia and Maria. As they've said, so my name is Nina. I currently work at the University of Oxford, but I did my Phd at the University of Bath. Maria is my primary supervisor, and I was funded by the SWDTP for my Phd. So it's really nice to be back and delivering.

this webinar. So Maria's kind of set the scene really nicely for the Can We Connect study? And I did this towards the end of my Phd. I was a research assistant, one of the research assistants on this project. But in my portion of this presentation, I'm going to talk a lot more about how we actually

undertook qualitative analysis with this group.

So my talk, I will go into what is reflexive thematic analysis, which is what we used for two of the papers that we published. I will talk about reflexive thematic analysis from a collaborative perspective, as I think it can be a bit controversial. I'll talk about some considerations.

for involving young co-researchers with qualitative analysis, what the process was through the different studies, what I feel the impact was, and then I'll reiterate some take-home messages that we spoke about in our commentary paper.

So I don't know how many of you know what reflexive thematic analysis is. I feel like nowadays it's a pretty popular method, so I won't drone on and on about it. But it is a qualitative method for systematically developing, analysing and interpreting patterns of meaning across a data set.

Originally referred to as thematic analysis, Brown and Clark, who I'm referring to in this, they wrote a 2006 paper which so many people have read. It was later refined to reflexive thematic analysis in 2018 to centre the reflexive researcher. And when I say reflexivity, this refers to the process of critically reflecting on

and interrogating what we do, how and why we do it, and the impacts and influences of this on our research. So, you know, traditionally, thematic analysis from Brown and

Clark's perspective, it's quite similar to reflexive thematic analysis, but I suppose it was confused with other
methods of thematic analysis. So for example, you have framework analysis that is a form of the thematic analysis. You have coding reliability thematic analysis. And so yeah, reflexive thematic analysis really distinguishes this approach and focuses on the researchers, the research team,
really, you know, using and thinking about their experiences, their values, their perspectives, everything like that, and how that, you know, goes into the development of the study, how it's done, the knowledge that is generated and produced, and how everything is shared and disseminated. And I think it's a really interesting method to use when you have
a group like we did for Can We Connect, where you've got, you know, mid-senior professionals, academics, you've got clinical researchers, you had young co-researchers, you had early career researchers. We're a really diverse bunch in some ways.
I think it's really interesting to engage in the process of reflexivity when we've got all these different outlooks and perspectives. And yeah, you know, reflexive thematic analysis as well is quite a theoretically flexible approach, and it's considered quite good for beginner qualitative researchers. Obviously, anyone can use it.
But in comparison to some other qualitative methods, I do feel like it is, yeah, a bit friendlier, a bit more intuitive. And when you're thinking of engaging young co-researchers who might never have done anything like this before, I think it is a consideration, you know, what approach is best for the data, but also how do we make sure we can evolve.
our population of interest and the people we want to work with and engage with.
So again, I might be preaching to the choir. So reflective thematic analysis from Brown and Clark's perspective has six phases. So you start with familiarization, so familiarising yourself with the data that you've got after reading, rereading, making some brief notes. You then go into coding,
where you often do line by line. So you read this transcript and you code interesting segments of the data that really address the research questions that you have in mind. And then, yeah, you do that for a lot of your data set. You then want to go into generating initial themes once you've coded the data set. And this is where you start to kind of compile codes into different clusters around these core ideas and these core concepts relevant to your research question, eventually kind of putting them

together into these candidate initial themes, but there's still plenty of movement. And then you go into the fourth stage where you start to really develop these initial themes. You're still quite flexible. You cheque if the themes work in relation to the quotes, the coded extracts you've got, but also the entire data set, always keeping your research questions in mind and really thinking, okay, what story is this telling? you know, do I need to change things? Do some themes need to expand or be moved or subsumed or anything like that? You then go into the fifth stage where you refine, define and naming themes. So again, ongoing analysis to make sure the themes really reflect

Your research questions, they answer them, they are true, say true to the data set that you've got, they're reflective of it. And really thinking about the overall story your analysis is telling, making sure you've got clear definitions and names that clearly say what they're about. And then you have the writing up stage.

where you do what it says on the tin. You write up the analysis, you select the extracts, the quotes you've got to really illustrate the analytic points you're making, and obviously refer it back to the research questions and things like that. And a really great thing about reflexive thematic analysis is that

These are suggested phases, you know, but actually how you do them, there is wiggle room, there is room for movement. This is just providing a guide and then you really take it on. And often these steps can mingle together. You know, I often find myself

going back and forth in writing up, you know, sometimes I'm still refining themes. I think I'm writing it, I'm thinking, is this actually answering my research question? Is it actually what I thought it would be? Do I need to move it still? And that's part of the beauty of this approach is quite forgiving as well.

Now, I've seen different responses to this. Are you allowed to do reflexive thematic analysis as a team? And I don't know if it was a review comment or something that I once saw. And someone was like, well, you can't, you can't do that. Brown Clark say you can't do that. I don't think that's true at all. I think it is absolutely possible to do reflexive thematic analysis as a team.

because it is flexible, you know, I think in some ways doing it by yourself is a more straightforward way to do it. You follow those phases and it's kind of presented in a way for one person, but it's absolutely possible to do it as a team. I do think that means negotiating and thinking about how

you do these different steps pragmatically. And the great thing about reflective

thematic analysis is that it's grounded in the idea that themes are actively generated by the researchers. They're not objectives, truths. So you give them to different researchers. People will identify different things. There might be similarities if you you know, got quite a rigorous study design, you'd hope there would be some similarities. But people pick up on different things and that's absolutely fine as well. And so when you have more researchers in flex of thematic analysis, that means there are more interpretations, there are more perspectives, experiences, ideas,
And that is not a bad thing that can really get more richness out of the data. And it's really important to remember, so in comparison to some other thematic analysis approaches, we're not aiming in RTA for consensus. We're not considering inter-rater reliability like, oh, out of these codes,
we had 80% agreement, things like that. And you're not looking to resolve disagreements because, you know, all of these different perspectives are valid. They're embedded in the research team. And so again, I think this is part of why this approach is quite nice and friendly for collaboration, for, you know, co-production, co-design, engagement, because it is really
flexible, but if you are doing it as a team, you need to be really transparent in reporting how you've done that. And I think that's something we were thinking about throughout. You have to be really clear on how you may be adapted for flexive thematic analysis to fit your team at the different stages and things like that. So
I would say I think it's really open, but make sure you were really transparent about what you actually did.
So, when you are considering specifically involving young co-research in reflexive thematic analysis, although I would say this is
relevant for a range of different groups. There are many different considerations, but here are some that I think are really worth considering. So I think involving Yonco researchers or, you know, the general public in this kind of thing, this analysis, you've got to think about training and knowledge.
You've got to think about that up front. You've got to, you know, I don't think you can kind of stumble into this and think, oh, okay, yeah, I need to do this. I think you need to have a plan for what kind of training you're going to provide, what depth it will be. So in advance, you do need to know how much you want to involve them to a degree. I think it's really important to consider scaffolding.
You know, how can you build on the training and knowledge in a way that's not overwhelming, that really supports the younger researchers or whoever you're

involving? But you do need to plan that out in advance. It can't be a last minute consideration. I think you've got to think about power in epistemic authority and epistemic justice. So, you know, even though you want to do something collaboratively, you know, you view young co-researchers as actively involved in this process as, you know, experts on their lived experience. There is still a power dynamic there with you as the researcher. So if you're having team meetings and you've all done this coding, you know, whose interpretations are prioritised?
Do the co-researchers feel comfortable genuinely challenging you and how do you facilitate that? You know, what even counts as a theme and all these different things. So again, you've got to really reflect on that. And I think it's worthwhile reflecting on that with the people you are involving. And also practicalities and accessibility.
You know, for us, we really had to think about school, about college, about people going to university by the end of the project. Think about session length, pacing, flexibility, payment and recognition. You know, I think payment is so important, but we've also got to fit it around the grants that we do have, what universities will allow you to pay people, because not everyone, not every web will allow you to
you know, put money in someone's bank balance, you know, it might be vouchers, it might be things like that. And also you've got to think about accessibility of language and materials. So those are just a few things to keep in mind.
So now I don't want to take up too much time, but I'm going to quickly go through the three papers we did and just think about the different levels of involvement. Because I think Can We Connect is a really nice example of it's not necessarily perfect, but it's a really good go at. And I think as we went through the different papers,
We learnt more and more and I think we improved what we were doing and I certainly learnt a lot since I did this study. So for this first paper of what we did, we involved after some initial training on how to code, the young researchers all familiarised themselves and coded one segment of a transcript.
script that we thought was quite rich. And then these coded transcripts were incorporated into the initial theme generation, which was done by some members of the research team, myself included. And then we met as a group to discuss our progress and share our thoughts. So before the meeting, the young co-researchers were asked to kind of, okay, in preparation for meeting, think back to the interviews you conducted because they were there and think about things that have really stood out to you in that time, patterns they remembered. And that was really

interesting because when we discussed it in the meeting, it was highlighting portions of the interviews that were most salient for them.
which were not necessarily the same as what the clinical researchers who had been with them had focused on, or we, as we were coding, were focusing on. So it was really nice to consider those different perspectives. We, in this meeting, presented 3 themes that we were a bit more confident on and one theme that we weren't so confident on and asked for, you know,
genuine, honest feedback, there was still a lot of room for movement with this. And so the co-researchers provided feedback, shared their thoughts, talked about areas they thought that we weren't focusing on enough. So for example, you know, they were really keen and really interested in how our participants have spoken about social media and we weren't necessarily emphasising that enough. So
in the end, in the final write up, we do have a sub theme that is focused on social media and I think it provides a really important piece of the paper. But as a research team, without their input, would we have focused on that so much? I'm not sure. So again, we're all generating this knowledge together.
And then another example, we initially had a theme that was called mismatch between what young people want and what they find. And one of the young co-researchers was really discussing how we needed to have the word hope in it, because that's what really came across to them in their interviews. There was this hope for what they would find online. And they felt like that was really reflective. So the final theme name
is mismatch between hopes and reality. So we really did incorporate their feedback and work with them to think, okay, based on your experience of doing this, what makes sense to you? How, you know, how can we integrate all our different perspectives? So we integrated their thoughts into the themes, continued to refine them, we drafted the initial manuscript,
and then the young researchers provided written feedback to us and edited the manuscript to contribute.
We then had a second study that was looking at a slightly different portion of the interview and we went a little a step further with this one and directly involved one of the co-researchers more thoroughly in the analysis. So we had two teams of two, we all familiarised ourselves with the transcripts.
And then we started double coding. So with these two teams of two, it meant that every transcript was double coded. And by double coding, we weren't trying to reach

consensus. We were just really interested in getting different perspectives, eyes on this data. And then we met to consider, okay, like, what did you think here? What did I think here? What did we spot?
why did we spot these things, which was a really nice part of the flexive process. And then one of the researchers went away, looked at the codes, you know, and created a final list of codes for us, ones where we were basically getting at the same point or ones where we weren't getting at the same point. We picked up on completely different things, you know,
everything was valid, nothing was removed, there was no of that, none of that, you know, trying to reach this consensus. And then we ended up with a single list of codes. We then did initial theme generation and started to do refinement with the wider team.
And then the paper was written with the research team and again, co-researchers provided further feedback.
And Maria has already talked about this last study, which was the commentary, but again, the young co-researchers were even further involved with this, writing with us. You know, we had practically, we used a Google Doc and we had meetings, we discussed what we wanted to do with the paper and we would all actively
input in our own time to this Google Doc, we would comment on each other's, like what we'd written, thinking, okay, maybe you could add something in here. We would actively edit each other's work and we'd meet to discuss it. So that was a very, it was, you know, we didn't necessarily have, hadn't done this level of collaboration before, but it was a really interesting challenge. And
We were just honest with the young co-researchers and got them to, you know, tell us what is working for you, tell us if something isn't working for you, do we need to change stuff up? And that was a really, a really fun part of the project, to be honest. I don't want to go on too long, so I'm just going to wrap up quickly. I think the impact, we had increased richness, enhanced reflexivity,
upskilling for all and increased relevance of our findings. But there were areas for learning as well, and I think that's really important. You know, there are some good things, but there are also things we could have done better, like more role-playing of the interviews, more introduction earlier on to the analysis and maybe academia and co-production. So do you really think about,
you know, when you're involving people, what do they know? And actually, what of the broader context do we need to share with them to facilitate this? And then

finally, there are take home messages, but these are available in our commentary paper. So I am just going to leave it there and pass over to Natalia.

NK **Natalia Kika** 41:31

Thank you, Nina, just sharing my slides.

All right, there we go. So thanks everyone. As I said, I'm Natalia, I'm a final year Phd researcher and I'm supervised by Maria and Nina. And so just to give you a brief overview of what I would like to focus on,

So first of all, I'd like to tell you about what I did and how I led my parent advisory group and then going into some practical challenges, which hopefully will be useful to any other early career researchers. And I saw in the Q&A that we have quite a few Phd students. So I'm really hoping that some of this is helpful to you.

And then based on these challenges, how I perceived parental involvement versus participatory research. And finally, I'll share some of the top tips based on my learnings from this process. So because my research focuses on helping parents of young people in the UK, at the very start of my Phd, so literally in the first few months,

Maria encouraged me to form a parent advisory group. So we ended up with four to five initially UK parents of teens. And I think we managed to maintain a very consistent group, luckily, and we had maybe one or two join us along the way. But I'm very glad that throughout, you know, almost three years in,

throughout the PhD, I've had a consistent group of parent advisors. And I think for me, it was really important to involve them from the very beginning. So even though it was quite intimidating, you know, at the start of my PhD, I was still in that kind of planning stage, reading stage. So I didn't really have that much to offer. But actually, it was really good because I got to speak to my advisors about what my plans were. And

I still had a lot of room and space to implement their input. In terms of the format of how we sought parental input, I originally wanted it to mainly be, you know, really interactive, online meetings, kind of workshop style, but because of the practical constraints of a Phd, which I'll go into in a moment,

I also try to leverage e-mail input, written input, so sharing anything that they could read beforehand, sharing via e-mail, because that way you save a bit of time. And also using, as Nina mentioned, using Google Docs and getting their input that way. So in terms of what you can involve.

advisor with. It can be any stage of the research. So for example, I involved parents in the very early stages of things like study recruitment or study adverts. So sharing initial draughts of a study advert, asking them to send me their feedback or to share it in a meeting.
and then trying to implement that and refine the draft. Also got their input with a systematic review and meta-synthesis, which I'll talk about in a moment. And most recently, where I developed my intervention for parents, I shared several versions of the prototype with my parent advisors, and then we kind of
I iteratively refined it. I asked him about the kind of language that we were using. Is it relevant? Just kind of ensuring that it's appropriate and the tone makes sense to UK parents who are the target population of the intervention.
So, of course, especially if you're a Phd student right now or an early career researcher, you may be wondering how can I involve people as someone with limited time, with a limited budget. And, you know, in an ideal world, I would have loved to do participatory research, as Maria and Nina described, where I'm training parents to be
co-researchers. But the first hurdle to this was seeing that parents are a tricky population to reach because of how busy they are, because of their parenting duties, because they've got many things going on. And I think this is the case, as Maria and Nina mentioned, even if you're working with young people, they have school obligations.
any other adult population you're working with, they will probably be extremely busy. So realistically, that was the first challenge. So trying to keep them engaged and trying to, you know, be really fair with what I was kind of asking of them. So we went with this advisory kind of consultant approach of involvement.
Budget, of course, is a main concern for Phd students. So I am lucky to be funded by the university for my Phd. So I did have some budget and I used this to share vouchers with parents. And this was really, really important. And, you know, for me, I didn't want to compromise on this. So I would rather have gotten
less input on something, but made sure that I compensated them properly with vouchers than the other way around. Of course, timelines, you know, you've got Phd deadlines, you've got very strict kind of allocated amounts of time per study. So, you know, I didn't have infinite time, so I had to keep that in mind.
meeting attendance because of the population I was working with. So it would be quite tricky to get everyone to join the same meeting. So sometimes that meant

opting for written input for maybe one or two parents who just couldn't find the time to attend the meeting, or sometimes splitting a meeting. So instead of having one bigger one having two different time slots. And as I said, kind of switching up the input format and offering them different options. So, you know, asking them, and you can ask them anything at any point. You can literally ask them what kind of time slots work better for you. What kind of format would you prefer? Are you feeling up to?

up for a call right now or would you prefer a document? So giving them as many options as you can.

And as I mentioned, because of these challenges, and I knew from the start that I would only be drawing on the participatory research approach, but it would essentially be involvement, which is more broad and general, as I mentioned at the start of the session. And this was mainly because of Phd related constraints with time and budget. The time and budget that

are required to upskill the parents because, you know, that would have required a lot of training and explaining thoroughly what the research methods were that we were using. And although it doesn't have to be perfect, as you mentioned, Nina, I think I had to be pragmatic here and kind of trying to find the right balance.

So one example was where we conducted A qualitative systematic review and meta-synthesis. So the balance I aimed for was I would share two or three of the meta-themes for my research with the parents. And beforehand, I would send them a kind of summary of what a qualitative systematic review is.

and just to kind of give them an idea, but that wasn't really full training. I wasn't training them in how to conduct a systematic review. And then in the meeting, before presenting them some of the themes, but not all of them, so I was trying to kind of be selective with my time and budget, and I selected only the themes where I maybe really struggled to interpret them.

And then I would ask parents, you know, after explaining what themes are and what they mean in qualitative research, I would ask them, you know, does this make sense to you as a UK parent of a young person? Does my thinking process make sense? How do you perceive this meaning? So it was kind of a more light touch approach compared to what Maria and Nina did with

with their participatory reflective analysis. And as I said, something that was really, really important to me was rather than, you know, trying to send the parents a bunch of resources and maybe confuse them and overwhelm them and, you know, maybe

they're not even interested with the small amount of time they have in their lives, maybe they're not even interested at this moment in time to become
trained in any aspects of research. So I wanted to make sure that I'm explaining less, but that I'm explaining it meaningfully and thoroughly in terms of the methods we were using and to focus on the quality of the input I was getting rather than trying to cover a lot more content and be super ambitious, but then maybe get kind of more surface level input. So that was really important to me.
And based on my learnings, what I would advise other ECRs or Phd students, as I said, it's really rewarding to have a consistent group. It's really rewarding to engage with more or less the same people throughout. I think it makes them feel more valued and hopefully it's rewarding for them. And some of them have shared that, you know, they're glad that they were involved from the very early planning stages now a stage where we have something more concrete, like the intervention we've developed and the research findings that we have written up. And this isn't always possible, but I would say, yeah, wherever you can try to kind of nurture those relationships with your advisors. And in terms of practicalities, of course, being flexible, creative where you can, and
You know, if you get stuck like I did on a few occasions speaking to your supervisors, I've learned so much from my supervisors who have way more experience than I do. So yeah, trying to come up with different formats, Google Docs, whatever you need to do, and ensuring that...
you are managing your budget so that you have enough funding to send those vouchers and to compensate your advisors fairly and properly. And as I said, ensuring that the input you are seeking focuses and prioritises quality rather than the amount. And I know it can be quite tempting. You want to cover many things in one session. but kind of trying to, as I said, find a balance and be realistic in terms of what you can cover and maintaining rapport throughout your work. I think one of the things about Phd is, yes, you've got time constraints because you have tight deadlines and tight timelines. But on the other hand, you do have a few years where you can nurture those relationships with your advisor. So I think that's also a unique time. And something I found really valuable was when I was kind of onboarding an advisor was to meet them one-on-one, very briefly, could be 10 to 15 minutes, and to kind of, you know, from the start have that personal report with them. And that's something that maybe a busier senior researcher who has a much bigger advisory group would not have time and capacity for.

So especially if you're in the early stages of your Phd, I would say that is an upside of having a bit more space and flexibility with your schedule. And just finally, you know, one thing I found really important was to share vouchers promptly. So to kind of not let that linger. So communicate really promptly.
be available to answer questions. I always said to my advisors, if there's something that you're not sure about, we can also meet one-on-one to talk it through further and sending regular updates. So, you know, here is what you suggested, here is what we did, here is what we couldn't do. And importantly, explaining why we couldn't do it. So if it's practical reasons, you know, being really transparent about.
the scope of what feedback we could implement.
All right, so that's it for me, and that brings us to the end of our talks. Thank you so much for listening, and please share your questions in the Q&A.

JC **Jonathan Chow** 53:04
Wonderful. Thank you so very much to Maria, Nina and Natalia. Wonderful presentation, so much insight, both on the broader kind of end of the spectrum with concepts and things and also the practical tips, really, really helpful. Also, thank you for already responding to some of the questions we've got come through.
in the Q&A, if in the audience you sort of missed the responses, do feel free to have a read through some of those as well.
I will, we'll go through questions in a minute. We've got 5 minutes, so hopefully we can take a few. I'm just going to share a very quick link to a survey that we at the SWDTP would like to do. This just helps us make sure that any future training that we can put on for you is helpful to you. So much appreciated there if you can.
fill that out. Let's go to questions then. We've got a question, we've got a couple of questions from Eleanor. First question is, while doing RTA as a team, how would you account for very different or even contradictory codes or readings when you write up the results? Second question is, did you use any accessible tools for doing analysis together, such as visual tools.

NH **Nina Higson-Sweeney** 54:21
Yeah, I can take that one. So while doing RTA as a team, honestly, I don't feel like our codes were too contradictory. And I feel like that's partially because, you know, we had research questions that we'd built the study around. And, you know,
we'd all contributed somewhat to the design and the conduct of the study. So I do

feel like in some ways we were on a relatively similar page. So while we came up with different codes, we'd focus on different things, name codes differently as well, which is really interesting to consider why we were doing that and what would come to mind.
It didn't really happen. That said, I feel like if it did happen, I think it'd be totally appropriate to keep it in and also engage with discussions as a team and think, okay, why did you code this like that? Why did I not? I think it's all about having those conversations. But I think
The beauty, again, of reflective thematic analysis is that, you know, sometimes a pattern and a theme that you're focusing on, it's not just telling one story. There can be contradictory narratives in it, and that is the story itself. And so I think it can work quite nicely. But I think, you know, for a lot of these different answers, you've just got to work.
as a team to talk it through, but I wouldn't just discard something that was very different. And did you use any accessible tools? Honestly, we did a lot of screen sharing, Microsoft Teams meetings, you know, Google Docs so that we all had access to it and could access it at any time. Doing the analysis together,
We, I think most people coded on Word rather than using a software like in Vivo because that's not always accessible. If anyone's got any suggestions for accessible visual tools that you could use, please do put them in the Q&A because I'd be really interested in, yeah, hearing about them.

JC **Jonathan Chow** 56:22
Thanks, Nina. I'd like to make sure I don't miss any of the very kind of small detail oriented questions. So I am going to ask this. This came through, I think, when Natalia was presenting a question from Cal. How much did you pay the parent advisory group and how did you choose the amount?

NK **Natalia Kika** 56:39
Yes, thank you for the question. So we stuck to the NIHR PPIE payment guidance. So when I started my Phd, it was 25 pounds per hour. And then if we did something like written input, which we estimated would take 20 minutes or half an hour, then we would send 10 to 15 pound vouchers.
And I think that rate has since increased to 27.5 per hour. So we are just trying to keep up with those changes and making sure the amount reflects NHR guidance.

JC **Jonathan Chow** 57:11

Thanks, Natalia. Question from Han. Do any of you have experience of been negotiating ethics as a result of co-researcher input?

ML **Maria Loades** 57:22

I can probably take this one. Thanks, Jonathan. Yes, and I think this is tricky territory because I think it has felt like although ethics committees are becoming more familiar now with the concept of involving young people, particularly because of the vulnerable

considerations attached to that population, but the public in general as co-researchers rather than only as participants. And I think there are different ethical considerations. On the Can We Connect study in our ethics application that we made to conduct the study,

We included a description of how we would recruit our young people, co-researchers, and how they would be involved. But I think it's always trickier in knowing what you, of course, need to conduct anything you do as a researcher ethically and by ethical principles.

But some elements of participatory research, for example, our advisory groups, are actually to meaningfully contribute, we need to have them contribute before we've applied to ethics, because we want them to help us identify our research questions and to plan how we're going to do studies and what we're going to prioritise and what we're going to ask.

So I think it's really tricky space. And actually, I think there's a lack of clarity out there. It's an evolving picture, but there's a lack of clarity about when you need explicit ethical approval. And I would say you need that when you're doing something that is collecting data versus when you, of course, need to do it ethically.

But when you do it as part of your research processes that help you plan, design and conduct a study, where I would say we need to do it ethically, but we don't need research ethics approval, because that's not data. That's not people who are consenting to take part in research. They're part of our team working together to work out what a study is, what it does, what it asks.

JC **Jonathan Chow** 59:33

Thank you. Yeah, really good perspective. I know Maria might have to run off in a

minute, but I did really want to end on one final question from Josetta, one of our regular participants, one of our most engaged participants. Josetta, if I could give you a sticker for top fan like in Facebook, I would.
Jessa asks, how can I get involved in being part of a participatory research with marginalised communities?

Nina Higson-Sweeney 1:00:04
I mean, as like one of the people participating, I'm assuming that's what you mean. Like, so one of the, in this case, like co-researchers or.

Jonathan Chow 1:00:11
I think just that is a researcher, but perhaps perhaps just that would like to hear from either perspective.

Nina Higson-Sweeney 1:00:15
Okay.
Yeah, I mean, I've been part of both. Before I was doing research, I was part of PPI groups. And so I think if you want to be involved as that co-researcher, I think if you look online, there are tonnes of different websites that advertise the opportunities. So I know for younger people, McPin is great. I think there's also
shaping our lives. I feel like they have a board where they advertise opportunities. I think different research departments might have mailing lists you can sign up to for these opportunities to take part in these activities. In terms of, I guess, the other way around and how
you can start doing participatory research with marginalised communities. I mean, that's something I'm trying to do at the moment. So my current work is looking at OCD among ethnic minority adolescents. So I am engaging with marginalised communities. And I think there is a lot more guidance out there now than when I first started doing PPI or any lived experience involvement.
So I'd really look at published articles or reports, different groups that really focus on this. I'd work and see what guidance they've got. I then think more and more people are starting to specifically think about marginalised groups and the specific things you need to keep in mind while trying to engage them.
in research because there may be there may be differences. But yeah, I would reach out to different groups out there. There are quite a few organisations now that really

dedicate themselves to this work and they have wonderful resources. So hopefully that answers both sides of the question potentially.

JC **Jonathan Chow** 1:02:04
That's lovely. Thank you. Cool. Natalia, did I have anything to add to that or?

NK **Natalia Kika** 1:02:11
I think, yeah, Nina's more experienced in this area and Maria as well, so yeah, all good.

JC **Jonathan Chow** 1:02:17
All right, no worries. Well, okay, well, that is time. So thank you very much again to everyone who's joined us. Thank you once again to Maria, Nina and Natalia for the fantastic, fantastic presentation. And we hope to see you at one of our future sessions. Not long to go now. So, right, see you. Have a good rest of your day.

NK **Natalia Kika** 1:02:37
Thank you, Jonathan. Thanks, everyone. Bye.

JC **Jonathan Chow** 1:02:37
Bye.

NH **Nina Higson-Sweeney** 1:02:38
Yeah, thank you so much, everyone.

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