How to manage research and participation projects:

The ethics according to young people

Common Room North

January 2021

This report offers a summary of key findings from 20 online interviews undertaken with young people by Common Room North (CRN) between October and November 2020. Commissioned by AYPH, these interviews explored ethical considerations when involving young people in participation, research, and co-production. There was a rich diversity of interviewees in relation to their individual experience of involvement in research or participation projects as well as their age, location, ethnicity, sexual identity, faith, and disability.

Top tips: How to get it right

1. **Don't just rely on the same usual suspects.** Go the extra mile and take the time to ensure there is diversity among your participants

2. **Consider the impact of involvement on the young people.** Think what you can do to support them throughout

3. **Involve enough young people and the right young people** to truly represent your project

4. **Acknowledge and respect young people's involvement.** To work alongside them as partners will require thought, planning and investment

5. **Share the outcomes with young people.** Be clear and transparent about the impact of their work

6. **Show young people that you value their time and expertise.** Make sure expenses and incentives are given and their contributions are always acknowledged

7. **Have a clear authentic purpose for involving young people.** Avoid tokenism by making sure projects are meaningful and involve young people from day one

8. **Promote involvement opportunities in a way that reaches the right young people.** Use their platforms, language, and networks

9. **Understand the young people you want to work with.** Consider their experiences, needs and personal barriers they may face

10. **Give young people choice.** Where possible adapt to make the experience more comfortable for them

Be transparent, honest. Really try to actually engage.

When you're doing it, you can make it look really easy, but the skills you need to facilitate and run these things are really specialist, being able to run it and keep an eye on people's wellbeing and their needs.

There's no point in talking to young people if you don't listen to what they say.

You need to fight to be able to hear the voices of people who struggle to be heard. They're the ones who need to be heard most.

As a participant I found it really difficult feeling valued and respected, it always feels like the final decision lies with the people running the project, not the people participating. The power imbalance, you brought me here but you're not necessarily listening to me. Its whether you're treated as a tick box or an integral part of the project.

Key Themes

There were some clear common themes arising from our conversations with young people. Even with such a diverse group of participants with wide-ranging experiences these were strong across the whole group. We have grouped these common themes into 10 areas and outlined the main messages below.

1. Expectations of Young People

For several young people there were a range of pressures and expectations on them. For some this appeared to be becoming a burden or a stress that was having a negative impact on them.

"They just expect us to be happy to share our story and they don't understand the psychological trauma from that… I'm sharing my story; you're getting my experience. You can then take that back to your business or organisation. But what am I getting out of it?"

Several young people who had been involved in participation type work felt that they were called on repeatedly to be on panels or groups and this was often done without consideration for the impact on that young person in terms of time, energy, and emotional impact. Many of these young people indicated that they would often say 'yes' to being involved as they felt they had to 'give back' or needed to 'show willing' as they were worried about missing out of further opportunities.

"… you don't really want to say no because they're doing things to benefit you, and I feel like a lot of people understand they've helped you out and you're not going to say no due to you being grateful for things..."

"It does feel weird because you feel like you have to say nice things. At times it feels like you're paying debt, because they've done good things for you and now it's your time to do your part and do good for them."

Several young people talked about feeling the need to find other young people themselves to be involved to feel less pressure from the workload. Some also felt the burden of responsibility was on them as a lone young person to represent a large group.

"I get asked quite a lot to be involved in different groups and one of the things I'm trying to work on is removing this… not laziness, but the immediacy of going to the one person who's on every single group. Because I think I'm starting to fill that role in my area... it's not good for the patient involvement if I'm the only person on the group."

2. Wellbeing of Participants

Several participants spoke about the support they needed to be able to participate in projects, for

example, information in advance about the topic they were working on, and gave positive examples of this in practice:

> *"When we get sent stuff where we can read, I feel more prepared or more informed. And also, when you send emails beforehand you get to know the language being used and you can familiarise yourself with it."*

Others talked about positive experiences of support during and after the process:

> *"There's been a few times where I've been struggling and* [asked for] *a bit of a break', and they're like 'yep that's fine we're here if you need any support'. Getting wellbeing phone calls from them, genuinely caring which is nice."*

> *"I've found the best research ones also at the end of interviews give you like a sheet of paper with places you can go for support if you've found the interview particularly upsetting. If you're discussing mental health struggles this is where you can go for help."*

However, a supportive experience was not always achieved and there was a feeling among some interviewees that this can often feel like an afterthought, and adequate time and planning isn't always in place:

> *"They don't seem to care, or they do care but they don't have the time."*

> *"There wasn't much in terms of welfare or wellbeing or like working practice… I think it would've been really useful to have."*

3. Representation & Diversity

Many of the young people interviewed felt strongly about diversity and representation. There were various issues raised around this. Some young people felt that they were being asked to represent a large group of young people and found the pressure of this a lot to undertake.

> *"As much as I enjoy it, it can kind of get lonely sometimes because people are satisfied with having one person on the group. And I find that tricky because it's a lot of responsibility and it's also, I'm not sure if I'm able to do the best job because I'm just one person."*

Some found their own ways to consult other young people outside the boundaries of the project, as they wanted to ensure they gave a true representation.

> *"Some of the issues discussed on this panel I take them back to the young people*

because I feel like it shouldn't be just me representing everyone's voice on there so each time we get asked questions, beforehand I go off … and consult other young people."

Some talked about the impact on their ability to fully participate when they were in a minority:

"Especially when it comes to talking about race, there's this big cultural barrier. People are asking you about your experience and you're just like, 'do I have to explain my whole culture to you?'"

A few young people spoke about the need for the researcher or facilitators to understand the groups that they wish to engage:

"You can sit and tick a box to say you're care experienced or from a disadvantaged background… But if they don't understand what it means there's no point having that form."

"Particularly with inclusion around additional needs, e.g. ASD, learning disabilities, mental health needs etc, people don't want to get it wrong, so they don't try, they think it'll be so much extra work but it's not."

There were also some thoughts about young people being used for projects and becoming 'professionals' themselves due to their level of experience being involved. A few young people spoke about this and wondered if this then ceased to be an accurate representation of the client group or indeed hindered other young people from becoming involved:

"Young people who get involved can become like professionals at being young people. They're trained up and used over and over and that kind of undervalues the opinions of other young people, others can think I'm not as good as this person."

"… the reason for me why I've got so far in what I do is because I'm young, I'm a person of colour and I use a wheelchair. As sad as that is, I know those are things that tick boxes in academia. It's a sad truth that I don't think is realised or acknowledged, I have benefitted from this but there are lots of people that haven't because if they find me it's like 'oh we found a disabled brown person we don't need to think about other things', when I can't speak on behalf of everyone!"

4. Respect & Power Balance

There were lots of comments about power balance in these projects and how young people can feel

respected and valued (or not). Some gave positive examples:

"The steering group involved loads of different patients from completely different backgrounds as well as researchers and clinicians and it was a really, really valuable experience because I felt really valued…It was very collaborative; it was very kind of like horizontal. There wasn't any hierarchy at all, everyone's opinion was valid."

However, there were many examples where this was not the case. Some felt like they were not being listened to or taken seriously:

"The power that the people you're working with hold over you, so when you come in with an opinion, your opinion, your voice, you share your experience as it is but then… you sit at a table where everyone else is paid a full-time salary then you're just there for a £10 Amazon voucher or a £5, or even for free just because you want to see some change. I can sometimes feel like, is what I'm saying here really relevant, like are they taking this seriously?"

"When they're making you look like you don't know what you're talking about, you kind of want to step back, like 'well maybe this isn't the right thing to do'."

"As a participant I found it really difficult feeling valued and respected, it always feels like the final decision lies with the people running the project, not the people participating."

Others talked of feeling like an imposter or not valid:

"Someone keeps reminding me about their title and how much work they've done in a certain field so then if you're experience doesn't match what they have it's like woah I mean… it can feel like your experiences are not valid."

"Humanising everyone taking part – the whole thing about announcing titles MBE/OBE/Your Highness (lol)/ Member of parliament etc. that could be stopped cause all that does is reinforce those people in a position above you."

There were some simple suggestions that could be taken on board:

"The way they dress, you know something like more casual compared to sort of like a tie and a suit, stuff like that. It just makes you more comfortable I think, and it reduces that power imbalance."

"How people introduce themselves, so if I'm having an interview with someone and

they go 'Hi I'm Dr Blah' instantly you've positioned yourself higher than me… but if someone goes 'Hi I'm…' with their first name, you've kind of established a good rapport. There's less of a power imbalance."

5. Impact & Feedback

Young people spoke about having more clarity about the outcome of the work they have been involved in. Several young people felt that they would like to know what happened as a result of their involvement, they liked to know they had had an impact. There were examples given of where young people felt this was done well:

"They will just update us with what's going on with the project, things that have progressed, stuff like that and I think that is great and that I guess shows that you're valued because they care enough, even though they don't have to do it..."

"One of the key signs of good practice is to send out a summary or transcription of any interviews to participants."

"…taking the time out to send a link to me to show me and explain it to me, and explain how my involvement helped, that feedback was nice."

Other young people aired their frustrations at not being getting feedback or getting feedback that wasn't meaningful:

"Statistics, but that doesn't feel fulfilling, just numbers."

"…you get loads of... oh you're doing great... after a while if you've heard that so much... it's like. But what's actually happening? We want to see results, or you just feel like your time has been wasted"

6. Incentives

Most young people spoke about their experience and preferences around use of incentives and payments for participation. A lot of them stated that they weren't motivated by the financial incentive:

"…The biggest incentive is knowing that you're helping and making a change."

"I've been given vouchers I've been given money, I've had pizza I've had stuff like that and it is lovely, it is lovely but for me I love doing this and I really, really do, it's a passion."

The overwhelming consensus was that young people should be given some kind of payment and expenses for their time to show that their input is valued and respected:

"…if you're in a room of people who earn more money than you can imagine? And you're being paid a £20 voucher in a room of millionaires? That kind of stings."

"…it disadvantages the people that can't afford not to be paid for their time."

"When you're offered an incentive for taking part it's a recognition that you've taken time out of your day or from your job or something to take part in it."

"It's young people who they are coming to for expertise that they are seeking but they don't want to pay them for their services... it's not like we don't pay bills, we do..."

"The expenses should be definitely considered more, it's either ignored or comes up last minute, to say you pay for it first and well reimburse you… not everyone's got that money upfront."

Young people interviewed for this project were paid £40 for their time, this is within the guidelines stipulated by **HMRC** for small one-off payments.

A couple of young people highlighted some concern over the authenticity of involvement if incentives are given:

"…you're just getting paid and you do what your told you're just getting told to do things and they'll be like we'll pay you £100 just do this for us and you do it with no thought behind it, no choice whatsoever."

7. Tokenism

Young people seem to be acutely aware of when they are genuinely being consulted and involved and when the work was tokenistic and 'ticking a box':

"I feel like more recently mental health organisations are just involving people because… funders are starting to favour organisations that do…"

"It was clear that I was just a person on the list to say that they'd got patient involvement and that they'd tick that box."

Some positive examples where young people did not feel like a 'tick box' were shared also:

"There was really a sense of shared power and I felt like my voice was being heard. I

wasn't just there as a stat; I wasn't just there to tick a box and say we've had someone who's a young person. But I would get asked what my opinion was."

Some examples were given where young people were used to prove or drive projects' own agendas rather than truly wanting to hear the young person's voice:

"There was a point where someone actually asked me to share something on how much work had been done [around a high-profile public health topic specifically effecting BME communities] *I hadn't even heard this, he hadn't even asked my opinion of it he… explained why I should share it but then I wasn't asked about my opinion on it and what I thought of it…".*

"... it can feel like… you can easily get bullied. If you don't have any sort of experience or if you don't have anyone… your opinion can easily get swayed so they can write a narrative and then get you to speak on whatever it is they've set."

There was a desire from young people for their involvement to be part of planning from the outset of a project rather than an after-thought:

"If the planning, timing and funding doesn't think about the involvement of people, then this is just an add-on aspect that's just probably put in there to make the funding bid look nice and shiny. But there isn't any funding in the project for it to be actioned. If it is embedded, which is reinforced through funding applications with incentives and more time allocating a person resourced to it, that's where it feels more valued as there's more time for your words and thoughts to be actioned."

8. Promotion

There was some thoughts and ideas from several people about how opportunities are promoted. Most young people who spoke about this felt that opportunities weren't being promoted in the right places or the right ways to attract young people:

"I think we need to do way better on who we recruit, I think the current system of recruitment is just nowhere near good enough… we recruit a very small slice of the pie from the whole patient kind of cohort. A very, very small one."

"…try to think like a young person, try to think about what young people are interested in, what platforms they use…"

"…how many young people would actually 'like' their CCGs Facebook page… because I think that's the biggest barrier…"

"Even the wording of the groups you come across are an 'expert advisory group' and if you are a young person… it's like 'oh I don't have the expertise to bring to this'. The language that's used in there is quite… I think its off-putting."

9. Barriers

Young people highlighted a range of barriers, many of which have already been highlighted throughout the themes. In addition to these there were several comments about how their own health and mental health can be a barrier especially if this isn't managed well by projects:

"…because sometimes it can be very triggering, whatever you're talking about in a project, so a young person having a safe space they can go to and recentre themselves and breathe..."

"…this is going to take too much from me even if you feel like you might have something valuable to add"

Some young people spoke about their own fears and how participation work isn't always a positive experience for them:

"Fear, especially around the sort of things I research; suicide, self-harm, MH etc, there's a lot of fear of that getting back to people. There's this concern about airing out your family secrets, your secrets, it comes down to stigma and shame... We talk so much about it being empowering but I don't think its empowering, not at first. So many researchers live under the guise that they're giving people that space to open up and that's enough but f**k off mate. I don't have to tell you my life story."

Others talked about professionals understanding them and their needs or experiences:

"So many things people forget to ask about, access needs and what people might need for support."

"Some people aren't very educated through no fault of their own, for e.g. care leavers have a 1% chance of going to university, and they're invited to do research with academics and they've never set foot in an Uni in their life. I don't think academics are totally aware of this or aware of what it means for that person."

"For me, I use a wheelchair I use crutches, before I wasn't as confident as I am now, I didn't have the ability to be like I need this thing and I need this accommodating and is that okay. I think this is a big one as there are a lot of young people in this kind of

situation. It comes back to feeling like you're asking too much."

"They need to understand care experienced young people will have resentment against you but that's not your fault, that is just generally because they've been let down so much in the past."

10. Comfort

There were very mixed opinions on whether research and participation should take place face-to-face, online, one-to-one, in groups. All young people expressed a preference, but this varied across the whole group. Some young people preferred online for logistical reasons relating to long-term health or mental health conditions, others preferred online just for time saving or the comfort of being in their own home.

The main similarities that came across were, if doing groups to have smaller groups and if using physical locations try to keep these an 'un-clinical' as possible. Helping young people to access locations was also helpful for some young people, especially when the topic was relating to their mental health. There was a desire to have choice from young people about how they participate:

"I've never actually had the choice [of environment]*, it's just set and you either do it if you're comfortable or you don't because you're not comfortable. I think choice would be fantastic."*

Thank you to all twenty young people who were involved in the interviews. The following young people have chosen to be named in the report:

Damian Juma

Kianna Leader

Liv Powell

Louise

Nkem N Naeche

Nusaybah Choudhury

Rana

Sarah O'Brien

Tom Sharpe

The interviewers were:

Megan Alikhanizadeh, Liz Neill & Jeni Roussounis (Common Room North)

This paper was compiled for Common Room North by Jeni Roussounis, Associate Consultant.

January 2021

Appendix 1 - Interviewers crib sheet used by Common Room North Interviews lasted between 30 minutes and one hour

Experience/History:

Own experience of participation or research

What participation or research work have you been involved in previously?

What was your best experience and why?

What was a bad example? Why was it bad?

Fairness:

Ethics, what is fair to expect of someone, what is it ok to ask, where is the line of something going from ok to not ok?

Did you feel what was being asked of you was 'fair'?

Did you feel able to say if it felt unfair?

What would have made the experience feel more fair?

What feels fair in terms of engagement for you?

What helps you to feel the power balance is right?

Is an incentive/payment important to you?

- What type?

Confidentiality & Consent:

Knowing what was going to happen with your information

What do you think 'confidentiality' and 'consent' mean in relation to taking part?

Did you know what was going to happened with your information and did you agree to this? If so, how did you know and how did you agree?

What do you think you need to know if you're going to properly 'consent'?

Challenges:

Things that made it harder for you to participate

Was there anything that made it difficult for you to be involved?

- Physical barriers - location, people…
- Personal barriers - your status, identity …
- Approach barriers - how they went about it…

Safety & Comfort:

Things that were done or put in place that made you feel safe, comfortable, and valued

What makes you feel comfortable?

What makes you feel uncomfortable?

What makes you feel emotionally safe to be involved?

What would have helped you to feel more comfortable?

Before/during/after?

How did you know you were respected and acknowledged in the experience?

How did they make you feel valued?

How did you know that what you contributed was heard / made a difference?

Understanding:

Knowing what will be expected of you in advance and feeling good about that

How much did you know about what you were being involved in beforehand?

- What it's for?
- What will happen next?
- Who makes the decisions?
- How your information is shared?

Did this impact on how able you felt to be involved?

Did you want to know more?

Environment:

Location, surroundings, privacy…

What environment were you in?

- Online, group, public, private, group, individual…
- Did you have or want a choice? - did this matter?

How did the environment contribute to you being able / unable to contribute?

What worked well / did not work well about the environment?

What would you have changed about the environment?