

**Report on a qualitative focus group
study to explore the barriers and
facilitators to participation in Children
of the 90s activities**



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December 2023**

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Background

ALSPAC (“Children of the 90s” (Co90s)) is a birth cohort that recruited over 14,000 pregnant women between April 1991 and December 1992. Parents, children and children of the children from this cohort have been followed up at multiple timepoints and a wide variety of samples, exposures and outcome measures collected

As part of their re-engagement strategy, ALSPAC approached the QuinteT (Qualitative Research Integrated into Trials) research group at the University of Bristol to collaborate on a study to understand and explore barriers to participating in cohort research. This information would be elicited from the perspective of non-ALSPAC participants, matched for age and postcode with disengaged participants, who have not engaged in the study for over ten years or more. By identifying these barriers, we sought to explore facilitators that could encourage disengaged cohorts to take part.

Methods

Study design

The exploratory nature of the research aim fitted with a qualitative methodology. We elected to use focus groups rather than individual interviews as we sought to elicit views from a range of participants and were not seeking in-depth individual accounts.

Additionally, a focus group approach fitted well for practical reasons of time efficiency. Each focus group was facilitated by an experienced qualitative researcher supported by members of ALSPAC staff. They were held in community-based buildings in areas with relatively low levels of participation in ALSPAC activity. Only the researcher, ALSPAC staff and participants were present at each group.

Ethical approval, sampling & participant recruitment

The study protocol was reviewed by the University of Bristol Faculty of Health Sciences Research Ethics Committee with approval given in August 2022.

Information about the study was hosted on the ALSPAC website. Adverts for the group were posted on community Facebook groups, printed posters were displayed in community centres in each of the areas and the event was mentioned in an ALSPAC presentation as part of a community event in site 2. Potential participants were asked to complete an online form giving their name, age, postcode, preferred focus group location, and whether or not they had previously participated in medical or scientific research (Posters featured a weblink and QR code for potential participants to access the online form). Responses were reviewed and those who had stated a previous involvement in ALSPAC, experience of prior participation in research projects or other characteristics outside the remit of the ALSPAC cohort were excluded. The remainder were invited to a meeting, provided with written study information and asked to complete a consent form to bring to the focus group. Spare copies were made available at each meeting. Prior to each group beginning, the facilitator reminded participants of the purpose of the meeting, and reassured them that their participation would remain anonymous, Participants were asked not to discuss any personal information shared in the discussions outside of the meeting.

Data management & analysis

Focus groups were recorded using two password protected audio recorders. Recordings were uploaded to the University of Bristol servers, stored in an access restricted folder and deleted from the portable devices. Recordings were transcribed verbatim by two members of University of Bristol staff. Personal identifiers (names of participants) were not transcribed. Transcripts were checked for accuracy against the audio files and then uploaded to nvivo 12. Transcripts were read and the content of each summarised into overarching topics presented below.

Results

In all, 58 people responded to the invitations to join a focus groups (31 for FG1, 17 for FG2, 10 for FG3). Of these, 25 were excluded for not meeting the sample requirements (see above), and four did not attend. Details of the three groups, and the 29 participants are shown below. (table 1)

Table 1 – Focus group details

Group	Date/ duration	Facilitators	G0 age ¹	35-48	G1 age ²	Male	Female
FG1	29/9/22 / 82 mins	MJ + 2 x ALSPAC	6	2	2	10	1
FG2	4/10/22/ 80 mins	MJ + 4 x ALSPAC	6	2	2	5	3
FG2	6/10/22/ 85 mins	MJ + 2 x ALSPAC	7	2	1	5	5

Categorization of attendees / prior research experience

Despite it being outlined in the study adverts and information sheet that participants should ideally have no prior experience of participating in research, over half declared that they had previously been involved in research. These ranged from small scale market research such as *“the odd customer service feedback”* (G1P05) to psychology experiments: *“they give you a bit of pizza and see if you can do this jigsaw or something”*(G2P04) or in one case a participant had experience of longitudinal cohort research as a member of Biobank (G3P02). Three attendees stated that they had undertaken research themselves, in two cases as ‘mystery shoppers’ and in one administering surveys *“I worked for a company which actually did surveys”* (G1P07) and another had been involved in data collection for a biobank (G3P09). The remainder had typically not aware of being involved in research before: *I’ve not been involved in any research at all. So, this is my first time* (G2P06)

Awareness of and attitudes to Children of the 90s

Each session began with a brief presentation about the Co90s programme, delivered by a member of ALSPAC staff. At the end of each presentation, attendees were asked to comment on whether they were familiar with the Co90s programme and then to discuss their views on the programme based on this experience or the presentation.

A majority of participants stated they had heard of Co90s. In one case, an attendee’s partner was a participant in the cohort, more typically awareness came from friends or relations being part of the original cohort:

¹ G0 age represents parent members of the original cohort, likely to be 55 to 70 years old

² G1 age represents child members of the original cohort, likely to be 30 to 32 years old

My eldest son was just before the cut-off... a lot of his year group were involved with it..I used to hear the parents chatting about it on the school run and stuff like that.
(G2P07)

A colleague would be one of the original recruits... she's now a grandmother. And she always sort of says, "Oh, I've got my Children of the '90s. You know, we're still going."(G3P03)

Three attendees stated they had seen the project mentioned on the local news: *I saw something on BBC Points West... So, some familiarity with the name.* (G3P05). Six attendees were familiar with UK televised cohort studies (The 7-up series and Child of our Time) and in some cases had assumed Co90s was part of the same programme of work. This connection helpfully made Co90s relatable to these attendees: *I associated it with Seven Up! So, it wasn't until your colleague explained that it's actually a different study ...I kind of thought it was just all linked, really.* (G2P06)

All attendees were positive about the programme, based on what people they knew had told them about their experiences, or for those previously unfamiliar, because of what they had been told in the presentation: *Well I just think it sounds really interesting... I wish I was in some sort of a study like that to be honest* (G1P01). In one group, there was a suggestion that their positive perception of Co90s was linked to a pride in the city: *I'm also proud to live in Bristol, I suppose. So, it's great that the information's coming from somewhere I like to live* (G3P08)

Annual Questionnaires

Cohort members are asked to complete an annual questionnaire. Group attendees were shown paper copies of the questionnaire and asked their opinions about the document, initially as an open question, but then with prompts to consider the length and mode of delivery of the document.

Participants in two groups disliked the idea of being sent one long questionnaire, suggesting they would prefer a series of shorter documents over the course of a year, ideally

completable in c10 minutes each. For one participant, this would help develop a feeling of belonging that may thus encourage continued participation: *it makes you feel a part of something ongoing* (G1P07). Another also preferred a staged approach to completion the questionnaire, and suggested people could be rewarded for completing each stage:

I was thinking, does it have to be in one big lump of paper? ... 'Cause if you did it like over smaller amounts every month or something. And then it had little things in like, "You're one step closer to your £10 reward" (G3P02).

Conversely, two participants in the same group felt they would be more inclined to complete one whole questionnaire than have it broken down into stages. (G3P03 & P06)

Participants were asked about their preferred mode of receiving/completing the questionnaire – in paper or digital form. Across the groups there was no real consensus, with as many attendees preferring to receive the questionnaire digitally as a printed paper document. Those who preferred a printed document suggested that receiving it in this form would act as a physical reminder to complete it rather than if received electronically, which they may miss or ignore: *an email you can tend to just not read it properly* (G2P01). Those who thought this way also suggested that filling in a questionnaire manually would elicit more considered responses: *paper might make me think a bit more about my answers* (G2P08).

Conversely, other attendees talked about preferences for an option to receive and complete their questionnaire electronically: *I'd rather have mine personally as emails. Just 'cause I do everything that way* (G2P06) and this if this was the case, then providing questions in a format that would work on a smart phone was favoured: *If you're online you can do it on your phone on your lunchbreak or something like that.* (G1P02)

Finally, one participant queried the possibility of the annual questionnaire being completed over the telephone with support from a member of staff: *Do you do phone?...a phonecall to say, "would you like to do it on the phone with me?" that would work for me* (G1P03).

Another attendee in the same group agreed. Having previously stated that they did not like online forms, they also commented on how they would not be incentivised to go out and post a paper form:

Sometimes you can't physically get out anyway. ..for some people it's more aggro to fill it in than actually getting the £10, because, you know, by the time you piddle around and got the form done. Walked up there, walked back. It's just, "Uh. I can't be bothered to do that."

Discussions would suggest there is merit in offering options for people to complete the annual questionnaire, whether separating it into shorter sections completed over a period of months for some and on one occasions for others, and in different formats – either online or in paper format.

Two groups felt that there should be an explanation of the reasons why certain questions were being asked in the annual questionnaire and that doing so may encourage people to feel more invested in contributing responses. In G3 this came as a response to example questions about gambling and alcohol:

It might be interesting to know , like "Okay. Next lot of questions are because we're interested in studying alcoholism or gambling addiction..." ... it's interesting to know where that study's going. ...But if you've received the questionnaire and it just says, "Right. These next set of questions are gonna be this." I'd go, "Oh, well why are they looking at it?" (G3P07)

This point was taken up by other attendees in G3, where they suggested it would: *help people understand why you're asking some of those questions (G3P04)*, with one participant going further and wishing to know about funding sources: *If I'm gonna fill it in, I want to know who's providing the funding. Absolutely. (G3P09)*. In group one the discussion was similar, with a further suggestion to incorporate in the questionnaire details of how the prior research had contributed to knowledge:

I think I'd need some kind of feedback to say: 'this is what we're achieving'. Not just 'here's a questionnaire thank you'. You know, this is what we've done. This is what we've achieved. This is what it's helped with. (G1P07)

An additional idea to encourage people to complete annual questionnaires came in group 2, with one participant suggesting running local events for people to encourage them to come together and complete their questionnaires, with the idea taken up by others:

Do people ever meet in a group, to fill these things out?... could you run events where people could come and fill it in? So (you could) run something. There's coffee. There's food. And there's lunch (G2 P03)... A family fun day or something (G2P09)...yeah, Like a social thing, (G2P06)

The suggestion here was for these events to take place in local communities – to avoid the challenges of attending the Children of the 90s base (discussed below), but also as a means of creating a community of belonging for people involved in the cohort.

Clinics

Co90s regular data and sample collection clinics are used to update records of cohort participants. They are currently held at the Co90s offices in Clifton, Bristol. A clinic visit typically takes 2 – 3 hours. Measurements such as participants weight, height, blood pressure are taken, in-person questionnaires completed, bone density and liver scans, cardiovascular tests as well as blood and urine samples being taken. In the focus groups, a member of ALSPAC team outlined the details of the clinic visits. Attendees were asked an open question about their general feelings about these clinics and then to consider what factors might help/hinder them from attending clinics.

An initial misconception in the groups was that the availability of clinic visits would be limited to traditional office hours and that appointment times would be dictated to attendees. We can speculate that this may be based on people's experience of making appointments (for example) with health or social care providers where there may not be scope for the attendee to choose an appointment time. When facilitators explained that appointments were available outside office hours and that the clinics were a 7-day operation, this was viewed very favourably by attendees. They emphasised the importance of making this information explicit when inviting cohort members to have clinic appointments.

Across the groups, the location of the clinic was considered problematic. Group 1 members all highlighted challenges of travelling into Clifton relating to cost and parking:

It's really difficult to get to isn't it and it's expensive for people who don't drive (G1P03)... And if they do drive, it's what's parking like around there. (G1P07).

Similarly, group 2 and 3 attendees raised concerns about the geographic location of clinics: *Again, getting there is a drag isn't it? (G2P04).*

Group facilitators outlined the existing provisions in place for supporting people to attend clinics, including reimbursement for travel costs, or booking transport, but even with these supports several attendees felt the logistical challenges of attending clinics were too great:

For me the location is really difficult to get to... Having 3 children there's no way I would get 2 buses up to Clifton - no way. (G3P09)

When asked to consider how to mitigate for these concerns, suggestions typically focused on hosting clinics in local hub settings in the communities of interest. These varied from the suggestion of utilising mobile clinics or setting up clinics in community halls such as those used for the focus groups. Strongly supported suggestions in each group were for the provision of services local to the populations: *Could you not have local clinics like here or dotted around? (G2P06).*

When it was explained that the practicalities of remote clinics may limit the range of measurements that could be taken, group attendees were asked to consider ideas for what might encourage them to attend in-person clinics in the Clifton setting. A well-received idea was to provide social support alongside clinic appointments, this was initially outlined by the following attendee at one group:

When you're having your session, could you for example say, "And on Monday the 17th, we'll have someone there from the law clinic." So, if you're having a dispute with your landlord, the law clinic could be there. Or "On Tuesday the 18th, there'll be a 3rd year maths undergraduate there to help you with GCSE key stage whatever it is"? (GxP02)

This idea was developed by other attendees at the same group, suggesting for example attendance by Citizen's advice (GxP09), or further to connect with existing cohort members expertise to provide, for example, legal advice:

Is there anyone within who is already quite active within your research that actually can say, "...I'm a lawyer. I help you with a will." Or something like that? You know, someone who's actually within it can supply the service back into it. (GxP04)

All of the groups were interested in whether they could receive feedback on the day of their clinics on the basis of their measurements/assessments. In the main, the focus of this was on medical advice. In each session, a facilitator outlined what information could be available to clinic attendees, for example:

if you came and your blood pressure on the day was high, we would tell you and give you a letter to take to your GP so, because some people never have their blood pressure taken and it might be the first time they know about it. So, they would take that to their GP and their GP could arrange follow up. Assessments, we feedback on low haemoglobin, high glucose, so potential for diabetes, cholesterol, low bone density and liver if you've got a high fibrosis of the liver we'd feedback. But it's very specific and I know people often say that they'd just like to know their results. So, it's really interesting to hear what people think (G1Facilitator2)

This was well received, with most people very interested in having information from their measurements:

I'd want something (at a visit) that might interest me, as in health wise.... So, if you come along because you've already got the equipment and doctors there – I'd like to know what you've seen (G1P04)

Facilitators explained that previously (for example) clinic attendees had received copies of their 3D body scans for the purposes of 'interest and engagement' but also that there were limitations to how much information could be provided, this was accepted:

Well, it's just I didn't realise how much of the kind of data was collected... that'd be really interesting to look at - You're this percentage of all these things. And just like,

even though there's nothing I would do personally with any of that information, it just still feels interesting. (G3P03)

Whilst there are inevitably limitations of the level of feedback available at measurement clinics, the expectation of many people at these groups was that this should be made available in some form. A consideration therefore may need to be how this is explained to participants such that the reciprocal arrangements that many want – and often expect – are not missed.

Motivations to take part in cohort activities

When asked what would incentivise people to take part in cohort activities such as completing questionnaires or attending clinics, being paid for the time taken was at the forefront of discussions in every group. There were a small minority of attendees that stated they would purely be motivated by the financial reward:

Oh, I don't really care if it's interesting or not if there's financial incentive. I've sat through many a lecture where I've been bored to tears. (G2P04)

However, this was an uncommon view, more usually participants expected there to be a combination of interest to them alongside financial recompense. Speaking about a prior experience of participation in a discussion group this attendee summarised their motivation:

I'll be honest. I probably wouldn't have done it if there wasn't a financial incentive. I do enjoy it when I end up doing it. Generally. I'd say 90% of the time. Sometimes there might be something and you're just like, "Well I wanna join in with that, it sounds interesting" (G2P05)

Many attendees supported the notion of taking part in something that 'sounds interesting', often feeling motivated to contribute their viewpoint to this area of interest:

it was kind of the financial incentive [that encouraged them to take part in this group] but more also feeling like I wanted to give my opinion And have a chance to like speak about some of the things that matter to me. (G3P03)

Whilst a combination of payment and interest in the topic was the main motivation given, some attendees from group 3 spoke about altruistic reasons for participating in activities. For them, *giving something back* was sometimes more important than the financial reward:

There are sort of other things that I think would make people like me return, you know. As opposed to more of a cash incentive. Obviously, the £10 is nice. Don't get me wrong, but you know, you can only have so much of a cash incentive, and I think people are more motivated now by social issues and things like that. ...Of helping people. As opposed to having an extra £10 in their pocket. (G3P05)

The sense of giving back and being part of something was a common topic of discussion in each group. In relation to motivations to engage with clinic appointments and questionnaire completion there were contrasting opinions. On the one hand a proportion of attendees stated they were more highly motivated by receiving personal information (for example outcomes of their clinic measurements):

I think my personal opinion would be which is a very cynical view which is this is 'about you' and I think that you would achieve generally better results when you focus things on the person themselves, (G1P05)

This contrasted with those who placed greater value on the wider societal contributions that participation could bring. The following extracts coming in response to the statement from P05:

Yeah, I feel the opposite, I'm not having any argument with you, I feel the opposite because if I could ever leave a legacy behind that made the future a bit better I'd be happy with that. (G1P02) ...

... It's also your children, it might not necessarily be helping you, but it could benefit your children or your grandchildren or whatever so and I suppose you could have a point because it might well be helping the next generation. (G1P04)

Payments for participation in activities

Having established the common thread across the groups that cohort members should be reimbursed for their time, we explored what amount of payment would be deemed

reasonable. To frame the discussion group facilitators referenced the fact that attendees has been reimbursed £50 in shopping vouchers to attend the focus groups. In many cases attendees were honest and stated that the payment was the primary reason why they had attended. They also noted that in some cases, this may be the motivating factor for people to participate in cohort activities as well. In discussions, attendees felt that an appropriate payment for time given up for cohort activities would range from minimum wage, with refreshments included: *I'd look at minimum wage, Minimum wage per hour for sitting and talking, Sitting talking. Drinking coffee (G2P08)*, through to an enhanced hourly rate akin to the amount paid for attending the focus group:

I would do 2 hours for £40, £45 (G2P04).... £20-£25 an hour's about right. (G2P09)

Cohort participants are currently reimbursed for activities with Love 2 Shop vouchers. These are usable in a range of shops. Group attendees were also paid for their time in the same way. In one group, there was unsolicited feedback that suggested these were an unpopular form of payment. In all groups attendees were asked their views on the vouchers and preferred forms of payment for research participation. Attendees were virtually unanimous in their dislike for being reimbursed in this way, often because of the restrictions on where they may be used. Also, and relevant in attempts to increase participation from men, in group 2 one of the male attendees (supported by others) felt that love 2 shop vouchers could disincentivise men:

But wouldn't a man sort of think: "Oh, that's like - yeah Love2Shop....Women's stuff" You know, my wife does that sort of thing. I don't really understand what a Love2Shop voucher is. I expect more women to know. (G2P05)

When asked to propose alternative means of reimbursement, group 1 and 2 attendees preferred the idea of a voucher that could be used in a supermarket: *At the moment, I think supermarkets would be a big seller. ... Because people are on universal credit. Times are hard. (G1P06)*

It was noted that being able to do this would allow for greater flexibility for people, and one attendee referred to their own experience with receiving shopping vouchers from their local authority as a benefit:

I get the [local authority] vouchers for my children. And I usually pick somewhere like [lists supermarkets]. Because I can't just get the food. I can get the toiletries and washing powder and things like that. But also, clothes. (G2P06)

There were also discussions about payment in cash, however it was acknowledged that this could be detrimental to some participants benefit allowances:

The problem with... giving people money is if you've got people that are on universal credit and they're getting for instance - £80 for attending a clinic and travel. That may interfere with it. (G1P02)

Overall, the message from the groups about the mode of financial reward for cohort activities was the importance of flexibility, and specifically tailoring the reward to meet the wishes of the cohort member:

You should actually be contacting those people and saying, "Actually, what kind of voucher could we provide?" (G3P09)

Views on engagement

Attendees were asked to consider how to encourage people to re-engage with questionnaires or clinic visits, based on what motivated them to take part in activities. Several restated that the financial reward would be a primary motivating factor for them, with some supporting the idea that people may be offered an enhanced one-off payment for re-engaging:

What about like a kind of one-off welcome back bonus? You'd probably word it in a different way. But like, basically, a kind of an elevated amount, just to say, "Come back in. We'll open you with open arms" sort of thing. (G1P05)

In contrast, as discussed previously it was recognised that financial reward was not necessarily necessary for everyone, and that altruistic reasons may influence others:

I think, is it once again don't bring it back to a financial payment. A lot of people - I'm not saying everyone. Everyone can do with the money. But some people - It's nice to

do - read that: "Oh, well, I helped that person today by just spending twenty minutes there." You know? (G3P01)

In other discussion, one attendee felt it was necessary to generate a feeling that these activities were too good to miss:

You need to create a fear of missing out. Like, "Oh God. I wanna go there! I'm gonna miss out if I don't go down there!" (G2P07)

Whilst there was some thought that publicising events and activities using social media could be an appealing way of generating this 'fear of missing out', some advised that the choice of platform could be significant depending on the target audience:

P05: I think that's quite an interesting topic, actually. Because some of the charities and people that I work with have actually gone away from Facebook. Because Facebook is now considered an older person's format. ...if you say you use Facebook, you're showing your age, really. And I think people are more like - not necessarily things like Instagram. But definitely think it's more like Snapchat and TikTok. (G2P05)

One attendee thought that using GPs as a means of contacting people could be helpful:

GPs are more likely to have an up-to-date address than the Children of the '90s. So, what I mean is maybe go via them. G2P8

The group facilitator pointed out that this was one strategy being employed currently, but the consensus in the group was that this would be an acceptable means of approaching the disengaged.

When asked to consider how best to engage under-served communities, several participants suggested showing caution and considering that some people may have made a conscious effort to remain under the radar of formal services. For these people in mind, it would be important to engender a relationship of trust – particularly that by engaging with the cohort their data would not be shared:

It's a trust thing. Absolutely a trust thing because they've gone missing for one reason, that is not to be found by the authorities. I'm not talking about a massive crime, it's just.. I think if they know why you're doing it you've got a chance but if,

this just seems, could quite easily come across as just big brother. ... Yeah, absolutely. So it's really selling those benefits and often I guess. (G1P01)

In terms of raising awareness of the study in communities, groups talked about advertising in local press, although it should be accepted that these may not have a wide reach to all residents:

Well, there's a local free magazine that goes out to everyone...we've got [names publication]. (G2P07)

G2P03 (in response): I've spent 6 years living here. Today's the first time I've heard of that.

Group 3 attendees outlined the number of community events and locations that existed in their area, and suggested that having a presence at these places, where the potential benefits of participation were detailed, could be an effective way of enhancing engagement:

I think it's one of the most community parts of Bristol, by far... You've got places like the [NAME] Community Centre. There's everything going on there. The [Pub name], even though it is a pub, the amount of social interactions they do. You've got Base Cafe. Even the Methodist Church on [NAME] Road. There are so many community based project round here that are so well supported. (G3P01)

Engaging with men

In each group attendees were asked specifically for their thoughts about how to re-engage men with cohort activities. Typically people recommended it would be useful to identify and target places where communities of men gathered. When asked to suggest where this would be, the groups listed possible settings including sports clubs, pubs & men's social groups:

Just go down to Ashton Gate on a Saturday. ...Do you know what I mean? Like, you know, I don't watch the football, but it is primarily men. ...Of a certain age that are at those events. (G2P05)

Go where it would start a conversation with them (men). Like a bowls club. There are such a dearth, unfortunately, of working men's clubs. But there are such things. There are 5 a side places and this town is packed full of great little places that people will go to, like Men In Sheds groups. That kind of thing. (G1P08)

A majority of (female) attendees felt that one strategy for encouraging men to engage with activities was through the women in their lives such as mothers or partners:

The partners of the older ones, you could get the women to - you know, you could give them something. Say, "Get your husband back in and we'll bung you 20 quid." you know? (G2P08)

But you know - then, you know, other ones. 'Cause like my son. ... he might do something if I told him. 'Cause I think, you know, power to the women really. (G2P04)

Write to their wives. ...If you're allowed to do that. (G3P03)

However, one male attendee noted that this approach would not work for all, emphasising that: *relationships break down (G2P03)*. He went on to share his personal experiences of being a single parent and how there was a complete absence of communication between him and his estranged partner:

Now, not every relationship that breaks down is amicable. ...You know, so if they're not amicable...You know, so maybe the father needs to be approached separately? ...And often a totally different kettle of fish sort of thing. You know? ... I mean, I'm a single parent. I don't talk to my ex. I do not talk to her at all. ...You know, so if there was something that she knew about that I need to be involved in as well, I wouldn't know about it. You know because she wouldn't actually email me or message me or anything. (G2P03)

Other suggestions included: *having men's days at the clinic ... : 'Cause I think some men are intimidated being surrounded by women. In the same way that some women are intimidated being surrounded by men. (G2P03)*. Finally, a male participant in group 3 compared the challenges of the cohort study to his experience as a committee member on a rugby club.

Following the pandemic, numbers attending had dwindled and, as he put it: *no amount of incentives or begging or going to them, saying, "Look. We need you back. Come on back" has worked* (G3P04). However, what they had found – and this was suggested as potential a useful lever for re-engaging men with the cohort study – was tapping into current narratives about supporting men’s mental health. His suggestion was that if any findings from the Co90s programme related to men’s mental health could be publicised, they could be presented in a way that encouraged more men to re-engage on the basis that they would be seeing the real benefits of the study in an area that was relevant to them. As one female attendee in the same group put it:

My husband never spoke about mental health (but) he plays rugby and comes home speaking about how important mental health is now. ... And he really wouldn't have spoken about mental health. And not even his own. It's like his peers. (G3P09)

Discussion

We conducted a qualitative focus group study which sought to explore the attitudes towards participation in Children of the 90s activities. In doing so, we drew on the insights of people living in currently under-served communities (areas with higher levels of social deprivation), and with a focus on re-engagement of men. It was a major success of this study that 29 people in three groups across these areas, of which 24 were men, were willing to give their time to share their insights. Most attendees (23) were matched in terms of age and demographic with potential Co90s participants. Group members offered their insights into research participation more generally, and whilst some admitted they had been research participants, only a very small minority had any first-hand experience of cohort study work. Attendees were paid in vouchers for their time, but all were willing to contribute insights into group discussions, suggesting their motivations were more than purely financial.

Some attendees were familiar with the Co90s programme, but many were not. Once the programme of work was described to them, all attendees were positive about what had been achieved, they recognised the value of the study continuing, and often they shared their feelings of regional pride that the programme was a Bristol-based endeavour.

Attendees shared many specific insights into what they felt would encourage them to participate in specific Co90s activities such as completing annual questionnaires and attending in-person clinic appointments. We have presented these in the main report, but in this discussion we draw these together into overarching themes that came from the groups.

A strong motivating factor to engage in cohort study activities for these participants was a sense of **reciprocity**. For some, this simply meant being financial reimbursed for their time and efforts to a level that made it worthwhile for them. For many, it was important to know that their contributions had helped contribute to research findings that would make a difference. They suggested that throughout all cohort activities evidence of what benefits and changes to practice had come as a result of prior work should be foregrounded. The sense of reciprocity was also evident in their belief that participating in clinic activities should provide them with personalised feedback about their measurements that could be used to benefit their health.

A second cross-cutting theme in these data was the need for **flexibility**. This was connected to the mode of delivery and completions of questionnaires. People welcomed the opportunity to choose whether to receive materials in paper or electronic form. They wanted to be able to pause and revisit questions at their convenience, and they wanted it to be clear there was an option for them to choose which questions to complete. Finally, flexibility should be offered in the format of rewards given to cohort participants. The current voucher system was seen as inadequate by most. Giving people the opportunity to choose how they were remunerated for cohort participation was a very clear message from these groups.

Thirdly, there were discussions around the need for **adaptability**. This came out prominently in discussions about the physical locations of clinics, with strong suggestions about the benefits of offering provision away from the current Clifton location of Bristol. All groups felt that there needed to be some forms of outreach provision in the under-served communities to undertake clinic-type procedures. In particularly relevant for the recruitment and retention of men to the cohort, was targeting existing networks of men's groups be this

sports, social or support groups. Attendees told us about how people's circumstances change and that previously stable family groups may change.

Approaches which would develop and enhance the **sense of belonging** were popular across the groups. Suggestions for community days with activities in place where groups of cohort members attended en masse were favoured, as were providing opportunities for people to come together and be supported to complete questionnaires. Some attendees saw the clinic visit as an opportunity for a family outing, although this may not be appropriate for all.

To conclude, these groups showed that while there is no one-size fits all solution to re-engaging this sample of people, there are a series of interlocking pieces that need to be accounted for which may go some way to making participation in Co90s more appealing.

Appendices

Focus group topic guide

Understanding engagement in research Focus Group Topic Guide

Qualitative study to understand participant engagement in the ALSPAC @30 clinics

Please note ALSPAC and Children of the 90's are different names for the same study.

1. Set-up (pre-recording)

- Check have received information sheet and consent form.
- Check consent to audio record.
- Explain might use quotes in reports but will always be anonymous.
- Reinforce confidentiality. Any issues discussed not to be shared outside the meeting
- Emphasise that there are no right or wrong answers. We're keen to hear everyone's opinions
- Everyone will be encouraged and given the opportunity to talk
- Any questions before we start recording?

Press record

2. Introduction / Purpose of meeting

The aim of today's session is to help us understand barriers to participation in long term health research, from the perspective of people who have not been involved in this type of research before, or, if they have, not for a long time.

So what we're trying to find out is what things that could encourage people to take part and stay involved.

These findings will be used to further develop a strategy to increase participation in the ALSPAC @30 clinics by all groups that are representative of the original ALSPAC birth cohort.

3. Participant introductions

First of all let's go round the group and just introduce each other (name, or first name only is fine).

4. About ALSPAC

Before we start the discussion [NAME] will just give a short presentation about the Children of the 90s project

5. Guided discussion

- Okay so let's start the discussion. First of all, who would like to ask a question about the talk?
- Who has heard of the Co90s before?
- Where when?.....Do you remember it from school / growing up? Did you have friends in the study?
- Based on what they have heard, what do people think about CO90s?

(probe: familiar or not? if so where/when; interest?)

- We know that a lot of people who could take part in the CO90s research do not. In particular it is difficult to get men involved....

In general.....

- What do people see as barriers to taking part? *(note it is a cohort study, so it's an ongoing engagement/involvement...ask for more if needed here)*
- What things could be done to overcome these barriers?

For clinic visits in particular

- What do people see as barriers to coming in for a clinic visit? (Ask Mel to explain process) *ie. would you be more likely to attend if you could book online & reschedule etc., or not? Would they be more likely to go if they got a text or a phone call?*
- What things could be done to overcome these barriers?

6. Closing

- Summary of key points discussed
- Opportunity for participants to comment/ask questions
- Thank for participation
- Issue vouchers