Report on Children of the 90s Participation Event: ‘Planning the Future of Children of the 90’s’ June 2018

1. Background

On the 24th June 2018 we held an event for study participants at a popular museum in Bristol, called we the curious. The aim of the event was to discover the views and opinions of study participants on a range of topics and feed this into the application to fund Children of the 90s over the next five years.

The event was structured as two separate 2-hour workshops to discuss key areas for planning the next five years of the study:

1. Design of the ALSPAC@30 clinic
2. Children of the 90s App/portal
3. Future data collection
4. Feedback of results
5. Reconnecting with disengaged participants.

Interactive methods were used to create conversation and engage participants in these areas, including post it walls, milk bottles and tokens and balloons with gift tags. Over 100 people attended representing different cohort groups: G1 (original children aged in late twenties), G0 (original study mothers and fathers aged between 50 and 60) and some G2 (children of the children) were also present.

In addition to contributing ideas for the future of the study, a substantial number of participants put themselves forward to become ambassadors for the study and members of the participant advisory panel. These participants will work with us on media, social media and future events. This was an unexpected bonus in addition to the feedback gathered.

2. Feedback on key areas

Participants were asked to contribute to discussions on five key areas:

2.1 Clinic Design

We explained to participants that we are planning to run an open five-year clinic, inviting all Children of the 90s participants to a basic data and sample collecting appointment, with the possibility of extending the visit dependent on further funding.

We anticipate that they will be able to book one visit (or more for G2 or COCO90s participants) over the five-year period and combine their visit with those of other family members. They may be able to book their appointment in Bristol or at another convenient city in the UK.

Participants were supportive of this clinic design. On the whole clinic visits were preferable to questionnaires. One participant summed this up, saying: “I enjoy visits, not online. I would like more clinics, more often”. Participants would like flexibility to attend a clinic when it was most convenient for them, such as in the evening and weekends. One participant said, “There are not enough weekend/weeknight options”.

There was interest in ‘mobile’ clinics and the opportunity to attend the clinic with other family members. A number of participants suggested that the study could improve communication with local Bristol-based employers to aid attendance. One stated that “Flexibility around work hours is needed, for employers to allow time off”. Advertising the clinic as a ‘health check’ was...
considered a positive way to incentivise partners and siblings to attend, in particular to encourage more men to participate. We asked participants to suggest new names for the ALSPAC@30 clinic and a range of names were suggested, most a play on CO90s, Focus and @30.

2.2 Feedback of Results

We explained to participants that in the past we have given some individual results, such as blood pressure and/or cholesterol level and that we are now exploring the possibility of making more results available to participants after their clinic visit.

There was overwhelming support for feedback of results from clinic visits with all of participants asked stating that they wanted feedback. One participant summed this up by saying “I’d be happy to know all my results. In fact, I’d really like to hear more! It would be interesting and useful to know about my own body”.

Some concerns were raised around the potential to cause anxiety, the ability to interpret results and get support and security of data but it was felt that these could be overcome. A participant said, “There can be slight worry due to the effects it can have on a family too, but I like the idea of finding out everything or at least some results”. Another said, “Obviously make sure adequate medical context is provided so you don’t have a results - > Dr Google - > panic!”.

Participants felt that the study could be trusted with their information. There was no preference for the feedback to be given electronically or by post. Many participants commented that the feedback of results could be used as a motivational tool in the same way as the ‘health check’ could. One participant stated that “Incentives can be the FREE health MOT/check-ups & clinical results”.

2.3 Children of the 90s ‘App’

We explained to participants that we are developing a Children of the 90s App or portal. Participants would be able to view results, make appointments, complete questionnaires and update contact details through this web or mobile based app.

Overall, the development of a Children of the 90s app or portal was a popular addition and one which participants would appreciate and see as an improvement on the experience of participation.

This participant’s views echoed many others, “App notifications are more likely to be read than emails”. Participants liked the idea of an App which allowed for personal feedback, “The more personalized the better – personal info about what their input has been used for”. Many participants stated potential advantages, including: having a personalised interface, access to the study ‘on the go’, receiving notifications and centralised logins. Suggestions for further uses of the app included receiving vouchers, voting button, linking to other apps on phone, delivering news including general health news and the feedback of results. A few concerns were raised including safety of data, tracking location and the ability to keep content up to date and engaging.

2.4 Future data collection
We explained to participants that at recent workshops researchers had recommended concentrating on data collection in the following areas: mental health, heart health and diabetes, lifestyle such as sleep, physical activity and diet, emotional relationships (with family and others), social outcomes (such as employment and social status), and friendship networks (face-to-face and online).

We asked participants what data they would like us to collect on them over the next five years. Participants identified a wide range of areas of interest across four categories: mental health/wellbeing, social/environmental, hobbies & social media and medical/health. We asked participants what was important in their lives now and in the future and they told us the following were most important: mental health, work/life balance, finance, family and relationships, fertility and ageing.

2.5 Reaching out to disengaged participants

We asked participants to tell us what we could do better to re-engage participants who no longer took part in the study. They suggested that we continue to promote the study widely (including through social media).

It was suggested that disengaged participants may feel guilty or embarrassed and that they are no longer relevant to the study, particularly if they have spent a period away from the study. Participants recommended that we emphasize the relevance and importance of their contribution and make it clear that ‘it’s never too late to come back’.

Other strategies such as targeting schools, events, employers and incentives were mentioned. Many participants commented that it is important to target men, one stating that “Target men, emphasise the benefits of the study, what has been achieved, offer a free pint!” and “Target men via women participants, who are ‘gatekeepers’ - e.g. ask your brother/dad to fill this out”.

3 Next steps

Along with meetings with academics and study managers, the ideas generated from this event will contribute to planning the renewal application, in particular the content and design of the ALSPAC@30 clinic. Further opinions have been gathered via a participant engagement questionnaire which was completed by 2000 participants in two weeks, helping to shape core components and budget lines for the renewal application.

4 Feedback on the event

We asked the participants who attended the event to provide feedback and their comments afterwards were very positive:

"Was a great forum for communicating current and future plans of ALSPAC",

"Lovely day and a good atmosphere"

“I love the idea of being more directly involved in CO90s! Love this research project!!”