1. Background

In the run-up to ALSPAC’s funding bid, we created a short questionnaire, in collaboration with Wellcome and the ESRC, to elicit feedback from our participants, their families and interested members of the public in order to guide the future direction of the study and to obtain information on preferred modes of contact with participants.

In August 2018 we sent an invite to all eligible cohort members for whom we had an email address (14,242), which included a link to the questionnaire. The link was also promoted on social media. The questionnaire was live from the 1st of August with the objective to collect 2000 participant opinions (or run for 2 weeks – which ever came first). Ultimately these were coincident and by the 16th of August 2,022 respondents had been seen (Figure 1).

![Cumulative response graph](image)

2. Question responses

2.1 What is your connection with Children of the 90’s?

Just over half of respondents were original study offspring (now approaching age 30), and a further third were study mothers. Study fathers and other family members accounted for a much smaller percentage.

![Bar graph showing numbers of respondents and their connection with Children of the 90s](image)
2.2 What do you think Children of the 90s should be researching in the future?

We asked this as a free text question, as we did not want to place any limits on the responses. As illustrated by the word cloud below, mental health was far and away the topic that most respondents felt should be a focus of future research for the Children of the 90s (39%). Genetics and inherited disease and illness (17%), as well as health links within a family (11%), were also frequently suggested areas of research mentioned across the different groups of respondents. Cancer was one of the top five topics mentioned by both study children (9%) and study fathers (12%), with nutrition featuring in the top five for both the study mothers (11%) and fathers (10%).

Figure 1. Responses from YPs to ‘What do you think Children of the 90s should be researching in the future?’

2.3 What would be the best way for us to invite you to take part in data collection activities? Please tell us any other ways you’d like to be invited.

Respondents were invited to rate current invitation methods (letter, phone call, SMT/text, email, facebook, Instagram, twitter, WhatsApp and study App (in development) from most preferred option to least preferred option and also had an option to suggest other ways that they would like to be invited. Email was the clear stand out with 89% of respondents stating that they preferred this method of communication.

2.4 What would be the best way for us to keep you informed of study news such as research findings? Please tell us any other ways to inform you about study news.

Respondents were invited to rate current invitation methods (letter, phone call, SMT/text, email, facebook, Instagram, twitter, WhatsApp and study App (in development) from most preferred option to least preferred option and also had an option to suggest other ways that they would like to be invited. The two most preferred options were email (89%) and a study App (525) followed closely by letters (50%), and the two least preferred were phone calls (9%) and twitter (15%).

2.5 How do you think we should send questionnaires?

We were interested to find out whether participants would prefer to receive a questionnaire annually (as is current practice) or whether they would prefer to receive a smaller number of questionnaires over the year. There was a very clear preference, from all groups for several small questionnaire through the year. This varied slightly across cohort groups with 76% of study fathers, 70% study children preferring the smaller more frequent questionnaires.
2.6 What data collection activities would you be interested in taking part in the future?

We were interested in finding out which particular data collection activities participants wanted to take part in the future. Participants were asked to tick all options that applied from online questionnaires, postal questionnaires, clinic visits in Bristol and outside Bristol and remote data collection e.g. wearables. Respondents were interested in all activities with online questionnaires being most popular (95%), followed by clinic visits in Bristol (82%).

2.7 How can we make taking part in Children of the 90s activities easier?

We asked this as a free text question, as we did not want to place any limits on the responses. Of the people who responded to this question 4 large proportion said that it is already easy (study children – 38%; study mothers – 49%; study fathers – 53%; other family – 19%). For those who did give some suggestions, the most popular was to the clinic based in and around Bristol. Most respondents are of working age, there was a large emphasis on having clinic appointments in the evenings and on the weekends. The study children also mentioned that they would find an app to be a very useful tool as well as things being online, such as the questionnaire and clinic booking system. The study mothers expressed the need for easy car parking and a desire for shorter, but more frequent, questionnaires whereas the study fathers were keen to have more contact from the study and to be given more notice of upcoming data collections. The other family members who responded to this question also favoured online tools as well as suggesting data be collected via remote methods such as from phones or smartwatches and using video calls for those participants who live abroad and cannot attend a clinic.

2.8 Please tell us any of the reasons why you participate in Children of the 90s. Tell us any other reasons why you participate.

We were very interested in finding out why participants continue to participate in the study, nearly thirty years after the study was set up. We gave respondents four possible reasons – scientific interest, benefits to individual/society, family expectations and health check and they were also able to add any other reason in a free text box. The most popular reason was benefit to individual/society (92%), followed by scientific interest (86%) and health check (52%). The least popular reason was family expectation which may reflect the age of participants who are now into early adulthood. Many participants gave other reasons too. The general themes running through most of the responses to this question from all groups were that taking part in Children of the 90s is fun and enjoyable, it is interesting, it helps society and future generations, and the participants feel proud to be part of the study. Just over 10% of the YPs also said that it is ‘a part of life’. These are the original study children who have been enrolled since birth, or even beforehand, and so for them there is a feeling that it is just something that they have always done. Below are some quotes which illustrate these feelings.

“I enjoy it! It’s part of who I am at this point.” (Study child)

“Being part of a large study that has so many benefits to offer for future generations.” (Study mother)

“Proud to be a part of it, and it being part of my daughter’s life.” (Study father)

“Interested both as a sibling of a study child and just missing out on being a study child myself.” (Other family member)
2.9 Any other comments?

The content of the answers to this question was overwhelmingly positive, supportive comments such as:

"Thank you for all the amazing work you have done" (Study child)

“This is a fabulous study and I’m always so proud when any part of it is discussed in the media” (Study mother)

“Keep going! This is an extremely valuable study and I support it fully” (Study father)

“I think Children of the 90s is a fantastic study, long may it continue!” (Other family member)

These types of comments were echoed by 85% of the study children, 75% of the study mothers, 82% of the study fathers and 57% of the other family members. The answers were highly varied and specific. There were several comments from different respondent groups to say that they would welcome more information about study findings. Perhaps unsurprisingly, five out of the 14 ‘other family’ respondents expressed a wish to be more involved in the study.

There were very few negative comments, and, of these, most were constructive such as:

“I would like to know more about the samples I give. For example, COTN will contact a person if their samples show something abnormal or something that may be of concern. I would like to find out information even if everything is normal.” (Study child)

“I don’t personally like being weighed and measured with someone doing it, so maybe this can be done on your own or in a machine that does it for you.” (Study child)

“Make some of the sessions a joint visit for parent and study child to encourage participation from the study child.” (Study mother)

“As a sibling of a study child I have never actually been sent any questionnaires despite being very interested over the years. I think you could have done more with this.” (Other family member)

3. Summary and recommendations

We were extremely pleased that over 2,000 people (the vast majority of whom were study participants) responded in two weeks during the busy summer holiday period.

A number of recommendations are made as a result of this questionnaire. These are:

1. Mental health is the stand out topic of concern. Mental health should continue to be researched now and in the future across all cohort groups.
2. Participants should be offered a range of ways to keep in contact with the study and keep abreast of study findings. Email should be used as the first method of choice. However, it is preferable for participants to be offered their choice of contact methods. This will be possible through the development of the study app/portal, the pilot of which will be developed by the end of 2018.
3. Local clinics in Bristol are popular and should continue at times suitable for people of working age e.g. weekends and evenings. Consideration should be given to the costs and benefits of running clinics outside of Bristol.
4. Participants are interested in what the study can offer in terms of benefits to the individual and society as well as scientific findings arising from the research. Communications to participants such as newsletters and social media posts should reflect these more directly talk to these interests.

5. Online questionnaires are the preferred way to collect new data. There is a clear preference for smaller more frequent questionnaires. These should be offered to participants as soon as possible. It is preferable for participants to be able to choose how frequently they complete questionnaires and the study App/portal will facilitate this.

The results of this questionnaire, along with the feedback from participant events running in parallel will help inform Children of the 90’s staff as they plan the next five years of the study.