

Findings from the 2018 Aberdeen Children of the 1950s Participant Workshops

Background

The Aberdeen Children of the 1950s (ACONF) study consists of 12,150 individuals who were born in Aberdeen in the 1950s. The study includes health, education, and social data on the participants' childhood and adulthood. The last survey of members was almost 20 years ago. In the near future we plan to re-survey members of the Aberdeen Children of the 1950s to study ageing.

However, before we begin the next stage of the study, we felt it was very important to ask study members to help us co-design the research and the way we will interact with them in future research. In 2018 we held three workshops with members of the Aberdeen Children of the 1950s study to do this and the results are given here.

The workshops

Each workshop covered a different theme, although there were overlapping topics covered by all three. The workshops involved discussion between a researcher and between 8 and 10 Aberdeen Children of the 1950s study members. The advantage of these group sizes is that they are small enough to give all participants the opportunity to participate in the discussion and have their views heard. However, we recognise that it is also a limitation that only a small number of study members could be included. The research funding for this project allowed only three workshops, however by conducting the workshops we make it more likely we will secure further funding for future activities.

The workshops were recorded and the findings were summarised by members of the research team. The workshops were:

1. Healthy ageing

We gathered views on what healthy ageing means to participants in order to inform us how best to measure ageing in future research and what topics we should prioritise.

2. Recruitment and consent

We gathered views on what is important to study members when it comes to giving consent to participate in research. We sought opinions on the best ways to collect information and what participants feel are appropriate and reasonable ways to do this.

3. Maximising participation

We discussed different ways to collect information in research (such as questionnaires and blood tests). We sought views on approaches which would maximise participation by study members in future research. The findings of this workshop were similar to those of workshop two.

Findings

1: Healthy ageing

Workshop attendees viewed healthy ageing as keeping socially and physically active, taking responsibility for yourself, feeling confident and having a positive attitude to ageing. They felt we should be helping people learn how to do that from an early stage. In this group, many had gone through an education system that placed a lot of emphasis on prevention and staying healthy. They also felt that our genes play a part in how we age, and what diseases we suffer from.

Participants felt that early retirement was a good phase, and if you look after yourself, you could enjoy a long ageing period. Participants described poverty, loneliness, degenerative diseases, and care homes where the care is not appropriate for their needs as being factors hindering healthy ageing. They felt strategies should be put in place to care for an ageing population in the future.

Participants felt researchers should prioritise research into: dementia, technologies which can assist with ageing well, advice/information/education, improving the care system and engaging with hard-to-reach groups.

2: Recruitment and consent

In general, workshop attendees did not remember being part of ACONF as children. They welcomed the more recent contact by researchers (e.g. the newsletter). There was a sense that being part of ACONF was special and important. Participants were very keen for ongoing research and reported they had trust in researchers using their information appropriately.

The attendees reported the following as reasons to take part in research:

- Interesting
- Giving something back to future generations
- A good opportunity to have a check of their own health
- An opportunity to make changes to improve their health

When thinking about how best to conduct a future survey, participants generally preferred online survey methodologies over paper but felt that having the option of either paper or online is important. Participants would prefer shorter surveys (less than 30 minutes or 5 pages maximum). Flexibility over completion would help (e.g. being able to save and return to a survey at a later date).

There was little concern about more invasive tests (blood tests, scans). However, some felt they would not like to participate in these due to finding the tests unpleasant. Similarly, there was little concern about the collection of DNA or linking personal hospital and other records to the study.

Participants would prefer regular participation (e.g. every 2 or 3 years) as they feel this would maximise research benefits. They felt that the likelihood of participation is higher if study members understand clearly WHY a particular question is being asked and also if it is clear that it is for ACONF (clearly branded). Participants were also very keen to see their results and

the findings of the studies which are conducted using ACONF data. Flexibility in testing would be welcomed: e.g. online or paper survey, having in-person attendance fitted round schedule.

Participants were keen to be aware of research activities and gave suggestions as to how this could be achieved:

- More informative and accessible website
- Lunchtime events or conferences for participants to attend

Participants raised no issues regarding including their children and family but generally felt that their children in particular would have less time to participate and are more geographically dispersed which limits their ability to participate. Participants were keen to be involved in maximising recruitment e.g. by passing study details to others who may be in ACONF or to their children.

3: Maximising participation

Similarly to workshop 2, participants were generally happy to use the range of data collection methods discussed: questionnaires, applications and wearable devices, and in-person tests (both at home or in clinic). There were no major concerns regarding the nature of information or data collected (e.g. sensitive questions, DNA collection) although sharing digital content such as emails or texts was not acceptable. Participants felt their children would be likely to participate or that at least it would be acceptable to ask them to participate in the study.

Participants described the following as a way to maximise participation:

- Transparency over the use of individual data and how it will be protected
- Informing ACONF members of the potential health benefits to themselves or others
- Regular contact with participants (e.g. newsletter, face-to-face events, email, website, phone “app”)
- Informing ACONF members of the results of studies

Attendees felt questionnaire participation would be increased by having an option for paper or online completion, by informing participants how long it would take to complete and by giving a response time of approximately two weeks for completion. A longer survey every two

years, with contact between, was acceptable. A “smart-watch” rather than a smartphone was seen as a more feasible way to collect information and therefore would be more likely to lead to participation.

Flexibility over the timing and location of in-person testing may make participation more likely. It was recognised not all individuals may want to participate e.g. those fearful of clinical settings. Therefore, the location of in-person tests should include non-healthcare settings.

Next steps

As for all studies, in order to conduct detailed research, we need to secure funding from external agencies. This is a competitive process. The study team will be submitting applications to research bodies to source funding to re-recruit all members of the Aberdeen Children of the 1950s. The findings from the workshops will be a crucial part of these applications. In the meantime, there are a number of other studies in progress which are utilising the existing data we hold. Later in the year a newsletter summarising study activities will be sent to all members for whom we have contact details. We are in the process of organising a public talk to give members information on past and present research activities.

Further information

If you have any queries you can contact the study team via:

Tel: 01224 437288

Email: children1950s@abdn.ac.uk

Postal: Children of the 1950s study, Room 1:073, Polwarth Building, Foresterhill, Aberdeen, AB25 2ZD

If you know someone who may be part of ACONF but does not receive the newsletter, please let them know they can contact the study team if they wish to participate or find out more.

Information on previous and existing studies is available on the website:

www.abdn.ac.uk/birth-cohorts/1950s



You can also keep in touch by following our Facebook page: *@aberdeenbirthcohorts* or Twitter account: *@ABC_Aberdeen*