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Co-design of data collection with participants of the Aberdeen Children of the 1950s cohort study

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Background

The Aberdeen Children of the 1950s (ACONF) cohort contains 12,150 individuals born in Aberdeen, Scotland in the 1950s. The study includes rich early life data, information from questionnaire in middle age, and linkage to electronic healthcare records.

Involving the participants in designing future data collection and research is key to ensure research is acceptable and reflects public priorities.

Aim

To gather ACONF participants' views to inform how to: define healthy ageing, optimise recruitment and maximise participation.

Method

We undertook three co-design workshops with 8 to 10 ACONF members. The workshops operated as a discussion, led by a facilitator using guidance questions developed by the study team. Workshops were recorded and transcribed.

Results

Healthy ageing:

Participants viewed healthy ageing as keeping socially and physically active, taking responsibility for oneself and having a positive attitude to ageing. Key research priorities were: dementia, healthy living advice, improvements in the social care system and engaging hard-to-reach groups.

Optimising recruitment and participation:

Participants were keen for further involvement in research. Recruitment may be maximised by: more information online, involving participants in recruitment of other study members and clarity about potential benefits to themselves or others. It is acceptable to ask their offspring to participate.

There were high levels of trust in researchers, but ongoing data protection is vital. Participation may be improved by regular contact (informing participants of results, engagement events, newsletters, mobile phone "apps").

Participants were happy with data collection methods: questionnaires, applications, wearable devices, and in-person tests. They raised no concerns regarding DNA collection and electronic record linkage.

Conclusion

Participant involvement in research is a fundamental part of securing a social license for research. Participants were in favour of ongoing research, including recruitment of their children and linkage of electronic records. The workshops highlighted key considerations for future research and data collection.

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