

# CLS Cohorts Qualitative Research

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# Summary

## Project overview

The purpose of this project was to carry out qualitative research with a sample of cohort members from all four cohort studies to inform the scientific and methodological development of the studies over the next 10 years. The project sought to provide in-depth insight into attitudes towards and the acceptability of new innovations in data collection and participant engagement. Specific topics covered by the research were motivations for participating, new ways to keep in contact with study members, use of incentives, data collection mode and frequency (including conducting major surveys short 'in-between' surveys online), use of new technology (e.g. apps, activity trackers, GPS), novel data linkages (e.g. social media, banking) and collecting data and/or data linkage from partners and other family members.

## Methods

Ipsos Mori conducted 28 in-depth interviews (10 face-to-face and 18 via telephone) and one focus group with study members from each study. Focus groups involved 8 participants so in total 144 study members were involved in the research (112 in-depth interviews and 40 focus group participants). Fieldwork was conducted between 24 April and 11 June 2019.

Study members were approached by Ipsos Mori recruiters who, for the in-depth interviews used quotas including gender, ethnicity, household composition and qualifications to ensure that a diverse range of participants were involved. During recruitment information was also captured about use of technology and confidence with internet use. For the focus groups, study members were approached based on their proximity to the venues to be used (Manchester for MCS and Next Steps, London for NCDS and BCS70).

Discussion guides (with accompanying stimulus materials) for the in-depth interviews and focus groups were jointly developed by CLS and Ipsos Mori. In-depth interviews lasted around 60 minutes. Questions were tailored where appropriate to refer to the specific history and context of each of the four studies. Focus groups lasted around 90 minutes. A £30 incentive was given to in-depth interview participants, and £50 was given to focus group participants.

Ipsos Mori subsequently carried out 30 telephone interviews with family members of those who took part in the initial in-depth interviews (specifically parents of MCS cohort members, resident partners of NCDS, BCS70 and Next Steps cohort members and children over 16 and living at home of NCDS and BCS70 cohort members). The interviews lasted around 20 minutes. Participants were questioned about their awareness of the studies, and their views on potentially taking part in the studies in the future, either by participating directly or by consenting to data linkage. Fieldwork took place between 12<sup>th</sup> August and 5<sup>th</sup> September 2019. A £20 incentive was provided to participants.

## Findings

The report from this project provides in-depth insight into study member attitudes towards a full range of new potential innovations for the CLS cohorts. The key findings are summarised below.

- Levels of engagement and motivations for taking part varied between the cohorts. Members of the older cohorts (NCDS and BCS70) were more likely to cite the societal benefits of the studies as primary motivators for taking part and also a sense of civic duty, whilst members of the younger cohorts tended to be more neutral or indifferent, with MCS cohort members often reporting that taking part was 'just something they did' and Next Steps cohort members often mentioning the incentives received as key motivators.
- Participants from all four studies were keen to receive more information about study findings and for a wider range of modes of contact to be used to provide this information.
- NCDS cohort members did not think that taking part should be incentivised. This was also the strongest view amongst BCS70 cohort members. Next Steps participants have always received incentives. For some these were a major motivator, but others noted they would be happy to participate without. MCS study members would accept incentives but many did not expect them.
- NCDS cohort members were keen for major surveys to continue to be conducted face-to-face and felt these could take place more regularly. Views amongst BCS70 and MCS cohort members were mixed, some expressed a preference for face-to-face interviewing but others were keen on the convenience of being able to take part online (and many MCS participants spontaneously mentioned the participating via an app). Next Steps participants have been able to participate online for some time and were keen to continue being able to do so.
- Participants from all four studies were enthusiastic about more regular short web-surveys in between the major surveys.
- When asked for views on potential new forms of data collection (such as screen-time tracking or GPS tracking) and new types of data linkage (such as social media or financial transactions) participants from all studies had a number of concerns including fears that data could be used for commercial gain, particularly if third parties were involved and the feeling that such requests could feel overly intrusive or like 'surveillance'. It was widely suggested by participants that clear information would be required regarding what data is being collected, why it is needed, and how security will be assured.
- NCDS, BCS70 and Next Steps participants were broadly open to the idea of the studies collecting data from their partners and other family members. However, a consistently expressed view was that study members themselves should be asked for consent before any contact is made with others. MCS participants were positive about the continued involvement of their parents, but made it clear that they would now be expected to be treated as independent adults.
- Family members of the cohort members were asked about their views on participating in the study themselves – either directly or via data linkage. Family members from all four studies were broadly positive about the idea of being asked to provide data to the studies and could see the value that this would bring to the studies. Some hesitancy was expressed around data linkage and despite

reassurance around anonymity and confidentiality some expressed the view that they would rather provide information about themselves directly. MCS parents, were keen to both continue to take part and to receive information about the study.

## Next steps and recommendations

The detailed report from this project provides in-depth insight into study member attitudes towards a full range of new potential innovations for the cohorts, and these findings will be extremely informative and useful for CLS. The findings will be shared with and discussed by the scientific leads, the survey management team, the cohort maintenance team and communication team and will feed into key decisions around the potential adoption of these novel approaches over the coming years. They will directly feed in to future decisions on mode and incentives for future sweeps, in particular for Next Steps and MCS, and to the ongoing development of our participant engagement strategy. We are also aiming to supplement this qualitative research with quantitative feedback questions on similar topics administered during between-sweep web surveys, and for Next Steps this was included in the short web survey which took place in July/August 2019.

The differences between cohorts are striking and interesting, though not unexpected. The reasons for these differences will likely be multi-faceted and include differences in duration of involvement, generational differences in the importance of civic duty, age of participants and contextual differences between the studies in terms of how participants have been contacted and asked to take part. It is unlikely that differences in levels of engagement are strongly related to differences in data collection mode that have been used in the past.

In relation to new forms of data collection, it is clear that very careful weighing up of the potential scientific benefits and participant burden would be required before decisions were made to move forward with a particular project, as well as appropriate steps to minimise risk and ensure data security. Careful piloting, exploring acceptability amongst study members would be essential, and as expressed by study members in the qualitative work it would be vital to provide full clarity regarding what data is being collected, why it is needed, and how security will be assured. It should also be noted that for the qualitative research, participants were given much less information about the proposed new form of data collection than they would be if they were asked to do this, and the research sought their initial views about a number of different possibilities. The findings are less concerning regarding the future possibilities of collecting these new forms of data in this context.

In general, as the context of each of the cohort studies is very specific, the applicability of the findings to other studies is limited. Having said that, some of the cohort differences, particularly in preferences regarding mode and engagement, are likely to be due to generational differences and as such these findings would be of interest to other studies of similar generations. Additionally, the concerns raised with regard to new forms of data collection will doubtless be shared by participants in a wide range of different research studies, and may in fact be greater in studies which have not had so long to establish trust from participants.