

National Statistician's Data Ethics Advisory Committee

Correspondence Minute

Papers reviewed via correspondence, November 2021.

1. **Qualitative projects with under-represented groups, including; children with special educational needs and disabilities, Gypsy and Traveller groups, and disabled adults.**
- 1.1 This round of correspondence contained three applications from the Qualitative Team, Centre for Equalities and Inclusion, Office for National Statistics. The three projects were:
 - i. Gypsy and Traveller lived experiences project. NSDEC(21)17.
 - ii. Children with Special Educational Needs and Disabilities (SEND) school experiences project. NSDEC(21)18.
 - iii. Disabled adults' experiences with activities, goods and services project. NSDEC(21)19.
- 1.2 These projects followed on from the work of the Inclusive Data Taskforce (IDTF) which engaged with central government, local government, devolved administrations, academic and civil society organisations, as well as members of the public, to understand the barriers and facilitators to inclusive data in the UK. A comprehensive report was published alongside a set of recommendations detailing how to achieve this step-change in inclusivity.
- 1.3 The IDTF recommendations included the need for qualitative or creative methods to better understand the lived experiences of currently underrepresented groups and to improve research accessibility and inclusion. Three of the underrepresented groups that were identified were disabled children, Gypsy, Roma and Traveller communities, and disabled adults. The qualitative projects considered by the NSDEC intend to take forward the recommendations of the IDTF, through conducting qualitative research with these identified underrepresented groups, to better understand their lived experiences, priorities and needs.
- 1.4 **Gypsy and Traveller lived experiences project. NSDEC(21)17.**
- 1.4.1 This project is a three-stage qualitative research project with members of Gypsy and Traveller communities in England and Wales, examining their lived experiences, challenges, needs and priorities, in order to expand the evidence available within UK data holdings about these communities.
- 1.4.2 The three stages of the research include:
 - i. 10 online interviews with policy colleagues from other government departments working on policy which covers Gypsy and Traveller communities. A further 10 interviews will be conducted with employees of local authorities correlating to sites chosen for the research, responsible for policy implementation which directly affects Gypsy and Traveller communities.
 - ii. The second stage of the research will involve supporting employees of Civil Society Organisations with existing relationships with the community to conduct 50 life-story/narrative inquiry interviews with individuals in a range of accommodation types, from different age groups. The interviews will explore

topics of importance to participants, as well as participants' views on education, healthcare, accommodation, employment and crime.

- iii. The third stage of the research will then involve a series of 5 public dialogue discussion groups, held in the communities which featured in the interviews. This will give community members and policymakers the opportunity to discuss the findings of both stages of interviews and explore ways to move forward.

1.4.3 Based on the NSDEC's initial comments, the following points and assurances were provided during the round of correspondence:

- i. The researchers confirmed that information on safeguarding will be included in the consent forms which will be either given or read to participants. This assured the NSDEC that the participants would be aware of safeguarding commitments of the research team in line with the ONS safeguarding policy, and what the implications of it are.
- ii. The Committee emphasised the importance of ensuring that participants know that their interview data might actually influence government departments and policy, depending on the findings and how these are disseminated and used. The team assured the Committee that the information supplied to participants would accurately reflect the possibilities and the limitations of the research.
- iii. The NSDEC had noted that having combined policy, local government and community members in the same focus group discussions may be problematic due to the risk that such group heterogeneity might hinder free discussion or lead to confrontation. The researchers acknowledged the concerns but stressed the opportunity for community members, policymakers and local authority employees to meet and discuss findings and potential solutions is crucial to the efficacy of the research and the co-productive approach. The NSDEC was assured that steps would be taken throughout the planning and facilitation of these focus groups to ensure that potential risks of conflict are minimised.
- iv. The Committee advised that more thought should be given to the makeup of the focus groups; especially relating to whether holding single sex focus groups, which could skew results by creating artificial groups of people, is most appropriate.
- v. The NSDEC was assured that the exclusion of the Roma community for this project was due to the vast differences in the cultural, social and historical context of Roma communities. It was thus recommended, by the research team's advisory group, that if the Roma community were included, this may stretch the focus of the research, thereby undermining potential rigour and depth of meaningful insight.
- vi. The Committee advised that there be future research plans to ensure inclusivity for the Roma community. The research team confirmed that they intend to conduct qualitative research with Roma populations and are committed to taking this forward, however, this is reliant on the funding for the next financial year.
- vii. With regard to social distancing measures, if rules due to COVID-19 do not allow in person research, it was confirmed that a 'Plan B' has been discussed which would include conducting interviews via telephone calls,

videoconferencing software, or for interviews to be held outside (in a private location; weather permitting).

1.5 Children with Special Educational Needs and Disabilities (SEND) school experiences project. NSDEC(21)18.

- 1.5.1 This project aims to explore school experiences of children with special educational needs and disabilities (SEND) by conducting qualitative interviews with approximately 60 pupils and parents/carers of pupils attending secondary special schools, mainstream schools, pupil referral units and those who are home-schooled. The objectives are to explore the meanings that disabled children place on their school experiences, compare experiences across school settings and explore the broader context from the perspective of parents. This research should enable an improvement in understanding around what is important to children with SEND, where provision may fall short and how provision could be improved.
- 1.5.2 For the interviews with the children, a range of creative methods will be used as facilitative techniques to encourage children to feel more comfortable and engage in more accessible ways than is possible with traditional interview methods. Such techniques will tend towards participant-led interviews, which enable children to choose what they would like to talk about, thus focusing on what is important to children rather than exploring areas pre-determined by the researchers as being of importance.
- 1.5.3 Additionally, there will be four to five roundtable discussions with approximately 20 staff members who work with children with SEND to provide context of SEND provision and enable comparisons between educational settings.
- 1.5.4 Based on the NSDEC's initial comments, the following points and assurances were provided during the round of correspondence:
- i. The researchers submitted a literature review to the NSDEC which showed that there is a need to conduct research to understand the views of children with SEND due to this being an underrepresented area within research. The literature review assured NSDEC that this research is being grounded in current knowledge and addressing the identified need for research on children with SEND and their experiences in school.
 - ii. The Committee was assured that conversations have been held for the scoping phase of the research, as well as for analysis, which included the Department for Education (DfE) providing questions to be integrated into topic guides.
 - iii. The Committee was assured that there will be a flexible approach to data collection, meaning that the methods employed will be those most suitable to each individual and their needs. All the methods used will be evidence-based, developed and piloted with children with a range of needs prior to data collection. This assured the NSDEC that the various special needs or disabilities of the children, which may mean varying levels of guidance required, would be considered.
 - iv. It was confirmed that relevant background information would be gathered to determine whether someone, who the child is comfortable with, should be present to read any signs of when physical behaviour might occur to balance

the risk of potential harm to the interviewer with the confidentiality/anonymity of the participant. Others who are present during the interview will be asked to sign a consent form agreeing to confidentiality and interpretation to ensure the child's voice is reflected.

- v. Furthermore, the NSDEC were assured that all interviewers are fully briefed in, and familiar with the ONS safeguarding policy, and would also become familiar with individual school's safeguarding policies as well.
- vi. The researchers assured the Committee of the suitability of group discussions for the purpose of interviews with staff and committed to sharing the final topic guide with the NSDEC secretariat for review prior to data collection.

1.5.5 Action – The research team to share the final topic guide with the NSDEC secretariat

1.6. Disabled adults' experiences with activities, goods and services project. NSDEC(21)19.

- 1.6.1 This project will aim to take the IDTF recommendations forward, through examining disabled people's experiences with activities, goods and services. In-depth interviews with approximately 40-60 disabled people lasting 60-90 minutes each will be undertaken to explore their daily life experiences (including barriers to access) with a range of activities, goods and services, and identify solutions and recommendations for improving accessibility and engagement to these. An intersectional sample will be sought, including individuals with a range of impairment types and characteristics including sex, age, ethnicity, geography, socio-economic background, and employment status.
- 1.6.2 The aim is for the findings generated from this research to be used to inform policy and service provision, so these can be tailored to reflect and meet disabled people's needs. It is hoped that this research will also support the development of regulations to ensure disabled people can have the maximum possible participation in society in their daily lives.
- 1.6.3 Based on the NSDEC's initial comments, the following points and assurances were provided during the round of correspondence:
 - i. It was confirmed that the research participant will be asked their preference for interview arrangement, including whether they would like a personal assistant to be present as their support during the interview. If a personal assistant is chosen, this would be reflected on during data analysis, with the number of people present for each interview noted. This assured the NSDEC that it would not be assumed that an assistant is needed, as there may be instances where the presence of a personal assistant is not necessary and may compromise participant's freedom of expression.
 - ii. The research team confirmed that a sampling matrix will be suggested by the Supplier and approved by ONS, however the Committee was assured that the sampling approach will aim to include a variety of characteristics and experiences. The team stated that they will inform the NSDEC secretariat accordingly of the proposed approach to sampling.
- 1.6.4 **Action – The research team to supply the proposed approach to sampling to the NSDEC secretariat.**

1.7 Common points raised for all three projects

1.7.1 In addition to the points raised for each specific project, the NSDEC provided initial comments which applied to all three projects, the following points and assurances were provided:

- i. The NSDEC was assured of the rigour and importance of the qualitative methods being used, and explained the importance of collecting rich qualitative data, which has different implications for required sample sizes in comparison to quantitative data. The Committee was further assured that an iterative approach to data collection and analysis will be adopted, whereby approaches are adapted as data collection progresses to further explore emerging themes to ensure the research is not hindered by a small sample size.
- ii. The Committee was assured that qualitative research can make uniquely valuable contributions to policy development and evaluation, as well as service provision. Statistical data on its own cannot provide a comprehensive understanding of lived experience, and complex social issues benefit from insights beyond linear, standardised evidence. This assured the Committee as to how this work will be useful and lead to better informed policy making and service provision.
- iii. The research team explained that ONS will receive bespoke training from experts on both positionality and the reflective process. This will enable the ONS team members responsible for collecting, analysing and drawing conclusions from the study to reflect on how a researcher's positionality can shape the research they conduct. This assured the Committee that steps are being taken to mitigate the risk of bias arising from any lack of diversity among those analysing and drawing conclusions from the studies.
- iv. The Committee asked whether a process to assess the readability of the consent forms, to account for each participant's level of comprehension, will be conducted. The Committee was assured that for each of the projects measured are to be taken. This includes:
 - a. For the adults with disability project, the approach to sharing information will be adapted depending on individuals' needs, and there is also the option of information being provided through an audio format where preferable or more appropriate. Draft materials will be shared with advisory group members, including those with lived experience, to gain feedback on accessibility, appropriateness, and clarity, with materials being adapted accordingly.
 - b. The children with SEND project confirmed that there will be various versions of the consent forms available, including written, illustrated and other formats (e.g., brail) to suit the child's need. Participants will be able to select the forms they feel are most appropriate for them.
 - c. The Gypsy and Traveller lived experiences project confirmed that interview materials will be reviewed by the research partner, who have first-hand experience of writing materials for Gypsy and Traveller populations. Also, due to potential illiteracy among participants, the interviewers will be reading aloud all the information listed in the information sheet to participants, as well as supplying participants with a written copy.

- v. The research team assured the Committee that ONS research teams will be overseeing each project and will be fully engaged throughout the whole research process. This assured the NSDEC that despite the complex and in-depth nature of the research, the expert supplier would not be unfairly inundated with an unfeasible amount of work and responsibility. Further to this, details of the expert suppliers, who were recently awarded contracts, were provided:
 - a. It was confirmed that the Supplier adults with disability project is HumanKind Research. HumanKind is a research organisation with significant qualitative research experience and has a record of conducting inclusive research with vulnerable populations, including on sensitive topics.
 - b. For the Gypsy and Traveller lived experiences project will be overseen and managed by Derbyshire Gypsy Liaison Group (DGLG), in conjunction with several charitable community support organisations. DGLG are a well-established charity who provide support and advice to Gypsy and Traveller people in the UK.
 - c. The children with SEND project confirmed that the National Association for Special Education Needs (nasen) submitted the successful bid. nasen is the leading SEND organisation in the UK. They have extensive experience conducting qualitative research projects with children with a range of support needs.
- 1.8 The Committee thanked the research team for their thorough and thoughtful application, and responses.
- 1.9 **Action – The research teams from the Qualitative Team, Centre for Equalities and Inclusion, to keep the Committee updated on the three projects, and any further iterations.**