Paving the Way for Inclusive Research: Summary

Better Practice research with disabled people and people with long-term conditions

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Research Plan

Ofcom and the Communications Consumer Panel asked Magenta to carry out a research project. It looked at better practice for including disabled people and people with long-term conditions in research. Our aim was to have actionable recommendations to help us to make our research more inclusive.

We did a literature review and completed additional analysis of the language used in some of the reports. We spoke to 40 experts and 21 of those also came to a workshop. These experts came from different sectors, including charities, academia, market and social research, government departments and regulators and diversity and inclusion experts.

There are three key themes that have come out of the research, that cut across all the findings:

1. **Positive Intent:** What are your intentions behind the research and have you been clear with people taking part about these?
2. **Rationale:** Have you provided a reason for the choices you have made?
3. **Transparency**: Have you been open and honest in your reporting about the decisions you have made and any limitations?

Below are the main recommendations from the project, split across the different stages of a research project.

Describing people and writing about their experiences

- Language is important in making people feel included in research.
- The term ‘disabled people’ rather than ‘people with disabilities’ should be used in most cases.
- Researchers should think about how people describe themselves and reflect this.

- Researchers should be consistent in how they use language across a project.
- Researchers should be open about the choices they make about language in documents, such as a questionnaire.
- Writing reports in an inclusive way is key, making sure language does not stigmatise disabled people or portray disability as negative.

Definitions of disability

- Researchers should explain why they are asking about disability, so people know why the information is needed.
- The current Government Statistical Service (GSS) definition is important, and there are reasons for using it. These include consistency and comparisons with other data sources such as Official Statistics.
- But, there may be reasons not to use it sometimes, and other questions might work better. Considering the topic and nature of the research is important in deciding what definition might be used.
- Asking about barriers, access and support needs can be an added extra to the GSS definition or an alternative, and if the research does not require people to be grouped, ask people how they choose to describe themselves.

Sampling

- Some experts we spoke to, discussed the challenges of deciding who to recruit, and others did not want disabled people to be categorised as 'disabled' or by a disability type or condition.
- Being clear about using terms such as 'disabled people' is important, as well as explaining about what 'nationally representative' examples include.
- When conducting research, consider a minimum quota for nationally representative samples, but be clear about the challenges with this.
- Be clear about which demographic data (e.g. age, gender, ethnicity) you will be collecting from the start of a project.

Recruitment

- Ensuring different and appropriate ways of finding people to take part in research are used is important, and multiple methods, both online and offline, are important to this.
- Giving people enough information to make a choice about taking part in research is important, and can help build trust.
- Consider using easy-read materials, translate materials into British Sign Language and screen-reader accessible materials.
- Asking about access needs upfront is important.

Research Methods

- Access needs should be considered at all stages of a research project, to ensure that adjustments and accommodations can be made to allow for inclusive research.
- For specific research with disabled people, involving them in the process is important. Co-production, lived experience panels or advisory boards are examples of this.

Reporting

- From the start of any project, it should be clear to participants how findings will be reported, and how quotes and case studies will be used.
- If the sample size allows, think about analysis looking at different demographic characteristics, such as age, gender or ethnicity, alongside disability.
- In reporting qualitative research, reflecting how people describe themselves is important.
- Ensuring the reporting is in an accessible format is important, and shared with people who took part where possible.
- Where possible when reporting qualitative findings, report in ways that bring disabled people’s experiences to life.