

## 1 Introduction

### A note on definitions and use of language in this tool

#### 1. Person-first vs identity-first language

It is important to consider the language we use when working with disabled people in research. This is to ensure it is respectful and based on the participant's preference (Isaacson 2021). The participant can be asked if they prefer a person-first language or identity-first language:

- **Person-first language** recognises the person before their disability (Isaacson 2021). For example, saying 'person with disabilities'.
- **Identity-first language** recognises a person's disability as part of their identity (Isaacson 2021). For example, saying 'disabled person'.

It is always best to ask disabled people what their preferred choice of language is. However, both NHS England's style guide and UK government guidance call for the use of identity-first language in most instances (NHS England 2023; Disability Unit 2021).<sup>1</sup> As such, throughout this tool we use identity-first language.

#### 2. Universal and targeted adjustments

Throughout this tool we indicate examples of both universal adjustments and targeted adjustments that can be implemented to fieldwork processes. These are defined as:

- **Universal adjustments** refer to the process of designing everything to be usable by all people to the greatest extent possible, without the need for adaptation or specialist design (Disability Unit 2011).
- **Targeted adjustments** are accommodations that are made for individuals based on their needs. This includes considerations around settings, mode of response, and scheduling/timing.

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<sup>1</sup> Exceptions include but are not limited to people with a learning disability, epilepsy, diabetes, or anxiety and depression.

## 1.1 Overview

This tool sets out guidance and key principles for conducting inclusive and accessible fieldwork with disabled adults, and disabled children and young people. It was developed as part of activities related to Disability History Month, and is based on a rapid review of literature, toolkits and guidance on making social research accessible.

We are aware that referring to “disabled people” risks generalising highly varied populations with many different disabilities. Throughout this tool we refer to specific disabilities where possible. We also recognise that people with similar disabilities are likely to have very varied experiences and views, which will also be shaped by other aspects of their identity such as gender, race, ethnicity and sexuality. Therefore the information presented will not encompass the best way to involve everyone; individuals’ preferences, expertise, experience and needs will inform the best way to work alongside them.

## 1.2 Conducting fieldwork with disabled adults

### 1.2.1 What the guidance says

Guidance and toolkits suggests the following key questions to consider to make fieldwork accessible:

- What barriers to participation are our research participants likely to have (this may include barriers relating to the environment, attitudes or organisations) and what different types of support may be required to ensure that disabled people can meaningfully participate? (NSERC 2022).
- Which, if any, disabilities and impairments are our research participants likely to have, and what does this mean for the cost, time and resource we allocate to implementing both universal adjustments and targeted adjustments? (Unlimited 2017).
- Have we factored in an appropriate balance between making anticipatory adjustments, while also factoring in sufficient time and resource to make adjustments that participants might require as part of project delivery? (NSERC 2022).

Generally, there is consensus amongst the guidance that it is important to build in key considerations around making fieldwork accessible as early as possible in the research process. This includes factoring in sufficient time and resource to project plans and costings to design and implement anticipatory adjustments, and also to check with participants if they have particular access requirements.

### 1.2.2 Ask early, and ask everyone about accessibility needs

Guidance states that it is best practice to ask all research participants about their accessibility needs up-front. This is because doing this as part of standard intake processes, i.e. via scheduling emails, consent forms, and information sheets, shifts the burden of accessibility away from the disabled person (Inclusive Research 2017), and can ensure that the research team has sufficient time to plan the necessary adjustments (Rios et al 2016).

In addition, Rios et al. (2016) state that it can be useful to use a set of guiding questions to be developed to identify any needs related to the fieldwork. This means that participants are able to identify their needs without requiring them to provide a diagnostic label. This may include questions around needs relating to visual, hearing, cognitive or learning impairments. However, the exact nature of these questions should be adapted based on the fieldwork and project context, and the accommodations that can be made.

### **Example wording for asking research participants about reasonable adjustments (Inclusive Research 2017).**

*Please let me know if you require any accommodations to participate in this interview. This might include a break for concentration, a sign language interpreter, specialised technology, or receiving the questions in advance. We will do what we can to ensure that this is an accessible experience for you.*

At Cordis Bright, we aim to implement the principles of universal adjustments as part of our standard offer. This includes offering participation virtually as a default (in line with our digital first strategy), providing all research participants with detailed information in advance about what taking part in the research will entail, and taking a flexible approach to interview scheduling and duration (Isaacson 2021).

Where we can anticipate that we will be conducting fieldwork with disabled adults up-front, we also work closely with clients, delivery providers and practitioners to design and implement targeted adjustments to the research process in line with the project's brief, budget and objectives. We should also ask all research participants about accessibility needs as part of fieldwork recruitment activities. Individual targeted adjustments that are possible to implement on a case-by-case basis should be decided and agreed in proportion to key considerations around timescales, costings, ethics, the representativeness of the planned sample size, and the qualifications and skillset of the research team.

### **1.2.3 Collecting informed consent**

#### **Informed consent and the Mental Capacity Act**

The Mental Capacity Act sets out requirements for research with people who may not be able to make their own decisions. This might include people with more profound learning disabilities or certain severe cognitive or communication impairments, who may therefore not be able to provide informed consent to participate in the research.

Guidance from the NHS Health Research Authority sets out key considerations for drafting consent materials for research with adults who do not have capacity to provide informed consent. This guidance is available [here](#).

As with all social research, researchers must ensure that disabled research participants are given sufficient information to ensure that they can provide informed consent. However, participant information leaflets are often complex, and can be particularly inaccessible for dyslexic people, or people who have problems with reading, or understanding numbers (Coleman 2021).

The call out box below provides guidance on ensuring that the formatting, language and content of informed consent materials is as accessible as possible at baseline. However, different groups may have different levels of understanding, and/or visual and accessibility needs. These groups may all benefit from adapted versions of the same consent form. This decision should be made in proportion to the number and size of the groups in the research sample, in proportion to the available budget for research tool development.



#### Useful resources for drafting accessible informed consent materials

- Coleman et al (2021): Preparing accessible and understandable clinical research participant information leaflets and consent forms: a set of guidelines from an expert consensus conference. Available [here](#).
- CHANGE (2016): How to make information accessible. A guide to producing easy read documents. Available [here](#).
- Harding (2021): Doing research with intellectually disabled participants: reflections on the challenges of capacity and consent in research. Available [here](#).
- NHS Health Research Authority (2023) guidance sets out tips and principles on formatting, providing clear and informative explanations. Available [here](#).
- Additional government guidance on the mental capacity act for social scientists is available [here](#).

#### 1.2.4 Interviews and focus groups


Guidance provides the following examples of universal adjustments to make fieldwork as inclusive as possible:

- **Offering different methods of engagement for participants.** For example, participants can be offered virtual engagement methods, different times and durations, and different locations if the research is in-person.
- **Ensuring all research tools and materials are produced in an accessible format.** For example, all materials should be concise and simply formatted, include simplified summaries, with accessible visuals (Research Retold 2020).
- **Ensuring physical fieldwork venues are accessible.** Ideally, all fieldwork will be held in a venue with step-free access throughout and the meeting should be on ground floor where possible.
- **Ask for feedback.** After each interview, ask for feedback from participants on what they have enjoyed and what could have been done differently to cater to their needs, and ensure they are able to answer easily and comfortably (Angelfish Fieldwork 2023).

Guidance and toolkits provide the following advice for designing topic guides which maximise accessibility and inclusivity for participants:

- Avoid using long sentences. Include one main point per question, and only one or two clauses per sentence and question.
- Communicate in the active voice, rather than the passive, and avoid using the third person.
- Use simple words, without being patronising, and be prepared to repeat difficult or unfamiliar words.
- Avoid the use of jargon, abbreviations and acronyms, and abstract concepts.

*Figure 1* provides examples of targeted adjustments for semi structured interviews for people with hearing impairments, speech impairments, visual impairments, and learning difficulties and disabilities. Please note that this list is not exhaustive, and should not act as a substitute for consulting with the individual participant about what they may need to participate meaningfully.

 **Useful resources for implementing targeted adjustments to interviews**

- Government guidance from the Office for Disability Issues (2011). Available [here](#).

*Figure 1: Targeted adjustment examples for semi structured interviews*

Type of disability	Targeted adjustment examples
Hearing impairment	<ul style="list-style-type: none"> <li>• Visual aids, including the use of show card responses.</li> <li>• Showing written questions to respondents in advance.</li> <li>• Ensuring that the interviewer’s face is visible at all times.</li> <li>• Using a British Sign Language (BSL) interpreter.</li> <li>• Computer assisted self interviewing (CASI), i.e. where a respondent enters their answers directly into a laptop.</li> </ul> <div style="background-color: #ffe0b2; padding: 5px; margin-top: 10px;"> <p><b>Additional resources:</b></p> <p>Eleni et al (2014). Collecting data with the Deaf community. Available <a href="#">here</a>.</p> <p>Waltharow and Wayland (2022). Making qualitative research inclusive: Methodological Insights in Disability Research. (Focus on conducting research with people living with Deafblindness). Available <a href="#">here</a>.</p> <p>Young (2010), research with d/Deaf people. Available <a href="#">here</a>.</p> </div>
Speech impairments	<ul style="list-style-type: none"> <li>• Asking shorter, closed questions which do not require as much explanation, or which can be answered using gestures.</li> <li>• Offering written alternatives for in-depth open questions.</li> </ul>

Type of disability	Targeted adjustment examples
	<ul style="list-style-type: none"> <li>• Taking breaks and factoring in sufficient time for a response to each question.</li> <li>• Offering computer assisted self interviewing (CASI) or other self-complete options, such as the interviewer using speech and the respondent using written language.</li> </ul> <p><b>Additional resources:</b></p> <p>Jayes et al. (2021). Making public involvement in research more inclusive of people with complex speech and motor disorders. Available <a href="#">here</a>.</p>
Visual impairments	<ul style="list-style-type: none"> <li>• For partially sighted respondents, ensuring written communication is short and clear, uses a large font (i.e. size 14 or above), black text on a white background, in a non-ornate typeface.</li> <li>• Avoiding visual aids in interviews, and reading out and describing any visual prompts.</li> </ul> <p><b>Additional resources:</b></p> <p>Charles (2011). A brief guide to carrying out research about adult social care services for visually impaired people. Available <a href="#">here</a>.</p> <p>Horsford (2016). Research with visually impaired users. Available <a href="#">here</a>.</p> <p>Tanner et al (2018). Conducting Research with older adults with vision impairment: Lessons learned and recommended best practices. Available <a href="#">here</a>.</p>
Learning disabilities	<ul style="list-style-type: none"> <li>• Carry out preliminary research in order to uncover respondents' needs and build rapport.</li> <li>• Provide both respondents and carers with comprehensive and accessible information prior to taking part.</li> <li>• Use multiple methods – written, verbal and visual. Accessible show cards can aid understanding.</li> <li>• Adopt a flexible and informal approach – like a friendly chat rather than an interview.</li> <li>• Be realistic about who will be able to take part and what can be achieved.</li> <li>• Tailor the survey to the respondents' needs as far as possible.</li> <li>• Ground the questions in experience as far as possible to aid understanding.</li> </ul> <p><b>Additional resources:</b></p>

Type of disability	Targeted adjustment examples
	<p>Hollomotz (2018). Successful interviews with people with intellectual disability. Available <a href="#">here</a>.</p> <p>Nind (2008). Conducting qualitative research with people with learning, communication and other disabilities. Available <a href="#">here</a>.</p> <p>Nind and Vinha (2012). Practical considerations in doing research inclusively and doing it well: Lessons for inclusive researchers. Available <a href="#">here</a>.</p> <p>Northway (2021). People with learning disabilities, creativity and inclusion in research. Available <a href="#">here</a>.</p> <p>Tuffrey-Wijne (2010). Co-researching with people with learning disabilities. Available <a href="#">here</a>.</p>

### 1.2.5 Surveys

To ensure that surveys are accessible, it is important to use accessible survey platforms that are Web Compliance Accessibility Guidelines (WCAG) compliant. This ensures that disabled people who use assistive devices to access the web are able to access the survey (Isaacson 2021; Research Live 2021). Currently, SurveyMonkey is WCAG2 compliant if you use their accessible theme and follow their accessible survey checklist. Smart Survey is working towards WCAG 2.1 for their accessible survey theme, but not all question types are compliant (e.g. slider scale, ranking and semantic differential question types).

It is also important to ensure that the language, content and structure used within a survey design is as accessible as possible. This will make the survey easier to complete for all participants, as well as those with accessibility requirements (Imperial College London 2023).

Isaacson (2021) reports the following key universal design principles for online surveys:

- Ensure online surveys have accessibility functions which enable people to adapt the formatting to suit their needs. This includes ensuring compatibility with a text to speech reader.
- Make sure colour contrasts are clearly differentiated.
- Ensure text fields are close to row labels. This is to support people who use magnifying functions not to get lost if areas are too far apart.
- Use simple question formats, such as radio buttons, check boxes and open text. Where possible, avoid textbox and radio button matrices, as these are challenging to navigate using screen readers and mobile devices.

- Test the functionality of the survey by downloading a screen reader programme and using it to take the survey before it goes live.
- Consider alternative methods where survey questions are recorded in audio format, and respondents given the option to complete the survey through speech too.



### Useful resources for accessible survey design

- Imperial College London (2023). Writing accessible surveys. Available [here](#).
- Online Surveys (2020). Guidance on accessible survey language and design. Available [here](#).
- SmartSurvey (2021), Guidance on their “accessible theme”, question types which are WCAG compliant, and how to test and pilot surveys to ensure they are accessible. Available [here](#).
- Survey Monkey (2023), Guidance on making accessible surveys throughout their platform. Available [here](#).

## 1.3 Conducting research with disabled children and young people

### 1.3.1 Ethical considerations

The [Ethical Research Involving Children project](#) has produced extensive ethical guidance on conducting research with disabled children and young people. This includes the following considerations (MacDonald et al 2020):

- **Gaining parent/carer consent.** Parents/carers of disabled children and young people may have additional anxieties about the child in their care participating in research. It is important to acknowledge this, and explain the ways in which the research will address the child in their care’s individual accessibility needs.
- **Gaining young person consent or assent.** The Royal College of Paediatrics and Child Health (Modi et al. 2014; Oulton et al. 2016) state that in cases where children do not have sufficient capacity to provide informed consent, then researchers should seek assent instead. Assent can be ascertained through non-verbal cues and active participation with the questions and fieldwork (Parsons et al 2016; Ellis 2017).
- **Ensuring children and young people are provided with accessible information.** This should be both age appropriate and meet accessibility needs. Parents/carers or gatekeepers may be able to advise on the best format to communicate information to child or young person.
- **Withdrawing consent.** Before participation, discuss with the child or young person how they would like to tell the researcher that they would like to end the session. This could involve pointing to a “goodbye” symbol or picture, waving goodbye, or stating that they do not want to continue taking part.



- **Safety, protection and safeguards.** As with all research with children and young people, safeguarding processes should be clearly communicated to all members of the project team, and included in research tools. This should include clear rules around researcher behaviour, and the steps that will be taken if safeguarding concerns and/or emotional wellbeing concerns arise.

Disabled children and young people have the same rights to contribute in research and evaluation confidentially as other children and young people. However, this can be challenging if these children and young people require support to participate in the interview which can most effectively be provided by support workers who are also stakeholders in the research. This balance between enabling participation and ensuring confidentiality should be considered up-front. The implications for the research findings, including the possibility of any bias, discussed in the report.

### **Useful resources: Ethical considerations for conducting research with disabled children and young people**

The following resources provide additional guidance and advice on the ethical considerations for conducting research with disabled children and young people:

- Child ethics (2021). Ensuring research involving children with disabilities is inclusive, empowering and safe. Available [here](#).
- Institute of development studies (2020). How to ethically involve children with disabilities in research. Available [here](#).
- Jenkin et al (2015). Inclusive practice for research with children with disability: a guide. Available [here](#).
- Macdonald, G.M., McNeily, P., & Kelly, B (2020). Ethical considerations when conducting research with children and young people with disabilities in health and social care. Available here.
- National Disability Authority (2005). Research with children with disabilities: Guidelines and Checklist for good practice. Available [here](#).

## **1.3.2 Research methods**

Guidance states that appropriate research tools for conducting fieldwork with disabled children and young people often include a prompt or facilitator which supports the child to participate and answer research questions in a more playful or supportive way. The tools can be directly related to the research conversation, or also a separate activity they can play with to maintain engagement and enjoyment while they answer questions (e.g. such as kicking a ball) (Jenkin et al 2015).

Guidance and toolkits highlight the importance of adapting the tools and environment based on the individual young person's needs. This includes:

- Ensure the physical environment is appropriate to the child's needs (this includes space and noise/other disturbances).

- Offer each child a range of tools, and adapt based on their preferences or needs. For example, children with visual impairments may prefer tactile or aural tools and approaches.
- Allow enough time for the child to participate. Many disabled children may require additional time to think through answers, to become familiar with the tools, or to communicate their responses. Researchers should ensure that there is enough time to repeat questions and explanations as required.
- Adapt the tools to the characteristics of the child, e.g. adapt the gender of a doll to suit the child.
- Ask one question at a time, and use simple language.
- Do not feel need to fill gaps in the conversation. Slow down, and wait for the child to respond in their own time.
- Ensure you take a supportive, understanding, and active listening approach.

There are a range of methods and approaches which can be used when conducting research with disabled children and young people. The appropriate approach will depend on the individual's accessibility needs, and should be decided in collaboration with clients, ideally in line with the accessibility requirements which can be anticipated up-front. These decisions should be made in proportion to the project brief, budget, sample size and expertise of the research team.

### **Useful resources: Methods for conducting research with disabled children and young people**

The following resources provide additional guidance and advice on a range of methods which can be used to conduct research with disabled children and young people. However, please note that this list is not exhaustive, and these examples should not act as a substitute for consulting with the child's parent/carer, trusted adult or support worker about what they made need to participate meaningfully.

- Hill et al (2020). Research methods for children with multiple needs: Developing techniques to facilitate all children and young people to have a voice. Available [here](#).
- Jenkin et al (2015). Inclusive practice for research with children with disability: a guide. Guidance which provides step by step methodology for a range of research methods for children and young people with physical, visual, hearing and cognitive impairments. Available [here](#).
- National Disability Authority (2005). Research with children with disabilities: Guidelines and Checklist for good practice. Available [here](#).
- Office for Disability Issues. Research methods for children with disability. Available [here](#).

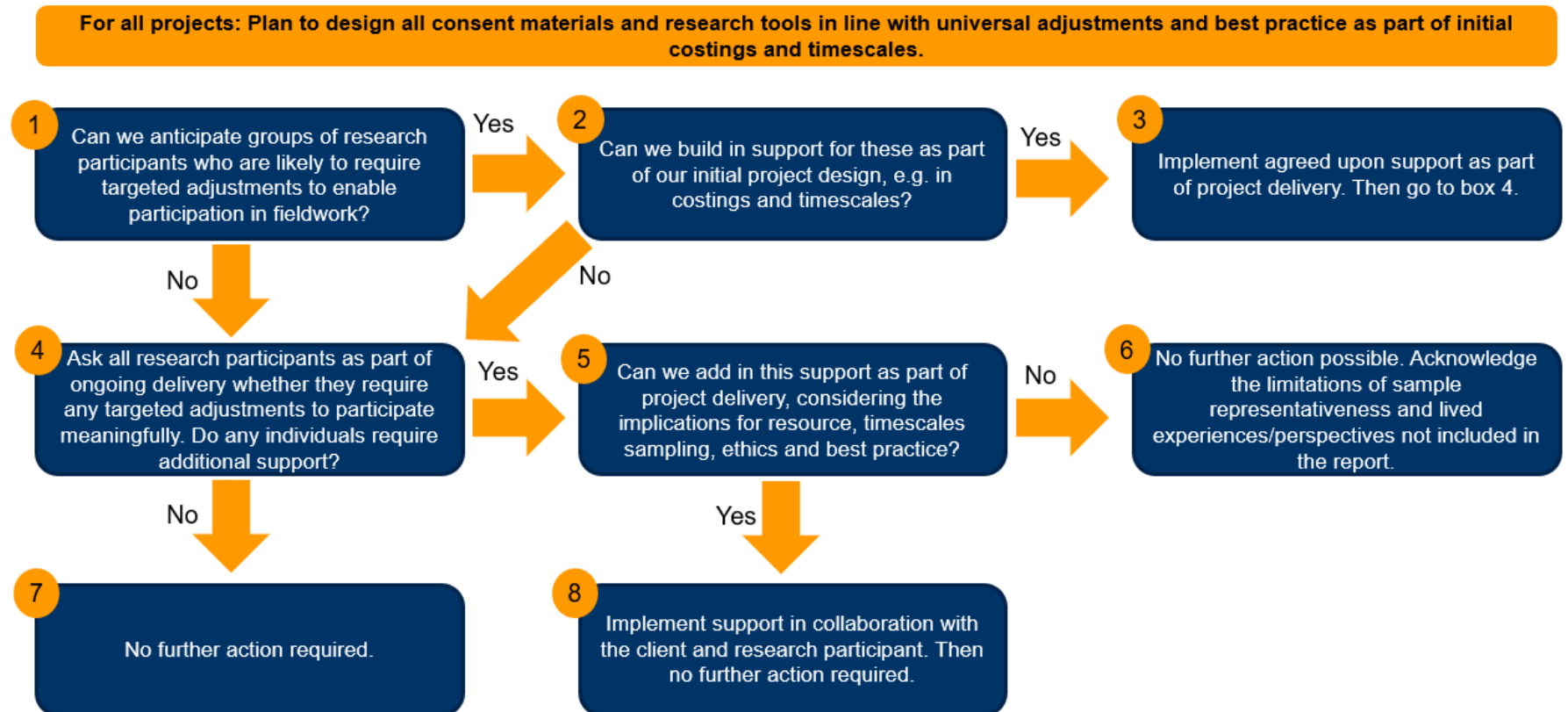
## 1.4 Decision making tool

As a baseline, we should ensure that all fieldwork practices (i.e. the methods we use to recruit participants, seek informed consent, and conduct fieldwork), are done in line with the principles of universal adjustments and best practice.

Where we can anticipate that research participants may require targeted adjustments (for instance, where we know we are conducting research with adults with a learning disability), we can build in solutions to these in our initial project design, such that the implications of this are accounted for in project costings and timescales. It is therefore important to both try to anticipate the potential barriers in project design and delivery, but also to provide the option for participants to tell you what participation accessibility requirements they might have and agree solutions to these in collaboration with clients, delivery providers and the research participants.

Figure 2 provides a decision making tool to help guide these decisions.

Figure 2: Decision making tool for conducting accessible research with disabled participants



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