

Údarás Náisiúnta Míchumais
National Disability Authority



Collaborative research with disabled people: Guidance for researchers

October 2023

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Statement on language

In this report, we use the terms “people/persons with disabilities” and “disabled people” interchangeably. Many people within the disability rights movement in Ireland recognise the term ‘disabled people’ because it is considered to acknowledge the fact that people with an impairment are disabled by barriers in the environment and society and so aligns with the social and human rights model of disability. However, we also recognise that others prefer the term “people/persons with disabilities”. This also reflects the language used in the United Nations Conventions on the Rights of Persons with Disabilities (UNCRPD). We also acknowledge that some people do not identify with either term.

The term ‘Deaf’ with an uppercase ‘D’ is used when referring to those who identify culturally and linguistically as part of the Deaf community. A lower case ‘d’ is used to refer to those who are deaf or hard-of-hearing and who do not identify culturally and linguistically as a member of the Deaf community. The term ‘d/Deaf’ is used to refer to both groups.

For further information on disability-related language and terminology, please refer to the NDA’s Advice Paper on Disability Language and Terminology.¹



¹ National Disability Authority, 2022a.

Table of Acronyms

| | |
|----------------|--|
| DPO | Disabled persons' organisation |
| EU | European Union |
| GRIPP 2 | Guidance for reporting the involvement of patients and the public 2 |
| ID | Intellectual disability |
| ISL | Irish Sign Language |
| LGBTQI+ | Lesbian, Gay, Bisexual, Transgender, Queer, Intersex+ |
| NDA | National Disability Authority |
| NIHR | National Institute of Health Research |
| PA | Personal Assistant |
| PPI | Public and Patient Involvement |
| SEB | Standard English Braille |
| UEB | Unified English Braille |
| UNCRPD | United Nations Convention on the Rights of Persons with Disabilities |
| WCAG | Web Content Accessibility Guidelines |



Introduction

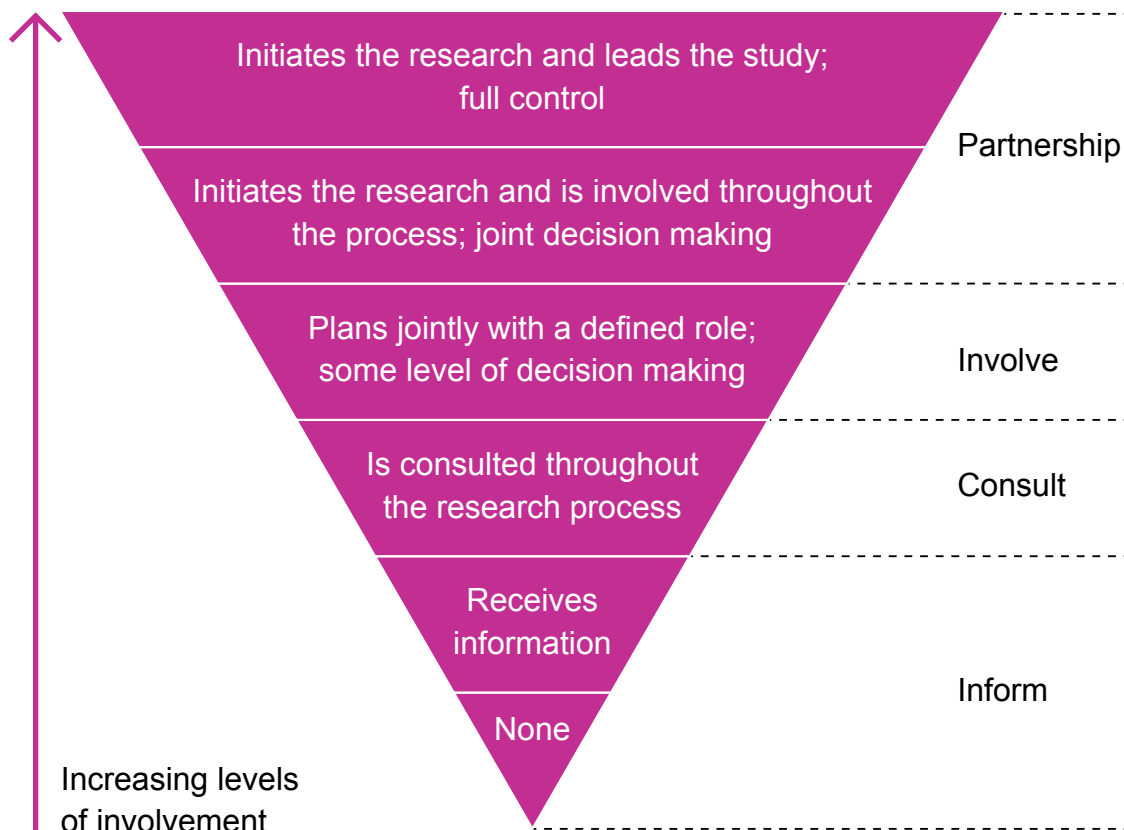
Introduction

What is this guidance document?

This guidance document is a practical resource to support researchers to meaningfully involve people with disabilities in collaborative research projects. This is a broad guidance document that applies to all levels of involvement in collaborative approaches to research. See Figure 1 for a description of the various levels of involvement.

This document is based on an extensive literature review, and a series of discussion groups with representatives of Disabled Persons Organisations (DPOs), disabled individuals, representatives of voluntary and community organisations, and researchers on the topic of collaborative research.

Figure 1. Various levels of involvement in collaborative approaches to research²



² Reproduced from 'Public and Patient Involvement (PPI) in Research', Irish Health Research Forum Document, April 2015. Image used with permission from HRCI/Irish Health Research Forum. Available at https://hrci.ie/wp-content/uploads/2019/09/MRCG_Briefing_Paper_27-9-16.pdf [last accessed September 2023]

Who is this guidance for?

This guidance is for researchers and organisations conducting research. It may also be a resource for disabled people who would like to be part of a collaborative research project.

This guidance may be useful for researchers who are new to collaborative research, it contains explanations of relevant terms and outlines things that need to be considered when conducting collaborative research.

How to use this guidance

You can read this guide from beginning to end or you can dip in and out of it for guidance on specific topics. The guide is divided into six sections:

Section One contains quick guides with important background information on key legislation and concepts which are essential to know about when thinking about, and doing, collaborative research.

Section Two explains what collaborative research is and the different levels of involvement. It also outlines some underlying principles of collaborative research.

Section Three outlines why we should engage in collaborative research, highlighting the benefits of this approach and the requirements under international legislation.

Section Four outlines how disabled people can be involved at each stage in the research process. It provides some examples of how to include people with disabilities in collaborative research.

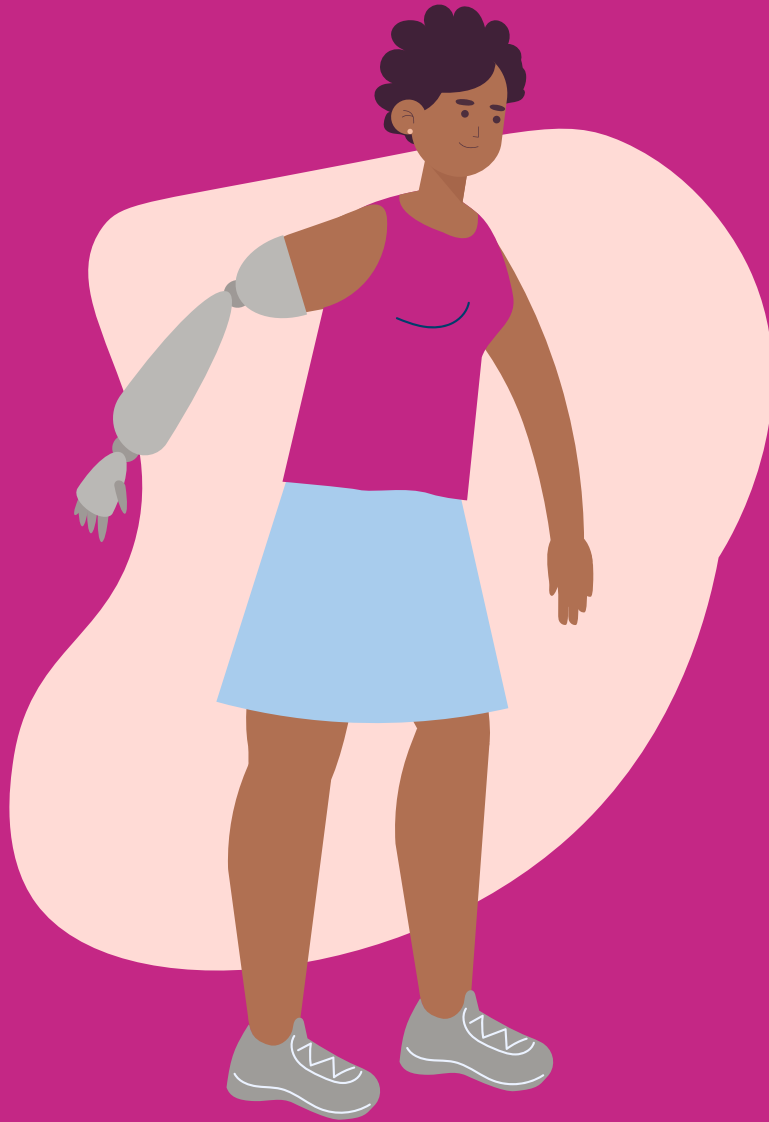
Section Five considers how researchers should think about who to involve in collaborative research, how they can find them and important things to consider.

Section Six outlines practical considerations for involving disabled people in research. This section is broken down into various aspects that need to be considered when embarking on a collaborative research project such as accessibility and resource considerations.

Key points!

- Involving disabled people as collaborative researchers should not be limited to projects on disability-related matters only. Most research and design can be enriched by including the voice of disabled people.
- Disabled people should be involved as early as possible in the research process including the conceptualisation and design stages.
- The collaborative researchers' roles and responsibilities must be communicated clearly from the beginning of the project.
- Some collaborative researchers already have research backgrounds and experience. Their research skills, expertise and knowledge should be drawn upon in addition to their lived experience as a disabled person.





Section 1.
Quick guides

Section 1. Quick guides

What is the UNCRPD?

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is an international human rights treaty.

Ireland ratified the Convention into Irish law in 2018. The Articles contained in the UNCRPD are binding on those States Parties that have ratified the Convention. This means that Ireland has made a commitment to protect and promote the rights of disabled people.

The Convention applies established human rights principles from the UN Declaration on Human Rights to the situation of persons with disabilities. It covers civil and political rights to equal treatment and freedom from discrimination, and social and economic rights in areas like education, health care, employment and transport.

The UNCRPD has set an international precedence for a commitment to human-rights based approaches in all practices. What this means for your research is explored further below.

What is a Human rights based approach?

The UNCRPD has changed the policy and legislative landscape in Ireland. There has been a fundamental shift across how disability services are thought of. It is the basis for what is known as a human rights based approach.

Human-rights based approaches can be defined as a conceptual framework for the promotion and protection of human rights based on international human rights standards.³ It recognises that there can be groups in society that must have their rights protected. The human rights based approach is underpinned by five key human rights principles: Participation, Accountability, Non-discrimination and Equality, Empowerment and Legality.

By embedding all future policy and legislation in a rights based approach, the UNCRPD works to ensure that the rights of people with disabilities are not only progressively realised, but that ongoing changes are made to ensure that they are constantly met.

³ European Network of National Human rights institutions: <https://ennhri.org/about-nhris/human-rights-based-approach/#:~:text=Principles,and%20Equality%2C%20Empowerment%20and%20Legality.>

In thinking about how we design research, we must look to the UNCRPD and the human rights based approach as our starting point.

As noted by a participant in the discussion groups:

within our research, which is on the lived experience, we are more likely to use language and approaches which then informs wider society and people are more likely to see value of everyone in society and more likely to treat everyone as equal...it is important not to underestimate the impact of peoples collaborative engagement in changing society to be a more equal one in general.

What is the social model of disability?

The social model of disability emerged as a result of the Disability Rights Movement. The Disability Rights Movement was started in Berkeley California by Ed Roberts who set up the first Center for Independent Living in 1972. The central ethos of the Disability Rights Movement is 'nothing about us, without us.' This has been enshrined within article 4.3 of the UNCRPD which states that:

In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations⁴

The central idea of the social model is that disability is created by society whereby a social disadvantage is imposed on people with impairments by the way society and it's structures are organised.

In other words, the social model of disability:

'looks at how society is structured and how it disables people. It is not based on a person's impairment, it is focussed on the barriers that exist in terms of attitudes, policy development, access or lack of supports that prevent people from participating in society as equals, with choice and control over their own lives'.⁵

⁴ <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>

⁵ ILMI Submission on Disability Matters, 2022

As a discussion group participant noted:

It's barriers and ablest policies and inaccessible environments that disable people not one's impairment or condition, whether that effects your body or your mind. Disability is something that is done to a person not something that a person has.

Another participant from the discussion groups noted:

If we are serious about the social model of disability, then there is no way we should be doing research that doesn't have some element of collaboration in it, because otherwise we're just disabling people all over again

What is a Disabled Person's Organisation

Disabled Persons' Organisations (DPOs) are a type of civil society organisation that are led, organised and informed by disabled people. They must have a clear majority of disabled people in their membership, and their operating principles must be rooted in the UNCRPD.⁶ General Comment No 7 of the UNCRPD states that Disabled Persons Organisations are the representative organisation of disabled people. DPOs are an important pool of knowledge for researchers to consult with in the research process. The value of involving a DPO is that it ensures that the lived experience of disability is being included.

There are also other kinds of organisations which work on disability rights issues, or which provide services to people with disabilities. These are not DPOs because they are organisations 'for' persons with disabilities, and not organisations 'of' persons with disabilities. It is important for researchers to be aware of the difference between DPOs and other types of organisations.

There is a special obligation under the UNCRPD to involve DPOs in decision-making processes relating to disabled people. For more information on this, and on how to engage with DPOs, please refer to the NDA's publication Participation Matters Guidelines.⁷

⁶ National Disability Authority, 2022b

⁷ Ibid



Section 2.
**What is collaborative
research?**

Section 2. What is collaborative research?

Defining collaborative research

The term collaborative research can be difficult to define as numerous terms are often used interchangeably to describe this approach to research.⁸ For example, the term ‘inclusive research’ is commonly associated with people with intellectual disabilities and is used, in the UK, as an umbrella term to describe a range of methodologies and approaches that aim to democratise the research process by engaging policy makers and communities in research and decision making.⁹ ‘Engaged research’ is another umbrella term which also describes a range of approaches that aim to understand and improve societal issues in collaboration with communities and stakeholders.¹⁰ Another term, Public and Patient Involvement (PPI), refers to ‘research carried out ‘with’ or ‘by’ members of the public¹¹ rather than ‘to’, ‘about’ or ‘for’ them’.¹²

In the current guidance, we use the term ‘collaborative research’ as an umbrella term encompassing the variety of approaches that are used to involve members of the public in the research process. In effect, we use collaborative research to refer to research in which the people who are likely to be impacted by the research are involved in decision making and the research processes. Although collaborative research can involve any member of the public, this guidance offers advice, and outlines important considerations, specifically for involving disabled people in the research process.

In the current guidance we use the term ‘co-researcher’ as an abbreviation of the term ‘collaborative researcher’. A collaborative researcher can be any member of the public, who is not a professional researcher, who is involved in the research process. In the current guidance we use the term to refer specifically to disabled people who are not professional researchers but who are involved in the research process.

8 Castro et al., 2016, Nind, 2014

9 Nind, 2014

10 Campus Engage, 2017, Holliman et al., 2015

11 In PPI, ‘public’ refers to patients and potential patients, people who use health and social care services, carers, and people from organisations that represent people who use services.

12 NIHR (INVOLVE), 2015

Distinction between collaborative researchers and research participants

A collaborative researcher (co-researcher) is someone from the community of interest (e.g. a disabled person, a member of the LGBTQI community, a member of an ethnic minority, a person with a specific health condition) who is, generally,¹³ not a professional researcher, but who is involved in making decisions about the research and the running of the research project.¹⁴ For example, a co-researcher might be involved in deciding what to research, writing the ethics application, designing a questionnaire, collecting and analysing the data and disseminating the research findings.

A research participant is a person who voluntarily participates in human subject research after giving informed consent to be the subject of the research. Research participants do not make decisions about the research and are not involved in the research process; for example, they do not decide the research topic, they do not collect, analyse or disseminate the data.

Continuum of involvement of people with disabilities in research collaborations

Although the various approaches under collaborative research all promote engagement with the communities of interest, the level of involvement exists on a continuum ranging from very little or no involvement to having full control over what gets researched and how.¹⁵

Considering the various contexts in which collaborative research takes place, as well as the various capabilities and experiences of the researchers, it is important to maintain a flexible approach to, and definition of, collaborative research. Whichever approach is taken, it is important that the level of involvement is meaningful, proportionate and appropriate to the project.

13 We acknowledge that there may be times when disabled people who are professional researchers take part in projects in a co-researcher role.

14 It is important to note that many co-researchers may also have research backgrounds. In such cases, it is important that their research skills, knowledge and expertise are drawn upon in addition to their lived experience.

15 McLaughlin, 2010, Walmsley and Johnson, 2003

Advisory/consultative approaches

Advisory roles often involve participating in activities such as setting research priorities, contributing as part of research advisory or steering groups, making recommendations about research proposals, or giving advice about specific issues or methods.¹⁶ People with disabilities who are involved in an advisory capacity rarely have much control over the research processes or decision-making, however. Rather, the decision making power tends to remain with the organisation or professional researchers.¹⁷ For this reason, advisory or consultative roles are not generally considered to be fully collaborative.¹⁸ Nevertheless, such roles are still a relevant and appropriate part of the research process.

Collaborative approaches

Collaborative involvement generally refers to research partnerships between co-researchers with lived experience of disability, who are not professional researchers and professional researchers, such as academics.^{19 20} Both groups contribute meaningfully in the research process.²¹ Collaborative approaches tend to be flexible and context driven rather than overly structured.²² Such approaches afford more ownership and control of the research to disabled people than advisory or consultation roles, however leadership often remains with the professional researchers.²³

User/consumer-led approaches

The highest level of involvement refers to disabled people having full control to initiate, lead and execute research.²⁴ Under this approach, disabled people may conduct the research entirely themselves (e.g. truly emancipatory) or they may be supported by professional researchers (e.g. user-led), but they will generally have control over the direction of the research and decision-making, and tend to be involved in all stages of the research process.²⁵

16 Smith-Merry, no date

17 Bigby, Frawley and Ramcharan, 2014

18 McLaughlin et al., 2010

19 Farmer and Macleod, 2011

20 There are, of course, many disabled people who are academics or other types of professional researchers, some of whom are involved in disability research. The focus of this guidance, however, is more in relation to working with disabled people who are not professional researchers.

21 Bigby, Frawley and Ramcharan, 2014

22 Smith-Merry, 2017

23 Bigby, Frawley and Ramcharan, 2014

24 ibid

25 Smith-Merry, no date

Underlying principles and values

Guiding principles of the various types of collaborative research have been articulated by various authors.²⁶ Although different approaches have different guiding principles, there are key principles that should underpin any collaborative research project. These include:

- **Empowerment and power sharing** – the research is jointly owned and people work together to achieve a joint understanding. The inclusion as early as possible of disabled people in funding decisions, strategy and decision-making, the co-design²⁷ and co-production²⁸ of research is essential. All contributions are valued and respected equally.²⁹
- **Including all perspectives and skills** – make sure the research team includes all those who can make a contribution, ensuring representation of various communities, identities and perspectives e.g. members of ethnic minorities, different cultures, different sexuality and gender identities.³⁰
- **Respect** – respecting and valuing the knowledge of all those working together on the research. The recognition of the roles, knowledge, insights, experiences, strengths, limitations and contributions across the research team and throughout the research lifecycle.³¹
- **Reciprocity** – everybody benefits from working together.³²
- **Accessibility** – the process, materials, and environment are as accessible as possible to all people. Everyone on the research team understands accessibility and the social model of disability.³³
- **Building and maintaining relationships and trust** – the building of reciprocal trust; this takes time to develop, is relationship based and needs to be consistently worked on.³⁴
- **Transparency** – the need for clear, open, mutual communication between the professional researchers and co-researchers about research decisions and progress. Ensure transparency in developing a clear, shared understanding of aims, roles, processes and other terms of involvement.

26 National Institute of Health Research (INVOLVE), 2015; Walsmsley and Johnson, 2003; PPI Ignite Network, 2022

27 Co-design can be used as an umbrella term to describe different processes of involving various partners in the development and/or provision of interventions (Albert et al. 2021)

28 Co-production emphasises the ability to explore where knowledge resides, how problems are framed, and how research can be mobilised in enacting new realities and research (Ersoy, 2017)

29 PPI Ignite Network, 2022; NIHR, 2015

30 PPI Ignite Network, 2022; NIHR, 2015

31 PPI Ignite Network, 2022

32 NIHR, 2015; PPI Ignite Network, 2022

33 National Disability Authority, 2022

34 PPI Ignite Network, 2022; NIHR, 2015

- **Recognition and flexibility** – The recognition of the time and other commitments involved in collaborative research and that this is acted upon in the research plan.³⁵ Ensure flexibility is built into the research plan.

Ethical considerations

It is important for collaborative research projects to consider not only typical research ethics and academic institutional ethics, but also ‘everyday ethics’, namely the everyday moral, contextual and relational elements of the research dynamic.³⁶

Ethical approval and co-research

Ethical approval is not required for involving members of the public in research as co-researchers because they are not the research participants.³⁷ Research ethics committees requiring that ethical approval and consent are needed to involve disabled people in research has been cited as a barrier to conducting collaborative research.³⁸ Requiring ethical approval and asking co-researchers to sign a consent form creates an inequality between co-researchers and professional researchers. In some cases, efforts will be needed to better inform ethics committees about the nature and principles of collaborative research. It is important to be aware, however, that there are likely additional considerations when working with certain groups such as children under 18 years and people with intellectual disabilities. These groups should not be deliberately excluded, however, unless this exclusion is consistent with the research question and aims of the study. While extra supports and processes may be necessary when involving such groups, it is important that they have the same opportunities to have their voices heard and to influence research as others.³⁹

Where possible, co-researchers should be involved early enough in the project so that they can contribute to the ethical approval process. Researchers will need to work with co-researchers to determine and provide the support required to facilitate involvement at this stage of the research process.

35 PPI Ignite Network, 2022

36 Banks et al., 2013 cited in Mann and Hung, 2018

37 <https://www.spcr.nihr.ac.uk/PPI/resources-for-researchers/faq/do-i-need-ethical-approval-to-run-an-involvement-activity>

38 Strnadová et al., 2016

39 Steel, 2004

Ethical challenges

Some ethical challenges that may arise when conducting a collaborative research project include:

- Confidentiality or anonymity issues that might arise in situations where the co-researchers know the research participants. This may be a particular risk if working with a community that has a small pool of people. In such cases it is recommended that professional researchers discuss with the co-researchers and research participants what they would be comfortable with.
- Sometimes co-researchers will have supporters present. When attending meetings, supporters might respond on behalf of the co-researcher, give their own view, interrupt the flow of communication or prevent co-researchers from feeling able to speak their minds. It is critical to consider the influence that the supporter could have on the group and the person they are supporting and to ensure that the voice or perspective of the co-researcher, rather than the supporter, is considered paramount. This can be achieved by being clear that the supporter's role is to enhance the communication of the participant rather than speaking on their behalf. Information forms can be developed to this effect and can be given to supporters to ensure that they are clear about their role. Such a form could be used as a tool to refer back to in order to manage a supporter who is going beyond their supportive role.
- It is not recommended to include the same people as both co-researchers and participants as this creates an inequality and questions the validity of the study. Participatory Action Research projects are potentially the only exception to this.
- When working with co-researchers under the age of 18, there may be challenges in balancing the ideals of empowerment with the demands and obligations to protect and safeguard the safety and wellbeing of the young people. Researchers should ensure they are aware of their organisation's safeguarding policies.

Power sharing and managing power imbalances

The issue of power inequalities and power sharing is one of the biggest challenges to conducting collaborative research. There is often an inherent power imbalance in research partnerships as the research project is often conceived by the professional researchers, and people with disabilities are invited or recruited to be involved as co-researchers. In addition, it may feel intimidating to some co-researchers to work with academics who have lots of qualifications or years of experience. The professional researchers need to find the right balance between providing support without taking too much control.

Some approaches that may help to manage and address inequities and power imbalances include:

- Encouraging open and ongoing discussion about imbalances and inequities.
- Challenging the idea that professional researchers are the only knowledge-holders.
- Ensuring ongoing review and reflection of interactions and processes and assumptions.
- Seeing the co-researcher as a researcher first as opposed to a person with a disability.
- Ensuring professional researchers truly value the insights of the co-researchers, will make necessary accommodations, and are willing to share power.
- Ensuring supervision and support are available to co-researchers when wanted and appropriate.
- Jointly establishing ground rules for meetings with co-researchers.
- Jointly creating guidelines and policies on power-sharing, decision-making and jointly deciding roles and responsibilities.
- Ensuring a shared decision-making approach and ensuring effective communication among the team. Structured processes for reaching consensus, such as the 5-finger method,⁴⁰ the Delphi process,⁴¹ and the Nominal Group Technique,⁴² may be helpful for facilitating shared decision making.
- Being reflexive throughout the research process - thinking about how co-researchers are affected by the power dynamics of the team and being mindful of how the professional researcher's position might impact the co-researchers, the relationships and the project.
- Avoiding stereotyping or making assumptions about co-researchers' capacity.
- Ensuring transparency by clearly outlining how decisions are made.

40 A structured process to facilitate effective and efficient communication and decision making. Holding up one finger means "yay, I approve, do it!", two fingers means "meh, I'm not thrilled but I'll approve", 3 fingers means "I am not sure, I need more information or discussion", 4 fingers means "I don't like, I don't approve it, but I can live with it", five fingers means "I hate this so much that I can't live with having my name associated with it" (Nicolaidis et al., 2011).

41 The Delphi process involves structured and repeated consultation and feedback with a group in order to reach consensus on a subject (Taylor, 2020).

42 The Nominal Group Technique is a structured form of brainstorming and discussion in a small group, where ideas are shared and voted on or prioritised by the group. More detailed information on this technique can be found here: <https://www.cdc.gov/healthyyouth/evaluation/pdf/brief7.pdf>

Tokenism

It is important to know when involvement is not meaningful. Tokenism happens when researchers want to appear to have involved disabled, or other underrepresented people, in their research, but have not done so meaningfully. Tokenism can also happen accidentally, when researchers do not understand how to meaningfully involve the communities of interest. Below are some examples of tokenism to avoid:

- Potential co-researchers are approached too late in the process, when all or most of the decisions about the research have already been made.
- The contributions of co-researchers are not taken on board and no rationale is provided.
- Co-researchers are not given enough time to make a meaningful contribution.
- Co-researchers are not provided with all the information they need in a format that is accessible and understandable to them in order to make a meaningful contribution.
- Co-researchers are not approached for the right reasons. For example, they are only approached as a requirement in a grant application so that the researcher can tick a box.
- The abilities of co-researchers are underestimated and the methods used to involve them are condescending.
- The contributions of co-researchers are edited, misrepresented or used to fit into a prescribed view already held by the researchers.
- Professional researchers rely on service providers⁴³ to contribute on behalf of disabled people.
- Professional researchers go ahead with a project despite concerns about the project that have been raised by disabled people they have approached for involvement; for example, if disabled people do not agree with the aims or purpose of the project because it comes from a medical model perspective.

⁴³ A service provider is an organisation that provides services or supports including, but not limited to, therapies, day services, or respite services for example.

Mitigating potential negative impacts of the research on co-researchers

Potential negative impacts of the research on co-researchers need to be considered and addressed to ensure the positive involvement of co-researchers in the collaborative research process. High workloads may lead to co-researchers feeling overwhelmed and under pressure, as well as being tired and unable to complete their work on time. Professional researchers need to balance what they wish to do with not overburdening co-researchers. Co-researchers may become emotionally drained or distressed during sensitive research or through being exposed to peers' sometimes-difficult stories and experiences. They may also feel burdened or responsible for improving the lives of the participants or the wider community through their work, or upset and disempowered if tasks do not go as planned. Professional researchers should ensure that ongoing support and debriefing is offered to co-researchers whenever they need it and that the amount of work planned is feasible.

A good relationship between the professional researchers and co-researchers is key to a successful collaborative research project. This requires mutual respect, honesty and trust and time should be taken to build these. It is important that feelings of trust are established early on and then maintained throughout the project. Professional researchers should be aware that some co-researchers may not feel confident or comfortable while conducting the research, especially in the beginning. Some people may not be used to being asked for their opinion or being given decision making power. They may have difficulties opening up, they may feel intimidated by professionals and others, they may feel uncomfortable being in the spotlight or participating in group discussions, or they may not have the confidence to do some of the tasks required and feel insecure about their added value. To mitigate some of the challenges that co-researchers may face, the professional researchers need to ensure that co-researchers do not feel used or under-appreciated for their work. Not doing so will have a detrimental impact on the relationship and ultimately the project. Some strategies that professional researchers can undertake to build trust and confidence with co-researchers include:

- Regularly focussing on building and maintaining trust.
- Being available outside of the usual research meetings to talk to co-researchers or listen to any queries or difficulties they are having.
- Taking time for informal discussions such as having a cup of tea and a chat.
- Celebrating project milestones.
- Avoiding tokenistic involvement.

- Providing regular updates on the research/keeping the co-researchers informed.
- Empowering co-researchers to have more control over the research agenda, methods, and individual roles.
- Encouraging co-researchers to raise issues that are important to them.
- Managing expectations by ensuring transparency throughout the project and providing clarity if certain options are not feasible.
- Ensuring equal power sharing and providing feedback on the co-researchers' work and on the outcomes of their involvement.
- Regularly asking co-researchers to feedback on their experience.
- Understanding the position of those engaged in collaborative research in terms of their enthusiasm, time, money and capacity, while giving due consideration to their disability or condition and the impact that may have on their involvement and their lives.
- Agreeing the channels and means of communication together.
- Providing feedback after meetings.
- Agreeing schedules and deadlines together.
- Clearly outlining the roles and parameters of the entire research team.
- Clearly outlining the expectations for and limitations of the research.
- Ensuring everybody is familiar with and operating under the ethos of the social model of disability.



Section 3.
**Why should we engage in
collaborative research?**

Section 3. Why should we engage in collaborative research?

Aligning research with the UNCRPD and human rights

Taking a collaborative approach to research helps to ensure research takes a rights-based perspective and is aligned with the UNCRPD and the social model of disability. Article 4(3) of the UNCRPD requires the consultation and active involvement of people with disabilities in decision-making processes concerning issues that affect them. Although, unlike public consultation, conducting collaborative research is not a direct requirement of the UNCRPD, the growth in this area over recent years demonstrates the increasing appreciation for the value of involving the public in research and the recognition that this is the right, or ethical, thing to do. This advancement is demonstrated by the establishment of funded initiatives such as the PPI Ignite Network, which supports researchers in higher education institutions and the public to collaborate in research; and the formation of research groups, such as the Inclusive Research Network (IRN), which is led by people with intellectual disabilities and supported by academic researchers. In addition, various funders now promote engaging with stakeholders and evidencing PPI as part of the research process in their funding calls.

Transparency around public funding and spending

Engaging in collaborative approaches to research promotes transparency over public spending. Research is often funded through public money or through donations. Including disabled people in the research process ensures that those who are supposed to be benefitting from funding have some level of oversight on the spending of public money and have a say about whether it's going to have a meaningful and positive impact on their lives.

Improving the research process

There is ample evidence that collaborative approaches to research can have a positive impact on the entire research process. Some of these benefits are listed below under the main research stages.

Planning and preparation

- Ensuring that research is grounded in the real concerns of people with disabilities ensures that issues that are important to them are highlighted and that research priorities are matched to those of people with disabilities. This can help to increase the value of the research to the target communities.
- Contributions of co-researchers often result in more relevant and culturally appropriate research projects. They can help to identify appropriate research questions and inform the type of research that should be conducted.
- Co-researchers can positively influence the overall design of the study. For example, they can help to ensure that the project is accessible for participants or that the interventions are relevant.
- Co-researchers can identify research ideas and questions to ask during research interviews that researchers have not thought of.
- Co-researchers can help to ensure that research designs are implementable as they may be better placed to foresee logistical issues in conducting the research that the professional researchers may not have anticipated. For example, barriers to implementing interventions, or issues with the overall design of the research and recruitment plans. Involving co-researchers in the early stages can mitigate such issues without negatively impacting on research timelines or budget as potential problems can be identified and addressed in advance.

Data collection

- Co-researchers often have wide networks and their 'insider status' could increase access to target populations, especially harder to reach groups as people with disabilities may be more likely to be involved in research when their peers are involved as researchers.⁴⁴
- Co-researchers can improve the accessibility of recruitment and data collection tools and materials including interview schedules, participant information sheets and consent forms, which may facilitate more successful recruitment of participants and enable participants to engage more meaningfully with the research without feeling patronised.
- Participants are less likely to drop out or withdraw from studies when co-researchers are involved

- Co-researchers can have a positive impact on research interviews as they can often achieve better rapport with research participants due to their shared experiences. This can help ensure that field work is conducted in a sensitive manner which helps to establish trust and can put participants at ease.
- The involvement of co-researchers can challenge the power imbalances that exist between researchers and research participants by creating a link between the two groups.

Data analysis

- Co-researchers can improve the quality of the data analysis and lead to deeper insights into, and better understanding of, the data and the topic under study.
- Co-researchers are often better able than professional researchers to interpret participants' experiences and stories, and offer explanations and nuances around participants' narratives due to a shared understanding.
- Co-researchers can bring a different perspective to the data analysis and interpretation, thinking about problems in ways that the professional researchers may not have thought of.
- The involvement of co-researchers can add credibility and validity to the findings by bringing an added richness to the data, combatting criticisms of bias and enhancing the transparency of the research process.

Dissemination and impact

- Co-researchers can help research reach more people. If co-researchers have felt a sense of ownership over the research and if the research is relevant to them, they may be motivated to share the research among their networks, who may not have accessed the research otherwise.
- Co-researchers can help ensure that dissemination materials and strategies are accessible and appropriate and can therefore be effectively disseminated back to the community.
- The involvement of co-researchers can improve interventions, maximise the impact of the research and ensure that the findings are genuinely useful and relevant to stakeholders and the populations of interest.

Challenging the status quo

Involving disabled people in collaborative research has the power to challenge societal assumptions, misconceptions and attitudes about disability.

- Being involved in collaborative research gives disabled people a 'seat at the table' and provides a platform from which they can be heard.
- Involvement as co-researchers allows disabled people to influence the research agenda and gives them control of what, and how, research is conducted.
- Involvement allows disabled people to directly represent themselves and their communities and take control over their own future.
- Involvement fosters equality and empowerment of disabled people while challenging stereotypes and stigmas.

Personal and professional development of all involved

By engaging in collaborative research, both researchers and co-researchers can develop their professional and personal skills.

- Involving co-researchers can help professional researchers to identify important research areas that they have missed otherwise.
- Professional researchers can gain knowledge about accessibility such as how to create accessible environments and materials. They will also learn how to work collaboratively with co-researchers and how their input can add value to the research.
- Professional researchers can gain valuable insight into the realities and daily lives of people with disabilities including the stigma, challenges and biases they face.
- Co-researchers can gain valuable experience and develop their research skills, many of which are transferable and so may improve their prospects for future employment or being involved in future research projects.
- The skills, knowledge and experiences gained by co-researchers may contribute to an increased sense of self-confidence, motivation and empowerment.



Section 4.
Involvement at each stage
of the research process

Section 4. Involvement at each stage of the research process

Disabled people can get involved in all stages of the research process. This includes helping to develop the research question, applying for funding or completing ethics applications, undertaking the research and analysis and disseminating the research findings. It is important to discuss the level of involvement with co-researchers at each stage, and not to assume that they do, or do not, want to be involved at any particular stage without asking them first. This ongoing flexibility is also important for ensuring that co-researchers do not become over-loaded or uncomfortable with the tasks they are assigned. This section outlines suggestions for different ways that disabled people can get involved in research as co-researchers. Keep in mind that this list is by no means exhaustive and that by being creative, there are many ways to involve disabled people throughout the research process.

Funding calls

Many funding bodies require evidence of PPI in their funding applications.⁴⁵ Other funders need to follow suit so that this becomes the norm. To achieve this, there may be a need to educate funding bodies about the nature and benefits of collaborative approaches to research. It is also important to ensure that funding bodies appreciate the need for the additional funding required for collaborative research projects so that, for instance, co-researchers can be paid and have all expenses covered right up to the end of the project. Requiring or encouraging collaborative research on grant applications will foster more uptake of such approaches in the wider research community.

Research topics, planning and design

Involving co-researchers as early as possible in a research project promotes the values of ownership, equity and power sharing that are key elements of collaborative research and will help to ensure that research is aligned with the UNCRPD and the research priorities of disabled people (See Appendix 1 for a planning checklist).

⁴⁵ The Health Research Board is one example of a funder who encourages evidence of PPI in their applications: <https://www.hrb.ie/funding/funding-schemes/public-and-patient-involvement-in-research/ppi-information-for-grant-applicants/>

Research prioritisation and idea generation

A good place to start, is to speak to Disabled Persons Organisations and disabled individuals and include them at the conceptual stages of a research project, where possible. One of the challenges of involving some co-researchers in the early stages of research (e.g. those with cognitive difficulties or more profound intellectual disability) is that some of the activities, like idea generation or planning research design, may require particularly abstract thinking.⁴⁶ Researchers should consider making tasks more concrete by using activities such as scenarios or descriptions of identifiable real life situations to facilitate the involvement of these groups.⁴⁷

If it is not possible to involve people at the prioritisation stage of a research project, there are resources available, such as the James Lind Alliance Priority Setting Partnerships, that can be consulted to ensure research is aligned with the priorities of the community of interest. The Priority Setting Partnerships bring together different stakeholders including people with specific health conditions or disabilities, clinicians and researchers to collaboratively and transparently develop a list of the top ten research priorities in that topic area. These lists of top ten research questions are then published on their website⁴⁸ for other researchers to refer to. Examples of topics for which priority lists have been developed include Autism, Parkinson's, Digital Technology for Mental Health, Life after stroke and Epilepsy. It is recommended researchers search the academic literature to see if other researchers have published the findings from priority setting exercises with the group of interest.

Funding and ethic applications

Where possible, co-researchers should be involved in the funding and ethics application phase of the research process. Funding and ethics application forms can be complex and dense in nature, so the professional researchers will likely need to provide support and guidance to co-researchers to facilitate meaningful involvement at this stage. Examples of how to do this include, breaking down the forms in to smaller pieces and working through these together or preparing plain English or Easy-to-Read versions of the forms. This will take more time and resources but that should not be used as a reason to exclude disabled co-researchers from this part of the process.

46 Suijkerbuijk et al., 2019

47 e.g. Mayer and Zach, 2013 cited in Suijkerbuijk *et al.*, 2019, Schneider et al., 2013 cited in Suijkerbuijk *et al.*, 2019, Span et al., 2015 cited in Suijkerbuijk et al., 2019, Wolters et al., 2016 cited in Suijkerbuijk *et al.*, 2019

48 James Lind Alliance <https://www.jla.nihr.ac.uk/priority-setting-partnerships/>

As with other stages of the research process, co-researchers will have valuable insights to add such as thinking of ethical issues or challenges that may not have been initially apparent to the professional researchers. It may be a good idea to contact the research ethics committee in advance to find out how well prepared they are to review collaborative research projects. For example, the ethics committee could be asked if they have any community representatives on the committee or if they have previously reviewed collaborative research ethics applications. It is a good idea to start early and dedicate extra time to the ethical review process, so that there is enough time to respond to specific information requests and to negotiate with the committee about aspects of the collaborative approach which may present tensions with standard ethical procedures.⁴⁹

Funding bodies also need to consider how to make their application processes more accessible so that research groups led by disabled people, who do not have full academic support, can also apply. Funding application forms can be very complex and are often subject to tight turnaround times. This can be very difficult for research groups that are led by non-academic disabled people to navigate. More flexible timeframes and formats are required to make the process as inclusive as possible

Undertaking the research

Desk based research

Co-researchers can be involved in desk-based research such as conducting reviews of the literature. There may be additional resource and time considerations for involving people at this stage as there are specific skills required for this type of task. The researchers and co-researchers should decide together if this would be the most valuable use of the co-researchers' time and contributions in a particular project.

Participant recruitment and data collection

Co-researchers can help to develop participant recruitment materials including information sheets and consent forms. They can facilitate participant recruitment and retention and help to refine the consent process.⁵⁰ Co-researchers can also collect the data (e.g. interviewing/facilitating/co-facilitating/collecting surveys or other data). It is important to consider in advance any challenges that may occur when collecting data.

49 <https://www.durham.ac.uk/media/durham-university/departments-/sociology/Ethical-guidance,-toolkit-and-cases,-final-version,-Dec-2023.pdf>

50 Crocker et al., 2018

For example, interviewing could be difficult for some co-researchers as it involves high demands on working memory, while focus groups require a variety of facilitation skills. It is important to ensure that co-researchers feel prepared for and comfortable doing data collection tasks. Below are some suggestions for how to achieve this:

- Provide accessible interviewing/facilitation skills training, where required.
- Develop and use tools or materials such as handbooks with information about the project, roles and responsibilities, schedules and timelines, step-by-step facilitation guides, plain language interview protocols and guides with timings and prompts.
- Allow co-researchers to practice in mock interviews or focus groups.
- Allow co-researchers to shadow or co-facilitate with more experienced researchers until they are comfortable doing it alone.
- Allow co-researchers to work in pairs when collecting data.
- Use video to illustrate the data collection and consent process.
- Have experienced researchers shadow co-researchers and then debrief and provide advice on what went well or what they could do differently.
- Have focus groups/interviews with D/deaf participants conducted by a D/deaf researcher and sign language fluent hearing researcher in partnership.
- Use creative ways to collect and generate data – e.g. body mapping,⁵¹ video, visuals, drawings, Image Theatre,⁵² personal objects, Photovoice,⁵³ storyboarding.
- Conduct debriefs with co-researchers after focus groups/interviews.
- Create a mentor or buddy system to support the co-researchers. This could be a peer who has more experience.

Data analysis

Data analysis is sometimes seen as difficult to conduct in an inclusive way due to the technical complexities involved in quantitative analysis and theoretical and conceptual complexities in qualitative analysis. However, by being flexible, supportive and creative, there are many ways to involve co-researchers in data analysis. Some examples of how to support involvement include:

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- 51 Whole-body mapping involves tracing around a person's body to create a life-sized outline, which is filled in during a creative and reflective process, producing an image representing multiple aspects of their embodied experience (Jager et al. 2016)
- 52 The Image Theatre approach uses non-verbal language and images to facilitate the exploration of real situations or abstract concepts (Rigano 2021; Enghart 2004 cited in Haya Salmón and Rojas Pernia, 2022)
- 53 Photovoice involves using photos/images to capture and express people's insights, perspectives, and realities (Wang and Burris, 1997)

- Video or audio record interviews to aid recall
- Use the advice of a research methodologist on how to tailor the data analytic approach to meet the aim of the research as well as the needs of a collaborative research approach
- Tailor the involvement of co-researchers in analysis to their preferences and the time limitations of the project. Ask the co-researchers how much they want to be involved in the analysis. Is it possible for them conduct only the parts of the analysis that suit their preferences, abilities and availability?
- Experienced researchers could analyse the data and then discuss the analysis with the co-researchers to obtain their views and provide opportunities to make suggestions
- Provide training in data analysis and workshops to practise data analysis where required
- Present raw data for analysis in more accessible ways:
 - by reducing the amount of information presented
 - by presenting the information slowly
 - by summarising data into Easy-to-Read summaries
 - by presenting data via posters, PowerPoint presentations, or on flip charts in large fonts, using colour contrasts to increase visual distinctiveness
 - by presenting data in a visual map of categories using sticky notes that could be rearranged
 - by using picture cards, word cards, storyboards and vignettes
 - by using role play
 - by using symbols and/or words
- Ensure a reflexive, probing approach to data analysis (to mitigate instances of co-researchers identifying strongly with participants)
- Using group discussions for data analysis. For example, watch videos of focus groups and interviews followed a facilitated discussion about analysis.
- Use a 10 step community of inquiry approach to data analysis⁵⁴
- Use a Participatory Theme Elicitation (PTE) methodology⁵⁵ which entails card sorting to identify themes in data

54 A Community of Inquiry is a 10-step approach to generating questions and facilitating discussion in response to a stimulus. See Disability Wales, 2019 for a worked example in practice.

55 The main task of PTE is to identify common groupings or 'themes' present in the data. The PTE technique then uses a Network Analysis technique to construct the groupings and highlight patterns in the data for further qualitative exploration, which stimulates a different perspective on the data. The PTE method involves a five-step process: Capacity building, data selection, data sorting, data grouping, analysis of thematic groups (Best et al., 2017 cited in McCartan et al., 2019)

- Watch video recordings of interviews multiple times to identify patterns
- Use the Photovoice method for the initial analysis
- Ensure appropriate breaks are taken
- Provide adequate time to complete tasks
- Ensure a relaxed, supportive and non-judgemental environment

Preparing and Disseminating Research Outputs

Writing up research

There are various means to involve disabled co-researchers in the writing up of research. Some people will require more support than others to engage in this process but that should not be used as a reason to exclude co-researchers from this part of the research process. With adequate planning, support and some creativity, co-researchers can successfully be involved at this stage. Some suggestions include:

- Researchers and co-researchers could write the report together.
- The professional researchers could prepare the initial report and Easy-to-Read or plain English summaries of each paragraph to enable the co-researchers to review and make suggestions for revisions of the content.
- The co-researchers could decide on the structure, recommendations and key points of the report or paper and the professional researchers could do the actual writing.
- Co-researchers can be responsible for different formats of the write up, including accessible publications, Easy-to-Read reports, video or audio summaries/abstracts of the report, blogs and think pieces.
- Professional researchers could link co-researchers with an experienced mentor who could help them write reports or papers.
- The research team could hold writing workshops as a group.
- Co-researchers could write certain sections of the report.

Authorship and acknowledgement

It is important to consider how co-researchers will be recognised and acknowledged in research outputs. Questions researchers should ask themselves at the beginning and throughout the research process are:

- Who will write up the report? Will co-researchers be involved?
- Who will be included amongst the authors and acknowledgements?
- Have some co-researchers made a greater contribution than others, if so, how will this be handled in any accreditations?

Previous literature has noted that it can sometimes be difficult for co-researchers to meet authorship requirements in academic papers.⁵⁶ Ensuring that co-researchers are engaged in the write up process, using some of the suggestions in the previous section, should help to overcome this.

If it is not possible for co-researchers to be recognised as authors, for example, if they do not meet authorship requirements set out by academic journals or they have worked on a type of report which does not identify authors, they should be listed in the acknowledgements. Some organisations and groups have now implemented policies that stipulate that their members must be acknowledged to ensure their contributions are recognised. Always ask the co-researchers if they would like to be acknowledged. Some people may prefer to remain anonymous or use a pseudonym.

Disseminating the research findings and outputs

It is important to plan for how co-researchers will be involved in disseminating the findings of the research from the very beginning. This means including any cost considerations at the funding application stage so that co-researchers can attend dissemination events such as academic conferences. Disabled individuals are often invited to speak at conferences. However, there is rarely consideration given to the fact that many disabled people will need to cover their own expenses, unlike academic or professional researchers whose expenses and conference fees will be covered by their organisation. When conference organisers invite disabled people to speak at their events, they should cover the costs. There should also be flexibility in submission deadlines for abstracts from disabled led research groups. For example, a group of co-researchers with intellectual disabilities may need more time and support to consider the submission guidelines and prepare an abstract. Flexibility in the format of submissions should also be considered, as academic abstracts are not accessible to everybody. Consideration should be given to allowing co-researchers to submit abstracts in various formats such as video, audio or in Easy-to-Read formats.

The way research findings are traditionally presented can be disabling and inaccessible to many disabled people and their supporters so it is important to consider more accessible and creative ways of disseminating research. Involving co-researchers will help to identify ways to do this and will ultimately help to increase the reach and impact of the research. Examples of dissemination activities that co-researchers can be involved in are listed below:

⁵⁶ Nicolaidis et al., 2019

Traditional methods:

- research events
- workshops
- talks/seminars
- launches
- conference presentations

Alternative methods of dissemination:

- A community event
- Co-researchers being interviewed by local media
- A theatre performance
- An art exhibition/photo exhibition
- A podcast
- Videos and films
- Comics and illustrations/magazines/newsletters
- Blog posts

Evaluating the process of involvement

It is important to document and evaluate the collaborative research process and impact of the research. Conducting and reporting formal evaluations will allow for assessment of the impact of collaborative research on the research project and the research team, and would add to the evidence base as to what approaches work best in collaborative research.

The collaborative research process can be documented through:

- Video and audio recordings, personal diaries, other field notes to reflect on and evaluate the process of involvement in the project.
- Using the Guidance for Reporting Involvement of Patients and the Public 2 (GRIPP 2) reporting checklist tool. However, it is important to note that while the GRIPP 2 tool does offer a standardised approach for recording the involvement of co-researchers in a project, it has been critiqued as having “no standards for evaluating and reporting the quality of the PPI or for systematically quantifying impact of PPI on research”.⁵⁷
- Providing brief progress reports at regular interviews.

⁵⁷ Miah et al., 2019, p.17

- Asking the co-researchers for feedback about how the process went for them. This will help to inform future projects. For example, did they feel included? Did they feel that they were “heard”? Were their recommendations accepted, if not, were the reasons given and were they considered to be valid by the co-researchers? Did they feel that their role and contribution was of significant value?
- Giving feedback on how co-researcher contributions were used and the impact they had on the project

Closing out the project

The end of a project can be a big adjustment for co-researchers, as they have often developed relationships and routines as part of their involvement. It is therefore important to support them in the transition out of the project and to provide a sense of closure. To achieve this, it is important to formally mark the end of the project with, for example, a celebratory event. It is also important to keep co-researchers updated on any further developments with the research after the project has ended, for example, will there be follow on projects, or did the research have any influence on policy or practice? Co-researchers have given their time, effort and expertise and most people will want to know what came of that.

Where relevant, professional researchers should also consider the team of co-researchers for future roles, especially considering the skills and expertise that they have developed during the current project and the investment, from all sides, that went into developing those skills.



Section 5.
**Who to involve in
collaborative research
projects and how to
find them**

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When deciding who best to involve it is important to think about the knowledge and perspectives that are required and what support will be available to the people who get involved.⁵⁸

Some key points to consider include:⁵⁹

- Be clear about the purpose of involving disabled people in research and what experiences and knowledge they can provide.
- Include a diversity of relevant views and perspectives
- Be aware that people can wear several hats, and their contributions may be broad because of their range of experiences.
- Consider that the type of lived experience required may vary depending on the focus of the research.
- The number of co-researchers you need will depend on the size of project. Where possible, involve more than one person.
- Where possible, aim to include a diversity of identities. Disabled people have lots of intersectional identities, so it is important to ensure, where possible, a diversity of ethnicity, gender identity, sexual orientation, socio economic status, geography and so on.

How to find people to involve

- A good first step is to speak to Disabled Persons Organisations (DPOs) and ask for their views on how to find the people you would like to involve. Be aware of the differences between DPOs and service providers as outlined in the UNCRPD.⁶⁰
- List potential sources for finding co-researchers from target groups: DPOs, service providers, media interviews, relevant websites. Search online for such relevant organisations, use social media such as Facebook or Twitter.

⁵⁸ National Institute for Health Research, 2021

⁵⁹ Adapted from National Institute for Health Research, 2021

⁶⁰ DPOs are a type of civil society organisation that are led, organised and informed by disabled people. They must have a clear majority of disabled people in their membership, and their operating principles must be rooted in the UNCRPD; Other kinds of organisations which work on disability rights issues, or which provide services to people with disabilities are not DPOs because they are organisations 'for' persons with disabilities, and not organisations 'of' persons with disabilities.

- Go out and engage with communities or groups where they already meet, whether that be in physical spaces or online forums. Spend time developing networks and building relationships.
- For specific communities, contact relevant community-based organisations, community leaders, or other individuals who can facilitate engagement with specific groups of people.
- Advertise the co-research opportunity in local shops, outpatient departments, local newspapers and on the radio.
- Hold information or recruitment days where potential co-researchers could meet with professional researchers to find out about the project.
- Use snowballing techniques. Ask people who are applying to be co-researchers to suggest other people or locations where potential co-researchers, with the relevant characteristics, may be located.
- If health issues are the research subject, then health care professionals may help in finding co-researchers by asking patients who have the relevant characteristics.
- Advertise co-research opportunities on the Opportunities Notice Board on the PPI Ignite Network Website.⁶¹

Potential challenges when recruiting people to be co-researchers

- In order to ensure that co-researchers are not taken advantage of, some organisations charge a fee when they are asked to find people to get involved in research activities, or they may require that co-researchers from their organisation are paid for their involvement. This should be considered and budgeted for at the planning stage of the project.
- Guardians or other carers may be sceptical about the ability of those with ID or dementia to be involved as co-researchers. To mitigate this scepticism, it is important to form a foundation of trust and transparency. Ensuring that gatekeepers/supporters/carers understand the whole research process, and the importance of including those they support as researchers, can help to facilitate recruitment.
- It is important to be aware that some people or organisations might choose not to get involved in the research project. This might be for a variety of reasons including that the time or practical costs of either getting involved themselves or finding somebody to get involved in the research is too great at that time.

⁶¹ <https://ppinetwork.ie/get-involved/ppi-opportunities-noticeboard/>

- People or organisations might choose not to get involved in the research if their aims do not align with those of the project. If this is the case, the professional researchers need to ask themselves why the aims do not align. For example, a disabled person or an organisation may not want to get involved in research that does not align with the social model of disability. In such cases, it is advisable to reconsider the perspective the research is taking. The disabled individuals or organisations who have been approached may be willing to offer guidance on how to re-frame the research. To avoid such a scenario altogether, it is better to involve disabled people as early as possible in the research process.

Making the process accessible

It is important that the process for recruiting co-researchers is accessible to all. Some things to consider include:

- Ensuring that all recruitment materials, including the advertisements and the processes of responding to advertisements, are accessible to people who use screen readers, to D/deaf people or to people with Intellectual Disabilities. To facilitate this, a variety of formats, such as videos and audio recordings, to advertise co-research opportunities should be considered.
- If holding an information or recruitment event, ensuring that the venue or technology being used for online events are accessible to all

Selecting co-researchers

It is important to think about the specific criteria that are required in co-researchers and what your expectations are. Consider involving people with disabilities, even if the research itself is not obviously directly relevant to people with disabilities. People with disabilities live in society and buy consumer goods, so most research will be relevant to, and could benefit from, input from disabled people. Remember that co-researchers are bringing more than lived experience, they are bringing other skills and competencies too.

Other things to think about when selecting co-researchers include:

- Being clear about what contribution they will be expected to make.
- Making sure the demands on people's time is reasonable.
- Thinking about the skills those involved will need to conduct the research. For example, research skills, language skills, communication and social skills, or experience of a certain condition.
- Considering whether co-researchers need to have previous research experience.

- Developing a glossary of relevant technical, research or project-related terms that co-researchers may not be familiar with to ensure meaningful involvement.
- Thinking about what training may be needed and whether training will be provided in-house or externally.
- Ensuring there is a contact person on the research team available for potential co-researchers to discuss the role and to provide accessible information



Define clear roles and responsibilities

To make the experience as positive and collaborative as possible, co-researchers need to know the plan, their role, why the research is being done and why they are being asked to be involved. Plan how you will ensure that the co-researchers are fully aware of:

- how the process will work and any limitations
- expected timelines
- what is expected of them
- what is expected of the project
- how they will be communicated with and kept informed about the project and their options to participate.

Where possible, agree the goals and outcomes of the project together. It is essential that co-researchers are included in discussions around roles and responsibilities. It is a good idea to develop an official role description or terms of reference that clearly defines the role, the purpose and scope of the project and describes the tasks required and the skills/knowledge needed to execute them.⁶² The professional researchers should ensure that everyone has read and understood their role and commitments before commencing. However, keep in mind that clarifying roles on paper may make the process appear more formal than it is and could make co-researchers feel under pressure. To avoid feelings of stress and pressure, roles should be re-negotiable and amendable as the project progresses. It is essential to check in regularly with the co-researchers throughout the process to ensure they are able to manage their roles and to give them the opportunity to let the professional researchers know if they are having difficulties. It is also important to plan for what you will do if co-researchers withdraw from the project before it finishes.

Discussing and managing expectations

It is important to discuss and manage the expectations of both the professional researchers and co-researchers. Professional researchers need to ensure that they don't overestimate what is feasible for co-researchers to achieve in the given timeframe. This type of overestimation may lead to disappointment and disempowerment in situations where tasks are not completed. On the other hand, co-researchers may also have unrealistic expectations about what is feasible and implementable as part of the research project or how quickly change can happen as a result of the research. Some suggestions for managing expectations include:

- being open and transparent from the beginning about the parameters of the project and expected outcomes
- ensuring each step is open to discussion and joint decision-making
- adapting to co-researchers' needs
- collaboratively deciding what is feasible to cover in meetings
- ensuring ongoing reflection by the entire research team.

62 See Appendices 2 and 3 for examples of what to include in role descriptions and advertisements



Section 6. Practical Considerations

Section 6. Practical Considerations

This section outlines some practical considerations for engaging in collaborative research projects with disabled co-researchers.

Funding, payment and expenses

It is likely that a larger budget will be required for research involving members of the public as co-researchers. It is important to plan for any budgetary costs at the outset. The provision of accessibility and accommodations are required under the Disability Act, the Equal Status Acts, and the Employment Equality Acts. So, the provision of accommodations for co-researchers should not be constrained by availability of funding. Various guidance exists regarding the payment and reimbursement of expenses for public involvement in research and other consultation activities.⁶³

Payment for involvement

It is generally recommended that, where possible, people involved as co-researchers, whether they are disabled people, other members of the general public or members of any other specific group, should be financially compensated for their involvement.⁶⁴ Payment acknowledges the unique skills and expertise co-researchers bring to the research and is a key way to demonstrate respect and address power imbalances. A co-research project that does not pay the co-researchers cannot be perceived as a model for equality. Not paying co-researchers may suggest that their contribution is not important, that it is not of a sufficiently high quality to warrant payment, or that the time given by co-researchers is not worthy of payment. Some things to consider in relation to payment:

- Before promising payment to co-researchers, check with your organisation/institution about what is possible. There may be policies in place that prevent you from paying co-researchers. If this is the case, be transparent with the co-researchers so they can make an informed choice about whether to get involved in your project or not.
- It is important that information on reimbursement is communicated clearly. Work with the co-researchers to agree what will work best for them in terms of payment. There may be concerns about the impact of earnings on their disability payments or other allowances.

⁶³ Department of Health, 2023; National Health Service, 2017; National Institute for Health Research (INVOLVE), 2016

⁶⁴ *ibid*

Professional researchers should be aware of things like the earnings disregards that allow people on some allowances to earn up to a certain threshold before impacting their Disability Allowance.⁶⁵ Not all potential co-researchers may be aware of this. There may also be tax implications.

- Ensure that the co-researchers understand the impact of any payments. They may choose to be volunteers rather than accept payments or expenses. This should all be discussed before commencing the role.
- Be flexible, where possible, in how co-researchers can be paid, for example, in cash, vouchers, equivalent credit or other forms of recognition, noting that different institutions have rules that may limit this flexibility.
- If using gift cards as payment, check that they are acceptable to, and accessible for, the co-researchers.
- It is important that all reimbursement is done via a straightforward simplified payment system and is paid promptly.

Payment for expenses

Any expenses incurred by co-researchers as part of their role as co-researchers should always be paid in a timely manner to reduce barriers to being involved. Factor in expenses across all stages of your research plan. This should be included in any grant or funding applications. Some examples of expense include:

- Travel and subsistence for co-researchers.
- Some disabled people may require, or prefer, to bring a support person or Personal Assistant (PA) with them. You need to consider covering the travel and subsistence of the support person or PA in addition to the co-researcher.
- Printing and ink (if not providing hard copies of documents).
- Cost of child or day care if the co-researcher has caring responsibilities.
- Consider who is going to pay for the assistive technology if a co-researcher does not have their own technology. If it is a requirement that they must have, then not providing it may limit their participation.
- Psychological support where warranted.
- Alternative research outputs suggested by co-researchers.
- Relationship building activities.

65 For more information on earnings disregards see the Department of Social Protection website: <https://www.gov.ie/en/publication/c075c7-operational-guidelines-disability-allowance/> and the Citizen's Information website: https://www.citizensinformation.ie/en/social_welfare/social_welfare_payments/disability_and_illness/disability_allowance.html#:~:text=You%20can%20work%20and%20earn,375%20are%20assessed%20in%20full

- Providing accessible information in different formats such as Easy-to-Read documents, Braille documents, or videos. In most cases you will need to go to an external provider to obtain these.
- Irish Sign Language interpretation may be needed for meetings and for providing translated videos of materials such as reports or surveys. Remember that a Deaf person will also need to respond in ISL so that also needs to be facilitated.
- Public transport may be inaccessible for some people with disabilities. Providing payment for taxis or mileage can help to reduce this barrier. Transport may be required for holding in-person meetings, or if co-researchers are doing fieldwork such as collecting data.
- Include dissemination plans and factor in resources or supports that will be required to ensure that co-researchers can be involved in the dissemination of a project, such as covering conference fees and travel and subsistence for attending conferences.

Accessibility and Supports

Article 9 of the UNCRPD focuses on accessibility and applies to the physical environment, transportation, information and communication, technologies and systems and to other facilities and services provided to the public. Identifying accessibility barriers that may arise throughout the research process is crucial to support the involvement of disabled co-researchers on an equal basis. Unnecessary delays and stress may occur if there is insufficient planning for the support needs of co-researchers and potential barriers they might face.

It is important to identify accessibility requirements together with the co-researchers and to identify solutions together. This should be done before commencing the project but also on an ongoing basis throughout the project. It is important to remember that two people who have the same disability may not have the same accessibility requirements and some co-researchers may have more than one disability or impairment. Further, one person's accessibility requirements may conflict with another person's accessibility requirements. If the research team is likely to involve people with a range of different disabilities, or people with multiple disabilities, think about how the team will accommodate that requirement. Finally, researchers need to be aware that some people may be reluctant to ask for what they need, so the researchers need to be proactive about checking with co-researchers what their accessibility requirements are. An individual or individuals from the team could be nominated to act as a liaison between the co-researchers and researchers, to help ensure that support needs are anticipated and met and that the project is flexible and adaptable throughout.

Training

It is recommended that the entire research team undergoes Disability Equality Training. Disability Equality Training goes beyond Disability Awareness Training and steers learners towards the social model of disability and the human rights based approach. Such training should ideally be led by, or at least include disabled people. Involving all members of the team, including those with disabilities, in disability awareness and equality training gives an opportunity for the disabled team members to know the type and level of disability awareness training provided and ensures that people with a particular disability better understand the needs of people with other disabilities.

Training and upskilling for co-researchers

Co-researchers may initially lack the expertise and skills required to conduct research so they may want, or need, some training and upskilling. The researchers and co-researchers should work together to identify what training and capacity building the co-researchers require, if any, so that they can make meaningful, effective and efficient contributions. Training will help ensure that co-researchers are on a more even footing with the professional researchers, so that they are not at a disadvantage and are empowered to fulfil their roles.⁶⁶ Decisions, therefore need to be made about what type of training to provide and how and when to provide it. To help with deciding on an approach to training, professional researchers should establish co-researchers' motivations, ambitions, accessibility needs and existing skills.⁶⁷ It is important to note that some co-researchers will have research backgrounds or previous experience and so those skills and expertise should be drawn as well as their lived experience as a disabled person. Where training is warranted, considerations include:

- Should training focus on project-specific skills and knowledge or generic research skills, or both? Check with the co-researchers which they would prefer. Some co-researchers will want to develop transferable research skills but others may not be interested in such training.
- Should full training be given at the beginning of the project or in stages throughout?
- Will refresher training be required during the course of the project?

⁶⁶ Gove et al. 2017

⁶⁷ Walmsley et al. 2004 in Frankena et al. 2015

- Who will provide the training? Do the professional researchers have the skills to provide the training themselves or do they need to find appropriate instructors or courses? Will disabled people be involved in designing and delivering any training?
- Consider the length of the training course and individual sessions.
- It may be necessary to consider more creative ways of delivering the training such as including role plays to practice skills and video demonstrations.
- Does everybody need the same level of training? Some co-researchers may be complete beginners while others may have more experience.
- Has the cost and time for ensuring that all training materials will be fully accessible been factored in?

Training and upskilling for professional researchers

Before embarking on a collaborative project, it is important that the professional researchers reflect on the skills and expertise they need to ensure meaningful collaboration. These skills should not be taken for granted. Some examples of areas that professional researchers should consider in terms of their own capacity building include:

- Training in collaborative research methods to ensure that they can effectively share tasks and responsibilities with co-researchers, are flexible and are able to adjust their working pace.
- Training to ensure they understand how to make the research process as accessible and inclusive as possible; for example, they may need training in producing accessible materials, or alternative forms of communication.
- Training to improve their skills for working with people, such as their communication or facilitation skills.
- Training may also be required when working with specific groups, for example, when working with Deaf co-researchers, it is critical for professional researchers to be aware of, and to value, Deaf culture.

Communication and information materials

Effective communication between researchers and co-researchers is crucial to collaborative research projects. People with disabilities communicate in different ways. Check with the individual co-researcher as to the type of communication preferred. Researchers should facilitate the choice of the co-researchers to communicate in the way that works best for them. You can find examples of various means of effective communication in Section 4 of the NDA's Participation Matters Guidelines⁶⁸ (see also Appendix 4 of this document for additional information on accessibility). Some specific points to consider in terms of the accessibility of communication:

- In order to facilitate equal and meaningful involvement, all information and materials need to be provided in fully accessible formats. Use plain English and jargon-free language and reduce reliance on abstract language or concepts. Consider providing a glossary of terms that are likely to be used as part of the project. Ensure you have plain language versions of all documents. If working with people with cognitive impairments such as intellectual disability, provide Easy-to-Read versions of all documents.
- Ensure ISL interpretation is available. Be aware that you may need to book ISL interpreters in advance for live events, meetings or to create ISL videos of materials. Deaf co-researchers must also be accommodated to respond in ISL.
- Consider the methods of communication used. For example, some people may prefer to be contacted by phone, others may prefer text messages or emails.
- Ask people if they would prefer to receive information or documents by post or by email.
- Send information in a timely manner to enable co-researchers to engage with it properly. Also give plenty of notice when scheduling meetings.
- Be cognisant of sending too much information in one go. For some people, it might be better to break information down into smaller pieces.
- Clearly communicate deadlines and work with co-researchers to negotiate the timelines for tasks.
- Facilitate a range of ways to participate and engage for example, face to face, by email, by teleconference or by videoconferencing.
- Adapt informational/reading materials, for example, using large font, using black writing on coloured paper and using pictures, word cards or storyboards as required.

Time

It is important that due consideration is given to the time required of co-researchers throughout the project.

- Think about timeframes. What is the timeline for the project? How will this impact on the co-researchers' capacity to be involved? How much time are co-researchers expected to give?
- How flexible is your timeline? Flexibility in the timeline is important for numerous reasons. For example, co-researchers are often juggling multiple roles such as work, education, caring responsibilities, or advocacy roles. Some people might have health conditions that may impact on their ability to complete tasks within the specified time.
- Due consideration needs to be given to how often and when meetings should occur based on the needs and availability of the co-researchers.
- Consider the timing of the meetings. For example, co-researchers who have other jobs, are in education or attend day services may not be able to attend during office hours. Other people who attend day services may only be able to attend during day service hours. Some people only have access to a PA during certain hours. Some people may have caring responsibilities. You will need to work out a suitable schedule with the entire research team.
- Consider the length of meetings and the meeting agenda. For example, the length of meetings may need to be adapted to accommodate adequate breaks and to allow co-researchers the time they need to complete tasks or process information and respond. Do not overload the meeting agenda, be realistic about what can be covered in the allotted time. Decide on the adequate length of meetings with the co-researchers before every meeting, whether it is online or in person.
- Consider the pace of the meeting. This will depend on the co-researchers. For example, someone who communicates non-verbally may need more time to make their contribution. Someone with Dementia or an Intellectual Disability may need more time to process the information and formulate a response. A Deaf person cannot passively listen like hearing people and so may need breaks from following the ISL interpretation.
- Co-researchers must be given adequate time for discussion to give input on decisions and to consider information materials they have been sent. It is recommended that plain language materials and topics for discussion are sent in advance of the discussion.

Meetings

The research process is almost certainly going to require planning and organising meetings. It is important to bring people together to, for example, discuss ideas or problems, to make decisions or to plan next steps. How this is done can have a big impact on how the co-researchers want or are able to get involved in your research. When planning meetings with co-researchers who have disabilities, there are some general considerations that should be taken into account. For more detailed information refer to Appendix 4 of this document and to the NDA Participation Matters Guidelines.⁶⁹

- Consider developing ground rules or terms of reference for meetings. This should be done in collaboration with the co-researchers.
- Allow time at the beginning of meetings for tea/coffee and chat to create a cohesive and friendly atmosphere.
- Ask everybody to introduce themselves.
- If accessibility needs of different co-researchers' conflict, such as venues, formats of documentation, or means of communication, work together as a group to find solutions.
- In some cases, it may be helpful to hold pre-meetings with co-researchers to help prepare for meetings.
- Considering the appropriate meeting size. For example, a large group might be unsuitable for people with certain disabilities.
- Share a summary of the event or any notes or minutes taken with the co-researchers. This should include any recommendations or outcomes.
- Provide feedback to co-researchers on any recommendations or outcomes.
- Allow sufficient time between meetings for people to consult with peers or their organisations if they wish to do so.
- Ask the co-researchers for feedback about the meeting to identify anything that could be done better in future meetings e.g. ask about the accessibility of the materials and the meeting in general, communication, did the co-researchers feel their contribution was heard/meaningful?

69 National Disability Authority, 2022b



Conclusion

Conclusion

A substantial body of research has indicated that involving disabled people in research can enhance the quality of research processes and outputs, and ensure that research aligns with the UNCRPD and the rights-based perspective.⁷⁰ It is generally accepted that there is no one best practice model of collaborative research between professional researchers and disabled co-researchers. However, there are common underlying principles that should be adhered to in any collaborative research project. These include being flexible, fostering empowerment and meaningful engagement and being transparent and respectful. By being flexible and creative, disabled co-researchers can be meaningfully involved at every stage of the research process, from idea conception through to disseminating the findings and measuring impact.

There are key points to consider when embarking on a collaborative project, such as the extra time, resources and planning that are likely to be needed. Accessibility needs and adjustments to the research design and activities need to be considered throughout all elements of the research based on individual co-researchers' needs and preferences. Providing support, offering training and paying co-researchers for their time are important measures to ensure the full and meaningful participation of co-researchers with disabilities.

Although the landscape for conducting collaborative approaches to research has changed and improved dramatically over the past couple of decades, there is still room for improvement. Funders need to drive commitment to collaborative approaches to research by encouraging and favouring projects that incorporate collaborative elements. Academic institutions and organisations need to ensure that there are no barriers to paying people for their involvement and more work needs to be done to develop proper employment opportunities in research institutions for co-researchers. A culture shift is required in terms of traditional academic processes, such as applying for funding or ethical approval, attending academic conferences and submitting research papers to academic journals. These processes need to be more flexible to ensure they are fully inclusive and accessible to all. Finally, work must continue to challenge ableist attitudes and misconceptions still held by some professional researchers regarding disabled people.

70 National Disability Authority, 2022c

It is hoped that this guidance will serve as a useful tool for gaining a high-level overview of key considerations when planning for collaborative research initiatives, especially for those who are new to this approach. We recommend that researchers consult with DPOs, other disability organisations and disabled individuals when considering conducting research with individuals who have disabilities.





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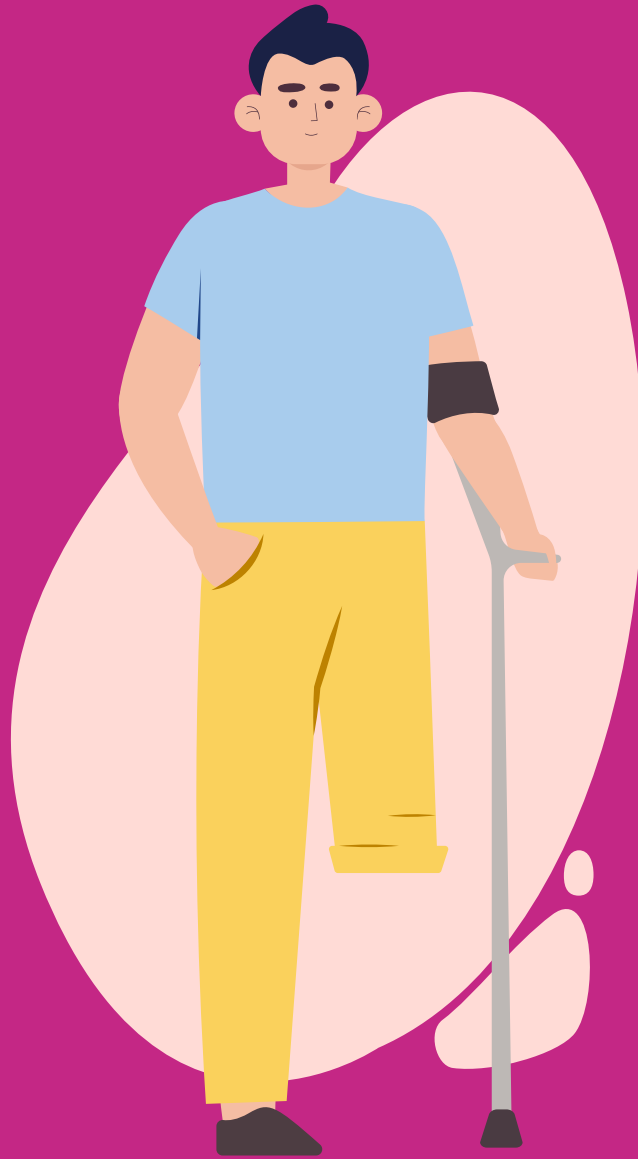
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Appendices

Appendices

Appendix 1. Planning Checklist

Use the below checklist to assist in your planning. In addition, the NDA's Customer Communications Toolkit for Services to the Public contains checklists covering written, spoken, signed and digital communication.⁷¹ The NDA's Participation Matters Guidelines for conducting public consultation also contains useful information and checklists that can be referred to when planning engagement with disabled co-researchers.⁷²

| Stage | Key considerations | Done? |
|------------------------------|---|-------|
| Research planning and design | Have co-researchers been engaged as early as possible? | |
| | Has a diversity of perspectives been considered? | |
| | Have roles, responsibilities and time commitments required been communicated clearly, discussed and agreed with the co-researchers? | |
| | Have timelines been outlined, including time for possible delays? | |
| | Has Disability Equality Training been provided to all team members? | |
| | Have training and upskilling needs been identified for professional researchers and co-researchers? | |
| | | |

⁷¹ National Disability Authority, 2023

⁷² National Disability Authority, 2022b

| Stage | Key considerations | Done? |
|--------------------|--|-------|
| | Has the provision of training been discussed and agreed with the entire research team? | |
| | Have potential power imbalances in the research team been thought through, along with ways of avoiding and addressing them? | |
| | Have co-researchers been asked about their accessibility requirements in relation to every stage of the project? | |
| | Are all materials available in accessible formats as required? | |
| | Has a glossary of relevant research and project terms been developed? | |
| | Are the professional researchers familiar with their institution's policies and procedures around remuneration and expenses for collaborative research projects? | |
| | Have methods for remuneration and expenses been discussed and agreed with the co-researchers? | |
| | Has involving the co-researchers in the dissemination phase been factored in, including budget considerations to facilitate this? | |
| | Have ways of gathering feedback or checking in with the research team throughout the process been considered and agreed? | |
| Funding and ethics | Have you checked the funder's specific expectations around involving members of the public in your research? | |

| Stage | Key considerations | Done? |
|-----------------|---|-------|
| | Has involving co-researchers in ethics and funding processes been considered and methods for involving co-researchers in these processes been agreed with the co-researchers? | |
| | Have potential tensions that may arise with the Research Ethics Committee been identified in advance and potential solutions been thought through? | |
| | Has the ethics committee been engaged with at an early stage? | |
| Collecting data | Have co-researchers been offered the opportunity to shadow researchers, to practice interviewing/facilitation skills, or any other forms of support required to facilitate data collection? | |
| | Has the impact of data collection processes on co-researchers been considered in terms of, for example, timelines, venues, transport, emotional impact, technology required, accessibility? | |
| | Has time for debriefs with co-researchers been planned? | |
| Analysing data | Have various ways of including co-researchers in data analysis been considered including alternative or creative styles of analysis? | |
| | Is there extra time allowed for discussion of the analysis? | |
| | Has accessible training on data analysis been offered where relevant? | |

| Stage | Key considerations | Done? |
|----------------------------|--|-------|
| | Has a relaxed and non-judgemental environment been created? | |
| Writing up the research | Has involvement in the write up of the research been discussed and agreed with co-researchers? | |
| | Has authorship and acknowledgement been discussed and agreed with the co-researchers | |
| | Have various formats of research outputs been explored with the co-researchers? | |
| Dissemination | Is the report available in accessible formats? | |
| | Has the co-researchers' involvement in disseminating the research findings been discussed and agreed? | |
| | Have the co-researchers been invited to dissemination events? | |
| | Have the co-researchers been given the opportunity to disseminate the findings to their own communities? | |
| Project end and evaluation | Has an evaluation of the collaborative research processes been completed with the entire research team? | |
| | Has the end of the project been marked and the project been formally closed out? | |
| | Has the requirement for any on-going communication or follow-up been discussed and agreed? | |

Appendix 2. What to include in an advertisement for recruiting co-researchers⁷³

- **WHO** is it for? for example, all disabled people/only those with a particular disability or health condition or experience?
- **WHAT** is it? Clear details of who you are and what you're expecting people to do.
- **WHEN** is it? be specific if this a one-off discussion group/regular sessions/ how long will each session take/over how many months?
- **WHERE** is it? Is it online or in person?
- **MONEY?** Will there be payment/reimbursement of travel costs/etc.
- **CLOSING DATE** for applications
- **MORE INFO?** If possible, give a web address, so that people can find out more without committing themselves. Also give a contact name and email/ phone number.



73 Adapted from <http://www.phwe.org.uk/wp-content/uploads/PHWE-Involvement-Opportunity-Checklist-April-2018.pdf>

Appendix 3. Role and person specifications

Appendix 3.1. Role specification

It may be helpful to develop role and person specifications for a specific project to provide clarity around roles and responsibilities. However, such documents risk making the process quite formal. It is important to remain flexible and it may be helpful to review the content at regular intervals during a project. Examples of role specifications are widely available online. See the PPI Ignite Network⁷⁴ and NIHR⁷⁵ websites in particular. Suggestions of what to cover in a role specification include:

Background to the organisation and project

Provide a brief introduction to the organisation. Provide a brief background to the research project and outline the aims and objectives.

Aims of collaborative element of the research

Outline what the aims of the collaborative element of the project are. What is hoped to be achieved by including people from the disabled community as co-researchers? What tasks will co-researchers be expected to carry out as part of their involvement?

Membership

Who is membership of the collaborative research team open to? For example, is it open to all members of the public or people with a specific lived experience? How many co-researchers are expected to be involved?

Time commitment

Outline the expected time commitment required including how long the role will continue for, and how much time the co-researcher will be expected to commit per week/month/year, as applicable.

⁷⁴ https://drive.google.com/file/d/1emqrDNKT5u65z_hVzM4dCzVMROI_NSGh/view

⁷⁵ <https://www.nihr.ac.uk/documents/nihr-public-committee-member-role-description-and-person-specification/12256>

Training and supports

Provide information on what type of training or ongoing supports will be provided.

Meetings

Outline how often meetings are expected to take place for example, once or twice per year? Once every three months? It should also be outlined where meetings will likely take place e.g. in person or online. Will there be options for blended meetings? What is the minimum attendance required per person? Who will chair the meetings? Will co-researchers be sent material in between meetings?

Confidentiality

Specify any information related to confidentiality, such as data sharing, and maintaining colleagues' confidentiality.

Accountability and responsibilities

Outline who the co-researchers and professional researchers are accountable to; for example, to each other, the research team? Identity the Principal Investigator/lead researcher/project manager. Specify the expected responsibilities of the co-researchers. It is also important to specify the responsibilities of the organisation or professional researchers to the co-researchers.

Payment, reimbursement and recognition

Include information about whether payment is an option and the reimbursement of expenses.

Organisational contact details for further information

Provide the contact details of people on the research team that potential co-researcher can reach out to for further information. Ideally, this should not be a general organisation email address.

Appendix 3.2. Person Specification

It may also be helpful to develop a person specification, particularly if you are looking for people with a specific lived experience or certain skills for example. See the NIHR website for examples of person specifications.⁷⁶ Things that can be included in a person specification are:

- The experience and knowledge the person has.
- The skills or personal attributes of the person.



76 <https://www.nihr.ac.uk/documents/nihr-public-committee-member-role-description-and-person-specification/12256>

Appendix 4. Accessible information and materials

Some common types of accessible information include:⁷⁷

Accessible word document

Many blind or partially sighted people use screen reader technology to read a document. Screen reader accessible documents are not difficult to create in Word. Using 'Styles', you can create a system of headings and subheadings that a person can use their screen reader to navigate through. If there are images or tables in the document, you must include a simple 'Alt text' description so that the reader can understand the image.⁷⁸

Braille document

Braille is a system of reading and writing using raised dots which are read by touch. Some blind and partially sighted people and some deafblind people prefer Braille and may request this format. There are two types of English Braille – Standard English Braille (SEB) and Unified English Braille (UEB). UEB was introduced in 2013, however some people learned to read Braille before 2013 prefer to use SEB Braille. Check with the individual which Braille they prefer.

Large Text documents

Providing documents with large text can make it easier to read for some partially sighted people.

Easy-to-Read documents

An Easy-to-Read document uses a combination of plain language and visual images, it is often preferred by people with intellectual disabilities. It also supports people with low literacy levels and people who prefer visual information. The Easy-to-Read format can be used for any type of document. Creating these types of document is a specialised skill and best practice dictates that a person with intellectual disability reviews the document for clarity.

77 Adapted from the National Disability Authority's Participation Matters Guidelines (National Disability Authority, 2022b)

78 There is a step-by-step guide on how to create an accessible Word document in the NDA's Customer Communications Toolkit for Services to the Public (National Disability Authority, 2023).

Irish Sign Language Video

Members of the Deaf community use ISL as their primary language. Not providing ISL interpretation can be a significant barrier to Deaf people being involved in research collaborations. It is not acceptable to rely only on written or email correspondence when working with members of the Deaf community. ISL interpretation will need to be provided for all meetings and ISL video versions of some materials will need to be provided. This might include, but is not limited to, information materials, surveys, reports or forms.

If there is no ISL or Deaf interpreter on the research team, contact the Sign Language Interpreting Service to be connected with a qualified interpreter. Allow at least two weeks to arrange for a video translation, depending on the size of the documents. Remember that ISL users will need to respond in the same language so make sure you have the facilities to accommodate this through ISL interpreters

Visual and audio

To complement or substitute for written information, you can use visual aids, video or audio such as pictures, mind maps or 'talking mats'.

Swell Symbols

Some Deafblind people used Swell Symbols. These are tactile raised lettering or pictures.

Accessible venues

If planning in-person meetings or disabled people need to go somewhere to do fieldwork, it is important to carry out an accessibility visit in advance, ideally with the co-researchers, to ensure it meets their needs. Even if a venue meets the requirements outlined in Part M of Building Regulations,⁷⁹ this does not necessarily mean it will meet the accessibility requirements of everybody. Adequate information about the venue and how to get there should be provided to participants in advance.

79 <https://www.gov.ie/pdf/?file=https://assets.gov.ie/241161/31b7614c-7df1-439c-abcb-0f16fb3e93a7.pdf#page=null>

Issues to assess include:

- Physical accessibility to the venue.
- Accessibility within the building.
- Accessibility to toilets and other facilities including coffee/lunch spaces. Consider whether a changing places toilet is required.
- Accessible parking.
- Accessible transport to the venue. It is also important to consider the transport and travel time to meetings and other research-related activities
- Accessible and adequate signposting.
- Space for service animals, wheelchairs and assistive devices.
- Consideration of the sensory environment by providing sensory supports and a quiet space.
- Provide clear information about the meetings, timings, venues and directions in advance.
- Where possible, meet in places which are familiar to co-researchers or which they are comfortable with. For people with certain disabilities, holding meetings in the same place every time may be helpful.
- Consider the need to accommodate support animals (e.g. space, water bowl).

In-person meetings

- It is often better to plan for late morning or early afternoon start to the meeting in case people have to travel some distance. Additionally, some people need additional time to get ready in the morning, or due to PA hours.
- In some instances, you may need to offer overnight accommodation. Always check with the co-researchers if they have any special requirements in relation to overnight stays.
- Ask co-researchers about their dietary requirements and ensure that they are catered for. Where possible, let co-researchers know in advance what refreshments will be provided
- Consider providing name badges in clear, large font.
- If planning to hold an in-person meeting, where possible, offer a hybrid-style meeting. This will maximise full inclusivity and accessibility of all meetings. It will also allow anyone who cannot attend in person to still attend if they wish.

Online meetings

Online meetings offer many advantages to disabled people in terms of being involved in research. They remove any issues which can be caused by inaccessible venues, geographical barriers, difficulties around public transport and cost. It may also allow the co-researcher more privacy and autonomy as they may not need to involve a support person or carer.

Ensure that the online meeting platform is accessible. Check whether the platform complies with WCAG 2.1 Standards and EN 301 549 accessibility requirements. If in doubt, ask the co-researchers if the chosen platform is accessible to them. Be willing to be flexible in terms of what platform to use.

- Allow attendees to send questions or comments in advance.
- Provide technological support before and during the meeting. Consider creating a tip sheet for online platforms with directions so people will feel comfortable with online platforms. The tip sheet can include step-by-step information about how to use the platform(s) and the option to attend training sessions about the platform(s) before the event. Be patient and do not rush attendees.
- Ensure there is an option for people to phone in so that they can participate without a computer or internet.
- Using the 'raise hand' function is common during online meetings and is a good way to ensure turn taking. However, this function may not be the best option for someone who is using a screen reader. At the beginning of the meeting, ask those in attendance what might work best.

Online meetings with people who are D/deaf or hard of hearing or have sensory disabilities⁸⁰

- Ensure ISL interpretation is available. For most meetings you will need to book two interpreters.
- Ensure live captioning is available for those who want/require it.
- Make sure your audio is clear; poor audio quality can make it hard for people to access the event.
- Use a headset whenever possible to improve audio.
- Hosts and presenters should use a quiet room where they won't be disturbed.
- Mute all attendees but those speaking to keep background noise to a minimum so that attendees can easily hear.

⁸⁰ Adapted from Leary (2020)

- Ask people speaking to say their name every time they speak, so captioners, ISL interpreters and attendees all know who is talking.

Online meetings with people who are blind or visually impaired or have sensory disabilities⁸¹

- Make sure the speaker's face is well-lit and can be clearly seen.
- If planning to use functions such as the 'raise hand' function, make sure these are accessible for participants. These functions are not always ideal for people who are using screen readers. Check with the group what would work best for them at the beginning of the meeting.
- Describe any images, read any text that appears on screen, and describe anything that you gesture at as if you were explaining it to someone who isn't in the same room as you.
- The chat function can be problematic for people who are using screen readers. It is recommended that the chat function be disabled to prevent interruption or distraction.
- Send all materials, such as presentation slides, to blind or visually impaired people in an accessible format (e.g. accessible word document) one to two weeks before the meeting.

Online meetings with people with intellectual disabilities⁸²

- Be patient with your attendees when you're explaining how to use online platforms, especially if they are new to the platform and haven't used it before. Repeat information if necessary.
- Use accessible, plain language during the event and avoid using jargon.
- Ensure all materials are presented in Easy-to-Read format
- Consider sending the topics for discussion to attendees in advance of the meeting so that they have time to think about and plan what they want to say
- Build processing time/breaks into the meeting.
- Leave ample time for questions.
- Offer the option for anyone using chat boxes to have their messages read aloud to everyone during the event (e.g. by the facilitator or note taker).

81 ibid

82 Adapted from Leary (2020)

Appendix 5. Useful resources

- Campus Engage Website: <https://www.campusengage.ie/>
- Department of Health (2023) Patient Voice Partner Policy – Draft for Public Consultation <https://assets.gov.ie/244950/1a383f15-9f00-4101-942c-71831efae3a4.pdf>
- National Institute for Health Research (INVOLVE) <https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371>
- National Institute for Health and Care Excellence (NICE) <https://www.nice.org.uk/about/nice-communities/nice-and-the-public>
- National Disability Authority (2023) ‘Customer communications toolkit for services to the public – A Universal Design approach’ <https://universaldesign.ie/products-services/customer-communications-toolkit-for-services-to-the-public-a-universal-design-approach/>
- National Disability Authority (2022) ‘Advice paper on disability language and terminology’ <https://nda.ie/publications/nda-advice-paper-on-disability-language-and-terminology>
- National Disability Authority (2022) ‘Engaging and consulting with disabled people in the development and implementation of legislation and policy’ <https://nda.ie/uploads/publications/Note-on-Engagement-with-Persons-with-Disabilities-and-DPOs-June-2022.docx>
- National Disability Authority (2022) ‘Participation Matters: Guidelines on implementing the obligation to meaningfully engage with disabled people in public decision making’ <https://nda.ie/publications/participation-matters-guidelines-on-implementing-the-obligation-to-meaningfully-engage-with-disabled-people-in-public-decision-making>
- PPI Ignite Network Website <https://ppinetwork.ie/>

