**Conducting Collaborative Research with People with Disabilities: A Literature Review**

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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 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]](#footnote-2)

# Executive Summary

This report sets out the findings of a literature review that synthesised recent literature pertaining to collaborative research partnerships between researchers and disabled persons.

## Introduction

The landscape in Ireland for conducting collaborative research with disabled persons has changed substantially over the past two decades, resulting in collaborative research approaches becoming much more common.[[2]](#footnote-3) This advancement is demonstrated by a number of developments. For example, the emergence of more Disabled Persons Organisations since Ireland’s ratification of the United Nations Convention on the Rights Persons with Disabilities who sometimes consult on policy development or research, the establishment of collaborative research groups such as the Inclusive Research Network, the establishment of the Public and Patient Involvement (PPI) Ignite network and the emphasis on engagement with stakeholders by funding bodies such as Horizon 2020 and the Irish Research Council. These developments suggest that it is now a good time to reflect and develop up-to-date guidance on conducting collaborative research with disabled people. The aim of this literature review, therefore, was to synthesise recent evidence regarding conducting collaborative research with people with disabilities to 1) identify recommendations for, and examples of, best practice and 2) outline the benefits and challenges associated with this approach. This is intended to inform a guidance paper for the National Disability Authority and the wider research community. The focus of this investigation is on collaborative research as opposed to consultation, for which we have produced a separate guidance document.[[3]](#footnote-4)

## Research questions

The research questions shaping this review are as follows:

1. What methods/models have been used in collaborative research projects with people with disabilities?
2. What are the benefits to engaging people with disabilities in collaborative research for people with disabilities, the researchers and the project?
3. What are the challenges to engaging people with disabilities in collaborative research for people with disabilities, the researchers and the project?
4. What is best practice/what lessons have been learned in collaborative research projects with people with disabilities?

## Methods

### Literature search, data extraction and synthesis

Literature searches were conducted across electronic databases, repositories, Google and Google Scholar. After screening for eligibility, 161 documents, which either explored the topic of collaborative research or described collaborative projects, were included in the review. Relevant information was extracted from each article into a coding framework based on the study’s research questions.[[4]](#footnote-5) The data were synthesised into common themes.

## Key Findings

### Involvement of persons with disabilities in collaborative research

The extent to which co-researchers with disabilities were involved in research projects varied across the studies reviewed. Co-researchers were most commonly involved in processes related to data collection (e.g. developing data collection instruments, collecting data). To a lesser extent they were involved in research planning, data analysis, write-up and dissemination. Co-researchers were rarely involved in funding applications or the ethical approval process.

Not all studies reviewed specified the type of disability, illness or condition co-researchers had. Of those that did, co-researchers with intellectual disabilities, learning disabilities[[5]](#footnote-6) or mental health issues were the most commonly involved in the included studies.

### **Benefits** of collaborative research

The included studies highlighted the many advantages of research collaborations between researchers and disabled people. Collaborative research had the power to challenge the status quo by giving disabled people a ‘seat at the table’,**[[6]](#footnote-7)** challenging assumptions about disabled people,**[[7]](#footnote-8)** tackling power imbalances**[[8]](#footnote-9)** and encouraging a rights-based approach to research.**[[9]](#footnote-10)** Collaborative research was also reported to improve the research process and outcomes.**[[10]](#footnote-11)** This included improved recruitment of research participants,**[[11]](#footnote-12)** better quality data,**[[12]](#footnote-13)** more meaningful data analysis;**[[13]](#footnote-14)** and more impactful dissemination.**[[14]](#footnote-15)** Being involved in collaborative research was also reported to be beneficial to the personal and professional development of all researchers. Co-researchers with disabilities developed valuable research-specific skills but also independent living skills.**[[15]](#footnote-16)** Researchers developed valuable skills for working with disabled individuals as researchers such as creating accessible materials.**[[16]](#footnote-17)** Working in a collaborative research team was also reported to foster a sense of belonging and support. Co-researchers reported feelings of solidarity, trust and equality with their colleagues.**[[17]](#footnote-18)** Finally, both co-researchers and researchers reported that being involved in collaborative research was a rewarding and enjoyable experience.**[[18]](#footnote-19)**

### Important considerations for designing and conducting co-research

The reviewed studies approached collaborative research projects in many different ways. For example, people with disabilities were involved at different parts of the research process and to various extents, studies differed as to whether co-researchers were paid or otherwise acknowledged for their role and studies varied in how prepared they were for addressing accessibility and accommodation needs of co-researchers. Overall, there does not appear to be one best practice model of collaborative research in the broadest sense. However, the reviewed studies had many commonalities with regard to issues that seem important to consider, and challenges that might be faced when designing and conducting collaborative research.

Consideration is required with regards to aligning the traditional research approach with a collaborative research approach as there may be a mismatch between priorities, procedures and underlying ethos.[[19]](#footnote-20) There may be additional ethical considerations associated with collaborative research, such as maintaining anonymity when working with small communities.[[20]](#footnote-21) Traditional means of obtaining funding and ethical approval, as well as the need for additional time and resources may cause difficulties for many collaborative projects and must be given due consideration early on.[[21]](#footnote-22)

Researchers need to give careful thought as to who will be recruited as co-researchers, to ensure diversity and meaningful representativeness.[[22]](#footnote-23) Consideration should also be given to how and when co-researchers will be recruited and how they will be compensated for their time and contributions.[[23]](#footnote-24) There was a general consensus that collaborative research projects often require more planning and preparation than traditional research projects. Care needs to be taken to clarify roles and responsibilities from the outset and decisions are needed regarding training that may be required for both co-researchers and researchers.[[24]](#footnote-25) Researchers need to consider what type of training would be most beneficial and appropriate, as well as how, when and by whom training will be delivered.[[25]](#footnote-26) Establishing trust, respect and honesty within the research team was important for meaningful involvement.[[26]](#footnote-27) Particular challenges to establishing good relationships and meaningful involvement, however, included communication and power inequalities.[[27]](#footnote-28)

The studies reviewed used a range of methods to facilitate the involvement of co-researchers in research projects. These included ensuring materials, venues, communication and transport were accessible and accommodations were provided where required.[[28]](#footnote-29) Studies also highlighted that any potential negative impacts of the research on co-researchers, such as distress, need to be considered and addressed to ensure the positive involvement of co-researchers in the research process.[[29]](#footnote-30) Studies differed in their opinion as to how much of the research project co-researchers with disabilities should be involved in. Involving co-researchers in the early stages of the research (e.g. idea conceptualisation, ethics and funding applications) was seen as particularly challenging[[30]](#footnote-31) and frustration about perceived tokenistic involvement was noted.[[31]](#footnote-32) Many studies referred to the importance of documenting and evaluating the collaborative research process.[[32]](#footnote-33) Conducting formal evaluations of the collaborative research process would provide rigorous evidence on the impact of collaborative research on the research project and research partners, and would provide a more comprehensive evidence base as to what approaches work best in collaborative research.

## Conclusion

This review of literature has identified that there is no one best practice model of collaborative research between researchers and disabled people. Key considerations for designing and conducting collaborative research include the extra time, resources and planning that are likely to be needed for a collaborative research project. This review, along with input from an advisory group and feedback from relevant stakeholders, will form the basis of NDA guidance for researchers in conducting collaborative research with disabled people in Ireland.

# Section 1. Introduction

## Introduction

The National Disability Authority (NDA) last published guidelines on conducting research with disabled people in 2002. Those guidelines covered involving disabled people in participatory research, on steering groups, in consultations and as research participants. The guidelines considered that:

…the inclusion of people with disabilities in research on issues which affect their lives is an essential element of ensuring that disability research accurately reflects the perspectives of people with disabilities and remains focused on the issues of greatest importance to them.[[33]](#footnote-34)

In the two decades since, the landscape in Ireland for collaborative research between researchers[[34]](#footnote-35) and disabled people has changed substantially. For instance, research groups, such as the Inclusive Research Network (IRN), which is led by self-advocates with intellectual disability and supported by academic researchers, have been established. A number of Disabled Person’s Organisations (DPOs) have been founded, who sometimes consult or advise on policy development or research around issues affecting the lives of people with disabilities and some of whom consult on research. The advancement in collaborative research in general is further demonstrated by the establishment of funded initiatives such as the Public and Patient Involvement (PPI) Ignite Network, which supports researchers in higher education institutions and the public to collaborate in research. In addition, various funders, including Horizon Europe and the Irish Research Council, now promote engaging with stakeholders as part of the research process in their funding calls. Ireland’s ratification of the United Nations Convention of the Rights of Persons with Disabilities (UNCRPD) in 2018 is also important to note, as involvement, equality and participation of disabled people are key principles of the UNCRPD.[[35]](#footnote-36) If Ireland is to fulfil its obligations under the treaty, disabled people must be involved in all research and decision-making in which they have a stake.[[36]](#footnote-37) Unfortunately, traditional research approaches are often poorly aligned with the CRPD requirements.[[37]](#footnote-38) Collaborative research approaches, on the other hand, share similar underlying principles with the CRPD; specifically those of involvement, equality and participation.

These advancements in the collaborative research and disability landscape in Ireland suggest that now is a good time to reflect on, and update, the NDA’s guidance on engaging in collaborative research with people with disabilities. The need for such reflection is further supported by a Campus Engage[[38]](#footnote-39) report, which recommended the development of a nationally agreed definition of collaborative approaches to research as well as the development of guidelines for best practice.[[39]](#footnote-40)

The aim of this literature review was to collate up-to-date evidence regarding best practice in the conduct of collaborative research with persons with disabilities, along with the challenges and benefits associated with this approach. The information gathered will then be used to develop a separate publication offering guidance to researchers regarding collaborative research with disabled people in Ireland. This guidance will differ from the 2002 guidelines as it will focus specifically on conducting collaborative research with people with disabilities. In addition, it will complement the NDA’s recently updated guidelines on engaging with disabled people in public participation processes.[[40]](#footnote-41)

## Defining collaborative research

Defining collaborative research is difficult as numerous terms are often used interchangeably to describe such an approach.[[41]](#footnote-42) For example, Nind (2014) noted that in the UK, the term ‘inclusive research’ is commonly used 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; whereas, in the USA, the term ‘collaborative research’ is more common.[[42]](#footnote-43) ‘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.[[43]](#footnote-44) Further, some terms associated with collaborative or inclusive research have been given slightly different definitions in the literature. For example, Cornwall and Jewkes[[44]](#footnote-45) defined participatory research as a ‘research-to-action approach’ that directly engages with communities to promote local priorities and perspectives.[[45]](#footnote-46) Whereas, Banks and Brydon Miller[[46]](#footnote-47) defined participatory research as a:

collaborative effort in which people whose lives are affected by the issues being researched are partners in designing, undertaking and disseminating research to influence socially just change.

In addition, the term inclusive research is most often associated with people with intellectual disabilities.[[47]](#footnote-48) However, the term has also been used in reference to other groups such as the LBGTQI+ community[[48]](#footnote-49) or students.[[49]](#footnote-50) While it is beyond the scope of this review to provide a full account of the various approaches to, and definitions of, collaborative research, Table 1 provides a list of some of the most common terms and definitions. This list is not exhaustive and variations of the various terms and definitions exist in the literature. Table 1 provides some examples only.

Table 1 - Various terminology describing collaborative research approaches

| Term | Definition/description  |
| --- | --- |
| **Advisory research** | Advisory research involves groups/communities, such as people with disabilities, in an advisory role only. Advisory research does not generally involve people with disabilities throughout the research process. It is therefore generally not considered to be collaborative research as people with disabilities do not tend to have ownership or control over the project.[[50]](#footnote-51) |
| **Co-design** | Co-design actively engages a diverse range of people in exploring, developing and testing responses to shared challenges.[[51]](#footnote-52) |
| **Collaborative research**  | Collaborative research describes research that is conducted by groups/communities such as people with disabilities and researchers in partnership. In collaborative research, people with disabilities can be involved in all or parts of the research process.[[52]](#footnote-53) |
| **Co-research** | Co-research has been defined as research carried out ‘with’ or ‘by’ members of the public/patients rather than ‘to’, ‘about’ or ‘for’ them.[[53]](#footnote-54) Co-research aims to foster empowerment of co-researchers by affording them more control over the project and offering opportunities to learn and reflect on their experience.[[54]](#footnote-55) |
| **Community Based Participatory Research (CBPR)** | CBPR is a branch of action research which is often focused on health-related issues and involves all partners, including researchers and community members, equally in all phases of the research process, from study design to dissemination.[[55]](#footnote-56) |
| **Co-production**  | 'Co-production is an approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge'.[[56]](#footnote-57) |
| **Emancipatory research** | Emancipatory research is often used in the context of disability research. Emancipatory approaches challenge power structures that exist in research as all power and control of the research lies entirely with the community members as opposed to trained/academic researchers/organisations[[57]](#footnote-58). In order to be considered truly emancipatory, some researchers argue that only people with disabilities should conduct disability research.[[58]](#footnote-59) |
| **Engaged research** | Engaged research describes a range of research approaches and methodologies that aim to improve, understand or investigate issues of public concern through engagement with communities. Engaged research is based on a collaborative ethos of researching with communities rather than about or for them.[[59]](#footnote-60) |
| **Experience-based co-design (EBCD)** | Experience-based co-design (EBCD) is a participatory research approach that combines a user-centred approach and a collaborative change process.[[60]](#footnote-61) EBCD brings end users and service providers together to collaboratively identify and design improvements to services.[[61]](#footnote-62) |
| **Inclusive research** | Inclusive research was originally coined by Walmsley and Johnson (2003) as an umbrella term to describe a range of approaches and methodologies that aimed to democratically engage people with learning/intellectual disabilities[[62]](#footnote-63) in the research process as ‘initiators, doers, writers, disseminators of research about themselves’.[[63]](#footnote-64) |
| **Public and Patient Involvement (PPI)** | PPI is ‘research carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them’.[[64]](#footnote-65) The term public in this definition 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.[[65]](#footnote-66) PPI generally refers to health and social care research. |
| **Participatory research** | Participatory research engages directly with the community of interest throughout the research process.[[66]](#footnote-67) The aim of participatory research is action or change achieved through collaboration between trained researchers and those who are not trained researchers but who represent the interests of those who are the focus of the research.[[67]](#footnote-68) |
| **Participatory Action Research (PAR)** | PAR combines participation and action to address societal issues.[[68]](#footnote-69) In PAR, researchers and participants engage in collective self-reflective inquiry in order to understand and improve their situations and practices.[[69]](#footnote-70) Central to PAR is that reflection is directly linked to action whereby researchers and co-researchers work together to understand a problem and explicitly aim to use that research to make changes in the lives of people with disabilities.[[70]](#footnote-71) PAR is based on an equal partnership between the researchers and co-researchers. The researcher acts as a consultant rather than an expert and the co-researchers, who are involved throughout the entire research process, make the key decisions around the focus and the direction the research.[[71]](#footnote-72) |
| **User-centred design research** | User-centred design research is an evidence-based approach that uses an iterative process and actively involves the end user in the design and development of the product or a service.[[72]](#footnote-73) |

Although there remain some difficulties around the conceptual clarity of the various collaborative research approaches, each approach and conceptualisation shares a common ethos of conducting research with and by individuals rather than on or about them. So, rather than being the subjects of, or participants in, research, in collaborative research projects, disabled people who are collaborating on the project, have an active role in all or parts of the research process including, but not limited to, designing, steering, conducting and disseminating the research.[[73]](#footnote-74) As such, there is general agreement that collaborative research promotes control over the research process and its outcomes by people with disabilities.[[74]](#footnote-75)

## 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 of communities and those with lived experience in research partnerships exists on a continuum.[[75]](#footnote-76) In 1969, Arnstein published the Ladder of Participation which depicts the level of citizen participation in service planning (Figure 1). Each rung of Arnstein’s ladder corresponds to the level of involvement and power citizens have in decision-making. This ranges from little or none at the bottom rungs (e.g. manipulation, informing) to having full control at the top of the ladder (e.g. partnership, delegated power, citizen control).[[76]](#footnote-77)

Arnstein’s ladder has often been cited as the guiding theory for conducting collaborative research with some authors adapting the model to suit inclusive research practices.[[77]](#footnote-78) Hanley *et al.* (2004), for example, developed a simpler version of Arnstein’s Ladder to apply specifically to service user involvement in research.[[78]](#footnote-79) Hanley categorises involvement into consultation, collaboration and user control. McLaughlin *et al.* (2010) later made the argument that tokenism, which is detailed in Arnstein’s Ladder but not Hanley’s, is important to include in order to reflect that service users are not always meaningfully included. In a review of peer-reviewed literature on involving people with intellectual disabilities in research, Bigby, Frawley and Ramcharan (2014b) also developed a conceptual framework which categorised the levels of involvement in inclusive research as advisory, collaborative, and leading and controlling. Below is a brief summary of the categories that correspond to Bigby, Frawley and Ramcharan’s (2014b) and Hanley’s (2004) frameworks.

**Figure 1. Arstein’s ladder of citizen participation[[79]](#footnote-80)**



### Advisory/consultative approaches

Advisory roles often involve participating in activities such as setting research priorities, contributing as part of steering groups, making recommendations about research proposals, or giving advice about specific issues or methods[[80]](#footnote-81) 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 academic researchers.[[81]](#footnote-82) For this reason, advisory or consultative roles are not generally considered to be collaborative research and are sometimes criticised for being tokenistic.[[82]](#footnote-83)

### Collaborative approaches

Collaborative or participatory involvement generally refers to research partnerships between co-researchers with lived experience of disability and professional researchers, such as academics.[[83]](#footnote-84) Both groups complement each other and are valued equally in the research process.[[84]](#footnote-85) Collaborative approaches tend to be flexible and context driven rather than overly structured.[[85]](#footnote-86) Such approaches afford more ownership and control of the research to disabled people than advisory or consultation roles, however leadership often remains with the senior/academic researchers.[[86]](#footnote-87)

### User/consumer-led approaches

The highest level of involvement refers to disabled people having full control to initiate, lead and execute research.[[87]](#footnote-88) 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.[[88]](#footnote-89)

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.[[89]](#footnote-90) Whichever approach is taken, it is important that the level of involvement is meaningful, proportionate and appropriate to the project.[[90]](#footnote-91) It may not always be appropriate or useful to include disabled people in all stages of the research. For example, if looking at customer satisfaction among various social groups, including disabled people, it may be appropriate to involve disabled people in decision-making around the disability-related component. It may be less appropriate or beneficial to involve them in decision-making for content related to other social groups. On the other hand, it would be appropriate to involve people with disabilities in all stages of a project which is specific to a disability-related issue, such as accessibility of public spaces.[[91]](#footnote-92) Thus, the relevancy of the project to people with disabilities and disability–related issues should guide the level of involvement.[[92]](#footnote-93)

## Principles of collaborative research

Guiding principles of the various types of collaborative research have been articulated by various authors. According to INVOLVE (2015), the underlying principles of co-production are:

* equity of power,
* respecting and valuing the knowledge of all involved in the research;
* including all voices;
* reciprocity; and
* building and maintaining relationships.

Similarly, according to Walmsley and Johnson (2003, p. 64), inclusive research with people with learning disabilities:

* is owned by disabled people;
* is conducted to further their interests and address issues which matter to them and should ultimately lead to improved lives for them;
* is collaborative, involving people with learning disabilities in the process of doing the research and accessing and representing their views and experiences;
* assures people with learning disabilities have some control over process and outcome and are treated with respect by the research community; and
* ensures the research question, process and reports are accessible to people with learning disabilities.

Although these are guiding principles for different approaches, there are some clear commonalities, namely that it is important that power and control are shared, that research is conducted collaboratively and that the research should further the interests of disabled people.

## Terminology and approach used in this review

For the purpose of this review, we defined collaborative research as a partnership between the co-researchers with disabilities and trained/professional researchers in which the contributions of all team members were considered meaningful. To be considered collaborative research, the co-researchers had to have some control or ownership of the research, or decision-making power over the research topic, approach, materials, processes or outputs. It is important to note here that this level of control, ownership or decision-making power was determined at face-value based on the information reported by the authors of the included studies. It is not possible to say with certainty if these reports reflected the true experiences and perceptions of the people with disabilities who were co-researchers.

In this review we use the term ‘co-researcher’ to identify people with lived experience of disability who are involved in the research process and we use the term ‘researcher’ to refer to trained/professional researchers (e.g. academic researchers, organisations, clinicians). Seale *et al.* (2015) highlight that some people argue that all researchers involved in the project should be called ‘researchers’ in an effort to remove power imbalances. However, due to the nature of this review, it was necessary to differentiate between co-researchers and researchers in order to describe the challenges and benefits of being involved in collaborative research for these different groups.

For the purpose of this review, we considered studies that reported on research collaborations between researchers and co-researchers with a range of disabilities including, but not limited to, physical disabilities, intellectual disabilities, sensory disabilities, and mental health conditions. We have amalgamated the findings in this report in order to inform guidance that could be useful to consider when conducting collaborative research with people in disabilities in general. This is not to suggest that disabled people are a homogenous group of people. Rather, the aim was to highlight some of the key and common learnings across studies that may be applicable to research collaborations with any person with a disability, or indeed any person who may need support to overcome barriers to their inclusion as research partners.

It is important to note that this review refers to collaborative research as opposed to consultation with disabled persons. The NDA has developed a separate guidance document specifically for conducting consultations with persons with disabilities on policy and legislation surrounding disability-related matters, such as the implementation of the UNCRPD.[[93]](#footnote-94)

## Research questions

The research questions shaping this review were as follows:

1. What methods/models have been used in collaborative research projects with people with disabilities?
2. What are the benefits to engaging people with disabilities in collaborative research for people with disabilities, the researchers and the project?
3. What are the challenges to engaging people with disabilities in collaborative research for people with disabilities, the researchers and the project?
4. What is best practice/what lessons have been learned in collaborative research projects with people with disabilities?

## Report outline

In the next section (section 2) of this report, the methodology for this review will be described. Section 3 will outline the reported benefits of collaborative research approaches and section 4 will detail the considerations for best practices related to conducting collaborative research, including reference to common challenges associated with this approach and potential solutions. Finally, section 5 will summarise the main findings of the report, outline the limitations of the review and outline the next steps in this work.

# Section 2. Methodology

## Literature search

Literature searches were conducted in 2020 on articles and reports published between 2015 and 2020[[94]](#footnote-95) using the search terms in Appendix A using the following electronic databases: Pubmed, Psychinfo, Cinahl and Cochrane, Embase and Medline, Google, Google Scholar, and repositories such as Lenus, Rian and other third level repositories. Searches were limited to the English language. This identified over 500 articles or reports. Articles were excluded for review if:

* They did not specifically relate to or involve collaborative research between researchers and people with disabilities/conditions/chronic illnesses
* People with disabilities/conditions/chronic illnesses were only research subjects/participants
* People with disabilities/conditions/chronic illnesses had no ownership, power or decision-making over the subject, materials, direction or outputs of the research.[[95]](#footnote-96)

After screening for eligibility, 161 documents were included in the review. The type of articles included were projects conducted via collaborative research or which explored the topic of collaborative research. The included papers comprised original research (n=99); scoping/narrative reviews, reflections, commentaries or summaries (n=50); systematic reviews (n=7); guidelines or guidance papers (n=2); a Master’s thesis (n=1); a blog post (n=1) and training materials (n=1).

Not all collaborative research studies reviewed were specific to one type of disability and not all specified the type of disability, illness or condition they referred to (n=30). Of those that did, studies most commonly involved or related to co-researchers with intellectual/learning[[96]](#footnote-97) or developmental disabilities (n=53) or mental health issues (n=29). A notable amount of studies also focused on co-researchers with dementia (n=25) or autism (n=10). The remaining studies related to co-researchers who were D/deaf (n=4), blind or visually impaired (n=1), were wheelchair users or mobility impaired (n=1), had neurodisabilities (e.g. neurotrauma; n=2), or had other chronic illnesses or conditions, such as cerebral palsy, arthritis, heart conditions, Friedrich's ataxia, cancer, and Type 1 diabetes (n=6).

## Data extraction and synthesis

Each article was reviewed and relevant information extracted into a coding framework based on the study’s research questions – namely, the methods used in collaborative research projects, benefits and challenges to the project, to researchers, to co-researchers and suggested best practice and solutions to challenges. [[97]](#footnote-98) While there was no clear model of best practice in collaborative research reported in the literature, common themes were apparent in relation to areas to consider when designing and conducting a collaborative research project. As such, the literature was synthesised under these common themes.

# Section 3. Benefits of co-research

The included studies highlighted the many advantages that may be obtained through research collaborations between researchers and people with disabilities. It was clear that both researchers and co-researchers could benefit from these partnerships. There were also many instances which suggested that the research projects themselves were improved due to the collaborative approaches employed, for example, collaborative research was noted to generate better quality data[[98]](#footnote-99) and more varied and accessible outputs.[[99]](#footnote-100) Research collaborations are not often formally evaluated however, and so the benefits outlined in this section have largely been obtained through anecdotal evidence provided by author reports in the included studies. Nonetheless, it is important to outline the reported benefits as they highlight why researchers and institutions should consider investing their time, energy and resources into developing and maintaining research collaborations and partnerships.

## Challenging the status quo

Several studies noted that being involved in collaborative research had the power to challenge assumptions and the status quo. Being involved in collaborative research gave disabled people a ‘seat at the table’ and provided a platform from which they could be heard.[[100]](#footnote-101) Co-researchers reported having felt listened to as a result of their involvement in research and that the value of their voices, experiences, thoughts and knowledge regarding their own lives was emphasised.[[101]](#footnote-102) Involvement as co-researchers has allowed disabled people to influence the research agenda and gave them control of what and how research was conducted.[[102]](#footnote-103) Being involved in collaborative research provided an opportunity for disabled people to air their frustrations and contribute their ideas.[[103]](#footnote-104) It also allowed them to directly represent themselves and their communities and take control over their own future.[[104]](#footnote-105) As one co-researcher put it:

…it means an awful lot…you’re getting people’s perspective on their lives, their feelings, their thoughts, whatever ideas they have and whatever experiences they’ve had.[[105]](#footnote-106)

It was reported that ensuring that the voices of disabled people were heard could challenge stereotypes, stigmas and assumptions about disabled people[[106]](#footnote-107). For example, involvement in collaborative research demonstrated that people with intellectual disabilities could take the lead in decision-making and make valuable contributions.[[107]](#footnote-108)

Several studies noted that the experience of working collaboratively with co-researchers challenged researchers’ own perceptions and assumptions.[[108]](#footnote-109) Researchers in one study cited that meeting service users as colleagues as opposed to patients was thought provoking and helped them stay focused on the outcomes.[[109]](#footnote-110) Further, some researchers became more aware of their own academic standards and frameworks and how these might interfere with an inclusive approach.[[110]](#footnote-111)

At the time I was working together with Liza to prepare the interview I was convinced that we worked it out together. After our talk at the university I started to reflect on it. Now I have my doubts about us working together. I was the one who guided this activity. My framework of conducting research was leading. I wanted to talk about a topic list and I invited Liza to join me. Now I see that this didn’t work out. My academic framework was not helpful, it even stood in the way.[[111]](#footnote-112)

The researchers in one study noted that after conducting an inclusive project, they were now more open to conducting new forms of research[[112]](#footnote-113). Additionally, some researchers experienced a reconceptualisation of their own personal values, with some taking a self-critical stance or moving towards a human rights-based perspective.[[113]](#footnote-114) Finally, several studies noted that the involvement of co-researchers challenged the power imbalances that exist between researchers and research participants.[[114]](#footnote-115)

## Improvements to the research process and outcomes

#### Improvements in research planning and preparation

The findings indicated that the contributions of co-researchers often resulted in more relevant and culturally appropriate research projects. Several studies noted the benefits co-researchers can bring to the planning and preparation stages of research. There was a general sense across the included studies that co-researchers positively influenced the overall design of the study.[[115]](#footnote-116) One study noted that discussion with members of an advisory group of people on the autism spectrum led to profound changes in the research, such as changing the eligibility criteria of participants, which improved the study.[[116]](#footnote-117) Another study noted that the co-researchers provided important support in deciding whether specific measures or interventions were included, excluded or revised to make the project better.[[117]](#footnote-118) Co-researchers were also considered invaluable for identifying research priorities and generating new thinking for future research.[[118]](#footnote-119) For example, a couple of studies noted that the co-researchers were instrumental in identifying appropriate research questions and informing the type of research that should be conducted.[[119]](#footnote-120)

Several studies also noted that co-researchers thought of things that researchers had not thought of, such as research ideas and questions to ask during research interviews.[[120]](#footnote-121) The involvement of co-researchers also helped to ensure that research designs were implementable. A number of studies noted that co-researchers were able to foresee logistical issues in conducting the research that researchers may not have anticipated.[[121]](#footnote-122) This included barriers to implementing interventions, issues with the overall design of the research and recruitment plans.[[122]](#footnote-123) 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.[[123]](#footnote-124) As one researcher reflected:

...well I can’t imagine how the trial would have run without it [PPI] because there were so many things we overlooked. We were so focused on methodology and how things are going to work statistically. But their priority was what is actually going to work.[[124]](#footnote-125)

#### Improvements to data collection

Data collection was one of the most common stages of the research process in which co-researchers were involved. As a result, many studies noted the advantages of their involvement in relation to data collection. One of the main advantages related to recruiting and retaining participants. Co-researchers often had wide networks and their ‘insider status’ could increase access to target populations, especially harder to reach groups.[[125]](#footnote-126) There was a general consensus that people with disabilities may be more likely to be involved in research when their peers were involved as researchers.[[126]](#footnote-127) In addition, some studies noted that recruitment of participants was more successful because co-researchers improved the accessibility of research and recruitment materials.[[127]](#footnote-128) It was also noted participants were less likely to drop out or withdraw from studies when co-researchers were involved[[128]](#footnote-129). In some cases, this meant that researchers had access to longer term data and could spend less time recruiting.[[129]](#footnote-130) Co-researchers also had a positive impact on research interviews. Co-researchers were reported to be able to achieve better rapport with research participants due to their shared experiences.[[130]](#footnote-131) One researcher noted:

When participants told stories about challenges, he [co-researcher] provided validation by acknowledging the difficulty of the situation and sharing a similar story from his life. Additionally, he expressed enthusiasm for the participants’ research, which encouraged them to share more information.[[131]](#footnote-132)

Co-researchers helped ensure that field work was conducted in a sensitive manner, which helped to establish trust in interview participants and helped them feel more at ease.[[132]](#footnote-133) This helped participants to speak more openly and frankly.[[133]](#footnote-134) Several studies also noted that co-researchers enhanced the accessibility and suitability of recruitment and data collection tools and materials including interview schedules, participant information sheets and consent forms.[[134]](#footnote-135) One study noted that the co-researchers asked novel follow-up questions based on their shared experiences with the participants.[[135]](#footnote-136) Such improvements in general could enable participants to engage more meaningfully with the research without feeling patronised.[[136]](#footnote-137) These improvements to data collection generated a general sense across the included studies that the co-researchers’ contributions resulted in richer, better quality data.[[137]](#footnote-138)

#### Improvements to data analysis

In most of the studies reviewed, co-researchers were involved in analysis of qualitative data. Several studies noted that co-researchers improved the quality of the data analysis and led to deeper insights into, and better understanding of, the data and the topic under study.[[138]](#footnote-139) It was reported that co-researchers were often better able than researchers to interpret participants’ experiences and stories, and could offer explanations and nuances around participants’ narratives due to a shared understanding.[[139]](#footnote-140) Additionally, it was noted that co-researchers brought a different perspective to the data analysis and interpretation, thinking about problems in ways that the researchers may not have.[[140]](#footnote-141) Such insights and perspectives, which were unlikely to have been gained through traditional research paradigms, helped to explain things that researchers may not have understood or considered otherwise and could therefore strengthen the evidence base.[[141]](#footnote-142) Some studies also noted that the involvement of co-researchers added credibility and validity to the findings by bringing an added richness to the data and by combatting criticisms of bias and enhancing transparency of the research process.[[142]](#footnote-143)

I found the experience very rewarding, working closely with the co-researchers to analyse the qualitative data provided me with alternative analytical perspectives. I believe this led to a more comprehensive and contextualised interpretation of the data, which would not have been possible without that collaboration.[[143]](#footnote-144)

#### Improvements to dissemination and research impact

Involving co-researchers in the project had advantages with relation to the dissemination and impact of research findings. Some studies reported that co-researchers helped ensure that dissemination materials and strategies were accessible and appropriate and could therefore be disseminated back to the community.[[144]](#footnote-145) Being involved in the research process motivated some co-researchers to share the findings of the study they were involved in with their communities, family and friends who may not have accessed the research otherwise.[[145]](#footnote-146) The authors of one study reported that:

Throughout the co-design process, the participant was motivated to share the results of the research with her friends on the network. Her vision was always to share the results of her work with other people who have similar disabilities.[[146]](#footnote-147)

In terms of impact, the involvement of co-researchers was reported to have improved interventions, maximised the impact of the research and ensured that the findings were genuinely useful and relevant to stakeholders and the populations of interest.[[147]](#footnote-148) Ensuring that the research was grounded in the real concerns of people with disabilities ensured that issues that were important to them were highlighted and that research priorities were matched to those of the people with disabilities,[[148]](#footnote-149) which may have helped to increase the value of the research to participants.[[149]](#footnote-150) A couple of studies noted that co-researchers also felt that they had had a positive impact on policy, practice and social change as part of their participation.[[150]](#footnote-151)

## Personal and professional development of all researchers

Many studies highlighted the personal and professional development experienced by both researchers and co-researchers.[[151]](#footnote-152) Co-researchers gained valuable experience and developed their research skillsets.[[152]](#footnote-153) Many of these skills were transferable and so could improve their prospects for future employment or being involved in future research projects.[[153]](#footnote-154) One study noted that co-researchers were given professional recommendations by the researchers, which enhanced their CVs.[[154]](#footnote-155) For some co-researchers, being involved in collaborative research was an opportunity to move away from receiving benefits to paid employment for the first time.[[155]](#footnote-156) By being involved as co-researchers, some disabled people also reported developing independent living skills, such as using public transport independently.[[156]](#footnote-157) Researchers also developed transferable skills through conducting collaborative research, such as how to develop and use accessible materials, how to build trust with co-researchers, how to meet the needs of a team of people with disabilities, and how to develop an appropriate informed consent process.[[157]](#footnote-158)

In addition to developing new skills, many studies noted that researchers and co-researchers gained new knowledge. For example, some co-researchers reported learning more about their own condition or situation[[158]](#footnote-159) and about issues important to them such as housing accessibility.[[159]](#footnote-160) As one co-researcher with intellectual disability stated:

[Through research] you found more things about everything – what you need to know….about your own life.[[160]](#footnote-161)

Researchers also reported gaining valuable insight into the realities and daily lives of people with disabilities.[[161]](#footnote-162)

Several studies highlighted that the skills, knowledge and experiences gained by co-researchers contributed to an increased sense of self-confidence, motivation and empowerment.[[162]](#footnote-163)

Being a part of this team has been wonderful and extraordinary, and “empowered” is not a strong enough word for how I feel. Thank you for letting me be involved – this project has completely transformed how I view the world of research and technology, and I will be forever grateful.[[163]](#footnote-164)

A number of studies noted that co-researchers reported feeling empowered to identify and make changes in their own lives or become activists or advocates,[[164]](#footnote-165) for example:

Taking part in the Patient and Public Involvement forum has boosted my self-confidence and knowledge that I can still make a useful contribution to society.[[165]](#footnote-166)

Other studies reported that being involved in collaborative research had motivated co-researchers to pursue new opportunities and some had already been able to use their new skills in jobs inside and outside of academic settings or had gone on to higher education.[[166]](#footnote-167)

The social element of involvement in collaborative research was something that the co-researchers also enjoyed as they made new friendships and widened their networks.[[167]](#footnote-168) Researchers also benefitted from widening their research networks[[168]](#footnote-169) with a couple of studies noting that they were able to develop long-term relationships with the communities of interest.[[169]](#footnote-170)

## Sense of belonging and support in collaborative research teams

The sense of belonging and being part of a team and the associated benefits experienced by researchers and co-researchers was a common observation.[[170]](#footnote-171) As one co-researcher with an intellectual disability noted:

Being part of a group…I’m less scared now and feel more confident because I came over to this country from Pakistan.[[171]](#footnote-172)

A number of studies commented that co-researchers reported feelings of solidarity with one another and felt they had a stronger voice together.[[172]](#footnote-173) Some co-researchers also experienced a sense of cohesion and trust in collegial and equal relationships with researchers.[[173]](#footnote-174)

Going back to the very beginning the feelings of respect have been present. . . It has developed into trust.[[174]](#footnote-175)

This sense of equality may have been obtained because the experience of involvement led to increased mutual understanding between the researchers and co-researchers[[175]](#footnote-176). Further, acknowledging each other’s diversity and valuing differences enabled the various members to empower each other and facilitated them in feeling more connected to each other.[[176]](#footnote-177) Several studies also noted that co-researchers reported feeling supported by their peers and the researchers both within and outside the project environment.[[177]](#footnote-178)

## An enjoyable and rewarding experience

Several studies noted that both researchers and co-researchers found the experience of conducting collaborative research enjoyable.[[178]](#footnote-179) Researchers reported finding the experience uplifting and rewarding as they were able to support people to achieve their desired outcomes.[[179]](#footnote-180) In one study, the researchers found the process liberating, as they could be creative when responding to ideas from co-researchers.[[180]](#footnote-181) As one researcher stated:

I’d just like you to note that it has been an amazing and uplifting experience for me, I’ve done lots of work around mental health and disability and this has been right up there. The researchers are an absolute pleasure to work with, it’s been brilliant to see them come alive and begin to fulfil their potential.[[181]](#footnote-182)

Co-researchers also reported finding the experience rewarding and fun.[[182]](#footnote-183) They reported enjoying applying the skills they had learned and presenting at conferences.[[183]](#footnote-184) In some cases, involvement was also reported to have had a positive effect on co-researchers’ wellbeing.[[184]](#footnote-185) In addition to enjoying the experience, a number of studies reported that co-researchers felt their involvement gave them a sense of being able to help others and to give back to the community.[[185]](#footnote-186) As a result, many co-researchers reported that they felt valued and developed a sense of pride and achievement in their involvement.[[186]](#footnote-187) In a study examining mental healthcare and cancer services users’ experiences of involvement in research, one participant stated:

More than anything I feel I have had an impact, generally beneficial for others. That level of satisfaction is often hard to achieve I have found over the years.[[187]](#footnote-188)

Working as co-researchers also offered the opportunities for new experiences such as travelling abroad.[[188]](#footnote-189) Finally, a few studies reported that some co-researchers who had mental health difficulties gained therapeutic benefits as part of their involvement and felt it helped in their recovery.[[189]](#footnote-190)

# Section 4. Important considerations on designing and conducting collaborative research projects

The reviewed studies approached collaborative research projects in many different ways. People with disabilities were involved at different parts of the research process and to various extents, studies differed as to whether co-researchers were paid or otherwise acknowledged for their role and studies ranged in how prepared they were for addressing accessibility and accommodation needs of co-researchers. Overall, there does not appear to be one best practice model of collaborative research. This is perhaps not surprising given such collaborations and partnerships are quite recent endeavours and with that, appear still to be developmental in nature. In addition, as previously noted, there have been limited systematic evaluations of the involvement of disabled people as partners in research so there is a lack of empirical evidence regarding effective practices. However, the reviewed studies do have many commonalities with regard to issues that seem important to consider when designing and conducting collaborative research, including the potential challenges faced by those engaged in collaborative research. These common issues and challenges are discussed in the sections below, as are solutions and recommended best practice suggested within these studies.

## Aligning the traditional research approach with a collaborative research approach

The studies reviewed highlighted that there can be tensions between traditional research and the collaborative research approach. For example, there can be a mismatch between organisational priorities and collaborative research priorities.[[190]](#footnote-191) For academic organisations, priorities are often focused on academic outputs, meeting deadlines and attracting funding,[[191]](#footnote-192) whereas collaborative research approaches may be more focused on societal impact and benefit.[[192]](#footnote-193) A divergence between academic culture, interests, and goals with those of community partners and co-researchers was also noted as a challenge.[[193]](#footnote-194)

Experiential knowledge is an important element of collaborative research, but academic knowledge tends to be valued more than experiential knowledge in traditional and clinical research.[[194]](#footnote-195) Of course, there will be research studies where the input of academic knowledge and professional researchers needs to be prioritised, but where there is an important place for experiential knowledge in a study, it should be equally as valued. Researchers have reported that it can be a challenge to let go of their own academic framework and this can create barriers to integrating different types of knowledge into the work.[[195]](#footnote-196) It has been reported that academic standards may perpetuate power imbalances[[196]](#footnote-197) and may create feelings that collaborative research will not be taken seriously.[[197]](#footnote-198) Several studies also noted the difficulty for researchers in trying to balance the demands of an academic career with being an effective inclusive researcher, which often requires more time and effort.[[198]](#footnote-199) In addition, collaborative research may not be valued by organisations[[199]](#footnote-200) or adequately accounted for in professional evaluation[[200]](#footnote-201) and so may not adequately support career advancement for academic researchers as effectively as traditional research.

Traditional research procedures and red tape were highlighted as causing issues for collaborative projects.[[201]](#footnote-202)These issues included funding and ethics constraints, being bound to short timeframes which made it difficult to develop good working relationships, and working within environments that favoured bureaucratic control and individual performance assessment.[[202]](#footnote-203) Due to academic pre-requisites, co-researchers are generally excluded from research grade appointments.[[203]](#footnote-204)

### Potential for bias and challenges to rigour

The traditional research process does not always fit the needs of everyone and researchers often need to develop innovative ways of facilitating the involvement of disabled people in research.[[204]](#footnote-205) This may pose challenges to balancing the practicalities of collaborative research and maintaining research fidelity and rigour.[[205]](#footnote-206) Several studies highlighted the potential for bias and challenges to rigour in collaborative projects. Some researchers argue that collaborative research cannot be objective[[206]](#footnote-207) and concerns were raised that co-researchers may bring their own biases to various stages of the research (although this could be true of all researchers).[[207]](#footnote-208) For example, concern was highlighted in one study, particularly during data collection, about whose story might dominate during data collection within the interviews, due to shared experiences between the co-researchers and the participants.[[208]](#footnote-209) Therefore, the advantage brought by the co-researcher- i.e. the lived experience- may also be a disadvantage if it blurs the co-researcher/participant roles and results in a loss of objectivity. Similarly, there could be difficulties associated with balancing the insider–outsider status, where the co-researchers believed they ‘knew’ what informants were implying.[[209]](#footnote-210)

Concern has also been raised that co-researchers may unintentionally or unconsciously influence participants’ responses.[[210]](#footnote-211) In one study, it was noted that co-researchers had to work to avoid using leading questions in their interviews.[[211]](#footnote-212) Some studies also noted that co-researchers may face challenges in collecting quality data.[[212]](#footnote-213) For example, co-researchers’ interviewing skills may vary, and data collection tools may not be thorough enough or suitable for some co-researchers and so may miss important information.[[213]](#footnote-214) An issue identified in some interviews was that opportunities for probing were missed by some co-researchers. Burke *et al.* (2018) recommend that transcripts could be peer reviewed as part of training to highlight these opportunities.

The potential for the researchers to bring bias to collaborative research projects was also raised. For example, one study involving Deaf and hearing researchers, noted the potential for the hearing academic researcher’s majority cultural view to influence the interpretations of Deaf participants’ contributions.[[214]](#footnote-215) The study also noted the potential for data to be influenced due to adaptations/modifications to signing required to facilitate interpretation by the hearing academic. In this study, to avoid bias, the team engaged in group dialogue and open negotiating to analyse data and increased credence was given to the Deaf collaborators.[[215]](#footnote-216)

Other suggestions for avoiding bias in the reviewed studies included approaching data analysis as a group, encouraging self-awareness through reflexivity, considering the impact of the research participants’ experiences, attitudes, and beliefs on the co-researchers,[[216]](#footnote-217) encouraging open and honest questioning during discussions,[[217]](#footnote-218) carefully working through validity issues and putting safeguards in place to ensure the research remains valid and findings are transferable.[[218]](#footnote-219)

### Ethos and values of co-research

From the studies reviewed, a picture emerged of the importance of a certain ethos needed for collaborative research, and of key values underpinning quality collaborative research. These may not typically be articulated with regard to traditional research processes, but in the case of collaborative research are necessary to consider. Box 1 illustrates the attributes of the ethos needed for inclusive research, as agreed by experts working in inclusive health research and experts with intellectual disabilities.[[219]](#footnote-220) Many of these attributes were shared by other studies. Overall, the impression from the studies in general is that a collaborative research approach necessitates respect,[[220]](#footnote-221) equity,[[221]](#footnote-222) power sharing,[[222]](#footnote-223) valuing of individuality and differences,[[223]](#footnote-224) and acknowledging the added value of the co-researcher.[[224]](#footnote-225) According, to Jim, a co-researcher with dementia:

To enable successful collaboration, I, Jim, believe that one of the essential characters that the researcher must have is to have full respect of the person with lived experience. The full respect also means being open to options, listen to the person, and open to amending the plan or considering other alternatives. It’s not right to discount the experiential knowledge and lived experiences. Sometimes Lillian might have to slow down a bit or repeat something but I (Jim) appreciated to be treated respectfully, instead of being over-protected. For me, Jim, positive collaboration means there is trust, respect and reciprocity.[[225]](#footnote-226)

Reflexivity of members is another important attribute of collaborative research,[[226]](#footnote-227) and this was noted as particularly important for the trained/professional researchers, in that they should reflect on their position, role, privilege, experiences and perspectives[[227]](#footnote-228) relative to the co-researchers’.[[228]](#footnote-229) Studies recommend that researchers also consider how the research might be shaped by their potential biases[[229]](#footnote-230) and predispositions.[[230]](#footnote-231) According to Wolsey *et al.* (2017), as well as respecting, appreciating and honouring differences in researchers and co-researchers as outlined above, other important elements to deaf/hearing research partnerships are integrity, beneficence, and justice. Some studies also refer to the importance of the research having direct relevance to improving the lives of people with disabilities.[[231]](#footnote-232)

Box 1. Attributes of an inclusive ethos[[232]](#footnote-233)

* “Meeting basic human rights
* Development and recognition of the influences of a group culture with open communication, respect, patience and understanding of limiting conditions
* Discussing, understanding and respecting cultural, representational differences, personal biases and power relationships
* Being aware that good collaboration starts before the onset of the study and continues through all stages of the study, as far as possible given funding and time constraints
* Ensuring all information is accessible to all team members and all team members can contribute in their own way, without coercing information.
* Recognising the potential for (emotional) difficulties and sensitivities of this work
* Ensuring all team members feel safe and supported
* Keeping decisions transparent and open for discussion”.

### Ethical considerations

One of the challenges regarding collaborative research is a lack of ethical guidance available for how to navigate these partnerships.[[233]](#footnote-234) Mann and Hung (2018) noted that it is important for collaborative research projects to consider not only typical research ethics and academic institutional ethics, but also ‘everyday ethics’,[[234]](#footnote-235) namely the everyday moral, contextual and relational elements of the research dynamic. A number of studies highlighted particular ethical challenges that need to be considered while conducting collaborative research. These include, addressing situations where researchers may know the participants (e.g. reassign interviewers[[235]](#footnote-236)) and maintaining anonymity and/or confidentiality during meetings/research, especially when working with small communities/groups where people may know one another.[[236]](#footnote-237)

In situations whereby co-researchers are supported by another individual (e.g. a carer or support worker), it is critical the voice or perspective of the co-researcher is considered paramount, yet the involvement of support workers needs to be respected.[[237]](#footnote-238) Asking co-researchers to sign a consent form can be considered problematic as they are not research participants and it creates an inequality relative to the researchers.[[238]](#footnote-239) Some studies may include the same people as both co-researchers and participants, which raises ethical questions as well as questions as to the validity of the study. Being involved as both a researcher and a participant may also feel uncomfortable to co-researchers and again, creates inequalities between the co-researchers and the researchers.[[239]](#footnote-240) One study, which involved adolescents with disabilities as co-researchers, noted the challenge of balancing the ideals of empowerment with the demands and obligations to protect and safeguard the safety and wellbeing of the young people.[[240]](#footnote-241) Similarly, Burton *et al.* (2019, p. 3) state:

Researchers need to ensure PPI representatives’ well-being, while avoiding over-protective and paternalistic attitudes that may hamper meaningful engagement.

### Ethics applications

The ethical approval process was also reported as challenging in collaborative research projects. The complexity of ethics applications and ethics committees’ attitudes and expressed concerns about collaborative research were noted as particularly problematic. For example, ethics committees sometimes wanted assurances for the competency of co-researchers,[[241]](#footnote-242) or were concerned about the objectivity of co-researchers,[[242]](#footnote-243) and about their ability to get the consent of participants and conduct interviews.[[243]](#footnote-244) Issues around equality have occurred when ethics committees have required that co-researchers with intellectual disabilities sign consent forms, whereas this is not a requirement for researchers.[[244]](#footnote-245) Other challenges included explaining concepts of inclusive research to ethics committees,[[245]](#footnote-246) the time it can take to get approval[[246]](#footnote-247) and the paradox of needing to have secured ethical approval before funding can be released.[[247]](#footnote-248)

Co-researchers were involved in the ethical approval process in a number of studies.[[248]](#footnote-249) To reduce the complexity of ethics applications, one study found that breaking the application into steps and discussing it in small groups was helpful for the research team.[[249]](#footnote-250) A few studies engaged with their ethics committees to try to address barriers. In Riches, O'Brien and CDS Inclusive Research Network (2020), two participants met with the ethics committee to train them on how a researcher with intellectual disabilities could be supported in their role. Another study noted that they were able to come to an agreement with the funding body, which entailed a staged ethical approval and funding process.[[250]](#footnote-251) This allowed them to include the co-researchers at these early stages. They also requested adjustments to their ethical approval process to ensure co-researchers with ID could participate fully. This included getting approval to develop an Easy Read ethics application, to submit an Easy Read study protocol, and having co-researchers attend a meeting of the ethics committee. Northway, Howarth and Evans (2015) outlined some of the lessons they learned regarding ethical approval:

* Don’t just accept policies and practices as they are, consider alternatives and make changes if necessary
* Engage with the ethics committee early in the approval process and continue to work with them
* Present solutions to the ethics committee instead of just problems
* Consider ethical approval as a process rather than a one- time event.

In addition, Ní Shé *et al.* (2018) suggested that researchers should educate ethics committees about inclusive research issues and Strnadová *et al.* (2016) noted that ethics procedures should be reviewed so that the intellectual competency/capacity of all researchers is assumed.

### Research funding

Research funding programmes and applications are a key challenge to collaborative research projects and one of the barriers to aligning the traditional research approach with a collaborative research approach.[[251]](#footnote-252) Challenges reported include the general lack of funding schemes that can support equal collaboration,[[252]](#footnote-253) funding models which aren’t suitable for inclusive research, funding models which underestimate the time and costs required to conduct collaborative research,[[253]](#footnote-254) and funders with inflexible or low expectations of such research.[[254]](#footnote-255) Researchers often cited that additional funding is required to conduct collaborative research properly, but the necessary funding can be difficult to obtain.[[255]](#footnote-256) A lack of funding to pay co-researchers beyond covering expenses was also an issue.[[256]](#footnote-257)

The funding application process can be complex, which can make it difficult for co-researchers to navigate.[[257]](#footnote-258) Only a few studies mentioned that co-researchers were involved in funding applications.[[258]](#footnote-259) One study highlighted that funding calls were not usually in plain English, which posed a barrier to many people.[[259]](#footnote-260) Academics who support a research group of people with ID noted that they translated funding calls into plain English for the group.[[260]](#footnote-261) However, they also noted that this was time consuming,[[261]](#footnote-262) and so it is not necessarily something that all supporting researchers would be willing or able to do.

There are varied opinions about involving co-researchers in funding applications. Some studies recommended that potential collaborative research projects should seek and secure funding early[[262]](#footnote-263) and secure funding before recruiting co-researchers.[[263]](#footnote-264) However, Disability Wales (2019) recommended that co-researchers should be involved in funding applications. One study noted that the provision of small grants for the development of proposals may be one means of ensuring that people with disabilities can be involved from the start of a project.[[264]](#footnote-265) Studies also made a number of recommendations for funding bodies to facilitate collaborative research projects:[[265]](#footnote-266)

* Provide funding for pre-proposal design and consultation[[266]](#footnote-267)
* Provide funding opportunities with ‘operational and budget flexibility’, to enable support needs to be addressed as appropriate throughout the research project[[267]](#footnote-268) and to pay for co-researcher suggestions not previously considered by project team[[268]](#footnote-269)
* Allow longer timelines for these kind of research partnership projects[[269]](#footnote-270)
* Consider resources needed to develop research with seldom heard from groups[[270]](#footnote-271)
* Make co-production a key element of funded disability projects[[271]](#footnote-272)
* Provide funding opportunities for projects collaborative/emancipatory research with seldom heard from groups, including people with disabilities[[272]](#footnote-273)

Finally, it was also noted that funding bodies should be aware that (ideally) they are not only funding a research project, but a research partnership.[[273]](#footnote-274)

### Resources and time

A number of studies referred to the additional time and resources required to conduct collaborative research compared to traditional research approaches.[[274]](#footnote-275) Several studies noted the additional time and effort required to prepare for meetings, to create accessible resources, to address communication issues and to create a positive atmosphere.[[275]](#footnote-276) The need to work at the pace of co-researchers was also noted by Morbey *et al.* (2019, p. 7) who stated that when working with people with dementia as co-researchers, ‘time is possibly the most important consideration’. All of this can lead to projects taking longer than originally anticipated.[[276]](#footnote-277)

Troya *et al.* (2019) discussed how they dealt with issues around time and resources and noted that they started planning co-researcher involvement eight months before the first research meeting, and ensured they had secured funding specifically for the co-researcher involvement. As well as the extra time and resources needed for some elements of collaborative research, a number of studies suggested structural solutions that would help save some time and resources across multiple collaborative research projects. For example, Powers *et al.* (2017) suggest creating action research partnerships, principles, structures, and tools that can have benefits across multiple studies. Campus Engage guidance (2017) suggests that a national database of engaged research projects, engaged researchers, and support staff would be a useful resource that could identify where existing research has already addressed issues of concern in order to reduce research waste and duplication. Such a database could also serve to provide examples of good quality research collaborations that others could learn from.

## Recruitment of co-researchers

A number of studies suggested good practice relating to recruitment of co-researchers, including open advertising,[[277]](#footnote-278) having an official job description,[[278]](#footnote-279) using gatekeepers and informal networking[[279]](#footnote-280) and supporting service providers and gatekeepers/supporters to understand the whole process to facilitate recruitment.[[280]](#footnote-281) A number of studies held information or recruitment days[[281]](#footnote-282) where potential co-researchers could meet with researchers to find out about the project. According to Di Lorito *et al.* (2017, pp. 13-14), this was a positive approach:

This mutual process of appraisal ensures that the selection process is mutual and non-tokenistic, as the decisional power is equally shared between the academic and the potential peer-researchers.

Another study had a contact person available for potential co-researchers to discuss the job and provide accessible information[[282]](#footnote-283) and another developed a plain language job description and gave applicants an interview guide prior to their interview.[[283]](#footnote-284) One study recommended that researchers ask co-researchers how their involvement might affect their current employment or other areas of life before beginning.[[284]](#footnote-285) This would help researchers to plan for any barriers to involvement that the co-researchers might experience and identify supports that may be required.

Studies mentioned that accessing and including the co-researcher population of interest could be a complex and lengthy process.[[285]](#footnote-286) One study mentioned that gatekeepers could sometimes discourage, prevent or forget about collaborative opportunities.[[286]](#footnote-287) A number of studies reported possible scepticism by guardians or other carers of the ability of those with ID or dementia to be involved as co-researchers.[[287]](#footnote-288) To mitigate this scepticism, St. John *et al.* (2018) noted that it was essential to form a foundation of trust and obtain voluntary, informed consent from both the guardian[[288]](#footnote-289) and the co-researcher. There may be other barriers to recruitment, including inaccessible academic language[[289]](#footnote-290) and a reluctance to get involved in collaborative research if people do not feel sufficiently aware of the research topic, understand how they could contribute or how they would be supported.[[290]](#footnote-291) Powers *et al.* (2017) suggested that researchers reach out directly to disabled people, disabled persons organisations and advocacy groups to improve community connections and Wadman *et al.* (2019) noted that improving such relationships is a key facilitator to collaborative research projects.

A number of studies stated that they sought to recruit co-researchers with diverse abilities, experiences, backgrounds and other demographics.[[291]](#footnote-292) Several studies offered specific details on the criteria they used to recruit co-researchers, including relevant personal experience,[[292]](#footnote-293) interest in the research,[[293]](#footnote-294) language skills,[[294]](#footnote-295) communication skills,[[295]](#footnote-296) social skills, and the ability to collaborate.[[296]](#footnote-297)

Several studies referred to issues to consider when recruiting co-researchers. These included the problem of studies recruiting only ‘privileged’ co-researchers – i.e. those with a certain level of computer literacy and education[[297]](#footnote-298) selecting only those who are particularly well-known[[298]](#footnote-299) or selecting someone based only on having a particular disability without considering other abilities needed to be a partner in the research.[[299]](#footnote-300) As there may be a tendency to include only easier to reach individuals,[[300]](#footnote-301) there are concerns about over-burdening, as the same individuals may be repeatedly called upon.[[301]](#footnote-302) There are also concerns that these people may not be representative of the wider community[[302]](#footnote-303) (although this could also be said for researchers). A few studies recommended that projects include a demographically diverse group of co-researchers.[[303]](#footnote-304) Members of some groups, such as those who are Deaf, reported feeling overlooked and not having opportunities to be included in research[[304]](#footnote-305). One study noted that on the advice of a psychiatrist, for ethical and safeguarding reasons, they did not recruit co-researchers who were experiencing severe mental health difficulties at the time of recruitment.[[305]](#footnote-306) Other studies have noted that some culturally and linguistically diverse marginalised communities had difficulties accessing research projects, which impeded them from getting involved[[306]](#footnote-307). One study improved perceived access to their project by ensuring that it was led by community representatives as well as researchers.[[307]](#footnote-308)

There is also a general lack of representation of individuals with profound intellectual disability[[308]](#footnote-309) or severe dementia as co-researchers[[309]](#footnote-310) in comparison to those with mild or moderate ID or dementia. This is not surprising given there will likely be challenges in confirming their wish and agreement to be co-researchers and in their abilities to be involved at different points to the research process. To ensure meaningful involvement of people with profound ID or dementia, studies would need to involve people with experience in communicating with and understanding those with profound ID or dementia, who can, for example, carefully observe any non-verbal exchanges.[[310]](#footnote-311) In Ireland, following the commencement of the ADM (2015) Act, the researchers would need to work closely with the individual’s decision-making assistant, supporter or representative, where appropriate. Overall, if the study under question relates to ID or dementia, involvement of people with profound ID or severe dementia as co-researchers should not be automatically ruled out by research teams.

### Payment of co-researchers

A number of studies stated that, if possible, co-researchers should be financially compensated for their time or contribution.[[311]](#footnote-312) Payment was referred to as ‘a token of power’[[312]](#footnote-313) that can address inequalities that may hinder the participation of people with disabilities in a research partnership.[[313]](#footnote-314) Payment acknowledges the unique skills and expertise people with disability can bring to the research[[314]](#footnote-315) and recognises that they are equals in the research.[[315]](#footnote-316) One study stated:

Suitable payment, recognising the professional and personal expertise required for the role, and the associated level of responsibility in relation to project aims, is a key way to demonstrate respect and address the power imbalance.[[316]](#footnote-317)

A notable number of studies reported that they had paid co-researchers for their time.[[317]](#footnote-318) While a notable number paid for co-researchers’ travel expenses.[[318]](#footnote-319) A number of studies also paid for the expenses of the individual’s support worker[[319]](#footnote-320) or care partner[[320]](#footnote-321) and some studies covered expenses such as overnight stays[[321]](#footnote-322) or meals.[[322]](#footnote-323) A number of studies used the UK’s National Institute for Health Research’s INVOLVE guidance[[323]](#footnote-324) on paying members of the public who contribute to research activities to help inform their payment process.[[324]](#footnote-325)

Other costs recommended by studies to consider for collaborative research partnerships are psychological support (depending on the research subject matter), funding for alternative research outputs suggested by co-researchers, relationship building activities, personal assistants,[[325]](#footnote-326) and any other disability–related supports.[[326]](#footnote-327) Studies noted that costs such as travel and subsistence would be needed for two people in cases where a support person accompanies the co-researcher.[[327]](#footnote-328) A few studies alluded to flexibility in how co-researchers could be paid – in cash, vouchers, equivalent credit or other forms of recognition.[[328]](#footnote-329)

Becoming paid employees may impact negatively on some co-researchers’ disability or social welfare benefits, even if only employed for a short time.[[329]](#footnote-330) Before any payments are made and accepted, the potential impact on disability benefits or welfare payments should be checked.[[330]](#footnote-331) In one study, co-researchers were offered independent advice on the impact of payment on their welfare payments prior to taking on their role.[[331]](#footnote-332) In another, the co-researchers all worked less than 16 hours a week to avoid impacting on their social welfare benefits.[[332]](#footnote-333) It was acknowledged that there can be administrative logistical challenges in making payments to co-researchers as ‘lay consultants’.[[333]](#footnote-334) Several studies raised the issue of co-researchers not being paid for their work and difficulties around claiming expenses due to complex forms and organisational red tape.[[334]](#footnote-335) A few studies referred to the need for clear communication on reimbursement,[[335]](#footnote-336) straightforward, simplified payment systems[[336]](#footnote-337) and prompt payment.[[337]](#footnote-338) Studies recommend that additional costs of collaborative research, including payment of co-researchers, should be included in funding applications and appropriately considered from the beginning of projects.[[338]](#footnote-339) Gove *et al.* (2017) note that if funds can be made available in studies for external subject matter experts, funds should also be available for co-researchers. A co-researcher with an intellectual disability who reflected on the successful elements of collaborative research recommended:

Work out the pay and get paid the right amount at the right time.[[339]](#footnote-340)

## Planning and preparing for a collaborative research project

While recruitment of co-researchers may take time, it is also likely that collaborative research projects will require more planning and preparation in general than traditional research projects. Some studies noted particular challenges in planning and preparation for collaborative research projects, including the time and resources required to prepare co-researchers, and a lack of structures in universities to support engagement at the pre-commencement stage.[[340]](#footnote-341) Planning can be long and difficult because there is no established model of best practice, and adjustments are often needed based on the topic, the methodology and the skills the co-researchers possess.[[341]](#footnote-342) Unnecessary delays and stress may also occur if there is insufficient planning for the support needs of co-researchers and potential barriers they might face.[[342]](#footnote-343) Many studies discussed important elements in planning for collaborative research projects. These included:

* Holding introductory meeting/s with co-researchers[[343]](#footnote-344)
* Considering the support needs of co-researchers[[344]](#footnote-345)
* Reaching a mutual understanding of what collaborative research is[[345]](#footnote-346)
* Agreeing the channels and means for team communication[[346]](#footnote-347)
* Agreeing meeting schedules[[347]](#footnote-348)
* Having a project terms of reference[[348]](#footnote-349)
* Agreeing ground rules[[349]](#footnote-350), general rules of working[[350]](#footnote-351), how the team will work together[[351]](#footnote-352), and establishing clear boundaries[[352]](#footnote-353)
* Agreeing when co-researchers would like to be involved in the research process[[353]](#footnote-354)
* Providing descriptions of tasks and the skills/knowledge required to execute them[[354]](#footnote-355)
* Discussing how decisions will be made[[355]](#footnote-356)
* Agreeing goals and outcomes of project[[356]](#footnote-357)
* Setting timelines,[[357]](#footnote-358) including time for possible delays[[358]](#footnote-359) and specifying time commitments required[[359]](#footnote-360)
* Planning for co-researchers’ withdrawal from the project before it finishes[[360]](#footnote-361)
* Planning for the end of the project.[[361]](#footnote-362)

### Roles and responsibilities

Defining clear roles and responsibilities is also considered a key part of the planning and preparation phase of collaborative research,[[362]](#footnote-363) particularly as a lack of clarity on these has been noted as a challenge in previous studies.[[363]](#footnote-364) To ensure clarity about roles and responsibilities, co-researchers should be provided with clear information and/or negotiated contracts.[[364]](#footnote-365) Van Schelven *et al.* (2020b) note the importance of including co-researchers in discussions around roles and responsibilities. Furthermore, the Drill Report (2018) notes that management should ensure that everyone has read and understood their role and commitments before commencing. According to Jim, a co-researcher with dementia:

To make the experience as positive and collaborative as possible, I, Jim needed to know the plan, my role and why.[[365]](#footnote-366)

Moule *et al.* (2016) cautioned, however, that clarifying roles on paper had the potential to put pressure on co-researchers. They recommended that contracts be re-negotiable and amendable as the project progresses. Additionally, there should be ongoing engagement throughout the process to check in with co-researchers to ensure they are able to manage their roles and to give them the opportunity to let researchers know if they are having difficulties.[[366]](#footnote-367)

#### Skills and competencies of co-researchers and researchers

The roles and responsibilities held by co-researchers will depend on their skills and competencies. A number of studies acknowledged the importance of first identifying the skills, competencies and capacity of co-researchers[[367]](#footnote-368) and then applying people’s skills and competencies to various parts of the research project.[[368]](#footnote-369) In one project, co-researchers could choose certain tasks based on their skillset, but they were also offered support to take part in tasks in which they were less confident.[[369]](#footnote-370) Another study made sure to identify the skills and interests of their co-researchers with the purpose of offering them further development opportunities in these areas.[[370]](#footnote-371) With regard to identifying people’s skills and competencies, Callus (2019) advised not to presume what the person can/cannot do – ask them at the outset.

Many studies have made recommendations regarding the skills and competencies needed for people to take take part in collaborative research projects. Embregts *et al.* (2018) advised that important competencies for co-researchers and researchers were being creative, adaptable, and able to contribute to finding solutions.

For co-researchers, studies have recommended that they have an interest in the research[[371]](#footnote-372), insight into their capabilities and limitations,[[372]](#footnote-373) have the ability to reflect and self-reflect, and are capable of doing research,[[373]](#footnote-374) e.g. are able to formulate research questions, make a research plan, interview others, understand research ethics, and communicate results.[[374]](#footnote-375) Of note, is that these kinds of abilities will preclude people with more profound ID or severe dementia from being co-researchers and it is important for studies of particular relevance to those with ID or dementia to consider how they might be innovative/creative in facilitating the involvement of people lacking some of these specific skills and competencies. Another important element when considering co-researchers is to acknowledge the heterogeneity of individuals with disabilities and to recognise the different skills and experiences they bring to a project.[[375]](#footnote-376) One study warned against stereotyping the skills or traits of autistic individuals in particular,[[376]](#footnote-377) while another reported a challenge for co-researchers was the assumption that their personal lived experience was representative of all people with disabilities.[[377]](#footnote-378)

In relation to the skills and competencies of the professional researchers, studies recommended that they have the ability to share tasks and responsibilities with co-researchers, are flexible,[[378]](#footnote-379) are able to adjust their working pace[[379]](#footnote-380) and according to a co-researcher with ID, they need to be organised, skilled, reliable, and able to get co-researchers involved without doing the work themselves.[[380]](#footnote-381) One study on Deaf/hearing research partnerships noted that it was critical for researchers to be competent and knowledgeable in a visual language and to value Deaf culture.[[381]](#footnote-382)

#### Training

Co-researchers may initially lack the expertise and skills to conduct research so often need some training and upskilling[[382]](#footnote-383). With this, researchers are faced with decisions about what type of training to provide, for example, whether they should focus on project-specific training or generic research skills training, and how and when to provide it.[[383]](#footnote-384) They also need to consider whether refresher training will be required during the course of the project.[[384]](#footnote-385) According to one study, co-researcher training should include general research methodological skills and specific training relevant to the study.[[385]](#footnote-386) The content of training varied across studies reviewed, but for the most part did include training on general research skills and knowledge.[[386]](#footnote-387) When relevant, some training also included knowledge and skills specific to the research topic[[387]](#footnote-388) or approach, for example, how to use a digital camera and take good photos[[388]](#footnote-389) or how to interview people with mental health difficulties[[389]](#footnote-390). A number of programmes also included training on how to manage difficult situations,[[390]](#footnote-391) self-care[[391]](#footnote-392) and self-protection during the project.[[392]](#footnote-393)

In many of the studies reviewed, co-researchers, and in some cases, researchers, underwent training to facilitate them to become partners in the collaborative research process. The majority of studies provided formal training developed by the researchers in advance of the project, while others provided more informal ‘on the job’ training throughout the project.[[393]](#footnote-394) Training was mostly delivered by the researchers, but in O’Hara *et al.* (2017) specific subject experts provided training and in Munro *et al.* (2018), disabled co-researchers trained the group on legislation and context relevant to the study.

The length of training sessions varied across studies; for example, in St John *et al.* (2018), training for one co-researcher was one hour, while in Herron, Priest and Read(2015), training took place over five sessions. A number of studies referred to the format of training depending on co-researchers needs,[[394]](#footnote-395) characteristics and existing skills[[395]](#footnote-396) and the stage of research they were involved in.[[396]](#footnote-397) Role play and practice was a key part of training in many projects.[[397]](#footnote-398) A number of projects provided accessible training materials to support training.[[398]](#footnote-399)

In several projects, training was specifically provided to the researchers on how to work with, support and assist co-researchers.[[399]](#footnote-400) Training researchers on collaborative research, the wider context for such research, on equality, and how best to support people with different needs to act as co-researchers was recommended by a number of other papers.[[400]](#footnote-401) Mann and Hung(2018, p.25) recommended training for researchers in “developing ethical sensitivity and responsibility in everyday ethics.” Smith-Merry (2017) recommended that collaborative research training should be included in university education to make researchers more comfortable in considering it, while a report by Campus Engage recommended that higher education institutions should work in partnership with relevant organisations to provide training on good practice for collaborative/engaged research.[[401]](#footnote-402) A number of studies also recommended culturally appropriate, formalised/accredited programmes to build capacity of, for example, community partners, in research.[[402]](#footnote-403) In one of the studies reviewed, the co-researchers were able to work towards a formal qualification in Social Research Skills.[[403]](#footnote-404)

Few studies discussed the impact of training on co-researchers. One study did report how the co-researchers appreciated that the training prepared them for the research,[[404]](#footnote-405) while another found that participants enjoyed the role play element of training.[[405]](#footnote-406) In terms of the effectiveness of training, Salmon, García Iriarte and Burns (2017) evaluated a pilot inclusive research module in a higher education institution and found it did help develop the research knowledge and skills of students with intellectual disabilities. Several studies highlighted issues with training including that it sometimes felt rushed or incomplete and was not always presented in a universally accessible format.[[406]](#footnote-407) If training is not done well, it can lead to co-researchers feeling that their knowledge and input is not valid.[[407]](#footnote-408) One review noted that training can be very intensive,[[408]](#footnote-409) and provided an example of a study where co-researchers were examined by the researchers following 15 weeks of research training.[[409]](#footnote-410)

Providing training was cited as resource intensive and sometimes difficult to deliver from the researchers’ perspective.[[410]](#footnote-411) Some researchers also referred to the challenges around deciding whether formal training was appropriate, querying whether upskilling co-researchers had implications for their contribution to the research.[[411]](#footnote-412) For example:

…questions have arisen about the wisdom of introducing models of training that re-position people with learning disabilities, whose key contribution comes from their knowledge based on insider, lived experience, into semi-trained researchers in academic likeness.[[412]](#footnote-413)

While this statement was made in regard to co-researchers with learning disabilities, it can be applied to any co-researcher whose lived experience is of particular value to the research. On the other hand, some argue, that it is important to offer training so that co-researchers are not at a disadvantage.[[413]](#footnote-414) According to a co-researcher with dementia in Roberts *et al.* (2020, p. 12):

I am or should be a part of the research team, a co-researcher and as such receive any prior training and knowledge that any member of the team will need to contribute effectively and efficiently.

Van Schelven *et al.* (2020b, p. 9), reporting on PPI projects involving young people with chronic conditions also stated that:

Project leaders state that training and coaching can make PPI less strenuous, as it improves the match between PPI activities and the knowledge and skills of young people.

Two studies reported that providing opportunities for disabled people with such training can make it more likely that they will be involved in or lead on research in future.[[414]](#footnote-415) To help with deciding on an approach for training, researchers should establish co-researchers’ motivations, ambitions and existing skills.[[415]](#footnote-416) Not all co-researchers want to be involved beyond the project they are currently involved in and some may already have existing research skills.[[416]](#footnote-417) Determining how best to provide training requires researchers to carefully consider what type of training would be most beneficial to co-researchers on a specific project and empower them to fulfil their roles.[[417]](#footnote-418) Box 2 illustrates the approach used by Fitzgerald and Walsh (2016) to train a diverse group of co-researchers.

Box 2. Training a diverse group of co-researchers[[418]](#footnote-419)

“The researcher training programme was developed in line with international best practice in the activation and empowerment of members of the public as researchers. This was a unique endeavour, given that it was the first time that individuals from the three groups of children and youth, older people and people with disabilities, with a wide range of abilities and intellectual capacities, had been brought together in such a training process. A training manual was developed to ensure that the training schedule and content of the training manual were accessible to all groups. Research scenarios, methodological examples and visual aids were featured throughout the manual and the workshop lesson-plan as illustrative tools and tutorials. Straightforward guidelines on what to do and not to do at each stage of the research process were presented within the manual”.

## Building a relationship between researchers and co-researchers

It was evident from the reviewed studies that the relationship between researchers and co-researchers was hugely important factor in collaborative research. It was particularly important for researchers and co-researchers to spend time building a relationship[[419]](#footnote-420) and developing trust between them.[[420]](#footnote-421) One co-researcher reflected that co-researchers need to be comfortable with the researchers, and there needs to be mutual respect, honesty and trust in their relationship.[[421]](#footnote-422) One study mentioned that they regularly focussed on building and maintaining trust[[422]](#footnote-423) and others referred to researchers being available outside of the usual research meetings to talk to co-researchers or listen to any queries or difficulties they were having[[423]](#footnote-424) - all of which could help to build trust.[[424]](#footnote-425) Other approaches which appeared important for building trust within the collaborative research partnership included: taking time for informal discussions[[425]](#footnote-426) “over cups of tea”,[[426]](#footnote-427) ensuring transparency in communication throughout the project,[[427]](#footnote-428) providing feedback on how co-researchers impacted on the research[[428]](#footnote-429) and celebrating project milestones.[[429]](#footnote-430)

We met monthly and shared important news about our personal and professional lives. We ate together when we celebrated holidays and our team’s achievements. Socializing together created closeness and trust that made us feel more equal as we related to each other as team members.[[430]](#footnote-431)

There can be challenges in how the collaborative research relationship develops, possibly linked to attitudes towards collaborative research and co-researchers among researchers. Several studies highlighted that co-researchers can feel used, underappreciated and even like ‘guinea pigs’.[[431]](#footnote-432) In some instances, studies noted that co-researchers reported not feeling listened to or taken seriously and some felt they had to work extra hard to prove themselves and attain recognition.[[432]](#footnote-433) A few studies noted that perhaps researchers sometimes underestimated what co-researchers could contribute.[[433]](#footnote-434) According to one researcher:

I had this sort of fixed idea of what dementia was […]. I thought people wouldn’t be able to be involved in my research, that they wouldn’t even consider it.[[434]](#footnote-435)

Some suggestions for ensuring that co-researchers do not have negative experiences include empowering them to have more control over the research agenda, methods, and individual roles, encouraging them to raise issues important to them, 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.[[435]](#footnote-436) Vaughn *et al.* (2019) recommended that researchers challenge any low expectations of co-researcher involvement. While Ashcroft *et al.* (2016) reported that patients and carers felt that clinicians and researchers could do more to understand the position of those engaged in collaborative research in terms of their enthusiasm, time, money and capacity, while giving due consideration to their illness or condition.

Co-researchers not feeling confident or comfortable while conducting the research was noted as a challenge in a number of studies. Issues included not feeling secure at first, having difficulties opening up and being vulnerable, feeling intimidated by professionals and others, feeling uncomfortable being in the spotlight, challenges participating in group discussions, not having the confidence to do some of the tasks required and feeling insecure about their added value.[[436]](#footnote-437) For these reasons, it is important that co-researchers feel supported at the beginning of the research process and that feelings of trust are established early on.[[437]](#footnote-438)

### Communication

A key element of relationship building is communication, and effective communication between researchers and co-researchers is crucial to collaborative research projects. However, communication difficulties were often raised as an issue in the included studies.[[438]](#footnote-439) Issues with the way researchers communicated included their use of inaccessible language and jargon,[[439]](#footnote-440) sending emails with too much information, sending information too late to enable co-researchers to engage with it properly and giving short notice for meeting times.[[440]](#footnote-441) Co-researchers also cited a lack of feedback from researchers as a challenge.[[441]](#footnote-442)

Researchers reported their own challenges, including difficulties explaining some language and terms, but also finding ways to effectively communicate with different groups.[[442]](#footnote-443) For example, in one study, communication challenges when researching with co-researchers with more profound disabilities were noted.[[443]](#footnote-444) Several studies highlighted challenges associated with collecting feedback from co-researchers, including difficulties collecting the same depth of feedback from all co-researchers, difficulties eliciting critical feedback if the co-researchers felt uncomfortable critiquing the researchers, and co-researchers having difficulties communicating their reflections or understanding questions on feedback forms .[[444]](#footnote-445)

In order to address communication issues, studies noted the importance of teams communicating regularly,[[445]](#footnote-446) using accessible language,[[446]](#footnote-447) avoiding jargon,[[447]](#footnote-448) developing and agreeing flexible processes and structures for effective communication,[[448]](#footnote-449) having a communication strategy,[[449]](#footnote-450) and using communication tools (such as Talking Mats.[[450]](#footnote-451) [[451]](#footnote-452) Some examples of the ways in which studies addressed communication between members include Nicolaidis *et al.* (2019), who developed a communication etiquette guide to use in their study and used the 5-finger method[[452]](#footnote-453) and Stevenson and Taylor (2019) used pre-existing guidance on communicating with people with dementia to help their approach. Studies also recommended the use of specific communication skills by the research team, including taking turns[[453]](#footnote-454), checking for understanding of co-researchers,[[454]](#footnote-455) communicating in a sensitive manner,[[455]](#footnote-456) giving people time to speak,[[456]](#footnote-457) ensuring people answer for themselves,[[457]](#footnote-458) and being responsive to non-verbal information.[[458]](#footnote-459)

Co-researchers in one study advised anyone considering getting involved as research partners:

Don’t be afraid to ask questions and to disagree, and challenge other people. It’s our time to be opinionated, it’s fine if people don’t always agree,[[459]](#footnote-460)

### Power sharing and decision-making

The issue of power inequalities and power sharing within collaborative research projects was raised quite often in the reviewed papers. Several studies highlighted that power imbalances could be a challenge for co-researchers.[[460]](#footnote-461) These related to researchers making more of the decisions, unequal rates of pay and the hierarchical categorisation of their employment status.[[461]](#footnote-462) In most of the studies reviewed, the research project was conceived by the researchers, and people with disabilities were invited or recruited to be involved – so from the beginning in many cases, there was a level of power afforded to the researchers that was not afforded to co-researchers.[[462]](#footnote-463) Relatedly, Carr (2019) noted that only people at a particularly senior level in academia or relevant organisations tend to be eligible to lead on funding bids. In addition, researchers often have to manage the entire research process (e.g. due to funding or organisation rules, or as they had the professional experience to do so), which can making power sharing challenging.[[463]](#footnote-464)

Managing power imbalances and shifting traditionally embedded power inequalities were commonly reported challenges for researchers in the included studies.[[464]](#footnote-465) Co-researchers often require support to conduct research; however, finding the right balance between providing support without taking too much control was a consistently reported challenge to researchers in the included studies.[[465]](#footnote-466)

A number of suggestions for approaches to manage and address inequities and power imbalances were noted in the included studies. These included encouraging open discussion of imbalances and inequities, challenging the idea that 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, and including researchers who truly value the insights of the co-researchers, who will make necessary accommodations, and who are willing to share power.[[466]](#footnote-467) Some structures and processes to overcome power imbalances mentioned by studies included: a structure for supervision and support of co-researchers, establishing ground rules for meetings, jointly creating guidelines and policies on power-sharing, decision-making and dissemination, ensuring a shared decision making approach and ensuring effective communication among the team.[[467]](#footnote-468) Dewa *et al.* (2020, p. 134) noted the importance of time and a safe space for ensuring the sharing of power:

Sharing power became easier and more evident as trust, confidence and mutual respect grew over time, particularly after a safe space was established.

Shared decision-making is a key part of power sharing within collaborative research. It can be a challenge in collaborative research projects to ensure that everyone in the group is involved in the decision-making processes and has their say so that a range of views, skills and expertise are effectively and authentically incorporated.[[468]](#footnote-469) A particular challenge reported was how to support the development of autonomy and ownership in co-researchers with intellectual disability, who may have had mostly subordinate roles in the past and who may not be used to being asked for their opinions or being encouraged to think independently.[[469]](#footnote-470) People with such experiences may begin their involvement with a hierarchical rather than collaborative mindset.[[470]](#footnote-471) For example, one study noted that co-researchers with ID sometimes initially relied on the researchers for direction during the research process rather than exercising autonomy.[[471]](#footnote-472) A small number of studies also mentioned needing to manage acquiescence and issues with some individuals being overly-influenced by other members of the group.[[472]](#footnote-473) Furthermore, when attending a meeting, 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.[[473]](#footnote-474) Structured processes for reaching consensus, such as the 5-finger method,[[474]](#footnote-475) [[475]](#footnote-476) Delphi process,[[476]](#footnote-477) and the Nominal Group Technique,[[477]](#footnote-478) [[478]](#footnote-479) may help ensure that all partners are included in the decision-making process while increasing efficiency. Decisions were made through a ‘framework of conversation and guided activities’ in Haya Salmón and Rojas Pernia (2020, p. 743), and through “discussion and enthusiastic debate” in Mathews, Marshall and Wilkinson (2020, p. 24).

Of note is that in one study where decision-making power fluctuated among the research partnership, it was reported that this did not have a negative impact on co-researchers’ involvement, as long as there was transparency regarding decisions and co-researchers could discuss these decisions.[[479]](#footnote-480) Similarly, according to the Partners2 Writing Collective (2020), limits to the feasibility of shared decision-making across the entire research project were accepted by the research team, with the authors hypothesising this was perhaps due to increased trust among members.

### Managing expectations

Discussing and managing expectations (e.g. what can reasonably be hoped to achieve from the project) was noted as an important part of the dynamic between researchers and co-researchers.[[480]](#footnote-481) However, managing expectations of what could be achieved in a project was reported as a challenge in several studies.[[481]](#footnote-482) Researchers could overestimate what co-researchers were capable of in the given timeframe and also what was feasible to cover in meetings.[[482]](#footnote-483) One study noted that tensions arose when researchers wanted people with intellectual disabilities to do the same activities as the researchers during the research process.[[483]](#footnote-484) This led to disappointment and disempowerment in situations where this did not work out. On the other hand, co-researchers may also have unrealistic expectations about what is feasible, implementable and how quickly change can happen.[[484]](#footnote-485) Some suggestions for managing expectations include 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, involving a neutral ‘knowledge broker’ in discussions, and ongoing reflection by the research team.[[485]](#footnote-486)

## Facilitating the involvement of co-researchers

Co-researchers with disabilities will require support and consideration to facilitate their engagement as research partners, due to not having had experience as a researcher previously, and/or due to particular support needs they might require. The studies reviewed used a range of methods to facilitate the involvement of co-researchers in research projects. In several studies co-researchers were able to participate in the project in a range of different ways,[[486]](#footnote-487) including face to face, by email, by teleconference or by videoconferencing.[[487]](#footnote-488) Other studies discussed using tools or materials to support involvement[[488]](#footnote-489) such as handbooks,[[489]](#footnote-490) telephone scripts[[490]](#footnote-491) and visual aids.[[491]](#footnote-492) Haya Salmón and Rojas Pernia (2020) using Image Theatre,[[492]](#footnote-493) personal objects, plastic and visual art. In a number of studies, an individual or individuals acted as a liaison between the co-researchers and researchers, ensuring for example, their support needs were anticipated and met, the project was flexible and their involvement was encouraged.[[493]](#footnote-494) Similarly, in a number of other studies, teams had access to individuals whose role it was to support PPI involvement.[[494]](#footnote-495) Co-researchers were also facilitated in various ways to take part in specific parts of the research process and these will be discussed in the later section “Involvement of co-researchers in different stages of the research process”.

### Accessibility and accommodations

Accessibility needs to be a key consideration in all collaborative research projects to enable the full and equal involvement of co-researchers with disabilities. One study recommended that accessibility be checked with co-researchers throughout the project.[[495]](#footnote-496) Consideration of accessibility is the minimum that should be expected in collaborative research projects. However, some co-researchers will have unique support needs,[[496]](#footnote-497) and many studies referred to other accommodations and supports that were or should be provided to facilitate the full involvement of co-researchers.[[497]](#footnote-498) Studies highlighted the need to ensure the accessibility and availability of necessary accommodations in the areas of communication and informational materials, venues and the working environment, transport and travel times for co-researchers to attend meetings and research activities, and with regard to time, support people, support animals, and technology. These will be discussed further in the sections below.

#### Communication and informational materials

Studies referred to the importance of accessible communication and informational materials. This included the accessibility of language used,[[498]](#footnote-499) e.g. simple and jargon-free language, and reducing the use of abstract language or concepts.[[499]](#footnote-500) Accessibility regarding the methods of communication[[500]](#footnote-501) also need to be considered, for example ensuring the provision of Sign Language or other interpretation or using techniques such as structured email formats or individualized alerts and reminders.[[501]](#footnote-502) As previously noted, Frankena *et al.* (2015) referred to the importance of using communication technology such as Talking Mats[[502]](#footnote-503) and in Dewa *et al.* (2020) co-researchers were able to take and store notes in a range of formats while using the Evernote app.[[503]](#footnote-504)

The accessibility of all informational materials pertaining to the research needs to be considered,[[504]](#footnote-505) including for example, meeting materials,[[505]](#footnote-506) and recruitment materials.[[506]](#footnote-507) This also includes project outputs[[507]](#footnote-508) which might include considering producing outputs that are not typical in traditional research including exhibitions and performances.[[508]](#footnote-509) Studies also referred to considering different formats of information, including visuals (e.g. PhotoSymbols[[509]](#footnote-510)), videos, and audio recordings.[[510]](#footnote-511) A number of studies discussed adapting informational/reading materials for co-researchers, for example, using large font,[[511]](#footnote-512) using black writing on coloured paper,[[512]](#footnote-513) and using pictures, word cards or story boards.[[513]](#footnote-514)

#### Venues, transport and travel time

The accessibility of venues needs to be considered in collaborative research, including venues for meetings, research activities and overnight accommodation.[[514]](#footnote-515) In addition to being physically accessible, consideration needs to be given to aspects such as lighting, signposting[[515]](#footnote-516) and ensuring they are non-stigmatising.[[516]](#footnote-517) Studies also referred to the importance of considering the working environment,[[517]](#footnote-518) including the importance of it feeling safe for co-researchers to fully engage.[[518]](#footnote-519) Other studies referred to the need to consider the sensory environment,[[519]](#footnote-520) to provide sensory supports[[520]](#footnote-521) and having a quiet space available for co-researchers who might need one.[[521]](#footnote-522) A few studies noted the importance of meeting in places which are familiar to co-researchers or which they are comfortable with.[[522]](#footnote-523) For example, Beighton *et al.* (2019) always held meetings in the same place.

The importance of accessible public transport[[523]](#footnote-524) and appropriate travel times[[524]](#footnote-525) to the location of research-related activities were also noted as important for collaborative research. Several studies also referred to the importance of supporting co-researchers with transport or travel where necessary.[[525]](#footnote-526) One study noted that transport was often unavailable or required advanced planning and scheduling.[[526]](#footnote-527) To address this, the research team dedicated time and resources to working around the schedules of the co-researchers, and provided training and held meetings at suitable locations, including individuals’ homes.[[527]](#footnote-528) Another study noted that accessing and using transport could be so upsetting for the co-researcher that it impacted his ability to fulfil his role when he arrived at the university.[[528]](#footnote-529) In this case, the researcher began to collect the co-researcher when requested, so that he did not have to use public transport.

#### Meetings

Meetings were a core element of the research activities in many of the studies reviewed[[529]](#footnote-530) and a number of elements to consider in terms of their accessibility were noted by studies (aside from their venue and transport). Frankena *et al.* (2015) reported that accessible meeting lengths were good practice in inclusive research, requiring researchers to ensure that the length of meetings are adapted to suit the needs of the co-researchers. A number of studies also referred to the need to plan for adequate breaks.[[530]](#footnote-531) In one study, breaks in meetings were provided every hour.[[531]](#footnote-532) The need to consider the size of the group in meetings was highlighted by Miah *et al.* (2019) and Drill Report (2018). For example, a large group might be unsuitable for people with certain disabilities.[[532]](#footnote-533) Two studies discussed helping prepare co-researchers for meetings by holding pre-meetings with them,[[533]](#footnote-534) while a further two studies sent feedback to members following each meeting summarising the inputs, actions and outcomes from each meeting to ensure the co-researchers had a record of how they had contributed and of the research progress.[[534]](#footnote-535)

#### Time

A number of studies referred to the importance of considering time in collaborative research projects[[535]](#footnote-536) – e.g. giving co-researchers adequate time for discussion,[[536]](#footnote-537) for giving input on decisions,[[537]](#footnote-538) and for reviewing informational materials.[[538]](#footnote-539) In Varkonyi-Sep, Cross and Howarth (2017), co-researchers were sent non-technical versions of issues that would be under discussion two weeks prior to the discussion. Vaughan *et al.* (2019) also referred to the need for flexibility in time frames to accommodate circumstances when it is challenging for co-researchers to contribute or to meet in person.

#### Other accessibility/ accommodation considerations

There were a number of other accessibility and accommodation considerations noted by studies, for example, ensuring that co-researchers had a support person available where necessary.[[539]](#footnote-540) One study also noted the importance of considering how to facilitate attendance if support staff or caregivers are unable to attend with a co-researcher.[[540]](#footnote-541) Support animals such as guide dogs need to be considered[[541]](#footnote-542) and Roche *et al.* (2020) also recommend having food available for people with particular conditions (e.g. diabetes). The use and provision of assistive technology (e.g. screen readers for those who are visually impaired) did not seem to be specifically mentioned in studies on collaborative research, however this is another important consideration.

Two studies referred to difficulties the co-researchers faced in getting necessary accommodations to fulfil their roles such as obtaining a C Pen[[542]](#footnote-543) [[543]](#footnote-544) or begin granted reasonable adjustments.[[544]](#footnote-545) Accessibility and accommodation requirements can be addressed by asking the co-researchers about how their disability might affect them in their role before commencing the work, assessing individual preferences for how information is presented, asking them what supports they may need[[545]](#footnote-546) and being flexible in approaches. Ultimately, according to Morbey *et al.* (2019, p.1), what is needed in collaborative research is a “flexible, responsive and adaptive approach”. This type of approach is particularly important as a challenge to projects once they begin relates to absenteeism and turnover of co-researchers.[[546]](#footnote-547) This may occur for various reasons, such as fatigue, changing health or cognitive status or no longer being able or willing to be involved.[[547]](#footnote-548) To manage personnel changes, Nicolaidis *et al.* (2019) recommend that accommodation needs should be assessed whenever a new co-researcher joins the group, and that those needs be reassessed regularly and adjusted as required.

### 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.[[548]](#footnote-549) Researchers need to balance what they wish to do with not overburdening co-researchers. However, a co-researcher with dementia stated:

…we still have the right to make our own choice and if we choose to be tired and we want to put our health at risk to be involved in this research, we have the right to do that.[[549]](#footnote-550)

Co-researchers may become emotionally drained or distressed during sensitive research or through being exposed to peers’ sometimes-difficult stories and experiences.[[550]](#footnote-551) They may also feel burdened or responsible for improving the lives of their participants or the wider community through their work,[[551]](#footnote-552) or upset and disempowered if tasks do not go as planned.[[552]](#footnote-553) Researchers should ensure that ongoing support and debriefing is offered to co-researchers whenever they need it[[553]](#footnote-554) and that the amount of work planned is feasible.[[554]](#footnote-555) One study considering collaborative research with mental health service users emphasised the importance of considering the emotions of all of the research team in such a partnership.[[555]](#footnote-556)

## Involvement of co-researchers in different stages of research

### Level of involvement of co-researchers

A number of studies noted that co-researchers were involved in all stages of the research, from idea inception to dissemination of research findings.[[556]](#footnote-557) Studies differed in their opinion as to how much of the research project co-researchers with disabilities should be involved in. Some felt that the most meaningful engagement would be to involve co-researchers in all research stages.[[557]](#footnote-558) Others noted that co-researchers with disabilities should have some ownership, choice and control over the research regardless of how many stages they are involved in.[[558]](#footnote-559) Others felt it was important to consider the extent to which the co-researchers wanted to be involved,[[559]](#footnote-560) which areas they wanted to be involved in,[[560]](#footnote-561) [[561]](#footnote-562) and how their skills matched different stages and tasks of the research project.[[562]](#footnote-563)

...which is more important – involving people in all research phases or is it more important that the participants are actively involved in deciding how much, how and when they will (not) participate in the research process?[[563]](#footnote-564)

As to which stages co-researchers should be involved in, some studies noted that the most important stages were at the very start of a research project (e.g. at research proposal stage)[[564]](#footnote-565) and in collecting data.[[565]](#footnote-566) From the studies reviewed, it seems that developing data collection instruments, collecting data and data analysis were some of the main areas co-researchers were involved in.

In the studies reviewed, frustrations were identified about perceived tokenistic involvement of co-researchers and a lack of their ownership over research. Some community organisations noted that they have sometimes been approached for input at the early stages of a project, only to have their suggestions ignored. This can create problems because co-researchers may feel that the time and resources they provided have not been valued or appreciated and were only sought as a box tick exercise to put on a grant application.[[566]](#footnote-567) Perceptions of tokenism may result in disillusionment and may mean that the community of interest may not fully benefit from the research,[[567]](#footnote-568) so it is important that researchers make every effort to avoid this by ensuring meaningful collaboration takes place.

Several studies highlighted issues around conducting a fully collaborative project. Involving co-researchers in the early stages of the project such as in grant and ethics applications, and in data analysis were particularly challenging.[[568]](#footnote-569) In some studies, the nature of the study was very technical which prevented the co-researchers from being involved fully.[[569]](#footnote-570) The presence of intellectual disability or a lack of confidence was also noted to be a challenge to involving co-researchers fully in all aspects of the process.[[570]](#footnote-571) In a review of studies about PPI in dementia and other conditions, Burton *et al.* (2019) noted that in one study, some co-researchers with learning disabilities who would have liked to be involved in data analysis were not given the opportunity.[[571]](#footnote-572) Oksnebjerg *et al.* (2018) cited ‘practical reasons’ as the explanation for not involving the co-researchers in the analysis, but acknowledge that they should have given more consideration to this at design stage of the research. This highlights the need for effective planning early in the research. Every effort should be made by the researchers to ensure that co-researchers can contribute to the stages of the research they want to be involved in.

### Research topics, planning and design

Involving co-researchers as early as possible in a research project would lend itself to promoting the values of ownership, equity and power sharing that are key elements of collaborative research. 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.[[572]](#footnote-573)A review by Suijkerbuijk *et al.* (2019) found a number of studies made such research tasks more concrete by using activities such as scenarios or descriptions of identifiable real life situations.[[573]](#footnote-574) A number of studies did specify that co-researchers played a role in influencing the research topic or questions.[[574]](#footnote-575)

More studies referred to co-researchers being involved in planning and designing the research.[[575]](#footnote-576) One of the most common ways co-researchers were involved in research projects was in the development of data collection instruments.[[576]](#footnote-577) The vast majority of these were focus group topic guides or interview schedules. A minority of co-researchers were part of designing surveys[[577]](#footnote-578) and co-researchers in one study were involved in developing an adapted question scale.[[578]](#footnote-579) In Aldersley *et al’s* (2018) study, co-researchers photographed barriers and facilitators they encountered in daily life as wheelchair users for a period of four months, which the research team would regularly discuss and then used to inform the content of research interviews. Regarding the involvement of co-researchers in other early stages of research, in some studies they were involved in literature searches and reviews,[[579]](#footnote-580) and in O’Hara *et al.* (2017), co-researchers came up with the study name and logo and were involved in providing project updates on social media. In Drill Report (2018), co-researchers also developed and used social media and a project website to promote the study. As noted earlier, it was not common for co-researchers to be involved in funding or ethics applications.

### Participant recruitment and data collection

Several studies noted that co-researchers had been part of developing participant recruitment materials[[580]](#footnote-581) including information sheets and consent forms,[[581]](#footnote-582) and others noted that co-researchers had been involved in participant recruitment[[582]](#footnote-583) and refining the consent process. In McCartan *et al.* (2019), the study held ‘brief and recruit schemes’ where co-researchers were available to talk to prospective participants about the research. As noted in the earlier section on benefits to collaborative research, a number of studies felt the involvement of co-researchers facilitated participant recruitment. On the other hand, a couple of studies felt that the involvement of co-researchers could have an adverse impact on recruiting participants and which in turn could impact on the rigour of the research. For example, in one study, employers were being interviewed by disabled co-researchers about their perceptions of barriers to employing and retaining people with disabilities.[[583]](#footnote-584) It became clear that employers were reluctant to discuss the topic with the co-researchers, which may have impacted on the response rate. Another study found that mental healthcare users were less likely to accept an invitation to participate in a research interview when it was revealed that the interviewer would be a co-researcher who was also a mental healthcare user.[[584]](#footnote-585) The potential for this dynamic between co-researchers and participants needs to be considered in the design of collaborative research projects.

One of the most common ways co-researchers were involved in research projects was in directly collecting data from participants,[[585]](#footnote-586) mainly in conducting interviews or focus groups.[[586]](#footnote-587) A number of accessibility challenges were highlighted that were specific to co-researchers collecting data, including transport[[587]](#footnote-588) and venues such as participants’ homes and public spaces.[[588]](#footnote-589) Interviewing could also be difficult for some co-researchers as it involves high demands on working memory,[[589]](#footnote-590) and focus groups require a variety of facilitating skills.[[590]](#footnote-591) Co-researchers did not always feel prepared to conduct interviews or focus groups.[[591]](#footnote-592) This could lead to feelings of anxiety and nervousness.[[592]](#footnote-593) In several studies, co-researchers were able to practice interviewing or facilitating before beginning the research[[593]](#footnote-594) or were supported by a researcher as they wanted.[[594]](#footnote-595)

Many of the studies adapted their data collection methods to facilitate the involvement of co-researchers or gave recommendations about how to adapt methods by:

* Using video to illustrate the data collection and consent process[[595]](#footnote-596)
* Using photos taken by participants to develop rapport and stimulate discussion with co-researchers[[596]](#footnote-597)
* Having co-researchers shadow the researchers[[597]](#footnote-598)
* Having researchers shadow co-researchers and then debriefing and advising them on what they might need to do differently[[598]](#footnote-599)
* Having co-researchers conduct interviews in pairs[[599]](#footnote-600) or co-facilitating with researchers[[600]](#footnote-601) or supporters[[601]](#footnote-602)
* Having focus groups/interviews with deaf participants conducted by a deaf researcher and sign language fluent hearing researcher in partnership[[602]](#footnote-603)
* Using a ‘round robin’ approach in focus groups to ensure every participant could contribute[[603]](#footnote-604)
* Providing co-researchers with a plain language interview guide with prompts[[604]](#footnote-605)
* Video recording interviews to aid recall[[605]](#footnote-606)
* Using creative ways to collect and generate data – e.g. body mapping,[[606]](#footnote-607) [[607]](#footnote-608) video, visuals,[[608]](#footnote-609) and drawings[[609]](#footnote-610)
* Conducting debriefs with co-researchers after focus groups/interviews.[[610]](#footnote-611)

In Munro *et al.* (2018) a co-production study on reimagining children and adult’s social care, the co-researchers with disabilities were also the participants. This project used a diverse and creative set of methods to collect data. These methods included focus groups, discussions, storyboarding, use of personas and visuals such as fishbone analysis. Please see Appendix C for more detail on the methods they used.

### Data analysis

Co-researchers were involved in data analysis in many of the studies reviewed.[[611]](#footnote-612) While in King *et al.* (2019) co-researchers analysed quantitative and qualitative data, in many other studies co-researchers were only involved in analysing qualitative data. Some academics felt that it was very difficult to conduct qualitative data analysis in an inclusive way due to the theoretical and conceptual complexities involved.[[612]](#footnote-613) Some quantitative data analysis was also perceived as too complex,[[613]](#footnote-614) and Di Lorito *et al.* (2017) noted that the complexity of quantitative analysis can pose challenges for power sharing in research between researchers and co-researchers. However, according to Smith-Merry (no year, p. 11):

It is ideal to include co-researchers as much as possible in the analysis. While some types of data analysis are too technically complex to be conducted by people who are new to research, most research data will be able to be analysed with training.

It is important that researchers implement effective strategies to enable co-researchers to take part in the process while ensuring the integrity of data analysis.[[614]](#footnote-615) Studies recommend that researchers devise creative ways of supporting co-researchers to conduct data analysis.[[615]](#footnote-616) One study used the advice of a research methodologist on how to tailor their data analytic approach to meet the aim of the research as well as the needs of a collaborative research approach.[[616]](#footnote-617) A number of studies tailored the involvement of co-researchers in analysis to their preferences and the time limitations of the project. For example, in Strnadová *et al.* (2016), the co-researchers chose not to be involved in any data analysis, in other studies co-researchers did not analyse all of the available data,[[617]](#footnote-618) and in Evans *et al.* (2019), co-researchers were not involved in coding data or thematic analysis. In some cases when co-researchers were not fully involved in data analysis, they were given the opportunity to discuss what was analysed by the researchers.[[618]](#footnote-619)

Jennings *et al.* (2018) outlined four characteristics for successful collaborative data analysis: that the process is co-produced, realistic (within time and resources), the demands on co-researchers are manageable and that group expectations and dynamics are appropriately handled. This study also devised a three-stage approach to collaborative data analysis: Preparation, Collaborative Data Analysis and Application (see Jennings *et al.* (2018) for more detail). Regarding planning collaborative data analysis sessions, Jennings *et al.* (2018, p. 6) note:

…a balance was needed between over-planning sessions (risking stifling creativity and encouraging PPI co-researcher passivity) and carefully planning the structure and content of sessions so as to generate the deepest and most collaborative analysis.

Other approaches taken or recommended to facilitate the involvement of co-researchers in data analysis include the following (bearing in mind that qualitative analysis was the predominant approach in the reviewed studies):

* Training in data analysis (as discussed earlier) and workshops to practise data analysis[[619]](#footnote-620)
* Considering the best way for data to be presented for analysis and discussion.[[620]](#footnote-621) In some cases, raw data was presented for analysis in more accessible ways:
* By reducing the amount of information presented[[621]](#footnote-622)
* By presenting the information slowly[[622]](#footnote-623)
* By summarising into easy read summaries[[623]](#footnote-624)
* By presenting it via posters[[624]](#footnote-625), PowerPoint presentations,[[625]](#footnote-626) or on flip charts[[626]](#footnote-627)
* In large fonts,[[627]](#footnote-628) using colour contrasts to increase visual distinctiveness[[628]](#footnote-629)
* In a visual map of categories using sticky notes that could be rearranged[[629]](#footnote-630)
* Using picture cards, word cards, storyboards and vignettes[[630]](#footnote-631)
* Using role play[[631]](#footnote-632)
* Using symbols and/or words[[632]](#footnote-633)
* Ensuring a reflexive, probing approach to data analysis (to mitigate instances of co-researchers identifying strongly with participants)[[633]](#footnote-634)
* Using group discussions for data analysis.[[634]](#footnote-635) In Vlot-van Anrooij *et al.* (2018) the discussion included a moderator with experience in facilitating group discussion with people with ID. In National Development Team for Inclusion, (2019), the group watched videos of focus groups and interviews, and a discussion was facilitated by a supporter or researcher.
* Using a 10 step community of inquiry approach to data analysis[[635]](#footnote-636) [[636]](#footnote-637)
* Using a Participatory Theme Elicitation (PTE) methodology[[637]](#footnote-638) which entails card sorting and was developed for lay researchers to identify themes in data
* Watching video recordings of interviews multiple times to identify patterns[[638]](#footnote-639)
* Using Photovoice method[[639]](#footnote-640) for the initial analysis[[640]](#footnote-641)
* Ensuring appropriate breaks are taken[[641]](#footnote-642)
* Providing adequate time to complete tasks[[642]](#footnote-643)
* Ensuring a relaxed, non-judgemental environment[[643]](#footnote-644)

### Write up of research/authorship

While involvement in the writing and publication of academic papers appears largely lacking in collaborative research projects,[[644]](#footnote-645) some studies did report on the involvement of co-researchers in writing up the research.[[645]](#footnote-646) The extent of involvement varied. In a number of studies co-researchers wrote parts of published articles[[646]](#footnote-647) and in Butler *et al.* (2020) the report was written by the researchers but the structure, recommendations and key points were all decided by the co-researchers. Several papers took a similar approach of having the researcher write the report at first, and this was then shaped and changed by co-researchers through their feedback and comments.[[647]](#footnote-648) In some studies, co-researchers were responsible for different formats of the write up, including accessible publications[[648]](#footnote-649) such as Plain English summaries,[[649]](#footnote-650) easy to read reports with quotes and pictures,[[650]](#footnote-651) and blogs and think pieces.[[651]](#footnote-652) Dewa *et al.* (2020) noted that co-researcher involvement in write up and dissemination was hampered in their study by limited funding being assigned to this stage of the research.

A number of articles went into detail regarding their process of collaborating to plan and write up research findings. Box 3 shows the process used by Vaughan *et al.* (2019) to develop their research article. In Haya Salmón and Rojas Pernia (2020), two researchers and two co-researchers with ID spent two months writing an academic article. One study found that some projects had linked co-researchers with ID with an experienced mentor who could help them write pieces.[[652]](#footnote-653) According to Riches, O'Brien and CDS Inclusive Research Network (2020), inclusive write-ups with co-researchers (with ID) take time, and there seems to be no best practice strategies by which co-researchers can be included in writing peer reviewed articles.

Box 3. Process of collaboratively developing a research article[[653]](#footnote-654)

“To develop the article, we came together for a series of four workshop-style group meetings, each lasting approximately two hours in length, over the period May–August 2018. These meetings aimed to elicit reflection and discussion about our individual and collective experience of inclusive research in practice…At each workshop, two or more members of the team would take notes, detailing key points arising in our discussions. Records from group brainstorming activities (documented via a white board) were photographed. We circulated these documents among the group, and through discussion of them at workshops and in between workshops at informal meetings or via email, decided upon the structure of this article and the key reflections that we wanted to share, with the writing shared among co-authors.”

A number of studies noted the importance of considering how co-researchers would be recognised and acknowledged in research outputs.[[654]](#footnote-655) Co-researchers were recognised as co-authors on some publications.[[655]](#footnote-656) Nicolaidis *et al.* (2019) found it challenging for co-researchers to fulfil authorship requirements but to address this they created a document placing each paragraph of the draft manuscript into one column of a table, with a lay translation in the second column. They then held group or individual meetings where they read and discussed the information in the lay translation column. This enabled the co-researchers to review annotated versions of manuscript and make substantive suggestions for revisions of the content and so they met authorship criteria. In a review of collaborative research papers, Smith-Merry (2017) found that just one third of papers in their review included co-researchers as authors. They noted that some journals may specify that a researcher needs to have written part of a paper to be named as an author, but questioned the ethics of excluding co-researchers who have been partners in the process:

…if the co-researchers have devised the project and contributed to a significant part of the data collection and/or analysis which is reported in the paper, it may not be ethical to exclude them from authorship.[[656]](#footnote-657)

### Dissemination

Studies have referred to the importance of collaborative research teams collaborating, discussing and agreeing on dissemination,[[657]](#footnote-658) on making dissemination accessible[[658]](#footnote-659) and on ensuring ways that co-researchers can present research findings.[[659]](#footnote-660) Box 4 displays the recommendations from Frankena *et al.* (2019a) on how to use results from collaborative research projects. While this study was specifically focused on co-researchers with ID, the advice could be applied to any collaborative research partnership.

Box 4. Consensus statement on how to conduct inclusive health research – Using results[[660]](#footnote-661)

i. Discussing with team members: how results will be disseminated in an accessible manner; how co-authorship will be arranged and how the voice of health researchers with intellectual disabilities will be represented; and how access to and ownership of the data will be ensured.

ii. Discussing and identifying possible new ideas, limitations and ethical issues with team members.

iii. Reporting on the process and added value of inclusive health research.

iv. Evaluating the dissemination of results.

v. Discussing academic and advocacy publications as well as different publication formats.

A number of studies did report that co-researchers were included in the planning and dissemination of research.[[661]](#footnote-662) Co-researchers in ImaYDiT (2018, p. 13) noted:

We talked about who we wanted to tell about our research and what we would like them to do to make it all happen.

Co-researchers engaged in traditional methods of dissemination in some studies, including research events, workshops, talks, seminars, launches and conference presentations – they either presented themselves or co-presented with researchers or supporters.[[662]](#footnote-663) A number of studies also reported using alternative methods to traditional research approaches. These approaches included:

* A community event[[663]](#footnote-664)
* Co-researchers being interviewed by local media[[664]](#footnote-665)
* A theatre performance[[665]](#footnote-666)
* An art exhibition[[666]](#footnote-667)
* A photo exhibition (with an accompanying podcast to support the experience of those who were visually impaired)[[667]](#footnote-668)
* Videos and films[[668]](#footnote-669)
* Comics and illustrations[[669]](#footnote-670)
* Magazines, newsletters[[670]](#footnote-671)
* Launch of a website.[[671]](#footnote-672)

The way research is traditionally presented was noted as disabling and inaccessible to many disabled people and their supporters.[[672]](#footnote-673) Few easy read journals exist and those that accept articles by inclusive research teams often have lower impact factors than those that are less accessible in language and style.[[673]](#footnote-674) There were also challenges around the varied priorities of different stakeholder groups in terms of outputs.[[674]](#footnote-675) For example, academic institutions were reported to be more focused on academic journals or books than co-researchers.[[675]](#footnote-676) Further, co-researchers sometimes felt there were not many opportunities to present research results to their communities.[[676]](#footnote-677) Relatedly, one study mentioned that co-researchers felt frustrated when their work did not lead to change or if they did not receive acknowledgement or responses from policy and decision makers.[[677]](#footnote-678)

### Closing out the project

The end of a project can be a big adjustment for co-researchers,[[678]](#footnote-679) as they have often developed relationships and routines as part of their involvement. For this reason, it was noted as important to support them in this transition and to formally mark the end of the project.[[679]](#footnote-680) Smith-Merry (no date) suggested having an event to celebrate the work done and to close out the project. This may help to give a sense of closure to everyone involved. In addition, if co-researchers finish their involvement before a project ends, they should be asked if they want to hear about the findings and outcomes of a research project.[[680]](#footnote-681) According to a co-researcher in Roberts *et al.* (2020, p. 14):

Due consideration must be given to the aftermath of research. If I take part in research, I want to know the outcomes. Too often, people living with dementia are asked for their opinion or to share the lived experience and have no idea where it goes. What happened next? Did the work influence public policy or care practice? Is there a next step and does that next step continue to involve people living with dementia?

## Documenting and evaluating the collaborative research process

Given the limited empirical analysis on collaborative research partnerships, it is not surprising that studies referred to the importance of documenting and evaluating the collaborative research process and impact.[[681]](#footnote-682) A number of studies documented the collaborative research process through video and audio recordings,[[682]](#footnote-683) personal diaries,[[683]](#footnote-684) other field notes[[684]](#footnote-685) and by using the Guidance for Reporting Involvement of Patients and the Public 2 (GRIPP 2)[[685]](#footnote-686) reporting checklist tool.[[686]](#footnote-687) [[687]](#footnote-688) While the GRIPP 2 tool does offer a standardised approach to 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”.[[688]](#footnote-689) Conducting formal evaluations of the collaborative research process would provide more rigorous evidence on the impact of collaborative research on the research project and research partners, and would provide a more comprehensive evidence base as to what approaches work best in collaborative research.

# Section 5: Conclusion

## Summary of findings

This review of literature has identified that there is no one best practice model of collaborative research between researchers and people with disabilities. Such research occurs under a broad range of labels, including, but not limited to, co-research, co-production, PPI, inclusive research and engaged research. Understanding these collaborative approaches is made more challenging as terms are often used interchangeably, practices differ within each labelled approach and involvement of disabled people can vary from a consultative role on one part of a research project to having influence and power over the research project as a whole.

For the purpose of this review, we defined collaborative research as a partnership between the co-researchers with disabilities and trained/professional researchers in which the contributions of all team members were considered meaningful. To be considered collaborative research, the co-researchers had to have some control or ownership of the research, or decision-making power over the research topic, approach, materials, processes or outputs. Despite the variation in practices across studies, this review did identify common themes to consider when designing and conducting a collaborative research project. Key considerations include the extra time, resources and planning that are likely to be needed for a collaborative research project. Accessibility needs to be considered throughout all elements of the research, including for example in communication and informational materials, venues where meetings or research activities take place and the transport and travel times to those locations. Other adjustments to the research design and other activities may need to be considered based on individuals’ needs and preferences. Providing such support, offering training and paying co-researchers for their time are important measures to ensure the full participation of co-researchers with disabilities.

Key challenges for collaborative research teams include aligning the traditional research approach with a collaborative research approach, balancing power sharing, how to involve co-researchers early in the process without any funding to do so, and ensuring any potential for bias and challenges to rigour in collaborative research projects are considered and addressed.

## Limitations

Articles were chosen for inclusion in this review based on the authors’ selection criteria that co-researchers had to have some control and ownership of the research or decision-making power over the research topic, approach, materials, processes or outputs. It is important to note here that this level of control or ownership was determined at face-value based on the information that was reported by the authors of the included studies. It is not possible to say with certainty if these reports reflected the true experiences and perceptions of the people with disabilities who were co-researchers.

This review has been limited by the fact that there is little empirical evidence available on the processes and impacts of collaborative research partnerships between researchers and co-researchers with disabilities. As such, this review relied on commonalities across studies and largely on the experiences reported by members of collaborative research teams as reported in their articles.

This review is also limited as the searches were restricted to a timeframe from 2015-2020 and to those published in English. This means that more recently published articles or articles in other languages have not been included. Similarly, excluding older articles may have resulted in some insights being missed. However, comprehensive searches were conducted within the selected timeframe and efforts were made to ensure that all types of collaborative research were considered.

## Next steps

This review will form the basis of NDA guidance for researchers in conducting collaborative research with disabled people in Ireland. This guidance will be developed in partnership with an advisory group of people with disabilities and will be shaped by feedback from relevant stakeholders.

We envisage that this guidance could be consulted as a first step when planning for collaborative research initiatives, especially for those who are new to this approach, as a means to gaining a high level overview of key considerations. Researchers will need to consult with DPOs, other disability organisations and disabled individuals when considering conducting research with individuals who have specific disabilities.

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# Appendix A – Search terms used in literature review

**Terms 1**

“co-research” or “coresearch” or “co research” or “inclusive research” or “collaborative research” or “engaged research” or “peer research” or “peer-research” or “participatory” or “user research” or “user-involvement” or “user involvement” or “involving users” or “involvement of users” or “community of practice” or “communities of practice” or “emancipatory disability research” or “action research” or “participatory evaluation” or “collaborative inquiry” or “public patient involvement” or “public and patient involvement” or “patient public involvement” or “patient and public involvement” or “steering committee\*” or “advisory committee\*” or “consultation\*” or “integrated knowledge translation” or “public patient engagement” or “public and patient engagement” or “patient public engagement’ or “patient and public engagement”

AND

“disab\*” or “impair\*” or “mental\*” or “deaf” or “blind” or “autis\*” or “learning difficult” or “ill\*” or “dementia”

**Terms 2**

“design-based research” or “design based research” or “co-design” or “co design” or “inclusive design” or “user-led design” or “user led design”

AND

“disab\*” or “impair\*” or “mental\*” or “deaf” or “blind” or “autis\*” or “learning difficult” or “ill\*” or “dementia” or “universal design”

# Appendix B - Campus Engage recommendations for funders

Align funding calls to societal needs articulated by public or professional service and product users, policy makers, civil and civic society organisations (CSOs) and researchers;

* Allow longer project timelines for engaged research projects;
* Include funding for pre-proposal design and consultation and post-project impact assessment;
* Earmark funding for existing programme or service evaluation research;
* Offer societal innovation vouchers for engaged research;
* Fund project management for larger-scale engaged research projects;
* Fund support staff to sustain engagement between HEIs and CSO partners between and during funded research projects;
* Fund national inter-institutional collaborations to provide leverage for smaller-scale projects to develop into impactful larger-scale projects that address issues of public concern across Ireland[[689]](#footnote-690).

# Appendix C – Methods used by Munro *et al.* (2018)

Munro *et al.* (2018) used a diverse and creative set of methods to collect data in their co-production study on reimagining children and adult’s social care, the co-researchers with disabilities were also the participants. These methods included focus groups, discussions, storyboarding, use of personas and visuals such as fishbone analysis. See Table D1.1 for more detail on the methods they used.

Table D1.1 Summary of methods employed by Munro *et al.* (2018) p. 8-14

| 5-D phase Overview | Method or activity | Purpose | Overview |
| --- | --- | --- | --- |
| **Discovery (stories about ‘what is’)** | Creating personas | To present significant people in parents’ stories of engagement with children’s and adult services | Disabled parents created persona for each person in their account. Personas are used as a method in design thinking and give a person to connect with to bring a story to life (Cooper, 1999). |
|  | Storyboarding | To assist the parents to share their journey (of involvement with children’s and adult services). | A process by which participants write their story against a timeline and present the people in their stories, including reflections on their feelings and thoughts. Further details about the disabled parents’ experiences were elicited using gentle questioning, prompting and probing (Bowling, 2002; Gray 2004). |
|  | Empathy mapping | Develop an understanding of people in the disabled parents’ stories and to illuminate what parents thought about their involvement at key points during their engagement with children’s and adult services | Empathy mapping is a technique to help people develop deep shared understanding and empathy for other people and allowed the rest of the group to connect with the stories that were being told (Gray, 2017). |
|  | Assessment of need mapping | Obtain parental reflections on what they thought social workers focused on during the assessment  | Parents were provided with a copy of the Assessment Triangle (a pictorial representation of the Framework for the Assessment of Children in Need and their Families so they could identify which dimensions of a child’s development needs, parenting capacity and family and environmental factors they thought social workers had taken into consideration as part of the assessment (Department of Health, Department for Department for Education and Employment and Home Office, 2000). |
|  | Service delivery mapping | Obtain parental reflections on which services were put in place and what was missing from the parents’ perspectives | Researchers explored with parents which services children’s and adult social services had put in place and whether they wanted these and felt they were needed. Parents were also asked whether there were additional services that they wanted but that were not offered. In order to make this visually interesting we invited parents to populate the template in a green, amber and red. |
|  | Concept reframing mapping | Obtain parental reflections on the principles underpinning the Care Act 2014 and Children Act1989. | Principles within Care Act 2014 and the Children Act 1989 were placed onto a target map. Parents and professionals were given red and green sticky dots. They were each invited to place their sticky dots on the target map. The green dots represented principles that the group were happy with and did not wish to change. The red dots represented concepts that were perceived to be problematic in respect of supporting disabled parents and their children. |
| **Dream (imagining the best of what could be)** | Creating new personas | Develop personas that reflect the characteristics that parents would like professionals to demonstrate in the future. | Parents decided from the discovery phase which personas they wished to take into dream. They subsequently developed a series of new personas to replace personas they did not wish to carry forward from the discovery phase. |
|  | Empathy mapping | Develop an understanding of the new personas | Parents decided from the discovery phase which empathy maps they wished to take into dream. They subsequently developed a series of new empathy maps to replace personas they did not wish to carry forward from the discovery phase. |
|  | Fishbone Diagram | Developing a goal to be achieved | Usually, fishbone analysis or ‘Ishikawa diagrams’ (1968) are used to find the root cause of problems. In Appreciative Inquiry, it can be used to do the opposite – an inclusive process to find the route tothe Dream. In the ‘head’ of the diagram, disabled parents and professionals write the part of the Dream that they want to bring into reality. In the boxes at the end of each spine of the fishbone they write an area for which action needs to be taken to make the Dream happen. Along each spine of the fishbone, parents and professionals placed post-it notes with the actions that have to be taken, or the things that have to be in place, to make that area support the dream goal. |
| **Design (statements of intention)** | Focus groups |  | A series of focus groups were conducted around the following themes: help seeking, the assessment, the service, service closure/continuation and outcomes and the principles of assessment |
|  | Snap shot big picture | Designing new principles to support best practice in working with disabled parents and their children | Browolski (2018) created the snap shot big picture method. The snapshot of the big picture is designed to clarify what individuals and teams are experiencing right now and to help them envision the desired future and create an action plan to get there. The snap shot big picture tool was used after the concept reframing mapping. The snap shot big picture enabled the group to think about the principles they wanted professionals to practice. Parents and professionals worked together to reimagine the principles they had highlighted as requiring reframing through the concept reframing mapping |
|  | Fishbone diagram | Developing a goal to be achieved | Parents and professionals used the Fishbone diagram to map out the characteristics and strengths of the new personas they had created in the dream phase |

# Appendix D - Short and long form Guidance for Reporting Involvement of Patients and the Public 2 (GRIPP 2) reporting checklist tool

Table G1.1 GRIPP 2 long form[[690]](#footnote-691)

| Section and topic | Item |
| --- | --- |
| **Section 1: Abstract of paper** |  |
| 1a: Aim  | Report the aim of the study |
| 1b: Methods  | Describe the methods used by which patients and the public were involved |
| 1c: Results  | Report the impacts and outcomes of PPI in the study |
| 1d: Conclusions  | Summarise the main conclusions of the study |
| 1e: Keywords  | Include PPI, “patient and public involvement,” or alternative terms as keywords |
| **Section 2: Background to paper** |  |
| 2a: Definition  | Report the definition of PPI used in the study and how it links to comparable studies |
| 2b: Theoretical underpinnings | Report the theoretical rationale and any theoretical influences relating to PPI in the study |
| 2c: Concepts and theory development  | Report any conceptual models or influences used in the study |
| **Section 3: Aims of paper** |  |
| 3: Aim  | Report the aim of the study |
| **Section 4: Methods of paper** |  |
| 4a: Design  | Provide a clear description of methods by which patients and the public were involved |
| 4b: People involved | Provide a description of patients, carers, and the public involved with the PPI activity in the study |
| 4c: Stages of involvement  | Report on how PPI is used at different stages of the study |
| 4d: Level or nature of involvement  | Report the level or nature of PPI used at various stages of the study |
| **Section 5: Capture or measurement of PPI impact** |  |
| 5a: Qualitative evidence of impact  | If applicable, report the methods used to qualitatively explore the impact of PPI in the study |
| 5b: Quantitative evidence of impact  | If applicable, report the methods used to quantitatively measure or assess the impact of PPI |
| 5c: Robustness of measure  | If applicable, report the rigour of the method used to capture or measure the impact of PPI |
| **Section 6: Economic assessment** |  |
| 6: Economic assessment  | If applicable, report the method used for an economic assessment of PPI |
| **Section 7: Study results** |  |
| 7a: Outcomes of PPI  | Report the results of PPI in the study, including both positive and negative outcomes |
| 7b: Impacts of PPI  | Report the positive and negative impacts that PPI has had on the research, the individuals involved (including patients and researchers), and wider impacts |
| 7c: Context of PPI  | Report the influence of any contextual factors that enabled or hindered the process or impact of PPI |
| 7d: Process of PPI  | Report the influence of any process factors, that enabled or hindered the impact of PPI |
| 7ei: Theory development  | Report any conceptual or theoretical development in PPI that have emerged |
| 7eii: Theory development  | Report testing of theoretical models, if any |
| 7f: Measurement  | If applicable, report all aspects of instrument development and testing (eg, validity, reliability, feasibility, acceptability, responsiveness, interpretability, appropriateness, precision) |
| 7g: Economic assessment  | Report any information on the costs or benefit of PPI |
| **Section 8: Discussion and conclusions** | Comment on how PPI influenced the study overall. Describe positive and negative effects |
| 8b: Impacts  | Comment on the different impacts of PPI identified in this study and how they contribute to new knowledge |
| 8c: Definition  | Comment on the definition of PPI used (reported in the Background section) and whether or not you would suggest any changes |
| 8d: Theoretical underpinnings  | Comment on any way your study adds to the theoretical development of PPI |
| 8e: Context  | Comment on how context factors influenced PPI in the study |
| 8f: Process  | Comment on how process factors influenced PPI in the study |
| 8g: Measurement and capture of PPI impact  | If applicable, comment on how well PPI impact was evaluated or measured in the study |
| 8h: Economic assessment  | If applicable, discuss any aspects of the economic cost or benefit of PPI, particularly any suggestions for future economic modelling. |
| 8i: Reflections/critical perspective  | Comment critically on the study, reflecting on the things that went well and those that did not, so that others can learn from this study |

PPI=Public and patient involvement

Table G1.2 GRIPP short form

| Section and topic | Item  |
| --- | --- |
| 1: Aim  | Report the aim of PPI in the study |
| 2: Methods  | Provide a clear description of the methods used for PPI in the study |
| 3: Study results | Outcomes—Report the results of PPI in the study, including both positive and negative outcomes |
| 4: Discussion and conclusions  | Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects |
| 5: Reflections/critical perspective  | Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience |

PPI=Public and patient involvement

1. National Disability Authority, 2022a [↑](#footnote-ref-2)
2. Campus Engage, 2017, O’Shea *et al.,* 2019 [↑](#footnote-ref-3)
3. National Disability Authority, 2022b. [↑](#footnote-ref-4)
4. Some studies may have involved research partnerships with other relevant stakeholders, such as service providers, carers or the general public – only information pertaining to the experience of co-researchers with disabilities was included in the review. [↑](#footnote-ref-5)
5. In the UK, ‘learning disabilities’ has been the preferred term since the 1980s (though there is evidence that this is beginning to be replaced by intellectual disabilities, Cluley, 2017), while in other countries, including Ireland, the preferred term is ‘intellectual disabilities’ (Inclusion Ireland, 2013). [↑](#footnote-ref-6)
6. Barry, 2016, Stanley *et al.,* 2019, [↑](#footnote-ref-7)
7. Beighton *et al.,* 2019, Bollard 2017, Frankena *et al.,* 2019a [↑](#footnote-ref-8)
8. Gratton, 2020, Joss *et al.,* 2016 [↑](#footnote-ref-9)
9. Smith-Merry, 2017, Werner-Seidler *et al.,* 2019 [↑](#footnote-ref-10)
10. Anderson *et al.,* 2019, Paul *et al.,* 2017 [↑](#footnote-ref-11)
11. Burke *et al.,* 2019 [↑](#footnote-ref-12)
12. Vaughn *et al.,* 2019 [↑](#footnote-ref-13)
13. Heffron *et al.,* 2018 [↑](#footnote-ref-14)
14. Burton, Ogden, and Cooper, 2019, Gould, Harris, and Fujiura*.,* 2017 [↑](#footnote-ref-15)
15. Disability Wales, 2019, Drill Report, 2018 [↑](#footnote-ref-16)
16. Puyalto *et al.,* 2016, Spencer Gonzalez *et al.,* 2020 [↑](#footnote-ref-17)
17. Frankena *et al.,* 2015, Tilly *et al.,* 2015 [↑](#footnote-ref-18)
18. Frankena *et al.,* 2019c, Hamidi *et al.,* 2015 [↑](#footnote-ref-19)
19. INVOLVE, 2015 cited in Di Lorito *et al.,* 2018, Paul *et al.,* 2017, Stanley *et al.,* 2019 [↑](#footnote-ref-20)
20. Swarbrick *et al.,* 2019 [↑](#footnote-ref-21)
21. IRN, 2019, O’Hara *et al.,* 2017, Riches, O'Brien and CDS Inclusive Research Network, 2020, Grayson *et al.,* 2013 cited in Smith-Merry, 2017, Strnadová *et al.,* 2016 [↑](#footnote-ref-22)
22. Burke *et al.,* 2019, Frankena *et al.,* 2019a [↑](#footnote-ref-23)
23. Haya Salmón and Rojas Pernia, 2021, Nicolaidis *et al.,* 2019, Powers *et al.,* 2017, Smith-Merry, 2017 [↑](#footnote-ref-24)
24. Gove *et al.,* 2017, King *et al.,* 2019 [↑](#footnote-ref-25)
25. Walmsley *et al.,* 2004 cited in Frankena *et al.,* 2015, Gove *et al.,* 2017 [↑](#footnote-ref-26)
26. Burton, Ogden, and Cooper, 2019, O’Hara *et al.,* 2017 [↑](#footnote-ref-27)
27. Smith-Merry, 2017 [↑](#footnote-ref-28)
28. Anderson *et al.,* 2019, Frankena *et al.,* 2015, Gove *et al.,* 2017, Ní Shé *et al.,* 2020, Nicolaidis *et al.,* 2019 [↑](#footnote-ref-29)
29. Bailey *et al.,* 2015, Scottish Dementia Working Group 2014 cited in Di Lorito *et al.,* 2017 [↑](#footnote-ref-30)
30. Barry, 2016, Durell *et al.,* 2016, Suijkerbuijk *et al.,* 2019 [↑](#footnote-ref-31)
31. Ní Shé *et al.,* 2020 [↑](#footnote-ref-32)
32. Frankena *et al.,* 2015, Frankena *et al.,* 2019a, Miah *et al.,* 2019 [↑](#footnote-ref-33)
33. NDA, 2002, p. 7 [↑](#footnote-ref-34)
34. In this review we use the term the term ‘researcher’ to refer to trained/professional researchers (e.g. academic researchers, organisations, clinicians) and ‘co-researcher’ to identify people with lived experience of disability who are collaboratively involved in the research process. It is important to note that trained or academic researchers may include people with lived experience of disability. [↑](#footnote-ref-35)
35. Brown and Dorris, 2022, Gomez *et al.,* 2020, McCausland *et al.,* 2018 [↑](#footnote-ref-36)
36. Brown and Dorris, 2022 [↑](#footnote-ref-37)
37. Salmon *et al.,* 2018 [↑](#footnote-ref-38)
38. Campus Engage is an Irish initiative dedicated to supporting civic and community engagement in all aspects of higher education institutions. [↑](#footnote-ref-39)
39. Campus Engage, 2017 [↑](#footnote-ref-40)
40. NDA, 2022b [↑](#footnote-ref-41)
41. Castro *et al.,* 2016, Nind, 2014 [↑](#footnote-ref-42)
42. Nind, 2014, Walmsley and Johnson, 2003 [↑](#footnote-ref-43)
43. Campus Engage, 2017, Holliman *et al.,* 2015 [↑](#footnote-ref-44)
44. Cornwall and Jewkes, 1995 [↑](#footnote-ref-45)
45. Vaughn and Jacquez, 2020 [↑](#footnote-ref-46)
46. Banks and Brydon Miller, 2018, p.3 [↑](#footnote-ref-47)
47. Nind, 2017, Walmsley, 2003 [↑](#footnote-ref-48)
48. Fenge, 2010 [↑](#footnote-ref-49)
49. Welikala, 2014 [↑](#footnote-ref-50)
50. Smith-Merry, no date [↑](#footnote-ref-51)
51. Blomkamp, 2018, Burkett, 2012 [↑](#footnote-ref-52)
52. Farmer and MacLeod, 2011 [↑](#footnote-ref-53)
53. INVOLVE, 2015 cited in Di Lorito *et al.,* 2018 [↑](#footnote-ref-54)
54. Durose *et al.,* 2011 cited in James and Buffel, 2022 [↑](#footnote-ref-55)
55. Nicolaidis and Raymaker, 2015, Vaughn and Jaquez, 2020 [↑](#footnote-ref-56)
56. Involve guidelines 2018, p.4 [↑](#footnote-ref-57)
57. Oliver, 1992, Vaughn and Jaquez, 2020, Zarb, 1992 [↑](#footnote-ref-58)
58. Bjornsdottir and Svensdottir, 2008 cited in Smith-Merry, 2017 [↑](#footnote-ref-59)
59. Campus Engage, 2017 [↑](#footnote-ref-60)
60. Donetto *et al.,* 2015 [↑](#footnote-ref-61)
61. Donetto *et al.,* 2015, Dominopoulis *et al.,* 2018 [↑](#footnote-ref-62)
62. In the UK, ‘learning disabilities’ has been the preferred term since the 1980s (though there is evidence that this is beginning to be replaced by intellectual disabilities, Cluley, 2017), while in other countries, including Ireland, the preferred term is ‘intellectual disabilities’ (Inclusion Ireland, 2013). [↑](#footnote-ref-63)
63. Walmsley and Johnson, 2003, p. 9 [↑](#footnote-ref-64)
64. INVOLVE, 2015 [↑](#footnote-ref-65)
65. INVOLVE, 2015 [↑](#footnote-ref-66)
66. Cornwall and Jewkes, 1995, Vaughn and Jaquez, 2020 [↑](#footnote-ref-67)
67. Cargo and Mercer, 2008, Vaughn and Jaquez, 2020 [↑](#footnote-ref-68)
68. Baum, MacDougall, and Smith, 2006 [↑](#footnote-ref-69)
69. Baum, MacDougall, and Smith, 2006 [↑](#footnote-ref-70)
70. Baum, MacDougall, and Smith, 2006, NDA, 2002, Vaughn and Jacquez, 2020 [↑](#footnote-ref-71)
71. NDA, 2002 [↑](#footnote-ref-72)
72. McCurdie *et al.,* 2012, Vaughn and Jaquez, 2020 [↑](#footnote-ref-73)
73. Bigby and Frawley 2010 [↑](#footnote-ref-74)
74. García Ingarte, O'Brien and Chadwick, 2014, Walmsley and Johnson, 2003 [↑](#footnote-ref-75)
75. , McLaughlin, 2010, Walmsley and Johnson, 2003 [↑](#footnote-ref-76)
76. Arnstein, 1969 [↑](#footnote-ref-77)
77. Frankena *et al.,* 2015 [↑](#footnote-ref-78)
78. Services users in Hanley’s model (2004) includes members of the public and persons who use health and social care services. [↑](#footnote-ref-79)
79. Adapted from Arnstein, 1969, p.217 [↑](#footnote-ref-80)
80. Smith-Merry, no date [↑](#footnote-ref-81)
81. Bigby, Frawley and Ramcharan, 2014b [↑](#footnote-ref-82)
82. McLaughlin *et al.,* 2010 [↑](#footnote-ref-83)
83. Farmer and Macleod, 2011 [↑](#footnote-ref-84)
84. Bigby, Frawley and Ramcharan, 2014b [↑](#footnote-ref-85)
85. Smith-Merry, 2017 [↑](#footnote-ref-86)
86. Bigby, Frawley and Ramcharan, 2014b, Farmer and MacLeod, 2011 [↑](#footnote-ref-87)
87. Bigby, Frawley and Ramcharan, 2014b [↑](#footnote-ref-88)
88. Smith-Merry, no date [↑](#footnote-ref-89)
89. Nind and Vinha, 2014 [↑](#footnote-ref-90)
90. Farmer and Macleod, 2011 [↑](#footnote-ref-91)
91. Farmer and Macleod, 2011 [↑](#footnote-ref-92)
92. Farmer and Macleod, 2011 [↑](#footnote-ref-93)
93. National Disability Authority, 2022b [↑](#footnote-ref-94)
94. Please note that as this search was conducted during 2020, it will not include all relevant 2020 publications. [↑](#footnote-ref-95)
95. In some instances, this was difficult to discern and involved the authors making a judgment call that study authors may not necessarily agree with, as to how much input into a research or design project was illustrative of power or ownership. [↑](#footnote-ref-96)
96. As noted, in the UK, ‘learning disabilities’ has been the preferred term since the 1980s (though there is evidence that this is beginning to be replaced by intellectual disabilities, Cluley, 2018), while in other countries, including Ireland, the preferred term is ‘intellectual disabilities’ (Inclusion Ireland, 2013). [↑](#footnote-ref-97)
97. Some studies may have involved research partnerships with other relevant stakeholders, such as service providers, carers or the general public – only information pertaining to the involvement and experience of co-researchers with disabilities was included in the review. [↑](#footnote-ref-98)
98. Anderson *et al.,* 2018, Sangill *et al.,* 2019 [↑](#footnote-ref-99)
99. O’Brien *et al.,* 2014 in Di Lorito *et al.,* 2017, Frankena *et al.,* 2019a, Walsh *et al.,* 2018 [↑](#footnote-ref-100)
100. Barry, 2016, Stanley *et al.,* 2019, [↑](#footnote-ref-101)
101. Ashcroft *et al.,* 2016, Beighton *et al.,* 2019, Moule *et al.,* 2016, Puyalto *et al.,* 2016 [↑](#footnote-ref-102)
102. Barry *et al.,* 2016, Beaumont 2019, O'Hara *et al.,* 2017, Rojas Pernia *et al.,* 2020, Salmon *et al.,* 2018 [↑](#footnote-ref-103)
103. Mogensen, 2010 cited in Bailey *et al.,* 2015, Street and Herts, 2005 cited in Bailey *et al.,* 2015, Brosnan *et al.,* 2016 [↑](#footnote-ref-104)
104. Beaumont *et al.,* 2019, Salmon *et al.,* 2018, Stack and McDonald, 2018 [↑](#footnote-ref-105)
105. P13 in Salmon *et al.,* 2018, p. 272 [↑](#footnote-ref-106)
106. Beighton *et al.,* 2019, Bollard 2017, Frankena *et al.,* 2019a [↑](#footnote-ref-107)
107. Gratton, 2020 [↑](#footnote-ref-108)
108. Callus, 2019, Joss *et al.,* 2016 [↑](#footnote-ref-109)
109. Green *et al.,* 2016 [↑](#footnote-ref-110)
110. Di Lorito *et al.,* 2018, Woelders *et al.,* 2015, [↑](#footnote-ref-111)
111. Academic researcher in Woelders *et al.,* 2015, p. 535 [↑](#footnote-ref-112)
112. Spencer Gonzalez *et al.,* 2020 [↑](#footnote-ref-113)
113. Smith-Merry, 2017, Werner-Seidler *et al.,* 2019 [↑](#footnote-ref-114)
114. Gratton 2012, Joss *et al.,* 2016, e.g. Livingstone *et al.,* 2014b cited in Smith-Merry, 2017, Rose *et al.,* 2008 cited in Smith-Merry, 2017 [↑](#footnote-ref-115)
115. Anderson *et al.,* 2019, Wykes, 2014 cited in Ashcroft *et al.,* 2016, Wykes and Marshall, 2004 cited in Ashcroft *et al.,* 2016 [↑](#footnote-ref-116)
116. Weksler-Derri, Shwed and Davidovitch, 2019 [↑](#footnote-ref-117)
117. Paul *et al.,* 2017 [↑](#footnote-ref-118)
118. Anderson *et al.,* 2019, Street and Herts 2005 cited in Bailey *et al.,* 2015, Morris, 2003 cited in Bailey *et al.,* 2015, Brosnan *et al.,* 2016, Fitzimons *et al.,* 2017, Tilly *et al.,* 2015, Walsh *et al.,* 2018 [↑](#footnote-ref-119)
119. Wykes, 2003 cited in Ashcroft *et al.,* 2016, Frankena *et al.,* 2019C, McCartan *et al.,* 2019 [↑](#footnote-ref-120)
120. Beighton *et al.,* 2019, Hamidi *et al.,* 2015, Sangill *et al.,* 2019, Schwartz and Durkin, 2020, St John *et al.,* 2018, Werner-Seidler *et al.,* 2019 [↑](#footnote-ref-121)
121. Burke *et al.,* 2019 [↑](#footnote-ref-122)
122. McCartan *et al.,* 2019, Walsh *et al.,* 2018 [↑](#footnote-ref-123)
123. Varkonyi-Sep, Cross and Howarth, 2017 [↑](#footnote-ref-124)
124. Participant 2 in Paul *et al.,* 2017, p. 13 [↑](#footnote-ref-125)
125. Bigby, Frawley and Ramcharan, 2014a, Burke *et al.,* 2019, O’Brien *et al.,* 2014 cited in Di Lorito *et al.,* 2018, Herron, Priest and Read, 2015, Sangill *et al.,* 2019 [↑](#footnote-ref-126)
126. O’Brien, Fossey and Palmer, 2021, Smith-Merry, 2017, Smith-Merry, no date [↑](#footnote-ref-127)
127. VIPER, 2012b cited in Bailey *et al.,* 2015, Noyes *et al.,* 2010 cited in Bailey *et al.,* 2015, Burton, Ogden, and Cooper, 2019 [↑](#footnote-ref-128)
128. Burton, Ogden, and Cooper, 2019, Savage *et al.,* 2006 cited in Varkonyi-Sep, Cross and Howarth, 2017 [↑](#footnote-ref-129)
129. Beaumont *et al.,* 2019, Frankena *et al.,* 2015 [↑](#footnote-ref-130)
130. Anderson *et al.,* 2019, Armstrong *et al.,* 2019, Burke *et al.,* 2019, Gratton *et al.,* 2020, Vaughn *et al.,* 2019 [↑](#footnote-ref-131)
131. Schwartz and Durkin, 2020, p. 120 [↑](#footnote-ref-132)
132. Anderson *et al.,* 2019, Beaumont, 2019, Butler *et al.,* 2019 in Di Lorito *et al.,* 2018, Joss *et al.,* 2016, King *et al.,* 2019, O’Brien, Fossey and Palmer, 2021, Smith-Merry, 2017 [↑](#footnote-ref-133)
133. Aldersey *et al.,* 2018 [↑](#footnote-ref-134)
134. Bigby, Frawley and Ramcharan, 2014a, Di Lorito *et al.,* 2018, Strnadová *et al.,* 2014 cited in Di Lorito *et al.,* 2018, Herron, Priest and Read, 2015, Walmsley, Strnadová and Johnson, 2018 [↑](#footnote-ref-135)
135. St. John *et al.,* 2018 [↑](#footnote-ref-136)
136. Cooper, Gillmore and Hogg, 2016, Disability Wales, 2019, Frankena *et al.,* 2019a, Frankena *et al.,* 2019c, Vlot-van Anrooij *et al.,* 2020, Walmsley, Strnadová and Johnson, 2018 [↑](#footnote-ref-137)
137. Aldersey *et al.,* 2018, Beaumont *et al.,* 2019, Burke *et al.,* 2019, O’Brien *et al.,* 2014 cited in Di Lorito *et al.,* 2018, Faulkner *et al.,* 2019, Herron, Priest and Read, 2015, King *et al.,* 2019, St John *et al.,* 2018, Vaughn *et al.,* 2019 [↑](#footnote-ref-138)
138. Barod Community Interest Company, 2019, Chapman *et al.,* 2014 cited in Di Lorito *et al.,* 2018, Heffron *et al.,* 2018, Jennings *et al.,* 2018, Stevenson and Taylor, 2019 [↑](#footnote-ref-139)
139. Beighton *et al.,* 2019, Puyalto *et al.,* 2016, Sangill *et al.,* 2019, Smith-Merry, 2017, Vlot-van Anrooij *et al.,* 2020, Williams, Ponting and Ford, 2015 [↑](#footnote-ref-140)
140. Rose, 2004 cited in Ashcroft *et al.,* 2016, Rose *et al.,* 2008 cited in Ashcroft *et al.,* 2016, Beighton *et al.,* 2019, Smith-Merry, 2017, Werner-Seidler *et al.,* 2019 [↑](#footnote-ref-141)
141. Beighton *et al.,* 2019, Cameron *et al.,* 2019, Faulkner *et al.,* 2019, Frankena *et al.,* 2019c, Green *et al.,* 2016, Hamidi *et al.,* 2015, Smith-Merry, 2017, Vlot-van Anrooij *et al.,* 2018 [↑](#footnote-ref-142)
142. VIPER 2012b cited in Bailey *et al.,* 2015, Gillard *et al.,* 2012 cited in Smith-Merry, 2017, Stack and McDonald, 2018 [↑](#footnote-ref-143)
143. ML, academic researcher in Dewa *et al.,* 2020, p. 138 [↑](#footnote-ref-144)
144. Anderson *et al.,* 2018, Frankena *et al.,* 2015, Gould, Harris, and Fujiura*.,* 2017 [↑](#footnote-ref-145)
145. Hamidi *et al.,* 2015, Haya Salmón and Rojas Pernia, 2021 [↑](#footnote-ref-146)
146. Hamidi *et al.,* 2015, p. 170 [↑](#footnote-ref-147)
147. Beighton *et al.,* 2019, Burton, Ogden, and Cooper, 2019, Campus Engage, 2017, Frankena *et al.,* 2019a, Frankena *et al.,* 2019c, Joss *et al.,* 2016, McConnell *et al.,* 2019, O’Brien, Fossey and Palmer, 2021, Paul *et al.,* 2017, Varkonyi-Sep, Cross and Howarth, 2017, Walsh *et al.,* 2018 [↑](#footnote-ref-148)
148. Cameron *et al.,* 2019, Frankena *et al.,* 2019a, Smith-Merry, 2017 [↑](#footnote-ref-149)
149. Davidson *et al.,* 2018 [↑](#footnote-ref-150)
150. Bollard, 2017, Walmsley, Strnadová and Johnson, 2018 [↑](#footnote-ref-151)
151. Anderson *et al.,* 2019, Bollard *et al.,* 2017, Di Lorito *et al.,* 2018, Drill Report, 2018 [↑](#footnote-ref-152)
152. Anderson *et al.,* 2019, Beighton *et al.,* 2019, Bollard 2017, Brosnan *et al.,* 2016, Drill Report, 2018, Frankena *et al.,* 2019a, Frankena *et al.,* 2019c, Haya Salmón and Rojas Pernia, 2021, Hollinrake, Spencer and Dix*,* 2019, IRN, 2019, McCartan *et al.,* 2019, Nind, 2017, St John *et al.,* 2018, Stack and McDonald, 2018, Walmsley, Strnadová and Johnson, 2018, [↑](#footnote-ref-153)
153. Anderson *et al.,* 2019, Conder *et al.,* 2011 cited in Di Lorito *et al.,* 2018, King *et al.,* 2019, Smith-Merry, 2017 [↑](#footnote-ref-154)
154. O’Hara *et al.,* 2017 [↑](#footnote-ref-155)
155. Williams, Ponting and Ford, 2015 [↑](#footnote-ref-156)
156. Disability Wales, 2019, Frankena *et al.,* 2019c [↑](#footnote-ref-157)
157. DRILL report, 2018, Brady *et al.,* 2019, Herron, Priest and Read, 2015, Puyalto *et al.,* 2016, Spencer Gonzalez *et al.,* 2020 [↑](#footnote-ref-158)
158. Burke *et al.,* 2019, Disability Wales, 2019, Green *et al.,* 2016, Tilly *et al.,* 2015 [↑](#footnote-ref-159)
159. Anderson *et al.,* 2019 [↑](#footnote-ref-160)
160. Tilly *et al.,* 2015 [↑](#footnote-ref-161)
161. Frankena *et al.,* 2019c, Nind *et al.,* 2017 [↑](#footnote-ref-162)
162. Anderson *et al.,* 2018, Anderson *et al.,* 2019, Beaumont 2019, Bollard *et al.,* 2017, Disability Wales, 2019, Drill Report, 2019, Evans *et al.,* 2020, Joss *et al.,* 2016, Oliver *et al.,* 2020, Roberts *et al.,* 2020, Sangill *et al.,* 2019, Williams, Ponting and Ford, 2015 [↑](#footnote-ref-163)
163. JJ in Dewa *et al.,* 2020, p. 138 [↑](#footnote-ref-164)
164. Barry, 2016, Nind 2017, Riches, O’Brien and CDS Inclusive Research Network, 2017, Vaughn *et al.,* 2019 [↑](#footnote-ref-165)
165. Oliver *et al.,* 2020, p. 46 [↑](#footnote-ref-166)
166. Anderson *et al.,* 2019, Disability Wales, 2019, Drill Report, 2019, Nicolaidis *et al.,* 2019, Salmon *et al.,* 2018, Sangill *et al.,* 2019, Williams, Ponting and Ford, 2015 [↑](#footnote-ref-167)
167. Anderson *et al.,* 2019, Staley 2009 cited in Ashcroft *et al.,* 2016, King *et al.,* 2019, Nind *et al.,* 2017, Smith-Merry, no date, Williams, Ponting and Ford, 2015 [↑](#footnote-ref-168)
168. Frankena *et al.,* 2019a [↑](#footnote-ref-169)
169. O’Brien, Fossey and Palmer, 2021, Nind *et al.,* 2017 [↑](#footnote-ref-170)
170. Drill Report, 2019, Green *et al.,* 2016, Schwartz *et al.,* 2020, Stack and McDonald, 2018, Tilly *et al.,* 2015 [↑](#footnote-ref-171)
171. Gratton *et al.,* 2020, p. 110 [↑](#footnote-ref-172)
172. Tilly *et al.,* 2015, Werner-Seidler *et al.,* 2019 [↑](#footnote-ref-173)
173. Bigby, Frawley and Ramcharan, 2014a, McCartan *et al.,* 2019 [↑](#footnote-ref-174)
174. Thomas in Stack and McDonald, 2018, p. 85 [↑](#footnote-ref-175)
175. Frankena *et al.,* 2015 [↑](#footnote-ref-176)
176. Woelders *et al.,* 2015 [↑](#footnote-ref-177)
177. Armstrong *et al.,* 2019, Ashcroft *et al.,* 2016, Drill Report, 2019, King *et al.,* 2019, Moule *et al.,* 2016, Sangill *et al.,* 2019, Smith-Merry, no date [↑](#footnote-ref-178)
178. Staley, 2009 in Ashcroft *et al.,* 2016, Frankena *et al.,* 2015, Hollinrake, Spencer and Dix, 2019, Schwartz, *et al.,* 2020 [↑](#footnote-ref-179)
179. DRILL report, 2018, Green *et al.,* 2016, Hamidi *et al.,* 2015, Schwartz *et al.,* 2020 [↑](#footnote-ref-180)
180. King *et al.,* 2019 [↑](#footnote-ref-181)
181. Drill Report, 2018, p. 70 [↑](#footnote-ref-182)
182. Frankena *et al.,* 2019c, IRN 2019, McCartan *et al.,* 2019 [↑](#footnote-ref-183)
183. Riches, O’Brien and CDS Inclusive Research Network, 2020, Smith-Merry, 2017 [↑](#footnote-ref-184)
184. Disability Wales, 2019, Gratton *et al.,* 2020 [↑](#footnote-ref-185)
185. Lightfoot and Sloper 2003 cited in Bailey *et al.,* 2015, Conder *et al.,* 2011 cited in Di Lorito *et al.,* 2018, Sangill *et al.,* 2019, Schwartz *et al.,* 2020, [↑](#footnote-ref-186)
186. Di Lorito *et al.,* 2018, Disability Wales, 2019, Drill Report, 2019, Hollinrake, Spencer and Dix, 2019, Moule *et al.,* 2016, Sangill *et al.,* 2019, Schwartz *et al.,* 2020, Stack and McDonald, 2018 [↑](#footnote-ref-187)
187. Ashcroft *et al.,* 2016, p. 30 [↑](#footnote-ref-188)
188. Tilly *et al.,* 2015, Williams, Ponting and Ford, 2015 [↑](#footnote-ref-189)
189. Paul *et al.,* 2017, Sangill *et al.,* 2019, Werner-Seidler *et al.,* 2019 [↑](#footnote-ref-190)
190. Paul *et al.,* 2017 [↑](#footnote-ref-191)
191. Rojas Pernia and Haya Salmón, 2020, Salmon *et al.,* 2018 [↑](#footnote-ref-192)
192. Campus Engage, 2017 [↑](#footnote-ref-193)
193. Anderson *et al.,* 2019, Barod Community Interest Company, 2019, Breault *et al.,* 2018, Strnadová *et al.,* 2014 cited in Di Lorito *et al.,* 2018, Gillard *et al.,* 2012 cited in Paul *et al.,* 2017, Ross *et al.,* 2005 cited in Paul *et al.,* 2017, Woelders *et al.,* 2015 [↑](#footnote-ref-194)
194. Paul *et al.,* 2017 [↑](#footnote-ref-195)
195. Paul *et al.,* 2017, Woelders *et al.,* 2015 [↑](#footnote-ref-196)
196. Barry, 2016 [↑](#footnote-ref-197)
197. Faulkner *et al.,* 2019 [↑](#footnote-ref-198)
198. Barry *et al.,* 2016, Salmon *et al.,* 2018, Pain *et al.,* 2014 cited in Vaughn *et al.,* 2019, Williams *et al.,* 2012 cited in Vaughn *et al.,* 2019 [↑](#footnote-ref-199)
199. Wadman *et al.,* 2019 [↑](#footnote-ref-200)
200. Rojas Pernia and Haya Salmón, 2020 [↑](#footnote-ref-201)
201. Campus Engage, 2017, Dorozenko *et al.,* 2016 cited in Smith-Merry, 2017, Stanley *et al.,* 2019 [↑](#footnote-ref-202)
202. Kramer *et al.,* 2011 cited in Di Lorito *et al.,* 2018, Disability Wales, 2019, Nind, 2017, Smith-Merry, 2017, Stanley *et al.,* 2019, Vaughn *et al.,* 2019, Woelders *et al.,* 2015 [↑](#footnote-ref-203)
203. Duerell, 2016 [↑](#footnote-ref-204)
204. Spencer Gonzalez *et al.,* 2020 [↑](#footnote-ref-205)
205. Paul *et al.,* 2017, Strnadová *et al.,* 2016 [↑](#footnote-ref-206)
206. e.g. Hancock *et al.,* 2012 cited in Smith-Merry, 2017, Kiernan *et al.,* 2009 in Tuffrey-Wijne *et al.,* 2010 cited in Smith-Merry *et al.,* 2017 [↑](#footnote-ref-207)
207. Anderson *et al.,* 2018, Barod Community Interest Company, 2019, Hollinrake, Spencer and Dix, 2019, Smith-Merry, 2017, Tilki, Palfreman and Chowdhury, 2019 [↑](#footnote-ref-208)
208. Hollinrake, Spencer and Dix, 2019 [↑](#footnote-ref-209)
209. Bradbury-Jones and Taylor, 2015 cited in Burke *et al.,* 2019 [↑](#footnote-ref-210)
210. Anderson *et al.,* 2018, Swarbrick *et al.,* 2019 [↑](#footnote-ref-211)
211. Dewa *et al.,* 2020 [↑](#footnote-ref-212)
212. Burke *et al.,* 2019, Conder *et al.,* 2011 cited in Smith-Merry, 2017 [↑](#footnote-ref-213)
213. Aldersley *et al.,* 2018, Chick *et al.,* 2018 [↑](#footnote-ref-214)
214. Anderson *et al.,* 2018 [↑](#footnote-ref-215)
215. Anderson *et al.,* 2018 [↑](#footnote-ref-216)
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217. Hollinrake, Spencer and Dix, 2019 [↑](#footnote-ref-218)
218. Smith-Merry, 2017 [↑](#footnote-ref-219)
219. Frankena *et al.,* 2019a [↑](#footnote-ref-220)
220. Armstrong *et al.,* 2019, Fletcher Watson *et al.,* 2018, Gove *et al.,* 2017, Gove *et al.,* 2018, O’Hara *et al.,* 2017, Vaughn *et al.,* 2019, Wolsey *et al.,* 2017 [↑](#footnote-ref-221)
221. Wolsey *et al.,* 2017 [↑](#footnote-ref-222)
222. Ní Shé *et al.,* 2020, Stack and McDonald, 2018 [↑](#footnote-ref-223)
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226. Chown *et al.,* 2017, Dewa *et al.,* 2020, Bertilsdotter Rosqvist *et al.,* 2019, [↑](#footnote-ref-227)
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232. Frankena *et al.,* 2019a, p. 6 [↑](#footnote-ref-233)
233. Troya *et al.,* 2019 [↑](#footnote-ref-234)
234. Banks *et al.,* 2013 cited in Mann and Hung, 2018 [↑](#footnote-ref-235)
235. Burke *et al.,* 2019 [↑](#footnote-ref-236)
236. Street and Herts 2005 cited in Bailey *et al.,* 2015, Lwembe *et al.,* 2017 cited in O’Brien, Fossey and Palmer, 2021, Swarbrick *et al.,* 2019 [↑](#footnote-ref-237)
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238. Strdanová *et al.,* 2016 [↑](#footnote-ref-239)
239. Cooper, Gillmore and Hogg, 2016 [↑](#footnote-ref-240)
240. Brady *et al.,* 2019 [↑](#footnote-ref-241)
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243. Northway, Howarth and Evans, 2015, Lincoln *et al.,* 2015 cited in Smith-Merry, 2017, Wadman *et al.,* 2019 [↑](#footnote-ref-244)
244. St. John *et al.,* 2018, Strnadová *et al.,* 2016 [↑](#footnote-ref-245)
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252. Mawn *et al.,* 2015, Ní Shé *et al.,* 2020, Paul *et al.,* 2017, Rojas Pernia and Haya Salmón, 2021 [↑](#footnote-ref-253)
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256. Nicolaidis *et al.,* 2019 [↑](#footnote-ref-257)
257. IRN, 2019, Nind 2017 [↑](#footnote-ref-258)
258. Anderson *et al.,* 2018, O’Hara *et al.,* 2017 [↑](#footnote-ref-259)
259. IRN, 2019 [↑](#footnote-ref-260)
260. IRN, 2019 [↑](#footnote-ref-261)
261. IRN, 2019 [↑](#footnote-ref-262)
262. Gove *et al.,* 2017 [↑](#footnote-ref-263)
263. Kirby, 2004 cited in Bailey *et al.,* 2015, Shaw *et al.,* 2011 cited in Bailey *et al.,* 2015 [↑](#footnote-ref-264)
264. Northway, Howarth and Evans, 2015 [↑](#footnote-ref-265)
265. Campus Engage, an Irish initiative dedicated to supporting civic and community engagement in all aspects of higher education institutions, made a number of recommendations for funders that can be found in Appendix B. [↑](#footnote-ref-266)
266. Campus Engage, 2017 [↑](#footnote-ref-267)
267. Ní Shé *et al.,* 2019 [↑](#footnote-ref-268)
268. Dewa *et al.,* 2020 [↑](#footnote-ref-269)
269. Campus Engage, 2017, Ní Shé *et al.,* 2019 [↑](#footnote-ref-270)
270. Ní Shé *et al.,* 2019 [↑](#footnote-ref-271)
271. Disability Wales, 2019 [↑](#footnote-ref-272)
272. Gove *et al.,* 2018, Ní Shé *et al.,* 2019, [↑](#footnote-ref-273)
273. Plumb *et al.,* 2004 cited in Northway, Howarth and Evans, 2015 [↑](#footnote-ref-274)
274. Ashcroft *et al.,* 2016, Dewa *et al.,* 2020, IRN, 2019, Morbey *et al.,* 2019, Nind *et al.,* 2017, O’Hara *et al.,* 2017, Van Schelven *et al.,* 2020a, Vega Cordova *et al.,* 2020, [↑](#footnote-ref-275)
275. Gove *et al.,* 2017, Gratton *et al.,* 2020, Morbey *et al.,* 2019, Townsend *et al.,* 2000 cited in Sangill *et al.,* 2019 [↑](#footnote-ref-276)
276. Veinot *et al.,* 2006 cited in Bailey *et al.,* 2015, Barod Community Interest Company, 2019, Burke *et al.,* 2019, Rojas Pernia and Haya Salmón, 2020 [↑](#footnote-ref-277)
277. Frankena *et al.,* 2019a [↑](#footnote-ref-278)
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280. Frankena *et al.,* 2019a [↑](#footnote-ref-281)
281. Di Lorito *et al.,* 2017, Haya Salmón and Rojas Pernia, 2021 [↑](#footnote-ref-282)
282. Hollinrake, Spencer and Dix, 2019 [↑](#footnote-ref-283)
283. Schwartz and Durkin, 2020 [↑](#footnote-ref-284)
284. Drill Report, 2018 [↑](#footnote-ref-285)
285. St John *et al.,* 2018 [↑](#footnote-ref-286)
286. Mogensen, 2010 cited in Bailey *et al.,* 2015, Morris, 2003 cited in Bailey *et al.,* 2015 [↑](#footnote-ref-287)
287. St John *et al.,* 2018, Waite, Poland and Charlesworth, 2019 [↑](#footnote-ref-288)
288. Once commenced, the Assisted Decision Making (Capacity) Act (ADM) 2015 will abolish the current system of wardship (legal guardianship) for adults in Ireland. Instead, people who need assistance or support to make particular decisions may appoint, or be appointed, a decision-making support. A tiered system of support will be introduced, ranging from the lowest level of support, a Decision-Making Assistant, who assists a decision-maker, to a middle level of support, a Co-Decision-Maker, who makes decision jointly with the decision-maker, to a high level of support, a Decision-Making Representative, who is appointed by the Court and given authority to make specific decisions on behalf of a person. At all stages of this new support system, the will and preferences of the relevant person must be at the centre of all decisions. Decisions will no longer be made in ‘the best interests’ of the relevant person, and they must be empowered and supported to be involved in all decisions relevant to their lives. The Assisted Decision-Making (Capacity) Act 2015 is currently awaiting the enactment of amending legislation, and should be commenced in Q4 of 2022. [↑](#footnote-ref-289)
289. Nicolaidis *et al.,* 2019 [↑](#footnote-ref-290)
290. Powers *et al.,* 2017 [↑](#footnote-ref-291)
291. Anderson *et al.,* 2018, Dewa *et al.,* 2020, Disability Wales, 2019, Frankena *et al.,* 2019a, King *et al.,* 2019, Kramer *et al.,* 2018 [↑](#footnote-ref-292)
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293. Butler *et al.,* 2020, Dewa *et al.,* 2020, Rojas Pernia and Haya Salmón 2020 [↑](#footnote-ref-294)
294. St John *et al.,* 2018, studies considered by Frankena *et al.,* 2019c [↑](#footnote-ref-295)
295. Studies considered by Frankena *et al.,* 2019c, Vega Cordova *et al.,* 2020 [↑](#footnote-ref-296)
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298. Herron, Priest and Read, 2015 [↑](#footnote-ref-299)
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300. Burke *et al.,* 2019, Fletcher-Watson *et al.,* 2018 [↑](#footnote-ref-301)
301. Paul *et al.,* 2017 [↑](#footnote-ref-302)
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303. Frankena *et al.,* 2019a, Joss *et al.,* 2016, Stevenson and Taylor, 2019 [↑](#footnote-ref-304)
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310. Nind, 2017 [↑](#footnote-ref-311)
311. Di Lorito *et al.,* 2018, Embregts *et al.,* 2018, Fletcher Watson *et al.,* 2018, Frankena *et al.,* 2019a, Gove *et al.,* 2018, Ní Shé *et al.,* 2019, Nicolaidis *et al.,* 2019, Roberts *et al.,* 2020, Smith-Merry, 2017, Smith-Merry, no date, Roberts *et al.,* 2020 [↑](#footnote-ref-312)
312. Williams *et al.,* 2020. P. 11 [↑](#footnote-ref-313)
313. Pellicano *et al.,* 2019 [↑](#footnote-ref-314)
314. Smith-Merry, no date [↑](#footnote-ref-315)
315. Williams, 1999 cited in Di Lorito *et al.,* 2018 [↑](#footnote-ref-316)
316. Fletcher Watson *et al.,* 2018, p. 7 [↑](#footnote-ref-317)
317. Anderson *et al.,* 2019, Lightfoot and Sloper, 2003 cited in Bailey *et al.,* 2015, VIPER, 2013 cited in Bailey *et al.,* 2015, Litherland *et al.,* 2018 cited in Burton, Ogden, and Cooper, 2019, Parveen *et al.,* 2018 cited in Burton, Ogden, and Cooper, 2019, Rapaport *et al.,* 2018 cited in Burton, Ogden, and Cooper, 2019, Butler *et al.,* 2020, Callus, 2019, Dewa *et al.,* 2020, Evans *et al.,* 2019, Giebel *et al.,* 2019, Gove *et al.,* 2017, Jennings *et al.,* 2018, Mathews, Marshall and Wilkinson, 2020, Mathias *et al.,* 2019, Morbey *et al.,* 2019, Munro *et al.,* 2018, Northway, Howarth and Evans, 2015, Schwartz and Durkin, 2020, Varkonyi-Sep, Cross and Howarth, 2017, Vlot-van Anrooij *et al.,* 2018, Williams *et al.,* 2020, Young, Ferguson-Coleman and Keady, 2018 [↑](#footnote-ref-318)
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319. Anderson *et al.,* 2019, Munro *et al.,* 2018 [↑](#footnote-ref-320)
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321. Evans *et al.,* 2019, Faulkner *et al.,* 2019 [↑](#footnote-ref-322)
322. Faulkner *et al.,* 2019, Herron, Priest and Read, 2015 [↑](#footnote-ref-323)
323. See <https://www.invo.org.uk/wp-content/uploads/2016/05/INVOLVE-internal-payment-policy-2016-final-1.pdf> and <https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392> [↑](#footnote-ref-324)
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342. Disability Wales, 2019, Drill Report, 2018 [↑](#footnote-ref-343)
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364. Ashcroft *et al.,* 2016, Gove *et al.,* 2018, Moule *et al.,* 2016 [↑](#footnote-ref-365)
365. Mann and Hung, 2018, p. 18 [↑](#footnote-ref-366)
366. Drill Report, 2018 [↑](#footnote-ref-367)
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368. Brady *et al.,* 2019, Dewa *et al.,* 2020, Fitzgerald and Walsh, 2016, Hollinrake, Spencer and Dix, 2019, Bertilsdotter Rosqvist *et al.,* 2019 [↑](#footnote-ref-369)
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426. Waite, Poland and Charlesworth, 2019, p. 767 [↑](#footnote-ref-427)
427. Lightfoot and Sloper, 2003 cited in Bailey *et al.,* 2016, VIPER, 2013 cited in Bailey *et al.,* 2016, Schwartz *et al.,* 2020, [↑](#footnote-ref-428)
428. Gregory *et al.,* 2018 cited in Burton, Ogden, and Cooper, 2019, Litherland *et al.* 2018 cited in Burton, Ogden, and Cooper, 2019, Rapaport *et al.,* 2018, cited in Burton, Ogden, and Cooper, 2019, Mann and Hung, 2018, Mayrhofer *et al.* 2018, Morbey *et al.,* 2019, Mann and Hung, 2018, Mayrhofer *et al.* 2018, Morbey *et al.,* 2019, Roberts *et al.,* 2020 [↑](#footnote-ref-429)
429. Breault *et al.,* 2018b, ImaYDiT, 2018 [↑](#footnote-ref-430)
430. Stanley *et al.,* 2019, p. 1664 [↑](#footnote-ref-431)
431. Brosnan *et al.,* 2016, Stack and McDonald 2018 [↑](#footnote-ref-432)
432. Ashcroft *et al.,* 2016, Charlesworth, 2018, Vaughn *et al.,* 2019 [↑](#footnote-ref-433)
433. Campus Engage, 2017, Vaughn *et al.,* 2019, [↑](#footnote-ref-434)
434. R1 in Waite, Poland and Charlesworth, 2019, p. 763 [↑](#footnote-ref-435)
435. Bailey *et al.,* 2015, Bigby *et al.,* 2014a cited in Frankena *et al.,* 2015, Bigby *et al.,* 2014b cited in Frankena *et al.,* 2015 [↑](#footnote-ref-436)
436. Frankena *et al.,* 2015, Puyalto *et al.,* 2016, Stanley *et al.,* 2019, Werner-Seidler *et al.,* 2019, Woelders *et al.,* 2015 [↑](#footnote-ref-437)
437. Drill Report, 2018, Puyalto *et al.,* 2016, Stanley *et al.,* 2019 [↑](#footnote-ref-438)
438. Smith-Merry, 2017 [↑](#footnote-ref-439)
439. Ashcroft *et al.,* 2016, IRN, 2019, Nicolaidis *et al.,* 2019, Woelder *et al.,* 2015 [↑](#footnote-ref-440)
440. Armstrong *et al.,* 2019, Ashcroft *et al.,* 2016, Frankena *et al.,* 2015, King *et al.,* 2019 [↑](#footnote-ref-441)
441. Moule *et al.,* 2016 [↑](#footnote-ref-442)
442. Anderson *et al.,* 2018, Anderson *et al.,* 2019 [↑](#footnote-ref-443)
443. Nind *et al.,* 2017 [↑](#footnote-ref-444)
444. Anderson *et al.,* 2019, Barod Community Interest Company, 2019, Burton, Ogden, and Cooper, 2019, Schwartz and Durkin, 2020 [↑](#footnote-ref-445)
445. Troya *et al.,* 2019 [↑](#footnote-ref-446)
446. Frankena *et al.,* 2015a, Swarbrick *et al.,* 2019 [↑](#footnote-ref-447)
447. Waite, Poland and Charlesworth, 2019 [↑](#footnote-ref-448)
448. Nicolaidis *et al.,* 2019, Rojas Pernia and Haya Salmón, 2020, Smith-Merry, 2017 [↑](#footnote-ref-449)
449. Smith-Merry, no date [↑](#footnote-ref-450)
450. Talking Mats is an evidence-based communication tool developed by speech and language therapists which use visuals to enable communication. See <https://www.talkingmats.com/> [↑](#footnote-ref-451)
451. Frankena *et al.,* 2015 [↑](#footnote-ref-452)
452. 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). [↑](#footnote-ref-453)
453. Frankena *et al.,* 2019a [↑](#footnote-ref-454)
454. Callus, 2019, Frankena *et al.,* 2019c [↑](#footnote-ref-455)
455. Chown *et al.,* 2017 [↑](#footnote-ref-456)
456. Chown *et al.,* 2017 [↑](#footnote-ref-457)
457. Frankena *et al.,* 2019a [↑](#footnote-ref-458)
458. Nind *et al.,* 2017 [↑](#footnote-ref-459)
459. Williams *et al.,* 2020, p. 17 [↑](#footnote-ref-460)
460. e.g. Durell *et al.,* 2016, Joss *et al.,* 2016, Kramer *et al.,* 2018, Vaughn *et al.,* 2019 [↑](#footnote-ref-461)
461. Disability Wales, 2019, Vaughn *et al.,* 2019 [↑](#footnote-ref-462)
462. McConnell *et al.,* 2019 [↑](#footnote-ref-463)
463. Dewa *et al.,* 2020 [↑](#footnote-ref-464)
464. Rapaport *et al.,* 2018 cited in Burton, Ogden, and Cooper, 2019, Nicolaidis *et al.,* 2019, Partners2 Writing Collective, 2020, Dybwad and Bersani, 1996, cited in Powers *et al.,* 2017, Powers *et al.,* 2002 cited in Powers *et al.,* 2017, Townsend *et al.,* 2000 cited in Sangill *et al.,* 2019, Smith-Merry, 2017, Stanley *et al.,* 2019, Van Schelven *et al.,* 2020a, Walmsley and Johnson, 2003 cited in Walmsley, Strnadová and Johnson, 2018 [↑](#footnote-ref-465)
465. e.g. Drill report, 2018, Durell, 2016, Ellis, 2018 [↑](#footnote-ref-466)
466. Brady *et al.,* 2019, Di Lorito *et al.,* 2017, Haya Salmón and Rojas Pernia, 2021, Nicolaidis *et al.,* 2019, Townsend *et al.,* 2000 cited in Sangill *et al.,* 2019 [↑](#footnote-ref-467)
467. Frankena *et al.,* 2015, Green *et al.,* 2016, Nicolaidis *et al.,* 2019, Nind *et al.,* 2017, Partners2 Writing Collective, 2020, Williams, Ponting and Ford, 2015, Wolesley *et al.,* 2017 [↑](#footnote-ref-468)
468. Brosnan *et al.,* 2016 [↑](#footnote-ref-469)
469. Strnadová *et al.,* 2014 cited in Di Lorito *et al.,* 2018, Bailey *et al.,* 2015 [↑](#footnote-ref-470)
470. Strnadová *et al.,* 2014 cited in Di Lorito *et al.,* 2018 [↑](#footnote-ref-471)
471. Williams *et al.,* 2005 in Williams, Ponting and Ford, 2015 [↑](#footnote-ref-472)
472. Ellis *et al.,* 2018, Frankena *et al.,* 2015, Smith-Merry, 2017 [↑](#footnote-ref-473)
473. Bailey *et al.,* 2015 [↑](#footnote-ref-474)
474. 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). [↑](#footnote-ref-475)
475. Nicolaidis *et al.,* 2019 [↑](#footnote-ref-476)
476. The Delphi process involves structured and repeated consultation and feedback with a group in order to reach consensus on a subject [↑](#footnote-ref-477)
477. The Nominal Group Technique is a form of brainstorming in a small group, where ideas are shared and voted on or prioritised by the group [↑](#footnote-ref-478)
478. Charlesworth, 2018 [↑](#footnote-ref-479)
479. Case 3 in Frankena *et al.,* 2019c [↑](#footnote-ref-480)
480. Brady *et al.,* 2019, Fletcher Watson *et al.,* 2018, Green *et al.,* 2016, Ní Shé *et al.,* 2020, Woelders *et al.,* 2015 [↑](#footnote-ref-481)
481. Armstrong *et al.,* 2019, Sloper and Lightfoot 2003 cited in Bailey *et al.,* 2015, Frankena *et al.,* 2015, O’Hara *et al.,* 2017, Tilki, Palfreman and Chowdhury, 2019, Walsh *et al.,* 2018, Woelders *et al.,* 2015 [↑](#footnote-ref-482)
482. Sloper and Lightfoot 2003 cited in Bailey *et al.,* 2015, O’Hara *et al.,* 2017, Tilki, Palfreman and Chowdhury, 2019, Woelders *et al.,* 2015 [↑](#footnote-ref-483)
483. Woelders *et al.,* 2015 [↑](#footnote-ref-484)
484. Walsh *et al.,* 2018 [↑](#footnote-ref-485)
485. Brady *et al.,* 2018, O’Hara *et al.,* 2017, Walsh *et al.,* 2018, Woelders *et al.,* 2015 [↑](#footnote-ref-486)
486. Litherland *et al.,* 2018 cited in Burton, Ogden, and Cooper, 2019, Rapaport *et al.,* 2018 cited in Burton, Ogden, and Cooper, 2019 [↑](#footnote-ref-487)
487. Breault *et al.,* 2018b [↑](#footnote-ref-488)
488. Frankena *et al.,* 2019a Haya Salmón and Rojas Pernia, 2021, Schwartz and Durkin, 2020 [↑](#footnote-ref-489)
489. Evans *et al.,* 2019, Frankena *et al.,* 2019a, IRN, 2019, Salmon *et al.,* 2018 [↑](#footnote-ref-490)
490. Drill Report 2018 [↑](#footnote-ref-491)
491. O’Brien *et al.,* 2014 cited in Di Lorito *et al.,* 2018 [↑](#footnote-ref-492)
492. This approach uses images to facilitate the exploration of real situations or abstract concepts. [↑](#footnote-ref-493)
493. Breault *et al.,* 2019b, Evans *et al.,* 2019, Varkonyi-Sep, Cross and Howarth, 2017 [↑](#footnote-ref-494)
494. Troya *et al.,* 2019, Rich *et al.,* 2014 cited in Van Schelven *et al.* 2020a, Sloper and Lightfoot, 2003 cited in Van Schelven *et al.* 2020a [↑](#footnote-ref-495)
495. Frankena *et al.,* 2019a [↑](#footnote-ref-496)
496. Callus, 2019 [↑](#footnote-ref-497)
497. Anderson *et al.,* 2019, Bailey *et al.,* 2015, Callus, 2019, Frankena *et al.,* 2015a, Stack and McDonald, 2018, Strnadová *et al.,* 2016, Vaughn *et al.,* 2019 [↑](#footnote-ref-498)
498. Burton, Ogden, and Cooper, 2019, Frankena *et al.,* 2015, Green *et al.,* 2016, Ní Shé *et al.,* 2020, Vega Cordova *et al.,* 2020 [↑](#footnote-ref-499)
499. Tanner, 2012 in Di Lorito *et al.,* 2017 [↑](#footnote-ref-500)
500. Frankena *et al.,* 2019c, Nicolaidis *et al.,* 2019 [↑](#footnote-ref-501)
501. Nicolaidis *et al.,* 2019 [↑](#footnote-ref-502)
502. Talking Mats is an evidence-based communication tool developed by speech and language therapists which use visuals to enable communication. See <https://www.talkingmats.com/> [↑](#footnote-ref-503)
503. EverNote is an app used for note taking and organisation – notes can be made in various ways – using, for example, text, pictures or audio. [↑](#footnote-ref-504)
504. Beighton *et al.,* 2019, Burton, Ogden, and Cooper, 2019, Chick, 2018, Dewa *et al.,* 2020, Frankena *et al.,* 2019a, Haya Salmón and Rojas Pernia, 2021, Puyalto *et al.,* 2016, Vasquez *et al.,* 2019, Vega Cordova *et al.,* 2020 [↑](#footnote-ref-505)
505. Barod Community Interest Company, 2019, Beighton *et al.,* 2019 [↑](#footnote-ref-506)
506. Green *et al.,* 2016 [↑](#footnote-ref-507)
507. Durrell 2016, Smith-Merry, 2017 [↑](#footnote-ref-508)
508. Smith-Merry, 2017 [↑](#footnote-ref-509)
509. National Development Team for Inclusion, 2019 [↑](#footnote-ref-510)
510. Giebel *et al.,* 2019 [↑](#footnote-ref-511)
511. Clarke *et al.,* 2018 cited in Burton, Ogden, and Cooper, 2019, Litherland *et al.,* 2018 cited in Burton, Ogden, and Cooper, 2019 [↑](#footnote-ref-512)
512. Breault *et al.,* 2018b [↑](#footnote-ref-513)
513. Clarke *et al.,* 2018 cited in Burton, Ogden, and Cooper, 2019, Litherland *et al.,* 2018 cited in Burton, Ogden, and Cooper, 2019 [↑](#footnote-ref-514)
514. Anderson *et al.,* 2019, Gove *et al.,* 2017, Mathews, Marshall and Wilkinson, 2020 [↑](#footnote-ref-515)
515. Gove *et al.,* 2018 [↑](#footnote-ref-516)
516. Mawn *et al.,* 2015 [↑](#footnote-ref-517)
517. Embregts *et al.,* 2018, Ní Shé *et al.,* 2019, Ní Shé *et al.,* 2020 [↑](#footnote-ref-518)
518. Chown *et al.,* 2017, Embregts *et al.,* 2018, Partners2 Writing Collective, 2020, Ní Shé *et al.,* 2020, [↑](#footnote-ref-519)
519. Fletcher Watson *et al.,* 2018, Gove *et al.,* 2018 [↑](#footnote-ref-520)
520. Nicolaidis *et al.,* 2019 [↑](#footnote-ref-521)
521. Fletcher Watson *et al.,* 2018 [↑](#footnote-ref-522)
522. Mann and Hung, 2018, Waite, Poland and Charlesworth, 2019 [↑](#footnote-ref-523)
523. Anderson *et al.,* 2019, Mawn *et al.,* 2015 [↑](#footnote-ref-524)
524. Frankena *et al.,* 2015 [↑](#footnote-ref-525)
525. Grayson *et al.,* 2013 cited in Di Lorito *et al.,* 2018, Disability Wales, 2019, Embregts *et al.,* 2018, Frankena *et al.,* 2015, Frankena *et al.,* 2019c, Schwartz and Durkin 2020 [↑](#footnote-ref-526)
526. St. John *et al.,* 2018 [↑](#footnote-ref-527)
527. St. John *et al.,* 2018 [↑](#footnote-ref-528)
528. Schwartz and Durkin, 2020 [↑](#footnote-ref-529)
529. Aldersey *et al.,* 2018, Breault *et al.,* 2018a, Hellzen, Haugenes and Østby, 2018, Hollinrake, Spencer and Dix, 2019, [↑](#footnote-ref-530)
530. Street and Herts, 2005 cited in Bailey *et al.,* 2015, VIPER, 2013 cited in Bailey *et al.,* 2015, Frankena *et al.* 2015, Troya *et al.,* 2019 [↑](#footnote-ref-531)
531. Barod Community Interest Company, 2019 [↑](#footnote-ref-532)
532. DRILL Report, 2018 [↑](#footnote-ref-533)
533. Frankena *et al.,* 2019a, Nicolaidis *et al.,* 2019 [↑](#footnote-ref-534)
534. Beighton *et al.,* 2019, Troya *et al.,* 2019) [↑](#footnote-ref-535)
535. Gove *et al.,* 2017, Morbey *et al.,* 2019, Ní Shé *et al.,* 2019, , Rojas Pernia and Haya Salmón, 2020 [↑](#footnote-ref-536)
536. Troya *et al.,* 2019 [↑](#footnote-ref-537)
537. Nicolaidis *et al.,* 2019 [↑](#footnote-ref-538)
538. Bollard, 2017, Gove *et al.,* 2017, Smith-Merry, 2017 [↑](#footnote-ref-539)
539. Anderson *et al.,* 2019, Armstrong *et al.,* 2019, Smith-Merry, 2017, Williams, Ponting and Ford, 2015 [↑](#footnote-ref-540)
540. Rapaport *et al.,* 2018 cited in Burton, Ogden, and Cooper, 2019 [↑](#footnote-ref-541)
541. Roche *et al.,* 2020 [↑](#footnote-ref-542)
542. A portable, pocket-sized device that scans written text line by line and reads it out loud. [↑](#footnote-ref-543)
543. Drill Report, 2018 [↑](#footnote-ref-544)
544. Vaughn *et al.,* 2019 [↑](#footnote-ref-545)
545. MacSweeney, Bowman, and Kelly, 2019, Troya *et al.,* 2019 [↑](#footnote-ref-546)
546. Barod Community Interest Company, 2019, DRILL report, 2018 [↑](#footnote-ref-547)
547. Giebel *et al.,* 2019, Gove *et al.,* 2017, Gove *et al.,* 2018, Nicolaidis *et al.,* 2019, Van Schelven *et al.,* 2020b, Vaughn *et al.,* 2019 [↑](#footnote-ref-548)
548. Ashcroft *et al.,* 2016, Drill Report, 2018, King *et al.,* 2019, Stanley *et al.,* 2019 [↑](#footnote-ref-549)
549. Di Lorito *et al.,* 2017, p. 11 [↑](#footnote-ref-550)
550. Anderson *et al.,* 2018, Beresford 2012 cited in Bailey *et al.,* 2015, Scottish Dementia Working Group 2014 cited in Di Lorito *et al.,* 2017, Disability Wales *et al.,* 2019, Hollinrake, Spencer and Dix, 2019, Mann and Hung, 2018 [↑](#footnote-ref-551)
551. Brady *et al.,* 2019 [↑](#footnote-ref-552)
552. Wolder *et al.,* 2015 [↑](#footnote-ref-553)
553. Bailey *et al.,* 2015, Scottish Dementia Working Group 2014 cited in Di Lorito *et al.,* 2017, Vaughan *et al.,* 2019 [↑](#footnote-ref-554)
554. Smith-Merry, 2017, Walsh *et al.,* 2018 [↑](#footnote-ref-555)
555. Partners2 Writing Collective, 2020 [↑](#footnote-ref-556)
556. Aldersey *et al.,* 2018, Anderson *et al.,* 2018, Brady *et al.,* 2019, Byrne *et al.,* 2019, Cameron *et al.,* 2019, Disability Wales, 2019, Hersch *et al.,* 2020, Riches, O’Brien and CDS Inclusive Research Network, 2017, Rojas Pernia and Haya Salmón, 2020 [↑](#footnote-ref-557)
557. Barry, 2016, Burke *et al.,* 2019, Campus Engage, 2017, Ní Shé *et al.,* 2019, Bertilsdotter Rosqvist *et al.,* 2019 [↑](#footnote-ref-558)
558. Chown *et al.,* 2017, Durell, 2016, Riches, O’Brien and CDS Inclusive Research Network, 2017, Riches, O’Brien and CDS Inclusive Research Network, 2020, Bertilsdotter Rosqvist *et al.,* 2019 [↑](#footnote-ref-559)
559. Di Lorito *et al.,* 2018, MacSweeney, Bowman, and Kelly, 2019, McConnell *et al.,* 2019, Parveen *et al.,* 2018, Bertilsdotter Rosqvist *et al.,* 2019 [↑](#footnote-ref-560)
560. Smith-Merry, 2017, Smith-Merry, no date, Parveen *et al.,* 2018 [↑](#footnote-ref-561)
561. See Swarbrick *et al.,* 2019 for the COINED Model which outlines how people living with dementia would like to be involved as co-researchers in research projects. [↑](#footnote-ref-562)
562. Herron, Priest and Read, 2015, Riches, O’Brien and CDS Inclusive Research Network, 2020 [↑](#footnote-ref-563)
563. Peuravarra *et al.,* 2015, p. 280 [↑](#footnote-ref-564)
564. Di Lorito *et al.,* 2018, Gove *et al.,* 2017, Gove *et al.,* 2018, Mann and Hung, 2018, Miah *et al.,* 2019, Northway, Howarth and Evans, 2015, Riches, O’Brien and CDS Inclusive Research Network, 2020, Roberts *et al.,* 2020 Van Schelven *et al.,* 2020b [↑](#footnote-ref-565)
565. Durell, 2016, Riches, O’Brien and CDS Inclusive Research Network, 2020 [↑](#footnote-ref-566)
566. Ní Shé *et al.,* 2020 [↑](#footnote-ref-567)
567. Allsop *et al.,* 2010 in Bailey *et al.,* 2015, Sloper, 2004 cited in Bailey *et al.,* 2015 [↑](#footnote-ref-568)
568. Barry, 2016, Durell *et al.,* 2016 [↑](#footnote-ref-569)
569. Beighton *et al.,* 2019 [↑](#footnote-ref-570)
570. Burke *et al.,* 2019, Perry and Felce, 2004 cited in Di Lorito *et al.,* 2018, Woelders *et al.,* 2015 [↑](#footnote-ref-571)
571. Oksnebjerg *et al.,* 2018 cited in Burton, Ogden, and Cooper, 2019 [↑](#footnote-ref-572)
572. Suijkerbuijk *et al.,* 2019 [↑](#footnote-ref-573)
573. 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 [↑](#footnote-ref-574)
574. Aldersey *et al.,* 2018, Bailey *et al.,* 2015, Hartley *et al.,* 2017, Hellzen, Haugenes and Østby, 2018, ImaYDiT, 2018, Puyalto *et al.,* 2016, Salmon *et al.,* 2018, Troya *et al.,* 2019 [↑](#footnote-ref-575)
575. Barod Community Interest Company, 2019, Burton, Ogden, and Cooper, 2019, Dewa *et al.,* 2020, Hartley *et al.,* 2017, Haya Salmón and Rojas Pernia 2021, ImaYDiT, 2018, IRN, 2019, Inclusion Scotland, 2020, O’Hara *et al.,* 2017, Puyalto *et al.,* 2016, Tilly *et al.,* 2015, Varkonyi-Sep, Cross and Howarth, 2017, Vega Cordova *et al.,* 2020, Vlot-Van Anrooij *et al.,* 2020, Williams *et al.,* 2020 [↑](#footnote-ref-576)
576. Bollard, 2017, Burke *et al.,* 2019, Davidson *et al.,* 2018, Dewa *et al.,* 2020, Disability Wales, 2019, Embregts *et al.,* 2018, Faulkner *et al.,* 2019, Gratton, 2020, Haya Salmón and Rojas Pernia, 2021, Hollinrake, Spencer and Dix, 2019, IRN, 2019, King *et al.,* 2019, Kramer *et al.,* 2018, McCartan *et al.,* 2019, Inclusion Scotland, 2020, Mathias *et al.,* 2019, National Development Team for Inclusion, 2019, Puyalto *et al.,* 2016, Riches, O’Brien and CDS Inclusive Research Network, 2020, Salmon *et al.,* 2018, Smith-Merry, 2017, St John *et al.,* 2018, Stanley *et al.,* 2019, Troya *et al.,* 2019, Varkonyi-Sep, Cross and Howarth, 2017, Vega Cordova *et al.,* 2020, Vlot-Van Anrooij *et al.,* 2020, Walsh *et al.,* 2018, Woelders *et al.,* 2015 [↑](#footnote-ref-577)
577. Breault *et al.,* 2018a, King *et al.,* 2019, [↑](#footnote-ref-578)
578. Morbey *et al.,* 2019 [↑](#footnote-ref-579)
579. Baines, 2018, Goeman *et al.,* 2019, IRN, 2019, Troya, 2019 [↑](#footnote-ref-580)
580. Bollard, 2017, Stanley *et al.,* 2019, Walsh *et al.,* 2018, [↑](#footnote-ref-581)
581. Dewa *et al.,* 2020, Herron, Priest and Read, 2015, Salmon *et al.,* 2018, Troya *et al.,* 2019 [↑](#footnote-ref-582)
582. Moule *et al.,* 2016, Salmon *et al.,* 2018, Troya *et al.,* 2019, Varkonyi-Sep, Cross and Howarth, 2017 [↑](#footnote-ref-583)
583. Drill Report, 2019 [↑](#footnote-ref-584)
584. Hamilton *et al.,* 2011 cited in Sangill *et al.,* 2019 [↑](#footnote-ref-585)
585. Frankena *et al.,* 2019c [↑](#footnote-ref-586)
586. Aldersley *et al.,* 2018, Anderson *et al.,* 2019, Anderson *et al.,* 2019, Bailey *et al.,* 2015, Barod Community Interest Company, 2019, Burke *et al.,* 2019, Butler *et al.,* 2020, Davidson *et al.,* 2018, Dewa *et al.,* 2020, Embregts *et al.,* 2018, Faulkner *et al.,* 2019, Frankena *et al.,* 2019b, Gratton, 2020, Haya Salmón and Rojas Pernia, 2021, Heffron *et al.,* 2018, Hellzen, Haugenes and Østby, 2018, Hollinrake, Spencer and Dix, 2019, ImaYDiT, 2018, IRN, 2019, King *et al.,* 2019, Kramer *et al.,* 2018, McCartan *et al.,* 2019, Mathews, Marshall and Wilkinson, 2020, National Development Team for Inclusion, 2019, Riches, O’Brien and CDS Inclusive Research Network, 2020, Salmon *et al.,* 2018, St John *et al.,* 2018, Schwartz and Durkin, 2020, Tilki, Palfreman and Chowdhury, 2019, Vega Cordova *et al.,* 2020, Woelders *et al.,* 2015 [↑](#footnote-ref-587)
587. Anderson *et al.,* 2019, Nind, 2017 [↑](#footnote-ref-588)
588. Anderson *et al.,* 2019 [↑](#footnote-ref-589)
589. Schwartz and Durkin, 2020 [↑](#footnote-ref-590)
590. IRN, 2019 [↑](#footnote-ref-591)
591. King *et al.,* 2019 [↑](#footnote-ref-592)
592. Gratton, 2020 [↑](#footnote-ref-593)
593. Anderson *et al.,* 2019, Burke *et al.,* 2019, Gratton *et al.,* 2020, Rojas Pernia and Haya Salmón, 2020 [↑](#footnote-ref-594)
594. Gratton *et al.,* 2020, Rojas Pernia and Haya Salmón, 2020 [↑](#footnote-ref-595)
595. Salmon *et al.,* 2018 [↑](#footnote-ref-596)
596. Hollinrake, Spencer and Dix, 2019 [↑](#footnote-ref-597)
597. Anderson *et al.,* 2019, Dewa *et al.,* 2020 [↑](#footnote-ref-598)
598. Dewa *et al.,* 2020 [↑](#footnote-ref-599)
599. St John *et al.,* 2018 [↑](#footnote-ref-600)
600. Riches, O’Brien and CDS Inclusive Research Network, 2020 [↑](#footnote-ref-601)
601. Salmon *et al.,* 2018 [↑](#footnote-ref-602)
602. Anderson *et al.,* 2018 [↑](#footnote-ref-603)
603. Garcia-Iriarte *et al.,* 2009 cited in Smith-Merry, 2017 [↑](#footnote-ref-604)
604. Schwartz and Durkin, 2020 [↑](#footnote-ref-605)
605. Stanley *et al.,* 2019 [↑](#footnote-ref-606)
606. This technique allows, based on the drawing of a body shape, to describe emotional, personal and social processes in order to produce an image representing multiple aspects of their embodied experience” De Jager *et al.,* 2016, p. X. [↑](#footnote-ref-607)
607. Haya Salmón and Rojas Pernia, 2021 [↑](#footnote-ref-608)
608. Frankena *et al.,* 2019a [↑](#footnote-ref-609)
609. Partner2 Writing Collective, 2020 [↑](#footnote-ref-610)
610. Hollinrake, Spencer and Dix, 2019 [↑](#footnote-ref-611)
611. Aldersey *et al.,* 2018, Barod Community Interest Company, 2019, Breault *et al.,* 2018a, Butler *et al.,* 2020, Clarke *et al.,* 2018, Davidson *et al.,* 2018, Dewa *et al.,* 2020, Disability Wales, 2019, Faulkner *et al.,* 2019, Haya Salmón and Rojas Pernia, 2021, IRN, 2019, Jennings *et al.,* 2018, Kramer *et al.,* 2018, McConnell *et al.,* 2019, Inclusion Scotland, 2020, Mathews, Marshall and Wilkinson, 2020, Mathias *et al.,* 2019, Puyalto *et al.,* 2016, Salmon *et al.,* 2018, Stevenson and Taylor, 2019, Troya *et al.,* 2019, Vasquez *et al.,* 2019, Williams, Ponting and Ford, 2015 [↑](#footnote-ref-612)
612. Salmon *et al.,* 2018 [↑](#footnote-ref-613)
613. Frankena *et al.,* 2019b, Smith-Merry, 2017, Strnadová *et al.,* 2016 [↑](#footnote-ref-614)
614. O’Brien, McConkey, and García-Iriarte, 2014 cited in Di Lorito *et al.,* 2018 [↑](#footnote-ref-615)
615. Smith-Merry, no date, Frankena *et al.,* 2019b [↑](#footnote-ref-616)
616. Frankena *et al.,* 2019b [↑](#footnote-ref-617)
617. Burke *et al.,* 2019, Meza *et al.,* 2016, Stevenson and Taylor, 2019 [↑](#footnote-ref-618)
618. Frankena *et al.,* 2019b, Gratton, 2020 [↑](#footnote-ref-619)
619. Aldersley *et al.,* 2018 [↑](#footnote-ref-620)
620. Chown *et al.,* 2017 [↑](#footnote-ref-621)
621. Kramer *et al.,* 2018 [↑](#footnote-ref-622)
622. Riches, O’Brien and CDS Inclusive Research Network, 2020 [↑](#footnote-ref-623)
623. Salmon *et al.,* 2018 [↑](#footnote-ref-624)
624. Kramer *et al.,* 2018, Vlot-van Anrooij *et al.,* 2018 [↑](#footnote-ref-625)
625. Vlot-van Anrooij *et al.,* 2018 [↑](#footnote-ref-626)
626. Stevenson and Taylor, 2019 [↑](#footnote-ref-627)
627. Clarke *et al.,* 2018, Riches, O’Brien and CDS Inclusive Research Network, 2020 [↑](#footnote-ref-628)
628. Clarke *et al.,* 2018 [↑](#footnote-ref-629)
629. Frankena *et al.,* 2019b [↑](#footnote-ref-630)
630. Clarke *et al.,* 2018 [↑](#footnote-ref-631)
631. Stevenson and Taylor, 2019 [↑](#footnote-ref-632)
632. Morbey *et al.,* 2019 [↑](#footnote-ref-633)
633. Hollinrake, Spencer and Dix, 2019 [↑](#footnote-ref-634)
634. Chown *et al.,* 2017, Frankena *et al.,* 2019a, Hollinrake, Spencer and Dix, 2019, Stevenson and Taylor, 2019, Vlot-van Anrooij *et al.,* 2018, [↑](#footnote-ref-635)
635. A Community of Inquiry is a 10-step approach to generating questions and facilitating discussion in response to a stimulus. [↑](#footnote-ref-636)
636. Disability Wales, 2019 [↑](#footnote-ref-637)
637. Best *et al.,* 2017cited in McCartan *et al.,* 2019 [↑](#footnote-ref-638)
638. Stanley *et al.,* 2019 [↑](#footnote-ref-639)
639. This involves using photos/images to capture and express people’s insights, perspectives, and realities. [↑](#footnote-ref-640)
640. Vega-Cordova *et al.,* 2020 [↑](#footnote-ref-641)
641. Jennings *et al.,* 2018 [↑](#footnote-ref-642)
642. Jennings *et al.,* 2018 [↑](#footnote-ref-643)
643. Tanner, 2012 cited in Stevenson and Taylor, 2019, Tuffrey‐Wijne and Butler, 2010 cited in Stevenson and Taylor, 2019 [↑](#footnote-ref-644)
644. Ashcroft *et al.,* 2016 [↑](#footnote-ref-645)
645. Butler *et al.,* 2020, ImaYDiT, 2018, King *et al.,* 2019, Callus, 2019, Davidson *et al.,* 2018, Mawn *et al.,* 2015, Salmon *et al.,* 2018, Tilly *et al.,* 2015, Van Schelven *et al.,* 2020b, Vega Cordova *et al.,* 2020 [↑](#footnote-ref-646)
646. Rojas Pernia *et al.,* 2020, Tilly *et al.,* 2015 [↑](#footnote-ref-647)
647. Dewa *et al.,* 2020, Goeman *et al.,* 2019, Mooney, Rafique and Tilly, 2018, Tuffrey-wijne *et al.,* 2020, Van Schelven *et al.,* 2020b [↑](#footnote-ref-648)
648. e.g. Dorozenko *et al.,* 2016 cited in Smith-Merry, 2017, Johnson *et al.,* 2014 cited in Smith-Merry, 2017, Povee *et al.* 2014 cited in Smith-Merry, 2017, Schneider, 2012 cited in Smith-Merry, 2017, Stanley *et al.,* 2019 [↑](#footnote-ref-649)
649. O’Hara *et al.,* 2017 [↑](#footnote-ref-650)
650. Case 1 in Frankena *et al.,* 2019c, Salmon *et al.,* 2018 [↑](#footnote-ref-651)
651. Brady *et al.,* 2019 [↑](#footnote-ref-652)
652. Riches, O’Brien and CDS Inclusive Research Network, 2020 [↑](#footnote-ref-653)
653. Vaughan *et al.,* 2019, p. 1229 [↑](#footnote-ref-654)
654. Campus Engage, 2017, Gove *et al.,* 2018, Howe, 2017, MacSweeney, Bowman, and Kelly, 2019, Miah *et al.,* 2019, Roberts *et al.,* 2020, Troya *et al.,* 2019 [↑](#footnote-ref-655)
655. Craven *et al.,* 2019, Dewa *et al.,* 2020, Frankena *et al.,* 2019b, Hamidi *et al.,* 2015, Mann and Hung, 2018, Schwartz and Durkin, 2020, Stack and McDonald, 2018, Stanley *et al.,* 2019, Van Schelven *et al.,* 2020b, Vaughan *et al.,* 2019, Vlot-van Anrooij *et al.,* 2018, Williams, Ponting and Ford, 2015 [↑](#footnote-ref-656)
656. Smith-Merry, 2017, p. 15 [↑](#footnote-ref-657)
657. Nicolaidis *et al.,* 2019 [↑](#footnote-ref-658)
658. Ní Shé *et al.,* 2019, Bertilsdotter Rosqvist *et al.,* 2019, Smith-Merry, 2017 [↑](#footnote-ref-659)
659. Beighton *et al.,* 2019, Swarbrick *et al.,* 2019 [↑](#footnote-ref-660)
660. Frankena *et al.,* 2019a, p. 7 [↑](#footnote-ref-661)
661. Butler *et al.,* 2020, Callus, 2019, Dewa *et al.,* 2020, Disability Wales, 2019, Fitzgerald and Walsh, 2016, Haya Salmón and Rojas Pernia, 2021, ImaYDiT, 2018, Mann and Hung, 2018, Mawn *et al.,* 2015, Puyalto *et al.,* 2016 [↑](#footnote-ref-662)
662. Barod Community Interest Company, 2019, Dewa *et al.,* 2020, Frankena *et al.,* 2019c, Gratton, 2020, King *et al.,* 2019, IRN, 2019, Mann and Hung, 2018, National Development Team for Inclusion, 2019, Riches, O’Brien and CDS Inclusive Research Network, 2017, Stanley *et al.,* 2019, Tilly *et al.,* 2015, Vasquez *et al.,* 2019, Vega Cordova *et al.,* 2020, Walsh *et al.,* 2018 [↑](#footnote-ref-663)
663. Vasquez *et al.,* 2019 [↑](#footnote-ref-664)
664. Walsh *et al.,* 2018 [↑](#footnote-ref-665)
665. e.g. Dorozenko *et al.,* 2016 cited in Smith-Merry, 2017, Johnson *et al.,* 2014 cited in Smith-Merry, 2017, Povee *et al.* 2014 cited in Smith-Merry, 2017, Schneider, 2012 cited in Smith-Merry, 2017 [↑](#footnote-ref-666)
666. e.g. Dorozenko *et al.,* 2016 cited in Smith-Merry, 2017, Johnson *et al.,* 2014 cited in Smith-Merry, 2017, Povee *et al.* 2014 cited in Smith-Merry, 2017, Schneider, 2012 cited in Smith-Merry, 2017 [↑](#footnote-ref-667)
667. Hollinrake, Spencer and Dix, 2019 [↑](#footnote-ref-668)
668. Barod Community Interest Company, 2019, Disability Wales, 2019, Riches, O’Brien and CDS Inclusive Research Network, 2020, Stanley *et al.,* 2019 [↑](#footnote-ref-669)
669. Riches, O’Brien and CDS Inclusive Research Network, 2020 [↑](#footnote-ref-670)
670. Flicker, 2008 cited in Van Schelven *et al.,* 2020a [↑](#footnote-ref-671)
671. Coyne *et al.,* 2016 cited in Van Schelven *et al.,* 2020a [↑](#footnote-ref-672)
672. Strnadová *et al.,* 2016 [↑](#footnote-ref-673)
673. Riches, O’Brien and CDS Inclusive Research Network, 2017 [↑](#footnote-ref-674)
674. Paul *et al.,* 2017, Riches, O’Brien and CDS Inclusive Research Network, 2017 [↑](#footnote-ref-675)
675. Riches, O’Brien and CDS Inclusive Research Network, 2020 [↑](#footnote-ref-676)
676. Riches, O’Brien and CDS Inclusive Research Network, 2017, Vega Cordova *et al.,* 2020 [↑](#footnote-ref-677)
677. Bailey *et al.,* 2015 [↑](#footnote-ref-678)
678. Smith-Merry, no date [↑](#footnote-ref-679)
679. Smith-Merry, no date [↑](#footnote-ref-680)
680. Gove *et al.,* 2018 [↑](#footnote-ref-681)
681. Burton, Ogden, and Cooper, 2019, Frankena *et al.,* 2015, Frankena *et al.,* 2019a, Miah *et al.,* 2019, Stevenson and Taylor, 2019, Swarbrick *et al.,* 2020, Van Schelven *et al.,* 2020b [↑](#footnote-ref-682)
682. Haya Salmón and Rojas Pernia 2021 [↑](#footnote-ref-683)
683. Drill Report, 2018 [↑](#footnote-ref-684)
684. Haya Salmón and Rojas Pernia 2021, St John *et al.,* 2018 [↑](#footnote-ref-685)
685. Staniszewska *et al.,* 2017 [↑](#footnote-ref-686)
686. See Appendix D for the short and long form of this checklist. [↑](#footnote-ref-687)
687. Dewa *et al.,* 2020, Miah *et al.,* 2019, Troya, Bartlam and Chew-Graham, 2018, Van Schelven *et al.,* 2020b [↑](#footnote-ref-688)
688. Miah *et al.,* 2019, p.17 [↑](#footnote-ref-689)
689. Campus Engage, 2017, p. 10 [↑](#footnote-ref-690)
690. Staniszewska *et al.,* 2017 [↑](#footnote-ref-691)