Optimising inclusive health research: where expectations and realities meet

Meaningful collaboration with people with intellectual disabilities

Tessa K. Frankena

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Colofon

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Kaft:	Benjamin Rangkouw, Activiteitencentrum De Heuvel, Het Dorp, Siza Ik heb bewust gekozen voor een ronde tafel, want dit symboliseert voor mij gelijkwaardigheid. De puzzelstukjes associeer ik met het Engelse woord "puzzled".
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For opa Ruud,

who taught me that togetherness is the most important thing of all.

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Chapter 1

General introduction

1.1 Patient participation in healthcare and research

Patients increasingly advocate for their voice to be heard, often organised in groups based on a specific illness or disability (Wilson et al., 2015). One of these groups is the disabled people's movement, which has adopted the slogan Nothing About Us Without Us. After the United Nations presented the Convention on the Rights of Persons with Disabilities (UNCRPD) in December 2006, awareness of the need for equality and respect towards people with disabilities accelerated (United Nations, 2015). The participation and active involvement of patients developed not only in healthcare, but also in education (Nind, 2014) and research (Sin & Fong, 2010).

Patient participation has its roots in health*care*, and patient participation in health *research* is gaining ground. Three arguments for patient participation in health research are mentioned structurally in the literature: the moral argument, the political argument, and the methodological argument (Boote et al., 2009). The moral argument emphasises people's right to be involved in all that affects them as, for example, enshrined in the UNCRPD (Nierse & Abma, 2011; United Nations, 2015). The political argument focuses on contemporary policies that emphasise the need for patient involvement (Boote et al., 2009). For example, funding bodies now increasingly require patients' active involvement in research proposals. The methodological argument addresses the expected added value of patient involvement in health research, such as a better match between research and practice (Beighton et al., 2017; Elberse, 2012).

People with intellectual disabilities (ID) experience more health disparities compared to the general population (van Schrojenstein Lantman-de Valk & Walsh, 2008), and too often they have "research done to them" instead of with them (Sutton & Gates, in press, p. 1). The participation of people with ID in research, also known as inclusive research, emerged in the 1980s (Walmsley, Strnadová, & Johnson, 2017). It provides an additional argument for patient participation in health research, in that *inclusive* health research (Frankena, Naaldenberg, Cardol, Linehan, & Van Schrojenstein Lantman-de Valk, 2015) is "more respectful, caring and socially just" (Nind, 2014, p. 533) and therefore leads to more complete research outcomes.

Inclusive research proceeds in tandem with other developments, such as the 2015 Dutch healthcare system reform, which had a strong focus on participation. Firstly, the introduction of the Social Support Act (Wet Maatschappelijke Ondersteuning) and the Long-term Care Act (Wet Langdurige Zorg) (ZorgWijzer.nl, 2014) changed long-term care and living arrangements so that people with ID can live as independently as possible within the community (Aedes-Actiz Kenniscentrum Wonen-Zorg, 2014). Secondly, the new Participation Law aimed to increase the employment of people who did not have easy access to the labour market (Rijksoverheid, 2018). These legislative changes aim to ensure that people are included in society as much as possible (ZorgWijzer.nl, 2016).

Aware of the importance of patient participation in general, the many arguments for the participation of people with ID in health research, and the healthcare system reforms, the Academic collaborative Stronger on Your Own Feet, a collaboration between nine Dutch healthcare providers for people with ID and the Radboud university medical center (www.sterkeropeigenbenen.nl), initiated PhD research aiming to optimise inclusive health research. In line with the inclusive mindset, this study will be done in collaboration with people with ID.

1.2 Definition of intellectual disabilities

The most commonly used definition of an intellectual disability is that proposed by the American Association of Intellectual Developmental Disabilities (AAIDD). It is comprised of three criteria; people have an ID if they: (1) have an IQ below 70, (2) experience limitations in adaptive behaviour, and (3) these limitations originate before the eighteenth year of life (AAIDD, 2013). Another definition states: “Firstly, people with learning disabilities [intellectual disabilities] have some form of difficulty with experiencing and acquiring new information. Secondly, this difficulty starts in childhood. Thirdly, the difficulty impacts on people’s ability to cope independently” (Seale, Nind, Tilley, & Chapman, 2015, p. 483).

The social model of disability (Shakespeare, 2013) complements these definitions by stating that it is also society that debilitates, not just a person’s impairment. For example, when a person with ID wants to submit a tax return and the tax authorities’ website is too difficult to read, he or she feels disabled. If the website is accessible by means of easy-read information and a read out loud function, he or she does not feel disabled. Therefore, the form or level of disability is unimportant, as a disability is based on when people *feel* disabled (Swain & French, 2000). Within disability studies, disability is viewed as a social construct, as “human differences are instilled with social meanings” (Ollerton, 2012, p. 3). With this in mind, people with ID are viewed as “able-bodied”. In this thesis, we follow a combination of the above definitions, with a strong focus on people’s abilities and presumed competence.

1.3 Development of inclusive (health) research

In 2003, Walmsley and Johnson, two of the founders of inclusive research, published the book *Inclusive research with people with learning disabilities: Past, present and futures*. This book includes a widely used definition of inclusive research: “research which includes or involves people with learning disabilities as more than just subjects of research” (Walmsley & Johnson, 2003, p. 61). On the basis of developments over the past three decades, Walmsley et al. (2017) updated this definition as shown in Box 1.1.

Since inclusive research emerged in the 1980s, two generations of inclusive research are identified in the literature. Whereas the first generation focused on the need for, challenges, and communication methods of inclusive research (Nind, 2016), the second generation addresses its outcomes, added value, effective methods and partnerships, and the benefits for both individuals and research teams (Grant & Ramcharan, 2009). As a result of the second generation of inclusive research, more and more individual accounts of inclusive research are shared, published in scientific journals, and presented at conferences.

Sharing individual experiences with inclusive research is important (Walmsley et al., 2017). However, the majority of these shared experiences are aimed at practicalities of inclusive research (Riches & O’Brien, 2017) and are often marginally documented (Flood, Bennett, Melsome, & Northway, 2013; Kramer, Kramer, García-Iriarte, & Hammel, 2011). The few inclusive research projects conducted in an academic setting might account for the lack of structural study (Riches & O’Brien, 2017). As we are now well into the second generation of inclusive research, we need to move beyond the focus on individual processes to study inclusive (health) research structurally on a larger scale, beyond individual experiences and over longer periods of time. Structural study helps to develop a consensual approach towards inclusive (health) research (Nind & Vinha, 2014).

1.4 Research objectives and questions

Inclusive health research is essentially about collaboration in a team of researchers with and without ID; this means that two very different worlds with different perspectives come together. Each has different expectations and realities. A lot remains unclear about the processes involved in this collaboration that eventually result in inclusive research. This thesis aims to observe both worlds and structurally study how expectations and realities of researchers with and without ID meet. All the inclusive health research stakeholder groups are involved (i.e., people with ID, academics, support staff, and experts with and without ID), in order to develop widely supported results. The two main objectives are (see Figure 1.1):

a) to gain in-depth insight into the *expectations* and *realities* of inclusive health research; and
b) to support inclusive research teams in *optimising* their inclusive health research design and implementation.

The following research questions have been developed from the research objectives:

1) What are the expectations regarding (1) the quality and added value and (2) the roles and responsibilities within inclusive health research, according to academics and people with ID?
2) What are the realities regarding (1) the quality and added value and (2) the roles and responsibilities of inclusive health research, according to inclusive research teams?
3) How can inclusive research teams optimise their inclusive health research design and implementation, according to experts with and without ID?

- “aims to contribute to social change, that helps to create a society, in which excluded groups belong, and which aims to improve the quality of their lives;
- is based on issues important to a group, and which draws on their experience to inform the research process and outcomes;
- aims to recognise, foster and communicate the contributions people with intellectual disabilities can make;
- provides information which can be used by people with intellectual disabilities to campaign for change on behalf of others; and
- is ‘standing with’ those whose issues are being explored or investigated” (Walmsley et al., 2017, p. 8).

Box 1.1 Updated definition of inclusive research

1.5 Methodological considerations

This thesis is being undertaken within the Academic Collaborative, Stronger on Your Own Feet (Sterker op eigen benen, www.sterkeropeigenbenen.nl), in which nine Dutch ID care service providers collaborate with the Radboud university medical center in Nijmegen, the Netherlands. In line with the Academic Collaborative’s cooperation agreements, the research team for this thesis will consult an advisory board consisting of people with ID, relatives, support staff, and researchers every three months. Additionally, during this PhD research, an inclusive approach will be adopted through structural collaboration with two co-researchers: Henk Jansen and Anneke van der Cruijsen. The bar on the right side of Figure 1.1 indicates how this project aims for the studies to become increasingly inclusive over time as our experience as an inclusive research team grows.

Multiple strategies are used within this thesis to minimise the effects of researcher bias and increase the validity of the study results. These are discussed in more detail in each chapter. In general, the strategies comprise:

1) Data triangulation: a variety of methodologies will be used to collect data within each study in this thesis.

2) Researcher triangulation: researchers from different backgrounds (i.e., disability studies, social sciences, medical sciences, etc.) will be involved in designing and conducting the studies in this thesis. All data analysis will be done by at least two academic researchers and in collaboration with the co-researchers, Henk and Anneke (as informants or collaborators).
3) Continuous reflection: throughout the course of this PhD continuous reflection with colleagues and peers will be organised in order to discuss research quality and inclusive research practicalities.
4) Methodological support: for all studies in this thesis advice from an experienced methodologist will be sought in order to ensure research quality while adopting an inclusive approach.

Figure 1.1 Outline of the PhD research

1.6 Outline of this thesis

Chapters 2 to 7 presented in this thesis aim to answer the research questions set out in section 1.4. These chapters are followed by a general discussion of the results in Chapter 8. **Chapter 2** provides a structured literature review, aiming to gain insight into the current knowledge on inclusive health research (research question 1). This chapter focuses on (1) existing theories, (2) inclusive methods, (3) added value, and (4) barriers and facilitators of inclusive health research.

Chapter 3 presents a structured interview survey exploring the participation of people with ID in research regarding: (1) frequency of participation, (2) methods used to participate, (3) motivations to participate, and (4) interests regarding study results. In **Chapter 4**, a Delphi study aiming to gain academics' agreement on: (1) designs and methods, (2) most important characteristics, and (3) outcomes of inclusive health research is described. **Chapter 5** presents a European-based case study of four inclusive (health) research projects in Ireland, Northern Ireland, and the Netherlands, aiming to gain insight into: (1) the reasons, (2) the attributes, and (3) the outcomes of inclusive (health) research in practice. In **Chapter 6**, a reflection is presented on the four-year collaboration between the PhD student and the two co-researchers on this project. **Chapter 7** presents the consensus statement on inclusive health research. This consensus statement was developed by a total of 17 experts on inclusive (health) research without ID, and 40 experts with ID collaborated in this consensus statement. Finally, the main findings of the studies in Chapters 2 to 7 are discussed in **Chapter 8**, including a reflection on the most important findings, methodological considerations, and implications. Chapter 8 also provides future research suggestions.

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Part I

Experiences

Chapter 2

Active involvement of people with intellectual disabilities in health research

A structured literature review

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Abstract

Actively involving people with intellectual disabilities (ID) in health research, also known as inclusive health research, is increasingly popular. Currently, insight into experiences of this type of research is scarce. To gain insight into this topic, a structured literature review was conducted focussing on (1) existing theories, (2) inclusive methods, (3) added value and (4) barriers and facilitators. Literature published between January 2000 and January 2014 was included covering keywords related to ID and inclusive health research. Searches were performed in Pubmed, CINAHL, PsycINFO, EMBASE and MEDLINE databases, resulting in 26 included papers. Papers were quality assessed and analysed using qualitative data analysis software. Four theories were often simultaneously addressed: participatory research, emancipatory research, inclusive research and Arnstein's ladder. Barriers and facilitators could be divided into preparing, undertaking and finalising phases of research. Authors indicated that their motivation to conduct inclusive health research was based on demands by policy and funding bodies or was based on ethical considerations (i.e., ethical notions and giving people with ID a voice). Upon completion, authors perceived increased quality and validity of their research and several benefits for stakeholders (i.e., people with ID, researchers and healthcare professionals). Overall, there was consistency in their perception of the most important aspects of inclusive health research. Based on the analysis of included papers, four recommendations of inclusive health research with people with ID were found. Inclusive health research should be: (1) tailoring to the specific study; (2) anticipating all stakeholders; (3) considering its added value; and (4) providing insight into its process.

2.1 Introduction

The idea that research “should not only be conducted ‘on’ patients but ‘with’ patients actively involved in decision-making” (p. 3) is increasingly popular (Elberse, 2012). Researchers realise that, in order to align research outcomes with patients’ needs, they should be actively involved. Three main drivers of active involvement were found in related literature: (1) patients have the democratic right to be involved in everything that affects their lives, including scientific research (Elberse, 2012; Nierse & Abma, 2011; United Nations, 2015), (2) inclusive research relies on experiential knowledge of patients, which is considered to be an important “source of knowledge” (Caron-Flinterman, Broerse, & Bunders, 2005), and (3) inclusive research is expected to lead to a better match between research outcomes and practice (Elberse, 2012). In addition to these drivers, national policies and funding bodies often demand inclusion of patients in research (Boyden, Esscopri, Ogi, Brennan, & Kalsy-Lillico, 2009; Tuffrey-Wijne & Butler, 2010; United Nations, 2004; Walmsley, 2004).

Active involvement of patients in research is prevalent in research concerning physical disabilities (e.g., rheumatism, lung diseases, cancer and burn victims). Involvement of people with intellectual disabilities (ID) as active participants in research is increasing (Walmsley & Johnson, 2003). As a result, more and more experiences are gathered regarding the active involvement of people with ID in research, however, a shared knowledge base is lacking. In addition, active involvement in research remains challenging, as people with ID are often assumed to lack the capacity to understand and discuss research related topics (Tuffrey-Wijne, Bernal, Butler, Hollins, & Curfs, 2007). They are often protected by well-intentioned family and carers (Tuffrey-Wijne, Bernal, Jones, Butler, & Hollins, 2006). In addition, Marshall (2012) believes that researchers might hesitate to include people with ID due to ethical concerns, since they are considered to be vulnerable and, therefore, should be protected from harm (Marshall, 2012).

There is an increasing demand for the active involvement of people with ID in research; however, sharing experiences of this research type is difficult. Firstly, views differ on which research methods lead to active involvement. According to Abma, Nierse and Widdershoven (2009), there is a difference between methods that view patients as “active participants” versus as a “source of information”

(p. 402). Secondly, literature on active involvement of people with ID in research uses a spectrum of terms. These terms are often used interchangeably, even though their meanings appear to be slightly different (Burke et al., 2003; Elberse, 2012; Tuffrey-Wijne & Butler, 2010). The multiple terms used in the literature suggest there is no consensus yet. Examples include: “inclusive research” (Walmsley & Johnson, 2003), “participatory research” (Morgan, 2013), “emancipatory research” (Walmsley, 2001), “participatory action research” (Garcia Iriarte, 2008), “patient participation” (Elberse, 2012) and “patient and public involvement” (INVOLVE, 2015). It is therefore important to clarify that this review adopts the term “inclusive research” as this is seen as the overarching term of people with ID’s involvement in research. Inclusive research is defined as: “research which includes or involves people with learning disabilities as more than just subjects of research” (Walmsley & Johnson, 2003, p. 61). This review paper specifically focuses on inclusive *health* research, since people with ID face more health disparities compared to the general population (van Schrojenstein Lantman-de Valk & Walsh, 2008). For this review, a broad perspective on health research is taken, ranging from research on access to health services to patient’s experiences with health services (World Health Organisation, 2015). A health focus on inclusive research might positively contribute to people with ID’s current health status and healthcare. According to Dedding and Slager (2013), “participation can be a goal as well as a means to improve the quality of healthcare” (p. 7).

The combination of, on one hand, the increasing knowledge base and growing demand for inclusive health research, and, on the other hand, the lack of clarity and the challenges experienced regarding inclusive health research demands more attention. Therefore, this structured literature review aims to gain insight into the current knowledge on inclusive health research with people with ID regarding (1) existing theories, (2) inclusive methods, (3) added value and (4) barriers and facilitators.

2.2 Methods

2.2.1 Search strategy

A search covering the key topics, intellectual disabilities and inclusive health research, was performed in January 2014. Search terms and databases were chosen with the assistance of an information specialist. An overview of the used search terms is presented in Table 2.1. Publications were included if they met the following inclusion criteria: (a) empirical studies conducting inclusive health research, (b) reflective papers on inclusive health research, or (c) evaluation papers on inclusive health research, and (d) published between January 2000 and January 2014. After duplication removal, and title and abstract screening, the remaining 91 publications were full-text screened (TF). Following text screening, 64 papers were excluded through a review process (TF and JN), resulting in a total of 27 publications to be included (Figure 2.1).

2.2.2 Working definition

A working definition was made based on (1) the approaches to public involvement by INVOLVE, the national advisory group on public involvement for the British National Health Service, which are (a) consultation, where people with ID are seen as objects of research, (b) collaboration, where researchers and people with ID work in a partnership and make joint decisions and (c) control, where people with ID have complete decision-making power (INVOLVE, 2014a), and (2) the cut-off point of minimal dialogue set by Abma et al. (2009) at interviews. Based on the latter, minimum dialogue occurs where research methods employ collaboration or control by means of interviews or other methodologies providing people with ID the opportunity for dialogue. Studies employing minimum dialogue methods were included in this review.

Table 2.1 Search terms

Database	Key topic 1: intellectual disabilities	Key topic 2: inclusive health research
PubMed	"Intellectual Disability"[MeSH] OR Intellectual Disabilit*[tiab] OR Mental Retardation[tiab] OR Mental Deficienc*[tiab] OR Learning Disorder*[tiab] OR Developmental Disorder*[tiab] OR Developmental Disabilit*[tiab] OR Learning Disabilit*[tiab]	"Cooperative Behavior"[MeSH] OR Collaboration*[tiab]) OR Cooperative Behavio*[tiab] OR Patient Participation[tiab] OR "Patient Participation"[MeSH] OR "Community-Based Participatory Research"[tiab]
CINAHL	MH "Intellectual Disability+" OR "intellectual disability" OR "intellectual disabilities" OR MH "Mental Retardation, X-Linked+" OR MH "Intellectual Disability+" OR "mental retardation" OR MH "Developmental Disabilities" OR "developmental disabilities"	MH "Consumer Participation" OR "patient participation"
PsycINFO	"exp Intellectual Development Disorder/" OR "intellectual disabilities.mp." OR "exp Developmental Disabilities"	"patient participation.mp." OR "exp Client Participation/"
EMBASE	"intellectual disabilities.mp." OR exp "intellectual impairment/"	"exp patient participation/" OR "patient participation.mp."
MEDLINE	"intellectual disabilities.mp." OR "exp Intellectual Disability/"	"patient participation.mp. or exp Patient Participation/" OR "exp Community-Based Participatory Research/" OR "exp Consumer Participation/"

2.2.3 Data analysis

Full-text copies of the included papers were imported in ATLAS.ti (Scientific Software Development) for qualitative data analysis. A code list was developed based on the research aim: to gain insight into the current knowledge on inclusive health research regarding (1) existing theories, (2) inclusive methods, (3) added value and (4) barriers and facilitators. Table 2.2 provides the final code list and definitions. Next, the developed code list was applied by four individual researchers (TF, JN, HO and CL). Discrepancies were discussed during meetings, in order to identify the source of these discrepancies (e.g., different definitions of codes or different parts of texts coded). Consensus was reached after elaborate discussions and repeatedly reading the papers. Discussions resulted in the exclusion of one paper (Johnson, Hobson, Garcia, & Matthews, 2011) due to insufficient information on its methods of inclusive health research.

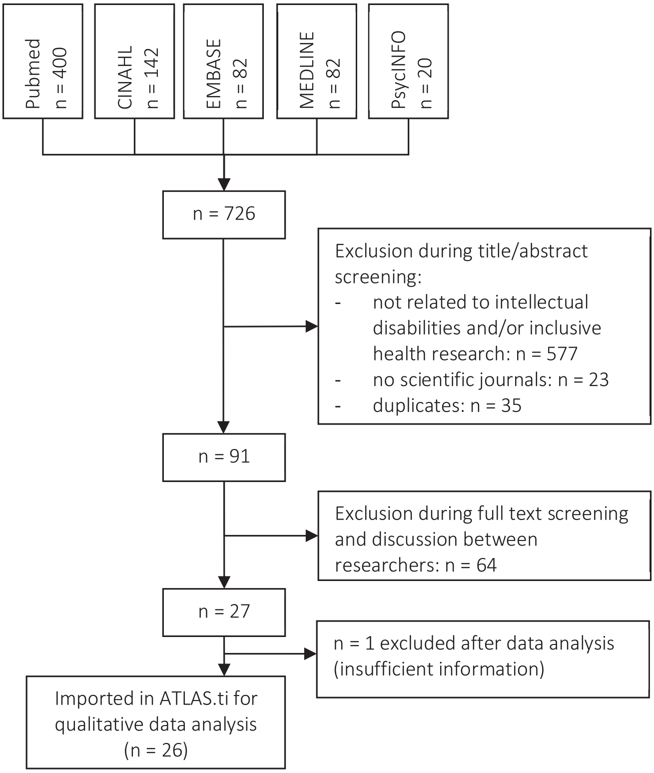

Figure 2.1 Search strategy

2.2.4 Quality criteria

Publications were quality assessed using eight quality criteria (see Table 2.2) (Naaldenberg, Kuijken, van Dooren, & van Schrojenstein Lantman de Valk, 2013). Sixteen points could be assigned: zero points per criterion if no description was provided, one point per criterion if minimal description was provided, and two points per criterion if discussion or rationale was provided. Fourteen points could be assigned to reflective papers, since “dropout rate” was not applicable. A maximum of 12 points could be assigned to literature reviews, since “number of participants” and “dropout rate” were not applicable. Quality criteria were added to the code list and were discussed among authors until consensus was reached.

Table 2.2 Final code list and quality criteria

Code	Definition
Quality: study design	Is a clear description of the study design provided and/or discussed?
Quality: study population	Is a clear description of the study population provided and/or discussed?
Quality: people with ID	Is a clear description of the active involvement of people with ID provided and/or discussed?
Quality: study aim/research question	Is a clear description of the study aim and research questions provided and/or discussed?
Quality: dropout rate	Is the dropout rate provided and/or discussed?
Quality: study limitations	Are the study limitations provided and/or discussed?
Quality: inclusive theories	What theories on inclusive research are described?
Quality: inclusive models	What models on inclusive research are described?
Level of ID	What level of ID do active participants have?
Other included stakeholders	What other stakeholders are included in the research? (e.g., carers, family, managers, etc.)
Level of inclusion	What detail is provided on the level of involvement of people with ID? (translated into the research cycle/moment of inclusion)
Recruitment strategies	What recruitment strategies are used for people with ID? (e.g., flyers, e-mails, post, etc.)
Informed consent methods	What informed consent methods are used for people with ID? (e.g., oral, written, via carers, etc.)
Training and preparation	What training and preparation is offered to include people with ID?
Inclusive research methods	What inclusive research methods are used?
Expected added value	What reasons are provided for using an inclusive methodology or is there any mention of added value accruing to these methods? (extracted from introductory sections of publications)
Experienced added value	What mention of experienced added value is given? (extracted from discussion sections)
Barriers	What are the experienced barriers of inclusive health research, and by whom are they experienced?
Facilitators	What are the experienced facilitators of inclusive health research, and by whom are they experienced?

2.3 Results

In Table 2.3, a distinction was made between “active participants” and “informants”. Active participants were people with ID with a degree of decision-making power over the study, while informants provided studies with data without any degree of decision-making power. Based on the working definition in Section 2.2.2, papers conducting in-depth interviews, focus groups or other methods providing people with ID the opportunity for dialogue were seen as actively involving their participants.

2.3.1 General characteristics

Table 2.3 presents the general characteristics of the included papers. Eleven papers reflected inclusive health research; ten papers conducted empirical inclusive health research; four papers addressed inclusive health intervention or model development; and one paper reviewed the literature. The majority (n = 14) of the research topics relate to the process or methodology of inclusive health research. Included publications originate from the United Kingdom (n = 12); Australia (n = 5); the United States of America (n = 4); the Netherlands (n = 3); Ireland (n = 1) and Canada (n = 1). Fifteen studies did not specify the level of ID of active participants and informants; four studies included people with mild and moderate ID; four studies stated that people were "not under legal guardianship" or had "minor ID" or Down syndrome; and one study included people with moderate ID.

2.3.1.1 Moment of inclusion

Figure 2.2 shows in which moments in the research cycle papers actively involved people with ID. The research cycle was adopted from INVOLVE (2014b). The moment of inclusion was discussed by several authors of included papers and various arguments were found. Stevenson (2014) questioned whether people with ID have "legitimacy in claiming authorship" (p. 31), while O'Brien et al. (2014) stated that collaborating with people with ID does not end after publication. Abma et al. (2009) preferred inclusion of people with ID throughout their research cycle and were aware of everyone's "interests and qualities" (p. 411). Stevenson (2010) tried to explore people with ID's potential as an important aspect of her methodology.

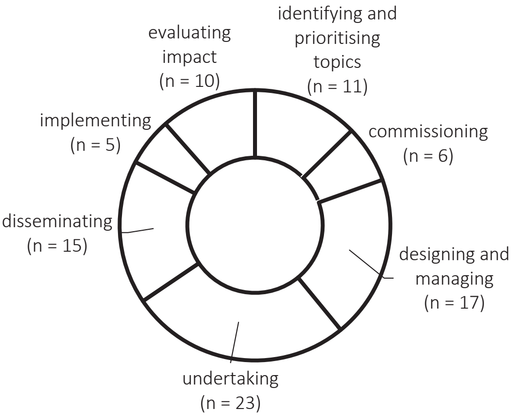

Figure 2.2 Moment of inclusion

Table 2.3 General characteristics of included papers

Author(s) (year), country	Research topic	Active participants	Informants	Level of ID	Other stakeholders	Theories mentioned	Inclusive methods	Quality score
Empirical studies								
Brooks et al. (2013), UK	Psychological therapy	5 research partners ? pilot study participants	50 questionnaires	Mild/moderate	n.a.	n.a.	Focus groups Research partners	13/16
Chapman (2014), UK	Support workers	24 focus group participants 4 research partners	24 observations and semi-structured interviewees	Not specified	Support workers	Participatory research Emancipatory research Inclusive research Collaborative research Action research People First model	Interviews Focus groups Research partners	9/16
Haigh et al. (2013), UK	Happiness and satisfaction	? research partners	23 interviewees	Not specified	Researcher Psychologist Support worker	n.a.	Interviews Research partners	12/16
Jurkowski & Paul-Ward (2007), USA	Health promotion	4 Photovoice participants	n.a.	Mild/moderate	Agency staff members	Participatory action research Feminist theory	Photovoice[1]	16/16
Llewellyn & Northway (2008), UK	Advocacy	23 focus group participants	n.a.	Mild/moderate	n.a.	Inclusive research	Focus groups Self advocates	12/16
Manthorpe et al. (2003), UK	Intellectual disability nursing	? focus group participants	n.a.	Not specified	Family members	Arnstein's ladder	Focus groups	8/16
Marshall (2012), Canada	Ethical issues	7 self advocates	10 retreat visitors	Moderate	Researchers Support staff	Participatory research Emancipatory research Inclusive research Community-based participatory research	Interviews Focus groups Self advocates	14/16
McDonald (2012), USA	Inclusive research	2 research partners 16 focus group participants	16 semi-structured interviewees	"Not under legal guardianship"	n.a.	n.a.	Interviews Focus groups Research partners	16/16

1 Photovoice enables active participants to take photographs relating to the research topic and reflect upon these photographs during interviews or focus groups (Jurkowski & Paul-Ward, 2007).

Table 2.3 continued

Author(s) (year), country	Research topic	Active participants	Informants	Level of ID	Other stakeholders	Theories mentioned	Inclusive methods	Quality score
McDonald et al. (2013), USA	Inclusive research	2 research partners 16 focus group participants	16 semi-structured interviewees	"Not under legal guardianship"	n.a.	Participatory research	Interviews Focus groups Research partners	14/16
Nierse & Abma (2011), The Netherlands	Research agenda	2 research partners 93 focus group participants	7 interviewees	Not specified	Parents Key informants Representatives of various organisations	Participatory research Emancipatory research Inclusive research Responsive research Enclave deliberation	Interviews Focus groups Research partners	12/16
Reflective studies								
Abell et al. (2007), UK	Inclusive research	? students 2 research partners	? interviewees	Not specified	Researchers	n.a.	Interviews Research partners	6/14
Abma et al. (2009), The Netherlands	Inclusive research	91 focus group participants 3 research partners	7 interviewees	People with "minor" ID	Parents	Participatory research Responsive research Dialogical approach Relational approach Arnstein's ladder	Interviews Focus groups Research partners	13/14
Bigby & Frawley (2010), Australia	Research partner	1 research partner	n.a.	Not specified	n.a.	Emancipatory research Inclusive research Action research Walmsley and Johnson's framework	Research partner	11/14
Boyden et al. (2009), UK	Psychology services	29 focus group participants	n.a.	Not specified	Speech therapists	n.a.	Focus groups	12/14
Burke et al. (2003), UK	Inclusive research	8 research partners	n.a.	Not specified	Clinicians Research partners	Participatory research Emancipatory research	Research partners	9/14
Flood et al. (2013), UK	Inclusive researchers	3 research partners	n.a.	Not specified	Researchers Research-assistants Managers	n.a.	Research partners	8/14

Table 2.3 continued

Author(s) (year), country	Research topic	Active participants	Informants	Level of ID	Other stakeholders	Theories mentioned	Inclusive methods	Quality score
O'Brien et al. (2014), Ireland	Inclusive research	20 research partners 168 focus group participants	n.a.	Not specified	Family researchers Service organisations Government representatives	Participatory research Emancipatory research Inclusive research Communities of practice	Focus groups Research partners	12/14
Stevenson (2010), Australia	Inclusive research	25 (not specified)	n.a.	Adults with Down syndrome	Key supporters Family Friends Community members Disability agencies	Participatory research Emancipatory research Inclusive research Social model Medical model Individualised model	Interviews Focus groups Research partners	11/14
Stevenson (2014), Australia	Inclusive data analysis	3 research partners	22 transcribed interviews	Not specified	Parents Staff Support person	Participatory research Emancipatory research Inclusive research	Interviews Research partners	12/14
Tuffrey-Wijne & Butler (2010), UK	Research partner	1 research partner	n.a.	Not specified	Researcher	Participatory research Emancipatory research Inclusive research Social model Medical model	Research partner	13/14
Walmsley (2004), UK	Inclusive research	n.a.	n.a.	n.a.	n.a.	Participatory research Emancipatory research Inclusive research	Interviews Focus groups Research partners Self advocates	6/14
Model/intervention development studies								
Abma & Broerse (2010), The Netherlands	Dialogue Model	7 case studies	n.a.	Not specified	n.a.	Participatory research Arnstein's ladder Dialogue model	n.a.	9/12
Ailey et al. (2012), USA	Challenging behaviour	3 cognitive interviewees	12 pilot study participants	Mild/moderate	Residential and day programme staff		Interviews	11/16

Table 2.3 continued

Author(s) (year), country	Research topic	Active participants	Informants	Level of ID	Other stakeholders	Theories mentioned	Inclusive methods	Quality score
Beadle et al. (2012), UK	Communication	? self advocates	n.a.	Not specified	Representatives of study programmes Lectures	Arnstein's ladder ROOT model	Self advocates Evaluation framework	8/16
Bigby et al. (2014a), Australia	Inclusive research	5 self advocates	8 interviewees	Not specified	Historian Research fellow PhD student Allies Government staff	Participatory research Emancipatory research Inclusive research Action research Collaborative group approach	Interviews Self advocates	9/16
Literature review								
Bigby et al. (2014b), Australia	Inclusive research	n.a.	n.a.	n.a.	n.a.	Participatory research Emancipatory research Inclusive research Collaborative group approach	Research partners Self advocates	9/12

2.3.2 Theories

Seven studies did not cite a theoretical framework of inclusive research to guide their methodology; three studies cited one theory; and 16 studies cited more than one theory. All papers citing theories did so in the introduction of the paper. The most frequently mentioned theories were Arnstein's ladder of citizen participation, participatory research, emancipatory research and inclusive research. The latter three are simultaneously addressed by 10 out of 26 included papers. All four theories are elaborated upon below in order to provide insight into similarities and differences between papers.

2.3.2.1 Participatory research

According to Burke et al. (2003) and Walmsley (2004), participatory research strives for a partnership between patients and researchers, meaning that control is shared between both parties (Chapman, 2014; Marshall, 2012). Abma et al. (2009) stated that sharing of control leads to a "horizontal relationship" (p. 404). Nierse and Abma (2011) emphasised that the lack of control by people with ID could result in "pseudo participation" or "tokenism" (p. 412). Therefore, according to Abma et al. (2009), the intention of participatory research is to offer people with ID real control over the research with appropriate support.

2.3.2.2 Emancipatory research

Bigby and Frawley (2010) stated that emancipatory research is based on the idea that research about people with disabilities should be initiated and conducted by people with disabilities themselves, providing them with complete control over the research process (Burke et al., 2003; Chapman, 2014; Stevenson, 2010; Tuffrey-Wijne & Butler, 2010; Walmsley, 2004). The idea of complete control is formulated mainly from a physical disability perspective. Both Bigby and Frawley (2010) and Stevenson (2010) are sceptical about the capabilities of people with ID to control the entire research process.

2.3.2.3 Inclusive research

The term "inclusive research" was coined by Walmsley in 2001 (Bigby, Frawley, & Ramcharan, 2014a; Chapman, 2014), and is defined as "research which includes or involves people with learning disabilities as more than just subjects of research" (Walmsley & Johnson, 2003). According to Nierse and Abma (2011), its main focus is the collaboration between people with ID and researchers, and the provision of appropriate support. Inclusive research is the collective term for participatory and emancipatory research (Chapman, 2014; J. Walmsley, 2004); however, these terms should not be used interchangeably, as they are defined differently (Burke et al., 2003; Tuffrey-Wijne & Butler, 2010).

2.3.2.4 Arnstein's ladder of citizen participation

Arnstein's ladder of citizen participation was frequently cited in the papers included in this review. According to Abma et al. (2009), Arnstein's ladder is a well-known model displaying different levels of participation, ranging from manipulation to citizen control. Abma and Broerse (2010) stated that the ladder easily translates to the health field, albeit it only displays levels of participation without specifying how they may be achieved (Abma & Broerse, 2010). Beadle, Needham and Dearing (2012) state that Arnstein's ladder is insufficient: "to link participation to a ladder means that it cannot stand alone and needs to be supported by an outside structure" (p. 352). The ladder model indicates that the higher the rung, the better the participation, while, in some situations, lower rungs of participation are more applicable (Abma & Broerse, 2010). According to Abma et al. (2009), only the highest three rungs (i.e., partnership, delegated power and patient control) address actual active involvement.

2.3.3 Inclusive methods

The following section addresses inclusive methods used within the selected papers. Most information was found on collaboration with research partners. Other inclusive methods (i.e., interviews and focus groups) mainly focused on data collection strategies accessible for research partners.

2.3.3.1 Interviews

Ten out of 26 papers used interviews to include people with ID in health research. Out of these 10 papers, four conducted interviews collaboratively with research partners or self-advocates with ID (Abma, Nierse, & Widdershoven, 2009; Bigby et al., 2014a; Chapman, 2014; Haigh et al., 2013). Ailey, Friese and Nezu (2012) actively involved people with ID by means of cognitive interviews, where people with ID got the opportunity to provide input on a social problem-solving training programme. The remaining five papers used interviews to consult people with ID (Abell et al., 2007; Marshall, 2012; McDonald, 2012; McDonald, Kidney, & Patka, 2013; Nierse & Abma, 2011). Flood, Bennett, Melsome and Northway (2013) collaboratively prepared interviews with their research partners; however, the paper did not explicitly describe the actual execution of the interviews. Finally, Llewellyn and Northway (2008) deliberately refrained from interviews, since this would put “the researcher in an authoritative position that could be daunting to participants” (p. 215).

2.3.3.2 Focus groups

Eleven papers used focus groups. Three studies conducted focus groups in collaboration with research partners with ID, where focus groups were planned and moderated by research partners with ID (Abma et al., 2009; Nierse & Abma, 2011; O’Brien, McConkey, & Garcia-Iriarte, 2014), and seven studies actively involved people with ID by means of focus groups, where people with ID were involved as participants only (Boyden et al., 2009; Chapman, 2014; Llewellyn & Northway, 2008; Manthorpe, Alaszewski, Gates, Ayer, & Motherby, 2003; Marshall, 2012; McDonald, 2012; McDonald et al., 2013). In the final paper, Flood et al. (2013) trained their research partners on focus group methodology, but did not address the execution of these focus groups. Even though focus groups are seen as an appropriate research method for people with ID (Abma et al., 2009; Boyden et al., 2009; Llewellyn & Northway, 2008; Manthorpe et al., 2003), the design demands extra attention compared to focus groups with people without ID due to issues such as the development of accessible materials (Abma et al., 2009; Boyden et al., 2009).

2.3.3.3 Research partners

People with ID working in a research team were referred to in multiple ways: “co-researchers”, “research advisors” and “research partners”. Eighteen out of 26 included papers collaborated with research partners (Abell et al., 2007; Abma et al., 2009; Beadle, Needham, & Dearing, 2012; Bigby & Frawley, 2010; Bigby et al., 2014a; Brooks, Davies, & Twigg, 2013; Burke et al., 2003; Chapman, 2014; Flood, Bennett, Melsome, & Northway, 2013; Haigh et al., 2013; Marshall, 2012; McDonald, 2012; McDonald et al., 2013; Nierse & Abma, 2011; O’Brien et al., 2014; Stevenson, 2010, 2014; Tuffrey-Wijne & Butler, 2010). Research partners were defined as “patients who join research teams on an equal basis with professional researchers. They share decision making power with professionals, and their degree of involvement is closer to the patient as advisor or the patient as research principal” (Abma et al., 2009). Bigby, Frawley, and Ramcharan (2014b) added, “the position of the people with intellectual disability is not privileged in terms of power or control and researchers are not simply there to assist" (p. 8). Box 2.1 shows research partners' activities in included papers.

- Deciding on the research topic, questions and methods
- Applying for ethical approval
- Reviewing literature
- Developing accessible materials
- Recruiting participants with ID
- Designing and conducting questionnaires
- Designing and conducting interviews
- Designing and moderating focus groups
- Analysing data
- Disseminating findings by presenting at conferences, writing accessible reports or making an accessible DVD

Box 2.1 Research partner's activities

2.3.4 Added value

The presence of two elements of added value was determined in each paper: expected and experienced added value. The expected added value, as cited by authors, was extracted from introductory sections of publications. Information was extracted relating to reasons for using an inclusive methodology or mention of any added value accruing to these methods. The reported expected added value was unspecific and mainly focussed on demands by policy and funding bodies or ethical grounds (i.e., ethical notion and giving people with ID a voice). The experienced added value was retrieved from discussion sections, which were more concrete and focused on the gains attributed to an inclusive methodology for specific stakeholders. People with ID: were empowered; gained skills; gained confidence; gained experiences; gained employment; felt they could contribute; felt respected; experienced personal development; and experienced mutual understanding. Research(ers): experienced increased quality and validity; developed appropriate research materials; facilitated research with people with ID; safeguarded ethical standards; developed relevant research and outcomes; learned new skills; improved data analysis; facilitated recruitment; improved data dissemination; and experienced mutual understanding. For health care professionals, inclusive health research resulted in awareness of people with ID's needs. Papers were inconsistent in terms of the information provided on expected and experienced added value. None of the added value was formally measured.

2.3.5 Barriers and facilitators

Some papers explicitly state that there is a dearth of knowledge on barriers and facilitators of inclusive health research (Abma et al., 2009; O'Brien et al., 2014). In addition, inclusive health research published in scientific journals provides little insight into experiences with including people with ID (Bigby & Frawley, 2010). As a result, there is little "conceptual clarity" (p. 9) on inclusive health research (Bigby, Frawley, & Ramcharan, 2014b). For the current review, papers were searched for mention of barriers and facilitators of inclusive health research. This search generated thirteen themes. These themes were chronologically ordered following the preparing, undertaking and concluding phases of research. For most barriers and facilitators, good practices were found to overcome barriers or facilitate inclusive health research (see Table 2.4).

2.3.5.1 Preparing phase

Barriers identified during the preparing phase were recruitment, heterogeneity of people with ID, and informed consent; facilitators were training, relationships and practical aspects. Good practices were found for all but one of these themes (see Table 2.4). In the preparing phase, several authors questioned whether formal training was appropriate (Abma et al., 2009; Bigby & Frawley, 2010; Walmsley, 2004). According to these authors, mere "technical scientific training" (Abma et al., 2009) might mould people with ID into "professional patients" (Abma et al., 2009) or "pseudo professionals" (Walmsley, 2004). Authors argued whether skilling up people with ID to this level would make them unrepresentative of the broader population of people with ID who would not typically be expected to hold these skills (Abma et al., 2009; Walmsley, 2004). Walmsley (2004) adds that many researchers "fail to identify what skills people with learning difficulties have, and what extra skills they might need to be effective researchers, or where the work is better done by trained researchers" (p. 58).

2.3.5.2 Undertaking phase

In the undertaking phase, academic systems, financial resources, communication and overburdening were found to be barriers, while support and shared decision-making power were found to be facilitators. For most of these themes, good practices were found (see Table 2.4). During the undertaking phase, authors commented on the challenges of dividing decision-making power, since "even in a democracy some people have more to say than others" (Abell et al., 2007,

p. 122). According to Abma et al. (2009), people with ID are easily "overruled by researchers" (p. 402). People with ID were often insecure about their added value (Abma et al., 2009; Bigby & Frawley, 2010). According to Bigby et al. (2014a; 2014b), decision-making power should be equally distributed in order to prevent tokenism.

2.3.5.3 Concluding phase

The only facilitator found in the concluding phase was reflection for both researchers with or without ID in joint collaboration (see Table 2.4). However, in spite of the importance of reflection, Walmsley (2004) stresses inclusive research deals with "tension between content and process" (p. 56), in which there is a strong focus on the process of including people with ID and less focus on the quality of the research (Bigby et al., 2014b). The implication of this tension is that, while the process of inclusive health research demands extra attention, it should not undermine the quality of the research itself.

2.4 Discussion and conclusion

In this structured literature review, we aimed to gain insight into experiences of inclusive health research with people with ID regarding (1) existing theories, (2) inclusive methods, (3) added value and (4) barriers and facilitators. The discussion will be structured accordingly, and will address emergent themes per topic.

2.4.1 Theory: lack of clarity

A lack of clarity was found regarding what precisely inclusive health research entails. Firstly, a discrepancy was found in the application of existing theories: some papers did not mention any while others cited multiple theories. It may be that these theories are too abstract to support the implementation of inclusive health research.

Secondly, differences were observed in authors' perspectives of the appropriate moment of inclusion. Thirdly, some of the papers included in this review prioritised the inclusive process of the research over the quality of the research design.

Table 2.4 Barriers and facilitators of the preparing, undertaking and concluding phase

Theme	Barriers, facilitators and good practices
Preparing phase	
Recruitment	*Barriers*: assessing capability; most appropriate vs. most likely participants; using gatekeepers prevents active involvement; and people with ID tend to consent due to prior relationships. *Good practices*: flyers and advertisements; using gatekeepers facilitates active involvement; informal networking; and accessible information.
Heterogeneity of people with ID	*Barriers*: representativeness of people with mild/moderate ID for people with severe ID; use of proxies; and the myth of homogeneity .
Informed consent	*Good practices*: briefings, meetings or discussions; accessible information and consent forms; emphasise voluntary nature and possibility of withdraw; and view as a continuous process.
Training	*Facilitators*: increases confidence; and improves communication and interaction. *Good practices*: formal vs. informal training; accessible materials; training, discussion or consultation sessions; practice research skills; and collaborate with support staff.
Relationships	*Facilitators*: people with ID feel at ease and trust researchers; good working environment; benefits collaboration; express genuine feelings; and shared understanding. *Good practices*: process of naturalisation; learn how to build relationships; and collaborate with pre-existing groups/familiar people.
Practical aspects	*Good practices*: time; planning; job description; accessible meetings (i.e., travel time, date, duration and location).
Undertaking phase	
Academic systems	*Barriers*: people with ID were historically exploited; researchers torn between beneficence and autonomy; little time to organise inclusion; and experiential knowledge often seen as inferior.
Financial resources	*Barriers*: needed to provide transport, support, remuneration, compensation and salary; and a lack inhibits meaningful inclusion. *Good practices*: check benefit schemes to prevent reduction.
Communication	*Barriers*: differences in expectations and language use; difficulties with abstract thinking and recall; inclined to give socially desired answers; insufficiency of written information; and heterogeneous group. *Good practices*: Talking Mats; focus on concrete experiences; Dialogue approach; read out loud; accessible language and illustrations; and develop communication tools in collaboration with people with ID.
Overburdening	*Barriers*: high workload; insufficient communication; and emotional impact of other's stories. *Good practice*: providing sufficient breaks.
Support	*Facilitators*: increases input of people with ID; confirms added value; builds confidence; and meaningful inclusion.
Shared decision-making power	*Facilitators*: results in respect, autonomy and motivation. *Good practices*: work in partnership; open to diverse forms of inclusion; decisions based on emotions; Dialogue approach; and practice with unscripted questions.
Concluding phase	
Reflection	Good practices: informal meetings; interviews with research partners; keeping a diary; and Dialogue approach.

As stated by Bigby et al. (2014b), there is little "conceptual clarity" (p. 3) on inclusive health research. According to Marshall (2012), a literature review on inclusive research "would be helpful in determining progress to date and potential next steps in developing more inclusive and emancipatory research practices" (p. 29). Butler, Cresswell, Giatras and Tuffrey-Wijne (2012) stated "we would really like other researchers to write about their experiences about doing research together, both the good and the bad, so we can learn from each other" (p. 142). Morgan (2013) identifies "transparency" (p. 9) as a key aspect of inclusive research. Future research should aim to resolve this lack of clarity and provide transparency, possibly by developing a guideline for inclusive health research.

2.4.2 Inclusive methods: best practices

Collaboration with research partners, as opposed to consultation or control (INVOLVE, 2014b), seems to be the only inclusive method resulting in the active involvement of people with ID throughout the entire research cycle. However, with regard to inclusive methods, the found barriers and facilitators in Section 2.3.5 seem to be the route towards meaningful, inclusive health research. One might state this is the actual inclusive method. The inclusive process needs to be tailored to each individual inclusive health research project in order to anticipate the needs of all stakeholders. Future research should explore what methods or considerations optimise inclusive health research.

2.4.3 Added value: expected vs. experienced

When comparing the expected and experienced added value in Section 2.3.4, differences emerged. In the initial stages of the research process, authors indicated their motivation to conduct inclusive health research was based on demands by policy and funding bodies or on ethics (i.e., expected added value). At the conclusion of the research, authors perceived increased quality and validity of their research and benefits for stakeholders (i.e., experienced added value). A shift can be identified from researchers feeling initially obliged to actively involve people with ID in health research to a perception at the conclusion of the research that stakeholders benefitted from the inclusive methodology. Papers provided inconsistent information on expected and experienced added value, and none of the added value was formally measured. These variations may reflect the fact that inclusive research remains in a developmental phase. Both Walmsley (2004) and Bigby et al. (2014b) addressed the need for insight into the added value of inclusive health research. Tuffrey-Wijne and Butler (2010) also emphasised that researchers need to consider when inclusive health research is of added value. Based on these findings, future research should continue to explore the added value of inclusive health research and measurement possibilities.

2.4.4 Barriers and facilitators: myth of homogeneity

Bigby et al. (2014b) addressed the difference between the most appropriate vs. most likely participants in inclusive health research. Researchers tend to actively involve easily accessible people with ID. However, these are not always the most appropriate participants for a given research topic. Inclusive studies should consider what experience people with ID need to answer the research question and what this means for the representativeness of the study. Relating to this, Stevenson (2010) addressed the "myth of homogeneity" (p. 42): not every person with ID can represent the rest of the population. Inclusive health researchers are not always aware of the diversity of the ID population, which is confirmed by the absence of people with severe or profound ID in research and attempts to represent them by proxy. Walmsley (2004) stated that current communication is insufficient for this part of the ID population. According to Brookes et al. (2012), "at the root of issues about language use are issues of power" (p. 148), making the active involvement of people with severe and profound ID even more challenging. Future research needs to focus on the representation of all people with ID in health research, notably how to actively involve people with severe and profound ID directly or by proxy.

2.4.5 Strengths and limitations

Due to the lack of a standard search term for inclusive health research, a working definition was used and the search strategy was developed in collaboration with an information specialist. We expect that the 26 papers (including papers from a special issue of JARID on inclusive research) provide a good representation of inclusive health research for people with ID published within the used timeframe. Note, the papers included in this review only addressed people with mild or moderate ID. Findings of this study might, therefore, not generalize to people with severe or profound ID.

During the analysis it became apparent that it was difficult to judge from written text whether the inclusion of people with ID was meaningful or tokenistic. Often more information on the process of inclusion was needed. To improve transparency in reporting inclusive health research and sharing research experiences, a guideline with points to address would be helpful. This review contributes to the knowledge base needed to develop such a guideline.

2.4.6 Conclusions and recommendations

Concluding from this extensive review, the following recommendations are proposed to advance inclusive health research: inclusive health research should (1) tailor the inclusive process to the specific research topic and stakeholders involved; (2) anticipate the skills, capabilities, and preferences of all stakeholders involved; (3) consider where the active involvement of people with ID is of added value; and (4) provide insight into the inclusive process. Future research can help to enhance transparency of inclusive practices in order to reduce the lack of clarity and facilitate reflection on inclusive health research.

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Chapter 3

An exploration of the participation of people with intellectual disabilities in research

A structured interview survey

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Abstract

Background: Even though participation of people with intellectual disabilities in research is increasingly common, there is little insight into how many people with intellectual disabilities participate, their motivations to participate, and their interests regarding study results.

Method: Five questions were added to the Panel Living Together (PLT) survey among 508 people with intellectual disabilities. The questions aimed to gain insight into the (i) frequency of participation, (ii) methods used to participate; (iii) motivations to participate; and (iv) interests regarding study results.

Results: Although 73.5 % (n=347) of the respondents enjoyed their participation and 71.6% (n=312) found it important to participate, only 11.8% (n=60) participated in research other than PLT. Of the respondents, 61% (n=261) indicated they wanted to be informed about study results, 29.1% (n=148) of this group stated they wanted to compare, learn, and share information.

Conclusions: Future research should focus on how motivations of people with intellectual disabilities to participate in inclusive research, such as "empowerment", can be supported in order to facilitate their involvement in research.

3.1 Introduction

Participation of people with intellectual disabilities in research, both as consultants as well as collaborators, is an emergent topic (Puyalto, Pallisera, Fullana, & Vila, 2015). This is in line with the United Nation’s Convention on the Rights of Persons with Disabilities (UNCRPD) and British Disability Studies movement’s motto “nothing about us without us”, which strive for people with intellectual disabilities’ participation in all aspects of life (Shakespeare & Watson, 2002; United Nations, 2006). Another movement contributing to the increase of people with intellectual disabilities’ participation in research is the “inclusive research movement”. The term inclusive research was coined by Walmsley and Johnson and is defined as: “research which includes or involves people with learning disabilities as more than just subjects of research” (Walmsley & Johnson, 2003), p. 61. It is based on the principles that: (i) the research topics studied matter to people with intellectual disabilities; (ii) the research presents people with intellectual disabilities’ perspective; and (iii) that people with intellectual disabilities are treated with respect (Nind & Vinha, 2014; Walmsley & Johnson, 2003). Inclusive research has its roots in the 1950s, where health service users demanded to have a voice in medical decisions affecting them. This evolved in health service users’ involvement through participatory research (Wilson et al., 2015), including people with intellectual disabilities. Over the past decades, two generations of inclusive research developed. The first generation confirmed and addressed the need for inclusive research. The second generation started more recently with a focus on outcomes, added value, effective methods and partnerships, and benefits for both individuals and research teams (Grant & Ramcharan, 2007).

People with intellectual disabilities can participate in research in several ways. Firstly, they can participate by means of consultation through, for example, questionnaires or interviews, which means people with intellectual disabilities are respondents or subjects of research. Secondly, they can participate by means of collaboration or control through, for example, the role of advisory board member or co-researcher, which is a more inclusive manner of participation (INVOLVE, 2014). Despite the increased focus on participation of people with intellectual disabilities in research, it has mostly been approached from an academic perspective and is only limited discussed with people with intellectual disabilities themselves (Puyalto et al., 2015). Insight into participation in research mainly focuses on individual experiences from co-researchers who have participated in a collaborative manner (Nind & Vinha, 2014). Little insight exists beyond individual experiences, for instance into the frequency in which people with intellectual disabilities participate in research, the way they participated and the extent to which participation fits their needs and interests. This study aims to contribute to this insight by involving the Dutch Panel Living Together, existing of 508 people with intellectual disabilities. The objective of this brief report is to explore the participation of people with intellectual disabilities in research by means of a structured interview survey amongst people with intellectual disabilities regarding: (i) frequency of participation; (ii) methods used to participate; (iii) motivations to participate; and (iv) interests regarding study results.

3.2 Method

3.2.1 Panel Living Together

Questions on "participation in research" were added to the Panel Living Together (PLT) questionnaire, which was established as part of a Dutch national research programme on community participation of people with intellectual disabilities in 2006 by the National Institute of Health Services Research (NIVEL). PLT consists of approximately 550 people with intellectual disabilities and 400 (in)formal carers, living in the Netherlands who were recruited via ambulatory care providers for people with intellectual disabilities and general practitioners. PLT members were included if they (i) were 15 years or older, and (ii) had mild to moderate intellectual disabilities (Cardol, Speet, & Rijken, 2007). A structured interview survey is conducted biannually among PLT members with intellectual disabilities covering the topics: living; leisure; work and daily activities; social contacts; finances; and Internet. The survey is conducted face-to-face by trained interviewers at the respondents' preferred locations. In 74% of the interviews, (in)formal carers assisted respondents. In November 2014, the survey included questions on the topic "participation in research". PLT offers the opportunity to use data on respondents' descriptives such as sex, age, and level of intellectual disabilities (NIVEL, 2015). PLT is registered with the Dutch Data Protection Authority (registration number 1342229), and data are collected according to the Authority's privacy protection guidelines (Dusseljee, Rijken, Cardol, Curfs, & Groenewegen, 2010). This paper addresses the results on the topic "participation in research" only.

3.2.2 Survey questions

Survey questions were compiled in collaboration with two co-researchers with intellectual disabilities and a PLT researcher (NB). The co-researchers and lead researcher discussed the PLT, its participants, and topics of interest to the co-researchers during several meetings over the course of 2 months. Recurring themes during these discussions were: “how many”, “how”, and “why” people with intellectual disabilities participated in research. Additionally, one of the co-researchers elaborated upon her personal experience while participating in research, where she received no feedback afterwards. She wondered whether other people with intellectual disabilities experienced the same. Eventually, the co-researchers and lead researcher agreed on the topics: (i) frequency of participation, (ii) methods used to participate, (iii) motivation to participate, and (iv) interests regarding study results. The PLT researcher provided input through e-mail correspondence on how questions, explanations and examples could be formulated. Additionally, literature was used to contribute to the answer categories. The final questions are listed in Box 3.1. In order to try to prevent socially desirable answers, respondents were not obliged to answer the questions to continue with the survey; however, this cannot entirely be prevented.

1 Have you ever participated in a scientific study besides the Panel Living Together? *(If ‘no,’ continue with question 3, otherwise continue with question 2)*
2 I will now state a number of ways in which you can participate in a scientific study. I would like to know whether you have actually participated in any of the following ways. *(Multiple answers are possible)*
    a. Physical tests or examinations?
    b. A questionnaire (online or on paper)?
    c. A one-to-one conversation with a researcher? This is also called an interview. For example, the Panel Living Together.
    d. A group interview with a researcher together with other people with ID, carers, and/or doctors for example?
    e. An advisory board or client council?
    f. Working as a researcher, for example by interviewing people with ID or carers together with a researcher?
3 I will now state a number of reasons for participating in a scientific study including the Panel Living Together. I would like to know why you participated in a scientific study. *(Multiple answers are possible)*
    a. Did you expect to enjoy it?
    b. Did you want to learn something from it?
    c. Did you think the research was important?
    d. Did you want to become a more confident person?
    e. Did you want to have something to do?
4 Do you want to be informed about the results of the scientific study?
5 What do you want to know about the results of the scientific study?

Box 3.1 PLT questions on participation in scientific research

3.2.3 Data analysis

Data from multiple-choice questions 1–4 were analysed using descriptive statistics (SPSS Statistics 20) by computing them into percentages per response category. Questions 1 and 4 consisted of four answer categories: 'yes', 'no', 'I don't know', and 'I can't answer the question'. Data from the open-ended question 5 were quantified and categorized. All questions have missing data as respondents were not obliged to answer every question to complete the survey, and, therefore, valid percentages and number of respondents are presented as results.

3.3 Results

A total of 508 respondents completed the entire PLT survey in 2014, of which 289 were men (56.9%). Respondents' descriptives are presented in Table 3.1.

Table 3.1 PLT respondents' descriptives in 2014 (n=508)

Variable	Answer category	N	Valid percent
Sex	Man	289	56.9
	Woman	219	43.1
Age	15–39 years	168	33.1
	40–64 years	268	52.8
	65+ year	72	14.2
Level of intellectual disabilities	Mild	311	61.2
	Moderate	197	38.8
Housing	Group home in residential setting	42	8.3
	Group home in community setting	62	12.2
	Independent in community, with support	200	39.4
	Independent in community, without support	34	6.7
	Family	25	4.9
	Other	5	1.0
	Unknown	70	13.8

Some data are missing as respondents were not obliged to answer every question to complete the survey. Therefore, valid percentages and number of respondents are presented.

3.3.1 Frequency of participation and ways to participate

Of the 508 respondents, 60 (11.8%) respondents indicated they were involved in research other than PLT surveys, 350 (68.9%) respondents stated they did not participate in other research, 65 (12.8%) respondents did not know whether they participated in other research, and 33 (6.5%) respondents could not answer the question. Table 3.2 presents the frequency of participation by respondents who have indicated to have participated in research other than PLT surveys (n=60; 11.8%). The majority of these respondents participated through consultation. Several respondents participated through collaboration, with advisory boards (43.3%) being the most frequent.

Table 3.2 Frequency and ways to participate in research other than PLT (n=60)

Method	Answer category	N	Valid percent (n=60)
Questionnaires	Yes	40	66.7
	No	17	28.3
	I don’t know	3	5.0
Interviews	Yes	34	56.7
	No	23	38.3
	I don’t know	3	5.0
Physical tests or examinations	Yes	29	48.3
	No	28	46.7
	I don’t know	3	5.0
Advisory boards	Yes	26	43.3
	No	31	51.7
	I don’t know	3	5.0
Focus groups	Yes	16	26.7
	No	41	68.3
	I don’t know	3	5.0
Working as a co-researcher	Yes	7	11.7
	No	51	85.0
	I don’t know	2	3.3

Some data are missing as respondents were not obliged to answer every question to complete the survey. Therefore, valid percentages and number of respondents are presented.

3.3.2 Motivation to participate

Nearly all respondents (n=471; 92.7%) answered the question on their motivation to participate in research. The majority indicated that they did so because they (1) expected to enjoy it (n=347; 73.5%) and (2) found research important (n=312; 71.6%). For all motivations except “enjoy it”, the answer category “I don’t know” is relatively high (Table 3.3).

Table 3.3 Motivation to participate (n=471; 92.7%)

Motivation	Answer category	N	Valid percent
Did you expect to enjoy it?	Yes	346	73.5
	No	21	4.5
	I don't know	75	15.9
	I can't answer the question	29	6.2
	Total	471	100
Did you find research important?	Yes	312	71.6
	No	21	4.8
	I don't know	100	22.9
	I can't answer the question	3	0.7
	Total	436	100
Did you want to learn from it?	Yes	212	48.0
	No	101	22.9
	I don't know	123	27.8
	I can't answer the question	6	1.4
	Total	442	100
Did you want to become a more confident person?	Yes	166	38.3
	No	89	20.6
	I don't know	177	40.9
	I can't answer the question	1	0.2
	Total	433	100
Did you want something to do?	Yes	138	31.9
	No	170	38.4
	I don't know	120	27.8
	I can't answer the question	4	0.9
	Total	432	100

Some data are missing as respondents were not obliged to answer every question to complete the survey. Therefore, valid percentages and number of respondents are presented.

3.3.3 Interests regarding study results

Of the 428 respondents who have completed question 4, 261 (61.0%) indicated interest in the results of studies to which they contributed, 100 (23.4%) did not find it important, 66 (15.4%) did not know whether they found it important, and one respondent (0.2%) could not answer this question. Of the respondents who wanted to receive results, 148 (29.1%) answered question 5. Answers to the open-ended question included a desire to receive as many study results as possible, because they were curious and interested. They wanted to use the results to compare themselves with others, learn from the results, and share the information with others.

3.4 Discussion

This structured interview survey aimed to explore the participation of people with intellectual disabilities in research. Although 73.5% (n=347) of the respondents enjoyed their participation and 71.6% found it important to participate (n=312), only 11.8% (n=60) participated in research other than PLT. Of the respondents who answered question 2 on participation methods (n=60), only 43.3% (n=26) participated as an advisory board member and 11.7% (n=7) as a co-researcher, which are seen as inclusive research methods (Frankena, Naaldenberg, Cardol, Linehan & van Schrojenstein Landman-de Valk, 2015). To our knowledge, no data exist on the frequency of participatory research with other patient groups or the general population, making comparison difficult. This study did not examine why people with intellectual disabilities did not participate in other studies (e.g., no opportunities or interest to participate). Additionally, when looking at inclusive research's definition, the emphasis is on how people with intellectual disabilities are included (e.g., 'as more than just subjects of research'), not on how many people are involved. Nonetheless, these percentages do not reflect the aim of inclusive research, where people with intellectual disabilities should have the chance to be actively involved (Walmsley & Johnson, 2003). The definition of inclusive research by Walmsley and Johnson (2003) leaves a lot of room for interpretation (Bigby, Frawley, & Ramcharan, 2014; Blunt et al., 2012) and researchers can have their own perception and interpretation of such research, resulting in a variety of inclusive methods.

This study provides insight into the motivations of people with intellectual disabilities to participate in research. Respondents in this study scored several motivations relatively highly (i.e., expecting to enjoy it, finding research important, learning from it, becoming a more confident person, and having something to do). In studies on experiences of co-researchers, topics such as increasing self-esteem, increasing social capital, learning new skills, and expressing yourself were mentioned as motivations to participate in research (Beighton et al., 2017; Puyalto et al., 2015), which correspond with findings from this study. A recent literature review comparing 26 studies applying inclusive research on characteristics including motivations found that many researchers expect “empowerment” to be people with intellectual disabilities’ core motivation to participate in research (Frankena et al., 2015). Empowerment might partly be a motivation for people with intellectual disabilities to participate in research – captured in topics such as learning new skills and increasing social capital; however, this is not the sole reason for people with intellectual disabilities to participate in research. Furthermore, 61% of the respondents expressed interests in the studies they participated in. Responding to these motivations and interests is a sign of commitment towards people with intellectual disabilities and greater attention should be given to this, expecting that it improves research. As a result of improved research through participation, we expect that the health care and overall quality of life of people with intellectual disabilities can improve through meaningful dialogue with this group.

3.4.1 Strengths and limitations

Questions were developed in collaboration with two co-researchers with intellectual disabilities. However, trained interviewers indicated that some respondents found these interview questions difficult to answer and the topic complicated. Interviewing people with intellectual disabilities can be challenging because of the risk of response bias, acquiescence, recency, and nay-saying (Finlay 2015; Finlay & Lyons, 2001). Thus, for future research purposes, methods should be explored to increase accessibility of the topic “participation in research”, in order for people with intellectual disabilities to be able to contribute meaningfully to research. One of these methods is developing accessible information in collaboration with co-researchers with intellectual disabilities.

The respondents in this study are not representative of the entire intellectual disabilities population in the Netherlands. People with more severe intellectual disabilities are excluded from PLT because of communication challenges, and, therefore, results cannot be generalized to people with severe and profound intellectual disabilities. Additionally, PLT consists of a select group of people with intellectual disabilities of which the majority has participated in previous PLT surveys and are more likely to have participated in other research. Thus, the frequency of their participation in research other than PLTs might be higher than that of the general population with mild to moderate intellectual disabilities. This is worrisome for the frequency of participation in research for the whole population with intellectual disabilities, as this is possibly even lower. However, because of PLT respondents' ability to speak from experience, their contribution on this scarcely researched topic is important. Moreover, this is one of first quantitative explorations of the participation of people with intellectual disabilities in research from people with intellectual disabilities' perspective. Future research should deepen the understanding of how people with intellectual disabilities can actively participate in research, especially through inclusive research methods, as this is expected to improve their health, healthcare and quality of life.

3.5 Conclusion

This structured interview survey has given initial insight into people with intellectual disabilities' participation in research. A minority of the respondents participated in research other than PLT, even less participated through inclusive methods, despite their response that they found research enjoyable and important. Almost half of the respondents indicated that they wanted to learn from research. Researchers' assumptions about people with intellectual disabilities' motivation to participate only partly concur with their actual motivation to participate. This calls for meaningful collaboration between people with intellectual disabilities and academics in order to explore each others' preferences, needs, and motivations.

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Chapter 4

Exploring academics' views on designs, methods, characteristics, and outcomes of inclusive health research with people with intellectual disabilities

A modified Delphi study

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Abstract

Background: The *British Medical Journal's* (*BMJ*'s) patient revolution strives for collaboration with patients in healthcare and health research. This paper studies collaboration with people with intellectual disabilities (ID) in health research, also known as inclusive health research. Currently, transparency and agreement among academics is lacking regarding its main aspects, preventing upscaling of the patient revolution.

Objective: This study aims to gain agreement among academics on 3 aspects of inclusive health research for people with ID: (1) designs and methods, (2) most important characteristics, and (3) outcomes.

Design: A Delphi study was conducted with academics with experience on inclusive (health) research and on people with ID. The study consisted of 2 sequential questionnaire rounds (n=24; n=17), followed by in-depth interviews (n=10).

Results: Academics agreed (1) the approach collaboration to be most suitable to inclusive health research, (2) characteristics regarding the accessibility and facilitation of inclusive health research, and (3) several outcomes of inclusive health research for people with ID and healthcare. Other characteristics agreed upon included: atmosphere, relationship, engagement, partnership, and power. It was stressed that these characteristics ensure meaningful inclusion. Interviewed academics voiced the need for a tool supporting the facilitation and evaluation of inclusive health research. There was ambiguity as to what this tool should comprise and the extent to which it was possible to capture the complex process of inclusive health research.

Discussion and conclusions: This study underlines the need for transparency, facilitation and evaluation of inclusive health research. The need for in-depth interviews after 2 Delphi rounds underlines its complexity and context dependence. To increase process transparency, future research should focus on gaining insight into inclusive health research in its context. A tool could be developed to facilitate and evaluate inclusive health research. This tool will be partially applicable to participatory research in general and thereby upscale the patient revolution.

4.1 Introduction

The *British Medical Journal* (*BMJ*) has been promoting the patient revolution since 2013. This revolution encourages collaboration between patients and healthcare professionals and aims to improve the quality of healthcare (Richards, Montori, Godlee, Lapsley & Paul, 2013). The next step in this revolution is patients' involvement in health research. This addresses the mismatch between research agendas and patients' needs as well as increasing the sustainability (Richards et al., 2013) of health systems and accountability in healthcare and research (Tudrej & Herve, 2014; Vayena, 2014). The patient revolution and participation in health research is of great importance to a vulnerable and marginalised group such as people with intellectual disabilities (ID) (Naaldenberg, Banks, Lennox, Oullette-Kunz, Meijer & van Schrojenstein Lantman – de Valk, 2015), as it is expected to improve the much needed healthcare they receive. Increasingly more papers are published on the participation of different patient groups in research, such as people with rheumatism (Hewlett et al., 2006), acquired brain injury (Schipper, Visser-Meily, Hendrikx & Abma, 2011), and mental health issues (Van der Ham, 2013), as well as on participatory research in general (Telford, Boote, & Cooper, 2004). It remains uncertain whether these studies fit the needs of people with ID when they collaborate in health research.

People with ID are identified as experiencing limitations in intellectual functioning and adaptive behaviour originating before the 18th year of life (AAIDD, 2013). As a result, they face a multitude of health inequities compared to the general population (Naaldenberg et al., 2015). These health inequities and unmet needs regarding their limitations complicate their active participation in health research, also known as inclusive health research (Frankena, Naaldenberg, Cardol, Linehan & van Schrojenstein Lantman de Valk, 2015; Walmsley & Johnson, 2003). Inclusive health research is defined as 'research which includes or involves people with learning disabilities as more than just subjects of [health] research' (Walmsley & Johnson, 2003, p. 61). On the basis of expected outcomes of the patient revolution, inclusive health research could contribute to resolving the health inequities and unmet needs of people with ID.

Despite increasing demands, it remains unknown why some inclusive health research activities succeed while others fail (Beadle, Needham & Dearing, 2012; Beierle & Konisky, 2000; Bollard, Lahiff & Parkes, 2012; Popay, Collins & Public involvement impact Assessment Framework Study Group, 2014). The evaluation of inclusive health research is challenged by ethical dilemmas such as inclusion being a right in itself regardless of its contribution to the research process (Van Veen, 2014b). In order to gain a scientific perspective and facilitate inclusive health research (deBronkart, 2015), knowledge and experiences should be shared among academics on three topics. First, a recent literature review has shown that it is unclear which research designs and methods best fit inclusive health research (Frankena et al., 2015). Second, there is little agreement on the important characteristics of inclusive health research (e.g., payment and training of people with ID) (Beadle, Needham & Dearing, 2012; Beierle & Konisky, 2000; Bollard, Lahiff & Parkes, 2012; Popay et al., 2014). Third, expected or experienced outcomes of inclusive health research, such as improved quality and validity of research or increased empowerment of people with ID, are often not explicitly evaluated or assessed (Elberse, 2012; Frankena et al., 2015; Van der Ham, 2013). The views of people with ID are of great importance, and their perspectives will be explored in another study. This study focuses specifically on academics with experience on inclusive (health) research, as many ambiguities exist among them and they have a responsibility in making research inclusive. Therefore, a Delphi study was conducted aiming to gain academics' agreement on: (1) designs and methods, (2) most important characteristics and (3) outcomes of inclusive health research.

4.2 Methods and participants

4.2.1 Delphi method

The Delphi method is commonly used to allow respondents in a certain field of work to achieve agreement on a set of criteria. In several rounds, respondents are independently questioned about their opinion, usually by means of a standardised questionnaire. After each round, the researcher provides the participating respondents with so-called controlled opinion feedback in the form of a summary of the results from the previous round. On the basis of this feedback, the respondents may choose to revise or retain their opinion in the next round. To prevent group pressure or undue influence of dominant individuals, the respondents remain anonymous throughout the course of the study and are not expected to communicate with one another. Respondents are not allowed to participate in the subsequent questionnaire, if they did not complete the previous one (Hsu & Sandford, 2007; Linstone & Turoff, 1975; Meijering, Kampen & Tobi, 2013; Powell, 2003). The current Delphi study consisted of two rounds. Figure 4.1 provides an overview of the study procedure.

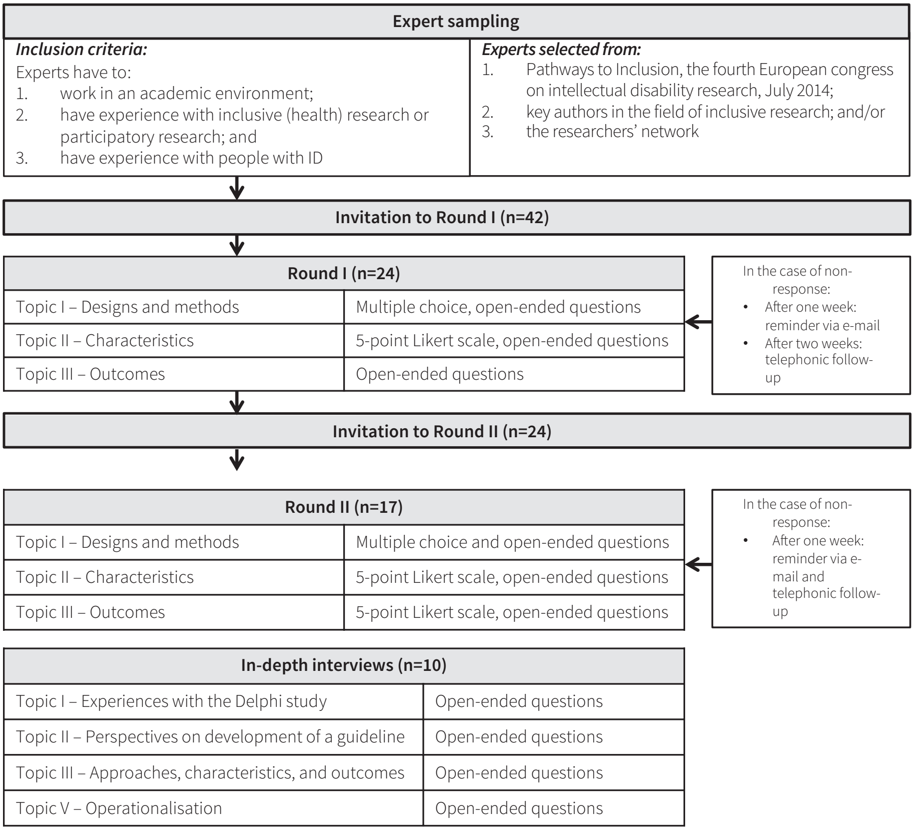

Figure 4.1 Overview of study procedure

For each round, a standardised questionnaire was designed, programmed as a web-survey using the online software survey tool LimeSurvey (LimeSurvey, 2016) and then language checked by a professional translation service. The first questionnaire ran from 1 August to 8 September 2014, with telephonic follow-ups to non-response after two weeks. The second questionnaire ran from 25 September to 4 October 2014, with telephonic follow-ups to non-response after 1 week. After the two questionnaire rounds, academics' rationales indicated that in-depth interviews were needed.

4.2.2 Patient involvement

This Delphi study is part of a PhD project on inclusive (health) research in which two people with ID collaborated as co-researchers. The characteristics in the questionnaires have been discussed with one of these co-researchers in order to gain her perspective on the matter. Additionally, the results of the study were discussed with both co-researchers. However, an adaptation of the Delphi study methodology accessible to people with ID is currently non-existent, resulting in information not suitable to a Delphi study paper. Moreover, presenting the discussions with both co-researchers goes beyond the scope of this study, as it is aimed at gaining agreement among academics. Reflections by the co-researchers on inclusive research, including this Delphi study, are a work in progress and will be published in a later stage of the PhD project.

4.2.3 Panel

An international panel of academic researchers was assembled. Academics were considered as respondent if they (1) had experience with inclusive (health) research or participatory research and (2) had experience in working with people with ID. Names of potential respondents were acquired from the conference proceedings of the fourth International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) European conference in June 2014 (www.iassidd.org) and the researchers' network. Additionally, key authors in the field of inclusive research were approached. A total of 42 academics were invited to round I. Details of the researchers are provided in the Results section.

4.2.4 Questionnaire design

The questionnaire for round I was designed on the basis of (1) a previously conducted structured literature review on inclusive health research (Frankena et al., 2015) and (2) a literature search on characteristics of inclusive health research. The questionnaire was piloted by means of cognitive interviews with academics (n=3). In a cognitive interview, interviewees are asked to fill in the questionnaire wile thinking out loud. The interviewer probes the thoughts of the interviewee with the aim to identify errors in the questionnaires (Willis, 2005). The interviewees who participated in the cognitive interviews did not participate in the actual Delphi study. The questionnaire for round II included controlled opinion feedback from round I, consisting of bar charts, medians, and IQRs (Bolger & Wright, 2011) as well as summaries of academics' rationales. Academics were asked to answer the same questions as in the previous round in light of this feedback. Both questionnaires contained three main topics:

1. Designs and methods: academics were asked to assign a list of research designs and methods to either or both of the following two approaches to participatory research (INVOLVE, 2014): (1) *collaboration*, where researchers and the public work in partnership and make joint decisions and (2) *control*, where the public has complete decision-making power. This subdivision should lead to insight into whether different research designs and methods lead to different types of inclusive health research. Additionally, academics were allowed to state that they 'don't know'. Academics were offered the opportunity to provide rationales for their decisions.
2. Characteristics: academics were asked to rate the importance of a list of characteristics (Table 4.1) of inclusive health research on a five-point Likert scale ranging from *very unimportant* to *very important*. With regard to inclusive health research in general, various characteristics within the following five themes were presented: recruitment, accessibility, facilitation, reflection, and evaluation. Additionally, several characteristics specific to the approaches *collaboration* and *control* were presented, as these were expected to differ because of differences in power dimensions. Academics were asked to provide rationales for their ratings.
3. Outcomes: in round I, academics were asked to name the two most important expected outcomes of inclusive health research for four different stakeholder groups: (1) people with ID, (2) research(ers), (3) healthcare and (4) society. In round II, a list of these outcomes was presented, and academics were asked to rate the importance of each outcome for each of the four stakeholder groups on a five-point Likert scale, again ranging from *very unimportant* to *very important*.

Table 4.1 Summary of characteristics of inclusive health research in the questionnaire

In general

Recruitment

- Description of recruitment process
- Representative sample of people with ID

Accessibility

- Accessible information
- Feedback on accessible information
- Accessible research outcomes
- Time provided to discuss information
- Accessible resources
- Description of provision of accessible information
- Description of development of accessible information
- Task definitions

Facilitiation

- Acknowledgement of extra resources by funding bodies
- Sufficient amount of time provided
- Participation as early as possible
- Structured and described decision-making process
- Inclusive distribution of research outcomes
- Involvement in research agenda setting
- Attention on helper-relations
- Inclusive implementation of research outcomes

Reflection

- Ethical reflection
- Reflection on justification

Evaluation

- Insight into added value
- Evaluation on personal learnings
- Evaluation on mutual learnings

Specific to collaboration approach	*Specific to control approach*
• Open, respectful, and confidential atmosphere • Relationship with research group • Training during participation • Partnership and shared decision-making power • Power to influence research • Training before participation • Salary • Remuneration • Number of people with ID higher than professionals	• Open, respectful, and confidential atmosphere • Engagement with research group • Training during participation • Power to influence research • Training before participation • Salary • Complete decision-making power • Remuneration • Number of people with ID higher than professionals

4.2.5 In–depth interviews

In round II, academics indicated that the standardised questionnaires limited them in providing the desired depth of information. In order to provide academics the opportunity to elaborate, they were invited to take part in in-depth interviews. To gain a variety of responses a selection was made from academics who either completed (n=5) or did not complete (n=4) both questionnaires. One academic who participated in the cognitive interviews was also included. Additionally, academics from varying fields of expertise were invited. On the basis of preliminary results from the questionnaires, the three main topics were discussed as well as the expressed need for the development of a tool or guideline for inclusive health research. Interviews took 45 min on average and were conducted via telephone or Skype between 17 October and 5 November 2014.

4.2.6 Data analysis

It was decided that agreement regarding designs or methods of inclusive health research (topic I) was achieved when ≥*70%* of the academics assigned it to a particular inclusive approach. Two steps were taken in order to decide whether agreement was achieved regarding the most important characteristics and outcomes of inclusive health research (topics II and III). First, the characteristic or outcome had to have a median of 5 (i.e. response category *very important*), indicating a high level of importance of the characteristic or outcome. Second, the characteristic or outcome had to have an IRQ of 0, indicating that the majority of the academics agreed the high level of importance of the characteristic or outcome. All quantitative analyses were conducted in SPSS Statistics 20. For topic II, only characteristics which reached agreement are presented in Tables 4.4 and 4.5 for the purpose of readability.

Rationales and in-depth interviews were used to provide academics the opportunity to identify and elaborate upon important themes within the questionnaire. Themes were identified as important when mentioned more than once. Academics' rationales were analysed for similarities and differences, grouped into themes and summarised. In-depth interviews were transcribed verbatim and imported into ATLAS.ti 7. Transcripts were independently coded by two researchers (TKF and JN) by means of a code book based on a previous literature review (Frankena et al., 2015) and preliminary results from the two questionnaires. Interpretations were compared and contrasted. For example, in some cases different codes were used for similar pieces of texts. After discussion the most appropriate codes were chosen.

Table 4.2 Descriptives

Field of expertise	Participant number	Number of academics in round I	Number of academics in round II	Number of in-depth interviews
Health and Disability Research • Intellectual Disability Research (n=8) • Disability and Health (n=2) • Epidemiology (n=1) • Speech-Language Pathology (n=1) • Health Science (n=1) • Disability Studies (n=4) • Community Care (n=1)	1, 2, 3, 4, 5, 6, 7, 9, 10, 11, 12, 13, 14, 18, 19, 20, 21, 24	18	12	4
Participatory Research • Participatory Action Research (n=1) • Inclusive Research (n=1) • Patient Participation (n=1)	8, 16, 23 NA	3	2	2
Mental Health Research • Mental Health (n=1) • Psychology (n=2)	15, 17, 22	3	3	3
Cognitive interview (n=2)	NA	NA	NA	1
Total		24	17	10

4.3 Results

The response rate to the first questionnaire was 57% (n=24) and to the second questionnaire 71% (n=17), resulting in a dropout rate of 29%. Reasons for non-response were: time constraints, sick leave, and maternity leave. Academics originated from the UK (n=6), the Netherlands (n=6), Ireland (n=3), Canada (n=3), Australia (n=2), South Africa (n=2), the USA (n=1) and Belgium (n=1). Other descriptives can be found in Table 4.2.

4.3.1 Topic I: Designs and methods for inclusive health research

Academics' rationales indicated that advisory boards, self-advocates and research partners are not seen as inclusive methods as such, but as roles in the research process which give people with ID (partial) control over the research. This distinction is adopted in Table 4.3. In round I, agreement was reached on the suitability of all methods and roles to the *collaboration* approach. In round II, complete agreement disappeared, where clinical research and randomised controlled trials (RCTs) were no longer agreed upon as methods allowing for *collaboration*. The low percentages for the *control* approach shows that no agreement on suitable designs, methods, or roles was reached after two rounds.

Table 4.3 Designs, methods, and roles in inclusive health research

	Collaboration		Control	
	Round I (%)	Round II (%)	Round I (%)	Round II (%)
Design and research methods				
• Clinical research	**71**	65	17	24
• RCTs	**79**	59	21	6
• Questionnaires	**88**	**82**	38	41
• (Semi)structured interviews	**88**	**82**	33	41
• In-depth interviews	**83**	**88**	21	53
• Focus groups	**92**	**82**	33	53
Roles				
• Advisory board	**79**	**77**	38	35
• Self-advocates	**71**	**77**	58	53
• Research partners	**88**	**100**	42	47

For each design, research method and role percentages per response category where calculated. Percentages ≥ *70%* (in bold) reflect agreement.

4.3.1.1 Academics' rationales regarding designs and methods for inclusive health research

Researchers should strive for the *collaboration* approach, as 'neither experts nor people with an intellectual disability would be expected to independently control the research' (academic 9). This is reflected in the level of agreement on collaboration in Table 4.3. Quantitative research (i.e. clinical research, RCTs, questionnaires) was seen as a consultation method. However, people with ID can collaborate in this type of research when given a role as advisory board member, self-advocate or research partner. In the end, it is the researcher's commitment to the inclusiveness of the study that really matters.

4.3.2 Topic II: Characteristics of inclusive health research

4.3.2.1 Characteristics of inclusive health research in general

Little change in agreement occurred between rounds I and II regarding the importance of general characteristics of inclusive health research. Table 4.4 shows that most agreement was reached on characteristics within the themes accessibility and facilitation. Within the theme recruitment, the importance of a description of the recruitment process was emphasised in the second round. However, representative sampling was not seen as important in either round. No agreement was reached on characteristics relating to the themes reflection and evaluation.

Table 4.4 Characteristics of inclusive research in general

Theme	Agreement upon characteristics Round I	Agreement upon characteristics Round II
Recruitment	None	Description of recruitment process
Accessibility	Accessible information Accessible research outcomes Time provided to discuss information Accessible resources	Idem round I and: Feedback on accessible information Description of provision of accessible information
Facilitation	Acknowledgement of extra resources by funding bodies Sufficient amount of time provided Participation as early as possible Structured and described decision-making process	Idem round I and: Inclusive distribution of research outcomes
Reflection	None	None
Evaluation	None	None

For each characteristic, agreement was achieved when: median=5 (category *very important*) and IQR=0.

4.3.2.2 Academics' rationales regarding characteristics in general

Inclusive health research is demanding in terms of resources and the way in which to include people with ID needs to be carefully considered. This is reflected by the many characteristics agreed on within the themes accessibility and facilitation but is in contrast to the few characteristics agreed upon for recruitment. The feasibility of expectations regarding inclusive health research needs to be considered: 'What is reasonable and realistic' (academic 2). Representation of people with moderate to severe ID is challenging, and methods to include them should be explored.

Although there was no agreement on the themes reflection and evaluation, academics' rationales reflected the need to gain insight into the process, outcomes and added value of inclusive health research, as it is in an early stage of development: 'We don't want to each be reinventing the wheel!' (academic 16). Reflection is key in reaching meaningful inclusion; however, reflections on the inclusive process should not overshadow the actual study.

4.3.2.3 Characteristics of collaboration and control

Table 4.5 shows that, within the approaches *collaboration* and *control*, agreement was reached mainly for characteristics on atmosphere, relationship, engagement, partnership and power rather than for straightforward characteristics such as remuneration, training and salary. The characteristics 'open, respectful, and confidential atmosphere' and 'training and preparation during participation' were identified as very important for both approaches, indicating that these are characteristics of inclusive health research in general.

Table 4.5 Characteristics of collaboration and control

Approach	Agreement upon characteristics Round I	Agreement upon characteristics Round II
Collaboration	• Open, respectful, and confidential atmosphere • Relationship with research group • Partnership and shared decision-making power	• Idem round I and: • Training and preparation during participation
Control	• Open, respectful, and confidential atmosphere • Engagement with research group • Power to influence research	• Idem round I and: • Training and preparation during participation

For each characteristic, agreement was achieved when: median=5 (category *very important*) and IQR=0.

4.3.2.4 Academics' rationales regarding characteristics of collaboration

Payment and valuing participants' time and expertise are seen as an important characteristic of inclusive health research, even though these are not among the agreed upon characteristics in Table 4.5. However, payment of people with ID does not necessarily in itself result in meaningful inclusion. To reach meaningful inclusion, training was seen as important to both people with ID and researchers in preparing both for their roles, rights, and responsibilities. In line with Table 4.5, training 'on the job' is preferred by most academics, because the context would help people with ID understand research. Researchers need to be aware that people with ID are not required to become trained experts-by-experience. A strong relationship between the research partner with ID and researcher as well as mutual respect are crucial to develop trust and confidence: 'It is at the heart of inclusive research' (academic 17).

4.3.2.5 Academics' rationales regarding characteristics of control

Academics were sceptical regarding the *control* approach because they found complete *control* unrealistic for any type of research: 'You can't just do it your own way' (academic 10). However, if one strives for control in (part of) the study, the following aspects are crucial: mutual respect and engagement; salary, which was seen as more important than for *collaboration* as it emphasises the role of people with ID in research; and training on research methods and ethics. Researchers' commitment to listen to and process the input of people with ID was expected to be most important to achieve *control*.

4.3.3 Topic III: Outcomes of inclusive health research

Table 4.6 presents expected outcomes of inclusive health research per stakeholder group as proposed by academics in this study during round I and whether academics agreed upon their importance in round II. Least agreement was found for outcomes relating to the stakeholders research(ers) and society. Across all stakeholder groups, agreement was found for the outcomes: improved health(care) and quality of life; more fulfilled needs; increased confidence; and insight into the lives of people with ID.

4.3.4 In-depth interviews

The in-depth interviews provided additional insight into characteristics on which no agreement on their importance was reached, as well as into topics missing from the Delphi study. The analysis of the in-depth interviews resulted in four themes that can be categorised as nuance, characteristics, operationalisation and added value.

Nuance is needed as to where inclusive health research is appropriate and necessary. Not all people with ID are able and/or want to contribute to research. They need experience with the research topic. ‘I think what we have to be open to is that there are certain research questions and certain decisions in the light of research that are better done with an inclusive research paradigm. But that isn’t to prescribe it as the sole paradigm as to move forward’ (academic 1).

The importance of the characteristics, ‘payment of people with ID’ and ‘informed shared decisions’ was stressed, even though no agreement on their importance was reached in the Delphi questionnaires. Despite their absence from the Delphi questionnaires, the characteristics ‘continuity of the inclusive process’ and ‘support’ were identified by interviewees as important. Interviewees also emphasised the importance of accessible research material as identified in the Delphi study and stressed that materials should be developed in collaboration with people with ID.

The need for operationalisation, transparency and evaluation of inclusive research was elaborated upon. Inclusive health research is seen as a complex and situational process, and there is no “blueprint” (Dedding, Jurrius, Moonen, & Rutjes, 2013) for inclusive health research (academic 14). The need for transparency and reflection was voiced without judgement on the quality of the inclusive health research.

Table 4.6 Outcomes of inclusive health research

Stakeholders	Agreement	No agreement
People with ID	• People with ID having a voice • People with ID feeling valued • Research questions relevant to people with ID • Reduction in health disparities among people with ID • Improved healthcare for people with ID • Empowerment of people with ID	• Improved communication between people with ID and healthcare professionals • Improved health/increased quality of life of people with ID • Knowledge translation • Involvement of people with ID in the community • Increased health literacy • Employment of people with ID • Acquisition of research skills by people with ID
Research(ers)	• Research outcomes suited to the needs of people with ID • Research questions relevant to people with ID	• Increases research validity • Increases knowledge among stakeholders • Increases understanding of the lives of people with ID • Complete picture • New way of thinking among researchers • Improved choice in research methods • Better understanding of inclusive health research • Focus on the transformative process of inclusive research • Improved communication within a research team
Healthcare	• Most urgent healthcare issues of people with ID • Healthcare suited to the needs of people with ID • Increased quality of life for people with ID • Improved healthcare for people with ID • Improved quality and accessibility of healthcare	• Mutual understanding between people with ID and healthcare (professionals) • Holistic view on healthcare • Up-skilling of healthcare professionals • Knowledge translation • Aligns healthcare with the UN Convention on the Rights of Persons with Disabilities
Society	• Reduction of health disparities among people with ID • Social change • Addresses problems relevant to society	• Inclusion of people with ID in society • Timely and relevant research for society • Empowerment of people with ID • Holistic view on people with ID • Society respecting/valuing the contribution of people with ID • Cost-effective services • Employment security for people with ID

For each outcome, agreement was achieved when: median=5 (category *very important*) and IQR=0.

Academics envisioned a tool, checklist or guideline providing guidance and support during the inclusive process and showing added value. This tool should support researchers with decisions on ownership and needed adaptations. According to academic 1, the tool should acknowledge 'that certain elements may not be relevant to their particular question or their particular methodology that they're going to embark upon'. The tool can be used to develop an inclusive research design as well as to reflect upon its process: ‘I would like to see some agreement on what should be documented in scientific papers to demonstrate and justify that it was inclusive research’ (academic 4). The tool should establish a common definition of inclusive health research, so that ‘we talk about the same thing’ (academic 4). On the basis of the interviews, the tool should pay attention not only to the conducting phase, but also to the planning, disseminating, and follow-up phase of inclusive health research. People with ID should be involved in the development of the tool.

4.4 Discussion

The aim of this Delphi study – to gain agreement among academics regarding (1) designs and methods, (2) most important characteristics and (3) outcomes of inclusive research – was partially achieved. Academics agreed upon (1) collaboration as the most applicable approach to inclusive health research, (2) the high importance of various characteristics regarding the accessibility and facilitation of inclusive health research and (3) the high importance of several outcomes of inclusive health research for people with ID and healthcare. It was challenging to reach agreement on the other topics, and academics indicated that this was due to the complex and context-dependent nature of inclusive health research. The additional in-depth interviews proved helpful in gaining more insight into these topics, such as the development of a tool for inclusive health research. This Delphi study addresses the need for specification of involvement of specific patient groups. Additionally, it makes a comparison with participatory research in general and addresses future research purposes for both inclusive health research and participatory research.

Although a Delphi study design is appropriate to gain agreement among academics, this proved challenging in this study. The dropout rate of 29%, academics’ rationales and need for telephone follow-ups indicated that academics found the questionnaires too restrictive. Responding to academics’ concerns, this study continued with in-depth interviews to thoroughly question the academics. It was successful in gaining in-depth information on the complexities surrounding inclusive health research and in providing more insight into topics to be explored in future research. Effort was made to collaborate with co-researchers with ID in this study; however, this proved to be challenging. For example, questions were raised how co-researchers could be involved meaningfully in a Delphi study. Co-researchers’ perspectives on these and other challenges will be published in a reflection paper in order to try and add to the growing knowledge base of inclusive (health) research. To our knowledge, this Delphi study is the first to approach scientifically, from an academics’ perspective, patients’ involvement in health research, and it contributes to the next step in the patient revolution.

It is uncertain whether experiences with participatory research can be translated into inclusive health research. However, this study has found similarities with regard to (1) power distributions and (2) research designs. First, power distribution is a well-discussed topic in participatory research (Baum, MacDougall & Smith, 2006) and could prove helpful in the inclusive research debate. The Social Model of Disability has been of great influence on participatory research and recognises cultural and social aspects of power relations, which could conceptualise inclusive research further (Oliver, 1984). Academics in this study agreed that inclusive health research was a collaborative effort; this corresponds to other inclusive research which states that researchers with and without ID should share control over research in order to collaborate meaningfully (García Iriarte, O’Brien & Chadwick, 2014). This indicates that power distributions should be equal. However, the majority of power in research lies with academics. This cannot be rectified without unravelling the existing power distribution and its underlying structures; this is in line with demands within participatory research (Muhammad et al., 2014). Second, participatory research recognises the full range of research designs while collaborating with patients (Baum et al., 2006). Academics in this study agreed that collaboration can be achieved by means of (semi)structured interviews, in-depth interviews, and focus groups, indicating that qualitative designs offer more opportunities than quantitative designs for inclusive health research. This is in line with findings by other inclusive researchers (O’Brien, McConkey & Garcia-Iriarte, 2014). However, academics in this study stated that quantitative designs such as trials and clinical research can be inclusive by offering people with ID the role of advisory board member, self-advocate or research partner. Quantitative research designs might require more effort to be inclusive. Nevertheless, all study designs can be inclusive if necessary. Thus, in this study, the full range of research designs was recognised as a means to collaborate with patients, similar to participatory research. These designs need a rationale for taking on a specific design (Strnadova & Cumming, 2014) and specification in order to develop inclusive research in the future (Bigby, Frawley & Ramcharan, 2014).

No agreement was reached on characteristics relating to the themes reflection and evaluation. Nonetheless, in rationales and in-depth interviews, academics strongly emphasised the need for a tool to provide transparency, facilitation, and evaluation of inclusive health research and its results. At the same time, academics warned against making judgements about what constitutes 'good quality' in inclusive research. Despite the reluctance to make value judgements, the quality and added value of inclusive health research should be studied in order to justify collaboration with people with ID in research. This calls for a critical view on inclusive health research in order to make it work in practice (Van Veen, 2014a). The current absence of a tool might be explained by the developmental phase in which inclusive health research is currently located and by the observed sensitivities with regard to value judgements on the quality of such research (Elberse, 2012). Agreement was reached on the importance of relational characteristics such as atmosphere, relationship, engagement, partnership, and power, which might complicate objective operationalisation. The aforementioned contradiction between the need for a tool and the sensitivities regarding value judgements underlines the fact that inclusive health research is entangled with ethical values and contextual complexities. Future research should explore inclusive health research in its context in order to study its situationality and what this would imply for developing a tool. Several toolkits and handbooks have been developed for participatory research in general. However, the majority are based on experiences with specific groups such as children and young people (Save the Children Norway, 2008) and people living in developing countries (Chevalier & Buckles, 2013; Krishnaswamy, 2004). We expect the broad terms for inclusive health research and participatory research, such as the aforementioned power distributions and research designs, to be similar. However, adaptations might be needed for detailed characteristics, to adjust for the specific needs of people with ID. In recent years, a number of studies have been published on the needs of this population specifically, which would provide a useful guidance when developing a tool. Examples are: Northway, Howard and Evans' (2015) paper on reasonable adjustments to promote meaningful participation of people with ID, a study by Nind, Chapman, Seale and Tilley (2015) on capacity building of people with ID working in research, and an article by McDonald and Stack (2016) that identifies success factors and challenges for community-based participatory research with people with ID.

Academics agreed upon suitable research outcomes and relevant research questions as outcomes of inclusive health research for the stakeholder group research(ers), suggesting that there is little added value of inclusive health research for research(ers). The aforementioned outcomes are in line with an earlier literature review on the added value of inclusive health research for research(ers) (Frankena et al., 2015), and overlap was found with expected outcomes of participatory research in general. Additionally, for the outcomes of participatory research, the emergence of new research questions and building on the sustainability of research outcomes were identified (O'Fallon & Dearry, 2002). Earlier inclusive research identified minimising researcher bias (O'Brien et al., 2014), increased quality of research for research(ers) (Frankena et al., 2015; O'Brien et al., 2014) and a means to new knowledge (García Iriarte et al., 2014) as outcomes of inclusive health research. To our knowledge, outcomes of participatory research and inclusive research have not yet been scientifically studied. Academics indicated that nuancing is needed as to where inclusive research is of added value. However, research indicates that one should have to argue for exclusion of people with ID instead of 'having to argue for their inclusion' (O'Brien et al., 2014). Thus, researchers should be made aware of the possible added value of inclusive health research and be nuanced about where the involvement of people with ID has no added value. Future research should explore when and how inclusive health research is conducted in the best way possible. Keeping in mind the specific context in order to approach the patient revolution scientifically is essential.

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Part II

Realities

Chapter 5

Contributing to inclusive research policy and practice

A synthesis of four inclusive research projects

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Abstract

Background

The active involvement of people with intellectual disabilities (ID) in research is expected to lead to relevant research outcomes, increased quality of life, improved healthcare, reduction of health inequities, and empowerment of people with ID. Despite the developments in inclusive health research, a lack of transparency remains with regard to how the partnership between researchers with and without ID is shaped, and structural study of inclusive health research is needed.

Specific Aims

This study aims to gain insight into the experiences of inclusive research teams in practice regarding (1) reasons, (2) attributes, and (3) outcomes of inclusive health research.

Method

A structural study of four inclusive research teams was conducted in Ireland, Northern Ireland, and the Netherlands using case study methodology. Data were triangulated through documents and individual and group interviews. Data were analysed and synthesised using domain and taxonomic analysis.

Findings

Reasons for conducting inclusive research ranged from personal to practical. Having an inclusive ethos was found to be crucial in conducting inclusive research meaningfully in practice. Based on data analysis, attributes of inclusive research consist of three interrelated themes, one focusing on methodological aspects and two focusing on active involvement and partnerships. Outcomes of inclusive research across cases were found within three categories relating to: research practice, inclusion itself, and interpersonal outcomes.

Discussion

Empowerment was found to be important. Although empowerment is not new to inclusive research, its positive effect on research quality appears to be new and needs further research. This study's results and the literature indicate that developing inclusive research policy and practice requires a realistic perspective,

with a balance between maximum collaboration and using researchers' strengths. The results of this study are transferrable to inclusive research using similar methods with other groups; however, when the aim is to share learning in groups, a shared language is needed.

5.1 Introduction

Increasingly more health research is conducted on, and with the involvement of, end-users. Examples include a systematic review on participatory research with older care-home residents (Backhouse et al., 2016), a study on methodological issues of involving older people in research (Ross et al., 2005), and a reflection on a collaboration with co-researchers with schizophrenia (Schneider, 2012). With regard to people with intellectual disabilities (ID), collaboration in health research is called inclusive health research, defined as: “research which includes or involves people with learning disabilities as more than just subjects of [health] research” (Walmsley & Johnson, 2003, p. 61). This definition has been revised in 2017 (Walmsley, Strnadová & Johnson, 2017). Inclusive health research is viewed as challenging because of, for example, people with ID’s perceived inability to participate (Tuffrey-Wijne, Bernal, Butler, Hollins, & Curfs, 2007). However, their involvement in health research is expected to lead to more relevant research and thus increased quality of life and improved healthcare, thereby contributing to a reduction in health inequities (Frankena, Naaldenberg, Cardol, Linehan, & Van Schrojenstein Lantman-de Valk, 2015; Frankena et al., 2016). Additionally, inclusive research empowers people with ID (Beighton et al., 2017).

Inclusive health research has been developing over the past three decades. The first generation identified the urgency of inclusive health research; the second generation now aims to improve and reinforce inclusive approaches (Nind, 2016). Walmsley and Johnson’s (2003) widely used definition has an umbrella-like character, leaving room for different interpretations of inclusive approaches, ranging from people with ID providing advice, to people with ID having control over the study (Bigby, Frawley, & Ramcharan, 2014b). Frankena et al.’s (2015) literature review on inclusive health research revealed that the preferred inclusive approach was collaboration with co-researchers. In a later literature review of studies on inclusive social and health research, all 13 studies involved collaboration with co-researchers, without it being part of the selection criteria (Di Lorito, Bosco, Birt, & Hassiotis, 2017). Despite the developments in inclusive health research, a lack of transparency remains with regard to how the partnership between researchers with and without ID is shaped (Walmsley, 2004).

A collective approach towards inclusive health research is needed to facilitate effective policy making and reinforce inclusive approaches in practice (Nind & Vinha, 2014). This will be helpful for providing transparency in inclusive health research and will eventually contribute to making research policy and practice more inclusive. Inclusive health research is a process between researchers and co-researchers, it is strongly context related, and inclusive studies are tailored to available resources and possibilities (Frankena et al., 2016). Through a synthesis of four inclusive research projects, this study aims to gain insight into the experiences of inclusive research teams in practice regarding (1) reasons, (2) attributes, and (3) outcomes of inclusive health research.

5.2 Methods

A study of inclusive research projects requires methods that are sensitive to the context of these projects and allow for insights beyond individual experiences of involved researchers by looking at the project and team as a whole. A case study methodology was deemed a suitable approach because it provides a detailed description of an event in its context, develops theories, allows generalisation to similar events, and provides the opportunity to adopt a collective perspective without losing contextual details (Levy, 2008). A multiple case study based on Rohlfing's integrative framework was conducted (Rohlfing, 2012). The intention of the chosen method was to gain an insight, not into the perspectives of all stakeholders in an inclusive research team separately, but rather into the inclusive research process as a whole.

5.2.1 Case selection

For this case study, data were collected from four European-based inclusive research cases. Cases had to meet the following scope criteria. They had to: (a) self-identify as inclusive, (b) be recently finalised or in the final phase, (c) be conducted in Europe, (d) be less than five years old, and (e) be conducted in collaboration with co-researchers with ID or with an advisory board that included people with ID. These criteria were chosen in order to include cases of inclusive research using a frequently used inclusive methodology so that results would be transferrable to other inclusive studies. Cases that were in their final phase (i.e., data analysed, but not published) were included, as the inclusive research team was still together and this reduced the risk of recall bias. The search was limited to Europe in order to make it possible to travel to cases for face-to-face data collection within the available time and funding constraints. Initially, this study aimed to focus specifically on inclusive *health* research because of its expected benefits. However, cases on health-related topics were limited. Therefore, the scope criteria were broadened to inclusive research with people with ID in general.

Figure 5.1 provides an overview of the case selection. A literature search identified 18 research departments or groups in Europe that published inclusive research projects. In the process of network consultation, these and other research departments and groups within the researchers' networks were contacted to determine potential cases. This meant that insight could be gained into inclusive projects that had analysed but not yet published their data. Eight potential cases were identified. Lead researchers of potential cases were initially contacted via e-mail, and further participation was discussed during Skype and face-to-face meetings. Lead researchers were offered an accessible information sheet on the case study (see Appendix I) and functioned as gatekeepers for co-researchers and advisory boards. After Skype and face-to-face meetings, three cases were excluded because they did not meet the scope criteria. One case was excluded because the funder did not consent. When all research team members (i.e., academic researchers and co-researchers or advisory board members) agreed to take part in this case study, data collection was planned with the selected four cases (one in Ireland, one in Northern Ireland, and two in the Netherlands). One of the cases addressed inclusive *health* research. Descriptives of included cases can be found in Table 5.1; to ensure participants' anonymity, cases are not further identified.

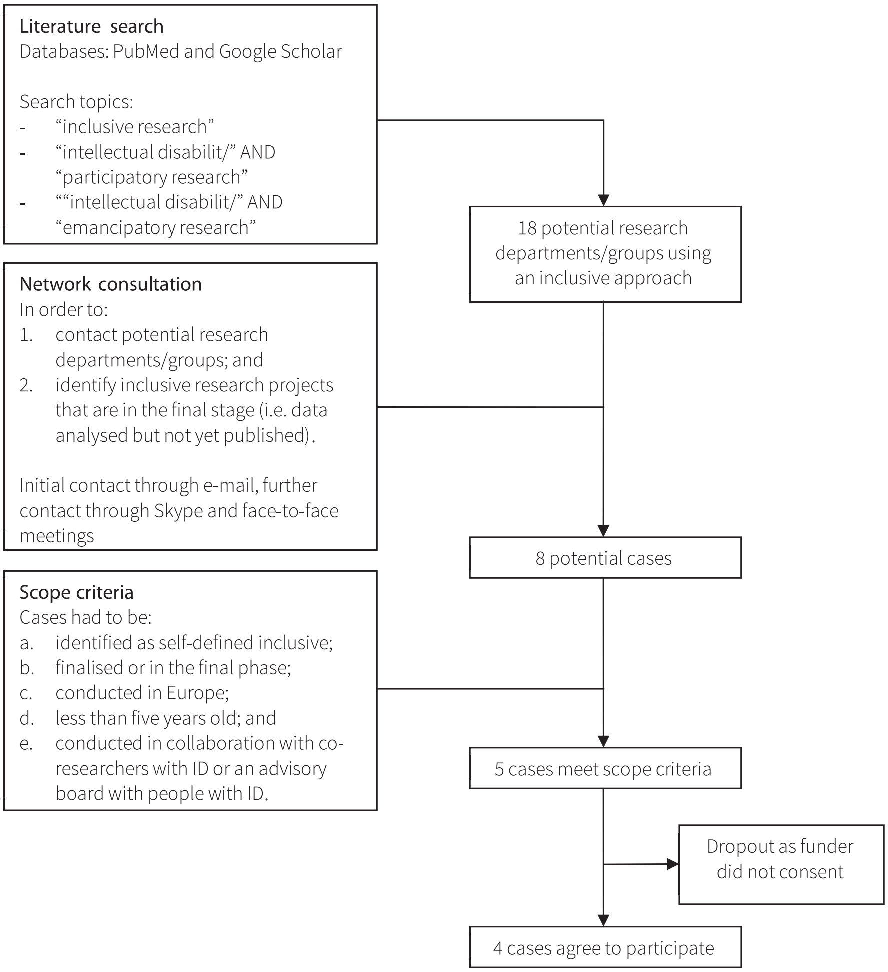

Figure 5.1 Case Selection

Table 5.1 Descriptives of included cases

Case	Country/ study topic/ inclusive method	Research team	Data
1	Ireland/ independent living/ co-researchers	>20 co-researchers 2 academic researchers >5 supporters	5 interviews with co-researchers 1 interview with academic researcher 2 interviews with supporters 1 interview with 1 supporter and 1 co-researcher 1 timeline with 3 co-researchers and 1 supporter
2	Northern Ireland/ diabetes/ advisory board	>5advisory board members 2 academic researchers 2 supporters	2 interviews with academic researchers 1 timeline with 3 co-researchers, 1 academic researcher, and 1 supporter
3	The Netherlands/ digital communication/ co-researcher	1 co-researcher 2 academic researchers	1 interview with co-researcher 2 interviews with academic researchers 1 timeline with co-researcher and 1 academic researcher
4	The Netherlands/ participation/ co-researcher	1 co-researcher 1 academic researcher	1 interview with co-researcher 1 interview with academic researcher 1 timeline with co-researcher and academic researcher

5.2.2 Data collection

Data from the cases in Ireland and Northern Ireland were collected face-to-face in October and November 2015 on site by the lead researcher (TF). Data from the Dutch cases were collected face-to-face between December 2015 and January 2016 on site by the lead researcher and co-researchers. Three Skype interviews were held with a supporter and a co-researcher from case 1 and both academic researchers from case 2 in January 2016, as they were unavailable between October and November 2015. Collected data included:

1) Documents developed before, during, and after the inclusive research projects. Documents of interest were for example: research designs, minutes of meetings, and logbooks. Documents, either digital or hard copy, were used to cross-check information during data analysis.
2) Individual interviews with co-researchers with ID, academic researchers, and, when available, supporters. Supporters were professional caregivers mostly present at day-care activity centres. The aim of the individual interviews was to gain insight into each

case, providing interviewees with room to address their personal experiences and preferences for future research. The interview guide is available in Appendix II. Individual interviews took 40 minutes on average (22–62 minutes).

3) Group interviews with the inclusive research teams to gain insight into the overall process of the inclusive project (interview guide is available in Appendix III). During the group interviews, timelines (March, Steingold, & Justice, 1997; Bigby, Frawley, & Ramcharan, 2014a) were created to prompt memories and create a shared overview of the research project. To support the collection of rich data, the group interviews applied not only timelines, but also visual aids such as flip-charts and post-its. Group interviews took 64 minutes on average (58–76 minutes).

Informed consent was obtained for the individual and group interviews through accessible informed consent sheets (see Appendices IV and V). The recordings from individual and group interviews were transcribed verbatim.

5.2.3 Data analysis

A methodologist (HT) was consulted for advice on the proper data analysis method. Table 5.2 provides insight into the sequential steps of the analysis procedures followed. First, data were analysed at case level to gain insight into each individual case (within-case level of analysis). Domain analysis was used because this approach provides insight into experiences and aims to understand the meaning of respondents' experiences in relation to a domain (Carballo-Cárdenas, Mol, & Tobi, 2013; Casimir &Tobi, 2011; Atkinson & Abu El Hap, 1996).

A domain consists of three elements: (1) a cover term, (2) a semantic relationship, and (3) an included term. The cover term is retrieved directly from interview transcripts, and the semantic relationship and included term are based on literature and scientific knowledge (Spradley, 1979). For example: *enjoying my work* (cover term) *is part of* (semantic relationship) *inclusive research* (included term). For this study, the semantic relationships (1) reasons, (2) attributes, and (3) outcomes and the included term inclusive research were derived from literature and previous studies, forming three domains.

In step 1, transcripts were read and coded for each domain using ATLAS.ti software, in order to identify important cover terms used by respondents by the lead researcher and another author (JN). In step 2, the cover terms within each domain were then grouped into themes and subthemes for each case by the lead researcher and JN, resulting in an overview of important themes per case and a within-case level of analysis. If there were striking differences between participants within a case, these were coded as well. Next, cases were compared to one another using the themes resulting from step 2, in order to create a cross-case level of analysis. In step 3, a taxonomy of themes and subthemes was developed by creating a map of the themes and subthemes in order to structure the similarities and differences across cases (Rohlfing, 2012; Spradley, 1979). Additional meetings were held to discuss the meaning and the interpretation of the final taxonomy.

5.2.4 Creditability and trustworthiness

The following steps were taken to increase reliability and validity (Silverman, 2014):

- data triangulation by conducting individual interviews, group discussions, and collecting documents;
- researcher triangulation by involving academic researchers from different backgrounds (i.e., social sciences, medical sciences, methodology), working in different professions (i.e., researchers, teachers, ID physicians), and including co-researchers as experts-by-experience;
- data analysis conducted by two academic researchers;
- consultation with a research methodologist before and during the data analysis; and
- routine discussions on the justification for cover terms, grouping, and taxonomy with another author of this paper (JN) and a methodologist (HT).

Table 5.2 Phases, actions, and aims of data analysis

Phase	1	2	3
Action	Coding transcripts for all domain relationships	Grouping cover terms into themes and subthemes for all three cases separately	Developing the final taxonomy
Aim	Finding important cover terms	Within-case level analysis	Cross-case level analysis

5.2.5 Inclusive approach

This study itself adopted an inclusive approach: co-researchers collaborated during the study design, data collection, data analysis, and data interpretation. The timeline and interview designs, consent forms, and information folder were developed in collaboration with two co-researchers with ID (AvdC and HJ). The co-researchers' knowledge proved of added value especially for writing easy-read text, adding appropriate pictures, and refining data analysis interpretations.

Data from the Dutch cases were collected face-to-face by this project's lead researcher and at least one of the co-researchers. Unfortunately, it was not possible to involve the co-researchers in the data collection in Ireland and Northern Ireland because of language barriers. Instead, data collection was discussed weekly through Skype sessions. An attempt was made to identify cover terms in collaboration with the co-researchers, but they indicated that this part of the analysis was too demanding. Therefore, the lead researcher identified cover terms for each domain from the transcripts.

Co-researchers provided a new perspective on the methodological process through their collaboration in this study as described above, leading to results that would not have been identified otherwise. For example, in the data analysis, many respondents mentioned that being able to "take part", "be part", "being part of" research was important for co-researchers. The lead researcher interpreted this as positive, whereas the co-researchers felt that it could be childish and tokenistic. Given the considerable amount of work and added value contributed by the co-researchers, they consented to be co-authors of this paper.

5.2.6 Ethical approval

As data were collected from three sites, ethical approval was obtained three times: from the Ethical Committee at Trinity College Dublin, Ireland (Ref. No. 581) and from the University of Ulster, Northern Ireland (Ref. No. REC/15/0116) and reviewed by the Research Ethics Committee Region Arnhem – Nijmegen, the Netherlands (Ref. No. 2015-1991).

5.3 Results

The results of this paper are structured in accordance with the aforementioned three domains: the reasons, the attributes, and the outcomes of inclusive research. Each of these domains is subdivided into themes and subthemes, representing the cross-case level of analysis (Table 5.3). To identify the origin of quotes, abbreviations are used for cases (C), co-researchers (CR), academic researchers (AR), supporters (S), and timelines (TL).

Table 5.3 Taxonomy

Domain	Themes	Subthemes
Reasons	· Gaining and extending experience with inclusive research · Increasing research quality and impact · Exercising rights · Intrinsic motivations · Gaining insider perspective	N.a.
Attributes	Research attributes	· Preparing phase · Undertaking phase · Concluding phase · Parallel phase
	Inclusion attributes	· Inclusive ethos · Facilitation · Learning process · Support (staff) · Obstacles
	Collaboration attributes	· Decision-making power · Division of tasks
Outcomes	· Research outcomes · Inclusion outcomes · (Inter)personal outcomes	N.a.

5.3.1 Domain 1: Reasons for conducting inclusive research

The taxonomy of *reasons for conducting inclusive research* consists of five themes: (1) gaining and extending experience with inclusive research, (2) increasing research quality and impact, (3) exercising rights, (4) intrinsic motivations, and (5) gaining an insider perspective. Together, these themes are motivations to design, or collaborate in, an inclusive study.

5.3.1.1 Gaining and extending experience with inclusive research

Having previous experience with inclusive research was often a reason to adopt an inclusive approach again. If a person had no previous experience, gaining this experience was mentioned as a reason. When building upon previous experience, respondents gave the following specific reasons for conducting another inclusive study: (1) to test and improve the inclusive approach and (2) to have a lower threshold for including people with ID.

5.3.1.2 Increasing research quality and impact

Participants in cases 1, 2, and 3 indicated that an inclusive methodology contributes to an appropriate study design. Additionally, it is educational for researchers and enriches their limited perceptions of people with ID. According to researchers from cases 3 and 4, co-researchers collect more information from interviewees with ID by making them feel at ease and being able to empathise with them. Moreover, the co-researchers' perspective improved data interpretation and understanding. Collaboration with co-researchers makes research more appropriate and better fitted to the needs of people with ID.

5.3.1.3 Exercising rights

Inclusive research was seen as facilitating the exercising of people with ID's basic human rights by: being accountable to people with ID, letting people with ID know they have rights, respecting people with ID, and accepting differences. People with ID's voices are thus heard. Participants used expressions such as "to have our say" (C1CR1), "knocking on doors" (C1S1), and "speaking up" (C2TL).

5.3.1.4 Intrinsic motivations

There was a large diversity in intrinsic motivations among co-researchers. These ranged from practical motivations such as having a stable job and salary, learning about research, and travelling, to personal motivations such as personal growth, helping others, making friends, and enjoying the process. Academic researchers' intrinsic motivations were: learning from people with ID, having a partner, enjoying the process, and developing personally.

5.3.1.5 Gaining an insider perspective

Gaining an insider perspective was reflected in statements such as: "we [co-researchers] know more than them [academic researchers], what it's like on the ground" (C1CR2). Participants stated that researchers are better off when working as a team: "we couldn't work without each other" (C1AR1). As a result of this teamwork, a different perspective is adopted, as people with ID have "ideas about certain things" (C2AR1).

5.3.2 Domain 2: Attributes of inclusive research

The taxonomy of attributes of inclusive research consists of three themes: (1) research attributes, (2) inclusion attributes, and (3) collaboration attributes. Each theme relates to a specific part of conducting inclusive research: research attributes focus on the methodological aspects; inclusion attributes relate to the active involvement of people with ID; and collaboration attributes address the partnership between, on the one hand, academic researchers and supporters and, on the other hand, co-researchers.

5.3.2.1 Research attributes

Research attributes (see Appendix VI for a detailed description) are divided into four phases: preparing, undertaking, concluding, and a parallel phase. The parallel phase consists of attributes of inclusive research that permeate the other three phases and are important during the whole research. For the parallel phase, two themes were identified: academia and meetings. Meetings run parallel to the project on a structural basis (i.e., monthly, biweekly, weekly). Meetings are held to discuss, brainstorm, feed back, consult, philosophise, and reflect on work. The academic structure can be rigid and this is a challenge throughout the project. The need for scientific underpinning and value complicates people with ID's involvement. Research group meetings are often too complicated for co-researchers and are fed back afterwards. Likewise, co-researchers' involvement in the writing and submission of scientific papers is challenging.

The preparing phase of inclusive research starts, as with any research project, with the employment of project staff. For all cases, potential co-researchers were suggested by supporters. Case 3 was the only case with an official application process, and participants from this case articulated several qualities needed by co-researchers: social skills, language skills, and communication skills. The job vacancy was publicised via the organisational newsletter, website, and a poster. The ability of the academic researcher and the co-researcher to collaborate was taken into account in the application process. Besides the application process, the study design and ethical approval have to be pursued. For both, it is important to ensure that co-researchers understand and agree with the process.

The undertaking phase consists of formulating interview questions, conducting interviews, and analysing data. Cases used only interviewing as a data collection method, as it was expected to be easier for co-researchers to be involved. There is much more input from co-researchers in the undertaking phase, compared to the preparing and the concluding phase. Data analysis suggests that, when interview questions are being developed, attention should be paid to discussing possibilities, cutting back and prioritising, adjusting formulations, and piloting questions. Similarly, when interviews are being conducted, time should be spent on preparing the interviews, asking questions and listening, recording interviews, and evaluating afterwards. Data analysis needs modification in collaborations with co-researchers, for example by using creative means. In our cases, co-researchers' analysis was often used in academics' "bigger analysis".

The concluding phase consists of report writing and conference attendance. In case 1 in particular, an extra effort was made to jointly write an easy-read report by talking about stories, picking quotes, suggesting pictures, reading and writing (the latter was done mostly by academic researchers), making decisions, and reviewing the report. Their report was presented at an official report launch. In cases 1, 3, and 4, collaborative presentations on the research were made at conferences.

5.3.2.2 Inclusion attributes

Inclusion attributes (see Appendix VII for a detailed description) were divided into three overarching themes: facilitation, learning process, and support (staff). In addition to these themes, the analysis resulted in a separate code describing an inclusive research ethos, presented in Box 5.1. The ethos consists of a set of researcher qualities that make up a mindset that is helpful for conducting inclusive research. For example, according to one of the academic researchers, you have to "go in with a bit of humour" (C2AR2), which means being positive and cheerful throughout the process.

- Inclusive researchers are:
- Respectful: view everybody as unique and accept differences
- Collegial: work as a team
- Interested and committed
- Critical and sensitive: wonder and question
- Responsible
- Honest and open towards one another
- Positive and cheerful
- On the side of people with ID as a group (not one person)
- Patient
- Intrinsically motivated to help people
- Not in it for the money
- Active in embedding the ethos in people's minds

Box 5.1 Inclusive research ethos

Facilitation entails several considerations. Participants indicated the importance of the co-researcher and the academic researcher building a relationship, with a distinction between a personal relationship and a working relationship. Whereas the latter needs to be in place, the first is not a prerequisite. Next, communication methods have to be adapted by, for example, listening, correcting, encouraging, and checking interpretations. To adapt communication, easy-read information needs to be developed. Simplifying words, enlarging font size, changing text order, rephrasing and summarising, using pictures, are ways to do this in practice. Other facilitative aspects are providing extra time, providing transport, being creative, building confidence, and providing structure and flexibility where needed.

Regarding the learning process, co-researchers and academic researchers have to be sensitive towards what is working well. Several things can be done to stimulate the learning process: improving new things, identifying productive and efficient ways, building upon previous experience, feeling one's way into it, doing it gradually, overcoming challenges, seeing what is possible, improvising and experimenting, using tools, and training based on co-researchers' needs.

With regard to support (staff), a clear distinction was made between, on the one hand, supporting tasks for academic researchers and support staff and, on the other hand, a supportive mind-set. Supporting tasks consist of activities such as helping co-researchers to speak up, making sure co-researchers go to meetings, answering questions, and stimulating discussions. The supportive mind-set consists of activities such as advising and guiding without interfering, keeping the door open, reflecting on one's own support role, and never sitting comfortably in a supportive role.

Finally, obstacles were mentioned by both co-researchers and academic researchers. Inclusive research: is difficult, hard, and challenging; is scary; leads to doubts; has lots of ambiguities; takes a long time; and is burdensome. Several co-researchers described it as “very traumatic” (C1CR1) to hear what other people experienced in their lives. Both academic researchers and supporters identified issues relating to difficulties that co-researchers might experience: forgetting things, wanting to please and agree, giving socially acceptable answers, level of comprehension, and expressing or not expressing needs. An advisory board member in case 2 stated that she did not “want to get it wrong” and would feel guilty if she gave the wrong answer (C2TL).

5.3.2.3 Collaboration attributes

Attributes were discussed relating to the collaboration between, on the one hand, co-researchers and, on the other hand, academic researchers and supporters. Decision-making power was distributed differently in each case. In case 1, decision-making power was seen as a “continuum” (C1AR1). In case 3, the co-researcher was involved in every step of the study. In this case, there was a strong focus on where involvement was of added value. According to case 3 participants, fluctuations in sharing decision-making power did not make involvement less satisfactory, as long as decisions were transparent and open for discussion. Likewise, the case 4 participants agreed that it was important to reflect on the co-researcher’s added value. The co-researcher did not want to be a “show piece” (C4CR) and emphasised that academic researchers should not feel guilty if they were not involving co-researchers in every step. After all, there can only be “one captain on the ship” (C4CR).

With regard to divisions of tasks, none of the cases had a clear distinction of roles and responsibilities between co-researchers and academic researchers. Although their roles were different, they were equally necessary. According to C1AR1: “people take responsibility for different things”. Both parties are there to “complement each other” (C4CR), and “each one is a piece of the jigsaw” (C1S1). Co-researchers’ tasks related to: providing experiential knowledge, having an agenda, collecting data, and having responsibility towards people with ID. Academic researchers’ tasks focused on: providing research knowledge, overseeing the process, supervising and advising, not interfering too much, and having responsibility towards co-researchers. Participants addressed differences between co-researchers' and academic researchers' skills; people with ID have experiential knowledge and academic researchers have research skills. A balance needs to be found between, on the one hand, doing as much together as possible, and, on the other hand, respecting each other's skills.

5.3.3 Domain 3: Outcomes of inclusive research

The taxonomy of outcomes is divided into three themes: research, inclusion, and (inter)personal outcomes. Research outcomes of inclusive research relate specifically to the research project itself. Inclusion outcomes relate to the inclusion of people with ID in research. (Inter)personal outcomes are personal or interpersonal outcomes of inclusive research.

5.3.3.1 Research outcomes

As with any research project, inclusive research leads to a report, a book, or an article with the aim of disseminating study results. Likewise, other research-related documents are developed with co-researchers, such as consent forms and information sheets that are also seen as outcomes. Co-researchers from cases 3 and 4 stated that they viewed a contract and, in some instances, financial compensation as another outcome of inclusive research.

5.3.3.2 Inclusion outcomes

Collaboration with co-researchers has many results during interviews: adapting interview questions, interviewees with ID understanding questions better, interviewees with ID being more comfortable and open, and getting different information from interviewees. Other outcomes of an inclusive approach relate to the research process itself: identifying different research questions, interpreting data and results differently, and having an easy-read report without it being patronising. Participants stated that inclusive research outcomes include: a successful programme, a different perspective, more impact, and being listened to better. In sum, including people with ID in research results in valuable adaptations of the study and increases research quality.

Having academics and people with ID as colleagues was another type of result. This allows academics to gain insight into people with ID's reality: "the real-life world comes in" (C2AR2) and an idea of what life is like for people with ID. Consequently, people with ID's voices are heard, their perspective is included, and new information that “you wouldn’t get” is gathered (C1S1). According to participants from case 3, this leads to “a complete picture” (C3TL). Through their involvement, people with ID get a sense of responsibility and acknowledgement, leading to a more equal working relationship. Both academic researchers and co-researchers as professionals gain knowledge on how to conduct inclusive research.

5.3.3.3 (Inter)personal outcomes

(Inter)personal outcomes relate mostly to co-researchers’ personal development, such as: having new experiences, becoming independent, taking ownership, being involved in the community, having their voice heard, gaining confidence, reducing performance anxiety, knowing their qualities and limits, making a difference, showing their vulnerable side, enriching other people with ID and academics, meeting new people and making friends, and becoming well known. In addition to these outcomes, co-researchers, academics, and supporters enjoyed the process of inclusive research, found it rewarding, and were happy to be part of it.

5.4 Discussion

The aim of this case study was to gain insight into the experiences of inclusive research teams in practice regarding (1) reasons, (2) attributes, and (3) outcomes of inclusive health research through a synthesis of the experiences of four European-based inclusive research teams. Reasons for conducting inclusive research were subdivided into five themes that describe participants’ motivations to design and collaborate in an inclusive study. Attributes of inclusive research were threefold: research attributes, inclusion attributes, and collaboration attributes. Outcomes of inclusive research were, again, divided in three: research outcomes, inclusion outcomes, and (inter)personal outcomes. The inclusive research ethos identified might contribute to resolving the lack of transparency surrounding inclusive research, as it addresses a side of inclusive research hitherto difficult to grasp.

The fact that we were able to identify only one case that addressed health research specifically can be seen as an indicator that people with ID’s involvement in health research is still marginal or that inclusive health research is not identified as such.

Although this study did not manage to include all participants involved in each case, it did ascertain the perspectives of the complete inclusive research teams (i.e., co-researchers, academic researchers, and supporters). Data were collected in Europe, using documents, individual interviews, and group interviews in order to triangulate the data. This study was successful in gaining insight into the experiences of inclusive research teams by, for example, identifying the inclusive research ethos. The results of this study are transferrable to inclusive research using similar methods (i.e., advisory boards and co-researchers). Likewise, the results of this study might overlap with participatory research with other groups (Nind, 2016); however, when the aim is to share learning in groups, a shared language should be in place (Seale, Nind, Tilley, & Chapman, 2015).

Both the intrinsic motivations and the (inter)personal outcomes presented in this study can be seen as aspects of inclusive research that empower co-researchers; and empowerment seems to be of great importance in inclusive research. This corresponds with findings by Stack and McDonald, who found the following reasons, relating to empowerment, to conduct inclusive research with people with ID: “to influence research, build knowledge, skills, and a sense of efficacy, use their expertise to benefit research, conduct socially relevant research, and produce beneficial social outcomes” (Stack & McDonald, 2014, p. 89). According to Johnson, Minogue, and Hopklins (2014), the empowerment of people with ID in inclusive research adds to the quality of research. Although empowerment of people with ID is not a new topic in inclusive research, its positive effect on research quality appears to be new. Future research should study how the empowerment of people with ID in inclusive research can be accommodated, so that people with ID as well as research quality can benefit.

Participants proffered the idea of balance between, on the one hand, collaborating as much as possible, and, on the other hand, respecting each other’s skills. Nind and Vinha (2014) agree, stating that inclusive research should be done in collaboration, but certain tasks can be executed on the basis of personal strengths. Opinions differ in this study between and within cases on how to reach this balance. Differences were found on how decision-making power was shared and tasks were divided. In some cases, the sharing of decisions and the division of tasks were based on the skills of both the academics and the co-researchers. In other cases, the aim was to collaborate in every aspect of the study, not focusing on the academics' and the co-researchers' abilities. The balance between the sharing of decisions and the division of tasks between academics and co-researchers seems to fluctuate over the course of the research project, with co-researchers more heavily involved in the undertaking phase and less involved in the preparing and the concluding phase. Goethals and colleagues identify this search for balance as a "messy struggle" and call for a move from an idealistic to a realistic perspective on inclusive research (Goethals, Hove, Breda, & Schauwer, 2016). Thus, when the aim is to adopt a collective approach towards inclusive research, a realistic perspective needs to be incorporated in policy in order to contribute to inclusive research in practice. The outcomes of the present study can contribute to policy development by creating consensus on inclusive research in practice.

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Chapter 6

A membership categorisation analysis of roles, activities and relationships in inclusive research conducted by co-researchers with intellectual disabilities

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Abstract

Background: Inclusive research is studied mainly in short-term collaborations between researchers with and without intellectual disabilities (ID) focusing on practicalities. Structural study of long-term collaborations can provide insight into different roles of inclusive researchers, thereby contributing to a collective approach.

Method: Interviews with inclusive research team members (n=3), colleagues (n=8), and managers (n=2) and three group discussions within the inclusive research team were held. Data were analysed following membership categorization analysis (MCA) adapted to the needs of the inclusive research team.

Results: This MCA provides insight into the complexity of inclusive research, reflected in the multitude of identified roles and activities. Analysis indicates that researchers with and without ID complement each other.

Conclusions: The activities identified in this study provide valuable information for discussing roles and responsibilities from the outset, so that dialogue starts at the core of inclusive research: the process between researchers with and without ID.

6.1 Introduction

Inclusive research promotes the active involvement of people with intellectual disabilities (ID) in research concerning their life and their health. The first generation of inclusive research established its urgency; the second generation now aims to improve and reinforce inclusive approaches (Nind, 2016b). Sharing individual contributions is viewed as an important aim of inclusive research (Walmsley, Strnadová, & Johnson, 2017), and many research papers focus on sharing practicalities of inclusive research in order to support others in conducting inclusive research (Riches & O'Brien, 2017). Examples include a paper by Tyrer et al. (2016) on their collaboration with service users with ID in a diabetes screening study in the UK, a paper by Puyalto, Pallisera, Fullana, and Vilà (2015) that explores the experiences of advisors with ID while collaborating in a project on the transition to adulthood, and a paper by Beighton et al. (2017) studying the perspectives of people with ID and their parents on their involvement in a study on annual health checks.

Inclusive research is a process that takes place between researchers with ID and researchers without ID. Identities and relationships influence how researchers with and without ID collaborate during inclusive research projects (Nind, 2016b). To date, the structural study of roles and relationships within inclusive research has received little attention and has focused mainly on short-term projects. Structured study of long-term collaborations can provide additional insights that can contribute to the development of a collective approach to inclusive research (Nind & Vinha, 2014); for instance, on the purpose, effect, and identity of inclusive researchers and people with ID (Tilly & Money, Friends and Making Ends Meet Research Group, 2015). This present research aims to gain in-depth insight into inclusive research teams by systematically studying the roles, associated activities, and relationships between different actors present within an inclusive research project. In order to do so, this study adopts membership categorization analysis (MCA) and adapts this method to facilitate researchers with ID in conducting this reflection on their research project.

6.2 Method

This paper studies the long-term (four-year) inclusive partnership between two co-researchers (Henk and Anneke) and a PhD researcher (Tessa). We jointly decided to use our first names throughout this paper to contribute to its readability. We adopted an inclusive approach with the aim of having a meaningful collaboration in which everybody's perspective is of importance, where decision-making power is shared, in order to propagate inclusive research.

6.2.1 Setting

The long-term inclusive partnership took place between April 2014 and April 2018. During this collaboration, we worked on a structured interview survey (Frankena, Naaldenberg, Bekkema et al., 2018), a Delphi study (Frankena et al., 2016), a case study (Frankena et al., In press), a consensus statement (Frankena, Naaldenberg, Cardol et al., 2018), and the study described in this paper. In order to prompt memory and celebrate achieved goals, we created a timeline of our partnership called 'on the road to research', with flowers representing milestones in our work (see Figure 6.1).

Figure 6.1 Timeline 'on the road to research'

6.2.2 Data collection

Data for the present study were collected by means of interviews with stakeholders and group discussions with the inclusive research team, reflecting on the developed timeline. Several steps were taken in order to make data collection inclusive. First, stakeholders were identified and visualized (Figure 6.2) during discussions between Henk, Anneke, and Tessa: (1) inclusive research team members (n=3), (2) direct colleagues (n=8), and (3) management staff (n=2). Next, interview questions and consent forms were developed, after which interview tasks such as completing the consent form, asking pre-set questions, and asking probing questions were identified and divided. The interviews were semi-structured and focused on roles, associated activities, and relationships by asking questions about stakeholders' activities regarding the inclusive study, who made decisions, and how collaboration was shaped. During the first interviews, Henk and Anneke preferred Tessa to take the lead; after two interviews, Henk and Anneke took more control over the interviews with Tessa in a supportive role. Henk, Anneke, and Tessa themselves were individually interviewed by a different interviewer (MC) to reduce interviewer bias. Additionally, Henk, Anneke, and Tessa held group discussions to discuss and reflect on the developed timeline. Data were collected between November 2016 and January 2017. Interviews and group discussions were audio recorded.

Figure 6.2 Circular model of stakeholders

Table 6.1 Inclusive MCA

Step	Aim	Action	Result
1 + 2	Identify roles	• Listening to an interview recording • Identifying roles • Ordering roles	Roles and MCDs of inclusive research (section 3.1)
	Identify activities	• Listening to an interview recording • Identifying activities • Placing activities under roles	
3	Identify relationships	• Constructing a visual map of roles and activities • Discussing the visual map • Discussing relationships between roles and categories • Rearranging roles and activities until consensus on MCDs was reached	Relationships between categories (section 3.2)

MCA = membership categorisation analysis, MCD = membership categorisation device

6.2.3 Membership categorization analysis

To facilitate the researcher and the co-researchers in the data analysis phase, a research methodologist (HT) was consulted to advise on an appropriate data analysis approach and on the tailoring of this approach to the research aim and needs of the inclusive research team. The objective was to structurally analyse the actors, roles, activities, and interactions within an inclusive partnership. The options were discussed with co-researchers Henk and Anneke, and it was decided to use membership categorization analysis (MCA).

MCA categorizes activities into roles in order to gain insight into a phenomenon, in this case, the inclusive research process (Schegloff, 2007). The activities that form a role are called membership categorization devices (MCDs) (King, 2010). For example, in ‘the farmer is ploughing the fields’, ploughing the fields is an activity that forms part of the farmer role. The combination of the activities ‘ploughing the fields’, ‘sowing crops’, and ‘harvesting crops’ constitutes the MCDs for the farmer role. In other words, if a person is not ploughing, sowing, or harvesting, s/he does not have a farmer role. MCA consists of three steps: (1) collecting roles, (2) collecting associated activities, and (3) identifying MCDs (Baker, 1997; Schegloff, 2007). These MCA steps were adapted and explicated to fit the needs of the inclusive research team, resulting in identifying (1) roles, (2) related activities, and (3) relationships between categories. Table 6.1 provides an overview of the steps taken during this inclusive MCA.

During the analysis it became clear that the co-researchers preferred to listen to recordings rather than read transcripts. Two approaches were tested in the first two analysis meetings to assess the workability of performing steps 1 and 2 simultaneously for each interview or first following step 1 for all interviews and then moving on to step 2. Taking steps 1 and 2 simultaneously per interview made it easier to recall what was discussed within each interview, and Henk and Anneke preferred this approach. Analysing all recordings was a strain for Henk and Anneke and proved unfeasible within the timeframe, as analysing one transcript took one 4-hour meeting. Therefore, for steps 1 and 2, at least one recording from each stakeholder group and the group discussion were analysed by Henk, Anneke, and Tessa, allowing a large set of roles and related activities to be defined. The other recordings were analysed by Tessa, and any newly identified roles and activities were discussed with Henk and Anneke. The recordings from the inclusive research team itself were analysed by another team member involved with this paper (JN), following the set of roles and activities constructed by Henk, Anneke, and Tessa to prevent bias in the analysis. The findings were added to the overall analysis, and again any new roles were discussed with Henk and Anneke.

For step 3 of the inclusive MCA, relationships between categories were mapped by using the family function of ATLAS.ti, after which a visual map was constructed during discussions between all analysing researchers (Henk, Anneke, Tessa, and JN). These discussions were visually supported by sticky notes of the roles and activities on flip charts, the relationships between roles and activities were discussed, and the roles and activities were rearranged until consensus on MCDs was reached about which set of activities formed one role. The discussions resulted in rigorous restructuring of the map and rearranging of the activities: some roles were split and others were merged, resulting in the development of new roles. During these discussions, three overarching categories were identified: researchers with ID, researchers without ID, and general. Each category consists of several roles, and each role consists of associated activities (i.e., MCDs), as described in the results section.

6.3 Results

Figure 6.3 provides an overview of the roles found in this study, subdivided into the three categories: researchers with ID, researchers without ID, and general. The results section of this paper firstly presents roles and MCDs (i.e., the set of activities that are part of a role) for the researchers with ID, the researchers without ID, and the general category. Thereafter, the relationships between categories are elaborated upon. The terms used for roles and activities presented in the results are a direct translation of the Dutch terms used by Henk and Anneke during the MCA. In another context or research setting, these terms might have a different meaning; however, the explanations in Tables 6.2–6.4 clarify what the co-researchers meant.

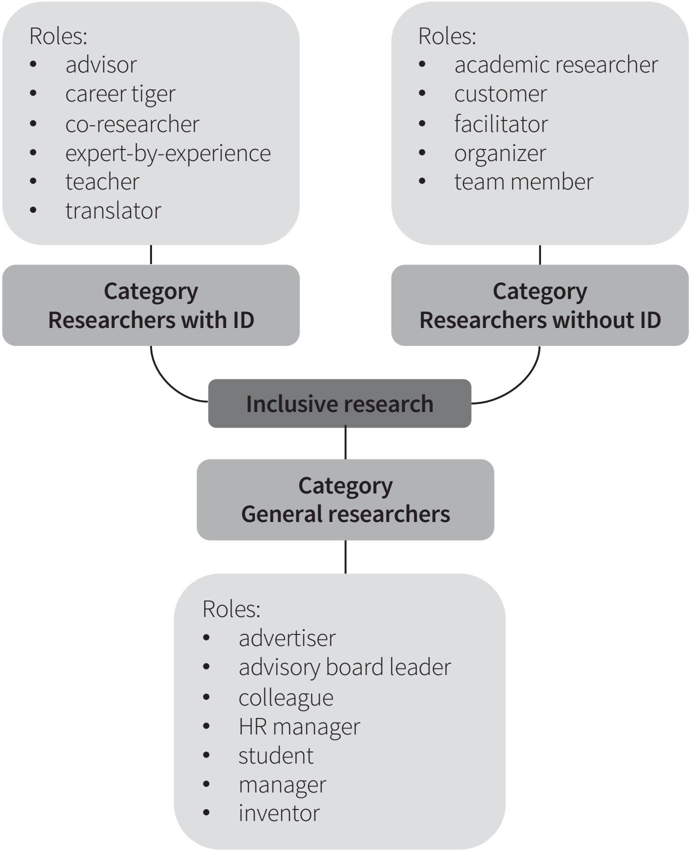

Figure 6.3 MCA of inclusive research

6.3.1 Roles and MCDs of inclusive research per category

Table 6.2 Roles and MCDs for researchers with ID

Roles	MCDs
Advisor	Giving advice in different ways, about different topics, and with different motivations for giving advice
Career tiger	• Handling new/unfamiliar things • Helping others • Communicating • Identifying strengths and weaknesses
Co-researcher	• Employment activities • Workplace accessibility • Research activities • Research accessibility • Getting used to, and gaining, experiences • Being appreciated
Expert-by-experience	Emphasizing what people with ID experience and need, being aware that you cannot speak for all people with ID
Teacher	Preparing and giving presentations in different formats and for different groups and creating awareness through these presentations
Translator	Translating different types of text in different ways and for different reasons

MCD = membership categorisation device

6.3.1.1 Researcher with ID category

The researcher with ID category includes all the roles that a person with ID can have when working in an inclusive research team. This category consists of the roles: advisor, career tiger (that is, a highly motivated person career-wise), co-researcher, expert-by-experience, teacher, and translator. One fulfils a particular role if one meets the MCDs as presented in Table 6.2, which provides a summary of the activities found for researcher with ID (for a complete list see Appendix VIII). For example, if someone prepares and gives presentations, in different formats and for different groups, and creates awareness through these presentations, s/he has a teacher role. Anneke gave a guest lecture for students at Wageningen University in October 2014 on an inclusive approach towards research, using a PowerPoint presentation. Students attending her lecture were not aware that it was possible to collaborate with a research group as such. These combined activities make up the MCDs of the teacher role that Anneke propagated at that juncture.

The majority of the roles associated with researchers with ID such as advisor, co-researcher, and teacher encompass activities that are easily visible in the work of a co-researcher. Some roles, such as career tiger, consist of MCDs that are very emblematic of the role of co-researcher but at the same time are harder to make visible and put into words. This role consists of MCDs such as handling unfamiliar things and identifying strengths and weaknesses, which are vital to research, and these qualities are necessary to be able to *grow* as a co-researcher. It also portrays the eagerness of some people with ID to become co-researchers. For example, a co-researcher who found it difficult to deal with the unfamiliarity of research and had difficulties addressing his own challenges eventually left his co-researcher position. He was not enthusiastic enough about the co-researcher job to deal with this. As Anneke noted: “research is not everybody’s cup of tea”.

6.3.1.2 Researcher without ID category

The researcher without ID category consists of roles attributed to academic researchers who conduct inclusive research. From the MCA, roles within this category are: academic researcher, customer, facilitator, organizer, and team member. Table 6.3 summarizes the MCDs for each of these roles, and a complete list of MCDs for researchers without ID is available in Appendix IX. Similar to the researcher with ID category, the researcher without ID category contains a research-related role: the academic researcher.

The analyses resulted in a division between customer and team member. The customer role applies to researchers without ID who give assignments to researchers with ID but are not members of the researchers with ID’s core research team. In this role, the customer makes the final decision on how to use co-researchers’ input. For example, a direct colleague asked Henk and Anneke to give advice on a script she had written for an information video for people with ID. After Henk and Anneke gave their advice, the colleague decided what she wanted to process within her available timeframe. The customer role shows how co-researchers can become part of research groups beyond their core team and research project. The team member role applies to researchers without ID who collaborate structurally with researchers with ID. As team members, the researchers with and without ID make decisions together. In the case of Henk and Anneke, Tessa was a team member until April 2018, as they worked together structurally on several research projects.

The facilitator and organizer roles both contribute to the involvement of researchers with ID, with the facilitator focusing on the accessibility of the study and the organizer focusing on practical conditions around the workplace. For example, as a facilitator, Tessa made sure that she communicated research topics in an accessible manner, by using drawings and accessible texts. As an organizer, Tessa ensured the physical accessibility of the workplace by arranging a customized desk and keyboard for Anneke and a ramp to access the building in a wheelchair.

Table 6.3 Roles and MCDs for researchers without ID

Roles	Activities
Academic researcher	• Academically trained • Providing room for others (in research project) • Having shortcomings
Customer	Providing and explaining assignments but making the final decision on how to use co-researchers' advice
Facilitator	• Sensitive to the needs of co-researchers • Accessible communication • Curious and open, and feeling for co-researchers • Adapting your attitude towards people with ID • Taking the limited time into account
Organizer	Organizing finance, transportation, practical conditions, and job appointments
Team member	• Preparing and planning activities • Accessibility activities • Identifying strengths and weaknesses • Gaining experiences • Shared decision making

6.3.1.3 General category

The roles within the general category are: advertiser, advisory board leader, colleague, HR manager, inventor, manager, and student. Table 6.4 provides a summary of MCDs for each of these roles, and a complete list is available in Appendix X. Although they might come across as specific, the roles found for the general category apply to everybody involved in and around the inclusive research project. For example, the activities under HR manager do not only apply to the organization's HR manager. In the case of the collaboration reflected upon in this study, the direct manager and Tessa took on HR activities such as sorting out how salaries could be arranged with regard to social benefits. Together, these roles contribute to an inclusive work environment in an academic setting, with not only physical (e.g., wheel chair accessibility) but also social (e.g., welcoming environment) inclusiveness.

6.3.2 Relationships between categories

6.3.2.1 Researcher with ID vs. researcher without ID

A number of notable points can be made with regard to the relation between the researcher with ID category and the researcher without ID category. These categories are mutually exclusive; if one is a researcher with ID, one cannot be a researcher without ID. The roles fulfilled by the researcher with ID when collaborating with a researcher without ID depend on the assignments they get from customers or the project on which they are working with team members. For example, when Henk and Anneke were asked by a colleague to give a presentation about their experiences of having a disability, they tapped into the roles of expert-by-experience and of teacher. When they collaboratively developed easy-read research material with Tessa, they took on the roles of co-researcher and of translator. In this way, the researcher with ID category is responsive to the situation.

The relation between the researcher with ID and the researcher without ID is characterized by roles that support the collaboration. For the researcher without ID, supportive MCDs are found in the regulator, facilitator, customer, and team member roles. For the researcher with ID, one role consists of supportive MCDs: the co-researcher role. This indicates that the researchers with and without ID complement each other and that researchers with ID are likely to need more support in conducting research than researchers without ID.

Table 6.4 Roles and MCDs for general researchers

Roles	Activities
Advertiser	Recommending inclusive research to others
Advisory board leader	Organizing, facilitating, and taking input from the advisory board for one's own research
Colleague	• Talking and having fun, and having a good relationship • Creating awareness as colleagues with ID • Dealing differently with colleagues with ID
HR manager	• Responsible for employees, contracts, and salaries • Working harder for appointment of co-researchers in light of, for example, social benefits and travel costs • Collaborating with other organizations
Inventor	Accepting a challenge, persevering, and doing what has never been done before
Manager	• Arranging things • Having affinity with inclusive research/wanting to employ people who do not have ready access to the labour market • Indirectly involved with co-researchers • Making decisions on financing and employment of co-researchers • Having to comply with rules and regulations, and sometimes being creative with them
Student	Learning about inclusive research and the added value of co-researchers

6.3.2.2 Researcher with ID and researcher without ID vs. general category

Within the general category, several roles are included that ensure that preconditions of inclusive research are in place, such as HR manager and manager. The colleague role consists of activities that contribute to social preconditions, which are stressed by interviewees as important to inclusive research. On the one hand, it relates to the researcher with ID category by making such researchers feel at ease and by facilitating collaboration. On the other hand, the colleague role affects the researcher without ID category by, for example, emphasizing the difference between the relation between doctors and patients and the relation between colleagues. In the case of our research group, several colleagues are doctors for patients with ID. Their collaboration with Henk and Anneke made them aware of the difference between a doctor–patient relationship and being colleagues of people with ID.

The inventor and student roles encompass activities that illustrate the novelty of inclusive research and apply to researchers with and without ID but also, for example, to managers who have to figure out how to shape inclusive research in their department. For example, in the inventor role, Henk, Anneke, and Tessa felt that they had pioneered ways to conduct data analysis together. The MCA in the present study is a good example of this. The advertiser role portrays the enthusiasm displayed by interviewees in this study about participating in inclusive research by trying to persuade others to collaborate in research. One of the interviewees called this “spreading the collaboration virus” amongst direct colleagues and researchers outside one’s own department.

6.4 Discussion

This research aimed to gain in-depth insight into inclusive research teams by systematically studying the roles, associated activities, and relationships between different actors present within one inclusive research project. Following an inclusive MCA approach, this study identified three categories in inclusive research: researcher with ID, researcher without ID, and general, consisting of different roles and MCDs. The results of this study provide insight into how inclusive research is structured through roles and activities and how these relate to each other. The results of the inclusive MCA include roles that can be expected within the researcher with ID category such as co-researcher, teacher, and expert-by-experience, but also several roles that maybe less evident, such as career tiger and translator. These roles consist of activities that are very emblematic of the role of co-researcher but at the same time are harder to make visible and put into words. With regard to the relation between categories, it was found that the researcher without ID category consists mainly of facilitative activities for co-researchers, besides doing research. This indicates that the researcher without ID focuses more on the accessibility of research compared with the researcher with ID. The general category consists of roles and activities applicable to all those involved in inclusive research and facilitates both physical and social inclusiveness.

One of the strengths of this study is the inclusive approach adopted through the partnership between two co-researchers and an academic researcher. The aim was to collaborate meaningfully in every step of the study, providing Henk and Anneke room to take the lead where preferred. Henk and Anneke took the lead in the second half of the interviews and the data analysis. Tessa took the lead in writing the English publications, and sections were frequently discussed with Henk and Anneke, who are co-authors, to ensure that it was representative of their work and ideas. We acknowledged one another's skills (i.e., Tessa's academic skills and Henk and Anneke's expert-by-experience perspective and critical view). An accessible video was developed by the inclusive research team to make dissemination of the study results more inclusive and share them in an accessible manner. Collaborative data analysis was especially challenging as not many examples of such inclusive data analyses were available in published literature, possibility due to its complexity. With the support of a methodologist, MCA procedures were adapted to this inclusive partnership. In this regard, the data analysis was innovative, as we "replicate familiar processes of data analysis while adapting them to be suitable to the challenging contexts in which they are used" (Seale, Nind, Tilley, & Chapman, 2015, p. 490). The long-term collaboration of our inclusive research team provided room to adopt different inclusive methods and grow as inclusive researchers over time. Future research adopting inclusive MCA can build on the knowledge gained in this study.

The complexity of inclusive research is reflected in the multitude of roles and activities identified in this study. Of the 18 roles described in this study, 11 have been previously identified and described in the literature. The roles found in our study can be linked to the identities as found by Nind (2016b, p. 190): “team member, co-researcher, inclusive researcher or advocate for inclusive research, proper researcher, lead researcher, expert by experience, research supporter, coordinator, advisor.” Other studies more implicitly describe roles within inclusive research. For example, Nind (2016a) in the title of her publication sees inclusive research as “a site of lifelong learning” for all involved; this corresponds with the student role. Similarly, the social activities relating to the colleague role are repeatedly described in the literature. Nind and Vinha (2014, p. 42) state that “strong collaboration was often depicted in terms of good knowledge of each other, having fun and spending time together, even being friends or a kind of family.” Riches and O’Brien (2017) identified togetherness as an important quality of inclusive research. Relational aspects are seen as one of the most important sides to inclusive research (Tilly & Money, Friends and Making Ends Meet Research Group, 2015). This study takes a next step by structuring and explicating inclusive research roles. The seven roles that were not found in previous studies are: career tiger, customer, team member, advertiser, advisory board leader, manager, and inventor; these all describe more implicit and tacit activities. However, this could also be a peculiarity of the inclusive partnership described in this study. Nevertheless, insight into both the explicit and implicit roles and related activities of inclusive research is important for understanding every facet of inclusive research, and it assists in assigning responsibilities within an inclusive research team.

Discussions in the literature on terminology (Ollerton, 2012), training (Di Lorito, Bosco, Birt, & Hassiotis, 2017), and participatory and emancipatory research (Strnadova & Walmsley, 2017) suggest that one of the goals of inclusive research is for co-researchers to approximate an academic researcher’s job as closely as possible. However, the researcher with ID and researcher without ID categories found in this study encompass roles and activities that are very different from each other. The researcher with ID category consists of more roles, and especially activities, compared with the researcher without ID category. However, this might be because the researcher with ID role is rather new and still in a developmental stage. The researcher without ID category consists of more facilitating roles and activities compared with the researcher with ID category; this is in line with previous research (Ollerton, 2012). The results of this study suggest that researchers with and without ID complement each other, implicating that roles and activities cannot be exactly the same. In addition, differences between researchers with and without ID are not based solely on their roles in inclusive research, but on their personalities and personal lives as well (Nind, 2016b). The MCDs identified in this study provide a valuable basis on which to discuss roles and responsibilities at the start of an inclusive research project. By doing so, the dialogue starts at the core of inclusive research, the process between researchers with and without ID. Sharing these dialogues in publications helps to create shared learning between inclusive researchers and to establish a more solid knowledge base in this field.

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Part III

Optimising inclusive health research

Chapter 7

A consensus statement on how to conduct inclusive health research

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Abstract

Background: The active involvement of people with intellectual disabilities in research, or inclusive research, is relatively common. However, inclusive *health* research is less common, even though it is expected to lead to appropriate healthcare and increased quality of life. Inclusive health research can build upon lessons learned from inclusive research.

Method: A total of 17 experts on inclusive (health) research without intellectual disabilities and 40 experts with intellectual disabilities collaborated in this consensus statement. The consensus statement was developed in three consecutive rounds: (1) an initial feedback round; (2) a round table discussion at the 2016 International Association for the Scientific Study of Intellectual and Developmental Disabilities World Congress; and (3) a final feedback round.

Results: This consensus statement provides researchers with guidelines, agreed upon by experts in the field, regarding attributes, potential outcomes, reporting and publishing, and future research directions, for designing and conducting inclusive health research.

Conclusions: Consensus was reached on how to design and conduct inclusive health research. However, this statement should be continuously adapted to incorporate recent knowledge. The focus of this consensus statement is largely on inclusive health research, but the principles can also be applied to other areas.

7.1 Introduction

When taking on a new or complex research methodology, most researchers seek expert guidance. A consensus statement is commonly developed by an independent expert panel on a particular issue in order to provide guidance to professionals in the field when they are dealing with this topic (Mosby's Medical Dictionary, 2009). An example of such a complex methodology is inclusive research (Bigby *et al.*, 2014), which is defined as 'research which includes or involves people with intellectual disabilities as more than just objects of research' (Walmsley and Johnson, 2003, p. 61). Inclusive research has developed over the past three decades and is expected to lead to a better match between research and practice (Elberse, 2012; Walmsley and Johnson, 2003). As a consequence of recent developments in healthcare, patients are now often viewed as partners rather than service users (Vayena, 2014). There is an emphasis on the rights of individuals to make decisions about their lives (Riddell and Watson, 2003) and, by extension, in research. Consequently, health researchers increasingly involve the patient's perspective in their study design (Richards *et al.*, 2013). This consensus statement adopts a broad definition of health research which includes all research that addresses 'the coverage, quality, efficiency and equity of health systems' (Alliance for Health Policy and Systems Research, 2007, p. 2). Unfortunately, people with intellectual disabilities are not structurally involved in health research yet, even though their involvement is expected to lead to appropriate healthcare and increased quality of life (Frankena *et al.*, 2016). These added values of inclusive health research are needed, as people with intellectual disabilities experience more health issues (van Schrojenstein Lantman-de Valk and Walsh, 2008) and barriers when accessing health services compared to the general population (Walmsley, 2004). Therefore, this consensus statement specifically addresses the involvement of people with intellectual disabilities in health research, also known as inclusive health research.

Inclusive health research can build on the knowledge base of inclusive research in general. For example, there is grey literature such as a document titled *I'm a researcher – Let me in!* by The Learning Difficulties Research Team (2006), which provides lessons from 12 inclusive projects within Valuing People in the form of an easy read report. However, currently there are many ambiguities in inclusive research. Although Walmsley and Johnson's definition of inclusive research is widely used, its umbrella-like character leaves room for individual interpretation (Bigby *et al*., 2014). This leads to different approaches to people with intellectual disabilities' involvement, possibly leading to less meaningful, tokenistic inclusive research (Grant and Ramcharan, 2007). Additionally, experiences with people with intellectual disabilities' involvement in research are scarcely documented, and therefore there is little insight into inclusive processes (Kramer *et al*., 2011; Flood *et al*., 2013). This consensus statement aims to build on existing knowledge on inclusive research, provide support to researchers when they are designing and conducting inclusive health research, and increase the transparency of the inclusive health research process.

This consensus statement specifically addresses four topics of inclusive health research based on scientific knowledge and expert experience: (1) attributes; (2) potential outcomes; (3) reporting and publishing; and (4) future research directions. Firstly, attributes of inclusive health research should provide researchers, both with and without intellectual disabilities, with detailed information on important considerations when designing and conducting the study. Secondly, the outcomes of inclusive health research may vary between different stakeholders. For example, for health researchers, an inclusive approach might influence their quality of work. For people with intellectual disabilities, inclusion in health research could have more personal outcomes such as improved quality of life. Awareness of and insight into differences between stakeholder groups is needed to generate sufficient support for inclusive health research (Frankena *et al*., 2016). Thirdly, guidelines on what to report when publishing inclusive health research would aid the transparency and understanding of inclusive health research methodologies. Finally, as with any consensus statement, this paper also addresses future research directions identified by experts; this should contribute to taking the next steps in inclusive health research (Mosby's Medical Dictionary, 2009). The aim of this consensus statement is to provide researchers with guidelines, agreed upon by experts in the field, regarding attributes, potential outcomes, reporting and publishing, and future research directions, when they are designing and conducting inclusive health research.

7.2 Consensus development

This consensus statement was developed in collaboration with the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) Health Special Interest Research Group (SIRG) and experts with and without intellectual disabilities on inclusive (health) research.

7.2.1 Participants in the consensus statement

Eighteen experts without intellectual disabilities were invited if they (1) had an accepted abstract on inclusive (health) research for the 2016 IASSIDD World Congress (IASSIDD, 2016) and/or (2) had peer-reviewed publications in the field. These experts were asked to identify experts with intellectual disabilities with whom they could collaborate on the consensus statement in order to gain their perspective. No criteria were attached to the inclusion of experts with intellectual disabilities. However, most of these experts were experienced co-researchers and had reading and writing abilities. Experts were mostly associated with university-based health research departments and had expertise in inclusive research. Experts without intellectual disabilities were invited to co-author the consensus statement, and experts with intellectual disabilities were invited to co-author an easy-read version of the statement. At the conclusion of this consultation, a total 17 experts without, and 40 experts with, intellectual disabilities collaborated in this consensus statement. Experts with and without intellectual disabilities are referred to as ‘experts’ in the rest of this paper if not specified otherwise.

7.2.2 Inclusive health research topics

As stated in the introduction, this consensus statement specifically addresses four topics of inclusive health research based on scientific knowledge and expert experience. Previous to this consensus statement, a structured literature review (Frankena *et al*., 2015), a Delphi study (Frankena *et al*., 2016), and an international multiple case study (Frankena *et al*., submitted) on inclusive health research were conducted. Outcomes from these studies and the knowledge of experts were combined in this consensus statement, leading to the topics: (1) attributes, (2) potential outcomes, (3) reporting and publishing, and (4) future research directions. These topics were the outline of the process leading to the final consensus statement.

7.2.3 Consensus statement process

This consensus statement was developed in three consecutive rounds. Table 7.1 provides an overview of the steps taken during the consensus development and the number of experts participating in each round. All communication during this process was conducted in the English language. Experts without intellectual disabilities often functioned as translators for the experts with intellectual disabilities; this was also the case for English speaking experts with intellectual disabilities. Several means were used to make the process inclusive for experts with intellectual disabilities, for example: an easy-read report was developed; a Skype meeting was organised to provide feedback; written feedback was provided, which in one case included photos from flip-overs used during discussion on the easy-read statement.

Firstly, an outline of the consensus statement was developed by the lead researchers on this project with (AC, HJ) and without (TF, JN, HL) intellectual disabilities (see section 7.2.2), after which it was distributed among experts to obtain their feedback. During the first round, experts received the outline and provided feedback. The experts all confirmed the need to include four topics as described in the outline and provided extensive input of their content.

Secondly, experts and additional Congress attendees participated in a roundtable discussion during the 2016 IASSIDD World Congress. In this discussion, the topics ‘attributes’, ‘potential outcomes’ and ‘future research directions’ were presented and discussed in small brainstorming sessions using flipcharts. Time constraints precluded discussion of the topic ‘reporting and publishing’. Roundtable participants agreed on the relevance of the developed outline, and additional content was added.

Finally, based on the roundtable discussion, a second draft of the consensus statement and an easy-read version were again circulated among the experts. The final round aimed to jointly develop a statement with consensus from all experts involved. An easy-read version was compiled by the lead researchers on this project with (AC, HJ) and without (TF) intellectual disabilities. These experts with intellectual disabilities specifically provided feedback on the easy-read version of the statement using their experience in research. Feedback provided by the experts during these three rounds was carefully compared, processed and implemented by the lead researchers. Remaining questions were asked in subsequent rounds. On the basis of the final feedback round, the lead authors of this paper then prepared the final version of the consensus statement, including the easy-read version, with additional references. The experts signified general agreement with the entire document and gave permission for co-authorship.

Table 7.1 Consensus development

Time	Action	Participants
June 2016	Invitation to experts and development of the outline of the consensus statement	18 experts and their colleagues with intellectual disabilities
July 2016	Round I: feedback on outline of the consensus statement	16 experts without intellectual disabilities
August 2016	Round II: roundtable discussion during 2016 IASSIDD World Congress on first draft of the consensus statement and topics ‘attributes’, ‘potential outcomes’ and ‘future research directions’	11 experts and 11 additional conference attendees
September 2016	Round III: feedback on second draft of the consensus statement and the easy-read statement	16 experts without, and 40 experts with, intellectual disabilities
January 2017	Agreement on final consensus statement and easy-read statement	17 experts without and 40 experts with intellectual disabilities

7.3 Findings that form the consensus statement

This consensus statement addresses (1) attributes; (2) potential outcomes; (3) reporting and publishing; and (4) future research directions of inclusive health research. Topics 1 and 3, attributes and reporting and publishing, give researchers practical guidance when they are designing, conducting, and publishing inclusive health research. The potential outcomes provide insight into benefits of inclusive health research and advocate for inclusive health research. Future research directions provide insight into the research agenda with regard to this topic, originating from inclusive health research practice. Each topic is presented in a separate section. This consensus statement addresses one particular inclusive approach: a team of university researchers collaborating with individuals with intellectual disabilities. However, some aspects may be relevant to other inclusive research approaches, such as researchers with intellectual disabilities looking to collaborate with university researchers or a university researcher looking to collaborate with an established group of researchers with intellectual disabilities; this focus should be noted here. Parallel to the development of this consensus statement, an easy-read version of the statement was developed by experts with intellectual disabilities (n=40) to facilitate access to the information (see Appendix XI for the easy-read statement). Whereas this consensus statement provides the academic underpinning and agreement among experts, the easy-read consensus statement provides more practical support for health researchers aiming to adopt an inclusive approach. The decision was made to use this inclusive approach following consultation with two experts with intellectual disabilities.

7.3.1 Attributes of inclusive health research

Inclusive health research design depends on study characteristics, research topic, research questions, researchers (both with and without intellectual disabilities), funding, and options with in academic structures. When inclusive health research is being designed and conducted, eight attributes identified by the experts in this consensus should be borne in mind (Table 7.2). For each attribute, researchers are provided with a detailed description of what inclusive health research entails and what the research team needs to take into consideration. However, in light of the multitude of ways in which inclusive health research can be conducted, not all attributes might be necessary for every project. Attributes should, therefore, be perceived as flexible and mouldable to the diverse research teams and topics. As this consensus statement addresses inclusive health research in particular, please be aware that study participants can be individuals with intellectual disabilities.

An important attribute and precondition is the inclusive research ‘ethos’, which is applicable during the whole research process. The ethos is a certain mindset put forward by experts in this statement. The ethos encourages meaningful inclusion, and discussion on this topic within the research team is essential. Other attributes are as follows: recruiting researchers; designing the study; facilitating the process; dealing with practicalities; generating data; analysing data; and using results. The attribute ‘recruiting researchers’ with intellectual disabilities is especially important for researchers new to inclusive health research, for whom it can be difficult to recruit researchers with intellectual disabilities if there is no network in place yet. Researchers without intellectual disabilities have to consider *how* to recruit a representative group of researchers with intellectual disabilities; how to deal with their service providers and/or support network; how to respond to everybody's competencies; and how to deal with financial compensation of researchers with intellectual disabilities. The attribute 'designing the study' focuses on roles; skills and competencies; research methodology; and creative and alternative ways to conduct health research inclusively. The attribute 'facilitating the study' provides information on how to make the study as inclusive as possible, by ensuring researchers with intellectual disabilities' meaningful inclusion through planning, discussion and decision making. The attribute 'dealing with practicalities' presents practical aspects of inclusive health research that have to be taken into account. The attributes 'generating data', 'analysing data' and 'using results' all support inclusion in data collection, analysis, and dissemination, whereby every step is discussed with the researchers with intellectual disabilities.

7.3.2 Potential outcomes of inclusive health research

When an inclusive approach is adopted, several outcomes that relate to the inclusive process can be expected (Table 7.3). We have grouped these outcomes into five levels that can support the research team when they are setting goals for their project and evaluating these goals afterwards. The five levels are personal, professional, research, healthcare and societal, where the personal level affects a few, and the societal level affects many people. At the personal and professional levels, outcomes affect researchers both with and without intellectual disabilities. The potential outcomes support the call for inclusive health research and help advocate for such an approach. Generally, inclusive research is said to empower people with intellectual disabilities and increase the relevance of study results. In this consensus statement we would like to draw attention to a myriad of other outcomes. In particular, the outcomes for research signify the potential of inclusive health research for, for example, contributing to appropriate data collection, quality of data and relevance of research outcomes.

Table 7.2 Attributes of inclusive health research

Ethos	• 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.
Recruiting researchers	• Aiming to recruit researchers with intellectual disabilities from different backgrounds and levels of intellectual disabilities to maximise the likelihood that the voices of those from different perspectives are involved, using an open advert. • Being aware that recruitment methods are not perfect and researchers with intellectual disabilities are not academics. • Considering the number of researchers with intellectual disabilities on the team, as influences rise with more members with intellectual disabilities. • Learning from, and attending to, recruitment strategies to optimise recruitment. • Supporting service providers and gatekeepers to understand the research process and expectations to support recruitment. • Identifying and discussing team members' required competencies and how competencies complement each other. Provide training for all if required competencies are not present, without influences or forms of coercing. • Discuss how researchers with intellectual disabilities can be financially compensated for their work (because of social insurance laws, their allowances might be affected) and support financial recognition. For example, by involving the HR department. • Discussing objectives, timelines, and outcomes and allowing withdrawal from the process, in order to ensure team members know what their job will entail using a job description. Include information on the temporary nature of projects.
Designing the study	• Discussing team members' roles in advance: at what point they would like to be involved; what their skills and competencies are; their modes of communication; and where these are of added value. • Discussing possible theoretical frameworks and methodological approaches with team members by looking outside traditional research designs and considering creative and alternative ways to conduct health research inclusively. Provide and receive training if needed for all involved. • Deciding upon the research topic, research questions, and methods by means of dialogue with team members. Funding providers' expectations may make this challenging. • Discussing research ethics, how to deal with potential ethical challenges and ensuring ethical approval procedures are transparent for all team members.

Facilitating the process	• Discussing team members' practical and emotional needs and responding to them as members of a team. • Developing easy to read information by using simplified text, large font size, pictures, translations, video, audio, creative and alternative formats, etc. Needs are diverse and accessibility should be continuously tested through collaboration with researchers with intellectual disabilities. • Considering preparation for meetings, for example by means of mentoring, pre-meetings, facilitation by more experienced team members, etc. • Adapting communication by inviting ideas and developing trust through routines such as taking turns, listening, stopping anybody from answering for somebody else, etc. • Planning and discussing: how to attend to need for structure and flexibility; how team meetings will be organised: frequency, time of day, location, planning, agendas, socialisation, access needed, etc. and how conflicts will be managed, ensuring a safe and structured process where problems can be reported. • Using tools to support the learning process: handbooks, videos, customised training, etc. • Ensuring ongoing critical reflection and evaluation of the research process and adjusting the process as required. • Considering equality training for the entire research department, as the research team interacts with others outside their own team.
Dealing with practicalities	• Discussing transportation needs with all members of the team to facilitate attendance. • Arranging and financing transportation and the development of accessible materials, if needed. • Allowing for extra time, in order to implement all aspects of an inclusive approach. • Planning when a break is needed: both short term (lunch or coffee break) and longer term (break from the project). • Discussing how team members prefer to be supported and providing support, if needed: both from academics to assist in conducting research and from support staff to assist in accessibility. • Discussing with support staff how they can support researchers with intellectual disabilities. • Discussing how to deal with (scientific) research team meetings, which people with intellectual disabilities might find challenging to attend meaningfully because of technical and complicated forms.
Generating data	• Discussing and identifying what is needed to collect and process data (practically and emotionally) with all team members. Provide training if needed. • Using alternative means of data gathering e.g. video, visual data. • Discussing and identifying means to generate data using creative means (e.g., for people with a hearing or speech impairment). • Identifying issues of confidentiality and developing solutions together. .
Analysing data	• Discussing and identifying means to analyse data with team members; consider non-traditional and creative means. Provide training if needed. • Comparing and discussing ideas about response patterns with team members. • See literature (Tuffrey-Wijne and Butler, 2010; Kramer *et al.*, 2011; Stevenson, 2014; Ollerton, 2012).

Using results	• 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. • Discussing and identifying possible new ideas, limitations and ethical issues with team members. • Reporting on the process and added value of inclusive health research. • Evaluating the dissemination of results. • Discussing academic and advocacy publications as well as different publication formats.

7.3.3 Reporting and publishing of inclusive health research

To facilitate learning from previous experiences with inclusive health research, reporting and publishing on the inclusive process in research papers is an essential step forward. Key elements to consider for making the inclusive process more transparent are listed in Box 7.1. This list can be used by authors and also by journal editors and reviewers when assessing papers that adopt an inclusive approach. We hope that this will help build the knowledge base of inclusive health research and help inclusive health research to maintain its momentum. The key elements needed are information on: motivation and experiences; decisions and modifications; and communication, support, task division, and financial compensation. An accessible abstract should also be provided.

1. Describe and explain why an inclusive research process was chosen.
2. Describe how decisions were made during the research process, including the level of engagement of team members in these decisions, regarding: recruitment, funding, ethics application, research topic and question, methodology, data collection, data analysis, and data dissemination.
3. Give all team members' reflection on their experiences with inclusive health research, including barriers, benefits, added value, outcomes, and lessons learned.
4. Describe how data were disseminated through non-scientific publications, how the voices of all team members were represented in outputs, and how decisions were made regarding authorship.
5. Describe how communication and dialogue were facilitated between team members with and without intellectual disabilities.
6. Describe how support was provided to all team members involved.
7. Describe the research team and each team member's role.
8. Describe how health researchers with intellectual disabilities were financially compensated (and, if not, why not).
9. Describe how modifications were made to the research design and process.
10. Provide an accessible abstract and report to be distributed among people with intellectual disabilities and service providers.

Box 7.1 Key elements of reporting and publishing

Table 7.3 Potential outcomes of inclusive health research

Level	Potential outcomes
Personal	• Enjoying the process • Gaining new experiences • Gaining personal skills • Meeting people you would not have met otherwise • Being heard and involved in research • Gaining insight into, and reflecting on, the experiences of (other) people with intellectual disabilities
Professional	• Contract and financial compensation • Feeling responsible • Getting acknowledgement and recognition of abilities and contributions • Gaining insight into an academic setting process • Gaining (research) skills that may be transferable to other projects, thereby enhancing employability • Experiencing a more equal working relationship • Hearing the voices of people with intellectual disabilities and having a more inclusive experience • Networking: meeting other inclusive health researchers, possibly leading to new opportunities • Learning new and creative modes of communication, research methods, analysis, and dissemination strategies and opportunities • Gathering new information and insights not otherwise identified • Seeing the larger picture
Research	• Increasing appropriateness of data collection methods • Investigating priority health areas identified by people with intellectual disabilities • Changing the quality of data and developing instruments by better suiting people with intellectual disabilities' needs • Increasing relevance of research outcomes for people with intellectual disabilities • Gaining insight into what it means to do research inclusively • Shifting the orientation of research away from normative methods that are not accessible or reflective of the lives, needs and preferences of people with intellectual disabilities.
Healthcare	• Improved identification of people with intellectual disabilities' most urgent healthcare issues • Better understanding and working within the healthcare system to reduce people with intellectual disabilities' health disparities • Developing healthcare services and policies to better meet people with intellectual disabilities' needs • Improving quality and accessibility of healthcare for people with intellectual disabilities • Increasing people with intellectual disabilities' quality of life
Societal	• Increasing people with intellectual disabilities' participation and inclusion • Working together to reduce health inequities between people with and without intellectual disabilities • Raising awareness of issues faced by people with intellectual disabilities • Suiting research findings to societal needs, thereby increasing the social relevance of research • Contributing to social change, challenging stigmas and assumptions about (in) abilities of people with intellectual disabilities

7.3.4 Future research directions for inclusive health research

Finally, this consensus statement identified a set of future research directions that are essential to further support the implementation of inclusive health research (Box 7.2). As mentioned in the introduction section, much inclusive health research remains ambiguous and scarcely documented; this is also known as the 'black box' (Edwards and Elwyn, 2006). We feel a strong need to open this black box and enhance the sharing of knowledge by providing this research agenda. The future research directions show a distinction between, on the one hand, complex issues and, on the other hand, practical challenges in inclusive research. Complex issues include power relations between researchers with and without intellectual disabilities and ethical issues arising as a result of taking an inclusive research approach. These complex issues are frequently discussed in inclusive research publications and need to be further investigated and reflected upon. Practical challenges such as models of inclusive research, training, and dissemination relate to the lack of insight into inclusive health research, and insight into these challenges is needed to open its black box.

- Evaluation of, and reflection on, inclusive research processes, especially by researchers with intellectual disabilities, to 'open the black box'.
- Enhance sharing of knowledge, information, and experiences with inclusive research.
- Explore the power relations between researchers with and without intellectual disabilities and sharing of academic privileges.
- Explore the moral and ethical issues in inclusive approaches and the roles of people with intellectual disabilities on ethics committees.
- Explore the relation and similarities between inclusive research designs and the self-advocacy movement.
- Use different models of inclusive research.
- Explore how and why inclusive research adds value to health research.
- Explore the dissemination of inclusive research outcomes to people with intellectual disabilities and effective accessible dissemination strategies.
- Develop training for researchers both with and without intellectual disabilities on inclusive research and support.
- Develop a research agenda supported by people with intellectual disabilities.

Box 7.2 Future research directions

7.4 Discussion and conclusion

This consensus statement aimed to provide researchers with insight into inclusive health research regarding: (1) attributes, (2) potential outcomes, (3) reporting and publishing, and (4) future research directions. The statement was developed in three consecutive rounds in collaboration with >37 experts on inclusive health research with and without intellectual disabilities and is the first of its kind. We strove to make the consensus statement development process as inclusive as possible, within the limits of the doctoral studies of the lead author. To make this statement as inclusive as possible, the development process was responsive to any feedback from researchers with intellectual disabilities, and an easy-read report was developed. The focus of this consensus statement is largely on inclusive health research, but the principles can also be applied to other areas, especially as it adopted a broad definition of health research not restricted to a specific methodology. For example, non-health-related research and the employment and education of people with intellectual disabilities are research areas that could benefit from this statement. Ethics committees and journal editors could use the statement as a tool to check whether researchers have addressed the guidance outlined in this consensus statement.

Experts, both with and without intellectual disabilities, expressed the need to consider whether following this consensus statement leads to meaningful inclusion of people with intellectual disabilities in health research. Meaningful inclusion can be encouraged by the ethos presented in this paper. However, a critical perspective is needed on whether people with intellectual disabilities are given an actual voice in research (Goethals *et al*., 2016). Inclusive research can be viewed as a partnership that values each others's skills, meaning that, at some junctures, things are done by the person best suited for the job. The struggle remains between meaningful involvement and academic possibilities (Nind and Vinha, 2014).

This consensus statement presents an overview of potential outcomes of inclusive health research on five levels. There must be awareness of the multiple stakeholders and their perspectives (Goethals *et al*., 2016). The experts explicitly stated that these outcomes are *potential outcomes*, as they have no scientific underpinning yet. However, in a Delphi study on inclusive health research, academics agreed on similar outcomes of inclusive health research (Frankena *et al*., 2016). These experts also identified the evaluation of, and reflection on, inclusive research processes as a future research direction, and outcomes are part of this process. This requires different inclusive methods: qualitative, quantitative, and mixed methods.

The 'reporting and publishing' and 'future research directions' sections in this consensus statement are work in progress. These sections aim to contribute to the development of inclusive health research by stimulating the sharing of experiences and the building of new knowledge with the inclusion of individuals with a disability in consideration on matters that are important to them. Thus far, publications on the inclusive research process have been limited (Kramer *et al*., 2011), and knowledge sharing is recommended (Stack and McDonald, 2014). Experiences and knowledge should feed back to this consensus statement to encourage and facilitate future publications. However, Johnson *et al*. (2014) warn of the tension between reporting the process of inclusive research and its added value to people with intellectual disabilities: the importance of personal outcomes of inclusive research are often underestimated (Johnson *et al*., 2014). For now, we have reached consensus on how to design and conduct inclusive health research. However, this statement should be continuously be discussed and adapted to new knowledge.

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Chapter 8

General discussion

8.1 Main objectives

In this general discussion, an overview of the main findings from the six research projects in this thesis is provided, based on the three topics in the research questions: quality and added value, roles and responsibilities, and supporting optimisation of inclusive health research. Next, the applicability of the findings beyond inclusive health research, methodological reflections, and suggestions for future research and the move towards the third generation of inclusive research are presented. The two main objectives were:

a) to gain in-depth insight into the expectations and realities of inclusive health research; and
b) to support inclusive research teams in optimising their inclusive health research design and implementation.

Figure 8.1 provides an overview of the results and outputs of the studies in this thesis in relation to the main objectives.

Optimising incluisve health research	**Products** 1. An inclusive research ethos 2. A taxonomy of roles and responsibilities in inclusive health research 3. A consensus statement on how to conduct inclusive health research
Realities	**Quality and added value** • Inclusive ethos increases clarity and transparency • Insight is obtained into added value of inclusive health research **Roles and responsibilities** • Need for balance between maximum collaboration and respecting each other's skills • Need for awareness of differences between inclusive researchers • Focus on how differences can be celebrated through dialogue
Expectations	**Quality and added value** • Need for clarity and transparency about what inclusive health research entails • Need for insight into the added value of inclusive health research • Need for a focus on accessibility and facilitation • Need for tailoring inclusive approaches **Roles and responsibilities** • Dialogue should be stimulated • Decision-making power should be shared (a.k.a. collaborative approach) • Need for a tool facilitating the designing and conducting of inclusive health research

Figure 8.1 Outline of main findings

8.2 Overview and main findings

Expectations of inclusive health research were studied through a structured literature review (Chapter 2), a structured interview survey (Chapter 3), and a modified Delphi study (Chapter 4). Overall, a strong need was voiced for more clarity and transparency about inclusive health research. Delphi study respondents stressed the need for insight into the added values of inclusive health research, with a focus on accessibility, facilitation, and tailoring of inclusive approaches. The study findings indicate a preference for a collaborative approach in which roles and responsibilities are shared and ample room is provided for dialogue. When the Delphi study questionnaires were administered, it came apparent that they were too restrictive for academics to reach agreement. According to respondents, inclusive health research was too complex and context related, and therefore in-depth interviews were conducted to deepen the probing. In the in-depth interviews, respondents contended that there was no blueprint for inclusive health research, making agreement on certain characteristics difficult. The need was voiced for a tool that facilitates a collaborative approach, providing transparency and reflection, without quality judgements. However, without judging the quality of inclusive health research, how can one know whether inclusive health research is optimal? Thus, it was decided to study inclusive health research realities, without any value judgement, and identify what is found to be of added value in practice.

Realities of inclusive health research were studied through a case study of four European-based inclusive research projects (Chapter 5) and a membership categorisation analysis (MCA) study of the four-year collaboration in the inclusive partnership that operated during this PhD research (Chapter 6). Although the expectations of inclusive health research suggested that more insight was needed, the realities reflected a situation where much intrinsic knowledge was already in place. However, this knowledge was challenging to pinpoint and share with others. The domain analysis in the case study resulted in the composition of an inclusive research ethos, identifying aspects of inclusive health research that contribute to its quality and added value in practice. Balance, which aims for maximum collaboration while respecting each other's skills, was identified as key in the sharing of roles and responsibilities. The taxonomy of roles and responsibilities resulting from the MCA study is helpful for inclusive research projects where researchers with and without ID engage in dialogue on their collaboration. Finally, the Consensus statement (Chapter 7) is the result of a combination of previous study results and a consensus procedure among experts on inclusive health research with and without ID. It provides researchers with guidelines regarding attributes, potential outcomes, reporting and publishing, and future research directions, for designing and conducting inclusive health research. Sections 8.2 to 8.4 further discuss and compare findings regarding the three main themes: quality and added value, roles and responsibilities, and applicability of findings beyond inclusive health research.

8.3 Quality and added value of inclusive health research

Added value is a frequent topic in this thesis and literature on inclusive health research; however, one could wonder why there is talk of *added value* and not just *value*. When the discussion would shift from inclusive health research being an added value to traditional research designs to it being of value as a research design itself it would contribute to normalisation of this approach. This thesis identifies and provides insight into the different levels of added value of inclusive health research: the personal, professional, healthcare, research, and societal levels (Chapter 7). Using empowerment as an example, it was found that this is not only an added value for people with ID, but for society as well, as it reduces health disparities of people with ID and leads to social change (Chapter 4). People with ID's motivations for participating in research originated not only from their sense of empowerment, but also from their feeling that research was important (Chapter 3). The literature states that inclusive research has a tendency to focus on its process, rather than on its added value for research practice (Walmsley, Strnadová, & Johnson, 2017), and the study of added value is often one-sided and seen in “attitudinal changes” (Williams, Ponting, & Ford, 2015, p. 43), such as the empowerment of people with ID (Nind & Vinha, 2014). Given the results of this thesis, this is only partially true. In this vein, Johnson, Minogue, and Hopklins (2014) state that empowerment in inclusive research adds to the quality of research, as it enriches the study design and results. Thus, the focus should not be solely on the process (Williams et al., 2015), but also on all levels of added value of inclusive health research. It is agreed in the literature that inclusive research is more expensive and time consuming than research conducted by academics only (Walmsley et al., 2017), as confirmed by the studies in this thesis. Insight into its added on all levels could be used to persuade sceptics and advocate for an inclusive approach.

The experts who contributed to the Consensus statement (Chapter 7) addressed the struggle between aiming for meaningful inclusion and meeting academic conditions. For instance, if the research design is rigid and there is no room to be responsive to the inclusive research team's needs, the quality of inclusive approaches can be undermined. The literature identified the same tension between research quality and the quality of inclusive approaches (Nind, 2014). Limitations imposed by academic structures can be problematic for the quality of collaboration between researchers with and without ID (Strnadová, Walmsley, Johnson, & Comming, 2016; Woelders, Abma, Visser, & Schipper, 2015). In the Delphi study, sufficient time and extra funding were recurrent topics in characterisations of inclusive health research (Chapter 4); this overlaps with findings in other research such as that by Beighton et al. (2017). Therefore, a call has been made for quality criteria to assess whether inclusive research is being conducted properly (Grant & Ramcharan, 2007). Similarly, Delphi study respondents expressed the need for a tool, checklist, or guideline to provide guidance and support during the inclusive process and show its added value.

Quality criteria for inclusive health research could benefit both the quality and the sharing of inclusive health research experiences (Beighton et al., 2017). This link was also made in the Consensus statement (Chapter 7): experts emphasised the need for future inclusive health research to enhance the sharing of knowledge, information, and experiences with inclusive research in order to improve its quality. Improving quality and sharing experiences could be viewed as a virtuous circle, with each new experience contributing to more insight into good quality inclusive health research. Similarly, Walmsley et al. (2017) state that there should be more focus on sharing practical insights about inclusive research. Nind and Vinha (2012, p. 43) listed five criteria for bringing good quality research and people with ID together; the research: "(1) answers questions we could not otherwise answer, but that are important, (2) reaches participants, communities and knowledge, in ways that we could not otherwise access, (3) involves using and reflecting on the insider, cultural knowledge of people with learning disabilities, (4) is authentic (recognised by the people involved), and (5) makes impact on the lives of people with learning disabilities." These quality criteria provide little practical support, and, therefore, the Consensus statement adds to these criteria by providing more practical support for conducting good quality inclusive health research. For example, eight attributes were identified that should be kept in mind when designing inclusive health research, each consisting of a detailed description of what inclusive health research entails and what the research team needs to take into consideration.

8.4 Roles and responsibilities in inclusive health research

Roles and responsibilities were studied in the case study (Chapter 5) and in the MCA study (Chapter 6), providing insight into collaboration between researchers with and without ID in practice. Roles and responsibilities in inclusive health research are very important in the shaping of an inclusive approach and the identification of where researchers with and without ID can contribute. Roles were divided into three categories: researcher with ID (teacher, expert-by-experience, co-researcher, and so on), researcher without ID (facilitator, team member, academic researcher, and so on) and general (manager, colleague, and so on). In inclusive research projects, roles and responsibilities can be assigned in different ways and at different junctures, thereby influencing the amount of decision-making power within the inclusive research team (Bigby, Frawley, & Ramcharan, 2014). In the MCA study, preference was given to a balance in collaboration, instead of providing a researcher with or without ID with more decision-making power than the other. When decision-making power is shared within the inclusive research team, the roles and responsibilities of team members can complement each other. This corresponds with Walmsley et al.'s (2017) finding that inclusive researchers should be "finding the shared spaces" (p. 7). Furthermore, the MCA study results indicate that the level of collaboration can fluctuate over time when different tasks and work shape the research project. This concurs with Seale, Nind, Tilley, and Chapman's (2015) finding that responsibilities are shared in line with the context and the circumstances of the study. Thus, inclusive health research is a process between researchers with and without ID and is influenced by the phase and context of the study; this calls for further research on how their collaboration takes shape in different situations.

As this thesis explored the expectations and realities of inclusive health research, the results contribute to moving from "ideology to research reality", as suggested by Goethals, Hove, Breda, and Schauwer (2016, p. 201). In the MCA study (Chapter 6), dialogue between researchers with and without ID, in which both need to be realistic about their own and each other's skills and flexible in the design of their study, was found to be key in collaboration. Through dialogue, differences between researchers with and without ID can be valued, rather than resolved (Woelders et al., 2015). This is in line with Nind (2014, p. 527), who states that there should be a "focus on collaboration and respect for different ways of knowing and different knowers with an explicit purpose of social transformation." Although these are important statements for the further development of inclusive health research, they provide little guidance on how to share roles and responsibilities in practice. The MCA study provides practical insight into the roles and responsibilities in inclusive health research realities through a taxonomy that can be used to support dialogue on the sharing of roles and responsibilities. However, the same study identified the challenge of uncovering implicit roles in inclusive health research. Further insight into both the explicit and implicit roles and related activities of inclusive research is important for understanding all facets of inclusive research and supporting in sharing decision-making power within an inclusive research team.

8.5 Applicability of findings beyond inclusive health research

This thesis focused on inclusive health research involving people with ID, which is a form of participatory research, but the results could be applicable to participatory research with other groups (Nind, 2016). The difficulty in comparing participatory research across groups is that a shared language is needed, to make sure that everyone is talking about the same thing (Seale et al., 2015). Although participatory research in general is familiar with the "democratic sharing of spaces" (Seale et al., 2015, p. 489), Strnadová and Walmsley (2017) state that inclusive research faces challenges unique to collaborating with people with ID. Comparing the knowledge based in this thesis with participatory research with other groups, it could be questioned whether the emphasised uniqueness of people with ID is of such great influence that participatory approaches should be developed per group, or whether knowledge can be shared across groups.

Participatory approaches within other groups vary greatly, ranging from, for example, consumer panel meetings with older persons (Ross et al., 2005) to structural collaboration with co-researchers with schizophrenia (Schneider, 2012). This is comparable to the multitude of approaches found in inclusive research, such as advisory boards and collaboration with co-researchers, as identified in the literature review (Chapter 2) and the Delphi study (Chapter 4). Another similarity is the forms of power distribution mentioned in participatory research with other groups: advisors and collaborators (Backhouse et al., 2016), equal partnerships (Collins et al., 2018), and consultation, contribution, collaboration, and control (Schneider, 2012). These are similar to the levels of inclusive health research identified in the Delphi study, where preference was given to collaboration. Likewise, the barriers and facilitators put forward are akin to those in inclusive health research: social and relational factors, individual skills, research resources and context, organisational resources, reflexivity, and, of course, power relations (Backhouse et al., 2016; Collins et al., 2018; Ross et al., 2005; Schneider, 2012).

Overall, there appear to be more similarities than differences between participatory research in varying groups. Similar to the need for tailoring found in this thesis, attention must be paid to the unique features of all those involved in participatory research, whether they are people with ID, people with mental health issues, or older persons. The knowledge gained in this thesis seems applicable to participatory research with other groups; this means that the inclusive research ethos (Chapter 5), the taxonomy of roles and responsibilities (Chapter 6), and the Consensus statement (Chapter 7) might prove useful for those who are designing and implementing any kind of participatory research. Additionally, the applicability of the output developed in this thesis might go beyond research, as experts in the Consensus statement suggested that ethics committees and journal editors could use the statement as a tool to check whether researchers have conducted good quality inclusive research. Likewise, policies such as the Dutch Participation Law could use a tool similar to the Consensus statement to evaluate the level of citizen participation. The knowledge gained could be of use in healthcare or in the employment and education of people with ID.

8.6 Methodological reflections

In order to gain a complete picture of the expectations and realities of inclusive health research, all potential inclusive health research stakeholders were involved: people with ID, academics, support staff, and experts with and without ID. These stakeholders all have different perspectives on inclusive health research, as can be seen in the roles and responsibilities for researchers with and without ID identified in Chapter 6. Whereas researchers with ID might focus on what their experiential knowledge can add to research, researchers without ID focus more on how this translates into research results. Stakeholders' perspectives were gathered internationally, through international literature (Chapter 2), online questionnaires with academics from all over the world (Chapter 4), interviews and focus group discussions with inclusive researchers in the Netherlands, Ireland, and Northern Ireland (Chapter 5), and online feedback rounds with experts around the world and at the 2016 IASSIDD World Congress (Chapter 7). However, these international perspectives are mainly from Western countries, and it would have been interesting to involve non-Western perspectives as well. Additionally, the international aspects of this thesis show that inclusive health research is partially subject to national policies, such as social benefits, which influence the salary of researchers with ID. This finding contributes to the awareness that inclusive health research is even more context related than initially expected.

The strategies used to reduce researcher bias and increase validity were: data triangulation, data saturation, researcher triangulation, continuous reflection, and methodological support. Several data sources were used to triangulate data: literature (Chapter 2), questionnaires (Chapters 3 and 4), interviews (Chapters 4, 5, and 6), focus group discussions (Chapters 5 and 6), study documents (Chapters 5 and 6), and a consensus process (Chapter 7). These data sources are suited to the main objectives of this thesis and resulted in insight into inclusive health research ranging from individual accounts to expert opinions. To upscale the knowledge gained, it would be interesting to focus on more quantitative inclusive research methods. Data were gathered until no new themes emerged and a feeling of saturation was reached. This PhD research has a strong reflexive component, as it aimed to both study inclusive health research and adopt an inclusive approach in the study. Meetings with the daily supervisor, Jenneken Naaldenberg, were scheduled every two weeks, and meetings with all supervisors were scheduled every two months. Researchers from differing backgrounds were involved in this PhD research: health sciences, medical sciences, disability studies, research methodology, and ID medical practice. Collaborating with researchers with ID required insight into social, health, and methodological processes and specific insight into the needs of people with ID. This resulted in unique perspectives on the study and contributed to rich discussions on, for example, data analysis.

The aim to study inclusive approaches was reflected in the methodology used in this thesis. First, an advisory board consisting of people with ID, relatives, support staff, and researchers met every three months to discuss the status and key decisions of this PhD research. The advisory board was, for example, heavily involved in the development of an easy-read information folder on the case study presented in Chapter 5. Through their involvement, the folder changed drastically and became more accessible to people with ID, making the study results more applicable to practice. Second, information and informed consent was provided and obtained through easy-read and accessible forms developed by the researchers with ID. Consent from people with ID can be challenging due to the risk of socially desirable answers without their fully comprehending the meaning of consent (Finlay, 2015; Finlay & Lyons, 2001). After providing input for this PhD research, the researchers with ID started advising other researchers in the group on their informed consent documents.

Figure 8.2 Level of inclusiveness of this thesis

An aim was that studies in this thesis would become increasingly inclusive as experiences grew. Therefore, the following inclusive approaches were adopted per study (see Figure 8.2):

1. Structured literature review: nobody with ID was actively involved.
2. Structured interview survey: survey questions were compiled in collaboration with two researchers with ID.
3. Modified Delphi study: one researcher with ID was consulted to discuss the elements in the questionnaires, and the results of the study were discussed with an additional researcher with ID.

4. Case study: two researchers with ID collaborated during the study design, data collection, data analysis, and part of the data interpretation.
5. Consensus statement: 40 experts on inclusive health research with people with ID provided feedback on the Consensus statement and developed the easy-read version of the statement. Two researchers with ID were consulted throughout this consensus process.
6. MCA study: two researchers with ID collaborated during the study design, data collection, data analysis, and data interpretation.

As can be seen from the above list, the inclusivity grew over time, with the first study in this thesis not actively involving researchers with ID (Chapter 2) and structural collaboration with researchers with ID taking place in the last three studies (Chapter 6). In order to be able to collaborate with researchers with ID, research methods needed to be adapted for understandability and workability purposes. This was a learning process, in which our inclusive research team had to get used to one another and develop an inclusive mindset. For instance, at the beginning of the collaboration with researchers with ID, the PhD graduate envisioned a collaboration in which the researchers with ID were in control. Over time, the aforementioned idea of balance emerged, resulting in the aspiration for an equal partnership. A methodologist was consulted to discuss possibilities regarding the adaptations of existing methods and ensuring research quality. Both the research design and the time schedule had to be flexible to be able to respond to the researchers with ID's input. For example, in the MCA study, several adaptation options for the data analysis had to be piloted before a decision could be made about which approach worked best. Overall, collaborating with researchers with ID in this thesis required extra effort, but the steps taken towards an inclusive approach (extra time, flexibility, responsiveness, methodological expertise, and so on) resulted in a rigorous inclusive approach and good quality research.

The literature review (Chapter 2) addressed the myth of homogeneity, which emphasises the diversity of people with ID and the impossibility of one person with ID representing the whole group. Respondents with ID in this thesis required a certain level comprehension. For example, they had to be able to understand concepts like project or participation. Although an effort was made to make the studies in this thesis accessible through collaboration with researchers with ID and involving a heterogeneous group of people with ID, mainly people with mild disabilities were involved. Therefore, the results might not be representative of the entire group of people with ID. However, as this thesis addresses the collaboration between researchers with and without ID, a diverse group of researchers with ID was involved based on different inclusive approaches, on national and international level, and in large- and small-scale inclusive projects.

8.7 Towards a third generation of inclusive research

The first generation of inclusive research identified the urgency to undertake inclusive health research; the second generation now aims to improve and reinforce inclusive approaches (Nind, 2016). More specifically, the second generation focuses on outcomes, added value, benefits for both individuals and research teams, and effective methods and partnerships (Grant & Ramcharan, 2007). First, this thesis has provided rigorous insight into outcomes, added value, and benefits for individuals and research teams resulting from studying outcomes and added value in the literature (Chapter 2), among people with ID and academics (Chapters 3 and 4), and in inclusive research teams (Chapters 5 and 6). These outcomes are agreed by experts with and without ID through a consensual process and are presented in the Consensus statement (Chapter 7). Second, this thesis has studied effective inclusive methods and partnerships through a structured literature review (Chapter 2), a modified Delphi study (Chapter 4), a case study (Chapter 5), and an MCA study (Chapter 6). Again, attributes of effective inclusive approaches are put together in the Consensus statement with agreement from experts in the field (Chapter 7). Thus, this thesis obtained in-depth insight into, and provides support for, the optimisation of inclusive approaches, thereby contributing to augmenting the second generation of inclusive health research.

In addition to contributing to the second generation, the results in this thesis identify steps towards the third generation of inclusive research. Experts in the Consensus statement suggested the key elements of reporting and publishing as a way to facilitate learning from previous experiences with inclusive health research. Reporting and publishing on the inclusive approach in research papers is identified by these experts as an essential step forward. Another step forward is the taxonomy of roles and responsibilities developed in this thesis, which can support dialogue on the design of inclusive research. By structuring and explicating roles and responsibilities, insight is obtained into partly implicit knowledge. Lastly, the inclusive research ethos provides insight into another implicit aspect of inclusive health research and consists of a set of researcher qualities that make up a mindset. In sum, in order to move towards the third generation of inclusive research, implicit knowledge, or the ‘black box’, needs to be studied in-depth, in order to fully understand all facets of inclusive health research. To contribute further to the next step in inclusive health research, based on needs expressed within several studies in this thesis, it would be desirable to structurally study and consciously develop the Consensus statement. This way, inclusive researchers will have a guideline that provides ideas and support on how to design and implement their inclusive approach.

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Chapter 9

Personal reflection on an inclusive partnership

During the course of this PhD research I collaborated with two researchers with ID: Henk and Anneke. I would like to share a personal reflection, as our collaboration existed of many practical, social and emotional challenges. I am using the I-perspective here, in order to emphasise that I am sharing observations based on my personal experiences and not as a scientific researcher. I would like to go into four topics: the initial inclusive design; the appointment of the researchers with ID, including John[1], who ended his research career early; internal conflicts; and, forthcoming, the inclusive design in practice and spreading of the inclusive research virus. Although the majority of these topics are echoed in other chapters of this thesis, I feel it is important to provide the reader a little more insight into these topics.

The initial research plan as stated by the academic collaborative Stronger On Your Own Feet included the aim to involve a researcher with ID in this project. I decided to collaborate with two researchers with ID, as this meant they would outnumber me and start with a little more power. In January 2014 the job vacancy for two researchers with ID was send to support staff in the field. As it turned out, the position was so novel that it was difficult for most of the support staff to understand what the vacancy entailed, which resulted in a lot of e-mailing back and forth. Eventually, a handful of applicants was invited for a job interview. Out of these applicants, two researchers with ID were hired: John and Anneke.

John was a young man with interests in music. He was recently diagnosed with a mild intellectual disability and felt the researcher job would be great way to come to terms with this. John was very independent; however, the support person who was present at his job interview addressed the fact that he had difficulties maintaining jobs. The first six months John worked at our research group, he received a trial placement from the Dutch Employee Insurance Agency [UWV]. This meant he could work at the university without it influencing his benefits. Meanwhile, we had time to figure out how we could reimburse John for his work without it having negative consequences for him financially. As six months went by, John showed up less and less, often without notice. Eventually, the trial placement ended and we wanted to organise a more permanent arrangement. During our biannual progress interview John decided he did not want to be a researcher anymore. This experience made me realise that research is not for

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[1] fictitious name

everybody, regardless of whether they have an ID or not, and it was very important to keep discussing how my colleagues experienced their job and leave room for withdraw.

Anneke is a very enthusiastic and creative young women with mild ID and physical disabilities. When she is not working, she is wheelchair dancing, doing yoga or designing greeting cards. Her appointment was very laborious for two reasons. Firstly, Anneke uses an electric wheelchair, which meant some form of transportation had to be organised and our office had to be wheelchair accessible. Secondly, she received benefits which meant she could not have a paid job for more than 6 hours a week, otherwise here benefits would be affected. These two issues took Anneke and myself a lot of time and patience to resolve. Luckily, our research group had a very motivated HR manager and Anneke had a great support person who both put in a lot of effort to arrange a paid researcher position. In this process Anneke's mother was also very involved and together we made sure that, after a trial placement of six months, Anneke got the appointment and salary she deserved. She started off with a year contract, but now has a permanent contract at our university.

After a small break of six months from recruiting and hiring researchers with ID, Anneke and I felt it was time to look for additional team member. In April 2015 we sent out the job vacancy to support staff in the field again. Through this process we got to meet Henk, who is an older man with mild ID and autism and with a passion for computers and all things digital. Henk's appointment was relatively easy, as he could be seconded from his sheltered workplace to our research group. Explaining his new work to his supervisors at his sheltered workplace was challenging. From May 2015 onwards, our inclusive research team was finally complete. We met every Wednesday from 10 a.m. to 2 p.m. and worked on this thesis together.

Anneke and I had been working together for a year when Henk arrived. For me, this made a big difference. In the beginning of our trio, I felt a stronger bond with Anneke and found it easier to understand what she needed and wanted. Luckily, after a few months, this same bond developed between Henk and I. A good partnership needs time to develop, as it does with any other partnership, regardless of anybody's intellectual abilities. However, the bond between

Anneke and Henk seemed to be inexistent until I went abroad to collect data in October and November 2015. Anneke and Henk attended our weekly meetings together, and we Skyped for at least an hour to keep each other updated every week. Because of this, Henk and Anneke were more dependent on each other (instead of me), and when I came back a friendship and mutual understanding had developed between them.

It is not all roses when it comes to inclusive research. There were several challenges that caused internal conflicts for me. For example, at the beginning of my collaboration with Anneke and John, it found it very difficult to let go of control. It was not only a learning curve how to collaborate with them, but also to let go of my own sense of responsibility and trust my colleagues. Also, at moments I found it difficult to identify to what extent Henk and Anneke experienced limitations due to their disability, and when I should try to support them to further develop. For instance, in the beginning Henk found it very difficult to give presentations and experienced a lot of stress when a presentation neared. According to him, this was partly due to his autism. I did not want to push Henk in doing things he did not feel comfortable with, but I did want to support Henk in learning new things. Eventually, over time, Henk became confident enough to give presentations together with Anneke and even independently. Another aspect I found challenging was the fine line between being a colleague and being a support person. When organising practical aspects for Henk and Anneke, the shift to emotional support was quickly made. Of course, this is normal when you are good work colleagues. But, sometimes I felt I became more of a support person when, for example, a financial situation was discussed. It took some time for me to realise that I could just ask Henk and Anneke in these situations: is this something I could help with, or should your support person do this? A great help during these internal conflicts were discussions with my supervisors, especially Jenneken, who supported me in resolving them, by asking reflexive questions. The question she asked me most frequently was: “what would you do if they were colleagues without an ID?”.

While working together with Henk and Anneke, we collaborated on five projects: the structured interview survey, modified Delphi study, case study, MCA study and consensus statement. Through the course of these projects, Henk and Anneke’s level of involvement increased. In the structured interview survey and Delphi study Anneke acted as an advisor and provided input on the questionnaire and data interpretation (Henk was not appointed at that time). In the case study, we got to work together from the onset of the study. Collaboratively we developed interview questions, conducted interviews and analysed data. However, the majority of the work was still done by me. At times Henk and Anneke were collaborators, but at other times they were advisors. The same goes for our collaboration in the consensus statement. However, our inclusive gem is the MCA study, where we started with jointly developing the research design and questions. Again, we developed interview questions, conducted interviews and analysed data together. Especially in the research designing and data collecting phase, Henk and Anneke took the lead and I did not make decisions without them there. The pendulum swung between them being collaborators and leaders of the research. I believe the increase of inclusivity was needed to develop a meaningful partnership as we had to learn how to collaborate step by step. Each increase in inclusivity, that is, from advisors to collaborators and from collaborators to leaders, revealed new challenges we had to tackle.

Overall, the inclusive aspect of my work on this thesis was challenging and sometimes even frustrating. I was forced to reflect on my own actions, which is not always fun. One could conclude that an additional advantage of collaborating with people with ID is the need for self reflection and discussion with others, resulting in more self-knowledge and insight into my own prejudices. Also, it resulted in insight into my research, as I had to word things differently in order to explain them to Henk and Anneke, and still make it scientifically comprehensive. Over the past four years, a steep learning curve emerged, and Henk, Anneke and I learned how to work together. It took me at least three years to get to a point where I felt like Henk and Anneke were truly and meaningfully involved in research. Henk and Anneke's participation in group outings, department meetings and annual interviews with the head of our research group contributed to their meaningful involvement. Although these might be obvious activities for any of my other colleagues, for Henk and Anneke this realisation had to grow over time. Eventually, they even won the Leaders-price [Koplopersprijs] during the annual network day of our department! Now, Henk and Anneke are researchers on another PhD project and are consulted by other researchers in our group when products are developed for people with ID. I believe the inclusive virus started during our partnership, and has spread into our research group, university and beyond.

Chapter 10

Summary
Nederlandse samenvatting
Makkelijk lezen samenvatting

10.1 Summary

Chapter 1
In Chapter 1, a general introduction is given to the topic of patient participation in health research, intellectual disabilities (ID), and inclusive health research. Inclusive (health) research:

- aims to contribute to social change that helps to create a society in which excluded groups, including healthcare, belong and the objective is to improve the quality of their lives;
- is based on issues important to a group and draws on their experience to inform the research process and outcomes;
- aims to recognise, foster, and communicate the contributions that people with intellectual disabilities can make;
- provides information that can be used by people with intellectual disabilities to campaign for change on behalf of others; and
- 'stands with' those whose issues are being explored or investigated.

A comparison is made between recent developments in policy and current inclusive health research practice, leading to the following research questions:

1) What are the expectations regarding (1) the quality and added value and (2) the roles and responsibilities within inclusive health research, according to academics and people with ID?
2) What are the realities regarding (1) the quality and added value and (2) the roles and responsibilities of inclusive health research, according to inclusive research teams?
3) How can inclusive research teams optimise their inclusive health research design and implementation, according to experts with and without ID?

During this PhD research, an inclusive approach is adopted through structural collaboration with two co-researchers: Henk Jansen and Anneke van der Cruijsen, with the aim for the studies to become increasingly inclusive over time as our experience as an inclusive research team grows.

Part I: Experiences

Chapter 2

Chapter 2 provides a structured literature review on the active involvement of people with ID in health research, also known as inclusive health research. The literature review focused on (1) existing theories, (2) inclusive methods, (3) added value, and (4) barriers and facilitators. Literature published between January 2000 and January 2014 was included covering keywords related to ID and inclusive health research. Searches were performed in Pubmed, CINAHL, PsycINFO, EMBASE, and MEDLINE databases, resulting in 26 included papers. The papers were quality assessed and analysed using qualitative data analysis software.

A lack of clarity was found regarding what precisely inclusive health research entails. Firstly, a discrepancy was found in the application of existing theories: some papers did not mention any, whereas others cited multiple theories. It may be that these theories are too abstract to support the implementation of inclusive health research. Secondly, differences were observed in authors' perspectives on the appropriate juncture for inclusion. Thirdly, some of the papers included in this review prioritised the inclusive process of the research over the quality of the research design.

Another finding is that collaboration with research partners, as opposed to consultation or control, seems to be the only inclusive method resulting in the active involvement of people with ID throughout the entire research cycle. However, with regard to inclusive methods, the barriers and facilitators found in this study seem to be the route to achieve meaningful, inclusive health research. Based on analysis, one might state that this is the actual inclusive method. The inclusive process needs to be tailored to each individual inclusive health research project in order to anticipate the needs of all stakeholders.

In the initial stages of the research process, the authors often indicated that their motivation to conduct inclusive health research was based on demands by policy and funding bodies or on ethics (i.e., expected added value). At the conclusion of the research, the authors perceived the increased quality and validity of their research and benefits for stakeholders (i.e., experienced added value). There was a shift from researchers feeling initially obliged to actively involve people with ID in health research to a perception at the conclusion of the research that stakeholders benefitted from the inclusive methodology.

With regard to the barriers and facilitators identified in this study, the most pressing was the so-called myth of homogeneity: not every person with ID can represent the rest of the population. Inclusive health researchers are not always aware of the diversity of the ID population; this is confirmed by the absence of people with severe or profound ID in research and attempts to represent them by proxy. Future research should focus on the representation of all people with ID in health research, notably how to actively involve people with severe and profound ID directly or by proxy.

Chapter 3

Chapter 3 describes a structured interview survey on participation in research in the broadest sense of the word. Even though participation of people with ID in research is increasingly common, there is little insight into how many people with ID participate, their motivations to participate, and their interests regarding study results. Five questions were added to the Panel Living Together (PLT) survey among 508 people with ID. The questions aimed to gain insight into (i) frequency of participation, (ii) methods used to participate; (iii) motivations to participate; and (iv) interests regarding study results.

Although the majority (73.5 %; n=347) of the respondents enjoyed their participation and most (71.6%; n=312) found it important to participate, only few (11.8%; n=60) participated in research other than the Panel Living Together survey. Of the respondents who answered question 2 on participation methods (n=60), almost half (43.3%; n=26) participated as an advisory board member and a couple (11.7%; n=7) as a co-researcher; these are seen as inclusive research methods. To our knowledge, no data exist on the frequency of participatory research with other patient groups or the general population, making comparison difficult. Additionally, in the definition of inclusive research, the emphasis is on how people with ID are included (e.g., “as more than just subjects of research”), not on how many people are involved. Nonetheless, these percentages do not reflect the aim of inclusive research, where people with ID should have the chance to be actively involved. The definition of inclusive research leaves a lot of room for interpretation, and researchers can have their own perception and interpretation of such research, resulting in a variety of inclusive methods.

Respondents in this study scored several motivations relatively highly (i.e., expecting to enjoy it, finding research important, learning from it, becoming a more confident person, and having something to do); these correspond with findings from other research. The literature review in Chapter 2 found that many researchers expect empowerment to be the core motivation for people with ID to participate in research. Empowerment might partly be a motivation for them to participate in research – captured in topics such as learning new skills and increasing social capital; however, this is not their sole reason to participate in research. Furthermore, over half (61%) of the respondents expressed interest in the results of the studies in which they participated. Responding to these motivations and interests by, for example, providing easy read information on results, is a sign of commitment towards people with ID, and greater attention should be given to this.

Chapter 4

Chapter 4 presents a Delphi study on inclusive health research published in the *British Medical Journal* (*BMJ*). The *BMJ's* patient revolution strives for collaboration with patients in healthcare and health research. Currently, transparency and agreement among academics are lacking regarding the main aspects of inclusive health research, preventing upscaling of the patient revolution. The Delphi study aimed to gain agreement among academics on three aspects of inclusive health research for people with ID: (1) designs and methods, (2) most important characteristics, and (3) outcomes. A Delphi study was conducted with academics with experience in inclusive (health) research and in people with ID. The study consisted of two sequential questionnaire rounds (n=24; n=17, respectively), followed by in-depth interviews (n=10), in order to gain agreement among academics.

Academics agreed upon (1) collaboration being the most suited approach to inclusive health research, (2) characteristics regarding the accessibility and facilitation of inclusive health research, and (3) several outcomes of inclusive health research for people with ID and healthcare. Other characteristics agreed upon included: atmosphere, relationship, engagement, partnership, and power. It was stressed that these characteristics ensure meaningful inclusion. Interviews were conducted in order to gain more in-depth information on inclusive health research. Interviewed academics voiced the need for a tool supporting the facilitation and evaluation of inclusive health research. There was ambiguity as to what this tool should comprise and the extent to which it was possible to capture the complex process of inclusive health research. This study underlines the need for transparency, facilitation, and evaluation of inclusive health research. The need for in-depth interviews after two Delphi rounds underlines its complexity and context dependence. To increase process transparency, future research should focus on gaining insight into inclusive health research in its context. A tool could be developed to facilitate and evaluate inclusive health research. This tool would be partially applicable to participatory research in general and thereby would contribute to the patient revolution.

Part II: Realities

Chapter 5

In Chapter 5, a structural study of four inclusive research teams is presented. The active involvement of people with ID in research is expected to lead to relevant research outcomes, increased quality of life, improved healthcare, reduction of health inequities, and empowerment of people with ID. Despite the developments in inclusive health research, a lack of transparency remains with regard to how the partnership between researchers with and without ID is shaped, and structural study of inclusive health research is needed. This study aimed to gain insight into the experiences of inclusive research teams in practice regarding (1) reasons, (2) attributes, and (3) outcomes of inclusive health research. A structural study of four inclusive research teams was conducted in Ireland, Northern Ireland, and the Netherlands using the case study methodology. Data were triangulated through documents and individual and group interviews. Data were analysed and synthesised using domain and taxonomic analysis.

It was found that reasons for conducting inclusive research ranged from personal to practical. Through data analysis an inclusive ethos was identified, which consists of a set of researcher qualities that make up a mindset that is helpful for conducting inclusive research. Having an inclusive ethos was found to be crucial in conducting inclusive research meaningfully in practice. Attributes of inclusive research consist of three interrelated themes, one focusing on methodological aspects and two focusing on active involvement and partnerships. Outcomes of inclusive research across cases were found within three categories relating to: research practice, inclusion itself, and interpersonal outcomes. Empowerment was found to be important. Although empowerment is not new to inclusive research and was largely related to co-researchers, however, its positive effect on research quality appears to be new and needs further research. This study's results and the literature indicate that developing inclusive research policy and practice requires a realistic perspective, with a balance between maximum collaboration and using researchers' strengths. The results of this study are transferrable to inclusive research using similar methods with other groups; however, when the aim is to share learning in groups, a shared language is needed. Based on the study results, an easy read information folder was developed in collaboration with co-researchers.

Chapter 6

Chapter 6 presents a membership categorisation analysis (MCA) of inclusive research. Inclusive research is studied mainly in short-term collaborations between researchers with and without ID, focusing on practicalities. Structural study of long-term collaborations can provide insight into different roles of inclusive researchers, thereby contributing to a collective approach. In this study, the long term collaboration between researchers with and without ID in this thesis takes a central place. Interviews with inclusive research team members (n=3), colleagues (n=8), and managers (n=2) and three group discussions within the inclusive research team were held. Data were analysed following MCA adapted to the needs of the inclusive research team.

The results of this study provide insight into how inclusive research is structured through roles and activities and how these relate to each other. Following an inclusive MCA approach, this study identified three categories in inclusive research: researcher with ID, researcher without ID, and general. These categories each consist of different roles and membership categorisation devices, which are activities that jointly form a role. The results of the inclusive MCA include roles that can be expected within the researcher with ID category, such as co-researcher, teacher, and expert-by-experience, but also several roles that maybe less evident, such as career tiger and translator. These roles consist of activities that are very emblematic of the role of co-researcher but at the same time are harder to make visible and put into words. With regard to the relation between categories, it was found that the researcher without ID category consists mainly of facilitative activities for co-researchers, besides doing research. This indicates that the researcher without ID focuses more on the accessibility of research compared with the researcher with ID. The general category consists of roles and activities applicable to all those involved in inclusive research and facilitates both physical and social inclusiveness.

The complexity of inclusive research is reflected in the multitude of roles and activities identified in this study. Of the 18 roles described in this study, 11 have been previously identified and described in the literature, often implicitly. This study takes a next step by structuring and explicating inclusive research roles. Insight into both the explicit and the implicit roles and related activities of inclusive research is important for understanding every facet of inclusive research, and it assists in assigning responsibilities within an inclusive research team.

Discussions in the literature on terminology and participatory and emancipatory research suggest that one of the goals of inclusive research is for co-researchers to approximate an academic researcher's job as closely as possible. However, the researcher with ID and the researcher without ID categories found in this study encompass roles and activities that are very different from each other. The results of this study suggest that researchers with and without ID complement each other, implicating that roles and activities cannot be exactly the same. In addition, differences between researchers with and without ID are not based solely on their roles in inclusive research, but also on their personalities and personal lives. The membership categorisation devices identified in this study provide a valuable basis on which to discuss roles and responsibilities at the start of an inclusive research project. By doing so, the dialogue starts at the core of inclusive research, the process between researchers with and without ID. Sharing these dialogues in publications helps to create shared learning between inclusive researchers and to establish a more solid knowledge base in this field.

Part III: Optimising inclusive health research

Chapter 7

In Chapter 7, the consensus statement on inclusive health research is presented. A total of 17 experts on inclusive (health) research without ID and 40 experts with ID collaborated in this consensus statement. The statement was developed in three consecutive rounds: (1) an initial feedback round, (2) a roundtable discussion at the 2016 International Association for the Scientific Study of Intellectual and

Developmental Disabilities World Congress, and (3) a final feedback round. This consensus statement provides researchers with guidelines, agreed upon by experts in the field, regarding attributes, potential outcomes, reporting and publishing, and future research directions, for designing and conducting inclusive health research. Although consensus was reached on how to design and conduct inclusive health research, this statement should be continuously adapted to incorporate recent knowledge. The focus of this consensus statement is largely on inclusive health research, but the principles can also be applied to other areas. An easy-read version of the consensus statement developed in collaboration with 40 experts with ID can be found in Appendix XI.

Chapter 8

In Chapter 8, there is a general discussion of this thesis, presenting an overview of the main findings and discussing three recurrent topics in this thesis: (1) quality and added value of inclusive health research, (2) roles and responsibilities in inclusive health research, and (3) applicability of findings beyond inclusive health research. Additionally, methodological reflections and suggestions for the move towards a third generation of inclusive health research are presented. The overarching research questions are answered here:

1) What are the expectations regarding (1) the quality and added value and (2) the roles and responsibilities within inclusive health research, according to academics and people with ID?
2) What are the realities regarding (1) the quality and added value and (2) the roles and responsibilities of inclusive health research, according to inclusive research teams?
3) How can inclusive research teams optimise their inclusive health research design and implementation, according to experts with and without ID?

With regard to quality and added value, the literature states that inclusive research tends to focus on its process, rather than on its added value for research practice, and the study of added value is often one-sided and seen in “attitudinal changes”. Given the results of this thesis, this is only partially true. In this vein, it is stated that empowerment in inclusive research adds to the quality of research, as it enriches the study design and results. Thus, the focus should not be solely on the process, but also on all levels of added value of inclusive health research (i.e., personal, professional, healthcare, research, and societal).

The experts who contributed to the consensus statement (Chapter 7) addressed the struggle between aiming for meaningful inclusion and meeting academic conditions. The literature identified the same tension between research quality and the quality of inclusive approaches. Limitations imposed by academic structures can be problematic for the quality of collaboration between researchers with and without ID. In Chapter 4, Delphi study respondents expressed the need for a tool, checklist, or guideline to provide guidance and support during the inclusive process and show its added value. Quality criteria for inclusive health research could benefit both the quality and the sharing of inclusive health research experiences. A further link was made in the consensus statement (Chapter 7): experts emphasised the need for future inclusive health research to enhance the sharing of knowledge, information, and experiences with inclusive research in order to improve its quality. The consensus statement adds to existing criteria by providing more practical support for conducting good quality inclusive health research.

The topic of roles and responsibilities in inclusive health research is very important in the shaping of an inclusive approach and the identification of where researchers with and without ID can contribute. In Chapter 6, roles were divided into three categories: researcher with ID (teacher, expert-by-experience, co-researcher, and so on), researcher without ID (facilitator, team member, academic researcher, and so on) and general (manager, colleague, and so on). In inclusive research projects, roles and responsibilities can be assigned in different ways and at different junctures, thereby influencing the amount of decision-making power within the inclusive research team. Throughout several studies in this thesis (Chapters 2, 4, 5, and 6), respondents proffered a balance in collaboration, instead of providing a researcher with or without ID with more decision-making power than the other. When decision-making power is shared within the inclusive research team, the roles and responsibilities of team members can complement each other. Inclusive health research is a process between researchers with and without ID and is influenced by the phase and context of the study; this calls for further research on how their collaboration takes shape in different situations.

As this thesis explored the expectations and realities of inclusive health research, the results contribute to moving from “ideology to research reality”. In Chapter 6, dialogue between researchers with and without ID, in which both need to be realistic about their own and each other’s skills and flexible in the design of their study, was found to be key in collaboration. Chapter 6 provides practical insight into the roles and responsibilities in inclusive health research realities through a taxonomy that can be used to support dialogue on the sharing of roles and responsibilities. However, the same study identified the challenge of uncovering implicit roles in inclusive health research. Further insight into both the explicit and the implicit roles and related activities of inclusive research is important for understanding all facets of inclusive research and supporting in sharing decision-making power within an inclusive research team.

Comparison of participatory research in varying groups revealed more similarities than differences. Similar to the need for tailoring found in this thesis, attention must be paid to the unique features of all those involved in participatory research, whether they are people with ID, people with mental health issues, or older persons. The knowledge gained in this thesis seems applicable to participatory research with other groups; this means that the inclusive research ethos (Chapter 5), the taxonomy of roles and responsibilities (Chapter 6), and the consensus statement (Chapter 7) might prove useful for those who are designing and implementing any kind of participatory research. Additionally, the applicability of the output developed in this thesis might go beyond research, as experts in the consensus statement suggested that ethics committees and journal editors could use the statement as a tool to check whether researchers have conducted good quality inclusive research. Likewise, policies such as the Dutch Participation Law could use a tool like the consensus statement to evaluate the level of citizen participation. The knowledge gained could be of use in healthcare or in the employment and education of people with ID.

10.2 Nederlandse samenvatting

Hoofdstuk 1
In Hoofdstuk 1 wordt een algemene introductie gegeven over de onderwerpen patiëntenparticipatie in gezondheidsonderzoek, verstandelijke beperkingen (VB) en inclusief gezondheidsonderzoek. Inclusief (gezondheids)onderzoek:

- heeft als doel om bij te dragen aan sociale verandering wat helpt bij het creëren van een participatie maatschappij, inclusief gezondheidszorg, met het doel is om de kwaliteit van leven van buitengesloten groepen te verbeteren;
- is gebaseerd op problemen die belangrijk zijn voor een groep en leert van ervaringen van deze groep, om het onderzoeksproces en de uitkomsten te informeren;
- heeft als doel het herkennen, stimuleren en communiceren van de toegevoegde waarde die mensen met een VB kunnen hebben;
- geeft informatie dat gebruikt kan worden om campagne te voeren voor mensen met een VB; en
- ‘staat met’ diegene wiens problemen uitgezocht en onderzocht worden.

Er wordt een vergelijking gemaakt tussen recente beleidsontwikkelingen en de huidige inclusieve praktijk van gezondheidsonderzoek, leidend tot de volgende onderzoeksvragen:

1) Wat zijn de verwachtingen ten aanzien van (1) de kwaliteit en toegevoegde waarde en (2) de rollen en verantwoordelijkheden binnen inclusief gezondheidsonderzoek, volgens academici en mensen met VB?
2) Wat zijn de realiteiten met betrekking tot (1) de kwaliteit en toegevoegde waarde en (2) de rollen en verantwoordelijkheden van inclusief gezondheidsonderzoek, volgens inclusieve onderzoeksteams?
3) Hoe kunnen inclusieve onderzoeksteams het ontwerp en implementatie van inclusief gezondheidsonderzoek optimaliseren, volgens deskundigen met en zonder VB?

Tijdens dit doctoraatsonderzoek wordt een inclusieve benadering gekozen door structurele samenwerking met twee co-onderzoekers: Henk Jansen en Anneke van der Cruijsen, met als doel het steeds inclusiever worden van de studies naarmate onze ervaring als een inclusief onderzoeksteam groeien.

Deel I: Ervaringen

Hoofdstuk 2

Hoofdstuk 2 beschrijft een gestructureerd literatuuronderzoek van de actieve participatie van mensen met VB in gezondheidsonderzoek, ook wel bekend als inclusief gezondheidsonderzoek. Het literatuuronderzoek concentreerde zich op (1) bestaande theorieën, (2) inclusieve methoden, (3) toegevoegde waarde, en (4) barrières en facilitators. Literatuur gepubliceerd tussen januari 2000 en januari 2014 welke gebruik hebben gemaakt van de trefwoorden VB en inclusief gezondheidsonderzoek is opgenomen in dit onderzoek. Zoekopdrachten werden uitgevoerd in Pubmed, CINAHL, PsycINFO, EMBASE en MEDLINE-databases, resulterend in 26 opgenomen artikelen. De artikelen werden beoordeeld op kwaliteit en geanalyseerd met behulp van kwalitatieve data-analyse software.

Er is onduidelijkheid over wat precies inclusief gezondheidsonderzoek inhoudt. Ten eerste werd een discrepantie gevonden in de toepassing van bestaande theorieën: in sommige artikelen werd er geen melding van gemaakt, terwijl anderen meerdere theorieën citeerden. Het kan zijn dat deze theorieën te abstract zijn om de implementatie van inclusief gezondheidsonderzoek te ondersteunen. Ten tweede werden verschillen waargenomen in het perspectief van auteurs op het juiste moment voor samenwerken met mensen met VB. Ten derde hebben enkele van de in de opgenomen artikelen prioriteit gegeven aan het inclusieve proces, in plaats van de kwaliteit van het onderzoek.

Een andere bevinding is dat samenwerking met co-onderzoekers met VB, in tegenstelling tot consultatie van of controle door mensen met VB, de enige inclusieve methode lijkt te zijn die resulteert in de actieve betrokkenheid van mensen met VB gedurende de hele onderzoekscyclus. Met betrekking tot inclusieve methoden lijken de barrières en facilitators die in deze studie worden gevonden de weg te zijn naar betekenisvol, inclusief gezondheidsonderzoek. Op basis van analyse kan worden gesteld dat dit de feitelijke inclusieve methode is.

Het inclusieve proces moet op maat worden gemaakt, voor elk individueel inclusief onderzoeksproject, om te anticiperen op de behoeften van alle betrokkenen.

In de beginfasen van het onderzoeksproces gaven de auteurs vaak aan dat hun motivatie om inclusief gezondheidsonderzoek uit te voeren te baseren op eisen van beleids- en financieringsorganen of op ethiek (d.w.z. verwachte toegevoegde waarde). Aan het einde van het onderzoek leken auteurs te hebben waargenomen dat inclusief gezondheidsonderzoek leidde tot toegenomen kwaliteit en validiteit van hun onderzoek en voordelen voor betrokkenen (d.w.z. ervaren toegevoegde waarde). Er was een verschuiving van onderzoekers die aanvankelijk verplicht waren mensen met VB actief te betrekken bij gezondheidsonderzoek tot een perceptie aan het einde van het onderzoek dat betrokkenen baat hadden bij de inclusieve methodologie.

Met betrekking tot de barrières en facilitators die in deze studie zijn geïdentificeerd, was de meest dringende kwestie de zogenaamde mythe van homogeniteit: niet elke persoon met VB kan de rest van de groep vertegenwoordigen. Inclusieve gezondheidsonderzoekers zijn zich niet altijd bewust van de diversiteit van de VB-populatie; dit wordt bevestigd door de afwezigheid van mensen met een ernstige en zeer ernstige VB in onderzoek en pogingen hen te vertegenwoordigen door anderen. Toekomstig onderzoek moet zich richten op het actief betrekken van alle mensen met VB in gezondheidsonderzoek, met name mensen met een ernstige en zeer ernstige VB rechtstreeks of via een proxy.

Hoofdstuk 3

Hoofdstuk 3 beschrijft een gestructureerd interviewonderzoek naar deelname aan onderzoek in de breedste zin van het woord. Alhoewel deelname van mensen met VB aan onderzoek steeds vaker voorkomt, is er weinig inzicht in het aantal deelnemers met VB, hun motivatie om deel te nemen en hun interesses met betrekking tot studieresultaten. Er zijn vijf vragen toegevoegd aan de enquête van Panel Samen Leven (PSL) onder 508 mensen met VB. De vragen waren gericht op het verkrijgen van inzicht in (i) frequentie van deelname, (ii) gebruikte methoden om deel te nemen; (iii) motivaties om deel te nemen; en (iv) belangen met betrekking tot studieresultaten.

Hoewel de meerderheid (73,5%, n = 347) van de respondenten genoten van hun deelname en de meesten (71,6%; n = 312) het belangrijk vonden om deel te nemen aan onderzoek, namen slechts weinig (11,8%; n = 60) deel aan ander onderzoek dan de PSL-enquête. Van de respondenten die vraag 2 over participatiemethoden hebben beantwoord (n = 60), nam bijna de helft (43,3%; n = 26) deel als adviseur en een paar (11,7%; n = 7) als co-onderzoeker; deze worden gezien als inclusieve onderzoeksmethoden. Voor zover wij weten, bestaan er geen gegevens over de frequentie van participatief onderzoek met andere groepen, waardoor vergelijking moeilijk is. Bovendien ligt in de definitie van inclusief onderzoek de nadruk op hoe mensen met VB worden betrokken (bijvoorbeeld "als meer dan alleen onderzoeksobjecten"), niet op hoeveel mensen er bij betrokken zijn. Desalniettemin weerspiegelen deze percentages niet het doel van inclusief onderzoek, waar mensen met VB de kans moeten hebben om actief betrokken te zijn. De definitie van inclusief onderzoek laat veel ruimte voor interpretatie en onderzoekers kunnen hun eigen perceptie van dergelijk onderzoek hebben, wat resulteert in een verscheidenheid aan inclusieve methoden.

Respondenten in dit onderzoek scoorden verschillende motivaties relatief hoog (d.w.z. verwachten ervan te genieten, belangrijk vinden, ervan leren, een zelfverzekerder persoon worden en iets te doen hebben); deze komen overeen met bevindingen uit ander onderzoek. Uit de literatuurstudie in Hoofdstuk 2 bleek dat veel onderzoekers verwachten dat *empowerment* de belangrijkste motivatie is voor mensen met VB om deel te nemen aan onderzoek. *Empowerment* kan deels een motivatie voor hen zijn om deel te nemen aan onderzoek - vastgelegd in onderwerpen als het aanleren van nieuwe vaardigheden en het vergroten van het netwerk; dit is echter niet de enige reden om deel te nemen aan onderzoek. Bovendien toonde meer dan de helft (61%) van de respondenten belangstelling voor de resultaten van de studies waaraan zij deelnamen. Reageren op deze motivaties en interesses door bijvoorbeeld makkelijk lezen informatie te geven over resultaten, is een teken van toewijding aan mensen met VB, en hieraan moet meer aandacht worden besteed.

Hoofdstuk 4

Hoofdstuk 4 presenteert een Delphi studie over inclusief gezondheidsonderzoek gepubliceerd in het *British Medical Journal*. De patiëntenrevolutie van het *BMJ* streeft naar samenwerking met patiënten in gezondheidszorg en gezondheidsonderzoek. Momenteel ontbreekt het aan transparantie en overeenstemming tussen academici over de belangrijkste aspecten van inclusief gezondheidsonderzoek, waardoor opschaling van de patiëntenrevolutie wordt tegengehouden. Het Delphi onderzoek had als doel om academici te bereiken over drie aspecten van inclusief gezondheidsonderzoek voor mensen met VB: (1) ontwerpen en methoden, (2) belangrijkste kenmerken en (3) uitkomsten. Een Delphi studie werd uitgevoerd met academici met ervaring in inclusief (gezondheids) onderzoek en mensen met VB. De studie bestond uit twee opeenvolgende vragenlijstrondes (n = 24; n = 17, respectievelijk), gevolgd door diepte-interviews (n = 10) om overeenstemming tussen academici te bereiken.

Academici waren het eens over (1) samenwerking als meest geschikte benadering voor inclusief gezondheidsonderzoek is, (2) kenmerken met betrekking tot de toegankelijkheid en facilitering van inclusief gezondheidsonderzoek, en (3) verschillende resultaten van inclusief gezondheidsonderzoek voor mensen met VB en gezondheidszorg. Andere overeengekomen kenmerken waren: sfeer, relatie, betrokkenheid, partnerschap en macht. Er werd benadrukt dat deze kenmerken zorgen voor een betekenisvolle betrokkenheid. Er werden interviews afgenomen om meer diepgaande informatie te verkrijgen over inclusief gezondheidsonderzoek. Geïnterviewde academici waren van mening dat er behoefte is aan een hulpmiddel ter ondersteuning van de facilitering en evaluatie van inclusief gezondheidsonderzoek. Er was onduidelijkheid hoe dit hulpmiddel er uit zou moeten zien en de mate waarin het mogelijk was om het complexe proces van inclusief gezondheidsonderzoek hierin te vatten. Deze studie onderstreept de behoefte aan transparantie, facilitering en evaluatie van inclusief gezondheidsonderzoek. De behoefte aan diepte-interviews na twee Delphi rondes onderstreept de complexiteit en contextafhankelijkheid. Om de procestransparantie te vergroten, moet toekomstig onderzoek zich richten op het verkrijgen van inzicht in inclusief gezondheidsonderzoek in zijn context. Een hulpmiddel zou kunnen worden ontwikkeld om inclusief gezondheidsonderzoek te faciliteren en te evalueren. Dit hulpmiddel zou gedeeltelijk van toepassing zijn op participatief onderzoek in het algemeen en zou daardoor bijdragen aan de patiëntenrevolutie.

Deel II: Realiteiten

Hoofdstuk 5

In Hoofdstuk 5 wordt een structurele studie van vier inclusieve onderzoeksteams gepresenteerd. De actieve betrokkenheid van mensen met VB in onderzoek wordt verwacht te leiden tot relevante onderzoeksresultaten, verbeterde kwaliteit van leven, verbeterde gezondheidszorg, vermindering van gezondheidsongelijkheden en *empowerment* van mensen met VB. Ondanks de ontwikkelingen in inclusief gezondheidsonderzoek blijft er een gebrek aan transparantie met betrekking tot hoe de samenwerking tussen onderzoekers met en zonder VB wordt vormgegeven, en is structurele studie van inclusief gezondheidsonderzoek nodig. Deze studie had tot doel inzicht te krijgen in de ervaringen van inclusieve onderzoeksteams in de praktijk met betrekking tot (1) redenen, (2) attributen en (3) uitkomsten van inclusief gezondheidsonderzoek. Een structurele studie van vier inclusieve onderzoeksteams werd uitgevoerd in Ierland, Noord-Ierland en Nederland met behulp van de *case study* methodologie. Gegevens werden getrianguleerd door het verzamelen van documenten en afnemen van individuele en groepsinterviews. Gegevens werden geanalyseerd en gesynthetiseerd met behulp van domein en taxonomische analyse.

Het bleek dat de redenen voor het uitvoeren van inclusief onderzoek varieerden van persoonlijk tot praktisch. Door middel van data-analyse werd een inclusieve ethos geïdentificeerd, dat bestaat uit een reeks kwaliteiten van onderzoekers die een *mindset* vormen welke nuttig is voor inclusief onderzoek. Het hebben van een inclusieve ethos bleek cruciaal om inclusief onderzoek betekenisvol uit te voeren in de praktijk. Attributen van inclusief onderzoek bestaan uit drie onderling verbonden thema's, één gericht op methodologische aspecten en twee gericht op actieve betrokkenheid en partnerschap. Resultaten van inclusief onderzoek in de verschillende inclusieve onderzoeksteams werden gevonden binnen drie categorieën: onderzoekspraktijk, inclusie en inter-persoonlijke uitkomsten. *Empowerment* bleek belangrijk te zijn. Alhoewel *empowerment* niet nieuw is voor inclusief onderzoek en grotendeels verband houdt met co-onderzoekers, lijkt het positieve effect ervan op de kwaliteit van het onderzoek nieuw te zijn. Dit moet verder onderzocht worden. De resultaten van deze studie en de literatuur geven aan dat het ontwikkelen van inclusief onderzoeksbeleid en -praktijk een realistisch perspectief vereist, met een balans tussen maximale samenwerking en het benutten van de sterke punten van onderzoekers. De resultaten van deze studie zijn overdraagbaar naar inclusief onderzoek met vergelijkbare methoden binnen andere groepen. Wanneer het echter de bedoeling is om van elkaar te leren, is een gedeelde taal nodig. Op basis van de studieresultaten werd een gemakkelijk leesbare informatiefolder ontwikkeld in samenwerking met co-onderzoekers.

Hoofdstuk 6
Hoofdstuk 6 presenteert een *memberschip categorisation analysis* (*MCA*) van inclusief onderzoek. Inclusief onderzoek wordt voornamelijk bestudeerd in korte termijn samenwerkingsverbanden tussen onderzoekers met en zonder VB, en vooral gericht op praktische zaken. Structurele studie van lange termijn samenwerking kan inzicht verschaffen in de verschillende rollen van inclusieve onderzoekers en zo bijdragen aan een collectieve aanpak. In deze studie staat de langdurige samenwerking tussen de onderzoekers met en zonder VB in dit proefschrift centraal. Interviews met leden van het inclusieve onderzoeksteam (n = 3), collega's (n = 8) en managers (n = 2) en drie groepsdiscussies binnen het inclusieve onderzoeksteam werden gehouden. Gegevens werden geanalyseerd door middel van *MCA* aangepast aan de behoeften van het inclusieve onderzoeksteam.

De resultaten van deze studie bieden inzicht in hoe inclusief onderzoek is gestructureerd aan de hand van rollen en activiteiten en hoe deze zich tot elkaar verhouden. Na een inclusieve *MCA*-benadering identificeerde deze studie drie categorieën in inclusief onderzoek: onderzoeker met VB, onderzoeker zonder VB en algemeen. Deze categorieën bestaan elk uit verschillende rollen en *membership categorisation devices* (*MCD's*), dit zijn activiteiten die gezamenlijk een rol vormen. De resultaten van de inclusieve *MCA* omvatten rollen die kunnen worden verwacht binnen de onderzoeker met VB-categorie, zoals co-onderzoeker, docent en ervaringsdeskundige, maar ook verschillende rollen die misschien minder duidelijk zijn, zoals carrièretijger en vertaler. Deze rollen bestaan uit activiteiten die zeer kenmerkend zijn voor de onderzoeker met VB, maar tegelijkertijd moeilijker zichtbaar te maken en onder woorden te brengen zijn. Met betrekking tot de relatie tussen categorieën, bleek dat de onderzoeker zonder VB-categorie voornamelijk bestaat uit faciliterende activiteiten voor onderzoekers met VB, naast het doen van onderzoek. Dit geeft aan dat de onderzoeker zonder VB zich meer richt op de toegankelijkheid van onderzoek in vergelijking met de onderzoeker met VB. De algemene categorie bestaat uit rollen en activiteiten die van toepassing zijn op alle betrokkenen bij inclusief onderzoek en faciliteert zowel fysieke als sociale inclusie.

De complexiteit van inclusief onderzoek wordt weerspiegeld in de veelheid aan rollen en activiteiten die in deze studie zijn geïdentificeerd. Van de 18 rollen die in dit onderzoek zijn beschreven, zijn er 11 eerder, vaak impliciet, geïdentificeerd en beschreven in de literatuur. Deze studie zet een volgende stap door het structureren en expliciteren van inclusieve onderzoeksrollen. Inzicht in zowel de expliciete als de impliciete rollen en gerelateerde activiteiten van inclusief onderzoek is belangrijk voor het begrijpen van elk facet van inclusief onderzoek, en het helpt bij het toewijzen van verantwoordelijkheden binnen een inclusief onderzoeksteam.

Discussies in de literatuur over terminologie van participatief en emancipatoir onderzoek suggereren dat één van de doelen van inclusief onderzoek is dat co-onderzoekers de baan van een academisch onderzoeker zo dicht mogelijk moeten benaderen. De onderzoeker met VB en de onderzoeker zonder VB-categorieën in deze studie omvatten echter rollen en activiteiten die erg van elkaar verschillen. De resultaten van deze studie suggereren dat onderzoekers met en zonder VB elkaar aanvullen, wat impliceert dat rollen en activiteiten niet exact hetzelfde kunnen zijn. Bovendien zijn verschillen tussen onderzoekers met en zonder VB niet alleen gebaseerd op hun rol in inclusief onderzoek, maar ook op hun persoonlijkheden en persoonlijke leven. De *MCD's* die in dit onderzoek zijn geïdentificeerd, vormen een waardevolle basis om rollen en verantwoordelijkheden te bespreken bij de start van een inclusief onderzoeksproject. Op deze manier begint de dialoog bij de kern van inclusief onderzoek: het proces tussen onderzoekers met en zonder VB. Het delen van deze dialoog in publicaties helpt bij het gezamenlijk leren tussen inclusieve onderzoekers en om een meer solide kennisbasis op dit gebied te creëren.

Deel III: Optimaliseren van inclusief gezondheidsonderzoek

Hoofdstuk 7

In Hoofdstuk 7 wordt het *consensus statement* over inclusief gezondheidsonderzoek gepresenteerd. In totaal hebben 17 experts op het gebied van inclusief (gezondheids)onderzoek zonder VB en 40 experts met VB aan het *consensus statement* meegewerkt. Het *statement* is ontwikkeld in drie opeenvolgende rondes: (1) een eerste feedbackronde, (2) een groepsdiscussie op de 2016 *International Association for the Scientific Study of Intellectual and Developmental Disabilities World Congress*, en (3) een laatste feedbackronde. Het *consensus statement* biedt onderzoekers richtlijnen, goedgekeurd door experts in het veld, met betrekking tot attributen, mogelijke resultaten, rapportage en publicatie en toekomstige onderzoeksrichtingen voor het ontwerpen en uitvoeren van inclusief gezondheidsonderzoek. Hoewel consensus werd bereikt over de manier waarop inclusieve gezondheidsonderzoeken moeten worden ontworpen en uitgevoerd, moet het *statement* voortdurend worden aangepast om recente kennis te integreren. De focus van het *consensus statement* ligt grotendeels op inclusief gezondheidsonderzoek, maar de principes kunnen ook op andere gebieden worden toegepast. Een eenvoudig leesbare versie van het *consensus statement*, ontwikkeld in samenwerking met 40 experts met VB, is te vinden in bijlage XI.

Hoofdstuk 8

In Hoofdstuk 8 wordt een algemene discussie van dit proefschrift gegeven, met een overzicht van de belangrijkste bevindingen en de discussie van drie terugkerende onderwerpen in dit proefschrift: (1) kwaliteit en toegevoegde waarde van inclusief gezondheidsonderzoek, (2) rollen en verantwoordelijkheden in inclusieve gezondheidsonderzoek, en (3) toepasbaarheid van bevindingen voorbij inclusief gezondheidsonderzoek. Daarnaast worden methodologische reflecties en suggesties voor de overgang naar een derde generatie inclusief gezondheidsonderzoek gepresenteerd. De overkoepelende onderzoeksvragen worden hier beantwoord:

1) Wat zijn de verwachtingen ten aanzien van (1) de kwaliteit en toegevoegde waarde en (2) de rollen en verantwoordelijkheden binnen inclusief gezondheidsonderzoek, volgens academici en mensen met VB?
2) Wat zijn de realiteiten met betrekking tot (1) de kwaliteit en toegevoegde waarde en (2) de rollen en verantwoordelijkheden van inclusief gezondheidsonderzoek, volgens inclusieve onderzoeksteams?
3) Hoe kunnen inclusieve onderzoeksteams het ontwerp en implementatie van inclusief gezondheidsonderzoek optimaliseren, volgens deskundigen met en zonder VB?

Met betrekking tot kwaliteit en toegevoegde waarde stelt de literatuur dat inclusief onderzoek de neiging heeft zich te concentreren op het proces, in plaats van op de toegevoegde waarde ervan voor de onderzoekspraktijk, en dat de studie van toegevoegde waarde vaak eenzijdig is en gezien wordt in 'attitudeveranderingen'. Gezien de resultaten van dit proefschrift is dit slechts gedeeltelijk waar. Er wordt gesteld dat *empowerment* in inclusief onderzoek bijdraagt aan de kwaliteit van onderzoek, omdat het ontwerp en uitkomsten van de studie verrijkt. De focus moet dus niet alleen liggen op het proces, maar ook op alle niveaus van toegevoegde waarde van inclusief gezondheidsonderzoek (d.w.z. persoonlijk, professioneel, gezondheidszorg, onderzoek en maatschappelijk).

De experts die hebben bijgedragen aan het *consensus statement* (Hoofdstuk 7) hebben de strijd benadrukt tussen het streven naar betekenisvolle inclusie en het voldoen aan academische voorwaarden. De literatuur identificeerde dezelfde spanning tussen onderzoekskwaliteit en de kwaliteit van inclusieve methoden. Beperkingen opgelegd door academische structuren kunnen een probleem vormen voor de kwaliteit van samenwerking tussen onderzoekers met en zonder VB. In Hoofdstuk 4, de Delphi studie, gaven respondenten aan behoefte te hebben aan een hulpmiddel, checklist of richtlijn om begeleiding en ondersteuning te bieden tijdens het inclusieve proces en de toegevoegde waarde ervan te tonen. Kwaliteitscriteria voor inclusief gezondheidsonderzoek kunnen zowel de kwaliteit als het delen van inclusieve ervaringen ten goede komen. Een verdere link werd gelegd in het *consensus statement* (Hoofdstuk 7): experts benadrukten de noodzaak van toekomstig inclusief gezondheidsonderzoek om kennis, informatie en ervaringen met inclusief onderzoek uit te wisselen ten behoeve van kwaliteitstoename. Het *consensus statement* voegt toe aan bestaande criteria door meer praktische ondersteuning te bieden voor het uitvoeren van kwalitatief goed inclusief gezondheidsonderzoek.

Rollen en verantwoordelijkheden in inclusief gezondheidsonderzoek zijn erg belangrijk bij het vormgeven van een inclusieve methode en de identificatie van waar en wanneer onderzoekers met en zonder VB kunnen bijdragen. In Hoofdstuk 6 werden de rollen verdeeld in drie categorieën: onderzoeker met VB (docent, ervaringsdeskundige, co-onderzoeker, enz.), onderzoeker zonder VB (facilitator, teamlid, academisch onderzoeker, enz.) en algemeen (manager, collega, enz.). In inclusieve onderzoeksprojecten kunnen rollen en verantwoordelijkheden op verschillende manieren en op verschillende momenten worden toegewezen, waardoor de verdeling van beslissingsbevoegdheid binnen het inclusieve onderzoeksteam wordt beïnvloed. Gedurende verschillende onderzoeken in dit proefschrift (Hoofdstukken 2, 4, 5 en 6), gaven respondenten aan een balans in samenwerking te prefereren, in plaats van een onderzoek waarbij onderzoekers met of zonder VB meer beslissingsbevoegdheid hebben dan de ander. Wanneer de beslissingsbevoegdheid binnen het inclusieve onderzoeksteam wordt gedeeld, kunnen de rollen en verantwoordelijkheden van teamleden elkaar aanvullen. Inclusief gezondheidsonderzoek is een proces tussen onderzoekers met en zonder beslissingsbevoegdheid en wordt beïnvloed door de fase en context van het onderzoek; dit vraagt om verder onderzoek naar hoe hun samenwerking vorm krijgt in verschillende situaties.

Aangezien dit proefschrift de verwachtingen en de realiteit van inclusief gezondheidsonderzoek heeft onderzocht, dragen de resultaten bij aan de overgang van “ideologie naar onderzoeksrealiteit”. In Hoofdstuk 6 bleek de dialoog tussen onderzoekers met en zonder VB de sleutel tot samenwerking, waarbij beide realistisch moeten zijn over hun eigen en elkaars vaardigheden en flexibel in het ontwerp van hun studie. Hoofdstuk 6 biedt praktisch inzicht in de rollen en verantwoordelijkheden in de inclusieve realiteit van het gezondheidsonderzoek door middel van een taxonomie die kan worden gebruikt om de dialoog over het delen van rollen en verantwoordelijkheden te faciliteren. In dezelfde studie werd echter de uitdaging geïdentificeerd van het ontdekken van impliciete rollen in inclusief gezondheidsonderzoek. Verder inzicht in zowel de expliciete als de impliciete rollen en gerelateerde activiteiten van inclusief onderzoek is belangrijk voor het begrijpen van alle facetten van inclusief onderzoek en ondersteuning bij het delen van beslissingsbevoegdheid binnen een inclusief onderzoeksteam.

Vergelijking van participatief onderzoek in verschillende groepen bracht meer overeenkomsten dan verschillen aan het licht. Net als de noodzaak voor afstemming in dit proefschrift, moet aandacht worden besteed aan de unieke kenmerken van iedereen die betrokken is bij participatief onderzoek, of het nu gaat om mensen met VB, mensen met psychische problemen of ouderen. De kennis die is opgedaan in dit proefschrift lijkt toepasbaar op participatief onderzoek met andere groepen; dit betekent dat het inclusieve ethos (Hoofdstuk 5), de taxonomie van rollen en verantwoordelijkheden (Hoofdstuk 6) en het *consensus statement* (Hoofdstuk 7) nuttig kunnen zijn voor degenen die elk soort participatief onderzoek ontwerpen en uitvoeren. Daarnaast zou de toepasbaarheid van de in dit proefschrift ontwikkelde output verder kunnen gaan dan alleen onderzoek, aangezien experts in het *consensus statement* suggereerden dat ethische commissies en redacteuren van wetenschappelijke tijdschriften het *statement* konden gebruiken als een instrument om te controleren of onderzoekers kwalitatief juist inclusief onderzoek hebben uitgevoerd. Evenzo zouden beleidsmaatregelen zoals de Nederlandse Participatiewet een hulpmiddel zoals het *consensus statement* kunnen gebruiken om het niveau van burgerparticipatie te evalueren. De opgedane kennis kan nuttig zijn in de gezondheidszorg of in het werk en onderwijs van mensen met VB.

10.3 Makkelijk lezen samenvatting

Hoofdstuk 1

- Dit boek gaat over inclusief gezondheidsonderzoek.
- Inclusief onderzoek = wanneer mensen met een verstandelijke beperking en onderzoekers samenwerken.
- Inclusief *gezondheids*onderzoek = wanneer inclusief onderzoek over de gezondheid van mensen met een verstandelijke beperking gaat. Bijvoorbeeld over iemands lichamelijke of emotionele gezondheid.
- Bij inclusief gezondheidsonderzoek zijn mensen met een verstandelijke beperking bij elke stap betrokken.

Dit onderzoek wilde 3 vragen beantwoorden:

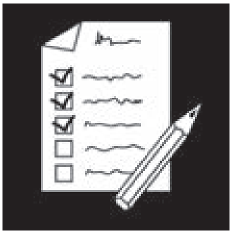
1. Hoe denken mensen over inclusief gezondheidsonderzoek?
2. Wat gebeurt er in het echt in inclusief gezondheidsonderzoek?
3. Hoe kunnen teams hun inclusief gezondheidsonderzoek zo goed mogelijk maken?

We hebben een makkelijk lezen versie gemaakt van dit hele boek.
Deze kan je opvragen de Academische werkplaats Sterker op eigen benen: www.sterkeropeigenbenen.nl.

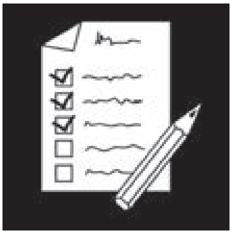
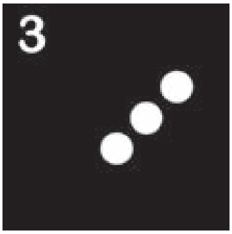
Hoofdstuk 2

	We hebben een literatuur onderzoek gedaan. We hebben naar 24 artikelen over inclusief gezondheidsonderzoek gekeken.
	Wat we geleerd hebben: • We hebben dingen die goed gingen en dingen die niet goed gingen gevonden. Dit hebben we ingedeeld in: voorbereiden, uitvoeren en afmaken van het onderzoek. • Voordat men onderzoek ging doen, wilde ze samenwerken met mensen met een verstandelijke beperking omdat het moest van beleid en geldschieters. • Door samen te werken met mensen met een verstandelijke beperking, zagen onderzoekers dat het project beter werd.
	We hebben 4 tips voor mensen die inclusief gezondheidsonderzoek willen doen: 1. Pas je aan, aan het onderzoek 2. Pas je aan, aan de mensen die meedoen 3. Bedenk wat echt nodig, en wat niet 4. Laat anderen zien wat je gedaan hebt

Hoofdstuk 3

	We hebben een vragenlijstonderzoek gedaan. 508 mensen met een verstandelijke beperking hebben onze vragenlijst ingevuld.
	De vragen in de vragenlijst waren: 1. Heb je wel eens meegedaan aan onderzoek? 2. Hoe vaak heb je meegedaan aan onderzoek? 3. Hoe heb je meegedaan aan onderzoek? 4. Waarom heb je meegedaan aan onderzoek? 5. Wat zou je willen weten over de uitkomsten van het onderzoek?
	Wat we hebben geleerd: • Veel deelnemers vonden het leuk en belangrijk om mee te doen aan onderzoek. • Weinig mensen met een verstandelijke beperking deden mee aan onderzoek. • Een deel van de deelnemers wilde de uitkomst van het onderzoek weten. Zo konden ze vergelijken, leren en informatie delen.

Hoofdstuk 4

 	We hebben een Delphi studie gedaan. Hiervoor hebben we vragenlijsten afgenomen bij 24 onderzoekers. Daarna hebben we interviews gedaan met 10 onderzoekers.
 	De vragenlijsten en interviews gingen over: 1. Manieren van inclusief gezondheidsonderzoek doen 2. Belangrijkste punten in inclusief gezondheidsonderzoek 3. Uitkomsten van inclusief gezondheidsonderzoek
 	Onderzoekers vonden 3 dingen belangrijk: 1. Hoe je samenwerkt moet passen bij het onderzoek 2. Toegang en makkelijk maken van onderzoek 3. Uitkomsten van inclusief gezondheidsonderzoek voor mensen met een verstandelijke beperking en gezondheidszorg

	Wat we hebben geleerd: In de interviews zeiden onderzoekers dat ze graag een hulpmiddel willen voor inclusief gezondheidsonderzoek. Bijvoorbeeld een richtlijn.

Hoofdstuk 5

	We hebben een Casus studie gedaan. We hebben met 4 teams in Ierland en Nederland gesproken die inclusief onderzoek deden.
	Wat we graag wilden weten: 1. Waarom ze samen onderzoek deden? 2. Wat belangrijk is bij samen onderzoek doen? 3. Wat de uitkomsten van samen onderzoek doen waren?
	Wat we hebben geleerd: - Onderzoeksteams hadden praktische en persoonlijke redenen om samen onderzoek te doen. - Het was heel belangrijk om de juiste manier van denken te hebben over samenwerken.

Hoofdstuk 6

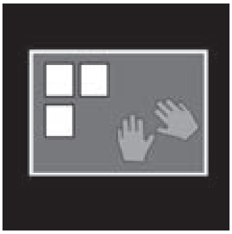
	• Henk, Anneke (co-onderzoekers) en Tessa (onderzoeker) hebben 4 jaar samengewerkt. • We hebben onze eigen samenwerking onderzocht.
	We hebben gesproken met collega's, managers en onderling.
	Wat we geleerd hebben: • We hebben heel veel verschillende rollen gevonden in onze samenwerking. • Onderzoekers met en zonder verstandelijke beperking zijn verschillend, maar vullen elkaar aan.

Hoofdstuk 7

	We hebben een richtlijn over inclusief gezondheidsonderzoek geschreven.
	57 experts met en zonder verstandelijke beperking hebben ons geholpen.
	De richtlijn geeft onderzoekers hulp bij het opzetten en uitvoeren van inclusief gezondheidsonderzoek.

Hoofdstuk 8

Drie onderwerpen waren belangrijk in dit boek:

	1. Hoe doe je goed inclusief gezondheidsonderzoek? • Er moet meer gekeken worden naar hoe je goed inclusief gezondheidsonderzoek doet. • Er moeten afspraken komen over hoe je het goed doet. • De richtlijn kan hierbij helpen.
	2. Wie doet wat tijdens inclusief gezondheidsonderzoek? • Onderzoekers met en zonder verstandelijke beperking vullen elkaar aan. • Er moet meer onderzoek gedaan worden naar wie wat doet.
	3. Wie kan er nog meer leren van dit boek? Wat we geleerd hebben in dit boek kan handig zijn voor andere projecten waarbij samen wordt gewerkt met de doelgroep.

Chapter 11

Acknowledgement/Dankwoord

Door dit hele proefschrift is het thema ‘samen’ verweven. Dit proefschrift had ik niet kunnen schrijven zonder dit *samen* te doen met een groep mensen. Hen wil ik hier graag bedanken.

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Mijn dank gaat uit naar de leden van de leescommissie: prof. Geert van Hove, prof. Tineke Abma en prof. Sandra van Dulmen. Graag wil ik u danken voor uw tijd en investering in dit proefschrift.

Catherine O'Dea, thank you for your flexibility and responsiveness while proof reading my documents. It was amazing how you could proof read and educate me in scientific English at the same time.

Christine Linehan and Edurne García Iriarte, thank you for the Irish adventure during my PhD. Christine, I admire your promptness and kindness. It was great working with you on the literature review and Consensus Statement. I have such great memories of our Italian dinner in Dublin, the birth place of our Consensus Statement. Edurne, you are one of the authors I look up to in inclusive research papers and I feel honoured to have been able to visit you at Trinity College Dublin. I learned so much of being part of Inclusive Research Network meetings and your analytic and reflective perspective.

De Academische Werkplaats Sterker op eigen benen heeft dit proefschrift mogelijk gemaakt door een samenwerking tussen het Radboudumc en verschillende zorgorganisaties: Dichterbij, Driestroom, 's Heeren Loo, Koraal, ORO, Philadelphia, Pluryn, Siza, en de Twentse Zorgcentra. Deze samenwerking bood de mogelijkheid om ideeën te bespreken en deelnemers te zoeken, waar ik erg dankbaar voor ben.

Mijn collega's van Het Dorp, Gerrie, Mark, Meredith, Bisharo, Kitty, Gerda, Frank, Floor en Wim, wij hebben elkaar leren kennen toen ik mijn proefschrift aan het afronden was. De nieuwe ervaringen en andere manieren van denken was een heerlijke frisse wind tijdens het laatste stukje. Dank hiervoor!

Mijn collega's bij de Academische Werkplaats Anja, Esther, Kristel, Maarten, Mathilde, Monique en Tonnie; wat hebben wij een geweldig team samen en wat ben ik hier dankbaar voor. Ondanks dat wij allemaal op ons eigen eilandje werken, is er altijd interesse in elkaars projecten en worden overwinningen gevierd (met ijs!). In het bijzonder wil ik mijn collega promovendi Noortje en Marloes bedanken. Met jullie heb ik mij nooit hoeven vervelen. Het was heel fijn om samen op te gaan in dit traject door van elkaar te leren maar ook stomme grapjes met elkaar te maken. Bedankt dat jullie als paranimfen aan mijn zijde hebben willen staan.

Graag bedank ik mijn vriendinnen die mij allen op een unieke manier steunden. Denise, door dat we samen HBO verpleegkunde en MPA hebben gedaan begreep jij mijn frustraties met onderzoek als geen ander. Het was heerlijk om herinneringen van stages op te halen waar we in hetzelfde schuitje zaten. Lian, met jou kon ik stoom afblazen als geen ander wanneer iets anders liep dan verwacht en feesten wanneer er iets te vieren viel. Lieve Noortje en Marloes, de gesprekken tijdens etentjes en fietsvakanties waren mijn favoriete momenten om energie op te doen. Wat hebben wij samen mooie herinneringen gemaakt en wat gaan er nog veel komen met onze drie musketiers.

Pappa, jij stimuleerde mij om door te blijven leren en zonder jouw aanmoediging was ik nooit aan een proefschrift begonnen. Dankjewel hiervoor. Mamma, dankjewel voor jouw luisterend oor en steun wat mij hielp om het af te maken. Kevin, Jessica, Saskia, oma Marina, opa Hans, oma Trix en familieleden die meeleefden met de vorderingen van mijn proefschrift: bedankt voor jullie steun en interesse. Kieften, wat zijn wij samen een sterk en liefdevol team geweest afgelopen jaar en wat had ik graag gewild dat opa Ruud dit kon lezen. Als er één ding is dat ik van opa en dit proefschrift heb geleerd: samenzijn is het allerbelangrijkste.

Allerliefste Kyle en Aidan, *my tribe*, ik ben trots op hoe sterk wij staan. Jullie zijn mijn team en met jullie wil ik altijd alles samen doen. Op naar ons volgende avontuur!

Chapter 12

List of publications
English Curriculum Vitae
Nederlands Curriculum Vitae
RIHS PhD Portfolio

12.1 List of publications

12.1.1 Peer reviewed

Frankena, T.K, van Schrojenstein Lantman – de Valk, H., Cardol, M., van der Cruijsen, A., Jansen, H., Leusink, G. & Naaldenberg, J., (Revisions submitted) Contributing to inclusive research policy and practice – a synthesis of four inclusive research projects. Journal of Policy and Practice in Intellectual Disabilities.

Frankena, T.K., Naaldenberg, J., Tobi, H., van der Cruijsen, A., Jansen, H., van Schrojenstein Lantman – de Valk, H., Leusink, G. & Cardol, M. (Submitted) A membership categorisation analysis of roles, activities and relationships in inclusive research conducted by co-researchers with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities.

Frankena, T. K., Naaldenberg, J., Cardol, M., Linehan, C., and Van Schrojenstein Lantman – de Valk, H. (2015). Inclusive health research with people with intellectual disabilities - A structured literature review. *Research in Developmental Disabilities*. *45-46*: 271-283.

Frankena, T.K., Naaldenberg, J., Bekkema, N., Van Schrojenstein Lantman – de Valk, H.J.M., Cardol, M. & Leusink, G. (2018). An exploration of the participation of people with intellectual disabilities in research – a structured interview survey. *Journal of Applied Research in Intellectual Disabilities*, *1*(6).

Frankena, T. K., Naaldenberg, J., Cardol, M., Meijering, J.V., Leusink, G. & van Schrojenstein Lantman – de Valk, H.M.J. (2016). Exploring academics' views on designs, methods, characteristics and outcomes of inclusive health research with people with intellectual disabilities: a modified Delphi study. *BMJ Open*, *6*.

Frankena, T. K., Naaldenberg, J., Cardol, M., Garcia-Iriarte, E., Buchner, T., … van Schrojenstein Lantman – de Valk, H. (2018). A consensus statement on how to conduct inclusive health research. *Journal of Intellectual Disability Research*. Epublication ahead of print.

Heutmekers, M., Naaldenberg, J., Frankena, T.K., Smits, M., Leusink, G.L., Assendelft, W.J.J. et al. (2016). After-hours primary care for people with intellectual disabilities in The Netherlands—Current arrangements and challenges. *Research in Developmental Disabilities, 59*, 1-7.

12.1.2 Not peer reviewed

Frankena, T.K. (2018). Inclusief gezondheidsonderzoek: wat zijn de voordelen van samenwerken met mensen met VB in onderzoek over hun gezondheid(szorg)? *Tijdschrift Arts voor Verstandelijk Gehandicapten*, *36*(2).

12.2 English Curriculum Vitae

Tessa Frankena was born in Heemstede (Municipality of Haarlemmermeer, the Netherlands) on the 18th of April, 1989. After completing secondary school at the 'Katholieke Scholengemeenschap Hoofddorp' in Hoofddorp in 2006, she started her Bachelor of Nursing at 'Hogeschool Leiden'. In 2010 she finished her Nursing degree and started the Premaster Health Sciences at the 'Vrije Universiteit' in Amsterdam. At the same university she continued with the Master Management, Policy Analysis and Entrepreneurship in Health and Life Sciences for which she obtained her degree in 2013. During her Bachelor, Premaster and Master's studies she worked as a nurse in several elderly care homes in the region of Haarlem and Amsterdam. In 2013 she started a full-time PhD trajectory at the Academic collaborative Stronger On Your Own Feet, in which several ID care organisations collaborate with the academic hospital Radboud University Medical center in Nijmegen. As of April 2018 Tessa combines her research work at the Stronger On Your Own Feet with a job as manager of the medical staff at Siza, a local care organisation. Tessa lives together with partner Kyle and son Aidan in Ede.

12.3 Nederlands Curriculum Vitae

Tessa Frankena is geboren in Heemstede (Gemeente Haarlemmermeer) op 18 april 1989. Na het behalen van haar HAVO diploma aan de Katholieke Scholengemeenschap Hoofddorp in 2006 startte ze haar HBO verpleegkunde opleiding bij Hogeschool Leiden. Deze opleiding rondde zij af in 2010 en begon aan de Premaster Gezondheidswetenschappen aan de Vrije Universiteit in Amsterdam. Aan dezelfde universiteit studeerde zij verder met de Master Management, Policy Analysis and Entrepreneurship in Health and Life Sciences, die zij succesvol afronde in 2013. Tijdens haar HBO, Premaster en Master opleiding werkte zij als verpleegkundige in verschillende verzorg- en verpleegtehuizen in regio Haarlem en Amsterdam. In 2013 startte zij een voltijd PhD traject bij de Academische werkplaats Sterker Op Eigen Benen, waarin verschillende zorgorganisaties voor mensen met een verstandelijke beperking samenwerking met het Radboudumc in Nijmegen. Vanaf april 2018 combineert Tessa haar werk als onderzoeker bij Sterker Op Eigen Benen met een baan als coördinator van het medisch team bij Siza, een zorgorganisatie voor mensen met een (verstandelijke) beperking. Tessa woont samen met partner Kyle en zoon Aidan in Ede.

12.4 RIHS PhD Portfolio

Institute for Health Sciences
Radboudumc

Name PhD candidate: *T.K. Frankena* ***Department:*** *Primary and Community Care* ***Graduate School:*** *Radboud Institute for Health Sciences*	**PhD period:** *01-08-2013 – 30-04-2018* ***Promotor:*** *Prof. H. van Schrojenstein Lantman – de Valk* ***Co-promotor(s):*** *Dr. J. Naaldenberg* *Dr. M. Cardol* *Dr. G. Leusink*

	Year(s)	ECTS
TRAINING ACTIVITIES		
a) Courses & Workshops		
- Pubmed introduction course	2013	0.1
- Endnote introduction course	2013	0.1
- Qualitative research methods in healthcare course	2013	1.75
- BROK course	2013	1.75
- RIHS PhD introduction course	2014	1.75
- Introductie Nijmeegse Curricula	2014	0.2
- Advanced academic writing course	2014	1.75
- Refresher course statistics	2015	1.75
- Summer School Case study research	2015	1.75
- Scientific integrity course	2016	0.8
- Loopbaanmanagement course	2016	1.75
- Education in a nutshell course	2016	1.75
- Presentation skills course	2016	1.75
- Effectieve schrijfstrategieën course	2016	1.75
- Subsidieaanvragen schrijven ZonMW course	2016	0.4
b) Seminars & lectures^		
- Kennismarkt VGN, Kennisplein gehandicaptensector, oral presentation	2016	0.25
- Studiedag Medische en Ouderenzorg in de VG, NVAVG, oral presentation	2016	0.25
- Annual CaRe days, oral presentation	2014-2017	1
- AVG regiovergadering, oral presentation	2014, 2016	0.5

c) Symposia & congresses^		
- IASSIDD Europe congress, oral presentation	2013, 2014, 2018	4.5
- Congres Cliëntenparticipatie in Onderzoek en zorg, Tilburg University, poster presentation	2014	1
- INVOLVE conference, poster presentation	2014	1.5
- RIHS conference, oral presentation	2014	0.5
- Focus op kennis en onderzoek, oral presentation	2015	0.5
- From client to participant conference, Radboud University, oral presentation	2015	0.5
- IASSIDD World congress, oral presentation	2016	2.5
- Disability Studies congress, oral presentation	2017	0.75
d) Other		
- Journal club, Department Primary and Community Care	2014-2018	1
- Refereer bijeenkomsten, Department Primary and Community Care	2015 – 2018	1
- Track director, IASSIDD Europe congress	2018	2
- Review scientific publication JPPID	2018	0.1
TEACHING ACTIVITIES		
e) Lecturing		
- Wageningen University, Master students, guest lecture	2014	0.15
- Radboud University, Medicine students, workshops and lectures	2015-2017	1.2
- Summer School Participatory Evaluation of Global Challenges in Healthcare, Radboudumc, lecture	2016	0.2
f) Supervision of internships / other		
- Supervising 12 students during the development and implementation of a Plan-Do-Check-Act cycle	2014, 2016	1
TOTAL		**38.5**

^Indicate oral or poster presentation

Radboud Universiteit Radboudumc

Appendices

Appendix I: Accessible information sheet

"Working together with researchers" project

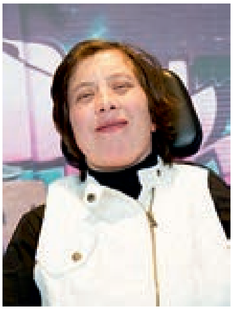
Information folder

Dear sir or madam,

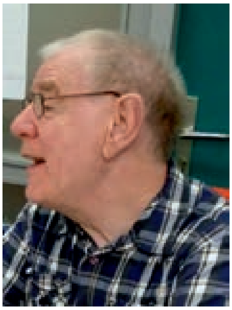
This folder is about the "Working together with researchers" project.

Who we are:

We would like to introduce ourselves.



Anneke



Henk

Tessa

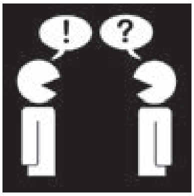
Anneke and **Henk** work as co-researchers on our project for 1 day a week. **Tessa** is the lead researcher of our project. Tessa will visit Ireland for our project in October and November 2015.

What our project is about:

Our project is about **inclusive research**. Inclusive research is research in which people with intellectual disabilities and university researchers work together as a team. People with intellectual disabilities are involved in every phase of the research and make decisions about a research.

Our project has 3 goals:

1. We want to know how inclusive research is done.
2. We want to know how people worked together.
3. We want to know how people felt about working together.



The project will be done with co-researchers, supporters and academic researchers.
The want to talk about the project they were involved in.
They will have a lot of experience with inclusive research.

We want to share what we learn with other people.
So other people doing inclusive research can learn from all these experiences.

We are looking for people who want to take part in our project!

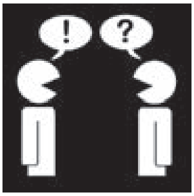
What we want to ask:

We want to ask you if you would like to take part in our project.

We ask you because:

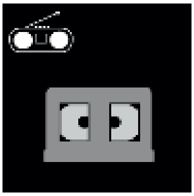
- You have worked on the Home and Independence study.
- You have experience with inclusive research.
- You have experience with working as a co-researcher, supporter or academic researcher.

If you want to participate, we would like to ask you to:

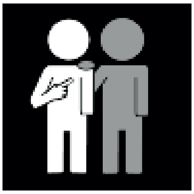


1. make a timeline of the Home and Independence study together with your research team and Tessa. This is an overview of what you have done during the study; and
2. take part in an one-on-one interview about your experiences with the Home and Independence study.

The timeline will take 1,5 hour.
The interview will take 1 hour.



We want to ask you if we can record the activities.



You can bring a support person if you like.

You can always say NO to taking part in our project, that is OK!
You can also say NO to recording and you can still take part in our project, that is OK!
If you say NO to recording Tessa will take notes.

What we want to do with the information you give us:

- We want to save the information you give us confidentially for 5 years.
- Henk, Anneke en Tessa will have access to your information.
- Tessa's supervisor will look at the information as well.
- We will write a report about what everybody has said.
- We will NOT use anybody's name in the report.

What you should know:

- You can decide where we do the activities.
- We will pay your travel expenses.
- We will make sure you get the outcomes of the project.
- You can ask us questions as well.

Please let us know if you want to participate:

- If you want to participate, we will ask again before the timeline and interview.
- You can always say NO or STOP with the project, that is OK!

If you have questions you can contact Tessa.

@ Tessa.Frankena@radboudumc.nl

☎ ***

S ***

Thank you!

Appendix II: Interview guide individual interview

Working together with researchers

– what can we learn from others?

Interview design

I’m going to ask you some questions about the *** study.
You don’t have to answer them if you don’t want to.
You can stop answering them at any time.

General questions

1. What is your name?

---

2. You are a:
   - ○ Man
   - ○ Woman

3. What is your date of birth?
   Alternative question:
   How old are you?

Questions about the *** study

4. What was working for the *** study like for you?
   Alternative question:
   How did you like working for the *** study?

5. What was your favourite experience?
   Alternative question:
   What did you like the most about the *** study?

6. How important was working in the *** study to you?

7. How was the atmosphere in the research team?
   Alternative question:
   Did you feel comfortable in the research team?

8. How important is a good atmosphere?
   Alternative question:
   How important is it to feel comfortable?

9. Can you tell me about your relationship with your colleagues of the *** study?
   Alternative questions:
   How well did you know your colleagues beforehand?
   How well do you know them now?
   Is it important to know each other well?

10. Did you feel you were working together as a team in the *** study?
    Alternative question:
    Did you feel you were collaborating with all your colleagues?

11. Did you collaborate in every part of the *** study?
    Alternative question:
    Were you working together in every part of the *** study?

12. Do you think it's necessary to collaborate in every part of the *** study?

13. Could you make important decisions in the *** study?
    Alternative questions:
    Did your colleagues listen to you?
    Do you feel you were taken seriously?

14. **Did your work in the *** study make a change? If yes, how?**
    Alternative question:
    Do you feel what you said made a difference in the study?
    Was your contribution meaningful?

15. **Did you ever talk about your collaboration with your colleagues of the *** study?**
    Alternative question:
    Did you ever discuss how you worked together with colleagues of the *** study?

16. **Would you recommend taking part in a study like the *** study to others and why?**
    Alternative question:
    Would you take part in a study like the *** study again?

17. **What would you do differently next time?**

18. **Did you share your experiences with the *** study with anyone?**
    Alternative question:
    Did you tell other people about your experiences with inclusive research?

19. **Did somebody else share his or her experiences with a study like the *** study with you?**
    Alternative question:
    Did somebody else talk about his or her experiences with inclusive research with you?

Appendix III: Interview guide group interview

Working together with researchers

– what can we learn from others?

Timeline design

I would like to ask you some questions about the *** study.
I would like to know which steps you have taken in the *** study.
I would like to make a timeline with you.
A timeline is an overview of all the steps you have taken in the *** study.
I would like to ask you to write the steps on post-its.
Or a support person or I can write it down.

Introductory round

I would like to get to know you a little better.
Therefore, I would like to play a game.
Take something out of your bag or pocket and describe yourself with it.
For example: A pen = I like writing.

Questions about the *** study

1. Tell be about the project.
   - What was it about?
   - What did you do?

2. What were the most important moments in the *** study?
   - When did you choose the research topic?
   - When did you decide on the research questions?
   - When did you get the money to do the *** study?
   - When did you decide to use *** (research method)?
   - When did you do the *** (research method)?
   - When did you do the analysis?

- When did you share your research findings with other people? (for example: by means of a presentation or report)

3. **Have you ever heard about the concept "inclusive research"? If yes, what does it mean to you?**

4. **How were you involved in the *** study?**

5. **At what times did you feel involved?**

6. **What did you do to speak up?**

7. **What were good and bad experiences?**

8. **When and how did you find the *** study?**
   Alternative question:
   Who were they asking for?
   Did they have special requirements for the people who could work on the *** study?

9. **When and how did you agree to take part in the *** study?**
   Alternative questions:
   Did the ask you to sign a form before you took part in the *** study?
   Did you participate in a meeting or workshop before you took part in the *** study?

10. **Did you receive training for your work in the *** study? If yes, how and when?**
    Alternative question:
    Did you take part in courses or workshops before the *** study?

11. **Tell me about the meetings.**

12. **How did you go to meetings?**
    Alternative questions:
    Did you have any support needs?
    Was the building accessible?
    Were all the research materials accessible?

13. **Did you feel you had an active role? Can you give me an example?**

14. **When and how long did you meet for the *** study? Did you have enough time?**

15. **Did you meet regularly?**
    Alternative questions:
    Were the meetings similar?
    What was the structure in the meetings?

16. **Could the plan for the *** study be adapted if it was necessary? How?**
    Alternative question:
    Was the *** study flexible?

17. **How did you talk in meetings for the *** study? Did you use any tools?**
    Alternative questions:
    How did you communicate?
    Did you use any communication tools?

18. **Did you get any help or support before, during and after meetings for the *** study?**
    Alternative question:
    Did you get any support?

19. **Can you remember some important decisions in the *** study? Can you give me an example?**

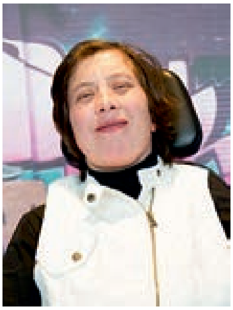
20. **Did you feel you were involved in these decisions?**

Appendix IV: Accessible informed consent sheet individual interview

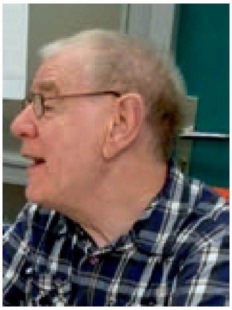
“Working together with researchers” project

Informed consent form interview

We are the research team:



Anneke



Henk

Tessa

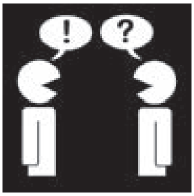
You have said you would like to take part in the “Working together with researchers” project.

We would like to ask you to take part in an interview.
The interview is about your experiences with the Home and Independence study.

This form is to:

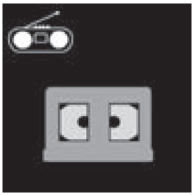
1. Set **agreements**
2. Ask your **permission**

Agreements



Your answers are not right or wrong.
It is about what you say and think.
If you do not want to tell something, you don't have to.

The interview will not take longer than 1 hour.



We would like to record the interview, so we can listen to and write about what you have said.
If you don't want us to record the interview Tessa will make notes. That is OK too!

We will not tell others what you have said.
Your name will not be mentioned in the report we write.
If other people read the report, the will not be able to see have you participated.

We want to save the information you give us confidentially for 5 years.
At the end of the interview we will repeat what you have said.
You can tell us if this is right.

Please tick the boxes if they apply to you:

- o I have read or someone has read the information form about this project.
- o All my questions have been answered.
- o I know I can always STOP taking part in this project at any time.

Permission

I agree to take part in an interview:

- Yes
- No

My interview can be recorded:

- Yes
- No

Date:
Name researcher:
Signature researcher:

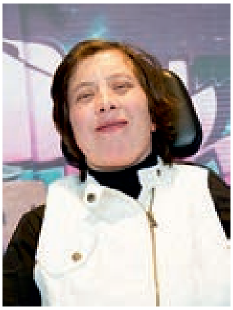
Date:
Name participant:
Signature participant:

Appendix V: Accessible informed consent sheet group interview

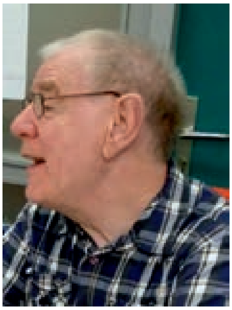
“Working together with researchers” project

Informed consent form timeline

We are the research team:



Anneke



Henk

Tessa

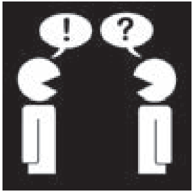
You have said you would like to take part in the “Working together with researchers” project.

We would like to ask you to take part in making a timeline of the Home and Independence study.
A timeline is an overview of all the things you have done during the Home and Independence study.
The timeline will be done together with the research team of the Home and Independence study.

This form is to:

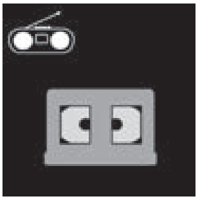
3. Set **agreements**
4. Ask your **permission**

Agreements



Your answers are not right or wrong.
It is about what you say and think.
If you do not want to tell something, you don't have to.

Making the timeline will not take longer than 1,5 hours.



We would like to record the timeline, so we can listen to and write about what you have said.
If you don't want us to record the timeline Tessa will make notes. That is OK too!

We will not tell others what you have said.
Your name will not be mentioned in the report we write.
If other people read the report, the will not be able to see have you participated.

We want to save the information you give us confidentially for 5 years.
At the end of the timeline we will repeat what you have said.
You can tell us if this is right.

Please tick the boxes if they apply to you:

- ○ I have read or someone has read the information form about this project.
- ○ All my questions have been answered.
- ○ I know I can always STOP taking part in this project at any time.

Permission

I agree to take part in making a timeline:

- ○ Yes
- ○ No

The timeline can be recorded:

- ○ Yes
- ○ No

Date:
Name researcher:
Signature researcher:

Date:
Name participant:
Signature participant:

Appendix VI: Research attributes

Research phase		*Research attributes*
Preparing	Study design	• Know why the study is being done • Discuss and decide upon different research topics • Approve research questions and design of methods • Look outside traditional research design
	Ethical approval	• Organise meeting on research ethics • Official ethics application made by academic researchers
Undertaking	Interview questions	• Discuss and identify interview questions • Develop initial set of interview questions • Cut back/prioritise interview questions • Adjust length and formulation of interview questions • Pilot interview questions • Develop final interview plan
	Interviews	• Prepare interviews • Decide who is conducting interviews: co-researcher with academic researcher or supporter • Conduct interviews • Have coffee with interviewees • Ask questions and talk to people • Listen to stories, experiences, and points of view • Use pictures • Get information • Record interviews • Use information confidentially • Evaluate interviews • Transcribe interviews: done by academic researchers and supporters
	Analysis	• Prepare: done by academic researcher (e.g., narrating) • Have meetings • Write stories: put stories and pictures together • Use a big poster or Excel sheet for overview • Watch information come together • Discuss topics and themes • Identify main topics/common themes • Interpret interviews and results • Discuss results • Do a lot of computer and paper work • Use analysis in academic researchers' "bigger analysis" • Academic researchers feed bigger analysis back

Continued

	Research phase	*Research attributes*
Concluding	Report writing	• Talk about stories • Pick the strongest quotes • Suggest pictures • Read and write a lot (mostly done by academic researchers) • Decide what should be in the report • Review report • Share report (e.g., report launch)
	Conference attendance	• Develop and practice presentation • Go abroad • Attend conferences • Present (preliminary) findings and share information • Give a demonstration of your work
Parallel	Academia	• Scientific underpinning is needed (i.e., theories) • Scientific value is important • Rigid academic structure • Many other stakeholders involved • Research group meetings too complicated for co-researchers • Feed research group meetings back to co-researchers • Research is in-depth and focuses on one thing • Research is big • Scientific papers submitted by academic researchers (not always in native language)
	Meetings	• Discuss, brainstorm, feed back, consult, philosophise, and reflect • Have a structural basis: monthly, biweekly, weekly • Have flexible planning during data collection • Use an agenda

Appendix VII: Inclusion attributes

Inclusion attributes	*Themes, examples, and explanation*		
Facilitation	*Build a relationship*	*Working relationship* • Introduce yourself • Have an introductory talk on practical and content aspects • Be friendly and genuine • Get to know each other • Get used to each other • Spend (a lot of) time together • Know what to expect from each other	*Personal relationship* • Be open to talking about personal things • Get to know each other's background and hobbies • Look at what is going on in people's lives • Talk about life events • Tell them your motivations • Meet on a social basis • Look out for each other/be there for each other
	Adapt communication	• Take turns when talking and do not talk before somebody else • Give others a chance to talk • Listen to others • Stop anybody from answering for somebody else • Correct anybody when needed (with a joke) • Learn to be silent yourself (academic researchers and supporters) • Encourage each other to speak up • Feel safe enough to speak up • Speak in private and have confidentiality • Present your own opinion • Say what you are feeling and thinking • Check whether interpretations are correct	
	Develop easy read information	• Use simple words and concepts • Enlarge font size • Change order of text • Rephrase and sum up text • Use photos and pictorial images • Provide easy to read graphs and format • Cut down the volume of information • Incorporate different information mediums • Repeat information • Question: would (other) people with ID understand?	
	Provide extra time	Inclusive research is a slow and lengthy process, thus extra time is needed	
	Provide transport	Co-researcher might need transport to get to certain locations in time. In cases 1, 2, and 4, transport was arranged and paid for	
	Use creativity	• Role play and drama • Be expressive • Think outside the box • Think on your feet • Look for alternative ways of collaborating	

Facilitation	*Build confidence*	• Take time • Give validation • Convince people with ID that it is about them • Stand up for each other • Do no put people down • Do not offend anybody • Have a familiar environment	
	Provide structure and flexibility	*Structure* • Be consistent • Have ground rules • Structure should create order	*Flexibility* • Do not be prescriptive • No strict planning • Be flexible and open
Learning process	• Try, learn, develop, and improve new things • Identify ways that are productive and efficient • Be sensitive towards what is working • Build upon previous experience • Feel your way into it • Do it gradually • Overcome challenges • See what is possible over time and grow into it • Improvise and experiment • Use tools for training: handbooks, videos, workshops, and mock interviews • Train based on co-researchers' needs		
Support (staff)	*Supporting tasks:* • Help co-researchers to speak up • Make sure co-researchers go to meetings • Answer questions • Stimulate discussions • Follow up on tasks • Administrate	*Supporting mind-set:* • Advise and guide without interfering • Keep the door open • Reflect upon one's own support role • Never sit comfortably in support role • Fulfil co-researchers' role realistically • Change support over time • Know it is difficult to ask for support	

Appendix VIII: Roles and activities of researcher with ID

Roles	Activities
Advisor	Giving advice in different ways Giving advice about different topics Having different motivations to give advice
Career tiger	Handling new/unfamiliar things Helping others Communicating Identifying strengths and weaknesses
Co-researcher	Applying for the job Becoming familiar/searching Making decisions about your contract Making the work environment accessible Planning Preparing research Asking questions Responding/adapting to other co-researchers Conducting research (in different ways) Getting assignments from colleagues Being of added value Being appreciated Adapting research to the possibilities Dividing tasks Gaining experience in research Feeling responsible/not being responsible Meeting new people Gaining experiences
Expert-by-experience	Telling what you are experiencing Knowing what people with ID need Putting people with ID in the centre Putting yourself in people with ID’s position Following expert-by-experience training Being aware that you can’t speak for everyone with ID
Teacher	Preparing for presentations Giving different types of education/presentations Giving education/presentations for different groups Growing in teaching/presenting Having different experiences with teaching/presentations Creating awareness Receiving a gift or a gift voucher
Translator	Having experience with translating Translating in different ways Translating for different reasons Translating different texts

Appendix IX: Roles and activities of researcher without ID

Roles	Activities
Academic researcher	Having academic training Learning to let go (of your research project) Having shortcomings Doing research/knowing how to do research
Customer	Coming with (different) assignments Explaining the assignment Taking the lead/making decisions Preparing for collaboration Being appreciated
Facilitator	Responding to the needs of co-researchers Listening to co-researchers Being open and aware Feeling responsible Adapting your attitude towards people with ID Working step-by-step Being curious Being of added value Taking the limited time into account Asking for clarification Communicating accessibly Taking the input of co-researchers into account
Organizer	Organizing finance Organizing transportation Organizing practical conditions Organizing the appointment of co-researchers Gaining experiences
Team member	Preparing collaboration Planning/using an agenda Dividing tasks Making research accessible to co-researchers Identifying strengths and weaknesses Gaining experience of collaboration Seeking (in the beginning) Making decisions together Experiences of collaboration

Appendix X: Roles and activities of general researchers

Roles	Activities
Advertiser	Telling others about our collaboration (through various media) Recommending collaboration to others Spreading the ‘collaboration virus’
Advisory board leader	Organizing/putting together the advisory board Discussing different things with the advisory board Experiencing added value from the advisory board Preparing advisory board meetings
Colleague	Talking with each other Dealing differently with co-researchers Finding the co-researcher to be a fun person Being colleagues makes collaborating easier Having a good relationship Doing fun stuff together Having people with ID as colleagues puts them at the centre Having fun Having a different relationship than a doctor–patient relationship
HR manager	Letting co-researcher make own decisions Sorting out travel costs Taking social benefits into account Working harder for appointment of co-researcher Being responsible for employees Having different experiences with HR work Sorting out the contract Sorting out the salary Involving other people and organizations in HR issues
Inventor	Doing work that has never been done Going on an adventure/taking up a challenge Persevering
Manager	Making decisions on financing co-researchers Organizing a lot of things Having affinity with inclusive research Looking for the right employee Using co-researchers’ knowledge Having annual interviews with employees Setting up new (inclusive) studies Complying with rules and regulations Facilitating inclusive research Providing a supportive work environment Being indirectly involved with co-researchers Discussing co-researchers via team members Employing/having to employ people without ready access to the labour market Being creative with rules and regulations Appreciating co-researchers as employees Making decisions about the employment of co-researchers
Student	Learning about inclusive research Learning about the added value of co-researchers Reflecting on collaboration Other people learning from our collaboration

Appendix XI: Easy read statement

Researchers with and without intellectual disabilities who work together

Heather Allan, Fionn Angus, Joan Body, Margaret Collins, Anneke van der Cruijsen, Gary Cunningham, Derek, Marie Dillon, Martin Dooher, Nathan Gray, Craig Hart, Kevin Head, Tyler Henderson, Brian Hogan, Karrissa Horan-LaRoche, Henk Jansen, Rex Marchi, Donna McCormick, Kevin McGrath, Lisa McHugh, Kathleen McMeal, Claire Mitchell, Murphy, Laura Murray, D. Noone, Donovan O'Neil Allen, Helen O'Regan, Wolfgang Orehounig, Carol-Ann O'Toole, Sean Rowley, Jaspreet Kaur Sekhon, Kyla Stewart, Michael Sullivan, Lisa Woelfl, and Members of the CDS Inclusive Research Network.

Contents

Chapter 1: What is this document about?

This document is about inclusive health research.

What is inclusive health research?

Inclusive research = when people with intellectual disabilities and university researchers work together.

Inclusive health research = inclusive research about the health of people with intellectual disabilities. For example about people's mental, physical and emotional health.

Inclusive health research says people with intellectual disabilities are involved in every step of the research.

Why do we need this document?

A lot of inclusive health research is done.

People want to learn about the best way to do inclusive health research.

But there is not a lot of information about how inclusive health research should be done.

What is this document about?

We think that these 4 questions are important:

1. What is important when you are doing inclusive health research?
2. What comes out of inclusive health research?
3. What should be shared when you are doing inclusive health research?
4. What do we need to know about inclusive health research?

How did we write this document?

This document was written with experts on inclusive health research.

These experts are researchers with and without intellectual disabilities who have done inclusive research.

Experts without intellectual disabilities wrote this easy read document.

Experts with intellectual disabilities said what was good and bad about it.

Forty experts with intellectual disabilities from all over the world helped us.

Chapter 2: What is important for doing inclusive health research?

8 important topics

Experts say that researchers need to think about 8 important topics when they are doing inclusive health research:

1. The **mindset** of the research team
2. How to **recruit researchers**
3. How to make the **research plan**
4. How to making the research **accessible**
5. How to deal with **practical things**
6. How to **collect data** for the research
7. How to **analyse data**
8. How to **share results**

We will talk about each of the 8 topics in more detail:

Mindset

These things are important in the mindset:

- Respecting human rights
- Working as a team
- Hearing everybody's voice
- Respecting differences
- Building a relationship
- Having accessible information
- Contributing in your own way
- Knowing it can be difficult
- Feeling safe and supported
- Making decisions together

Recruiting researchers

These things are important when researchers are being recruited:

- Asking people in different places
- Supporting service providers
- Knowing what skills team members need
- Providing training
- Finding out how researchers will be paid for their work
- Making goals clear
- Allowing people to stop at any time

Research plan

These things are important when you are making the research plan:

- Talking about each team member's role
- Having an accessible meeting place
- Knowing each team member's skills
- Providing training
- Deciding together on the research topic, research questions and methods
- Being creative

Accessibility

These things are important for making the research accessible:

- Talking about everybody's needs
- Finding an accessible place to meet
- Developing easy read information
- Adapting communication
- Talking about structure and flexibility
- Planning team meetings
- Talking about how problems will be handled
- Using tools

Practical things

These practical things are important:

- Transport
- Extra time
- Breaks
- Easy-read information
- Other formats, for example audio
- Support

Collecting data

These things are important for collecting data:

- Talking about what is needed to collect data
- Training on collecting data
- Being creative

Analysing data

These things are important for analysing data:

- Talking about how information will be analysed and who will analyse it
- Training on data analysis
- Comparing and discussing the analysis

Sharing results

These things are important when you are sharing results:

- Talking about how results can be shared
- Deciding together how results will be shared
- Organising meetings for the public
- Talking about who will write the report
- Making sure everybody is happy with the sharing of results

Chapter 3: What comes out of inclusive health research?

This is what experts say comes out of inclusive health research:

Personal outcomes

- Enjoying the research
- Getting new experiences
- Learning how to do research better
- Learning to talk up
- Learning about your rights
- Meeting new people
- Being listened to
- Getting insight into the experiences of other people

Professional

- Contract and (sometimes) salary
- Feeling responsible
- Getting recognition
- Learning how the university works
- Having a more equal working relationship
- Hearing and including the voices of people with intellectual disabilities
- Meeting other researchers
- Learning new and creative ways of communicating
- Getting new information
- Seeing the bigger picture

Research

- Better ways of collecting data
- Researching what people with intellectual disabilities find important
- Research outcomes suit people's lives better
- Learning what it means to do inclusive health research
- Research that takes people with intellectual disabilities into account

Healthcare

- Learning the most important healthcare issues for people with intellectual disabilities
- Reducing healthcare issues for people with intellectual disabilities
- Better fitting healthcare to the needs of people with intellectual disabilities
- Improving the quality and accessibility of healthcare for people with intellectual disabilities
- Improving the quality of life of people with intellectual disabilities

Community

- Reducing health differences between people with and without intellectual disabilities
- Raising awareness of problems faced by people with intellectual disabilities
- Raising awareness of the rights of people with intellectual disabilities
- Knowing how to support people with intellectual disabilities in their rights
- Suiting research findings to community needs
- Starting a change in the community

Chapter 4: What should be shared when you are doing inclusive health research?

Researchers usually write a report.
Experts have identified a top 10 list of things that need to be written in this report.
This top 10 should help share experiences of inclusive health research.

Experts say that research teams should share these 10 things:

1. Who chose to do inclusive health research, and why.
2. How decisions were made during the inclusive health research.
3. How all team members experienced the inclusive health research.
4. How information was shared with people with intellectual disabilities.
5. How team members with and without intellectual disabilities communicated.
6. How team members were supported.
7. The role of all the team members.
8. How researchers with intellectual disabilities were paid. And, if not, why not.
9. How the research was made accessible.
10. Easy-read abstract and report, shared with people with intellectual disabilities and service providers.

Chapter 5: What do we need to know about inclusive health research?

Experts in this document talked about what we don’t know about inclusive health research.
They made a list of things that we need to know about inclusive health research.

This is the list they made:

- Experiences from researchers with intellectual disabilities: we need personal stories!
- Sharing experiences and knowledge on inclusive health research
- Relationships between researchers with and without intellectual disabilities
- Ethical issues in inclusive health research
- Similarities between inclusive health research and advocacy
- Different ways of doing inclusive health research
- Sharing inclusive health research results with people with intellectual disabilities
- Training for researchers with and without intellectual disabilities
- Research ideas coming from people with intellectual disabilities

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