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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 roundtable 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.

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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.

Keywords inclusive research, intellectual disabilities, health research, participation, user involvement

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 (Walmsley and Johnson, 2003; Elberse, 2012). 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.

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.

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.

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.

Consensus statement process

This consensus statement was developed in three consecutive rounds. Table 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 (A.C., H.J.) and without (T.F., J.N., H.L.) intellectual disabilities (see Section 0.0), after which it was distributed among experts to obtain their feedback. During the first round, experts received the

Table 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

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 (A.C., H.J.) and without (T.F.) 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.

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 SI for 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.

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 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.

Potential outcomes of inclusive health research

When an inclusive approach is adopted, several outcomes that relate to the inclusive process can be expected (Table 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 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.

Table 2. *(Continued)*

	• 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; Ollerton, 2012; Stevenson, 2014).
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.

Table 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

Table 3. *(Continued)*

Level	Potential outcomes
	• 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

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 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 the following: motivation and experiences; decisions and modifications; and communication, support, task division and financial compensation. An accessible abstract should also be provided.

Box 1 Key elements of reporting and publishing

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.

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 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.

Box 2 Future research directions

- 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.

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 >57 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 other'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 discussed and adapted to new knowledge.

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Supporting Information

Additional Supporting Information may be found online in the supporting information tab for this article.

Appendix SI. Easy read consensus statement