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Perceptions, barriers and facilitating strategies of inclusive research: a qualitative study with expert interviews

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ABSTRACT

Scientific research should be relevant to and include those considered to be disadvantaged and underrepresented. Investigating perceptions, barriers and strategies of inclusive research experienced by researchers can help address some of the challenges to inclusive research. This study explores what inclusive research is, why inclusive research is important, which barriers researchers experience, and which strategies they propose and deploy to address these barriers. We interviewed 15 researchers from the health sciences, (bio)medical sciences, and social sciences who have experience with inclusive research and conducted qualitative content analysis. We identified four important aspects of inclusive research: involvement of researched groups, accessibility, diversity and representativeness and enabling positive change. Societal, methodological, educational and ethical arguments were provided as reasons for why inclusive research is important. Main barriers were researchers' lack of skills, lack of time and budget, and non-inclusive research materials. This study provides strategies for conducting inclusive research throughout the research cycle, applicable to a wide range of academic fields. We conclude that there is not one correct way to conduct inclusive research. Rather, the strategies can increase inclusivity in qualitative and quantitative studies.

Keywords: inclusive research, participation, representative research

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INTRODUCTION/BACKGROUND

The term "inclusive research" was developed in the field of disability studies, which has aimed to involve people with physical and other types of disabilities in research. Not as passive providers or consumers of research knowledge, but as active and critical generators of such knowledge (Walmsley & Johnson, 2003). Inclusive research involves people who have experiential knowledge related to the research topic in order to produce knowledge and findings that are scientifically robust, meaningful and applicable to the lives of the people being studied (Cornish et al., 2023). Although the concept of inclusive research has been applied particularly in the field of learning disabilities, attention to inclusive research is growing in various fields of research. Inclusive research is increasingly recognized as an essential component of ethical and high-quality research (Gehlert & Mozersky, 2018; Jadotte, 2022; Osuafor et al., 2021; Slade et al., 2021).

Studies indicate that, besides living with a disability, being female, being genderqueer, being poor, having little formal education and/or belonging to certain ethnic groups can mean that people are disadvantaged, less involved and underrepresented in scientific research (Alderman et al., 2013; Benuto et al., 2020; Bodewes & Kunst, 2016; Fenge, 2010; Shayo et al., 2012; Spinella et al., 2020). Experiencing disadvantage can mean experiencing discrimination, a lower socioeconomic position, a limited political voice or limited engagement in socio-scientific issues (Dawson, 2012). From a social justice perspective, scientific research should be relevant to and include those considered to be disadvantaged and underrepresented and foster their engagement throughout research projects (Pratt, 2019; Pratt & De Vries, 2018). Moreover, when such disadvantaged groups are underrepresented in scientific research, the generalizability of research is limited (Gilbert & Standaert, 2020). For example, risks in clinical trials may not be assessed equally across underrepresented populations with sometimes harmful consequences (Boden-Albala, 2022).

Many researchers have emphasized the importance of involving underrepresented, disadvantaged and marginalized groups in all stages of research projects (Knox et al., 2000; Stevenson, 2010). Besides including these groups as participants in research, they can also be involved as co-researchers when setting research topics and formulating research questions, developing appropriate research methods and materials, collecting, analyzing and interpreting data and in implementation and dissemination. Participatory action research, for example, involves participants actively in the research process to tackle problems that participants experience, such as health problems or problems caused by unequal and harmful social systems (Cornish et al., 2023; Reason & Bradbury, 2008). Including people actively in the research process can increase the quality, relevance and applicability of research and policies (Salimi et al., 2012; La Scala et al., 2024).

Inclusive research has been shown to build trust and relationships between researchers and communities, resulting in more meaningful and impactful research outcomes (Oetzel et al., 2018) as well as improved recruitment and retention of study participants (Nicholson et al., 2015). This highlights the value of applying inclusive research methods across the entire research cycle in both qualitative and quantitative research. However, the actual application of inclusive research methods can vary. Some studies involve minorities or members of disadvantaged groups in decision-making processes and in the execution of scientific research, while, in other studies, involvement is rather tokenistic (Askheim, 2021; Bigby et al., 2014; Walmsley et al., 2018). Tokenistic involvement issuperficial or symbolic as it appears to include various participants and perspectives but lacks genuine engagement and decision power.

While some practical challenges to inclusive research have been identified—it usually requires extra budget and time (Walmsley et al., 2018) —little is known about the barriers experienced by researchers. As most of the literature on inclusive research has been conducted in the field of disability studies by and with people with learning disabilities (e.g. Iriarte et al., 2023; Kramer et al., 2011; Salmon et al., 2018; Strnadová et al., 2014; Tuffrey-Wijne & Butler, 2010), we have a limited understanding of how inclusive research is conducted in other health-related research fields, such as health sciences, social sciences, and (bio)medical sciences. In studying how researchers from these fields experience and view inclusive research, we aim to support the development of inclusive research methods and help address potential challenges in applying such methods. This study therefore explores, from researchers' perspective, (1) what inclusive research is in health sciences, social sciences, and (bio)medical sciences, (2) why, according to researchers, inclusive research is important, (3) which barriers they experience across the research cycle, and (4) which practical strategies they propose and deploy to overcome these barriers.

RESEARCH METHOD

Participants

We conducted one-on-one, semi-structured qualitative interviews with 15 researchers in the Netherlands. All interviewees were approached via email for recruitment. We included (1) researchers who have experience with carrying out inclusive research in their field, and (2) researchers who study inclusive research as a topic and also have experience with carrying out inclusive research (Table 1). Participants have institutional affiliations to a university, a university of applied sciences, a center of expertise, or work as entrepeneurs. Although the differences are not that clear cut, in general university of applied sciences provides more specific training for a profession and focuses more on the application of existing knowledge in comparison to a university. A center of expertise is an independent Public Benefit Organization that can focus on research, policy and practice-based advice.

Researchers were selected and approached based on their experience with the topic "inclusive research", and based on their work in this field (e.g. publications, academic profiles and involvement in research or practice-based projects). We recruited experts who could provide insights based on their understanding and experience with inclusive research. The recruitment criteria were: (1) having experience with carrying out inclusive research in a specific field, or (2) studying inclusive research as a topic while also having experience with carrying out inclusive research. Some researchers were (former) colleagues of the authors and we recruited further participants through snowball sampling. Upon recruitment, we asked interviewees to confirm that they had experience with conducting and/or studying inclusive research. We followed this approach (as opposed to sending out a wider call to different groups of researchers) due to the necessity of specialized expertise.

Interviews were terminated after n = 15. The determination of the sample size in this study was pragmatically guided by considerations of time and financial resources. Given the constraints inherent in the study timeline and budget, a purposive sampling approach was employed to recruit participants who could provide rich and relevant insights within the available constraints.

Table 1
Expertise of interviewees

	Expertise	Field of study	Type of institution
1	Participation, (youth) care and people with acquired brain injuries	Healthcare sciences	-University -University of Applied Sciences
2	Inclusion of people with intellectual disability in research	Health sciences & methodology	-University
3	Power structures in the field of diversity, equity and inclusion	Diversity, Equity and Inclusion	-Entrepeneur
4	Patient participation of chronically ill patients	Health sciences & methodology	-University -University of Applied Sciences
5	Citizen engagement in research	Philosophy, sociology, anthropology and law	-University
6	Labour participation, health & inclusion	Sociology	-University of Applied Sciences
7	Participation of children & young people in (health)care and research	Medical anthropology & Health sciences	-University
8	Determinants of social stigma & its effects across various conditions and identities	Health sciences and social psychology	-University
9	Determinants of stress, poor health	Social epidemiology	-University

	and socioeconomic health inequities		
10	Stigma, disadvantaged populations, substance use disorders and policy analysis	Health science, anthropology & criminology	-Center of expertise (Public Benefit Organization)
11	Health inequities and participation	Health sciences & philosophy	-University
12	Healthcare, addiction, health care policy	Health sciences	-University
13	Mental and physical health, behavioral interventions, inclusion, diversity, equity and access	Health psychology, behavioral psychology	-University
14	Inclusive science, health literacy, quality of care	Healthcare sciences	-Center of expertise (Public Benefit Organization)
15	Patient participation, co-creation, patient-provider interaction, oncology, complementary medicine	Communication in healthcare	-University

Data collection

Interviews were conducted one-on-one on a video conferencing software (Zoom) by the first and second author, who are both trained in qualitative interviewing. Individual interviews were chosen over group-based interviewing because we aimed to explore individual experiences and perspectives in depth. The interviews lasted 30-45 minutes. Interviewees did not receive a reimbursement for participation in the interviews. Interviews were performed between July 2020 and January 2021. Interviewees were asked questions about (1) their knowledge about inclusive research, (2) their experience with inclusive research, and (3) guidelines, barriers and strategies for inclusive research. They were also asked questions about strategies to increase inclusivity during various research stages. These questions helped interviewees to think beyond their own experience and reflect on ways to increase inclusivity in the entire research cycle. The topic list can be found in Supplementary Table 1. The items listed in the topic list were included as probes for further questioning. The interviewer made sure that these topics were covered, although not necessarily in the order listed in the topic list.

Analysis

The interviews were audio-recorded and transcribed verbatim. We performed qualitative content analysis (Forman & Damschroder, 2007) which is an approach described as codebook thematic analyses by Braun and Clarke (2021). In contrast to methods that bring to bear theoretical perspectives (e.g. Grounded Theory), qualitative content analysis focuses on the informational content of the data. Code development was based on deductive and inductive reasoning, starting with deductive coding but remaining open to new topics suggested by the data. Deductive codes were developed by assigning categories to questions of the interview topic list and to various stages of the research cycle. The first author then read the transcripts, highlighted passages that seemed important to the research questions and noted inductively emerging codes in the margins. A codebook was developed to organize all the codes. Based on the answers, overarching themes were assigned to sets of codes, and the codebook with all codes and themes was shared with the second author. The second author re-read all codes and the assigned themes.

Reflexivity statement

We are attentive to our positionality and recognize that our various insider positions (e.g. our shared identity as researchers with our participants) and outsider positions (e.g. different national and ethnic backgrounds) may have impacted the research design, analysis and interpretation of the data (Braun & Clarke, 2021; Clarke & Braun, 2013). The first author, who as a project leader was most extensively involved in the analysis and interpretation of the data, identifies as a cisgender, heterosexual Dutch Tunisian woman. Her research focuses on health promotion, participatory research and socioeconomic health inequalities. The second author, who assisted the first author in the practical execution of this study, identifies as a cisgender, heterosexual Dutch woman, who studied health sciences, global health and public policy and human development. This study focuses on experts in the fields of health sciences, social sciences and medical sciences because researchers in these fields were easier to recruit for the authors due to their own positions in these fields.

RESULTS

What is inclusive research?

Various aspects of inclusive research were mentioned by experts. Aspects can be categorized into the following themes (1) involvement of the researched group (2) research accessibility, (3) diversity and representativeness of the research population, (4) enabling positive change.

Involvement of the researched group is about the interaction between the researched group and the researcher, in which the researched group is involved as more than just research subjects or respondents. Based on the interviews, we define the researched group as a segment of a population that researchers want to say something about in research. Involvement of the researched group requires not only an active approach on the part of the researcher (e.g. actively reaching out to the researched group, building a relationship with the researched group and maintaining regular contact), but also an active role on the part of the researched group: They can shape and describe their own involvement in various phases of research. For instance, it was mentioned: “It’s about involving all kinds of people, making sure that they can have their voices heard in their own way” (R1). Another expert added that ideally this should happen in an early stage: “When applying for funding, discuss what participation looks like: Involving people in the project group or (sounding) board” (R4).

The second theme considers the accessibility of research to the researched group. If research is to serve the interests of its study population, then it needs to be accessible for the entire group. Accessibility of research requires research and research materials to be developed in a way that is understandable and easy to use. Moreover, it requires the researched group to have control in the development of research materials, making sure that the research materials are in line with their own skills, preferences and needs. It was mentioned: “[It’s about] making research accessible to people with different backgrounds, capabilities and limitations” (R1).

Having a diverse respondent group in research was explicitly mentioned by researchers in relation to the generalizability of study results. It was mentioned that by giving voice to a diverse group of people, researchers become more sensitive to what is ‘under the radar.’ Accordingly, an expert stated: “The power of the research is to show variation” (R3).

It was also mentioned that inclusive research should be representative, for the purpose of creating valuable data that could serve the broader population without leaving people out. Inclusive research therefore seeks to account for all characteristics that are present in the target population, including the ones that diverge from the norm.

Inclusive research is also considered as enabling positive change for people: “For me, inclusive research is always action-oriented. That is, it must benefit the people it concerns. So that’s part of it too. So, it also means that change for the better has to happen for people. That it contributes to their quality of life” (R2). An example is: “16-year-old children who actively participate in research about a playground in Flanders.” (R2) The interviewee elaborated: “And then of course you have to see it within the context of those children of that age. But that can be very valuable. These children provide information and paint a picture that differs greatly from the planning that adults have.” Inclusive research can be action-oriented and can also lead to a larger societal impact. For instance, in the fields of human rights and children’s rights, research often concerns social problems. According to some experts we interviewed, such research should be done with the people themselves, if possible.

Why is inclusive research important?

Four main arguments for the importance of inclusive research could be identified in the interview data. One argument revolves around the eventual (societal) impact of research. Although not applicable to all types of studies (e.g. descriptive studies), when research is conducted in an inclusive manner, more people will be reached and the results of it will bring about positive change desired by the study population. This is particularly relevant in health sciences and medical sciences, as research often aims at changing behavior. Inclusive research is important because of “empowerment of the target group which causes research results to have a larger impact” (R5).

The methodological argument concerns decreasing researcher bias, improving measurements and quality of the research and improving external validity. Experts pointed out: “Researchers have blind spots” (R8) and “researchers are biased in their thinking” (R6). This prevents researchers from having or obtaining knowledge that is important to understand societal issues and reach societal impact. Also, research that takes into account the skills, needs and wishes of the researched group improves the validity of the study results because the measurements are more in line with the skills, needs and wishes of the researched group. Therefore, the methodological quality of the research improves. Inclusive research also leads to improved external validity as a diverse sample that is more representative of society increases the generalizability of a study.

The educational argument concerns the increased exchange of perspectives, experiences and knowledge between researchers and participants, which has educational value for both parties. Differences between people can be a source of knowledge. The importance of researchers listening to and learning from the study population were mentioned: "Differences between people are a source of learning and knowledge" (R11) and "it is important to listen to the target group, such as people in high conflict-areas" (R5). This means that both researchers and participants can learn from each other's perspectives and become acquainted with each other's experiences. Another important aspect is participants' ownership of knowledge, as opposed to exclusive ownership by the researcher. Ownership of knowledge can lead to more autonomy of participants during the research and learning process. According to some interviewees, inclusive research is important because "the target group becomes the owner of knowledge" (R7). Shared ownership can be achieved by involving participants at an early stage: "[I]t just helps if people have already been part of developing that intervention earlier, for example. Then you also get the feeling of, a kind of feeling of shared ownership; that they are also responsible for this in some way" (R10).

The ethical argument assumes that it is a right of participants to think along about matters that concern them, including scientific research. In addition, inclusive research is considered as a matter of justice and even an ethical obligation for researchers. This argument stresses that inclusive research gives people, who often historically have not had a say in scientific research but who are closest to the issue under study, a voice in the matter. For example, an expert indicated: "There's an ethical argument to give people a voice in the research that concerns them" (R1).

What are barriers to inclusive research?

Various barriers to inclusive research were mentioned by experts: (1) lack of skills of the researcher, (2) lack of time, (3) non-inclusive methods and study designs, (4) perception of inclusive research as not scientific, (5) lack of budget, (6) agenda setting of organizations or local or national policymakers, (7) tokenistic inclusivity, (8) third parties such as gatekeepers and ethical committees. A summary of specific instances of these barriers is provided in Table 2.

The lack of skills on the part of the researcher was referred to in different ways, including the lack of openness, empathy and/or diligence to meet different needs, cooperative skills and the fear to lose control over research. As one expert mentioned: "The communication of your results, or your intervention, often requires a different set of skills than the standard research skills" (R2). Specifically, it is important to not use terminology that might exclude groups or might have a negative connotation for some groups. Also, the academic background of the researcher might be a barrier as some populations might mistrust academics. For example, one researcher who works with risk groups indicated: "Some communities may not be used to it [research] or not familiar with it, or they may be suspicious of researchers at the university. And of course, I'm also a white woman and I'm from college. Then you are in a certain box. You just have to take more time and that also costs more money" (R5).

Lack of time was mentioned as an obstacle to conducting research inclusively: "The meaningful involvement of people asks for time and flexibility" (R5). Time and devotion are valuable, as "standardized questionnaires capture standardized visions. If you want to dig deeper, you need other methods, but you also need more time. You need different approaches to capture the variation in your data" (R11). Time is not only a scarce resource among researchers but also among study participants. According to some interviewees, women and minority groups tend to carry time-intensive social burdens which do not leave them the time for participating in research. Related to this barrier was also the finding that some researched groups such as women or minority groups could be overburdened with having to spend extra time in relation to inclusivity-related activities and tasks. For example: "You can ensure that there are more women in the appointment committees and committees that determine who is appointed. But if there are only three women in a faculty to do that, then they always have to sit on all those committees and they cannot do that" (R8).

The methods and measurements used in studies can also be barriers to inclusive research, because questionnaires, informed consent forms, or other study materials can be difficult to understand for participants. The format or inclusion criteria into which people must fit in order to participate in research are restrictive (e.g. language skills or training requirements). Similarly, participants' limitations in skills and communication are barriers for inclusive research.

Inclusive research is also sometimes perceived as not scientific because classic experimental designs are still seen as the 'golden standard'. In experimental research, participants are often selected based on specific criteria to meet the study objectives and exclusionary criteria limit the participation of certain groups. Specifically finding a balance between the internal validity and external validity of a study was mentioned as a difficulty. One interviewee noted: "You have to make a choice between the highest possible internal validity and the highest possible external validity. I think that's a bit of a problem. So, sometimes you are actually exclusive. You are explicitly conducting exclusive research, in order to maximize internal validity" (R9).

A limited budget for recruitment of respondents is another barrier. One expert indicated: "Participants and co-researchers need to be paid fairly of course. I do not want them to be involved as 'volunteers'" (R5). Furthermore, developing inclusive materials can be expensive, and therefore a lack of funding can limit inclusive research. An interviewee pointed out: "If I do want to include them [minority groups], I have to develop a questionnaire, which costs me a lot of time and money" (R9). Another expert emphasized: "We try our best and it can be better, but there is a cost to that and the efforts you have to make to include those people" (R9).

Inclusive research may also be too far removed from the agendas of organizations or policymakers: "Agenda setting is of course a major problem, because it is very strongly influenced politically. And certainly, with marginalized groups, you don't always have access to that political agenda" (R2). Moreover, there are structures in organizations, such as universities and universities of applied sciences, that are not geared towards inclusive research: "The structure that can promote inclusive research does not exist at the moment. So, that also means that structural things have to change. [...] But I think that, for that, you need a change within how universities and universities of applied sciences are set up" (R3).

An important pitfall is that inclusivity is sometimes used as a token. This means that certain groups may be involved in scientific research in order to give the appearance of inclusivity, when in reality the involvement or influence of the person concerned has been downplayed: "A pitfall is often that inclusiveness is used as a kind of token. That we pretend when in fact the influence of the person concerned has been trivialized. [...] so people aren't actually involved, but they're already being told what to do" (R2).

Other barriers to reaching and involving participants are gatekeepers who limit accessibility to a study population, and ethical committees that restrict research in, for example, difficult to reach (conflict) areas. For instance, the following was mentioned by an interviewee: "We see very often, especially in psychiatry, that it is said: 'no, the pathology does not allow this client to participate.' This also means that many clients do not get the chance to make their voices heard, because gatekeepers, care providers and parents, think that it is not good" (R2).

Table 2

Barriers to inclusive research

Research phase	Barriers
Agenda setting	• Specific communities or individuals may disagree with the research and its political agenda and may thus be unwilling to participate • Some funding organizations do not fund research with certain groups because the results can be politically controversial • Administrative work may increase if diverse groups are involved because of frequent contact with study-participants and keeping track of work and payments • Universities currently do not reflect the diversity in society due to a lack of diversity in academic staff. Consequently, universities are not always well-informed about societal issues
Research question	• By involving study participants as co-researchers, scientists may feel that they position themselves as not having sufficient knowledge or expertise themselves to formulate the research question • Some researchers assume that participants might not have sufficient knowledge or expertise to formulate the research question
Recruitment & response	• It is difficult to investigate whether participants differ from those who are not participating in the study, and it is therefore difficult to increase inclusivity • Researchers are not always able to return to areas in which conflicts exist (e.g. areas with territorial disputes, violence or protests)

	• Some groups in societies are stigmatized and are less inclined to participate in (co-)research • Increasing polarization and income inequality in society may lead to people feeling misunderstood and disconnected from research, and they may therefore be unwilling to participate
Design of intervention	X
Data gathering	• When co-researchers collect data on each other (e.g. in the form of interviews), concerns about research confidentiality may arise • The safety of research participants might not be protected, for instance, if they help investigate criminal offenses
Drop-out	X
Data analysis	• People with intellectual disabilities might experience difficulties with the conceptual understanding of data analysis • Some participants or co-researchers have an interest in specific results or may be biased towards specific results
Dissemination	• Academics are evaluated based on the number of publications in scientific journals and are not equally evaluated based on other types of publications (videos, podcasts, etc.) which can reach a wider audience

What are strategies for facilitating inclusive research?

The following strategies to facilitate inclusive research were mentioned by the interviewees: (1) improving the skills of researchers, (2) awareness of and sensitivity to inclusivity (3) creative, suitable and comfortable measurement settings and methods, (4) providing resources, (5) structural changes, (6) having co-researchers think along about the design and execution of the study, (7) using toolboxes. An overview of specific strategies is provided in Table 3.

Different skills on the part of researchers are considered to be relevant to inclusive research. For example, in some instances—when a researcher has a more privileged background (with a higher socioeconomic position)—they need to develop relational skills to understand and communicate to the researched group. The ability to step outside of one's comfort zone, visit communities and talk with people helps some researchers to understand their study population. An 'open' attitude is therefore necessary to work inclusively: "You need to be open to new insights that you don't necessarily expect, and [that] may perhaps be even difficult" (R2). For this purpose, researchers need to be "flexible" and adjust to the researched group through continuous interaction, such as talking with the researched group and keeping everyone involved in all phases of research.

Inclusive research also requires a certain quality of the researcher: "Being aware of your own role in your story; think about exclusion mechanisms within your research and describe them" (R3). According to some interviewees, researchers should critically reflect on the research process and the use of terminology to foster inclusivity. A researcher should not use concepts blindly without reflecting on their meanings, connotations and associations (for instance, the concepts 'Western vs. Non-Western'). Researchers should be aware of the meaning of the concepts that they use in their work, as some concepts could exclude groups and influence the (societal) image of these groups. Furthermore, there is no single strategy that serves as a 'golden bullet' to reaching more inclusive research. There is no checklist that a researcher can simply 'tick-off'. Rather, there is a need for researchers to develop "awareness and sensitivity for inclusiveness" (R11), which is mentioned by multiple participants. Thus, more inclusive research requires more awareness and sensitivity of the researcher. In order to increase the validity, meaningfulness, democracy and relevance of research, members of the study population should be involved throughout the entire research cycle, from agenda-setting to dissemination. Also, it can be beneficial to connect with artists and listen to those groups in society who are often not heard, because that is when researchers can become sensitized to inclusivity: "I think you can become sensitive to inclusivity in other ways. [...] you continuously have a kind of openness in your science and are sensitive to people who think about things in a different way" (R11).

Practical strategies to increase inclusivity include determining a setting or context for measurements that is suitable or more comfortable for participants (e.g. walking while interviewing instead of sitting at a table) and alternative ways of measurements or collecting data (e.g. taking notes instead of recording conversations). Strategies for working more inclusively can be creative. Examples from the interviews include photovoice as a method used to document and reflect reality in data collection and analysis, making key figures in the study population ambassadors in the recruitment phase, and creating songs in the dissemination phase. In terms of content, strategies to foster more inclusive research are discussing with the members of the study population the accessibility, direction, and results of the research as well as the roles of co-researchers.

Furthermore, it is important to consider resources for inclusive research in grant applications (e.g. budget, network, time). Also, support through policy and university arrangements that allows research in vulnerable populations can help to facilitate more inclusive research: “I think they [ethical committee] support that very well and actually make a lot possible. That is really their goal to make certain research possible. And there is now an arrangement as well, since two years now, for research in conflict areas. I am allowed to do real research [...]” (R5).

Structural changes are also needed to reach and involve study populations in research, such as a change in the research culture and research traditions of universities. One example of this would be to change the assessment criteria for researchers and co-researchers: “When I look at PhD students who are employed by us, they have an assessment form [...]: How many publications have you achieved? How many presentations have you given and so on. And it doesn’t say: how many contact hours did you spend with the target group? That’s not in the assessment form” (R12). Other interviewees stressed the importance of diverse research teams, including researchers from various backgrounds.

In some of the interviewees’ own research, their participants (co-researchers) took the lead in thinking about the design of the study (e.g. research question and method) and were actively involved in the execution of the study (e.g. data collection, analysis, reporting, communication): “In the strongest case, people with intellectual disabilities start doing research themselves. They are then in the lead in the investigation. They come up with research questions that they find relevant. They choose a research method, carry out the research, analyze the results, interpret the results, present the results and also work on implementation” (R2). It was also mentioned that frequent meetings with members or representatives of the researched group were needed to discuss what participation could look like for this group. These discussions could already take place in writing a grant application, but if this was not possible (for example, in the case of patients with dementia) meetings with patient representatives were held.

Some interviewees had experience in offering toolboxes to participants for different research phases with various low-threshold methods and options for conducting inclusive research. These methods could be deployed by researchers and co-researchers alike. For instance, it was noted that questionnaires, surveys, focus groups and interviews, could take place in different formats. An interviewee elaborated: “We only create a situation where research becomes possible and then offer toolboxes from which they can draw. [...] offering them a toolbox with different options and discussing with them ‘what is the question that you have formulated together and what are the methods’. Finally, they choose a method and they implement it” (R2).

Table 3
Strategies facilitating inclusive research

Research phase	Strategy
Agenda setting	• Consulting members of the study population in determining the research topic • Checking the relevance of the research topic with members of the study population • Investing in networks and long-lasting relationships with members of the study population • Lobbying for funds for addressing questions articulated within a specific study population
Research question	• Involving the study population in writing the research proposal, formulating research questions and specifying the use of terminology • Rewriting the research questions together with members of the study population
Recruitment & response	• Visiting the community in person, establishing personal contact and getting to know each other • Building trust and investing in networks and long-lasting relationships

	• Involving gatekeepers, ambassadors and community organizations in recruitment • Using snowball sampling • Providing more accessible locations for the study population • Compensating participants in a way that is interesting and worthwhile for them (e.g. cash, supermarket vouchers) • Testing the recruitment strategy, recruitment text, the information letter and letter of consent among members of the study population with regards to language, readability and comprehensibility • Using multiple languages for recruitment text, information letters and letters of consent (if applicable to the study population)
Design of intervention	• Involving members of the study population at an early stage and establishing a non-hierarchical, equal relationship
Data gathering	• Involving and training the researched group in collecting data • Involving the researched group in the development of measurement instruments and methods • Combining data collection modes (e.g. interviews, written questionnaire, video, calling) to suit the needs of individuals
Drop-out	• Sharing progress and achievements with study participants
Data analysis	• Ensuring that data analysis (e.g. coding) is conducted by a variety of people with different characteristics
Dissemination	• Using different forms of publication that are understandable and accessible for non-academic audiences (e.g. blogs, workshops, symposia or arts-based publication) • Presenting the message of the study participants, not of the researcher

	• Publishing in national journals in local languages • Training researchers to write for non-academic audiences • Incentivizing academics to use alternative forms of publication

DISCUSSION

This study has explored (1) what inclusive research means within the health sciences, social sciences, and (bio)medical sciences, (2) why, according to experts, inclusive research is important, (3) what barriers experts experience in the research cycle, and (4) which practical strategies they propose and deploy to increase inclusivity.

Important aspects of inclusive research are: involvement of the study population, research accessibility, diversity and representativeness of the research population, and enabling positive change. There is no one correct way to conduct more inclusive research. Rather, the various identified strategies can be applied to both qualitative as well as quantitative approaches to enhance inclusivity in studies.

There are different perspectives on “involvement of the researched group” and to what extent people can and should be involved. For example, it can range from collaborations in which participants share ideas and make contributions (Hewitt et al., 2023) to participants actively shaping all phases of research including the selection of methods and data analysis (Vega-Córdova et al., 2020). One explanation for why one aspect of inclusive research—involving members of study populations in participatory approaches—is not yet fully integrated and sustained in scientific research is that there might be beliefs among researchers that non-academics (lay people) lack expertise or skills to hold equal power and make decisions at various stages in the research process (Askheim, 2021; Fenge, 2010; Hodgson & Canvin, 2005). Researchers may need to acquire skills to better provide support to those involved in different phases of research while also obtaining participants’ feedback to adjust and improve the support provided (Vega-Córdova et al., 2020). Some studies on providing support to people with learning disabilities emphasize the importance of an inclusive approach to training in which co-researchers have control over their training needs and over the training they receive in contrast to formal training that tends to address ‘deficits’ (Iriarte et al., 2023; Nind, 2017). Furthermore, we argue that the extent to which participants are involved in the research process depends on the methodological nature of the research as well as societal, educational and ethical aspects. In making methodological choices about the involvement of study participants, the needs and wishes of participants themselves, the added value for co-researchers (educational argument and ethical argument), the quality of the research process and the results (methodological argument) and the increased societal impact of research (societal argument) can all provide guidance. These aspects are based on the results of our study and are in line with previous studies as well (Oetzel et al. 2018; Nind, 2017; Slade et al., 2021). By considering these aspects, researchers can make informed decisions about the level of participant involvement that is possible for their study, balancing methodological aspects with societal, educational and ethical considerations.

To increase accessibility, it is important for researchers to understand the lives and skills and 'speak the language' of the study population. Before applying for a research grant, researchers should consult and involve members of the study population to establish a plan that is feasible, relevant for the study population, and has impact. Involving members of the study population in the research process asks for mutual trust, building on personal relationships. In line with our findings, Embregts et al. (2018) identify a variety of competencies for establishing collaborative relationships between people in inclusive research projects, such as building mutual relationships and achieving a collaboration in which everyone involved can contribute and become aware of required skills and needs. Also, researchers need to acquire skills to better communicate and explain their research to others in a way that enables members of the study population to participate in the process (Embregts et al., 2018). Improving skills of researchers, providing resources as well as enhancing awareness and sensitivity of the researcher were also mentioned as important facilitators to more inclusive research in this study.

This study shows that inclusive research requires a shift towards more 'inclusive mindsets' of researchers. Stimulating such a shift is more useful than creating criteria or check-lists for the practice of inclusive research. An expansive, continuously developing vision of inclusive research is necessary for its increased implementation and sustainability (Nind & Vinha, 2013).

This study has identified barriers for inclusive research, for example, lack of skills of the researchers, lack of time, non-inclusive research materials, a closed-minded attitude of researchers and lack of budget. Results of this study are in line with previous studies in the field of disability studies, which indicate attitudinal barriers (e.g. inflexible expectations of researchers or funders), institutional barriers (e.g. obstructive university policies, funding schemes) and material barriers (e.g. lack of transport, financial resources, inaccessible research materials) hindering inclusivity in research (Nind, 2017). It seems that despite more awareness and achievements regarding inclusive research (Salmon et al., 2018), we still learn about how more inclusive research strategies can be applied in various approaches and research methods used across academic fields. For instance, a study on the embedding of inclusive research principles in the design and execution of clinical trials found that patients from minority backgrounds might mistrust healthcare systems and that the recruitment of minority populations was often poorly addressed in research studies. The study concluded: "[W]e have to rethink and redesign the systemic framework for clinical trial execution to incorporate various multi-faceted approaches that will help lower the barriers and increase access for underserved communities to participate in clinical trials" (Peters et al., 2023, p. 191).

Our findings also highlight the importance of structural changes in academic institutions. Time, funding, training, systemic biases, inadequate reimbursement (Peters et al., 2023) as well as a change in the research culture and research traditions within universities, funding agencies, journal editorial boards and conference committees are required to increase more inclusive research practices (Asmal et al., 2022). For instance, increasing inclusivity in research needs to be supported by recognition and appreciation for inclusive practices and their positive contributions to science and society (Sutton et al., 2023). This is in line with other studies highlighting the importance of greater diversity and inclusivity, not only among researched groups, but also among researchers. Despite the fact that diversity in research teams is associated with increased scientific novelty and innovation (Nielsen et al., 2018), studies suggest that the scientific careers of underrepresented groups often end prematurely (Hofstra et al., 2020). Novel contributions by these groups are less likely to translate into their own academic career success, which is known as the "diversity-innovation paradox" (Hofstra et al., 2020). This stresses the need for addressing biases and a change in the research culture.

Strengths and limitations

A strength of our study is that this study provides new knowledge and a wide range of methods and strategies for more inclusive research, which can be applicable to a wide range of fields, such as health sciences, psychology, medicine and biomedical sciences. Other strengths are that we examined perceptions, barriers and facilitators across the research cycle and that we interviewed researchers with various backgrounds.

The study also has some limitations. This study was conducted from the perspective of researchers only, not from the perspectives of participants of the researchers we interviewed. Also, our participants are mostly white women (80%), working in the health sciences or medical sciences at a university, university of applied science, centre of expertise or as entrepeneurs. In this study, we did not ask interviewees how their institutional affiliation or their type of work impacted their capacities to conduct inclusive research. While the pragmatic sampling approach allowed for the efficient use of resources, it is essential to acknowledge that the study's findings should be interpreted within the context of these limitations. Future research endeavours with more extensive timeframes and financial resources could benefit from employing larger and more diverse samples, thereby enhancing the robustness of the findings.

The results of this article apply mostly to the scientific fields that are aimed at understanding the factors that influence human behavior, behavior change and decision-making. This indicates that the barriers and strategies outlined in this paper might be less applicable to scientists working in other fields (e.g. historians, philosophers). For instance, one of our findings is the facilitating strategy "presenting the message of study participants, not of the researcher" for dissemination of research results. Scientists from other fields might argue that nobody has epistemic authority, neither the researcher nor the study population, but that inclusive research implies engaging in a co-creation process of data generation, analysis, and interpretation (Smolka 2021). This means that the strategies for inclusive research, presented in this paper, cannot be uniformly applied. The strategies require individualized assessment and customized implementation, as what works for one situation or person may not work for another.

CONCLUSION

This study has identified important facilitators and barriers for more inclusive research practices at various stages of the research process. Societal, methodological, educational and ethical arguments have been identified as reasons for the importance of inclusive research. There is not one correct way to conduct inclusive research. Rather, an inclusive mindset needs to be cultivated among researchers. The various identified strategies can increase inclusivity in both qualitative as well as quantitative studies.

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