Abstract

Background. Co-research with people with intellectual disability (ID) is a distinct form of patient and public involvement (PPI). This systematic review summarises published studies and protocols to report on the process of co-research for all stakeholders.

Method. Relevant studies were identified using electronic searches on ASSIA, PsycInfo and MedLine. Study quality was assessed and information relevant to the process of working with co-researchers was extracted and thematically analysed.

Results. Thirteen studies were retrieved. Data are reported under three themes: 1) challenges of co-research; 2) facilitators of co-research; 3) benefits of co-research. Best practice is presented as a model of co-research. Content analysis on 12 research protocols identified four themes related to PPI.

Conclusions. All stakeholders involved in co-research with people with ID can benefit, providing there is adequate infrastructure to accommodate and empower the co-researchers. Many current ID research projects still lack systematic involvement of PPI members.

Introduction

Intellectual disability (ID) is the most common developmental disability, currently affecting 1 to 3% of the population worldwide (Maulik et al., 2011; WHO, 2007). Various terminologies are used to identify ID, including learning disability, learning difficulty, intellectual disability/developmental disorder, developmental/cognitive delay and mental retardation (WHO, 2007). However, the diagnostic criteria all include significant impairment in the conceptual (e.g. language, reasoning, memory), social (e.g. empathy, communication) and practical (e.g. personal care, money management) domains of the individual (American Psychiatric Association, 2013).

Historically, people living with ID have been excluded from research (Wilkinson & Hubbard, 2003; Wilkinson, 2002), because it was generally held that their cognitive impairment precluded participation in population research (Moore & Hollett, 2003; Dewing, 2002; Downs, 1997). During the 1990s, in parallel with a growing societal interest in the rights of marginalised groups, the disability movement challenged traditional views about the involvement of service users in research with the slogan '*Nothing about us without us*' (Charlton, 1998). This resulted in increasing opportunities for people with disabilities to participate in research (Wilkinson & Hubbard, 2003; Wilkinson, 2002).

In 1995, Minkes et al. published "Having a voice: Involving people with learning difficulties in research", which advocated for a co-participatory standpoint in research. The affirmation of the Emancipatory Disability Research framework (Barnes, 2001), grounded in the 'social model' of disability (Oliver, 1990; Finkelstein 1980; UPIAS 1976) enabled academic researchers to challenge their traditional view that people with ID could only be involved in research as participants (Walmsley & Johnson, 2003). Emancipatory Disability Research, advocating that disabled people, rather than academics, should control the research process, funding and agenda, positively affected people with ID, who began to be involved as informants in research providing accounts of their experience, responding to questionnaires and taking part in clinical trials and studies (Moore & Hollett, 2003; Dewing, 2002; Downs, 1997). However, their involvement as participants was distinctly different from having an active role in the research process.

From the early 2000s, researchers working in the social and health care sectors in the United Kingdom started to acknowledge the added value of the lived experience of people with ID (Ward et al., 2012; Williamson et al., 2010; Clough et al., 2006; Miller et al., 2006; Reed et al., 2006; Warren & Cook, 2005). This was also reflected at the international level, with a proliferation of studies grounded in principles of inclusive research, particularly in Australia, New Zealand, Ireland, Canada, and the United States of America, where partnership in research with service users was most valued (Walmsley & Johnson, 2003).

In the United Kingdom, following the publication of the white paper 'Valuing People' (Department of Health, 2007), the Department of Health awarded £2 million to thirteen projects involving people with ID in the research process as part of the Learning Disability Research Initiative (LDRI) (Grant & Ramcharan, 2007). Involvement ranged from being part of an advisory group, to conducting interviews and data analysis. One of these projects, led by The Learning Difficulties Research Team (LDRT, 2006) received funding to report on the quality of user-involvement in the other projects. The group identified examples of good practice, but concluded:

"In most cases involvement occurred in limited, traditional and fairly unimaginative ways. In very few cases was real power-sharing happening. Research is still 'done to' people with learning difficulties not 'done by' us. Effort to involve people often didn't work very well because there wasn't enough time, money, support or outreach. For these reasons, people with learning difficulties had little influence over the topics, processes, conclusions and dissemination of research" (LDRT, 2006, pp. 81-82)

This report highlighted how much still needed to be accomplished to fully involve people with ID in the research process.

More recently, the National Institute for Health Research (NIHR) has made it mandatory that each research application should include details of Patient and Public Involvement (PPI) (NIHR, 2014). This initiative also applies to research in ID. PPI has several tiers, ranging from advisory roles - such as commenting whether research questions are relevant to particular population groups and disease categories or advising on research materials and study promotion - to more active participation in the research process, under the umbrella term “Inclusive research”, which translates into different methodologies (Nind, 2017).

Methodologies badged as inclusive research include Participatory Research, in which people with ID collaborate with academic researchers in planning and conducting research that investigates their own experience (Bergold & Thomas, 2012). In Action Research, the insight generated through participatory research works towards the change of social reality. Co-research (also known as peer-research) is defined as research carried out ‘with’ or ‘by’ members of the public/patients rather than ‘to’**,** ‘about’ or ‘for’ them (INVOLVE, 2015). In co-research, people with ID collaborate with academics to investigate the experience of their own peers (people with ID) (Staley, 2009; Frankham, 2009; Repper et al., 2007; Turner & Beresford, 2005).

Examples of co-research with adults with ID are diverse. They vary in terms of the role of co-researchers, the authorship of publication and dissemination materials and the retention of control over the research process. Different studies may have different numbers of co-researchers, who are involved at different stages of research and they may also differ in the aims and objectives of involvement.

Despite the advancements in the establishment and practice of PPI, and the fact that systematic reporting around co-research with other vulnerable individuals, such as people with dementia have been carried out (Di Lorito et al., 2017), thus far, to our knowledge, no systematic review of the international literature has been carried out to synthesise the abundance of information around co-research with adults with ID. Several books have provided information around the process of doing and experiencing co-research in ID (Nind, 2014; Walmsley & Johnson, 2003). In order to draw together understanding about practice in the UK, Nind & Vinha have carried out a focus group study with inclusive researchers in the learning disability field (Nind & Vinha, 2012) and produced a methodological review report published by the National Centre for Research Methods (Nind & Vinha, 2013). The report, which highlights the challenges the authors encountered throughout all phases of the research process, derives useful insight for good practice. The authors, however, concluded that if *'more of the methodological learning can be brought together in resource documents like this review paper, it may be that inclusive researchers are freed up to put more of their energies into creating substantial, substantive knowledge'* (Nind & Vinha, 2013).

A systematic review with an international focus could be instrumental in expanding on the existing resources available for researchers who are interested in undertaking co-research with adults with ID in health and social care research. The benefits of systematic reviews as a method to further current knowledge derive from their clearly formulated question, use of systematic and explicit methods and criteria to identify, select, and critically appraise relevant literature (The Cochrane Collaboration, 2005) and standardised reporting systems [i.e. the PRISMA guidelines (Moher et al., 2009)]. We therefore aim to systematically review the existing international literature reporting co-research with adults with ID.

Our review questions are:

1. What are the barriers of co-research with adults with ID in health and social care research?
2. What are the facilitators?
3. What is the impact of co-research for all those involved?

We further aim to identify and describe in detail a model of good practice in co-research, which will add to our review findings.

In addition, at a time when national clinical research funders (e.g. National Institute for Health Research) are seeking greater evidence of involvement by experts by experience, we report on the role and the use and extent of PPI in recently funded work. We therefore aim to examine the published protocols of current ID research projects and report whether -and if so- how PPI was carried out.

In addition, peer-review papers often take time to come to press and therefore the papers retrieved through our systematic review are likely to report practice from previous years. As this is a rapidly developing field of practice, a search of current protocols would provide more up-to-date information of the status of PPI (and co-research) in ID. Our focus on PPI in protocols, rather than on co-research only, is justified by the fact that the latter is still uncommon practice and a narrower search may potentially yield very few results.

Methods

Systematic review of the literature reporting co-research with adults with ID

This review conforms with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher et al., 2009). We made use of the PICO (Population, Intervention, Comparison, Outcome) worksheet and search strategy for conducting systematic reviews (Sayers, 2008) to define our inclusion/exclusion criteria for the selection of sources.

Inclusion criteria

- The study is peer-reviewed and it focuses on health and social care research. We acknowledge that co-production does not only occur in research but also in service development and implementation (Roberts et al., 2012). However, in this review we focus only on co-research, which is less common practice, given traditional views on people with ID not being able to take part in more cognitively demanding tasks.
- Participants are adults with ID and have undertaken research alongside academic researchers (i.e. they took on the role of co-researchers) at any stage of the research process.
- The study was conducted after 1996. The publication of the report "Whose Voice" (Minkes et al., 1995) advocating that people with ID should be involved in research is considered a turning point in the development of co-research in the UK. From the mid-nineties, co-research started to emerge as standard practice also at the international level (Bigby, Frawley & Ramcharan, 2014; Walmsley, 2004).
- No restrictions on country or language were applied.

Exclusion criteria

- The study focuses on Patient and Public Involvement (PPI) but does not report on co-research (i.e. people with ID did not take on the role of co-researchers).
- The study includes non-adult co-researchers, co-researchers without ID and/or it is not possible to isolate the experiences of those with ID.
- The study was carried out by people with ID or academic researchers independently (i.e. without collaboration between the two groups).

Search methods

We carried out a systematic literature search on ASSIA, PsycInfo and MedLine between December 2015 and March 2016. In brief, we searched for and combined terms from two domains: (i) the Intellectual Disability domain, including terms such as: Cognitive Impairment, Learning Disability, Intellectual Disability, Autism and Learning Difficulty; (ii) the co-research domain, including terms such as: Co-research, peer-research, participatory research and involvement (Appendix).

Although we made every effort to keep the search strategy as consistent as possible across databases, minor changes were made to respond to the different characteristics of the databases. We further searched on Google Scholar by considering the first 100 hits. The references of the sources retrieved through the searches were screened for relevant literature. Two independent reviewers (CDL and LB) carried out title and abstract screening and excluded the sources that were clearly ineligible. They then accessed the full texts of the remaining sources and excluding those which did not respond to the inclusion criteria. Any disagreement was resolved within the research team.

Quality appraisal of the studies

Once we identified relevant literature, two independent raters within the research team (CDL and AB) carried out further appraisal of the suitability of the studies through the Critical Appraisal Skills Programme (CASP) checklist for qualitative research.

Based on the guidelines of CASP, a study was considered unsuitable for review on the grounds of poor quality and dismissed if it did not include a clear statement of the aims of the research and if a qualitative methodology was not appropriate to investigate the research questions (items 1 and 2 in the CASP checklist).

The remaining 8 items of the CASP checklist (items 3 to 10) were instead used for quality screening purposes only on all the studies selected for full review. Discrepancies between the two raters were resolved by consensus within the research team.

Data extraction and analysis

We extracted data onto NVivo 11 and adopted a deductive approach to thematic analysis (Braun & Clarke, 2006), whereby the themes were based on our research questions. These were:

1) Meeting the challenge: This theme outlines the barriers of co-research with adults with ID.
2) Adapting and accommodating: This theme outlines the facilitators of co-research with adults with ID.
3) Making a difference: This theme outlines the benefits to the co-researchers, academic researchers, participants and research outputs.

Three authors (CDL, AB and LB) independently extracted the data from the articles and placed them into the relevant theme sections. Following any discrepancies between authors in the categorisation of data, a decision was made within the team by consensus of all the authors. Once all the data were categorised by themes, two authors (CDL and AB) developed sub-themes. At the initial stage, 15 sub-themes were generated; following team discussion the number was reduced to 12, as some themes were consolidated and others did not address the research questions.

Identification and description of a model of good practice

Based on our quality appraisal, we identified the study with the highest overall score and provided detailed description of the stages of research where co-research occurred and the benefits and barriers, as identified by the authors.

Screening of current ID research protocols

Inclusion criteria

- The protocol was on research in Intellectual Disability. We therefore searched for the subject heading/key term “Intellectual disability” or “Learning disability”.
- The protocol reported on PPI. This was ascertained by searching for the following terms: PPI, Involve*, consult*, patient*, public, advis*.
- The protocol was published online on the NIHR Evaluation Trials and Studies (NETS), BioMed Central Psychiatry and/or BioMed Central Trials.
- A full text of the protocol was available
- Any year of publication.

We carried out our systematic search between September 2016 and October 2016. Upon selecting the relevant protocols, we ran a content analysis to identify themes related to PPI.

Results

Systematic review of the literature reporting co-research with adults with ID

The initial search retrieved 5,244 papers. Excluding duplicates and following title or abstract screening, we identified 68 papers. Two independent reviewers (CDL and LB) assessed the papers against the inclusion/exclusion criteria and excluded 55 papers, of which 36 focus on Patient and Public Involvement (PPI) but do not report on co-research, 7 include non-adult co-researchers, co-researchers without ID and/or it is not possible to isolate the experiences of those with ID, and 12 focus on adults with ID conducting research independently (i.e. without collaborating with academic researchers). 13 studies were selected for full review. The selection process is reported through a PRISMA 2009 Flow Diagram (Moher et al., 2009) in Figure 1.

[Figure 1 near here]

Quality appraisal of the studies

Results from our quality assessment are fully reported in table 1. In brief, the quality of the studies varied, but we did not exclude any study. The studies were found to have good quality in terms of: formulation of research questions (item 1); choice of the appropriate research methodology (item 2) and design (item 3); reporting on the relationship between researchers and participants (item 6); discussion of the findings (item 9); and implications for practice (item 10). We found it most challenging to attribute score to the quality of data analysis (item 8), which is indicative of the fact that many of the studies did not report their co-research methodology in detail. The highest number of "No's" (showing poorer quality) was recorded in relation to the recruitment strategy (item 4) and potential ethical issues (item 7).

[Table 1 near here]

Study characteristics

The main characteristics of the studies are reported in table 2. In brief, eight studies were conducted in the United Kingdom, three in Australia, one in the United States of America and one in New Zealand. Twelve studies involved only adults with ID as co-researchers and one was a mixed group of co-researchers with ID and mental health service users.

The number of co-researchers varied greatly across studies, ranging from one to 187. In two studies this information was not reported. The experience of co-researchers was discussed in nine studies, while in four cases the study explored solely the views of the academic researchers.

The studies also varied in terms of design, aims and objectives. One was a feasibility study testing training for co-researchers (Perry et al., 2004) while the remaining twelve were case reports on the experience of co-research. Of these, three studies were based on participatory action research (PAR)

(Stevenson, 2014; Conder et al., 2011; Kramer et al., 2011). PAR is defined as inquiry and action based on questions which are relevant to co-researchers (Reason & Bradbury, 2008) and appears to be one of the most often used design in PPI with adults with ID.

The production of research also varied substantially, from being mostly user-led (March et al., 1997), to being equally shared between the academic and co-researchers (Williams & Simons, 2005). In one instance, however, the academic researcher acted as the lead and elements of co-research were only present at certain stages of the research process (Stevenson, 2014). This was also reflected in the authorship of the materials for dissemination. In March et al. (1997), for example, the co-researchers acted as the sole authors of the paper, while in Strnadova et al. (2014), the responsibility was equally shared between academics and co-researchers.

[Table 2 near here]

Themes

1. Meeting the challenge: The barriers of co-research with adults with ID

1.1. Change of culture

One of the most common issues emerging from our review was the change of culture necessary to pursue ethical involvement of co-researchers (Strnadova et al., 2014). Traditionally, the control and power in research has been a stronghold of academics, who in light of their technical skills, have tended to see themselves as the repository of knowledge. To avoid a tokenistic type of involvement, academic researchers have had to abandon the idea of “exclusionism” in research and become aware that co-researchers may actively contribute not only to practical research tasks such as interviewing, but their input could be helpful even at the more abstract level, such as in theory development (Stevenson, 2014).

A change of culture may also be necessary among co-researchers, who may be within a culture that does not encourage independent thinking in people with ID and therefore may begin their involvement with a hierarchical mindset (Strnadova et al., 2014). This can present as a challenge, as one academic researcher reported:

“I am positive that we are providing maximum encouragement of their independence, self-determination, etc., but we just cannot expect that they will change overnight. The only way of being they know so far is being told what to do, when to do it and where. It will take time for them to take control in our research group and change this perspective” (Strnadova et al., 2014, p.18).

Here, the challenge lies in academic researchers acting as facilitators and champions to enable people with ID to feel and act as equal partners in research production. However, Williams (1999) warns on the ethical risks of the practice of “giving up” research power, contending that handing control over to co-researchers still places academics in a vertical relationship with co-researchers (Williams, 1999). Williams and Simons (2005) defines this risk as the “Paradox of empowerment” (p. 9) and call for a different strategy to make sure that co-researchers are on a par with academics, which consists in making them aware of the power they already possess when entering collaboration.

1.2. Extent of involvement and how full involvement is defined

Linked to the ethical challenges of co-research is the extent of involvement. Ideally, involvement should happen from the conception of the study, or even develop from people’s ideas about what is worth researching and should be consistent throughout the project (Strnadova et al., 2014). However, as it appears from our review, there were several issues that challenged the achievement of full involvement. For example, the presence of ID limited the ability of co-researchers to contribute effectively to more intellectually demanding research tasks, such as data analysis (Perry & Felce, 2004). However, if academic researchers implement effective strategies to enable co-researchers to take part in the process while ensuring the integrity of data analysis, these barriers can be overcome (O'Brien et al., 2014). As evidenced in all the included studies, academic researchers need to be flexible and open to discussion with co-researchers about their (changing) interests and wishes of involvement throughout the project (Burke et al., 2003).

1.3. Increased research costs

On the practical front, a challenge of involvement that emerged from our review was that budgetary constraints and research deadlines imposed by funding bodies are rarely reconciled with the demands of co-research, as conflicting schedules between academic and co-researchers may dilute the project's timeframe (Kramer et al., 2011). Similarly, creating the conditions necessary to work with adults with ID may, to a certain extent, increase research costs (Burke et al., 2003), but underfunding can also be an issue at times. Careful consideration of research costs including commensurate remuneration of co-researchers is a crucial step in pursuing high-quality involvement.

2. Adapting and accommodating: The facilitators of co-research with adults with ID

2.1. Recruitment

Findings from our review illustrate that involvement from the inception of the study is key to enable the co-researchers to be equal members of the research team, fully committed to the success of the venture. Motivation to be involved can be boosted through meetings where the academic team presents the research project and where potential co-researchers have a chance to appraise whether the project matches their interests (Grayson et al., 2013). These sessions are a valuable opportunity to make co-researchers aware of the role they will have in the research team and discuss the potential benefits and challenges of involvement (Burke et al., 2003).

This is also an opportunity for the academic team to recruit co-researchers. Few papers reported using selection criteria when recruiting co-researchers. However, Williams and Simons (2005) state that simply being a person with ID or having previous research experience does not qualify someone to be able to work as a co-researcher. Crucial to the success of the co-research initiative are factors such as motivation, a genuine interest in the project, full commitment, and the ability of the person to relate with the research team and others (Williams & Simons, 2005).

2.2. Research training

Training of co-researchers was reported to be of great importance in all the reviewed articles and it was offered in all studies by the academic researchers. Some elements of the training sessions aimed to develop technical skills such as dealing with information sheets and consent forms, operating tape-recorders, taking notes and conducting interviews (March et al., 1997), while others focused on developing relational skills, such as learning how to be a good listener or how to relate to people with different background (O'Brien et al., 2014).

The format of the training sessions depends on the stage of research at which collaboration occurs and on the needs of co-researchers (Chapman, 2014). It is reported to be good practice to adopt training techniques that make use of user-friendly material, such as those described in the account of one co-researcher:

“We did it in ways that people can understand. A lot of people can't understand writing…We've done a lot of talking and Paula (the academic researcher) wrote what we said and drew pictures. We had words on bits of paper and pulled them out of a hat to talk about them. We stuck up stickers on posters” (March et al., 1997, p. 77).

There are multiple benefits of research training: For the newly recruited co-researchers, it was an opportunity to understand the project and build up research skills through on-the-job training (Butler et al., 2012). In addition, the training sessions were seen as helpful in creating cohesion within team members and in developing a relationship based on trust, which is considered necessary for effective teamwork (Strnadova et al., 2014). The importance of team time together, even outside of research time, was emphasised in several studies (Strnadova et al., 2014). Out-of-research activities include informal chats, such as discussions pre and post-research sessions (Strnadova et al., 2014). These off-the-record meetings represent an opportunity for co-researchers to share their feelings around their involvement and for academic researchers to develop a deeper understanding of the experience of living with ID (Strnadova et al., 2014).

2.3. Research roles

Another fundamental element of successful co-research is defining the role of researchers and support workers within the research team (Conder et al., 2011; Butler et al., 2012). In all of the papers, the academic researcher’s role was to be supportive but never intrusive or patronising toward the co-researchers, who always took the lead during the process. Research roles however, were never fixed and would inevitably change over time, as co-researchers gradually became more confident in their skills (Williams, 1999). For this reason, it was reported that a good quality of the academic researcher should be to show flexibility and adapt to the changes of circumstances (March et al., 1997).

Research roles should also be negotiated for support workers, whose assistance may be needed during the research sessions alongside the co-researcher (Burke et al., 2003). The added challenge here is to try and minimise the support workers' input as much as possible, as they may form a pattern to speak on behalf of the person with ID (Burke et al., 2003).

Also, key to successful co-research relationships is the ability to grasp the extent to which the co-researcher wishes to be involved, as some adults with ID do not necessarily want or are able to engage in all of the research tasks. For example, March et al. (1997) reported that during involvement, the co-researchers expressed that they did not wish to lead interview sessions, as highlighted in the following statement by a co-researcher:

"There are times when we felt angry, sad or upset. Sometimes it was hard to understand. We felt a bit nervous and shy and we didn't want to do the interviewing. But we think that's OK. People should be able to do whatever parts they can" (March et al., 1997, p. 79).

A successful approach was reported as one that avoided defining roles a priori and which was flexible enough to consider the individual wishes and the potential of single co-researchers to contribute effectively to the process in a number of different ways (Conder et al., 2011).

2.4. Good Planning

Co-researching with adults with ID comes with added practicalities that need careful consideration. For instance, the venue (i.e. the research base) where research activity takes place needs to be easily accessible for co-researchers (Burke et al., 2003). Time of travel and transport also play a major role in involvement and therefore scheduling team meetings well ahead of time could be helpful (Burke et al., 2003). Some co-researcher may need support to arrange travel or to organise for personal assistants to be present at research sessions (Grayson et al., 2013). Crucial, therefore, is getting the external support necessary to meet these challenges (O'Brien et al., 2014). Paid or family carers of co-researchers need to support the co-researcher's involvement to ensure that these issues are effectively managed (Burke et al., 2003). For example, attention should be given to keeping the carers well-informed about how involvement is proceeding.

Ensuring the mental and physical wellbeing of all those involved in research is good practice (Grayson et al., 2013). During the research process, especially when there is direct interaction between co-researchers and participants, there may arise the need for psychological support, which should always be offered. Salary for co-researchers is another theme discussed in two of the papers. Adequate financial remuneration is a way of showing co-researchers they are equals in research and therefore it should be budgeted for in research planning (Williams, 1999). An issue that has emerged in a minority of studies was that being paid a salary may not be compatible with disability benefits (Butler et al., 2012).

2.5. Working with people with cognitive impairment

Adults with ID may experience memory problems, difficulties in expressive or receptive language or information processing, presenting a challenge to the academic researcher to find meaningful and effective ways of working which meet the needs of co-researchers. Among the most common strategies used were visual aids such as coloured arrows or laminated cards to aid co-researchers during the administration of interview questions (Perry & Felce, 2004). All of the studies in our review used strategies that responded to the needs of the specific population of co-researchers and to the stage of research where involvement occurred. In general, academic researchers put great emphasis on being able to capture the non-verbal cues of co-researchers as these may point to the co-researcher feeling overwhelmed or stressed or not knowing how to manage the interviews (O'Brien et al., 2014).

3. Making a difference: The benefits of co-research with adults with ID

3.1. Benefits for co-researchers

All the studies reported on the benefits for co-researchers. In the area of personal development, taking part as equal partners in the research process and dissemination may help co-researchers feel empowered and in control (March et al., 1997). As one co-researcher reported:

“I think my power started up when talking in conferences and to people, and that’s what has given me more power and strength” (Williams & Simons, 2005, p. 11).

Co-researchers may develop a more assertive attitude in expressing their views and a sense of pride and accomplishment by having their voices heard in a professional context (Kramer et al., 2011):

“I usually need support with writing, but my articles have made me feel that my message has got across, and it’s been accepted” (Williams & Simons, 2005, p.11).

Butler et al. (2012) argued that empowerment was reflected in co-researchers becoming role models and advocates for their peers. The notion of giving back to the community was emphasised by a co-researcher who reported:

“I would like people to have a better life style, to know their rights in life. (…) We need to find out more about people with disabilities lives so that we are able to help them” (Strnadova et al., 2014, 18).

In terms of professional development, the skills developed during co-research can be transferred and used for future employment opportunities or in daily living (Conder et al., 2011). In relation to the social opportunity offered by involvement, the studies reported that working in the academic environment may give co-researchers the possibility to extent their social and support network (Grayson et al., 2013).

3.2. Benefits for academic researchers

Collaboration can benefit the academic researchers too. Commonly reported was the change of expectations and assumptions on how to conduct research with adults with ID (Butler et al., 2012;

Chapman, 2014). Academic researchers appeared challenged in their ideas about research roles, as they became aware that each co-researcher brought their own strengths and added value to the project (Chapman, 2014):

"In working together, the team soon recognized that each of us had different strengths and could assist one another in many different ways" (Chapman, 2014, p. 52).

Another common experience was the change of attitude toward co-researchers. The academic researchers frequently reported that as involvement progressed, they understood that the process of learning through co-research was mutual and that much can be learned from individuals who have invaluable lived experience (Chapman, 2014).

3.3. Benefits for participants

The participants to the study can also benefit from having their peers involved in research, in particular when there is face-to-face interaction, such as in focus groups or interviews. In the presence of their peers, participants seemed to feel more at ease (Butler et al., 2012). Being in front of people who have the same condition may help to create a bond of trust from the outset, allowing participants to open up more easily about their experience (O'Brien et al., 2014), as they may feel that their difficulties can be better understood (Butler et al., 2012). Co-researchers may also represent successful role models to participants who may be supported in challenging their assumptions about their condition, as illustrated by the following exchange between a co-researcher and a participant with ID:

"When I was younger, my doctor said to me you can't do this, you can't do that, you haven't got the personality, you haven't got the brain. You have got the brain. You can do what you want to do, and you can find a pen pal. Don't listen to other people. Do what you want to do" (Strnadova et al., 2014, pp. 19-20).

In those instances, when the participants had severe impairment and experienced difficulties in understanding the interview questions, the co-researchers could help them by reformulating difficult statements in a more appropriate language (Strnadova et al., 2014), making the experience of being research participant less demanding or daunting. As reported by a co-researcher:

"…if somebody with a learning difficulty doesn't understand what you're talking about and saying, they can …ask you to describe that word and what it means" (Williams & Simons, 2005, 11).

3.4. Benefits for the research project

Having co-researchers with lived experience of the condition, their expertise can benefit all stages of research (March et al., 1997). For example, when developing the interview protocol, co-researchers may help to tailor the questions so they can be user-friendly, concrete, specific and relevant for participants (Strnadova et al., 2014). For example, during the design of qualitative questionnaires investigating participants' experience of support carers, a co-researcher, as described through the words of the academic researcher:

"...added the question 'Do your carers change often?' which is an example of her using her own experience and expertise to assist in the design of the interview instrument" (Strnadova et al., 2014, 19).

In data analysis, co-researchers may come up with unique insight and ideas that may contribute to research outputs (Chapman, 2014). The added value of involvement can also be reflected in the dissemination of findings, as co-researchers can ensure that findings are reported in a concise, accessible and audience-specific format (O'Brien et al., 2014).

Identification and description of a model of good practice

The study by O'Brien et al. (2014) was the only one totaling the highest possible quality score. We developed a vignette to summarise the strategy that the authors adopted to undertake co-research, and the benefits and barriers that they encountered during the process (Fig. 2).

[Fig. 2 near here]

Screening of current ID research protocols

Our search on the databases yielded 985 results. Upon title screening, we dismissed 957 results, as these were not eligible for various reasons (e.g. not related to health and social care sciences, not specifically around ID, protocol not available/accessible, several duplicates). We screened a total number of 28 protocols, twelve of which engaged in and reported on PPI (42.8%) (Table 3)

[Table 3 near here]

Through our content analysis of these protocols, we identified four themes related to PPI:

1. Type.
2. Aims and objectives.
3. Stakeholders involved.
4. Facilitators.

Type

In relation to the type of PPI, five studies made use of consultation/reference groups and two of advisory groups. In three cases, PPI members acted as equal partners in collaboration and production of research and in two as co-researchers conducting interviews alongside academics.

Aims and objectives

The aims and objectives of PPI varied extensively among different projects and often reflected the type of PPI. For consultation, the aim was to gather feedback on the overall project to ensure its appropriateness, accessibility and sensitivity or on specific aspects of research including the study protocol, information sheets, consent forms and questionnaires.

In the case of advisory groups, PPI members were asked to advise on relevant study outcomes. A more collaborative stance was adopted in co-production, in which they were involved alongside the team academic team in developing accessible materials, including instruments, patient information sheets, consent forms, project webpages and dissemination materials.

In co-research, PPI members acted as equal partners of academic researchers, administering qualitative interviews to their own peers.

Stakeholders involved

The stakeholders' groups included people with ID, carers and the general public. People with ID were involved either as independent individuals collaborating directly with the academic team (n=3) or as a group of people with ID from established third sector organisations/networks (n=9), usually liaising with the academic team through a representative/facilitator. The carers were involved in eight projects and were usually a parent/guardian of the person with ID. The general public was involved in two projects.

Facilitators

Given the practical challenges of PPI, the authors reported several strategies to facilitate the process, including the development of user-friendly material, the delivery of research skills training and the discussion of roles and responsibilities within the research team. They also rely on the support of third sector organisations, which often serve as mediators between the academic team and PPI members and of members of the academic team with expertise in PPI, who acted as mentor/point of reference throughout involvement.

Discussion

The aim of our review was to gather the existing evidence-base on co-research with adults with ID and by describing a model of good practice in health and social care co-research, to derive guiding principles for researchers and professionals wishing to undertake PPI whilst setting up and carrying out a research project. We further aimed to examine the protocols of current ID research projects to report on whether, and if so, how PPI is carried out. Our work is novel and adds to the current understanding of co-research in ID, for several reasons. It represents the first systematic review of the literature around co-research with people with ID. Given the highly-standardised procedure we adopted (PRISMA), our work expands on the existing key groundwork undertaken by others and contributes to the development and advancement of evidence-based practice for undertaking co-research with adults with ID. In addition, our work represents the first investigation around the extent of PPI in current published research protocols in ID research and how it has been carried out. We deem such investigation relevant, at a time when health research funders are increasingly expecting evidence of PPI.

In relation to our findings, we conclude that co-research with adults with ID is clearly becoming an essential element of research in social and health sciences and increasingly, adults with ID are included as active members of the research team, carrying out various tasks during the research process. Results from our screening of the current ID research protocols however, evidenced that much remains to be accomplished. Less than half of the protocols reported PPI (42.8%) and in several instances, involvement only occurred for consultative/advisory purposes. Overall, the more extensive/challenging the involvement, the fewer the examples we retrieved. Co-research was carried out in two instances (7.1%). We therefore advocate that PPI be carried out more systematically, in compliance with current NIHR policy and in light of the added value of PPI evidenced in our review.

The most valid example of good practice identified through our quality appraisal scoring system was the model by O'Brien et al. (2014). The excellent elements of this model are reflected in the inclusion of co-researchers in the project advisory team and in the dissemination of findings, to ensure that they had real control over the whole research process.

O'Brien et al. (2014) also crucially understood the relevance of including carers as facilitators of involvement and acknowledged the diversity of adults with ID, which was echoed in an accurate process of selection of co-researchers. In line with our findings on good practice, the academic team also provided practical, concrete and focused-on-research training, supplemented by the use of inclusive materials to aid data collection and analysis and adopted a flexible approach in offering support, based on the co-researchers' needs.

O'Brien et al.'s (2014) model generated similar benefits to those reported in other social health care research areas, such as with mental health service users (Pinfold et al., 2015) (see also McPin foundation: http://mcpin.org/) and people with dementia (Di Lorito et al., 2017). These include the development of user-friendly research design, service-user informed perspective on research data and the identification of relevant research questions for the stakeholders (see http://www.jla.nihr.ac.uk/ for examples of Priority Setting Partnerships [PSP] between patients, carers and clinicians).

The model was characterised by some limitations, which we wish to highlight to the benefits of researchers and professionals wishing to engage in effective co-research. For example, the strategies adopted for data collection and analysis are hardly applicable to quantitative research, requiring the development of alternative plans of action to ensure full inclusion of adults with ID in different research methodologies. Another barrier pertained to the inclusion of carers, who often adopted patronising/gate-keeping attitudes toward the co-researcher with ID they cared for. Unfortunately, gate-keeping behaviours often extended to third sector organisations/groups, which should assist in recruiting co-researchers. Finally, O'Brien's model failed to envision a post-involvement plan responding to the question "Now what?". In order to maximise the impact of co-research, we advocate that full involvement should not end in itself, but should aim to generate change, long after co-research is over.

Limitations of review

Our review has limitations, mainly due to the characteristics and quality of the studies we included. A limitation, evidenced through the CASP checklist, relates to what Young-Southward et al. (2016) have defined as 'functional status confounding results', in that results may be unrepresentative of the general population, given the recruitment of high functioning individuals with ID to be involved as co-researchers. Apart from exceptions (see O'Brien's model above), many of the co-researchers had previous work experience of research in an academic context and their experiences may not reflect the real challenges of co-research with the general (and less experienced) population of adults with ID.

The unrepresentativeness of the sample is also reflected in the exclusion of adults with more severe ID from the activity of co-research. Although this is partly justifiable in terms of feasibility of the process, we argue that given the broad spectrum of IDs, it is crucial to involve a more diverse and representative sample of co-researchers. There are various techniques to include service users with severe ID in co-production. For example, Bunning et al. (2016) have developed through co-research Talking Mats® to gather the views of people with severe ID on television viewing.

Another limitation relates to potential ethical issues due to report bias in the samples. Four studies only focused on the accounts of the academic researchers rather than that of the co-researchers. McIntyre et al. (2004) argues that proxy reporting for people with ID in relation to subjective experiences is unacceptable. Similarly, we argue that in order to investigate thoroughly the positive impact of a subjective experience such as that of working as a co-researcher, it is essential to listen to the voices of the people with ID.

Traditionally, in research with vulnerable populations, it is academics who have decided research outcomes and how to assess impact (Bartlett, 2014). We argue that instead the study outcomes should be assessed against the views of people with ID, whose lives are directly affected by research. In the UK, Patient Reported Outcome Measures (PROMS), which are health outcomes valued by patients and proxy measures of quality of care, are widely used within the National Health Service (NHS) as a means to ensure that the services provided are patient-centred.

Similar strategies are emerging in health and social care research. For example, in Participatory Action Research (PAR), individuals with ID generate research questions and “action” these through a collaborative effort with academic researchers to find evidence-based solutions to things that matter in their lives (Stack & McDonald, 2014). It has been evidenced that people with ID have clear ideas on research goals (Wiliams et al., 2008). The academic researcher’s role is to provide support to turn these ideas into a scientific process which leads to achieving goals.

Conclusion

In conclusion, our findings confirm that living with an ID does not necessarily prevent adults from effectively contributing to research outputs. However, the benefits that co-research can generate do not simply occur during the process. They require extensive work prior to and throughout the research process in order to create a solid “architecture of involvement” which will maximise and optimise the input of co-researchers (Brett et al., 2010). This architecture includes adequate consideration of crucial practical aspects such as detailed pre-planning, training of co-researchers in research and team working (potentially from people with ID who have themselves been co-researchers), flexibility and problem solving within the research team to accommodate the unique needs of working adults with ID.

These practical aspects of good practice should be accompanied by ethical considerations, which we believe are crucial in co-research with adults with ID, who have been traditionally stigmatised and excluded from research. These elements include striving for equality within the research team, avoiding tokenistic involvement, respecting the autonomy of co-researchers, and safeguarding their dignity.

Co-researchers with ID can potentially bring added value to research through the unique stand point of lived experience. Pursuing good practice in involving adults with ID in the research process represents an essential step forward in the pursuit of empowerment and self-agency for people with ID. As emphasised by Martin (2006):

"…There is a way forward that things can change. Our future is tied to one word, to one concept, and that is inclusion" (p. 127).

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Table 1. Study quality assessment through the CASP checklist

Articles reviewed	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Chapman (2014)	Yes	Yes	Yes	Yes	Can’t tell	Yes	Yes	Can’t tell	Yes	No
Stevenson (2014)	Yes	Yes	Yes	No	Yes	Yes	Yes	Can’t tell	Yes	Yes
Strnadova et al. (2014)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can’t tell	Yes	No
O’Brien et al. (2014)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Butler et al. (2012)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
Grayson et al. (2013)	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Yes	Yes	Yes
Conder et al. (2011)	Yes	Yes	Yes	No	Yes	Can’t tell	No	Can’t tell	Yes	Yes
Kramer et al. (2011)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Williams & Simons (2005)	Yes	Yes	Yes	No	Yes	Yes	No	Yes	Yes	Yes
Perry et al. (2004)	Yes	Yes	Yes	No	Yes	Yes	No	Yes	Yes	Yes
Burke et al. (2003)	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Yes	Yes	Yes
Williams (1999)	Yes	Yes	Yes	Can’t tell	Can’t tell	Yes	Can’t tell	Can’t tell	Yes	Yes
March et al. (1997)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can’t tell	Yes	Yes

Legend

1. Was there a clear statement of the aims of the research?

2. Is a qualitative methodology appropriate?

3. Was the research design appropriate to address the aims of the research?

4. Was the recruitment strategy appropriate to the aims of the research?

5. Was the data collected in a way that addressed the research issue?

6. Has the relationship between researcher and participants been adequately considered?

7. Have ethical issues been taken into consideration?

8. Was the data analysis sufficiently rigorous?

9. Is there a clear statement of findings?

10. How valuable is the research?

Table 2. Articles selected for review

Author	**Year**	**Country**	**Population of co-researchers**	**Study design**	**Methodology**	**N. of co-researchers with ID**	**Stages of research where involvement occurred**	**Does study report views of co-researchers?**
Chapman	2014	United Kingdom	Adults with ID	Case report (discussion on an inclusive team approach to research)	Semi-structured interviews, observations and focus group sessions	5	Carried out interview, observations, focus groups, qualitative data analysis.	Yes
Stevenson	2014	Australia	Adults with ID	Case report (discussion on data from participatory action research project)	Qualitative interviews	3	Carried out qualitative data analysis, writing of report	Yes
Strnadova et al.	2014	Australia	Adults with ID	Case report (discussion on an inclusive team approach to research)	Video-recordings and personal diaries	4	Research planning and training sessions.	Yes
O'Brien et al.	2014	Australia	Adults with ID	Case report (discussion on research experience of a community of practice)	Focus groups sessions guided by semi-structured questions	187	Carried out focus groups, development of questionnaire, qualitative data analysis, dissemination of findings	No

Grayson et al.	2013	United Kingdom	Adults with ID and mental health service users	Case report (discussion on experience of research involving service users and carer-researchers	Qualitative interviews	6 (including carers)	Carried out qualitative interviews	Yes
Butler et al.	2012	United Kingdom	Adults with ID	Case report (discussion on an inclusive team conducting focus groups)	Focus groups through structured questionnaire	2	Carried out focus groups, qualitative data analysis, writing of report	Yes
Conder et al.	2011	New Zealand	Adults with ID	Case report (discussion on a participatory action research)	Field notes and written report	Not reported	Carried out focus groups, development of questionnaire, data collection, data entry, writing of report	Yes
Kramer et al.	2011	United States of America	Adults with ID	Case report (discussion on a participatory action research)	Field notes and observations	17	Carried out quantitative data analysis	Yes
Williams & Simons	2005	United Kingdom	Adults with ID	Case report (academic researcher's discussion on working with co-researchers)	Reflexive observations of authors	3	Setting the agenda, data collection, qualitative data analysis	No

Perry et al.	2004	United Kingdom	Adults with ID	Feasibility study on training a co-researcher to conduct interviews	Testing of inter-rater reliability, response bias consistency, test-re-test reliability and consistency of responses of co-researcher against academic researcher	1	Carried out qualitative interviews	No
Burke et al.	2003	United Kingdom	Adults with ID	Case report (discussion on the initial stages of inclusive research)	Reflexive observations of authors	25 (including support workers)	Carried out literature review, planned qualitative interviews.	No
Williams	1999	United Kingdom	Adults with ID	Case report (discussion on co-researchers carrying out group interviews)	Reflexive observations of authors	Not reported	Setting the agenda, qualitative interviews, data analysis	Yes
March et al.	1997	United Kingdom	Adults with ID	Case report (discussion on experience of co-researchers of doing research)	Authors' notes and pictures	3	Developing the questions of the qualitative interviews.	Yes

Table 3. Protocols selected for screening of PPI in current ID research

Title of study	Type of PPI	Aims/objective of PPI	Stakeholders group involved	Facilitators	Recurrence of PPI
Outcomes from forensic services for people with intellectual and/or developmental disabilities: evidence synthesis and expert and patient consultation	Consultative	Identify relevant outcomes	Service users and carers	Easy-read materials	-
Clinical and cost effectiveness of staff training in Positive Behaviour Support (PBS) for treating challenging behaviour among people with learning disability: a multicentre cluster randomised controlled trial	Collaborative	• Develop accessible research materials • Develop topic guide • Recruitment • Feedback on project and ethics • Study progress and dissemination	Service users and carers	Use of facilitators to mediate between PPI group and researchers	• Throughout the study • Consulted every three months
An Evaluation of the Effectiveness of Annual Health Checks and Quality of Health Care for Adults with Learning Disability	Consultative	• Inform choice of outcome measures • Develop ideas for analysis • Interpret findings • Develop recommendations	Service users	-	Consulted every three months
Identifying the factors affecting the implementation of strategies to promote a safer environment for patients with learning disabilities in	Co-research	• Ensure appropriateness of data collection • Develop user-friendly tools	Service users and carers	• Research training • Support from academic researcher	-

NHS hospitals: a mixed-methods study		• Conduct interviews and data analysis		during administration of interviews	
Pay More Attention: A national mixed methods study to identify the barriers and facilitators to ensuring equal access to high quality hospital care and services for children and young people with and without learning disability and their families	Consultative and advisory	• Ensure appropriateness of all phases of research	Service users and carers	• Training in roles and responsibility of being in advisory panel • Mentorship and support available	-
Managing with Learning Disability and Diabetes	Consultative	Provide input in research materials	Service users and carers	Involvement of third sector organisations to mediate between PPI group and researchers	Consulted every three months
Guided self-help for depression in adults with autism spectrum disorders	Advisory	• Ensure representativeness of views of people with severe ID • Advise on phases of research • Identify relevant outcomes	Service users, carers and general public	Involvement of third sector organisations to mediate between PPI group and researchers	Consulted every three months

Extended brief intervention to address alcohol misuse in people with mild to moderate intellectual disabilities living in the community (EBI-ID): study protocol for a randomised controlled trial	Co-research	• Development of research materials • Conducting interviews • Interpretation of interviews • Write up of findings • Dissemination	Service users and carers	• Research training • Support from academic researcher during administration of interviews	-
Supported self-management for adults with type 2 diabetes and a learning disability (OK-Diabetes): study protocol for a randomised controlled feasibility trial	Co-research	• Selecting information materials • Testing data collection forms • Developing protocol	Service users	-	-
Wordless intervention for epilepsy in learning disabilities (WIELD): study protocol for a randomized controlled feasibility trial	Consultative	• Reviewing research material	Service users, carers and general public	-	-
Piloting a manualised weight management programme (Shape Up-LD) for overweight and obese persons with mild-moderate learning disabilities: study protocol for a pilot randomised controlled trial	Collaborative	• Development of research material	Service users	-	-

Appendix

ASSIA

1. “Cognitive impair*” or “Learning disabilit*” or “Intellectual disabilit*” or “autis*” or “learning difficult*”
2. “Co-research*” or “Peer-research*” or “Participatory research” or “Involv*”
3. 1 and 2

PsycINFO

1. exp Learning Disabilities
2. exp Cognitive Impairment/
3. exp Intellectual Development Disorder/ or exp Autism/
4. "autism spectrum disorder*".ti,ab.
5. ("cognitive impairment*" or "learning disabilit*" or "intellectual disabilit*" or autis*).ti,ab.
6. 1 or 2 or 3 or 4 or 5
7. "participatory research".ti,ab.
8. "user research".ti,ab.
9. ("co-research*" or "co research*" or "peer-research*" or "peer research*").ti,ab.
10. exp Involvement/
11. exp "Communities of Practice"/
12. exp Participation/
13. "participatory research".ti,ab.
14. ("involving people" or "involvement of people" or "user-involvement" or "involving users" or "involvement of users").ti,ab.
15. "as researchers".ti,ab.
16. exp Collaboration/
17. 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15
18. 6 or 16
19. limit 17 to (english and yr="1996 -Current")

Medline

1. exp Learning Disabilities/ or exp Intellectual Development Disorder/
2. "autism spectrum disorder*".ti,ab.
3. ("cognitive impairment*" or "learning disabilit*" or "intellectual disabilit*" or autis*).ti,ab.
4. "learning difficult*".ti,ab.
5. Exp Mild Cognitive Impairment/
6. Exp Autism
7. "participatory research".ti,ab.
8. "user research".ti,ab.
9. ("co-research*" or "co research*" or "peer-research*" or "peer research*").ti,ab.
10. ("involving people" or "involvement of people" or "user-involvement" or "involving users" or "involvement of users").ti,ab.
11. exp Collaboration/
12. "doing research".ti,ab.
13. 3 or 4 or 5 or 6 or 8 or 10
14. 13 and 14
15. limit 15 to (English and yr=”1996- Current”)