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**Co-research with adults with Intellectual Disability:
A systematic review**

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66 **Running head:** Review on co-research with adults with ID
67

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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 in social and health care research.

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.

105 **Introduction**

106
107 Intellectual disability (ID) is the most common developmental disability, currently affecting 1 to 3%
108 of the population worldwide (Maulik et al., 2011; WHO, 2007). Various terminologies are used to
109 identify ID, including learning disability, learning difficulty, intellectual disability/developmental
110 disorder, developmental/cognitive delay and mental retardation (WHO, 2007). However, the
111 diagnostic criteria all include significant impairment in the conceptual (e.g. language, reasoning,
112 memory), social (e.g. empathy, communication) and practical (e.g. personal care, money
113 management) domains of the individual (American Psychiatric Association, 2013).

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

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

133 From the early 2000s, researchers working in the social and health care sectors in the United Kingdom
134 started to acknowledge the added value of the lived experience of people with ID (Ward et al., 2012;
135 Williamson et al., 2010; Clough et al., 2006; Miller et al., 2006; Reed et al., 2006; Warren & Cook,
136 2005). This was also reflected at the international level, with a proliferation of studies grounded in
137 principles of inclusive research, particularly in Australia, New Zealand, Ireland, Canada, and the
138 United States of America, where partnership in research with service users was most valued
139 (Walmsley & Johnson, 2003).

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

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

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

155 More recently, the National Institute for Health Research (NIHR) has made it mandatory that each
156 research application should include details of Patient and Public Involvement (PPI) (NIHR, 2014).

157 This initiative also applies to research in ID. PPI has several tiers, ranging from advisory roles - such
158 as commenting whether research questions are relevant to particular population groups and disease

159 categories or advising on research materials and study promotion - to more active participation in the
160 research process, under the umbrella term “Inclusive research”, which translates into different
161 methodologies (Nind, 2017).

162 Methodologies badged as inclusive research include Participatory Research, in which people with ID
163 collaborate with academic researchers in planning and conducting research that investigates their own
164 experience (Bergold & Thomas, 2012). In Action Research, the insight generated through
165 participatory research works towards the change of social reality. Co-research (also known as peer-
166 research) is defined as research carried out ‘with’ or ‘by’ members of the public/patients rather than
167 ‘to’, ‘about’ or ‘for’ them (INVOLVE, 2015). In co-research, people with ID collaborate with
168 academics to investigate the experience of their own peers (people with ID) (Staley, 2009; Frankham,
169 2009; Repper et al., 2007; Turner & Beresford, 2005).

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

175 **There have been advancements in the establishment and practice of PPI, including systematic**
176 **reporting around co-research with other vulnerable individuals, such as people with dementia (Di**
177 **Lorito et al., 2017). However, it appears there has been no systematic review or synthesis of the**
178 **international literature around co-research with adults with ID.** Several books have provided
179 information around the process of doing and experiencing co-research in ID (Nind, 2014; Walmsley
180 & Johnson, 2003). In order to draw together understanding about practice in the UK, Nind & Vinha
181 have carried out a focus group study with inclusive researchers in the intellectual disability field (Nind
182 & Vinha, 2012) and produced a methodological report published by the National Centre for Research
183 Methods (Nind & Vinha, 2013). The report, which highlights the challenges the authors encountered
184 throughout all phases of the research process, provides useful insights into what is good practice in

185 co-research. The authors, however, concluded that if *'more of the methodological learning can be*
186 *brought together in resource documents like this review paper, it may be that inclusive researchers*
187 *are freed up to put more of their energies into creating substantial, substantive knowledge'* (Nind &
188 Vinha, 2013).

189 A systematic review with an international focus could be instrumental in expanding on the existing
190 resources available for researchers who are interested in undertaking co-research with adults with ID
191 in health and social care research. The benefits of systematic reviews as a method to further current
192 knowledge derive from their clearly formulated question, use of systematic and explicit methods and
193 criteria to identify, select, and critically appraise relevant literature (The Cochrane Collaboration,
194 2005) and standardised reporting systems [i.e. the PRISMA guidelines (Moher et al., 2009)]. We
195 therefore aim to systematically review the existing international literature reporting co-research with
196 adults with ID.

197 Our review questions are:

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

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

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

207 In addition, peer-review papers often take time to come to press and therefore the papers retrieved
208 through our systematic review are likely to report practice from previous years. As this is a rapidly
209 developing field of practice, a search of current protocols would provide more up-to-date information

210 of the status of PPI (and co-research) in ID. Our focus on PPI in protocols, rather than on co-research
211 only, is justified by the fact that the latter is still uncommon practice and a narrower search may
212 potentially yield very few results.

213 **Methods**

214

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

216

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

221 *Inclusion criteria*

222

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

236

237

238 *Exclusion criteria*

239

240 • The study focuses on Patient and Public Involvement (PPI) but does not report on co-research
241 (i.e. people with ID did not take on the role of co-researchers).

242 • The study includes non-adult co-researchers, co-researchers without ID and/or it is not
243 possible to isolate the experiences of those with ID.

244 • The study was carried out by people with ID or academic researchers independently (i.e.
245 without collaboration between the two groups).

246 *Search methods*

247

248 We carried out a systematic literature search on ASSIA, PsycInfo and MedLine between December
249 2015 and March 2016. In brief, we searched for and combined terms from two domains: (i) the
250 Intellectual Disability domain, including terms such as: Cognitive Impairment, Learning Disability,
251 Intellectual Disability, Autism and Learning Difficulty; (ii) the co-research domain, including terms
252 such as: Co-research, peer-research, participatory research and involvement (Appendix 1).

253

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

261

262 *Quality appraisal of the studies*

263

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

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

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

274
275 *Data extraction and analysis*

276
277 We extracted data onto NVivo 11 and adopted a deductive approach to thematic analysis (Braun &
278 Clarke, 2006), whereby the themes were based on our research questions. These were:

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

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

290 Identification and description of a model of good practice

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

294 Screening of current ID research protocols

295 *Inclusion criteria*

296

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

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

307 **Results**

308

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

310

311 The initial search retrieved 5,244 papers. Excluding duplicates and following title or abstract
312 screening, we identified 68 papers. Fifty-five papers were excluded, of which 36 focused on Patient
313 and Public Involvement (PPI) but did not report on co-research, 7 included non-adult co-researchers,
314 co-researchers without ID and/or it was not possible to isolate the experiences of those with ID, and
315 12 focused on adults with ID conducting research independently (i.e. without collaborating with
316 academic researchers). 13 studies were selected for full review. The selection process is reported
317 through a PRISMA 2009 Flow Diagram (Moher et al., 2009) in Figure 1.

318 [Figure 1 near here]

319 *Quality appraisal of the studies*

320

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

330 [Table 1 near here]

331 *Study characteristics*

332

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

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

340 The studies also varied in terms of design, aims and objectives. One was a feasibility study testing
341 training for co-researchers (Perry et al., 2004) while the remaining twelve were case reports on the
342 experience of co-research. Of these, three studies were based on participatory action research (PAR)
343 (Stevenson, 2014; Conder et al., 2011; Kramer et al., 2011). PAR is defined as inquiry and action

344 based on questions which are relevant to co-researchers (Reason & Bradbury, 2008) and appears to be
345 one of the most often used design in PPI with adults with ID.

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

353 [Table 2 near here]

354 *Themes*

355

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

357

358 1.1. Change of culture

359

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

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

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

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

383 1.2. Extent of involvement and how full involvement is defined

384

385 Linked to the ethical challenges of co-research is the extent of involvement. Ideally, involvement
386 should happen from the conception of the study, or even develop from people’s ideas about what is
387 worth researching and should be consistent throughout the project (Strnadova et al., 2014). However,
388 as it appears from our review, there were several issues that challenged the achievement of full
389 involvement. For example, the presence of ID limited the ability of co-researchers to contribute
390 effectively to more intellectually demanding research tasks, such as data analysis (Perry & Felce,
391 2004). However, if academic researchers implement effective strategies to enable co-researchers to
392 take part in the process while ensuring the integrity of data analysis, these barriers can be overcome
393 (O'Brien et al., 2014). As evidenced in all the included studies, academic researchers need to be
394 flexible and open to discussion with co-researchers about their (changing) interests and wishes of
395 involvement throughout the project (Burke et al., 2003).

396 1.3. Increased research costs

397

398 On the practical front, a challenge of involvement that emerged from our review was that budgetary
399 constraints and research deadlines imposed by funding bodies are rarely reconciled with the demands

400 of co-research, as conflicting schedules between academic and co-researchers may dilute the project's
401 timeframe (Kramer et al., 2011). Similarly, creating the conditions necessary to work with adults with
402 ID may, to a certain extent, increase research costs (Burke et al., 2003), but underfunding can also be
403 an issue at times. Careful consideration of research costs including commensurate remuneration of co-
404 researchers is a crucial step in pursuing high-quality involvement.

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

406

407 2.1. Recruitment

408

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

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

422 2.2. Research training

423

424 Training of co-researchers was reported to be of great importance in all the reviewed articles and it
425 was offered in all studies by the academic researchers. Some elements of the training sessions aimed
426 to develop technical skills such as dealing with information sheets and consent forms, operating tape-
427 recorders, taking notes and conducting interviews (March et al., 1997), while others focused on

428 developing relational skills, such as learning how to be a good listener or how to relate to people with
429 different background (O'Brien et al., 2014).

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

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

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

448 2.3. Research roles

449
450 Another fundamental element of successful co-research is defining the role of researchers and support
451 workers within the research team (Conder et al., 2011; Butler et al., 2012). In all of the papers, the
452 academic researcher's role was to be supportive but never intrusive or patronising toward the co-
453 researchers, who always took the lead during the process. Research roles however, were never fixed
454 and would inevitably change over time, as co-researchers gradually became more confident in their

455 skills (Williams, 1999). For this reason, it was reported that a good quality of the academic researcher
456 should be to show flexibility and adapt to the changes of circumstances (March et al., 1997).

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

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

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

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

472 2.4. Good Planning

473

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

481 researchers need to support the co-researcher's involvement to ensure that these issues are effectively
482 managed (Burke et al., 2003). For example, attention should be given to keeping the carers well-
483 informed about how involvement is proceeding.

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

492 2.5. Working with people with cognitive impairment

493
494 Adults with ID may experience memory problems, difficulties in expressive or receptive language or
495 information processing, presenting a challenge to the academic researcher to find meaningful and
496 effective ways of working which meet the needs of co-researchers. Among the most common
497 strategies used were visual aids such as coloured arrows or laminated cards to aid co-researchers
498 during the administration of interview questions (Perry & Felce, 2004). All of the studies in our
499 review used strategies that responded to the needs of the specific population of co-researchers and to
500 the stage of research where involvement occurred. In general, academic researchers put great
501 emphasis on being able to capture the non-verbal cues of co-researchers as these may point to the co-
502 researcher feeling overwhelmed or stressed or not knowing how to manage the interviews (O'Brien et
503 al., 2014).

504

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506

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

508

509 3.1. Benefits for co-researchers

510

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

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

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

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

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

523 *“I would like people to have a better life style, to know their rights in life. (...) We need to find out*
524 *more about people with disabilities lives so that we are able to help them”* (Strnadova et al., 2014,
525 18).

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

531

532 3.2. Benefits for academic researchers

533

534 Collaboration can benefit the academic researchers too. Commonly reported was the change of
535 expectations and assumptions on how to conduct research with adults with ID (Butler et al., 2012;
536 Chapman, 2014). Academic researchers appeared challenged in their ideas about research roles, as
537 they became aware that each co-researcher brought their own strengths and added value to the project
538 (Chapman, 2014):

539 *“In working together, the team soon recognized that each of us had different strengths and could*
540 *assist one another in many different ways”* (Chapman, 2014, pp. 52).

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

545 3.3. Benefits for participants

546

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

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

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

564 *“...if somebody with a learning difficulty doesn’t understand what you’re talking about and saying,*
565 *they can ...ask you to describe that word and what it means”* (Williams & Simons, 2005, 11).

566 3.4. Benefits for the research project

567

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

574 *“...added the question ‘Do your carers change often?’ which is an example of her using her own*
575 *experience and expertise to assist in the design of the interview instrument”* (Strnadova et al., 2014,
576 19).

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

581 Identification and description of a model of good practice

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

585 [Fig. 2 near here]

586 Screening of current ID research protocols

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

591 [Table 3 near here]

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

- 593 1. Type.
- 594 2. Aims and objectives.
- 595 3. Stakeholders involved.
- 596 4. Facilitators.

597 *Type*

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

601 *Aims and objectives*

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

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

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

612 *Stakeholders involved*

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

619 *Facilitators*

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

626 **Discussion**

627
628 The aim of our review was to gather the existing evidence-base on co-research with adults with ID
629 and by describing a model of good practice in health and social care co-research, to derive guiding
630 principles for researchers and professionals wishing to undertake PPI whilst setting up and carrying
631 out a research project. We further aimed to examine the protocols of current ID research projects to
632 report on whether, and if so, how PPI is carried out. Our work is novel and adds to the current
633 understanding of co-research in ID, for several reasons. It represents the first systematic review of the
634 literature around co-research with people with ID. Given the highly-standardised procedure we
635 adopted (PRISMA), our work expands on the existing key groundwork undertaken by others and
636 contributes to the development and advancement of evidence-based practice for undertaking co-

637 research with adults with ID. In addition, our work represents the first investigation around the extent
638 of PPI in current published research protocols in ID research and how it has been carried out. Our
639 work may be relevant at a time when social and health care research funders are increasingly
640 expecting evidence of PPI and user involvement in research is conceived of and carried out in many
641 different ways. In addition, ways in which previous studies have dealt with patient involvement in
642 research may be outdated and given the rapid developments in the area, we deem it timely to
643 synthesise the current evidence-base.

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

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

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

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

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

680 [Limitations of review](#)

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

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

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

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

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

712 Finally, in this review co-research was predominantly facilitated within research exploring health and
713 social care delivery. There is an opportunity to investigate whether the practice of co research with
714 adults with ID is supported in other research domains.

715 Conclusion

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

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

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

734 “...There is a way forward that things can change. Our future is tied to one word, to one concept, and
735 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? | 6. Has the relationship between researcher and participants been adequately considered? |
| 2. Is a qualitative methodology appropriate? | 7. Have ethical issues been taken into consideration? |
| 3. Was the research design appropriate to address the aims of the research? | 8. Was the data analysis sufficiently rigorous? |
| 4. Was the recruitment strategy appropriate to the aims of the research? | 9. Is there a clear statement of findings? |
| 5. Was the data collected in a way that addressed the research issue? | 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-retest 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Ensure appropriateness of data collection • Develop user-friendly tools 	Service users and carers	<ul style="list-style-type: none"> • Research training • Support from academic researcher 	-

NHS hospitals: a mixed-methods study		<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Ensure appropriateness of all phases of research 	Service users and carers	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Development of research materials • Conducting interviews • Interpretation of interviews • Write up of findings • Dissemination 	Service users and carers	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Development of research material 	Service users	-	-

Appendix 1

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")

Figure 1. Selection of papers for the systematic review of the literature reporting co-research with adults with ID

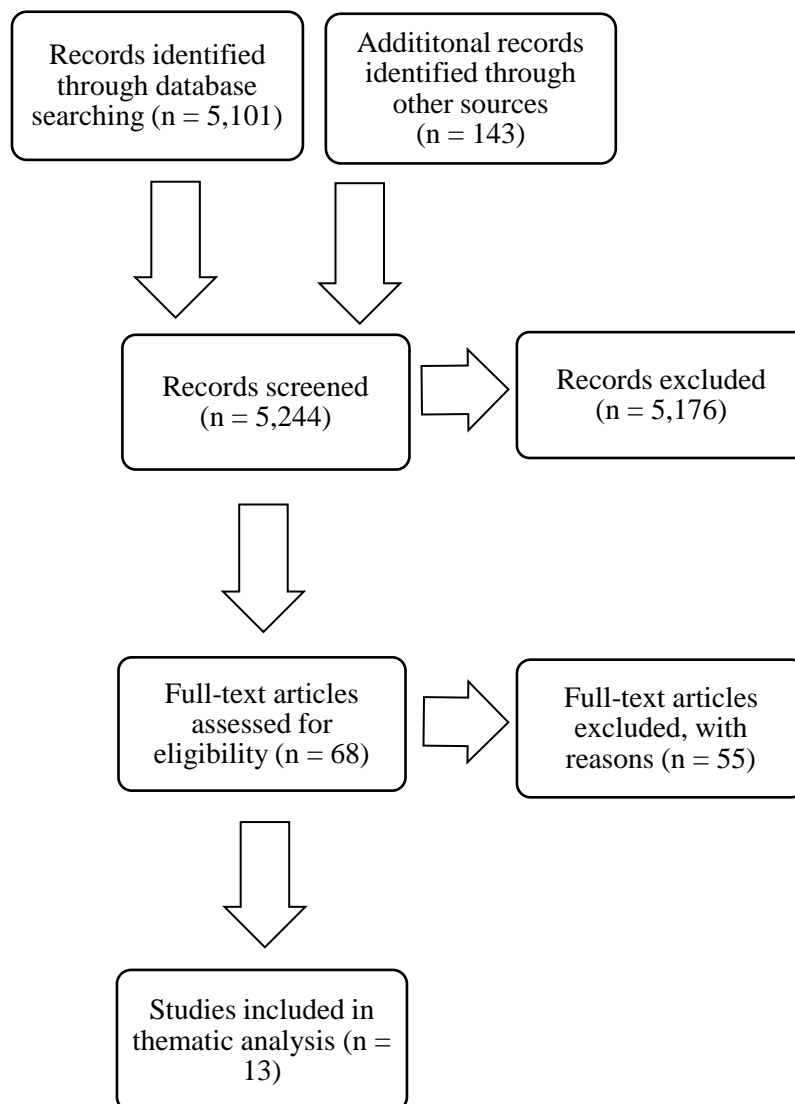
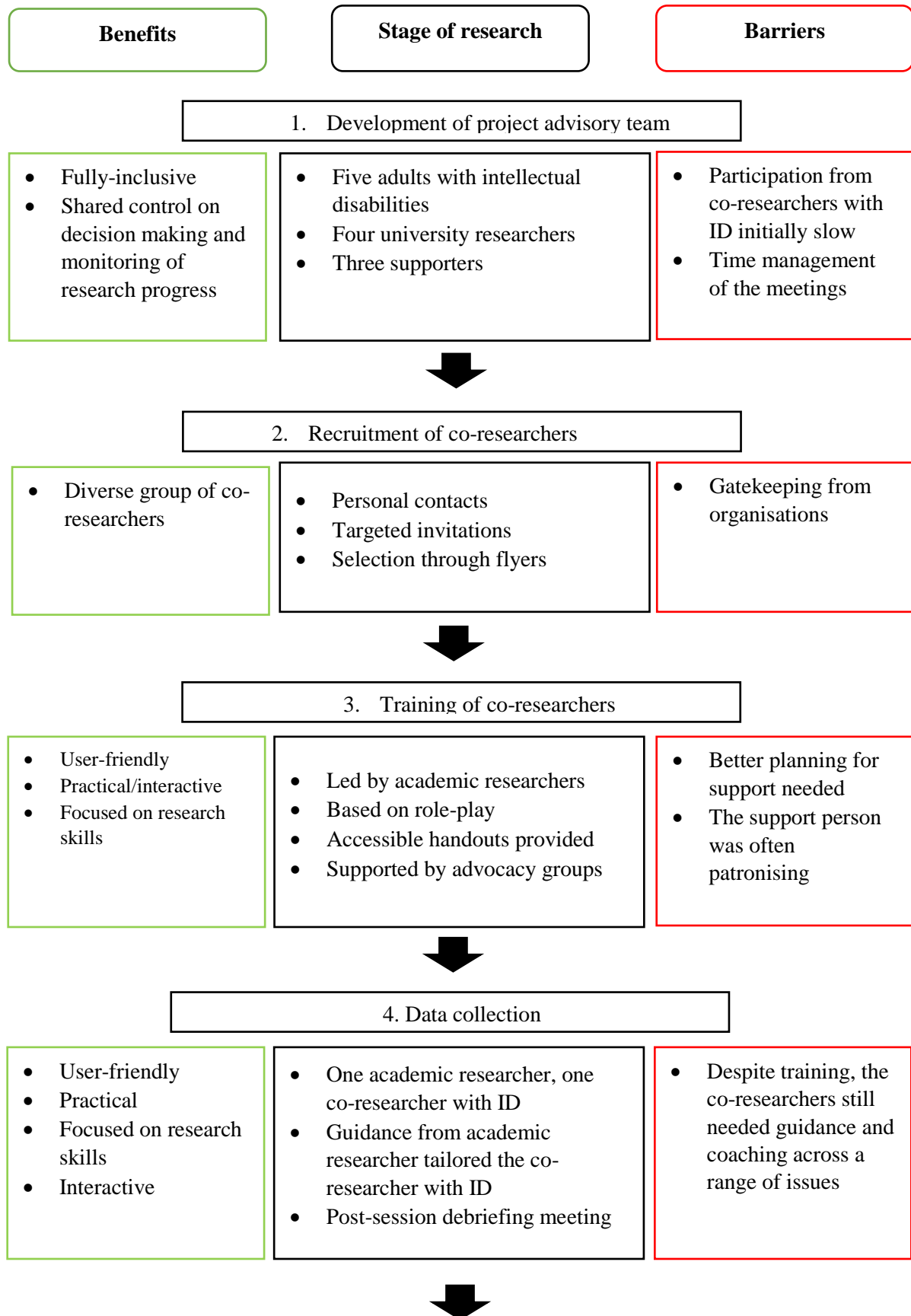


Figure 2. A model of qualitative co-researching with adults with ID (Adapted from work by O'Brien et al., 2014).





5. Data analysis

- Witnessing the selection of themes by the co-researcher with ID was further data source
- Visual materials made process accessible

- Transcription and generation of themes by academic researchers
- Refining of themes by co-researchers through a paper with a square in the middle in which to place the most important themes
- Subthemes rated by importance

- This strategy only applies to qualitative data analysis



6. Dissemination of findings

- Dissemination was relevant to people with ID
- Training effective to improve presentation skills of co-researchers with ID

- Drafts by academic researchers
- Advisory group edited drafts and prepared presentations
- Co-researchers with ID delivered presentations, following training

- Needed Further training to present
- Post-dissemination plan to bring about change not planned