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Identifying barriers and facilitators to the inclusion of older adults living in UK care homes in research: a scoping review

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Abstract (word count = 262)

Background With an ageing population, older adults will have more complex health and social care needs and many of these older adults will be living in care homes. Despite the growth in care home populations, care home residents are often excluded from research that could potentially benefit their care. The purpose of this scoping review is to explore resident-related barriers and facilitators to including older people living in UK care homes in research and to identify potential approaches to modify such barriers.

Method The 6-stage scoping review methodology framework proposed by Arksey and O'Malley guided this review. Five electronic databases (MedLine, PsychINFO, Scopus, Web of Science, CINAHL) and grey literature were searched. Identified articles went through two levels of screening, and those deemed relevant were collated, summarised and reported using a thematic analysis approach.

Results 90 reports were eligible for inclusion and, were synthesised into 7 themes and related subthemes: (1) research design; (2) understanding and beliefs about research (resident and care home staff); (3) communication; (4) relationships; (5) eligibility criteria (resident and care home); (6) preference-based decisions; and (7) care home staff and environment. Given the complex interplay of the factors identified, both direct and indirect factors were included.

41 **Conclusions** A number of recurring barriers and facilitators to the inclusion of care home
42 residents in research are reported. However, isolating resident-related barriers was complex as
43 both direct and indirect factors must be considered as influential. Understanding the barriers and
44 facilitators to inclusion will enable these factors to be addressed as increase the evidence-base for
45 care provided to older people living in care homes.

46

47 **Keywords** Care home, Residential home, Nursing home, Older Adults, Barriers, Facilitators,
48 Research, Inclusion, Participation, Scoping review

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66 **Introduction**

67 It has been estimated that by 2037, adults over the age of 65 will account for 24% of the
68 UK population [1]. There are already an estimated 490,326 care home residents in the UK [2-4].
69 As a result of the ageing population, many more older adults may require the level of support
70 provided by care homes [5].

71 Far less research is conducted in care homes compared to other healthcare settings,
72 despite twice as many people living in care homes as there are hospital beds in the UK [6-7].
73 Additionally, it has been reported that care home staff generally have less access to research
74 training and support [7]. Staff would likely benefit from the development of interventions to
75 support the creation of environments where opportunities for resident participation in research is
76 able to take place and can be integrated into care [7]. Research priorities in care homes have been
77 identified in previous research, including the need for better individualised and person-centred
78 care [8].

79 Older adults, who often experience the most disease and require the most complex care
80 needs, are generally underrepresented in research [9]. This results in research evidence that may
81 not be generalisable to those who may require it the most [10-11]. Although the prevalence of
82 chronic health problems increases with age [12], older adults are often excluded from research
83 due to both explicit and implicit restrictions, for example age limits or decisional capacity
84 abilities [13-14]. If research findings are to effectively inform practice, study participants should
85 reflect the population to which the research is being applied [15]. Furthermore, there is a lack of
86 research which has identified appropriate research methodology and strategies for recruiting

87 older adult populations [15]. Underrepresentation and exclusion of older adults in research is
88 apparent in facilities dedicated to the care of older adults, such as care homes [6].

89 The exclusion of care home residents in research has been suggested to be partly due to
90 practical difficulties and ethical concerns about including this ‘vulnerable’ group in research
91 [16]. However, all people have the right to be included in research regardless of their place of
92 residence or cognitive abilities. According to the Alzheimer’s Society, 80% of older adults living
93 in care home are estimated to have either dementia or severe memory problems (17). A high
94 number of care home residents therefore lack the capacity to consent to research and are less
95 likely to be included in research as a result. Where care home residents are included, it is often
96 through proxy decision-makers, who may have little knowledge of what their views and attitudes
97 may be or find the process too difficult, thereby limiting residents’ opportunities to express their
98 own wishes [18-19]. Proxy decision-makers, often termed personal consultees or personal legal
99 representatives, refer to people who are engaged in caring for the participant (not professionally
100 or for payment) or are interested in their welfare and are prepared to be consulted [20].

101 A previous systematic review, published in 2018, identified a number of challenges to
102 conducting research in care homes [21]. The challenges were categorised into eight main themes:
103 facility/owner factors; resident factors; staff caregiver factors; family caregiver factors;
104 investigator factors, ethical/legal factors; methodological factors; and budgetary factors. The
105 reasons for the exclusion of care home residents are multi-factorial, including structural
106 inequalities from less research infrastructure and research capacity, a reduced research-orientated
107 culture, and individual resident-related factors, such as cognitive impairment [21]. Reference to
108 UK based studies or resident-related challenges were also primarily nested within a larger study,
109 which limits the findings due to international differences in care homes and residents and thus

110 the transferability of studies. The available international literature reporting challenges to
111 conducting research in care homes is limited due to the fact that care homes, care provision and
112 care home residents differ considerably between different countries [22-23]. Further research is
113 needed to explore these challenges with a focus on care home residents themselves. This will
114 enable greater opportunities for research inclusion for residents, subsequently allowing them to
115 have their voices heard, and receive quality, evidence-based care in the future [24].

116

117 To better understand why older adults living in UK care homes are often excluded, and therefore
118 underrepresented, in research, this scoping review aimed to:

- 119 - identify resident-related barriers and facilitators to including older people living in UK
120 care homes in research
- 121 - identify potential approaches to appropriately modify identified barriers and facilitators.

122

123 The term 'care home' is used throughout this paper to refer to any long-term care
124 facilities that older adults live in full time. This includes care homes, residential homes, and
125 nursing homes.

126

127

128 **Methods**

129

130 ***Protocol and Registration***

131 The protocol for this scoping review followed the scoping review protocol framework by
132 Peters et al. (2022; [25]) and can be found at: <https://osf.io/fdy78>

133

134 *Design*

135 This review follows the scoping review methodology framework proposed by Arksey and
136 O'Malley (2005; [26]) with recommendations from updated versions of the framework by Levac
137 et al. (2010; [27]) and the Joanna Briggs Institute [25,28] taken into consideration when relevant.
138 According to the methodological framework there are six different stages to consider when
139 undertaking a scoping review: identifying the research question; identifying relevant studies;
140 selecting studies; charting the data; collating, summarising, and reporting the results; and
141 consultation. Whilst the consultation stage is suggested as optional by Arksey and O'Malley, it
142 was included in this study in order to strengthen the findings and their relevance.

143 The broad nature of a scoping review, as discussed by Munn et al. [29] was deemed the
144 best fit for this review from which some basic concepts in the research area, as well as key
145 sources, concepts, gaps, and the amount and nature of available literature need to be identified.
146 Guidelines from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses,
147 Scoping Review extension (PRISMA-ScR; [30-31]) were also followed in this review.

148

149 **Stage 1: Identifying the Research Question.** The research question driving this scoping
150 review was: “What are the resident-related barriers and facilitators to including older people
151 living in UK care homes in research?”

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153 **Stage 2: Identifying Relevant Articles.** For the purpose of consistency, the term
154 ‘articles’ will be used throughout to refer to included materials (published papers, websites,
155 protocols, blogs).

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Eligibility Criteria. The identification of relevant articles followed the Population, Concept, Context (PCC) framework (see Table 1.), as recommended by the JBI [25,28]. Articles were included in the review if they: (1) included care home residents, residents’ family members, care home staff, or researchers; (2) mentioned barriers or facilitators to inclusion, or suggestions/advice for modifying barriers or facilitators; and (3) took place in UK care home settings. In line with the broad nature of the review, no limits were placed on study design. Conference proceedings, protocols and systematic and literature reviews were excluded; however, the reference lists of review articles were searched to ensure that no key articles were missed. Only English language articles were included in this review considering the language abilities of the researchers, as well as time and cost constraints. Searches of all sources were confined to articles published between January 2005 and the date the searches were conducted (March 2022). This time limit ensured that the literature reviewed was relevant to the Mental Capacity Act (2005; [21]) before which the process for including people who lacked capacity to consent was not formalised. The Mental Capacity Act governs how incapacitated adults can be involved in research and provides for another person to be consulted for advice before an individual lacking capacity is included in the research [32]. The geographic context for the search was limited to the UK as different countries have different types of residential care for older adults. Additionally, different countries have different legal frameworks for research involving adults lacking capacity to consent.

	Inclusion Criteria
Participants/Population	Care home residents Care home residents' relatives Care home staff Researchers
Concept	Barriers and/or facilitators to inclusion Resident-related factors
Context	UK care homes (residential homes, nursing homes, long-term care facilities)
Type of Source	Journal articles and other reports, both peer and non-peer reviewed Date of publication between 2005 and review commencement (March 2022) Published in English

180 *Table 1. Proposed inclusion criteria for scoping review relevant to PCC framework*

181 **Information Sources and Search Strategy.** Electronic database searches of: Medline,
182 Web of Science, Scopus, CINAHL and PsychINFO, were conducted by BN on 23-25th March
183 2022. A combination of terminologies, separated by key concepts, were tailored to each database
184 with the help of a subject specific librarian. See Table 2. for search strategy.

185 Additionally, grey literature was investigated through unpublished literature (EthOS),
186 whole site searches of relevant organisations (ENRICH, AlzheimersUK, British Society of

187 Gerontology) as well as existing networks. Whole site searches were conducted using a Google
 188 search tool recommended by a consulted subject specialist librarian ('search term:website').

189

	Key Concepts		Search terms
	Care homes (titles and abstracts)	OR	"care home*", "nursing home*", "residential home*", "long-term care facilitat*"
AND	Research (titles)	OR	"research*", "study*", "trial*", "investig*", "explor*", "observ*"
AND	Participation (titles and abstracts)	OR	"research subject*", "research particip*", "particip* research", "recruit*", "involv*"
AND	Barriers and facilitators (titles and abstracts)	OR	"barrier*", "challeng*", "factor*", "facilitat*", "perception*", "perceive*", "view*", "attitude*", "experience*"

190 *Table 2. Proposed search terminologies to be input into each database, separated by key concept*

191 **Stage 3: Selecting Articles.** One author (BN) performed the screening after having
 192 piloted implementing the eligibility criteria alongside another author (VS) with a random
 193 selection of articles. In screening level one, the title and abstract were reviewed for eligibility.
 194 During screening level two, the full article was reviewed against the eligibility criteria and
 195 advice was sought from another author (VS) for any articles where inclusion was unclear. Any
 196 disagreement about inclusion between BN and VS was referred to another author (FW) for
 197 discussion and resolution.

198

199 **Stage 4: Charting the Data.** Data were extracted from the included articles according to
200 the following fields: author(s) and year; source type; purpose; population; concept (barriers and
201 facilitators); context; relevant author suggestions/advice for modification; and any other relevant
202 comments.

203 The data charting form was taken from scoping review resources developed by the JBI
204 (<https://jbi-global-wiki.refined.site/space/MANUAL/4687579>) and modified as relevant, per
205 instruction of the JBI (see supplementary material for chart). Data charting for all included
206 articles was completed independently by BN, with feedback provided by FW and VS.

207 After further familiarisation with the articles, barriers and facilitators were extracted and
208 the number of articles that discussed each factor was recorded.

209

210 **Stage 5: Collating, Summarising, and Reporting the Results.** Following identification
211 of the barriers and facilitators to inclusion of care home residents in research, factors were placed
212 into categories based upon the system level to which they were related (i.e., staff-related,
213 resident-related, care home-related, research-related). Although aiming to identify resident-
214 related barriers and facilitators only, due to the complex interactions with other system-level
215 factors other intersecting and influential indirect factors were included. Each of the barriers and
216 facilitators identified therefore fell into either direct or indirect categories, all with the potential
217 to impact the inclusion of UK care home residents in research. Following familiarisation with the
218 barriers and facilitators identified in the included articles, as is usual with scoping review
219 methodology [30], the themes and sub-themes were iteratively developed through discussion
220 with the team.

221

222 **Stage 6: Consultation.** An online meeting was held in January 2023 with stakeholders to
223 discuss the initial draft of the scoping review. The meeting included five participants, three of
224 whom were Patient and Public Involvement (PPI) group members identified through Health and
225 Care Research Wales. Perspectives shared by the stakeholder patient and public involvement
226 members included those of care home staff, care home resident relative, and researcher.

227 A brief presentation of the scoping review was sent to members a week in advance with
228 instructions to consider contributing input in the meeting based around their own expertise and
229 perspectives. The aim of this consultation meeting was to clarify and/or validate our preliminary
230 findings. The same presentation was shared in the meeting and members shared and discussed
231 their own thoughts and perspectives, based on their own experiences, of the information
232 presented.

233 The PPI group were consulted earlier on in the project during the initial stages of
234 identifying barriers and facilitators to the inclusion of older adults living in UK care homes in
235 research and so were familiar with the project and able to contribute valuable views.

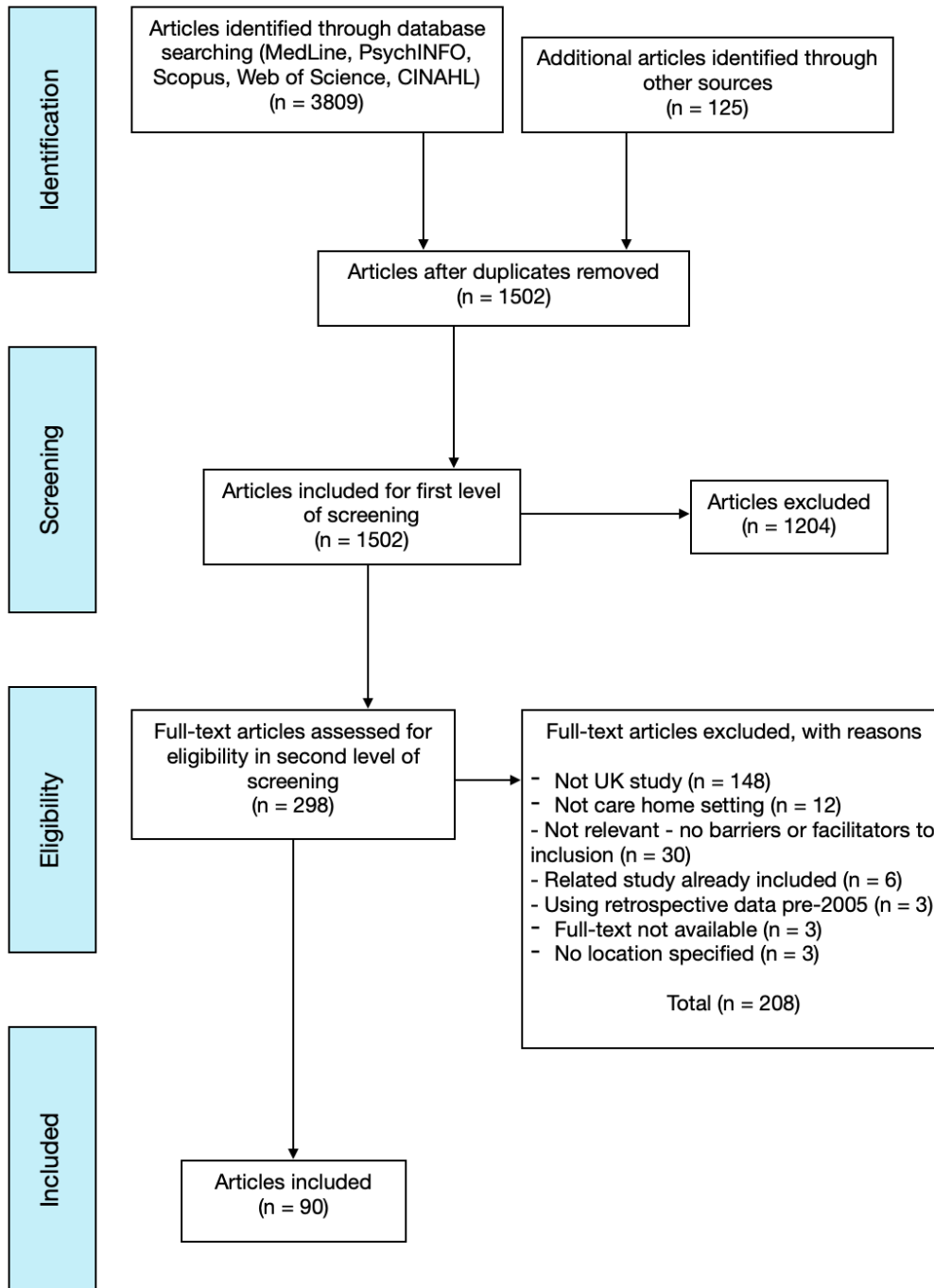
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237 **Results**

238 A total of 3809 articles were identified from the database searches and a further 125 from
239 grey literature and other sources (see Figure 1. for PRISMA-ScR flow chart). Following
240 deduplication of articles, 1525 articles remained. All articles were uploaded to a reference
241 management system, Endnote, where data management and both screening levels were
242 completed against the eligibility criteria. After the screening of titles and abstracts during
243 screening level 1, using the predefined eligibility criteria, a total of 1204 articles were excluded,

244 resulting in 313 articles. Following the second level of screening, 223 were excluded based on
245 full-text review, resulting in 90 articles for data extraction.

246



247

248 *Figure 1. PRISMA-ScR flow chart of article selection*

249 *Article Characteristics*

250 The general characteristics of the articles included in this scoping review are reported in
251 Table 1. 3809 journal articles and 125 articles from the grey literature search were initially
252 retrieved. Of the 90 articles included, 84 reported potential barriers and 75 reported potential
253 facilitators of inclusion of UK care home residents in research (see Table 3). Of the included
254 articles, 30 also included advice or suggestions for improving the inclusion of care home
255 residents in research (see Table 4).

256

257 *Barriers and Facilitators to the Inclusion of UK Care Home Residents in Research*

258 Alongside resident-related factors that directly affected the inclusion of care home
259 residents, a number of indirect factors were identified which were viewed as important and
260 influential and so warranted inclusion. Factors directly affecting inclusion refers to factors which
261 are solely related to and impact the resident, such as cognitive impairment, whereas indirect
262 factors to inclusion refer to impactful factors that residents have no control over and may even be
263 unaware of, such as gatekeeping.

264 The complex barriers and facilitators to the inclusion of UK care home residents in
265 research were synthesised into seven thematic categories: (1) research design; (2) understanding
266 and beliefs about research (resident and care home staff); (3) communication; (4) relationships;
267 (5) eligibility criteria (resident and care home); (6) preference-based decisions; and (7) care
268 home staff and environment. See Table 5.

269

270 **Research Design.** A number of research design issues were discussed in the included
271 articles, which posed barriers and facilitators to the inclusion of care home residents in research.

272 The use of existing networks during recruitment was a common approach and resulted in being
273 an indirect facilitator to the inclusion of care home residents in research [33-52]. However, the
274 sole use of existing networks, including ‘research ready’ care homes for example, may also
275 present an indirect barrier for the inclusion of UK care home residents in research [33,36,47,51],
276 as the approach excludes those care homes that are not within those networks.

277 The piloting of the recruitment process was mentioned in two of the included articles and
278 poses a potential indirect facilitator to inclusion [34,52]. Piloting was considered helpful in terms
279 of identifying challenges which can be addressed prior to recruitment. Researcher flexibility,
280 including tailoring research methods and/or requirements to specific care home settings and/or
281 residents was discussed in a number of included reports [48-49,53-54], as was the importance of
282 researcher experience in care home settings [55].

283 The research design choice of relying on care home staff to determine study eligibility
284 was commonly reported by the included articles, posing a potential barrier to the inclusion of
285 care home residents in research through issues of recruitment bias [38-39,41,44,56-69]. Further,
286 the burden, on care home residents and staff, of the chosen methods of data collection, including
287 monitoring periods were discussed in included articles [40,53-54,70-71], as were designs which
288 require significant time and environmental requirements [55,72-73], such as private space, all of
289 which present potential barriers to the inclusion of care home residents in research.

290

291 **Understanding and Beliefs about Research (resident and care home staff).**

292

293 **Resident.** A number of the included articles discussed barriers around residents’ general
294 lack of interest in participating in research, as well as initial interest and then disengagement [36-

295 37,47,53,57,61,72,74-75]. Resident understanding about what research is, what is required of
296 them, and other related concerns also posed a potential barrier for inclusion [76-78].
297 Highlighting to residents the potential benefits of research was the most common facilitator
298 discussed in the included articles [53-54,72,79,80-81], followed by residents' altruism [54,76].

299
300 **Care Home Staff.** A lack of understanding by care home staff and negative beliefs about
301 research, including underlying research motives were discussed in a number of included articles
302 [35,40,46,55,61,73,82-83]. Ensuring accurate understanding about the nature of the research
303 being conducted, and staff having positive beliefs about the research was reported in a number of
304 included articles and offered a potential indirect facilitator to resident inclusion [48,77,83].

305
306 **Communication.** The approach to presenting research information to potential
307 participants was discussed in some of the included articles, posing both a potential barrier and
308 facilitator to the inclusion of care home residents in research [61,76]. Communicating
309 information to residents in an accessible, tailored manner was considered to be a direct facilitator
310 to resident inclusion [46,57,61,70,72,76,84]. Providing clear and honest information from the
311 start, as well as facilitating positive, clear and consistent communication with all stakeholders
312 were factors also considered to be helpful [48-50,52-54,67,69,72-73,76-78,80,82,85]. One
313 included article discussed the importance of effective communication ensuring true
314 understanding [77]. Difficulties in communication, including those caused by cognitive
315 impairment and loss of verbal skills were reported as direct barriers for inclusion in research for
316 care home residents [76,79]. Fluctuations in resident capacity and in resident mood also posed
317 challenges to participation in research [53,57,74-75].

318 Poor communication between care home staff, researchers, and relatives posed another
319 potential indirect barrier to inclusion [53,82], as did poor communication between the research
320 team and staff [34,49-50,73,76,79,83].

321

322 **Relationships.** The importance of building rapport between the research team, residents,
323 care home staff and relatives was discussed in many included articles. The importance of
324 researchers spending time at care homes before study commencement was particularly
325 commonly discussed and is a potential facilitator to inclusion [35,44,69,73,76,84,86-87]. The
326 benefits of developing positive relationships with gatekeepers, such as care home managers,
327 were discussed also [67,71].

328 The use of a collaborative working style between the research team, residents, staff, and
329 relatives proposed a potential facilitator to the inclusion of care home residents in research
330 [46,51,54,57,61,63,67,70,72,80,84-85,88-89,90-91]. Providing personalised feedback and a
331 feeling of inclusivity for care home staff and residents was also mentioned as a positive
332 experience and may indirectly facilitate resident inclusion in research [48,50].

333

334 **Eligibility Criteria (resident and care home).**

335

336 ***Eligibility of Residents.*** Strict resident eligibility criteria were the most common direct
337 resident-related barriers to inclusion, with exclusion often based on age limits [33-39,40,56-
338 59,60,70,92-103] and comorbidity (e.g., learning disability, terminal illness, cognitive
339 impairment) being the most common [39,41-42,56-57,60-62,70,76-77,79,92,94-95,98-111]. The
340 exclusion of participants who lacked the capacity to consent to participation, with no option of

341 utilising a personal consultee, were reported [35,38-39,43-45,63-65,70,74,95,100,105,111] as
342 well as those who did not have an adequate ability to communicate, understand, or engage in
343 conversation [38,45-46,60,62,104-105,109]. The requirement of a clinical diagnosis of dementia
344 (as opposed to a likely diagnosis) was a potential barrier in a number of included articles
345 [37,42,58-59,100,103-105,109,111-113], as was the requirement to understand and communicate
346 in English [35,42,44,46,57,60,62,64,76-77,97,104-105,109,111]. The requirement of a study
347 partner posed a potential barrier was discussed in two articles [54,111].

348 The allowance of another person being able to consent to participation on behalf of a
349 resident who lacks the capacity to consent, i.e., a personal consultee, was the most frequently
350 mentioned potential facilitator to inclusion in the included articles [33,41-42,46,55,59,60-
351 61,66,70,76-77,79,81,84-88,90,92-94,96-97,99,102-103,107-110,113-118]. Additionally,
352 utilising minimal eligibility criteria was also found to be a potential facilitator to the inclusion of
353 care home residents in research [33,43,45,51,54,66,81,86,90,93,106,108,112,115-116,119].

354
355 *Eligibility of Care Homes.* The presence of strict care home eligibility criteria proposed
356 an indirect resident-related barrier to inclusion for UK care home residents. Most commonly
357 reported were the need to meet criteria for the location and type of care home [33-34,41-
358 42,44,46,56,76,86,109 and 33-34,37-38,42,44,46,56,76-77,112-113, respectively]. The size of
359 care homes was another common eligibility criteria [34,38,42,46,59,86,92], as were the
360 rating/quality of care homes, as awarded by organisations such as the Care Quality Commission
361 [34,37-38,46,48,68,76-77,112]. Care homes who were requiring special support from their local
362 authorities were also reported to be excluded from some research [112-113].

363

364 **Preference-Based Decisions.** Residents’ expressions of perceptions of disempowerment,
365 including lack of autonomy, confidence, apathy and having worries about research participation
366 were discussed in a number of included articles and posed barriers relating to participation in
367 research [46,57,61,63,66,76,113]. Further, a lack of awareness about research participation
368 opportunities and being overlooked with regards to participation posed potential barriers to
369 inclusion [54,76,120]. Providing residents with the opportunity to participate in research, by
370 directly asking them, is a potentially empowering facilitator to inclusion which was discussed in
371 one article [76].

372 Relatives’ unwillingness to take part, or in cases where a personal consultee option was
373 available, refused to consent or make a decision regarding resident participation, presented a
374 barrier to inclusion [40,53,57,85,88,92,121], as did the impact of what article authors referred to
375 as “gatekeeping” and “overprotective relatives” [53,56,67,71-72,76,79,89,93,114,119].
376 The impact of external influences was discussed in included articles and were potential indirect
377 barriers to research inclusion. The impact of research ethics committees was discussed in one
378 article [55], as was the impact of legal frameworks [121].

379
380 **Care Home Staff and Environment.** Factors relating to the care home, including the
381 care home staff and the care home environment creates both direct and indirect barriers and
382 facilitators to the inclusion of care home residents in research.

383 Providing and communicating the benefits and incentives of research participation to care
384 home staff was mentioned in a number of included articles and may provide an indirect
385 facilitator to research inclusion [48,50,52,54,73,108]. Care home staff interest, support, and
386 engagement in research were reported to provide an indirect facilitator to research inclusion

387 [40,48,52,54,57,70,72-73,78,83,103,110,118], as did care home manager interest specifically
388 [105,116]. A number of included articles also discussed the benefits of providing staff training
389 and opportunities for knowledge development as part of the research process [48,52,72,74,78].
390

391 The impact of research on care home staff was the most common indirect resident-related
392 barrier to inclusion, with time pressure felt by care home staff and workload factors most
393 commonly discussed [44,48-49,50,55,61,67,73,75,77-78,80,82], followed by high staff turnover
394 [40,50,54-55,67,72-73,80,83,85]. Staff lack of interest, engagement and negative attitudes
395 towards research, were the next most frequently discussed [40,46,48,55,57,61,77,79,83]. A lack
396 of confidence in facilitating research was discussed in two included articles [61,86]. Perceived
397 lack of support from the care home manager [35,76-77,80,83] and the culture within care homes
398 [54,56] were also discussed in included articles. Conversely, manager support for the study was
399 reported as an indirect facilitator [76,79-80,83,104,110].
400

401 Limitations of the care home environment, including a lack of private space in which to
402 consent residents and collect data, and disruption of daily routines caused by research, posed a
403 barrier to resident inclusion [35,56-57,61,67,69,75-76,79-80]. However, in a number of included
404 articles, it was shown that the care home environment can be used to facilitate research
405 participation, such as positive use of spaces that were chosen by residents, for example residents'
406 own bedrooms, to conduct research which facilitates privacy [53,63,67,76,106]. However,
407 residents' ability to have their own private room is not always available in all care homes.
408 Furthermore, the culture of care homes, specifically care homes with a culture of inclusiveness,
409 was reported as a facilitator to the inclusion of residents in research [46].

410

411 *Consultation Stage*

412 When presenting our early synthesis to our PPI partners, we received comments about
413 our choice of vocabulary, much of which reflected terms used by the authors of the literature
414 included in the review. For example, the use of the word ‘overprotective’ in relation to relatives
415 was disliked by one member, stating that it felt harsh and unfair.

416 Suggestions of additional visualisations of the results were made, such as the inclusion of
417 a graphic showing the weighting of barriers and facilitators depending on how many times each
418 came up in the included literature. The inclusion of a table stating which barriers could be
419 tackled most easily compared to those more difficult to tackle was discussed also.

420 Further discussion related to one member’s own experiences of working in different types
421 of care homes. For example, for researchers to consider that care home staff may have different
422 time and workload demands dependent upon whether they are working in a residential or nursing
423 home.

424 Overall, the discussion supported our preliminary findings, including the importance of
425 care home staff as a factor. PPI members expressed their interest in taking part in the review
426 process and shared their views on the importance of the topic throughout. One member shared
427 their own experiences of visiting a relative living in a care home and the apparent issues of
428 recruitment and pressures of high workload. This member also shared the view that staff often do
429 not have English as a first language, making them more cautious towards research, and that it
430 may be a lower priority for them as it contributes towards their already high workload. The
431 facilitatory benefits of researchers spending time in care homes prior to study commencement
432 was discussed and strongly agreed with by the group members. A suggestion for future research

433 surrounding the topic of how to facilitate conversation between researchers and care home staff
434 about research and its benefits was made by one member.

435

436 Changes made in light of the consultation stage included:

- 437 • The clarification of our definition of ‘care homes’ as homes which care is provided for older
438 adults and not other types of care homes which might provide care for younger adults with
439 disabilities.
- 440 • Adding more information to clarify that terms which may be less favourable, such as
441 ‘overprotective’ have been used as these were terms used in the literature
- 442 • Including the suggestion of exploring the topic of how to facilitate conversation between
443 researchers and care home staff in future research.

444

445

446 **Discussion**

447 This scoping review set out to understand why older adults living in UK care homes are
448 often excluded, and therefore underrepresented, in care home research with the aim of
449 identifying resident-related barriers and facilitators to their inclusion and identify potential
450 interventions to appropriately modify identified barriers and facilitators. The barriers and
451 facilitators identified in the existing literature have been collated, synthesised, and reported in
452 this review.

453 The majority of included articles were research articles conducted in care home facilities,
454 although there were also a number of commentary articles from researchers about the processes
455 of conducting research in care homes. Frequently reported barriers and facilitators to the

456 inclusion of care home residents in research were grouped into seven thematic categories: (1)
457 research design; (2) understanding and beliefs about research (resident and care home staff); (3)
458 communication; (4) relationships; (5) eligibility criteria (resident and care home); (6) preference-
459 based decisions; and (7) care home staff and environment. Approaches or solutions we suggest in
460 light of these findings are presented in Table 5.

461

462 *Barriers*

463 Barriers to the inclusion of care home residents in research were mainly related to factors
464 outside of the residents' control, such as research methods and the communication and
465 relationships between research systems and care systems.

466 The use of existing networks during recruitment, whilst beneficial when used alongside
467 other methods of recruitment, poses a barrier when used as the sole method of recruitment. For
468 example, the use of 'research ready' care homes results in the exclusion of the majority of care
469 homes in the UK that we know are not registered as 'research ready' or actively engaging with
470 research.

471 Strict eligibility criteria for participation, both for residents and for care homes, were
472 identified in a majority of the included articles. Whilst necessary for any study to provide
473 eligibility criteria in order to focus their population of interest, strict criteria relating to
474 characteristics of care home residents, such as age, prevents the inclusion of residents that could
475 otherwise provide a representative sample of the targeted population. The potential impact of
476 excluding representative participants based on characteristics which may be unrelated to the
477 research aim, or interfere with the research findings, may be unfavourable in relating findings to
478 practice. Further, strict eligibility criteria for care homes, such as size, rating/quality and type

479 limit research opportunities from even reaching care home residents who represent a population
480 who reside in the variety of care homes available in the UK. This is in line with discussion by
481 Patino and Ferreira (2018; [122]) regarding the impact of inclusion and exclusion criteria on the
482 external validity of a study.

483 The lack of an opportunity for a relative or personal consultee to consent on behalf of
484 residents who lacked capacity to consent to their own participation presented a barrier to
485 inclusion. It is likely that including extra stages to obtain informed consent from those lacking
486 capacity can be both time-consuming for researchers and present additional costs. This finding is
487 in line with research which suggests that care home research can be challenging to conduct due
488 to practical difficulties and ethical concerns [17]. Other practical difficulties and ethical concerns
489 were identified from the review relating to the impact of external factors such as legal
490 frameworks and research ethics committees. These findings are in line with a recent review of
491 barriers and facilitators by Ritchie et al. (2023 [123]), which discusses data privacy regulations
492 as a barrier to recruitment causing care home staff to involuntarily act as ‘gatekeepers’. Ritchie
493 and colleagues suggest that by establishing residents’ and representatives’ preparedness to be
494 approached at the point of care home admission, this barrier could be removed. Further,
495 relatives’ unwillingness to take part in care home research or their refusal to consent on behalf
496 of, or make a decision on, their relatives’ participation posed a barrier to resident inclusion. It
497 may be possible that by establishing stakeholders’ preparedness at the point of care home
498 admission, as suggested by Ritchie and colleagues, this barrier can be overcome.

499 More barriers than facilitators were identified in this scoping review relating to the theme
500 of preference-based decisions. Residents’ lack of awareness of opportunities to participate in
501 research were shared by a number of included articles and present an important barrier

502 suggesting that current recruitment strategies are ineffective. Whilst research generally aims to
503 investigate and discover ways in which we can improve quality of life of a target population,
504 there is a paucity of research aiming to understand how care home residents feel about and
505 understand the purpose and benefits of research, thus in some cases impacting their willingness
506 to contribute or participate. Expressions of disempowerment by residents, where they questioned
507 their abilities to contribute in a useful way to research, was apparent in the included articles
508 alongside apparent lack of autonomy, confidence, apathy and worries about research
509 participation. According to Self Determination Theory (SDT; Deci & Ryan, 1985 [124], 1991
510 [125]), perceived autonomy can result in feelings of empowerment and improve motivation to
511 carry out tasks which are felt to be a product of one's own choice. Improving perceived
512 autonomy of older adults living in care homes could be beneficial in this research area.
513 Informing and educating older adults living in care homes about research, and how they can be
514 involved, may be a useful step towards increasing opportunities for inclusion.

515

516 *Facilitators*

517 Not surprisingly, this review has identified that a number of facilitators to care home
518 resident inclusion in research correspond to identified barriers. For example, poor
519 communication between researchers and residents, relatives and care home staff resulted in more
520 barriers, whereas clear, consistent, and positive communication between individuals and
521 organisations were a facilitator to resident inclusion. Further, researchers providing personalised
522 feedback and a feeling of inclusivity for staff and residents was reported in the included literature
523 as a positive experience for stakeholders. Ritchie et al. (2023 [123]) also identified challenges
524 relating to communication between the research team and care home staff outside of the care

525 home setting. Furthermore, difficulties in communication experienced by residents, which may
526 pose a barrier to inclusion, can be rectified through the presentation of research information in an
527 accessible and tailored manner, thus facilitating inclusion. Researchers are responsible for
528 modifying most factors which present as barriers to the inclusion of care home residents in
529 research. Researcher flexibility and experience working with care homes and residents is of great
530 importance in tackling challenges.

531 Within the theme of relationships, a number of other facilitators were identified. The use
532 of a collaborative working style between all stakeholders was discussed as beneficial in a number
533 of articles as beneficial as were the benefits of developing positive relationships with
534 gatekeepers, such as care home managers. Building rapport with stakeholders, for example by
535 researchers spending time in care homes before study commencement, was a facilitator identified
536 in a number of included studies. These findings are aligned with reports of beneficial research
537 outcomes of collaborative working styles in other health care settings [126].

538 Within the care home staff and environment theme, capitalising on the unique care home
539 environment such as private rooms and communal social spaces, can facilitate resident inclusion,
540 as shown in some of the included articles. In addition, the high workload and time pressures
541 faced by staff, identified in the included articles, may be addressed by manager support of the
542 research study making researchers aware of the most suitable times to carry out research related
543 tasks. Investing in staff development through training may facilitate positive staff engagement in
544 research, which was identified as a facilitator to the inclusion of care home residents in research.
545 This finding is in line with Gordon et al. (2022 [127]), who suggest that investing in the
546 development of the care home workforce can help to make staff feel more valued and give them
547 the recognition they deserve to match the importance of their work.

548 Further, by removing additional research pressures, care home staff may be more willing
549 to facilitate resident recruitment. This flexibility relates to suggestions from other included
550 articles, stating that patience, flexibility and need for understanding complexities of care home
551 environments are key researcher qualities needed for successful recruitment and data collection.

552

553 *Strengths and Limitations*

554 In accordance with scoping review methodology, we did not include an assessment of the
555 methodological quality of included articles. However, the aim of this review was to identify
556 underlying concepts in the research area, as well as key sources and the nature of available
557 literature [30], for which a scoping review was the most appropriate approach [25]. Whilst a
558 large amount of literature was identified, we identified a number of common themes which
559 allows confidence in our application of the broad yet rigorous scoping review
560 methodology.

561 Although a comprehensive search was carried out, with a focused but inclusive search
562 strategy, it is possible that all published articles in this area were not identified.

563 A strength of this review is the inclusion of both direct and indirect barriers and facilitators
564 which were identified during data extraction and are thought to have a great impact on older
565 adults' inclusion in research. Other strengths include that data were included from a wide range
566 of study types and stakeholders' experiences, enabling the findings to be drawn from these wider
567 perspectives rather than those of individuals studies or groups. A further strength of this scoping
568 review was the inclusion of the consultation stage of Arksey and O'Malley's methodology
569 framework which allowed the exploration and clarifying of our preliminary findings using
570 additional expertise and perspectives of stakeholders.

571

572 *Future Research and Practical Implications*

573 This scoping review provides new insights on the barriers and facilitators to UK care
574 home residents' research participation presented in the existing literature. Many of the barriers
575 have the potential to be modified, thus improving recruitment and inclusion. It may be of interest
576 for future research to investigate barriers and facilitators for different types of care home or for
577 residents with differing characteristics (e.g., those with capacity to consent and those without).
578 Furthermore, future research may also consider the different barriers to the inclusion of care
579 home residents in research depending on the type of research methodology (e.g., randomised
580 controlled trials vs survey).

581 Apparent from the findings of this review was a lack of literature reporting the views of
582 relevant stakeholders (i.e., residents, relatives, staff, and researchers) about the opportunities for
583 older adults living in care home to get involved in research.

584 Future research may also consider focusing on the development of a simpler process of
585 involving people with capacity to consent in research, with a specific focus on care home
586 residents. This would need to include individuals living with dementia who represent the
587 majority of older adults living in care homes.

588 Furthermore, future research to explore how residents' wishes and feelings about research
589 participation, and the quality of understanding about research by this population may be useful in
590 improving recruitment practice.

591 Finally, attempts to address the identified barriers to resident inclusion can be made using
592 the solutions identified in this review. Tools have recently been developed which aim to help
593 researchers to design trials that are more inclusive of particular underserved populations (e.g., the

594 INCLUDE Ethnicity Framework [128], and the INCLUDE Impaired Capacity to Consent
595 Framework [129]) but have not yet been applied to trials being conducted in care homes. If these
596 are successful, researchers may expect their results to be more generalisable to this
597 underrepresented population who may benefit the most.

598

599 **Conclusions**

600 Care home residents remain an under-served group in research, which results in less
601 evidence about how to best care for this group than those receiving care in other settings. This
602 scoping review identified a number of complex, interacting barriers and facilitators to the
603 inclusion of older adults living in UK care homes in research.

604 The findings have enabled a better understanding of common barriers and facilitators to
605 the inclusion of care home residents in research, as well as presenting potential ways these
606 factors can be modified to improve research within the field.

607 Further research is required in order to explore the interaction between the direct and
608 indirect barriers and facilitators to UK care home resident inclusion in research and identify
609 interventions that target the modifiable barriers and facilitators to improve inclusion.

610

Table 3. General characteristics of included articles

Author(s)	Year	Article type	Purpose/Title	Location	Setting	Participant/Perspective	Barriers	Facilitators	Advice included
NIHR (ENRICH)	2015	Interview blog	Overcoming the challenges of recruiting care homes to research	UK-wide	N/A	Researcher	✓	✓	✓
NIHR (ENRICH)	2015	Interview blog	Talk to the people who know - consulting widely before starting care home research	UK-wide	N/A	Researcher		✓	✓
Aguirre et al.	2012	Intervention study	Cognitive simulation therapy (CST) for people with dementia - who benefits most?	London, Essex, and Bedfordshire, UK	Care homes and community settings	113 care home residents	✓		
Airlie, Forster and Birch	2022	Randomised Controlled Trial	An investigation into the optimal wear time criteria necessary to reliably estimate physical activity and sedentary behaviour from ActiGraph	West Yorkshire, UK	Care homes	94 care home residents	✓	✓	

			wGT3X+ accelerometer data in older care home residents						
Amador et al.	2014	Observational Study	Emergency ambulance service involvement with residential care homes in the support of older people with dementia: An observational study	East of England, UK	Care homes	133 care home residents	✓	✓	
Aspray et al.	2006	Survey study	Low bone mineral density measurements in care home residents—a treatable cause of fractures	Newcastle upon Tyne, UK	Care homes	392 care home residents	✓	✓	
Ballard et al.	2018	Randomised Controlled Trial	Impact of person-centred care training and person-centred activities on quality of life, agitation, and antipsychotic use in people with dementia living in nursing homes: A cluster-randomised controlled trial	South London, North London, and Buckinghamshire, UK	Care homes	757 care home residents	✓	✓	

Barber et al.	2009	Prospective study	Care homes' use of medicines study: Prevalence, causes and potential harm of medication errors in care homes for older people	West Yorkshire, Cambridgeshire, and central London, UK	Care homes	256 care home residents		✓	
Bartlett, Milne and Croucher	2019	Reflective paper	Strategies to improve recruitment of people with dementia to research studies	UK-wide	N/A	Researchers	✓	✓	✓
Butler et al.	2020	Randomised Controlled Trial	Effect of Probiotic Use on Antibiotic Administration among Care Home Residents: A Randomized Clinical Trial	UK	Care homes	310 care home residents	✓	✓	
Carter et al.	2008	Observational Study	Chronic kidney disease prevalence in a UK residential care home population	East Kent, UK	Residential homes	250 care home residents	✓	✓	
Churcher et al.	2017	Pilot intervention study	An adapted mindfulness intervention for people with dementia in care homes: Feasibility pilot study	UK	Care homes	31 care home residents	✓		

Clarke et al.	2019	Interview study	A qualitative interview study comparing and contrasting resident and staff perspectives of engaging in meaningful activity in a UK care home	South London, UK	Care homes	9 care home residents, 11 care home staff members	✓	✓	
Close et al.	2013	Interview study	"It's Somebody else's responsibility" - perceptions of general practitioners, heart failure nurses, care home staff, and residents towards heart failure diagnosis and management for older people in long-term care: a qualitative interview study	Northeast England, UK	Residential and care homes	17 care home residents, 8 care home staff	✓	✓	
Costa, Ockelford and Hargreaves	2018	Mixed methods qualitative study	The effects of listening to preferred music on symptoms of depression and anxiety amongst elders in residential care: A qualitative, mixed methods study	London, UK	Care homes	113 residents	✓	✓	

Cunneen et al.	2011	Observational study	An investigation of food provision and consumption in a care home setting	East of Scotland, UK	Care homes	25 care home residents	✓	✓	
Davies et al.	2014	Reflective paper	Enabling research in care homes: An evaluation of a national network of research ready care homes	UK-wide	N/A	Researcher	✓	✓	✓
Donnelly et al.	2017	Qualitative study	Burden of a Remote Trial in a Nursing Home Setting: Qualitative Study	Dublin, Ireland, UK	Care homes	11 care home residents, 10 care staff members	✓	✓	
Ellmers	2011	Thesis	A qualitative study of sleep and the night-time in care homes for older people	Guilford, UK	Care homes	38 care home residents, 39 care home staff members	✓		
Ellwood et al.	2018	Reflective paper	Recruiting care homes to a randomised controlled trial	UK-wide	N/A	Researcher	✓	✓	
Evans et al.	2011	Reflective paper	Evaluating services in partnership with older people: Exploring the role of 'community researchers'	UK-wide	N/A	Researcher	✓	✓	

Ferguson	2020	Thesis	Supporting older people living in care homes: a qualitative network approach	Scottish Central Belt, UK	Care homes	36 care home residents	✓	✓	
Fleetwood-Smith, Tischler and Robson	2021	Reflective paper	Using creative, sensory and embodied research methods when working with people with dementia: a method story	UK-wide	N/A	Researcher	✓	✓	✓
Forster et al.	2021	Randomised Controlled Trial	An intervention to increase physical activity in care home residents: results of a cluster-randomised, controlled feasibility trial (the REACH trial)	Yorkshire, UK	Care homes	152 care home residents	✓	✓	✓
Fossey et al.	2020	Qualitative study	"We should see her like part of the team": An investigation into care home staff's experiences of being part of an RCT of a complex psychosocial intervention	London, Oxfordshire, and Buckinghamshire, UK	Care homes	41 care home staff members	✓	✓	

Gallagher et al.	2017	Action Research	Realising dignity in care home practice: An action research project	South of England, UK	Care homes	Care home staff		✓	✓
Gillespie et al.	2015	Prospective cohort study	Antibiotic prescribing and associated diarrhoea: a prospective cohort study of care home residents	South Wales, UK	Care homes	279 care home residents	✓	✓	✓
Gine-Garriga et al.	2020	Interview study	Mission (im)possible: Engaging care homes, staff and residents in research studies	Glasgow, UK	Care homes	2 care home staff members	✓	✓	
Godfrey et al.	2012	Qualitative study	An exploration of the hydration care of older people: a qualitative study	Southwest England, UK	Care homes	5 care home residents	✓		
Goodman et al.	2013	Qualitative study	Preferences and priorities for ongoing and end-of-life care: A qualitative study of older people with dementia resident in care homes	East of England, UK	Care homes	18 care home residents	✓	✓	

Goodman et al.	2011	Reflective paper	Culture, consent, costs and care homes: Enabling older people with dementia to participate in research	UK-wide	N/A	Researcher	✓	✓	✓
Gordon et al.	2014	Cohort study	Health status of UK care home residents: a cohort study	Nottingham, UK	Care homes	227 care home residents	✓	✓	
Graham et al.	2020	Randomised Controlled Trial	A posture and mobility training package for care home staff: results of a cluster randomised controlled feasibility trial (the PATCH trial)	Yorkshire, UK	Care homes	146 care home residents	✓	✓	
Griffiths et al.	2019	Trial process evaluation	Barriers and facilitators to implementing dementia care mapping in care homes: results from the DCM TM EPIC trial process evaluation	West Yorkshire, Oxford, and London	Care homes	726 care home residents	✓	✓	✓
Hall et al.	2019	Qualitative study	Moving beyond 'safety' versus 'autonomy': a qualitative exploration of the ethics of	Northern England, UK	Care homes	3 care home residents, 24 care home staff members, 9 relatives	✓	✓	

			using monitoring technologies in long-term dementia care						
Hall and Beatty	2014	Interview study	Assessing spiritual well-being in residents of nursing homes for older people using the FACIT-Sp-12: A cognitive interviewing study	London, UK	Care homes	17 care home residents	✓		
Hall et al.	2013	Qualitative study	'It makes me feel that I'm still relevant': A qualitative study of the views of nursing home residents on dignity therapy and taking part in a phase II randomised controlled trial of a palliative care psychotherapy	London, UK	Care homes	49 care home residents	✓		
Hall et al.	2011	Qualitative study	Implementing a quality improvement programme in palliative care in care homes: a qualitative study	London, UK	Care homes	11 care home residents, 26 care home staff members, 7 relatives	✓	✓	

Hall, Longhurst and Higginson	2009	Reflective paper	Challenges to conducting research with older people living in nursing homes	Southeast London, UK	Care homes	18 care home residents	✓	✓	✓
P. Higgins	2013	Reflective paper	Involving people with dementia in research	UK-wide	N/A	Researcher	✓	✓	✓
Horne et al.	2018	Reflective paper	Improving trial recruitment in care homes: the Falls IN Care Homes (FINCH) experience	UK-wide	N/A	Researcher	✓	✓	
Hsu et al.	2015	Randomised controlled feasibility study	Individual music therapy for managing neuropsychiatric symptoms for people with dementia and their carers: a cluster randomised controlled feasibility study	UK	Care homes	17 care home residents, 10 care home staff members	✓	✓	
Jain et al.	2021	Qualitative study	Dog-assisted interventions in care homes: A qualitative exploration of the nature, meaning and impact of interactions for older people	Southeast of England, UK	Care homes	54 care home residents	✓	✓	

Jenkins et al.	2016	Reflective paper	Overcoming challenges of conducting research in nursing homes	UK-wide	N/A	Researcher	✓	✓	✓
LaFrenais	2015	Reflective paper NIHR blog	Understanding Care Home Research	UK-wide	N/A	Researcher	✓	✓	✓
Law	2016	Thesis	Research in care homes: issues of participation and citizenship	Scotland, UK	Care homes	Researcher	✓	✓	✓
Law et al.	2021	Survey study	Motivating and constraining factors for research participation in Scottish care homes	Scotland, UK	Care homes	Care home staff	✓	✓	
Law and Ashworth	2022	Interview study	Facilitators and Barriers to Research Participation in Care Homes: Thematic Analysis of Interviews with Researchers, Staff, Residents and Residents' Families	Scotland, UK	Care homes	12 care home residents, 15 care home staff members, 6 relatives, 8 researchers	✓	✓	

Lee and Bartlett	2021	Ethnographic study	Material Citizenship: An ethnographic study exploring object-person relations in the context of people with dementia in care homes	Southern England, UK	Residential home	15 care home residents, 16 care home staff members, 8 relatives		✓	
Livingston et al.	2012	Intervention study	Improving the end-of-life for people with dementia living in a care home: an intervention study	London, UK	Care homes	Care home residents, care home staff members, and relatives		✓	
Luff et al.	2015	Reflective paper	A guide to research with care homes (2015)	UK-wide	N/A	Researchers	✓	✓	✓
Maidment et al.	2018	Intervention study	Medication review plus person-centred care: A feasibility study of a pharmacy-health psychology dual intervention to improve care for people living with dementia	West Midlands, UK	Care homes	108 care home residents	✓	✓	✓

Maluf	2017	Thesis	The social lives of older men living in care homes and the implications for their wellbeing	UK-wide	Care homes	Care home residents, care home staff members, relatives	✓	✓	
Moore et al.	2017	Intervention study	Implementing the compassion intervention, a model for integrated care for people with advanced dementia towards the end of life in nursing homes: a naturalistic feasibility study	Northern London, UK	Care homes	9 care home residents	✓		
NIHR	2019	Blog post/interview	Helen's Story	UK-wide	N/A	Researcher	✓		
O'Neill et al.	2022	Interview study	'Waiting and Wanting': older peoples' initial experiences of adapting to life in a care home: a grounded theory study	UK-wide	Care homes	17 care home residents	✓		✓

Orellana et al.	2019	Qualitative study using interviews and observations	Older care home residents' and their relatives' knowledge, understanding and views of shift handovers: an exploratory, focused-ethnographic qualitative study using interviews and observations	Southeast England, UK	Care homes	10 care home residents, 5 care home managers, 6 relatives	✓		
Orrell et al.	2007	Randomised Controlled Trial	A cluster randomised controlled trial to reduce the unmet needs of people with dementia living in residential care	London, North Wales, and Manchester, UK	Care homes	238 care home residents	✓		
Paddock et al.	2019	Qualitative case study using interviews and observations	Care Home Life and Identify: A Qualitative Case Study	Greater Manchester, UK	Care homes	9 care home residents, 4 relatives, 5 care home staff members	✓	✓	✓
Parsons et al.	2015	Feasibility study	Development and Application of Medication Appropriateness Indicators for	Northern Ireland, UK	Care homes	15 care home residents	✓	✓	

			Persons with Advanced Dementia: A Feasibility Study						
Patchwood, et al.	2020	Qualitative study using interviews and observations	Six-month reviews for stroke survivors: A study of the modified Greater Manchester Stroke Assessment Tool with care home residents	Northwest of England, UK	Care homes	71 care home residents	✓	✓	
Perfect et al.	2019	Reflective paper	Collecting self-report research data with people with dementia within care home clinical trials: Benefits, challenges and best practice	UK-wide	Care homes	Researcher	✓		✓
Powell et al.	2017	Pilot parallel Randomised Controlled Trial	Pilot parallel randomised controlled trial of protective socks against usual care to reduce skin tears in high risk people: 'STOPCUTS'	Exeter, Exmouth/Sidmouth, and Mid Devon, UK	Care homes	54 care home residents	✓	✓	
Rajkumar et al.	2016	Factorial Cluster Randomised Controlled Trial	Apathy and Its Response to Antipsychotic Review and Nonpharmacological	UK-wide	Care homes	273 care home residents	✓	✓	

			Interventions in People With Dementia Living in Nursing Homes: WHELD, a Factorial Cluster Randomized Controlled Trial						
NIHR	N/A	Interview/Blog	Taking part in research – the care home perspective	UK-wide	N/A	Researcher/Care home manager	✓	✓	✓
Riazi et al.	2012	Qualitative study	Quality of life in the care home: A qualitative study of the perspectives of residents with multiple sclerosis	Within 100 miles of London, UK	Care homes	37 care home residents	✓	✓	
Richardson et al.	2020	Reflective paper	Research with older people in a world with COVID-19: Identification of current and future priorities, challenges and opportunities	UK-wide	N/A	Researcher	✓	✓	✓
Sackley et al.	2015	Cluster Randomised Controlled Trial	An occupational therapy intervention for residents with stroke related disabilities in UK care homes (OTCH):	UK-wide	Care homes	1042 care home residents	✓	✓	✓

			cluster randomised controlled trial						
Sampson et al.	2018	Prospective cohort study	Living and dying with advanced dementia: A prospective cohort study of symptoms, service use and care at the end of life	Greater London, UK	Care homes	70 care home residents	✓	✓	✓
Shamshirsaz	2015	Thesis	Apply QFD methodology to capture 'unheard' voices of UK care home residents and translate them into quality measurement targets for future improvement	Peterborough and West London, UK	Care homes	15 care home residents	✓		
NIHR – Shepherd	2020	Blog post	How care homes can support the inclusion of people with impaired capacity	UK-wide	N/A	Researcher		✓	
Shepherd et al.	2015	Reflective paper	Setting up a clinical trial in care homes: challenges encountered and	UK-wide	N/A	Researcher	✓	✓	✓

			recommendations for future research practice						
Shrotri et al.	2021	Prospective cohort study	Vaccine effectiveness of the first dose of ChAdOx1 nCoV-19 and BNT162b2 against SARS-CoV-2 infection in residents of long-term care facilities in England (VIVALDI): a prospective cohort study	England, UK	Long-term care facilities	10412 care home residents	✓	✓	
Siddiqi et al.	2016	Feasibility cluster Randomised Controlled Trial	The PiTSTOP study: a feasibility cluster randomized trial of delirium prevention in care homes for older people	UK-wide	Care homes	215 care home residents	✓	✓	✓
Simpson et al.	2017	Feasibility study	The challenges and opportunities in researching intimacy and sexuality in care homes accommodating older people: a feasibility study	Northwest England, UK	Care homes	6 care home residents and their partners, 16 care home staff members	✓	✓	

Smith et al.	2019	Reflective paper	Encouraging managers of care homes for older adults to participate in research	UK-wide	N/A	Researcher	✓	✓	
Stow et al.	2018	Cluster randomised feasibility trial	Care home resident and staff perceptions of the acceptability of nutrition intervention trial procedures: a qualitative study embedded within a cluster randomised feasibility trial	UK-wide	Care homes	4 care home residents, 12 care home staff members	✓	✓	
Subramaniam, et al.	2014	Randomised Controlled Trial	Life review and life story books for people with mild to moderate dementia: A randomised controlled trial	North Wales, UK	Care homes	23 care home residents	✓		
Towers et al.	2019	Cross-sectional study	A cross-sectional study exploring the relationship between regulator quality ratings and care home residents' quality of life in England	Southeast England, UK	Care homes	293 care home residents	✓	✓	

Tzouvara et al.	2016	Reflective paper	Lessons learned from recruiting nursing homes to a quantitative cross-sectional pilot study	UK-wide	N/A	Researcher	✓	✓	
Underwood et al.	2013	Randomised Controlled Trial	Exercise for depression in care home residents: a randomised controlled trial with cost-effectiveness analysis (OPERA)	Northeast London, Coventry, and Warwickshire, UK	Care homes	891 care home residents	✓	✓	
Usman et al.	2019	Prospective cohort study	Measuring health-related quality of life of care home residents: comparison of self-report with staff proxy responses	East Midlands, England, UK	Care homes	117 care home resident and staff matched pairs	✓	✓	
Watkins et al.	2017	Qualitative interview study	Exploring residents' experiences of mealtimes in care homes: A qualitative interview study	Southwest England, UK	Care homes	11 care home residents	✓	✓	✓

Wenborn et al.	2013	Cluster Randomised Controlled Trial	Providing activity for people with dementia in care homes: A cluster randomised controlled trial	London, UK	Care homes	210 care home residents	✓	✓	✓
Whelan et al.	2013	Reflective paper	Impact of the demand for 'proxy assent' on recruitment to a randomised controlled trial of vaccination testing in care homes	UK-wide	N/A	Researcher	✓		
Windle et al.	2018	Mixed-methods longitudinal investigation	The impact of a visual arts program on quality of life, communication, and well-being of people living with dementia: A mixed-methods longitudinal investigation	Northeast England, UK	Care homes	48 care home residents	✓	✓	
Wood et al.	2013	Qualitative study	Consent, including advanced consent, of older adults to research in care homes: a qualitative study of	South Wales, UK	Care homes	14 care home residents, 14 relatives, 10 GPs, care home staff	✓	✓	

			stakeholders' views in South Wales						
Wylie et al.	2017	Pilot randomised controlled trial	Podiatry intervention versus usual care to prevent falls in care homes: pilot randomised controlled trial (the PIRFECT study)	East of Scotland, UK	Care homes	43 care home residents	✓	✓	✓
Zamir et al.	2018	Implementation study	Video-calls to reduce loneliness and social isolation within care environments for older people: an implementation study using collaborative action research	Devon and Cornwall, UK	Care homes	8 care home residents	✓	✓	
Zermansky et al.	2007	Reflective paper	Striving to recruit: the difficulties of conducting clinical research on elderly care home residents	UK-wide	N/A	Researcher	✓	✓	✓

Table 4. identified barriers and facilitators to the inclusion of UK care home residents in research

Barriers	Facilitators
Research Design	
<p>The sole use of existing networks, including ‘research ready’ care homes for example [33,36,47,51]</p> <p>Care home staff responsible for choosing who they deemed as eligible to participate [38-39,41,44,56-69]</p> <p>The research burden of the chosen methods of data collection, including monitoring periods were discussed in included articles [40,53-54,70-71]</p> <p>Designs which require significant time and environmental requirements such as private space [55,72-73]</p>	<p>The use of existing networks during recruitment [33-52]</p> <p>Piloting of the recruitment process [34,52]</p> <p>Researcher flexibility, including tailoring research methods and/or requirements to specific care home settings and/or residents [48-49,53-54]</p> <p>Researcher experience in care home settings [55]</p>
Understanding and beliefs about research	
<p>Resident</p> <ul style="list-style-type: none"> - Residents’ general lack of interest in participating in research, as well as initial 	<p>Resident</p> <ul style="list-style-type: none"> - Highlighting the potential benefits of research [53-54,72,79,80-81] - Residents’ altruism [54,76]

<p>interest and then disengagement [36-37,47,53,57,61,72,74-75]</p> <ul style="list-style-type: none"> - Resident misunderstanding about what research is, what is required of them, and other related concerns [76-78] <p>Care home staff</p> <ul style="list-style-type: none"> - Lack of care home staff understanding and negative beliefs about research, including underlying research motives [35,40,46,55,61,73,82-83] 	<p>Care home staff</p> <ul style="list-style-type: none"> - Ensuring true understanding about the nature of the research being conducted, and staff having positive beliefs about the research [48,77,83]
<p>Communication</p>	
<p>The approach to presenting research information to potential participants [61,76]</p> <p>Difficulties in communication, including those caused by cognitive impairment and loss of verbal skills [76,79]</p> <p>Fluctuations in resident capacity and in resident mood [53,57,74-75]</p> <p>Poor communication between care home staff researchers, and relatives [53,82]</p>	<p>The approach to presenting research information to potential participants [61,76]</p> <p>The communication of research information to residents in an accessible, tailored manner [46,57,61,70,72,76,84]</p> <p>Providing clear and honest information from the very start, as well as facilitating positive, clear and consistent communication with all stakeholders [48-50,52-54,67,69,72-73,76-78,80,82,85]</p>

<p>Poor communication between the research team and staff [34,49-50,73,76,79,83]</p>	
<p>Relationships</p>	
	<p>Researchers spending time at care homes before study commencement [35,44,69,73,76,84,86-87]</p> <p>The benefits of developing positive relationships with gatekeepers, such as care home managers, were [67,71]</p> <p>The use of a collaborative working style between the research team, residents, staff, and relatives [46,51,54,57,61,63,67,70,72,80,84-85,88-89,90-91]</p> <p>Providing personalised feedback and a feeling of inclusivity for care home staff and residents [48,50]</p>
<p>Eligibility criteria</p>	
<p>Resident</p> <ul style="list-style-type: none"> - Age limitations [33-39,40,56-59,60,70,92-103] - Comorbidity (e.g., learning disability, terminal illness, cognitive impairment) 	<p>Resident</p> <ul style="list-style-type: none"> - The allowance of another person being able to consent to participation on behalf of a resident who lacks the capacity to consent, i.e., a personal consultee [33,41-42,46,55,59,60-61,66,70,76-

<p>[39,41-42,56-57,60-62,70,76-77,79,92,94-95,98-111</p> <ul style="list-style-type: none"> - The exclusion of participants who lacked the capacity to consent to participation, with no option of utilising a personal consultee [35,38-39,43-45,63-65,70,74,95,100,105,111] - Exclusion of those who did not have an adequate ability to communicate, understand, or engage in conversation [38,45-46,60,62,104-105,109] - The requirement of a clinical diagnosis of dementia [37,42,58-59,100,103-105,109,111-113] - The requirement of an ability to understand and communicate in English [35,42,44,46,57,60,62,64,76-77,97,104-105,109,111] - The requirement of a study partner [54,111] 	<p>77,79,81,84-88,90,92-94,96-97,99,102-103,107-110,113-118]</p> <ul style="list-style-type: none"> - Utilising minimal eligibility criteria [33,43,45,51,54,66,81,86,90,93,106,108,112,115-116,119]
<p>Care home</p> <ul style="list-style-type: none"> - Location of care home [33-34,41-42,44,46,56,76,86,109] - Type of care home [33-34,37-38,42,44,46,56,76-77,112-113] - Size of care homes [34,38,42,46,59,86,92] 	

<ul style="list-style-type: none"> - Rating/quality of care homes, as decided by organisations such as the Care Quality Commission [34,37-38,46,48,68,76-77,112] - Care homes receiving special support from their local authorities were excluded in some included studies [112-113] 	
<p>Preference-based decisions</p>	
<p>Residents' expressions of perceptions of disempowerment, including lack of autonomy, confidence, apathy and having worries about research participation [46,57,61,63,66,76,113]</p> <p>A lack of awareness about research participation opportunities, and being overlooked with regards to participation [54,76,120]</p> <p>Relatives' unwillingness to take part, or in cases where personal consultee option was available, refused to consent or make a decision regarding resident participation, [40,53,57,85,88,92,121]</p> <p>The impact of gatekeeping and overprotective relatives [53,56,67,71-72,76,79,89,93,114,119]</p> <p>The impact of research ethics committees [55]</p>	<p>Providing residents with the opportunity to participate in research, by directly asking them [76]</p>

<p>The impact of legal frameworks [121]</p>	
<p>Care home staff and environment</p>	
<p>Time pressure felt by care home staff and workload factors [44,48-49,50,55,61,67,73,75,77-78,80,82]</p> <p>High staff turnover [40,50,54-55,67,72-73,80,83,85]</p> <p>Staff lack of interest, engagement and negative attitudes towards research, participation, and facilitation [40,46,48,55,57,61,77,79,83]</p> <p>A lack of confidence in facilitating research was discussed in two included articles [61,86]</p> <p>Perceived lack of support from the care home manager [35,76-77,80,83]</p> <p>The culture within care homes [54,56]</p> <p>A lack of private space and disruption of daily routines caused by research [35,56-57,61,67,69,75-76,79-80]</p>	<p>Providing and communicating the benefits and incentives of research participation to care home staff [48,50,52,54,73,108]</p> <p>Care home staff interest, support, and engagement in research [40,48,52,54,57,70,72-73,78,83,103,110,118]</p> <p>Manager interest in research [105,116]</p> <p>Providing staff training and opportunities for knowledge development as part of the research process [48,52,72,74,78]</p> <p>Manager support of the research study [76,79-80,83,104,110]</p> <p>Positive use of spaces that were chosen by residents, for example residents' own bedrooms, to conduct research [53,63,67,76,106]</p>

	The culture of care homes, specifically care homes with a culture of inclusiveness [46]
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Table 5. Advice and recommendations taken from included articles for modifying barriers and facilitators

Issues	Proposed solutions
Research Design	<p>Work with stakeholder organisations when designing studies e.g., Care Quality Commission (CQC), local authorities – consider the perspectives of each individual shareholder but also take into account the relationships and hierarchy both within a care home and between it and other organisations and health professionals</p> <p>Embed Public Involvement (PPI) throughout and consider how to support their involvement through taking account of residents’ needs due to cognitive impairment and physical frailty</p> <p>Allow care home staff to play a key role in identifying eligible residents, share information and introduce researchers to residents</p> <p>Consider how the consent arrangements will impact on the study – for example ensuring that residents who lack capacity to consent can participate through the involvement of a consultee or legal representative</p> <p>For each step in recruitment, make extensive plans that build in time, including time to be flexible in the face of unexpected hurdles. Adapt measures or questions to potential participants.</p>

	<p>Understand that recruitment is a resource intensive process and that it requires a lot of preparatory work. There are many layers of permissions needed to support the recruitment process in care homes</p> <p>Provide training so that staff can better understand how to support decisions about capacity and communication approaches, and ensure person-centred inclusion research processes</p> <p>Understand that the staffing pressure and the unique environment of care homes may impact on research – be patient, flexible, supportive and understand the complexities involved, and minimise additional workload for care home staff and any costs associated with taking part</p> <p>Identify realistic targets with the manager at the start. Take the time to learn about shift patterns and mealtimes – understand that care always comes first, research is not the top priority for staff</p> <p>Researchers should develop their skills in order to support residents with dementia to participate in research</p> <p>Be open, responsive, and sensitive – talk to, and work WITH, care home staff</p> <p>Provide accessible, tailored communication tools in order to have the best chance of supporting residents to understand the research and provide informed consent</p>
Communication	<p>Recognise that staff have an invaluable role in supporting residents to understand information about a study and maximise their ability to provide</p>

	<p>consent if they want to participate. Staff can act as a bridge for communication and advise researchers on any communication aids, best times to approach etc</p> <p>Ensure that staff have genuine understanding of the research study, so they share correct information, as well as developing a good relationship with them so that they are happy to help. Consider making them research partners so they feel more included and part of the team</p> <p>Communicate well with the care home so that staff know when researcher is coming so they can plan ahead – provide opportunities for meetings and be transparent</p> <p>Identify realistic targets with the manager at the start. Take the time to learn about shift patterns and mealtimes – understand that care always comes first, research is not a top priority for staff</p> <p>Provide accessible, tailored communication tools in order to have the best chance of getting residents to be fully informed and understand the research – e.g., use of pictorial or print text cards</p>
Relationships	<p>Care home managers can support with recruitment when explaining studies to residents, the early involvement of residents’ families, data collection that takes account of residents’ needs, tailored information and support for care home staff</p> <p>Understand the differences in each care home’s culture. The influence of the culture within a care home may impact on how care home staff engage with the</p>

	<p>research, define dementia, and interpret their roles as mediators, protectors and gatekeepers</p> <p>Develop good and trusting relationships with staff and demonstrate willingness to work with staff – be a respectful researcher and support staff, be guided by managers and staff, try to allay concerns faces by any of the stakeholders, provide active appreciation through feedback</p>
Eligibility criteria	<p>Avoid intentional and unintentional exclusion of potential participants because of age, multi-morbidity or frailty, or impaired capacity to consent</p>
Preference-based decisions	<p>Utilise legal arrangements that can be put in place if residents want to participate but have no family to act as a consultee/legal representative e.g., ensuring care home staff can act as a consultee/legal representative</p> <p>Provide accessible, tailored communication tools in order to have the best chance of getting residents to be fully informed and understand the research</p>
Care homes	<p>Allow care home staff to play a key role in identifying eligible residents, share information and introduce researchers to residents</p> <p>Staff can act as a bridge for communication</p> <p>Recognise that staff have an invaluable role in supporting residents to understand information about a study and maximise their ability to provide consent if they want to participate</p>

	<p>Staff can advise researchers on any communication aids, best times to approach etc</p> <p>Care home managers can support with recruitment when explaining studies to residents, the early involvement of residents’ families, data collection that takes account of residents’ needs, tailored information and support for care home staff</p> <p>Provide training so that staff can better understand how to support decisions about capacity and communication approaches, and person-centred inclusion research processes</p> <p>Become a ‘research ready’ care home</p>
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Abbreviations

- PPI** – Patient and Public Involvement
- CQC** – Care Quality Commission
- MCA** – Mental Capacity Act

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Availability of data and materials

Supporting data and materials used in this paper can be accessed online through various public databases. The datasets used and/or analyses during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors contributions

BN: investigation, formal analysis, writing – original draft, **VS:** conceptualisation, validation, supervision, writing – review and editing, **KH:** validation, supervision, writing – review and editing, **CW:** validation, supervision, writing – review and editing, **FW:** validation, supervision, project administration, writing – review and editing

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