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3 The uptake and use of a minimum data set (MDS) for older people living and dying in care
4 homes in England – a realist review protocol
5

6 **Corresponding Author:** Claire Goodman

7 Centre for Research in Public health and Community Care (CRIPACC) University of
8 Hertfordshire AL10 9AB

9 E-mail: c.goodman@herts.ac.uk

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15 **Contributing authors: Please insert your contact details**

Authors	E-mail addresses	Address
Mr Massirfufulay Kpehe Musa	m.musa2@herts.ac.uk	Centre for Research in Public health and Community Care (CRIPACC) University of Hertfordshire AL10 9AB
Dr Gizdem Akdur	g.akdur@herts.ac.uk	Centre for Research in Public health and Community Care (CRIPACC) University of Hertfordshire AL10 9AB
Professor Barbara Hanratty	barbara.hanratty@newcastle.ac.uk	Population Health Sciences Institute Biomedical Research Building (Second floor) Campus for Ageing and Vitality Newcastle University Newcastle upon Tyne NE4 5PL
Dr Sarah Kelly	sarah.kelly@thisinstitute.cam.ac.uk	Institute of Public Health University of Cambridge CB2 0SR
Dr Adam Gordon	adam.gordon@nottingham.ac.uk	School of Medicine University of Nottingham DE22 3DT

Dr Guy Peryer	g.peryer@uea.ac.uk	Faculty of Medicine and Health Sciences, University of East Anglia, NR4 7TJ
Professor Karen Spilsbury	k.spilsbury@leeds.ac.uk	School of Healthcare, Faculty of Medicine and Health, University of Leeds, Leeds, LS2 9JT
Dr Anne Killett	a.killett@uea.ac.uk	Faculty of Medicine and Health Sciences University of East Anglia Norwich Research Park NR4 7TJ
Dr Jennifer Burton	Jenni.Burton@glasgow.ac.uk	Institute of Cardiovascular and Medical Sciences, University of Glasgow, New Lister Building, Glasgow Royal Infirmary, G31 2ER
Professor Julienne Meyer	J.Meyer@city.ac.uk	National Care Forum
Ms Sue Fortescue	sfortescue@hotmail.co.uk	Alzheimer Society Research Network
Ms Ann-Marie Towers	a.towers@kent.ac.uk	Centre for Health Services Studies University of Kent CT2 7NF
Ms Lisa Irvine	l.irvine@herts.ac.uk	Centre for Research in Public health and Community Care (CRIPACC) University of Hertfordshire AL10 9AB
Professor Claire Goodman	c.goodman@herts.ac.uk	Centre for Research in Public health and Community Care (CRIPACC) University of Hertfordshire AL10 9AB

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27 **ABSTRACT**

28 **Introduction:** Care homes provide nursing and social care for older people who can no longer live

29 independently at home. In the UK, there is no consistent approach to how information about

30 residents' medical history, care needs, and preferences are collected and shared. This limits

31 opportunities to understand the care home population, have a systematic approach to assessment

32 and documentation of care, identify care home residents at risk of deterioration, and review care.

33 Countries with standardised approaches to residents' assessment, care planning and review (e.g.

34 Minimum Data Sets (MDS)) use the data to understand the care home population, guide resource

35 allocation, monitor services delivery and for research. The aim of this realist review is to develop a

36 theory-driven understanding of how care homes staff implement and use MDS to plan and deliver

37 care of individual residents.

38 **Methods and analysis**: A realist review will be conducted in three research stages.

39   ***Stage one*** will scope the literature and develop candidate programme theories of what
40   ensures effective uptake and sustained implementation of an MDS.

41   ***Stage two*** will test and refine these theories through further iterative searches of the
42   evidence from the literature to establish how effective uptake of an MDS can be achieved.

43   ***Stage three*** will consult with relevant stakeholders to test or refine the programme theory
44   (theories) of how an MDS works at the resident level of care for different stakeholders and in
45   what circumstances. Data synthesis will use realist logic of analysis to align data from each
46   eligible article with possible context-mechanism-outcome (CMO) configurations, or specific
47   elements that answer the research questions.

48 **Ethics and dissemination:** The University of Hertfordshire Ethics Committee has approved this study

49 (HSK/SF/UH/04169). Findings will be disseminated through briefings with stakeholders, conference

50 presentations, a national consultation on the use of an MDS in UK long-term care settings, publications

51 in peer-reviewed journals, and in print and social media publications accessible to residents, relatives,

52 and care home staff.

53 **Review registration number**: This review protocol is registered on the International Prospective

54 Register of Systematic Reviews (PROSPERO) - CRD42020171323.

55

56   **Keywords:** Care Home, minimum data set, geriatric assessment, nursing tools, older people care

57

BACKGROUND

There are nearly 12 million (11,989,322) people aged 65 years and above in the United Kingdom (UK) of which an estimated 1.6 million are aged 85 years and above, and more than 500,000 (579,776) people are aged 90 years and above.[1] However, with greater longevity (e.g. age 85 years and above) comes higher levels of dependency, dementia and comorbidity,[2] which in turn intensify the need for social care services.[3] Approximately 420,000 older people in England and Wales live in care homes.[4] Care home is a generic term that refers to facilities where a number of older people live together and have staff available 24 hours to provide personal care (e.g. residential care or assisted living/supportive housing facilities), and those facilities where a qualified nurse is required on duty 24 hours to provide additional nursing care for more dependent residents (e.g. nursing homes or skilled nursing facilities).[5] The care home population represents the oldest and most vulnerable group of older people,[6] with approximately 70% of them living with cognitive impairment,[6 7] and 76% requiring assistance with mobility.[8]

In the UK, there is no consistent approach to how information about residents' medical history, care needs, and preferences is collected and used. The absence of a national mandate, lack of links with National Health Services (NHS) data, and implementation challenges have meant that a minimum data set (MDS) and data-driven approaches to resident assessment have been limited to single projects.[9] The lack of a link between care home data and the NHS data recently became evident when figures reported by the Office for National Statistics during the first three weeks of Covid-19 underestimated the impact of the pandemic among care home residents.[10] All care homes, however, routinely collect

5

86 large amounts of data about their residents. The challenge is to establish systems of assessment and

87 recording that are evidence-based, accessible and valuable to those using, providing, commissioning

88 and regulating care services. Without a unified record there may be duplication of assessments,

89 communication failures and, unmet care needs.[11] [12] Over the next two decades the number of older

90 people likely to need long term care will increase;[2] so determining consistent ways to assess and

91 document care for residents in these settings is a priority.

92

93 A minimum data set (MDS) in this realist review is defined as a comprehensive, standardised account

94 of the characteristics and needs and ongoing care of residents living in long-term care (care home)

95 settings. The review concentrates on how an MDS is used by care home staff and what supports

96 effective uptake for the benefit of individual residents. It also takes account of the involvement of

97 residents themselves and their family in influencing how an MDS is used.

98

99 There are multiple versions of MDS, which are often country specific. However, all versions of MDS

100 share a common language and are designed to support an integrated system of care that can support

101 cross-sector clinical and managerial decision-making. One example of an MDS is the International

102 Resident Assessment Instrument (InterRAI), developed for long term care facilities (LTCF).[13] The use

103 of an MDS is often mandated and/or linked to national reimbursement systems and quality

104 monitoring. Research has demonstrated the value of an MDS to commissioners and service providers

105 in enabling identification of care needs and residents at risk of ill health.[14-18] They can provide a

106 comprehensive account of resident characteristics, resource use, and care outcomes in key areas (e.g.

107 activities of daily living, cognitive performance, pain, cost of care, and infection).[19] However, Kontos

108 and colleagues argue that a standardised process such as the MDS fails to consistently result in

109 individualised care planning, which may suggest problems with content of an MDS.[20]

110

111 For long term care settings making the transition to standardised approaches to data collection, little

112 is known about what needs to be in place to implement an MDS and how its use impacts on staff work,

113 time away from care, knowledge of the care home residents, working with other health care

114 professionals and benefits (or not) to residents, staff and residents' families.

115

METHODS AND ANALYSIS

Review aim and objectives

Aim

To develop a theory-driven understanding of how care homes' staff can effectively implement and use MDS to plan and deliver care of individual residents.

Objectives

1. Develop a programme theory describing contexts that can support the uptake and use of an MDS in care homes.

2. Identify in what circumstances the use of an MDS produces improved outcomes (including resource use) for an individual resident, their family, and the care home staff and their employing organisation.

Study design

We will conduct a realist review which seeks to formulate, test and refine the programme theory while assessing whether and how the programme succeeds in the local setting,[21] in order to generate important insights for the United Kingdom. A programme theory is an overarching theory or model of how a programme, or an intervention is expected to work[22] and it helps to explain (some of) 'how and why, in the "real world", a specific programme "works", for whom, to what extent and in which contexts'.[23] The unit of analysis in a realist review is the ideas and assumptions (i.e., the programme theories) that underlie an intervention and explain how it works to achieve the desired outcomes.

A realist review is an interpretive, theory-driven approach to evidence synthesis[24 25] to develop a programme theory of the causal processes and context-specific factors that can explain how an intervention or programme is expected to work. Realism is a methodological paradigm which sits between positivism (the world is real and can be observed directly) and constructivism (given that all we know has been processed through the human mind, we can never be sure exactly what reality is).[26] It is flexible to changes and embedded in a social reality that influences how a programme is implemented and how various actors in that reality respond to it.[21]

Programmes like the minimum data set (MDS) will always rely on human agency to affect change. A realist approach argues that the features or elements of the programme will produce a range of

147   potential responses to the programme which will impact on the outcomes.[21 24] It assumes that there

148   is a knowable, independent reality that will shape how different participants react to a programme,

149   whether they are aware of these influences or not.[27] Thus, uptake and implementation of an MDS can

150   lead to different outcomes for different stakeholders (e.g. residents and their relatives, staff,

151   commissioners, regulators) depending on who is involved, the resources available and how the MDS

152   is used.[28 29]

153

154   Using a realist approach,[21] there are four key linked concepts for explaining and building a theory of

155   how a programme works: (i) contexts (C), which are often the 'backdrop' of interventions;[24] (ii)

156   mechanisms (M), which are not observed directly but account for what it is about programmes that

157   make them work,[30 31] characterised as *"a process that bring about or prevents some change in a*

158   *concrete system"*[32] (iii) outcomes (O) of the intervention (planned or unplanned, visible or not) or

159   strategies of the intervention;[33] It is the Context-Mechanism-Outcome (CMO) configurations (models

160   indicating how programmes activate mechanisms for whom and in what conditions, to elicit

161   outcomes) that are the building blocks of the theory.[25] Thus, in care home settings, staff understanding

162   of their responsibility for completing an MDS could be a context (C), which triggers how staff prioritise

163   recording information as part of care work (M) to identify residents at risk of deterioration (O).

164

165   The review will follow Pawson's five practical stages of conducting realist reviews: clarify the scope of

166   the review, search for evidence, appraise primary studies and extract data, synthesise the evidence

167   and draw conclusions, and disseminate the findings.[21] Organised in three stages, we will first

168   undertake a scoping of the literature to identify care home specific work on the uptake of MDS and

169   develop relevant theories around staff uptake and implementation and outcomes specific to the use

170   of an MDS in long term (care home) settings. Stage two will test and refine the emergent theories that

171   underpin the use of an MDS and that leads to both intended and unintended outcomes for staff and

172   residents. Stage three will synthesise the findings to establish how and when the use of an

173   MDS achieves different outcomes for residents, families, staff and organisations.

174

Stages of the review process

Stage 1: Defining the scope of the review, identifying existing theories and theory development

This review is nested within a larger review ("*A systematic review of process and contextual factors that influence research implementation in care homes and identification of key measures and outcomes in care home research*"; PROSPERO reference: CRD42020155923). The literature identified from the larger review will be the starting point for the scoping work.

The scoping of the literature will focus on studies that report on how an MDS is used in long term care (care home) settings. Outcomes of interest will be established by the project team as an iterative process but are likely to include evidence of its impact on: accuracy of reporting, needs assessment, staff workload, quality of care, resource use, staff satisfaction and access to care.

Literature search strategy

Searches for relevant evidence will include databases of peer-reviewed literature (MEDLINE, EMBASE, CINAHL, ASSIA (Applied Social Sciences Citation Index and Abstracts) and sources of grey literature (including OpenGrey and websites of organisations relevant to care homes and care of older people). Studies for inclusion will be limited to English language. We will search data from January 2009 to March 2020. These initial searches will be complemented by:

1. Searching of both lateral and forward citations of included papers paying particular attention to seminal papers on the uptake and use of an MDS in long term care settings;

2. Contact with experts who have developed and/or use an MDS.

The search strategy will be iterative because predetermined linear search strategies are unlikely to generate search results that are adequate for purposes of conducting knowledge-building and theory-generating reviews.[34] Throughout the proposed review and based on the scoping review findings we will introduce new , targeted search terms not defined in the initial searches.[34 35] We will use search terms such as care homes, nursing homes, and skilled nursing facilities (Supplementary Table S1). We will then combine these terms with other terms such as MDS, Minimum Data Set, Inter-RAI, Research Assessment Instrument, and RAI using Boolean logic (Supplementary Table S1). A comprehensive list

204   of search terms and databases used will be provided in subsequent publications on completion of the

205   proposed research.

206

207   *Literature screening process*

208   Search results relevant to MDS will be downloaded into Covidence software. Screening and selection

209   of articles will take place in two stages (title and abstract, and full text).[36] Two reviewers (MKM and

210   GA) will independently screen titles and abstracts identified by electronic search and applied the

211   selection criteria to potentially relevant full-text papers.[37] The two reviewers (MKM and GA) will then

212   independently screen 10 articles and cross-check results to discuss emergent ideas and themes and

213   establish consensus on the relevance of the documents. Disagreement between MKM and GA will be

214   resolved by the third reviewer, CG.

215

216   Based on earlier work that used an MDS to collect data and cross team discussions,[38] the initial

217   programme theory will focus on how an MDS is used in long term care. This will be the basis for scoping

218   the literature on the challenges of changing systems of care, the need for a policy or regulator

219   mandate, how it affects patterns of working in the care home, staff involvement in data entry and

220   changes in residents' care. At this stage we will not be assuming causality but we will recognise that

221   these are likely to influence uptake and use and resident and staff outcomes. Studies that have used

222   MDS, or similar approaches to document resident, staff and organisational outcomes but do not

223   address questions of implementation and use will be reviewed to identify supplementary evidence on

224   related issues of interest (e.g. accuracy of data, time commitment and how information was used and

225   by who). The search strategy will include citation searching and grey literature, and will be iteratively

226   extended and refocused as the review progresses.

227

228   *Formulating initial programme theories*

229   At this stage, we will investigate demi-regularities in outcome patterns by developing a series of 'if-

230   then statements' from the scoping literature to summarise the dominant arguments and supporting

231   evidence of what supports the uptake and use of MDS in long-term care settings. This will inform the

232   development of hypotheses that posit possible contexts (C) that are the backdrop to successful (or

233   not) uptake[24] of MDS; the mechanisms (M) they trigger[32] and planned or unplanned Outcomes (O)

234   arising from the use of MDS.[33] Possible context-mechanism-outcome (CMO) configurations will be

235   discussed across the research team and with subject experts on MDS and will inform stage two of the

236   review phase and additional searches.

237

238   There are several ways to conceptualise the development and uptake of MDS as many have their roots

239   in medical approaches to assessment and health systems design. It is therefore likely that the review

240   will be informed by and aim to build on theories of implementation in long-term care,[32 39] uptake of

241   technological innovation[40 41] assessment of older people with complex needs,[2 4 8] person-centred

242   care,[42 43] and risk management and quality assurance.[44]

243

244   The introduction of an MDS in care homes is sensitive to the resource and policy constraints under

245   which the care homes operate. Candidate theories will therefore consider the role of the regulator

246   and legal frameworks that incentivise (or not) data sharing across organisations.

247

248

249   Literature selection, quality appraisal and data extraction criteria

250   There will be no restriction on the types of study design for eligibility.[45] Article selection will be based

251   on the extent to which research on the uptake and routine use of an MDS can contribute to the

252   development of a programme theory of implementation of MDS in long term care settings.

253

254   Included studies are likely to cover the following:

255   • Studies on the introduction and development of an MDS with care home staff;

256   • Studies that focus on the inclusion and engagement of care home staff, residents and their
257   representatives in sharing resident data with the specific remit of improving resident
258   outcomes;

259   • Implementation studies that provide evidence on what facilitates and inhibits the shared
260   documentation and care planning in care home setting including digital innovation;

261   • Studies on commissioning services for care homes based on care home generated data;

262   No geographical restrictions will apply, although we will only include studies that are published in

263   English and focus on the uptake and use of an MDS in long term care settings.

264

265

266   **Quality appraisal of included articles**

267   The quality of included papers will be carried out in accordance with previous appraisal work within a

268   realist project.[29 36] The quality appraisal of included studies will be combined with data extraction, a

269   technique usually employed in realist review.[46] Realist reviews employ various techniques to assess

270   the quality of evidence by drawing on evidence from a wider range of sources unlike traditional

271   systematic reviews that only focus on the methodological quality of studies.[29 36] As quality of evidence

272   is not limited to the methodological quality, or hierarchy of evidence in realist reviews,[29] each article

273   in this review will be assessed based on its trustworthiness and applicability to the research questions.

274   Consistent with the realist approach, we will use an iterative approach to determine whether an article

275   is considered "*good enough and relevant*" to answer our research questions.[47] Good enough will be

276   based on the reviewers' own assessment of the quality of evidence, for example if it is considered to

277   be of a sufficient standard for the research question, and relevance will relate to whether the authors

278   provided sufficient descriptive detail and/or theoretical discussion to contribute to the initial

279   programme theories development.[37]

280

281   The quality appraisal in this review will be assessed on a case by case basis considering the

282   opportunities for learning, scientific rigor of evidence and relevance to the review questions.[46] Two

283   reviewers (MKM and GA), in consultation with CG will lead this process. Weaker papers and those

284   with equivocal or negative findings will be considered if they contribute to the overall programme

285   theories.

286

287   **Data extraction**

288   Data extraction will be conducted on the basis of relevance to the review questions and will be based

289   on realist guidelines to address questions that explore "what is it that supports (or hinders) an MDS

290   implementation in care homes, and how care home staff use and interpret an MDS to guide residents'

291   care?"[36] From the extracted data, two reviewers (MM and GA) will independently rate the studies as

292 either yes, no, or maybe in terms of whether the particular article meets inclusion criteria. We will use

293 "maybe" for issues that cannot be answered based on the information available in the publication.

294 Then the two reviewers (MM and GA) will meet with a third reviewer (CG) who will serve as an

295 adjudicator to verify, confirm, or reject inclusion of the data. From relevant articles, several 'if-then'

296 statements will be made from which initial programme theories will be made.

297

298 **Data synthesis**

299 Data synthesis of the scoping phase will use realist logic of analysis to align data from each eligible

300 article with possible context-mechanism-outcome (CMO) configurations,[21] or specific elements that

301 answer the research questions. These emerging findings, and putative patterns of association within

302 the data will be tested further in stage two, to build causal explanations based on the observed

303 interactions between context, mechanism, and outcomes.

304

305 Stage 2: Testing and refining the programme theories

306 Further iterative searches of the evidence will be directly informed by the CMOs developed in stage

307 one as candidate programme theories. The iterative circle will continue throughout the course of the

308 review until theoretical saturation has been achieved. [21 48]

309

310 Data will be extracted using a bespoke data extraction form. It will include descriptive data on study

311 characteristics and is likely to focus on what can be learnt about the role and work of staff, the

312 resources required to implement an MDS, the features of the settings (e.g., workforce capacity, size

313 of care homes), explicit and implicit theories for how interventions were anticipated to work, and

314 patient and carer outcomes. A sample of the papers, including those that appear to offer most

315 learning and their completed data extraction forms will be shared across the project team to support

316 ongoing discussion and debate of the candidate theory(ies) and their supporting evidence.

317

318 Stage 3: Analysis and synthesis of evidence from the proposed programme theories

319 To support hypothesis refinement and "fine tune" the theory(ies) that show the most promise, we will

320 further test findings from stage two in a series of interviews.[49] We will do this through stakeholders'

321 consultation (Box 1). It is acknowledged in realist research that published literature alone cannot help

322   to unearth the reasoning of end users of a programme.[21 26 31] Therefore, the inclusion of primary data

323   from stakeholders in the review will be an added value.

324

325   We will carry out up to eight individual semi-structured interviews with frontline staff (staff from care

326   homes who use predominately paper based records and staff who routinely use electronic records for

327   their residents) and care home managers, and stakeholders who are experts regarding the use of care

328   home residents' data. The semi-structured interviews will be guided by emerging programme theories

329   from the early stages of the review.

330

331   Participants' selection will be purposive based on their knowledge of using MDS in and with care

332   homes. All participants will be sent a detailed participant information sheet via email and consent

333   form prior to the interview.   Interviews will be either h face-to-face, online, or telephone

334   conversations. Interviews will be audio recorded and transcribed.[21] Data will help to refine or refute

335   the demi-regularities seen in outcome patterns emerging from the empirical literature.[26].

336

337   At the end of the interviews, we will present and discuss the programme theories, with the

338   supporting evidence for discussion, with the whole research project team.

339

340
| **Box 1: Stakeholders' consultation** |
| During stakeholders' consultation interviews, we will explore: |
| i)   The fit between the emerging programme theories and how stakeholders understand what is needed for the development and use of MDS in long term care settings
    ii)   Alternative explanations stakeholders identify as relevant for the successful use of MDS by care home staff |

345   A summary of the review process is presented in Figure 1. The double arrows within or between

346   stages indicate iterative processes of the review.

347

348   *Figure 1: The Realist Review Processes*

350 The final programme theories will be synthesised narratively, by logic models, and/or summary
351 tables where appropriate. The findings of the review will be written up according to the Realist And
352 Meta-narrative Evidence Syntheses: Evolving Standards (RAMESES) guidance.[48]

353

Patient and Public Involvement

355 To keep the person being cared for at the centre of our thinking in ways that inform delivery of care

356 or care home resident benefit, we will convene two care home based resident Patient and Public

357 Involvement (PPI) groups that will meet throughout this review project. A member of this realist

358 review, who is a former carer and IT specialist, will lead the PPI groups. We anticipate that input

359 from residents and carers will help us to identify and understand the important contextual factors,

360 and the resource and reasoning that support the implementation of an MDS in long term care

361 settings. The PPI groups input will help us to tailor the stakeholders' consultation, inform our theory

362 (or theories) development and ensure that the final refined programme theory(ies) resonates with

363 care home staff and residents' experience.

364

DISCUSSION

366 This realist review will provide a theory-driven understanding of what needs to be in place for the

367 successful implementation an MDS systems in care home settings to benefit residents, staff, families,

368 service managers and commissioners.

369

370 Research has demonstrated the value of minimum data sets to commissioners and service providers

371 in the identification of care needs.[50-54] A research study that used care home specific MDS identified

372 specific implementation challenges.[38] It enabled comprehensive analysis of baseline resident data and

373 residents at risk but there was limited staff capacity to support and sustain its completion over time

374 when it was not linked to other data collection responsibilities.[38] This review addresses a gap in the

375 evidence about what is needed to support uptake and implementation of an MDS, what needs to be

376 in place for effective uptake and how an MDS is used in different circumstances to enable key care

377 outcomes for residents. By identifying the causal mechanisms at work the review findings will directly

378 inform decision-making about how to design, tailor and implement an MDS that is acceptable to staff

379 and can inform residents' everyday care.

407

CONTRIBUTORS

Concept and design of the review are embedded in the Developing research resources And
minimum data set for Care Homes' Adoption and use (DACHA) study. SK conducted the initial
literature search and MKM, GA and CG wrote the first draft of the manuscript. Critical review and
refinement of the manuscript was provided by GP, KS, AK, JB, BH, AG, JM, SF, AMT and LI. MKM, GA
and CG approved the final version.

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Supplementary Table S1: Proposed search terms for care homes minimum data set (MDS)

1. Combined searches for scoping review and process evaluation review (DACHA Study's workpackage-1)

1. *Homes for the Aged/
2. *Nursing Homes/
3. *Long-Term Care/
4. *Residential Facilities/
5. *Respite Care/
6. *Intermediate Care/
7. "care home$".ab,ti.
8. "nursing home$".ab,ti.
9. "residential care".ab,ti.
10. ("long term care" or "long-term care" or "longterm care").ab,ti.
11. "home$ for the aged".ab,ti.
12. "care facilit*".ab,ti.
13. "old$ people$ home$".ti,ab.
14. (retir$ adj2 home$).ab,ti.
15. ("old$ adult$" adj3 (facilit$ or residential or accommodation)).ab,ti.
16. ("old$ people$" adj3 (facilit$ or residential or accommodation)).ab,ti.
17. ("old$ person$" adj3 (facilit$ or residential or accommodation)).ab,ti.
18. ((geriatric$ or elder$ or senior$ or retir$) adj3 (facilit$ or residential or accommodation)).ab,ti.
19. "respite care".ti,ab.
20. "intermediate care".ti,ab.
21. or/1-20
22. *Randomized Controlled Trials as Topic/
23. Randomized controlled trial/
24. Random allocation/
25. Double blind method/
26. Single blind method/
27. Clinical Trial/
28. Clinical trials as Topic/
29. "randomi*ed".ab,ti.
30. randomly.ab,ti.
31. controlled clinical trial.pt.
32. Evaluation Study/
33. Comparative Study/
34. "before and after study".ti,ab,mp.
35. or/22-34
36. "Outcome and Process Assessment (Health Care)"/
37. *Implementation Science/
38. "process evaluation".ab,ti.
39. (process$ adj3 evaluation$).ab,ti.
40. (program$ adj3 evaluation$).ab,ti.
41. implementation.ab,ti.
42. context$.ab,ti.
43. fidelity.ab,ti.
44. or/36-43
45. *Qualitative Research/
46. *Focus Groups/
47. *Interviews as Topic/
48. *Narration/
49. (("semi-structured" or semistructured or unstructured or informal or "in-depth" or "indepth" or "face to face" or structured or guide) adj3 (interview$ or discussion$ or questionnaire$)).ab,ti.
50. or/45-49
51. 44 or 50
52. 21 and 35
53. 51 and 52
54. limit 52 to yr="2009 -Current"
55. 53 or 54

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