

## MODEM: a comprehensive approach to modelling outcome and costs impacts of interventions for dementia. Protocol paper

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1           **MODEM: A comprehensive approach to modelling outcome and costs impacts of**  
2                                   **interventions for dementia. Protocol paper**

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27

## 28 **ABSTRACT**

### 29 **Background**

30 The MODEM project (*A comprehensive approach to MODelling outcome and costs impacts*  
31 *of interventions for DEMentia*) explores how changes in arrangements for the future  
32 treatment and care of people living with dementia, and support for family and other  
33 unpaid carers, could result in better outcomes and more efficient use of resources.

### 34 **Methods**

35 MODEM starts with a systematic mapping of the literature on effective and (potentially)  
36 cost-effective interventions in dementia care. Those findings, as well as data from a  
37 cohort, will then be used to model the quality of life and cost impacts of making these  
38 evidence-based interventions more widely available in England over the period from now  
39 to 2040. Modelling will use a suite of models, combining microsimulation and  
40 macrosimulation methods, modelling the costs and outcomes of care, both for an  
41 individual over the life-course from the point of dementia diagnosis, and for individuals  
42 and England as a whole in a particular year.

43 Project outputs will include an online *Dementia Evidence Toolkit*, making evidence  
44 summaries and a literature database available free to anyone, papers in academic journals  
45 and other written outputs, and a *MODEM Legacy Model*, which will enable local  
46 commissioners of services to apply the model to their own populations.

### 47 **Discussion**

48 Modelling the effects of evidence-based cost-effective interventions and making this  
49 information widely available has the potential to improve the health and quality of life

50 both of people with dementia and their carers, while ensuring that resources are used  
51 efficiently.

52

### 53 **Keywords**

54 Dementia, costs, outcomes, treatments, social care, carers, microsimulation model,  
55 economics, cost-effectiveness

56

### 57 **BACKGROUND**

58 There are currently around 835,000 people in the United Kingdom (UK) who have dementia  
59 [1], and an estimated 670,000 unpaid dementia carers, most of them family members [2].

60 If current rates of prevalence of dementia by age and gender remain unchanged, this  
61 number will grow to more than 1 million by 2021 and 2 million by 2051 as a consequence  
62 of population ageing [1]. Even if prevalence rates are declining slightly, as some recent  
63 studies suggest [3, 4] the numbers of people living with dementia will still increase  
64 nationally and globally, where it is projected that the number will grow from 46.8 million  
65 people today, to 131.5 million in 2050 [5].

66 If service models remain unchanged, the costs of treatment and care for people with  
67 dementia are likely to increase more rapidly than total prevalence over the same period,  
68 since care services are highly labour-intensive and wage inflation usually runs ahead of  
69 other price increases. This will put considerable pressure on already stretched health and  
70 social care budgets and generate major increases in reliance on family carers. (We use the  
71 term ‘family carers’ in preference to ‘unpaid’ or ‘informal’ carers as neither of the latter  
72 terms is fully accurate; most carers of people with dementia in England are family  
73 members and our reference group have expressed a preference for this term.)

74 The MODEM project (*A comprehensive approach to MODelling outcome and costs impacts*  
75 *of interventions for DEMentia*) explores how changes in arrangements for the future  
76 treatment and care of people with dementia, and support for carers, could result in better  
77 outcomes and more efficient use of resources. To do this, the MODEM team is reviewing  
78 international evidence on effective and (potentially) cost-effective interventions in  
79 dementia care, and then using those findings, with analyses of existing and new cohort  
80 data, to model the quality of life and cost impacts of making these interventions more  
81 widely available in England over the period from now to 2040. The MODEM project began  
82 in 2014 and runs until February 2018. It is funded by the UK Economic and Social Research  
83 Council (ESRC) and the National Institute for Health Research (NIHR).

84

## 85 **Conceptual framework**

86 Conceptually, the project is rooted in the ‘disablement process’ model and the  
87 ‘production of welfare’ framework.

88 The ‘disablement process’ model, proposed by Verbrugge and Jette [6], builds on previous  
89 models developed by the World Health Organization (WHO) and others. It conceptualises  
90 the ways in which needs for long-term care arise (from pathology to impairments in  
91 specific body systems which lead to restrictions in basic physical and mental actions, and  
92 finally to disability), as well as how and at what stages individual risk factors and  
93 environmental factors might influence this process. Similarly, the International  
94 Classification of Functioning, Disability and Health (ICF) describes decreases in function as  
95 the complex and dynamic interaction of health conditions (pathology) with extra- and  
96 intra-individual factors acting to mitigate or exacerbate the process [7]. However, where  
97 the endpoint of the Verbrugge and Jette model was disablement, the ICF outline includes  
98 participation in society as the ultimate goal to attain. In addition, the more linear  
99 pathway from disease to disability in the Verbrugge and Jette model has been loosened.

100 At each stage of the disablement process (in this model) there are potential opportunities  
101 to halt or even reverse the process. These include altering individual risk factors for  
102 chronic conditions (e.g. through changes in lifestyle, such as smoking and exercise) or  
103 implementing improvements in the management of chronic conditions. The consequences  
104 of functional limitations associated with disability can also sometimes be reduced through  
105 aids and adaptations, information and communication technology, occupational therapy,  
106 suitable housing or relevant changes in the wider environment.

107 Once needs have emerged, we use the 'production of welfare' framework [8, 9] to capture  
108 the potential relationships between needs, resources and outcomes. This framework has  
109 underpinned much of the work of the Personal Social Services Research Unit (PSSRU) in  
110 social care, mental health and other areas over a 40-year period. The framework  
111 represents a simplification of the multifarious links between budgets, staff and other  
112 'inputs' (and their associated costs), the services that are produced, the 'non-resource'  
113 influences on what services can achieve (such as personal resilience and staff attitudes)  
114 and the health and wellbeing outcomes that potentially result for people with dementia,  
115 their families and relevant others.

116

## 117 **Project aims and objectives**

118 The MODEM project aims to generate new evidence to inform policy and practice to better  
119 and more efficiently meet needs, promote health and wellbeing for people with dementia  
120 and their family and other carers.

121 The project objectives are to:

- 122 1. build a comprehensive conceptual, integrated framework that covers impacts of  
123 dementia on cognition, functioning and behaviour, responses from carers, responses  
124 from health and social care systems, the effectiveness and resource impacts of these  
125 interventions, and the potential long-term funding implications;

- 126 2. develop a suite of linked quantitative models, employing both microsimulation and  
127 macrosimulation techniques, to project future numbers of people with dementia, their  
128 dependency and other needs, comorbidities, levels of unpaid and formal care and  
129 associated expenditure;
- 130 3. to estimate typical life-time costs of dementia, under varying assumptions about risk  
131 factors, patterns of care and support, and preferences;
- 132 4. review the literature for evidence on interventions that could delay onset, slow  
133 deterioration in cognition, functioning or behaviour, or reduce their adverse impacts  
134 on health wellbeing, both for people with dementia and carers, and also evidence on  
135 costs;
- 136 5. gather evidence on the lives of people with dementia and their carers by collecting  
137 primary data from a new cohort, by conducting qualitative interviews and focus  
138 groups, and by examining data from previous trials and observational studies;
- 139 6. use the evidence from objectives 4 and 5, in combination with the micro- and macro-  
140 simulation models, to produce projections to 2040 of the numbers of older people with  
141 dementia in England, their needs for care and support, and associated public and  
142 private expenditure, together with projected outcomes and costs of a range of  
143 interventions to prevent or delay dementia incidence, slow symptom development,  
144 provide treatment and care, and support carers;
- 145 7. develop a *Dementia Evidence Toolkit* to make available evidence summaries of the  
146 effectiveness and cost-effectiveness of dementia care and treatment interventions and  
147 a searchable bibliographic database; and
- 148 8. develop a publicly available web-tool (*MODEM Legacy Model*) to enable service  
149 commissioners, providers, advocacy groups, individuals and families to access the  
150 findings and outputs of the project, and to make their own projections of expected  
151 needs for care and support, outcomes and costs.

152

153 **METHODS**

154 ***Over-arching research strategy***

155 We first provide an over-arching summary of the interconnected activities of the project,  
156 and then describe each of the main elements in more detail.

157 We are engaging with people living with dementia, carers and others at all stages of the  
158 project. We are starting by examining extant data to understand the links between the  
159 characteristics of individuals and families, their dementia-related and other needs for care  
160 and support, and the services and treatments that could be available to them. We are  
161 then looking at the effects of care, support and treatments on outcomes for individuals  
162 and carers - how those interventions can improve their health and wellbeing - and also on  
163 the costs of support.

164 We will use this information, as well as specially collected data from a cohort, to make  
165 projections of how many people there will be with dementia in England over the period to  
166 2040, the family or other unpaid support they are likely to have available, and the costs to  
167 provide care services for them. Second, we are examining whether there are better ways  
168 to support people with dementia and their carers by making evidence-based forms of care  
169 and treatment more widely available. We are relying on previous evaluations of these  
170 interventions to demonstrate the effects on health and wellbeing, and on costs. We are  
171 potentially including a wide set of interventions, including medication, cognitive  
172 stimulation and other therapies, exercise programmes, nutrition advice, telecare, case  
173 management, community initiatives, respite and training for carers.

174 We are also collecting primary data from a new cohort 300 people with dementia and their  
175 carers at two points of time, 12 months apart. We are not testing any interventions with  
176 these people; rather, we are collecting information to allow an analysis of the relationship  
177 between measures (i.e. 'cross-walking') and to fill gaps in available evidence. We are



178 additionally conducting qualitative interviews and focus groups to gain further  
179 ‘experiential’ evidence.

180 A range of quantitative methods will be used, including dynamic micro-simulation  
181 projection modelling, to understand the disabling consequences of dementia, and a series  
182 of care pathways models to show how evidence-based interventions can influence  
183 outcomes, service use and costs. A life-time costs model will generate estimates of the  
184 overall costs of the care pathway for each intervention, and a macro-simulation projection  
185 model will generate estimates of long-term care needs and costs to 2040.

186 Our final task will be to create a ‘MODEM legacy model’ to allow commissioners,  
187 providers, individuals and advocacy groups to make their own projections of needs,  
188 outcomes and costs using our estimates.

189

#### 190 ***Involving people with dementia, carers and other stakeholders***

191 The project benefits from the regular input of key stakeholders, including members of our  
192 overarching Advisory Group, our Reference Group of people with dementia, carers and  
193 service providers, and our Impact Advisory Group (chief executives and public policy  
194 leads). The research team is building on existing links with key central government  
195 departments in England (e.g. Health, Communities and Local Government, Work and  
196 Pensions, and Treasury), third sector organisations (e.g. Alzheimer’s Society, Alzheimer’s  
197 Research UK, Carers UK), National Health Service (NHS) England and Public Health  
198 England, and local councils and their umbrella bodies (the Association of Directors of Adult  
199 Social Services, Local Government Association).

200

#### 201 ***Mapping the literature and conducting evidence reviews***

202 A systematic mapping of relevant literature will be conducted with the aim of identifying  
203 interventions that can prevent or delay dementia onset, reduce symptom severity and/ or  
204 improve quality of life of people with dementia and/ or family and other carers.

205 We are first identifying previously published systematic reviews and meta-analyses and  
206 then searching for papers that have not been included in previous systematic reviews (for  
207 example, because they have been published more recently). We will also identify relevant  
208 literature in areas that have not been covered by previous reviews, carrying out our own  
209 new reviews where there are gaps.

210 Our careful consideration of the available evidence will inform the selection of  
211 interventions to be modelled later in the project.

212 The review of evidence should be of value in its own right as it will identify areas in which  
213 there is strong existing evidence, as well as where there has been little research  
214 undertaken and interventions for which there is insufficient evidence. Some of the outputs  
215 from the evidence review, a coded bibliographic database and a set of evidence  
216 summaries written in non-technical language, will be made publicly available through a  
217 website, the *Dementia Evidence Toolkit*, so that people with dementia, carers, care  
218 providers, commissioners, researchers and others can access the resources.

219 It is expected that the review process will also draw out the implications of using different  
220 research methods for the usability of evidence in modelling and in commissioning.

221

222 ***Modelling future numbers of people with dementia and their carers, costs and***  
223 ***outcomes***

224 The core of the project involves the development of a suite of linked quantitative models,  
225 using micro- and macro-simulation, to project future numbers of people with dementia,  
226 unpaid and formal care and associated expenditure, and to estimate typical life-time costs

227 of dementia. The projections will be based on assumptions about risk factors, patterns of  
228 care and support, and individual preferences.

#### 229 *Macrosimulation model*

230 We are developing a macro-simulation model to produce overall projections of future  
231 numbers of people with dementia and future expenditures on their treatment and care. It  
232 will take as inputs the outputs of the microsimulation and interventions models described  
233 below. This model builds on previous cognitive impairment and long-term care models  
234 developed at PSSRU [10, 11]. It projects future use of care and associated costs and  
235 quality of life of people with dementia and carers.

236 A key feature of this new model is that it will differentiate between groups of people with  
237 dementia by severity of cognitive impairment and physical disability, and it will 'assign'  
238 packages of care to people with dementia based on their characteristics including severity  
239 of condition and comorbidities. The model will use data from the latest MRC Cognitive  
240 Function and Ageing Study (CFAS II) [12], the English Longitudinal Study of Ageing (ELSA)  
241 [13], official data from the Health and Social Care Information Centre, the baseline data  
242 of various trials of interventions for people with dementia (see below) and new data  
243 collected as part of this study (the cohort study described above).

#### 244 *Microsimulation epidemiological model*

245 A micro-simulation population model (MicSIMPOP) is being developed to examine the  
246 health and associated care needs of the English population over the coming decades, and  
247 the impact of interventions for risk factor reduction, disease prevention and treatments  
248 that slow down progression to disease (including dementia) and disability. This is a more  
249 comprehensive, up-to-date version of a previous macro-simulation population model  
250 (SIMPOP) [14].

251 The model will be based on longitudinal data from *Understanding Society* (adults 35 years  
252 and over in community dwellings [15]), ELSA (adults aged 50 years and over in community

253 dwellings) and the new CFAS II cohort (adults 65 years and over, including those in  
254 institutions). These three datasets, suitably weighted, will allow inferences to be made for  
255 the older English population (65 years and over) to 2040. Baseline characteristics  
256 generated on these individuals will be of three types: socio-demographic (differentiated  
257 by the following variables: age, gender, living arrangements, marital status, education,  
258 retirement status); lifestyle behaviours (smoking, alcohol consumption, physical activity,  
259 body mass index, social engagement); and diseases (cognitive impairment/ dementia,  
260 coronary heart disease, stroke, hypertension, diabetes, respiratory disease, arthritis,  
261 cancer) as well as geriatric conditions (hearing and vision impairment). Mortality rates  
262 from the most recent population projections will be applied by age and gender. The  
263 outcome variable will be disability measured by the interval of need scale [16], which  
264 categorises people on the basis of Activities of Daily Living/ Instrumental Activities of Daily  
265 Living in terms of the intensity of care required.

266 The primary output will be tabulations of disability by age and gender in the presence of  
267 cognitive impairment/ dementia and any other diseases which will be used as inputs to the  
268 macro-simulation framework model described earlier. The issue of co-morbidity will  
269 become crucial when determining the types of care packages required, and their cost. For  
270 other conditions, known trends in disease risk factor prevalence will be incorporated, such  
271 as smoking and obesity, as well as changes in socio-demographic variables (education,  
272 marital status, living circumstances). We will use bootstrapping to provide measures of  
273 uncertainty around estimates; the work will also include individual biographies to feed  
274 into the life-time costs model as well as calculation of disability-free life expectancy to  
275 allow exploration of the likelihood of compression or expansion of disability given  
276 different health scenarios.

### 277 *Intervention modelling*

278 The impact of interventions in dementia care, particularly the impacts on costs and  
279 outcomes of care for particular groups of people with dementia and for their family and

280 other carers, will be modelled using intervention-specific models. The degree of  
281 sophistication of the models will vary depending on the nature of the impacts of different  
282 interventions and the type of evidence available on them. We envisage that some of the  
283 models may be simple decision models, while we expect to be able to carry out  
284 microsimulation analyses for other interventions. The outcomes of interventions modelling  
285 will be integrated into the macro-simulation model to produce national-level projections  
286 of changes in costs and quality of life arising from their wider adoption.

287 We will model only one intervention at a time, except in cases where we have evidence of  
288 combinations of interventions being evaluated together, such as maintenance cognitive  
289 stimulation therapy and donepezil [17, 18]. This is because we are not able to assess the  
290 'additive' impact of different interventions unless they have already been evaluated in  
291 combination.

292 The choice of interventions included in this modelling will be influenced by what we find  
293 from our evidence reviews (described earlier), by what data we can access (either directly  
294 on those interventions or by parameter estimation in simulation models) and by the views  
295 of experts in the field.

#### 296 *Lifetime model*

297 We are also developing a 'lifetime' model to examine the individual costs of dementia  
298 over a lifetime, and the impact on quality of life. This model considers the average  
299 duration of dementia from onset (i.e. the time at which it could first be diagnosed) to end  
300 of life. This duration is divided between periods of mild, moderate and severe dementia,  
301 and between residence in the community and in a care home. Costs of care appropriate to  
302 the severity of cognitive impairment and the type of care are attached to each month of  
303 the dementia pathway, and costs are then aggregated over the whole duration with  
304 dementia.

305

306 **Data sources**

307 As there is no single dataset that has all the data we need for the modelling, we will bring  
308 together data from a variety of sources. As we have already described, the  
309 epidemiological model will draw upon data from three major longitudinal studies:  
310 Understanding Society, ELSA and CFAS II, this being the first time that these three studies  
311 have been combined. We also use data from ELSA and the Health Survey of England (HSE)  
312 to complement the information on use of care services and unpaid care at national level.  
313 For our intervention models, we will carry out detailed modelling of the impact of  
314 interventions on costs and outcomes using individual-level baseline or 'usual care' group  
315 data from a number of recently completed or ongoing dementia trials in the UK (details  
316 available on request). In this way we can understand the relationships between particular  
317 patterns of needs (e.g. cognitive impairment, behaviour, functional disability), individual  
318 characteristics (e.g. age, gender, co-morbidities) and circumstances (e.g. living alone,  
319 socioeconomic status) of the person with dementia and their carers.

320

321 ***Primary data collection***

322 Since our models will combine data from various population surveys, clinical trials and  
323 observational studies, we need to be able to combine and compare different measures of  
324 the same underlying domains (e.g. cognition, carer impact or quality of life). We are able  
325 to use trial' data to explore associations between two or more different measures of the  
326 same domain, but these only provide some of the information we need. We are therefore  
327 collecting primary data from a cohort of people with dementia and carers.

328 In face-to-face interviews, we ask 300 dyads of people with a diagnosis of dementia and  
329 their carers to complete a selection of overlapping measures of need, care use and  
330 outcomes. Analysis of the resulting data enables us to 'cross-walk' between the different  
331 measures and studies. In addition the dataset will provide valuable information in its own

332 right. For example, we use an adapted version of the Client Service Receipt Inventory  
333 (CSRI) [19] so that, as well as gathering information on use of services by people with  
334 dementia and support from family and other carers, evidence can be built up on some key  
335 associations (such as carer age and gender, and their links to carer wellbeing).

336 Individuals included in this cohort study have been identified from the clinical populations  
337 served by the Sussex Partnership NHS Foundation Trust with support for recruitment  
338 through the Join Dementia Research initiative funded by the Department of Health and  
339 delivered in partnership with the National Institute for Health Research, Alzheimer  
340 Scotland, Alzheimer's Research UK and the Alzheimer's Society. Participants are drawn  
341 from East and West Sussex and Brighton and Hove, a population of 500,000 older adults,  
342 which includes an estimated 30,000 people with dementia; similar to the national  
343 population except with respect to deprivation and ethnicity (although it is unlikely this  
344 will have a major bearing on the cross-walking of parameters). People with dementia  
345 involved in the study all have a clinical diagnosis of dementia, established using ICD-10  
346 criteria. The cohort is being stratified by dementia severity, with 100 people with mild  
347 dementia (i.e. scoring 20+ on the standardised Mini-Mental State Examination (sMMSE)  
348 [20]), 100 people with moderate dementia (scoring 10-19) and 100 people with severe  
349 dementia (scoring 0-9). A sample of 300 subjects gives sufficient precision to generate the  
350 insights we need into relationships between variables.

351 People with dementia and their carers are being interviewed at baseline and 52 weeks  
352 later in either the clinic that they usually attend or in their own home. Interviews are  
353 designed to minimise respondent burden while still collecting comprehensive data. Data  
354 collection is split between people with dementia and carers, who are interviewed  
355 simultaneously by researchers operating in pairs. Individuals are sent a written invitation  
356 to take part in the study by their clinical team; this is followed up by telephone contact to  
357 arrange a home or clinic visit. At the first meeting the researchers assess capacity and

358 obtain appropriate consents; if consent is given, the people with dementia and their main  
359 family carer are interviewed.

360

361 ***Analysing relationships between characteristics, needs, resources and outcomes***

362 A key part of the project involves gaining a better understanding of the relationship  
363 between the individual characteristics and circumstances of both people with dementia  
364 and unpaid carers, their needs, resources, and how these relationships are likely to affect  
365 the outcomes of interventions. We are using both quantitative and qualitative methods to  
366 understand these relationships, which will provide the key parameters for the models. We  
367 are focussing in particular on the following areas.

368 *Relationships between personal characteristics, need factors, use of paid and unpaid care*  
369 *and quality of life*

370 Using as a framework the 'production of welfare' approach, we are analysing a number of  
371 datasets to understand better the relationships between personal characteristics such as  
372 age, gender, household type, education, severity and type of care needs, the use of family  
373 and paid care, and the quality of life of people with dementia and their carers.

374 Multivariate analyses will provide us with parameters that will be used in the simulation  
375 models (see above).

376 *Social interaction and participation over the life-course*

377 Factors associated with cognitive ability and dementia include age, gender, education,  
378 socioeconomic status, and smoking [21]. There is also growing awareness of the protective  
379 or buffering effect of social participation, while indicators of social isolation are risk  
380 factors for cognitive decline [22, 23]. This may reflect both effects of social interaction on  
381 cognition and effects of social resources on coping strategies adopted in the face of  
382 impairment, as proposed in the theoretical models of selection, optimisation and  
383 compensation [24]. As children are an important source of social support for older people,



384 we have investigated whether fertility histories are associated with social participation  
385 and with cognitive function in later life [25]. Results suggest disadvantages for childless  
386 older people, even after taking into account socio-economic status, health-related  
387 behaviours and social contacts. We are undertaking further work on possible direct or  
388 indirect effects of long-term social interaction on cognitive functioning in early and later  
389 old age. We are also examining the effect of accumulated social support networks on  
390 formal help-seeking and receipt of services, among those with cognitive impairment.

391 'Cognitive reserve' is a widely used construct to explain how, in the face of  
392 neurodegenerative changes similar in nature and extent, individuals vary in their severity  
393 of cognitive ageing and clinical dementia [26]. People with high reserves may have  
394 increased capacity for continued learning and adaptation, despite age-related changes.  
395 Data on cognitive functioning are taken from the National Child Development Study (NCDS)  
396 and ELSA [27]; both used the same measure at key waves (age 50 for NCDS (and  
397 educational performance indicators up to age 16); ages 50 and above from Waves 1-5 of  
398 ELSA). They also include measures of social networks, support and, in the case of ELSA,  
399 service use. Social interaction is defined in terms of contacts with social network  
400 members, and includes size, type, and support; social participation is defined by  
401 engagement in social and leisure activities, including physical activity.

#### 402 *The wellbeing of family carers: investigating gender and relational differences*

403 A PhD studentship attached to MODEM (held by KL) is investigating the influence of age  
404 and gender on the wellbeing of male and female family carers of people with dementia,  
405 distinguishing those of the same and next generation. The two core research questions  
406 are:

- 407 • Are there measurable differences in the wellbeing of male and female family carers  
408 for people with dementia of the same and next generation?

- 409 • Does the wellbeing of unpaid carers for people with dementia differ from the general  
410 British population?

411 To answer this research question, data from three sources will be pooled and analysed:  
412 the StrAtegies for RelaTives study (START) [28], the Support at Home: Interventions to  
413 Enhance Life in Dementia: Carer Supporter Programme –Remembering Yesterday Caring  
414 Today (SHIELD CSP RYCT) [29] and data from the MODEM cohort described above. All three  
415 studies share important variables on carer characteristics, standardised measures for carer  
416 wellbeing, as well as some important variables related to the person with dementia.

417 The second part of this PhD work focuses on the qualitative aspects of how men and  
418 women of different ages experience the provision of unpaid dementia care and construct  
419 wellbeing. In-depth interviews are being conducted with participants of the MODEM cohort  
420 study. Thematic analysis will be used to analyse the data.

421 The third part investigates the costs incurred by family carers. For this an amended form  
422 of the Resource Utilization in Dementia (RUD) instrument [30] is being collected as part of  
423 the MODEM cohort study. The study aims to analyse whether there are differences in costs  
424 by gender and relationship to the care recipient.

#### 425 *Understanding the experiences of people with dementia and their carers*

426 Interactive focus group settings will provide opportunities for people with dementia and  
427 family carers to discuss their attitudes, beliefs and experiences with others. The  
428 discussions will be based on issues emerging from the modelling and cohort survey, with  
429 potential participants to be recruited through voluntary sector organisations for people  
430 with dementia and carers, and the team's existing contacts. The groups will help provide  
431 insights and understandings for interpreting quantitative findings, including carers'  
432 experiences of the processes of accessing dementia-related services.

433 Group discussions have potential advantages over individual interviews for people with  
434 cognitive impairments, including enhanced quality of interaction, reduced pressure on

435 individuals to respond, mutual support, and that shared experiences can trigger ideas and  
436 memories.

437 Using skilled facilitators with experience of working with people with dementia has been  
438 found to be important, especially in giving prompts to move people on to new areas of  
439 discussion and to avoid leading anyone with answers.

440 We will set up four focus groups of eight people each with dementia of mild severity, and  
441 four separate groups of eight carers each (held at same venues, at the same times), at key  
442 points within the project to aid interpretation of modelling and quantitative analyses.

#### 443 ***MODEM Legacy model***

444 The final objective of the study is to develop a legacy model, to enable stakeholders to  
445 access the findings and outputs of the project, and make their own local projections of  
446 expected outcomes and costs by entering data relevant to local needs. This will be  
447 publicly available on the World Wide Web, and is aimed at service commissioners, policy  
448 makers, providers, advocacy groups, and individuals and families affected by dementia. It  
449 will enable high-level planning of services and will allow commissioners and providers to  
450 explore the implications of demand for services and associated costs, based on varying  
451 assumptions of prevalence rates of dementia in the future and patterns of care. It will be  
452 user-friendly, with an easy-to operate 'front end' and accessible user guide. We will  
453 consult people with dementia, family carers and representatives of the NHS, local  
454 authorities and voluntary sector organisations in our planning of the legacy model.

455

#### 456 **DISCUSSION**

457 Dementia has enormous impacts on the health and quality of life for people with the  
458 condition, their families and other people who care for them. Many people with dementia  
459 need care in many areas of their lives, and use a range of health and social care services,  
460 as well as getting support from their family carers. As the symptoms of dementia worsen,

461 some people will need to move into care homes. The costs of care and support can  
462 therefore be high. As the English population ages over the coming decades, so the number  
463 of people with dementia will increase considerably. This poses a potentially major  
464 challenge for health and care systems that are already very stretched: how can we ensure  
465 a good quality of life for people with dementia and their carers at a cost that is  
466 considered by society to be affordable?

467 The MODEM project is using a range of interconnected methods to feed new evidence into  
468 this national debate about how to respond to the challenge of dementia. We are  
469 developing a comprehensive, integrated set of quantitative models to estimate current  
470 and future needs, and the outcomes and costs of interventions aimed at meeting them,  
471 taking into account the complexity of individuals' lives. We are collecting rich qualitative  
472 data to help us interpret the associations in those models. And we are then simulating the  
473 impacts of interventions for which there is robust or promising evidence from completed  
474 or on-going trials or other studies.

475

#### 476 **List of abbreviations**

477 CFAS II: Cognitive Function and Ageing Study

478 CSRI: Client Service Receipt Inventory

479 ELSA: English Longitudinal Study of Ageing

480 ESRC: Economic and Social Research Council

481 HSE: Health Survey of England

482 ICF: International Classification of Functioning, Disability and Health

483 MicSIMPOP: Micro-SIMulation POPulation model

484 MODEM: MODelling outcome and costs impacts of interventions for DEMentia.

- 485 NCDS: National Child Development Study
- 486 NHS: National Health Service
- 487 NIHR: National Institute for Health Research
- 488 PSSRU: Personal Social Services Research Unit
- 489 RUD: Resource Utilization in Dementia
- 490 SHIELD CSP RYCT: Carer Supporter Programme – Remembering Yesterday Caring Today
- 491 SIMPOP: macro-SIMulation POPulation model
- 492 sMMSE: standardised Mini-Mental State Examination
- 493 START: StrAtegies for RelaTives study
- 494 UK: United Kingdom
- 495 WHO: World Health Organization

496

497 **Ethics approval and consent to participate**

498 Ethical approval was obtained for three component parts of the MODEM study: the cohort  
499 data collection (Social Care REC reference: 15/ IEC08/ 0005), the focus groups (NHS HRA  
500 Social Care REC reference 15/ IEC08/ 0029) and the qualitative interviews carried out for  
501 the attached PhD study (REC reference: 16/ IEC08/ 0012).

502 **Consent for publication**

503 Not applicable

504

505 **Availability of data and material**

506 Primary data are currently being collected in the cohort study component of MODEM. The  
507 dataset will be lodged with the ESRC Data Archive.

508

#### 509 **Competing interests**

510 The authors declare they have no competing interests.

511

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516 collection, analysis or interpretation of data, or the writing of this manuscript.

517

#### 518 **Authors' contributions**

519 MK is the Principal Investigator of the MODEM project and ACH is the Academic Project  
520 Manager. Together with RW, DMD SB, AB, EG and CJ they conceived and designed the  
521 project. NF and KL have written sections of the protocol and DL contributed to the  
522 drafting of the manuscript. All authors revised and approved the submitted manuscript.

523

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531

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537

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