Supplementary Data

Appendix 1 - Additional References


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Appendix 2 – Ovid Medline and Ovid Embase Search Strategies

Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present searched January 2013
1. Residential Facilities/
2. Nursing Homes/
3. Homes for the Aged/
4. exp Nursing Homes/
5. Long-Term Care/
6. (home? adj1 (nursing or care or residential?)).tw.
7. "residential facilit**”.mp.
8. "nursing home**”.mp.
10. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9
11. Epidemiologic studies/
12. Exp case control studies/
13. Exp cohort studies/
15. Case- control.mp.
16. (cohort adj (study or studies)).mp.
17. Cohort analy$.mp.
18. (Follow up adj (study or studies)).mp.
19. (observational adj (study or studies)).mp.
20. Longitudinal.mp.
21. Retrospective.mp.
22. Cross sectional.mp
23. Cross-sectional studies/
24. 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23
25. 10 and 24
26. exp Great Britain/
27. exp Ireland/
28. exp Northern Ireland/
29. exp Wales/
30. exp Scotland/
31. exp England/
32. 26 or 27 or 28 or 29 or 30 or 31
33. 25 and 32
34. limit 35 to ("all aged (65 and over)" or "aged (80 and over)")

Ovid Embase 1974 to 2013 January 08 searched January 2013
1. Residential Home/
2. Long-Term Care/
3. nursing home/
4. residential home/
5. "residential facilit*".mp.
7. "care home".mp.
8. "convalescence home".mp.
9. (home? adj1 (nursing or care or residential?!)).mp.
10. (residential adj (care or facilit$ or setting?!)).mp.
11. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10
12. Clinical study/
13. Case control study/
14. Longitudinal study/
15. Retrospective study/
16. Prospective study/
17. Cohort analysis/
18. (Cohort adj (study or studies)).mp.
19. (Case control adj (study or studies)).mp.
20. (follow up adj (study or studies)) .mp.
21. (observational adj (study or studies)) .mp.
22. (epidemiologic$ adj (study or studies)) .mp.
23. (cross sectional adj (study or studies)) .mp.
24. 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23
25. 11 and 24
26. exp United Kingdom/
27. exp Ireland/
28. exp Northern Ireland/
29. exp Wales/
30. exp Scotland/
31. exp England/
32. 26 or 27 or 28 or 29 or 30 or 31
33. 25 and 32
34. limit 33 to aged <65+ years>
Appendix Table 1: Studies that collect data on care home residents
(The studies in this table are organised by study design and number of participants)*
<table>
<thead>
<tr>
<th>Study Name (study design)</th>
<th>Baseline sample and geographical region</th>
<th>Year (total number of respondents at most recent data collection =n)*</th>
<th>Care home respondents (n)*</th>
<th>Health related variables collected over course of study</th>
<th>Interview Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Census for England and Wales (National repeat cross sectional)</td>
<td>Population of England and Wales</td>
<td>2011 (n = 56.1m)</td>
<td>365,352 (census only)</td>
<td>Sociodemographic data, including caregiving. Self-rated health and limited activities. Additional data linked in the ONS LS including births, deaths and cancer registrations.</td>
<td>The 2011 individual form included two questions on whether a proxy informant was used and the relationship of the proxy informant to the respondent.</td>
</tr>
<tr>
<td>ONS Longitudinal Study (ONS LS) (Longitudinal Cohort)</td>
<td>1% of the census population linked to event data from 1971</td>
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<tr>
<td>Scotland Census (National repeat cross sectional)</td>
<td>Population of Scotland</td>
<td>2011 (n = 5.3 m)</td>
<td>2011 data released in Winter 2013</td>
<td>Sociodemographic data, including caregiving. Self-rated health, long lasting conditions and limited activities. Additional data linked in the SILS including births, deaths, cancer registrations and hospital discharges.</td>
<td>The 2011 individual form included instructions for proxy reporting, but did not record if a proxy informant was used.</td>
</tr>
<tr>
<td>Scottish Longitudinal Study (SILS) (Longitudinal Cohort)</td>
<td>5.5% of the census population linked to event data from 1991</td>
<td></td>
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</tr>
<tr>
<td>Census of Population of Ireland (National repeat cross sectional)</td>
<td>Population of the Republic of Ireland</td>
<td>2011 (n = 4.6m)</td>
<td>20,802</td>
<td>Sociodemographic data, including care giving. Self-rated health, long lasting conditions and limited activities.</td>
<td>The 2011 individual form did not record if a proxy informant was used.</td>
</tr>
<tr>
<td>Study</td>
<td>Sample</td>
<td>Year(s)</td>
<td>Number</td>
<td>Variables</td>
<td>Notes</td>
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<tr>
<td>North Ireland Census (National repeat cross sectional)</td>
<td>Population of North Ireland</td>
<td>2011</td>
<td>1.8m</td>
<td>Sociodemographic data, including care giving.</td>
<td>Self-rated health, long lasting conditions and limited activities. Additional data linked in the NILS including births and deaths.</td>
</tr>
<tr>
<td>Northern Ireland Longitudinal Study (NILS) (Longitudinal Cohort)</td>
<td>28% of the census population linked to event data from 2001</td>
<td>(n = 500,000)</td>
<td></td>
<td></td>
<td>The 2011 individual form included two questions on whether a proxy informant was used and the relationship of the proxy informant to the respondent.</td>
</tr>
<tr>
<td>Million Womens Study (Longitudinal Cohort)</td>
<td>Women aged 50-64 between 1996 and 2001 in England and Scotland</td>
<td>2012</td>
<td>1.3m</td>
<td>Sociodemographic data.</td>
<td>Health behaviours, medical history, general health, reproductive health, medication, physical activity, diet, social factors; cancer registrations, deaths, hospital admissions.</td>
</tr>
<tr>
<td>Understanding Society (Longitudinal Panel)</td>
<td>Sample of adults aged 16+ in the UK in 2009</td>
<td>2010-2011</td>
<td>60,394</td>
<td>Sociodemographic data, including caregiving.</td>
<td>Self-reported health, disability, SF12, GHQ-12, health behaviours, nutrition, mental health and wellbeing, psychological traits including general trust, attitudes to risk, self-efficacy.</td>
</tr>
<tr>
<td>British Household Panel Survey (Longitudinal Panel)</td>
<td>Sample of adults aged 16+ in Great Britain in 1991</td>
<td>2009-2010</td>
<td>14,419</td>
<td>Sociodemographic data, including caregiving.</td>
<td>Self-reported health conditions, activities of daily living (ADLs), use of health services, health behaviours, subjective health and wellbeing, SF36.</td>
</tr>
<tr>
<td>Study</td>
<td>Sample</td>
<td>Year</td>
<td>Sample Size</td>
<td>Data Collection</td>
<td>Note</td>
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<tr>
<td>Health Survey for England (HSE) (Repeat cross sectional)**</td>
<td>Sample of adults in private households. Care home residents aged 65+ in England were surveyed in 2000 only</td>
<td>2000 (n = 10,481)</td>
<td>2,493</td>
<td>Sociodemographic data, including activities and facilities in care homes, and social support. Self-rated health and reported diagnoses, life limiting illnesses (LLIs), use of health services, MRC respiratory questionnaire, chest pain and claudication, cardiovascular disease (CVD), accidents and fractures, disability, eating habits, health behaviours, dental health, incontinence, GHQ 12, use of prescribed medicines and vitamin or mineral supplements. Physical measures including anthropometric measures, blood pressure, electrocardiogram (ECG), blood sample, saliva sample and cognitive function.</td>
<td>Proxy interviews conducted with 1,273 (51%). Proxy interviews were usually conducted with a member of the care home staff. Nurse visits were not conducted if interview by proxy, although estimates of height and weight were obtained.</td>
</tr>
<tr>
<td>English Longitudinal Study of Ageing (ELSA) (Longitudinal Cohort)</td>
<td>Sample of men and women aged 50+ and their partners in England in 1998-2001</td>
<td>2010-2011 (n = 10,274)</td>
<td>70</td>
<td>Sociodemographic data, including caregiving and social participation. Self-reported health, LLIs, eyesight, hearing, dental health, specific symptoms and diagnosis, pain, ADLs, instrumental activities of daily living (IADLs), health behaviours, mental health, incontinence, use of health services, sleep patterns, bowel, breast and prostate cancer screening, fractures and falls, cognitive function and psychosocial health. Physical measures include walking speed, blood pressure, lung function, blood sample, anthropometric measures, grip strength, leg raises, chair rises, balance and saliva sample.</td>
<td>Institutional interviews were limited to questions on individual demographics, health, work and pensions, income and assets and a reduced number of questions on household demographics. Proxy institutional interviews were conducted with 58 of the 70 participants in care homes. Proxy interviews were completed by any responsible adult over 16 who knew enough about the participant to answer the questions.</td>
</tr>
<tr>
<td>British Regional Heart Study (BRHS)</td>
<td>Men aged 40–59 in 1978 in 24 towns in</td>
<td>2007 (n = 3014)</td>
<td>42</td>
<td>Sociodemographic data. Medical history, chest pain, leg pain, respiratory symptoms and</td>
<td>Participants were not excluded from data collection if they were in care homes.</td>
</tr>
<tr>
<td>Study Name</td>
<td>Description</td>
<td>Participants</td>
<td>Data Collection Information</td>
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<tr>
<td>(Longitudinal Cohort)</td>
<td>England, Scotland and Wales</td>
<td>current medication, health behaviours, physical activity, physical disabilities. Physical measures include anthropometry, blood pressure, blood sample, urine sample, lung function, ECG.</td>
<td>Participants were not excluded from data collection if they were in care homes, but no data were collected that would allow identification of residence in institutions.</td>
<td></td>
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<tr>
<td>Hertfordshire Cohort Study (HCS) (Longitudinal Cohort)</td>
<td>Men and women born between 1931-1939 in Hertfordshire, England</td>
<td>2007 (n = 2299) N/A</td>
<td>Sociodemographic data including marital status, age left full-time education and family history including father’s social class. Medical history, self-rated general health, health behaviours, chest pain and leg pain, respiratory symptoms, fracture history, lower back pain, current medication, falls, strokes, SF36, anxiety and depression. Physical measures include anthropometric measures, blood pressure and pulse rate, lung function, ECG, blood sample, urine sample, grip and quadriceps strength, timed walks, chair rises, timed one leg stands and clinical hand examinations.</td>
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</tr>
<tr>
<td>Boyd Orr Cohort (Longitudinal Cohort)</td>
<td>Men and women aged up to 19 years between 1937–3916 in 16 urban and rural districts in Scotland and England</td>
<td>2002-2003 (n = 799) N/A</td>
<td>Sociodemographic data, including social participation Self-reported major diseases, chest pain and respiratory symptoms, health behaviours, dietary information, medication, GHQ scores, indices of pain, and locomotor disability. Physical measures include anthropometric measures, dental examination, blood pressure, ECG, heart rate variability, lung function, carotid and femoral arterial ultrasound scans, ankle systolic pressure, fingerprints, timed walk, blood samples and cognitive functioning.</td>
<td></td>
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</tr>
<tr>
<td>Lothian Birth Cohorts of 1921 and 1936 (Longitudinal Cohort)</td>
<td>Men and women born in 1921 and in 1936, in Lothian, Scotland</td>
<td>1921 Cohort - 2007-2008 (n = 237) 1936 Cohort - 2007-2010</td>
<td>Sociodemographic data. History of disease and medication use, anxiety and depression, health behaviours, self-reported wellbeing and personality Physical measures include disability scale, height, weight, blood</td>
<td>Participants were not excluded from data collection if they were in care homes.</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Participants</td>
<td>Year(s)</td>
<td>Demographics</td>
<td>Measures</td>
<td>Additional Notes</td>
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<tr>
<td>Hertfordshire Ageing Study (HAS) (Cohort)</td>
<td>Men and women born between 1920-1930 in Hertfordshire, England.</td>
<td>2003-2005 (n = 359)</td>
<td>N/A</td>
<td>Sociodemographic data.心血管症状、呼吸系统症状、处方药物、健康行为、认知功能（包括MMSE（Mini Mental State Examination）、生殖历史、SF36、跌倒和虚弱。身体测量包括体重、生物阻抗（身体成分—脂肪和水）和血液样本。Data on demi-span.</td>
<td>Participants were not excluded from data collection if they were in care homes, but no data were collected that would allow identification of residence in institutions.</td>
</tr>
<tr>
<td>Newcastle 85+ Study (Longitudinal Cohort)</td>
<td>Men and women born in 1921 residing in Newcastle, England in 2006</td>
<td>2011-2012 (n = 344)</td>
<td>55</td>
<td>Sociodemographic data, including social participation.</td>
<td>For older adults who lacked capacity and were unable to consent to the study, a legal representative was asked to provide an opinion on study participation. If participating, data collection was conducted with the assistance of another individual who knew the participants well (e.g. a...</td>
</tr>
</tbody>
</table>
(half the distance between hands outstretched either side), waist and hip circumference, tooth count, blood pressure, hand-grip strength, walking test, chair stand test, cognitive function including MMSE or computerised assessment of memory and attention, ECG and exhaustion were collected except in cases where a proxy informant was used. Data were also recorded on older adults who had capacity but required or requested assistance from another individual. In the most recent wave 41 required approval from a legal representative and 48 had a proxy informant.

<table>
<thead>
<tr>
<th>Study</th>
<th>Group</th>
<th>Year</th>
<th>Sample Size</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive Function and Aging Study I</td>
<td>Men and women aged 65 + in 1991 in six centres in England and Wales</td>
<td>2008 (n = 95)</td>
<td>10</td>
<td>Sociodemographic data. Self-reported health, ADLs, IADLs and health and social care contact. Cognitive functioning including MMSE, the GMS (Geriatric Mental State Examination), the CAMDEX (Cambridge Examination for Mental Disorders in the Elderly) and the CAMCOG (Cambridge Cognition Examination).</td>
</tr>
<tr>
<td>Cambridge City over-75s Cohort</td>
<td>Men and women aged 75 + in 1985 in Cambridge, England</td>
<td>2010 (n = 7)</td>
<td>5</td>
<td>Sociodemographic data including social participation. Self-rated health and reported diagnoses, falls, medication, health behaviours, affect and loneliness, anxiety and depression, ADLs and IADLs. Physical performance testing, blood and saliva samples, MRI brain scans and quantitative ultrasound heel scans and cognitive functioning, including the MMSE and CAMCOG.</td>
</tr>
</tbody>
</table>

Proxy informants were used if respondents were deemed to be too frail to answer questions. Participants were not excluded from data collection if they were in care homes.
*Numbers based on available data from the most recent wave of the study, data from on-going data linkages may differ.

** The 2000 wave of the Health Survey for England included care home residents, to date following waves have not.