

## **A Survey of Older Peoples' Attitudes Towards Advance Care Planning.**

### **Abstract**

**Background:** Advance care planning (ACP) is a process to establish an individual's preferences for care in the future; few UK studies have been conducted to ascertain public attitudes towards ACP.

**Objective:** The aim of this study was to assess the attitudes of older people in East Midlands through the development and administration of a survey.

**Design:** The survey questionnaire was developed on the basis of a literature review, exploratory focus groups with older adults and expert advisor input. The final questions were then re-tested with lay volunteers.

**Setting:** 13 general practices were enrolled to send out surveys to potential participants aged 65 or older. There were no additional inclusion or exclusion criteria for participants.

**Methods:** Simple descriptive statistics were used to describe the responses and regression analyses were used to evaluate which items predicted responses to key outcomes.

**Results:** 1823/5375 (34%) community-dwelling older people returned questionnaires. 17% of respondents had prepared an ACP document of whom with 4% had completed an Advance Decision to Refuse Treatment (ADRT). 5% of respondents stated that they had been offered an opportunity to talk about ACP. Predictors of completing an ACP document included: being offered the opportunity to discuss ACP, older age, better physical function and male gender. Levels of trust were higher for families than for professionals. One-third would be interested in talking about ACP if sessions were available.

**Conclusion:** Although a third of the respondents were in favour of discussing ACP if the opportunity was available with their G.P., only a relative minority (17%) had actively engaged. Preferences were for informal discussions with family rather than professionals.

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## **Introduction**

Advance care planning (ACP) is a process of assessment and person-centred dialogue to establish an individual's needs and goals of care and if a person wishes to document any expressed preferences for future care and treatment, if the person loses capacity. Policy initiatives have promoted ACP as a means of extending 'choice' in end of life care, but there is little evidence about whether these assumptions are reflected in the attitudes of the public or to what extent there is uptake of ACP. ACP may result in one or more outcomes. Firstly, 'advance' directives, often known colloquially as 'living wills', which record views about specific treatments. Secondly, the nomination of a proxy to represent the individual in the event that they lose capacity. Under the Mental Capacity Act 2005 [1] these are termed 'lasting powers of attorney' and can relate to health and welfare or financial issues. Thirdly, statements of values and views about care and treatment to inform 'best interests' (termed 'advance care plans' or 'advance statements').

Despite substantial international literature on ACP [2, 3], there is a paucity of information on the attitudes of the UK public towards ACP. A 2005 poll of 1,027 people showed that 67% of those aged over 65 years had prepared a financial will, whilst only 8% had completed an ACP document of any kind [4]. Studies using focus group techniques with older people have shown that 'end of life care' means different things to different people [5] and that worries and anxieties are associated with thinking about and discussing ACP issues [6], whether with relatives or with health care professionals. Sampson *et al* interviewed carers of people with advanced dementia who had recently been hospitalised and found a reluctance to plan for the future, even when given the support of a nurse experienced in advance care planning discussions [7].

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In the UK, one validated survey has assessed ACP from the perspective of patients with advanced illnesses. However, this study focused on hospitalised patients rather than the views of community dwelling individuals [8].

The aim of this study was to assess the attitudes and views of people over the age of 65, in a large mixed urban and rural area of the UK (East Midlands) through the development, validation and application of a survey.

### **Methods**

#### ***Study population and design***

Domains of questioning were identified through a series of steps. These included:

- Existing literature reviews informed focus group areas for discussion.
- Themes from exploratory focus group informed the survey and in addition relevant items from previous surveys were reused to aid comparison with other studies [9].
- A further workshop was held involving an expert advisory team about the design of the survey questionnaire based on the outcomes of the focus group work.
- The final questions for each item were tested with the lay volunteers and a local patient and public involvement forum.

The survey was sent out to community-dwelling older people in Leicestershire and Nottinghamshire.

#### **Part I –Development and Validation of Survey**

We involved older people in four focus groups to generate domains for a survey. General ideas around ACP drawn from a broader literature review [2, 3, 4, 6, and 8] and evidence based knowledge were introduced to promote discussion amongst participants. Participants for the focus groups were recruited via a local Patient and Public Involvement group, which included representatives from

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AgeUK and community groups. Information about and inviting focus group participation was distributed at community centres and volunteers identified. Focus groups consisted of six to eight participants and lasted approximately two hours to allow adequate time for all participants to elaborate on experiences. Discussions were recorded and then transcribed. We used a constant comparative method, based broadly on grounded theory approaches [10] to data analysis to group the responses of focus group participants into thematic areas (**Appendix 1**). Four overarching themes were identified, highlighted in bold below:

### ***Level of action already taken by people:***

The level of response varied between "no action taken", "having made some kind of plan/will", "leaving it to God" and informal action such as verbal instructions.

### ***Level of understanding of relevant issues around ACP:***

This theme captured the way in which subjects demonstrated their understanding of pertinent issues regarding ACP. Many drew on personal experiences with death and illness and this seemed to inform their understanding of death and care planning. An example from one individual included:

*"I've made a will with my husband as well, but we've also done a lasting power of attorney, because we've had experience of this with our own mothers "*

### ***Disclosing wishes ( including motivation to take part in ACP and values and attitudes towards ACP ):***

Ideas identified included having the resources to support ACP and the importance of leaving guidance for families. One participant stated:

*"the plan should be talked over with the family, because the family are the ones who have to decide...the person who's ill might not be in a position to make any decisions, so it should be with the family before..."*

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### **Values and attitudes towards ACP:**

Values and attitudes amongst individuals ranged from not wanting to plan to the fear of addressing death:

*"I have got no power over the death, it's all in God's hands...it's a natural process."*

*"I've made a will and a power of attorney but I haven't done anything about the medical things because it's too scary."*

Others were more pro-active about wanting to leave an advance care plan:

*"Well I think that everybody should make plans beforehand....because nobody knows when death is coming. So everybody should be ready, kept ready, like a passport... so when the time comes.....everything should be ready. It's a plan..."*

### **Barriers to ACP:**

Some individuals were not able to perceive the idea of being ill or losing capacity:

*"I am a carer....I do see a lot of people with dementia and I dread to be in that situation myself.....I haven't made any plans because nobody thinks you're going to get dementia, nobody thinks that..."*

Other [barriersthemes](#) included lack of resources and wishes being respected:

*"....it's all very well saying yes we'll write out a plan for this, but is it going to be able to happen? .....what provision is going to be there?... it's all very well putting these plans down but whether they can actually happen is another thing"*

*"...the GPs don't have time. You make an appointment to see them and they've got 10 minutes. Well 10 minutes isn't long enough if it's planning your life"*

The themes from the focus group data were drawn upon to develop survey items, in conjunction with the findings from an earlier literature review. A further workshop was held involving members of the research team and an expert

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advisor to make decisions about the design of the survey questionnaire based on the outcomes of the focus group work. A draft survey was then tested for face validity using the Patient and Public Involvement Group. Revisions and clarifications were made based on responses.

Finally, test-retest reliability was ascertained on a sample of 15 people, two weeks apart. The overall reliability was moderate (kappa 0.53); five questions had a kappa <0.4. In four of the questions the disagreement could be accounted for by changes in responses from 'agree' to strongly agree' – rather than substantial changes from agree to disagree. The remaining question with a kappa score <0.4 reflected concerns that making an advance care plan would lead to doctors stopping treatment too soon. This may reflect the fact that questions were being misinterpreted on different occasions as there was some variability within individual responses.

Important baseline data were incorporated into the survey, including:

- Demographics (age, gender)
- Educational level and occupation
- Functional status (modified Katz index) **[11]**

The final survey can be found in **Appendix 2.**

### **Part II - Survey**

The final survey was sent out to community-dwelling people (aged 65+) in Leicestershire and Nottinghamshire. Leicester and Nottingham are both large post-industrial cities in the East Midlands of England, each with a catchment population of around 1 million, with an approximate 50% urban-rural split. The combined population over the age of 65 in Leicestershire and Nottinghamshire is around 270,000.

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Considering that not all general practices would engage with the survey and that the individual response rate to surveys of this nature is often low, we anticipated a sample size of around 1000 individual responses.

There were no exclusion criteria to ensure a diverse range of backgrounds and ethnic minorities were represented. General practices were purposefully selected to ensure rural and urban practices with varying degrees of deprivation (measured using the 'Index of Multiple Deprivation - IMD).

### ***Data analysis***

Hierarchical responses (such as those using Likert scales) were dichotomised and along with other categorical responses were described using proportions and 95% confidence intervals.

Univariate logistic regression analysis was used to describe the relationship between baseline data (demographics, education, occupation and function). It was anticipated that the Katz scores would be heavily skewed and it was planned to dichotomise at the median point and use the dichotomous outcomes in the regression analyses. Age was categorised to 65-74, 75-84 or 85+ when included in the regression models.

Forward stepwise multivariate logistic regression analysis was performed to determine which items predicted responses to key outcomes such as completion of an advance care plan. In the model, clinically important parameters were retained (forced) as were parameters with a p-value <0.2 in the univariate analysis.

### ***Ethical and governance approvals***

Ethical approval was obtained from the University of Leicester Ethics Committee for the focus group work. For the survey, ethical approval was obtained from the National Research Ethics Committee [12].

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### **Results**

#### ***Study population***

Thirteen general practices agreed to support the study; the characteristics of the practices can be found in **Appendix 3**. The majority were from inner city Leicester (8/13), two from Leicestershire, one from Nottingham City and two from Nottinghamshire County. The proportion of ethnic minorities within the practices varied, with slightly higher representation in the Leicester City practices. The deprivation score ranged from 6% to 52%, and the practice list size ranged from 1573 to 14067.

5375 potential participants were mailed a survey by their General Practice, 1832 (34%) were returned, nine were blank and so excluded. The demographics of the participants returning the survey are shown in **Appendix 4**. The majority of the respondents were from the "young old" population; the median age was 73 years and women predominated (59%). The majority of the population were functionally independent but 28% had some level of dependency (Katz <21). The majority of respondents described their ethnicity as white and of Christian faith. There was an equal spread across the social class groups, however, a relatively smaller proportion (3%) were from the professional group.

#### ***Responses to ACP questions***

##### *Having made an advance care plan*

The first four questions looked at whether individuals had been involved in advance care planning, had made an advance decision to refuse treatment (ADRT) or had ever approached anyone about this topic. Only 84 of 1823 respondents (4.6%, 95% CI 4.0-5.7%) stated that they had been offered an opportunity to talk about ACP. This was consistent across the various GP practices (range 0-8%). 58 out of the 84 (70%) respondents who had discussed ACP, had prepared an ACP document (which included an ADRT or an advance statement of

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wishes and preferences). Multivariate predictors of completing an ACP document included: being offered the opportunity to discuss ACP (Odds Ratio (OR) 16.5, 95% CI 13.2 - 35.9), older age group (OR 1.5, 95% CI 1.1-2.0), better physical function using the Katz scores (OR 0.6, 95% CI 0.4-0.9) or male gender (OR 0.5, 95% CI 0.3-0.8).

Overall, 231 of 1823 respondents (13%) stated they had prepared an advance statement of wishes and preferences. 77 of 1823 respondents (4%, 95% CI 1.5-7.9%) had prepared an advance decision to refuse treatment. Again there was no significant association with the size or location of the GP practice. Multivariate predictors of ADRT completion included: being offered the opportunity to discuss ACP (OR 10, 95% CI 4.5- 19.7); older age (OR 1.5, 95% CI 1.0-2.2) and male gender (OR 0.5, 95% CI 0.2-1.0).

219 of 1823 respondents (12%) had approached someone to talk about advance care planning. Of these, 159 respondents (73%) had discussed these plans with friends or family members but only 38 respondents (18%) had discussed these plans with their GP and 15 respondents (5%) had discussed this with a doctor, nurse or social worker. A further 63 respondents had also discussed ACP with "others". These consisted predominantly of family members and friends. Nine had discussed it with a solicitor and one with a support group for older men. Of these 219 respondents, 97 (44%) had prepared an advance statement of wishes and preferences and 44 (15%) had prepared an ADRT.

### *Motivation to take part in advance care planning*

1350 of 1823 (74%) respondents felt it would give them comfort knowing they have left some guidance for their family through engaging with ACP, whilst 57 (3%) respondents' disagreed. 1101 (60%) respondents would only talk about ACP if the topic was raised with them.

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796 of 1823 (44%) respondents replied that if they were unable to express themselves, they would leave decisions about their health to others. Of these, 603 (76%) agreed with the statement that they would trust their doctor/health professional to make these decisions and 749 people (94%), would trust their families to make the right decisions for them. Overall, despite whether the respondents would leave decisions to others or not, 1557 of 1823 respondents (85%) would trust their families to make the right decision for them and 1078 of 1767 (61%) respondents would trust their doctor. Finally, 1557 of 1823 respondents (85%) would rather discuss decisions informally than write them down.

### *Barriers to advance care planning*

611 of 1823 respondents (34%) replied there is no point in planning as it would not change what will happen in the future, however, 856 (47%) respondents disagreed. The remaining 19% of respondents did not respond or selected 'neither'. Those that agreed tended to be older, but overall there were no consistent differences in the demographic characteristics of those responding either agree or disagree compared to those responding 'neither'.

From the focus group work we found the above barrier was a particular viewpoint from those of an Asian background and with strong religious beliefs. Although differences were identified according to religion from the survey for this question, the sub-groups were small and the confidence intervals overlapping making any meaningful comparison difficult.

1228/1823 (67%) respondents felt there was no point in planning unless help was available to meet these wishes and 1076 (59%) of people felt it was difficult to know if their wishes would be respected if a care plan was prepared. 636/1823 (35%) respondents were worried that doctors would stop treatment too soon if they had an ACP.

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### *Future planning*

About one third of respondents 597/1823 (33%) were interested in attending sessions on ACP if available. 696/1823 (38%) people would not be interested, whilst 507/1823 (28%) people were not sure.

In the multivariate analysis, independent predictors of willingness to engage in ACP training session included: male gender (OR 0.6, 95% CI 0.5-0.8), and older age (OR 0.6, 95% CI 0.5-0.8).

More than one third of respondents 648 (36%) would be interested in talking with their GP about ACP at an annual check-up, with 422 (23%) respondents not being interested and 293 (16%) people being unsure.

### **Discussion**

The main findings from this survey of nearly 2000 older people in the East Midlands were that 17% of respondents had prepared an advance statement of some form, with 4% completing an ADRT. The most important predictor of completing an advance statement or an ADRT was being offered the opportunity to discuss the issues in the first place.

For most, ACP was predominantly an 'informal' activity. Respondents placed higher levels of trust in their families than in professionals. The explanation for this is not completely clear from the study as this was not explored. However, the focus group discussions highlighted that participants perceived issues relating to ACP to be of a sensitive nature and that they felt more comfortable discussing these with loved ones in an informal environment. Thirty five percent (35%) of the survey respondents were worried that doctors would stop treatment too soon if they had an advance care plan and 59% were concerned that even with an advance care plan in place their wishes might not be respected. The survey did not look into the reasons to why respondents expressed these views. Reflections from the focus group work suggests some reasons may include not having a clear

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understanding what an advance care plan entails and the care plan not being available in all care settings due to lack of efficient systems.

In contrast to previous UK surveys which found ACP documentation rates of 8% [4], this survey found that formal ACP documentation rates (advance statement of preferences or an ADRT) was 17%. This may reflect the differing nature of questions in each of the surveys; equally it may reflect an increased use of ACP over time. The frequency of completion of ACP records worldwide varies markedly, with very low take up reported in most countries except in some areas in North America [13]. A US [14] study looked at the results of a health style survey and found the completion rate of an advance directive (equivalent to both an ADRT or advance statement of preferences) was 26%. In contrast, one study in New South Wales, Australia, has shown that less than one percent of people have a record in their notes of any discussion about advance care planning [15].

Respondents reported that professionals were relatively absent from ACP discussions (<5% of respondents had been offered a discussion) yet the impact of professionals initiating discussion leading to an ACP action is high, as seen in previous studies [16-19]. An overview of seven systematic reviews considered interventions specifically to increase the completion rate of advance directives. Among the wide range of interventions evaluated, the most effective method was a combination of informative material and repeated conversations between patients and health care professionals over clinical visits and with interactive opportunities [20]. Whether the predominately informal ACP process observed in this survey is a result of professional disengagement or a reflection of patient choice is not clear. If an individual has very little chronic disease, no end of life issues or very minimal contact with health professionals the likelihood of these discussions taking place in a professional context are low. This was demonstrated in a US study [14] which found respondents with advance directives were more

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likely to have interacted with health professionals involved in managing their long term conditions.

While UK surveys of geriatricians indicate high levels of support for ACP in general [21], an interview of hospitalised older people found that patients would prefer for families to act as health care proxies rather than professionals [22] as also demonstrated in this study. Issues raised by Poppe *et al* [23] included staff difficulties such as lack of confidence in discussing end of life care, uncertainty about dementia progression and difficulties with patient and carers who had not accepted the dementia diagnosis.

Strengths of the study include the robust development of survey items and purposeful inclusion of a range of settings (urban vs. rural, various levels of deprivation). 15% of the respondents were non-Christian and 5% were non-white, therefore, people from ethnic minorities may well have been

underrepresented which was a weakness of the study. A very brief and broad explanation was given of the ACP at the beginning of the survey and depending on how this may have been interpreted may have affected the responses which may also be a weakness of the study.

### **Conclusion**

A third of respondents would be keen~~were keen~~ to explore Advance Care Planning with their G.P., but only a relative minority (17%) had actively engaged; those that had been active had predominantly been so through non-professional routes.

It is not clear from this study if older people would like more engagement from professionals or not. Further qualitative exploration work is needed to explore the issues raised from the survey in more depth including what the population understand by ACP, views from different ethnic groups, reasons for the lack of engagement with health professionals as suggested by the study and how we can improve ACP in patients who already lack capacity such as in dementia-

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### **Key points**

- Despite increasing awareness over the years of advance care planning the uptake remains low in the UK.
- Few studies have been done on community dwelling older adults' views on advance care planning.
- Only a minority (17%) of respondents had actively engaged with advance care planning and discussions tended to be informal with families rather than professionals.
- Predictors of completing any ACP document included: being offered the opportunity to discuss ACP, older age, better physical function represented by Katz scores and male gender.

### **Acknowledgements**

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### **Appendix 1 – Themes from the focus group work**

<b>MAIN THEMES AND RELATED IDEAS</b>	
<p><b><u>LEVEL OF ACTION</u></b></p> <p>Types of action and the amount of action taken so far e.g. no action at all; thinking or not thinking about health, illness and death; partial planning; made a written plan; leaving it to God.</p>	<p><b><u>LEVEL OF UNDERSTANDING OF RELEVANT ISSUES</u></b></p> <p>Different levels of knowledge and understanding e.g. experiential knowledge; ideas about capacity, decision-making and responsibility; media and cultural influences.</p>
<p><b><u>DISCLOSING WISHES</u></b></p> <p>Views expressed about how to convey and record wishes; awareness that some wishes may be conflicting e.g. wanting to be close to family while at the same time avoiding burden.</p>	<p><b><u>BARRIERS TO PLANNING</u></b></p> <p>Obstacles to proceeding with ACP and risks perceived e.g. timing, uncertainty, system issues; trust; lack of awareness and information.</p>

### **Appendix 2 – Survey (link)**

### **Appendix 3 – Demographics of GP practices.**

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<b>GP</b>	<b>Practice size</b>	<b>Deprivation score</b> <b>England average (21.5)</b>	<b>Ethnicity estimate</b>	<b>% people over 65</b> <b>England average (16.3%)</b>	<b>% long standing health condition</b>	<b>% health related problems in daily life</b>	<b>No of surveys sent out</b>	<b>Response rate (%)</b>
<b>1</b>	3809 (Leics City)	12.6	21% Asian, 2.2% black, 8% other non-white ethnic	17.3%	59.3%	42.6%	210	82 (39%)
<b>2</b>	1573 (Leics City)	37.4	Not available	2.1%	36.5%	43.6%	45	22 (49%)
<b>3</b>	3950 (Leics City)	15.7	1.6% Asian, 1.6% other non-white	19.4%	61.8%	56.3%	294	100 (34%)
<b>4</b>	7681 (Leics City)	34.7	2.5% mixed, 6.6% Asian, 5.0% black, 4.1% other non-white ethnic	10.6%	49.4%	54.2%	824	265 (32%)
<b>5</b>	9132 (Leics City)	22.4	Not available	12.4%	46.1%	54.4%	541	136 (25%)
<b>6</b>	6862 (Leics City)	52.0	Not available	5.4%	44.8%	51.0%	202	49 (24%)
<b>7</b>	10953 (Leics County)	19.8	1.5% mixed, 4.4% Asian, 4.4% non-white ethnic	17%	62.2%	55.2%	484	195 (40%)
<b>8</b>	4334 (Leics County)	6.16	1.3% mixed, 32.2% Asian, 1.3% Chinese, 3.4% other non-white ethnic	14.4%	50%	39.1%	500	215 (43%)
<b>9</b>	8469 (Leics City)	31.7	4.0% mixed, 10.3% Asian, 4.0% black, 0.8% other non-white ethnic	14.4%	42.8%	56.3%	496	131 (26%)
<b>10</b>	2587 (Leics City)	26.3	20.7% Asian, 1.7% black, 5.0% non-white ethnic	23.5%	51.1%	49.7%	526	178 (34%)
<b>11</b>	14067 (Nott County)	23.6	2.7% non-white ethnic	16.5%	53.1%	44.5%	500	184 (37%)
<b>12</b>	7380 (Nott City)	42.2	2.5% mixed, 2.5% black, 1.7% other non-white	18.2%	63.4%	55.7%	255	64 (25%)

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<b>13</b>	12174 (Nott County)	15.9	2.1% black, 1.4% non- white ethnic	20.6%	58.6%	52.8%	498	201 (40%)
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### Appendix 4 – Demographics and characteristics of respondents

**Table 1: Characteristics of individuals returning survey**

<b>Age (years)</b>	
65-74	1057/1802 (59%)
75-84	542/1802 (30%)
85 +	203/1802 (11%)
Missing	21 / 1823 (<1%)
	Median 73 ( IQR 68-79, Range: 65–103)
<b>Gender</b>	
Male	746/1808 (41%)
Female	1062/1815 (59%)
Missing	15/1823 (<1%)
<b>Religion</b>	
Christian	1337/1573 (85%)
Atheist	154/1573 (9.9%)
Buddhist	6/1573 (0.4%)
Hindu	41/1573 (2.6%)
Islam	11/1573 (0.7%)
Jehovah's witness	5/1573 (0.3%)
Sikhism	9/1573 (0.6%)
Judaism	2 /1573 (0.1%)
Other	8/1573 (0.5%)
Missing	250/1823 (1%)
<b>Social class group</b>	
Professional	51/1512 (3%)
Managerial	259/1512 (17%)
Skilled manual	230/1512 (15%)
Non-skilled manual	426/1512 (28%)
Semi-skilled	237/1512 (16%)
Unskilled	309/1512 (20%)

## A Survey of Older Peoples' Attitudes Towards Advance Care Planning.

Missing	311/1823 (<1%)
<b>Age complete full time education</b>	
<16 years	799/1401 (57%)
>16 years	602/1401 (43%)
Missing	422/1823 (2%)
<b>Ethnic group</b>	
White Scottish/British/Irish/Welsh	1714/1809 (95%)
Asian	61/1809 (3%)
Afro- Caribbean	20/1809 (1%)
Other	14/1809 (1%)
Missing	14/1823 (<1%)
<b>Katz Score</b>	
≤20 Dependent	514/1811 (28%)
=21 Independent	1297/1811 (72%)
Missing	12/1823 (<1%)
	Mean 20 (SD=2), median 21, (range 0-21)