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Poverty and Social Exclusion in the UK:  
The 2011 survey

**Working Paper series: No. 2**

**Improving Poverty and Social  
Exclusion Measures for Older  
People**

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## Poverty and Social Exclusion in the UK: The 2011 survey

### Overview

The Poverty and Social Exclusion in the UK Project is funded by the Economic, Science and Research Council (ESRC). The Project is a collaboration between the University of Bristol, University of Glasgow, Heriot Watt University, Open University, Queen's University (Belfast), University of York, the National Centre for Social Research and the Northern Ireland Statistics and Research Agency. The project commenced in April 2010 and will run for three-and-a-half years.

The primary purpose is to advance the 'state of the art' of the theory and practice of poverty and social exclusion measurement. In order to improve current measurement methodologies, the research will develop and repeat the 1999 Poverty and Social Exclusion Survey. This research will produce information of immediate and direct interest to policy makers, academics and the general public. It will provide a rigorous and detailed independent assessment on progress towards the UK Government's target of eradicating child poverty.

#### Objectives

This research has three main objectives:

- To improve the measurement of poverty, deprivation, social exclusion and standard of living
- To assess changes in poverty and social exclusion in the UK
- To conduct policy-relevant analyses of poverty and social exclusion

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## Abstract

This paper provides a focused review of various measures pertaining to older people used in the 1999 Poverty and Social Exclusion (PSE) survey and offers suggestions for improvement for the PSE 2011 main survey. This review did not cover the full range of domains/sub-domains found in the Bristol-Social Exclusion Matrix (or B-SEM)<sup>1</sup> but focused rather on areas which had the greatest scope for improvement in terms of measuring the poverty and social exclusion of older people. The following six measurement areas were identified: deprivation; social capital; limitations in activities of daily living; receipt of informal care; receipt of health and social services; and, provision of unpaid care. The review concludes that subject to time constraints necessary improvements can be achieved through a combination of expanding on existing PSE questions, adding new questions from other UK national surveys, and through follow-up questions to FRS 2010/11 main survey.

Key words: poverty, social exclusion, poverty measurement, older people

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<sup>1</sup> Living standards and health/disability, for example, will be critically reviewed in separate measures' review papers.

## Aim

This paper aims to provide a focused review of various measures pertaining to older people used in PSE1999 and offers suggestions for improvement in the PSE2011 main survey. This review is not intended to cover the full gamut of domains/sub-domains found in the Bristol-Social Exclusion Matrix (or B-SEM)<sup>2</sup> but rather focuses on areas which have the greatest scope for improvement in terms of older people. Existing and planned national surveys were reviewed as potential sources for specific questions and items in the following key areas: deprivation; social capital; limitations in activities of daily living; receipt of informal care; receipt of health and social services; and, provision of unpaid care. Following the reviews of these key areas and potential questions, specific suggestions for improvement are forwarded with additional commentary provided on the feasibility of including improved and/or additional measures for older people in the PSE2011 main survey.

### ***The Family Resources Survey***

PSE2011 will be a follow-up survey to the 2010/11 Family Resources Survey (FRS). The [FRS](#) is an annual survey of about 24,000 private households conducted under the auspices of the DWP. All household members are interviewed (or information obtained from another household member as a proxy). Among many detailed questions asked about employment, housing, assets and savings, income and earnings, taxes and benefits, are three series especially relevant to this measure's review paper: one on material and social deprivation; one on long-standing illness, disability or impairments; and, one on help or support (care) received and provided.

Where possible in this measures review paper, improvements to the PSE1999 were considered (where applicable and adequate) first in terms of existing questions in the FRS 2010/11, for example, whether simple follow up questions to the FRS main survey could be asked in the PSE2011 main survey. Where adequate information was neither available in the FRS nor previous PSE surveys, a wider search for applicable questions which inform constituent B-SEM domains and sub-domains was initiated. The expanded search has resulted in some overlapping measurement areas (e.g. care provided and received) and a degree of duplication in questions which could be used to improve measures for older people. However, we have tried to keep these overlaps and duplications to a minimum.

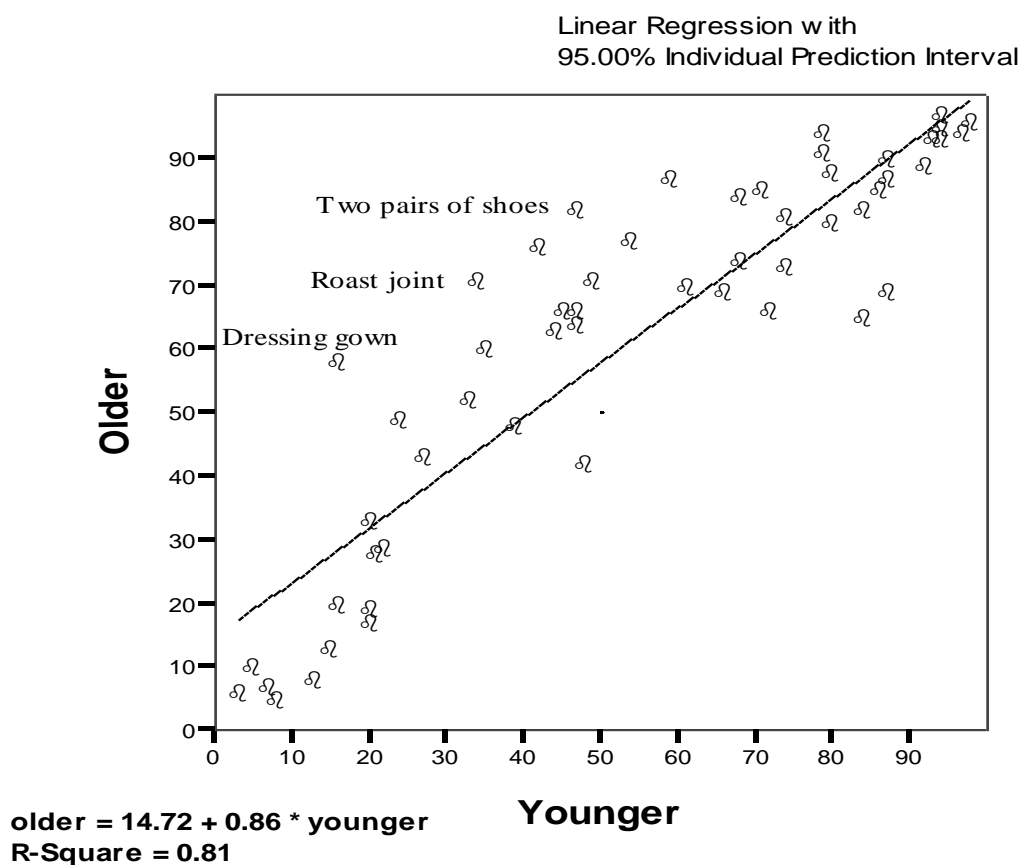
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<sup>2</sup> Living standards and health/disability, for example, will be critically reviewed in separate measures' review papers.

# 1. Deprivation items: older people versus adults?

One of the strengths of the PSE1999 was, of course, the items and activities used to measure adult deprivation. The items used in the PSE deprivation module did work quite well and were expanded upon slightly in the PSENI. However, original work on the PSE1999 showed that there is more disagreement on which items constitute the necessities of life when we examine differences among younger people and the older people, although there still remains a consensus. Some items have attracted strong disagreement (e.g. a “dressing gown”, a “roast joint or vegetarian equivalent”, or “two pairs of shoes” (see Figure 1 below). All three items are more likely to be seen as essential by people aged over 65 than those aged between 16 and 24 (Pantazis *et al.* 2000).

**Figure 1: Perception of necessities: Comparing younger and older people**



Source: Pantazis *et al.* 2000.

Since PSE1999, there have been reviews (and several critiques) in the literature about the utility of PSE items in measuring deprivation amongst older people (Berthoud *et al.* 2006; Dominy & Kempson 2006; Legard *et al.* 2008; McKay 2004, 2008, 2010; Smith & Hancock 2004).

Berthoud *et al.* (2006) stated “although the ratings are broadly consistent by age, the sensitivity of the 50 per cent threshold means that only 24 items in the list would be classified as agreed necessities for the younger group, compared with 34 items for the older group...But the overall conclusion is that the more complex index adjusting for age variations in perceptions of what constitutes a necessity makes little difference to the results, and one might as well stick to the simpler formula” (Berthoud *et al.* 2006: 38). They also carried out some age group analyses on ‘real needs’ (75% agreed it a necessity) versus ‘luxuries’ (25% agreed it a necessity) and found that “both real needs and luxuries are strongly associated with income...But the characteristic of old age is no longer a higher living standard than would have been expected on a given income. People in their 70s and 80s report few real needs that they ‘can’t afford’ (good) but also few luxuries (bad). Younger people – age 50 and lower – have the apparently contradictory pattern of many real needs they ‘can’t afford’, but also many luxuries.” (p. 41). These are important differences to bear in mind, not only for the creation of the deprivation indices but perhaps use of more than the 50% consensual line to include items which inform a living standards, versus, an index of poverty or deprivation.

Smith *et al.* (2008) questioned the extent to which we needed an age specific measure of consensual poverty for older adults using data from the PSE1999. They found that,

of the 54 items, older people were more likely to identify 34 of them as a necessity, and younger people were more likely to identify 12 of them as a necessity. The biggest percentage differences were seen among consumables (dressing gown, television, and two pairs of all weather shoes), which older people were more likely to classify as necessary (p. 616).

The authors conclude that “the consensual definition of poverty is similar for older and younger adults and therefore may be a useful measure for exploring inequalities in health for all ages, particularly older adults. The time specificity of this measure however must be recognised and it may need to be updated. It is comparatively easy to implement and “incorporates the views of members of the public, rather than judgments by social scientists, about what are the necessities of life in modern Britain”. The PSE1999 Omnibus Survey suggests that identifying people lacking more than one of these “necessities” is a good identifier of those in poverty. However, the authors do go on to comment that the list of necessities “lacks the ability to differentiate between more advantaged groups but could be combined with information on some measurement of income or access to financial resources to explore gradients in health inequalities” (p. 616-17).

### ***Separate necessities and material deprivation measures for older people?***

In the background work for revising the questions on material deprivation found in the FRS, McKay (2008) states unequivocally that,

Any comparison between older and younger people, using the existing measures, is more likely to mislead than to provide useful information. We therefore propose questions that provide a more reliable and helpful indication of the level of material deprivation among older people. (p. 9).

In addition, his research concluded that standard questions are not appropriate for pensioners as they tend to respond “do not want” rather than “cannot afford”.

McKay revisited those items that are regarded as necessities – but with an emphasis on what are seen as necessities for those aged 65 or older. The interviews for the 2008 NatCen Omnibus survey took place in Britain between 17 January and 10 March 2008 with adults aged 16 or older. Information was also collected, for those aged 60 plus, on which items they had and the reason why they were missing (for those without these items). It is worth noting that NatCen were asking the same people what they think is a necessity for those aged 65 plus and whether they had that particular item (if aged 60 plus) (McKay 2008: 21).

There were 41 items and activities in total in the 2008 NatCen Omnibus. Eighteen (18) items/activities could be compared between 2008 NatCen and 1999 ONS Omnibus surveys (see Table 1 below). Whilst older people were more likely than younger age groups to identify particular goods and services as necessary, this was not universally true, e.g. over the counter medicines. “However, the main result is really the overall similarity in the answers given by those aged 16-64 and those aged 65 and over. Only four items were rated as necessary by the older age group, and not the younger, with levels of support often very close.” (McKay 2008: 23). The four items were:

- Having a home with clean windows
- Having a holiday once a year
- Having a well-kept garden, if they have one
- Having items dry cleaned occasionally



**Table 1: NatCen Omnibus 2008, Items (n=41) being rated necessities for 'older people', compared with ONS Omnibus 1999**

	All	aged 16-64	aged 65+	PSE19 99 Omnib us	
Keeping their home damp-free	99	99	99	94	Damp-free home
Having adaptations to their home where needed	99	99	98		
Maintaining central heating, gas, electrics, plumbing and drains	99	98	99		
Having mobility aids such as a walking stick or mobility scooter, if needed	98	98	98		
Going to the opticians, as needed	98	98	99		
Being able to replace their cooker if it breaks down	97	97	98		
Having help in the home with personal care, where needed	97	97	96		
For those that care for others, that they occasionally have a break for a few days from their caring responsibilities	97	97	97		
Being able to pay regular bills, like Council Tax, without cutting back on essentials	97	97	97		
Keeping their home in a good state of repair	96	95	98	82	Money to keep home in a decent state of decoration
Being able to get to and from local shops	94	94	96		
Having a telephone to use regularly	94	93	96	71	Telephone
Having a warm waterproof coat	93	93	96	85	Warm, waterproof coat
Being able to afford good quality window and door locks	93	92	97		
Seeing friends or family regularly	93	93	93	84	Visits to friends or family
Going to the dentist regularly	91	92	88		
Eating fresh fruit and vegetables every day	89	89	90	87	Fresh fruit and vegetables daily
Having a home that is regularly cleaned	89	88	94		
Eating two filling meals a day	89	91	79	91	Two meals a day
Being able to pay an unexpected expense of £200	80	78	87		
Eating the food that they would like to eat or that culturally important to them on most days	80	79	84	56	Roast joint/vegetarian equivalent once a week
Having access to a car or taxi, whenever needed	78	77	83	38	Car

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	All	aged 16-64	aged 65+	PSE19 99 Omnibus	
Being able to pay for their funeral	72	69	84		
Buying over the counter medicines	71	74	59		
Being able to attend funerals	71	72	67	80	Attending weddings, funerals
Having a warm dressing gown	70	68	81	34	Dressing gown
Being able to go out socially on a regular basis	67	67	66	37	An evening out once a fortnight
Having a good pair of slippers	64	61	80		
Visiting the hairdresser or barbers regularly	62	58	78		
Buying presents for grandchildren/other close family members	57	53	71	56	Presents for friends/family once a year
Having a smart outfit for social occasions	56	51	74	51	An outfit for social occasions
Buying a newspaper or magazine at least once a week	54	51	69	30	Having a daily newspaper
Having good fitted carpets	53	51	58	67	Carpets in living rooms and bedrooms
<b><i>Rated necessary by older only, not younger</i></b>					
Having a home with clean windows	47	42	68		
Having a holiday once a year	46	43	56	55	Holiday away from home once a year not with relatives
Having a well-kept garden, if they have one	44	41	61		
Having items dry cleaned occasionally	35	32	51		
<b><i>Not regarded as necessities</i></b>					
Buying vitamin/dietary supplements	44	46	35		
Having a mobile phone	34	33	37	7	Mobile phone
Attending a gym or going swimming regularly	23	24	18		
Belonging to a club or society which requires a paid subscription	21	20	26		
Weighted base	2,134	1,728	406	1,855	
Unweighted base	2,134	1,297	837	1,855	

Source: McKay 2008: 26.

McKay (2008) also informed the current measure's review by extending the time horizon to consider changes in items regarded as necessities from 1983 onwards (see Table 2 below). Bearing in mind that the question wording does sometimes differ, he notes,

- That many goods/services seem to increase in their significance over time, becoming more likely to be seen as essentials. A possible exception to this is goods that are overtaken by technology – analysts have stopped asking about VCRs, for instance.
- Generally speaking, goods are more likely to be regarded as necessities for older people than more widely. However, an important exception is taking a holiday, which is not regarded as a necessity for older people specifically, despite being seen as a necessity for everyone. However, more than half of older people themselves did regard a holiday as a necessity (p. 27).

**Table 2: Necessities for people in 1983, 1990, 1999, 2002 and 2008**

Item (2008 wording)	Breadline Britain All people (1983)	Breadline Britain All people (1990)	PSE All people (1999)	PSENI All people (2002)	NatCen Older people (2008)
Keeping their home damp-free	96	98	94	98	99
Keeping their home in a good of repair	-	92	82	92	96
Having a telephone to use regularly	43	56	71	81	94
Having a warm waterproof coat	87	91	85	93	93
Eating fresh fruit and vegetables every day	-	88	87	92	89
Eating two filling meals a day	64	90	91	-	89
Having access to a car or taxi, whenever needed	22	26	38	53	78
Having a warm dressing gown	38	42	34	-	70
Being able to go out socially regular basis	36	42	37	40	67
Buying presents for grandchildren/other close family members	63	69	56	72	57
Having a smart outfit for social occasions	48	53	51	75	56
Having good fitted carpets	70	78	67	-	53
Having a holiday once a year	63	54	55	60	46

**Source: McKay 2008: 27.**

Dominy and Kempson's (2006) qualitative research funded by the DWP provides the most direct analysis of the new FRS material deprivation questions that were seen to be working well, and those that seemed ill-suited to measuring deprivation for older people. Four particular questions came out as being the highest priorities for older people. These were:

- having two pairs of all weather shoes;
- keeping their home adequately warm;
- being able to replace broken electrical goods such as a refrigerator or washing machine; and
- a hobby or leisure activity.

The other items that were considered by older people to be less important to have, were (in order of importance):

- having home contents insurance;
- keeping their home in a decent state of decoration;
- a holiday away from home for one week a year, not with relatives;
- replacing any worn-out furniture;
- having a small amount of money to spend each week on themselves, not on their family;
- having friends or family for a drink or meal at least once a month;
- regular savings (of £10 a month) for rainy days. (McKay 2008: 29).

### ***Cognitive testing of new FRS questions on material deprivations for older people***

The DWP commissioned a programme of work to explore the feasibility of developing reliable and robust ways of using material deprivation measures to track pensioner poverty (see Legard *et al.* 2008). NatCen was asked to undertake a small-scale programme of cognitive testing (building on the existing qualitative evidence base), to understand more about why the existing question wording and items did not work effectively for older people and to develop new questions for use on the FRS.

Legard *et al.* (2008) found a number of limitations with the wording of some of the questions:

- having non-specific time frames attached to some of the questions made it difficult to provide a sensible answer, or one that was consistent across respondents, e.g. questions related to going out socially on a regular basis and seeing friends and family regularly.
- who is responsible for keeping certain aspects of the housing fabric in good order, e.g. questions about gardens or keeping a house in a good state of decoration will be difficult to answer for tenants (and older people are more likely to be tenants than those in middle age).

- The relevance of particular questions to older people, responses to which they divided into three groups: (a) no need; (b) no desire; and (c) no choice.
  - A person may have no need for, say, adaptations to their home to address reduced mobility or issues relating to frailty. They might have no desire to participate in more social activities or to pay for membership of a club. Someone with no living relatives might have no choice about issues of visiting family or buying presents for them on special occasions. (McKay 2008: 29-30)

Four measures stand out as being particularly important with more than five per cent of those aged 60 and over being unable to afford them<sup>3</sup>. These were:

- being able to pay an unexpected expense of £200 (11 per cent unable to afford);
- being able to pay for their funeral (11 per cent);
- being able to pay regular bills, like Council Tax, without cutting back on essentials (8 per cent);
- having a holiday once a year (7 per cent).

New questions and items were suggested for use on the FRS. These suggestions were discussed with researchers who had worked on other aspects of the programme of work to improve the material deprivation questions for older people on the FRS. As a result new questions and items were included for older people on the FRS from spring 2008 (McKay 2008).

### ***New material deprivation questions for older people - revised FRS items***

The DWP funded research resulted in a new set of questions of material deprivation questions, beginning in the FRS 2009-10, targeted at older people (aged 65 plus). The questions (listed in Table 3 below) were specially designed to collect information on material and social deprivation of older people (McKay 2008). A new pensioner material deprivation indicator will be introduced to the HBAI series in the HBAI publication due to be published in May 2011 as a National Statistics series using data from 2009/10 onwards.

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<sup>3</sup> Full ownership levels of the deprivation indicators, by age (ordered by levels of 'cannot afford') can be found in McKay 2008 (p. 32).

**Table 3: New FRS material deprivation questions targeted at older people**

ITEM A:	Do you eat at least one filling meal a day?	Yes/No
ITEM B:	Do you go out socially, either alone or with other people, at least once a month?	Yes/No
ITEM C:	Do you see your friends or family at least once a month?	Yes/No
ITEM D:	Do you take a holiday away from home for a week or more at least once a year?	Yes/No
ITEM E:	Would you be able to replace your cooker if it broke down?	Yes/No
ITEM F:	Is your home kept in a good state of repair?	Yes/No
ITEM G:	Are your heating, electrics, plumbing and drains kept in good working order?	Yes/No
ITEM H:	Do you have a damp-free home?	Yes/No
ITEM I:	Is your home kept adequately warm?	Yes/No
ITEM J:	Without cutting back on essentials, are you able to pay regular bills like electricity, gas or Council tax?	Yes/No
ITEM K:	Do you have a telephone to use, whenever you need it?	Yes/No
ITEM L:	Do you have access to a car or taxi, whenever you need it?	Yes/No
ITEM M:	Do you have your hair done or cut regularly?	Yes/No
ITEM N:	Do you have a warm waterproof coat?	Yes/No
ITEM O:	Would you be able to pay an unexpected expense of £200?	Yes/No

If **Yes** for **ITEM O**: How would you pay for this [unexpected expense of £200]? CODE ALL THAT APPLY

- I would use my own income but would need to cut back on essentials
- I would use my own income but would not need to cut back on essentials
- I would use my savings
- I would use a form of credit (e.g. credit card or take out a loan)
- I would get the money from friends or family as a gift or loan.
- Other (not on showcard)
- DK (not on showcard)

### ***Comparison of Adult versus Older Person FRS deprivation measures***

As Table 4 below shows, there is very little overlap/consistency in the deprivations measures asked separately of adults and older people. In addition, the adult deprivation indicators were only collected for those adults less than 65 years of age. This creates a problem in terms of making direct comparisons between older people and those less than 65 years of age.

The introduction of a new measure of material deprivation, based on different questions, means that it is not possible to make direct comparisons of material deprivation between older people and the rest of the population. The argument for the new questions for older people is that, in any case, such comparisons were inherently misleading and did not adequately reflect poverty among older people. (McKay 2010: 6)

**Table 4: Comparison of Adult versus Older People material deprivation in the FRS**

FRS 2009-10 Adult items/activities	FRS 2009-10 Older People items/activities
	Do you eat at least one filling meal a day?
	Do you go out socially, either alone or with other people, at least once a month?
friends or family around for a drink or meal at least once a month?	Do you see your friends or family at least once a month?
a holiday away from home for at least one week a year, whilst not staying with relatives at their home?	Do you take a holiday away from home for a week or more at least once a year?
replace or repair major electrical goods such as a refrigerator or a washing machine, when broken	Would you be able to replace your cooker if it broke down?
enough money to keep your home in a decent state of decoration	Is your home kept in a good state of repair?
	Are your heating, electrics, plumbing and drains kept in good working order?
	Do you have a damp-free home?
In winter, are you able to keep this accommodation warm enough (yes/no)	Is your home kept adequately warm?
	Without cutting back on essentials, are you able to pay regular bills like electricity, gas or Council tax?
	Do you have a telephone to use, whenever you need it?
	Do you have access to a car or taxi, whenever you need it?
	Do you have your hair done or cut regularly?
	Do you have a warm waterproof coat?
make regular savings of £10 a month or more for rainy days or retirement	Would you be able to pay an unexpected expense of £200?
two pairs of all weather shoes	
household contents insurance	
replace any worn out furniture	
a small amount of money to spend each week on yourself (not on your family)	
a hobby or leisure activity	

### ***Differences in response categories for adult versus older people items***

For all but “*ITEM O: Would you be able to pay an unexpected expense of £200?*” (see above), the revised FRS items for measuring the material deprivation of older people have the following response categories:

Q2. Why do you not/would you not be able to [‘item where NO stated at question1a’?]

CODE ALL THAT APPLY

- A. I do not have the money for this
- B. This is not a priority for me on my current income
- C. My health/disability prevents me
- D. It is too much trouble/too tiring
- E. There is no one to do this with or help me
- F. This is not something I want
- G. It is not relevant to me
- H. Other (not on showcard)
- I. DK (not on showcard)

These response categories differ from those asked in the PSE1999 sections on Adult and Children deprivation indicators, which were as follows:

1. [I/We] have this
2. [I/We] would like to have this but cannot afford this at the moment
3. [I/We] do not want / need this at the moment
4. [Does not apply]

According to McKay (2010) these revised response categories go beyond deprivation caused by financial restraints to include ill health, disability and social isolation. The revised FRS material deprivation questions will count those responding with any of reasons A to E and H as being deprived for that item.

Given the importance of some of these non-financial aspects for pensioners and as possible drivers for deprivation it is important to include a wide range of these follow ups in defining deprivation. To illustrate this, two pensioners can be considered who lack the same items – e.g. a filling meal, unable to keep house warm, cannot go out socially once a month – where one lacks them because they cannot afford it and the other due to their ill health/disability or social isolation. These would both be considered as deprived on that item because inclusion of any of the follow ups A-E and H classes the pensioner as deprived for that item. (DWP 2011: 2-3)



### ***Suggestions for improvement***

There is scope to revise and improve the list of items and activities appearing in the PSE2011 main survey. We recommend:

- Expanding on PSE1999 items and activities to reflect current necessities/desirables.
- Merge and harmonise PSE1999/FRS0910 items/activities (and questions/response categories) for adults and older people.
- Extended response categories for 'reasons not using' should be considered across all items/activities and age groups.
- If response categories for enforced versus chosen deprivation on items and activities remain, some thought needs to go into how we can recode expanded options in older people questions to match adult deprivation items/activities in order to make valid comparisons.

## 2. Social capital: social networks and social support

Contact with, and support from, family and friends are important sources of social capital and are a measure of the extent to which someone is excluded from personal relations with family and friends. The number and types of exchanges between people within the network, and shared identities that develop, can influence the amount of support an individual has, as well as giving access to other sources of help (Green and Fletcher 2003: 8).

### *a. Social networks and social contact*

#### **Contact with family and friends**

Although the PSE1999 questions allowed us to construct potential support networks in terms of number of family members/friends see, there was a problem in determining the type/period of social contact (see table below).

**Table 5: Contact with social network**

<b>PSE1999</b>	<b>PSENI02</b>
See or speak to every day or nearly every day? (then asked to give numbers of persons)	Speak to, see, relatives, friends, neighbours
	Every day
	5 or 6 days a week
	3 or 4 days a week
	Once or twice a week
	Once or twice a month
	Once every couple of months
	Once or twice a year
	Not at all in last 12 months

#### **ONS harmonisation programme**

The cross-governmental harmonisation programme<sup>4</sup> can be drawn upon to improve PSE2011 main survey questions on contact (and frequency of contact) with family and friends. The following questions on type of contact and frequency of contact with family and friends is part of the set of [Harmonised Secondary Standards](#) for social sources. In particular, the secondary set of harmonised concepts and questions on social capital<sup>5</sup> includes relevant questions on social contact (copied in below).

<sup>4</sup> <http://www.ons.gov.uk/about-statistics/harmonisation/index.html>

<sup>5</sup> <http://www.ons.gov.uk/about-statistics/harmonisation/secondary-concepts-and-questions/S10.pdf>

**SNIntro**

The next few questions are about how often you personally contact your relatives, friends and neighbours. Not counting the people you live with, how often do you do any of the following?

**26. Spkrel**

Speak to relatives on the phone

SHOW CARD G:

1. On most days
2. Once or twice a week
3. Once or twice a month
4. Less often than once a month
5. Never
6. (SPONTANEOUS) Don.t know

**27. Wrtrel**

Write a letter or note to relatives

SHOW CARD G

**28. Txtrel**

Text or email relatives, or use chatrooms on the internet to talk to relatives

SHOW CARD G

**29. Spkfr**

Speak to friends on the phone

SHOW CARD G

**30. Wrtfr**

Write a letter or note to friends

SHOW CARD G

**31. Txtfr**

Text or email friends, or use chatrooms on the internet to talk to friends

SHOW CARD G

**32. Spkng**

Speak to neighbours

SHOW CARD G

SNIntro to Spkng emphasise how often the respondent personally contacts relatives, friends and neighbours to deter married or cohabiting people from including contacts made by their partner.

**33. FreqMtR**

How often do you meet up with relatives who are not living with you?

SHOW CARD G

**34. FreqMtF**

How often do you meet up with friends?

SHOW CARD G

***b. Social support and assistance***

**Actual versus potential social support**

The seven questions on affective and instrumental support in the PSE1999 did work well in terms of what they were designed to measure, i.e. potential social support and were subsequently replicated in the PSENI02 (see table below).

However, the questions ask about potential, not actual, support, so some thought might be given to asking about each instrumental/affective support scenario within the last 12 month period. Alternatively, we can ask the same questions, supplemented by a short, “did such a situation occur in the last 12 months” (or something similar), thereby allowing us to gauge both potential and actual support. However, issue of recall may affect the follow-up question proposed.

**Table 6: Potential support comparisons**

PSE1999	PSENI02
If you needed help around the home if you are in bed with flu/illness	If you needed help around the home if you are in bed with flu/illness.
If you needed help with heavy household or gardening jobs that you cannot manage alone, e.g. moving furniture	If you needed help with heavy household or gardening jobs that you cannot manage alone, e.g. moving furniture.
If you needed advice about an important change in your life, e.g. changing jobs, moving to another area	If you needed advice about an important change in your life, e.g. changing jobs, moving to another area.
If you were upset because of problems with your spouse or partner	If you were upset because of problems with your spouse or partner.
If you were feeling a bit depressed and wanting someone to talk to	If you were feeling a bit depressed and wanting someone to talk to.
If you needed someone to look after your children, an elderly or a disabled adult you care for	If you needed someone to look after your children, an elderly or a disabled adult you care for who depends on you.
If you needed someone to look after your home or possessions when away	If you needed someone to look after your home or possessions when away

Again, the secondary set of harmonised concepts and questions on social capital<sup>6</sup> may prove useful in helping improve this section of the PSE2011 (copied in below).

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<sup>6</sup> <http://www.ons.gov.uk/about-statistics/harmonisation/secondary-concepts-and-questions/S10.pdf>

SitIntro

I am going to describe two situations where people might need help. For each one, could you tell me if there is anyone you could ask for help?

(IF MORE THAN ONE PERSON IN HOUSEHOLD ADD: Please include people living with you and people outside the household)

**35. Illbed**

You are ill in bed and need help at home. Is there anyone you could ask for help? Yes/no

.Help at home. means help with domestic tasks such as cooking, cleaning and making a cup of tea.

**36. Money**

You are in financial difficulty and need to borrow some money to see you through the next few days. Is there anyone you could ask for help? Yes/no

Loans from banks or other financial institutions should be excluded.

If Illbed = Yes then Whohlp; If Money = Yes then Whohlp2:

**37. WhoHelp/WhoHelp2**

Please can you look at this card and tell me who you could ask for help?

SHOW CARD H

CODE ALL THAT APPLY

1. Husband/wife/partner
2. Other household member
3. Relative (outside household)
4. Friend
5. Neighbour
6. Work colleague
7. Voluntary or other organisation
8. Other
9. Would prefer not to ask for help
10. (SPONTANEOUS) Don.t know

**38. PCrisis**

If you had a serious personal crisis, how many people, if any, do you feel you could turn to for comfort and support?

IF MORE THAN 15, CODE AS 15.

(0-15, Don.t know)

This question needs to be dealt with sensitively, as it can be upsetting for people who are socially isolated.

If respondents have difficulty giving a number, the interviewer should ask them to give an estimate.

### ***Financial and other types of help/support given and received***

Financial and other types of assistance provided by family and friends are important material and social resources for older (and younger) people. The FRS asks a series of questions on financial or other types of help (including some that might result from difficulties in carrying out activities of daily living) from their family or friends. These include items partly paid for by family or friends (but exclude members of the household as family or friends) (copied in below).

Over the past 12 months (since [date a year ago]) have your family or friends helped you by...

1. ...buying or bringing you food or meals?
2. ...paying towards bills (such as utility bills, rent or grocery bills (excluding food))?
3. ...helping you to manage your money or deal with your benefits?
4. ...helping with home repairs or decoration whether by paying for it or doing it for you?
5. ...helping with household chores (such as cleaning, gardening) whether by paying for it or doing it for you?
6. ...giving you lifts to places or paying for travel costs (such as taxi, train or bus fares)?
7. ...paying for trips/holidays?
8. ...buying or giving you clothes?
9. [...buying clothes, toys or other equipment for your child(ren)?]
10. ...buying a big electrical item like a cooker, boiler, fridge or washing machine?
11. Other help received
12. None of these
13. SPONTANEOUS - Not applicable has no family or friends

#### Loans received

Over the past 12 months, have your family or friends ever given or lent you money?

1. Regularly give money
2. Sometimes give money
3. Lend money
4. None of these

The FRS also collects information on financial or other types of help given to their family or friends.

Over the past 12 months (since [DATE A YEAR AGO]) have you helped your family or friends by...

1. ...buying or bringing them food or meals?
2. ...paying towards bills (such as utility bills, rent or grocery bills (excluding food))?
3. ...helping them to manage their money or deal with their benefits?

4. ...helping them with home repairs or decoration whether by paying for it or doing it for them?
5. ...helping with household chores (such as cleaning, gardening) whether by paying for it or doing it for them?
6. ...giving them lifts to places or paying for travel costs (such as taxi, train or bus fares)?
7. ...paying for trips/holidays?
8. ...buying or giving them clothes?
9. ...buying clothes, toys or other equipment for their child(ren)
10. ...buying a big electrical item like a cooker, boiler, fridge or washing machine?
11. Other help given
12. None of these
13. SPONTANEOUS - Not applicable has no family or friends

#### Loans given

Over the past 12 months, have you ever given or lent your family or friends money?

1. Regularly give money
2. Sometimes give money
3. Lend money
4. None of these

### ***Presents of useful or needed items***

Dominy and Kempson's (2006) qualitative research (6 focus groups, 42 in-depth interviews) showed that nearly half of older people interviewed received some financial and other types of help from family and friends. This help was often not direct financial help, but given as presents of useful or needed items:

**Practical Support:** decorating, transport, shopping, food, gardening, cleaning

**Financial support (presents):** electrical items, clothes, holiday, car, furniture, bills, food

**Social support:** daytrips and outings, home visits, providing holiday/respite in their home

**Financial advice and support:** managing finances and payment of bills, providing financial advice, withdrawing and spending money (Dominy & Kempson, 2006: 55)

In listed order of prevalence these presents (listed above) were: giving electrical items (most common), clothes, holidays, car, furniture, bills and food. In addition many received practical help, such as decorating (most common), transport, shopping, food, gardening and cleaning (Dominy & Kempson 2006: 5). "So, what may appear to be apparently high living standards (or low deprivation) for those on a low level of income, may actually be attributed to

help from others – rather than, say, skill in managing on a budget” (McKay 2008: 11). McKay goes on to state, “

An important policy issue is whether such help and support counts as a family responding to poverty, or just represents a level of reciprocity one might expect and not deserving of further analysis. In many places, and at different times, helping older relatives would be a strong expectation on families, its absence more worthy of comment than its taking place. It is not readily possible to discern if family support for older people is signalling a problem of poverty (being addressed by families in informal ways) or merely the kind of exchanges that one would expect between families. (2008: 12)

Some of the items on financial help and social support were covered in the PSE1999 adult necessities, but not adequately, so the FRS questions on financial and other types of help should provide some important information on the extent to which financial (gifts) and other types of help indicate both levels of material and social reciprocity, and how these can be help to alleviate poverty and prevent social exclusion. This would expand the affective and instrumental support outlined above to include items and durable goods which, although they may not be able to afford, they do have, as a result of a family/friend gifting it to them.

### ***Spending and social activities***

In addition to the findings on presents of useful or needed items, Dominy and Kempson (2006) found that ‘lack of engagement in social activities did lead to a reduction in discretionary spending’ (p.7). They also highlighted problems with reasons why items were absent, and that people had items without considering if it was themselves or others paying for them or providing them. Respondents also tended to say they did not need items when they really could not afford them. The existing FRS items performing best were:

- Home contents insurance
- Home decoration
- Saving for a rainy day
- Holiday
- Replacing electrical goods
- Hobbies/leisure
- Two pairs of shoes (as cited in McKay 2008: 5)

### ***Spending and social relations***

Finch and Kemp (2006) examined pensioners who did not spend all of their income. Many older people save money, arguably inconsistent with a simple life-cycle perspective on assets, and spending fell more rapidly with age than did income. Whilst describing the results as ‘far from conclusive’ (p.6) they



suggest that low spending relative to income is associated with increasing frailty, itself associated with important factors around declining social relations. Pensioners would be more likely to spend their incomes, and maintain their living standards, by continuing to be independent and part of a social network (as cited in McKay 2008: 5).

The relevance of these findings to older people is in terms of ensuring we capture frailty/dependence and the structure/depth of the actual/potential support networks (see sections above on *actual versus potential support* and below on *health problems which cause difficulties*, as well as *paid/unpaid/voluntary support needed to remain independent*).

### ***Suggestions for improvement:***

#### **a. Social networks and social contact**

- Use harmonised questions on social networks and social contact from social capital module of ONS harmonisation programme

#### **b. Social support**

- Asking supplemental questions on actual social support, which will allow us to distinguish between potential versus actual support
- Consider amalgamating FRS financial and other types of help with additional items found in related qualitative research (car, furniture, holiday/respite in their home, etc).

### **3. Health Problems which cause Activities of Daily Living (ADL) difficulties**

According to Price (2008) “frailty, illness and disability are virtually ignored in the measurement of poverty, despite the increased needs and changed patterns of consumption that accompany transitions into poorer health” (p. 1). The focus in the following section is on limitations in activities of daily living (ADLs) such as bathing, cooking, and shopping, whereas the section following it examines source(s) of assistance for these activity limitations. Taken together they cover the general area of care and support for older people with a long-standing illness, disability or infirmity. In some surveys (FRS and Census, for example), it is common practice to refer to problems associated with - or related to - age or ageing; a phrase which is vague, biased and potentially pejorative in respect of older people. However, it is retained when recommending questions from the FRS as this is the terminology used in many of its questions.

#### ***General health and long-standing illness***

Questions on self-perceived health and long-standing illness (limiting or non-limiting) should be considered for all persons along the life course. This paper does not deal with this area in depth as it is covered in more detail in the health/disability measures review papers. What follows is a general overview ADLs, which might be considered for use in the PSE2011.

#### ***Activities of Daily Living (ADLs)***

ADLs refer to the abilities we all need to live independently and which can be affected by the long-term physical and mental conditions which become more prevalent in later life. The ability to carry out ADLs is an important element of both poverty and social exclusion for older people as they impact on one’s ability to earn an income, look after oneself and others, and to be able to participate in family and other social activities.

Detailed information on ADLs for older people (aged 65 plus) living in private households were not in the PSE1999, but could be found in the General Household Survey (GHS) 1998 ‘trailer’.

There are six basic categories of ADLs:

- Hygiene (bathing, grooming, shaving and oral care)
- Continence
- Dressing
- Eating (the ability to feed oneself)
- Toileting (the ability to use a restroom)
- Transferring (actions such as going from a seated to standing position and getting in and out of bed)

## ***Instrumental Activities of Daily Living (IADLs)***

IADLs are more nuanced and complex social activities than ADLs. IADLs can include, but are not limited to:

- Finding and utilising resources (looking up phone numbers, using a telephone, making and keeping doctor's appointments)
- Driving or arranging travel (either by public transportation or private car)
- Preparing meals (opening containers, using kitchen equipment)
- Shopping (getting to the shops and purchasing necessities like food or clothing)
- Doing housework (doing laundry, cleaning up spills and maintaining a clean living space)
- Managing medication (taking prescribed dosages at correct times and keeping track of medications)
- Managing finances (basic budgeting, paying bills and writing cheques).

## ***I/ADLs in UK surveys***

What follows below is a brief summary and analysis of the key ADLs found in UK surveys. A full crosswalk of ADLs appearing in major UK surveys can be found in Appendix 1.

### **FRS**

Although the FRS does not follow the typical ADL delineations listed above, it does have a set of 10 items which would allow us to follow up with type and source of help or support (care) for long-standing physical or mental ill-health or disability in a meaningful way. According to the FRS documentation, these questions have been refined to bring the FRS in line with the Disability Discrimination Act (DDA) definitions. The DDA questions are also asked in the Office for Disability Issues new Life Opportunities Survey (LOS). The advantage in using the existing FRS questions on 'difficulties' is that they are asked after the filter question on longstanding illness (LSI) and limiting longstanding illness (LLSI) (copied in below).

#### **Health**

Asked of all respondents.

\*Do you have any long-standing illness, disability or infirmity? By 'long-standing' I mean anything that has troubled you over a period of at least 12 months or that is likely to affect you over a period of at least 12 months.

If 'yes' to **Health**.

\*Does this physical or mental illness or disability (Do any of these physical or mental illnesses or disabilities) limit your activities in any way?

If 'yes' to **Health**.

**HProb**

Does this/Do these health problem(s) or disability(ies) mean that you have substantial difficulties with any of these areas of your life?

- 1: Mobility (moving about)
- 2: Lifting, carrying or moving objects
- 3: Manual dexterity (using your hands to carry out everyday tasks)
- 4: Continence (bladder and bowel control)
- 5: Communication (speech, hearing or eyesight)
- 6: Memory or ability to concentrate, learn or understand
- 7: Recognising when you are in physical danger
- 8: Your physical co-ordination (eg: balance)
- 9: Other health problem or disability
- 10: None of these

Of course, it would be helpful to have a question or two on managing personal affairs (banking/insurance and care arrangements) but the above list is usable if we cannot expand on it due to survey time constraints. However, the English Longitudinal Study of Ageing (ELSA), General Household Survey (now called the General Lifestyle Survey, or GLF), Life Opportunity Survey (LOS), and recent NatCen Module on Social Care for Older People offer sound options for expanding coverage of ADLs and IADLs (and for establishing both informal and formal sources of care/support for ADL limitations).

**ELSA**

ELSA<sup>7</sup> is a study of people aged 50 and over and (if applicable) their younger partners, living in private households in England. As it is a longitudinal study the same group of people will be interviewed three times, at two year intervals, to measure changes in their health, economic and social circumstances. Many of the measures adopted in ELSA are comparable with measures used in the US Health Retirement Study (HRS) and the Survey of Health, Ageing and Retirement in Europe (SHARE). Four Waves of data are currently available (2002-2009). ELSA asks questions on both ADLs and IADLs (copied in below).

**HEADLA**

We need to understand difficulties people may have with various activities because of a health or physical problem. Please tell me whether [youname[PNum]] [havehas[PNum]] any difficulty doing each of the everyday activities on this card. Exclude any difficulties that you expect to last less than three months. Because of a health problem, [ldodoes[PNum]] [heshe[PNum]] have difficulty doing any of the activities on this card?

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<sup>7</sup> <http://www.ifs.org.uk/elsa/>

INTERVIEWER:PROBE - 'What others?'....Code all that apply.

- 01 Walking 100 yards
- 02 Sitting for about two hours
- 03 Getting up from a chair after sitting for long periods
- 04 Climbing several flights of stairs without resting
- 05 Climbing one flight of stairs without resting
- 06 Stooping, kneeling, or crouching
- 07 Reaching or extending arms above shoulder level (either arm)
- 08 Pulling or pushing large objects like a living room chair
- 09 Lifting or carrying weights over 10 pounds, like a heavy bag of groceries
- 10 Picking up a 5p coin from a table
- 96 None of these

**[code maximum 10 out of 11 possible responses]**

## HEADLB

Here are a few more everyday activities. Please tell me if [youname[PNum]] [havehas[PNum]] any difficulty with these because of a physical, mental, emotional or memory problem. Again exclude any difficulties you expect to last less than three months. Because of a health or memory problem, [ldodoes[PNum]] [heshe[PNum]] have difficulty doing any of the activities on this card?

INTERVIEWER:PROBE - 'What others?'...Code all that apply.

- 01 Dressing, including putting on shoes and socks
- 02 Walking across a room
- 03 Bathing or showering
- 04 Eating, such as cutting up ^hisher[pnum] food
- 05 Getting in or out of bed
- 06 Using the toilet, including getting up or down
- 07 Using a map to figure out how to get around in a strange place
- 08 Recognising when you are in physical danger
- 09 Preparing a hot meal
- 10 Shopping for groceries
- 11 Making telephone calls
- 12 Communication (speech, hearing or eyesight)
- 13 Taking medications
- 14 Doing work around the house or garden
- 15 Managing money, such as paying bills and keeping track of expenses
- 96 None of these

**[code maximum 16 out of 16 possible responses]**

As can be seen ELSA provides quite an extensive list of ADLs, some of which might be drawn upon to inform the PSE2011 main survey. However, the existing ELSA list in its current form would be quite time intensive if each ADL were asked of every member of the household reporting a long-standing illness, disability or infirmity.

### **GHS (1980, 1985, 1991, 1994, 1998, 2001)**

Questions in the GHS relating to specific ADL tasks (and help with daily living tasks) were asked about separately in the GHS Elderly Supplements or 'trailers' appearing in 1980, 1985, 1991, 1994, 1998 and 2001. The format of the GHS questions varies depending on whether the questions relate to help with domestic tasks or personal care tasks. Questions about help with personal care tasks are *only* asked if the person is unable to perform the task without help from someone else or finds it fairly or very difficult to perform the task on their own. On the other hand, questions on domestic tasks collect information about help received by anyone who does not perform a particular domestic task, whether or not they could perform this task if they had to (Pickard 2008: 5).

The general format of the GHS questions on (I)ADLs and associated help (covered more fully in section 4 below) were as follows:

#### **PERSONAL CARE TASKS:**

##### **BATHING**

#### **40. CanHlp4 If finds it difficult to bath, shower or wash all over (BathEasy = 3 or 4)**

Although you said you usually manage on your own, does anyone help you bath, shower or wash all over?

Yes.....1 [go to Q41]

No.....2 [go to Q44]

#### **41. BthHlp If needs help to bath, shower or wash all over (Bath = 2 or CanHlp4 = 1)**

Who usually does this for you? Is it someone in the household, or someone from outside the household?

Someone in the household.....1 [go to Q42]

Someone from outside the household.....2 [go to Q43]

#### **79. BthHlpA If usually gets help from someone in the household (BthHlp = 1)**

Who is the person in the household?

#### **80. BthHlpB If usually gets help from someone outside the household (BthHlp = 2)**

Who is the person from outside the household?

Son.....2

Daughter.....	3
Brother.....	4
Sister.....	5
Other relation.....	6
Friend/Neighbour.....	7
Social Services.....	8
District Nurse/Health Visitor.....	9
Paid help.....	10
Other.....	15
Nobody does it.....	16

**DOMESTIC TASKS:**

**SHOPPING**

**77. ShopOwn If does not do the household shopping themselves (Shopping = 2)**

**Could you if you had to?**

Yes.....	1 [go to Q78]
No.....	2 [go to Q78]

**78.ShpHlp Who usually does this for you? Is it someone in the household, or someone from outside the household?**

Someone in the household.....	1 [go to Q79]
Someone from outside the household.....	2 [go to Q80]

**79.ShpHlpA If usually gets help from someone in the household (ShpHlp = 1)**

Who is the person in the household?

**80. ShpHlpB If usually gets help from someone outside the household (ShpHlp = 2)**

Who is the person from outside the household?

Son.....	2
Daughter.....	3
Brother.....	4
Sister.....	5
Other relation.....	6
Friend/Neighbour.....	7
Social Services.....	8
District Nurse/Health Visitor.....	9
Paid help.....	10
Other.....	15
Nobody does it.....	16

The key challenge in using the GHS questions to inform activity limitations (in addition to the length of the question set) is that the help or support with domestic tasks is asked even if the respondent does not report any difficulty carrying out the task, which overestimates the real level of help or support related directly to actual or expressed ADL needs. If the GHS questions are to be considered for use in the PSE2011, then a filter question about ability to carry out both personal care and domestic tasks will need to be consistent.

## GLF

From April 2005 the General Household Survey (GHS) was restructured to fit the requirements of the *European Union Statistics on Income and Living Conditions* (EU-SILC) and became known as the GHS (L). Whilst there will be a lot of continuity of coverage from the long series of cross-sectional surveys that make up the GHS, there will also be some significant changes in the new series. The new survey will be known as GHS(L) or GSL. In 2008 the GHS(L) was merged into the Integrated Household Survey and became known as the GLF.

The GLF also asks a series of questions pertaining to self-rated health and long-standing (limiting) illness, as well as a follow-up question on degree of limited activity (i.e. limited, strongly limited, etc.) and the need to cut down (including number of days in the past 2 weeks) on any of the things people usually do (about the house/at work or in your free time) because of illness or injury. However, there is little in the way of ADL-specific needs as is found in ELSA or previous GHS supplements. There are a couple of questions on whether people felt that they needed an examination from a GP or dentist but didn't get one and the reason(s) for this (including affordability). The GLF also includes a series of questions on contact with a variety of health professionals and settings (practice nurse, casualty).

## LOS

The *Life Opportunities Survey* (LOS)<sup>8</sup> commissioned by the Office for Disability issues launched in June 2009 includes the same DDA questions as the FRS as well as many of the ADL and IADL items included in existing UK surveys (see Appendix 1). Since the LOS covers similar questions to the FRS, there is little need to repeat the questions here. However, the LOS does have specific mobility and dexterity related DDA questions in its survey (copied in below).

### **396. IMobil APPLIES TO ADULTS >15 AND CHILDREN 11 – 15 (by proxy)**

#### **ASK OR RECORD**

Do you have any mobility difficulties, for example moving about, walking, climbing stairs; or use special equipment or support

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<sup>8</sup> <http://www.officefordisability.gov.uk/research/survey.php>



services to help you to be mobile?  
[Interviewer Instruction] Include wheelchairs and crutches as equipment.

- (1) Yes
- (2) No

**397. MobAid**

**APPLIES IF: IMobil = Yes**

ASK OR RECORD

Can I just check, do you use any special equipment or have support services to help you to be mobile?

- (1) Yes
- (2) No

**398. MobA**

**APPLIES IF IMobil = Yes**

SHOWCARD S1

(With this equipment or support service), how would you describe your mobility difficulty?

- (1) No difficulty
- (2) Mild difficulty
- (3) Moderate difficulty
- (4) Severe difficulty
- (5) Cannot do

**399. MobLim**

**APPLIES IF: MobA >1**

SHOWCARD S2

How often does this limit the amount or kind of activities that you can do?

- (1) Always
- (2) Often
- (3) Sometimes
- (4) Rarely
- (5) Never

**400. IDex APPLIES TO ADULTS >15 AND CHILDREN 11 – 15 (by proxy)**

Do you have any dexterity difficulties, by that I mean lifting, grasping or holding objects, or use special equipment to help you with these actions?

[Interviewer instruction] Include those who cannot lift, grasp or hold at all

- (1) Yes
- (2) No

**401. DexAid**

**APPLIES IF: IDex = Yes**

ASK OR RECORD

Can I just check, do you use any special equipment to help you lift, grasp or hold objects?

- (1) Yes
- (2) No

**402. DexDiff**

**APPLIES IF: IDex = Yes**

SHOWCARD S1

(With your equipment) how would you describe your difficulty lifting, grasping or holding objects?

- (1) No difficulty
- (2) Mild difficulty
- (3) Moderate difficulty
- (4) Severe difficulty
- (5) Cannot do

**403. DexLim**

**APPLIES IF: DexDiff > 1**

SHOWCARD S2

How often does this limit the amount or kind of activities that you can do?

- (1) Always
- (2) Often
- (3) Sometimes
- (4) Rarely
- (5) Never

**NatCen Survey Question Module on Care for Older People**

More recently, the Department of Health and the Nuffield Foundation have funded the development of a module of survey questions<sup>9</sup> covering A/IADLs, receipt of formal and informal care for A/IADLs, payment for formal care services and provision of informal care for people aged 65 and over living in private households (not residential care). This has resulted in the creation of a new module on social care for older people which will be included in the Health and Social Care Survey (England) beginning in 2011. The module of questions that has been developed reflects the way the social care system in England and Wales currently operates and covers receipt of care services and related benefits, payment for care services and provision and receipt of informal care.

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<sup>9</sup> Released 12 November 2010, see <http://www.natcen.ac.uk/events-and-training/our-events/events/launch-of-new-survey-question-module/social-care-questions-for-over-65s#downloads>

Similar to the question routings found in the GHS, ADL tasks questions are asked for each ADL/IADL in turn, before moving onto task help for each ADL and IADL in turn (see section 4 below). Task help is asked for all ADLs/IADLs regardless of the answer to tasks (showcards copied in below).

**SHOWCARD A - ADLs and IADLs**

1. getting in and out of bed on your own
2. washing your face and hands
3. having a bath or a shower, including getting in and out of the bath or shower  
INTERVIEWER: IF RESPONDENT SAYS THEY CAN DO ONE BUT NOT THE OTHER, ASK THEM TO THINK ABOUT THE WASHING FACILITIES THEY HAVE.
4. dressing or undressing, including putting on shoes and socks
5. using the toilet
6. eating, including cutting up food
7. taking the right amount of medicine at the right times.  
INTERVIEWER: Include prescribed medicines and medicines you can buy over the counter
8. getting around indoors
9. getting up and down stairs
10. getting out of the house, for example to go to the doctors or to visit a friend
11. shopping for food including getting to the shops, choosing the items, carrying the items home and then unpacking and putting the items away
12. doing routine housework or laundry
13. doing paperwork or bills

**Tasks**

Thinking about [ADL/IADL], please look at this card and tell me the option which best applies to you?

1. I can do this without help from anyone
2. I have difficulty but manage on my own
3. I can only do this with help from someone
4. I cannot do this

***Suggestions for improvement***

There are a variety of options for gathering information about ADL limitations and mobility difficulties, the most helpful of which are found in the GHS2001, ELSA, LOS and recent NatCen Module on Social Care for Older People. We recommend that:

- If not covered in the health/disability section (and survey space permitting), a range of ADL/IADL items might be considered for use in the PSE2011 which are also designed to capture degree of limitation (i.e. limited not all, somewhat, to a great degree, etc.) or ability (i.e. can

do this without help from anyone, have difficulty but manage on my own, etc.).

- If not covered in the health/disability section (and survey space permitting), a specific question on the level of difficulty with mobility (either in an ADL section or part of the health/disability section).

## 4. Receipt of help or support for ADL limitations/LSI, disability or infirmity

Appropriate help or support and services can help older people to remain independent and enjoy living in their own homes and communities for as long as possible. Available and appropriate help or support (when needed) also allows older people to live their lives in their homes in the way they want. In regards to the PSE2011, we are suggesting a focus on that help or support which is related directly to ADL limitations (or alternatively the presence of a long-standing illness, disability or infirmity).

### **FRS**

The FRS asks the household respondent is if anyone in the household receives help or support (copied in below), or if anyone in the household provides help or looks after anyone outside the household.

#### **Anyone Needing Help**

##### **[NeedHelp]**

(Jump 13)

In some households, there are people who receive help or support because they have long-term physical or mental ill-health or disability, (or problems relating to old age).

#### **SHOW CARD D1**

##### **Keeping an eye out, 'being there':**

Being available if needed

Making your whereabouts known so you can be contacted if needed

##### **Social support and assistance:**

Sitting with

Chatting with/ listening to/reading to

Making/receiving telephone calls to talk to them

Encouraging them to do things for themselves

##### **Accompanying on trips out to go:**

Shopping

To hospital/ GP/optician/dentist/chiroprapist

To the park/place of worship/restaurant

##### **Paperwork/official/financial:**

Helping with paperwork

Dealing with 'officials' (including by phone)

##### **Home and garden:**

Making meals  
Going shopping for someone  
Washing/ironing/changing sheets  
Cleaning /housework  
Gardening  
Odd jobs/maintenance

**Medical:**

Collecting prescriptions/giving medication  
Changing dressings

**Moving about the home: Giving help with**

Getting up and down stairs  
Moving from room to room  
Getting in and out of bed

**Personal care: help with**

Getting dressed  
Feeding  
Washing/bathing/using the toilet

**Is there anyone in this household who receives any of these kinds of help or looking after?**

INTERVIEWER: INCLUDE HELP FROM WIFE/HUSBAND/PARTNER /OTHER FAMILY MEMBER

Questions are then asked about whom is receiving the help or being looked after. There are then follow-up questions for each person named about who provides the help and the frequency of help or support. Time of help (day or night) is only asked if help is received or provided continuously or several times a day. The follow-up questions are only asked for those receiving help or support at least once a week.

The advantage of the FRS questions on receiving (and providing help or support) is that they are asked specifically in terms of a long-term physical or mental ill-health or disability, (or problems relating to old age). However, one key limitation is that the householder is the person asked the question about help or support received or given and not the actual person receiving or giving the help or support (although in some instances the householder may be in fact the person who is receiving and/or providing help or support).

Another key drawback of the FRS section on the receipt of help is that it covers a wide range of personal care and domestic tasks without actually identifying the specific A/IADL limitations or level of need or dependency of the person receiving help or support. This makes it quite difficult to distinguish between those who have high levels of dependency (needing more intense

help or support) and those who might need a little bit of extra help to live independently (and well) in their own home. This raises another shortcoming of the FRS as it excludes those living in residential care.

Moreover, there appears to be a lack of clarity in terms of what kinds of tasks should be considered everyday help or support and that 'care' related directly to long-standing physical or mental ill-health (or problems related to ageing). For example, if someone in the household is cooking supper and one of the members living in the household has a long-standing disability and cannot cook for themselves, but all the members of the household eat together, then should this fall under help or support for an ADL limitation or fall under normal day-day-activities?

To sum up, whereas the FRS provides a potentially rich source of information on help or support received (and given) it does not actually prescriptively define or operationalise what should be counted as 'care', only that it is that help or support because of a long-term physical or mental ill-health or disability (or problems relating to old age). Moreover, there is little information in the extent to which this help or support meets the ADL needs of those being care for or looked after and the impact on the 'carer' of providing help or support to those people in need.

Turning to the first issue of what should be defined as care, there are other national and local surveys (in existence and going into the field soon) which collect information on the specific nature of care and support received by older people. Below, however, we have chosen to focus on one such survey, the NatCen Module, which covers a wide spectrum of help or support (care) received by older people living in private households.

### ***NatCen Survey Question Module on Care for Older People***

The new NatCen Module offers the greatest scope for inclusion in the PSE2011 as it focuses on specific ADL needs and the specific tasks and sources of care for limitations in carrying out daily activities, rather than asking generally about help and support because of a long-term physical or mental ill-health or disability (or problems relating to old age). Specific sources of assistance with ADLs are identified as is frequency and hours (intensity) of help or support. In addition, there are both short and long versions of the NatCen module (identified where applicable below).

After being asked a series of questions on ADLs/IADLs (see section 4 above), respondents are then asked if they receive any help with the specific ADL item (copied in below).

#### **TaskHelp**

Have you received help from anyone with [ADL/IADL] in the **last month?**

1. Yes

2. No

Subsequent times **TaskHelp** is asked use:

What about [ADL/IADL]?

(Have you received help from anyone with [ADL/IADL] in the **last month**?)

If respondent answers 'No' to all parts of TaskHelp, they will be taken straight to A6 (MealProv)

*{IF TaskHelp=YES only for 'shopping for food', doing paperwork or bills, or 'housework or laundry' or a combination of these (i.e. no help received with any other ADLs/IADLs)}*

**CHECK A**

Do you receive this help with [*shopping for food/ housework and laundry /doing paperwork or bills*] because of long standing physical or mental ill-health, disability or problems relating to old age?

1. Yes for some or all
2. No, none of this help is because long standing physical or mental ill-health, disability or problems relating to old age

**A2 – WHO HELPS WITH ADL/IADLS**

LONG VERSION: ASK Helpinf AND Helpform FOR EACH ADL/IADL RECORDED AT TaskHelp (USED IN THE LAST MONTH) on a loop but with some ALDs/IADLs combined:

1. Having a bath or shower
2. Getting in and out of bed /washing your face and hands /dressing or undressing / eating/ taking the right amount of medicine at the right times
3. Getting around indoors/ getting up and down stairs
4. Using the toilet
5. Getting out of the house /shopping for food / doing routine housework or laundry /doing paperwork or bills

SHORT VERSION: ASK Helpinf AND Helpform x3 times, For:

1. Having a bath or shower
2. Getting in and out of bed /washing your face and hands /dressing or undressing/ using the toilet/ eating, including cutting up food/ taking the right amount of medicine at the right times/ getting around indoors/ getting up and down stairs/
3. Getting out of the house / Shopping for food / Doing routine housework or laundry/ doing paperwork or bills

**Helpinf**

**In the last month**, who has helped you with [ADL/IADL(s) from *grouped list*]. First, please tell me about all of the people from this list who have helped you?



CODE ALL THAT APPLY:

1. Husband/Wife/Partner
2. Son (including step son, adopted son or son in law)
3. Daughter (including step daughter, adopted daughter or daughter in law)
4. Grandchild (including Great Grandchildren)
5. Brother / Sister (including step / adopted / in-laws)
6. Niece / Nephew
7. Mother/father (including mother-in-law/ father-in-law)
8. Other family member
9. Friend
10. Neighbour
11. None of the above

**HelpFam**

You've told me that your [*answer from HelpInf*] helped you. Can I just check, does he/she live here with you?

1. Yes
2. No

**Helpform**

Now, please tell me about all of the people from this list who have helped you with [*ADL/IADL(s) from grouped list*] in the last month?

CODE ALL THAT APPLY:

1. Home care worker /Home help/Personal Assistant
2. A member of the reablement / intermediate care staff team
3. Occupational Therapist / Physiotherapist
4. Voluntary helper
5. Warden / Sheltered housing manager
6. Cleaner
7. Council's handyman
8. Other (please specify)
9. None of the above

**Hhelp**

You have told me that a home care worker/home help/personal assistant helped you in the last month. Do you have just one person helping you, or do you have more than one?

1. One
2. More than one

**A3 - HOURS OF CARE (INTENSITY)**

**HelpHours**

Thinking about [*person who helps*], in the last week how many hours have they helped you in person with these kinds of tasks?

1. No help in the last week
2. Less than one hour
3. 1-4 hours
4. 5-9 hours
5. 10-19 hours
6. 20-34 hours
7. 35-49 hours
8. 50-99 hours
9. 100 hours or more

#### **A4 – ARRANGING AND PAYING FOR CARE**

{ASK IF ANY FORMAL CARERS AT HelpForm, OR INFORMAL CARERS HelpInf, FOR 20+ HOURS (HelpHours=6, 7, 8 or 9)}

##### **LAhelp**

How was the help from [*person who helps*] arranged?

1. Arranged without involvement from the local authority, council or social service
2. Local authority, council or social services arranged this help for me
3. Local authority, council or social services told me about the help but I arranged it myself or my family arranged it for me
4. Other

##### **HaveDP**

Local Authorities/councils/ social services offer different ways of arranging payment for people's care. Which of the following apply for the care you receive?

INTERVIEWER: Only include payments for social care. Do not include other payments, for example from a pension or from benefits such as Attendance Allowance.

1. Direct payments
2. Council manages the money
3. Neither of these

##### **PersB**

Do you have a **Personal Budget**, sometimes known as an **Individual Budget**?

1. Yes, have Personal Budget/Individual budget
2. No do not have Personal Budget/ Individual Budget

##### **IncAss**

Has the local authority or council made an assessment of what you can afford for any of your care needs? This is sometimes called an income assessment or means testing.

1. Yes, had income assessment
2. No

### **Anypay**

Do you [*IF PARTNER LIVES IN HHLD: or your partner*] pay or give any money for the help given by [*list of all formal any hours/informal 20+ hours who helped*]? Please include any payments made for this care, even if not made directly to the care provider. Do not include gifts, treats or occasional payments of expenses such as petrol money or lunch.

1. Yes
2. No

### **Howpay**

How do you usually pay or give money for the care provided by [*list of all formal providers who help/informal 20+ hours who helped*] for helping you?

I use money from:

1. my own personal income, savings, pension or benefit (such as Attendance Allowance)
2. my Direct Payment or Personal or Individual Budget from the Local Authority/ council/Social Services
3. from another source

### **Allcost**

Does this payment cover all the cost of this help or some of the cost of this [*any formal hours/informal 20+ hours who helped*] help?

1. All
2. Some

### **Addpay**

(+And in addition to what you pay), as far as you are aware does anyone else or any organisation pay or give money to [*list of all formal providers who help*] for the care you receive - for example the council or a family member. Do not count any benefits such as Carers Allowance or Attendance Allowance?

1. Yes, the council / local authority /social services
2. Yes, a family member (with their own money)
3. Yes, other
4. No, nobody else pays

*{IF ADDPAY=1 (LA PAYS)}*

### **LAPay**

And does the local authority, council or social services pay [*list of all formal providers who help*] directly or is it through your Direct Payment or a Personal Budget?

CODE ALL THAT APPLY:

1. Social services or council pay directly
2. Paid through Direct Payments / Personal or Individual Budgets

### **Nopay**

You have told me that no payment was made for [*list of all formal providers who help/informal 20+ hours who helped*] helping you. Why was this?

UNPROMPTED RESPONSE:

1. They provided their help for free/there is no charge for the service
2. Sometimes I give them money or gifts for the help they give me
3. Other

As can be seen, the NatCen Module provides an extensive array of questions for gathering information on the extent to which older people receive care and support related to ADL limitations. However, including the full NatCen module in the PSE2011 would be time intensive and some would argue that all the areas covered are not necessarily the most pressing indicators or drivers of poverty and social exclusion or would add wholly different information than that already covered in the FRS main survey.

In recommending suggested improvements to PSE measures for older people, there needs to be a balance between getting up-to-date information on receipt and provision of care with potentially important information on poverty and social exclusion. One key area for improvement is the costs associated with care. Price (2008) states that “if the additional costs associated with many health conditions are not accounted for in some way the poverty of older people will always be understated” (p. 4). The NatCen Module questions (see above) can be used to establish whether there are any costs of care, how they are met and whether there are any shortfalls.

Second, most would agree that it is important to determine the extent to which current care arrangements meet the needs of older people as this has an impact on their ability to live independently (and well) in their own homes (or preferred setting) for as long as possible. For this we can turn to ELSA which gauges the extent to which help received meets the needs of the person in receipt of ADL help (copied in below).

*Would you say that the help you receive...*

*INTERVIEWER: Read out...*

- 1 ...Meets needs all the time,*
- 2 usually meets needs,*
- 3 sometimes meets needs,*
- 4 or, hardly ever meets needs?*

### ***Suggestions for improvement***

Based on these caveats, we therefore recommend using the existing FRS main survey questions on the receipt and provision of help with the addition of the following:

- A follow up question to FRS main survey asking individuals reporting a long-standing illness, disability or infirmity and who are in receipt of help or support, the extent to which the help and support received meets needs their needs (using ELSA question)
- A follow up question to FRS main survey asking whether someone with a long-standing illness, disability or infirmity pays for any of the care/support they receive and whether this payment adequately covers the costs of care/support needed (using NatCen Module questions)

## 5. Health and personal social services for older people with a LSI, disability or infirmity

This was probably the weakest section in the PSE1999 and PSENI02 in relation to the analyses of public/private services pertaining to older people (see table below). There a wide variety of in-situ and community-based services in addition to those listed which older people and their carers can use in order to both remain 'independent' in 'included' the community, i.e. day centres and luncheon clubs and so on.

Given the increased targeting of health and personal social services to fewer households, the advent of personalised budgets, and potential declines in service levels resulting from the Comprehensive Spending Review, much could potentially be learned from examining more closely not only the type of support received but also the exact nature of the service use by those reporting a long-standing illness, disability or infirmity (or ADL limitation).

**Table 7: Comparison of support services for older people in PSE1999 and PSENI02**

PSE1999	PSENI02
[IF >64 & longill], Do you use home help (+adequacy)	IF longill, Do you use ....home help (+adequacy)
[IF >64 & longill], Do you use Meals on Wheels (+adequacy)	IF longill, Do you use ....meals on wheels (+adequacy)
[IF >64 & longill], Do you use Special transport for those with mobility problems (+adequacy)	IF longill, Do you use ....special transport (+adequacy)

### ***NatCen Survey Question Module on Social Care for Older People***

The NatCen Module on Social Care for Older People (covered above, see **Helpinf** and **Helpform**) provides a comprehensive list of specific sources of support for ADLs and IADLs, however we should consider using questions from ELSA to expand on the specific types of health and social support services used by older people themselves. Although used specifically for older people, the following question sets could be used to survey all adults in the household 16+ years of age.

#### **ELSA**

ELSA also respondents to identify use of a number of health related services (copied in below).

### **HEHPSZ**

CODE ALL THAT APPLY.

- 01 Occupational therapist or physiotherapist
  - 02 Chiropodist
  - 03 Exercise classes including yoga, pilates, gym
  - 04 Osteopath
  - 05 Chiropractor
  - 06 Massage
  - 07 Acupuncture
  - 08 Other alternative therapies e.g. reflexology, aromatherapy, homeopathy
  - 09 Gym/health club
  - 10 Swimming/aqua aerobics
  - 11 Hydrotherapy
  - 12 Private exercise classes including dance, yoga, pilates
  - 85 Other answer - not codeable 01-13
  - 86 Irrelevant response - not codeable 01-13
  - 95 Other
  - 96 None of these
- [Don't Know and Refusal are not allowed]

ELSA also asked respondents aged 65 plus whether or not they have used any of the three following services, but this was not directly linked to ADLs. Recommend that we ask about these in relation to a long-standing illness, disability or infirmity.

### **HECLUB**

Have you ever used the following services ...READ OUT...

CODE ALL THAT APPLY.

- 1 Lunch club?
- 2 Day care centre?
- 3 Meals on wheels?
- 96 None of these

**[code maximum 4 out of 4 possible responses]**

There is also follow-up question on frequency of use.

### **HELIC**

SHOW CARD C17

How often do you attend a lunch club?

- 1 Every day or nearly every day
- 2 Two or three times a week
- 3 Once a week
- 4 Two or three times a month
- 5 Once a month or less
- 6 SPONTANEOUS - do not currently use

In addition to expanding on the public/private services for older and the

frequency in which they are used, we might also consider adding a new question (taken from ELSA and perhaps revised slightly) on the extent to which these public/private services meet the needs of older people using them. A reference period is not included, but one could be added of course.

### **Survey of Carers in Households 2009/10**

The *Survey of Carers in Households 2009/10* (covered in more detail in section 6 below) includes a section on the main person cared for, covering both regular visits from health and social care providers as well as visits to see health and social care services (and the reasons for not using them).

Although asked about carers responding in the survey, the health and social services covered as well as the reasons for non-use of these services could be helpful for harmonising the list of potential services to ask about in the PSE2011 main survey. Again, the intention here would be to ask the actual individual who reports a long-standing illness, disability or infirmity.

ASK IF MAIN PERSON BEING CARED FOR IS A RELATIVE, OR LIVING IN THE HOUSEHOLD

#### **40. Dvis**

**I am now going to ask a few questions about (MAIN PERSON CARED FOR)**

**SHOWCARD G Does (NAME OF PERSON CARED FOR) receive regular visits at least once a month from any of these people?**

CODE ALL THAT APPLY

- Doctor.....1 >Q41
- Community/district nurse / Community Matron.....2>Q41
- Health visitor.....3>Q41
- Social worker/care manager.....4>Q41
- Home help/care worker.....5>Q41
- Meals on wheels.....6>Q41
- Voluntary worker.....7>Q41
- Occupational therapist.....8>Q41
- Educational Professional...9>Q41
- Specialist / nursing care / palliative care.....10>Q41
- Community mental health services.....11>Q41
- Other professional visitor.12>Q41
- No, none.13>Q41
- Don't know.....14>Q41

ASK IF MAIN PERSON BEING CARED FOR IS A RELATIVE, OR LIVING IN THE HOUSEHOLD

#### **41. Dcon**

**SHOWCARD G Does (NAME OF PERSON CARED FOR) have regular contact, at least once a month from any of these [other] people? Please think about face-to-face contact where (NAME OF**



**PERSON CARED FOR) visits any of these people.**

CODE ALL THAT APPLY

- Doctor.....1>Q42
- Community/district nurse / Community Matron.....2>Q42
- Health visitor.....3>Q42
- Social worker/care manager.....4>Q42
- Home help/care worker.....5>Q42
- Meals on wheels.....6>Q42
- Voluntary worker.....7>Q42
- Occupational therapist.....8>Q42
- Educational Professional...9>Q42
- Specialist / nursing care / palliative care....10>Q42
- Community mental health services.....11>Q42
- Other professional visitor.12>Q42
- No, none.....13>INSTRUCTION BELOW
- Don't know.....14>Q42

**IF 'NO, NONE' CODED AT BOTH Q40 AND Q41 GO TO Q42.**

ASK IF MAIN PERSON CARED FOR DOES NOT RECEIVE  
REGULAR VISITS OR CONTACT FROM ANY OF THE PEOPLE  
LISTED ABOVE

**42. Dnurs**

SHOWCARD H **What are the reasons for (NAME OF PERSON  
CARED FOR) not receiving regular visits at least once a month  
from any of the above? Please choose your answers from the  
card. CODE ALL THAT APPLY**

- Not available/not offered....1>Q43
- Not needed2>Q43
- Tried, but not helpful.....3>Q43
- Not wanted by you.....4>Q43
- Not wanted by the person you care for.....5>Q43
- Not at a convenient time.....6>Q43
- Too expensive.....7>Q43
- Not eligible.8>Q43
- Don't know who to ask.....9>Q43
- Other.....10>Q43

ASK IF MAIN PERSON CARED FOR IS A RELATIVE, OR LIVING IN  
THE HOUSEHOLD

**43. DGo**

SHOWCARD I **Does (NAME OF PERSON CARED FOR) regularly go  
to any of the places or activities listed on this card?**

- Work.....1>Q44
- Day centre.2>Q44
- School or college.....3>Q44
- Day hospital.....4 >Q44

Social club, support group or other club.....5>Q44  
None of these.....6 >Q46

ASK IF MAIN PERSON CARED FOR DOES NOT REGULARLY GO  
TO THE PLACE OR ACTIVITIES AT Q43

**46. DGoNot**

SHOWCARD J **What are the reasons that (NAME OF PERSON  
CARED FOR) does not go to any outside activities ?**

CODE UP TO 4 REASONS

Not available / not offered.1>Q47

Tried, but not helpful / suitable .....2>Q47

Not tried because it's not suitable.....3>Q47

Not wanted by you.....4>Q47

Not wanted by the person you care for.....5>Q47

Not at a convenient time....6>Q47

Too expensive.....7>Q47

Activity too tiring (for person cared for).....8>Q47

Transport not available, too expensive, not reliable, journey too  
tiring.....9>Q47

Other.....10>Q47

***Suggestions for improvement***

- Supplementing the sources/hours of informal and formal care by asking about specific health and social services used (in-situ and community-based):
  - GP/doctor
  - Community nurse/district nurse/health visitor
  - Specialist nurse / nursing care / palliative care
  - Home care (in addition to home help)
  - Social worker/care manager
  - Community mental health services
  - Chiropodist
  - Day centres
  - Day hospital
  - Luncheon clubs/social club/support group
  - Transport services (car services, community transport schemes and vouchers for free taxis, in addition to Special Transport)
- Including follow-up questions on: a) frequency of use of health and social services (including transport) and b) the extent to which the health/social services and transport services meets the needs of the older person (in order to identify shortfall in help or support).
- Include follow-up questions on reasons why: a) person does not use in-situ health and social services (including transport?) and b) why person does not use community-based health and social services (including transport).

## 6. Providing unpaid care

Informal care is help or support provided to older people by relatives, friends, neighbours and others who are generally not paid for the help and support they provide. Due to the growth of the number of older people in the UK and the increased substitution of formal care by 'community care', the importance of care provided informally has increased over the past decade. The provision of unpaid care also has implications in terms of availability for paid employment, impact on the physical and mental well-being of carers, and the additional expenses associated with providing care and support to older people requiring help with a long-standing illness, disability or infirmity.

### **FRS**

As mentioned earlier, the FRS asks the householder whether anyone provides help or looks after anyone living outside the household. There are follow-up questions about who is receiving help and how often. For the purpose of gathering information on the B-SEM sub-domain on unpaid care, the FRS should be more than adequate for these purposes (keeping the caveats reviewed earlier in mind).

However, there are other surveys and questions modules which can be drawn upon to give a fuller picture of the extent and degree of care provision in the UK and which could add potentially important areas of further query in PSE2011. These include, amongst others, the NatCen Survey Question Module on Care for Older People (covered in detail above). The Department of Health as part of the Government's Carers' Strategy<sup>10</sup> programme has developed the Survey of Carers in Households (covered in more detail below). The UK Census of 2001 and 2011 also ask a question about provision of unpaid care.

### ***NatCen Survey Question Module on Care for Older People***

The questions pertaining to the provision of care in the NatCen module are copied in below.

#### **B: PROVISION OF CARE**

##### **B1 - IDENTIFYING PROVIDERS OF CARE AND WHO IS HELPED**

This module has been designed and tested to ask people aged 16+ about care given to people aged 65+. However there is scope for flexibility and HSE are including help given to all adults aged 16+.

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[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_085345](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085345)

{ASK ALL AGED 16+}

INTERVIEWER READ: The next few questions are about help or support that people provide to others. (We are only interested in help and support provided to people because they have long-term physical or mental ill-health, disability or problems relating to old age) <sup>9</sup>.

### ProvHlp

Have you personally provided help or support to anyone **in the last month** because they have long-term physical or mental ill-health, disability or problems relating to old age? Do not include help given in a professional capacity or as part of a job but include help or support given to your family, friends or neighbours.

INTERVIEWER: Include help for wife, husband or partner

1. Yes
2. No (GO TO END).

### Helpno

How many people **aged 65** or over do you provide this kind of help and support to?

UNPROMPTED RESPONSE:

Range 0....20

The rest of this module (i.e. up until the end of the questionnaire) is asked if the respondent helps someone who is aged 65 or over (Helpno=1 or more).

{IF 4 OR MORE AT HelpNo}

### Intro

Now I'd like you to think about the **three** people aged 65 or over that you provide the **most** help and support to.

### PrRel

Thinking about [*the person you help/ answer from PrName 1/2/3*], what is their relationship to you?

1. Husband/Wife/Partner
2. Mother/ father (including mother-in-law/ father-in-law)
3. Son (including step son, adopted son or son in law)
4. Daughter (including step daughter, adopted daughter or daughter in law)
5. Grandparent
6. Grandchild (including Great Grandchildren)
7. Brother / Sister (including step / adopted / in laws)
8. Niece / Nephew
9. Other family member
10. Friend
11. Neighbour

12. Somebody I help as a professional carer
13. Somebody I help as a voluntary helper
14. Other (PLEASE SPECIFY)

No further follow up if professional care giver (PrRel=12) – go to end of the questionnaire.

### **PrHHold**

Does [your answer at PrRel]/ [answer from PrName1/2/3], who you help, live in the same household as you or in a different household?

1. Same household
2. Different household

{If PrHHold=1 (same household)}

### **HHGrid**

**CODE HH GRID No.** age and sex will be taken from household grid.

{IF PrHhold=2 or no household grid}

### **Agehlp**

How old is [your answer at PrRel] / [answer from PrName1/2/3]?

{IF PrHhold=2 or no household grid, unless PrRel= 3 or 4}

### **Gendhlp**

INTERVIEWER CODE OR ASK: Is [your answer at PrRel] / [answer from PrName1/2/3] male or female?

1. Male
2. Female

## **B2 - INTENSITY OF CARE (HOURS)**

FOR EACH PERSON WHO IS HELPED LOOP *PrHours* AND *PrHours* AS APPLICABLE

INTRODUCTION: I'm going to ask you about the amount of time you spend helping. Please look at SHOWCARD U, the next question is about the time you spend **in person** helping with tasks like this.

INTERVIEWER: Please ensure the respondent has sufficient time to look at Showcard U.

### **PrHours**

Thinking only about the types of tasks and activities I showed you, how many hours did you spend helping [your answer at PrRel] / [answer from PrName1/2/3] in the **last week**?

1. No help in the last week
2. Less than one hour
3. 1-4 hours
4. 5-9 hours
5. 10-19 hours

6. 20-34 hours
7. 35-49 hours
8. 50-99 hours
9. 100 hours or more

**PrUsHrs**

How many hours do you help [*your answer at PrRel*]/ [*answer from PrName1/2/3*] in a **usual** week?

1. Less than one hour per week
2. 1-4 hour per week
3. 5-9 hours per week
4. 10-19 hours per week
5. 20-34 hours per week
6. 35-49 hours per week
7. 50-99 hours per week
9. 100 hours or more per week

**PrOldHr**

Thinking about the total time you spend providing support or help to all of the people aged 65 and over that you care for, [*answer from PrName 1/2/3*], about how many hours altogether did you spend **last week** helping them?

1. Less than one hour per week
2. 1-4 hour
3. 5-9 hours
4. 10-19 hours
5. 20-34 hours
6. 35-49 hours
7. 50-99 hours
8. 100 hours or more

**B3 - DETAILS OF HELP GIVEN, SUPPORT RECEIVED AND PAYMENTS FOR CARING**

THE REST OF THE QUESTIONS IN THIS SECTION WILL BE LOOPED FOR UP TO 2 PEOPLE CARED FOR, WHERE 20 HOURS OR MORE HELP WAS GIVEN IN THE LAST WEEK (I.E. PRHOURS=6,7,8 OR 9)

{THIS QUESTION IS IN A LOOP FOR UP TO TWO PEOPLE}  
SHOWCARD U

**Prtask**

Which of the following activities do you help or support [*your answer at PrRel*]/ [*answer from PrName1/2/3*] with? Please think only of help or support given because of long-term physical or mental ill-health, disability or problems relating to old age.  
CODE ALL THAT APPLY

1. getting the person in and out of bed

2. washing their face and hands
3. having a bath or a shower, including getting in and out of the bath or shower
4. dressing or undressing, including putting on shoes and socks
5. using the toilet
6. eating, including cutting up food
7. taking the right amount of medicine at the right times.  
INTERVIEWER: Include prescribed medicines and medicines you can buy over the counter
8. getting around indoors
9. getting up and down stairs
10. getting out of the house, for example to go to the doctors or to visit a friend
11. shopping for food including getting to the shops, choosing the items, carrying the items home and then unpacking and putting the items away
12. doing routine housework or laundry
13. doing paperwork or bills

### **Recpay**

Do you receive any money for helping [*your answer at PrRel*]/ [*answer from PrName 1/2/3*]?

INTERVIEWER DO NOT INCLUDE GIFTS, TREATS OR OCCASIONAL PAYMENTS OF EXPENSES SUCH AS PETROL MONEY OR LUNCH  
CODE ALL THAT APPLY

1. Yes, this person pays me from their own income, pensions or savings
2. Yes, this person pays me from a personal budget or direct payment
3. Yes, I receive a carer's allowance
4. Yes, I receive money in another way
5. No, I receive no money for helping this person.

Does [*your answer at PrRel*]/ [*answer from PrName 1/2/3*] receive any of these types of support?

1. Attends a day centre or lunch club
2. Receives help from professional care staff (e.g. home help/care worker)
3. Receives meals on wheels
4. Receives help from a Nurse or Health Visitor
5. Lives in sheltered or very sheltered housing
6. Receives other types of support
7. No, none of these

### **B4 - EFFECTS OF CARING**

INSERT AN INTRODUCTION: "The next few questions are about the effects of caring on you and about support you may receive with your care responsibilities"

{THIS QUESTION IS IN A LOOP FOR UP TO TWO PEOPLE}

### **Support**

Do you receive any of these types of support in caring for [*your answer at PrRel*]/ [*answer from PrName1/2/3*]? Please think only about help or support given directly to you.

1. Help from GP or nurse
2. Access to respite care
3. Help from professional care staff
4. Help from carers' organisation or charity
5. Help from other family members
6. Advice from local authority/ social services
7. Help from friends/neighbours
8. No, I don't receive any of these

{ASK ONCE ABOUT ONE OR ALL PEOPLE CARED FOR}

### **HealthA**

In the **last three months**, has your own health been affected, in any of the ways listed on this card, by the help or support that you give to [*your answer at PrRel*]?

(Please read out the numbers that apply from this card)

*IF Helpno=2 OR MORE*}

### **HealthA**

In the **last three months**, has your own health been affected, in any of the ways listed on this card, by the help or support that you give the people aged 65 or over that you care for?

(Please read out the numbers that apply from this card)

CODE ALL THAT APPLY

1. Feeling tired
2. Feeling depressed
3. Loss of appetite
4. Disturbed sleep
5. General feeling of stress
6. Physical strain
7. Short tempered
9. Developed my own health condition
10. Made an existing condition worse
11. Other
12. No, none of these

{ASKED IF R IS AGE 64 OR UNDER}

### **HlthEmp**

Has your ability to take up or stay in employment been affected, in any of the ways listed on this card, by the help or support that you give [*your answer at PrRel*]/ the people aged 65 or over that you care for? Please read out the numbers that apply from the card.



CODE ALL THAT APPLY

1. Left employment altogether
2. Took new job
3. Worked fewer hours
4. Reduced responsibility at work
5. Flexible employment agreed
6. Changed to work at home
7. Other
8. Employment not affected

{ASK ONCE FOR ALL WHO CARE FOR SOMEONE AGED 65+}

**LAass**

Have the Local Authority (council) carried out a carer's assessment as a result of the help or support that you provide to give [*your answer at PrRe*] / the people aged 65 or over that you care for]?

1. Yes
2. No

As can be seen once again, the level of detailed information in the NatCen module is very extensive; far too much for a household survey on poverty and social exclusion (as well as some key areas being covered already in the FRS main survey). But the sections regarding support in the caring role and the impact or effect of caring show potential areas for improving measures in the PSE2011 in regards to those providing unpaid care. In terms of the former, it might be advantageous to inquire about the type(s) and level of support carers have access to in providing help and support to others. This would enable us to determine the extent to which the caring function is shared not only within households but with public/private community care services. As far as the effects of caring are concerned, the NatCen Module provides some scope for asking about the impacts of caring on health and employment, both of which are key sub-domains found in the B-SEM.

### ***Survey of Carers in Households 2009/10***

The NHS Information Centre for health and social care (NHS IC) undertook responsibility for this survey which was funded by the Department of Health and the Department for Work and Pensions. GfK NOP was commissioned to carry out face-to-face interviews over 11 months of fieldwork in a representative sample of homes in England. The *Survey of Carers in Households 2009/10*<sup>11</sup> contains information on the prevalence of caring, the demographic profile of carers, the impact of caring duties upon the carer, details of the services carers receive and a profile of the people who are cared for. Carers who were under 16 years of age were excluded from the survey, as were people in communal establishments (residential care).

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<sup>11</sup> <http://www.ic.nhs.uk/pubs/carersurvey0910>

In terms of specific content, the *Survey of Carers* provides information on:

- differences between help provided to person(s) living in the same household and to person(s) outside the household
- the relationship of the respondent to the person(s) cared
- type of illness of the person cared for
- type (and frequency) of assistance/help provided geared around major ADL classifications (i.e. personal care, domestic help, etc.)
- hours and years care has been provided
- an extensive section on the main person cared for (covered above in section 4)
- carer specific services (i.e. carer's assessment/review of needs and services/help resulting)
- impacts of caring
- travelling distance to main person cared for.

The key question sets informing the list cited above are copied in below.

### **Differences between help provided to person(s) living in the same household and to person(s) outside the household**

#### **14. DepLivIn [\*]**

ASK IF THERE IS MORE THAN ONE PERSON IN THE HOUSEHOLD (HOUSEHOLD SIZE >1), OTHERS Q15

May I check, is there anyone living with you who is sick, disabled or elderly whom you look after or give special help to, other than in a professional capacity (for example, a sick or disabled (or elderly) relative/husband/ wife/child/friend/parent, etc)?

CODE 'NO' IF GIVES FINANCIAL HELP ONLY

Yes.....1 > Q15

No.....2 > Q15

Not sure..3 > Q15

#### **15. DlivOut [\*]**

ASK ALL FULLY CO-OPERATING ADULTS

Is there anyone, not living with you who is sick, disabled or elderly whom you look after or give special help to, other than in a professional capacity, (for example, a sick or disabled (or elderly) relative/husband/wife/child/friend/parent, etc)?

CODE 'NO' IF GIVES FINANCIAL HELP ONLY

CODE ALL THAT APPLY

Yes; in another household2 >Q17

No.....3 >END QUESTIONNAIRE IF 2 OR 3 CODED AT Q14  
AS WELL

Not sure.....4> END QUESTIONNAIRE IF 2 OR 3 CODED AT Q14  
AS WELL

#### **16. DlivNo**

ASK IF RESPONDENT IS CARING FOR SOMEONE IN HOUSEHOLD  
(DEPLIVIN = 1 OR DLIVOUT = 1)

**Do you look after or help one sick, disabled or elderly person  
living with you,  
or is it more than one?**

IF MORE THAN 6 CODE AS 6

1 .. 6 >Q18

**17. DOutNo**

ASK IF RESPONDENT IS CARING FOR SOMEONE IN ANOTHER  
HOUSEHOLD (DLIVOUT = 2)

**Do you look after or help one sick, disabled or elderly person  
living elsewhere, or is it more than one?**

IF MORE THAN 6 CODE AS 6

1..6 \_ >Q18

**Relationship of the respondent to the person(s) cared**

**18. Drellnf**

IF RESPONDENT IS CARING FOR SOMEONE (IN THIS OR  
ANOTHER HOUSEHOLD) ASK THE FOLLOWING BLOCK OF  
QUESTIONS FROM QUESTION DRELINF TO MORETIME, FOR  
EACH PERSON CARED FOR IN TURN, STARTING WITH PEOPLE  
LIVING IN THE HOUSEHOLD (DEPLIVIN = 1 OR DLIVOUT = 1 OR 2)

**Who is it (in your household/ not living with you) that you look  
after or help?**

Spouse/partner.....1 >20

Own/adopted/step child.....2 >20

Foster child..3>20

Parent.....4 >20

Parent-in-law.....5>20

Grand-parent.....6>20

Other relative.....7>20

Friend or neighbour.....8>20

Client of voluntary organisation.....9 > next dependent

.....or question 38 if not

Other.....10>20

**Type of illness of the person cared for**

**28. Dillness**

ASK IF PERSON CARED FOR IS NOT LIVING IN A HOSPITAL,  
RESIDENTIAL OR NURSING HOME (DPERSN <15 OR LIVINST = 2)

ASK (or RECORD if already mentioned by respondent)

SHOWCARD C

**May I check, why does (NAME OF PERSON CARED FOR) need**

**care? Just call out the letters that apply.**

**CODE ALL THAT APPLY**

B Dementia G A physical disability D Sight or hearing loss

A A mental health problem

F A learning disability or difficulty

C Long-standing illness

E Terminal illness

H Alcohol or drug dependency

I Other

Problems connected to ageing (SPONTANEOUS ONLY)

**Type (and frequency) of assistance/help provided geared around major ADL classifications (i.e. personal care, domestic help, etc.)**

**31. Dhelp**

ASK IF PERSON CARED FOR HAS A PERMANENT ILLNESS/DISABILITY (DILLCHK = 1)

**What kinds of things do you usually do for (NAME OF PERSON CARED FOR)? IF IS IN HOUSEHOLD (over and above what you would normally do for someone living with you/a child of his/her age?)**

SHOWCARD D

PROMPT FIRST ITEM AS EXAMPLE.

CODE ALL THAT APPLY

**Do you usually help with.....**

**Personal care ?**

(e.g. dressing, bathing, washing, shaving, cutting nails, feeding, using the toilet)1

**Physical help?**

(e.g. with walking, getting up and down stairs, getting into and out of bed) .....2

**Helping with dealing with care services and benefits?** (e.g. making appointments and phone calls, filling in forms) 3

**Helping with other paperwork or financial matters?** (e.g. writing letters, sending cards, filling in forms, dealing with bills, banking)

.....4

**Other practical help?**

(e.g. preparing meals, doing his/her shopping, laundry, housework, gardening, decorating, household repairs, taking to doctor's or hospital)

.....5

**Keeping him/her company?**

(e.g. visiting, sitting with, reading to, talking to, playing cards or games)

.....6

**Taking him/her out?**

(e.g. taking out for a walk or drive, taking to see friends or relatives)

.....7

**Giving medicines?**

(e.g. making sure he/she takes pills giving injections, changing

dressings) .....8

**Keeping an eye on him/her to see he/she is all right? .....9**

**Other help? .....10 > Q 34**

**IF ANY ARE CODED 1-9, GO TO Q32**

**32. DhelpMre**

ASK ALL WHO CODE 1-9 AT Q31

**And how often do you help [NAME OF PERSON CARED FOR] with ... ?**

SHOWCARD E.

**CODE FREQUENCY OF EACH TYPE OF ACTIVITY**

Type of Activity	More than once a day	Once a day	Most days	2-3 times a week	Once a week	Less than once a week, but at least once a month	Less often
Personal care?							
Physical help?							
Helping with dealing with care services and benefits?							
Helping with other paperwork or financial matters?							
Other practical help?							
Keeping him/her company?							
Taking him/her out?							
Giving medicines?							
Keeping an eye on him/her to see he/she is all right							

**Hours and years care has been provided**

**34. HelpHrs**

ASK IF CARER GIVES MORE THAN FINANCIAL HELP (DFINCHK = 2)

**About how long do you spend EACH WEEK looking after or helping (NAME OF PERSON CARED FOR) – that is doing the things you’ve mentioned and including time when you just need to be there (apart from when you are asleep/ including time travelling to and from his/her home)?**

SHOWCARD F

(Use ‘apart from when you are asleep’ if the cared-for person is in the household; use ‘including time travelling to and from his/her home’ if the cared-for person is not in the household)

0-9 hours per week.....1 >Q35

10-19 hours per week.....2 >Q35

20-34 hours per week.....3 >Q35  
35-49 hours per week.....4 >Q35  
50-99 hours per week.....5 >Q35  
100 or more hours per  
week.....6 >Q35  
Varies – Under 20 hours..7 >Q35  
Varies – 20 hours or more8 >Q35  
Other.....9 >Q35

### 35. HelpYrs

**About how long have you been looking after or helping (NAME OF PERSON CARED FOR) IF PERSON CARED FOR IS IN HOUSEHOLD (that is doing things for him/her over and above what you would normally do for someone living with you/a child of that age)?**

PROMPT AS NECESSARY

Less than 6 months.....1>Q36  
6 months, less than 1 year2>Q36  
1 year, less than 3 years...3>Q36  
3 years, less than 5 years.4>Q36  
5 years, less than 10 years.....5>Q36  
10 years, less than 15 years.....6>Q36  
15 years, less than 20 years.....7>Q36  
20 years or more.....8>Q36

### 38 ThepHrs

AFTER ASKING ABOUT EACH CARED-FOR PERSON IN TURN

**If more than one person is cared for (excluding clients of a voluntary organisation) (TotDep>1), others Q39**

**May I check; thinking about the total time you spend assisting (SPECIFY ALL PERSONS CARED FOR), about how long altogether do you spend each WEEK looking after or helping them?**

SHOWCARD F

0-9 hours per week.....1 > Q39  
10-19 hours per week.....2> Q39  
20-34 hours per week.....3> Q39  
35-49 hours per week.....4> Q39  
50-99 hours per week.....5> Q39  
100 or more hours per week.....6> Q39  
Varies - Under 20 hours...7> Q39  
Varies - 20 hours or more.8> Q39  
Other.....9> Q39

## Carer specific services

ASK ALL

**63. Have you ever been offered a carer's assessment of your own needs by your local social services or health authority?**

Yes.....1>Q64  
No.....2>Q72  
Don't know3>Q72

ASK ALL WHO HAVE BEEN OFFERED A CARER'S ASSESSMENT

**64. CareAssess**

**And have you ever had a carer's assessment?**

Yes.....1>Q65  
No.....2>Q72

ASK ALL WHO HAVE HAD AN ASSESSMENT

**65. Have you ever been offered a review of your own needs by your local social services or health authority?**

Yes.....1>Q66  
No.....2>Q67  
Don't know >Q67

ASK ALL WHO HAVE BEEN OFFERED A REVIEW OF THEIR OWN NEEDS

**66. CareRev**

**Have you had a review of your own needs by your local social services or health authority in the last year?**

Yes.....1>Q67  
No.....2 >Q67

**67. CareServ**

SHOWCARD N **Did you receive any services or help as a result of the assessment or review?** CODE ALL THAT APPLY

No Services.....1>Q68  
Information about the condition of the person you care for.2>Q68  
Information about other organisation providing services.....3>Q68  
Information on support to remain in paid work or return to paid work.....4>Q68  
Information about benefits.5>Q68  
Information about support group.....6>Q68  
Break in own home.....7 >Q68  
Break away from home.....8>Q68  
Information about direct payments.....9>Q68  
Assessment of the person you care for....10>Q68  
Services for the cared for person.....11>Q68  
Equipment (e.g. mobility aids).....12>Q68  
Received a direct payment.....13>Q68  
Other.....14>Q68

**Impacts of caring**

**72. Careimpct**

I'd like to ask you whether caring for others has affected any other aspects of your life, such as your health, employment, education, leisure or relationships,

ASK ALL

**Why did you start looking after or giving special help to [NAME]?**

CODE ALL THAT APPLY.

No one else available >Q73

I was willing / I wanted to help out >Q73

I had the time because I was not working >Q73

I had the time because I was working part time >Q73

I have particular skills / ability to care >Q73

Social Services ( local Authority ) suggested I should provide care

>Q73

It was expected of me (It's what families do) >Q73

He/she wouldn't want anyone else caring for them >Q73

Cared for person requested my help/care >Q73

I took over caring responsibilities from someone else >Q73

Other (SPECIFY) >Q73

### **73. CareRel**

**Have your personal relationships, social life or leisure been affected by the assistance you give to (NAME OF PERSON BEING CARED FOR)?**

Yes.....1>Q74

No.....2>Q75

ASK IF RESPONDENT HAS BEEN AFFECTED

**74. In what way have you been affected?** CODE ALL THAT APPLY.

Too tired to go out >Q75

Less time for leisure activities >Q75

Unable to go on holiday >Q75

Providing care has affected my own health >Q75

I am more aware of disabled people's needs >Q75

Other (SPECIFY) >Q75

ASK ALL

**75. SHOWCARD P If we were to define "quality of life" as how you feel overall about your life, including your standard of living, your surroundings, friendships and how you feel day-to-day, how would you rate your quality of life?** SINGLE CODE ONLY

Very good >Q76

Fairly good >Q76

Neither good nor bad >Q76

Fairly bad >Q76

Very bad >Q76

(Don't know) >Q76

ASK IF CARING FOR SOMEONE (IN THIS OR ANOTHER



HOUSEHOLD)

**76. Careh1th**

**SHOWCARD Q Has your own health been affected by the care you provide in any of the ways on this card? (FOR ALL RESPONSES, THESE SHOULD BE AS A RESULT OF THE CARING AND NOT FOR OTHER REASONS)**

CODE ALL THAT APPLY

- Feeling tired.....1 See Q77
- Feeling depressed.....2 See Q77
- Loss of appetite.....3 See Q77
- Disturbed sleep.....4 See Q77
- General feeling of stress.....5 See Q77
- Physical strain (e.g. back).....6 See Q77
- Short tempered/irritable.....7 See Q77
- Had to see own GP...8 See Q77
- Developed my own health condition .. 9 See Q77
- Made an existing condition worse....10 See Q77
- Other.....11 See Q77
- No, none of these....12 See Q77

ASK ALL WHO ARE UNDER 70 YEARS OTHERS GO TO Q78

**77. Carewrk**

**SHOWCARD R Has your ability to take up, or stay in, EMPLOYMENT been affected by the assistance you give to (NAME OF PERSON(S) CARED FOR) in any of the ways on this card? (FOR ALL RESPONSES, THESE SHOULD BE AS A RESULT OF THE CARING AND NOT FOR OTHER REASONS. IF CHANGED JOB, INCLUDE ALL REASONS FOR THE CHANGE, FOR EXAMPLE, NEW JOB WITH LESS RESPONSIBILITY) CODE ALL THAT APPLY**

- Left employment altogether (due to caring responsibilities)1>Q78
- Took new job.....2>Q78
- Reduced employment hours.....3>Q78
- Reduced responsibility at work.....4>Q78
- Flexible employment agreed.....5>Q78
- Changed to work at home.6>Q78
- Other.....7>Q78
- No, employment not affected because of caring responsibilities.....8>Q78

ASK IF CARING FOR SOMEONE

**78. Carestdy**

**SHOWCARD S Has your ability to take up, or stay in, EDUCATION been affected by the assistance you give to (NAME OF PERSON(S) CARED FOR) in any of the ways on this card? (FOR ALL RESPONSES, THESE SHOULD BE AS A RESULT OF THE CARING AND NOT FOR OTHER REASONS) CODE ALL THAT APPLY**

Unable to study (due to caring responsibilities).....1>Q79  
Reduced study hours.....2>Q79  
Flexible study time agreed3>Q79  
Changed to study at home4>Q79  
Other.....5>Q79  
No, none of these.....6>Q79

ASK ALL

**79. Careleisure**

SHOWCARD T **Has your ability to spend time doing leisure or social activities been affected by the assistance you give to (NAME OF PERSON(S) CARED FOR) in any of the ways on this card? This includes seeing friends and family, spending time with a spouse or partner. (FOR ALL RESPONSES, THESE SHOULD BE AS A RESULT OF THE CARING AND NOT FOR OTHER REASONS)**  
CODE ALL THAT APPLY

Unable to socialise or take part in social or leisure activities at all (due to caring responsibilities).....1>Q80  
Reduced time with spouse or partner.....2>Q80  
Reduced time with other family members..3>Q80  
Reduced time with friends.4>Q80  
Difficulties making new friends.....5>Q80  
Reduced time spent doing sport or physical activity.....6>Q80  
Reduced time spent doing pastime or hobby.....7>Q80  
Other.....8>Q80  
None of these.....9>Q80

**80. Which of these best describes the special help you provide to ...(NAME)? READ OUT. CODE ONE ONLY.**

There is a regular pattern >Q81  
Regular pattern some minor variation >Q81  
Irregular pattern – changes from week to week >Q81  
Irregular pattern changes from day to day >Q81

**81. SHOWCARD U And do you think that over the next 5 years the amount of time that you spend looking after or helping [NAME] will ... ? CODE ONE ONLY.**

C Increase significantly >Q82  
D Increase slightly >Q82  
A Remain the same >Q82  
E Decrease slightly >Q82  
B Decrease significantly >Q82  
Don't know >Q82

**Travelling distance to main person cared for.**

ASK IF MAIN CARED FOR PERSON LIVES IN ANOTHER

#### HOUSEHOLD

**82. How far do you travel to look after or help [NAME]?** Please include the total distance travelled there and back.

Short walking distance 1>Q83

Under a mile 2>Q83

Over 1 mile under 5 miles 3>Q83

Over 5 miles under 10 miles 4>Q83

Over 10 miles under 15 miles 5>Q83

Over 15 miles under 20 miles 6>Q83

Over 20 miles 7>Q83

To sum up, much like the *NatCen Module*, the *Survey of Carers* provides extensive choice on gathering information on the provision of care. But both provide far too much detailed information than is needed for the purposes of the PSE2011, some of which will be available from the FRS main survey. However, two key additions might be considered for use: assessment of carer's needs and the impact of caring on various aspects of the carer's life.

### **Census 2011**

A question on carers was first included in the 2001 Census. Information on the numbers and distribution of people providing care for family and friends has become increasingly important in recent years. The question below is recommended for the 2011 Census subject to approval by Parliament through the legislative process.<sup>12</sup> It is important that we include a similar question in the PSE2011 main survey.

**14** Do you look after, or give any help or support to family members, friends, neighbours or others because of either:

- long-term physical or mental ill-health/disability?
- problems related to old age?

➤ Do not count anything you do as part of your paid employment

No

Yes, 1 - 19 hours a week

Yes, 20 - 49 hours a week

Yes, 50 or more hours a week

### **Suggestions for improvement**

There are many potential areas of interest in terms of the provision of unpaid

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<sup>12</sup> <http://www.ons.gov.uk/census/2011-census/2011-census-questionnaire-content/question-and-content-recommendations-for-2011/final-recommended-questions-2011---health.pdf>

care. Of course, like many of the areas covered in the measures review paper thus far, we are hoping to capture those most likely to impact upon on poverty and social exclusion. Keeping in mind that the FRS main survey already collects information on the provision (and receipt) of help or support, we suggest the following additions to the PSE2011:

- A follow up question to FRS main survey asking individuals who provide help or support whether their needs have been formally assessed and reviewed, and what if any, support services they receive (covered by questions found in both NatCen Module and the Survey of Carers)
- A follow up question to FRS main survey asking individuals who provide help or support about the impact of caring in terms of health, employment, education, leisure or relationships (covered extensively in the Survey of Carers in Households).

## Concluding remarks

A number of different areas for improvement for the PSE2011 have been identified in this measures review paper. Admittedly, including all the suggested areas for improvement is not feasible given the time limitations of a household survey. We have tried to highlight, however, priority areas in terms of the poverty, deprivation and social exclusion of older people in the UK. These will form the basis for making specific recommendations in terms of questions to appear in the main PSE2011 survey.

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## Appendix 1: Crosswalk and (I)ADLs in British Surveys

Activity	BHPS	ELSA	GHS 2001	MRC FCS	FRS	HSE	LOS	NatCen 2010
<b>Traditional ADLs and personal care</b>					frs	hse	los	
Bathing	X	X	X	X				
Toilet		X	X**	X				X
In and out of bed	X	X	X**					X
Dressing		X	X**					X
Shoes and socks		X		X				
Feeding		X	X**					X
Cutting toenails	X		X	X				
Medicines		X	X					X
<b>IADLs</b>					frs	hse	los	
Heavy housework				X				
Shopping		X	X	X				X
Cooking		X	X	X				
Snacks			X					
Cup of tea			X					
Personal affairs		X	X					X
Light housework	X***			X				X
Dishes			X					
Windows			X					
Vacuum			X					
Laundry			X					X
Work around house or garden		X						
Map reading		X						
Telephone		X						
<b>Mobility questions</b>					frs	hse	los	
Stairs	X	X	X	X				X
Indoor walking	X		X					X
Outdoor walking	X		X					X
Walking (100 yards)		X						
Public transport			X	X				

**Notes:**

\*\*Questions asked only to those who reported difficulty going up and down stairs

\*\*\*Questions asked only to those who reported health limited daily activity

**FRS**=Family Resources Survey, **HSE**=Health Survey for England, **LOS**=Life Opportunities Survey

<sup>frs & los</sup> refer to 1) 'mobility (moving about)' and 2) 'lifting, carrying or moving objects' and 3) 'manual dexterity (using your hands to carry out everyday tasks)' generally, but not specific actions/tasks.

<sup>los</sup> also includes two sets of questions on 'mobility' (moving about, walking, climbing stairs; or use special equipment or support services to help assist mobility) and 'dexterity' (lifting, grasping or holding objects, or use special equipment to help you with these actions) difficulties, full questionnaire available at:

[http://www.statistics.gov.uk/about/methodology\\_by\\_theme/downloads/life-opportunities-questionnaire-june-2010.pdf](http://www.statistics.gov.uk/about/methodology_by_theme/downloads/life-opportunities-questionnaire-june-2010.pdf), pp. 133-35.

<sup>hse</sup> asks about long-term illness which limits activities in past two weeks but no specific activities listed

Source for BHPS, ELSA and GHS: Jagger *et al.* (2009), Table 2, pp. 12-14.

**NatCen**= NatCen Survey Module on Social Care for Older People, available at: <http://www.natcen.ac.uk/social-care-questions-for-over-65s>

NatCen notes: a) also includes item on 'washing your face and hands' b) putting on socks shoes included in dressing and undressing c) laundry included in routine housework.