Calibrating disability measures across British national surveys

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Summary

The ability, or difficulty experienced, in performing Activities of Daily Living (ADL) (for example bathing, dressing, toileting) is widely used as a measure of disability, in particular for older people, as it is a good predictor of the use of health and long-term care services. Since the first ADL scale was proposed in the 1960s, many other scales have been developed and used in surveys and these different scales reflect different approaches to defining and measuring disability. This poses an important challenge to attempts to compare the disability rates obtained from different surveys and from different countries.

This report investigates the comparability of the measures of limitations in ADL, Instrumental Activities of Daily Living (IADL) and mobility questions in five British surveys, the British Household Panel Study (BHPS), the English Longitudinal Survey of Ageing (ELSA), the Family Resources Survey (FRS), the General Household Survey (GHS), and the Medical Research Council Cognitive Function and Ageing Study (MRC CFAS). It further uses the hierarchical nature of ADLs and IADLs measures to identify a comparable measure of disability in older people, at a level indicating need for social care, across the surveys.

We found considerable differences in the number and type of (I)ADL items used in the surveys, in particular the FRS questions relate to functional limitations (body functions) rather than activities. We therefore excluded the FRS from further analysis. In the remaining four surveys there were two items present in all surveys and considerable overlap in others.

After reviewing the structure and description of the items in each survey, we selected those that appeared most comparable and compared the standardised prevalence for each item in the different surveys. We then confirmed for each survey that the items lay on a single underlying disability continuum and that they formed a hierarchical scale. After further exclusion of a few items which did not satisfy the scale assumptions, we confirmed that the hierarchies were highly comparable across the surveys with items ranked similarly. From the review and analysis of the surveys and since it was measured in all surveys with a similar prevalence of disability of around 15%, we selected difficulty with bathing as a comparable measure across the surveys.

The continued ageing of the UK population through increased life expectancy even in the oldest age groups and relatively low levels of fertility, alongside the greater health and social care needs in later life, makes it imperative that good data are available to estimate needs of older people and the resources required to meet them. Each of the major surveys we have considered has particular strengths or a focus on certain areas, for example the economic aspects of ageing in comparison with social aspects. It is therefore imperative that the surveys are in some way 'joined together' by collecting certain key variables in the same way and activities of daily living should be contained in this set of key variables since they form the basis of measures of disability.

In view of our findings on the comparability of activities included in the different surveys and the analysis of the hierarchies in the older population we make the following recommendations:

- the major UK surveys could agree on a core set of (I)ADL items to be included in each with exactly the same wording of questions and structure
- the FRS could include a few (I)ADL items to complement the measures of functional limitation
- the GHS and BHPS could include two ADL items towards the top of the hierarchy, for instance feeding and using the toilet, to be asked of all respondents.

Background

The raw building blocks of most disability scales are information on limitations in activities of daily living, often distinguishing activities relating to basic personal care such as bathing, dressing, etc usually referred to as ADLs, and Instrumental Activities of Daily Living (IADL) items relating to domestic tasks such as shopping and housework, and additionally in some cases activities such as using the telephone or managing money (1, 2). The ability, or difficulty experienced, in performing ADLs is widely used as a measure of disability, especially for older people, as it is a good predictor of the use of health and long-term care services (3). Since the first ADL scale was proposed by Katz et al. (1), many different scales measuring ADLs have been developed and used in surveys, with ADL style questions often being incorporated into wider ranging measures of disability. These different scales reflect different approaches to defining and measuring disability and pose an important challenge to attempts to compare the disability rates obtained in different surveys and in different countries. A review by Gudex and Lafortune (4) identified 25 surveys in 19 OECD countries that included ADL questions.

The original development of ADLs recognised that items formed a hierarchy, Katz (1) maintaining that abilities were lost in the opposite order to which they were gained during childhood. Since that time there have been other confirmations of the joint hierarchy of ADL and IADL (5, 6), of mobility items (walking, going up and down stairs) in particular (7) including longitudinal analyses where the loss of an activity is observed within individuals (8-10). Though the majority of research has focussed on determining a hierarchy of (I)ADL items within a single study, similar techniques of scale analysis have been used to compare patterns across cross-national studies (11, 12).

Comparison of disability levels across surveys is often made difficult because individual surveys use different sets of items to define disability. Even when the same sets of items are used the wording of the questions or possible responses may vary. Moreover the use of self-reported indicators, as (I)ADLs usually are, may introduce bias (13, 14). In particular disability can be defined using the cutpoint of without/with difficulty with an item or with not requiring/requiring help to perform the task. This report investigates the comparability

of the measures of performance of ADL and IADL in five British surveys: the British Household Panel Survey (BHPS), English Longitudinal Study of Ageing (ELSA), Family Resources Survey (FRS), General Household Survey GHS) and Medical Research Council Cognitive Function and Ageing Study (MRC CFAS). First we compare these surveys in terms of methodological factors that may impact on disability prevalence, then we review (I)ADL questions in the surveys in terms of the actual items used and the wording of the questions and responses. We then compare the age- and sex-standardised prevalence of disability across the surveys for the population aged 65 years and older using each (I)ADL and different cutpoints and finally we use the hierarchy of (I)ADLs to produce a broadly equivalent level of disability across the surveys. In the conclusion we discuss how this measures fits with other definitions of disability for more general populations, namely that used in the UK Disability Discrimination Act (DDA) and the World Health Organisation's International Classification of Functioning, Disability and Health (ICF)(15).

The Surveys

Brief details of each survey used are given below. In order to compare across surveys, we aimed where possible to use data from similar points in time and therefore where surveys had multiple waves we chose those nearest in time.

BHPS

The British Household Panel Survey began in 1991 with the aim of furthering understanding of social and economic change at the individual and household level in Britain and, since 2001, the UK. It is a multi-purpose study following the same representative sample of individuals over a period of years. Although the original sample was of people in private households, they are followed into institutions if necessary. Children born to original sample members become permanent sample members themselves. The sample was extended in 1999 with recruitment of additional households in Scotland and Wales, and in 2001 with households in Northern Ireland. Data is collected from every member of the household where the sample member is living in any wave; in this way the sample remains representative of households as well as of persons, although immigrants to England since 1991 had no chance of inclusion before 2008. Wave 11 data, used here, was collected in 2001 (total aged 65 or over living in Britain: n=2705, men=1,153, women=1,552).

ELSA

The English Longitudinal Survey of Ageing (or ELSA) covers people aged 50 or more living in private households in England. The survey sample is drawn from respondents to the Health Survey for England (HSE) - a study conducted jointly by the Department of Epidemiology and Public Health, UCL, and the National Centre for Social Research, on behalf of the Department of Health. Around 12,000 respondents from three separate years of the HSE survey were initially recruited to provide a representative sample of the English population aged 50 and over (16) and the population is refreshed at each follow-up so that it remains representative of community-dwelling older people in England. Information about ADLs was obtained via self-report. The questions were based on those asked in the Health and Retirement Survey (HRS) in the USA, a sister survey to ELSA (17). Data from ELSA wave 1 was collected in 2002/3 (total aged 65+ n=5,400, men=2,290, women=2,790).

FRS

The Family Resources Survey (FRS) is a continuous cross-sectional survey of around 25,000 British households each year, commissioned by the Department for Work and Pensions (DWP). The survey began in October 1992 and is designed to collect a detailed set of socio-economic characteristics of the population who live in private households in Great Britain. Since 2002 FRS sample coverage has been extended to United Kingdom. The 2001/2 wave survey comprised a total of 44,748 respondent (men=21,010, women=23,738).

GHS

The General Household Survey (GHS) is a multi-purpose continuous survey carried out by the Social Survey Division of the Office for National Statistics (ONS) which collects information on a range of topics from people living in private households in Great Britain. The survey started in 1971 and has been carried out continuously since then, except for breaks in 1997/98 (when the survey was reviewed) and 1999/2000 when the survey was re-developed. Questions specifically designed to cover aspects of the lives of older people have been included in the survey in 1980, 1985, 1991, 1994, 1998 and 2001. The module of questions asks people aged 65 and over about their living circumstances, their health, their ability to perform a range of ADLs, domestic and other tasks, and the use they make of health and social services. In total 3,356 people aged 65 and over were interviewed in person for the 2001 GHS; 56% (1,882) were women and 44% (1,474) were men. These

interviews took place in 2,546 households containing at least one person aged 65 and over (referred to as 'elderly households') (18). In this report we used GHS 2001/2 data (total 3,221, men=1,407, women=1,814).

MRC CFAS

MRC CFAS is a population based longitudinal study of individuals aged 65 years and over living in the community and in institutions, in six centres in England and Wales (Cambridgeshire, Gwynedd, Newcastle, Nottingham, Oxford, Liverpool) with over-sampling of those aged 75 years and over. The original aim of MRC CFAS was to examine the descriptive epidemiology of dementia. A full description of the MRC CFAS study design can be found elsewhere (19). The fieldwork for this study began in 1991/2 and all individuals were interviewed by trained interviewers with a structured questionnaire including the modified Townsend activities of daily living scale (20) which includes ADL and IADL items. The MRC CFAS data used in MAP2030 is from the baseline wave and the five centres excluding Liverpool (since this centre had a slightly different design and timing) (total n=13004, men=5262, women=7742). Although the main analyses reported here use the baseline MRC CFAS, we performed sensitivity analyses comparing baseline with wave 10, collected in 2002.

Differences in survey methodology

The literature on measuring disability has identified a number of possible methodological factors that may explain differences in the prevalence estimates of ADLs obtained using different surveys (3, 4, 21). These are discussed below.

Population coverage

A major source of discrepancy between estimates of the prevalence of disability could be the population coverage of the surveys: the geographical area sampled from, whether the survey covers people in the community and/or in institutions and the age and gender composition of the sample.

The GHS covers the population of Great Britain. ELSA covers England, the BHPS covers the UK but only people living in Great Britain have been included in this analysis. The MRC CFAS

study population is drawn from the five centres in England and Wales mentioned previously, these centres were chosen to reflect national variations in health and mortality (22).

Both the GHS and ELSA (wave 1) cover only private household populations. CFAS includes older people in institutions. The BHPS drew its initial sample from private households but attempts to document whether sample members have moved into institutions. With regard to age coverage, ELSA covers people aged 50 or more whereas the GHS section on disability cover people aged 65 or more. The BHPS has no age limits. Clearly any comparisons should only use data on common age groups; here we refer to people aged 65 and over on whom data were available in all the surveys. Table 1 shows the number of respondents aged 65 and over by gender and five age groups in the four surveys. Even at the oldest ages there is a very similar age-sex distribution in all the surveys.

Table 1: Distribution of survey respondents by age and gender, N (% within sex)

	BHPS	**ELSA Wave 1**	**FRS**	**GHS**	**MRC CFAS***
Women	N (%)	N (%)	N (%)	N (%)	N (%)
65-69	404 (26.0)	824 (26.1)	1,452 (28.1)	496 (25.7)	2,051 (26.5)
70-74	393 (25.3)	774 (24.5)	1,350 (26.1)	486 (25.2)	2,074 (26.8)
75-79	348 (22.4)	673 (21.3)	1,117 (21.6)	442 (22.9)	1,455 (18.8)
80-84	254 (16.4)	490 (15.5)	745 (14.4)	300 (15.6)	1,231 (15.9)
85+	153 (9.9)	400 (12.7)	513 (9.9)	204 (10.6)	931 (12.0)
Total	***1,552***	***3,161***	***5,177***	***1,928***	***7,742***
Men					
65-69	330 (28.6)	748 (31.3)	1,323 (31.9)	445 (31.2)	1,698 (32.3)
70-74	342 (29.7)	655 (27.4)	1,162 (28.1)	412 (28.9)	1,632 (31.0)
75-79	242 (21.0)	505 (21.1)	888 (21.4)	288 (20.1)	959 (18.2)
80-84	162 (14.1)	301 (12.6)	446 (10.8)	189 (13.2)	647 (12.3)
85+	77 (6.7)	181 (7.6)	324 (7.8)	94 (6.6)	326 (6.2)
Total	***1,153***	***2,400***	***4,143***	***1,428***	***5,262***

* includes those in institutions

Interview method

One of the issues that may affect the disability estimates obtained is the way in which the information is collected since self-administered questionnaires have been found to result in 13% higher prevalence rates of ADL-disability than interviewer-based surveys (21).. The reasons for this are unclear though it may be that respondents are less likely to admit to

disability if an interviewer is present. All the surveys considered here are interviewer-administered.

Use of proxies

Some surveys collect information from proxies on behalf of respondents who are unable to answer some questions themselves; differential inclusion of information from proxies might affect estimates of disability collected in different surveys. However, in all the surveys we consider proxy respondents were few accounting for only 111 (0.85%) in MRC CFAS; FRS does include some proxies but these cannot be distinguished from main respondents and in the GHS, BHPS and ELSA (I)ADL items were not asked of proxies.

Differences in the (I)ADL items

The way in which questions are asked has been found to have a substantial impact on the estimates of disability obtained (3). From their study of ADL questions in Dutch surveys Picavet and van den Bos (21) concluded that seemingly minor differences in structure and wording resulted in major differences in the estimates of disability.

The full form of the questions and responses for each survey is given in Appendix 1. The FRS questions on disability entail asking respondents who report having a limiting long-standing illness/disability whether that illness/disability means they have significant difficulties with any of the following areas of life: 'mobility (moving about); ability to lift, carry or otherwise move everyday objects; manual dexterity (using your hands to carry out everyday tasks); continence (bladder control); communication (through speaking, listening, reading or writing); memory or ability to concentrate; understanding when you are in physical danger; physical co-ordination (e.g. balance)'. Since the FRS items are significantly different to those collected in the other surveys, comprising functional limitations rather than (I)ADL items, we decided to exclude the FRS from further analyses as there was no overlap at all in items. Nevertheless we discuss this issue later in the report and specifically within the recommendations. In the remaining four surveys the scales used contain questions that cover ADLs, IADLs and some aspects of mobility. There are clear differences between the surveys in the wording used to describe the activities.

Who is asked the questions

In the GHS four of the ADL questions (toilet, in and out of bed, dressing and feeding) are only asked of people who report having difficulty going up and down stairs. This could affect prevalence estimates, in particular for activities that are not affected by lower body limitations. In ELSA and CFAS the ADL questions are asked of all respondents. In the BHPS the questions are asked of all interviewees aged 65 and over. Analysis requiring high levels of comparability would need to exclude the GHS ADL questions that are filtered by the "stairs" question.

Number and type of (I)ADLs measured and the wording used in the questions

Differences in the number of activities included in an ADL scale affect the prevalence estimates, as the greater the number of activities included, the higher is the probability of reporting ADL disabilities (3, 23).

Research has also shown that there is a hierarchical relationship between the ADL and IADL activities (5)′(6-8, 10, 11), which means that the activities are not interchangeable. This suggests that, ideally, comparison of (I)ADLs should cover the same activities, or activities that are equivalent in terms of the severity of disability they represent.

There is substantial variation in the activities covered in the four surveys. Table 2 lists the ADL, IADL and mobility questions contained in the four surveys and shows the apparent overlaps. As discussed in the next section, the wording used to describe the different activities varies considerably between the surveys, to the extent that in some cases it is debatable whether the items are equivalent at all. Only two activities are covered in the four surveys: bathing and ability to manage stairs (although the wording used varies between surveys). At least five activities are present in three of the surveys.

Table 2: Activities covered in the four surveys

Activity	BHPS*	ELSA*	GHS (2001/2)*	MRC CFAS*
Traditional ADLs and personal care				
Bathing	Do you usually manage to bath, shower or wash all over ?	Bathing or showering	Do you usually manage to bath, shower or wash all over ?	Are you able to wash all over or bathe ?
Toilet		Using the toilet,	Do you usually manage	Are you able to get to

		including getting up or down	to get to the toilet?**	or use the toilet?
In and out of bed	Do you usually manage to get in and out of bed ?	Getting in or out of bed	Do you usually manage to get in and out of bed?**	
Dressing		*Dressing, including putting on shoes and socks*	do you usually manage to dress and undress yourself**	
Shoes and socks		*Dressing, including putting on shoes and socks*		Are you able to put on your shoes and socks or stockings
Feeding		Eating, such as cutting up food	do you usually manage to feed yourself**	
Cutting toenails	Do you usually manage to cut your toenails		do you usually manage to cut your toenails yourself or does someone else do it for you	Are you able to cut your own toe nails
Medicines		Taking medications	do you need medical care such as taking medicines or pills, having injections or changes of dressing	
IADLs				
Heavy housework				Are you able to do heavy housework (for example washing floors)
Shopping		Shopping for groceries	Do you do the household shopping yourself	Are you able to shop and carry heavy bags
Cooking		Preparing a hot meal	Do you prepare hot meals for yourself	Are you able to prepare and cook a hot meal (if you had to)
Snacks			Do you prepare snacks for yourself	
Cup of tea			Do you make cups of tea	
Personal affairs		Managing money such as paying bills and keeping track of expenses	Do you deal with personal affairs – for example, paying bills, writing letters – by yourself	
Light housework	Housework***			Are you able to do the light housework
Dishes			Do you wash up and dry dishes	
Windows			Do you clean windows inside yourself	
Vacuum			Do you use a vacuum cleaner	
Laundry			Do you wash small amounts of clothing by hand	
Work around		Work around house		

house or garden		or garden		
Map reading		Using a map to figure out how to get around in a strange place		
Telephone		Making telephone calls		
Mobility questions				
Stairs	Do you usually manage to get up and down stairs or steps	Climbing several flights of stairs without resting And Climbing one flight of stairs without resting	Do you usually manage to get up and down stairs or steps	Are you able to go up and down stairs
Indoor walking	Do you usually manage to get around the house (except for any stairs)		Do you usually manage to get around the house (except for any stairs)	
Outdoor walking	Do you usually manage to go out of doors and walk down the road		Do you usually manage to go out of doors and walk down the road	
Walking		Walking 100 yards		
Public transport			Do you use public transport nowadays	Are you able to get on a bus

*See Appendix 1 for full wording of questions
**Questions asked only to those who reported difficulty going up and down stairs
***Questions asked only to those who reported health limited daily activity

Description of the activities

Table 2 also shows that there are clear differences in the wording used to describe the activities in the surveys, except between the GHS and BHPS, which use nearly the same wording for all the activities except for cutting toenails. In most questions the ELSA wording is more specific than that used in the other surveys and it can be argued that a higher level of ability would be required to perform the activities in the way they are described in ELSA. Below is a list of all the activities that are present in at least two surveys and a comparison of the way in which the activities are described.

ADLs and personal care activities

Bathing

The GHS and BHPS allow "washing all over" as an alternative to bathing or showering, whereas in ELSA the question covers bathing and showering only. This could potentially

result in lower rates reporting difficulties in the GHS and BHPS than in ELSA. MRC CFAS does not mention showering, it covers only "washing all over" and bathing.

Toilet

It could be argued that "getting to the toilet", as asked in the GHS, requires a lower level of ability/mobility than "using the toilet including getting up or down", as asked in ELSA. The wording used in MRC CFAS could potentially require an even lower level of ability as the question is phrased as "getting to or using the toilet". This means that someone who could not get to the toilet unaided but could use it once there could potentially answer that they could perform that activity.

In and out of bed

The description of this activity in the three surveys that contain this question, GHS, ELSA and the BHPS is identical.

Dressing

The GHS asked about both dressing and undressing. The ELSA wording includes putting on shoes and socks, which some of the respondents may not necessarily consider part of dressing. Picavet and van den Bos (21) found that including "putting on shoes" in the dressing ADL resulted in higher estimates of disability prevalence.

Socks and shoes

This question is present in MRC CFAS and it partially overlaps with the "dressing, including putting on socks and shoes" in ELSA.

Feeding

The ELSA version of this question seems to require a higher level of ability than the GHS version. Arguably, the GHS would "allow" feeding using specially prepared meals that do not require cutting up, whereas ELSA specifies "cutting up your food".

Cutting toenails

The description of this activity in the three surveys that contain this question, GHS, MRC CFAS and the BHPS is identical.

Medicines

This activity is present in the GHS and ELSA. Both questions cover taking medications, but the wording in the GHS includes other medical care tasks such as having injections or changes of dressing, which means that the GHS question is likely to capture more respondents than that in ELSA.

IADLs

Shopping

This question is present in the GHS, ELSA and MRC CFAS. However there are substantial differences in the way in which this activity is described. Firstly, in the GHS the question specifies "household shopping", whereas in ELSA it is "shopping for groceries". This difference is unlikely to result in substantial differences in the estimates. The question in MRC CFAS does not specify which type of shopping but, on the other hand, aims to capture a higher degree of difficulty as it adds "and carry heavy bags". Fleishman found substantial differential item functioning between men and women in responses to the IADL item shopping, meaning that men and women at the same level of disability reported difficulty with this item differently (24).

Cooking

This activity is described very similarly in the GHS and ELSA, both refer to "preparing a hot meal". MRC CFAS makes the description slightly more inclusive by specifying "preparing and cooking a hot meal".

Personal affairs/finances

In the GHS there is an activity described as "dealing with personal affairs, for example paying bills, writing letters", which partly overlaps with one in ELSA that asks about "managing money such as paying bills and keeping track of expenses".

Mobility questions

Stairs

This activity is present in all four surveys. The wording used in the GHS and BHPS is identical ("get up and down stairs and steps") and appears to be very similar to that used in MRC CFAS ("go up and down stairs"). In ELSA there are two questions relating to stairs. One asks whether the respondent can "climb one flight of stairs without resting" and the other whether the respondent can "climb several flights of stairs without resting". The version used in ELSA, even in the less strenuous version of one flight of stairs, is likely to capture more respondents than the versions used in the other three surveys because it specifies a whole flight of stairs (compared to possibly just a few steps in the other surveys) and "without resting".

Indoor walking and outdoor walking

These questions are phrased identically in the GHS and the BHPS. There could potentially be some overlap with the question in ELSA about "walking 100 yards".

Public transport

There is some overlap between the GHS question "do you use public transport nowadays" and the MRC CFAS question "are you able to get on a bus".

Structure of the questions

There are substantial differences in the structure of the questions. The biggest differences overall are between ELSA and the other surveys. In ELSA (wave 1) people are asked whether, "because of a health or memory problem they have any difficulties doing" any activities from a list. The activities are then listed one after the other. Respondents are not asked whether they can perform the activities on their own or whether they need help performing them. In all other three surveys the questions are asked one at a time.

In the GHS 2001/2 most questions are asked in two or even three stages, and there are differences in the way different types of questions are asked. As discussed before, some ADL questions are only asked of people who report needing help or difficulty with going up

and down stairs. For most ADL and mobility questions the respondent is first asked if they "usually manage" to perform the activity and, if they respond that they "manage on their own" then they are asked about the degree of difficulty. In the medicines and the public transport questions the respondent is first asked whether they "need medical care/use public transport" and, if they need it/use it, the question then takes the same format as the other ADL and mobility questions. The IADL questions in the GHS are asked in a different form. The respondent is first asked whether they perform the activity by themselves and if they say "no", whether they could do it if they had to.

The ADL and IADL questions in MRC CFAS are asked in a way that a single questions elicits whether help is needed, whether the respondent can perform the activity with difficulty or whether they perform it with no difficulty.

The BHPS questions on ADLs and mobility are asked in the same two-stage format as the ADLs in the GHS (first asking about ability to perform on their own and, if they do so, whether it is difficult).

Duration of disability

In ELSA people are asked to disregard any difficulties that they expect to last less than three months, whereas in the other surveys there is no specified duration. Picavet and van den Bos (21) estimated that the use of a "duration" introduction to the question lowered the estimated prevalence of disability in mobility by 13.7 percentage points.

In the BHPS and the GHS (for the ADL and mobility questions) people are asked whether they can "usually" perform activities, whereas in the GHS they are simply asked whether they perform the activities. In MRC CFAS people are asked whether they perform the activities, without qualifying whether they can do it all the time or not.

Health attribution

In ELSA the respondents are asked whether they have any difficulties as a result of a health or memory problem. It is possible that respondents who have difficulties that they do not

attribute to a particular health or memory problem (for example, problems they attribute to ageing) may not report them. Dubuc et al. (25) found that there was a 5.8% average increase in cumulative disability when persons reported disability without attribution to health, indicating that there are factors other than health that have an influence. In the other three surveys there is no health attribution.

Ability vs performance

Glass (26) investigated the impact on estimated ADL disability of asking people whether, hypothetically, they are able to carry out an activity, compared to actually observing them carrying out the activity at home. He found substantial discrepancy between the answers to hypothetical questions compared to the actual performance of the activities. These differences were greater in older people, leading to concern that questions based on hypothetical performance may underestimate the prevalence rates of disability. It has also been suggested that the use of hypothetical questions may lead to biases by gender in estimates of disability if, for example, people who do not undertake particular tasks for gender role reasons report not being able to undertake them (e.g. men and cooking). In all four surveys people are asked hypothetically, rather than being observed.

Performance: difficulty vs. ability to perform.

The impact of using different rating scales was investigated in detail by Jette (27) who suggests that scales designed to rate individual ADLs take "three standard forms: (1) the degree of *difficulty* in performing certain activities: how hard it is to perform an activity; (2) the degree of *assistance or dependency:* whether or not a person uses or needs assistance to perform an activity; and/or (3) whether or not the activity is *performed*." His study found that "measures which used 'difficulty' produced estimates of disability in specific ADLs anywhere from 1.2 to 5 times greater than 'human assistance' scales". The effect of the rating method varied substantially across ADLs. He also found that the discordance between 'difficulty and functional dependence scales is related to characteristics of the respondent, in particular age and health status'. Picavet and van den Bos (21) concluded that using different response categories results in estimates that are not comparable.

As Wiener at al. (3) discuss, differences in how questions are asked and who is counted as being disabled are often the result of trying to answer different research questions. Needing help to perform an activity is more likely to be of interest to researchers investigating the need for long-term care services, whereas measures of difficulty are likely to be of interest from an epidemiological point of view.

In the GHS respondents are asked whether they usually manage to perform the activity on their own, whether they need help or cannot manage it at all. If they answer that they can perform the activity on their own, they are then asked whether they find it very easy, fairly easy, fairly difficult or very difficult to do it on their own. In ELSA the question makes no reference to needing help.

In ELSA people are asked whether they have "difficulty with the activity", without actually asking whether the activity is performed. In the BHPS and GHS (ADLs and mobility questions) people are asked "do you usually manage…", which comes closer to asking about performance. In MRC CFAS people are asked whether they are "able to" and in the GHS (IADLs) people are asked "do you", which would appear to be closer to asking about performance of the activity.

Table 3 below shows the final selection of the (I)ADL items that were felt to be reasonably comparable across the surveys and whether the cutpoints "difficulty" and "help" were available for each of the surveys. The GHS items which were filtered by the question on use of stairs were not included. In addition help could not be coded for use of public transport (as we could not assume those not using it required help). However we did assume that those who did not cut their own toenails had difficulty in doing so. Within the BHPS and GHS, respondents were asked whether they usually managed a number of tasks, with the response categories; "on your own", "only with help", and "not at all". Those that replied that they could perform the task "on your own" were asked whether they found it "very easy", "fairly easy", "fairly difficult" or "very difficult". Respondents were classified as having difficulty if they responded that they could not do the task or they could do the task on their own but found it fairly or very difficult. In MRC CFAS participants were asked whether they were able to perform a number of activities, with response categories: "No,

needs help", "Yes, with some difficulty", "Yes, no difficulty". Those that responded "No, needs help" or "Yes, with some difficulty" were coded as having difficulty.

Table 3: (I)ADL items and cutpoints by survey

	No difficulty/difficulty					No help needed/help needed			
Item	**BHPS**	**ELSA**	**GHS**	**MRC CFAS**		**BHPS**	**ELSA**	**GHS**	**MRC CFAS**
Cutting Toenails	✓		✓	✓		✓		✓	✓
Bathing	✓	✓	✓	✓		✓		✓	✓
Public transport				✓					✓
Stairs	✓	✓	✓	✓		✓		✓	✓
Heavy housework				✓					✓
Shoes & socks				✓					✓
Toilet		✓		✓				✓	✓
Light housework	✓			✓					✓
In/out of bed	✓	✓				✓			
Hot meal		✓		✓				✓	✓
Dressing		✓							
Shopping		✓		✓					✓
Feeding		✓							

Comparison of standardised prevalence of disability over time in MRC CFAS

The baseline MRC CFAS interview was carried out in 1992 some ten years prior to the other surveys. Although MRC CFAS wave 10 is contemporaneous with the other surveys in this analysis, it is a survivor sample and therefore is not representative of the entire population aged 65 years and over in 2002, when the interviews took place. Rather it comprises all those left after attrition (through death, withdrawal and loss to follow-up) from those aged 65 years and over in 1992 (baseline interview), and so contains data on people aged 75 years and over only. We applied attrition rates to the wave 10 data to compare the

prevalence and ordering of items at baseline with wave 10. This could only be done for the population aged 75+ as wave 10 was a survivor sample. Figures 5 and 6 compare the standardised prevalence of ADL items between the baseline interview and wave 10 for men and women aged 75+. Using the cutpoint of difficulty to define disability the shoes and socks item ordered earlier for women at baseline than at wave 10. However the needs help definition produced consistent ordering at baseline and wave 10 for both men and women. The magnitude of the standardised prevalence were also similar between baseline and wave 10 confirming it is appropriate to use the baseline data for comparison with the other surveys.

Comparison of standardised prevalence of disability across the surveys

Firstly, for each survey, we compared the standardised prevalence of disability (standardised to the European population by age and sex) for each item using each of the cutpoints "difficulty" and "help" for men and women aged 65+.

Figures 1-4 show prevalence rates by gender and definition of disability for the BHPS, ELSA GHS and MRC CFAS respectively. There was no significant difference in the hierarchy of items by gender within the BHPS (Figure 1). For ELSA (Figure 2) the only difference in ordering between men and women was seen with difficulty with dressing and bathing reversed and with confidence intervals not overlapping for either gender. For GHS (Figure 3) the hierarchy for difficulty was identical between men and women but the position of needing help with hot meal was different with a higher prevalence for men than women. In MRC CFAS (Figure 4) the hierarchy differed for hot meal and shopping between men and women for both difficulty and needs help. For all surveys the ordering of items within gender but across definitions of disability was very similar.

Calculation of the hierarchy of (I)ADLs within surveys

We first undertook analyses within each survey to (i) confirm that the (I)ADL items could be regarded as being on a single underlying disability continuum, and (ii) to determine the hierarchy of items. Full details of the analyses for each survey can be found in Appendices 2-5 but a summary is given below.

Confirmation of a single underlying disability continuum

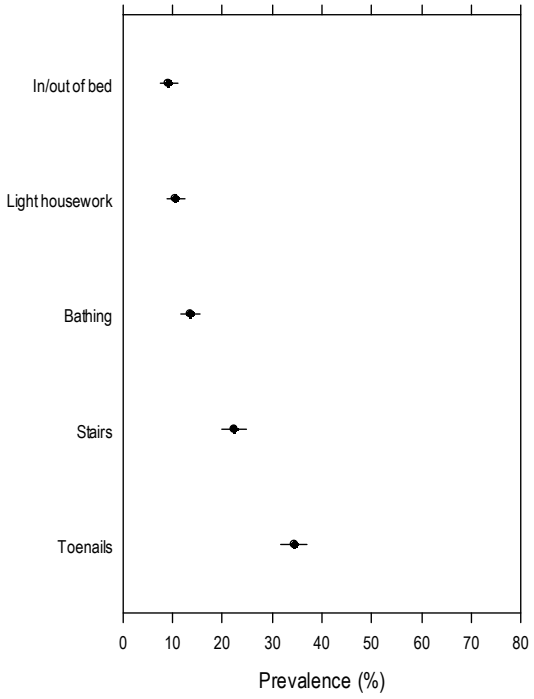
To confirm the unidimensionality of items we used Principal Component Analysis (PCA) based on polychoric correlations for BHPS, ELSA and MRC CFAS as the item responses were on an ordinal scale. For the GHS, where the number of items differed between the difficulty and the needs help cutpoints, we performed one PCA with the maximum number of items (needs help) and using tetrachoric correlations as these were on a binary scale. The number of dimensions was determined by examination of the Scree plot in conjunction with inspection of eigenvalues with inclusion of those greater than one (Kaiser's Criterion) (28). Cronbach's alpha was also calculated to examine internal consistency of the scale.

PCA confirmed a single underlying dimension with only one eigenvalue greater than one for each survey, these eigenvalues explaining 61% (BHPS), 43% of the variance (ELSA), 45% (GHS), and 76% (MRC CFAS). Cronbach's alpha was between 0.72(GHS) and 0.92 (MRC CFAS), showing good internal consistency in all scales. There was mostly no strong evidence at this point to exclude items though three items were highlighted for possible exclusion in certain of the surveys: cutting toenails in the BHPS and GHS, toilet in ELSA and MRC CFAS, and feeding in ELSA.

Figure 1: Has difficulty and needs help with ADLs by gender: BHPS

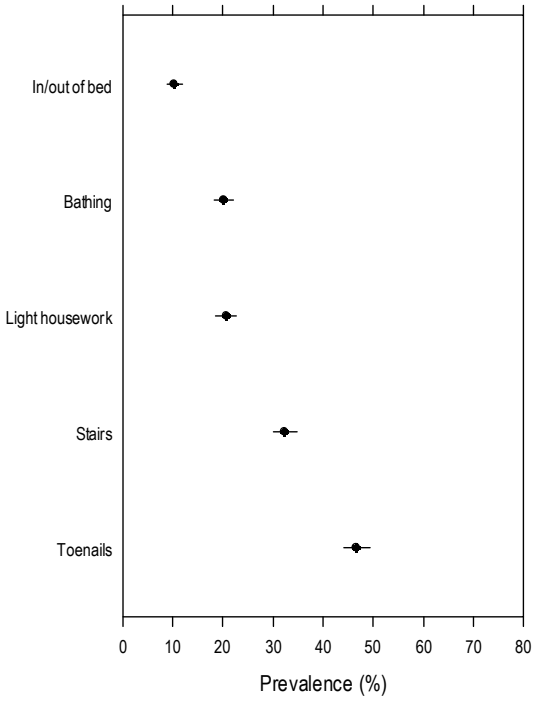
Men

BHPS: Prevalence of 'difficulty' with ADL's in men age 65+

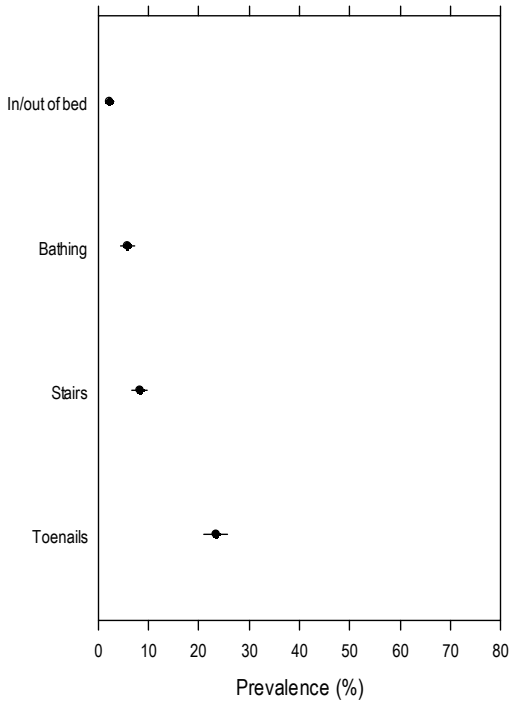


Women

BHPS: Prevalence of 'difficulty' with ADL's in women age 65+



BHPS: Prevalence of 'needs help' with ADL's in men age 65+



BHPS: Prevalence of 'needs help' with ADL's in women age 65+

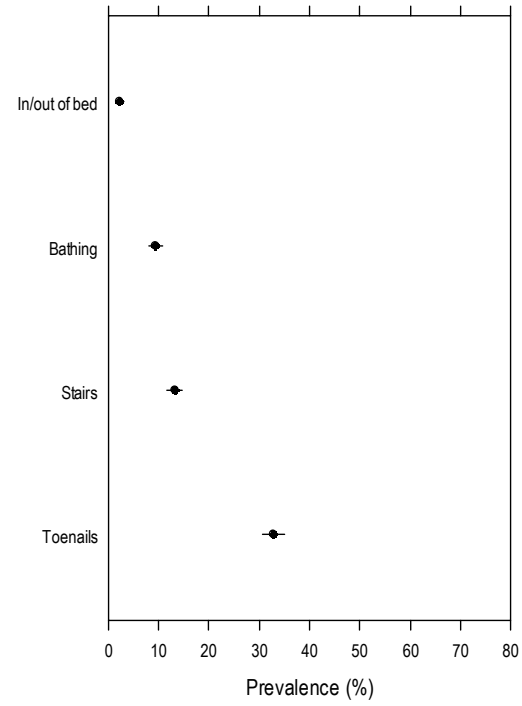
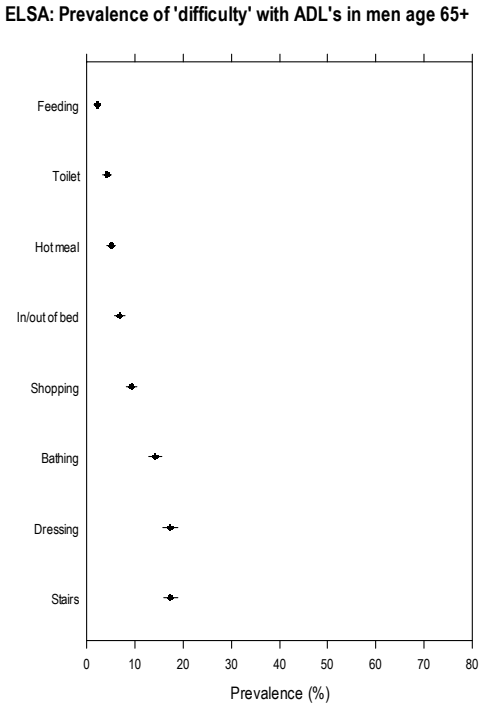


Figure 2: Has difficulty with ADLs by gender and age group: ELSA

Men



Women

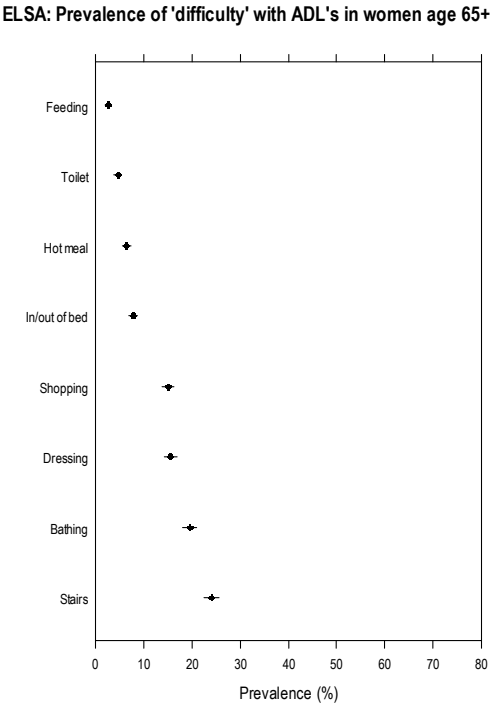
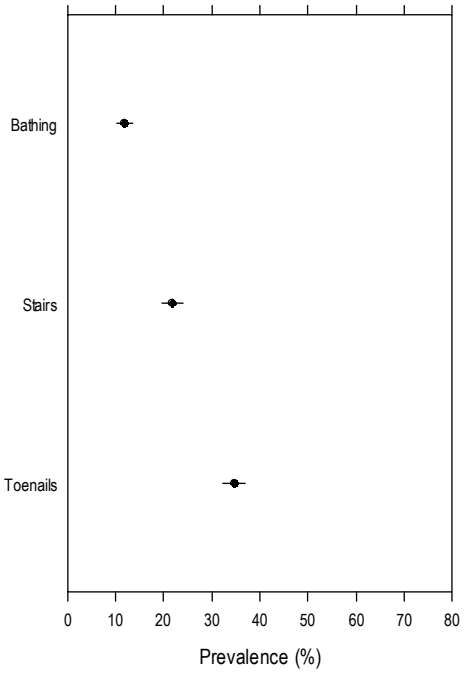


Figure 3: Has difficulty and needs help with ADLs by gender and age group: GHS

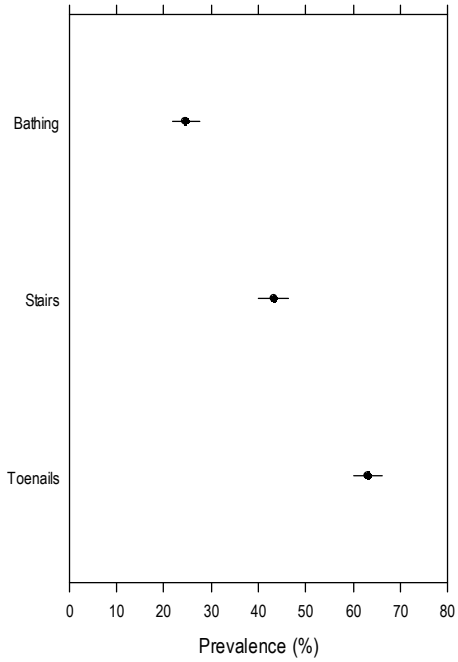
Men

GHS: Prevalence of 'difficulty' with ADL's in men age 65+

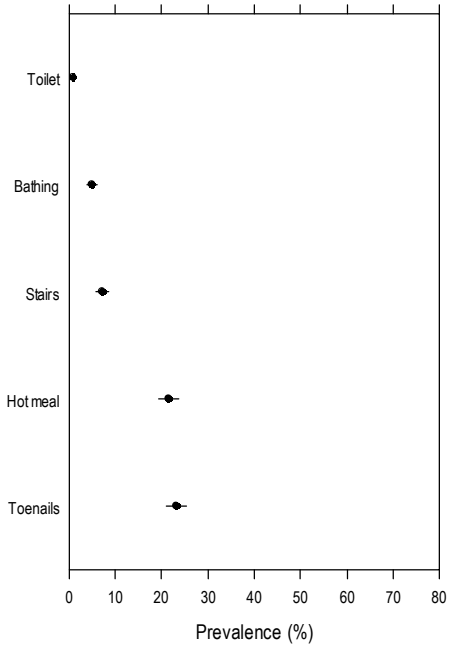


Women

GHS: Prevalence of 'difficulty' with ADL's in women age 75+



GHS: Prevalence of 'needs help' with ADL's in men age 65+



GHS: Prevalence of 'needs help' with ADL's in women age 65+

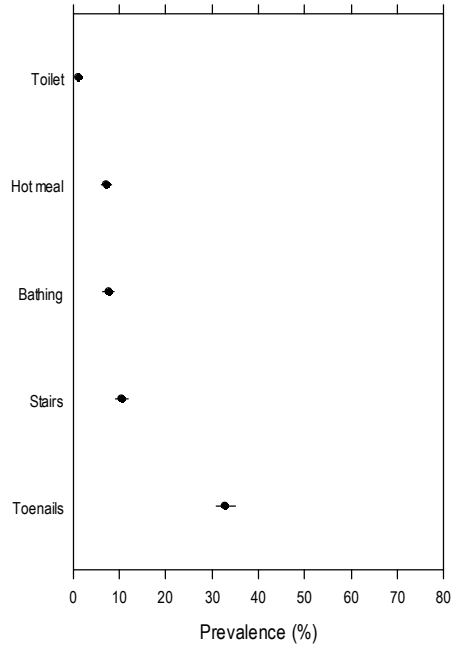
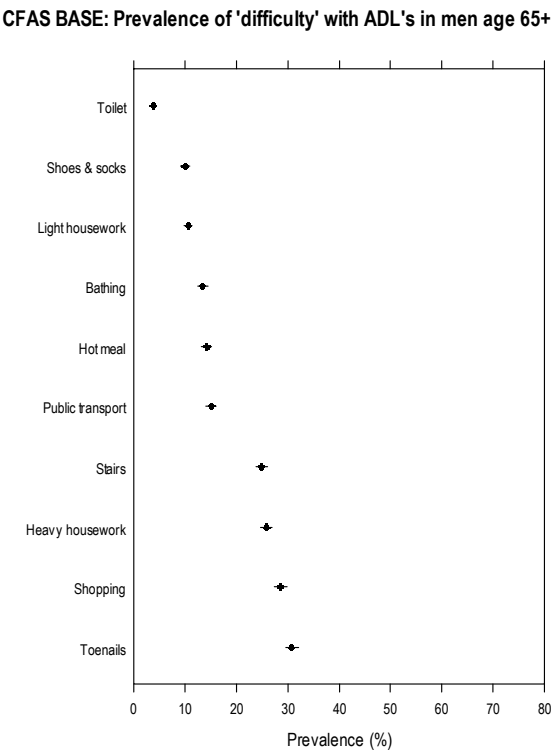
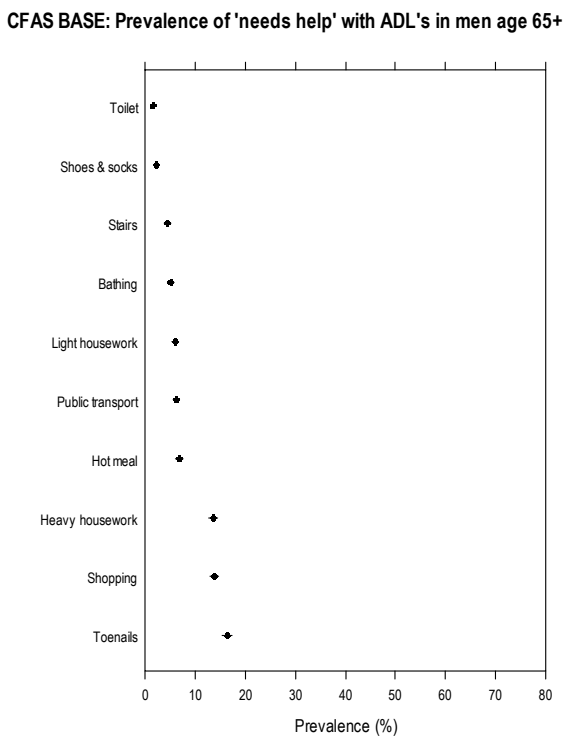


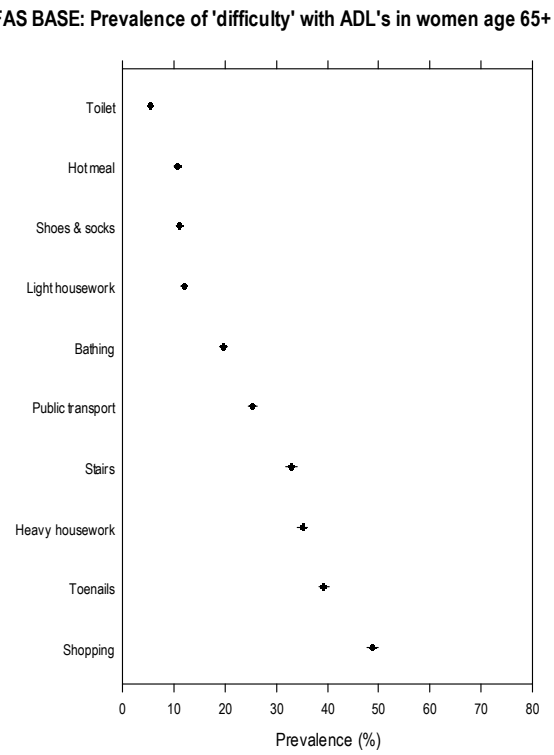
Figure 4: Has difficulty and needs help with ADLs by gender and age group: MRC CFAS Baseline

Men





Women



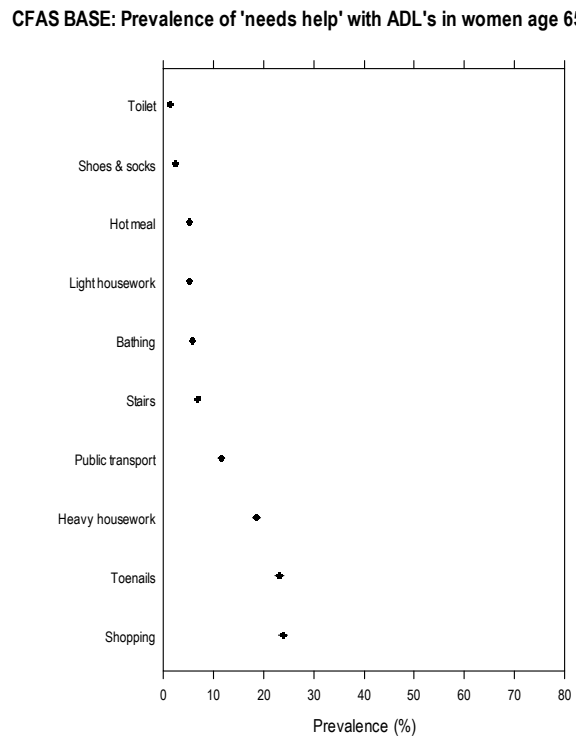
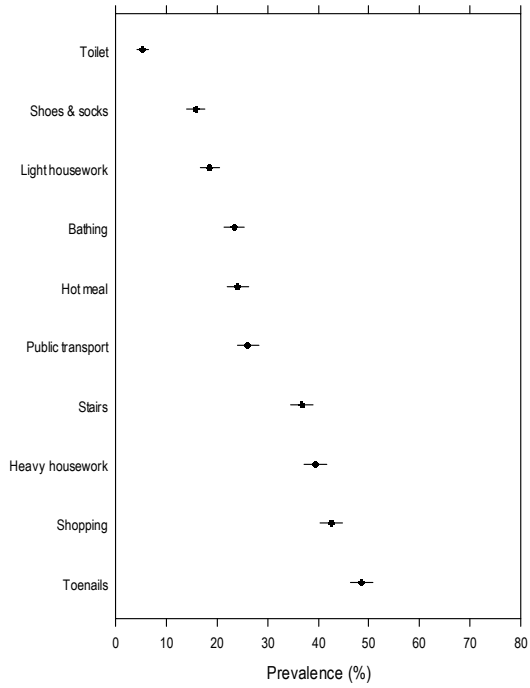


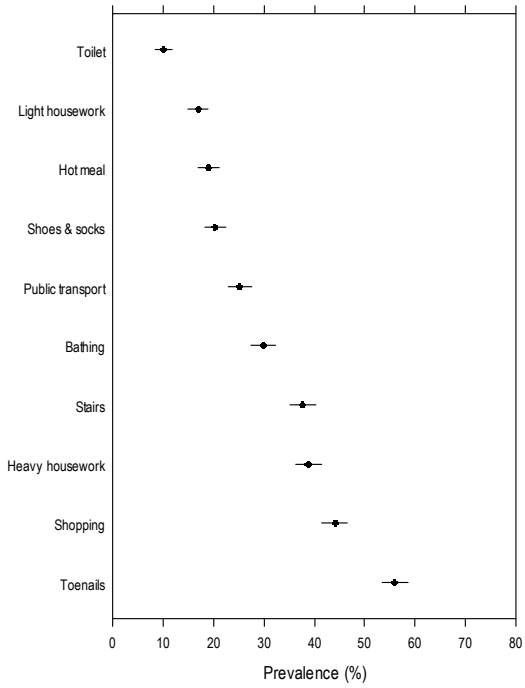
Figure 5: Standardised prevalence of “difficulty” at baseline and wave 10: MRC CFAS

Men

CFAS BASE: Prevalence of 'difficulty' with ADL's in men age 75+

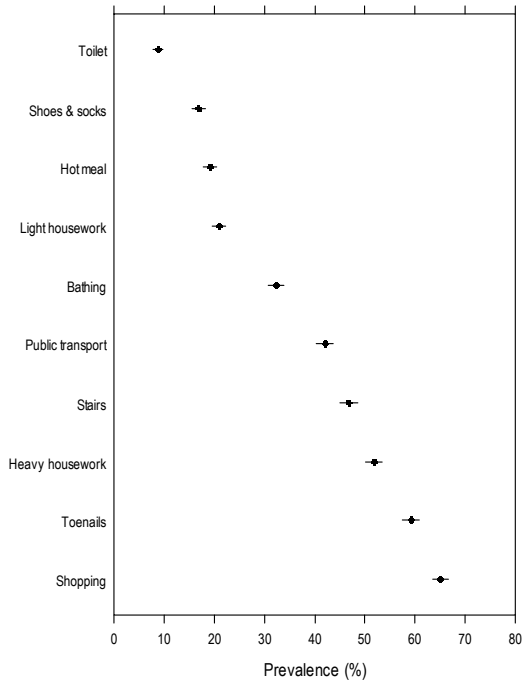


CFAS Wave 10: Prevalence of 'difficulty' with ADL's in men age 75+



Women

CFAS BASE: Prevalence of 'difficulty' with ADL's in women age 75+



CFAS Wave 10: Prevalence of 'difficulty' with ADL's in women at age 75

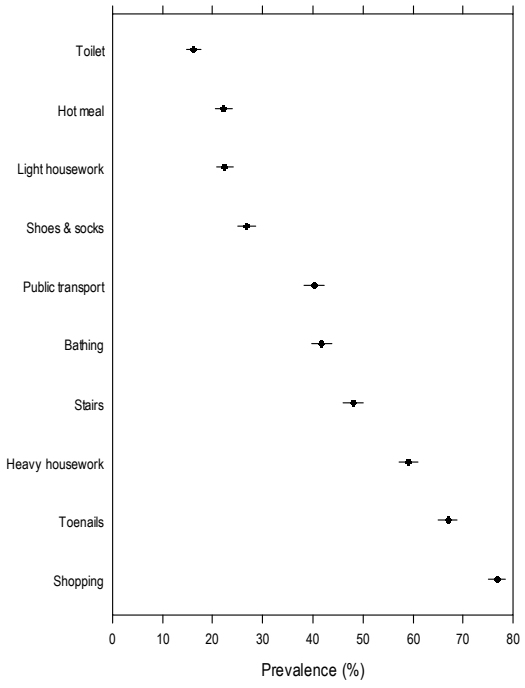
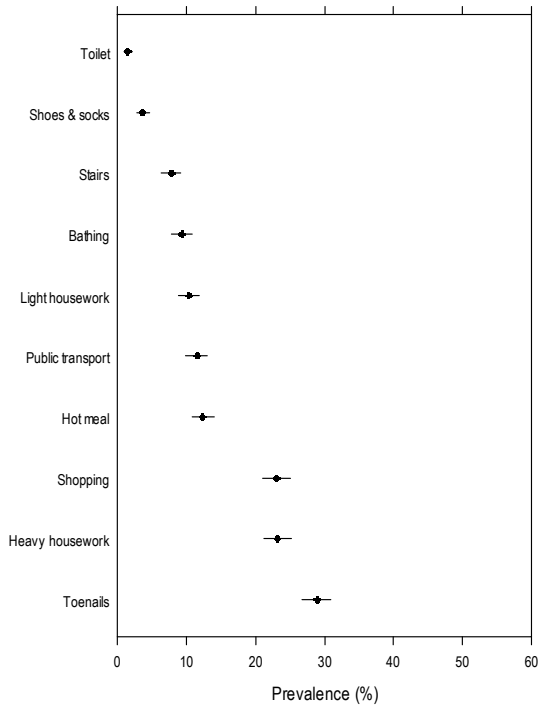


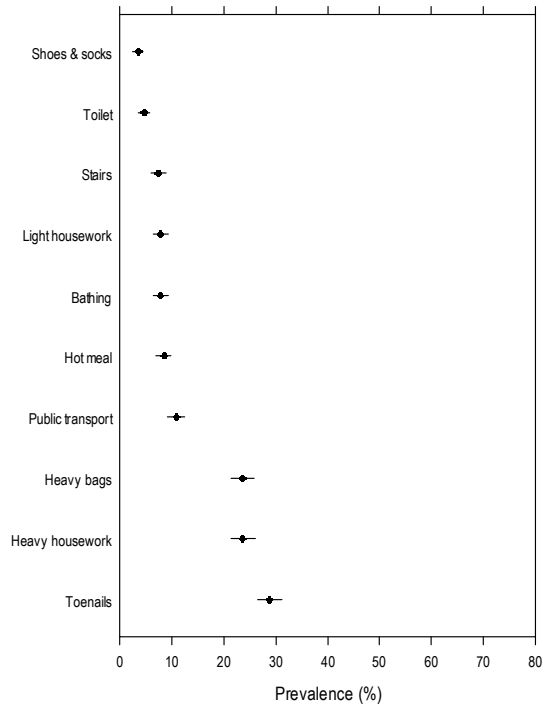
Figure 6: Standardised prevalence of “needs help” at baseline and wave 10: MRC CFAS

Men

CFAS BASE: Prevalence of 'needs help' with ADL's in men age 75+

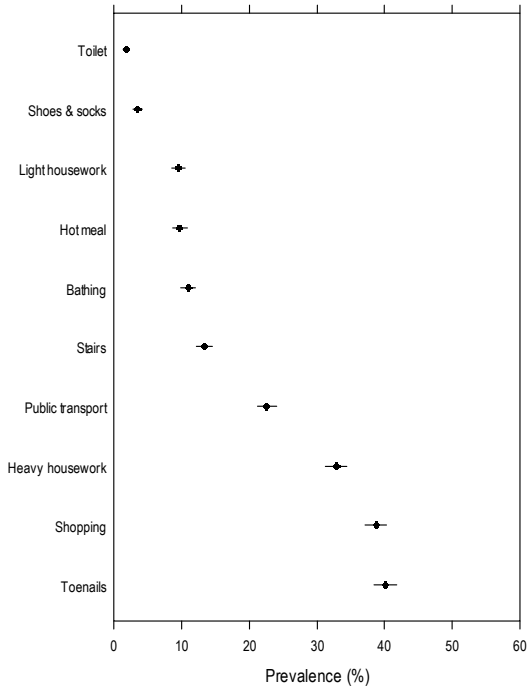


CFAS Wave 10: Prevalence of 'needs help' with ADL's in men age 75+

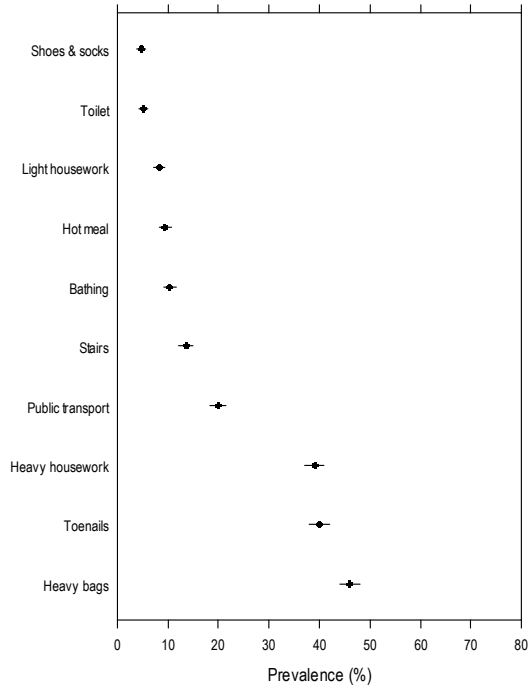


Women

CFAS BASE: Prevalence of 'help' with ADL's in women at age 75



CFAS Wave 10: Prevalence of 'needs help' with ADL's in women at age 75



Calculation of hierarchy of (I)ADL items within each survey

After the identification of a single underlying dimension, Mokken Scaling was used to determine the hierarchy of the items using the difficulty and needs help cutpoints separately. The strength of the items conforming to a hierarchy was assessed by the Loevinger Scalability Coefficient (H) (29), with values of 0.5 -1 indicating a strong scale and 0.4-0.49 an acceptable scale (30). Items were deleted from the scale if the assumption of double monotonicity (item overlap) was not satisfied. Analyses were repeated for men and women separately.

Living alone is a further factor which may influence whether a person reports difficulty or needing help and may thus affect the prevalence of inability to perform ADL items between surveys if the proportions living alone differ. Within the BHPS sample 39% were living alone, similar to 37% in both GHS and ELSA and 38% in MRC CFAS. We repeated analyses of each survey separately for the subsamples living alone and living with others and in MRC CFAS excluding those in institutions (n=593, 4%). We further deleted items from the scale if the position in the hierarchy differed substantially by gender or living arrangement.

Using the difficulty definition, for all four surveys the Loevinger Scalability Coefficient (H) lay between 0.55 (ELSA) and 0.74 (GHS) reflecting that the items formed a strong hierarchical scale. The assumption of double monotonicity was violated in some cases though none exceeded the 0.03 limit considered acceptable (31). Separate analysis by gender generally confirmed previous results. Exceptions were: in MRC CFAS hot meal and shopping ranked differently for men and women; dressing was ranked differently by gender in ELSA.

Using the needs help definition for the three surveys (this definition was not possible for ELSA) the Loevinger Scalability Coefficient (H) lay between 0.62 (GHS) and 0.73 (BHPS) reflecting that the items formed a strong hierarchical scale. The assumption of double monotonicity was again violated but only in a few cases with none exceeding the 0.03 limit. Separate analysis by gender generally confirmed previous results though for MRC CFAS hot meal and light housework and in the GHS hot meal were ranked further up the hierarchy for men than women suggesting men needed help with this task at a lower level of dependency than women.

Separate analysis of those living alone and those living with others, for both definitions of disability, revealed a few differences: in MRC CFAS hot meal and in ELSA dressing differed in their position in those who lived alone compared to those who lived with others. Repeating analysis of MRC CFAS including those in institutions made no difference to conclusions.

Comparison of hierarchies across surveys

Table 4 shows the hierarchical ordering of the items using the definitions of difficulty and needs help. Items which showed a difference for men and women (ELSA: dressing; MRC CFAS, GHS: hot meal) were excluded from the final scales since any scale needs to be gender independent. Thus, with these items removed, the ordering of items across the surveys is very similar see Table 5 (difficulty) and Table 6 (needs help) apart from shopping in ELSA. This is further confirmed by Figures 7 (difficulty) and 8 (needs help) with the standardised prevalence for each item from each of the four surveys plotted together.

Common disability measure

Since the ordering of items within the surveys appears to confirm an overall hierarchy of items, we looked for items in each survey that gave a similar prevalence of disability across the surveys. With the cutpoint of difficulty, the item bathing (or washing all over) is present in all surveys and is of similar standardised prevalence, ranging from 14.1 (GHS) to 16.9 (ELSA) (Table 5). If an indicator of less severe disability is required, then difficulty with stairs is a candidate as it is included in all surveys with standardised prevalence ranging from 20.7 (ELSA) to 29.0 (MRC CFAS). It was impossible to define disability with the cutpoint of needing help in ELSA for any item (Table 6).

Table 4: Hierarchy of (I)ADL items from Mokken analysis by definition of disability and survey

	No difficulty/difficulty					No help needed/help needed			
Item	**BHPS**	**ELSA**	**GHS**	**MRC CFAS**		**BHPS**	**ELSA**	**GHS**	**MRC CFAS**
Shopping		4		1					2
Toenails	1		1	2		1		1	1
Heavy housework				3					3
Stairs	2	1	2	4		2		2	5
Public transport				5					4
Bathing	3	2	3	6		3		3	7
Dressing		3*							
In/out of bed	5	5				4			
Hot meal		6		7*				4*	6*
Light housework	4			8					8*
Shoes & socks				9					9
Toilet		7		10				5	10
Feeding		8							

*to be excluded from final scale due to gender differences

Table 5: Standardised prevalence of difficulty with (I)ADL items in hierarchy order by survey, 95% CI in parentheses

Item	**BHPS**	**ELSA**	**GHS**	**MRC CFAS**
Shopping		12.2 (11.4,13.0)		38.7 (37.9,39.6)
Toenails	40.6 (38.8,42.4)		39.9 (38.2,41.5)	35.1 (34.3,35.9)
Heavy housework				30.5 (29.7,31.3)
Stairs	27.4 (25.7,29)	20.7 (19.7,21.8)	25.1 (23.6,26.6)	29.0 (28.2,29.8)
Public transport				20.2 (19.6,20.9)
Bathing	16.8 (15.5,18.1)	16.9 (15.9,17.9)	14.1 (13,15.3)	16.6 (15.9,17.2)
Light housework	15.6 (14.3,17)			11.3 (10.7,11.8)
Shoes & socks				10.6 (10.0,11.1)
Bed	9.8 (8.7,10.9)	7.3 (6.6,8)		
Hot meal		5.8 (5.1, 6.4)		
Toilet		4.4 (3.8,4.9)		4.6 (4.2,4.9)
Feeding		2.4 (1.9,2.8)		

Table 6: Standardised prevalence of needing help with (I)ADL items in hierarchy order by survey, 95% CI in parentheses

Item	BHPS	GHS	MRC CFAS
Toenails	28.1 (26.5,29.7)	28 (26.5,29.5)	19.8 (19.1,20.5)
Shopping			18.8 (18.1,19.5)
Heavy housework			16.1 (15.4,16.7)
Public transport			8.9 (8.4,9.4)
Stairs	10.7 (9.6,11.8)	8.9 (7.9,9.9)	5.6 (5.2,6.0)
Bathing	7.6 (6.7,8.6)	6.4 (5.5,7.2)	5.4 (5.0,5.8)
In/out of bed	2.4 (1.8,2.9)		
Shoes & socks			2.3 (2.0,2.6)
Toilet		1.1 (0.7,1.5)	1.4 (1.2,1.6)

Comparisons of the new common disability measure with previous measures of disability

Although this piece of work has wider applicability, it is necessary for the Modelling Ageing Populations to 2030 (MAP2030) project (see www.lse.ac.uk/collections/MAP2030) since all the workpackages use one of the four surveys assessed here to measure disability. However it should be stressed that the analyses undertaken and the conclusions drawn are based on defining a measure of disability of a level to require social care and in older adults (aged 65 years and over). An earlier measure of disability from MRC CFAS was used in a background paper to the 2006 Wanless Review of Social Care (32). Here the threshold for disability was being unable to perform at least one of five ADLs without human help: transfer to and from a chair (from interviewer assessment), put on shoes and socks, prepare a hot meal, get around outside, and have a bath or an all-over wash. The age- and sex-standardised prevalence of disability for this threshold was 14.1, at the same level as the proposed common disability scale of difficulty with bathing or having an all-over wash.

The PSSRU (Personal Social Services Research Unit) Long-term Care Financing Model (33) uses a disability classification based on the GHS ADL and IADL items which allows the model to select groups with different severity of disability. The classification used is cumulative so that it is assumed that all those who have difficulty bathing would also have problems with at least 1 IADL, that those in the "difficulty with 1 or more ADL other than bathing group" did also have difficulty bathing and so on (Table 7). In that analysis the distinction between

bathing and the other ADLs was based on the hierarchy of ADLs literature (5, 6) and on the fact the other ADLs present in the GHS have been filtered by the stairs filter.

Table 7: Disability cut-off points used in the PSSRU model.

	Proportion disabled using the different cut-off points
Does not perform 1 IADL or more	0.27
Difficulty bathing	0.19
Difficulty 1 or more ADL other than bathing	0.15
Needs help with 1 or more ADL	0.08
Needs help with 2 or more ADL	0.03

The focus in this analysis has been to define a common metric of disability for older people across the five major UK studies at a level indicating need for long-term care. This is different to other definitions of disability, particularly that used by the UK Disability Discrimination Act (DDA) and the World Health Organisation's ICF. For the former, the original definition included the impact on 'normal day-to-day activities' which were described as activities like eating, washing, dressing and going shopping, thus essentially ADLs and IADLs. However in 2005 the DDA amended the definition of disability to ensure that people with HIV, cancer and multiple sclerosis were deemed to be covered by the DDA from the point of diagnosis, rather than from the point when the condition affected their ability to carry out normal day-to-day activities. It is therefore possible that an individual may meet the DDA definition of disability but not reach the threshold for our new measure. In this context a new UK disability survey, the Life Opportunities Survey (LOS) commissioned by the Office for Disability issues will be launched in June 2009 and will include the DDA questions as well as many of the ADL and IADL items included in the existing UK surveys. With regard to the ICF, although ADLs are considered, the framework include a perspective of disability as a result of social and environmental barriers that restrict participation.

Figure 7: Prevalence of difficulty with items ranked all studies

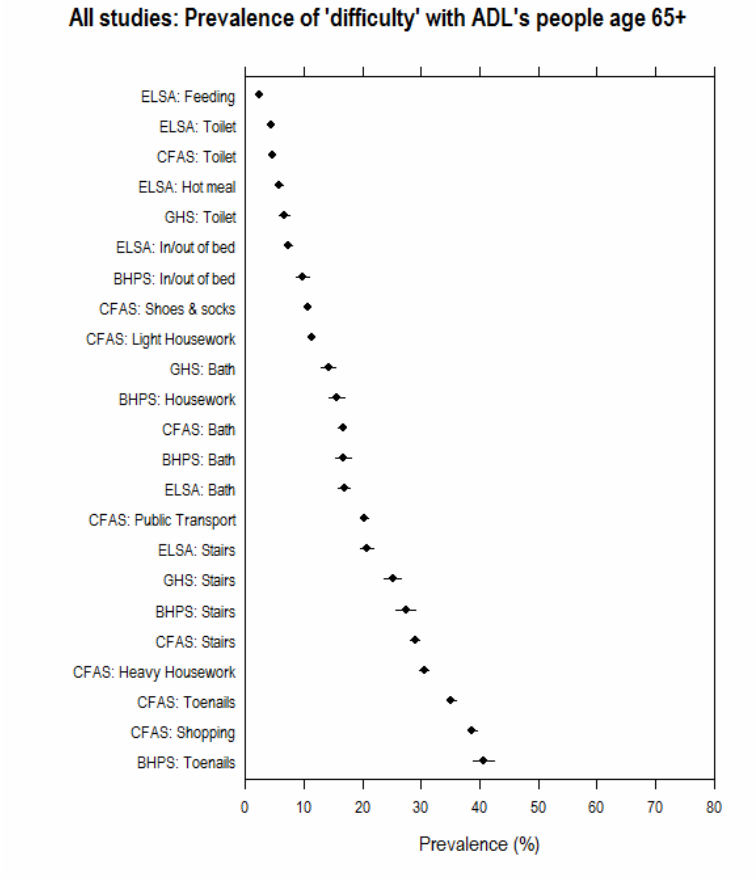
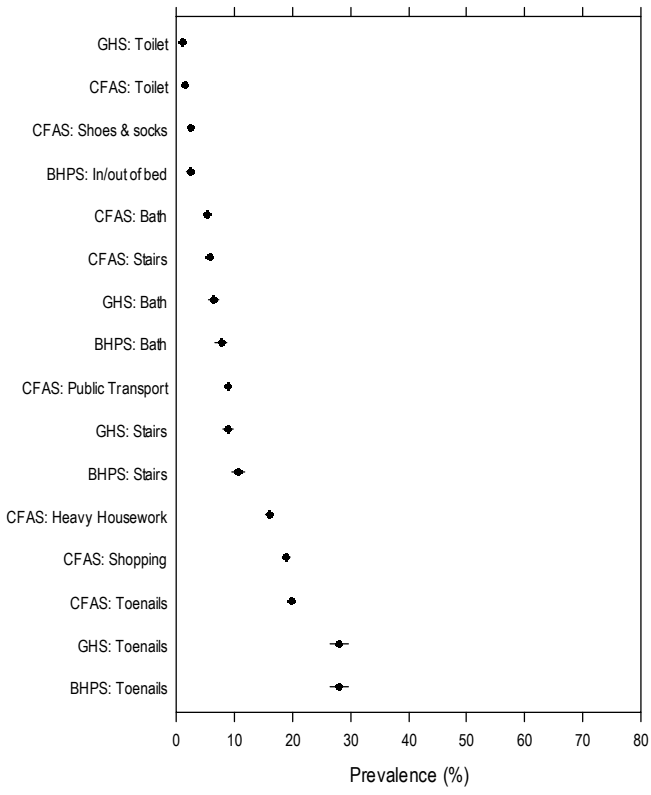


Figure 8: Prevalence of needing help with items ranked all studies



Conclusion

In this report we reviewed factors that might account for differences in the prevalence of disability between five British surveys (BHPS, ELSA, FRS, GHS and MRC CFAS), including survey methodology and the description, number of ADL and IADL items and the structure of the question. After selecting the set of IADL and ADL items that were most similar between the surveys we then tested that the items formed a hierarchical scale and then compared the ordering of items between the surveys. From this we were able to find one item (bathing) which was asked in all surveys and which gave a similar prevalence (after standardisation) across the surveys.

With regard to methodological factors that could potentially cause differences in the prevalence of disability, we reviewed population coverage, interview method and the use of proxy respondents and found considerable consistency across the surveys. For instance in all surveys, participants self-reported on activities directly to interviewers rather than using self-completion questionnaires. However when we reviewed the description, number of items and structure of the questions considerable variation was found. Firstly the FRS items were significantly different to those in the other surveys as they comprised functional limitations rather than IADLs or ADLs. The FRS was therefore excluded from further analysis. The GHS in particular used a filter question for some of the items, thus questions were only asked of respondents who had difficulty going up and down stairs. The number and type of activities included in each survey varied substantially. Though this may affect the prevalence of disability if defined as "difficulty in one or more ADLs", since inclusion of more ADLs would increase the chance of difficulty with at least one, this was less of a problem in our analysis as activities were considered singly and there was overlap between the surveys.

However, even when the same items were included in different surveys, the wording of the question could vary, for instance due to reference to the duration of the disability (in ELSA people are asked to disregard short-term difficulties), the attribution of the disability to health problems or whether the respondent was asked if they had difficulty or required help to perform the activity. Other potential structural differences that could impact on prevalence include asking about each activity in turn rather than using a list of activities.

Taking all these differences into consideration we defined a subset of items that had reasonable comparability across the surveys with considerable overlap in the items.

Detailed analysis showed that the items in each survey appeared to fit a strong hierarchical single dimension scale with the ordering of items similar across the surveys. Since it was impossible to define disability with the cutpoint of needing help in ELSA for any item we concentrated on finding a consistent level of disability across surveys using the cutpoint of difficulty. We identified one item (bathing or washing all over) as being present in all surveys and of the level of severity to reflect the need for care as previously defined by PSSRU (33). We suggest that this level of disability be defined as having difficulty bathing or with any of the items ranked higher in that survey (e.g. for ELSA the definition would be having difficulty with bathing, in/out of bed, toilet and feeding; for BHPS it would be having difficulty with bathing, in/out of bed and light housework; for MRC CFAS difficulty with bathing, shoes and socks and toilet; for GHS having difficulty with bathing).

If an indicator of a milder level of disability is required, then a suitable item is the question on stairs. This again is present on all surveys and again the definition of disability would be having difficulty with stairs or any item ranked more higher in the hierarchy in that survey.

Recommendations

The continued ageing of our population through increased life expectancy even in the oldest age groups and relatively low levels of fertility, alongside the greater health and social care needs in later life, makes it imperative that good data are available to estimate needs and the resources required to meet them. Each of the major surveys we have considered has particular strengths or a focus on certain areas, for example the economic aspects of ageing in comparison with social aspects. It is therefore imperative that the surveys are in some way 'joined together' by collecting certain key variables in the same way, to allow researchers to crosswalk between surveys and that this should include a consistent set of activities of daily living as they are a key component in defining disability, especially for older people.

The analysis reported here showed that the (I)ADL items used in the major British surveys covering the older population: ELSA, BHPS, GHS and MRC CFAS, were compatible across the surveys in the way they formed into hierarchies. However only two items (bathing or having an all-over wash and using stairs) were common to all surveys and the wording of the question differed between surveys. At the level of individual surveys, the FRS contained no ADLs or IADLs but focussed on functional limitations (single body functions) only. The GHS had no items toward the top of the hierarchy (i.e. the last items to be lost) asked of all the sample members and MRC CFAS had few, thus these surveys are more limited in their ability to assess more severe disability (Table 5). The aim is for surveys to contain items that range evenly over the entire hierarchy, thus allowing a range of severity levels to be measured.

We therefore recommend that:

- the major British surveys could agree on a core set of (I)ADL items to be included in each with exactly the same wording of questions and structure
- the FRS could include a few (I)ADL items to complement the measures of functional limitation
- the GHS and BHPS could include two ADL items towards the top of the hierarchy, for instance feeding and using the toilet, that are asked of all the sample members.

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