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LABOUR MARKET AND SOCIAL POLICY - OCCASIONAL PAPERS NO. 44

**AN INVENTORY OF HEALTH AND DISABILITY-RELATED SURVEYS IN
OECD COUNTRIES**

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96356

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SUMMARY

There is strong policy interest in monitoring trends on the prevalence of chronic diseases and disability rates, both nationally and internationally, in light of rising life expectancy and population ageing. However, international comparisons of health and disability survey data are difficult because different instruments are used to measure various health and disability dimensions in national surveys.

This inventory examines the comparability of survey instruments used to measure health and disability in various OECD countries. It extends a similar inventory prepared by the Danish Institute of Public Health for Eurostat in 1999. Some 30 surveys from 23 OECD countries are reviewed in detail and compared. These include a mix of cross-sectional and longitudinal surveys, general health and disability-specific surveys, and surveys covering the entire population and some targeting the elderly population only. The domains covered include selected health conditions (chronic physical conditions, mental health and pain) and various activity limitations (ADL, IADL, limitation in work and social activities, and general limitations in usual activities). The main finding is that, beside a few items related to the prevalence of chronic conditions (both generally and for a few important diseases) and general activity limitations, current differences in measurement instruments limit the comparability of data only to those countries that are using the same instrument (e.g., SF-36, EuroQol-5D, HUI-3 or the WHO-Europe long-term disability list). The main problem is not “what” is being measured in various surveys (since the health dimensions and activity limitations tend to be fairly common) but rather “how” specifically these health conditions and limitations are measured. Unless progress is achieved in using some common instrument(s) to measure these health and disability dimensions, cross-survey (and cross-country) comparisons will remain limited.

RÉSUMÉ

On constate un intérêt politique marqué à mesurer l'évolution de la prévalence des maladies chroniques et de l'invalidité, tant au niveau national qu'international, en raison de l'accroissement de l'espérance de vie et du vieillissement de la population. Toutefois, il est difficile présentement de faire des comparaisons internationales des données des enquêtes nationales sur la santé et sur l'invalidité parce que les instruments de mesure varient d'une enquête à l'autre.

Cet inventaire a pour but d'examiner la comparabilité des instruments de mesure de la santé et de l'invalidité dans les enquêtes nationales de différents pays de l'OCDE. Il prolonge un inventaire similaire préparé par l'Institut danois de santé publique en 1999 pour le compte d'Eurostat. Quelques 30 enquêtes de 23 pays de l'OCDE sont examinées et comparées en détail. Celles-ci comprennent des enquêtes transversales et longitudinales, des enquêtes générales de la santé et d'autres portant spécifiquement sur l'invalidité, et des enquêtes couvrant toute la population tandis que d'autres se concentrent uniquement sur la population âgée. Les domaines couverts incluent divers problèmes de santé (les maladies chroniques physiques, la santé mentale et la douleur) et différents types de limitations d'activités (les activités de la vie quotidienne de type ADL, les activités instrumentales de la vie quotidienne de type IADL, les limitations dans le travail et les activités sociales, et les limitations générales dans les activités normales). La principale conclusion de cet inventaire est que, mis à part quelques items reliés à la prévalence des maladies chroniques (à la fois générale et pour un petit groupe de maladies importantes) et les limitations dans les activités normales, les variations existantes dans les instruments de mesure limitent la comparabilité des données uniquement aux groupes de pays qui utilisent le même instrument (SF-36, EuroQol-5D, HUI-3 ou la liste de questions sur l'invalidité à long terme de l'OMS-Europe). Le problème principal n'est pas ce qui est mesuré dans les différentes enquêtes (puisque'il y a beaucoup de points communs dans les dimensions de la santé et des limitations d'activités qui sont mesurées), mais plutôt comment ces conditions de santé et ces limitations d'activités sont mesurées. A moins que des progrès soient réalisés dans l'utilisation d'instruments de mesure communs dans les enquêtes nationales, les comparaisons entre pays resteront limitées.

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INTRODUCTION

1. Population ageing, along with concerns about the economic and social exclusion of persons of all ages with disabilities, lie behind the strong interest in monitoring trends on the prevalence of chronic health conditions and disability rates in many OECD countries, and to compare policy and programme experiences internationally. Policy-makers and researchers in OECD countries use indicators of health status and disability for a number of different purposes, including:

- i. For monitoring social and health progress over time, within and across countries, including through the construction of summary measures of population health;
- ii. For health and social policy planning, such as making costs projections for various care needs;
- iii. For evaluating the outcomes of various health policies and health care interventions.

2. In particular, there has been in recent years a strong interest across OECD countries in monitoring past trends and making projections of disability rates, particularly among the elderly population, because of their potential impacts on social and health care programmes and related costs (Jacobzone *et.al.*, 2000).

3. This report deals with the measurement of health status and disability in national surveys. It does not address the more specific issue of how disability is defined as an eligibility criteria for various disability-related programmes and benefits¹.

4. In recent decades, a growing number of countries have expanded their effort to use and improve their national health interview surveys, as an important source of information on the overall level and distribution of morbidity and disability in the population. Most OECD countries currently have questions in their national health surveys on self-rated general health and on the prevalence of chronic conditions and disability. Over the last few years, *OECD Health Data* has started to collect statistics on self-rated general health (specifically, the proportion of people reporting their health to be “good/very good/excellent” combined). Data on a few specific chronic conditions (e.g., congenital anomalies) have also been collected, but these have been gathered through national or international disease-specific registers. Data on disability have not yet been included in *OECD Health Data* because of a lack of international comparability of the measurement instruments in national surveys. The expert meeting on ageing and disability held by the OECD on 9-10 December 1999 highlighted the fact that policy discussions on disability-related issues are seriously hampered by the lack of internationally comparable data.

5. The purpose of this inventory is to examine more closely the comparability of survey instruments used to measure health and disability in OECD countries. It builds on an inventory of “Survey data on disability” in EU countries prepared for Eurostat (Gudex *et.al.*, 1999), which compared disability-related items in 15 surveys from 11 European Union countries. This Eurostat inventory showed that although there are significant variations in instruments used to measure health and disability, it is possible to compare data

1. A separate OECD project on “Policies to support and integrate the working-age disabled” will collect information on the definitions of eligibility criteria for various disability-related programmes.

on at least a few “core” items related to chronic illness and general limitations in daily activities across a significant number of countries.

6. This OECD wide inventory covers 30 recent or planned national surveys from 23 OECD countries. It is designed to help fill gaps in *OECD Health Data*, by identifying items for which there are now reasonably comparable data across a fairly large number of OECD countries. It is also designed to promote informed discussions on the use of common items (or modules) to measure health status and disability in upcoming national surveys, for the purpose of improving international comparisons.

7. The structure of this report is the following. We first review briefly the scope and focus of this inventory. This is followed by a brief description of the 30 national surveys included in this report (along with the European Community Household Panel); all the details about the formulation of questions in each of these surveys are provided in Annex 2. Before examining the comparability of measurement instruments across these surveys, we discuss briefly the definitions of disability suggested at the international level and those effectively used in various countries. We also review quickly the development of disability measurement instruments over time and the move towards the development of more generic health measurement instruments, as well as past and current efforts to promote the international standardization of these instruments. The bulk of the report then examines the comparability of survey instruments for each health and disability item covered in this inventory. The final section summarizes the main findings of this review and draws some conclusions on ways to promote more comparable health and disability data.

SCOPE AND FOCUS OF THIS REVIEW

8. Health-related surveys in OECD countries typically include questions on health conditions and the consequences of health problems on functional and activity limitations (i.e., “disability”). The items covered in this inventory of national surveys are, accordingly, divided in two categories:

- i. health conditions; and
- ii. activity limitations.

9. As indicated in Box 1, these domains cover a range of health conditions and activity limitations. The items on health conditions include both the assessment of physical and mental conditions, with a focus on questions related to physical health problems. This inventory does not review the comparability of the question on self-rated general health, as this indicator is already included in *OECD Health Data* with the proper documentation on sources and methods. The items on activity limitations (or “disability”) cover a wide spectrum of activities, with a focus on items related to activities of daily living (ADLs) and general (unspecified) activity limitations due to health problems².

10. The focus of this inventory is on chronic conditions and long-term disability (as opposed to acute conditions or short-term disability), although it is often proving difficult to make a clear distinction between the two. This is particularly the case for measurements of mental health, which tend to focus more on measuring acute (or current) conditions than chronic problems.

2. The term “item” is used here to refer to the individual questions and response formulations used in surveys.

Box 1. Coverage of health and disability dimensions in this report*1. Health Conditions*

- 1.1 General questions asking about the prevalence of chronic conditions but which do not list particular conditions (General prevalence)
- 1.2 Items which list certain conditions (Specific conditions/illnesses)
- 1.3 Mental health, which includes both emotional/psychological well-being (items relating to anxiety, depression, etc) and cognitive ability (items relating to memory, thinking, etc.)
- 1.4 Pain

2. Activity Limitations

This is a broad domain, which moves from the more specific ADL items to more complex activities and general items about activity limitations:

- 2.1 Self-care: mostly relates to traditional ADL items, i.e. washing, dressing, feeding
- 2.2 Mobility: includes the ability to walk, to climb stairs, and to get in and out of bed (transfer)
- 2.3 Communication/senses: relates to the ability to see, hear and talk
- 2.4 IADL (Instrumental activities of daily living): items that specify activities necessary to live independently in the community such as shopping, specific housework chores, preparing meals and handling personal finances
- 2.5 Work/social activities: items that focus on limitations in work or social activities; 'work' here includes housework but only where it is not further detailed, in which case it would come under IADL
- 2.6 General items on limitations in usual activities: where the activities are not further specified beyond a description such as limitation in 'daily (usual) activities', with or without a list of broad examples (e.g. work, household chores, social and leisure activities)

IDENTIFICATION OF SURVEYS

11. Building on the surveys covered in the 1999 Eurostat inventory, a search was extended to include other recent or planned health surveys conducted in OECD countries, mainly through contacts with OECD Health Data national correspondents. A total of 30 national surveys from 23 countries are included in this inventory (see Table 1) along with a review of the European Community Household Panel. It is important to keep in mind that this list of surveys is far from being exhaustive. In many of the 23 countries included in this inventory as well as in countries not covered in this report, other surveys have been conducted (or are planned) which may provide information on health and disability-related issues included in this report. As a result, the national coverage of various health and disability measures noted in this paper should be viewed as a minimum, since other survey data sources may also be available.

12. Table 1 shows that in about half of the OECD countries, national authorities have decided to conduct both general health surveys (covering the entire population) as well as disability-specific surveys

(with the latter often focussing on the elderly population). In other countries, only a general health survey is conducted, often including (short or long) modules on disability-related items. Most of the surveys are conducted regularly, with the time interval between surveys normally varying from 1 to 5 years. Sample size and sampling frames vary across the surveys, in particular on whether or not children and people living in institutions are included. The main characteristics of each survey are reviewed briefly in Annex 2³.

13. In addition to these national surveys, reference to the European Community Household Panel – an annual EU-wide survey conducted since 1994 which contains a short module on health and disability – is made where appropriate. The European Community Household Panel provides a source of comparable data for up to 14 EU countries on some of the general items included in this inventory.

14. Before reviewing in detail the comparability of instruments used in national surveys to measure the various health and disability items, it is useful to discuss briefly first issues related to the definition and measurement of disability and the evolution of disability measurement over time.

3. This report does not focus on comparability issues arising from variations in sample designs and other survey methodologies, with the exception of issues related to population coverage by age group.

Table 1: Summary of national surveys included in the inventory

| Country & Survey no. | Survey title | Contact | Population | Data collection | Internet address |
|---------------------------------|--|--|--|---|---|
| Australia AL01 | National health and nutrition survey | Australian Bureau of Statistics | All; includes institutions | 1995; every 5-6 years | |
| Australia AL02 | Survey of disability, ageing and carers | Australian Bureau of Statistics | People with disability; ≥60 yrs; carers; includes institutions | 1998; every 5 years | |
| Austria AT01 * | Microcensus survey on physical disabilities | Austrian Central Statistical Office | All; includes institutions | 1995; approx. every 10 yrs | |
| Belgium BL01 * | Health interview survey | Scientific Institute of Public Health | All | 1997, 2001 | www.iph.fgov.be/epidemiologie/index4.htm |
| Canada CA01 | National population health survey | Statistics Canada | All; includes institutions | 1998/9; every 2 yrs (longitud.) | http://www.statcan.ca/enquetes_santewww.statcan.ca/health_surveys |
| Canada CA02 | Health and activity limitation survey | Statistics Canada | All; includes institutions | 1991; every 5-10 yrs (planned for 2001) | |
| Czech Republic CZ01 | Health interview survey | Institute of Health Information and Statistics | ≥15 yrs | 1999; every 3 yrs | |
| Denmark DK01 * | Danish health and morbidity survey | Danish Institute for Clinical Epidemiology | ≥16 yrs | 1987, 1994, 2000 | www.dike.dk |
| Finland FIN01 * | Health behaviour among Finnish adult population | National Public Health Institute | 15-64 yrs | 1999, 2000 (annual) | |
| France FR01 * | National health interview survey | INSEE | All; excludes institutions | 1970, 1980, 1991, 2001-2 | |
| France FR02 * | National disability interview | INSEE | All; includes institutions | 1998-2001 | |
| Germany DEU01 | National health examination and interview survey | Robert Koch Institute | 18-79 yrs; excludes institutions | 1998 | |
| Iceland ICE01 | Health and living conditions in Iceland | Statistics Iceland & University of Iceland | 18-75 yrs; excludes institutions | 1998; irregular | |
| Ireland IRE01 | National health and lifestyle survey | Department of Health and Children | ≥18 yrs; excludes institutions | 1998; every 3 yrs | |
| Italy IT01 | Survey of health conditions and use of health services | National Institute of Statistics | All; excludes institutions | 1999-2000; every 4 yrs | |

Table 1: Summary of national surveys included in the inventory (continued)

| Country & Survey no. | Survey title | Contact | Population | Data collection | Internet address |
|--------------------------|--|--|---|-------------------------------|--|
| Japan JP01 | Household survey of physical and mental health | Department of Health Statistics | ≥12 yrs | 2000 | |
| Korea KR01 | National health interview survey | Korean Institute for Health and Social Affairs | | 1995; every 3 yrs | |
| Netherlands NL01 * | Health interview survey | Statistics Netherlands | All; excludes Institutions | Annual | |
| New Zealand NZ01 | New Zealand health survey | Statistics New Zealand | All; excludes institutions | 1996-7 | www.moh.govt.nz |
| New Zealand NZ02 | New Zealand disability survey | Statistics New Zealand | All; excludes institutions | 1996 | |
| Norway NR01 | Health interview survey | Statistics Norway | All; excludes institutions | 1995; every 10 yrs | |
| Portugal PR01 * | Health interview survey | Ministry of Health | All; excludes institutions | 1998/9; every 3 yrs | |
| Spain SP01 * | Survey on disability, impairment and health status | National Institute of Statistics | All | 1999 | |
| Sweden SWE01 * | Survey of living conditions | Statistics Sweden | 16-84 yrs | Annual | |
| Switzerland SZ01 | Swiss Health Survey | Office fédéral de la statistique | ≥15 yrs; excludes institutions | 1997; every 5 yrs | |
| England UK01 * | Health Survey For England | Department of Health | ≥2 yrs; England only | 1995, 1996 (annual) | www.mimas.ac.uk/surveys/hse/hse.info |
| United Kingdom UK02 * | Labour Force Survey | Office for National Statistics | Men 16-64 yrs; women 16-59 yrs; GB + N. Ireland | 1998/99 (annual) | |
| Great Britain UK03 | Disability in Great Britain survey | Office for National Statistics | All; excludes institutions | 1996 | |
| United States US01 | National health interview survey | National Center for Health Statistics | All; excludes institutions | 1998; annual | www.cdc.gov/nchs/nhis.htm |
| United States US02 | National long-term care survey | Duke University | ≥65 yrs; includes institutions | 1999; every 5 yrs (longitud.) | www.cds.duke.edu/nltcs_intro |

* indicates surveys covered in the 1999 Eurostat report

Note: In addition to these national surveys, relevant information from the European Community Household Panel – a survey covering 14 European countries which contains a brief module on health and disability-related matters – is included in this inventory.

DEFINITION OF DISABILITY

15. As it stands, the most commonly used general definition of disability is the one proposed by the WHO in the 1980 International Classification of Impairment, Disability and Handicap (ICIDH-1):

“A disability is any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being” (WHO, 1980, p. 143)

16. In ICIDH-1, disability therefore was defined as the consequences of diseases and other impairments on activity limitations. The ICIDH is currently under revision. One of the objectives of the current revisions is to put more emphasis on the use of more positive language, such as “activity” and “participation” rather than “disability” and “handicap”. The proposed revisions to the ICIDH also include a broadening of the definition of “disability”, to include not only problems related to “activities” but also those related to the “body systems/structure” (previously called “impairment”) and those associated with “participation” (previously called “handicap”) (WHO, 1999, p.12). Although the definition of disability in ICIDH-2 might therefore be broadened, it is clear that a core part of the definition will continue to be centred around activity limitations.

17. To define “disability” as an “activity limitation” is an important conceptual first step; however it raises issues about what “activities” and what levels of “limitation” should be used in implementing the definition.

18. A review of operational definitions of “disability” used by national authorities and researchers in various OECD countries shows that, generally, they have been consistent with the 1980 ICIDH definition of disability as being an activity limitation, although there are important variations in the specific definitions used (Table 2). At least two broad approaches have been used in operationalizing the definition of disability (Mathers, 1997):

- the first approach – the most commonly used -- has been to define disability as a limitation in basic activities of daily living (also referred more narrowly as “functional limitations” or “functional disability”). This definition of disability has tended to focus primarily on problems related to elderly people, although it has been used as well for population-wide estimates of disability;
- the second approach has used a broader definition of disability, based on people reporting limitations in usual activities generally (unspecified). This definition has been used mainly to provide estimates of the prevalence of disability for the entire adult population.

19. In some countries (like Australia and Canada), these two different approaches have, in the past, been combined to provide a single estimate of the adult population with a disability; in other countries (like the United Kingdom) researchers have provided estimates of the disabled population separately using each of these two different approaches⁴.

4. In addition to these two broad approaches, a number of other approaches have been used to define and measure disability. A 1998 REVES paper provides a list of the various types of disability and health expectancy measures that have been estimated in various OECD countries (REVES, 1998).

Table 2: Examples of definitions of 'disability' in OECD countries

| | |
|-------------|--|
| Australia | Disability defined as having one or more of the following conditions lasting more than 6 months: any physical functional limitations (loss of sight, hearing, speech, dexterity), any mental, cognitive or emotional problems, any other chronic conditions or impairments that restrict everyday activities (Australian Bureau of Statistics, 1998) |
| Canada | Disability defined as having one or more of the following conditions lasting more than 6 months: any ADL limitations, any mental or cognitive problems, any limitations in daily activities (at home, at school, at work, etc) due to physical or mental problems (Statistics Canada, 1991) |
| Finland | Disability defined as limitations in work or other daily activities (Valkonen <i>et.al.</i> , 1994) |
| France | Disability defined as a limitation in usual activities generally (work, school, etc). In addition, 'severe' disability defined as people confined to their homes (including all people living in institutions) (Robine et Mormiche, 1993) |
| Germany | Disability based on reported days that people are unable to perform their usual activities due to ill-health or injury (Bruckner, 1997) |
| Korea | Disability defined as one or more ADL limitations (Lee, 1997) |
| Netherlands | Disability defined as people having one or more functional or ADL limitations, based on the OECD long-term disability list (data also broken down by main areas of functional limitations – mobility, seeing, hearing) (RIVM, 1998) |
| New Zealand | Disability defined as having one or more functional limitations (Ministry of Health, 1998) |
| UK | Disability defined as having a general limitation in usual activities due to health problems (Bebbington and Darton, 1996) Disability defined as having a problem or a limitation related to 13 physical and mental health conditions and ADLs (Bebbington, 1992) |
| USA | Disability defined as limitations in both major and secondary activities ('major' activities include able to go to work, go to school, do housework, while 'secondary' activities are activities such as going to church and recreational activities) (Crimmins <i>et.al.</i> , 1997) |

20. Different approaches to defining and measuring disability obviously result in different prevalence rate estimates. For instance, in the case of Great Britain, the more encompassing definition, based on general "limiting long-standing illness", provided an estimate of 21% of the adult population (16 years and over) being "disabled" in 1985 (using the 1985 General Household Survey). On the other hand, the alternative definition of disability, based on a more specific measurement of 13 ADL limitation and health condition items, resulted in an estimate of 14% of the adult population 16 years and over with any disability in Great Britain in 1985, based on the 1985 OPCS surveys of disability (Bebbington, 1992). The latter estimate was even lower for more severe levels of disability calculated on the basis of the various scales attached to each ADL.

21. Even when only ADL-based measures are used to estimate disability prevalence, significant differences have been reported depending on which specific ADL instrument is used (Wiener and al., 1990). These different results highlight the importance of specifying how disability is defined and measured.

A BRIEF HISTORY OF DISABILITY MEASUREMENT

22. Because of its importance for social and health care planning, there has been a proliferation of instruments to measure disability in OECD countries over the last 40 years. The early development of disability indicators focussed on measuring basic functional ability, with a focus on limitations in activities of daily living (ADL); one of the prime examples was the ADL scale proposed by Katz *et.al.* (1963). These ADL instruments were originally aimed at assessing the severe disablement commonly found among institutionalised patients and the elderly population (measuring, for example, independence in bathing, dressing, moving around the house and eating).

23. Later, Lawton & Brody (1969) introduced the notion of Instrumental Activities of Daily Living (IADL) to cover a broader range of activities, including activities required to live independently (such as the ability to manage personal finances, do housework and shopping). These IADLs tend to be more complex and demanding than basic ADLs. They have been used, among other things, to measure less severe levels of disability. One of the disadvantages of IADLs for the purpose of international comparisons is that the performance of these activities tends to be affected by gender-specific roles in various cultures. By comparison, basic ADL items are more likely to reflect pure functional ability.

24. Over the years, a number of other instruments have been developed to measure similar types of ADLs and IADLs. McDowell and Newell (1996) reviewed a sample of 16 such ADL and IADL scales.

25. Somewhat more recently, there has been a strong development of more generic health measurement instruments which contain disability-related components along with items on physical and psychological health. These instruments are referred either as “generic health status measures” or as “measures of health-related quality of life”. Prime examples of such generic instruments include the SF-36 questionnaire (and its abbreviated versions, such as SF-12), the EuroQol-5D instrument and the McMaster’s Health Utilities Index (HUI-3). These instruments are used to provide health profiles which describe health status in a set of scores (e.g., for physical health and mental health in the case of SF-36 or SF-12) or health indices which can summarize health status in a single number (in the case of EuroQol-5D and HUI-3). These generic health measurement instruments are increasingly being used in national surveys to measure health and activity limitations, either as a complement or as a substitute to disability-specific instruments.

Efforts to Promote International Standardization

26. One of the first attempts to standardize disability measures across countries was undertaken by the OECD in the late 1970s, as part of a broad programme to develop social indicators. This effort led to the so-called “OECD long-term disability list” (McWhinnie, 1982). The instrument proposed by the OECD at that time focussed on the measurement of long-term disability, based on an ADL scale covering mobility, self-care and communication items (Table 3). The main objective of the OECD long-term disability list was to allow better international comparisons of disability across countries, through its implementation in national surveys. The instrument was implemented, for a period of time at least, in 8-10 OECD countries. Some countries, like the Netherlands, continue to use this set of questions in their health surveys, while other countries continue to use only selected items. Various assessments of the instrument showed that its focus on basic ADL limitations made it more valid as a measure of severe levels of disability, and most relevant to assess activity limitations for people over 65 (McDowell and Newell, 1996).

27. A more recent attempt to standardize disability measures was undertaken by WHO-Europe, in collaboration with Statistics Netherlands, as part of an on-going effort to standardize methods and

instruments in health interview surveys (WHO-Europe, 1996). WHO-Europe (along with Statistics Netherlands) made recommendations for standardized instruments to measure both short-term disability and long-term disability. As for the OECD list, the WHO-Europe “long-term disability list” is designed to measure disability through ADL-type limitations, covering the same key basic activities related to mobility, self-care and communication (Table 3). This recommended instrument has now been incorporated in some recent surveys in European countries (e.g., Belgium, Czech Republic, Portugal as well as in the 1995 Health Survey for England with some adjustments). Although the proposed instrument does not seem to have been assessed yet to the same extent as its OECD predecessor, it is also likely to prove to be most relevant in measuring relatively severe levels of disability more frequently found in the population 65 and over. The current phase of the WHO-Europe EUROHIS project is attempting to complete the set of recommended instruments for national health surveys, by proposing common instruments related to the measurement of chronic physical conditions, mental disability as well as overall measures of quality of life.

28. The Euro-REVES Network (Réseau espérance de vie en santé), with support from the European Commission, also recently released a set of recommendations for survey instruments in five areas (i.e., physical and sensory functional limitations, ADL limitations, limitations in usual activities, self-rated general health and mental health), as part of an effort to develop a consistent set of health expectancies across European countries (Euro-REVES, 2000). The Euro-REVES recommendations build on previous recommended instruments by WHO-Europe. In the area of self-rated general health and for some aspects of mental health (emotional well-being), the Euro-REVES recommended instruments are the same as those recommended previously by WHO-Europe. In the area of disability, Euro-REVES has proposed to break down the WHO-Europe “long-term disability list” into two components: some of the questions would be used to measure “physical and sensory functional limitations”, while the other questions would be used to measure “ADL restrictions” (see footnote 5 to Table 3). This distinction has been justified on the grounds that “functional limitation and activity restriction refer to different levels of disability leading to different types of consequences on daily life, and towards which different public health actions can be addressed”. Euro-REVES recognizes however that “the distinction [between functional limitation and activity restriction] is not straightforward, especially because existing measurement instruments are most of the time combining these two levels and are relying on apparently similar questions”⁵.

29. The Euro-REVES network also proposes to include four severity levels in functional and ADL limitations (as opposed to three for most of the WHO-Europe questions), by making a clear distinction in the ability to function or carry out basic activities of daily living with or without special aids (such as glasses or hearing aids).

30. In addition, the Euro-REVES network proposes a global (single) question on disability in usual activities, which can be administered to a population of all ages. The proposed instrument is a variation on the question used in many surveys to measure the general prevalence of disability or “limiting long-standing illness” (see section 2.6 below).

5. In the present report, the categories “mobility” and “communication” under activity limitations are roughly equivalent to what the Euro-REVES network has called “physical and sensory functional limitations” while the category “self-care” is roughly equivalent to their more narrow definition of “ADL restrictions”.

Table 3: Reference instruments for measuring functional and ADL disability*

| Katz (1963)¹ | OECD (1982)³ (*Long term disability 10 items minimum core set) | WHO-Euro (1996)⁴ and Euro-REVES (2000)⁵ |
|--------------------------------|--|--|
| | | |
| Dressing | Dress and undress* | Dress |
| Transfer from bed and chair | Get in and out of bed* | Transfer from bed |
| | | Transfer from chair |
| Bathing | | Wash hands and face |
| Toileting | | Get to and use the toilet |
| Feeding | Can you cut your own food* | Feed, including cutting up food |
| Continence | | Continence |
| Nagi (1976)² | | |
| Standing for long periods | | |
| Lifting or carrying weights | Carry an object of 5 kilos for 10 meters* | |
| Going up and down stairs | Walk up and down one flight of stairs without resting* | Stairs (optional) |
| Walking | Walk 400 meters without resting* | Locomotion |
| Stooping, bending or kneeling | Bend down (when standing) and pick up shoe | Retrieval (optional) |
| Using hands and fingers | | |
| Reaching with either/both arms | | |
| | Move between rooms* | Mobility |
| | Speaking* | Speaking (optional) |
| | Hear normal conversation with another* Hear normal conversation with 3 or 4 other persons | Hearing |
| | Read ordinary newsprint* See the face of someone from 4 metres | Seeing |
| | Run 100 meters | |
| | Cut your toenails | |
| | Bite and chew on hard foods | |

* Adapted from Robine and Jagger (1999).

¹“Do you perform” without supervision, direction or personal assistance.

²“Do you have any difficulty.....” ; coded as no difficulty, some difficulty, great difficulty.

³“Can you” ; coded as yes without difficulty, with minor difficulty, major difficulty, unable to do.

⁴“Can you” ; coded as without difficulty, with some difficulty, only with someone to help.

⁵ The last seven items relate to the Euro-REVES recommendations to measure “physical and sensory functional limitations” while the first five items relate to their recommendations for measuring “ADL restrictions” (with some adjustments).

31. In addition to these efforts to promote the use of standard disability instruments, there have also been a number of academic efforts to promote the use of common generic health measurement instruments internationally. These include the EuroQol-5D instrument in Europe (which has been incorporated in the 2000 Health and Morbidity Survey in Denmark, the 2000 Health Survey in Finland, the 2000 Health Survey in Hungary, the 1998 national Health and Lifestyle Survey in Ireland and the 1996 Health Survey for England), the SF-36 instrument and its abbreviated versions initially developed in the U.S. (which have now been included in surveys in Australia, Denmark, Germany, Italy, New Zealand and the United Kingdom) and the Health Utilities Index Mark 3 (incorporated in Canadian health surveys as well as in other non-OECD countries). Table 4 provides an overview of these three leading generic health measurement instruments, while Annex 1 provides the detailed formulation of questions. The three instruments include items on some basic functional ability (e.g., mobility) and other aspects of physical and emotional well-being. They vary however in their coverage of health and disability dimensions, with the HUI-3 putting more emphasis on measuring functional health, while the SF-36 and EuroQol-5D place a greater emphasis on measuring limitations in daily activities. There is also a notable difference in the number of items used in each instrument to measure different activities, with EuroQol being the most parsimonious in using only one item by dimension covered, while the SF-36 and the HUI-3 use several items to measure mobility and other functional/activity limitations.

Table 4: Overview of three generic health measurement instruments

| | EuroQol-5D | SF-36 | HUI-3 |
|-----------------------------|-------------------------------|---|--|
| Number of questions | 5 | 36 | 31 |
| Skip Patterns | No | No | Yes |
| Reference Period | Today | Last four weeks | Usual |
| Number of Dimensions | 5 | 8 | 8 |
| Dimensions | Mobility (1) Self-care (1) | Mobility (9) & Self-care (1) | Mobility (7) Dexterity (4) Vision (5) Hearing (5) Speech (4) |
| | Anxiety/depression (1) | Emotional well-being (5) | Emotional well-being (1) Cognition (2) |
| | Pain/Discomfort (1) | Pain (2) | Pain (3) |
| | | Vitality/energy/fatigue (4) | |
| | Usual activities (1) | Role limitations due to physical problems (4) Role limitations due to emotional problems (3) Social functioning due to physical or emotional problems (2) | |
| | | General health perceptions (6) | |

Note: Numbers in brackets indicate the number of items related to each dimension.

ANALYSIS OF COMPARABILITY BETWEEN SURVEYS

32. Let's turn now to reviewing the comparability of the health and disability-related items across the 30 national survey included in this inventory (and the European Community Household Panel).

Overview of Coverage

33. The specific items used in each survey are listed in annex 2. Table 5 summarises the broad health status and disability-related components covered in each survey. The specific items used in each survey are listed in Annex 2. Traditional ADL components are included in most surveys, with all but 3 surveys including self-care and mobility items, and 24 surveys including the ability to communicate. Just under half of the surveys (14) include IADL items, while about two-thirds of the surveys include items on work/social limitations or a general item on limitations in usual activities (the European Panel also includes a general question on "limiting long-standing illness").

34. Items asking about the presence of specific health conditions (23 surveys) are more common than a broad item on the general prevalence of any chronic condition (11 surveys). Here as well the European Panel includes a general question on the prevalence of chronic conditions. Three-quarters of the surveys (23) include some items on mental health, and half include questions related to pain.

35. We turn now to a more detailed review of the comparability of survey items in each domain.

Table 5: Health and disability-related domains included in selected national health surveys

| | Health conditions | | | | Activity limitations | | | | | |
|-------------------|--------------------|---------------------|--------|------|----------------------|----------|---------------|------|-------------|----------------|
| | General prevalence | Specific conditions | Mental | Pain | Self-care | Mobility | Communication | IADL | Work/Social | General item |
| AL01 | No | √ | √ | √ | √ | √ | No | No | √ | √ |
| AL02 ¹ | No | √ ² | √ | No | √ | √ | √ | No | √ | √ |
| AT01 | √ | √ | No | No | √ | √ | √ | √ | √ | No |
| BL01 | √ | √ | √ | √ | √ | √ | √ | No | √ | √ |
| CA01 | √ | √ | √ | √ | √ | √ | √ | √ | √ | √ |
| CA02 | No | No | √ | No | √ | √ | √ | √ | √ | √ |
| CZ01 | √ | √ | √ | No | √ | √ | √ | No | No | No |
| DK01 | √ | √ | √ | √ | √ | √ | √ | No | √ | √ |
| FIN01 | No | √ | √ | √ | No | No | No | No | √ | No |
| FR01 | No | √ | No | No | √ | √ | √ | √ | √ | No |
| FR02 | No | No | √ | No | √ | √ | √ | √ | √ | √ |
| DEU01 | No | √ | √ | √ | √ | √ | No | No | √ | √ |
| ICE01 | No | √ | No | No | √ | √ | No | √ | √ | No |
| IRE01 | No | √ | √ | √ | √ | √ | √ | No | No | √ |
| IT01 | No | √ | √ | No | √ | √ | √ | √ | √ | √ |
| JP01 | No | No | √ | √ | No | No | No | No | No | √ ³ |
| KR01 | No | √ ⁴ | No | No | √ ⁵ | √ | √ | No | √ | No |
| NL01 | √ | √ | √ | √ | √ ⁶ | √ | √ | No | No | √ |
| NZ01 | √ | √ | √ | √ | √ | √ | No | No | √ | √ |
| NZ02 | No | No | No | No | √ | √ | √ | √ | √ | No |
| NR01 | √ | √ | No | No | √ | √ | √ | √ | √ | √ |
| PR01 | No | √ | No | √ | √ | √ | √ | No | No | No |
| SP01 | No | √ | √ | No | √ | √ | √ | √ | √ | √ |
| SWE01 | √ | No | √ | √ | √ | √ | √ | √ | No | √ ⁶ |
| SZ01 | √ | √ | √ | √ | √ | √ | √ | No | No | √ |
| UK01 | √ | √ | √ | √ | √ | √ | √ | No | No | √ |
| UK02 | √ | √ | √ | No | No | No | √ | No | √ | √ |
| UK03 | No | No | √ | √ | √ | √ | √ | √ | No | √ |
| US01 | No | √ | √ | √ | √ | √ | √ | √ | √ | √ |
| US02 ⁷ | No | √ | √ | No | √ | √ | √ | √ | No | No |

1. Only asked to people with disability or ≥60 years
2. Only asked if a disability has already been identified
3. Specifies due to strain, stress or pressure
4. Respondents are asked if they have 'Diseases of respiratory system', etc, but conditions are not specified
5. It is assumed here that 'Activity of daily living' includes self-care items
6. Only for persons aged ≥55 years (NL01) or old-age pensioners (SWE01)
7. Only for persons aged ≥65 years

1. Health conditions

1.1 General prevalence of chronic conditions

36. Eleven of the 30 surveys (covering 10 different countries) include a general item similar to 'Do you have any long-standing/chronic illness or health problem? Yes/No'. In addition, the ECHP also includes a similar general question on long-standing or chronic conditions, providing a source of data for up to 14 European countries (at least 5 of these countries also use a similar instrument in their national surveys – Austria, Belgium, Denmark, the Netherlands and the United Kingdom – thereby providing at least two sources of survey data).

37. There are at least two main variations in the wording of the question used in various surveys for this item. First, "long-standing/chronic illness" is sometime defined as a condition lasting for 6 months or more, or lasting 1 year or more. Sometime it is not defined at all in terms of duration. It is not known to what extent these variations in the reference period affect the comparability of data across surveys.

38. A second source of variation relates to the explicit reference to mental health problems in the question. For instance, the European Panel explicitly asks whether respondents suffer from any "chronic physical or mental health problem", while most other national surveys refer generally to any "chronic health problem", without specifying whether these are physical or mental. The explicit reference to possible mental health problems in surveys such as the ECHP might be expected to increase (at least slightly) the prevalence of chronic conditions compared with surveys that do not include an explicit mention of such conditions. No one however appears to have done a direct comparison of the impact of the explicit mention of mental health problems with similar questions which do not.

39. Overall, a recent source of comparable survey data on the general prevalence of chronic conditions would seem to be available for at least 20 OECD countries (the 14 EU countries which have administered the European Community Household Panel and Canada, Czech Republic, New Zealand, Norway, Sweden and Switzerland).

1.2 Specific conditions/illnesses

40. While it is useful to have a general indication of the prevalence of chronic conditions in the population, health researchers and policy-makers are also interested to know more specifically the main chronic conditions that people suffer from. In countries like Canada, recent data shows that the reported prevalence of certain chronic conditions, such as asthma and diabetes, have tended to increase over the last few decades (Statistics Canada, 2000).

41. Table 6 shows the 9 chronic conditions most commonly asked in the 23 surveys which contain a check list of specific conditions⁶. Nearly all of these surveys enquire about: high blood pressure, heart disease, asthma or chronic bronchitis (either separately or together in one item), and diabetes, thereby providing a source of survey data on the prevalence of these conditions.

6. The Korean Health Interview Survey has not been included as the conditions do not seem to be sufficiently specified.

Table 6: List of specific chronic conditions commonly asked in national health surveys

| | High blood pressure | Heart disease ¹ | Asthma/ chronic bronchitis | Diabetes | Stroke | Arthritis ² | Allergy ³ | Epilepsy | Stomach/ duodenal ulcer |
|-------------------|---------------------|----------------------------|----------------------------|----------------|----------------|------------------------|----------------------|----------------|-------------------------|
| AL01 | √ | No | √ | √ ⁴ | No | √ ⁴ | √ | No | √ |
| AL02 ⁵ | √ | √ | √ | √ | √ | √ | No | √ | √ |
| AT01 | √ | √ | √ | √ | √ | √ | √ | No | No |
| BL01 | √ | √ | √ | √ | √ | √ | √ | √ | √ |
| CA01 | √ ⁴ | √ ⁴ | √ ⁴ | √ ⁴ | √ ⁴ | √ ⁴ | √ ⁴ | √ ⁴ | √ ⁴ |
| CZ01 | √ | √ | √ | √ | √ | √ | No | √ | √ |
| DK01 | √ | √ | √ | √ | √ | No | √ | √ | √ |
| FIN01 | √ ⁴ | √ ⁴ | √ ⁴ | √ ⁴ | No | √ ⁴ | No | No | √ ⁴ |
| FR01 | √ ⁴ | √ ⁴ | √ ⁴ | √ ⁴ | √ ⁴ | √ ⁴ | No | No | √ ⁴ |
| DEU01 | √ | √ | √ | √ | √ | √ | √ | √ | √ |
| ICE01 | √ | √ | No | √ | √ | No | No | No | No |
| IRE01 | √ ⁴ | √ ⁴ | No | √ ⁴ | √ ⁴ | No | No | No | No |
| IT01 | √ | √ | √ | √ | √ | √ | √ | √ | √ |
| NL01 | √ | √ | √ | √ | √ | √ | No | √ | √ |
| NZ01 | √ | No | √ | √ ⁴ | No | No | No | No | No |
| NR01 | √ ⁴ | √ ⁴ | √ ⁴ | √ ⁴ | √ ⁴ | √ ⁴ | √ ⁴ | √ ⁴ | √ ⁴ |
| PR01 | √ ⁴ | No | √ ⁴ | √ ⁴ | No | No | √ ⁴ | √ ⁴ | No |
| SP01 | √ ⁴ | √ ⁴ | √ ⁴ | √ ⁴ | √ ⁴ | √ ⁴ | √ ⁴ | √ ⁴ | √ ⁴ |
| SZ01 | No | No | No | No | No | No | √ | No | No |
| UK01 | √ | √ | √ | √ | √ | √ | √ | √ | √ |
| UK02 | √ | √ | √ | √ | No | √ | √ | √ | No |
| US01 | √ ⁴ | √ ⁴ | √ ⁴ | √ ⁴ | √ ⁴ | No | √ ⁴ | No | √ ⁴ |
| US02 ⁶ | √ | √ | √ | √ | √ | √ | No | √ | No |

1. Items asking about angina, heart attack (myocardial infarction), coronary heart disease, any/other heart disease
2. Items specifying rheumatoid arthritis or osteoarthritis (arthrosis)
3. Includes items asking about allergy (not specified further), hay fever, food allergies, skin allergy
4. The question specifies that the condition should have been diagnosed by a health professional
5. Only to people with disability or ≥60 years
6. Only for persons aged ≥65 years

42. There are, however, three important variations in the formulation of items across surveys:

- i) Surveys vary as to whether or not they specify that the conditions should have been diagnosed by a health professional. It can be expected that surveys that include the additional criterion that the condition should have been verified by a health professional (such as the National Population Health Survey in Canada and the National Health Interview Survey in the United States) would report lower prevalence rates than those which do not impose that condition (since not all people suffering from a chronic condition may seek verification and help from a health professional).
- ii) Various conditions are sometimes combined together into one group, preventing a more specific decomposition. For instance, some surveys include emphysema with asthma and bronchitis in one item, while others ask about these separately. Another example is that while most surveys ask

separately about angina and heart attack, some combine angina, heart attack, arrhythmia and/or other heart disease as part of one response category only. For the purpose of cross-survey comparisons, some grouping of chronic conditions might therefore be required.

- iii) As is the case for the general question on chronic conditions, the reference period varies between surveys, with some surveys referring to conditions the respondent currently has (AL01, AL02, CA01, CZ01, FR01, PR01, SP01, SZ01, US02), others referring to conditions the respondent has ever had (AL01, DEU01, IRE01, SP01, US01), while others combine these and refer to conditions the respondent currently has or has ever had (DK01, IT01).

43. Despite these variations, the chronic nature of the conditions listed here (excluding possibly stroke and ulcer) and the likelihood of health service contact for treatment of these conditions make it more likely that the data on the prevalence of these various chronic conditions would be comparable across surveys. The reliability of these survey data might also be tested by comparing results with other sources of morbidity data such as administrative records or disease-specific registers.

1.3 Mental health

44. Modules on mental health are increasingly included in national health surveys, with three-quarters of the surveys covered in this inventory including items related to some aspects of mental health and their impact on activity. This reveals a growing interest in measuring mental well-being in population surveys, as an important complement to the measurement of physical health conditions. However, reflecting the traditional emphasis on physical health conditions, international databases such as *OECD Health Data* now only include a few proxy indicators of mental health conditions (e.g., suicide rates).

45. Defining precisely the boundaries of measures of mental health has proven to be difficult. As McDowell and Newell note, “there have been many attempts to specify what is being measured – to distinguish, for example between “distress” and “disorder” and between “psychological”, “emotional” and “mental” well-being... [these] attempts have not always been successful” (McDowell and Newell, 1996, p. 178). In this report, the term “mental health” is used to include both psychological/emotional problems (e.g., nervousness, anxiety and depression) and cognitive functioning (e.g., ability to think and remember).

46. In general, modules on mental health in national surveys have not been designed to diagnose specific mental disorders (such as dementia or Alzheimer disease) or psychological/emotional distress (such as depression). Very specific instruments are available in clinical settings to screen for or diagnose specific mental disorders (these include the Mini-Mental State Examination, the Alzheimer’s Disease Assessment Scale, the Dementia Scale, etc.). Rather, the instruments to measure mental health in national surveys are designed to provide a general indication of the mental health conditions in a population and the likelihood of mental problems.

47. Table 7 shows that more than half of the surveys in this inventory include the measurement of various aspects of psychological/emotional well-being, such as nervousness, depression or the level of vitality/energy, through one instrument or another. The mental health component of the SF-36 questionnaire (5 questions) has been used to measure mental health in a number of national surveys (Australia, Denmark, Germany, Italy, New Zealand and the 1996 Health Survey for England). The General Health Questionnaire (GHQ-12; Goldberg, 1972) – an instrument designed specifically to detect psychological/emotional problems -- has also been used in some national surveys in Europe (e.g., Belgium and England)⁷. In addition, surveys using the EuroQol-5D and HUI-3 also measure

7. The GHQ-12 has also recently been recommended by the Euro-REVES network as a standard instrument to measure mental health in Europe (Euro-REVES, 2000).

psychological/emotional well-being through a single question on anxiety/depression (in the case of EuroQol-5D) and general feelings (in the case of HUI-3).

Table 7: Coverage of mental health and pain items in national health surveys

| | Mental: emotional | | | Mental: cognitive | | Pain | |
|---------------------|-------------------|-----------|--------|-------------------|--------|---------|----------|
| | Nervous | Depressed | Energy | Think | Memory | General | Specific |
| AL01 ¹ | √ | √ | √ | | | √ | |
| AL02 ¹ | √ | √ | √ | | | | |
| BL01 ² | √ | √ | √ | √ | | √ | √ |
| CA01 | √ | √ | √ | √ | √ | √ | |
| CA02 | √ | √ | | √ | √ | | |
| CZ01 | √ | √ | √ | | | | |
| DK01 ¹ | √ | √ | √ | | | √ | |
| FIN01 | √ | √ | | | | | √ |
| FR02 | | | | | √ | | |
| DEU1 ¹ | √ | √ | √ | | | √ | √ |
| IRE01 | √ | √ | | | | √ | |
| IT01 ¹ | √ | √ | √ | | | | |
| JP01 | √ | √ | √ | | | | √ |
| NL01 | √ | | √ | | | | √ |
| NZ01 ¹ | √ | √ | √ | | | √ | |
| PR01 | | | | | | | √ |
| SP01 | | | | √ | √ | | |
| SWE01 | √ | | | | | | √ |
| SZ01 | | | √ | | | | √ |
| UK01 ^{1,2} | √ | √ | √ | | | √ | |
| UK02 | √ | √ | | | | | |
| UK03 | √ | √ | | √ | √ | √ | |
| US01 | √ | √ | | | √ | | √ |
| US02 | | | √ | | √ | | |

1. Indicates the use of the SF-36 (or SF-12) mental health instrument

2. Indicates the use of GHQ-12

48. Differences in item formulations and in scoring procedures limit the comparability of survey responses on mental health (psychological/emotional problems) only to those surveys using the same instrument. Based on the present review, these would include 7 surveys (covering 6 countries) using the SF-36 instrument, a few surveys using the GHQ-12 and other surveys using the EuroQol-5D and HUI-3.

49. Fewer surveys covered in this inventory (only 8) include items related to cognitive functioning, such as the ability to think, to concentrate, to make decisions or to remember. The measurement instruments for these cognitive skills also tend to vary from one survey to another. In some cases, these items are part of a broader, more generic health measurement instrument (such as HUI-3). The current use and degree of harmonization of measures of cognitive functioning in national surveys are lagging behind the measurement of emotional well-being.

1.4 Pain

50. Pain is another important aspect of health that is increasingly being measured in national surveys (Table 7, last columns). About one-third of the surveys covered in this inventory try to measure pain (or discomfort), mainly through the use of a generic health measurement instrument (such as EuroQol-5D, SF-36 or HUI-3). A few surveys might be comparable on that basis, possibly as part of a broader range of health and disability conditions measured through these generic instruments. In other cases, questions are asked about pain in specific parts of the body, such as back pain. Other question formulations also attempt to build a link between pain and limitations in work or other activities (see section 2.5 below).

2. Activity limitations

51. National health surveys typically include a number of items related to activity limitations due to health problems as a way to measure the prevalence of various types of disability in the population. Modules on activity limitations range from a detailed list of ADL items, to fewer questions on IADLs and limitations in work or other social activities, to the use of a single question on general activity limitations. Not surprisingly, disability-specific surveys tend to include a greater number of specific activity limitations than more general social or health surveys.

ADL items

52. The use of ADL items has become commonly used to measure functional and activity limitations, particularly as they relate to the elderly population. Disability measures based on ADL limitations have been found to be a good predictor of the use of a wide range of health care services, such as admission to a nursing home, use of paid home care and hospital services (Wiener and al., 1990). Recent OECD work on trends in disability among the elderly used the fairly common definition of people reporting at least 1 or more ADL restrictions to estimate trends in “severe disability” (Jacobzone *et.al.*, 2000).

53. Consistent with the ADL items included in the 1982 OECD and the 1996 WHO-Europe long-term disability lists, three main types of ADL are typically measured in national surveys: self-care activities (typically covering the ability to wash, dress and feed oneself); mobility (which includes the ability to walk, climb stairs and get in and out of bed); and communication (the ability to see, hear and speak) (Table 8). As noted before, the Euro-REVES network has recently proposed to make a clearer distinction between items related to “physical and sensory functional limitations” (covering more or less the items referred here as “mobility” and “communication”) and those related to “ADL restrictions” (covering the items referred here as “self-care”).

Table 8: Items related to functional and ADL limitations in national health surveys

| | Self-care | | | Mobility | | | Communication | | |
|--------------------|----------------|----------------|----------------|----------|----------------|-----|---------------|----------------|----------------|
| | Wash | Dress | Feed | Walk | Stairs | Bed | See | Hear | Speak |
| AL01 | √ ¹ | √ ¹ | | √ | √ | √ | | | |
| AL02 ² | √ | √ | √ | √ | √ | | | | |
| AT01 | √ ¹ | √ ¹ | | | | √ | | √ | |
| BL01 ³ | √ | √ | √ | √ | √ | √ | √ | √ | |
| CA01 | √ ⁴ | √ ⁴ | √ ⁴ | | | | √ | √ | √ |
| CA02 | √ | √ | √ | √ | √ | √ | √ | √ | √ |
| CZ01 | √ | √ | √ | √ | √ | √ | √ | √ | √ |
| DK01 | √ ¹ | √ ¹ | | √ | √ | √ | √ | √ | √ ⁵ |
| FR01 | √ | √ | √ | √ | √ | √ | √ | | |
| FR02 | √ | √ | √ | √ | √ | √ | √ | √ | √ |
| DEU01 | √ ¹ | √ ¹ | | √ | √ | | | | |
| ICE01 | | √ | √ | | √ | | | | |
| IRE01 | √ ¹ | √ ¹ | | | | √ | | √ | |
| IT01 | √ | √ | √ | √ | √ | √ | √ | √ | √ |
| NL01 ⁶ | √ | √ | √ | √ | √ | √ | √ | √ | |
| NZ01 | √ ¹ | √ ¹ | | √ | √ | | | | |
| NR01 | √ | √ | √ | √ | √ | √ | √ | √ | |
| PR01 | √ | √ | √ | √ | √ | √ | √ | √ | √ |
| SP01 | √ | √ | √ | | √ | | | √ ³ | √ |
| SWE01 ⁷ | √ | | | | √ | √ | √ | √ | |
| SZ01 | | √ | √ | √ | | √ | √ | √ | √ |
| UK01 | √ | √ | √ | √ | √ | √ | √ | √ | √ |
| UK02 | | | | | | | | | √ |
| UK03 | √ | √ | √ | √ | √ | √ | √ | √ | |
| US01 | √ | √ | √ | √ | √ ⁸ | √ | | | |
| US02 ⁹ | √ | √ | √ | √ | √ | √ | √ | √ | √ |

1. Washing & dressing combined in one item

2. Self-care and mobility items only asked if people reported being disabled, based on a broad definition of disability

3. Self-care and mobility items (excluding SF-36 items, which are administered to all respondents) only asked to people 60 years and over, or people 15 years and over who answered positively to previous screening questions on disability

4. Washing, dressing and eating combined in one item

5. Interviewer assessment

6. Self-care, Stairs & Bed items only asked to people 55 years and over

7. Washing & Bed items only asked to people reporting long-standing illness, problems with sight or mobility, or aged 75-84 years

8. Specifies "without using any special equipment"

9. Only for persons aged 65 years and over

54. Although the measurement of this core group of activities is very common, various ADL instruments are used to measure these activities (or functional limitations) in different surveys, thereby preventing (or at least complicating) comparisons of estimates across surveys. There are at least four main variations in the ADL instruments used in various national surveys:

i) Number and type of activities measured

55. The total number of ADL items range from 2 (in the case of the very concise EuroQol instrument) to 10 or more items (in the case of the WHO-Europe long-term disability list and the SF-36). Breaking this down by type of activities, some surveys include, for instance, only one or two questions related to self-care, while others include four questions or more.

56. Differences in the number of items included in a questionnaire is likely to affect disability prevalence estimates. As a general rule, the more activities that are being measured, the larger will be the number of people identified as disabled, if disability is defined as having one or more ADL limitations (Wiener *et.al.*, 1990; Rodgers and Miller, 1997; Madden and Wen, 1999). For the purpose of international comparability, it is therefore important to specify as much as possible the core group of items that should be included in the calculation of ADL-based disability, if no common instrument is used.

ii) Qualifiers/Scales (with/without help or special aids)

57. The use of qualifiers, such as with/without difficulty, with/without help or with/without special aids, are designed to measure the severity of the activity limitation (or disability).

58. A first important definitional issue is whether to count as disabled all the people who simply report having “some difficulty” in performing an activity (usually considered a “moderate” level of disability), only those who report having “a lot difficulty” or only those who rely on someone’s help or are not at all able to perform the activity (more “severe” levels of disability).

59. A second important source of comparability problems in ADL-based estimates is the differences in the qualifiers/scales used in various surveys. There is broad agreement now that the measurement of ADL activities (such as self-care) should distinguish clearly between those people who are able to do the activities on their own compared with those who can only do it with someone’s help (i.e., the inclusion of a “need for human assistance” scale). There is however less agreement on whether response scales for functional and ADL limitations should systematically distinguish between those who can do the activity without special aids and people who can only do it with special aids. The current practice in most surveys (but not all) is to allow the use of common aids, such as glasses and hearing aids, in asking people about their ability to do the activity. The Euro-REVES network recently recommended however a more systematic distinction in the measurement of functional and ADL limitations of people who can do the activity without or with special aids only (Euro-REVES, 2000).

iii) Question formulation (e.g., capacity versus performance)

60. While most surveys use a question formulation related to the “capacity” to do the activity ('can you...?') for ADL items, some surveys use different wording. These include:

- a 'performance' formulation, i.e. 'Do you...?' (in the French version of FR02)
- a 'limit' formulation (used in the SF-36 items), i.e. 'Does your health now limit you in these activities?' (AL01, DK01, GR01, NZ01)
- a 'difficulty' formulation, i.e. 'Do you find [this activity] difficult to do?' (AL02), 'Do you have any difficulty with...?' (CA02, IRE01, SP01, UK03), 'How difficult is it for you to...?' (ICE01, US01, US02).

61. Different item formulations may result in different answers. The issue of whether to use a 'capacity' wording (can you...?) versus a 'performance' wording (do you...?), and the resulting impact on prevalence estimates, has been examined in several studies (Box 2). In general, it seems that a module using a "capacity" formulation might overestimate the actual ability of a respondent to perform such an activity by about 15% to 20%.

Box 2. Measuring Capacity versus Performance in ADL Limitations

There are at least two ways of formulating questions on functional or activity limitations. One is to ask what a person "can" do while the other asks the person what he "does" do.

Anderson *et.al.* (1977) reported that capacity scores from self-completed questionnaires were approximately 20% higher than performance scores obtained through interviews in their study of 1324 San Diego residents. While scores were potentially confounded by the different data collection methods, the difference was attributed to the capacity versus performance formulations. Patrick *et.al.* (1981) also attributed lower (by 15-20%) disability prevalence estimates to the use of capacity formulations. More recently, in a study involving a very small number of physically disabled children, Young *et.al.* (1996) found that on average 17% fewer children 'did do' an activity that they reported they 'could do'.

Van der Wiel *et.al.* (1999) compared responses to capacity and performance items from 272 inhabitants of Leiden in the Netherlands, aged 85 years and over. Good agreement between capacity and performance items were found for slightly more complex activities such as 'shopping', 'telephone use' and 'walking outdoors', while poor agreement was found for basic activities such as 'dressing', 'washing' and 'transfers'. A "capacity" formulation items also identified less disability related to housework activities (such as cleaning and doing the laundry) than a "performance" formulation: 20% of the respondents claimed to be capable of doing these activities, but did not perform them on a regular basis (these respondents were typically men with higher incomes).

Branch and Meyers (1989) noted that the 'do you' formulation assumes that the activity is one that people absolutely need to do or would prefer to do themselves. This formulation appears to be most suitable to measure basic ADLs, such as self-care. However, for more complex IADL-type activities (such as doing housework), the 'can you' formulation is more suitable, since people may be able to perform these activities, but may prefer not to do these themselves. This is particularly relevant for those activities, such as housework, which tend to be gender-based.

iv) Population coverage

62. While some surveys ask the same ADL questions regardless of people's age or regardless of their reported health conditions, several others only asked a set of ADL questions to people above a certain age or people who have identified themselves as suffering from a disability (broadly defined). Amongst the latter group of surveys, the age threshold for asking ADL items varies from 55 years of age (in the case of the Dutch Health Interview Survey) to 60 (in the case of the Belgian Health Survey) to 65 (in the case of the French Health Interview Survey). Other surveys using ADL scales are designed to be administered solely to the elderly population (for instance, the National Long-Term Care Survey in the U.S. covers only the population 65 years and over). For the purpose of international comparisons, a larger number of countries might therefore be compared on ADL-based disability indicators for the population 65 years and over.

63. These are some of the main general variations between the various ADL scales presently used in national surveys. There are also some more specific variations in the instruments used to measure self-care, mobility and communication ability in different surveys. These are briefly reviewed.

2.1 Self-care

64. Twenty-five surveys include self-care items that are either the same or at least roughly similar to those recommended by WHO-Europe (Table 8). The most common are the ability to dress/undress (24 surveys from 19 countries) and to wash (23 surveys from 18 countries); over half of the surveys (18 surveys from 14 countries) also include at least one question on the ability to feed oneself.

65. Beside the type of variations in ADL instruments mentioned above, a few notable variations relate more specifically to how self-care activities are measured across surveys.

i) Combination of items

66. Seven surveys combine 2 or 3 activities into one item (mostly those using the SF-36 question combining the ability to wash and dress). For the purpose of cross-survey comparisons, the core group of self-care activities (washing, dressing, eating) might therefore be combined together into one category of activities. The disadvantage of this approach would be that it would generate comparability problems with those surveys that only ask questions related to one or two of these activities (e.g., the Swedish Survey of Living Conditions).

ii) Qualifiers/Scales

67. As already noted, an important difference in how surveys measure ADL activities such as self-care relates to qualifiers used in assessing the ability to perform the activity.

68. A fairly common approach – recommended in the WHO-Europe instrument - is to use a three-point response scale, along the following lines: “Can you dress/wash/feed yourself? Yes, without difficulty/Yes, with some difficulty/Only with help”. This range of responses allows the construction of a disability scale ranging from 'no disability', to 'moderate' levels of disability, to more 'severe' levels of disability (i.e., people requiring assistance).

69. Different scales are used however in different surveys. A distinction can be made between surveys that use a “difficulty” scale versus those that use a “need for human assistance” scale. Among those surveys that use a “difficulty” scale, some surveys (e.g., those using the OECD list or the SF-36) make a distinction between “no”, “minor” or “major” difficulty, while others only specify “with difficulty” or “without difficulty”. Some surveys use items where the level of difficulty is specified within the question (e.g. Can you...without difficulty? or 'do you have any difficulty...?), with a simple “Yes/No” answer. This is equivalent to a ‘with or without difficulty’ response formulation. The use of a two-point or three-point scale for assessing the degree of “difficulty” in performing an activity can influence disability estimates (Box 3).

Box 3. Variations in ADL limitations in the Netherlands: The effect of various scales

Picavet and van den Bos (1995) examined the impact of differences in survey methodology on the prevalence of ADL-based disability in surveys of elderly people in the Netherlands. They concluded that seemingly minor differences in the structure and wording of the questionnaires resulted in major differences (up to 15.6 percentage points) in prevalence estimates of disability. These differences were mainly associated with the severity level of the disability implied by the wording of questions and answers.

Nine surveys targeted at the Dutch elderly were found to use disability items with response categories that included levels of severity (e.g. 'with difficulty', 'needing help' or 'unable to carry out the activity'). Two particular differences were studied with respect to ADL items: the distinction between minor and major difficulty and the distinction between 'unable to' and 'needing help' to carry out the activity as the most severe level of disability.

Where a distinction between minor and major difficulty was made (6 surveys), more people reported either 'minor' or 'major' difficulty (approximately 24%) compared to the number reporting simply 'difficulty' (approximately 19%), for almost all ADL items. Picavet and van den Bos concluded that the response category 'with difficulty' does not simply cover both minor and major difficulty, but instead represents something in between; as a result, the prevalence estimates obtained through these two different types of item formulation are not strictly comparable.

Where a distinction was made between 'unable to' (2 surveys) and 'only with help' (4 surveys) as the most severe level of disability, considerable variations were also seen in the proportion of respondents suffering from the most severe disabilities. These terms are therefore not interchangeable.

70. Consistent with the WHO-Europe recommended instrument, many surveys offer a "need for human assistance" response ('Only with help'), often as the most severe limitation (in some cases, they also offer an "unable to" category as the most severe restriction). A number of surveys however make no reference at all to help from others in their items (e.g., AL01, DEU01, ICE01, NZ01, SP01); they typically include "a lot of difficulty" as the most severe limitation.

71. Jette (1994) reported some large discordance between results coming from 'difficulty' scales and those coming from 'need for human assistance' scales. Comparing prevalence estimates of disability in a sample of 1818 adults aged 70 and over, Jette found that measures using a 'need for human assistance scale' produced lower estimates of disability, ranging from 1.6% persons disabled in walking to 8.6% disabled in bathing. By comparison, the use of a 'difficulty' scale produced estimates up to 5 times greater, especially for disability in walking (8.1%) and getting in and out of bed/chair (13.4% versus 3% obtained through a "need for human assistance" scale). The proportion of people reporting "difficulty" in bathing (12.2%) was also significantly higher than those reporting a "need for assistance" (8.6%). Differences across scaling methods were smaller in areas such as dressing and eating.

2.2 Mobility

72. Twenty-four surveys include mobility-related items (Table 8). The most common activities measured are the ability to climb stairs (21 surveys from 17 countries), to walk (19 surveys from 15 countries) and to get in and out of bed (18 surveys from 16 countries).

73. There are at least two types of variations regarding mobility items.

i) *Intensity of activities*

74. Beside differences in the number of activities that are being measured, there are also some variations in the intensity of the specific activity measured. This is particularly the case with respect to the ability to walk where there are significant variations across instruments regarding walking distance (ranging from a few steps, to 100 or 200 metres or more). Some instruments also include the specification to walk a certain distance “without resting” while others don’t.

ii) *Qualifiers*

75. As discussed for self-care activities, mobility items in different surveys vary with respect to whether or not they specify only “with/without difficulty” or also “with/without help”. This raises again the issue of comparability of data, particularly between the majority of surveys that use a “need for human assistance” scale versus those which use a ‘difficulty’ scale.

76. In addition, there are differences in the treatment of special aids across surveys. Most surveys do not specify whether the person is able to walk or climb stairs with special aids if necessary. Only 3 of the 16 surveys which include an item on walking ability specify 'with a walking stick [or other aids] if necessary' (IT01, UK01, UK03). On the other hand, the National Health Interview Survey in the US specifies whether people can walk and climb stairs 'without using any special equipment'. Allowing the use of various technical aids should obviously result in a lower percentage of respondents being defined as disabled compared with those surveys which do not allow the use of those technical aids.

2.3 *Communication*

77. Twenty surveys include seeing, hearing and speaking items more or less similar to those recommended by the OECD and WHO-Europe (Table 8). The most common items relate to hearing (18 surveys from 16 countries), seeing (16 surveys from 13 countries), while 12 surveys from 10 countries also include items related to speaking ability.

78. Here as well there are two types of variations in the instruments used to measure these abilities.

i) *Specific reference situation*

79. Various questions can be used to measure eyesight in population surveys. The most common way is to ask people whether they “can see well enough (with glasses or contact lenses if necessary) to recognize a face at a distance of four metres”. This specific item was included in both the OECD and WHO-Europe list; it is designed to measure the ability to see at a distance. The OECD list also included another item which continues to be used in several surveys related to the ability “to read ordinary newspaper”; this question is designed to measure eyesight at a close distance. These two different questions measure different aspects of the ability to see; they cannot be taken as being interchangeable.

ii) *Qualifiers/Scales*

80. Some surveys specify 'without difficulty' in the questions related to seeing and hearing (DK01, SP01, SWE01, UK03, US02), with a simple “yes/no” response category, while others offer various levels of difficulty (no/some/a lot of difficulty) in the answer categories (FR01, FR02, IRE01, NL01, SZ01). This variation might create again problems of data comparability.

81. As noted before, most surveys do not try to make a distinction between people who are able to see or hear with or without a special aid, by including in the question “with glasses/contact lenses/hearing

aids if necessary". The Irish National Health and Lifestyle Survey appears to be an exception as it stands in specifying "without a hearing aid" in measuring hearing capacity.

Summary on ADL Items

82. This inventory confirms that ADL scales are commonly used to measure various activity limitations, in particular as they relate to the elderly population. Table 8 has shown that there is a core group of activities that are being measured across most surveys. These include activities related to self-care, mobility and communication.

83. However, a number of different ADL instruments are now being used in national surveys, resulting in a lack of data comparability. These ADL instruments vary notably in terms of the number of specific activities being measured and the scales used in assessing the degree of activity limitations (e.g., "difficulty" versus "need for human assistance" versus "need for special aid" scales). As a result, the only ADL-based disability estimates that are strictly comparable across surveys (and countries) are those using the same instrument. Based on this inventory, these would include the group of countries using:

- the WHO-Europe "long-term disability" instrument (Belgium, Czech Republic, Portugal and the 1995 Health Survey for England);
- the SF-36 instrument (Australia, Denmark, Germany, Italy, New Zealand and the 1996 Health Survey for England);
- the EuroQol-5D instrument (Denmark, Ireland and the 1996 Health Survey for England).

2.4 IADL

84. Instrumental Activities of Daily Living (IADL) comprise a number of activities beyond ADL which are considered important for people to live independently in the community. Although reported limitations in IADL may reflect somewhat less severe levels of disability than limitations in ADL, such limitations may nonetheless express a need for social support.

85. Fourteen surveys (from 11 countries) include at least some IADL items, with the majority asking about the ability to do housework, shopping and prepare meals (Table 9). Other IADL items are also used in different surveys, complicating cross-survey comparisons, particularly when IADL 'disability' is defined as being limited in at least one of these activities. The greater the number of IADL activities, the more likely it is that someone will be limited in at least one of these activities.

86. Beside the number of IADL items, another difference relates to the intensity of the activity measured across surveys. For instance, some surveys refer to "light" housework while others mention "heavy" work.

87. On the other hand, nearly all IADL items include a 'need for human assistance' scale (in either the question or the response categories), except for ICE01 and SP01 which only measure the degree of difficulty.

88. Taking the above into account, a dozen surveys (from 11 countries) might provide reasonably comparable data of IADL limitations, if these focus only on the more common activities measured across surveys (i.e., housework, shopping, meal preparation).

Table 9: IADL and more general activity limitation items in OECD surveys

| | IADL | | | | | |
|--------------------|----------------|----------------|------------------|----------------|----------------|----------------|
| | Housework | Shopping | Meal preparation | Work | Social | General items |
| AL01 | | | | √ | √ | √ |
| AL02 | | | | √ ¹ | √ ¹ | √ ¹ |
| AT01 | √ | √ | √ | | √ ² | |
| BL01 | | | | √ | √ | √ |
| CA01 | √ | √ | √ | √ ² | | √ ² |
| CA02 | √ | √ | √ | √ ² | | √ ² |
| DK01 | | | | √ | √ | √ |
| FR01 | | | √ | | | |
| FR02 | √ | √ | √ | √ | | √ |
| DEU01 | | | | √ | √ | √ |
| ICE01 | √ | | | √ | | |
| IRE01 | | | | | | √ ² |
| IT01 | √ | √ | √ | √ | √ | √ |
| KR01 | | | | | √ ³ | |
| NL01 | | | | | | √ |
| NZ01 | | | | √ | √ ² | √ ² |
| NZ02 | √ | √ | √ | √ | | |
| NR01 | √ | √ | | | | √ ² |
| SP01 | √ ² | √ ² | √ ² | | √ ² | √ |
| SWE01 ⁴ | √ | √ | √ | | | √ |
| SZ01 | | | | | | √ |
| UK01 | | | | | | √ |
| UK02 | | | | √ | | √ |
| UK03 | √ | √ | √ | | | √ ² |
| US01 | √ | √ | | √ | √ | √ |
| US02 ⁵ | √ | √ | √ | | | |

1. Work item asked if the respondent is disabled and employed; Social and General items asked if disabled and aged ≥15 yrs
2. Item specifies restrictions due to condition lasting at least 6 months (CA01, CA02, NZ01) or 1 year (SP01)
3. Only asked if a person has mobility problems
4. Only asked if old-age pensioners or if the person has a long-standing illness, reduced sight, mobility problems or aged 75-84 years (IADL items)
5. Only for persons aged ≥65 years

Illustrative types of questions

IADL:

Housework: “Can you do your own heavy/light housework/cleaning/laundry” or, turn the other way around, “Do you need help with...?”

Shop: “Can you do your own shopping?” or “Do you need help with...?”

Meals: “Can you prepare your own meals?” or “Do you need help with...?”

Work: “Does your health/illness/chronic condition restrict/limit/interfere with your work?”

Social: “Are you restricted in your social activities due to your health/illness/chronic condition?”

General: “Are you restricted in your daily activities due to your health/illness/chronic condition?”

2.5 Limitations specific to work and social activities

89. Seventeen surveys (from 13 countries) include items that specifically ask about limitations in work and/or social activities (Table 9). Seven of these surveys (6 countries) use the SF-36 items (AL01, AL02, DK01, DEU01, IT01, NZ01 and UK01), which include eight items about the effect of health problems (both physical and psychological) on work and social activities and an item on the effect of pain on work (including housework). Most other surveys use a more general formulation along the lines 'Does your health affect your social activities/work?', with a simple "Yes/No" answer. One survey (AT01) refers to the need for help in carrying these activities, while three surveys enquire about the level of difficulty (ICE01, SP01 and US01).

90. With respect to the reference period, except for those surveys using SF-36 items, which refer to the previous 4 weeks, limitations in work and/or social activities relate to the current situation.

91. The comparability of survey instruments to measure limitations in work or other social activities appear to be limited to those using a similar instrument (e.g., either the SF-36 or a more general question formulation with a "Yes/No" response).

2.6 General item on limitation in usual activities (also referred as global activity limitation)

92. A general question (or a few questions) on limitations in usual activities is designed to provide a summary measure of people who report being disabled because of health problems. In most countries where data based on this indicator is available, between 15% and 25% of the adult population report being limited in their usual activities because of health problems. Because the question does not specify the type of activities, it can be administered to a population of all ages. However, the general (unspecified) nature of the question also means that responses to it are more subjective and more subject to reporting biases than responses to more specific questions on well-defined activity limitations.

93. Twenty surveys (from 16 countries) include at least one question on general limitations in usual activities (Table 9; last column). The European Community Household Panel also includes a general item on "limiting long-standing illness", thereby broadening the number of countries for which comparable data might be available. The most common formulation refers to whether or not usual activities are limited (or hampered/restricted/affected) due to health problems (BL01, CA01, CA02, IRE01, NL01, NR01, SZ01, UK02, UK03)⁸.

94. There are at least three sources of variations however in the specific item formulation used across surveys.

i) Qualifiers

95. A first important source of variations across surveys relates to the response formulation. Three types of response scales are offered to the general question on activity limitations:

- a number of surveys offer a simple "Yes/No" answers to the question "are you limited in your usual activities due to a health problem?" These surveys include the two Canadian health surveys, the New

8. The Euro-REVES network recently proposed the use of a new global activity limitation instrument, in national surveys, that is: "For the past 6 months or more have you been limited in activities people usually do because of health problem? Yes, strongly limited/Yes, limited/No, not limited" (Euro-REVES, 2000).

Zealand Health Survey (NZ01), the Spanish survey, the Health Survey for England (UK01) and the U.S. National Health Interview Survey (US01).

- other surveys offer a “difficulty” scale, typically ranging from “Yes, severely/Yes, to some extent/No, not limited”. These include surveys using the EuroQol-5D instrument (e.g., Denmark, Ireland), the Norwegian Health Interview Survey, the Swedish Survey of Living Conditions, as well as all the national results based on the European Community Household Panel.
- a few other surveys offer a “chronic” scale, with responses ranging from “Continually/At intervals/Not or seldom”, to measure to what extent the limitation in usual activities tends to be chronic or temporary. Such a response formulation is used in the Belgian and Dutch Health Interview Surveys.

96. The effect of using a “difficulty” scale versus a simple “yes/no” scale on the comparability of results across surveys hasn’t been fully examined yet. Ideally, such a comparison should be done directly in a single study, using the same population sample and the same survey method. It is possible however to obtain a general sense of the comparability of results, by comparing the national estimates from the European Community Household Panel (using a “difficulty” scale) with those from countries which also conduct a national survey using a simple “yes/no” scale, such as the Health Survey for England. The data from these two different item formulations appear to be generally consistent, with 25% of people in the United Kingdom reporting being hampered in their usual activities due to health problems in the 1996 ECHP (with 8% reporting being severely hampered and 17% being hampered to some extent), compared with 26% of people responding “yes” to the question about “limiting long-standing illness” in the 1996 Health Survey for England. If anything, one might have expected higher “disability” rates from the ECHP item formulation, given that its scale is designed to capture both severe and more moderate limitations in usual activities. Further work is required to examine whether and how estimates from a binary (yes/no) response need to be adjusted to be comparable with estimates from a “difficulty/severity” scale.

ii) Number of questions and degree of specificity

97. Another important source of variation across surveys relates to the number of questions used to measure usual activity limitations generally, and the specification of the health problems causing the activity limitation. Surveys which use the SF-36 items (AL01, AL02, DK01, DEU01, IT01, NZ01) include 4 questions related to the effect of physical health on activity limitations, and 3 items concerning the consequences of any emotional problems on limitations in usual activities. This compares with only one general question on activity limitations for most other surveys. The results coming from more specific question formulations are not likely to be comparable with those coming from a single (more general) item.

98. Some surveys (such as CAN01 and CAN02) specify broad categories of activities in their question formulation, such as activities “at home”, “at work” or “at school”. This formulation may not pose significant problems of comparability with those surveys that do not specify any activities, if the estimates for the various broad types of activities can be added into a summary estimate of overall activity limitations: (as is done in Canada).

iii) Reference period

99. There is also some variation in the reference period mentioned in the question. While most of the surveys refer to the current situation, an alternative formulation found in those surveys using the SF-36 asks about limitations in usual activities during the past month.

100. Finally, a more minor source of variation concerns the treatment of medication in the item formulation. The U.K. Labour Force Survey (UK02) appears to be unique in stipulating that general activity limitations should be answered ignoring the effect of any medication or treatment. Such a

specification can be expected to increase the percentage of people reporting “limiting long-standing illness” from that survey.

101. In summary, the comparability of a general question on limitations in usual activities is limited by the use of different response scales. Further work is required to determine to what extent estimates based on a “difficulty/severity” scale for this question (mainly used in European countries and in the European Panel) are comparable with estimates from a simple binary (“yes/no”) response scale (presently used mainly in non-European countries like Canada, New Zealand and the U.S.).

SUMMARY AND CONCLUSIONS

Main Findings

102. The main finding of this review of 30 surveys from 23 OECD countries (plus the European Community Household Panel) is that, beside a few general items related to the prevalence of chronic conditions and general limitations in usual activities, differences in measurement instruments in domains such as mental health and specific activity limitations seriously limit the comparability of data to only those sub-group of countries using the same measurement instrument. Table 10 summarizes the degree of comparability of different survey items, based on this inventory and on information already collected in OECD Health Data with regard to self-rated general health.

Table 10. Comparability/availability of items addressing health and disability in national surveys

| Items | Comparability/availability |
|--|-------------------------------------|
| Self-rated general health ¹ | + |
| Chronic conditions: General (yes/no) | + |
| Chronic conditions: Disease-specific | + |
| | (only for a core group of diseases) |
| Mental health: Psychological/Emotional | - |
| Mental health: Cognitive | - |
| Pain | - |
| Disabilities: ADL | - |
| Disabilities: IADL | - |
| Disabilities: General (yes/no) | + |

+: reasonably comparable/available - : comparability/availability limited

1. The comparability of survey questions on self-rated general health hasn't been covered in this report; the information on this item is available in the "sources and methods" section of *OECD Health Data*.

103. The main problem in terms of comparability is not “what” is being measured in the various surveys, since there tends to be a fairly common group of health domains and activity limitations measured across surveys. Rather, the problem for comparability purposes lies in “how” specifically these health conditions and activity limitations are being measured. This is probably best illustrated by the review of activities of daily living (ADL) items in different surveys. While most surveys use some ADL items to measure disability rates in the population (in particular amongst the elderly population), the use of various ADL scales (e.g., the OECD long-term disability list, the WHO-Europe long-term disability instrument or the SF-36 instrument) limits the comparability of data only to those group of countries using the same instrument.

104. Based on this inventory, it would seem possible to now collect reasonably comparable data for a fairly large number of OECD countries for the following health and disability indicators:

- i. General prevalence of chronic conditions (Yes/No)
- ii. Prevalence of a few specific chronic conditions (e.g., high blood pressure, heart disease, asthma and chronic bronchitis, and diabetes), although the reliability of survey data on these specific conditions should be tested by comparing survey estimates with other sources of morbidity data
- iii. General activity limitations (Yes/No)

105. Even for these few (mainly general) items, the comparability of data would be improved by moving towards the use of common instruments in existing or new national (and international) surveys.

Approaches to improve the comparability of health status and disability-related data

106. There is keen interest in many OECD countries to monitor the health status of the population and disability rates, both nationally and across countries, to promote informed policy discussions on the impact of population ageing and the integration of persons with disabilities in social and economic activities. Three broad approaches might be pursued to achieve greater international comparability of health status and disability-related indicators:

- i. developing and administering international surveys
- ii. encouraging the use of common instruments in national surveys
- iii. applying some “post-harmonization” methods (to adjust for variations in survey instruments)

i. Development and administration of international surveys

107. Probably the surest way to obtain internationally comparable data on health status and disability is through the development and administration of a common international health-related survey across all participating countries. But this is also the most ambitious and resource-intensive approach. The European Community Household Panel (although it contains only a few general questions on health and disability issues) provides an example of such an international survey which has been developed and administered at the European level. The development of an *ad hoc* module on disability to be included in the European Union Labour Force Survey of 2002 will provide another source of comparable data on a few disability-related items for the working-age population at the European Union level.

108. At the OECD level, the International Adult Literacy Survey provides an example of a co-operative international effort involving national statistical agencies, research institutions and the OECD Secretariat to develop and administer a common survey, thereby providing comparable data in the area of education, training and literacy skills across the 20 participating countries. Such a survey however requires a substantial and sustained commitment of time and resources from all partners.

ii. *Encourage the use of common instruments in national surveys*

109. A “second best” approach to developing more comparable health status and disability indicators relies on the willingness of national statistical agencies to use some common instrument(s) to measure at least a few key aspects of health and disability in upcoming national surveys.

110. At the European level, a number of projects have recently been completed or are presently underway to further develop and recommend common instruments to measure health and disability in national surveys. These projects include the past and current phases of the EUROHIS project, led by WHO-Europe and funded by the European Commission, and the recent Euro-REVES network project to develop a consistent set of health expectancies in Europe (also funded by the European Commission). Table 11 summarizes the instruments recommended thus far through these two European projects for selected health and disability indicators. While these European projects are proposing the use of these instruments, the ultimate success of these efforts to promote data comparability will depend on their actual implementation in national surveys. We have noted that the 1996 WHO-Europe recommended instruments to measure mental health and long-term (ADL) disability have been used in a few recent surveys in Europe, while the Euro-REVES recommendations on the measurement of disability (both ADL-related limitations and general disability) are too recent to have been implemented.

Table 11. Recommended instruments for selected health and disability items in Europe: WHO-Europe (1996 and current EUROHIS project) and Euro-REVES (2000)

| Items | Recommended instrument(s) |
|--|---|
| General health status | WHO-Europe (1996): “How is your health in general? very good, good, fair, bad, very bad” |
| Chronic conditions: General (yes/no) | WHO-Europe (under development in EUROHIS) |
| Chronic conditions: Disease-specific | WHO-Europe (under development in EUROHIS) |
| Mental health: Psychological/Emotional Problems | WHO-Europe (1996) and Euro-REVES (2000): General Health Questionnaire– 12 items (see Goldberg, 1972) |
| Disabilities: ADL (including both functional and activity limitations) | WHO-Europe (1996): Long-term disability instrument (13 questions plus 3 optional) Euro-REVES (2000): proposes adjustments to WHO-Europe long-term disability instrument (e.g., breakdown of items to measure “physical and sensory functional limitations” versus “activity restrictions”, and greater range of severity levels) |
| Disabilities: General (yes/no) | Euro-REVES (2000): “For the past 6 months or more have you been limited in activities people usually do because of a health problem? Yes, strongly limited/ Yes, limited/No, not limited” |

111. In addition, the present inventory has identified three leading generic health status measurement instruments which have been used to measure key aspects of health status and activity limitations in more than one national survey. These are:

- i. the SF-36 instrument (or its abbreviate versions), which has been included in national surveys in different parts of the OECD (Australia, Denmark, Germany, Italy, New Zealand and the 1996 Health Survey for England);
- ii. the EuroQol-5D instrument, which has been included in the surveys of some European countries (Denmark, the 2000 Health Survey in Finland, the 1998 National Health and Lifestyle survey in Ireland and the 1996 Health Survey for England as well).
- iii. the HUI-3, which has been included in health surveys in Canada as well as in a few other non-OECD countries (e.g., Singapore).

112. These generic health measurement instruments have become increasingly used as a way to provide summary health profiles (in the case of the physical and mental health components of the SF-36 or SF-12) or health indices which can summarize health status in a single number (in the case of EuroQol-5D and HUI-3). Table 4 provided an overview of the coverage of these leading generic instruments. The main differences between these instruments relate to the number of specific health and disability dimensions measured and the emphasis placed on measuring functional health status as opposed to measuring general activity limitations.

113. A first important strategic issue in moving towards the use of common instruments across national surveys is whether to encourage the use of *existing* measurement instrument(s) or whether to develop and recommend *new* instrument(s). As a general rule, given the proliferation of health measurement instruments in recent years and the increasing number of recommendations for “standard” instruments, it would seem preferable and more expeditious to build as much as possible on current leading instruments rather than start with the construction and recommendation of new ones, unless it can be shown that such new instrument(s) would be superior in measuring certain aspects of health or easier to implement in national surveys.

114. A number of guiding criteria can be used to select recommended measurement instruments whether these are generic instruments or more specific ones. In addition to meeting the basic criteria of validity and reliability, the choice of “standard” measurement instruments to be recommended for use in national surveys might be based on the following three criteria:

- saliency: the instrument should measure what are considered to be important dimensions of health and disability across countries;
- conciseness: the instrument needs to achieve a balance between measuring the multi-dimensional nature of health and/or disability and the practical requirement to be as concise as possible to facilitate implementation in national surveys;
- cross-country comparability: the instrument should contain questions/items that are the least susceptible to being influenced by social and cultural differences across countries.

115. An on-going dilemma in choosing survey instruments is to strike a balance between comprehensiveness (in terms of covering all important aspects of health and activity limitations in sufficient detail) and conciseness (to facilitate survey implementation). Another important dilemma or constraint faced by national statistical agencies in moving towards the adoption of common measurement instrument(s) in national surveys is the need to maintain the continuity of existing time series. This is

obviously not a constraint for new surveys. In the case of surveys that have been conducted for some years, an interesting approach is the one that has been adopted in the 2000 Health and Morbidity Survey in Denmark, whereby a new leading measurement instrument (EuroQol-5D) has been administered for at least some sub-samples of the population, in addition to the items used in previous Danish health surveys (including the SF-36 instrument which has been included in both the 1994 and 2000 Danish surveys). This “juxtaposition” approach allows both the maintenance of existing (national) time series and greater international comparability with countries using the same common measurement instrument(s).

116. This approach obviously faces its own limitation, since there are limits to the overall number of questions that can be included in national surveys. Conciseness will be a definite advantage for promoting the diffusion of leading instruments across national surveys.

117. An important issue related to promoting the use of common measurement instruments across countries is to address the problems associated with finding the equivalent translation and adaptation of questions and answers in various languages and for various cultures. In the past, not enough attention has been paid to the equivalent translation of recommended instruments for use in different countries.

iii. Application of post-harmonization methods

118. The third possible method for more comparable data across surveys is to try to use some “post-harmonization” methods, to adjust for existing variations in survey instruments and also to try to correct for any systematic reporting biases.

119. In this report, we have reviewed some of the available evidence on the effect of various item formulations on the comparability of estimates. For instance, we have noted that the effect of a “capacity” formulation for ADL items may lead to estimates of the ability of people to carry out these activities about 15% to 20% higher than those obtained from a “performance” formulation. We have also reviewed the influence of using various scales (e.g., “difficulty” versus “need for assistance” scales) in measuring ADL-based limitations (with evidence from a study of elderly people in the U.S. suggesting that for some activities, such as walking and getting in and out of bed, a “difficulty” scale may produce disability estimates up to five times greater than a “need for human assistance” scale).

120. It may be possible to make some adjustments to survey estimates that use different item formulations, to make them more comparable with data from other surveys. However, this “post-harmonization” approach will be limited to areas where sufficient studies have been done about the precise effect of differences in item formulations, to come up with an acceptable adjustment factor. In cases where an adjustment factor is derived from the study of the response pattern of one group of the population in one country, questions can be raised about the extent to which these results can be extended (generalized) to other population groups in that country and to populations in other countries. To become fully acceptable, these adjustment factors would need to be validated across various populations through direct studies of the effect of differences in item formulations.

121. “Post-harmonization” efforts often lead to a search for the “lowest common denominator” across surveys. This is particularly the case for the various scales used to assess the degree of activity limitations, where the lowest common denominator is often to collapse responses in a simple “Yes/No” category. In some cases, there is no evidence that such a move towards the “lowest common denominator” affects the comparability of results, while in other cases there is some evidence that it might.

122. This report has not addressed another important issue regarding the cross-country comparability of survey data, that is, the possibility of systematic reporting biases due to social or cultural differences in response patterns across countries. Over and above differences in survey questions, serious reservations

have been expressed by WHO-Geneva and others about the overall reliability of survey data to allow meaningful comparisons of health and disability across populations. The general concern is that people's *self-report* of their health may suffer from a number of reporting biases (e.g., differences in health knowledge, expectations and norms, or differences in the availability of disability-related programmes), thereby providing some misleading information about their *true* health status. WHO-Geneva has started to use different statistical techniques (e.g., factor analysis, Item Response Theory model) to try to correct for reporting biases at the individual and population level, by re-scaling survey responses (Sadana and al., 2000). Although the initial results of these attempts to improve the comparability of survey data across populations have been disappointing, WHO-Geneva intends to pursue its effort to "calibrate" survey data to make them more comparable across populations.

123. In general, any "post-harmonization" methods will be facilitated if instruments used in different surveys are as similar as possible, so that the instruments are indeed measuring more or less the same health condition or activity limitation. Therefore, efforts to harmonize input (survey questions) and output (adjustments to variations in survey questions or for reporting biases) are complementary and need to be carried out simultaneously, if we are to improve the international comparability of health and disability data.

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ANNEX 1: SELECTED GENERIC HEALTH MEASUREMENT INSTRUMENTS

This Annex provides the item formulation for three leading generic health measurement instruments:

1. EuroQol (EQ-5D)

| | |
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2. McMaster's Health Utilities Index (HUI-3)

EuroQol (EQ-5D) (Brooks *et.al.*, 1996)

Respondents are asked to choose one statement from each component below, which best describes their current health state:

Mobility

- I have no problems in walking about
- I have some problems in walking about
- I am confined to bed

Self-care

I have no problems with self-care
I have some problems washing or dressing myself
I am unable to wash or dress myself

Usual activities (e.g. work, study, housework, family or leisure activities)

I have no problems with performing my usual activities
I have some problems with performing my usual activities
I am unable to perform my usual activities

Pain/discomfort

I have no pain or discomfort
I have moderate pain or discomfort
I have extreme pain or discomfort.

Anxiety/depression

I am not anxious or depressed
I am moderately anxious or depressed
I am extremely anxious or depressed

MOS 36-item Short Form General health survey (SF-36) : Items from the UK English version¹

(Ware and Sherbourne, 1992, Jenkinson et al 1993)

Mobility & Self-care

Does your health limit you in these activities:

Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports?

Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf?

Lifting or carrying groceries? Climbing several flights of stairs? Climbing one flight of stairs? Bending, kneeling or stooping? Walking more than a mile? Walking half a mile? Walking 100 yards? Bathing or dressing yourself?

Yes, limited a lot/Yes, limited a little/No, not limited at all.

Daily activities

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities, as a result of your physical health? Y/N

- a) cut down on the amount of time you spent on work or other activities
- b) accomplished less than you would like
- c) were limited in the kind of work or other activities
- d) had difficulty performing the work or other activities (e.g. it took extra effort)

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities, as a result of any emotional problems (such as feeling depressed or anxious)? Y/N

- a) cut down on the amount of time you spent on work or other activities
- b) accomplished less than you would like
- c) didn't do work or other activities as carefully as usual

During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

Not at all/Slightly/Moderately/Quite a bit/Extremely

Emotional well-being

How much time during the past month:

Did you feel full of life? Have you been a very nervous person? Have you felt so down in the dumps that nothing could cheer you up? Have you felt calm and peaceful? Did you have a lot of energy? Have you felt downhearted and low? Did you feel worn out? Have you been a happy person? Did you feel tired? Has your health limited your social activities (like visiting with friends or close relatives)? All of the time/Most of the time/A good bit of the time/Some of the time/A little of the time/None of the time.

Pain

How much bodily pain have you had during the past 4 weeks?

None/Very mild/Mild/Moderate/ Severe/Very severe

During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)? Not at all/A little bit/Moderately/Quite a lot/Extremely

1. Only includes items related to domains covered in this inventory.

McMaster Health Utilities Index (HUI-3)

(Furlong, Feeny, Torrance, et. al, 1998)

Vision

1. Are you *usually* able to see well enough to read ordinary newsprint *without* glasses or contact lenses? Yes (Go to Q4)/No
2. Are you *usually* able to see well enough to read ordinary newsprint *with* glasses or contact lenses? Yes (Go to Q4)/No
3. Are you able to see at all? Yes /No (Go to Q6)
4. Are you able to see well enough to recognize a friend on the other side of the street *without* glasses or contact lenses? Yes (Go to Q6)/No
5. Are you able to see well enough to recognize a friend on the other side of the street *with* glasses or contact lenses? Yes/No

Hearing

6. Are you *usually* able to hear what is said in a group conversation with at least 3 other people *without* a hearing aid? Yes (Go to Q10)/No
7. Are you *usually* able to hear what is said in a group conversation with at least 3 other people *with* a hearing aid? Yes (go to Q8)/No
8. Are you able to hear at all? Yes/No (Go to Q10)
9. Are you *usually* able to hear what is said in a conversation with one other person in a quiet room *without* a hearing aid? Yes (Go to Q10)/No
10. Are you *usually* able to hear what is said in a conversation with one other person in a quiet room *with* a hearing aid? Yes/No

Speech

11. Are you *usually* able to be understood *completely* when speaking with strangers in your own language? Yes (Go to Q14)/No
12. Are you able to be understood *partially* when speaking with strangers? Yes/No
13. Are you able to be understood *completely* when speaking with those who know you well? Yes (Go to Q14)/No
14. Are you able to be understood *partially* when speaking with those who know you well?

Mobility

15. Are you *usually* able to walk around the neighbourhood *without* difficulty and *without* mechanical support such as braces, a cane or crutches? Yes (Go to Q22)/No
16. Are you able to walk at all Yes/No (Go to Q19)
17. Do you require mechanical support such as braces, a cane or crutches to be able to walk around the neighbourhood? Yes/No
18. Do you require the help of another person to be able to walk? Yes/No
19. Do you require a wheelchair to get around? Yes/No (Go to Q22)
20. How often do you use a wheelchair? Always/Often/Sometimes/Never
21. Do you need the help of another person to get around in the wheelchair? Yes/No

Dexterity

22. Are you *usually* able to grasp and handle small objects such as a pencil or scissors? Yes (Go to Q26)/No
23. Do you require the help of another person because of limitations in the use of hands or fingers? Yes/No (Go to Q25)
24. Do you require the help of another person with: Some tasks/Most tasks/Almost all tasks/ All tasks?

25. Do you require special equipment, for example, devices to assist in dressing because of limitations in the use of hands or fingers? Yes/No

Emotional well-being (Feelings)

26. Would you describe yourself as being *usually*: Happy and interested in life/Somewhat happy/Somewhat unhappy/Unhappy with little interest in life/So unhappy that life is not worthwhile?

Cognition (Memory and thinking)

27. How would you describe your *usual* ability to remember things? Able to remember most things/Somewhat forgetful/Very forgetful/ Unable to remember anything at all
28. How would you describe your *usual* ability to think and solve day-to-day problems? Able to think clearly and solve problems/Having a little difficulty/Having some difficulty/Having a great deal of difficulty/Unable to think or solve problems

Pain and discomfort

29. Are you *usually* free of pain or discomfort? Yes (Go to next section)/No
30. How would you describe the *usual* intensity of your pain or discomfort? Mild/Moderate/Severe
31. How many activities does your pain or discomfort prevent? None/A few/Some/Most

**ANNEX 2: LISTING OF SELECTED HEALTH STATUS AND DISABILITY-RELATED ITEMS
INCLUDED IN 30 NATIONAL SURVEYS
(AND THE EUROPEAN COMMUNITY HOUSEHOLD PANEL)**

This annex provides listings of selected health status and disability-related items included in the 30 surveys from 23 OECD countries covered in this inventory (plus the European Community Household Panel at the end). For each survey, a brief description of the survey objectives and methodology is first provided. Then follows a listing of the survey items, along the following health conditions and activity limitations.

1. Health conditions

1.1 General prevalence of chronic conditions (condition/illness not specified)

1.2 List of specific conditions/illnesses

1.3 Mental health

1.3.1 Emotional well-being

1.3.2 Cognitive ability

1.4 Pain

2. Activity limitations

2.1 Self-care

2.2 Mobility

2.3 Communication/senses

2.4 IADL (Instrumental activities of daily living)

2.5 Limitations specific to work and/or social activities

2.6 General items on limitation of daily activities

Where surveys include generic health measurement instruments (e.g. SF-36, EuroQol-5D, HUI-3), the items from these instruments are listed under the appropriate domain.

AUSTRALIA (AL01): 1995 National health and nutrition survey

Brief description of survey

The Australian Bureau of Statistics has conducted national health surveys in 1977-8, 1983, 1989-90 and 1995, with the objective of providing trend data on a broad range of health status indicators and health-related behaviours of Australians. It is intended to repeat the National health survey every 5 years. In 1995, the sample covered approximately 55,000 persons living in private households and institutions. All persons aged 15 years and over were interviewed, while parents or guardians provided data for children under 15 years of age. A self-administered questionnaire, which included the SF-36, was completed by all respondents.

Disability-related items included in the survey

1. Health conditions

1.2 List of specific conditions/illnesses

Have you ever been told by a doctor or a nurse that you have.. Y/N

Diabetes? High sugar levels in your blood or urine? Arthritis? Rheumatism? Gout?

Do you have any of the following long-term health conditions? Y/N (include only those that have lasted, or are likely to last, for six months or more)

Asthma? Bronchitis? Hay fever? High blood pressure? Sinus allergy or sinusitis? Stomach ulcers?

1.3 Mental health

1.3.1 Emotional well-being

SF-36: How much of the time during the past 4 weeks: All of the time/Most of the time/A good bit of the time/Some of the time/A little of the time/None of the time.

Did you feel full of life? Have you been a very nervous person? Have you felt so down in the dumps that nothing could cheer you up? Have you felt calm and peaceful? Did you have a lot of energy? Have you felt down? Did you feel worn out? Have you been a happy person? Did you feel tired?

1.4 Pain

SF-36: How much bodily pain have you had during the past 4 weeks? None/Very mild/Mild/Moderate/Severe/Very severe

2. Activity limitations

2.1 Self-care

SF-36: Does your health now limit you in these activities? Limited a lot/Limited a little/Not limited at all. Bathing or dressing yourself?

2.2 Mobility

SF-36: Does your health now limit you in these activities? Limited a lot/Limited a little/Not limited at all. Lifting or carrying groceries? Climbing several flights of stairs? Climbing one flight of stairs? Bending, kneeling or stooping? Walking more than 1 km? Walking half a kilometre? Walking 100 metres?

2.5 Specific to work and/or social activities

SF-36: During the past 4 weeks:

How much did pain interfere with your normal work (including both work outside the home and housework)? To what extent has your physical or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups? Not at all/Slightly/Moderately/Quite a bit/Extremely
How many times has your physical health or emotional problems interfered with your social activities (like visiting with friends or relatives)? Always/Most of the time/Sometimes/A little of the time/Never

2.6 General items on limitation of daily activities

SF-36: During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities, as a result of your physical health? Y/N

Cut down on the amount of time you spent on work or other activities? Accomplished less than you would like? Were limited in the kind of work or other activities? Had difficulty performing the work or other activities (for example, it took extra effort)?

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities, as a result of any emotional problems (such as feeling depressed or anxious)? Y/N

Cut down on the amount of time you spent on work or other activities? Accomplished less than you would like? Didn't do work or other activities as carefully as usual?

AUSTRALIA (AL02): 1998 Survey of disability, ageing and carers

Brief description of survey

The Survey of disability, ageing and carers has been carried out in 1981, 1988, 1993 and 1998, with the intention of measuring the prevalence of disability in Australia and consequent need for support. The survey covers people living in households and in institutions.

In each selected household, a computer-assisted personal interview is conducted to establish the number of people with a disability, people aged 60 years or more, and people who care for a person with disability. A personal interview is then conducted with people identified in any of these 3 groups (using proxy interviews for children under 15 years). The interview includes completion of the SF-12. The disability items listed here are for persons aged 6 years and over.

People are considered as having a disability if they have one of the following conditions that have lasted or are likely to last for more than 6 months: Any loss of sight or inability to see normally wearing glasses or contact lenses; any loss of hearing; anything wrong with speech; shortness of breath or difficulty breathing; chronic pain or recurrent pain or discomfort; blackouts, fits or loss of consciousness; difficulty learning or understanding things; not full use of arms and fingers/feet or legs; difficulty gripping or holding things; nervous or emotional condition; restricted in physical activities or in doing physical work; disfigurement or deformity; needs help or supervision due to mental illness; has head injury, stroke or other brain damage.

Disability-related items included in the survey

1. Health conditions

1.2 List of specific conditions/illnesses

Specified causes of disability include: diabetes, stroke, angina, asthma, bronchitis, hypertension, arthritis (all forms), rheumatism, stomach/duodenal ulcer, epilepsy.

1.3 Mental health

1.3.1 Emotional well-being

(For persons with a disability aged 15 years or more: SF-12)

How much of the time during the past 4 weeks: All of the time/Most of the time/A good bit of the time/Some of the time/A little of the time/None of the time.

Have you felt calm and peaceful? Did you have a lot of energy? Have you felt down?

2. Activity limitations

2.1 Self-care

(For persons with a disability, excluding those with hearing and/or speech difficulties only)

Do you ever need help or supervision? Y/N [If No: Do you find it difficult to do? Y/N]

To shower or bathe? To dress, for example doing up shoe laces, buttons or zips? When eating a meal, for example cutting up food? Using the toilet?

2.2 Mobility

(For persons with a disability, excluding those with hearing and/or speech difficulties only)

Do you ever need help or supervision with the following? Y/N [If No: Do you find it difficult to do? Y/N]
When going to or getting around a place away from home? To move about the house? To get in or out of a bed or chair?

(For persons with a disability, excluding those with hearing and/or speech difficulties only)

Can you easily walk 200 metres? Y/N Can you walk up and down stairs *without* a handrail? Y/N [If Yes: Can you do this *without* difficulty? Y/N] Can you easily bend and pick up an object from the floor *without* any assistance? Y/N

(For persons with a disability aged 15 years or more: SF-12)

Does your health now limit you in climbing several flights of stairs? Limited a lot/Limited a little/Not limited at all.

2.3 Communication/senses

(For persons with a hearing loss:) Does your hearing loss make it difficult for you to communicate with others? Y/N [If use hearing aid: Can you hear normally with a hearing aid, for example in a crowded room? Y/N]

2.5 Specific to work and/or social activities

(For employed persons with a disability)

Does your condition:

Restrict the type of job you can do? Restrict the number of hours you can work? Make it more difficult to change jobs or get a better job? Y/N

(For persons with a disability aged 15 years or more: SF-12)

During the past 4 weeks:

How much did pain interfere with your normal work, including both work outside the home and housework? Not at all/Slightly/Moderately/Quite a bit/Extremely

How much of the time has your physical health or emotional problems interfered with your social activities, like visiting with friends, relatives, etc.? All of the time/Most of the time/Some of the time/A little of the time/ None of the time.

2.6 General items on limitation of daily activities

(For persons with a disability aged 15 years or more: SF-12)

During the past 4 weeks:

Have you accomplished less than you would like as a result of your physical health? Were you limited in the kind of work or other regular daily activities you do as a result of your physical health? Have you accomplished less than you would like as a result of any emotional problems, such as feeling depressed or anxious? Did you not do work or other regular daily activities as carefully as usual as a result of any emotional problems, such as feeling depressed or anxious? Y/N

AUSTRIA (AT01): 1995 Microcensus survey on physical disabilities

Brief description of survey

The Austrian Central Statistical Office conducts a national Microcensus four times a year, consisting of a core questionnaire and a supplementary questionnaire. In 1976, 1986 and 1995, the supplementary questionnaire was a survey on physical disabilities, which asked about the living conditions of people with ocular, aural, skeletal or disfiguring impairments, or other chronic diseases. It is intended that this supplement on disabilities will be repeated approximately every 10 years. The survey is conducted through face-to-face interviews and the sample size is approximately 60,000, i.e. 1% of all dwellings. It includes all age groups, as well as people resident in institutions, although the latter are only asked a limited set of disability questions in order to establish what sort of disability they have.

Disability-related items included in the survey

1. Health conditions

1.1 General prevalence (condition/illness not specified)

Do you suffer from any (long-term) ocular, aural, skeletal or disfiguring impairment (deficiency or other impairment like paralysis or disfigurement) or other chronic disease (e.g. heart disease or allergy)?

1.2 List of specific conditions/illnesses

List of chronic conditions including: heart disease, high blood pressure, stroke, respiratory disease (asthma), rheumatism/arthritis, diabetes, allergy.

2. Activity limitations

2.1 Self-care

(Only difficulties due to chronic impairments are registered)

Can you wash and dress yourself? Without help from others/Only with help from others/Not at all.

Do you get help with any personal activities (washing and dressing yourself, eating etc.) from family members/relatives, friends/social services/others? Y/N

2.2 Mobility

(Only difficulties due to chronic impairments are registered)

Can you: Get up and lie down? Walk up and down in your dwelling?

Without help from others/Only with help from others/Not at all.

2.3 Communication/senses

[Does the interviewee indicate a normal or near-normal vision using glasses or contact lenses? Y/N]

Do you have difficulties in listening to a conversation between two or more persons? Y/N

2.4 IADL

Can you: Do 'easy' housework? Do 'harder' housework? Go shopping? Without help from others/Only with help from others/Not at all.

Do you receive help with activities of daily living (purchasing, cooking etc) from persons/services? Y/N

2.5 Specific to work and/or social activities

(Only difficulties due to chronic impairments are registered)

Can you go out and visit friends? Without help from others/Only with help from others/Not at all.

BELGIUM (BL01) : 1997 Health interview survey

Brief description of survey

The Scientific Institute of Public Health carried out the first Belgian health survey in 1997, with the aim of describing health status and health needs of the population, and analysing social (in)equality in health and health access. The sample population consisted of all inhabitants of Belgium. More than 10,000 people were interviewed. The next survey is likely to be in 2001.

The survey consisted of three parts: a household interview, a face-to-face questionnaire completed by selected persons (could also be filled by a proxy), and a written questionnaire completed by selected persons over 15 years (no proxies). The 1996 WHO-Europe recommended list of instruments, with some adjustments, was used to measure long-term disability. The survey also includes some items from the SF-36 and uses the 12-item version of the General Health Questionnaire to measure mental health, as recommended by WHO-Europe.

Disability-related items included in the survey

1. Health conditions

1.1 General prevalence (condition/illness not specified)

Do you suffer from one or more longstanding illnesses, chronic conditions or handicaps? Y/N

1.2 List of specific conditions/illnesses

Have you any of these diseases/conditions or have you had any of them during the last 12 months?
Asthma/chronic bronchitis/chronic pulmonary disease? Allergy? Serious heart disease or heart attack?
Hypertension? Diabetes? Epilepsy? Arthrosis of knees/hips/hands? Arthritis of hands or feet? Other
rheumatoid arthritis for more 3 months? Stroke and effects of stroke? Stomach or duodenal ulcer?

1.3 Mental health

1.3.1 Emotional well-being

Do you sleep easily and do you sleep well? Do you often feel tired? Do you often get upset? Do you often feel listless? Do you often feel nervous? Do you get tired sooner than you would consider normal? Are you often irritable? Y/N

a) Have you recently lost much sleep over worry? Have you recently felt constantly under strain? Have you recently felt you couldn't overcome your difficulties? Have you recently been losing confidence in yourself? Have you recently been thinking of yourself as a worthless person?

Not at all/No more than usual/Rather more than usual/Much more than usual.

Have you recently been feeling unhappy and depressed? Not at all/Same as usual/Less[More?] than usual/Much less[more?] than usual

b) Have you recently felt you were playing a useful part in things? Have you recently been able to face up to your problems? Have you recently been feeling reasonably happy, all things considered? Have you recently been able to enjoy your normal day-to-day activities?

More than usual/Same as usual/Less than usual/ Much less than usual

1.3.2 Cognitive ability

Have you recently... Been able to concentrate on whatever you're doing? Felt capable of making decisions about things? More than usual/Same as usual/Less than usual/ Much less than usual

1.4 Pain

Do your bones or muscles ever ache? Are you often troubled by back-ache? Do you often have pains in the chest or heart region? Do you often have headaches? Are you rheumatic? Do you regularly have pains in the stomach region? Y/N

SF-36: How much bodily pain have you had during the past 4 weeks? None/Very mild/Mild/Moderate/ Severe/Very severe

2. Activity limitations

2.1 Self-care

SF-36: Does your health now limit you in these activities? Limited a lot/Limited a little/Not limited at all. Bathing, showering or dressing yourself?

(Asked if Yes to any long-term disability [i.e. limitations in mobility items listed below or in bathing, showering or dressing] or if person is aged over 60 years):

Can you dress and undress yourself on your own? Can you wash your hands and face on your own?

Can you, without the help of someone else, feed yourself and cut up food yourself? Can you get to and use the toilet on your own?

Yes, without difficulty/Yes, with some difficulty/Only with someone to help me.

2.2 Mobility

(Asked if Yes to first question on illness, chronic condition or handicap): Are you bedridden due to this (these) illness(es), chronic condition(s) or handicap(s)? Continually/At intervals/Not or seldom.

SF-36: Does your health now limit you in these activities? Limited a lot/Limited a little/Not limited at all. Lifting or carrying groceries? Climbing several flights of stairs? Climbing one flight of stairs? Bending, kneeling or stooping? Walking more than 1 km? Walking a few hundred meters? Walking one block?

(Asked if Yes to any long-term disability items or if person is aged over 60 years):

Are you permanently confined to bed even though there may be help to get you out? Do you sit in a chair (not a wheelchair) all day even though there may be help for you to walk? Are you confined to your house/flat and garden? Y/N

What is the furthest you can walk on your own *without* stopping and *without* severe discomfort? Only a few steps/More than a few steps, but less than 200 metres/200 metres or more

Can you get in and out of bed on your own? Can you get in and out of a chair on your own? Yes, without difficulty/Yes, with some difficulty/Only with someone to help me.

2.3 Communication/senses

(Aids normally used by the respondent must be taken into account).

Can you see well enough to recognise a friend at a distance of four metres (across a road)? Y/N [If No: Can you see well enough to recognise a friend at a distance of one metre (at arm's length)? Y/N]

Is your hearing good enough to follow a TV programme at a volume others find acceptable? Y/N [If No: Can you follow a TV programme with the volume turned up? Y/N]

2.5 Specific to work and/or social activities

SF-36: During the past 4 weeks:

How much did pain interfere with your normal work (including both work outside the home and housework?) To what extent has your physical or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups? Not at all/Slightly/Moderately/Quite a bit/Extremely
How many times has your physical health or emotional problems interfered with your social activities (like visiting friends or relatives)? Always/Most of the time/Sometimes/A little of the time/Never

2.6 General items on limitation of daily activities

(Asked if have illness, chronic condition or handicap): Are you restricted in your daily activities due to this (these) illness(es), chronic condition(s) or handicap(s)? Continually/At intervals/Not or seldom.

CANADA (CA01): 1998 National population health survey

Brief description of survey

The National population health survey is carried out every 2 years under the responsibility of Statistics Canada. It is conducted as a computer-assisted personal interview and includes items on health status, health behaviour and health care utilisation. The sample population covers all ages and includes people living in institutions. One person in each household sampled is randomly selected to participate in the longitudinal portion of the survey. The health status component includes the various dimensions of McMaster's Health Utility Index (HUI).

Disability-related items included in the survey

1. Health conditions

1.1 General prevalence (condition/illness not specified)

Do you have any long-term disabilities or handicaps? Y/N

1.2 List of specific conditions/illnesses

Interested in 'long-term conditions' that have lasted or are expected to last 6 months or more and that have been diagnosed by a health professional. Do you have... Food allergies? Any other allergies? Asthma? Chronic bronchitis or emphysema? Epilepsy? Heart disease?

Asked if age 12 or more: Arthritis or rheumatism? High blood pressure? Diabetes? Stomach or intestinal ulcers? Effects of a stroke?

1.3 Mental health

1.3.1 Emotional well-being

Would you describe yourself as being usually: Happy and interested in life/Somewhat happy/Somewhat unhappy/Unhappy with little interest in life/So unhappy that life is not worthwhile?

For each question, answer with a number between 1 and 7.

a) How often do you have the feeling that you don't really care about what goes on around you?

Many people, even those with a strong character, sometimes feel like sad sacks (losers) in certain situations; how often have you felt this way in the past? 1=very seldom/never; 7=very often.

How often in the past were you surprised by the behaviour of people whom you thought you knew well?

How often have people you counted on disappointed you? 1=never; 7=always.

b) How often do you have the feeling you're being treated unfairly? How often do you have the feeling you are in an unfamiliar situation and don't know what to do? How often do you have very mixed-up feelings and ideas? How often do you have feelings inside that you would rather not feel? How often do you have the feeling that there's little meaning in the things you do in your daily life? How often do you have feelings that you're not sure you can keep under control? 1= very often; 7=very seldom/never.

Until now has your life had no clear goals or purpose (1) or has it had very clear goals and purpose (7)?

When something happens, do you generally find that you overestimate or underestimate its importance (1) or do you see things in the right proportion (7)?

Is doing the things you do every day a source of great pleasure and satisfaction (1) or a source of pain and boredom(7)?

(Non-proxy only and age ≥ 12): During the past month, about how often did you feel: All the time/Most of the time/Some of the time/A little of the time/None of the time

So sad that nothing could cheer you up? Nervous? Restless or fidgety? Hopeless? Worthless? That everything was an effort?

(If Yes to any of above): Taking them altogether, did these feelings occur more often in the past month than is usual for you, less often than usual or about the same as usual?

[If More often: Is that a lot more, somewhat more or only a little more often than usual? How much do these experiences usually interfere with your life or activities? ? A lot/Some/A little/Not at all]

[If Less often: Is that a lot less, somewhat less or only a little less often than usual?]

[If Same as usual: How much do these experiences usually interfere with your life or activities? A lot/Some/A little/Not at all]

During the past 12 months, was there ever a time lasting 2 weeks or more when you:

Felt sad, blue, or depressed? Lost interest in most things like hobbies, work or activities that usually give you pleasure? Y/N

[If Yes to either of these: For the next few questions, please think of the 2-week period during the past 12 months when these feelings were the worst. During that time, how long did these feelings usually last? All day long/Most of the day/About half of the day/Less than half of a day. How often did you feel this way during those 2 weeks? Every day/Almost every day/Less often

(If Yes to feelings): During those 2 weeks did you lose interest in most things? Did you feel tired out or low on energy all of the time? Did you gain weight, lose weight or stay about the same? Did you have more trouble falling asleep than you usually do? (If Yes: Every night/Nearly every night/Less often) Did you have a lot more trouble concentrating than usual? At these times, people sometimes feel down on themselves, no good or worthless; did you feel this way? Y/N

About how many weeks altogether did you feel this way during the past 12 months? x weeks.]

1.3.2 Cognitive ability

How would you describe your usual ability to remember things: Able to remember most things/Somewhat forgetful/Very forgetful/Unable to remember anything at all.

How would you describe your usual ability to think and solve day-to-day problems: Able to think clearly and solve problems/Having a little difficulty/Having some difficulty/Having a great deal of difficulty/Unable to think or solve problems.

1.4 Pain

Are you usually free of pain or discomfort? Y/N [If No: How would you describe the usual intensity of your pain or discomfort? Mild/Moderate/Severe. How many activities does your pain or discomfort prevent? None/A few/Some/Most.]

2. Activity limitations

2.1 Self-care

Because of any condition or health problem, do you need the help of another person in personal care such as washing, dressing or eating? Y/N

Are you usually able to grasp and handle small objects such as a pencil or scissors? Y/N [If No: Do you require the help of another person because of limitations in the use of hands or fingers? Y/N If Yes: Do you require the help of another person with: Some tasks/Most tasks/Almost all tasks/All tasks?]

2.2 Mobility

Because of any condition or health problem, do you need the help of another person in moving about inside the house? Y/N

Are you usually able to walk around the neighbourhood without difficulty and without mechanical support such as braces, a cane or crutches? Y/N If No: Are you able to walk at all? Y/N [If No: Do you require a wheelchair to get around? If Yes: How often do you use a wheelchair? Always/Often /Sometimes/Never.

Do you need the help of another person to get around in the wheelchair? Y/N]

[If Yes: Do you require mechanical support such as braces, a cane or crutches to be able to walk around the neighbourhood? Y/N Do you require the help of another person to be able to walk? Y/N]

2.3 Communication/senses

Are you usually able to see well enough to read ordinary newsprint without glasses or contact lenses? Y/N [If No: Can you do this with glasses/contact lenses? Y/N If No: Are you able to see at all? Y/N]

Are you able to see well enough to recognize a friend on the other side of the street without glasses or contact lenses? Y/N [If No: Can you do this with glasses/contact lenses?]

Are you usually able to hear what is said in a group conversation with at least 3 other people without a hearing aid? Y/N [If No: Can you do this with a hearing aid? Y/N If No: Are you able to hear at all?]

Are you usually able to hear what is said in a conversation with one other person in a quiet room without a hearing aid? Y/N [If No: Can you do this with a hearing aid? Y/N]

Are you usually able to be understood completely when speaking with:

Strangers in your own language? Y/N [If No: Can you be understood *partially*? Y/N]

Those who know you well? Y/N [If No: Can you be understood *partially*? Y/N]

2.4 IADL

Because of any condition or health problem, do you need the help of another person...

Preparing meals? Shopping for groceries or other necessities? Doing normal everyday housework? Doing heavy household chores such as washing walls or yard work? Y/N

2.6 General items on limitation of daily activities

(Conditions that have lasted or are expected to last 6 months or more)

Because of a long-term physical or mental condition or a health problem, are you limited in the kind or amount of activity you can do - at home? - at school? - at work? Y/N

[If any Yes: What is the main condition or health problem causing this?]

[If longitudinal respondent and worse/better since previous questionnaire: Is this due to a new activity restriction or disability or to the worsening of an old one? Is this due to the disappearance or improvement of an old activity restriction or disability, to the use of special equipment (e.g. artificial limb), or to something else?]

(If Yes to pain or discomfort) How many activities does your pain or discomfort prevent? None/A few/Some/Most.

CANADA (CA02): 1991 Health and activity limitation survey

Brief description of survey

This survey has been conducted in 1986 and 1991, with the purpose of collecting data on disability. The next survey is planned for 2001. HALS consists of two components. In the Household survey component, persons identified from the 1991 Census as having a physical or psychological disability were interviewed, mostly by telephone, as were a sample of persons who had replied negatively to disability. In the Institutions survey component, face-to-face interviews were conducted with persons living in a sample of institutions, such as nursing homes and hospitals. The surveys used items from the OECD 1982 list to measure some aspects of disability.

Disability-related items included in the survey

1. Health conditions

1.3 Mental health

1.3.1 Emotional well-being

Have you ever: Y/N

All of a sudden, felt frightened or anxious in a situation when most people would not be afraid or anxious? Had a period of 6 months or more when you felt worried or anxious most of the time? Had two weeks or more when you felt sad, blue or depressed nearly every day? Had two weeks or more when you lost interest in most things like work, hobbies or things you usually liked to do for fun?

1.3.2 Cognitive ability

Do you have any ongoing difficulty with your ability to remember or learn? Do people often tell you that you are not doing the right thing at the right time? Do you often have difficulty solving day to day problems? Explaining your ideas when speaking? Doing an activity that has many steps e.g. following a recipe? Y/N

2. Activity limitations

2.1 Self-care

Do you have any difficulty... Dressing and undressing yourself? Cutting your own food? Cutting your own toenails? Using your fingers to grasp or handle (such as using pliers or scissors)? Y/N
Because of your condition or health problem, does someone usually help you with personal care e.g. washing, grooming, dressing or feeding yourself? Y/N

2.2 Mobility

Do you have any difficulty... Walking 350 metres or 400 yards without resting (about 3 city blocks, about half a kilometre or quarter of a mile)? Walking up and down a flight of stairs (about 12 steps)? Carrying an object of 4.5 kg for 10 metres or 10 pounds for 30 feet (e.g. a bag of groceries)? Moving from one room to another? Standing for more than 20 minutes? When standing, bending down and picking up an object from the floor (e.g. a shoe)? Getting in and out of bed? Y/N

2.3 Communication/senses

Do you have any difficulty... Seeing ordinary newsprint, with glasses or contact lenses if usually worn? Clearly seeing the face of someone across a room (i.e. from 4 metres/12 feet) with glasses or contact lenses

if usually worn? Hearing what is said in a conversation with one other person? Hearing what is said in a group conversation with at least 3 other people? Speaking and being understood? Y/N
Are you able to hear what is being said over a telephone? With/Without an aid/No

2.4 IADL

Because of your condition or health problem, does someone usually help you with...
Preparing your meals? Shopping for groceries or other necessities? Normal everyday housework e.g. dusting, tidying up? Heavy household chores e.g. washing walls, yard work, snow removal? Personal finances, e.g. banking, paying bills? Y/N

2.5 Specific to work and/or social activities

Because of your condition or health problem...
Have you ever changed the kind of work you do? The amount of work you do? Your job? Are you limited in the kind or amount of work you can do at your present job or business? Are you completely prevented from working at a job or business? Y/N

2.6 General items on limitation of daily activities

Because of a long-term physical condition or health problem, that is one that is expected to last 6 months or more, are you limited in the kind or amount of activity you can do... At home? At school? At work? In other activities such as travel, sport or leisure? Y/N

Because of a long-term emotional, psychological, nervous or psychiatric condition, that is one that is expected to last 6 months or more, are you limited in the kind or amount of activity you can do... At home? At school? At work? In other activities such as travel, sport or leisure? Y/N

CZECH REPUBLIC (CZ01): 1999 Health interview survey

Brief description of survey

The Institute of Health Information and Statistics administers the Health interview survey every 3 years. The main objectives are to monitor the population's health and to determine the prevalence and incidence of health conditions. The survey is conducted as an interview-administered questionnaire, with a random sample of people aged 15 years and over. It uses the WHO-Europe recommended instrument to measure "long-term" disability.

Disability-related items included in the survey

1. Health conditions

1.1 General prevalence (condition/illness not specified)

Are you suffering at the present time from one or several chronic diseases? No/I suffer from one or several chronic diseases, but they do not limit me in my work, social or family function/I suffer from one or several chronic diseases and I am limited partly/severely/fully.

1.2 List of specific conditions/illnesses

Which of these chronic diseases are you suffering from at the present time:

Asthma/chronic bronchitis/chronic non-specific respiratory disease? Serious heart disease/heart attack? Hypertension? Stroke and effects of stroke? Stomach/duodenal ulcer? Diabetes? Arthrosis of knees, hips or hands? Arthritis of hands/feet? Other rheumatoid arthritis for more than 3 months? Epilepsy?

1.3 Mental health

1.3.1 Emotional well-being

How often (how long) during the last weeks have you felt:

Cheerful and in good spirit? Calm and relaxed? Active and vigorous? Waking up fresh and rested? Your days of life being filled with things that interest you? Exhausted and tired? Depressed and sad?

All the time/Most of the time/Quite often/Rarely/Never

2. Activity limitations

2.1 Self-care

Can you wash your hands and face on your own? Can you dress and undress yourself on your own? Can you feed yourself including cutting up food? Can you get to and use the toilet on your own? Without difficulty/With some difficulty/Only with someone to help me

2.2 Mobility

Are you permanently confined to bed even though there may be help to get you up? Do you sit in a chair (not a wheelchair) all day even though there may be help for you to walk? Are you confined to your house/flat and garden? Y/N

Can you get in and out of bed on your own? Can you get in and out of a chair on your own? Without difficulty/With some difficulty/Only with someone to help me

What is the furthest you can walk on your own without stopping and without severe discomfort? Only a few steps/More than a few steps but less than 200 meters/200 meters or more

Can you walk up and down a flight of 12 stairs without resting? Yes/Yes, but not without resting/No

Can you when standing bend down and pick up a shoe from the floor? Y/N

2.3 Communication/senses

Is your hearing good enough to follow a TV program at a volume others find acceptable (with hearing aid if necessary)? Yes/No, I need higher volume/No, I don't hear at all

Can you see well enough to recognise a friend at a distance of four meters (across a road)? Yes/No, but I can do it at 1 meter

Can you speak without difficulty? Y/N

DENMARK (DK01): 2000 Health and morbidity survey

Brief description of the survey

This survey has been undertaken regularly since 1987 by the National Institute of Public Health to provide data on the health and health behaviour of the Danish population. A study sample of 20,000 people is drawn from the population aged ≥ 16 years using the central population register. Data are collected through personal interviews, supplemented by a self-administered questionnaire which included the SF-36 in 1994, and the SF-36 and EuroQol in 2000 (administered to approximately one-third of respondents). The 2000 sample also includes re-interviews with some of the 1994 sample.

Disability-related items included in the survey

1. Health conditions

1.1 General prevalence (condition/illness not specified)

Do you suffer from any long-standing illness, long-standing after-effect from injury, any disability or other long-standing condition? Y/N

1.2 List of specific conditions/illnesses

Do you now or have you previously suffered from any of these illnesses?

Diabetes? Epilepsy? High blood pressure? Myocardial infarction or angina pectoris? Cerebral hæmorrhage/stroke? Chronic bronchitis? Asthma? Allergy? Stomach ulcer?

1.3 Mental health

1.3.1 Emotional well-being

(SF-36) How much of the time during the past 4 weeks: All of the time/Most of the time/A good bit of the time/Some of the time/A little of the time/None of the time.

Did you feel full of life? Have you been a very nervous person? Have you felt so down in the dumps that nothing could cheer you up? Have you felt calm and relaxed? Did you have a lot of energy? Have you felt down? Did you feel worn out? Have you been a happy person? Did you feel tired?

(EuroQol) Which statement best describes your own health state today: I am not anxious or depressed/I am moderately anxious or depressed/I am extremely anxious or depressed.

1.4 Pain

Do you have long-standing/chronic pain which has lasted for 6 months or more? Y/N

(SF-36) How much bodily pain have you had during the past 4 weeks? None/Very mild/Mild/Moderate/Severe/Very severe

(EuroQol) Which statement best describes your own health state today: I have no pain or discomfort/I have moderate pain or discomfort/ I have extreme pain or discomfort.

2. Activity limitations

2.1 Self-care

(SF-36) Does your health now limit you in these activities? Limited a lot/Limited a little/Not limited at all. Bathing or dressing yourself?

(EuroQol) Which statement best describes your own health state today: I have no problems with self-care/I have some problems with washing or dressing myself/I am unable to wash or dress myself.

2.2 Mobility

Are you normally able to do the following with no difficulty, with minor difficulty, with major difficulty, or not at all? Walk 400 metres without resting? Walk up and down a staircase from one floor to another without resting? Carry 5 kg (e.g. shopping bag)?

(SF-36) Does your health now limit you in these activities? Limited a lot/Limited a little/Not limited at all.

Lifting or carrying groceries? Climbing several flights of stairs? Climbing one flight of stairs?

Bending, kneeling or stooping? Walking ≥ 1 km? Walking half a kilometre? Walking 100 metres?

(EuroQol) Which statement best describes your own health state today: I have no problems in walking about/I have some problems in walking about/I am confined to bed.

2.3 Communication/senses

Are you normally able to do the following with no difficulty, with minor difficulty, with major difficulty, or not at all? Read ordinary newspaper print (with glasses, if normally worn)? Hear what is said in a normal conversation between 3 persons or more (with hearing aid, if normally worn)?

Completed by interviewer: Speaks with no difficulty/With minor difficulty/With major difficulty

2.5 Specific to work and/or social activities

Due to illness, injury or ailment, have you ever been forced to: Go part-time/Retire/Change job or work tasks? Within the past year, how many days did you have to stay home from work due to illness, injuries or complaints (include work days only)? x days within the past year

(SF-36): During the past 4 weeks:

How much did pain interfere with your normal work (including both work outside the home and housework)? To what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups? Not at all/Slightly/Moderately/ Quite a bit/Extremely

How much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc)? All of the time/Most of the time/Some of the time/A little of the time/ None of the time.

2.6 General items on limitation of daily activities

Within the past 2 weeks has illness, injury or ailment made it difficult or impossible for you to carry out your usual daily activities (work outside the home or domestic work, spare time activities etc)? Y/N

Have these difficulties been of a chronic nature (i.e. have lasted/are expected to last ≥ 6 months)? Y/N

(SF-36) During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities,

As a result of your physical health: Cut down on the amount of time you spent on work or other activities? Accomplished less than you would like? Were limited in the kind of work or other activities? Had difficulty performing the work or other activities (e.g. it took extra effort)? Y/N

As a result of any emotional problems (e.g. feeling depressed or anxious): Cut down on the amount of time you spent on work or other activities? Accomplished less than you would like? Didn't do work or other activities as carefully as usual? Y/N

(EuroQol) Which statement best describes your own health state today: I have no problems with performing my usual activities (e.g. work, study, housework, family or leisure activities)/I have some problems with performing my usual activities/I am unable to perform my usual activities.

FINLAND (FIN01): 1999 Health behaviour among the Finnish adult population

Brief description of survey

The Finnish Health behaviour survey is conducted annually by the National Public Health Institute (KTL). It consists of a postal questionnaire which is sent to approximately 500 persons aged between 15 and 64 years.

Disability-related items included in the survey

1. Health conditions

1.2 List of specific conditions/illnesses

Have you had any of the following diseases diagnosed or treated by a doctor during the last year?
Elevated blood pressure, hypertension? Diabetes? Myocardial infarction, heart attack? Angina pectoris (chest pain during exercise)? Heart failure? Rheumatic arthritis? Chronic bronchitis, emphysema? Bronchial asthma? Gastritis or ulcer?

1.3 Mental health

1.3.1 Emotional well-being

Have you had any of the following symptoms or troubles during the last month (30 days)? Y/N
Insomnia? Depression?
Have you felt depressed during the last year? Not at all/Not more than before/Somewhat more than before/Much more than before.
Have you been tense, stressed or under high pressure during the last month? Yes, my life is nearly unbearable/Yes, more than is usual for people in general/Yes, somewhat but not usually so/Not at all.

1.4 Pain

Have you had any of the following symptoms or troubles during the last month (30 days)? Y/N
Chest pain during exercise? Joint pain? Back pain? Neck-shoulder pain? Headache? Toothache? Sciatica?

2. Activity limitations

2.5 Specific to work and/or social activities

How many days during the last year (12 months) were you absent from work or did not carry out your normal duties because of illness? x days

FRANCE (FR01): 1991-92 National health interview survey⁹

Brief description of survey

INSEE has conducted this survey approximately every 10 years, most recently in 1991-92. The aim is to provide national data on health status and health care utilisation of the non-institutionalised population in France. The survey is conducted through interviewer-administered questionnaires and approximately 8,000 households covering 21,000 people of all ages are sampled each time.

Disability-related items included in survey

1. Health conditions

1.2 List of specific conditions/illnesses

Does anyone in the household currently suffer from any of these illnesses, health problems, handicaps, disabilities? Heart diseases, angina pectoris, heart arrhythmia, myocardial infarction? High blood pressure? Cerebral vascular accident with paralysis or hemiplegia, stroke? Lumbago, sciatica, osteoarthritis, arthritis, painful joints, osteoporosis, rheumatism? Chronic bronchitis, asthma, tuberculosis, frequent cough, emphysema? Stomach pains, stomach ulcer? Diabetes, thyroid problem?

2. Activity limitations

2.1 Self-care

Can you wash yourself without anyone's help? Can you dress and undress yourself without help? Can you get to the toilet and use it without anyone's help? Can you eat without help, including cutting up your food? Without difficulty/Without too much difficulty/With a lot of difficulty/No.

2.2 Mobility

Are you permanently confined to bed, even if you could have someone's help to get up? Do you have to stay all day in a chair (not a wheelchair), even if you could have someone's help to walk? Are you confined to your house or apartment, including your garden? Y/N

Can you lie down and get up from bed without help? Can you climb and descend one flight of stairs without stopping? When you are standing, can you bend down to pick something up that has fallen on the ground? Without difficulty/Without too much difficulty/With a lot of difficulty/No.

What is the furthest you can walk on your own without stopping or serious discomfort? A few steps only/More than a few steps but <200 metres/≥200 metres.

2.3 Communication/senses

Do you have difficulty reading road signs (with your glasses if you use them for far sight)? Do you have difficulties threading a needle (with your glasses if you use them for close vision?) Y/N

Can you see well enough (with glasses) to read a book or newspaper or to do a crossword? Can you usually follow a telephone conversation? Without difficulty/Without too much difficulty/With a lot of difficulty/No.

2.4 IADL

Can you usually prepare your meals without help? Without difficulty/Without too much difficulty/With a lot of difficulty/No.

2.5 Specific to work and/or social activities

Since starting in active working life, has anyone in your household, for medical reasons (not including normal pregnancy): Stopped working for at least 6 consecutive months? Changed profession? Y/N

9. The English translation of this survey has not been validated and has therefore no official status.

FRANCE (FR02): 1998-2000 National disability interview

Brief description of survey

This survey is conducted by INSEE and is the first national disability survey to be conducted in France. Data are being collected separately for people living in institutions (a sample of people aged 15 years and over) and in households (20,000 people). The survey has a longitudinal component with people living in institutions being interviewed twice, in 1998 and 2000, and those living in households being interviewed in 1999 and then again in 2001.

Disability-related items included in survey

1. Health conditions

1.3 Mental health

1.3.1 Emotional well-being

Is your sleep often disturbed due to your state of health? Y/N

1.3.2 Cognitive ability

Do you sometimes forget what time of the day it is? No, never/Yes, sometimes/Yes, always.

Do you have trouble finding your way when going out? No, never/No, provided that I always go on the same routes/Yes, I sometimes get lost or I need help/Yes, I always need someone to guide me.

2. Activity limitations

2.1 Self-care

Can you wash without anybody's assistance? Yes, without assistance and without any trouble/Yes, without assistance, but with some difficulty/Yes, without assistance, but with much difficulty/No, I need partial assistance/No, I need assistance for everything.

Can you dress and undress without any assistance? Yes, I can manage without any assistance and without any trouble/ Yes, I can manage without any assistance, but with some difficulty/Yes, I can manage without any assistance, but with much difficulty/No, I need partial assistance/No, I can't, I need help for everything.

Can you cut your food without any assistance? Yes, without any difficulty/Yes, but with some difficulty/Yes, but with much difficulty/No, I need assistance.

Once the food is ready, can you eat and drink without any assistance? Yes, without any difficulty/Yes, but with some difficulty/Yes, but with much difficulty/No, I need assistance.

Can you do the following without assistance:

Use the toilet? Cut your toenails? Use your hands and fingers (e.g. to open a door, turn taps on and off, grip a pencil, use scissors)? Yes, without any difficulty/Yes, but with some difficulty/Yes, but with a lot of difficulty/ No, I need assistance.

2.2 Mobility

Must you usually (excluding an accident or temporary illness) permanently stay...In bed/In your room/ Inside home/No, can go out

Can you get in and out of bed with any assistance? Can you get seated and get up from your chair without any assistance? Yes, without any difficulty/Yes, but with some difficulty/Yes, but with much difficulty/No, I need assistance.

Can you move about without any assistance in all the rooms on the floor where you are? Yes, I can do it without any assistance/Yes, but only in certain rooms on the floor/No, I usually need assistance to move from one room to another.

Can you go up and down one flight of stairs without any assistance? Can you use the lift without any assistance? Yes, without any difficulty/Yes, but with some difficulty/Yes, but with much difficulty/No, I need assistance.

Can you go out of your home without any assistance? Can you do all your shopping by yourself? Can you carry a five kilo object on a ten metre distance (e.g. a shopping bag or a schoolbag)? Yes, without any assistance and without any difficulty/Yes, without any assistance, but with some difficulty/Yes, without any assistance, but with much difficulty/No, I need assistance.

2.3 Communication/senses

Can you see well close to (to read a paper, a book, draw, do crosswords), with your glasses or contact lenses if necessary? Do you recognise someone's face at a distance of 4 metres (with glasses or contact lenses if you wear any)? Without difficulty/With some difficulty/With a lot of difficulty/No.

Do you hear what is said in a conversation (with a hearing aid if necessary)? Without difficulty even if there are several people/Only if one person is speaking, although at a normal volume/Only if one person is speaking and loudly/No.

Do you have difficulties speaking? Not at all/Yes, except with people who know me well/Yes, a lot of difficulty/Do not talk (e.g. autistic).

2.4 IADL

At present, can you cook your meals without any assistance? At present, can you do the common house chores without any assistance (dish-washing, doing the laundry, ironing, cleaning, tidying up...)? Yes, without any difficulty/Yes, without much difficulty/Yes, but with much difficulty/No, I need assistance.

At present, can you fill in plain forms without any assistance? Can you manage to order/take a taxi, or use public transportation on your own?/Do you take the medicines prescribed by your doctor? Yes, I take care of it/do it alone without any difficulty/Yes, I do it alone, but with some difficulty/Yes, I do it alone, but with much difficulty/No I could not manage alone.

2.5 Specific to work and/or social activities

Since starting in active working life, for medical reasons (excluding normal pregnancy), have you:

Stopped working for at least 6 consecutive months? Changed profession for medical reasons?

Changed your employment without changing your profession (including a geographical move)? Y/N

Because of a handicap or health problem: Are you limited in the type or amount of work you can do?

Have your employment conditions been altered? Y/N [If Yes: How? Someone's help/Altered working hours/Special transport/Modified duties/Possibility of working from home etc.]

2.6 General items on limitation of usual activities

Do you experience difficulties (physical, sensory, intellectual, mental) in everyday life due to an accident, chronic illness, congenital problem, disability, ageing...? Y/N If yes, what?

GERMANY (DEV01): 1998 National health examination and interview survey

Brief description of survey

The National health examination and interview survey (Bundes-Gesundheitssurvey) is carried out every 6-8 years by the Robert Koch Institute. Data are collected through a face-to-face interview and the completion of a self-administered questionnaire. In the 1997-9 survey, which included the SF-36 instrument, approximately 7,100 non-institutionalised persons aged 18-79 years were sampled.

Disability-related items included in the survey

1. Health conditions

1.2 List of specific conditions/illnesses

Have you ever had any of the following illnesses/diseases? Y/N

High blood pressure? Disturbed blood supply to the heart, stricture of the coronary blood vessels, angina pectoris? Cardiac infarction? Cardiac weakness, cardiac insufficiency? Stroke? Disturbed blood supply to the brain (only if accompanied by paralysis, dysaesthesia or speech disorders and not caused by migraines)? Bronchial asthma (pulmonary asthma, allergic asthma)? Chronic bronchitis? Stomach or duodenal ulcer? Diabetes mellitus with/without insulin treatment? Arthrosis of the hip or knee joint or of the spinal column? Inflammatory disease of the joints or spinal column (e.g., chronic polyarthritis, rheumatoid arthritis, Morbus bechterew)? Epilepsy? Hay fever, allergic conjunctivitis (allergic rhinitis)? Allergic contact dermatitis (skin rash)? Food allergies? Hives? Other allergies (Specify)?

1.3 Mental health

1.3.1 Emotional well-being

How much do you suffer from the following complaints? Severely/Moderately/Hardly/Not at all
Weariness? Irritability? Brooding? Subjective feeling of unrest? Insomnia?

SF-36: How much of the time during the past 4 weeks: All of the time/Most of the time/A good bit of the time/Some of the time/A little of the time/None of the time.

Did you feel full of life? Have you been a very nervous person? Have you felt so down in the dumps that nothing could cheer you up? Have you felt calm and peaceful? Did you have a lot of energy?

Have you felt down? Did you feel worn out? Have you been a happy person? Did you feel tired?

1.4 Pain

Have you had any of the following aches and pains in the last 12 months? Y/N

Headache? Facial pain, in the jaw muscles, jaw joint or in the ear area? Pain in the neck? Pain in the shoulder? Pain in the upper arms, elbows or forearms? Pain in the fingers or hands? Pain in the chest? Stomach aches/pains? Back ache? Abdominal pain? Pain in the hips? Pain in the thighs, knees or lower legs? Pain in the feet or toes? (Women only:) Pain in the breasts?

[If Yes to any of these: In the last 7 days which pain have you suffered from the most? How severe is or was this pain? Tick one box from the following scale denoting the degree of pain: 1 to 9, where 1=Hardly noticeable pain; 9=Unbearable pain.]

How much do you suffer from the following complaints? Severely/Moderately/Hardly/Not at all
Piercing pain, pain or aches in the chest? Heartburn/acid eructation? Pain in the back? Pain in the neck or shoulders?

SF-36: How much bodily pain have you had during the past 4 weeks? No bodily pain/Very mild/Mild/Moderate/Severe/Very severe

2. Activity limitations

2.1 Self-care

SF-36: Does your health now limit you in these activities? Limited a lot/Limited a little/Not limited at all.
Bathing or dressing yourself?

2.2 Mobility

SF-36: Does your health now limit you in these activities? Limited a lot/Limited a little/Not limited.
Lifting or carrying groceries? Climbing several flights of stairs? Climbing one flight of stairs? Bending, kneeling or stooping? Walking more than 1 km? Walking half a kilometre? Walking 100 metres?

2.5 Specific to work and/or social activities

SF-36: During the past 4 weeks:

How much did pain interfere with your normal work (including both work outside the home and housework)? To what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups? Not at all/Slightly/Moderately/ Quite a bit/Extremely

How much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc)? All of the time/Most of the time/Some of the time/A little of the time/None of the time.

2.6 General items on limitation of daily activities

SF-36: During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities, as a result of your physical health? Y/N

Cut down on the amount of time you spent on work or other activities? Accomplished less than you would like? Were limited in the kind of work or other activities? Had difficulty performing the work or other activities (for example, it took extra effort)?

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities, as a result of any emotional problems (such as feeling depressed or anxious)? Y/N

Cut down on the amount of time you spent on work or other activities? Accomplished less than you would like? Didn't do work or other activities as carefully as usual?

ICELAND (ICE01): 1998 Health and living conditions in Iceland

Brief description of survey

The Health and living conditions survey is undertaken jointly by Statistics Iceland and the University of Iceland. It is conducted irregularly, the last time being in 1998. It is conducted as a postal survey. The sample includes people aged 18-75 years and excludes individuals living in institutions. In 1998, questionnaires were sent to 1,924 individuals.

Disability-related items included in survey

1. Health conditions

1.2 List of specific conditions/illnesses

Have you had... in the past 12 months?

High blood pressure? Diabetes? A stroke? CHD, angina pectoris or heart attack?

2. Activity limitations

2.1 Self-care

How difficult is it generally for you to dress? How difficult is it generally for you to eat?

Not difficult at all/Slightly difficult/Rather difficult/Very difficult

2.2 Mobility

How difficult is it generally for you to move around? How difficult is it generally for you to get out of the house? How difficult is it generally for you to climb stairs?

Not difficult at all/Slightly difficult/Rather difficult/Very difficult

2.4 IADL

How difficult is it generally for you to do housework? Not difficult at all/Slightly difficult/Rather difficult/Very difficult

Have you had any work loss or days of restricted housework due to illness or injury in the past 6 months?
Y/N

2.5 Specific to work and/or social activities

How difficult is it generally for you to work at a job? Not difficult at all/Slightly difficult/Rather difficult/Very difficult

Have you had any work loss or days of restricted housework due to illness or injury in the past 6 months?
Y/N

IRELAND (IRE01): 1998 National health and lifestyle survey

Brief description of survey

The Irish Health and lifestyle survey was carried out for the first time in 1998. It was commissioned by the Department of Health and Children and was carried out by the Department of Health Promotion in the National University of Ireland. It is anticipated that the survey will be conducted every 3 years, with the objective of collecting data on the health, lifestyle and attitudes of people in Ireland. The survey is a self-administered postal questionnaire, sent to non-institutionalised persons aged 18 years and over. The 1998 survey obtained data from approximately 6,500 persons and included the EuroQol instrument as a generic measure of health status.

Disability-related items included in survey

1. Health conditions

1.2 List of specific conditions/illnesses

Have you ever been told by a doctor that you have or have had any of the following? Angina? Heart attack (coronary thrombosis, myocardial infarction)? High blood pressure? Stroke? Diabetes?

1.3 Mental health

1.3.1 Emotional well-being

(EuroQol) Which statement best describes your own health state today: I am not anxious or depressed/I am moderately anxious or depressed/I am extremely anxious or depressed.

1.4 Pain

(EuroQol) Which statement best describes your own health state today: I have no pain or discomfort/I have moderate pain or discomfort/ I have extreme pain or discomfort.

2. Activity limitations

2.1 Self-care

(EuroQol) Which statement best describes your own health state today: I have no problems with self-care/I have some problems with washing or dressing myself/I am unable to wash or dress myself.

2.2 Mobility

(EuroQol) Which statement best describes your own health state today: I have no problems in walking about/I have some problems in walking about/I am confined to bed.

2.3 Communication/senses

Can you follow a TV programme at a volume others find acceptable and without any aid to hearing? With great difficulty/With moderate difficulty/With little difficulty/With no difficulty.

2.6 General items on limitation of daily activities

Is your daily activity or work limited by a long term illness, health problem or disability? Y/N

(EuroQol) Which statement best describes your own health state today: I have no problems with performing my usual activities (e.g. work, study, housework, family or leisure activities)/I have some problems with performing my usual activities/I am unable to perform my usual activities.

ITALY (IT01): 1999-2000 Survey of health conditions and use of health services¹⁰

Brief description of survey

This survey is carried out approximately every 4 years. Municipalities are used as the primary sampling units and in 1994 the survey covered 25,000 households with 75,000 persons. Data are collected through interviewer-administered and self-completed questionnaires. Some items are the same as those recommended in the WHO-Europe "long-term disability" list, while others are similar to SF-36 items with some adjustments in question formulation or response categories.

Disability-related items included in survey

1. Health conditions

1.2 List of specific conditions/illnesses

Do you currently suffer or have you suffered in the past from any of the following illnesses or illnesses? If Yes, was it diagnosed by a doctor?

Allergic illness? Diabetes? Hypertension? Myocardial infraction? Angina pectoris? Other heart disease? Thrombosis, embolus, cerebral haemorrhage? Chronic bronchitis, emphysema, respiratory insufficiency? Bronchial asthma? Osteoarthritis, rheumatoid arthritis? Stomach or duodenal ulcer? Parkinson's disease, Alzheimer's disease, epilepsy?

1.3 Mental health

1.3.1 Emotional well-being

During the last 4 weeks, how much of the time have you felt:

Calm and relaxed? Full of energy? Lacking confidence and depressed?

Always/Nearly always/Much of the time/Part of the time/Mostly never/Never

During the last 4 weeks, have you had difficulty concentrating at work or when doing other activities because of your emotional state (e.g. depressed, anxious)? Y/N

2. Activity limitations

2.1 Self-care

Due to a chronic illness/handicap (and with the use of stick, wheelchair or other aids if necessary):

Can you dress and undress on your own? Can you bathe or shower on your own? Can you wash your hands and face on your own? Can you eat and cut up your food on your own? Without difficulty/With some difficulty/Only with help

2.2 Mobility

Does your health limit you...Doing moderate physical activity (e.g. moving a table, vacuum cleaning, riding a bicycle)? Climbing several flight of stairs? Limited a lot/Limited partially/Not limited at all.

Due to a chronic illness/handicap (and with the use of stick, wheelchair or other aids if necessary):

Are you permanently confined to bed even though there may be help to get you up? Do you sit in a chair (not a wheelchair) all day even though there may be help for you to walk? Are you confined to your house (flat) (include garden, if it exists) for physical or psychological reasons? Y/N

¹⁰ The English translation of this survey has not been validated and has therefore no official status.

Can you walk up and down one flight of 12 stairs alone without stopping? When standing up, can you bend down to pick up a shoe from the floor? Without difficulty/With some difficulty/With a lot of difficulty/Unable.

Can you lie down and get up from bed on your own? Can you sit down and get up from a chair on your own? Without difficulty/With some difficulty/Only with help.
What is the furthest you can walk alone without stopping and without getting too tired? 200 metres or more/More than a few steps but <200 metres/Only a few steps

2.3 Communication/senses

Due to a chronic illness/handicap (and with the use of glasses/contact lenses/hearing aid if necessary):
Can you see well enough to recognise a friend at a distance of 4 metres (across a street)? Y/N [If No: Can you recognise a friend at a distance of 1 metre (at arm's length)? Y/N]
Can you hear well enough to follow a TV programme at a volume others find acceptable? Y/N [If No: Can you follow a TV programme with the volume turned up? Y/N]
Can you speak without difficulty? Y/N

2.4 IADL

Are you usually able to:
Shop? All shopping without help/Small things without help/Always with help/Not able at all.
Prepare food? Completely/If ingredients are provided/Can only warm and serve a meal/No, meals have to be prepared and served by others.
Take care of the house? Occasional help for hard jobs/Can do simple daily jobs (dishes, beds)/Only very simple daily jobs and cannot keep house properly clean/Always need help/Not at all.
Wash your clothes? All (including with washing machine)/Only small things e.g. socks/Not at all. Take care of personal finances? All (budgeting and keeping accounts, writing checks, paying bills)/Can do daily shopping but need help for larger items and accounts/Not able

2.5 Specific to work and/or social activities

During the last 4 weeks, to what degree has pain limited the work you usually do (at home and outside the home)? Not at all/Very little/Part of the time/Very much
How much of the time has your physical health or emotional state interfered with your social activities, with family and friends? Always/Nearly always/Part of the time/Mostly never/Never

2.6 General items on limitation of daily activities

Do you have a chronic illness or permanent handicap that reduces your personal autonomy to the point that you need someone else's help in daily life at home or outside the home? No/Affected in some things/Affected all the time or in important things

During the last 4 weeks, have you:
Accomplished less than you would like at work or in your daily activities... Because of your physical health? Y/N Because of your emotional state (e.g. depressed, anxious)? Been limited in the amount of work or other activities you could do because of your physical health? Had difficulty concentrating at work or when doing other activities because of your emotional state (e.g. depressed, anxious)? Y/N

JAPAN (JP01): 2000 Household survey of physical and mental health¹¹

Brief description of survey

The Household survey of physical and mental health is conducted by the Department of Health Statistics, with the objective of obtaining basic information about people's health and welfare in order to inform health policy, particularly in the area of mental health. The survey is conducted as a self-administered questionnaire, sent to persons aged 12 years and over. The sample size in 2000 is expected to be approximately 37,000 people.

Disability-related items included in survey

1. Health conditions

1.3 Mental health

1.3.1 Emotional well-being

During the past month did you tend to feel tired? Did you still feel tired when you woke up in the morning? Did you become irritated? Y/N

During the past month:

Response categories: Rarely or none of the time (less than 1 day)/Some or a little of the time (1-2 days)/Occasionally or moderate amount of time (3-4 days)/Most or all of the time (5-7 days)

I was bothered by things that usually don't bother me. I did not feel like eating; my appetite was poor.

I felt that I could not shake off the blues even with help from my family or friends. I had crying spells.

I had trouble keeping my mind on what I was doing. I felt depressed. I felt that everything I did was an effort. I thought my life had been a failure. My sleep was restless. I felt sad. I talked less than usual. I felt lonely. People were unfriendly. I felt that people dislike me. I could not get going. I felt fearful.

I enjoyed life. I felt hopeful about the future. I felt that I was just as good as other people. I was happy.

Have you been under or felt you were under any strain, stress, or pressure? Quite a bit/Some/A little/Not at all

1.4 Pain

During the past month did you have: Headaches? Back pain and/or a lame hip? Y/N

2. Activity limitations

2.6 General items on limitation of daily activities

(If Yes to strain, stress or pressure): Have you had any trouble in daily living or social life because of strain, stress, or pressure? A lot of difficulty/Some difficulty/A little difficulty/No difficulty

¹¹ Only partial English translation is available.

KOREA (KR01): 1995 National health interview survey¹²**Brief description of survey**

The National health interview survey is conducted every 3 years by the Korean Institute for Health and Social Affairs with the objective of providing national data on health status and health care utilisation. It takes the form of an interview-administered questionnaire, in which questions are completed for all household members.

Disability-related items included in survey**1. Health conditions***1.2 List of specific conditions/illnesses*

During the past 12 months (1 year), has anyone in your family had any of the following conditions, or have been ill for more than 3 months ? Y/N

Diseases of the musculoskeletal system? Diseases of the digestive system? Endocrine, nutritional or metabolic diseases? Diseases of the circulatory system? Diseases of the respiratory system?

2. Activity limitations*2.1 Self-care*

Refer to the family members who have any difficulty getting around inside and outside the home, and need assistance. Activity of daily living? (Reason for limitation? Degree and type of assistance?)

2.2 Mobility

Refer to the family members who have any difficulty getting around inside and outside the home, and need assistance. Reason for limitation? Degree and type of assistance?

2.3 Communication/senses

Refer to the family members who have any difficulty getting around inside and outside the home, and need assistance. Hearing? Seeing? (Reason for limitation? Degree and type of assistance?)

2.5 Specific to work and/or social activities

Refer to the family members who have any difficulty getting around inside and outside the home, and need assistance. Social handicap? (Reason for limitation? Degree and type of assistance?)

¹²

The English translation of this survey has not been validated and has therefore no official status.

NETHERLANDS (NL01): Health interview survey

Brief description of survey

Statistics Netherlands (CBS) has conducted a continuous Health interview survey since 1981. The objective is to monitor health trends, life style, preventive behaviour and health care utilisation of the Dutch population. The survey is conducted as a computer-assisted personal interview among a random sample of people living in households (excluding institutions), and includes all age groups (proxies are used for children). A maximum of four people are interviewed in each household and approximately 10,000 people are interviewed each year. A self-administered questionnaire is also used to collect supplementary information.

The health items listed below have been included in the survey since 1989. The survey questionnaire includes the Subjective health inventory (VOEG), which produces an overall score based on 23 items. A long-term disability score is constructed based on seven items from the 1982 OECD list.

Disability-related items included in survey

1. Health conditions

1.1 General prevalence (condition/illness not specified)

Do you suffer from one or more chronic conditions or handicaps? Y/N

1.2 List of specific conditions/illnesses

Checklist of chronic conditions: Asthma, chronic bronchitis or chronic non-specific respiratory disease? Serious heart disease or heart attack? Hypertension? Stroke and effects of stroke? Stomach ulcer or duodenal ulcer? Diabetes mellitus? Arthrosis of knees, hips or hands? Arthritis of hands or feet? Other rheumatoid arthritis for longer than 3 months? Epilepsy?

1.3 Mental health

1.3.1 Emotional well-being

(As part of VOEG - Subjective health inventory – based on 23 items):

Do you get to sleep easily and do you sleep well? Do you often feel tired? Do you often get upset?

Do you often feel listless? Do you often feel nervous? Do you get tired sooner than you would consider normal? Are you often irritable? Y/N

1.4 Pain

(As part of VOEG - Subjective health inventory – based on 23 items):

Do your bones or muscles ever ache? Are you often troubled by back-ache? Do you often have pains in the chest or heart region? Do you often have headaches? Are you rheumatic? Do you regularly have pains in the stomach region? Y/N

2. Activity limitations

2.1 Self-care

(ADL for persons aged 55 years and over): Can you: Wash your face and hands? Wash your whole body? Dress and undress? Eat and drink?

Without difficulty/With some difficulty/With great difficulty/Only with help from others.

2.2 Mobility

Are you bedridden due to any complaints, disease or disability? Continually restricted/Restricted at intervals/Not or seldom restricted.

(ADL for persons aged 55 years and over): Please indicate for every item whether you can perform it: Without difficulty/With some difficulty/With great difficulty/Only with help from others.

Getting in and out of a chair? Getting in and out of bed? Moving towards another room on the same floor? Walking up and down the stairs? Leaving and entering the house? Moving along outside the house?

Can you: Carry an object of 5 kg for 10 metres, e.g. a full shopping bag? When standing, bend down and pick up something from the floor? Walk 400 meters without resting (with walking stick if necessary)? Yes, without difficulty/Yes, but with minor difficulty/Yes, but with major difficulty/No

2.3 Communication/senses

Is your eyesight good enough (with glasses if necessary): To read small letters in the newspaper? To recognise someone's face at a distance of 4 metres? Yes, without difficulty/Yes, but with minor difficulty/Yes, but with major difficulty/No

Can you: Hear what is said in a group of 3 or more persons (with hearing aid if necessary)? Carry on a conversation with one other person (with hearing aid if necessary)? Yes, without difficulty/Yes, but with minor difficulty/Yes, but with major difficulty/No

2.6 General items on limitation of daily activities

Are you restricted in your daily activities due to any complaints, disease or disability? Continually restricted/Restricted at intervals/Not or seldom restricted

NEW ZEALAND (NZ01): 1996-7 New Zealand health survey

Brief description of survey

This survey is administered by Statistics New Zealand at the request of the Ministry of Health, and has so far been carried out in 1992-3 and 1996-7. The objective is to measure the health status and health needs of New Zealanders, and to collect information on health behaviour and health service use. The survey consists of both an interview-administered questionnaire and a self-administered questionnaire. The study population covers the non-institutionalised civilian population of New Zealand of all ages. A sample of 7-8,000 people is used, with one respondent per household. The self-administered questionnaire includes the SF-36, which is completed by all respondents aged 15 years and over.

Disability-related items included in survey

1. Health conditions

1.1 General prevalence (condition/illness not specified)

Do you have any disability or handicap that is long-term (lasting 6 months or more)? Y/N

1.2 List of specific conditions/illnesses

Have you ever been told by a doctor that you have diabetes (other than during pregnancy)? Have you ever taken or are you currently taking pills regularly for high blood pressure? In the last 12 months, have you had an attack of asthma? Y/N

1.3 Mental health

1.3.1 Emotional well-being

SF-36: How much of the time during the past 4 weeks: All of the time/Most of the time/A good bit of the time/Some of the time/A little of the time/None of the time.

Did you feel full of life? Have you been a very nervous person? Have you felt so down in the dumps that nothing could cheer you up? Have you felt calm and peaceful? Did you have a lot of energy? Have you felt down? Did you feel worn out? Have you been a happy person? Did you feel tired?

1.4 Pain

SF-36: How much bodily pain have you had during the past 4 weeks? None/Very mild/Mild/Moderate/Severe/Very severe

2. Activity limitations

2.1 Self-care

SF-36: Does your health now limit you in these activities? Limited a lot/Limited a little/Not limited at all. Bathing or dressing yourself?

2.2 Mobility

SF-36: Does your health now limit you in these activities? Limited a lot/Limited a little/Not limited at all. Lifting or carrying groceries? Climbing several flights of stairs? Climbing one flight of stairs? Bending, kneeling or stooping? Walking more than 1 km? Walking half a kilometre? Walking 100 metres?

2.5 Specific to work and/or social activities

SF-36: During the past 4 weeks:

How much did pain interfere with your normal work (including both work outside the home and housework)? To what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups? Not at all/Slightly/Moderately/ Quite a bit/Extremely

How much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc)? All of the time/Most of the time/Some of the time/A little of the time/None of the time.

Does a health problem, or a condition, you have (lasting 6 months or more) cause you difficulty with, or stop you doing: Communicating, mixing with others or socialising? Y/N

2.6 General items on limitation of daily activities

Does a health problem, or a condition, you have (lasting 6 months or more) cause you difficulty with, or stop you doing: Everyday activities that people your age can usually do? Any other activity that people your age can usually do? Y/N

SF-36: During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities, as a result of your physical health? Y/N

Cut down on the amount of time you spent on work or other activities? Accomplished less than you would like? Were limited in the kind of work or other activities? Had difficulty performing the work or other activities (for example, it took extra effort)?

SF-36: During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities, as a result of any emotional problems (e.g. feeling depressed or anxious)? Y/N

Cut down on the amount of time you spent on work or other activities? Accomplished less than you would like? Didn't do work or other activities as carefully as usual?

NEW ZEALAND (NZ02): 1996 New Zealand Household disability survey

Brief description of survey

This survey, which was the first national survey of disability in New Zealand, was conducted by Statistics New Zealand as a post-censal survey, linked to the 1996 Census. The main objectives were to measure prevalence of disability among the non-institutionalised population and to provide information on the nature, severity and origin of disability. Two filter questions in the 1996 Census established a sample frame of people with long-term illnesses or disabilities, who then received a Screening Questionnaire to identify those who were disabled. Those identified as being disabled were asked the questions below as part of an interview-administered questionnaire.

The Disability survey is based on the 1986 Health and activity limitation survey (HALS) run by Statistics Canada. A functional concept of disability was used, defined as any limitation in activity resulting from a long-term condition or health problem. The limitation had to be for a minimum of 6 months (or expected to last that time) and not be eliminated through the use of simple corrective devices such as glasses. For children under 15 (reported via proxy), a broader definition was used which also included specific chronic conditions and support needs.

Disability-related items included in survey

2. Activity limitations

2.1 Self-care

Because of your condition or health problem, do you get help with your personal care, such as washing and dressing and taking medication? Y/N

In the last 12 months, have you needed help with your own personal care, housework or shopping because of your condition or health problem? Y/N

2.2 Mobility

Because of your condition, do you use any special features to enter or leave your present home?

To enter or leave your present home, do you need any special features which you do not already have?

Because of your condition or health problem, does your home have any special features inside?

Inside your home, do you need any special features which you do not already have?

Y/N [If Yes: Specify which features]

Do you use, or do you need, any equipment to help you move about, e.g. a walking stick or wheelchair?

Do you use, or do you need, any special equipment or a limb replacement to help you in the use of your hands or arms? Y/N [If Yes: Specify what equipment]

2.3 Communication/senses

Because of your condition or health problem, do you get help in communicating with other people, such as when you see a doctor or at a job interview? Y/N

2.4 IADL

Because of your condition or health problem, do you get help preparing your meals? For groceries and other things you need? With normal everyday housework, e.g. tidying up, cleaning and laundry? With

heavy household work such as spring cleaning, gardening or mowing lawns? With looking after your private finances, such as banking or paying bills? Y/N

In the last 12 months, have you needed help with your own personal care, housework or shopping because of your condition or health problem? Y/N

2.5 Specific to work and/or social activities

Because of your condition or health problem, do you need any of the following to be able to work in your present job? A person to help you (e.g. a reader, sign language interpreter)/Technical equipment and devices/Modified or different duties/Modified hours or days, reduced work hours/Building modifications... (If not in labour force): Does your condition or health problem completely stop you from working at a job or business? Y/N

NORWAY (NR01): 1995 Health interview survey

Brief description of survey

This survey is conducted by Statistics Norway every 10 years to collect data on health and illness, health inequalities and health care utilisation in Norway. The survey includes both an interviewer-administered questionnaire and a self-administered questionnaire. A sample of approximately 5,000 households is used (excluding institutions). All household members are interviewed, with a parent or guardian responding for children under 15 years.

Disability-related items included in survey

1. Health conditions

1.1 General prevalence (condition/illness not specified)

Do you suffer from any illness or disorder of a more long-term nature, any congenital disease or the effect of an injury? (i.e. that have lasted or are expected to last for 6 months or more) Y/N

1.2 List of specific conditions/illnesses

Have you any of the illnesses listed on this card? Has a physician ever said you have this condition? Diabetes? Epilepsy? High blood pressure? Heart disease? Myocardial infarction? Stroke? Chronic bronchitis? Asthma? Hay fever/pollen allergy? Allergic skin condition? Rheumatism? Rheumatoid arthritis? Osteoarthritis? Stomach ulcer?

2. Activity limitations

2.1 Self-care

If problems with any of the mobility questions below: Can you manage to do your shopping without help from others? Y/N Can you manage to clean your dwelling/flat without help from others? Y/N [If No to either of these: Can you dress and undress yourself? Can you manage to attend to your own personal hygiene? Can you eat by yourself, including cutting up your food? With no difficulty/With some difficulty/Only with the help of others.]

2.2 Mobility

The following questions apply to more long-term problems, i.e. that have lasted or are expected to last at least six months. Can you run for a short distance, say 100 metres, if you're in a hurry? Can you walk up or down one flight of stairs without resting? Y/N

[If No to either of above questions: What is the furthest you can walk without help from others, without stopping and without difficulty (on a road in dry weather)? Just a few steps /More than a few steps but less than 200 metres/200 metres or more.

If less than 200 metres: Can you sit down in and get up from a chair without help from others? With no difficulty/With some difficulty/Only with the help of others. Can you get in and out of bed without help from others? With no difficulty/With some difficulty/Only with the help of others.]

(Asked of people with long-term illness and/or disability): Owing to permanent health problems or disabilities, have you had trouble getting out of your dwelling on your own? Yes, not possible/Yes, extremely difficult/Yes, somewhat difficult/No.

2.3 Communication/senses

Can you without difficulty, wearing glasses if necessary, see ordinary newsprint? Y/N [If No: Can you see well enough, wearing glasses if necessary, to recognise a friend at a distance of 4 metres? Y/N]

Can you without difficulty, or wearing a hearing aid if necessary, hear what is said during the course of a normal conversation with at least two other people? Y/N [If No: Is your hearing good enough, wearing a hearing aid if necessary, to follow a TV programme with the sound at a level others find acceptable? Y/N
If No: Can you follow along with a TV programme if the sound is louder? Y/N]

2.4 IADL

(If problems with any of the mobility questions above): Can you manage to do your shopping without help from others? Can you manage to clean your dwelling/flat without help from others? Y/N

2.5 Specific to work and/or social activities

Owing to permanent health problems or disabilities, have you:

Had trouble implementing or initiating the education or training you want? Had trouble finding a job you could manage? (If aged 16-79 years): Had trouble doing your job?

Had trouble participating in clubs or associations? Had trouble participating in other recreational activities?

Had trouble establishing contact with or talking to other people?

Yes, not possible/Yes, extremely difficult/Yes, somewhat difficult/No.

2.6 General items on limitation of daily activities

To what extent do the permanent illnesses/disabilities you have mentioned affect your everyday life?

To a large extent/To some extent/To a small extent/Not at all

PORTUGAL (PR01): 1998/9 Health interview survey

Brief description of survey

The Health interview survey is conducted by the Ministry of Health every 3 years. In 1995/6 it included items on long-term disability for the first time and the same items were repeated in 1998/9. These items were largely taken from the WHO-Europe recommended instrument. The survey is based on a sample of approximately 17,000 households, and excludes people living in institutions.

Disability-related items included in survey

1. Health conditions

1.2 List of specific conditions/illnesses

Do you suffer from: Diabetes (blood sugar)? Epilepsy? High blood pressure?
Do you have or have you had in the last 12 months: Asthma? Chronic bronchitis? Allergy
[If Yes to any of these: Were you told you suffer this disease by a doctor or a nurse? Y/N]

1.4 Pain

Do you usually have a lower backache? Y/N

2. Activity limitations

2.1 Self-care

Can you: Get to and use the toilet? Dress and undress? Wash your hands and face? Eat (including cutting up food)? On your own, with no difficulty/On your own, with difficulty/Only with help.

2.2 Mobility

Are you permanently confined to bed even though there may be help to get you up? Do you sit in a chair (not a wheelchair) all day (except during night) even though there may be help for you to walk? Are you confined to your house (flat) (including garden)? Y/N

Can you get in and out of bed? Can you get in and out of a chair? When you are standing up, can you bend down and pick up, for example, a shoe from the floor?

On your own, with no difficulty/On your own, with difficulty/Only with help.

What is the furthest you can walk on a level ground without stopping and without severe discomfort? 200 metres or more/More than a few steps but <200 metres/Only a few steps/Can't walk but use a wheelchair/Can't walk.

Can you walk up and down a flight of 12 stairs? Not resting/Taking a rest/Can't, even if take a rest.

2.3 Communication/senses

Can you see well enough to recognise a friend (with or without glasses or contact lenses) at a distance of 4 metres, e.g. from across the road/At a distance of 1 metre/Not even at a distance of 1 metre?

Can you follow a TV or radio programme (with or without a hearing aid)? At a volume others find acceptable/With volume turned up/Not even with volume turned up.

Do you have speaking difficulties? Y/N

SPAIN (SP01): 1999 Survey on disability, impairment and health status

Brief description of survey

This survey was conducted for the first time in 1999, by the National Institute of Statistics. It is conducted as a face-to-face interview and consists of three questionnaires. The first asks about socio-demographic characteristics of all household members, the second enquires about household members with disabilities, and the third (completed by one member of the household) contains questions on health. In 1999, approximately 79,000 households were surveyed. The items listed here are for respondents aged ≥ 6 years. Further questions are asked for children aged 0-5 years, covering ability to walk, see, hear, and physical and cognitive development.

Disability-related items included in survey

1. Health conditions

1.2 List of specific conditions/illnesses

Has your doctor told you that you are suffering from one or more of the following problems or chronic illnesses? Chronic bronchitis, asthma, emphysema? Allergies of any kind (skin, respiratory etc.)? Epilepsy? Diabetes? High blood pressure? Heart diseases? Arthrosis and rheumatic problems (neck, shoulder and lumbar region)? Stomach or duodenal ulcer, atrophic gastritis?

(Asked if Yes to any disability on Household questionnaire:) Have you been diagnosed as having any of the following illnesses? Y/N Rheumatoid arthritis or ankylosing spondylitis? Myocardial infarction or ischaemic heart disease? Stroke?

1.3 Mental health

1.3.2 Cognitive ability

Do you have any difficulty with the following activities? Y/N Recognising persons, objects and relationships in space and time? Remembering recently/past acquired information and/or events? Carrying out simple tasks? [If Yes: What level of difficulty? No difficulty/Moderate difficulty/Severe difficulty/Unable]

2. Activity limitations

2.1 Self-care

Do you have any difficulty with the following activities (disabilities suffered or expected to be suffered for at least 1 year; using aids if necessary, e.g. walking stick, crutches, oxygen etc.)? Y/N Washing oneself and personal care? Dressing? Eating & drinking? Manipulating small objects? [If Yes: What level of difficulty, using aids if necessary)? No difficulty/ Moderate difficulty/Severe difficulty/Unable]

2.2 Mobility

Do you have any difficulty with the following activities (disabilities suffered or expected to be suffered for at least 1 year; using aids if necessary, e.g. walking stick, crutches, oxygen etc.)? Y/N Lying down? Getting up, sitting down and maintaining a standing or seated position? Moving around your own home? [If Yes: What level of difficulty, using aids if necessary)? No difficulty/Moderate difficulty/Severe difficulty/Unable]

Do you now have any difficulty in coping normally in any of the following places due to a temporary health-related problem or any impairment from which you suffer: In the entrance hall to your house? On the stairs? In the bathroom? In other rooms of your home? In other places?

2.3 Communication/senses

Do you have any difficulty with the following activities (disabilities suffered or expected to be suffered for at least 1 year; using aids, e.g. glasses/contact lenses/hearing aid, if necessary)? Y/N Seeing in the far distance? Seeing in the near distance and/or in detail? Hearing (e.g. 2 persons speaking)? Speaking? [If Yes: What level of difficulty, using aids if necessary)? No difficulty/ Moderate difficulty/Severe difficulty/Unable]

2.4 IADL

Do you have any difficulty with the following activities (disabilities suffered or expected to be suffered for at least 1 year)? Y/N Taking care of daily necessities (including shopping)? Taking care of meals? Laundry and caring for clothes and footwear? Taking care of dwelling? [If Yes: What level of difficulty, using aids if necessary)? No difficulty/Moderate difficulty/Severe difficulty/Unable]

2.5 Specific to work and/or social activities

Do you have any difficulty with the following activities (disabilities suffered or expected to be suffered for at least 1 year)? Y/N Maintaining family relationships? Making new friends and maintaining relationships with friends? Interacting with persons in formal settings? [If Yes: What level of difficulty? No difficulty/Moderate difficulty/Severe difficulty/Unable]

2.6 General items on limitation of daily activities

(If not completed Disabilities or Limitations questionnaire:) Have your everyday activities been limited on health-related grounds in the last month? Y/N [If Yes: number of working and non-working days?]

SWEDEN (SWE01): 1999 Survey of living conditions (ULF)¹³**Brief description of survey**

Statistics Sweden (SCB) has conducted this survey annually since 1975. Each year, a random sample of 7,000 people aged 16-84 years is drawn from the Swedish population. The survey is interviewer-administered and includes questions on social relations, work, health and physical environment. A special component on health is included every 8 years i.e. 1980-1, 1988-9 and 1996-7. The items listed below are core health items that are included each year.

Disability-related items included in survey**1. Health conditions***1.1 General prevalence (condition/illness not specified)*

Do you suffer from any long-term illness, after-effects of an accident, disability or other ailment? Y/N

*1.3 Mental health**1.3.1 Emotional well-being*

Have you any of the following: Nervousness, worry or anxiety? Yes, a great deal/Yes a little/No

1.4 Pain

Have you any of the following: Pain in shoulder or neck? Back or hip pain? Pain in hands, elbows, legs or knees? Yes, a great deal/Yes a little/No

2. Activity limitations*2.1 Self-care*

(Asked if Yes to long-standing illness, reduced sight, mobility problems or aged 75-84 years)

Can you do the following yourself or do you need help with it: Showering or bathing? Y/N

2.2 Mobility

Can you take a short walk, e.g. 5 minutes, at a fairly quick pace? Can you climb stairs without difficulty? Y/N

(Asked if Yes to long-standing illness, reduced sight, mobility problems or aged 75-84 years)

Can you do the following yourself or do you need help with it: To stand up or lie down? Y/N

2.3 Communication/senses

Can you without difficulty read ordinary text in a newspaper (with or without eyeglasses)? Y/N

Can you without difficulty hear what is said in a conversation between several persons (with or without a hearing aid)? Y/N

2.4 IADL

(Asked if Yes to long-standing illness, reduced sight, mobility problems or aged 75-84 years)

Can you do the following yourself or do you need help with it: Cleaning? Housework? Buying food? Preparing meals? Laundry? Y/N

2.6 General items on limitation of daily activities

(*Old-age pensioners only*): Do you find it difficult to do any of your normal activities as a consequence of your illness (es)? To a great extent/To some extent/Not at all

¹³

The English translation of this survey has not been fully validated and has therefore no official status.

SWITZERLAND (SZ01): 1997 Swiss health survey¹⁴

Brief description of survey

The Swiss health survey is undertaken by the Swiss Federal Statistical Office every 5 years. The main objectives are to monitor the population's health and to provide data to help the development of health policy. The survey sample includes private households throughout Switzerland, and excludes people living in institutions. Data are collected by telephone interviews (15-74 year olds) and personal interviews (≥ 75 years), as well as supplementary self-completed questionnaires. In 1997, 13,000 people participated in the survey. The items listed below are included in both the telephone and the interview-administered questionnaire.

Disability-related items included in survey

1. Health conditions

1.1 General prevalence (condition/illness not specified)

Today there are a number of people who have a physical or a psychological problem that limits their daily activities. Do you have such a problem or an illness of this type which you have had for more than one year? Y/N [If Yes: Is that due to physical causes, psychological causes, both or neither? What is the problem exactly? (Interviewer: list two problems): List of health problems according to ICD-10]

1.2 List of specific conditions/illnesses

Do you have allergies, including hay fever? Y/N

1.3 Mental health

1.3.1 Emotional well-being

Have you been in treatment for psychological problems during the course of the last 12 months? Y/N

During the last 4 weeks: Have you felt tired or lacking in energy? Have you had difficulty sleeping? Not at all/A little/A lot

1.4 Pain

During the last 4 weeks: Have you had back pain? Have you had headaches or facial pain? Have you had pain in your limbs or joints? Not at all/A little/A lot

2. Activity limitations

2.1 Self-care

Alone, are you able to dress and undress yourself, get out of bed and eat without help and without difficulty? Yes, I can do all of these by myself without difficulty/No, I cannot do all of these alone, without difficulty.

[If No: Can you dress and undress yourself without help? Can you eat without help, e.g. are you able to cut food such as meat, fruits, etc.? Yes, without difficulty/Yes, without too much difficulty/Yes, but with major difficulty/No]

¹⁴ The English translation of this survey has not been validated and has therefore no official status.

2.2 Mobility

(If cannot dress and undress, get out of bed and eat without help and without difficulty): Are you able to get into and out of bed by yourself? Without difficulty/Without too much difficulty/With major difficulty/No (If With difficulty or No: Are you bedridden, even if someone were able to help you get up? Y/N)]

Over what distance are you able to walk alone (unassisted) without stopping and without too much difficulty? ≥ 200 meters/More than a few steps, but < 200 meters/Few steps only/Cannot get around or walk

2.3 Communication/senses

Do you see well enough to read a book or a newspaper (with glasses or contact lenses if you usually wear them)? Can you follow a conversation with at least two other persons?

Yes, without difficulty/Yes, without too much difficulty/ Yes, but with major difficulty/No

Can you speak without difficulty? Y/N

2.6 General items on limitation of daily activities

For how many days during the last 4 weeks have you been handicapped by a health problem to the extent that you have not been able to participate in your normal activities? Never/x days

[If Yes: For what reason? Illness/Accident/Both/Other]

And for how many days during the last 4 weeks have you not been able to work or do your usual activities (e.g. housecleaning)? x days/Never

UNITED KINGDOM (UK01): 1995 and 1996 Health Survey for England

Brief description of survey

The Health Survey for England is an annual survey commissioned by the Department of Health since 1991. Initially, the survey was carried out by the Social Survey Division of the Office for National Statistics (ONS). Since 1994, it has been carried out by the Joint Health Surveys Unit of Social and Community Planning Research and the Department of Epidemiology and Public Health at University College, London. The 1991 and 1992 surveys had a limited population sample of about 3,000 and 4,000 adults. For 1993 to 1996, adult sample was boosted to about 16,000. In 1995, a sample of about 4,000 children (aged 2 years and over) was introduced. As a result, the annual sample frame consists of approximately 11,000 households in England, covering 20,000 people aged 2 years and over. A parent or guardian responds for children aged 2-12 years, while children aged 13-15 years are interviewed in person with consent from a parent or guardian. Computer-assisted personal interviewing is used, as well as a health examination which includes height, weight and blood pressure measurements and the taking of blood samples. Information on the “core” topics is collected every year; “non-core” topics vary and reflect the focus of interest in a particular year.

‘Core’ topics

- general health
- smoking and drinking behaviour
- blood pressure
- height and weight
- mental health, through the use of GHQ-12 (except in 1996, to make room for generic measures)

‘Non-core’ topics

- cardiovascular disease (1991-94, 1998)
- asthma and other respiratory diseases (1995-97)
- generic health status measures, through the use of EuroQol and SF-36 (1996) – SF-12 to be included in 2000
- disability, through the use of WHO-Europe “long-term disability” instrument with some adjustments (1995) – a special disability module is also planned for 2001

The following provides a list of items included in the 1995 and 1996 surveys combined, to provide fuller coverage.

Disability-related items included in survey

1. Health conditions

1.1 General Prevalence (condition/illness not specified)

Do you have any long-standing illness, disability or infirmity? Yes/No (By long-standing I mean anything that has troubled you over a period of time, or that is likely to affect you over a period of time)

1.2 List of specific conditions

[If Yes to previous question] What is the matter with you? (possibility to record up to six long standing illnesses; these conditions are reported along various ICD chapters including: musculoskeletal system, hearth and circulatory system, respiratory system, digestive system, nervous system, skin complaints, mental disorders, neoplasms and benign growths).

1.3 Mental Health

1.3.1 Emotional well-being

1995 Survey

(GHQ-12) Have you recently lost much sleep over worry? felt constantly under strain? felt you couldn't overcome your difficulties? been losing confidence in yourself? been thinking of yourself as a worthless person? been feeling unhappy and depressed? Not at all/No more than usual/Rather more than usual/Much more than usual.

Have you recently felt you were playing a useful part in things? been able to face up to your problems? been feeling reasonably happy, all things considered? been able to enjoy your normal day-to-day activities? been able to concentrate on whatever you're doing? felt capable of making decisions about things? More than usual/Same as usual/Less than usual/ Much less than usual

1996 Survey

(SF-36) How much of the time during the past 4 weeks: All of the time/Most of the time/A good bit of the time/Some of the time/A little of the time/None of the time.

Did you feel full of life? Have you been a very nervous person? Have you felt so down in the dumps that nothing could cheer you up? Have you felt calm and relaxed? Did you have a lot of energy? Have you felt down? Did you feel worn out? Have you been a happy person? Did you feel tired?

(EuroQol) Which statement best describes your own health state today: I am not anxious or depressed/I am moderately anxious or depressed/I am extremely anxious or depressed.

1.4 Pain

(SF-36) How much bodily pain have you had during the past 4 weeks? None/Very mild/Mild/Moderate/Severe/Very severe

(EuroQol) Which statement best describes your own health state today: I have no pain or discomfort/I have moderate pain or discomfort/ I have extreme pain or discomfort.

2. Activity limitations (items 2.1, 2.2 and 2.3 are taken from the 1995 questionnaire)

2.1 Self-care

Do any of the things on this card apply to you (only problems expected to last more than 1 year)?

Cannot: Wash hands and face without difficulty? Dress and undress without difficulty? Get to and use toilet on own without difficulty? Feed, including cutting up food without difficulty? Y/N [If Yes: Can you do this with some difficulty or only with someone to help you?]

2.2 Mobility

Do any of the things on this card apply to you (only problems expected to last more than 1 year)?

Cannot get in and out of bed on own without difficulty? Y/N [If Yes: Can you do this with some difficulty or only with someone to help you?]

Cannot get in and out of a chair without difficulty? Y/N [If Yes: Can you do this with some difficulty or only with someone to help you, or are you chair-bound?]

Cannot walk 200 yards or more on own without stopping or discomfort (with walking aid if normally used)? Y/N [If Yes: What is the furthest you can walk on your own without stopping or discomfort (with walking aid if normally used)? A few steps only/More than a few steps but <200 yards/Cannot walk at all.]

Cannot bend down and pick up a shoe from the floor when standing? Y/N

Cannot walk up and down a flight of 12 stairs without resting? Y/N [If Yes: Can you walk up and down a flight of 12 stairs if you hold on and take rests? Y/N]

2.3 Communication/senses

Do any of the things on this card apply to you, using glasses/contact lenses or hearing aid if normally worn? (only problems expected to last more than 1 year)

Cannot see well enough to recognise a friend across a road (4 yards away)? Y/N [If Yes: Can you do this one yard away (at arm's length)? Y/N]

Cannot follow a TV programme at a volume others find acceptable? Y/N [If Yes: Can you do this with the volume turned up? Y/N]

Cannot speak without difficulty? Y/N Do you have a problem communicating with other people, that is, have problem understanding them or being understood by them? Y/N (If Yes: Are your communication problems to do with your speech? Your hearing? Your vision? Y/N]

2.6 General item on limitation of daily activities

Does this [longstanding] illness or disability (or do any of these illnesses or disabilities) limit your activities in any way? Yes/No

UNITED KINGDOM (UK02): 1998/99 Labour force survey (annual)**Brief description of survey**

This is a continuous survey covering private households in Great Britain and Northern Ireland, with an additional sample drawn from people registered with the National Health Service. Sample size is 68,250 households per quarter. Respondents are questioned five times at 13-week intervals and one-fifth of the sample is replaced each quarter. Data are collected through computer-assisted personal interviews (first wave) and by telephone (2nd-5th waves).

Disability-related items included in survey**1. Health conditions***1.1 General prevalence (condition/illness not specified)*

Do you have any health problems or disabilities that you expect will last for more than a year? Y/N

1.2 List of specific conditions/illnesses

(If yes to health problems): Do you have: Problems or disabilities (including arthritis or rheumatism) connected with your arms or hands? legs or feet? back or neck? Severe disfigurement, skin conditions, allergies? Chest or breathing problems, asthma, bronchitis? Heart, blood pressure or blood circulation problems? Diabetes? Epilepsy?

*1.3 Mental health**1.3.1 Emotional well-being*

Do you have depression, bad nerves or anxiety? Do you have mental illness or suffer from phobias, panics or other nervous disorders? Y/N

1.3.2 Cognitive ability

Do you have severe or specific learning difficulties (mental handicap)? Y/N

2. Activity limitations*2.3 Communication/senses*

Do you have difficulty in seeing (while wearing spectacles or contact lenses?) Do you have difficulty in hearing? Do you have a speech impediment? Y/N

2.5 Specific to work and/or social activities

(Applies to all population of working age, i.e. men aged 16-64 and women aged 16-59, who responded "yes" to having a long-standing illness): Does this health problem affect the *kind* of paid work that you might do? The *amount* of paid work that you might do? Y/N

2.6 General items on limitation of usual activities

Does this (these) health problem(s) or disability(ies) (when taken singly or together) substantially limit your ability to carry out normal day to day activities? (If you are receiving medication or treatment, please consider what the situation would be without the medication or treatment) Y/N

UNITED KINGDOM (UK03): 1996-97 Disability survey

Brief description of survey

The UK Disability survey is conducted irregularly, the last time being in 1996-97. All persons aged 16 years and over in selected private households are interviewed, using proxies for adults not at home or ill at the time of interview. Data are collected through computer-assisted personal interviews. The survey includes some items from the EuroQol instrument, and also asks many detailed questions about mobility, vision, hearing and the use of special aids and services. Only those items most similar to those used in other surveys are listed here.

Disability-related items included in survey

1. *Health conditions*

1.3 *Mental health*

1.3.1 Emotional well-being

Do you suffer from severe depression or anxiety which affects your daily activities? Y/N [If No, ask EuroQol item: Which statement best describes your own health state today: I am not anxious or depressed/I am moderately anxious or depressed]

Do you often feel hostile or aggressive towards other people? Do you find it difficult to stir yourself to do things? Do you have such difficulty sleeping that it interferes with daytime activities? Do you often feel scared or panicky for no reason? Y/N

1.3.2 Cognitive ability

Can you think clearly, or do your thoughts tend to be muddled or slow?

Do you frequently get confused about what day or time it is, or where you are or who people are? Do you often lose track of what is being said in the middle of a conversation? Do you often forget the names of people in your family or friends whom you see regularly? Y/N

1.4 *Pain*

(EuroQol) Which statement best describes your own health state today: I have no pain or discomfort/I have moderate pain or discomfort/ I have extreme pain or discomfort.

2. *Activity limitations*

2.1 *Self-care*

Do you have difficulty: Washing your hands and face? Washing yourself all over? Dressing and undressing yourself? Feeding yourself, including cutting up food? Getting to the toilet on your own? No difficulty/Some difficulty/Need help

Do you have great difficulty holding, gripping or turning things? Y/N

2.2 *Mobility*

Do you have difficulty: Getting in and out of bed on your own? Getting in and out of a chair? No difficulty/Some difficulty/Need help

Do you have difficulty walking for a quarter of a mile on the level (with walking stick or other aids if necessary)? Y/N [If Yes: What is the furthest you can walk on your own without stopping and without severe discomfort? ≥ 200 yards/ < 200 yards but ≥ 50 yards/ < 50 yards but more than a few steps/Only a few steps]

(If can walk more than a few steps or can walk quarter of a mile with no difficulty): Do you have great difficulty walking up or down steps or stairs? Y/N [If Yes: Can you walk up and down one step on your own? Can you walk up and down a flight of 12 stairs on your own? Without holding on and without stopping for a rest/By holding on but without stopping for a rest/By holding on and stopping for a rest/Not at all/Need someone's help.]

Can you bend down and pick something up from the floor and straighten up again, holding on if necessary? Always/Sometimes/No

2.3 Communication/senses

Using glasses or lenses if necessary, do you have difficulty... Recognising a friend across the road? Reading ordinary newspaper print? Can you see well enough to recognise a friend...Who is an arm's length away? Across a room? Y/N

Using a hearing aid if necessary, do you have difficulty... Hearing someone talk in a quiet room? Y/N If Yes: Can you follow a TV programme with the volume turned up? Y/N [If Yes: Can you hear someone talking in a loud voice in a quiet room without difficulty? Y/N If Yes + can hear doorbell + use telephone: Can you follow a TV programme at a volume others find acceptable? Y/N]

2.4 IADL

Do you have difficulty with the following (or would you if you had to do them):

Preparing a hot meal for yourself? Washing up and drying the dishes? Washing clothes or bed linen? Using a vacuum cleaner? Doing the household shopping? Dealing with paperwork (e.g. paying bills, writing letters)? No difficulty/Some difficulty/Need help

2.6 General items on limitation of usual activities

Do you have any long-term health problems or complaints which affect your everyday activities? Y/N

UNITED STATES (US01): 1998 National health interview survey

Brief description of survey

The National health interview survey (NHIS) has been conducted annually since 1957 under the responsibility of the National Center for Health Statistics. It provides national data on the health, illness and disability status of the civilian non-institutionalised population aged 17 years and over. Approximately 40,000 households covering 100,000 persons are sampled each year, with data collected through interview-administered questionnaires. A fixed core component includes questions on chronic and acute health conditions, use of health services and health behaviour, while a supplementary component varies each year. The items listed below are part of the core component used for adult respondents.

Disability-related items included in survey

1. Health conditions

1.2 List of specific conditions/illnesses

Have you *ever* been told by a doctor or other health professional that you had...?

Hypertension, also called high blood pressure? Y/N Coronary heart disease? Angina, also called angina pectoris? A heart attack (also called myocardial infarction)? Any other kind of heart condition or heart disease? A stroke? Asthma? Diabetes or sugar diabetes? An ulcer (stomach, duodenal or peptic ulcer)? [If Yes: Have you had an ulcer during the past 12 months? Y/N]

During the past 12 months, have you been told by a doctor or other health professional that you had...?
Hay fever? Chronic bronchitis?

1.3 Mental health

1.3.1 Emotional well-being

During the past 30 days, how often did you feel:

All of the time/Most of the time/Some of the time/A little of the time/ None of the time.

So sad that nothing could cheer you up? Nervous? Restless or fidgety? Hopeless? That everything was an effort? Worthless?

[If any responses are 'All/Most or Some of the time', ask: Altogether, how much did these feelings interfere with your life or activities during the past 30 days? A lot, a little, or not at all?]

1.3.2 Cognitive ability

Are you limited in any way because of difficulty remembering or because you experience periods of confusion? Y/N

1.4 Pain

(Refers to pain that lasted a whole day or more, not to aches and pains that were fleeting or minor)

During the past three months, did you have neck pain? Low back pain? Facial ache or pain in the jaw muscles or the joint in front of the ear? Severe headache or migraine? Y/N

2. Activity limitations

2.1 Self-care

Because of a physical, mental or emotional problem, do you (anyone in your family) need the help of other persons with personal care needs, such as eating, bathing, dressing, or getting around inside this home? Y/N

[If Yes: Do you need the help of other persons with.. Bathing or showering? Dressing? Eating? Getting in or out of bed or chairs? Using the toilet, including getting to the toilet? Y/N]

By yourself, and without using any special equipment, how difficult is it for you to use your fingers to grasp or handle small objects? Not at all difficult/Only a little difficult/Somewhat difficult/Very difficult/Can't do it at all

2.2 Mobility

By yourself, and without using any special equipment, how difficult is it for you to:
Not at all difficult/Only a little difficult/Somewhat difficult/Very difficult/Can't do it at all
Walk a quarter of a mile – about 3 city blocks? Walk up 10 steps without resting? Stand or be on your feet for about 2 hours? Sit for about 2 hours? Stoop, bend or kneel? Reach up over your head? Lift or carry something as heavy as 10 pounds such as a full bag of groceries? Push or pull large objects like a living room chair?

2.3 Communication/senses

Do you have any trouble seeing, even when wearing glasses or contact lenses? Y/N [If Yes: Are you blind or unable to see at all? Y/N]
Have you ever worn a hearing aid? Y/N Which statement best describes your hearing without a hearing aid: good, a little trouble, a lot of trouble, deaf?

2.4 IADL

Because of a physical, mental or emotional problem, do you need the help of other persons in handling routine needs, such as everyday chores, doing necessary business, shopping, or getting around for other purposes? Y/N

2.5 Specific to work and/or social activities

Does a physical, mental or emotional problem now keep you from working at a job or business? Y/N
Are you limited in the kind or amount of work you can do because of a physical, mental or emotional problem? Y/N

During the past 12 months, about how many days did you miss work at a job or business because of illness or injury (do not include maternity leave)? x days

By yourself, and without using any special equipment, how difficult is it for you to...
Not at all difficult/Only a little difficult/Somewhat difficult/Very difficult/Can't do it at all
Go out to things like shopping, movies or sporting events? Participate in social activities such as visiting friends, attending clubs and meetings, going to parties?

2.6 General items

(Only asked if have not answered positively to any of the above): Are you limited in any way in any activities because of physical, mental or emotional problems? Y/N [If Yes: What conditions or health problems cause these limitations?]

UNITED STATES (US02): 1994 National long-term care survey

Brief description of survey

This survey is conducted by Duke University every 5 years. It is a longitudinal survey and samples the US population aged 65 years and over, living either in private households or institutions. Items listed here are from the 1994 survey, although the survey has also been undertaken in 1999.

Disability-related items included in the survey

1. Health conditions

1.2 List of specific conditions/illnesses

Do you have any of the following? Rheumatism or arthritis? Epilepsy? Diabetes? Y/N

Have you had any of the following in the last 12 months? A heart attack? Any other heart problems? Hypertension or high blood pressure? A stroke? Bronchitis? Asthma? Y/N

1.3 Mental health

1.3.1 Emotional well-being

How often do you avoid doing things because you do not have enough energy to do them? All of the time/Most of the time/Some of the time/Once in a while/Never.

Do you ever feel you need the help of a doctor or counsellor for a mental or emotional problem? Y/N

Sometimes people lose their temper and throw, kick, slam or destroy things. Does this happen to you? Frequently/Occasionally/Not at all.

Taken altogether, how would you say things are these days. Would you say you were very happy, pretty happy or not too happy?

1.3.2 Cognitive ability

In the past month: Did you lose your way and not find the way back? Take any money or anything else that didn't belong to you without realising it? Forget to do important things like eat, take medicine or pay bills? Y/N

Mental state assessment: Ten questions assessing memory, orientation and ability to subtract numbers.

2. Activity limitations

2.1 Self-care

(Exclude any difficulties you expect to last less than 3 months) How difficult is it for you to:

Bathe or shower without help? Eat without help? Dress without help?

Not at all difficult/A little difficult/Somewhat difficult/Very difficult or can't do.

How difficult is it for you to use your fingers to grasp and handle small objects? Not difficult/ Somewhat difficult/Very difficult/Can't do it at all.

2.2 Mobility

(Exclude any difficulties you expect to last less than 3 months) How difficult is it for you to:

Walk several blocks? Walk one block? Get up from a chair after sitting for long periods? Get in and out of bed without help? Climb several flights of stairs without resting? Climb one flight of stairs without resting?

Lift or carry weights >10 pounds, e.g. a heavy bag of laundry? Stoop, kneel or crouch?

Not at all difficult/A little difficult/Somewhat difficult/Very difficult or can't do.

2.3 Communication/senses

Do you usually see well enough to read ordinary newsprint, with or without glasses or contact lenses?

Do you usually hear and understand what is being said to you without difficulty either with or without a hearing aid? Can most people understand your speech? Y/N

2.4 IADL

If you had to do the following activities, could you do them? Y/N [If No: Is this because of a disability or health problem (including old age) Y/N]

Heavy work around the house such as moving furniture, scrubbing floors or washing windows? Light work around the house such as straightening up, putting things away, or washing dishes? Your own laundry? Prepare your own meals? Do your own grocery shopping? Manage your own money? Make your own telephone calls?

EUROPEAN COMMUNITY HOUSEHOLD PANEL (1995 questionnaire)

Brief description of survey

The European Community Household Panel (ECHP) is a EU-wide, longitudinal survey which contains a short module on health and disability-related questions. The longitudinal (“panel”) design of the ECHP makes it possible to follow up and interview the same private households and persons over several consecutive years. ECHP data are collected by “National Data Collection Units” – either National Statistical Institutes or research centres depending on the country. In the first wave of the survey (in 1994), a sample of some 60,500 nationally representative households – i.e., approximately 130,000 adults aged 16 years and over – were interviewed in 12 countries. Austria (in 1995) and Finland (1996) have joined the project since then (Sweden remains the only EU country not participating in this survey). The survey is administered every year since 1994, and there is a commitment to continue with successive waves of the survey until 2001.

Disability-related items included in the survey

1. Health conditions

1.1 General prevalence (condition/illness not specified)

Do you have any chronic physical or mental health problem, illness or disability? Yes/No

2. Activity limitations

2.6 General items on limitation of usual activities

Are you hampered in your daily activities by this physical or mental health problem, illness or disability? Yes, severely/Yes, to some extent/No

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