Selection of a Coherent Set of Health Indicators
for the European Union

Phase II: Final report

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Contents

Rationale for Euro-REVES 2

Comparable health indicators across the whole of Europe are important to begin to address the inequalities in the health of our populations. As well as the OECD Common Development Effort on Disability Measures, the Regional Office for Europe of the WHO, as a part of Health for All, has recommended common health instruments to be introduced into European Health Interview Surveys. Most European countries run regular health interview surveys to monitor population health. However the longest established surveys, such as the United Kingdom General Household Survey, began before the current desire to harmonize health information within the European Union, and, as a result:

- countries with the longest experience tend to be the most reluctant to implement the recommended instruments;

- the relevance of previously recommended instruments was not always obvious to policy-makers who did however know the utility of their own national instruments;

- instruments were rarely accompanied by recommendations on the specific study designs to contain them, thus producing a further obstacle for comparability of the collected information;

- countries were not made aware of the implications when they amended the instruments (through question wording, selection of items, change in response categories).

To address these concerns for a particular set of population health indicators, health expectancies, the Euro-REVES 2 project, "Setting up of a coherent set of health expectancies for the European Union", was begun in 1997 under the European Health Monitoring Programme. At that time, health expectancies were currently available for 49 countries worldwide but their direct comparability was impossible due to the differing definitions, survey and analytic methodologies. The project aimed, therefore, to select a concise set of instruments from which a comprehensive set of health expectancies could be produced.

Health expectancies extend the concept of life expectancy to morbidity and disability and, being independent of the size and age structure of populations, allow -in theory- direct comparison of the different groups that make up populations (e.g. sexes, socio-professional categories, regions or countries) as well as estimating changes over time. Calculation of potential gains in health expectancies, brought by the simulated elimination of different diseases, gives relevance and definition to public health targets and priorities. The relevance of these indicators lies in their ability to simultaneously assess the evolution of mortality, morbidity and disability and thus to assess the likelihood of whether we are exchanging longer life for poorer health.

As health expectancies combine life expectancy with a health indicator, there are as many possible health expectancies as health indicators. The profusion of possible indicators made it necessary for us to decide how to meet the main aim of the European Health Monitoring Programme, since **too many indicators may divert attention; too few indicators may hide the possible trade-off between the different facets of health as well as the effects.** We therefore decided that it was important to define, at the outset, the conceptual framework for health we would work to and the selection of the domains in which we would develop instruments within the Euro-REVES 2 project. Another important facet of this work was to develop both **global** (single item) **instruments** and more **specific** ones, the briefer indicators providing the first overview comparison between countries or regions and the more specific indicators allowing a deeper understanding of differences. The project work fell into two phases, with the same methods and researchers, to cover the totality of the instruments. This report is essentially on Phase II although we shall present the complete set of instruments developed in both phases.

Design of Euro-REVES 2

Euro-REVES 2 is made up of 7 research teams from six countries (Denmark, France, Italy, the Netherlands, Spain, United Kingdom) and the multi-disciplinarity, consisting of psychologists, statisticians, social scientists, demographers, epidemiologists, brings different strengths and approaches to the project. After the initial discussion meetings to choose and refine the common reference framework and domains (detailed below), the group split into the 7 teams to cover the main domains. The remit for each team was to:

- systematically review research on the domain and measurement instruments, particularly wording, underlying concepts;
- review the relevant questions in European Health Surveys;
- recommend an instrument and any further work needed.

After the initial scoping of instruments and related research, each team presented their preliminary recommendations to the whole group and then to invited policy-makers from a range of countries for further input and agreement. Where other European groups were working on associated indicators, every effort was made to agree common instruments either through consensus meetings, for example in the field of mental health, or by working closely with the group, for example chronic morbidity. In addition the project group looked closely at the choice of domains and terminology to be in keeping with the International Classification of Functioning, Disability and Health (ICF – World Health Organization, 2001), which was finalised during our project. Finally, the format of final reports of both phases and the presentation of the recommendations was given particular thought by the group with work presented in a standard format.

The common reference framework and chosen domains

The profusion of health concepts, clearly illustrating the multi-dimensional nature of health, made it necessary first to clearly define a conceptual reference framework. The framework chosen is based on a life-course definition of health and the acknowledgement of different perspectives on health and approaches of assessing health status as well as the existence of specific conceptual models for each approach. The framework also acknowledges the importance of the dimension of mental health. The life-course definition of health is the justification for the use of health expectancies as fundamental health indicators for populations since health expectancies measure the lifetime spent in different health states.

The classical bio-medical approach, where psychological and social issues were barely acknowledged and mental illness represented a grey area, worked well when the most common diseases were infectious with known aetiologies. Following the epidemiological transition, the functional approach was developed in the last twenty years, mainly to assess the consequences of the emerging chronic morbidity on daily life. This disease/disability model formed the basis of the original ICIDH framework and is also the basis for the recent ICF. As well as developing **chronic disease** indicators to tap the beginning of the process, we have covered two key elements in the functional approach: body **functional limitations** including the brain (at the level of the person or organism) and **activity restrictions** (at the level of a life situation, i.e. a person in the society), in keeping with the approach and terminology of the ICF. Currently, public health is strongly concerned with the future need for assistance to be provided for the growing number of increasingly older individuals. It is important that the pathways to disability, through limitation to restriction in personal care activities are both included since knowledge of limitation early in the process will provide more effective intervention strategies to slow down the decline. Analysing information on functional limitations and activity restrictions together allows us to do this. The global instrument, the Global Activity Limitation Instrument (GALI) we have proposed provides policy makers with easily obtainable information on the perception of limitations that could result in a need for support. The more specific instruments assess functional health (including the separate areas of seeing, hearing, mobility and agility) and activity restriction of a population independently of the level of development and social organisation of a country, in particular of the availability of special aids or human assistance.

The need to elicit an individual's assessment of their health status has been recognized in the perceptual approach with the notion of **self-perceived health** (assumed to be equivalent to the terms self-rated health, self-defined health and self-assessed health). Self-perceived health is important because of the way it complements functional health, being an independent predictor of survival in older people and associated with a number of other health outcomes and the use of health services. It is considered to be one of the best health indicators; the level of perception of bad health in the population is a clear indication of unmet needs, services and health care, at a global level. Self-perceived health should be clearly distinguished from self-reported health since, health which is perceived (or felt) by the individual and that reported are not always the same. As a consequence of disease, self-perceived health can be viewed as a subjective judgement on the overall situation, a global self-assessment based on the internal assessment by the individual of specific health problems.

Mental disorders are now recognized as one of the principal causes of disability and consumes a significant proportion of the health budget in western countries. The World Health Organization has already set a series of specific targets for improving health in relation to **mental health** in Europe and a number of individual European countries have also individually set targets for mental health. Despite these targets, health surveys have not commonly included instruments to measure the mental health of their populations, partly due to difficulty but also to the stigma of mental illness perceived by individuals.

We have focussed, at present, on these four domains: chronic morbidity, functional limitations, activity restriction and self-perceived health, recommending instruments, **both global and specific**. In addition we pay special attention to the

dimension of mental health, largely forgotten in previous attempts at harmonization. As well as their inclusion in current health surveys, attesting to their relevance, these domains together with the instruments recommended and even the reasons for our choice of response categories have been defined in terms of their relevance to health policy. Our choice of domains and instruments provides a coherent yet comprehensive coverage of population health. This makes it possible at the same time to measure the extent of the differences in health between countries, to appreciate the causes, to specify the profile of each country and the differences between the various concepts of health. Moreover the choice of question forms and responses will allow measurement of the gap between met and unmet need in a number of areas to be measured, thus providing potential solutions for policy-makers.

Outcomes of Phase 2

The present report of phase II of the project builds upon the indicators proposed in Phase 1 in each of the domains, specifically (1) <u>Chronic morbidity</u>: During phase I, the methodological aspects of this indicator were developed and links made with other groups working in the area. In Phase II the set of diseases has been developed, thus enabling disease-free life expectancy indicators to be calculated and evaluated. (2) <u>Cognitive functional limitations</u>: Physical and sensory functional limitations had already been developed in Phase 1 and Phase II allowed completion of the functional limitations components with indicators of cognitive functional limitations. (3) <u>Instrumental activities of daily living</u>: Difficulties in personal care aspects of daily life (ADLs) had been covered in Phase I. During Phase 2, specific indicators for difficulties in household care and other routine activities (IADL) are recommended as a complementary dimension for the assessment of the disablement process. (4) <u>Activities of daily living for adults at working age</u>: Since ADLs and IADLs are suited more to assessing the disablement process with ageing, other activities have been proposed in Phase 2 to better assess disability at younger adult ages. (5) <u>Limitations in usual activities</u>: during Phase 1 the global item on activity limitation (GALI) was developed and Phase 2 was concerned with translation of this indicator. (6) <u>Health perceptions</u>: The global item on perceived health was recommended in Phase 1 and in Phase 2 this work was developed to enable future quality-assessments/validations of the recommended indicators. These methodologies include both statistical methods and qualitative interview methods. (7) <u>Mental health</u>: indicators were proposed in Phase 1 but adjusted in Phase 2 after a consensus meeting with other groups from the European Health Monitoring Programme working on similar indicators. (8) <u>Decomposition indicators</u>: over both phases of the project, a method was developed to map disability to disease, taking into account that disability may be caused by more than one disease (or other factors) and that disability may occur in persons without any chronic disease. This method is illustrated, in combination with the developed decomposition technique, by using real data from the Netherlands for men and women. Once comparable data from the Health Monitoring Programme becomes available, the method can be used to examine differences in the contribution of diseases to health expectancies between Member States.

This report is divided into three sections: in Section 1 we introduce the four new indicators for chronic morbidity, cognitive functional limitations, instrumental activities of daily living, and activities of daily living for adults at working age. Section 2 updates and continues the work on indicators already developed in Phase 1 (limitations in usual activities and health perceptions). Finally Section 3 is devoted to methodology: the decomposition indicators.

Conclusions

Over the last years a number of inventories of European health surveys have been made by several international organizations, including the WHO Regional Office for Europe, Eurostat, the European Health Monitoring Program and the OECD. At first sight, it appears that European health surveys all cover the same fields and often use the same questions. However the deeper analysis we have undertaken through Euro-REVES 2, in conjunction with current scientific research, underlines the significant differences that exist in the wording of the existing questions. We think that the main reason for this is the absence of two factors: firstly the absence of a rationale behind the questions clearly demonstrated in the recommendations; secondly the absence of the science behind specific questions forms, more particularly the effect of changes in the wording on the responses;

Any instrument recommended to facilitate international harmonization, should have relevance for policy-makers at the national level as there seems little point in recommending instruments that do not substantially improve upon current recommendations where they exist. **Any recommendation should be accompanied by a plan of implementation as well as regular evaluation of the number of countries using the instrument and the quality of the information collected.** A further stumbling block to the adoption of recommended instruments by countries is the need to retain questions to protect

the calculation of trends over time. To address this issue we intend, ultimately, to provide two types of each indicator: one at a **global** level, therefore being concise and requiring little room and time in surveys, to **describe** all the existing differences on this issue between the EU countries, whether they are due to " real " health problems, problems of social organization or culture; secondly, a more **specific** instrument to **explain** the differences between these countries. The central point of this set of indicators is that an increase in the life expectancy with at least one chronic disease or with functional limitations does not necessarily imply an increase in life expectancy with activity restrictions. Between these two, lies the response of the health system in the broadest sense, with its successes and its failures, and this set of indicators aims also to measure these gaps between countries.

Our proposals acknowledge all these issues. Wherever possible, unless there is confusion with the current concepts of the field, our instruments are based on existing recommendations, this being the case "perceived health" where the question chosen is that already recommended by the WHO-Euro. For the measurement of disability, we propose to update the long-term disability instruments of the OECD and the WHO-Euro which both currently mix functional limitations and activity restrictions. This is more in keeping with the new ICF.

In total we have made proposals for 10 instruments:

 (1)   a general question about chronic morbidity,
(2)   a set of specific questions on chronic morbidity,
(3)   a set of specific questions on physical and sensory functional limitations,
(4)   a set of specific questions on cognitive functional limitations,
(5)   a general question about activity restrictions,
(6)   a set of specific questions on personal care activities,
(7)   a set of specific questions on household activities,
(8)   a set of specific questions on other activities of daily living,
(9)   a general question about perceived health,
(10)   a set of specific questions on mental health.

This coherent set of 10 instruments, the exact wording of which is given below, will lead to many health state expectancies covering the totality of the conceptual framework of the measurement of population health. This number is a good compromise between too little and too many, making it possible at the same time to measure the extent of the differences in health between the European Union countries, to appreciate the causes, to specify the profile of each country and the differences between the various concepts of health: chronic disease, functional limitations, activity restrictions, mental health and health perceptions.

Proposed Instruments

We recommend after linguistic validation for the final wording, the following instruments:

1) Chronic morbidity: general question

An open-ended question should be used to measure the global indicator on chronic morbidity. The exact wording of the question depends on the cross-cultural applicability and validity, for this reason the instrument proposed is a conceptual translation of the Chronic Disease question developed by ISTAT for EuroHIS: the brackets have been used for the main keywords that could better address the <u>concept</u>.

The reference wording is :

Do you <u>suffer from</u> *(have)* any <u>chronic</u> (*long standing*) <u>illness or condition</u> (*health problem ?*)
-     *No*
-     *Yes*

From this instrument chronic condition-free life expectancy may be calculated.

2) Chronic morbidity: disease-specific

The reference wording and the list of diseases are the following:

For each diseases in the checklist, it is recommended to ask: **Do you have (suffer from) or have you ever had (suffered from) one or more of the following chronic (long-standing) illnesses or conditions (health problem)?** (reply to each of the illnesses)				
Disease or condition *(checklist)*	**Do you have or have you ever had?**		**Have you had this problem in the past 12 months**	
Asthma	No	Yes	No	Yes
allergic asthma	No	Yes	No	Yes
Allergy (excluding allergic asthma)	No	Yes	No	Yes
Diabetes	No	Yes	No	Yes
Cataract	No	Yes	No	Yes
Hypertension (high blood pressure)	No	Yes	No	Yes
Heart attack	No	Yes	No	Yes
Stroke, cerebral haemorrhage	No	Yes	No	Yes
Chronic bronchitis, emphysema	No	Yes	No	Yes
Arthrosis, (rheumatic) arthritis	No	Yes	No	Yes
Osteoporosis	No	Yes	No	Yes
Gastric or duodenal ulcer	No	Yes	No	Yes
Malignant tumour (including leukaemia and lymphoma)	No	Yes	No	Yes
Migraine or frequent headache	No	Yes	No	Yes
Chronic anxiety or depression	No	Yes	No	Yes

Two main types of health expectancy may be computed:

1- Diseases specific-free life expectancy (based on life time prevalence) and
2- Life expectancy without co-morbidity, i.e. life expectancy free of severe chronic condition (at least 3 diseases of the above list)

3) Specific questions on physical and sensory functional limitations

The 12 selected descriptors of functional abilities and the wording, using one of the descriptors as an example are as follows:

Selected descriptors
   1/ See clearly newspaper print
   2/ See clearly the face of someone 4 metres away (across a road)
   3/ Hear distinctly what is said in a conversation with one other person
   4/ Walk without difficulty 500 metres
   5/ Go up and down a flight of stairs without difficulty
   6/ Speak clearly to others
   7/ Bite and chew on hard foods (such as a firm apple) without difficulty
   8/ Reach out an arm to shake someone's hand without difficulty
   9/ Use fingers to grasp or handle a small object (like a pen) without difficulty
   10/ Turn a tap without difficulty
   11/ Bend down and kneel down without difficulty
   12/ Lift and carry a full shopping bag of 5 kilos without difficulty

Suggested wording (Using *seeing clearly newspaper print* as an example):

Think about situations you may face in everyday life. Please ignore temporary problems:

   1/ *Can you clearly see newspaper print* **without glasses or any other aids/devices?** Yes / No*
         If no: **With your glasses or other aids/ devices, can you clearly see newspaper print?**
               Yes / No / Have no glasses or other aids/devices
      * *if answer "I am blind or I cannot see at all", go to question 3/ (skipping other questions on seeing)*

From these, functional limitation-free life expectancy may be calculated according to the following levels of severity:

1- Life expectancy free of any functional limitation;

2- Life expectancy with moderate functional limitation: *i.e. with some functional limitations but not unable to perform the actions under consideration when using aids/devices;*

3- Life expectancy with severe functional limitation: *i.e. totally unable to perform at least one of actions under consideration;*

4- Life expectancy with extreme functional limitation: *i.e. totally unable to perform any of the actions under consideration.*

4) Specific questions on cognitive functional limitations

The final form of the test battery awaits the decision of the Study of Health and Retirement in Europe (SHARE) group whose final form will be found on www.share-project.org. This set of tests could be completed in 10-15 minutes on average**.**

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1. A few key **orientation** items can be placed at the start of the interview to establish whether the interview is likely to be productive or whether a proxy will need to be sought. These questions can be asked in a very natural manner as follows:

> "Let me just check, your name is ….?"
> "What was your age last birthday?"
> "What is your current address?"
> "What is today's date?"

2. **Cognitive test** items can be placed later in the interview. This section flows well if the items are introduced by one or more self-report questions to establish whether the subject has any concerns about their cognitive function. The following set of items can be used, each coded no, occasionally, often or very often:

> "First, can you tell me if you have any difficulty with your memory?" If yes, "Does this embarrass or bother you or cause you inconvenience?"
> "Do you forget what you have read or heard?"
> "Do you forget people's names?"
> "When speaking, do you have difficulty finding the word you want or do you sometimes say the wrong word?"
> "Do you find it difficult to concentrate?"
> "Do you forget to do things which you intended to do, such as post a letter?"

If only a single self-report item is to be used, it would be:

> "In general, would you say your memory is excellent, very good, good, fair or poor?"

3. **Prospective memory** instructions can be given next. These can take the form of:

> "Later on I am going to …. [e.g. hand you a sheet of paper]. When I do, I would like you to …..[eg. write your initials in the top left-hand corner of the page]. Can you remember that?"

4. **New learning** can be assessed by presenting a random list of common words, usually concrete nouns which can easily be formed into a visual image. The CERAD 10-item word list can be used or a 15-item word list. Some instruments (e.g. ADAS-Cog, TICS) use a single presentation of the word list, while others use three to five presentations of the word list with recall following each presentation (e.g. the CERAD battery, Welsh et al., 1991). Where possible, both immediate and delayed recall should be tested.

5. **Language** can be assessed using a verbal fluency test e.g. naming as many different animals as possible in one minute. Success on this test also involves an element of executive function i.e. categorizing animals into domestic, wild, birds, insects etc. and shifting between categories.

6.**Literacy and numeracy** can be assessed by
   (a) asking the subject to write their name and address, or writing a name and address to dictation and
   (b) asking them to make simple calculations e.g.

> "If a drink costs 85 cents and you give the shopkeeper 100 cents (1 Euro) how much change should you get back?"
> "If the risk of having a disease is 10%, how many people out of 1,000 would be expected to have the disease?"

7. **Attention** can be assessed using a backwards counting task (e.g. counting backwards from 100 by 3 or by 7), or by means of a visual search task such as symbol or letter cancellation i.e. crossing out all examples of one or more symbols or letters on a sheet of random symbols or letters in a given time. The Trail-making test (Reitan, 1958) is another possibility. Trails B requires shifting between numbers and letters so is also a measure of attentional set shifting.

8. **Visuo-spatial ability** can be assessed by a copying task (overlapping pentagons, 3-dimensional house) or a drawing task (drawing a clock and setting the hands to ten minutes past 11).

9. **Executive function** is most easily assessed using similarities, which requires abstract thinking e.g.,

> "In what way are an apple and a banana alike?"
> "In what way are a table and a chair alike?"
> "In what way are a plant and an animal alike?"

10. **Delayed recall** of the word list can be tested at the end, along with recall of the prospective memory instruction.

From this instrument life expectancy free of cognitive functional limitations may be calculated.

5) General question on limitations in usual activities

The Global Activity Limitations Indicator (GALI) is currently translated in 10 European languages and the wording of the proposed instrument in English is:

For at least the last 6 months, have you been limited because of a health problem in activities people usually do ?
            Yes, strongly limited
            Yes, limited
            No, not limited

The instrument permits calculation of an Activity Limitation Free Life Expectancy. The introduction of three response categories (not limited, limited and strongly limited) allows testing of the plausibility of the scenario of a dynamic equilibrium (Manton, 1982).

6) Specific questions on personal care activities (Activity restriction).

The selected items and an example of the wording using one of the items (feeding) is:

Selected items
In everyday life, ignoring temporary problems, do you usually without any difficulty and without (human / technical) help:
        1/ *feed yourself*
        2/ *transfer in and out of bed*
        3/ *dress and undress yourself*
        4/ *use toilets*
        5/ *bath or shower yourself*
 	
Suggested wording (using *feeding* as an example)
   Think about your personal care activities in everyday life. Please ignore temporary problems:
 	
  1/ Do you, usually, *feed yourself* **without any difficulty and completely on your own?**   Yes/No
 	
    [if Yes go to 2/]
    [if No, go to a) and b)]
 	
    a) **Does someone help you to** *feed yourself***?***   Yes/No
 	
    [if Yes to a)]
 	
    b) **Are you satisfied with the help received or are there problems you still need help with?**
       Yes, I am satisfied / No, there are still problems

*   Can also ask WHO if answer YES to receiving help;

Allow complementary questions on use of special equipment: Do you (also) use special equipment Yes/No. In addition the use of personal help or aids or adaptations are collected separately.

A short form of the instrument, suitable for general surveys is:

Think about your <u>personal care</u> activities in everyday life, for example feeding yourself, getting in and out of bed, dressing, bathing, using toilets, taking medication. Please ignore temporary problems:
1/ Do you, usually, perform such activities without any difficulty and completely on your own?   Yes/No
    [if Yes go to 2/]
    [if No, go to a) and b)]
        a) **Does someone help you to perform your personal care activities?***   Yes/No
    [if Yes to a)]
        b) **Are you satisfied with the help received or are there problems you still need help with?**
       Yes, I am satisfied / No, there are still problems

From either of these instruments, two main health expectancies may be computed:

1- personal care activity restriction-free life expectancy and
2- dependence-free life expectancy (including or not severity levels).

7) Specific questions on household activities

Selected items (refer to Branch 2000):
> Use telephone
> Do all the shopping
> Prepare meals
> Do routine light housework
> Do periodic heavy housework
> Do the laundry
> Take care of/manage your financial matters

Suggested wording (using *preparing meals* as an example)

Think about your activities at home in everyday life. Please ignore temporary problems:

1/ Do you, usually, *prepare meals* **without any difficulty and completely on your own?**
> (i) Yes, without difficulty and completely on my own
> (ii) No, with difficulty but completely on my own
> (iii) No, not completely on my own
> (iv) Do not prepare meals

[if (i) go to 2/]
[if (ii) go to b)]
[if (iii) or (iv) go to a)]

     a)   **Could you do it on your own without any difficulty if you had to or wanted to**   Yes/No

[if No to 2/]

     b)   **Do you require (more) help in getting** *meals prepared* **to your satisfaction?**   Yes/No

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A short form of the instrument, suitable for general surveys is:

Think about your <u>household and other routine activities</u> in everyday life such as shopping, preparing meals, doing housework, doing the laundry, taking care of financial matters or using telephone. Please ignore temporary problems:

1/ Do you, usually, perform such activities without any difficulty and completely on your own?

> Yes, without difficulty and completely on my own
> No, with difficulty but completely on my own
> No, not completely on my own
> Do not perform such activities

From either of these instruments, two main health expectancies may be computed:

1- household and routine activity restriction-free life expectancy and
2- dependence-free life expectancy (including or not severity levels).

8) Specific questions on other activities of daily living

The selected items and form of wording is:

Selected items
> Your usual school/work/home* activities
> Your usual leisure and social activities
> Going where and when you want to go

Wording (using school/work/home activities as an example)

Think about your other activities in everyday life. Please ignore temporary problems:

1/ As a result of your health or the way you feel, do you have any difficulty with or have you had to cut down <u>your usual school, work or home activities</u>?

    1.1) Yes at school/No/NA**
    1.2) Yes at work/No/NA**
    1.3) Yes at home/No

[if Yes go to a)]***

[otherwise, go to 2/]

        a)   **Do you use special equipment to <u>do your usual school/work/home activities</u>**   Yes/No
        b)   **Do you received special assistance to <u>do your usual school/work/home activities</u>** Yes/No
        c)   **Are there any remaining problems in <u>doing your usual school/work/home activities</u> to your**
satisfaction that you require (more) help with?   Yes/No

*If household activity instrument (7) used then home may be omitted.
** NA= Not applicable: Not at school/work/no leisure or social activities for other non-health reasons/no commuting
*** Can allow collection of or prompt for supplementary information on flexibility of attendance/hours attended or whether special school/sheltered work

This instrument allows calculation of:

1-   life expectancy without school or work restrictions,
2-   life expectancy without restriction in social or leisure activities,
3-   life expectancy without mobility restriction.

9) Perceived health: General question:

We recommend the current Self Perceived Health question of WHO-Europe (WHO-Europe, 1996):

> How is your health in general? Very good/ good / fair/ bad / very bad.

The instrument permits the calculation of health expectancy in good perceived health, using suitable cutpoints, for example very good, good/fair, bad very bad.

Self-perceived health has been used in health expectancy calculations in several countries including the United States, Australia and throughout Europe, including the Netherlands, Denmark, Sweden, Finland, Spain and the UK to name only a few (REVES, 1998).

<u>10) Specific questions on mental health</u>.

The European Mental Health Consensus meeting recommended the 5-item MHI (in conjunction with the CIDI-SF – not shown here) to measure psychological distress and the energy/vitality item from the SF-36 and a single item on happiness to measure positive mental health:

<u>Psychological distress</u>

How much, during the past 4 weeks….

1) Did you feel very nervous?
2) Have you felt so down in the dumps, nothing could cheer you up?
3) Have you felt calm and peaceful?
4) Have you felt down-hearted and depressed?
5) Have you been happy?
> **Response**: All of the time/Most of the time/Some of the time/A little of the time/None of the time

<u>Positive mental health</u>

How much, during the past 4 weeks….

1) Did you feel full of pep?
2) Did you have a lot of energy?
3) Did you feel worn out?
4) Did you feel tired?
> **Response**: All of the time/Most of the time/Some of the time/A little of the time/None of the time

Would you describe yourself as being usually”:

> happy and interested in life,
> somewhat happy,
> somewhat unhappy.
> unhappy with little interest in life, or
> so unhappy that life is not worthwhile?

When cutpoints are determined from further validation, these instruments will allow calculation of life expectancy in good mental health.

Part 1: New indicators

Chapter 1: Chronic morbidity

Contributors: Viviana Egidi, Roberta Crialesi

Section 1: Definition

1. Definition

The main problem in measuring chronic morbidity is the definition. Actually the main international reference for the definition used for chronic conditions is that of the commission on chronic illness (1957):

Chronic diseases comprise all impairments or deviations from normal which have one or more of the following characteristics:

- are permanent;

- leave residual disability;

- are caused by non-reversible pathological alterations;

- require special training of the patient for the rehabilitation;

- may be expected to require a long period of supervision, observation or care.

The ICD-10[1] provides an exhaustive systematic nomenclature of all conditions, from an etiological point of view. However the definition above doesn't solve the problem of selecting the most relevant diseases that can be properly described as conditions to be included in a survey. From an empirical point of view the conditions selected for survey should be mainly those which are important in number and severity. Chronic conditions are not necessarily permanent, rather they have been or are likely judged to be of long duration.

2. Relevance

Chronic diseases represent one of the main public health concerns. The growing importance of chronic morbidity is due not only to the ageing of the population but also to therapeutic improvements. Surviving longer with chronic diseases is a challenge for the quality of life, especially for older people. At the individual level, the human organism's capacity to defend and mechanism of recovery decrease as people age, therefore diseases become more and more likely. Many of these diseases are progressive and their impairments may be cumulated over time. The treatments are often very expensive in terms of drugs and use of health care services. Chronic diseases are, in fact, the main cause of use of health care services

Measuring chronic morbidity, in terms of the extent of the phenomenon and the types of diseases is very useful for overall evaluations in the domain of health status. It is also useful for the study of health care systems in terms of evaluation and policy formulation.

The instruments proposed should be able to measure the prevalence of chronic morbidity, to monitor specific chronic diseases with increasing life expectancy and to monitor the impact of chronic morbidity on the functional status and health perceptions of individuals (Myers G., Maggi S.,1991).

Section 2: Relationship with the other indicators

According to the functional approach, that was developed, in the last twenty years, mainly to assess the consequences of the emerging poor health status on daily life activities, chronic morbidity is strongly related to the disability indicators since many impairments or disorders, which are usually parts of the "diseases process" can result in long term disability; more exactly, the consequences of the diseases can conduct an individual to suffer from functional limitations and activity restrictions as a result of interaction between physical conditions and social environment.

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[1] International Statistical Classification of Diseases and Related Health Problems, Tenth Revision. Vols. 1-3. Geneva WHO, 1992-1994

Self perceived health status is also strongly related to chronic morbidity. Over 90% of people declaring a poor health state suffer from a chronic disease. People suffering from chronic diseases include a higher percentage of people with a bad health perception is higher. Obviously different chronic diseases do not influence the perception of health state in the same way: respondents with chronic diseases declare a good state if the diseases do not imply limitations on daily life activities (Buratta V. 1997, Istat 2001).

Section 3: Important issues

According to the recommendation of the EuroHis project, it is necessary to have at least two different approaches on collecting data on chronic morbidity (EuroHIS, 2000):

a global approach based on an open-ended question: respondents are questioned whether or not they are affected by a chronic disease

a specific approach based on diseases specific questions: respondents are questioned whether or not they have a condition included in a specific checklist

The two approaches have two different purposes. The global question is mainly used for general descriptive analysis. It provides a broad information on the health status of a population and on the impact of chronic morbidity on social behaviours (Egidi V. Crialesi R. 1995, Crialesi R. Reale A.,1997). The disease specific questions are mainly used to estimate the prevalence and/or the incidence of specific conditions, to estimate the prevalence of co-morbidity and also to give insight in the relation with socio-economic status and other health related behaviours.

The most important issue concerns the criteria that should be used for selecting the most relevant diseases or conditions that have to be included in the checklist. In the specific approach there is a general agreement about the following criteria (EuroHis, 2000):

- prevalence;

- severity of the disease;

- economic cost;

- use of health care services;

- Amenability to self-reporting.

According to these criteria, an agreement is reached by the countries involved in EuroHis project on the following diseases list:

Asthma
    If yes, is it allergic asthma?
Allergy (excluding allergic asthma)
Diabetes
Cataract
Hypertension (high blood pressure)
Hearth attack
Stroke, cerebral hemorrhage
Chronic bronchitis, emphysema
Arthrosis, (rheumatic) arthritis
Osteoporosis
Gastric or duodenal ulcer
Malignant tumour (including leukaemia & lymphoma)
Migraine or frequent headache
Chronic anxiety or depression

Of course this list of diseases is not exhaustive. From an empirical point of view, it suggests that these diseases should be considered while surveying the chronic conditions in health interview survey, in order to promote comparable data collection on these outcomes in the countries. Sharing common instruments based on agreed concepts and definitions, is a main step towards the harmonisation of the indicators. Nevertheless it is important to underline that a number of factors may impact on achieving a satisfactory level of international comparability. The sources of incomparability are related to the

whole process of the collection of the statistical information that involve sample design, survey techniques (face to face, CAPI or CATI interview), respondent selection (self or proxy responses) and quality profile (quality control and evaluation process) (Guenzel PJ et al.,1983). Comparison between countries may be also affected by proportional differences in the numbers of people institutionalised and the population as a whole.

When measuring chronic conditions there are a number of recurrent problems that need to be taken into account.

The first problem concerns the '*information or awareness*' of the respondents: they might not know their bad health status or, on the contrary, they might report a specific disease not necessarily diagnosed. For example diabetes or hypertension (Fifth Report of the Joint National Committee on Detection, Evaluation, and Treatment of High Blood Pressure, 1992) are strongly affected by "unawareness", due to the fact that these disease are in many cases without symptoms.

The second group of problems is linked to *the time-period of the survey*: The prevalence of certain diseases can be affected by seasonal effects and persons interviewed may tend to respond according to whether the disease has become more acute during the survey period or not. This is the case of arthritis or bronchitis, whose prevalence estimates may be higher in a winter period. This is also true for allergies there is a seasonal effect since they become more acute in the Spring period. As far as hypertension is concerned there does not appear to be a seasonal effect and growth over recent years would seem to be linked to the overall ageing of the population and to diagnostic improvement. For other diseases, such as osteoporosis, the prevalence is increasing due to more effective diagnostic techniques: today more is known of the true diffusion of this disease.

The third group of problems regards the *onset of the disease*: An important element in micro-analysis is the exact determination of the moment of onset of a disease for an individual, an occurrence which often precedes the first manifestations of the process and its diagnosis by a long period of time. This element is certainly a point that cannot be overlooked, however, it is less critical in macro-analysis inasmuch as, for the (economic and social) impact of the disease, the period during which an individual is affected by a disease but is not conscious of it can be ignored since it does not exert any particular demands on society. It only becomes important to monitor the latent period with greater accuracy in macro-analysis when the need is to evaluate dynamics of morbidity over time or its differentiation between population groups. Actually, the earlier age of contraction of a disease and an increase of its duration could be explained by an improvement in diagnostic capabilities and by an increase in health education. Today these permit the identification of a disease much sooner than in the past and in a different ways in different population groups (Egidi V. & Frova L., 1996). Establishing the onset is an extremely important factor also for comparison between health interview survey and other sources of data (e.g., hospital records and diseases registers) (Harlow SD, Linet MS,1989).

The final problem concerns medical diagnosis. The experience on the health surveys that have included a question concerning the diagnosis made by a doctor, shows that in more than 80% of the cases of chronic disease the diagnosis had been made (Istat,2001). The least frequently diagnosed diseases, as expected, were those showing a greater variability due to seasonal effects (Kehoe R., Wu S.Y, Leske C, et al.,1994).

Section 4: Current position within Europe

Chronic morbidity indicators have been officially adopted as relevant to policy by the Member States of the WHO for evaluation of national health policies, and they have been included as a field of actions in the EuroHIS project[2] (WHO-Euro, granted by the Union, BIOMED 2). The project aims at selecting the common instruments and methodology to be used in the European Region by all the Member States in the context of health interview surveys.

The work conducted by the EuroHIS project, as well as it provides an international comparison based on the most recent Health Interview Surveys or Health Related Surveys available for each country, also recommends the steps needed to reach an harmonisation.

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The surveys (18) and countries (17) considered in the international review are shown in Table1.

In surveying chronic conditions, two types of questions are used: open-ended questions and disease-specific questions. The open-ended question inquires whether respondents have a chronic condition and, eventually, which one. The disease-specific question includes a checklist of condition or diseases (or a card that has to be shown) and respondents are questioned whether or not they are affected from one or more of them.

Of the 18 questionnaires that include at least one question on chronic conditions:

7 surveys include only disease specific questions (A06, FIN01, F08, D07, IRL01, E02, UCR01);

4 surveys include only open ended questions, and these questions usually include mental health problem and/or disability (FIN05, N01, S01, UK09). In addition respondent are questioned to define and specify which condition they are affected from.

7 surveys include both open ended questions and specific disease questions (B01, DK01, I03, NL03, P01, CH01, UK10). In these surveys all the respondents, whether or not they reported a chronic condition, had to answer the specific disease questions. That is, the overall open ended question is not a filter for the specific diseases.

Table 1 Surveys and Countries included in the international review of EuroHIS project

Country	ID survey	Year
Austria	A06	1999
Belgium	B01	1997
Denmark	DK01	1994
Finland	FIN01, FIN05	1996,1996
France	F08	1998
Germany	D07	1998
Ireland	IRL01	1998
Italy	I03	1999/2000
The Netherlands	NL03	1999
Norway	N01	1995
Portugal	P01	1995/1996
Spain	E02	1997
Sweden	S01	1996
Switzerland	CH01	1997
Ukraine	UCR01	1999
England	UK09	1996
Scotland	UK10	1996

Open ended questions used by different countries rarely refer only to physical conditions, generally they refer to "any chronic conditions, defect or injury". In most cases open ended questions explicitly include mental conditions and disabilities. This is, for instance, the case of the open ended question used by European Community Household Panel (ECHP). The question in fact covers different types of condition since is formulated as follow:

> *Do you have any chronic physical on mental health problem, illness or disability?*
> - *Yes*
> - *No (go to question…)*

A draft proposal for the harmonisation of the open ended question has been formulated (EuroHis 2000?) and states as follow:

> - *Do you have any long-standing illness or health problem?*
> - *Yes*
> - *No (go to question…)*

Similar problems are found in the disease specific questions: the checklists used by the different country vary considerably. Differences can be founded in the number and type of the diseases included in the list. The wording of the questions is also not comparable: the checklist may include formal medical terms or description of symptoms and/or complaints. Overall fourteen surveys include a checklist (A06, FIN01, F08, D07, IRL01, E02, UCR01, B01, DK01, I03, NL03, P01, CH01, UK10). The number of diseases on the checklist varies from 6 to 45. More then half of the surveys includes more than 20 diseases. This large variability reflects the difficulty of achieving a compromise between the exhaustive detailed listing of disease and the broad groupings which may be all that is possible in a survey. Table 2 shows the specific diseases most frequently listed in the surveys, by major group of diseases. Analysis of the groups that are most frequently investigated shows general agreement on the definition and the criteria recommended in surveying chronic diseases. In fact, at least one of the following criteria can be found: prevalence, severity of the disease, economic cost, use of health care services, amenability to self-reporting.

All surveys include at least one specific disease that refers to the **circulatory** group. *Hypertension* is investigated by all countries. Moreover, questions about *angina*, *heart attack*, *cerebral stroke* can frequently be found (respectively 10, 11 and 7 times). All countries pay particular attention to this group: usually 20% (or more) of the number of specific diseases included in the checklist refer to the circulatory system.

Thirteen surveys include at least one question on **metabolic disorders**, that usually refers to *diabetes* (13 surveys) and often also to *thyroid trouble* and *goitre (5 surveys)*.

Thirteen surveys include at least one question on **respiratory diseases**. *Bronchial asthma* and *chronic bronchitis* are the most investigated, in fact they are included (with different wording) in 10 and 11 checklists, respectively.

Twelve surveys have one or more questions on **back disorders and other musculo-skeletal troubles**: in 11 surveys the disease-specific question refers in particular to *back or lumbar pain*. Another important disease that refers to this group is *arthritis* that is surveyed in 7 countries, thought the wording adopted varies widely among countries.

Ten checklists also include **psychiatric troubles**, particularly *depression* and *anxiety* (9 surveys, usually listed together).

Ten surveys inquire about **nervous disorders:** *migraine and frequent headache* in 9 and *epilepsy* in 7.

Ten lists include questions on the **digestive system**, in particular in 8 cases they refer to *gastric and/or duodenal ulcer*.

Uro-genital troubles are questioned in 10 surveys. This group includes several diseases that differ widely in severity and prognosis. Attention is usually focused on *serious kidney diseases* (10 surveys), such as chronic glomerulo-nephritis, renal chronic insufficiency and chronic nephropathy, chronic pyelonephritis, kidney stones.

Allergy is surveyed in 9 countries. In seven cases the exact wording adopted is Allergy. An exception is given by Germany and Austria. In Germany, respondents are asked about 5 different items (hay fever, contact dermatitis, food allergies, etc.), while in Austria they are asked only about allergic contact dermatitis.

Cancer is investigated in 8 surveys. In four cases all malignant and benign tumour are listed together. Only the United Kingdom inquires about lung cancer and on other forms of cancer separately.

Seven surveys inquire about **serious skin diseases**, such as eczema, bullous dermatosis, psoriasis, vitiligo, skin chronic ulcer, hives.

An agreement is reached by the countries involved in EuroHis project on the following diseases list:

**Table 2. Type of disease or condition group included in the 14 checklists considered,
and specific diseases most frequently listed**

Disease or condition group	No. of surveys	Specific disease most frequently cited
Circulatory diseases	14	Hypertension Angina Heart attack Cerebral stroke
Metabolic disorders	12	Diabetes Thyroid trouble
Respiratory diseases	12	Bronchial asthma Chronic bronchitis
Back disorders and other musculo-skeletal troubles	11	Back pain Osteoporosis
Arthrosis and/or arthritis	7	
Psychiatric troubles	10	Depression Anxiety
Nervous disorders	10	Migraine Epilepsy
Digestive system	10	Gastric or duodenal ulcer Gallstones
Uro-genital troubles	10	Kidney stones Renal insufficiency Prostate
Allergy	9	Allergy
Cancer	8	Cancer
Other complaints or diseases	8	
Skin diseases	7	Serious skin diseases
Paralysis and other handicaps	6	Sight troubles Hearing troubles
Blood diseases	2	Anaemia
Sexually infectious diseases	1	Sexually infectious diseases

> *Asthma*
>   *If yes, is it allergic asthma?*
> *Allergy (excluding allergic asthma)*
> *Diabetes*
> *Cataract*
> *Hypertension (high blood pressure)*
> *Hearth attack*
> *Stroke, cerebral haemorrhage*
> *Chronic bronchitis, emphysema*
> *Arthrosis, (rheumatic) arthritis*
> *Osteoporosis*
> *Gastric or duodenal ulcer*
> *Malignant tumour (including leukaemia & lymphoma)*
> *Migraine or frequent headache*
> *Chronic anxiety or depression*

The proposed list is based on a selection of the most frequently investigated diseases: each disease was analysed according to the above mentioned criteria (see section 2), and only if a general agreement was achieved, the specific disease has been included in the list. This list should be considered a "core" of relevant diseases selected for international comparability purposes.

The item "*other chronic conditions, specify*", may give the respondents the possibility of reporting their conditions not already mentioned in the questionnaire. These conditions may be serious of nature and therefore important for the respondent.

Section 5: What should be proposed?

Instrument n.1: Open-ended Question

An open-ended question should be used to measure the global indicator on chronic morbidity. The exact wording of the question depends on the cross-cultural applicability and validity, for this reason the instrument proposed is a conceptual translation of the Chronic Disease question developed by ISTAT for EuroHIS: the brackets have been used for the main keywords that could better address the <u>concept</u>.

The **reference wording** is :

Do you <u>suffer from</u> (*have*) any <u>chronic</u> (*long standing*) <u>illness or condition</u> (*health problem ?*)
-     *No*
-     *Yes*

The keyword "chronic" (or long standing) is important as it allows to distinguish between chronic conditions, such as diabetes, and acute conditions, such us a broken leg or a respiratory tract infection.

Data Collection:

The instrument is independent of the type or objectives of the survey. The short format and simplicity of the question make it suitable both for use in general social surveys and in health interview surveys.

Representativeness:

It should be administrated to a general population of all ages.

Global indicator:

The overall prevalence of chronic conditions.

Health expectancy:

The data collected with this instrument enables the calculation of **chronic condition-free life expectancy**

Method of calculation:

Sullivan method.

Justification:

There is a general agreement among countries about the appropriateness of the instrument proposed.

The open-ended question introduces the topic of a health problem and it provides a broad coverage of health problems, since it includes not only chronic physical conditions, but also mental health problems, in a very simple fashion.

Additional comments:

To evaluate progress in the health status of the population, estimates of crude chronic morbidity rate are considered insufficient. Additional questions for analysis are required in order to better investigate chronic conditions and to interpret the situation of people with health problems and to influence future developments.

Instrument n.2: Disease-specific questions

The instrument proposed is a conceptual translation of the EuoHIS proposal. The reference wording and the list of diseases are the following:

For each diseases in the checklist, it is recommended to ask:

Do you have (suffer from) or have you ever had (suffered from) one or more of the following chronic (long-standing) illnesses or conditions (health problem)? (reply to each of the illnesses)

Disease or condition *(checklist)*	Do you have or have you ever had?		Have you had this problem in the past 12 months	
Asthma	No	Yes	No	Yes
allergic asthma	No	Yes	No	Yes
Allergy (excluding allergic asthma)	No	Yes	No	Yes
Diabetes	No	Yes	No	Yes
Cataract	No	Yes	No	Yes
Hypertension (high blood pressure)	No	Yes	No	Yes
Heart attack	No	Yes	No	Yes
Stroke, cerebral haemorrhage	No	Yes	No	Yes
Chronic bronchitis, emphysema	No	Yes	No	Yes
Arthrosis, (rheumatic) arthritis	No	Yes	No	Yes
Osteoporosis	No	Yes	No	Yes
Gastric or duodenal ulcer	No	Yes	No	Yes
Malignant tumour (including leukaemia and lymphoma)	No	Yes	No	Yes
Migraine or frequent headache	No	Yes	No	Yes
Chronic anxiety or depression	No	Yes	No	Yes

Data Collection:

There is a general agreement on the importance of investigating chronic physical conditions together with other aspects of health, in particular with health behaviours (use of health care services and preventive care). The instrument should be used in a health interview survey.

Representativeness:

It should be administrated to a general population of all ages.

Global indicator:

The data collected by this instrument allows the calculation of three kind of indicators: life time **prevalence of a specific chronic disease**, **year prevalence of a specific chronic disease** and **prevalence of chronic co-morbidity**.

Co-morbidity indicates those who are affected by more than one chronic disease. It can be considered an indicator of the 'severity' of the chronic health condition. Therefore to measure co-morbidity, it is recommended to include more than two diseases (at least three).

Health expectancy:

Two main types of health expectancy may be computed: **Disease specific-free life expectancy** (based on life time prevalence) and **Life expectancy without co-morbidity,** i. e. Life expectancy free of severe chronic condition (at least 3 diseases of the above list)

Method of calculation:

Sullivan method

Justification:

There is a general agreement among the countries participating in the EuroHIS project about the appropriateness of the instrument proposed, confirmed by the result of the field-test (EuroHIS 2002).

The checklist method is to be preferred to open-ended questions for the following reasons:

- every respondent has the same chance of reporting conditions;
- estimation of the prevalence of specific conditions are likely to be more accurate;
- less coding problems.

An important issue is whether surveys should measure incidence, prevalence or both. For the great majority of conditions, prevalence can be regarded as most important in a European context.

Additional comments (other recommended aspects):

The question referring to the list of diseases cannot be put after other questions requiring a heavy effort to answer them. The order of the diseases in the list has to be the same for all the countries.

The most severe diseases must not be cited on the top of the checklist in order to avoid an underreporting of less severe diseases. Countries that would like to survey diseases not included in the above list are recommended to put them at the end of the checklist.

The open question on the presence of other diseases (not considered in the checklist) should be at the end of the disease list

Presently, the idea of a global indicator of co-morbidity requires in depth research on the reliability and validity of the indicator.

Section 6: Conclusion

Despite the efforts made towards an international comparability, the problem of having a global question to measure physical chronic conditions and of comparing the chronic health status between European countries still remains (Hupkens C.,1998).

The work done by EuroHIS and EuroREVES has resulted in recommendations on the steps required to achieve harmonisation within Europe: the primary focus has to be an agreement on the concepts and definitions; the concepts can then be translated into instruments.

The future direction of research should be a validation of the instruments proposed, including .the co-morbidity indicator.

The comparability of prevalence based on co-morbidity is not really fair. The differences mentioned above for disease specific and open ended questions are still valid while considering co-morbidity and should be taken into account while comparing different countries.

Chapter 2. Cognitive Functional Limitations

Contributors: Felicia Huppert, Carol Jagger and Jean-Marie Robine

Section 1. Definition

Cognitive function is difficult to define but is the ability to know, or be aware of oneself and one's surroundings, and to interact appropriately with the physical and social environment. There is no simple and coherent model of cognitive function (Bowling, 2001) but a number of domains of cognitive function are recognised as important for independent living. These include memory (learning and remembering), communication (comprehension and expression), orientation, perception, attention and executive function (categorization, abstract thinking, planning, decision making). In this chapter we make a clear distinction between the measurement of limitations in cognitive function and dementia. Although cognitive functional limitations are a part of the syndrome of dementia, the aim of this chapter is to recommend suitable instruments or items for use in health interview surveys to detect decline in cognitive function not to diagnose or screen for dementia.

Section 2. Relationship to other health indicators

Until relatively recently, the major focus of disability was the physical components rather than the mental ones. With the strong positive relationship between the prevalence of dementia and age, and the increasing life expectancy being experienced by Europeans, and other, populations, quantification of impaired mental function at older ages and recognition of its role in disability is essential. Indeed Gruenberg (1977) predicted the consequence of further increases in the length of life would be 'a pandemic of mental disorders'.

Nagi's model of the disablement process specifically describes three dimensions within functional limitations - physical, emotional and mental (Nagi, 1991). Limitations in cognitive function have enormous repercussions for both Activities of Daily Living (ADLs) and, more particularly, for household activities or Instrumental Activities of Daily Living (IADLs). Inability to perform ADLs is one of the features of dementia and is usually a part of the diagnostic process. However impaired cognitive function has also been shown to be predictive of dependence in daily care tasks (Little et al., 1986; Steen et al., 2001) as well as IADL limitations indicating cognitive impairment (Barberger-Gateau et al., 1992). The role of cognitive function in the performance of IADLs needs to be seen in the changing cultural context. During the period when the majority of the workforce was engaged in agricultural or manual labour, physical and sensory functioning were important, but there were few demands on cognitive function. Nowadays the increasing use of new technology at work and at home (microwave ovens, washing machines) as well as in managing money and leisure activities, places increasing cognitive demands on the population. Cognitive functional ability will therefore play an increasingly important role compared to physical and sensory function in the performance of IADLs.

It is clear that cognitive function has a role in the disablement process over and above that of sensory function and it is important to differentiate the two. However lower scores in cognitive function tests can be a result of visual or auditory impairment (Jagger et al., 1992a; Lindenberger & Baltes, 1994, 1997). Moreover, possible interventions to ameliorate activity restriction, the stage in the disablement process following functional limitation, will be quite different depending on whether the restriction is a result of sensory or cognitive functional limitations or indeed physical limitations.

Role of cognitive function items in HIS

Measuring cognitive function in a health interview survey is somewhat different to measuring other health conditions since the condition itself may not only affect responses to the question but also the accuracy of other information collected. Thus many surveys include a few key items assessing cognitive function, particularly orientation and memory, close to the beginning of the questionnaire. Many of the current instruments use the same set of items (age, date of birth, date today, day of week, place) and these are easily positioned at the beginning of any interview without any threat to the subject and may be introduced as the interviewer checking details. If the responses indicate to the interviewer the presence of impaired cognition, a proxy may then be sought.

Section 3. Main domains of cognitive function

There are several approaches to identifying the main domains of cognitive function which should be assessed in health surveys. Clinical neuropsychology has tended to focus on 5 broad areas: memory, language, perception, praxis and

executive function, as is evidenced in DSM-IV (APA, 1994) and ICD-10 (WHO, 1993) criteria for dementia. Cognitive psychology is more concerned with a theoretical understanding of the processes underlying cognitive performance and draws distinction within each of these broad domains e.g. differentiating semantic memory (general knowledge, rules and procedures) from episodic memory (memory for specific items or events recalled in context). Cognitive psychology also identifies a slowing in the speed of information processing as a fundamental process which underlies much of the age-related decline in cognitive performance (e.g. Salthouse, 1996). In this section we take a more pragmatic, functional approach to identifying the main domains of cognitive ability.

Basic cognitive functions :

1. Ability to communicate - comprehension and expression of oral and written information, both verbal (literacy) and numerical (numeracy).

2. Memory - orientation, general knowledge (semantic memory), remembering specific items or events (episodic memory) and remembering to carry out intentions (prospective memory) such as remembering to take medication or to turn off electrical appliances.

3. Attention - monitoring the environment (sustaining and shifting attention, searching, multi-testing)

4. Visio-spatial ability - perception of objects, pictures and verbal information (needed for recognising faces, road signs, computer icons etc.), and performing actions in an appropriate manner and sequence (e.g. making a cup of tea).

5. Executive function - categorising, abstract thinking, planning, problem solving, mental flexibility.

Section 4. Instruments currently in use

As with other assessments of functional limitations, limitation or impairment of cognitive function can be assessed using self-report, informant report or objective tests. In self-report measures, the subjects are asked about the frequency with which they experience common problems, particularly of memory. Most studies or standardised instruments use only a few self-report items, but detailed scales are also available (e.g. the Cognitive Failures Questionnaire – CFQ of Broadbent et al., 1982). Where self-report measures are useful for indicating the level of concern which an individual feels about their cognitive function, self-report measures do not correlate well with performance measures, and are strongly influenced by depression. Another difficulty with subjective assessment of cognitive function, particularly memory, is that individuals with memory impairment do not remember that they have memory problems. For these reasons, standardised informant interviews have been developed (e.g. the IQCODE of Jorm et al., 1994). While focusing on memory impairment, these instruments also cover difficulties in language and communication, visuo-spatial performance (e.g. finding one's way around the environment) and decision making.

Except where individuals are moderately or severely impaired, the majority of research assesses cognitive function using objective tests. There is no single instrument which covers all the cognitive domains listed above. However some instruments have a very comprehensive coverage (e.g. CAMCOG, the neuropsychological section of CAMDEX (Roth et al., 1988), assesses all areas except prospective memory), while others are designed to assess one specific area of functioning (e.g. the Boston Naming Test of Kaplan et al., 1983). Some instruments such as the Mini-Mental State Examination (MMSE - Folstein et al, 1975) or ADAS-Cog (Mohs et al, 1984) cover several functional domains, but combine them into a single score to provide a global estimate of cognitive function. Other measures provide both a total score and subscale scores (e.g. CAMCOG). One measure of global cognitive function has been developed to be administered over the telephone – the Telephone Interview for Cognitive Status (TICS - Brandt et al., 1988).

A list of instruments currently in use in Europe (Table 1) has been taken primarily from two reference sources, one focussing on psychiatric measures (Burns et al., 1999) and the other a more general reference on measuring health with a specific chapter on psychological scales (Bowling, 2001). For each measurement instrument, Table 1 shows the domains covered, the total score and the average time taken to complete the test. Measures that require rating by a clinician have been excluded. This list is not intended to be comprehensive, but serves to illustrate some of the more widely used instruments. Table 2 gives examples of specific items used in these instruments to assess individual cognitive domains.

Section 5. Important issues

I. Properties of suitable cognitive tests

Since the focus of the cognitive measures is to assess capability rather than to screen for dementia, the chosen measures need to yield a wide range of scores within the normal population. Tests such as the MMSE, IMC, AMT, SPMSQ etc. are not suitable because they suffer from ceiling effects, with a high percentage of normal people obtaining maximum or near-maximum scores. A wide range of scores, and the avoidance of ceiling effects are required if we want the tests to be sensitive to change. Ideally, each of the main cognitive domains should be assessed, with separate scores available for each domain, although a total score can also be helpful. The reality of health interview surveys is that the assessment of any one area of health (e.g. cognitive function) usually needs to be relatively brief, but unfortunately the briefest instruments neglect many domains and suffer from ceiling effects.

New developments in psychometric theory and application are likely to provide an evidence-based solution to this dilemma in the near future. The aim is to identify those items or tests which provide the greatest amount of information in the shortest time. The methods of Item Response Theory (IRT) (Mungas & Reed, 2000; Teresi et al., 2000) are currently being used to develop more streamlined measures.

II. Type of assessment items and their limitations

Items for measuring physical and sensory functional limitation by self-report are often in the form of everyday scenarios posed to the respondent, for example being able to recognise a person across a room. This form has not been used generally for measuring cognitive function because comparisons with test-based measures have resulted in low correlations together with high correlations with education, socio-economic status and depression. Low correlations with test-based measures, and a high correlation with education, socio-economic status and depression are also found for many other health status measures, so the problem is not unique to cognitive function. However, just as the gold standard for the assessment of physical and sensory capability must be an objective examination rather than a self-report measure, so too the gold standard for cognitive capability must be objective measures. Self report measures provide valuable information about perceived limitations, but not about functional ability.

Correlations between education or socio-economic status and cognitive function measures (both self-report and test measures) can be problematic. Ideally one would develop measures which are unaffected by education, or socio-economic status, but this may be impossible. Adult cognitive function is related to cognitive function in childhood which is a major determinant of educational attainment, which in turn influences socio-economic status. A more realistic approach is to compare an individual's performance with that expected for their educational or socio-economic group (Huppert & Wilcock, 1997).

Some of the test-based measures are also affected by sensory functional limitations, particularly vision problems (Jagger et al., 1992a). Thus, if test-based measures are to be recommended, they should be independent of visual problems, although hearing impairment if severe may be more difficult to circumvent. Providing written instructions for those with severe hearing impairment may appear to be an option, but would produce data which is not strictly comparable with oral presentation.

Another possibility is that questions on impairment or decline are asked of proxies, not of the subject themselves, using for example the IQCODE (Jorm et al., 1988) and its short form version (Jorm, 1994). The problem here is that a proxy can usually be found for those with severe cognitive functional limitations as they are usually not living alone, whereas for the many without such limitations, proxies may not be so readily available.

Section 6. Current position in Europe

The Health Monitoring Programme on "Health Interview Surveys and Health Examination Surveys census" (HIS-HES, 1999) has provided a database containing the methodological aspects and questionnaires of the recent European health or disability surveys. The work conducted here was based on a search for all questions assessing cognitive function in this database. Both HES and HIS were searched. In HES cognitive function assessment or test was specified precisely. In HIS the topic codes general mental health (213), aspects of mental health (214) and disease specific morbidity (204) were searched for cognitive function items. All studies included on the database are shown in Table 3.

A total of 3 of 8 health examination surveys, from 2 countries (two surveys from Finland and one from Spain) included cognitive function assessments, in all cases these were the MMSE. In addition verbal fluency and the word list recall from CERAD (reference) were also included in the Finnish survey.

Five countries (Belgium, Finland, France, Norway, United Kingdom) had in total seven health interview surveys containing items covering cognitive function, mostly items covered the domains of memory and concentration (Table 4). In addition, in three countries the surveys included more global mental health questions that could detect cognitive functional limitations but might be answered in the affirmative for other mental health conditions (Table 3). In Spain the 1999 survey includes a question on whether the respondent has been diagnosed as having dementia or Alzheimer's disease (Table 2). The most recent version of the HIS-HES database (2001) includes other surveys that also include cognitive function items, such as the UK Health Survey for England (2000).

Translating a test from one language into another is not as straightforward as it may seem. There are usually several ways in which a question can be worded, and a translation needs to capture the subtle shades of meaning and response categories which the originator intended. In the case of objective tests, the relative difficulty of an item may differ between different national or language groups, and in the case of tests which use pictorial material the appropriateness of the pictures for different cultural contexts needs to be considered. For these reasons, the adoption of common instruments to be used across Europe requires a harmonization process. Such a process was recently undertaken by Verhey and colleagues in Maastricht – the European Harmonization Project for Instruments in Dementia (EURO-HARPID) For the initial harmonization project, the investigators selected the MMSE, ADAS-Cog and CAMCOG and versions were harmonized in Belgium, France, Germany, Italy, the Netherlands, Spain, Sweden and the United Kingdom (Korten et al., In Press; Verhey et al., 1998).

In the early 1990s, the Division of Mental Health of the World Health Organisation began development of the WHO Cognitive Assessment Battery. Following numerous consultations and consensus meetings, an impressive test battery was developed, using primarily non-verbal materials designed to be culture fair. The battery covered most of the cognitive domains listed above. Regrettably, this battery does not appear to have been used in field tests and is unknown to most of the research community.

A very recent European initiative which involves harmonization of cognitive measures is the Study of Health and Retirement in Europe (SHARE). The age range of the proposed sample is 50 years and above. Updates on the consultation and decision-making process and the final form of the test battery when available, can be found on www.share-project.org SHARE has developed out of two earlier projects, the Health and Retirement Survey (HRS) which has been taking place in the US since 1991 (www.umich.edu/~hrswww), and the English Longitudinal Study of Ageing (ELSA) which began in 2001 (www.ifs.org.uk/elsa). There has also been extensive work by OECD (1997), to develop measures of literacy and numeracy for cross-national comparison. While producing invaluable data, these measures are complex and very time-consuming, and therefore not suitable for use in health surveys. However, ELSA, HRS and SHARE are currently developing common items for the brief assessment of literacy and numeracy, to augment their assessment of cognitive function.

Section 7. Conclusion

Few European health surveys to date have included an assessment of cognitive function. Of those which have, the majority have used brief screening tests for dementia. These are not well suited to assessing cognitive function in the general population since the items are too easy, and the resulting high scores mask underlying differences between individuals. However, brief cognitive screening is desirable in health interview surveys, whatever the survey topic, to ensure that the respondent's answers are likely to be reliable, and to determine whether a proxy needs to be sought. Such questions should be placed near the beginning of the survey. Some of the test-based items ("What is your name, age, what is the address of this place?") are easy to administer at the start of an interview and can be asked in a very natural way. Other cognitive items are best left until later in an interview, when rapport has been established between subjects and interviewer.

Based on a consideration of the daily living needs of people in an increasingly technological environment, the following domains of cognitive function should be assessed where possible: communication, memory, attention, visuo-spatial ability and executive function. Communication includes literacy and numeracy as well as the comprehension and expression of oral language. Memory encompasses general knowledge and new learning as well as prospective memory – remembering to carry out an intention. Prospective memory is relatively easily tested in an interview by requiring the subject to carry out instructions at a further point in the interview. Attention involves both monitoring information and shifting focus where

appropriate. Visuo-spatial function involves recognition of objects and symbols and interacting with them appropriately. Executive function includes higher processes such as abstract thinking, organisation and mental flexibility. Measures of these functions should be test-based, but self-report questions are useful for establishing the extent to which the subject is concerned about their cognitive limitations.

Recommendations

1. A few key orientation items can be placed at the start of the interview to establish whether the interview is likely to be productive or whether a proxy will need to be sought. These questions can be asked in a very natural manner as follows:
> "Let me just check, your name is ….?"
> "What was your age last birthday?"
> "What is your current address?"
> "What is today's date?"

2. Cognitive test items can be placed later in the interview. This section flows well if the items are introduced by one or more self-report questions to establish whether the subject has any concerns about their cognitive function. The following set of items can be used, each coded no, occasionally, often or very often:
> "First, can you tell me if you have any difficulty with your memory?" If yes, "Does this embarrass or bother you or cause you inconvenience?"
> "Do you forget what you have read or heard?"
> "Do you forget people's names?"
> "When speaking, do you have difficulty finding the word you want or do you sometimes say the wrong word?"
> "Do you find it difficult to concentrate?"
> "Do you forget to do things which you intended to do, such as post a letter?"

If only a single self-report item is to be used, it would be:
> "In general, would you say your memory is excellent, very good, good, fair or poor?"

3. Prospective memory instructions can be given next. These can take the form of:
> "Later on I am going to …. [e.g. hand you a sheet of paper]. When I do, I would like you to …..[eg. write your initials in the top left-hand corner of the page]. Can you remember that?"

4. New learning can be assessed by presenting a random list of common words, usually concrete nouns which can easily be formed into a visual image. The CERAD 10-item word list can be used or a 15-item word list. Some instruments (e.g. ADAS-Cog, TICS) use a single presentation of the word list, while others use three to five presentations of the word list with recall following each presentation (e.g. the CERAD battery, Welsh et al., 1991). Where possible, both immediate and delayed recall should be tested.

5. Language can be assessed using a verbal fluency test e.g. naming as many different animals as possible in one minute. Success on this test also involves an element of executive function i.e. categorizing animals into domestic, wild, birds, insects etc. and shifting between categories.

6.Literacy and numeracy can be assessed by
> (a) asking the subject to write their name and address, or writing a name and address to dictation (as in the IMC of Blessed et al., 1968) and
> (b) asking them to make simple calculations e.g.

"If a drink costs 85 cents and you give the shopkeeper 100 cents (1 Euro) how much change should you get back?"
"If the risk of having a disease is 10%, how many people out of 1,000 would be expected to have the disease?"

7. Attention can be assessed using a backwards counting task (e.g. counting backwards from 100 by 3 or by 7), or by means of a visual search task such as symbol or letter cancellation i.e. crossing out all examples of one or more symbols or letters on a sheet of random symbols or letters in a given time. The Trail-making test (Reitan, 1958) is another possibility. Trails B requires shifting between numbers and letters so is also a measure of attentional set shifting.

8. Visuo-spatial ability can be assessed by a copying task (overlapping pentagons, 3-dimensional house) or a drawing task (drawing a clock and setting the hands to ten minutes past 11).

9. Executive function is most easily assessed using similarities, which requires abstract thinking e.g.,
> "In what way are an apple and a banana alike?"
> "In what way are a table and a chair alike?"
> "In what way are a plant and an animal alike?"

10. Delayed recall of the word list can be tested at the end, along with recall of the prospective memory instruction.

This set of tests could be completed in 10-15 minutes on average**.**

Table 1 Instruments currently used to measure cognitive function, domains covered and time taken to administer

Test	Domains covered	Time to administer	Comments
Mini-Mental State Examination (MMSE) *(Folstein et al, 1975)*	Orientation, attention and calculation, language, memory, praxis	10 minutes	Translated into many languages; Population norms (Max. score 30)
Information-Memory-Concentration (IMC) Test *(Blessed et al., 1968)*	Information, memory, concentration		Cognitive component of the Blessed Dementia Scale
Abbreviated Mental Test (AMT) *(Hodkinson, 1972)*	Information, memory, concentration	3 minutes	Short dementia screening test developed from the IMC (Max score = 10)
Short orientation-memory-concentration test *(Katzman et al., 1983)*	Orientation, concentration, memory	<5 minutes	Short test developed from the IMC
Short Portable Mental Status Questionnaire (SPMSQ) *(Pfieffer,1975)*	Orientation, memory, concentration	2 min	Brief dementia screening test
Clifton Assessment Scale (CAS) of the Clifton Assessment Procedures for the Elderly (CAPE) *(Pattie & Gilleard, 1979)*	Information, orientation, concentration, psychomotor performance	10-15 minutes	(Max score not given in paper)
7 Minute Screen *(Solomon et al., 1998)*	Memory, verbal fluency, visuospatial, orientation	7 minutes	(Max score not given in paper)
Trail-making test *(Reitan, 1958)*	*Attention, executive function*		*Score based on time to completion*
ADAS-Cog *(Mohs et al, 1983)*	*Orientation ,memory, language, praxis*		*Includes CERAD word list. Mainly used in clinical trials. Max. score 75 (=severe impairment)*
Cambridge Cognitive Examination (CAMCOG) *(Roth et al 1988,1999 ; Huppert et al, 1995)*	*Orientation, language, memory, attention/calculation, praxis, perception, executive function*	*20 minutes*	*Incorporates MMSE, AMT, Population norms Max. score 107, plus separate subscale scores*
Syndrom Kurztest (SKT) *(Erzigheit, 1989)*	Language, memory, attention, praxis, executive function	<15minutes	Designed for use in clinical trials. Each score is time-based, requiring subjects to respond rapidly. Provides subscale scores on two factors: memory and attention and a total score.
Telephone Interview for Cognitive Status (TICS) (*Brandt et al 1988*)	*Orientation, memory, language, praxis, reasoning*	*5 min*	*Designed as a telephone screening test for dementia. Incorporates CERAD Max. score 41 points*
Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) *(Jorm, 1994)*	Memory, language, executive function, concentration	10-15 minutes	Informant ratings of changes in everyday cognitive function independent of premorbid ability
Short-Comprehensive Assessment and Referral Evaluation (Short-CARE) *(Gurland, 1984)*	Memory, language	NK	Informant questionnaire
DECO *(Ritchie & Fuhrer, 1996)*	Memory, orientation, concentration	NK	Informant questionnaire to detect change in cognitive function

Table 2 Commonly used tests of cognitive function

General domain	Specific function	Tasks
1. Communication	Comprehension	Carrying out oral or written instructions e.g. "If you are older than 50, put your hands behind your head" (CAMCOG)
	Expression	Naming communal objects or pictures
	Verbal fluency	e.g. naming as many different animals as possible in 1 min.
	Writing	Writing a name and address
	Calculation	e.g. "If a drink costs 85 cents and you give the shopkeeper 100 cents (1 Euro) how much change should you get back?"
		"If the risk of having a disease is 10%, how many people out of 1,000 would be expected to have the disease?" (used in ELSA)
2. Memory	Orientation	Orientation in time and place (MMSE)
	Semantic memory	General knowledge e.g. "Who is the President of the US?"
	Episodic memory	New learning e.g. a 10-word list (used in CERAD, TICS, ELSA)
	Prospective memory	Remembering to carry out an instruction given earlier e.g. "Later on I am going to …. e.g. hand you a sheet of paper. When I do, I would like you to …..eg. write your initials in the top left-hand corner of the page. Can you remember that?" (used in ELSA)
3. Attention	Concentration	Counting backwards from 100 (MMSE)
	Monitoring, search	Letter cancellation – crossing out all the Ps and Ws on a sheet of random letters in 1 min. (used in CFAS, ELSA)
	Set shifting	Trail Making Test (Trails B)
4. Visuo-spatial	Recognition	Recognising pictures of famous people or objects from unusual angles (CAMCOG)
	Copying a design	Copying overlapping pentagons (MMSE); 3-dimensional drawing of a house (CAMCOG)
	Drawing	Drawing a clock and setting the time (CAMCOG)
5. Executive function	Abstract thinking	Similarities – e.g. "In what way are an apple and a banana alike?"
		"In what way are a table and a chair alike?"
		"In what way are a plant and an animal alike?"
	Categorization	Card sorting (e.g. Weigl test)

Table 3 Surveys included in the "Health Interview Surveys and Health Examination Surveys census" (HIS-HES) database

Austria	1995 (A02); 1997 (A04); 1999 (A01)
Belgium	1997 (B01)
Denmark	1994 (DK01); 1998 (DK05)
Finland	2000 (FIN01); 1997 (FIN02); 2000 (FIN03) ; 1996 (FIN05)
France	1991/92 (F01); 1999 (F02) ; 1998 (F03)
Germany	1998 (D02); 1998 (D05)
WHO-Europe	1996 (INT01)
Ireland	1998 (IRL01); 2000 (IRL02)
Italy	1999-2000 (I01)
Norway	1998 (N01)
Portugal	1995 (P01)
Spain	1995 (E01); 1999 (E04); 1996/1997 (E06)
Sweden	1999 (S01)
Switzerland	1997 (CH01)
The Netherlands	1998 (NL01)
United Kingdom	2000 (UK01); 1998 (UK02); 1998 (UK09); 1996/1997 (UK04); 1998 (UK09); 1995 (UK010); 1993/94 (UK05); 1991/92 (UK03)

Table 4: Form of question included in European surveys by domain

Number manipulation

United Kingdom	1996/97	UK04	173. IF Depress=1 or Depres2=2 or Getting=1 or Confused=1 or Handicap=1 or Mental=1 or Psych=1 Do you have difficulty with sums and calculations? Yes 1 No 2

Memory

France	1999	F02	BORI1. Do you (he/she) sometimes forget what time of the day it is? 1. No, never 2. Yes, sometimes 3. Yes, always 7. Irrelevant : too young 8. Will not answer 9. Does not know
United Kingdom	1996/97	UK04	157. IF Depress=1 or Depres2=2 or GettngOn=1 or Confused=1 or Handicap=1 or MentIll=1 or Psych=1 Do you often forget what you are supposed to be doing in the middle of something? Yes 1 No 2
United Kingdom	1996/97	UK04	158. IF Depress=1 or Depres2=2 or GettngOn=1 or Confused=1 or Handicap=1 or MentIll=1 or Psych=1 Do you often lose track of what is being said in the middle of a conversation? Yes 1 No 2
United Kingdom	1996/97	UK04	165. IF Depress=1 or Depres2=2 or GettngOn=1 or Confused=1 or Handicap=1 or MentIll=1 or Psych=1 If a neighbour came to the door with a message for someone else, could you remember the message and pass it on correctly? Yes 1 No 2
United Kingdom	1996/97	UK04	166. IF Depress=1 or Depres2=2 or GettngOn=1 or Confused=1 or Handicap=1 or MentIll=1 or Psych=1 Do you often forget to turn things off such as fires, cookers or taps? Yes 1 No 2
United Kingdom	1996/97	UK04	167. IF Depress=1 or Depres2=2 or GettngOn=1 or Confused=1 or Handicap=1 or MentIll=1 or Psych=1 Do you often forget the names of people in your family or friends whom you see regularly? Yes 1 No 2
United Kingdom	1993/94	UK05	Have you noticed any problems with forgetting things in the past month?
United Kingdom	1993/94	UK05	How long have you been having the problems with your concentration/memory as you have described? (less than 2 weeks to 2 years or more)
United Kingdom	1993/94	UK05	Earlier you said you have been forgetting things. Have you forgotten anything important in the past seven days?
United Kingdom	1993/94	UK05	Since last (day of week), on how many days have you noticed problems with your concentration/memory?

Attention (concentration)

Belgium	1997	B01	Have you recently been able to concentrate on whatever you're doing? 1 Better than usual 2 Same as usual 3 Less than usual 4 Much less than usual
Norway	1998	N01	Have you been bothered with any of the problems mentioned on this list during the past three months? Consider only permanent or recurring problems. SHOW CARD 3 .... concentration problems
United Kingdom	1991/92	UK03	35b. Within the last month have you suffered from any problems with .. Difficulty concentrating? Yes No
United Kingdom	1993/94	UK05	In the past month, have you had any problems in concentrating on what you are doing?
United Kingdom	1993/94	UK05	How long have you been having the problems with your concentration/memory as you have described? (less than 2 weeks to 2 years or more)
United Kingdom	1993/94	UK05	In the past week, have these problems with your concentration actually stopped you from getting on with things you used to do or would like to do?
United Kingdom	1993/94	UK05	Since last (day of week), on how many days have you noticed problems with your concentration/memory?
United Kingdom	1993/94	UK05	In the past week could you concentrate on a TV programme, read a newspaper article or talk to someone without your mind wandering?

Executive function

United Kingdom	1996/97	UK04	161. IF Depress=1 or Depres2=2 or GettngOn=1 or Confused=1 or Handicap=1 or MentIll=1 or Psych=1 Can you think clearly, or do your thoughts tend to be muddled or slow? Can think clearly 1 Thoughts muddled and slow 2
Finland	1997	FIN02	Next we pose you some personal questions. Think of the past month. Please circle the alternative which best describes how often the asked thing or symptom has been on your mind. Do you get confused when you have to do something quickly? Often Sometimes Not at all

Orientation

France	1999	F02	BORI2. Do you (he/she) have trouble finding your (his/her) way when going out ? 0. Irrelevant : does not go out or cannot go out alone for a physical health reason 1. No, never 2. No, provided that I always go on the same route(s) 3. Yes, I sometimes get lost or I need help 4. Yes, I always need someone to guide me 7. Irrelevant: too young 8. Will not answer 9. Does not know
United Kingdom	1996/97	UK04	162. IF Depress=1 or Depres2=2 or GettngOn=1 or Confused=1 or Handicap=1 or MentIll=1 or Psych=1 Do you often get confused about what time of day it is? Yes 1 No 2

Global questions

Switzerland	1997	CH01	Have you been in treatment for psychological problems during the course of the last 12 months? Yes (1) No (2)
Spain	1999	E04	Have you been diagnosed to have any of the following illnesses? 15. Dementia/Alzheimer's disease Answer categories: yes no
Finland	1996	FIN05	not for a proxy. Do you now suffer from any sort of mental problem? 1 Yes 2 No
United Kingdom	1996/97	UK04	143.In the last 12 months have you seen a psychiatrist or other specialist because of a mental, nervous or emotional problem? Yes 1 No 2

Chapter 3. Instrumental Activities of Daily Living (IADLs)

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Section 1. Definition

Instrumental Activities of Daily Living (IADLs) such as shopping, doing the laundry, cleaning, were first introduced by Lawton and Brody (1969) to "tap a level of functioning hereto inadequately represented in attempts to assess everyday functional competence" of older people. Items, question forms and responses were devised for simplicity, ease of use between different health professionals and to indicate real service needs. As opposed to Activities of Daily Living (ADLs) (Katz et al., 1963) which measure the ability of an older person to perform basic <u>self-care</u> activities (washing, dressing, getting to and from the toilet, feeding), IADLs measure the ability to live independently in and maintain an ordinary/usual household, that is they measure the ability to perform <u>household</u> care activities, including functioning in the social world and the world outside the home.

Section 2. Relationship with the other indicators

Within the various models of the disablement process, IADLs fall either within the category of 'disability' (Nagi, 1965; 1976; 1991; World Health Organization, 1980; Wood, 1975) or, more accurately, within activity restriction (Wood, 1975). Nagi described disability as "the inability or limitation in the fulfilment of activities and social roles in relation to work, the family and an independent life" (Nagi, 1991). Within these models, disability and activity restriction are measured at the level of the person in his surroundings and they follow functional limitation "limitations in performance at the level of the whole organism with three dimensions - physical, emotional and mental" (Nagi, 1991). Indeed, physical performance measures such as balance and grip strength have been shown to be associated with IADL independence (Judge et al., 1996). In addition, lower body function has been more heavily implicated in IADL disability (Lawrence and Jette, 1996).

The hierarchical nature of ADLs has been well researched but studies have also found a gradient of severity for IADLs together with a combined ordering for IADL and ADL items together, with IADL items generally preceding ADL items in the prevalence of dependency. Finch found that the IADL items *shopping* and *cleaning the house* were at the bottom of the range of severity whilst *meals preparation* and *taking medicines* were the most severe level for IADL and indeed ranged among the lower severity ADL levels (Finch et al., 1995). Spector and Fleishman attempting to built a 15 ADL/IADL items indicator, referring to the need for help came out with the following hierarchy: feeding, continence, *telephone*, toileting, transferring, dressing, *light housework*, getting around inside, *managing money*, *taking medication*, *preparing meals*, getting around outside, bathing, *laundry*, *shopping*, *going outside on a long distance* (Spector and Fleishman, 1998). Similar unidimensional, hierarchical scales including ADL and IADL items have been reported using a variety of statistical techniques (Kempen et al., 1996; Bath and Philp, 1998; Ferrucci et al., 1998; Kane et al., 1998; Manton et al., 1998). An interesting scale, developed by combining ADLs and IADLs to produce a measure of need for health and social care if the 'Interval of Need' scale. The lowest level of need (long interval need) would require intervention once per day or less with help required to go out of doors alone, shop, do light housework or wash clothes (Isaacs and Neville, 1976).

Although historically developed to cover complementary areas of functioning and competence of older people, the placement of IADL items earlier in the disablement process has meant that they are often included to detect lesser levels of care burden than ADLs. Interestingly, a comparison of the rankings of ADL and IADL items by experts in long-term care and ageing with those made by older people found that older people themselves rated IADLs more highly than experts, stressing the importance of these activities in the lives of older people (Kane et al., 1998; Philp et al., 1998). IADLs also require a higher level of cognitive functioning than ADLs and, as in ADLs, dependency will not necessarily occur solely due to a physical cause. Hence the assessment of functional limitations is necessary to explain possible IADL and ADL restriction and to address needs.

Section 3. Main domains

The domains covered in the first IADL scale (Lawton and Brody, 1969) are shown in Box 1.

Box 1: Instrumental Activities of Daily Living Scale (Lawton and Brody, 1969)

Ability to use the phone: operates on own initiative… / dials a few well known numbers / answer but does not dial / does not use

Shopping: takes care of all shopping needs / shops for small purchases / needs to be accompanied / completely unable to shop

Food preparation: plans, prepares, serves adequate meals / prepares adequate meals if supplied ingredients / heats and prepares adequate meals but does not maintain adequate diet / needs to have meals prepared and served

Housekeeping: Maintains house alone or with occasional assistance / performs light daily tasks such as dish washing, bed making / performs light daily tasks but cannot maintain adequate cleanliness / needs help for house maintenance / does not participate in housekeeping tasks

Laundry: does personal laundry / launders small items-rinses stockings etc… / all laundry must be done by others

Mode of transportation: travels independently on public transportation or drives car / arranges own travels by taxi but does not otherwise use public transportation / travels on public transportation when accompanied by others / travel limited to taxi or automobile with assistance of others / does not travel at all

Responsibility for own medication: Is responsible for taking medication in correct dosages at correct times / takes responsibility of medication if prepared in advance in separate dosages / is not capable of dispensing own medication

Ability to handle finances: Manages financial matters (budgets, writes checks, pays rents, bills, goes to banks), collects and keeps tracks of incomes / manages day to day purchases but needs help with banking, major purchasing… / incapable of handling money

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Other scales have also extended these domains to include the areas of socialization/hobbies/leisure (Fillenbaum, 1978; Lincoln and Gladman, 1992), work (Holbrook and Skilbeck, 1983; Law et al., 1994) and home maintenance (Williams et al., 1991).

Section 4. Instruments currently in use

In 1998 a review of IADL assessments in use with older people was reported (Ward et al., 1998), many of these having grown out of the field of rehabilitation and occupational therapy for use with stroke patients. A systematic review of the literature since this paper was undertaken to bring the review up-to-date. Only three further scales could be added to the previous list of 14 scales: the Assessment of Living Skills and Resources (ALSAR) (Williams et al., 1991), the Groningen Activity Restriction Scale (GARS) (Kempen et al., 1996) and the Assessment of Motor and Process Skills (AMPS) (Fasher, 1995). The scales are listed in Table 1.

Section 5. Important issues

Domains covered

Table 2 shows the coverage of domains by each of the IADL scales in current use although the domain of *home maintenance* is omitted since it is included in only one scale (Williams et al., 1991). The domain covered by the majority of IADL scales was *cooking* followed by *housework*, *shopping* and *laundry*. The domains covered by the fewest scales were *medication*, *work* and *telephone*.

IADLs already require a higher level of cognitive ability than ADLs but the need for such abilities may increase further in the future. Already *shopping* for many goods, including food, and their delivery to the home, can be accomplished using the Internet. Similarly the advent of the microwave oven and ready prepared meals has made *meal preparation* and *cooking* much easier. Cognitive limitations were classified as the second most common source of difficulty with everyday activities in one study of older people, in particular declarative knowledge which guides initial attempts to perform an unfamiliar task (Rogers et al., 1998). Leisure activities, transportation and housekeeping were activities most often mentioned and in particular the impact of new technology, for instance videocassette recorders, telephone menus, answering machines, cameras and credit card scanners. The future might therefore see a change of balance from physical functional abilities to cognitive functional abilities to perform IADLs.

Scale construct

Whether the activity is assessed by self reported capacity (could you do …), self-reported abilities (can you do …), self-reported performance (do you do…) or measured performance has already been discussed for ADLs. Glass (1998) has shown how the differences between capacity, ability and performance can describe different stages of the disablement process. In particular he reported results from the MacArthur Studies of Successful Aging in which 7% of the high-

functioning group of older people stated that the were able to do heavy housework but did not actually do any (Glass, 1998). Differences between self-assessment of abilities of respondents and actual performance have also been reported (Kempen et al., 1996; Reuben et al., 1995). It should be noted that the AMPS (Williams et al., 1991) is conceptually very different to the other scales since (a) the older person themselves chooses the IADL tasks they are to be assessed on from a range of possible tasks; (b) direct observation is used rather than self-report and (c) the underlying motor and process skills used in each task are rated rather than the ability to do the task.

In general, self-reported performance is preferred to self-reported ability in the case of ADLs. However, IADLs are not as straightforward as ADLs since ADLs are basic personal care items that a person must perform daily whilst IADLs may be undertaken by other family members, particularly as certain roles/activities are gender specific. Indeed, Lawton and Brody (1969) originally created a separate IADL scale for men and women, omitting the three items of food preparation, housekeeping and laundry from the male version. However, although an elderly man may not do the cooking because his wife does so (and therefore if asked about his performance in this domain he would be classified as dependent), he may take over this role if his wife becomes ill (thus having the capacity). Additionally, if IADLs are asked only of households and not separate individuals, or if abilities are questioned and not capacity, we have no real understanding of the vulnerability or needs of the remaining partner if the composition of the household changes, for instance on the death of a spouse.

Many of the scales presented in Table 1 used a three category scale (independent, with assistance, dependent or unable to do) to rate an individual's ability to carry out the activity (Lawton and Brody, 1969; Fillenbaum, 1978; Benjamin, 1976; Sheikh et al., 1979; Sonn and Asberg, 1991). Others included an extra category or categories to include an assessment of the level of difficulty (Kempen et al, 1996; Lincoln and Gladman, 1992, Byres and Parker, 1992). Measuring actual disability (with the use of aids and equipment) or intrinsic difficulty (without aids and equipment) also varies in these scales, some allowing the use of such devices (Kempen et al., 1996) whilst others consider a person cannot be independent if using equipment (Byres and Parker, 1992; Fuhrer, 1987).

Yet other scales have taken a completely different approach. The Assessment of Living Skills and Resources (ALSAR - Wiliams et al., 1991) rates individuals on two separate ordinal scales, accounting for skill level and utilization of resources. A resource is defined as a support extrinsic to the person for task accomplishment and may be human or technical, formal or informal. One of the responses to limitations is that a task is delegated to others, perhaps purchasing it from others such as cleaning the house (Rogers et al., 1998). This may be one reason for some of the apparent discrepancies reported earlier in those high-functioning older people who were able to perform a task but did not actually perform it (Glass, 1998). The Canadian Occupational Performance Measure (COPM - Law et al., 1994) gives three scores for each activity: the importance of the activity to the person, performance and satisfaction with performance. Satisfaction is also an inherent part of other scales (Yerxa et al., 1988).

Response categories for both ADL and IADL are to report disability and often needs, met or unmet. The assumption of need from use of help for an IADL task are closely aligned with measuring capabilities, abilities and performance with one solution being to use a combination of measures of actual performance (do you …) with satisfaction and if help is received a measure of capacity (could you …) (Branch, 2000).

If indicators are to be suitable at both a population and individual level, they need to be able to detect changes in performance and dependency. This has been assessed for the Extended Activities of Daily Living Scale (EADL) with stroke patients and suggests that the EADL would be sensitive to the effect of interventions aimed at changing independence of two or more ADLs (Gompertz et al., 1994). However, if we are really to detect changes at a level early enough to intervene, we need to elicit earlier changes in IADLs, perhaps through the use of questions eliciting task modification or decreased frequency of performance (Fried et al., 1996). In a population of older people, Fried reported that 16.2% of the study population reported no difficulty with heavy housework but had modified the task and a further 4.7% had decreased the frequency. Such early indications of decreasing capacity may allow interventions to delay the onset of frank disability.

Section 6. Current position within Europe

The Health Monitoring Programme on "Health Interview Surveys and Health Examination Surveys census" (HIS-HES, 1999) has provided a database containing the methodological aspects and questionnaires of the recent European health

or disability surveys. The work conducted here was based on a search for all questions measuring IADLs in this database. All studies included on the database are shown in Table 2.

A total of 8 surveys from 7 countries included items on IADLs in the main domains of cooking, housework, transport, social/leisure, laundry, shopping, managing finance, work, medication and telephone. Table 3 shows the domains covered by each of the surveys whilst Table 4 compares the forms of the questions under each domain. *Shopping* and *housework* were the domains most commonly included in European surveys although the total incomparability of the items is highlighted in Table 4. Six surveys included only global questions on IADL and these are listed in Table 5.

Section 7. Conclusions

Existing European questions are far from comparable and most are a long way from satisfying requirements on coverage of domains and the forms of questions and response categories.

Recommendations

Taking into account all the previous comments we propose further development and validation of a new common instrument for European surveys, with a specific form for surveys focusing on the disablement process or on the elderly and a global form for more general social or HIS.

Specific form

a) Selected items

> *Use the telephone*
> *Do all the shopping*
> *Prepare meals*
> *Do routine light housework*
> *Do periodic heavy housework*
> *Do the laundry*
> *Take care of/manage your financial matters*

b) Suggested wording

Think about your household and other routine activities in everyday life. Please ignore temporary problems:
1/ Do you, usually, *prepare meals* **without any difficulty and completely on your own?**
Yes, without difficulty and completely on my own (i)
No, with difficulty but completely on my own (ii)
No, not completely on my own (iii)
Do not prepare meals (iv)
[if (i) go to 2/]
[if (ii) go to b)]
[if (iii) or (iv) go to a)]
a) **Could you do it on your own without any difficulty if you had to or wanted to**   Yes/No
[if No to 2/]
b) **Do you require (more) help in getting** *meals prepared* **to your satisfaction?**   Yes/No

Global form

Think about your household and other routine activities in everyday life, for example shopping, preparing meals, doing housework, doing the laundry, taking care of financial matters or using the telephone. Please ignore temporary problems:

1/ Do you, usually, perform such activities without any difficulty and completely on your own?

Yes, without difficulty and completely on my own (i)

No, with difficulty but completely on my own (ii)

No, not completely on my own (iii)

Do not perform such activities (iv)

Table 1: Coverage of domains by current IADL assessments

IADL scale/author (year)	Cooking	Housework	Transport	Social/ leisure	Laundry	Shopping	Financial	Work	Medicine	Telephone
Lawton and Brody (1969)	✓	✓	✓		✓	✓	✓		✓	✓
Northwick Park (Benjamin, 1976)	✓									
OARS (Fillenbaum, 1978)	✓	✓	✓			✓	✓		✓	✓
Sheikh et al. (1979)	✓									
Whiting and Lincoln (1980)	✓	✓	✓		✓	✓	✓			
Fortinsky et al. (1981)	✓	✓			✓	✓				
Klein and Bell (1982)										✓
Frenchay (Holbrook and Skilbeck, 1983)	✓	✓	✓	✓	✓	✓		✓		
FIM (Hamilton et al., 1987)				✓						
Yerxa et al. (1988)	✓	✓	✓	✓	✓		✓	✓		
Sonn and Asberg (1991)	✓	✓	✓			✓				
ALSAR (Williams et al, 1991)	✓	✓	✓	✓	✓	✓	✓		✓	✓
Byres and Parker (1992)	✓	✓			✓	✓				
EADL (Lincoln and Gladman, 1992)	✓	✓	✓	✓	✓	✓	✓			
COPM (Law et al., 1994)	✓	✓	✓	✓	✓	✓	✓	✓		
AMPS (Fisher, 1995)	✓	✓		✓	✓					
GARS (Kempen et al., 1996)	✓	✓			✓	✓				
TOTAL	**15**	**13**	**9**	**7**	**11**	**11**	**7**	**3**	**3**	**4**

Table 2: Surveys included in the "Health Interview Surveys and Health Examination Surveys census" (HIS-HES) database

Austria	1995 (A02); 1997 (A04); 1999 (A01)
Belgium	1997 (B01)
Denmark	1994 (DK01)
Finland	2000 (FIN01); 1997 (FIN02); 1996 (FIN05)
France	1991/92 (F01); 1998 (F03)
Germany	1998 (D02); 1998 (D05)
WHO-Europe	1996 (INT01)
Ireland	2000 (IRL02); 1998 (IRL01)
Italy	1999-2000 (I01)
Norway	1998 (N01)
Portugal	1995 (P01)
Spain	1999 (E04); 1995 (E01)
Sweden	1999 (S01)
Switzerland	1997 (CH01)
The Netherlands	1998 (NL01)
United Kingdom	2000 (UK01); 1998 (UK02); 1998 (UK09); 1996/1997 (UK04); 1995 (UK010); 1993/94 (UK05); 1991/92 (UK03)

Table 3: Coverage of domains by European surveys

European Survey (year)	Cooking	Housework	Transport	Social/ leisure	Laundry	Shopping	Financial	Work	Medicine	Telephone
Finland (1986) FIN04				✓						
France (1999) F02	✓	✓	✓			✓	✓		✓	✓
Ireland (1998) IRL02		✓				✓			✓	
Italy (1999-2000) I01	✓	✓	✓		✓	✓	✓		✓	✓
Norway (1988) N01		✓		✓		✓				
Spain (1995) E01				✓						
United Kingdom (1996/7) UK04	✓	✓			✓	✓	✓		✓	✓
United Kingdom (1998) UK02						✓	✓			
TOTAL	**3**	**5**	**2**	**3**	**2**	**6**	**4**		**4**	**3**

Table 4: Form of question included in European surveys by domain

Cooking

France	1999	F02	BMEN1. At present, can you **cook you meals** without any assistance? 0. Irrelevant : always eats out 1. Yes, without any difficulty 2. Yes, but with some difficulty 3. Yes, but with much difficulty 4. My partner or a household member cooks them, but I could do it if necessary 5. My partner or a household member cooks them, and I would have much difficulty doing it if necessary 6. Someone else does it for me (home help, charwoman...), but I could do it if necessary 7. Someone else does it for me (house help, charwoman...) and I would have much difficulty doing it if necessary 9. Does not know
Italy	1999-2000	I01	2.3 Is he/she usually able to **prepare meals** ? - Yes, he/she autonomously plans, prepares and serves nutritionally balanced meals - Yes, he/she prepares nutritional balanced meals, if all of the ingredients are supplied - Yes, he/she only warms up and serves meals prepared by others, or prepares meals, but not nutritionally balanced - No, meals must be prepared and served by others - Not applicable (never done or not possible)
United Kingdom	1996/1997	UK04	229. Do you have difficulty **preparing a hot meal** for yourself (or would you, if you had to)? yes / no

Housework

France	1999	F02	BMEN2. At present, can you do the common **house chores** without any assistance, (dish-washing, doing the laundry, ironing, cleaning, tidying up...) ? 1. Yes, without any difficulty 2. Yes, but with some difficulty 3. Yes, but with much difficulty 4. My partner or a household member does them, but I could do them if necessary 5. My partner or a household member does them, and I would have much difficulty doing them if necessary 6. Someone else does them for me (house help, charwoman...) but I could do them if necessary 7. Someone else does them for me (house help, charwoman...) and I would have much difficulty doing them if necessary 9. Does not know
Italy	1999-2000	I01	2.4 Is he/she usually able to take **care of his/her home** ? - Yes, he/she keeps his/her home tidy alone or with occasional help (for heavier jobs) - Yes, but he/she only does the simplest, daily chores, such as dishwashing and making beds - Yes, he/she does the simplest daily chores, but cannot manage to keep things acceptably clean - Yes, but he/she needs helps with all types of household chores - No, he/she does not do any housecleaning chores at home - Not applicable (never done or not possible)
Norway	1998	N01	Can you manage to **clean your dwelling/flat** without help from others yes / no
United Kingdom	1996/1997	UK04	244. Do you have difficulty using a **vacuum cleaner to clean the floor** (or would you, if you had to)? yes / no
United Kingdom	1996/1997	UK04	315. Do you have difficulty if you need to **change sheets or night-clothes** during the night (for example because of night-sweats or incontinence)? yes / no
Ireland	1998	IRL01	If you go out **shopping**, what kind of **transport** do you usually use? (Please tick one box only) Car [ ] / Walk [ ] / Bicycle [ ] / Public Transport [ ] / I never go out shopping [ ]
Ireland	1998	IRL01	Are you **regularly taking any prescribed pills or medication**? Yes [ ] / No [ ] If yes, do you ever have difficulties reading the instructions? Yes [ ] / No [ ]

Transport

France	1999	F02	BMEN4. Can you manage to **order/take a taxi, or use public transportation** on your own? 0. Irrelevant : never goes out 1. Yes, I can do it alone without any difficulty 2. Yes, I can do it alone, but with some difficulty 3. Yes, I can do it alone, but with much difficulty 4. No, I can't. A relative, friend or child comes with me, but I could manage on my own if necessary 5. No, I can't. A relative, friend or child comes with me, and I would have much difficulty managing on my own if necessary 6. No, I only go out in an ambulance 9. Does not know

Italy	1999-2000	I01	2.6 Is he/she usually able to use means of **public transport** ? - Yes, he/she travels alone by public transport and/or drives a private car - Yes, he/she organises his/her movements by taxi, but not by public transport - Yes, but he/she only travels by public transport if accompanied by someone - Yes, but he/she only travels by taxi or car in the company of someone else - No, he/she is no longer able to use means of public transport - Not applicable (never done or not possible)

Social/leisure

Spain	1995	E01	During the past two weeks, i.e. between ...... (date) and yesterday, have you had to restrict or cut back your usual leisure activities (e.g. hobbies, walks, visits, games, etc.) as result of any pain or symptom? - Yes / - No / - No answer.
Finland	1986	FIN04	... Does it hinder your relations with other people: a great deal / to some extent / not at all?
Norway	1998	N01	During the past 4 weeks, 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

Laundry

Italy	1999-2000	I01	2.5 Is he/she usually able to **wash his/her clothes** ? - Yes, he/she does all his/her clothes washing alone (also using a washing machine) - Yes, but he/she only washes small things: stockings or socks, etc. - No, all the clothes washing must be done by someone else - Not applicable (never done or not possible)
United Kingdom	1996/1997	UK04	239. Do you have difficulty **washing clothes or bed linen** (or would you, if you had to)? yes / no

Shopping

France	1999	F02	BACH1. Do you (he/she) do all your (his/her) **shopping** yourself (himself/herself) ? 1. Yes, I do it without any assistance and without any difficulty 2. Yes, I do it without any assistance, but with some difficulty 3. Yes, I do it without any assistance, but with much difficulty 4. No, I only partially take care of my shopping 5. No, I do not take care of it at all 8. Will not answer 9. Does not know
Italy	1999-2000	I01	2.2 Is he/she usually able to do the **shopping** ? - Yes, he/she does all the shopping alone - Yes, he/she shops alone, but only makes small purchases - Yes, but must always be accompanied by someone - No, he/she is not at all able to go shopping - Not applicable (never done or not possible)
Norway	1998	N01	Can you manage to do your **shopping** without help form others yes / no
United Kingdom	1996/1997	UK04	249. Do you have difficulty doing the household **shopping** on your own (or would you, if you had to)? yes / no
United Kingdom	1998	UK02	I would like to ask you about some tasks that some people may be able to do without any difficulty, while others may find difficult or impossible. Please look at this card and tell me whether you find it not difficult, quite difficult, very difficult or impossible. How difficult is it for you to... Do the household **shopping** on your own? 1 Not difficult / 2 Quite difficult / 3 Very difficult / 4 Impossible
Ireland	1998	IRL01	If you go out **shopping**, what kind of **transport** do you usually use? (Please tick one box only) Car [ ] / Walk [ ] / Bicycle [ ] / Public Transport [ ] / I never go out shopping [ ]

Finance

France	1999	F02	BMEN3. At present, can you **fill in plain forms** without any assistance? 0. Irrelevant : is under guardianship 1. Yes, I take care of it alone, without any difficulty 2. Yes, I do it alone, but with some difficulty 3. Yes, I do it alone, but with much difficulty 4. My partner or a household member does it, but I could do it if necessary 5. My partner or a household member does it, and I would have much difficulty doing it if necessary 6. Someone else does it for me (social service) 9. Does not know
Italy	1999-2000	I01	2.8 Is he/she usually able to **manage his/her own finances** ? - Yes, he/she manages his/her own financial matters (plans the shopping, fills in checks, pays the rent and bills, goes to the bank), collects money and keeps accounts - Yes, he/she manages daily purchases, but needs help for banking, larger purchases etc. - No, he/she is incapable of managing money - Not applicable (never done or not possible)
United Kingdom	1996/1997	UK04	254. Do you have difficulty **dealing with paperwork** (e.g. paying bills, writing letters) -- (or would you, if you had to)? yes / no

United Kingdom	1998	UK02	How difficult is it for you to... Deal with **personal affairs** (e.g. paying bills, writing letters, if you had to)? If does not deal with personal affairs, ask could you if you had to 1 Not difficult / 2 Quite difficult / 3 Very difficult / 4 Impossible

Work

Medication

France	1999	F02	BMEN5. Do you **take the medicines** prescribed by your doctor without any assistance? 0. Irrelevant : does not take medicines 1. Yes, I do it alone, without any difficulty 2. Yes, I do it alone, but with some difficulty 3. Yes, I do it alone, but with much difficulty 4. No, a friend, relative or nurse gets them ready for me or reminds me to, but I could manage alone 5. No, a friend, relative or nurse gets them ready for me or reminds me to, and I could not manage alone 9. Does not know
Italy	1999-2000	I01	2.7 Is he/she usual able **to take medicine** by him/herself ? - Yes, he/she is able to take the right dose at the right time - Yes, he/she is able to take medication, if it is prepared in separate doses - No, he/she is not able to take medication without assistance - Not applicable (never done or not possible)
United Kingdom	1996/1997	UK04	259. Do you have difficulty **taking tablets or medicines** -- or making sure that you take the right medicine at the right time? yes / no
Ireland	1998	IRL01	Are you **regularly taking any prescribed pills or medication**? Yes [ ] / No [ ] If yes, do you ever have difficulties reading the instructions? Yes [ ] / No [ ]

Telephone

France	1999	F02	BTEL. Can you **use the phone** without any assistance ? 0. Irrelevant : does not own a phone 1. Yes, I can call and answer alone without any difficulty 2. Yes, I do it alone, but I only call a small amount of numbers 3. Yes, I answer alone, but I cannot call someone 4. No, I cannot do it alone 7. Irrelevant : too young 9. Does not know
Italy	1999-2000	I01	2.1 Is he/she usually able to **use the telephone** ? - Yes, he/she uses the telephone autonomously, finding the number in the listings, dialling it, etc. - He/She only dials clearly pre-noted numbers - Yes, he/she answers the phone but never calls out 3 - No, he/she is not able to use the telephone - Not applicable (never done or not possible)
United Kingdom	1996/1997	UK04	101. (Wearing your hearing aid...) Can you **use an ordinary telephone**? yes / no

Table 5: Surveys including only global questions on IADL

Austria	1999	A01	To all persons of 15 years or older, who have answered question B 36 with "never" or "sometimes" : Are you unable, for health reasons, i.e. as a result of a chronic illness, permanent incapacity or for reasons of old age, to perform important activities of daily life (e.g. going shopping, preparing meals, doing the washing…) yourself and are you therefore sometimes – frequently or always dependent on the help of others, or is this not applicable?
Austria	1995	A02	Practice of the following activities possible: going to bed, getting up - washing and dressing oneself - walking up and down in the dwelling - eating, drinking - "easy"' housework -"harder" housework - purchasing - going out, visiting friends. A mark at each activity shall be made: Yes, the practice is possible without help of others - Yes, it's possible only with the help of others - No, it's not at all possible. Only difficulties due to chronic impairments have to be registered!
Belgium	1997	B01	The following items are about activities you might do during a typical day. Does your health now limit you in these activities. If so, how much? Moderate activities, such as moving a table, pushing a vacuum clean, swimming or cycling
Sweden	1999	S01	Do you need help with the following activities? a) Cleaning? b) Buying food? c) Cooking? d) Washing clothes? e) Baths or showers? f) Getting up and going to bed YES / NO If you need help with anything mentioned in Question 85a-f, pleas
Finland	1986	FIN04	Are you in good enough condition to be able to carry out the following activities without help from another person: a. grocery shopping? b. preparing food? c. washing clothes and cleaning the house? d. dressing and undressing? e. personal hygiene?
Spain	1999	E04	Disabilities suffered at present by the persons in the household aged 6 years and over, whose total duration (time that the disability has been suffered and/or is expected to be suffered) is over 1 year. Do you suffer from the disability? Procuring and taking care of daily necessities (including shopping and supervision of supplies and services) Taking care of meals Taking care of dwelling Laundry and caring for clothes and footwear Taking care of well-being of household members
United Kingdom	1993/94	UK05	Do you have any difficulty ... With personal care such as dressing, bathing, washing, or using the toilet? Getting out and about or using transport? With medical care such as taking medicines or pills, having injections or changes of dressing? With household activities like preparing meals, shopping, laundry and housework ? With practical activities such as gardening, decorating, or doing household repairs? Dealing with paperwork, such as writing letters, sending cards or filling in forms? Managing money, such as budgeting for food or paying bills?

Chapter 4: Measuring activity restrictions in young adults in Europe

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Section 1. Definition and presentation of the proposed instrument

1. Definition

According to the conceptual framework of the disablement process, activity restriction corresponds to difficulty in performing activities of daily life due to limitations in mental, physical or sensory body functions or environmental barriers. Activity restrictions are at the junction of the functional status of the individual and the activities he or she has to perform to maintain a level of activity congruent with what is expected in his or her society, at his or her age. Measuring activity restrictions at the population level requires definition of specific domains of activities representative of "normal" social integration. To target younger adults, other activities may need to be selected to better represent the level of activities that is expected from them in our societies (work, social activities…).

The aim of this chapter is to measure activity restriction in young adults in whom functional limitation and subsequent restrictions are not frequent. In young adults, rehabilitation, training and special assistive devices are used to compensate for functional limitation and remain independent. Instrument should provide information on actual restrictions and if possible compensatory strategies and the date of the onset of the functional problems. Domains of activities should be selected to reflect the "normal functioning" of the young adults through a limited number of activities. We select the following domains:

> *Independence: personal and domestic care activities*
>
> *Major occupation: school or university activities / work / home activities*
>
> *Mobility independence: to go to places where individuals need to or want to go*
>
> *Social activities: relationship with others / involvement in outdoor activities*

The collected information proposed is:

> *Activity restriction: cut down or stop activities*
>
> *Compensation: change the type or amount*
>
> *Use of help: use equipment, go to specialised institution, has adapted the nature of the activity*

2. Policy Relevance

The measurement of activity restrictions is mainly oriented towards older people to assess disability and dependency in daily life, as a consequence of aging and increased risks of chronic disease with age. Nevertheless, in recent years, surveys were specifically devoted to disability and the researchers of the field tried to abolish the distinction between "dependency in old people" and "people with disability". Recently, research programmes on health statistics for the European Union have been oriented towards the measurement of the social integration of people with disability: studies show clear disadvantage in social relationships, satisfaction with main activity, work organisation and occupational status for young adults reporting being hampered in daily life. Assessing activity restriction at young ages would require monitoring differentials in social participation between those with and those without functional limitations. Moreover, measuring activity restrictions in younger adults can help in understanding the whole disablement process and the mechanisms that lead more or less rapidly from diseases and impairments to dependency, at young ages or have postponed to later ages. The challenge is to provide clues for intervention in the disablement process, being able to identify people at risk in early adulthood.

3. Wording

Because, instruments to assess restrictions in personal care and household activities are mostly applied in surveys to the whole population, data on independence in these areas of younger adults can easily be obtained. For the other domains, an additional module can be included to supplement the usual ADL and IADL modules.

We suggest the following approach:

<u>Items:</u>   A. 1. activities at school or university

2. activities at work

3. activities at home for maintenance or management of the house (cleaning, washing clothes, repair, money management)

B. 1. mobility to go somewhere you need or want to go (outside the house, using private vehicle or public transportation)

2. relationship with the others (contacts with spouse, family, friends, neighbourhood...)

3. cultural, political or religious activities (involvement in societies and groups, reading, going to cinema, museum, theatre...)

<u>Wording</u>:

A. I would like to know if, as a **result of accident, disease, emotional or physical problems**, you have **ever** cut down in the **type or amount** of the activities at school, at work or at home?

1. **Have you ever cut down in school or university activities** due to sequels of accident, disease, emotional or physical problems?   Yes / No / I have never been at school or university due sequels of accident or other problems / I have stopped or I have never been at school or university for other reasons
[if Yes go to 1.2]
[if No go to 1.1]

     1.1   Did you **stop** school or university activities at all   [if No go to 1.2]
if Yes   Did you **keep your activities a while** after the onset of your accident, disease, emotional or physical problem?
At what age did you meet these difficulties?

     1.2   At what age did you meet these difficulties?
Do or did you use **special equipment** to attend to school or university
Do or did you go in a **specialised institution** to attend to school or university
Do or did you receive a **special assistance** to attend to school or university
Do or did you have **adapted hours of attendance**

The wording proposed here corresponds to a computer assisted system of interview. The wording would depend on the administration mode. In the case of self administrated, the filters might be too complicated.

4. Justification

Domains of relevance have been listed on the basis of the work done in this field, to define "social roles" and relevant domains to assess the level of social participation of those with functional limitations. Among possible domains some have been selected for this present work on the basis of the census of European surveys displaying the existing questions in this field and the most frequent domains in which restrictions are measured. Other domains could have been added but the number of questions should be limited to fit in surveys as well as supposed to cover a large part of the population to expect a sufficient number of cases.

The specification for the wording are the following:
Questions should look at *activity performance* through the difficulties met rather than capacities. For work, school or other social activities, a *health related* wording appears necessary to focus on restrictions that are really part of the disablement process. The information collected should refer to *long lasting* problems. Possibility of reporting *past episodes* of school or work restrictions can help in obtaining information on the overall disablement process, even if individuals have managed progressively to cope with their limitations. In the same way, those who report past or current restriction should be able to *date the onset of problems*. Because younger adults are more inclined to maintain activities through individual or collective compensatory strategies, it is important to give the opportunity to individual to report *changes in type or amount of activities* rather than only on performance and difficulties. The terms used should not been negative or stigmatising and should be intuitive for individuals.

5. Scoring system

The proposal allows both the assessment of the level of restriction and the possible compensatory strategies. It also allows collection of information on possible restriction experienced in the past for those who are not performing anymore the activities under consideration. A set of additional questions for those who maintained their activity can assess the means of compensation. The age of onset can help in controlling for possible impact of the duration on the compensatory abilities.

Activity restriction:

- Moderate activity restriction: *cut down in school or university activities as a result of accident, disease, emotional or physical problems*

- Severe activity restriction: *never performed the activity as a result of accident or other problems*

For further analysis :

Compensatory strategies

- For those who stopped: *keep your activities a while after the onset of your accident, disease, emotional or physical problem*

- For those who only cut down: *special equipment / specialised institution / special assistance /adapted hours of attendance*

6. Health expectancies:

The proposed instrument allows to compute life expectancy without **school and university activity restrictions**, without **work restriction**, without **mobility restriction**, without restriction in **socialisation**. For this later, the information on relationship with others and social activities can be combined or used separately. Due to the possibilities of collecting data on past experience, the measures refer to both the current and past situation. The age of the individuals together with the information on the age at onset will help in disentangling this double information and computing when separate indicators are needed.

Section 2: Background

I. Definition and policy relevance

Definition

According to the conceptual framework of the disablement process, activity restriction corresponds to the difficulties in performing activities of daily life due to limitations in mental, physical or sensory body functions or environmental barriers. Functional limitations are the consequences of disease, accident, deformity, impairment or the result of the ageing process. They constitute intrinsic characteristics of the individual, independently from his environment or the aids he or she can get. Meanwhile, activity restrictions are at the junction of the functional status of the individual and the activities he or she has to perform to maintain a level of activity congruent with what is expected in his or her society, at his or her age. Functional limitations can be measured in the same way for the whole adult population. As explained in chapter on Functional Limitations in Part I, measurement instrument is made of questions on specific situations in which various body functions (mobility, sensory, dexterity, memory) are involved to help individuals figuring out possible problems: difficulty in *walking a certain distance*, *hearing a conversation*, *picking up an object* or *remembering something*. Measuring activity restrictions at the population level requires definition of specific domains of activities representative of "normal" social integration, in accordance with the age, sex and the social organisation of the population under consideration; most existing instruments are oriented towards activities strictly required to remain independent in daily life: personal care, domestic activities. To target younger adults, other activities should be selected to better represent the level of activities that is expected from them in our societies (work, social activities…).

Relevance

This extended interest towards young adult level of activity is also growing with the evidence for a life long process in health deterioration, starting during childhood, or even during childbearing, and cumulating until the oldest ages. Concerning disability, French researches conclude a strong contribution of the early life conditions, especially work conditions, on the later onset of diseases and disability (Cassou et al., 2000). Poor functional status is source of disadvantage in many domains of life and over the whole life. Therefore, research to improve the quality of the additional years of life to be lived should focus on the different periods of life, including young adult ages. Measuring activity restrictions in young adults can help in understanding the whole disablement process and the mechanisms that lead more or less rapidly from diseases and impairments to dependency, at young ages or postponed in later ages.

The challenge is to provide clues for intervention in the disablement process, being able to identify people at risk in early adulthood.

II. Important issues

What age range should be considered

The age bracket associated with adults younger than 60 or 65 years old is often defined as working ages. This corresponds to the stage in the life course over which individuals can have access to an independent life from an economic point of view, before retiring from the labour market and benefiting from pensions and returns from the working life assets. With such a definition, the age bracket is more or less common to all developed societies: ages 16 to 64 years old. In recent years, the changing regulation for retirement in most countries, as well as the lengthening of school life, make the two ends of the age bracket more variable. Working life and adulthood do not necessary correspond anymore. Still, access to labor market is possible from age 16 years old, and, therefore, this could be kept as an official lower end for the age range to be considered. The upper end of the age bracket is not important as long as the activities selected are reflecting young adults. Indeed, the objective is not to isolate a specific age bracket but to represent young adults and young adults activities; among them, some are still relevant for the elderly. The activities selected to reflect social roles in such an age range should cover many domains: economic and non-economic activities, among which are school and university, domestic and leisure activities.

Domains of relevance

In the framework of the *International Classification of Impairments, Disabilities and Handicaps* (ICIDH) of the WHO, as early as in its first version, activity restriction or more generally disability leads to handicaps defined as a "disadvantage that limits or prevents the fulfilment of a role that is normal depending on age, sex, and social and cultural factors" (WHO, 1980). The Classification lists six major roles: the activity restrictions for personal care correspond to the role of *physical independence*. The five other roles are: *Orientation* in individuals' surrounding, *mobility* in individuals' surrounding, *occupation* customary to individuals' sex, age and culture, *social integration* through individuals' participation and maintenance of customary social relationship, *economic self-sufficiency* to sustain customary socio-economic activity and independence. In the International Classification of Functioning, Health and Disability (ICF), the new version of the ICIDH, activities and roles are grouped under the level of "activities and participation" (WHO, 2001). Several chapters are considered among which *self-care*; *mobility*; *domestic life*; *relationships*; *education, work and economic life*; *community, social and civic life*. Compared to the first version, some chapters have been added. But for domains such as *community* or *social and civic life*, both underlying concepts and measurement instruments are not as clear as they are for domains such as *independence*. Nevertheless, either the ICIDH or the ICF can be useful to propose and select adequate domains of activities to assess restrictions at young ages. Similarly, Eurostat has launched a programme in order to assess the level of integration of those with disability in the European countries. In this purpose, the domains of interest at the individual level are listed as follow: *mobility* for assessing the accessibility policy, *education and school integration*, the *employment* and the *social participation* through participation in cultural, religious, political, sportive activities and through *social relations* (ISTAT, 2001). As will be displayed later in this chapter, among these different possible domains of relevance, the most commonly considered are: independence for usual activities of daily living; independence for mobility, not viewed as locomotor functions but as abilities to get to chosen places; occupation; social integration through questions on leisure and relationships with others.

Relationship with other activity restriction instruments

Previous chapters have presented the measurement instruments related to the roles of minimal independence (ADL), for the ability to live alone in a private household (IADL), mainly oriented towards elderly population (see Chapter 2, part I and Chapter 3, part II). The present chapter deals with the relevance of these ADL and IADL indicators for the young adult population, as well as with the selection of other dimensions that might be better adapted to measure restrictions in young adults.

One of the leading ideas is to provide a third set of questions, completing the personal care and instrumental activities of daily living and covering major occupations, social integration and mobility. In this perspective, some authors have proposed to introduce the concept of Advanced Activities of Daily Living being added to the Physical or Personal, or Basic activities (corresponding more or less to the personal care activities) and to the Instrumental activities of daily

living. This third level of activities appeared in 1990 in a study where it refers to physical exercise and mobility (Ruben et al, 1990). Recently, Johnson proposed the distinction between Basic ADL, relating to personal care (walking, dressing, getting in and out of bed, bathing, using toilets) and the AADL referring to complex activities assumed to depend on neurological functioning (eating, driving, handling telephone, calls, taking medications, managing money); these questions come from the AHEAD surveys in the United States, and are mainly based on IADL items (Johnson, 2000). But some activities, representing advanced activities of daily activity, have been added in some surveys. Questions on driving are found in most surveys dealing more specifically with disability: 1993 Australian survey, 1998/2000 French survey or 2001 Canadian survey. The Canadian survey on activity limitation (2001) also includes at this level the difficulty in child care for those who have children less than 15 years old; this refers to the parental role, which can be considered as one of the social roles for young adults. Even if this concept of *advanced activities* appears not as consensual as can be the ADL and IADL in term of selected activities, this gives the idea of a logical way to measure further levels of activity restrictions: beside strict independence in daily life, the disability surveys commonly explore independence in mobility, social activities (meeting friend, going out...) and school or job attendance.

III. Current position in Europe

The Health Monitoring Programme on "Health Interview Surveys and Health Examination Surveys census" (HIS-HES) has provided a database which contains the methodological aspects and questionnaires of the recent European health or disability surveys. The works conducted here was firstly based on the research of the disability related questions in this database; numerous questions were found in 30 surveys produced since the beginning of the 1990's as well as in the Health Interview Surveys instruments recommended by the WHO-Europe (see Table 1). Questions were classified according to their domain of relevance.

1. Domains covered in the European surveys

The role of minimal independence is assessed through global questions on personal care or for instrumental activities of daily living. Detailed scales for ADL or IADL were not considered here (see Chapters 2 part I and 3 part II). Mobility independence is assessed through questions on confinement and inside/outside mobility. Restrictions in major occupation are assessed through questions on work status (absenteeism, change in work status), questions on domestic activities for those who do not performed a paid work; and questions on school/university activities. Integration is assessed through questions on leisure and relationships with others. Questions being related to concepts other than strictly activity restrictions such as functional limitations as well as questions that were mixing several levels of the disablement process such as functional limitations and activity restrictions were not considered. We summarise here the findings displaying the diversity of the questions used in the various activity domains (wording, response categories…). Table 2 shows the domains of coverage in the various recent European surveys reviewed in this study. The wording of the questions found is displayed later in this chapter.

Table 1. European surveys under consideration

Austria	1995 (A02); 1997 (A04); 1999 (A01)
Belgium	1997 (B01)
Denmark	1994 (DK01)
Finland	2000 (FIN01); 1997 (FIN02); 1986 (FIN04)1996 (FIN05)
France	1991/92 (F01); 1999 (F02)
Germany	1998 (D02); 1998 (D05)
Ireland	2000 (IRL02); 1998 (IRL01)
Italy	1999-2000 (I01)
Norway	1998 (N01)
Portugal	1995 (P01)
Spain	1999 (E04); 1995 (E01)
Sweden	1999 (S01)
Switzerland	1997 (CH01)
The Netherlands	1998 (NL01)
United Kingdom	2000 (UK01); 1998 (UK02); 1998 (UK09); 1996/1997 (UK04); 1995 (UK10); 1993/94 (UK05); 1991/92 (UK03)
WHO-Europe	1996 (INT01)

Table 2. Young adults activity restriction, domains coverage in recent European Surveys

		Global ADL/IADL question	Major occupation (work, school, home)	Mobility independence question	Leisure, relationship, social activities
A	1995 (A02)	✓			
	1999 (A01)	✓			
B	1997 (B01)	✓			
FIN	1986 (FIN04)	✓			✓
	1996 (FIN05)		✓		
F	1991/92 (F01)			✓	
	1999 (F02)	✓			
IRL	1998 (IRL01)	✓			
I	1999/2000 (I01)			✓	
P	1995 (P01)			✓	
E	1999 (E04)	✓		✓	✓
S	1999 (S01)		✓	✓	
CH	1997 (CH01)	✓			
N	1998(N01)				✓
NL	1998(NL01)	✓		✓	
UK	1998 (UK02)			✓	
	1993/94 (UK05)	✓	✓		
INT	1996 (INT01)			✓	

2. Specification

General specifications for measuring activity restrictions in young adults

Several types or specifications are discussed to help in designing the activity restriction questions. The following issues raised are common to most of the instruments discussed in this book.

Performance versus capacities: (See Chapter 2, phase I) Measuring restriction in work, school or social activities rises similar but also new problems of wording. As with domestic care activities, work, school or social activities can be *not performed* for other reason than health. But compared to domestic activities, they are generally not performed by other people: individuals *perform them* or *not perform them* or they *can be assisted* in these activities. In that sense, it does not rise the problem of *not doing because someone else does it*. But in these fields, much more than in the field of personal care or domestic care the reasons for *not performing* are numerous; the sources of possible difficulties are multiple and mostly independent on health problems. This explains why an alternative wording should be used to orient the question using a "health related" wording, as it is generally done in "global disability questions". This specification appears necessary, even if information on functional limitation is collected in a separate module.

Health related: As for the global indicator GALI, the health problem should be mentioned in the question (Chapter 3, part I): "*Do you have difficulties, due to health, with work / home / social .. activities?*". This type of wording still questions the performance level, through the potential difficulties met to perform the selected activities, and screens in the same time for *health related* restrictions. As for the wording proposed in the previous paragraph, such a question has to be implemented with appropriate response categories: "*No, I have no difficulty / Yes, I have difficulties because of health / I am not working or I have difficulty in activities at work, for other reasons than health*". The terms used to refer to health problems is important as it should orient in the right direction the individuals. People with functional limitations do not consider themselves as having health problems in a systematic way especially if the limitations is not caused by a disease and is not associated with health condition (respiratory problems, medical treatments); *health problems* can be completed by referring to functional limitation but through usual terminology. Another issue is the under-report of restrictions in daily life due to "mental" problems such as depression which are often not linked to a disease or health problems; some global question therefore refers to emotional problems. It is also strongly recommended to avoid negative terminology as a "stigmatising" word can lead to an underestimation of the restriction: handicap or disability are often banned from the vocabulary. To be more neutral, question could refer to the consequences of disease or accident: *"Due to sequels of accident, disease, emotional or physical problems, do you have difficulties in your work/ domestic/ social activities?"*.

Time reference: Questions on activity restriction usually refer to long term problems in usual activities rather than short term consequences of injuries or acute diseases. For instance the work on the General Activity Limitation Indicator (GALI) in Chapter 5, based on the current knowledge in this field, has concluded on a 6 months or more period as an optimal time reference to tackle long term restrictions. Looking more specifically at activities at work or at school for young adults, questions should also encompass this long term approach. Especially because functional limitations can have occurred at any time, for instance at birth or during childhood, and still be source of restrictions, while the individual is used to cope with it and feels like "normally restricted". Therefore, the reference to the long term can help the individual to think of these early sources of restrictions. *"As a long term result of accident, disease, emotional or physical problems"*. Moreover, restrictions can concern past school episode or past job experiences, so it could be relevant to collect this information. Wording could give the opportunity of reporting past episodes consequences of functional problems: *"As a long term result of accident, disease, emotional or physical problems, have you ever had difficulties with school / work activities"*. In that sense for instance, questions on school activity restrictions could be addressed to the whole adult population to help understanding the disablement process.

Causality: It can be useful to collect more chronological information on the onset of the functional problems and their consequences while the sense of causality between being restricted in social or major activities and being in poor health is not unilateral, especially if individuals refers to long term situation. The relationship between activity restriction, health status and their determinants is not straightforward. Studies show a higher risk of activity restriction and dependency for those with low level of education: this result is often interpreted as an expression of socio-economic differentials in health risks. But a health problems in childhood, can be responsible for a limitation in school attendance and, as a postponed consequence, can be both the reason for low level of education and activity restrictions. Therefore, it could be possible to clarify the causal relationship between the functional problem and the activity restriction, also by dating the occurrence of the activity restriction. Regarding the previous paragraph,

information about possible school restriction during childhood could partly document on the possible causality effect. Also, information about the date of onset allows to control for the impact of the duration on the abilities to cope with a functional limitation; the duration partly can explain some differentials in compensatory strategies. Further questions could help to date the episode over life course in order to find the possible causality relationship: "at what age / at what school level did this happened".

Adaptation to functional problems: An essential issue in activity restriction in young adult ages is the ability to compensate for functional limitation. Compensatory strategies allow to maintain a certain level of activity permanently or temporarily, even if the amount of activity have been reduced or if the type of activity have been changed. In this respect, instead of rising questions in terms of "having difficulties", a set of questions can help in documenting this aspect for those who report difficulties: "Did you stop at all / change the type of amount of your activities at work / home...?.

Need for help: As for personal care activities or instrumental activities of daily living, looking at the need for help provides a different, but complementary information to the level of difficulty in performing activities. It gives information on the level of dependency. The *need* for help is also different from the *use* of help or assistance; the former refers to the *actual needs* and the latter refers to the *met and unmet* needs. As for ADL instruments, the need for help could be approached as a secondary step of questions, when a difficulty as been first reported. Depending on the domain of activity under consideration, the need for help does not correspond to the same issue (need for help in *chore activities* versus need for help in *school activities*) and also can be some time not well adapted (*social integration* or *occupation*). Questions on adaptation for those who report they maintain their activities could be more relevant: "*Do you use special equipment / have a shelter job…?*".

Introductory speech: As for personal care activities or domestic activities sets of questions, a short introductory speech could help in providing the general context of the module and in having a lighter wording for each question: *I would like to know if, due to sequels of accident, disease, emotional or physical problems, you have ever cut down in the type or amount of the activities at school, at work or at home?*" After this introduction, questions could be more simply formulated*: "Have you ever cut down in your activities at school / at work... due to sequels of accident, disease, emotional or physical problems ?".*

<div align="center">

Specifications related to the different domains of activity

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1. Independence through global questions on personal care and instrumental activities of daily living

The European census of survey instruments has shown that ADL scales are applied to the whole adult population in most health surveys, even if the collected information is merely used over age 60, due to the low level of prevalence of restriction for such activities below this age (Chapter 2 part I). Nevertheless, activity restrictions for personal care and domestic activities remain an essential issue to assess its magnitude and time trends, as part of social roles. ADL and IADL items have hierarchical properties, describing a gradient in the burden of care and assistance to be provided when individuals report restriction. This has been shown for elderly and can be explained by a progressive loss of function with age making more and more difficult to perform these activities. Restriction in feeding corresponds to the more severe level of restriction, restriction in bathing and showering correspond to the least severe level, and can be considered as a predictor of further restrictions. Such a gradient can be changed with age. When considering an "accidental" loss of specific functions, rather than a progressive functional decline, the restrictions can appear in a different order. Data collected for young ages could be used to test a possible change in the hierarchy of ADL, IADL with age; if equivalent levels can be found between these usual activities, grouping of items can be proposed to represent this type of restrictions.

In this direction, some surveys use a single question which lists the different ADL items or IADL items instead of asking questions on each item: being more general allows to rise the number of individuals targeted and could be used to assess severe disability at young ages. For instance in the 1999 Austrian surveys, the following question is asked: "Are you unable, for health reasons, i.e. as a result of a chronic illness, permanent incapacity or old age, to carry out important personal functions yourself (e.g. eating, washing/bathing, going to the toilet....), and are you therefore sometimes — frequently or always dependent on the help of others, or is this not applicable?". In the United States, a general question of this type is asked in the National Health Interview Survey, operating as a screening question: "Because of a physical, mental or emotional problem, does anyone in the family need the help of others with personal care needs such as such as eating, bathing, dressing, or getting around inside the house?". If the answer is positive, the items are detailed. This question applies to almost all the population except the very young children.

The "Participation and activity limitation survey" in Canada (2001) asks questions in term of receiving help, after having browsed the different conditions reported by the respondents and their possible impact on various activities: "Because of your condition, do you receive help with personal care such as washing, dressing or taking medication". Here, taking medication is considered as a personal care activity. The census of European surveys has also shown the use of single question on IADL restriction in the same way that the general ADL question. Here again, this allows to rise up the number of individuals concerned and also make the questionnaire lighter, such as in the Austrian survey (A01) with the question "Are you unable, for health reasons, i.e. as a result of a chronic illness, permanent incapacity or for reasons of old age, to perform important activities of daily life (e.g. going shopping, preparing meals, doing the washing...) yourself and are you therefore sometimes, frequently or always dependent on the help of others, or is this not applicable?". Several global questions can also be asked, depending on the nature of the activities and the related level of severity.

As mentioned earlier, IADL items rise the problem of those who do not have to perform the selected activities, for instance gender oriented activities in the elderly population. Testing for "equivalent" activities in term of the degree of severity, as suggested earlier, could help to formulate global questions suggesting activities to covering the whole population: cleaning the house, changing light bulbs, small repairs.... It is noteworthy that some activities, in addition to the degree of severity they refer to, can be classified as related more to sensory, to physical or to cognitive functional limitations. This point should be taken into account if several activities are gathered within a single question.

Examples of global personal care and chore activities questions in the European surveys

Austria	1999	A01	Are you unable, **for health reasons, i.e. as a result of a chronic illness, permanent incapacity or old age**, to **carry out important personal functions** yourself (e.g. eating, washing/bathing, going to the toilet....), and are you therefore sometimes — frequently or always dependent on the help of others, or is this not applicable?
			Are you unable, **for health reasons, i.e. as a result of a chronic illness, permanent incapacity or for reasons of old age**, to **perform important activities of daily life** (e.g. going shopping, preparing meals, doing the washing...) yourself and are you therefore sometimes – frequently or always dependent on the help of others, or is this not applicable?
Austria	1995	A02	**Practice of the following activities possible**: going to bed, getting up - washing and dressing oneself - walking up and down in the dwelling - eating, drinking - "easy"' housework - "harder" housework - purchasing - going out, visiting friends. A mark at each activity shall be made: - Yes, the **practice is possible without help** of others - Yes, it's possible only with the help of others - No, it's not at all possible. **Only difficulties due to chronic impairments have to be registered!**
Belgium	1997	B01	The following items are about **activities you might do during a typical day**. **Does your health now limit** you in these activities. If so, how much? Moderate activities, such as moving a table, pushing a vacuum clean, swimming or cycling
Finland	1986	FIN04	Are you **in good enough condition** to be able to **carry out the following activities without help** from another person: a. grocery shopping? / b. preparing food? / c. washing clothes and cleaning the house? / d. dressing and undressing? / e. personal hygiene?
Ireland	1998	IRL01	By placing a tick in one box in each group below, please indicate which statement best describes your own health state today. Group 2: Self-care I have no problems with self-care ? / I have some problems with washing and dressing myself ? / I am unable to wash and dress myself [ ]
Norway	1998	N01	Can you **manage to attend to your own personal hygiene** with no difficulty / with some difficulty / only with the help of others
Switzerland	1997	CH01	**Alone, are you able to** dress and undress yourself, get out of bed and eat without help and without difficulty? 1 Yes, I can do all of the above by myself without difficulty, (go to question 18.20) 2 No, I cannot do all of the above alone, without difficulty

| United Kingdom | 1993/ 94 | UK05 | Do **you have any difficulty** ...
With personal care such as dressing, bathing, washing, or using the toilet? ? / Getting out and about or using transport? ? / With medical care such as taking medicines or pills, having injections or changes of dressing? ? / With household activities like preparing meals, shopping, laundry and housework ? ? / With practical activities such as gardening, decorating, or doing household repairs? ? / Dealing with paperwork, such as writing letters, sending cards or filling in forms? ? / Managing money, such as budgeting for food or paying bills? |
| France | 1999 | | **Does one person or more regularly help** you to do certain daily tasks because of a handicap or a health problem? (washing, eating, cleaning, shopping, administrative procedures). |

2. Major occupations

At young ages, restriction has to be assessed based on the "major activity": this is mainly work when considering working ages, but an important proportion of women is not working at a given date, even if some have had some past work activities or expect to have some in the future. Moreover, as mentioned in introduction, due to extending period of study and period of retirement, work activities is not representing neither the whole adult male population. Therefore, definition of major occupation, which was mainly work oriented, have to be extended to other activities at school and at university or at home. One of the key issue discussed above deal with the possible questioning on past experience in these different activities, to better represent the life course impact of functional limitation and changing activities. Most surveys in Europe use an indicator of short term disability in major activities as recommended by WHO-Europe; the wording of the question is the following (WHO-Europe, 1996).

> Think about the two weeks ending yesterday. Have you cut down on any things you usually do about the house, at work or in your free time because of illness or injury? Yes / No

Specific modules on work activities can be found to assess work restrictions (Lerner et al., 2000; Lerner et al., 2001). Nevertheless, such modules are rather large and more devoted to studies looking at specific group of populations, at risks of disability: for instance surveys seek for the consequences of selected diseases on work conditions and life conditions on cohort of patients. In most surveys, work conditions and employment status are documented separately from functional health status questionnaire. Still, the census of the European surveys shows some questions disseminated in the surveys which can help in assessing work activity restriction, in a more general way. A general question can be asked such as in the Swedish Living Conditions surveys (S01 yearly since 1975): "Is your working capacity reduced as a result of your illness(es)?". Some modules are also dedicated to absenteeism due to health such as in United Kingdom survey of psychiatric morbidity (UK05 1993/94): "Has your health or the way you have been feeling caused you to take time off work in the past year?". Other ones are referring to an adaptation strategy at work due to health problems, such as in Finnish Health Care survey (FIN05 1995/96): "Change the contents of your present (latest) work? Change to another working place? / Change your profession?". Other questions can be addressed dealing with the nature of the employment, sheltered jobs, use of specific equipment, the reduction in the number of hours of work. Looking at surveys devoted to disability such as the Australian survey (1993) or the Canadian survey (2001), questions are enquiring about the "reduction or change in the type of activities at work or at school, aids or assistance received, adaptation of the hours of works or attendance".

As presented in the key issues to measure activity restriction, referring to past work activities and possible restriction could be fruitful. Moreover, looking at current and earlier experiences in several type of major activities (at work, at home, at school) would allow to represent almost all the population and possible situations. Have you ever cut down in activities at school or university / at school / at home due to sequels of accident, disease, emotional or physical problems? Then questions would help to further describe the situation of those who report some restrictions, and possible compensatory strategies : Stopped at all these activities due to health... / maintained a while the activity despite the health problem... / changed the type or amount... / uses special equipment or adapted hours of work...

3. Mobility

Numerous questions exist to assess the ability to move as necessary to conduct a normal life. Here the problematic is not to assess the locomotor functions of the individual but their level of independence in going from one place to another when needed or wanted. In the United States and in some European surveys, *moving within the house*, or *moving between rooms* is often included in the ADL set of activities (see ADL chapter). Despite it was not originally part of such activity set, more dedicated to personal care activities, these items constitute a relevant indicator of

activity restriction. The WHO-Europe has presented a mobility restriction indicators to be introduced in the surveys, concerning severe levels of disability, dealing with situation such as bedridden or housebound.

> 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?

With such a module, it is possible to depict a gradient of mobility restriction from which a level of social disadvantage can be deducted. Some surveys have applied this recommendation but in the most recent ones, other wordings are used and some get further in the mobility restriction than the confinement level. General questions can be asked to report on mobility restriction as in the French survey : *Do you regularly find it difficult to move around ?* The IADL question on the use of own vehicle of public transportation, has been some time developed. For instance, surveys devoted to disability such as the French ones, contains various questions on accessibility problems to a place or to the transportation. Several surveys refer to the use of a car to move around. But the question of driving a car rises the problem of the complex activities that requires many functional abilities, as illustrated by the module in the Spanish survey. Furthermore a part of the population cannot drive a car for other reason than health. Finally, only asking questions on abilities to drive a car do not allow to measure the possible compensatory strategies of people with functional problems; some use on a daily basis other types of transportation to maintain their level of mobility and to get *where they need or want to*. Therefore, browsing different means of transportation that could be used to move around, such as in the French survey, helps in document on the mobility level of those who do not drive but still manage to be independent in getting in places they need to: *Can you manage to order/take a taxi, or use public transportation on your own?* In this domain also, this could be relevant to get a general question on mobility restriction, followed by others allowing to further describe the possible adaptation to functional limitations.

Examples of questions on mobility restrictions in European surveys

Italy	1999-2000	I01	Is he/she **forced to always stay at home** without being able to go out for physical or psychological reasons ? (home includes the eventuality of space outside) NO (check and go to the next questions) / YES (check and go to the next questions)
			Is he/she **usually able to use means of public transport** ? - Yes, he/she **travels alone by public transport** and/or drives a private car - Yes, he/she **organises his/her movements** by taxi, but not by public transport
Spain	1999	E04	Do you (or would you have) any **difficulties in walking along the street** due to health-related problems? YES / NO Specify whether or not you have (or would you have) the following difficulties in walking along the street: 1. To get up kerbs / 2. To cross the street when the traffic lights are green for pedestrians / 3. To cope with obstacles on the footpaths / 4. Other problems
			Do you (or would you have) **difficulties in driving your** car due to health-related problems? YES / NO Specify whether or not you have (or would you have) the following difficulties in driving your car: 1. To get to the car / 2. To get into the seat / 3. To change gear, move the steering-wheel, etc. / 4. Other problems
			Do you (or would you) have difficulties in **using public transport** due to health-related problems? YES / NO
Sweden	1999	S01	Can you **get on to a bus easily**? 1 YES / 2 NO
Portugal	1995	P01	Are **you housebound, i.e. unable to leave your dwelling** (including the garden, if any)? 4. Why are you in this condition? : Accident / Rheumatism/joint pain / Cerebral thrombosis / Heart disease / Other (specify) / Don't know 5. Since what age...
The Netherlands	1998	NL01	Now I am going to read a few activities that some people have difficulty with. Please indicate for every item whether **you can perform without difficulty**, with difficulty or only with help from others. - **move towards another room** on the same floor? / - **leave the house** and enter it? / - **move along outside** the house without difficulty / - with some difficulty / - with great difficulty / - only with help from others

France	1991-92	F01	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?
France	1999	F02	**When you go out of your home, are you bothered by** a disability or a health problem ? 0. Irrelevant : not allowed to go out / 1. Not bothered / 2. Bothered, but can go about on his/her own on all routes / 3. Bothered, but can go about on his/her own on some routes / 4. Cannot go about alone / 9. Does not know
			Do you **have a car driving licence** 1. Yes / 2. No / 9. Does not know If the answer is 'no', Is it **because of a health problem** ? 1. Yes / 2. No / 9. Does not know If the answer is 'yes', Is your driving licence "**adapted**"
			Can you (he/she) have **access to normal public transportation**? 1. Yes, with no difficulty / 2. Yes, but with difficulty / 3. No, it is too far from home / 4. No, getting to it or using it is too difficult / 9. Does not know
			Would you **like to be able to go out more often** ? 1. Yes / 2. No / 9. Does not know
			If you have the **use of a car** (yours or relatives'), is it **adjusted to a disability** or a health problem you have ? 0. Irrelevant : does not have the use of a car / 1. Yes, for driving / 2. Yes, I drive a car that does not need a licence / 3. Yes, for transportation / 4. No, but I would need it / 5 No, I do not need it / 9. Does not know
			In the past three months**, were there places you (he/she) could not have access** to because you are disabled or have a health problem ? 1. Yes / 2. No / 9. Does not know / If the answer is 'yes', which ones ?
			Must you (he/she) usually (excluding an accident or temporary illness) **permanently stay** ... 1. ...In bed /2. ...In your room / 3. ...Inside home / 4. No, can go out / 7. Irrelevant
			Can you **move about without any assistance** in all the rooms on the floor where you are ? 1. Yes, I can do it without any assistance / 2. Yes, but only in certain rooms on the floor / 3. No, I usually need assistance to move from one room to another / 7. Irrelevant : too young / 8. Will not answer / 9. Does not know
			Can you (he/she) **use the lift** without any assistance ? 0. Irrelevant : it never happens (no lift) / 1. Yes, without any difficulty / 2. Yes, but with some difficulty / 3. Yes, but with much difficulty / 4. No
			Can you (he/she) **go out of your home** without any assistance ? 1. Yes, I often go out, and I can move away without any assistance / 2. Yes, but I hardly ever go out / 3. Yes, but I can't move away from home without assistance / 4. No, I never go out without assistance because of my physical problems / 5. No, I never go out without assistance because of my psychological or emotional problems / 7. Irrelevant : too young / 8. Will not answer / 9. Does not know
			Can you **manage to order/take a taxi, or use public transportation** on your own? 0. Irrelevant : never goes out / 1. Yes, I can do it alone without any difficulty / 2. Yes, I can do it alone, but with some difficulty / 3. Yes, I can do it alone, but with much difficulty / 4. No, I can't. A relative, friend or child comes with me, but I could manage on my own if necessary / 5. No, I can't. A relative, friend or child comes with me, and I would have much difficulty managing on my own if necessary / 6. No, I only go out in an ambulance / 9. Does not know
			Do you **regularly find it difficult to move around** ? no / yes: 1 I do not get out of my bed / 2 I can get up a little /3 I can get around with the help of another person / 4 I can get around with the help of a frame or stick / 5 I require no assistance, but feel some limitations
			During the course of the last twelve months, did you **experience difficulties in getting around outside your domicile**, without the assistance of someone ? 1. Yes, often or always / 2. Yes, sometimes / 3. No, never / 9. Do not know

United Kingdom	1998	UK02	I would like to ask you about some tasks that **some people may be able to do without any difficulty, while others may find difficult or impossible**. (not difficult, quite difficult, very difficult or impossible) Mobility: **Get around the house**, except for stairs, on your own? How difficult is it for you to...: 1 Not difficult / 2 Quite difficult / 3 Very difficult / 4 Impossible

4. Leisure and social activities

Another important issue in the field of the disablement process is the restrictions in social activities, which represent another aspect of human roles with the social participation and involvement. Activities dealing with socialisation (meeting people), leisure and integration in social life (involvement in associations or groups) can be looked at. Some questions relating to this domain, and explicitly referring to the consequences of health problems, have been found in European surveys. But most of the time, this type of questionnaire is disconnected from the health status.

Examples of questions on social activities restrictions in European surveys

Spain	1995	E01	During the past two weeks, i.e. between ...... (date) and yesterday, have you **had to restrict or cut back your usual leisure activities** (e.g. hobbies, walks, visits, games, etc.) as result of any pain or symptom? - Yes / - No / - No answer.
Finland	1986	FIN04	... **Does it hinder your relations with other people**: a great deal / to some extent / not at all?
Norway	1998	N01	During the past 4 weeks, 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

IV. What should be proposed

The census of the European health surveys and the discussion on the general specification related to measurement instruments show various directions to assess activity restriction in young adults. The first direction is the regular activity index --ADL, IADL-- applied to young adults which is now found in all surveys but more rarely exploited under age of 65 years old. The combination of several ADL activity responses can be made to create larger domains of personal care activity restrictions. IADL items can be asked in the same way than ADL activities but enlarging the response categories to take into account the fact that such activities are not necessary performed by everybody: examples can be added for each item to target the largest possible population. In this specific domain, due to the fact that almost all the surveys ask ADL, IADL type questions to the whole adult population, we recommend to apply adapted analysis of the collected data for assessing activity restriction in young adults. Designing a specific global question will be most of the time redundant with the operational scales already available. The second direction is related to the main activity of this population group, relating mostly to professional activity, but with attention also to school or university participation and housework. Third, mobility is an important aspect of young adult independence. The accessibility of the usual places, the use of public or private transportation, are key issues in the social participation of adults. The fourth direction is the domain of social and leisure activities; these activities draw increasing attention regarding the impact of isolation on health and disability and could be useful for young adult in which such a social involvement is normally expected.

No recommendation is made in these different domains and the census of surveys shows a dispersion in the instruments used for these various domains (wording, response categories, added or suppressed items). The census allows to make some proposals of directions in which questionnaires could go. The proposals made here are (1) to cover the domains considered as essential for a normal integration in developed countries' societies, (2) to apply a wording in accordance with the proper way to collect information on activity restrictions, and to follow the specifications (eg performance-based wording, appropriate response categories, time reference...), (3) to propose activities scales allowing to target also people with moderate activity restrictions who are considered as highly at risk for problems in later life, (4) to collect relevant information (past experiences, adaptation strategies...).

To summarise, the specifications presented in this chapter are the following. Questions should look at *activity performance* through the difficulties met rather than capacities. For work, school or other social activities, a *health related* wording appears necessary to focus on restrictions that are really part of the disablement process. The collected information should refer to *long lasting* problems. Possibility of reporting *past episodes* of school or work restrictions can help in obtaining information on the overall disablement process, even if individuals have managed

progressively to cope with their limitations. In the same way, those who report past or current restriction should be able to *date the onset of problems*. Because young adults are more inclined to maintain activities through individual or collective compensatory strategies, it is important to give the opportunity to individual to report *changes in type or amount of activities* rather than only on performance and difficulties. The terms used should not be negative or stigmatising and should be intuitive for individuals. The optimal set of questions should take into account these specifications.

The proposed module of questions aims to look at restriction in major activity (work, school, housework), mobility and social activities in relation to health and to document on change and adaptation of the activities to possible functional limitations. As for ADL or IADL sets of questions, this module proposes different activities and rises questions in term of performance. This can show how functional limitation at young ages can be cause of interruption or a change in school participation and further disadvantage in access to occupations requiring high level of education.

Question on chore activities, addressed in the same way than job or school activities performance, can help collecting the information for those inactive or unemployed, but also for the others who are still expected to perform some of these activities at home. In this case, the IADL set of questions becomes redundant. If both instrument are competing in the survey, a choice has to be made, according to the room available in the questionnaire and to the type of population under consideration. The relationship between such a module and the global question on disability, GALI, is the same than the one existing between ADL, IADL sets of questions and the GALI: it allows to get a detailed information in the domains of activities in which the persons meet difficulties and provides additional information on the possible compensatory strategies. The questions allows to look at life course events and can be applied to young adults but also elderly, for those who have never worked or those who have stopped to work, by looking at past episodes and experiences. This latter information can be enhanced by collecting information on functional limitations in another module as proposed in the chapter on Functional Limitations (Chapter 1, part I). The reference to health problems in the questions allows to focus on the restriction part of the disablement process and does not decrease the interest of getting the functional status. It is needed to understand the mechanisms of the pathways between functional limitations and activity restrictions: this allows to assess which type of limitations (sensory, cognitive, physical) better predict restriction at work, at school.... An example of the type of questions to be asked, taking into account the different issues is presented in Box 1.

V Conclusion

The review of the European health or disability survey questionnaires shows different directions to assess the level of activity in the «young» adult population and a great variation in the instruments used. It has been eventually possible to depict the different domains that appear in a recurrent way in surveys, and which correspond basically to the domains selected on the basis of the WHO International Classification Handicaps (ICIDH) and part of its new version, the International Classification of Functioning (ICF).

Wording and structure of the proposed instruments as well as the possibility to limit the size or to add questions (need for assistance and unmet needs...) should be discussed further. The stage of validation and testing has to help in choosing all or a selection of the proposed domains of activity restrictions appropriate to fit in the general health monitoring programme. Finally, trying to formulate the questions, difficulties of definition appear: how to define social activities (cultural, religious, political...)? At this stage, we have been able to identify needs for information, some key issues in the measurement of activity restriction at young adult ages and direction in which questions could be developed. Next step is therefore to finalise the wording proposed in Box 1, through the exercise of translation and back translation and by running the questions in pilot studies.

Box 1: Module for measuring activity restrictions in young adult population

A. I would like to know if, due to **sequels of accident, disease, emotional or physical problems**, you have **ever** cut down in the **type or amount** of the activities at school, at work or at home?		
A1	**Have you ever cut down in school or university activities** due to sequels of accident, disease, emotional or physical problems?	Yes — A1.1 No — A2 I have never been at school or university due sequels of accident or other problems — A2 I have stopped or I have never been at school or university for other reasons — A2
A1.1	Did you **stop** school or university activities at all Did you **keep your activities a while** after the onset of your accident, disease, emotional or physical problem? At **what age** / at **which level of education** did you meet these difficulties?	If No — A1.2.1 Yes/No -
A1.2.1	At **what age** / at **which level of education** did you meet these difficulties?	-
A1.2.2	Do or did you use **special equipment** to attend to school or university	Yes/No
A1.2.3	Do or did you go in a **specialised institution** to attend to school or university	Yes/No
A1.2.4	Do or did you receive a **special assistance** to attend to school or university	Yes/No
A1.2.5	Do or did you have **adapted hours of attendance**	Yes/No
A2	**Have you cut down in your activities at work due to** sequels of accident, disease, emotional or physical problems?	Yes — A2.1 No — A3 I have never worked due sequels of accident or other problems — A3 I have stopped working or I am not working for other reasons — A3
A2.1	Did you **stop** working at all ? Did you **keep working a while** even after the onset of your accident, disease, emotional or physical problem? At **what age** did you did you meet these difficulties?	If No — A2.2.1 Yes / No
A2.2.1	At **what age** did you did you meet these difficulties ?	-
A2.2.2	Did you change the type or amount of your work activities	Yes/No
A2.2.3	Do or did you use special equipment to work	Yes/No
A2.2.4	Do or did you work in a sheltered job	Yes/No
A2.2.5	Do or did you receive a special assistance to work	Yes/No
A2.2.6	Do or did you have adapted hours of attendance	Yes/No
A3	**Have you cut down in activities at home for chore, maintenance or management of the house** (cleaning, washing clothes, repair, money management) due to sequels of accident, disease, emotional or physical problems?	Yes — A3.1 No — B I have never done such activities due sequels of accident or other problems — B I have never done or I have stopped doing such activities for other reasons — B
A3.1	Did you **stop** performing chore, maintenance or management activities at all? Did you keep your activities a while even after the onset of your accident, disease, emotional or physical problem? At what age did you meet these difficulties?	If no — A3.2.1 Yes / No -
A3.1.1	At what age did you meet these difficulties?	-

A3.2.2	Did you change the type or amount of such activities	Yes/No		
A3.2.3	Do or did you use special equipment to perform these activities	Yes/No		
A3.2.5	Do or did you receive special assistance to perform these activities	Yes/No		B

B. I would like to know if, due to **sequels of accident, disease, emotional or physical problems,** you have **ever cut** down in the type or amount of leisure and social activities?			
B1	**Have you cut down in your mobility to go to a place you need to or you want to go** (outside the house, using private vehicle or public transportation) due to sequels of accident, disease, emotional or physical problems?	Yes No I have never moved to place I need or want to due sequels of accident or other problems I have never moved or stopped moving to place I need or want to for other reasons	B1.1 B2
B1.1	Did you stop moving to go to places you need to or want to go at all? Did you keep your mobility a while even after the onset of your accident, disease, emotional or physical problem? At what age did you meet these difficulties?	If no Yes/No -	B1.2.1
B1.2.1	At what age did you meet these difficulties?	-	
B1.2.2	Did you change the type or amount of your mobility	Yes/No	
B1.2.3	Do or did you use special equipment to move	Yes/No	
B1.2.4	Do or did you receive a special assistance to move	Yes/No	
B2	**Have you cut down in your relationships with the others** (contacts with spouse, family, friends, neighbourhood...) due to sequels of accident, disease, emotional or physical problems?	Yes No I have never had relationships with others due to sequels of accident or other problems I have had never or I have stopped to have relationships with others for other reasons	B2.1 B3
B2.1	Did you stop having relationships with others at all? Did you keep having relationships with others a while even after the onset of your accident, disease, emotional or physical problem? At what age did you meet these difficulties?	If No Yes/No	B2.2.1
B2.2.1	At what age did you meet these difficulties?	-	
B2.2.2	Did you change the type or amount of your relationships with others	Yes/No	
B2.2.3	Do or did you use special equipment to keep relationships with others	Yes/No	
B2.2.4	Do or did you meet others in a specialised institution	Yes/No	
B2.2.5	Do or did you receive a special assistance to keep relationships with others	Yes/No	
B3	**Have you cut down in your in cultural, political or religious activities** (involvement in societies and groups, reading, going to cinema, museums, theatre...) due to sequels of accident, disease, emotional or physical problems?	Yes No I have never had such activities due to sequels of accident or other problems I have never had or I have stopped to have such activities for other reasons	B3.1 end
B3.1	Did you stop having cultural, political or religious activities at all? Did you keep having such activities a while even after the onset of your accident, disease, emotional or physical problem? At what age did you meet these difficulties?	If No Yes/No	B3.21
B3.2.1	At what age did you meet these difficulties?	-	
B3.2.2	Did you change the type or amount of these activities	Yes/No	

B3.2.3	Do or did you use special equipment to keep these activities	Yes/No
B3.2.4	Do or did you go in a specialised institution to perform these activities	Yes/No
B3.2.5	Do or did you receive a special assistance to perform these activities	Yes/No end

Part 2: Further work on phase I indicators

Chapter 5: Limitations in usual activities, a global approach

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Section 1: Definition and presentation of the proposed measurement instrument

1. Defining the concept of a Global Activity Limitation Indicator: (GALI)

A Global Activity Limitation Indicator (GALI, previously referred to as Global Disability Indicator (Verbrugge, 1997) is defined as an instrument that is able to identify subjects, in both general and/or specific populations, who perceive themselves to have long-standing, health-related limitations (restrictions) in the usual activities.

According to the ICF an activity is defined as: '*the execution of a task or action by an individual*' and thus activity limitations are defined as '*the difficulties the individual experience in executing an activity*' (World Health Organization, 2001) Within the framework of the ICF, limitations should be due to a health condition.

In the definition of the GALI, the term "usual activities" refers to the fact that the limitations in the execution of actions and tasks are assessed against a generally accepted population standard, relative to cultural and social expectations.

2. Defining the measure

The aim of a GALI-instrument is to estimate the perception of the activity limitations within a population using a concise set of questions and preferably a single question. The conciseness of the instrument, defined by the number of questions (between 1 and 3 questions maximum), the length of the questions and the response categories should be its main strength. Other criteria a GALI should meet are:

1. Presence of long-standing limitations: duration at least 6 months
2. Cause of activity limitation: a general health problem
3. Usual activities : the reference is to activities people usually do
4. Severity of limitations: inclusion of full range in the response with at least three levels
5. No preceding screening for health conditions

The justification for these criteria is given in more detail in section 2 of this chapter.

3. Policy relevance and utility

There are two main reasons to develop a GALI for public health policy. First, due to the ageing of populations and the change in the morbidity-profile to chronic health conditions, simple information on health has to be extended with a concise instrument which provides policy makers with easily obtainable information on the **perception of activity limitations** that could result in a need for support. Further activity limitations may lead to disadvantages in social participation.

Instruments to measure limitations in usual activities are normally complex (multi-item) instruments. The output of these instruments depends on the specific activities included. In different countries or surveys different instruments are used, making comparisons almost impossible.

Secondly, similar to the concept of perceived health, there is a search for developing a global single question instrument to measure these activity limitations, independently of the type of activity, the specific life situations, the kind of health problem causing the activity limitation, specific age groups, sexes or other subgroups.

A single question instrument should make it more acceptable for countries and researchers to include it in their different surveys, making comparison between countries and subgroups possible.

Although in surveys the activity limitations are never observed, the proposed instrument is not intended to measure the exact amount of observable nor the type of activity limitations in a community. The instrument will allow estimation of the number of persons in a population that perceive themselves to have limitations in their activities, estimating the prevalence of the perceived activity limitations of that population.

It can be expected that the perception of the activity limitations is of more relevance to health policy, because the health care needs and consumption depend to a large extent on the perception of health problems. A similar relationship is found between global self-perceived health status and health care (ambulatory or hospital) consumption.

4. Proposed Global Activity Limitations Indicator

The wording of the proposed instrument to estimate the Global Activity Limitations Indicator is as follows :

> **For at least 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**

Depending on the type or the objectives of the survey and the need for more information, the GALI instrument can be extended by additional questions providing information on the life situations in which the activities are limited, on the causes of the activity limitation and on the use of personal assistance and/or devices. Those extensions of the GALI are given in an annex to this chapter.

5. Population category

In order to provide good estimates of the perceived activity limitations of a population, this instrument should be administered to a general population of all ages or to special groups within a population. The wording of the proposed instrument does not relate to any age group in particular. The simple wording should also allow administration in institutionalized populations.

6. Health expectancy

The instrument permits calculation of an Activity Limitation Free Life Expectancy. The introduction of three response categories (not limited, limited and strongly limited) will allow testing of the plausibility of the scenario of a dynamic equilibrium (Manton, 1982).

Section 2: Background

I. History of the instrument

Scientific discussion on a 'Global Disability Indicator' started during the 9th REVES meeting in Rome (1996), as a result of extensive E-mail discussions (Verbrugge and van den Bos, 1996) and has been further elaborated by Verbrugge (Verbrugge, 1997). The purpose of this section is to continue this development and to justify the proposal of an instrument to define a global activity limitation indicator.

The 'Global Disability Indicator' was little related to any conceptual framework. The revision of the ICIDH -ICF, (World Health Organization, 2001) - gives us an opportunity to better relate a Global Activity Limitations Indicator to a conceptual framework. In the revision, activity limitations are defined as the difficulties the individual experiences in executing an activity, due to a health condition. Activity is defined as: '*the execution of a task or action by an individual'*. The activity dimension of the ICF gives a profile of an individual's functioning in terms of activities, from simple to complex ones, and deals with the performance of the individual. The activity limitations are assessed against a generally accepted population standard, relative to cultural and social expectations.

The following steps were taken in developing the proposal for a GALI :

- the conceptual framework of the ICF, and previous work in the framework of REVES was used to develop a set of criteria for evaluation of candidate GALI instruments ;

- instruments were collected for evaluation by a Medline search, over the time period 1990-1999 and using key words disability/measurement/activity limitations, and by an extensive E-mail survey among experts in the field of disability research ;

- instruments were qualitatively screened for a set of criteria (tables 1 and 2);

- selection of existing or the creation of a new instrument to be proposed ;

- if a new instrument is to be created, the evaluation of the instrument against the same criteria.

The different instruments were reviewed based on some critical conceptual and practical criteria (tables 1 and 2). The instruments reviewed are given in detail in part 3.

In the subsequent section, we will give a brief introduction of the conceptual criteria. For the practical criteria we refer to the standard methodological literature (Verbrugge, 1997).

Table 1: Conceptual criteria

1. A concise set of questions: between 1 and 3 questions maximum ;
2. Presence of long-standing limitations: duration at least 6 months ;
3. Cause of activity limitation: a general health problem ;
4. Usual activities: the reference is to activities people usually do ;
5. Severity of limitations: inclusion of full range in the response with at least three levels ;
6. No preceding screening for health conditions ;

Table 2: Practical criteria

1. Questions compact and in simple words;
2. Same instrument for total population (including institutionalized population) ;
3. Same instrument for all age categories ;
4. To be used without further explanation or instructions ;
5. To be used in self administered, face-to-face or telephone survey ;
6. To be used in general, health and disability surveys ;
7. No comparison with same age group, sex or with previous periods ;
8. Validated ;
9. If necessary the GALI can be extended by sub-questions, indicating specific life situations: school/work, house, leisure time ;
10. Specific question for identification of the health causes of the activity limitation ;
11. Specific question for use of devices or assistance ;

1 A concise set of questions: between 1and 3 questions maximum

The aim of a GALI-instrument is to estimate the perception of activity limitations within a population using a concise set of questions and preferably a single question. The conciseness of the instrument, defined by the number of questions, the length of the questions and the response categories should be its main strength. This should facilitate, in a similar way compared to the single question instrument on self-perceived health, the use in both general and health or disability surveys. However one should also be aware that the conciseness is at the same time also a drawback as the validity of such an instrument may be lower due to a smaller differentiation rate and the problems related to translating complex concepts into a single simple statement.

2 Presence of long-standing limitations: duration at least 6 months

The purpose of the instrument is to measure the presence of long-standing limitations, as the consequences of these limitations (e.g. care, dependency) are more serious. Although not empirically based, a 6 months period is often used to define chronic or long-standing diseases in surveys. Other authors use a duration of 3 months to define chronicity of a disease (van den Bos, 1989) however for activity limitations this period seems too short, as it also includes short-term limitations with a period of rehabilitation. We will define long-standing as a time period of 6 months or more. The time period refers to the duration of the activity limitation and not of the health condition, as the focus of a GALI instrument is on the activity limitations and not as much on the health problems.

3 Cause of activity limitation: a general health problem

The GALI should refer to health-related problems as cause of the limitations. The indicator is not meant to measure limitations due to financial, cultural or other none health-related causes. To be general, specification of health concepts (e.g. physical and mental health) should be avoided. Existing instruments sometimes refer only to physical health problems, other instruments to physical and mental health problems and a few of them to additional problems, mainly combined in one question, but often in up to three specific questions. This makes comparison more difficult.

4 Usual activities : the reference is to activities people usually do

People with long-standing limitations due to health problems, have passed through a process of adaptation. This may result in a selection or reduction of the set of activities they do. In order to identify the existing limitations a reference is necessary. Although some instruments include an explicit external reference to the age-group of the subject, this is not preferred. Therefore the activity limitations are assessed against a generally accepted population standard, relative to cultural and social expectations by referring only to activities ***people*** ***usually do***.. This is consistent with the self-perceived health instrument (see next chapter) and gives no restrictions by culture, age, gender or the subjects own ambition.

5 Severity of limitations: inclusion of full range in the response with at least three levels

As mentioned above, one of the limitations of a concise instrument is a smaller differentiation rate. Therefore the response scale should cover the full range of severity levels, including the absence of limitations (Verbrugge, 1997). A two level scale (e.g. yes/no or limited/not limited) merely estimates the presence or absence of limitations, not the severity. However, one should be aware that the robustness of the scale does not allow too detailed categorisation. The calculation of health expectancies - including the possibility of testing for the plausibility of the dynamic equilibrium hypothesis (Manton, 1982) - requires at least a distinction between absence of limitations and the presence of mild and severe limitations.

6 No preceding screening for health conditions

The focus of the instrument is on limitation. A preceding screen for health conditions acts as a filter, introducing a selection, and will therefore not be used.

II. Measuring GALI, in Europe and elsewhere

To collect GALI candidates, an inventory study was carried out with the work of Verbrugge forming the starting point (Verbrugge, 1997, Verbrugge and van den Bos, 1996) . After this, a Medline search was carried out over the time period 1990-1999 and using the key words disability/measurement/activity limitations. A short questionnaire was also sent to around 50 experts in the field of disability research, mostly members of the International Network on Health Expectancy (REVES) and the Euro-REVES 1 project. This questionnaire requested information on the existence of a 'global disability indicator' in the country of the respondent and the wording, the survey in which this indicator was included and scientific references.

These actions resulted in about 30 candidate GALIs. A first screening revealed that some instruments were almost identical. Some other instruments only referred to short-term limitations. The findings of the review of the 22 remaining instruments are presented in table 3. Table 3 also includes the results of the evaluation of the proposed GALI instrument and the extended GALI instrument against the criteria. (For detailed description of the instruments, see Part I, pages 151 to 176).

III. Essential characteristics of the instrument

To meet the criteria of tables 1 and 2, the ideal instrument should :

- have only 1 item ;
- refer to long-standing activity limitations (at least 6 months or more) ;
- refer only to general health problems ;
- refer to activities people usually do ;
- include at least three levels of severity ;
- in order to avoid selection, should not be preceded by a screening question on health problems ;
- be usable for all age categories (to calculate a uni-dimensional activity limitation free life expectancy starting from a certain age, preferably birth) ;
- be extendable by questions on causes, the use of personal or devices assistance and the life situations in which the activity limitations occurs.

For the evaluation following qualitative categories are used in table 3:

The number of questions: the number is given

Long-standing activity limitations:
 ++ : 6 months or more
 + :duration less than 6 months
 - : duration not defined

Health related problems:
    ++ : general health problems
    + : specific health concepts (physical, mental)
    - : no reference to health problems

Usual activity:
    ++ : usual activities without any specification or restriction
    + : usual activity within specific broad life situations
    - : specific activities description

Rating (range of severity):
    + : 3 or more categories in the response categories
    - : binary response categories (only presence or absence of activity limitations

No preceding screener:
    + : there is no preceding screening question(s) on health problems
    - : there is a preceding screener

Usable for all ages:
    + : usable for all ages
    - : is age specific or has different questions for specific age groups

Causes included:
    + : has a question (often an open-ended question) to identify the health cause(s) (disease, condition, etc.) of the activity limitation
    - : does not have such a question

Assistance:
    + : has a question on the use of personal and/or device assistance to carry out the activity
    - : does not have such a question on this

Activity description:
    + : the activity limitation is assessed for a list of specific task or activities in the response categories
    - : does not have such a list

Table 3: Results by comparing candidates (numbers 1 to 22)

	Reviewed instruments																						Proposed	
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	GALI	GALI+ Optional questions
Number of questions	1	4	4	4	1	2	5	6	3	12	4	3	5	2	4	8	2	5	2	4	3	3	1	6
Long-standing limitations	-	+	-	-	-	-	-	-	+	-	-	-	-	-	++	-	++	-	+	++	-	-	++	++
Health related problem	-	+	+	+	++	+	+	+	-	++	+	++	+	++	++	+	+	+	++	++	++	++	++	++
Usual activities	-	++	+	++	++	++	+	+	+	+	+	+	+	+	++	+	+	+	+	+	++	+	++	++
Range of severity	+	+	-	-	+	-	+	+	+	-	-	-	+	-	-	-	-	-	-	-	+	+	+	+
No preceding screener	+	-	+	-	+	-	+	-	+	+	+	+	+	+	+	-	+	-	+	-	+	+	+	+
All ages	+	+	+	+	+	+	+	+	+	-	-	+	+	+	+	-	+	-	+	+	+	+	+	+
Causes included	-	+	-	+	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	+
Assistance	+	-	-	-	-	-	-	-	-	+	-	-	-	-	+	+	+	-	-	-	-	-	-	+
Activity description	+	-	-	-	-	-	-	-	-	-	+	-	-	-	-	-	-	-	-	-	-	-	-	-

Score: see text

Numbers 1 to 22 refer to instruments in the following surveys: (for detailed description of the instruments, see Part I, pages 151 to 176)

1. <u>Austria</u>: Living conditions of persons aged 60 years or more (June 1998) - B. Wiederhofer (1998) Soziale Fragen: Senioren: Unterstützung durch Angehörige, Freunde, Soziale Dienste. Ergebnisse des Mikrozensus-Sonderprogramms ;

2 <u>Belgium</u>: Health Interview Survey, 1997 - H. Van Oyen, Scientific Institute of Public Health (1997) *Belgian Health Interview Survey*. Bruxelles: SIPH

3 <u>Canada</u>: National Population Health Survey (NPHS), restriction of activities part - Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362

4 <u>Great Britain</u>: General Household Survey for Great Britain (2000)

5 <u>International</u>: REVES Harmonisation Committee - Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

6 <u>International</u>: European Community Health Panel - Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

7 <u>The Netherlands</u>: Permanent Onderzoek Leefsituatie (POLS) (first version) - Ooijendijk WTM, Geurts J (1998) *De ontwikkeling van een globale beperkingen indicator*. Manuscript.

8 <u>The Netherlands</u>: Permanent Onderzoek Leefsituatie (POLS) (second version)

9 <u>The Netherlands</u>: Peilingen WVG - Ooijendijk WTM, Geurts J (1998) *De ontwikkeling van een globale beperkingen indicator*. Manuscript.

10 <u>USA</u>: National Health Interview Survey U.S. (NHIS), Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

11 <u>USA</u>: Disability questions in U.S. Census of Population 1990, Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

12 <u>USA</u>: National Health and Nutrition Examination Survey III (NHANES III), Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

13 <u>USA</u>: Survey of Income and Program Participation 1984 (SIPP), Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

14 <u>USA</u>: National Medical Expenditure Survey. 1987 (NMES), Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

15 <u>USA</u>: Behavioral Risk Factor Surveillance System (BRFSS), 1995 Quality of Life/Functional Status (QOL/FS) Optional Module, Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362, and Verbrugge LM. Merrill SS, Liu X (1995) *Measuring disability with parsimony: Proceedings of the 1995 Public Health Conference on Records and Statistics*. Hyattsville. MD: National Center for Health Statistics.

16 <u>USA</u>: Behavioral Risk Factor Surveillance System: Other QOL/FS Questions [drafted and considered by CDC staff]

17 <u>USA</u>: Behavioral Risk Factor Surveillance System (proposed)

18 <u>USA</u>: National Health Interview Survey, Disability Supplement 1994-95, Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

19 <u>USA</u>: Medical Outcomes Study Short-form Health Survey (MOS-20), Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

20 <u>USA</u>: International Center for the Disabled Survey 1985 (ICDS), Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

21 <u>USA</u>: Baltimore Longitudinal Study of Aging Follow-up, Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

22 <u>USA</u>: Pilot Study on Subjective Health, NCHS, Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

From this review of the 22 instruments the following conclusions can be drawn:

1. Only two instruments can be classified as single item instruments. Most instruments (12/22) had more than 3 questions.

2. Few instruments refer to long-standing limitations (6/22). Only 3 instruments refer to limitations that have lasted for 6 months or longer although it should be noted that some instruments in their wording refer to long-standing or chronic health conditions as a cause of limitations, but not to long-standing limitations.

3. Most instruments refer to health-related problems. Some instruments (10/22) refer to health in general (marked with ++). Other instruments (marked with +) (10/22) refer to specific health concepts (e.g. physical health and/or mental health).

4. Few instruments (6/22) refer to usual activities in a general way. Most instruments (15/22) refer to specific life situations (work/school, household, leisure).

5. Less then half the number of instruments (9/22) have a range of severity included in the response categories. Most instruments only register the presence or absence of limitations.

6. Instruments (7/22) with a preceding screen have the drawback that they only cover those persons with activity limitations that pass the screen. If a person has activity limitations, but does not pass the screen, he or she will not answer the question(s) on activity limitations.

7. Almost all instruments (19/22) do not have limits on age included. However, it is possible that some instruments are part of a questionnaire that is directed at specific age groups.

8. Almost no instruments (2/22) have causes included in the body of the instrument.

9. In some instruments (5/22) the use of personal assistance or assistance devices is part of the range of severity. In other instruments, a separate question on personal assistance or assistance devices is included.

10. In two questions a set of specific tasks and activities is explicitly mentioned in the question wording or in the response categories. This is a drawback, because it limits the possible limitations to be measured.

Regarding all criteria together, three instruments meet almost all of the criteria and particularly the criterion of long-standing limitations (numbers 15, 17 and 20). Two of these instrument (number 15 and 20) have four questions, one has only two questions. None of these instruments however include a simple range of severity in the response. Number 17 has the drawback that it refers to specific health problems (physical, mental, emotional, or communication-related condition) and refers to specific life situations (activities at home, school, work, or in the community), making the wording of the question rather complex.

IV. Conclusion

Since none of the instruments met all or most of the criteria in tables 1 and 2, a new instrument is proposed (see section 2 of this chapter). According to the criteria (tables 1-3):

*   The proposed instrument is a global single item instrument. The additional questions (see annex) are optional. The wording is simple and compact, and usable in specific populations such as e.g. institutionalized populations.

*   There is no comparison to external reference groups except a generally accepted population standard, relative to cultural and social expectations: 'the activities people usually do'.

*   Because there is no reference to specific type of activities, the same instrument can be used for subgroups in a population : age, gender, cultural. All these specific subgroups have their own usual activities.

*   The proposed instrument has no preliminary screening question. The optional question about possible causes (see annex) should not be used as a preliminary screening question.

*   Because the wording is straightforward, no introduction or explanation seems to be necessary.

- Because the wording is simple, application in different survey methods (face-to-face, postal or telephone) seems possible.

- Within the concept of the ICF, the instrument makes no restriction on the type of activities for which a limitation exists. It also makes no restriction in the context in which the limitation is experienced (life situations as work, home, leisure time). However, it refers to general and not specific health-related problems.

- The question is concisely formulated. It focuses on limitations which are long-standing (in order to exclude short-term limitations), caused by non-specified health problems. The wording is simple and the terms used are straightforward and commonly understood: limitations, 6 months, activities people usually do. The only undefined concept is 'health'. Translation into different languages seems feasible.

- As it is a single question instrument, it is especially suitable in general surveys. In health and particularly disability surveys it can be used as a screen.

- The instrument allows for optional questions (5 in number) to specify life situations in which the activity limitations occurs (3 questions: school/work, home, leisure time), to specify the health cause of the activity limitation (1 question) and to specify if assistance (personal or device) is used (1 question)

The proposed instrument is currently available in all European languages. As the proposed indicator is a newly formulated question, it is not yet evaluated. The instrument (French, Dutch and German version) is used in the 2001 National Health Survey in Belgium and will be evaluated against other instruments, among others the SF-36 Physical Module, the WHO-Europe disability instrument, the Longstanding illness instrument, when the data are available. The instrument is meant to be 'general' and therefore the health problem is not divided into specific dimensions such as physical or mental health. The purpose of the instrument is to measure long-standing limitations, since the consequences of these limitations (e.g. care, dependency) are more burdensome. In the response categories, a distinction is made in three levels of severity. These distinctions allow for more nuance (e.g. changes over time, comparison between groups) and also for testing the plausibility of different epidemiological scenarios: expansion of disability, compression of morbidity and dynamic equilibrium (Gruenberg, 1977; Kramers, 1980; Fries, 1980; Manton, 1982) .

V The GALI in other European languages

A standard procedure was set up to develop the GALI-instrument in the different languages of the European Member States (MS). In a first step a translation procedure was developed with focus on the concept rather than the technical translation. The formulation into an other language was done by both a linguist and a public health scientist independently; another linguist and public health scientist were then responsible for a back translation. All were provided with technical information explaining the concept of the GALI. After the control through back-translation the proposed version was evaluated against the major concept within the instrument:

Activity limitations or restriction

- Caused by a health problem or condition
- Duration of the limitation: at least 6 months before the interview
- Population norm : activities people usual do

The GALI-instrument is currently translated in 10 languages.

English:
For at least the last 6 months, have you been limited because of a health problem in activities people usually do ?
      Yes, strongly limited
      Yes, limited
      No, not limited

Danish:
Gennem de seneste 6 måneder eller længere har De (da) hele tiden været begrænset I at udføre almindelige dagligdags gøremål på grund af helbredsproblemer?
      Ja, meget begrænset
      Ja, noget begrænset
      Nej, ikke begrænset

Spanish :
¿Durante los últimos seis meses o más, ha tenido que limitar sus actividades habituales, debido a algún problema de salud?

      Sí, mucho
      Si, algo
      No, no las he limitado

Swedish:
Har du under de senaste 6 månaderna eller längre tid begränsats av något hälsoproblem när det gäller att utföra vanliga aktiviteter?

      Ja, i stor utsträckning
      Ja, i viss utsträckning
      Nej

Greek:
να κάνουν οι άνθρωποι, λόγω κάποιου προβλήματος υγείας?

      Ναι, έχω πολύ περιορισθεί
      Ναι, έχω περιορσθεί
      Οχι, δεν έχω περιορισθεί

Italian:
È limitato da almeno sei mesi nelle attività che le persone svolgono abitualmente, a causa di un problema di salute?

      Si, fortemente limitato
      Si, limitato
      No, non limitato

Portuguese:
Durante os últimos 6 meses, ou mais, o senhor(senhora) esteve limitado nas actividades que as pessoas realizam habitualmente, devido a um problema de saúde ?

      Sim, Fortemente limitado
      Sim, Limitado
      Não

German (Germany, Austria):
Waren Sie aus gesundheitlichen Gründen die letzten 6 Monate oder noch länger in der Ausübung allgemein üblicher Aktivitäten eingeschränkt?

      Ja, stark eingeschränkt
      Ja, eingeschränkt
      Nein, nicht eingeschränkt

German (Belgium):
F¨hlen Sie sich seit mindestens 6 Monaten infolge eines Gesundheitsproblems in den gewöhnlichten Tätigkeiten beeinträchtigt?

      Ja, sehr beeinträchtigt
      Ja, beeinträchtigt
      Nein, überhaupt nicht

French (France, Belgium):
Etes vous limité depuis au moins 6 mois, à cause d'un problème de santé, dans les activités que les gens font habituellement ?

      Oui sévèrement limité
      Oui, limité
      Non, pas limité

Dutch (Belgium):
Is u , vanwege een gezondheidsprobleem, sinds 6 maanden of langer beperkt in activiteiten die mensen gewoonlijk doen?

      Ja, erg beperkt
      Ja, beperkt
      Neen, niet beperkt

Dutch (The Netherlands):
Bent u , vanwege een ziekte, aandoening of handicap al minstens 6 maanden beperkt in activiteiten die mensen gewoonlijk uitvoeren?

     Ja, erg beperkt
     Ja, beperkt
     Neen, niet beperkt

Annex: Optional additional questions:

Options : referring to specific life situations

Question 2 A :
For the past 6 months or more have you been limited in activities people usually do at school or work because of a health problem ?
        Strongly limited
        Limited
        Not limited

Question 2 B :
For the past 6 months or more have you been limited in activities people usually do at home because of a health problem ?
        Strongly limited
        Limited
        Not limited

Question 2C :
For the past 6 months or more have you been limited in activities people usually do during leisure time because of a health problem ?
        Strongly limited
        Limited
        Not limited

Question 3
Which health problem causes these limitations:
        a. an accident/injury, namely…….
        b a disease /disorder, namely.......
        c. old age, namely….
        d at birth, namely…….
        e other cause, namely.....
        f don't know.

Question 4
Do you use any kind of equipment or devices or do you use assistance from other people to carry out activities people usually do?
        Yes, only equipment or devices
        Yes, only assistance from people
        Yes, both equipment or devices and assistance from people
        No
        Refusal
        Do not known
        No answer

Chapter 6: Perceived health

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Section I. Presentation and definition of the proposed measurement instrument

In recognition of the need to elicit an individual's own assessment of their health and of the considerable advantages of measuring overall health through the use of a simple question, the notion of 'self-perceived health' (SPH) has become popular. SPH is a global measure that includes the different dimensions of health, i.e. physical, social and emotional function and biomedical signs and symptoms. Whereas with many health indicators we get only a partial indication of health, SPH appears to be an effective summary of health.

1. Definition

In view of the varied interpretations and methodologies in measuring 'perceived health', it is a difficult notion to define. In the current context, the following defining framework is suggested.

First, it is more relevant to use the term 'self-perceived health', rather than just 'perceived health'. This is to emphasise that the notion is restricted to an assessment coming from the individual him/herself and not from anyone outside that individual, whether an interviewer, health care worker or relative. This is not to say that SPH is not influenced by impressions or opinions from others, but rather that it is the result after these impressions have been processed by the individual in relation to their own beliefs and attitudes.

Second, the notion of 'perception' implies an immediate, subjective process or emotional reaction rather than a detailed and systematic cognitive analysis. In addition, the assessment is of overall, global health rather than of different sub-attributes or dimensions of health. Hence, the reliance on only a few questions, or even one alone, instead of the battery of questions which is more usual in the assessment of, for example, social functioning and activities of daily living.

Thirdly, it is important to note that 'self-reported health' is not necessarily the same as 'self-perceived health'. One may report something about oneself without having actually evaluated or reached a decision about it. It is essential that it is the individual's own evaluation, rather than an objective' description of activities or performance, based on self-reporting, such as commonly used in the assessment of activities of daily living, e.g. "Can you walk stairs?" etc.

While the term 'health' is used, this could also be interpreted as 'health state' or 'health status', although some might argue that these latter two are not the same as 'health in general'. It is also debatable whether or not, in this context, 'health' is different from 'health-related quality of life' (which is itself usually interpreted as a part of overall quality of life). While it would appear that 'health' and 'quality of life' are very different notions, the operationalisation of 'health' and 'health-related quality of life' measurement are similar, in this context. Thus, both include diverse aspects of functioning (including physical, social and psychological), both can be rated by the individual him/herself and both involve subjective assessments. It should also be noted here, that the notion of 'health' as used here, embodies both negative and positive definitions. While the negative aspects refer to sickness/disease/illness, the concept of health is more than the mere absence of disease or disability. It implies 'completeness' and 'full functioning' or 'efficiency' of mind and body and social adjustment, the ability to cope with stressful situations, high morale and even levels of physical fitness (Bowling, 1991).

2. Searched information

A simple question on the self-perception of health status is one of the most commonly used in health interview surveys (WHO-Europe, 1996). Despite its very general, seemingly subjective character, such a question appears to be very useful as a public health indicator. The assessment of SPH is associated with a number of other health measures and the use of health services (Idler & Benyamini, 1997) and it also appears to be an independent predictor of survival rate in elderly people (Kaplan et al., 1988).

During the project several additional SPH domains has been considered, and particularly 'vitality' and 'sense of coherence'. Vitality comprises the degree to which an individual feels that he/she has the power, strength or force to manage life in the way that he/she wishes, a question about "vitality" could be an important domain in any future work. A number of studies have shown that there is a close relation between health and energy/vitality (Ryan & Frederick

1997). Low energy or loss of energy is very often related to poor health, both physical and mental health, despite the fact that is difficult to conclude whether low energy is a consequence of poor health, or little energy results in poor health. Nevertheless, it is generally agreed that health and vitality are closely connected with one another.

Sense of coherence (SOC) pertains to whether or not an individual views the world that he/she lives in as comprehensible, manageable and meaningful. The concept and its relevance to health has been introduced by Antonovsky. The so called SOC scale has been used in more recent studies. SOC is strongly developed if a person sees the world as comprehensible, manageable, and meaningful. Lack of coherence and lack of perception of coherence will lead to losses and lacks in other domains. Empirically it has been shown, that SOC has associations with other indicators of health, including health status and self-perceived health (Forbes 2001). Poor SOC is associated with low self-rated health and a high prevalence of symptoms (Nilsson et al. 2000; Due & Holstein 1998), while a strong sense of coherence is associated with various aspects of good perceived health (Suominen et al. 2001).

3. Policy relevance and utility

Health is a multidimensional concept that can be approached from different points of view. Although for health policy purposes it is often more useful to deal with a summary measure that provides a comprehensive picture of the health status of a population. For the moment therefore only the single question on general perceived health is recommended. The advantage of SPH over the other measures on the specific dimensions of health is that it provides a global approach to health rather than a partial one. In addition, it provides in a simple figure a measure of population health. Self-perception of health can be easily measured using a single instrument that can be administered through all types of surveys to a general population of all ages. Thus, its "holistic" approach and its generalizability of the health concept, as well as the comprehensiveness of the population responses, allows it to be used when comparing different populations. In health monitoring and planning, the analysis of regional differences and temporal trends of population health could be easily addressed by using self-perceived health as a global index of health. Several examples to illustrate this point can be found (REVES, 1998).

SPH is considered to be one of the best health indicators at both, the individual and population level. As is shown in this review, several cross-sectional and longitudinal studies have demonstrated its relationship with other health status variables, thus reinforcing its validity as a global indicator of health. SPH has consistently been shown to be a good predictor of general and specific mortality, by selected causes, over both the short and long term, as well as of the future functional capacity of individuals. This characteristic has stimulated the increased use of SPH in clinical and public health surveys as a key indicator of individual health status. It has become a commonly used indicator available in many countries. Furthermore, the association between SPH and physical symptoms, limitations on daily activities and the use of health services has also been well documented. The level of perception of bad health in the population is a clear indication on the needs, services and health care requirements of a community.

In addition, SPH is important from a political and normative perspective, because it focuses on 'democratic' activities, such as participation, involving citizen's views, etc. It is the citizens` own criteria of good and poor health and such an approach settle that the individual is a good observer of her or himself.

The second target of the WHO Health for all strategy 2000, states that all people should have the opportunity to develop their own health potential. They recommend using several indicators (including Healthy Life Expectancy) to monitor such progress. However, at that time standard methods could not yet be recommended, as the conditions on comparability and harmonisation of data were not completely fulfilled. According to the present proposal, however, the Health Expectancy indicator calculated using SPH could accomplish all the requirements and could be used as the indicator to monitor progress on health and health related quality of life throughout the European region.

4. Wording

The instrument we propose to measure SPH is that recommended by the World Health Organization (WHO-Europe, 1996).

<div style="border:1px solid black; text-align:center">

How is your health in general?

very good – good – fair – bad - very bad

</div>

5. Justification of the choice

Among all the reviewed instruments measuring SPH, it is the proposed question that best captures the simplicity, generalizability and global interpretation of the SPH concept.

The exact wording of a question to measure SPH, including the choice of a comparative or non-comparative format, depends partly on the underlying framework used. Here, we are interested in the standardisation of the variable in order to facilitate cross-national, as well as regional, comparability of health data. Thus, it would be desirable to refer to a general state of health, to adjust the answer categories and to adopt a general non-comparative perspective. The proposed indicator is an absolute, single-item measure of SPH with five response categories. Two of the response categories are positive (very good, good), one is neutral (fair) and two are negative (bad, very bad). The question is absolute in that it omits any reference to either an age or time comparison. WHO argues that the inclusion of such comparisons would prevent the monitoring of progress in the average health of a population. The question is not time limited. The reference is to 'health in general' rather than 'present state of health', as the question is not intended to measure temporary health problems. In addition, the question is a single-item measure in that it does not specifically refer to the different sub-attributes or dimensions of health.

6. Scoring system

In addition to question wording, careful consideration must also be given to the number and type of response categories to be used. For example, rating scales ranging from 1 to 10 or from A to E may not be suitable for international comparison because they have different meanings in different cultures. While the same can be said about worded scales, i.e. very good, good, fair, bad, very bad, it is the intention that any differences in interpretation, due to cultural and social factors, can be accounted for in the translation of the response categories into various languages. The WHO Regional Office for Europe recommends that five verbally indicated categories be used, stating that terms such as 'good' and 'bad' are more commonly understood. Therefore, we propose the original five categories. Two (very good and good) are at the upper end of the scale and two (bad and very bad) are at the lower. The intermediate category 'fair' should be neutral.

It is also important to note that the intermediate category 'fair' should be translated into an appropriately neutral term, as far as possible keeping in mind cultural interpretations, in the various languages. This point has an implication on the scoring system as well as on the category used to establish the cut-off point to calculate the prevalence of good or bad self-perceived health to be applied to Health Expectancy calculations.

7. Population categories

In order to provide good estimates of the health status of a population, this instrument should be administered to a general population of all ages. While most national health interview surveys target adults, generally those of age 16 and older, some surveys also obtain information for those under 16, usually with a parent or proxy answering on behalf of the child. As the health status of the proxy respondent may influence their responses on the health of the child, it has been suggested that the proxy respondent also be questioned about his or her own health (Rajmil, 1998). It should also be noted that residential status, e.g. institutionalised or non-institutionalised should be given special consideration, as those living in an institutionalised setting often have existing health problems and, therefore, lower self-perceived health which may confound results if not accounted for.

8. Health expectancies

The instrument permits the calculation of **health expectancy in good perceived health** according to Sullivan's method. As several categories of responses often have to be collapsed in order to provide prevalence at the population level of the two main states: good or bad health, it is important to consider the cut-off points.

Self-perceived health has been used in health expectancy calculations in several countries including the United States, Australia and throughout Europe, including the Netherlands, Denmark, Sweden, Finland, Spain and the UK to name only a few (REVES, 1998).

Section II. Background

I. History of the instrument

1. Reference instrument

It appears that the first published article referring to self-perceived health (SPH) was by Heyman & Jeffers (1963), in which the authors asked American adults to answer the question,

"How would you rate your health at the present time?"
Excellent - Excellent for my age – Good - Good for my age – Fair - Fair for my age – Poor - Very Poor

Mossey & Shapiro (1982) found, again in a US study, a significant correlation between SPH and mortality over the next six years. SPH showed, in fact, a better correlation with mortality than did 'objective health' based on health service use and self-reported illness. Similarly, Kaplan & Camacho (1983) found that mortality was 2-3 times greater for people who reported their health as poor than for those who rated their health as excellent.

Since then, a series of longitudinal studies have been undertaken, both in the USA and Europe, although nearly all of these have been conducted among older respondents ($\geq$60 years). In a review of 27 studies, Idler & Benyamini (1997) confirmed the strong relationship between SPH and mortality, which appeared to be independent of other factors (e.g. chronic illness, level of physical functioning, use of health services, education, income, smoking, social network) and to be stronger for men than for women.

Fewer studies have investigated the relationship between SPH and morbidity and most of these have been cross-sectional rather than longitudinal studies. Kristensen et al. (1998) reviewed the literature and concluded that there were four main factors showing significant correlation with SPH: physical symptoms, chronic illness, functional ability and psychological symptoms. SPH has also been shown to be important in aspects of adjustment to major illness (Hunt et al., 1980) and associated with personality characteristics (e.g. neuroticism as measured with Eysenck Personality Inventory, Blaxter, 1990) and use of health services (Goldstein et al., 1984). SPH has been found to have predictive value for decline in functional ability among the elderly (Idler & Kasl, 1995) and among the general population (Ferraro et al., 1997).

With respect to socio-demographic and lifestyle variables, Kind et al. (1998) found that the main variables influencing SPH (using age as a covariate) were education (significantly higher EuroQol visual analogue scale (VAS) scores for those with higher or further education than those who received no further education after school), employment (higher VAS scores for those in work or studying compared to those unemployed) and smoking behaviour (higher VAS scores for non-smokers than smokers). Housing tenure, marital status and social class did not appear to influence SPH. Kristensen et al. (1998) concluded similarly that longer education and being in work were correlated with better SPH. In her Health & Lifestyle survey, Blaxter (1990) asked respondents to assess their own health as 'excellent, good, fair or poor, compared with someone of your own age'. Steep and systematic differences in SPH were found when comparing different social groups. Thus, those in lower social classes, single parents, unemployed and those living in inner cities or industrial areas were all more likely than their peers to give a lower evaluation of SPH.

2. Measurement of self-perceived health

Despite the apparent correlation of SPH with mortality and with aspects of morbidity, the measurement of SPH has been criticised (Bowling, 1991; McDowell & Newell, 1987). This is on the grounds that it provides no information about why people rate themselves as being in good or poor health, that single items cannot capture the complexity of a theme that is generally argued to be multidimensional and that only a limited number of response choices are provided.

There have been various attempts to investigate what people are actually answering when they respond to a global question on perceived health. Blaxter (1990) found that 71% of her British respondents defined their health as at least good. This did not necessarily exclude disease or mean that the respondent was free from symptoms of illness. Indeed, many disabled and/or elderly people insisted on calling their health excellent, even when this seemed optimistic. They meant 'is excellent, considering my advanced years' or 'despite my disability'. She also identified a preference among the public to define one's own health as good if at all possible. Blaxter went further into how people defined good and

poor health and suggested that the use of different concepts of health was associated with defining one's own health as good/excellent or fair/poor. Those who thought their own health was good were more likely to use the concept of 'never ill, not diseased' and, especially among men, health as 'fitness', e.g. 'I am not as fit as I should be, therefore, even if I have no illness, I am not healthy.' Van Dalen et al. (1994) found that the biomedical dimension was dominant in defining both good and poor health and that there were few significant differences in definitions of health according to socio-demographic variables. Positive health was related to being fit, energetic and 'feeling on top of the world', while poor health was not being able to do daily activities and tasks and feeling poorly.

Although we are primarily interested in a single-item measure of SPH, mention must also be made of more complex, multi-item measures. The Health Perceptions Questionnaire (HPQ, Davies & Ware 1981), the Short Form–36 (SF-36, Ware & Sherbourne, 1992) and the European Quality of Life Scale (EuroQol, McDowell & Newell, 1996) are three examples. They are by no means the only examples, but they are generally accepted as three of the more well known instruments. The HPQ consists of 29 items, of which 22 are used to calculate a General Health Rating Index. In addition, six dimension scores can be calculated (current health, prior health, health outlook, resistance to illness, health worry/concern, and sickness orientation). It was designed as a measure of SPH for use in the evaluation of medical care and assessment of population health status. The Short Form–36 covers eight sub-scales, one of which is general health perception (consisting of five questions). The instrument itself is widely used as a measure of health status and there is increasing evidence of the different sub-scales' validity and reliability (Brazier et al., 1992; Jenkinson et al., 1995; McHorney et al., 1994). The EuroQol covers five dimensions of health. It is a general scale intended to form one component of a measurement battery supplemented, for example, by disease specific questions.

II. Measuring self-perceived health in Europe

1. Census of instruments to measure self-perceived health in the European Health surveys

The surveys examined for the purposes of this report were identified through the European Commission's "European Health Interview and Health Examination Surveys" database (European Commission, 2001). The surveys are required to be national surveys, conducted by face-to-face interview, telephone interview or a self-administered questionnaire that includes a question on SPH (see Annex 1). All types of surveys are included, whether health interview surveys, health examination surveys or similar surveys with a substantial health component.

A total of 33 European surveys containing questions on SPH were identified. However, seven surveys (CH01, DK01, IRL01, IS01, N01, UK03 & UK04) included more than one SPH question. As a result, 43 questions have been examined. No information was obtained for Greece as the country's national health survey did not include a question on SPH.

2. Population categories

All of the examined surveys are conducted at the national level and the majority are general population surveys, with questions on SPH included amongst other variables or as a special module. Most surveys target adults, generally those 16 years of age and older. A few surveys, however, also obtain information for those under 16 and this is done with a parent or guardian answering on behalf of the child. While the majority of the surveys have no upper age restriction, some do, and it ranges in age from 64 to 84 years. Generally surveys are directed at those persons living in private (non-institutional) households, although a few surveys have included people living in institutions as well. Sample sizes vary from 1500 to 230,000. The majority of surveys are undertaken on a regular basis, ranging from annually to every 10 years.

3. Formulation of question measuring self-perceived health[3]

While a question measuring the self-perception of health is one of the most commonly used in health interview surveys, there has been little consensus on just how the question and response categories should be worded and whether or not a reference to age or time should be included. A closer examination of the European health surveys serves to illustrate this fact.

Three surveys (F01, F08 & UK03) use an age-related format to measure SPH (see Annex 2). These questions ask respondents to make a comparative judgement of their own health with others of the same or similar age.

Seventeen surveys (B01, CH01, D02, D05, DKOI, E01, FIN01, FIN04, FIN05, F07, INT03, IRL01, IS01, N01, UK01, UK03 and UK04) are time limited, as they include a reference to time in their question to measure SPH (see Annex 3). In the majority of these surveys, respondents are asked about their 'present' or 'current' state of health.

Twenty surveys (B01, D05, DK01, E04, F03, FIN02, I02, INT01, INT02, IRL01, IRL02, IS01, L01, N01, P01, S01, UK02, UK05, UK09, UK10) use an absolute format to measure SPH (see Annex 4). In an absolute format respondents are not specifically asked to compare their health with others of the same age or with their own previous or future health state. While this format corresponds with WHO's recommendation of omitting reference to either an age or time comparison, the questions vary significantly with regards to specific wording and the number and type of response categories.

Even among the absolute format questions, few of the health surveys have worded the question on SPH in exactly the same way. Nine surveys correspond with the recommendation of the WHO/CBS, namely B01, INT01, INT02, IRL02, S01, UK02, UK05, UK09 and UK10. Differences in wording among the absolute format questions appear according to:

- What respondents are asked to do with respect to SPH, e.g. six different verbs are used: perceive (1 time), say (4 times), rate (1 time), indicate (1 time), find (1 time), and feel (1 time).

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[3] It should be noted that the translation of questions and responses from their original language into English was not undertaken by the authors. The questions are taken directly from the report on "Coverage of Health Topic by Surveys in the European Union" (Hupkins, 1997).

- What respondents are asked to rate, e.g. respondents are asked to rate: state of health (4 times), general health (1 time), mental well-being (1 time), health (5 times), health status (1 time) and health in general (9 times).

- Use of a generalizing word, e.g. in general (5 times), generally speaking (1 time) and on the whole (1 time).

In addition to the specific wording of the questions, major differences also appear in the response categories. Ten surveys use five response categories (i.e. very good, good, fair, bad, very bad) that are comparable with the WHO recommendation. Seventeen surveys also include five response categories, but the wording of these categories does not correspond with the recommendation. There are variations in the distribution of positive, neutral and negative response categories. So, although a number of surveys include the same number of response categories, slight deviations in the wording of the responses makes it impossible to compare results.

4. Language variations

Idler & Benyamini (1997) concluded that the relationship between SPH and mortality is relatively insensitive to language variations. The pattern of answers to a question on SPH can differ considerably, however, between cultures and countries (Eurostat, 1997; WHO, 1997). Angel & Guarnaccia (1989) interviewed Mexican-Americans living in the US using either Spanish or English and found striking differences between the two language interviews: while 48% of the Mexican-Americans interviewed in English assessed their own health as 'excellent' or 'very good', only 15% of those interviewed in Spanish did so. It was suggested that while these results may reflect the effect of acculturation, they may also be due to a different use and interpretation of words describing health.

Responses to the question on SPH in a Eurostat survey (Eurostat, 1997) tend to fall along a north-south gradient, with a greater percentage of respondents in the countries of northern Europe considering themselves to be in good health compared to their southern counterparts. The negative responses 'bad' and 'very bad' to the perceived health question are most frequent in Portugal, followed by Spain and Italy. 53% of the (adult) Danish respondents reported 'very good' health compared to only 8% of the Portuguese respondents. In a similar study, Appels et al. (1996) used a standard SPH question among both Lithuanians and Dutch men and reported that 51% of the Dutch men considered themselves to be in good health compared to only 11% of the Lithuanian men. It is uncertain to what extent these findings reflect linguistic differences, despite careful translation, or actual health or health perception differences.

III. Essential characteristics of a self-perceived health measurement instrument

1. Reliability

Reliability refers to the extent to which the same results are consistently obtained when an indicator is administered multiple times in different circumstances. Compared to the wide use of the SPH indicator and the large number of methodological studies on it, surprisingly few studies have examined the test-retest reliability of SPH. The results of a Finnish study (Martikainen et al., 1996) suggest good reliability, both in terms of overall agreement and in terms of kappa values. More than 85 percent of the respondents gave similar answers in the initial interviews and in the re-interviews. The weighted kappa values varied between 0.59 and 0.65.

Lundberg & Manderbacka (1996) reported test–retest reliability of SPH from two Swedish studies, with intervals of 22 days and 4 weeks between the first and second interview, respectively. Reliability of SPH was as good or even better than most of the more specific health questions, with kappa values of 0.6-0.7.

2. Validity

There has been little formal evaluation of the validity of the SPH measurement. Most studies have centred on its relationship with mortality and, to a lesser extent, morbidity. The results on predictive validity of SPH, and its subsequent ability to predict outcomes such as mortality or disability, suggest that the indicator is comprehensive measure of health. An association between SPH and subsequent mortality was first found in the 1970s (LaRue et al., 1979; Singer et al., 1976). Since then, similar results have been reported in several studies. In a recent review, Idler and Benyamini (1997) summarise studies from several countries (Europe, Canada and the US). In 23 of these studies, a consistent and clear association was found: SPH predicted mortality even when known health risk factors had been controlled for. The consistency of findings suggests that SPH is an effective summary of the respondents' health regardless of whether it has an independent effect on mortality or not (Manderbacka, 1998).

SPH has also been found to have predictive value for decline of functional ability among the elderly (Idler & Kasl, 1995) and among the general population (Ferraro et al., 1997). Wilcox et al. (1996) found that SPH six weeks after a major medical event predicted disability after six months even after controlling for the severity of the event. Blank and Diderichsen (1996) found that SPH had predictive value for self-reported long-standing illness in a seven-year follow-up.

SPH has been compared with more complex, multi-item summary measures of general health suggesting concurrent validity. Rowan (1994) summarises results from these studies and concludes that SPH provides information that is, at the very least, consistent with more complex measures of general health assessment. Manderbacka et al. (1998) found that SPH was a reliable indicator of overall health and showed an unambiguous association with ill health and its functional consequences.

3. Scoring

Category labels, such as those used in the proposed instrument to measure SPH, are generally assumed to generate ordinal data since, although the responses are rank-ordered, the distance between categories is unknown and may be unequal. We can never be sure that distance between 'good and 'very good' is the same as between 'bad' and 'very bad'.

The Delighted-Terrible Faces Scale (Andrews & Withey, 1976) does not use descriptive terms and therefore has a stronger claim to interval level scaling. Ladder scales and visual analogue scales also achieve interval level measurement since each point on ladder can be assumed to be equidistant from its neighbours. The use of diagrams or symbols (such as a ladder or a series of faces) may be simpler to apply than a series of worded categories and may provide a more direct representation of the feelings involved. The diagrammatic scales can also be used with children and others who would have difficulty completing a worded questionnaire. In addition, such scales would go far in addressing the issues surrounding any translation and interpretation of worded response categories.

Andrews & Withey report that a survey of wellbeing by Campbell at al. (1976) reported that one half to two-thirds of respondents selected one of the two most satisfied categories presented to them. They felt that this concentration at the 'satisfied' end of the scale posed statistical and conceptual problems. Apart from the original work by Andrew & Withey, which reported good reliability and validity, there have been few published studies reporting usage of this scale.

There have been relatively few studies on the scaling procedures used in measures of SPH and only one could be found referring specifically to the single-item question on SPH (Badia, 1999). Badia compared a five-point category rating scale (excellent, very good, good, fair and poor) to a VAS (0-100) and found considerable overlap between the three categories at the upper end of the scale (good, very good and excellent). This suggests that additional categories should be introduced in order to investigate further the effect.

4. Cut-off points

In order to calculate health expectancy (HE) with the proposed SPH question, the cut-off point is an important issue to be considered. Usually several categories of responses have to be collapsed to provide the prevalence at the population level of the two main states: good or bad health. Depending on the categories used to confirm the two states, the results could be very different as shown by the following example. Using the same health interview survey and mortality data, two studies in Spain calculated two very different health expectancies both for men and women. One of the studies included 'fair' with the responses 'good' and 'very good' and calculated a HE of 67.7 years for men and 72.2 years for women. The other study, however, included 'fair' with 'bad' and 'very bad' and calculated a HE of 51.4 years for women and 54.0 years for men (Gispert, 1997).

5. Response categories

An illustration of the importance of comparable response categories can be found in the Danish Health and Morbidity Survey (1994). The survey consists of both an interview-administered questionnaire and a self-administered questionnaire, both of which have questions on SPH. In the interview-administered format, respondents are asked to rate their present state of health in general as 'really good, good, fair, bad, or very bad'. In the self-administered version (where the question of SPH is the same one used in the SF-36), respondents are asked whether they perceive their health in general as 'excellent, very good, good, fair, or poor'. Both questionnaires consist of five response categories, but there are slight differences in the wording that make accurate comparisons difficult. In the former, 39.4 % of respondents rate their health at the upper-most end of the scale (e.g. 'really good'), whereas in the latter, 11.5 % do the same ('excellent'). In the interview-administered version 15.2 % rate their health as 'fair' compared to 8.8 % in the self-administered version. While these results may reflect the method of interviewing (e.g. interview-administered or self-administered), they may also be due to the different use of categories.

IV Quality assessment

It is essential to acknowledge that self-perceived health is an assessment or valuation and not simply a state or condition. Conceptually, self-perceived health is a special construction because it, by definition, does not have an external validation criterion. Furthermore, many different factors not particularly and direct health related can influence the individual's perception of health.

Several studies have shown that there are differences between how people from different cultures and countries rate their own health. In some cases, the difference may be due to the fact that there exists real variation between the cultures and countries being compared, while in other cases, it may be the result of methodological differences. The following procedures are proposed continuous quality assessment when measurement of perceived health and other health perceptions are used cross nationally. The elements are described shortly below. The procedure has 3 main elements: careful translation, qualitative cognitive testing, and psychometric and other statistical methods.

1. Systematic translation

First of all a necessary condition for crosslingual application is a valid translation into all the languages. A standard procedure has been recommended and tested according to chapter 5 (Limitations in usual activities, a global approach).

2. Qualitative cognitive testing

Cognitive testing, which bases assessments on feedback from qualitative interviews with people who are asked to respond to the indicator, will be discussed here. After development and subsequent translation, it is necessary to determine and describe how respondents within a particular country or culture understand the indicator. Qualitative testing provides a format in which interviewers disclose what respondents' mean i.e. by good health. This is particularly important in the case of validating cross-national indicators, where there is obvious potential for misunderstanding. Asking respondents to explain their understanding of a particular question or on what basis they arrive at an answer or give an answer, will clarify the rationale and reasoning behind the respondents replies (Mallinson 2002). This information will then be used to create a sort of 'profile' for each country, based on 'typical' responses and perceptions of what constitutes good or bad self-perceived health.

Below are given some examples on how to apply cognitive testing. Basis is the respondent's answer to the question: "How do you perceive your health in general?" A suggestion for a semi-structured interview guide is given.

Interview 1.
The respondent has chosen the response category: **Very good**

Interviewer (I): How come you have reached the conclusion that your health is really good?

Respondent (R): It is because I always feel very fit and I am seldom, very, very seldom ill. I feel that I can handle all the things that I want to. I am not limited in any ways in what I do.

Interview 2.
The respondent has chosen the response category: **Good**

I: And when you reach the conclusion that your health is good, what then do you think about, what makes you say that your health is good?

R: Then I think about the fact, that I am generally always well, I am very seldom ill. That is probably what I associate with being in good health, that one is seldom ill.

Interview 3.
The respondent has chosen the response category: **Good**

I: Why have you chosen to tick off good?

R: Because my health situation is not totally great, but a little above average when I compare myself with those of my age.

I: What does it mean to be in good health?

R: You don't have any physical disabilities and not any bigger mental problems.

Interview 4.
The respondent has chosen the response category: **Good.**

I: Why have you chosen to tick off good?

R: Because considering my age, I think I am doing really well.

I: What does it mean to do well?

R: That you are fit, happy, get up to do your work and manage your work. And that you think you are fairly in control of things. That you have energy to take care of your family and the duties you have - as in my case, where I am both mom, grandmother and wife.

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3. Psychometric and statistical analysis

By applying statistical techniques like factor analysis, correspondence analysis, item response theory, or graphical models, meaningful comparisons of existing and proposed indicators across different populations can be obtained hereby allowing quality assessment. These four methods all seek to determine the inter-relationship between single items or variables and identifying dimensionality of data, i.e. the psychometric properties of self-reported items.

Factor analysis

An attempt to improve and facilitate the comparability of severities and distribution of health across populations based on different data collections, is seen in a recent WHO technical report (Sadana et al. 2000). The study utilized confirmatory factor analysis and estimated factor scores on two different surveys from Denmark both conducted in 1994: the European Community Household Panel (ECHP) and the Danish Health and Morbidity Survey (DHMS), to test convergent validity. From the ECHP survey was applied four questions addressing health status, whereas in the DHMS was applied 36 items (SF-36) for current health status. This approach showed an appropriate method to compare health and assess construct validity of the information content on health status from different surveys. The WHO results provided evidence that it is possible to compare the component of health from different surveys conducted in the same population.

Correspondence analysis

The purpose of the correspondence analysis is similar to that of the factor analysis. It is an exploratory multivariate technique that enables a visual interpretation of associations between variables and dimensions, and can provide a method for examining the interdependence between various measures of disability and thereby forming the basis for constructing a scale of health on specific items including health perceptions assessed to lie on the same dimension. (Sharma 1996).

IRT

Item response theory (IRT) is psychometric techniques with the objective of developing and testing models that describe response profiles (trace lines, latent traits) for single items in surveys. The technique for estimating these are the so-called logistic item response models, among which the Rasch model is the most well-known. The technique has been applied in a HMP project (van Buuren et al 2001). Basis for the analysis is a thorough control of the model, concerning data's dimensionality and assessment of item characteristic stability and respondent's independence of sub-groups. These psychometric techniques make a calibration of different surveys to the same scale feasible. The strength of the method is the ability to test a hypothesis of a specific latent trait or dimension and whether different subgroups have different response patterns (differential item function, DIF). The weakness is in the exploration of which dimensions or traits that are existing in a given set of items (Streiner & Norman 1995).

Graphical models

Graphical models are in the family of log-linear models for multi-dimensional contingency tables. They are useful to apply when focus is on understanding the structure of data from surveys studying complex interactions and phenomena. The graphical model is defined by a set of assumptions about conditional dependency of certain variables given the other variables. Each conditional distribution (a block of variables) is defined in a directional graph with arrows to illustrate the relationship between variables at different levels (blocks). The method has been applied on data from the Danish Health interview survey showing that disability is affected by various other variables that are not directly health related (such as physical and psychosocial working conditions) (Thoning 2000). When analysing data from different cultures and countries differences or similarities in these patterns will indicate different or similar dimensions in the disability indicators analysed.

V Conclusion

Over the last 40 years there has been increasing interest in the measurement of health from a personal point of view. In recognition of the need to elicit an individual's assessment of his/her health, the notion and measurement of self-perceived health has become popular. As a result, a question on the self-perception of health status, in general terms, is one of the most commonly used in health interview surveys. While SPH has been repeatedly demonstrated to be a

reliable and valid measure of health, differences in structure and wording of both questions and response categories have severely limited the international comparability of SPH data. In recognition of the need for a common measurement instrument we follow the WHO recommendation and propose the following:

> **How is your health in general?**
>
> *very good – good – fair – bad - very bad*

The measurement of SPH is, by its very nature, subjective. In fact, the notion of 'perception' implies an immediate and subjective reaction rather than a detailed analysis. However, it is this very same 'subjectivity' that hampers harmonisation and limits the possibilities to make valid comparisons across countries. Europe is comprised of many countries, each with its own unique language and cultural traditions. Differences in language point to the need for a simple, single-item global question to assess SPH. However, even with agreement on the structure and wording of the SPH question, it is likely that answers will at least partly reflect cultural differences in health perception. Such differences in cultural traditions illustrate the importance of ongoing validity studies to ensure that the SPH question is being interpreted and understood in the same way. Ideally, these should include both cognitive and psychometric testing. The former approach can help to examine various interpretations of the question and response categories, while the later, which includes statistical techniques such as multivariate analysis and cluster analytical techniques could also be employed to compare the correlation between the SPH question and other relevant variables.

Although the use of a general question to measure SPH is almost universal in the countries conducting health interview surveys, the formulation of the question differs widely. In order to provide more insight into this dimension of health and in the geographical variations among countries, a set of more specific items will be proposed to complement the main question on perceived health.

The aspects to be covered by these alternative questions should be related to the topics that traditionally comprise the more general dimension of perceived health. These include physical health (including energy, vitality, etc), psychological health (positive feelings, self-esteem, etc), coping and adaptation (personal abilities), sense of coherence (how one views one's world) and external threats (the impact of social and personal life-events). These topics or similar concepts are sometimes included in several other measures of health, including the scales of health-related quality of life or psychological well-being.

Several questions have been identified in some of the best-known instruments measuring health status (i.e. psychological general well-being index, SF36, Nottingham health profile (general questions), WHOQOL-BREFF, etc.). Although most of these instruments are supported by a significant number of scientific studies, more research is required into the use of single item global measures. The priorities of further work should be to elucidate if there exists current international recommendations covering these topics, to identify the main psychometric properties and to determine the general applicability and transcultural adaptation of the measures.

Annex 1: List of European Health surveys

Survey no.	Country	Survey Title	Year	Collection method[1]	Frequency	Sample size (persons)[2]
B01	Belgium	Health interview survey	1997	FTF & SA	every 3 years	10,000
CH01	Switzerland	Swiss health survey	1997	FTF, SA & TEL	every 5 years	13,000
D02	Germany	Survey on living conditions, health and environment	1998	SA	irregular	6000
D05	Germany	German national health examination and interview survey	1998	FTF & SA	every 6-7 years	7124
DK01	Denmark	Danish health and morbidity survey	1994	FTF & SA	every 6-7 years	6,000
E01	Spain	National health survey	1999	FTF	irregular	8,600
E04	Spain	Impairments, disabilities and health status survey	1999	FTF & SA	irregular	230,000
F01	France	Health and care interview survey	1996	FTF	every 10 years	21,500
F03	France	Health and social protection survey	1998	FTF, SA & TEL	every 2 years	23,000 households
F07	France	Continuous survey on household living conditions	2000	FTF	yearly	11,000
F08	France	French survey on living conditions and aspirations	1999	FTF	yearly	2000
FIN01	Finland	Survey on health behavior	2000	SA	yearly	5000
FIN02	Finland	FinRisk 2002	1997	FTF & SA	every 5 years	11,500
FIN04	Finland	Living conditions survey_ECHP	1986	FTF	every 10 years	8650
FIN05	Finland	Finnish health care survey	1996	TEL	irregular	6000 households
I02	Italy	Aspects of daily life	1994	FTF & SA	yearly	60,000
INT01	International	Recommendations WHO-Euro	NA	NA	NA	NA
INT02	International	Eurostat, Unit E3, health and safety section	2000	FTF	yearly	NA
INT03	International	European Commission, Eurobarometer	1996	FTF	2 X year	1000
IRL01	Ireland	Survey of lifestyle. attitudes and nutrition (SLÁN)	1998	SA	every 4 years	6539
IRL02	Ireland	Living in Ireland survey	2000	FTF	yearly	10,103
IS01	Iceland	Omnibus survey	1996	TEL	irregular	1,500
L01	Luxembourg	Socio-economic panel Living in Luxembourg	1996	FTF	yearly	6605
N01	Norway	Health interview survey	1995	FTF, SA & TEL	every 3-4 years	7125
P01	Portugal	National health survey	1995/96	FTF	every 3 years	50,000
S01	Sweden	Survey on living conditions	1996	FTF	yearly	6,000
UK01	United Kingdom	General household survey	2000	FTF	continuous	20,000
UK02	United Kingdom	Health education monitoring survey	2998	FTF	irregular	5800
UK03	United Kingdom	Health and lifestyle survey	1991	FTF	every 7 years	5,352
UK04	United Kingdom	Disability survey	1996	FTF	irregular	8816
UK05	United Kingdom	Survey of psychiatric morbidity	1993/94	FTF & SA	irregular	10,108
UK09	United Kingdom	Health survey for England	1998	FTF & SA	continuous	20,000
UK10	United Kingdom	Scottish health survey	1995	FTF & SA	every 3 years	7232

[1] FTF = face to face interview
SA = self-administered questionnaire
TEL = telephone-administered questionnaire
[2] Sample size shown is for the latest survey conducted unless otherwise stated

Annex 2: Formulation of age-comparative self-perceived health questions

1. Austria - A05: Consumption of alcohol & psychoactive substances
Wenn Sie Ihren Gesundheitszustand mit anderen Leuten Ihres Alters vergleichen. Wurden Sie sagen, Ihr Gesundheitszustand ist sehr gut, gut es gut, nicht besonders gut oder gar nicht gut?
sehr gut – gut - es gut - nicht besonders gut - gar nicht gut

2. France - F01: Enquête sur la santé et les médicaux
Actuellement, compte tenu de votre âge, comment estimez-vous votre état de santé?
très bon – bon – moyen - médiocre - franchement mauvais

3. France - F06: Baromètre santé grand public
Par rapport aux personnes de votre âge, diriez-vous que votre état de santé est pas du tout satisfaisant, peu satisfaisant, plutôt satisfaisant ou très satisfaisant?
pas du tout satisfaisant - peu satisfaisant - plutôt satisfaisant - très satisfaisant

4. France - F08: Enquête conditions de vie et aspirations des Français
Par rapport aux personnes de votre âge, pensez-vous que votre état de santé est très satisfaisant, satisfaisant, peu satisfaisant, plutôt satisfaisant ou pas satisfaisant du tout?
très satisfaisant – satisfaisant - peu satisfaisant - pas satisfaisant du tout

5. United Kingdom - UK03: Health and lifestyle survey
Would you say that for someone of your age your own health is generally excellent, good, fair or poor?
excellent – good – fair – poor

Annex 3: Formulation of time limited self-perceived health questions

1. Belgium - B01: Health interview survey
Compared to one year ago, how would you rate your health in general now?
Much better than last year – somewhat better – about the same – somewhat worse – much worse

2. Switzerland - CH01: Swiss health survey
How do you feel now? (telephone)
Very well – well – fair – badly – very badly

If you compare your health now with your usual state of health, so you feel definitely better, as usual, or less well than you usually feel? (telephone)
Definitely better – as usual – less well than usual

3. Germany - D02: Survey on living conditions, health and environment
How would you describe your present state of health?
Very good - good – satisfactory – not very good - poor

4. Germany - D05: German national health examination and interview survey
Compared to one year ago, how would you perceive your health in general now?
Much better – somewhat better – about the same – somewhat worse – much worse

5. Denmark - DK01: Danish health interview survey
How do you rate your present state of health in general? (face to face)
excellent – good – fair – bad - very bad

Compared to one year ago, how would you perceive your health in general now? (self-administered)
Much better – somewhat better – about the same – somewhat worse – much worse

6. Spain - E01: National health survey
Would you say that, in the past 12 months, i.e. since the end of August 1994, your state of health had been very good, good, fair, poor or very poor?
excellent – good – fair – bad - very bad

7. France - F07: Continuous survey on household living conditions
At present, do you consider your state of health to be:
very good - good – average – moderate – poor – very poor

8. Finland - FIN01: Survey on health behaviour
What is your own assessment of your present state of health?
good – reasonably good – average – rather poor - poor

9. Finland - FIN04 Living conditions survey
Which of the following alternatives best describes your present state of health?
very good – good – moderate – poor – very poor

10. Finland – FIN05: Finnish health care survey
Is your present state of health in your own opinion?
good - fairly good – average - rather poor – poor

11. International – INT03: Eurobarometer
Over the last 12 months, would you say your health has on the whole been very good, fair, bad or very bad?
very good - good – fair - bad – very bad

12. Ireland – IRL01: Survey of lifestyle, attitudes and nutrition (SLÁN)
To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is 0.
We would like you to indicate on this scale how good or bad your own health state is today, in your opinion. Please do this by drawing a line from the box opposite to whichever point on the scale indicates how good or bad your health state is.

13. Iceland - IS01: Omnibus survey
How do you rate you physical health these days? Do you find your physical health to be good, adequate, or bad?
very good – fairly good – adequate – fairly bad – very bad

14. Norway - N01: Survey on living conditions
Compared to one year ago, how would you rate your health in general now?
much better – somewhat better – about the same – much worse

15. United Kingdom - UK01: General household survey
Over the last 12 months would you say your health has on the whole been good, fairly good, or not good?
good - fairly good - not good

16. United Kingdom - UK03: Health and lifestyle survey
a) Do you think that compared to seven years ago your health is generally?
better - worse – about the same
b) If better do you think it is
a bit better – a lot better – can't say
c) If worse do you think it is
a bit worse – a lot worse – can't say

17. United Kingdom - UK04: Disability survey
To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is 0.
We would like you to indicate on this scale how good or bad your own health state is today, in your opinion. Please do this by drawing a line from the box opposite to whichever point on the scale indicates how good or bad your health state is.

Annex 4: Formulation of absolute self-perceived health questions

1. Belgium - B01: Health interview survey
In general, would you say your health is?
very good – good – fair – bad – very bad

2. Germany - D05: German national health examination and interview survey
In general, would you say your health is:
excellent – very good – good – fair - poor

3. Denmark - DK01: Danish health and morbidity survey
How do you perceive your health in general?
excellent - very good – good – fair - bad

4. Spain E04: Impairments, disabilities and health status survey
How would you rate the state of your health generally?
very good – good – fair – poor – very poor

5. France - F03: Health and social protection survey
Can you indicate between 0 and 10, your state of health?

6. Finland – FIN02: FinRisk 97

How do you find your health status? Is it?
excellent – quite good – average – quite bad – very bad

7. Italy - I02: Aspects of daily life
How is your health in general? (give a score from 1 to 5: 1 is the worst state and 5 is the best one)

8. International – INT01: Recommendations WHO-EURO
How is your health is general?
very good – good – fair – bad – very bad

9. International – INT02: European community household panel
How is your health is general?
very good – good – fair – bad – very bad

10. Ireland – IRL01: Survey of lifestyle, attitudes and nutrition (SLÁN)
How satisfied are you with your health?
very dissatisfied – dissatisfied – neither satisfied nor dissatisfied – satisfied – very satisfied

In general, would you say your health is
excellent – very good – good – fair – poor

11. Ireland – IRL02: Living in Ireland survey
In general, how good would you say your health is? Would you say it is:
very good – good – fair – bad – very bad

12. Iceland – IS01: Omnibus survey
How is your mental well being? Do you feel good, adequate or bad?
very good – fairly good – adequate – fairly bad – very bad

13. Luxembourg - L01: Socio-economic panel living in Luxembourg
Do you feel that you enjoy?
Very good health – good health – more or less good health – poor health – very poor health

14. Norway - N01: Health interview survey
How would you describe your own general health? Would you say it is:
very good – good - neither good nor bad / average – poor - very poor

In general, will you say your health is:
excellent – very good – good – fair - poor

15. Portugal - P01: National health survey
What is your general state of health?
very good – good – reasonable – poor - very poor

16. Sweden - S01: Living conditions survey
In your opinion, how is your state of health? Is it:
very good – good – fair – bad - very bad

17. United Kingdom - UK02: Health education monitoring survey
How is your health in general? Would you say it was:
very good – good – fair – bad - very bad

18. United Kingdom - UK05: Survey of psychiatric morbidity
How is your health in general? Would you say it was:
very good – good – fair – bad - very bad

19. United Kingdom - UK09: Health survey for England
How is your health in general? Would you say it was:
very good – good – fair – bad - very bad

20. United Kingdom – UK10: The Scottish health survey
How is your health in general? Would you say it was:
very good – good – fair – bad - very bad

Chapter 7. Mental Health Consensus Meeting

Carol Jagger, Jean-Marie Robine

I. Introduction

In the past health measurement have tended to overlook the important dimension of mental health, and indeed its contribution to more physical manifestations. During Phase 1 of Euro-REVES 2 it became obvious that there were a number of groups working on mental health indicators for the European Health Monitoring Programme, either having a specific remit, or recognising the need to include mental health measures to provide a fuller coverage of health measurement. Since these groups, with different focuses and certainly different expertise may come to different recommendations on indicators, we decided that, in the interests of the European Health Monitoring Programme outcomes, that as much consensus should be achieved as possible. Thus we hosted a meeting in Montpellier in March 2001, with the purpose to come to a consensus on the choice of mental health indicators between the European project "EuroHIS" of the WHO Europe (Harmonization of Health Interview Surveys in Europe), and the different groups working on mental health indicators for the Health Monitoring Programme of the European Union (HMP Mental Health group and Euro-REVES group). The meeting was a priori restricted to indicators that require data collected through population surveys (as HIS).

2. Participants

The list of participants and the groups they represented were:

Henriette Chamouillet (EU Health Monitoring Programme)

Roberta Crialesi   (EuroHIS – Chronic Morbidity Indicators)

Carol Jagger   (HMP – Disability-free life expectancies)

Vivianne Kovess   (HMP – Mental Health Group)

Howard Melzer   (EuroHIS – Mental health indicators)

Karen Ritchie   (HMP – Mental health expectancies)

Jean-Marie Robine   (HMP and EuroHIS –Health expectancy indicators)

3. Format and outcomes of the meeting

The meeting brought together three main groups working in the field of mental health indicators: EuroHIS, the HMP Mental Health Group and the Euro-REVES Mental Health Group. Each of the three groups presented the aims of their project and the recommendation of instruments made to date. The consensus stage then began with a discussion on whether there was agreement for the domains that should be covered by mental health indicators within EuroHIS, HMP Mental Health and Euro-REVES. After this a list of the previous recommendations to date of the groups (Table 1) was used as a basis for reaching a consensus on instruments.

Consensus decisions made by the meeting are shown below with the final list of instruments in Table 2:

- The HMP dimensions of positive and negative mental health were agreed with negative mental health containing diagnoses, sub syndromes and psychological distress.

- Subject to agreement of the EuroHIS group, it was agreed to recommend the CIDI-SF (Wittchen et al., 1995) on depression and anxiety with the time interval changed to 12 months. This would be sufficient also for the needs of the Euro-REVES group. (Post meeting note: EuroHIS agreed to the change).

- It was agreed to recommend the MHI-5 and the CIDI-SF (depression and generalised anxiety as a minimum but it would be better to include items covering OCD, panic disorder and phobias as well).

- If the CIDI-SF was considered too long the meeting recommended that the GHQ-12 should be used.

- The meeting agreed that the MHI-5 should not be collected alone.

- These decisions then meant that there was consensus on the recommendation of MHI-5 for psychological distress.

- The meeting agreed that a minimum level of alcohol consumption needs determining before the CAGE questions are applicable and this level may be problematic between countries.

- The HMP group recommended drug-related death rate as the indicator for drug-dependency. EuroHIS questioned the reliability of data collected on this topic through health interview surveys. No further decisions were made.

- There was agreement on a question covering attempted suicide during the last 12 months.

- It was agreed that the HMP would consider instruments for cognitive function and sleep problems subject to receiving information on IQCODE and that this could be piloted.

Table 1: Comparison of health domains and measures between EuroHIS, HMP Mental Health Group, Euro-REVES

Domain	EuroHIS	HMP Mental Health	Euro-REVES
Psychological distress	MHI-5	MHI-5	GHQ-12
Positive Mental Health/Psychological wellbeing	WHOQUOL positive feelings	SF-36 energy/vitality + Andrews item on happiness	
Anxiety and depression	CIDI-screen	CIDI- SF (Kessler)	
Alcohol and drug dependency	CAGE	CAGE	
Suicide attempt	4 items covering suicide thoughts as well	1 item	
Dementia/Alzheimer			
Cognitive functioning/cognitive deficit	2 items from StatCan on memory and concentration		✓
Sleep problems	WHO Health and responsiveness survey		
Role limitation	SF-36 role limitation	SF-36 role limitation	
Social functioning	3-item Oslo scale	3-item Oslo scale	
Social isolation		4 items from StatCan	
Chronic stress		✓	
Life events		LTE	
Self-mastery		Perlin 5-item	
Optimism		LOT-R	

✓Measure not agreed

Table 2: Comparison of health domains and measures between EuroHIS, HMP Mental Health Group, ECHI project, Euro-REVES post meeting

Domain	EuroHIS	HMP Mental Health	Euro-REVES
Psychological distress	MHI-5 if also using CIDI-SF otherwise GHQ-12		
Positive Mental Health/Psychological wellbeing	SF-36 energy/vitality + Andrews item on happiness		
Anxiety and depression	CIDI- SF (Kessler)		
Alcohol and drug dependency	CAGE		
Suicide attempt	1 item although EuroHIS would have extra items covering suicide thoughts		
Dementia/Alzheimer			
Cognitive functioning/cognitive deficit	IQCODE		
Sleep problems	WHO Health and responsiveness survey		
Role limitation	SF-36 role limitation		
Social functioning	3-item Oslo scale		
Social isolation		4 items from StatCan	
Chronic stress		✓	
Life events		LTE	
Self-mastery		Perlin 5-item	
Optimism		LOT-R	

✓Measure not agreed

Part 3: Methodology

Chapter 8. Decomposition of differences or changes in health expectancy

Wilma J. Nusselder, Caspar W.N. Looman

I. Introduction

Health expectancy, being an extension of life expectancy, is increasingly being used to monitor population health, as it takes into account not only the length of life (adding years to life), but also the healthfulness of life (adding life to years). Once comparable data have become available periodically from the Health Monitoring System, an important application of health expectancies for the European Union and its Member States is making comparisons of population health status between (sub)populations and over time. However, after having made these comparisons, it is important to obtain insight into the contribution of specific diseases to differences or changes in health expectancies. Such information may assist policy makers in the evaluation of past trends or current differences, may facilitate the definition of priorities and objectives in the field of public health and the assessment of targeted health priorities.

Decomposition techniques have been developed in mortality research by Arriaga (Arriaga 1984; Arriaga 1989), Pressat (Pressat 1985), Pollard (Pollard 1988) and Andreev (Shkolnikov et al. 2001) to indicate the contribution of specific diseases (or age groups) to the observed differences in life expectancy. These tools have been used to explain differences in life expectancy between sexes (Bah 1998; Trovato and Lalu 1998)**,** races (Kochanek et al. 1994), regions (Bah 1998; Velkova et al. 1997) and over time (Conti et al. 1999; Tas 1994). However, despite their increasing relevance, decomposition techniques are not yet available for health expectancy.

Within Euro-REVES, we developed a life-table method to decompose differences in health expectancy between (sub) populations or over time into the contribution of specific diseases, similar to decomposition of differences in life expectancy. In this User's Guide, we focus on the Principles of the method, the data required and we give an illustration of its use. Detailed information on the methods is given in the appendices. For the ease of explanation, we describe the technique in terms of change in life expectancy with and without disability, but the procedure is identical for differences between (sub) populations and for other definitions of health expectancy. Since internationally comparable data on health expectancy are not yet available, we illustrate the method by decomposing male-female differences in health expectancy for the Netherlands. In the future, similar analyses can be performed to compare health expectancies between Member States (e.g. France and Italy) or over time (e.g. France: 1980/84 and 1990/94).

II. Principles of the method to decompose differences in health expectancies

The technique to decompose changes in health expectancy is based on the Sullivan method (see Chapter X). The decomposition technique is an extension of the Arriaga method (Arriaga 1984; Arriaga 1989), which relates changes in life expectancy to changes in underlying age-and cause-specific mortality rates. Whereas changes in life expectancy are caused solely by changes in mortality, changes in health expectancy might be the result of changes in mortality and/or in disability. Therefore, the decomposition of changes in health expectancy is more complex. We first describe the Principles for the decomposition of the change in health expectancy into the contribution of mortality changes and disability changes, leaving out of consideration different causes of death and disability. Next, we explain how causes of death and disability are incorporated in the decomposition technique. Finally, we describe how disability data by cause can be estimated from individual data on disability and disease when information on the cause of disability is not available.

1. Decomposition of changes in health expectancy into the mortality and disability effect

Starting point is the Sullivan method for the calculation of health expectancy at age a, with an initial cohort of 1 ($l_{a}=1$). In each age group*,* the number of person-years with disability $_{i}\pi_{x}\,_{i}L_{x}$ is the product of the number of person-years lived ($_{i}L_{x}$) and the proportion with disability ($_{i}\pi_{x}$). A change in $_{i}\pi_{x}\,_{i}L_{x}$ occurs if the number of person-years changes (due to mortality changes) and/or if the proportion with disability ($_{i}\pi_{x}$) changes. Thus, a change in the number of person years with disability is the sum of two components. The first component is the change in the number of person years with disability due a change in the number of person years lived (ceteris paribus). Since any change in the number of person years lived is caused by a change in mortality, this is termed the

'mortality effect'. The mortality effect is the change in the number of person years with disability that would occur in case only mortality rates would change. A negative mortality effect for instance, reflects a decline in the number of person years lived with disability due to an increase in the mortality. The second component, termed the 'disability effect' is the change in the number of person-years with disability due to a change in the proportion with disability (ceteris paribus). The disability effect is the change in the number of person-years with disability that would occur if only the proportion with disability would change. A negative disability effect reflects a decline in the proportion disabled. Summation of mortality effect and disability effect across age gives the total mortality and disability effect, respectively. For the decomposition of the change in the number of years without disability, the approach is similar. The only difference is that the proportion without disability is used.

2. Decomposition of mortality and disability effect by cause

The mortality effect is decomposed into the contribution of specific causes of death by using an adjustment of the Arriaga method. First the change in the number of person years is decomposed into the contribution of different age groups and next the contribution of these age groups is further decomposed by cause. The main difference is that for decomposition of changes in life expectancy (Arriaga method), it is not necessary to know in which age group person-years are added or removed, whereas for the decomposition of changes in health expectancy (based on the Sullivan method) it is. This relates to the fact that in the Sullivan method the proportion with disability in a specific age group is multiplied by the number of person-years lived in that age group. Therefore, whereas the Arriaga method relates changes in age-specific central mortality rates to changes in the total number of years lived (T_x) we relate these changes to the change in the number of persons years lived in a certain age *group x, x+i* ($_iL_x$). To avoid confusion between the age group where the mortality changes originate and where the person years are added to or removed from, we distinguish between the age of origin (of the mortality change) and the age at destination (of the person years added or removed). The age of origin should be used for decomposition by age (not presented in this Chapter). A second difference with the original Arriaga method is that we included an additional step in order to avoid that the results of the decomposition depend on whether the first or second population is used as reference. Similar to the method by Andreev and Pressat, we averaged the components of the difference between population 1 and 2 (with 2 as baseline) with the respective components of the difference between population 2 and 1 (with 1 as baseline) (Shkolnikov et al. 2001).

Formulas of the decomposition of the mortality effect are given in appendix 1.

In order to decompose the disability effect by cause of disability, the change in the proportion with disability needs to be attributed to different causes of disability. Based on disability data by cause, the change in the disability proportion by cause is simply obtained by subtraction of the cause-specific proportion at time *t* from that at time *t+n*.

Summation of the mortality and disability effect by cause gives the decomposition of the total change in health expectancy by cause.

3. Reconstruction of disability by cause data

Often disability data by cause, required for the decomposition of the disability effect by cause, are not available and may need to be reconstructed from cross-sectional data on diseases and disability in a health interview survey. This reconstruction should take into account that in the survey data: (1) persons *without* a (specified) disease have disability (i.e. there is a risk of disability, irrespective of diseases people report), (2) some persons have *more* diseases (co-morbidity) and (3) that disability is used as a dichotomous outcome in the Sullivan method, indicating its presence or absence. Although the Population Attributable Risks (PARs, derived from the data directly or from logistic regression) can be used for conclusions about the consequences of elimination of a single disease from the current population, they cannot be used for conclusions regarding the number of disabled persons in the current population due to the disease. The main reason is that the PARs of different diseases are not additive: the PAR of disease A plus the PAR of disease B is not unequal to the PAR of disease A or B.

For the reconstruction of the number of persons disabled due to a disease, competition between causes (i.e censoring) should be taken into account for a situation where persons can be disabled from more causes (i.e. background risk and one or more reported diseases). We developed a method to estimate the part of the proportion of disability in the population (i.e. probability of disability as disability is present or absent) attributable to a specific disease, taking into account competing causes. This method uses information on the probabilities of disability in different disease groups (e.g. probability of disability for a group without any disease and probability of disability for a group with heart disease). The basic principle of the method is that a hazard (i.e., rate) transformation is used to convert the proportion of disability into a hazard of disability. This allows the method to make use of the additive property of hazards, which brings along that the sum of all cause-specific hazards of disability for causes that are present and the background hazard equals the total hazard of disability. Transforming the cause-specific hazards back to probabilities gives cause-specific probabilities adjusted for competing causes. Summation of the cause-specific probabilities of disability across causes gives the total probability of disability. The calculation and interpretation of these cause-specific probabilities is similar to the crude cause-specific probabilities commonly used in mortality research (Manton and Stallard 1984).

The result of the reconstruction is that disability in persons without any reported disease is attributed to background, disability of persons with *one* disease partly to 'background' and partly to the disease, and disability in persons with *two (or more)* diseases is partly attributed to 'background', partly to each disease and partly to the combination of the two diseases (seen as a separate cause if co-morbidity is included in the model).

Smoothed cause-specific disability probabilities by age can be estimated with a regression technique using the GLIM software packet. The details of the attribution method and of the smoothing are given in appendix 2.

III. Data required

For the decomposition technique the following data is required:

- Sullivan life table, or data on the population and the number of deaths by age and sex, and age-specific proportion with disability

- Data on the number of deaths by age, sex and underlying cause of death

- Data on the number of disabled persons by age, sex and disease, or individual data on age, sex, the presence of disability and diseases

- in case the institutionalized population is not included in the health interview survey, separate data on the number of disabled persons in institutions by age, sex, and disease (or individual data on age, sex, the presence of disability and diseases to estimate disability by cause) are needed.

IV. Specialized calculation unit

We propose to do the decomposition of health expectancy differences between member states and changes over time in individual member states at a specialized central unit for the European Union. A central unit has several advantages above doing the calculation in each member state. Firstly, the decomposition method, in particular the part to attribute disability to disease requires specialized software (GLIM), which might not be available at each statistical bureau. Secondly, the attribution tool might be too complex to be used routinely at each statistical office. Thirdly, comparisons between member status would require that besides the data of one own country, one requires data of the country(ies) of comparison. That is, a moving of data between countries. Fourthly, doing the calculation at a central place increases the comparability of the outcomes.

V. Illustration of the decomposition of sex differences in health expectancy

We illustrate the decomposition method by comparing male-female health expectancies in 1990-94 using Dutch data from the Health Interview Survey.

1. Data

a) Mortality

Data on the population and the number of deaths by age, sex and underlying cause of death for the period 1990-1994 were obtained from Statistics Netherlands (Statistics Netherlands 1995; Statistics Netherlands annually). Causes of death were classified according to the ninth revision of the International Classification of Diseases, Injuries and Causes of Death (ICD-9). The selected (underlying) causes of death are summarized in Table 1. Crude mortality rates in three broad age groups are presented for each cause in Table 2.

Table 1   Disease Clusters and Related Chronic Diseases and Causes of Death

Disease Clusters	Health Interview Survey[a]	Cause of Death[b]
Chronic Obstructive Lung Disease	Chronic bronchitis; emphysema; asthma	490-496
Heart disease	Heart complaints, cardiac failure	393-398; 410-414; 415-417; 420-429
Stroke	Stroke	430-438
Diabetes mellitus	Diabetes mellitus	250
Back complaints	Backache longer than 3 months, slipped disk	720-724
Arthritis	rheumatism, arthritis; arthrosis	710-716, 719; 725-729
Cancer	Cancer	140-239
Other diseases	all other chronic diseases	all other

[a] Conducted by Statistics Netherlands, 1990-1994.

[b] Based on codes taken from the *International Classification of Disease*, 9th edition.

b) Disability

Cross-sectional data on long-term disability and chronic diseases were obtained from the Netherlands Health Interview Survey 1990-1994 (Statistics Netherlands 1994). This health interview survey is a random sample among the non-institutionalized population (N=32936). This study used a subsample of 26541 respondents aged 16 and over, because for younger ages no information on long-term disability was collected. Long-term disability was measured using the Organization for Economic Co-operation and Development (OECD) indicator. This indicator consists of 16 items that refer to a person's ability to carry out a number of activities of daily living, mobility, and communication that are essential for daily independent functioning (McWhinnie 1981). Of these, 10 items were selected, dealing with the ability to bend down and pick something up, to get in and out of bed, to dress and undress, to move between rooms, to walk 400 m, to carry a 5-kg object for 10 m, to read small print in a newspaper, to recognize someone's face, to have a conversation with another person and to follow a conversation in a group. People were considered to be disabled if they indicated that they needed help from another person or were unable to carry out one or more of the selected activities included in the indicator without (great) difficulty. People who were able to carry out all the activities with some or no difficulty were considered to be without disability. Using equipment such as eyeglasses or a hearing aid was not considered indicative of a disability if the respondent did not need help or was able to carry out the activity with little or no difficulty.

Table 2 Total and cause-specific mortality rates (1990-1994) and total and cause-specific disability prevelence in the non-institutionalized population, The Netherlands, by age group and sex.

Cause	Age group	Cause-specific mortality (per 1000)		Cause-specific prevalence of disability (per 1000)	
		Men	Women	Men	Women
Total	15-44	1.0	0.6	33.0	53.7
	45-64	7.7	4.4	171.1	211.2
	65+	63.4	46.2	297.9	484.4
COPD	15-44	0.0	0.0	1.7	1.69
	45-64	0.2	0.1	4.6	3.49
	65+	4.8	1.4	16.4	8.04
Heart disease	15-44	0.1	0.0	0.2	0.26
	45-64	2.2	0.7	5.1	3.36
	65+	18.0	13.1	15.7	22.30
Stroke	15-44	0.0	0.0	0.1	12.12
	45-64	0.3	0.2	3.3	22.59
	65+	5.6	6.1	13.5	36.85
Diabetes Mellitus	15-44	0.0	0.0	0.1	0.21
	45-64	0.2	0.1	1.2	1.30
	65+	1.2	1.6	4.8	11.14
Back Complaints	15-44	0.0	0.0	7.2	0.83
	45-64	0.0	0.0	27.9	6.73
	65+	0.0	0.0	23.2	27.37
Arthritis	15-44	0.0	0.0	2.1	10.83
	45-64	0.0	0.0	14.1	33.47
	65+	0.2	0.4	36.1	41.41
Cancer	15-44	0.2	0.2	0.1	4.19
	45-64	3.1	2.4	0.7	35.18
	65+	18.9	9.6	5.2	103.10
Other diseaes	15-44	0.2	0.3	5.0	0.31
	45-64	3.1	0.8	14.6	2.33
	65+	18.9	14.0	29.5	5.74
Background	15-44	n.a	n.a	16.5	23.24
	45-64	n.a.	n.a.	99.7	102.75
	65+	n.a.	n.a.	153.4	228.45

Data on people living in institutions by were collected by TNO/PG. For institutions covered by the AWBZ (including nursing homes, psychiatric hospitals, homes for the mental deficit), data were originally obtained from the Central Administration of the AWBZ. Data on People living in homes from the elderly were derived from surveys (Social and Cultural Planning Office 1991; Statistics Netherlands 1984). People living in an institution were considered to be disabled, however an adjustment was made for persons living in home for the elderly without disability, based on survey data surveys (Social and Cultural Planning Office 1991; Statistics Netherlands 1984).

Disability data by cause were reconstructed from individual data on disability and chronic diseases in the Health Interview Survey, as no information on causes of disability was present. Chronic diseases were assessed on the basis of a structured list comprising a broad spectrum of somatic disorders and conditions. From the original chronic conditions, the following disease clusters were selected: Chronic Obstructive Pulmonary Disease (COPD), heart diseases, stroke, cancer, diabetes mellitus, arthritis, back complaints, and 'other diseases'. For a description of these disease clusters see Table 1. In the attribution of disability to disease, we assumed independence of causes of disability (i.e. diseases). That is, we do not take into additional effects of co-morbidity on disability. The major reason is that for mortality we do not have information on the effect of co-morbidity. Taking into account effect of co-morbidity for disability would imply that the disability effect is partitioned in more causes (co-morbidity is handled as a separate cause) than the mortality effect. This would hamper the comparison between causes of disability and mortality. In addition, including effect of co-morbidity would also make the illustration less transparent.

Prevalence of disability by cause in three broad age groups is presented for each cause in Table 2. The cause 'background' reflects to disability in persons without a disease. Because people living in institutions were not included in the Survey, we treated institutionalization as a separate 'cause' of disability.

2. Method

Starting point was the Sullivan life table for men and women. These were based on abbreviated life tables starting at age 15. According to the Sullivan method, the number of person years lived in a five-year age interval ($_5L_x$) was subdivided into years with and without disability by multiplying the number of person years with the proportion with disability ($_5\pi_x$). Because we had separate data for the institutionalized and non-institutionalized population, we calculated the number of person-years with disability in each population, and added these two components to obtain the total number of person-years lived with disability. In the decomposition, a stepwise approach is followed:

a) Decomposition by kind of effect

The male-female difference in health expectancy is decomposed by kind of effect that is into the mortality effect and disability effect. Men are used as baseline. For the decomposition of the difference in life expectancy with disability we used $_i\pi_x$ and for difference in life expectancy without disability $1-_i\pi_x$.

b) Decomposition of mortality effect by cause

The mortality effect is decomposed into the contribution of specified causes of death. Here we illustrate the procedure for age group 25-29 years of the Sullivan life table (age refers here to age at destination) for one cause: heart disease, with men as reference. The procedure was followed for each age group of the Sullivan life table and all causes of death.

- The sex-difference in the number of person years lived between age 25-29 (ΔL_{25-29}) is decomposed by age group of origin of the mortality change (*y)*. For instance, the sex difference in L_{25-29}, partly originated from the mortality difference in this age group ($TOT_{25-29,25-29}$, i.e., the direct effect) and partly from mortality differences in all younger age groups of origin (i.e., 15-19: $TOT_{25-29,15-19}$, and 20-24: $TOT_{25-29,20-24}$, i.e., indirect and interaction effects of mortality changes at younger ages).

- For each age group of origin *y*, the total difference in the number of person years lived ($TOT_{25-29,y}$) is decomposed by cause of death using the fraction $_iC_{yk}$ (the contribution of the mortality change attributable to cause *k* in the age group of origin *y*. For example, if 6.5% of the sex-difference in mortality between age 15-19 can be attributed to heart diseases, we multiply $TOT_{25-29,15-19}$ with 0.065 to obtain the contribution of differences in heart-disease mortality between age 15 and 19 ($TOT_{25-29,15-19, heart}$) to the sex-difference in the number of person years lived between age 25-29.

- The cause-specific contributions are added across each age group of origin (y) to obtain the sex difference in the number of years lived between age 25 and 29 due to difference mortality from hearth diseases (e.g. $TOT_{25-29,15-19, heart} + TOT_{25-29,20-24, heart} + TOT_{25-29,25-29,heart}$).

- The difference in the number of years lived between age 25 and 29 due to difference mortality from hearth diseases is multiplied with the (unchanged) average proportion with disability in the age group 25-29 ($_5\pi_{25}$) to obtain the mortality effect ($_5MOR_{25}$) due to heart diseases.

The calculations are repeated with women as reference and averaged, in order to avoid that the results of the decomposition depend on whether men or women were chosen as reference.

c) Decomposition of disability effect by cause

The disability effect is decomposed into the contribution of different causes of disability, in two steps.

- Cause-specific disability proportions by age in women are subtracted from those in men to obtain the age-specific male-female difference in disability.

- The disability effect is decomposed by cause of disability. Since cause-of disability data are not available for the institutionalized population, institutionalization is treated as a separate 'cause' of disability.

d) Decomposition of total effect by cause

The mortality effect and disability effects by cause are added to obtain the decomposition of the male-female difference in health expectancy by cause.

3. Results

Table 3 summarizes the outcomes of the Sullivan life tables for men and women. Women live 6.36 years longer with disability and 0.48 years less without disability. The difference in total life expectancy is 5.89 years in favor of women. Without a decomposition tool, these are the results of an analysis of sex differences in health expectancy. Looking at sex differences in mortality and disability rates (for a summary see Table 2) can shed some light on these differences. For instance, it is clear that the combination of lower mortality and higher prevalence of disability rates cause the longer life expectancy with disability in women. However, it remains unclear to what extent the longer life expectancy is caused by mortality differences and to what extent by disability differences. Also the virtually absent sex difference in disability-free life expectancy is not easily understood. The decomposition helps better understanding these differences.

Table 3   Total life expectancy (LE), life expectancy with disability (LWD) and life expectancy without disability (DFLE) at age 15 for men and women and female-male difference, The Netherlands, 1990-1994

	LE (in years)	DFLE (in years)	LWD (in years)
Men	59.9	51.5	8.4
Women	65.8	51.1	14.8
Male-female difference (men = baseline)	5.89	-0.48	6.36

The first step of the decomposition analysis shows that of the 6.36 years longer life expectancy with disability, 3.55 years were caused by higher disability prevalence and 2.82 years by lower mortality in women (Table 4). This means that if only disability differed between the sexes, women would have lived 3.55 years more with disability than men. The remaining 2.82 years with disability are caused by lower mortality in women. For life expectancy without disability, the disability effect of -3.55 year is almost completely nullified by the mortality effect of 3.1 years. The net difference is small, but is masking large differences in mortality and disability.

Table 4   Decomposition of the male-female difference in Total life expectancy (LE), life expectancy with disability (LWD) and life expectancy without disability (DFLE) at age 15, The Netherlands, 1990-1994

	LE (in years)	DFLE (in years)	LWD (in years)
Total Difference (men is baseline)	**5.89**	**-0.48**	**6.36**
Mortality effect	5.89	3.07	2.82
Disability effect	0	-3.55	3.55

Figures are rounded to 2 decimal points.

To obtain information on the contribution of selected causes to the difference in life expectancy with and without disability, a further decomposition of the mortality effect and disability effect by causes is useful. Although a comparison of cause-specific mortality rates between the sexes would already give an indication of which causes of death are responsible for the observed differences in life expectancy caused, to explain the difference in years with and without disability, disability data should be considered as well. The decomposition of the mortality effect by cause takes this into account and shows that of the 2.82 additional years with disability in women caused by lower mortality, 0.89 years are due to heart disease 0.90 years due to cancer (Table 5). The contribution of these causes to differences in life expectancy with disability is not the same as to life expectancy without disability. The contribution of cancer to the disability-free life expectancy was smaller (0.78 years) and

that of heart disease larger (1.03 years). This reflects differences in the ages where the differences in cause-specific mortality occur.

Table 5   Decomposition of the mortality effect of the male-female difference in health expectancy at age 15 by cause of death, The Netherlands, 1990-1994

	LE, y	DFLE, y	LED, y
Total mortality effect	5.89	3.07	2.82
Chronic Obstr. Lung Disease	0.51	0.22	0.29
Heart disease	1.92	1.03	0.89
Stroke	0.19	0.09	0.10
Diabetes mellitus	0.02	0.02	0.00
Back complaints	0.00	0.00	0.00
Arthritis	-0.02	-0.01	-0.01
Cancer	1.68	0.78	0.90
Other diseases	1.59	0.95	0.64

Figures are rounded to 2 decimal points.

To obtain insight into the causes of disability responsible for the differences in years with and without disability, we decomposed the disability effect by cause (Table 6). The most important cause of disability being responsible for male-female differences in years with and without disability is arthritis. Higher disability in women associated with arthritis is responsible for 1.21.years additional years with disability. That is, if only disability due to arthritis would have differed between the sexes, women would have spent 1.21.years more with disability. A large part of the disability differences is not attributable to diseases; this reflects disability in persons without (specific) diseases.

Table 6. Decomposition of the disability effect of the male-female difference in health expectancy at age 15 by cause of disability The Netherlands, 1990-1994

	LE, y	DFLE, y	LED, y
Total disability effect	0	**-3.55**	**3.55**
Chronic Obstr. Lung Disease	0	0.15	-0.15
Heart disease	0	-0.01	0.01
Stroke	0	0.07	-0.07
Diabetes mellitus	0	-0.39	0.39
Back complaints	0	-0.43	0.43
Arthritis	0	-1.21	1.21
Cancer	0	-0.03	0.03
Other diseases	0	-0.38	0.38
Non-attributable to diseases	0	-0.82	0.82
Institutions	0	-0.49	0.49

Figures are rounded to 2 decimal points.

Table 7 gives the decomposition of the total male-female difference in health expectancy by cause. Causes here reflect causes of disability and death. Arthritis is the most important cause of sex differences in life expectancy with disability (1.20 years), followed by 'other diseases' (1.02), heart disease (0.91 years) and cancer (0.94 years). Comparison of these results with the previous tables indicates that for arthritis is disability effect is most important (0.121 as compared to total effect of 0.120) and for cancer and heart disease the mortality effect (0.90 out of 0.94 and 0.89 out of 0.91, respectively). The smaller effect of chronic obstructive lung disease (COPD) of 0.14 years, is the net effect of 0.29 more years due to lower mortality in women and 0.15 less years due to lower disability in women from COPD. Thus the effects of both a more favorable mortality and disability regime partly nullify each other. Looking at the causes responsible for the sex differences in disability free life expectancy shows positive and negative contributions. Heart diseases (+1.01), cancer (+0.74) and other diseases (+0.58) contributed positively to a larger disability-free life expectancy. The negative contributions of arthritis (-1.22), back complaints (-0.43) and diabetes mellitus (-0.37) completely nullified this effect and were responsible for a smaller disability-free life expectancy in women (under the ceteris paribus clause). These negative contributions were caused by unfavorable disability patterns of these causes.

**Table 7   Decomposition of male-female difference in health expectancy at age 15 by cause,
The Netherlands, 1990-1994**

	LE, y	DFLE, y	LED, y
Total difference	**5.89**	**-0.48**	**6.36**
Chronic Obstr. Lung Disease	0.51	0.37	0.14
Heart disease	1.92	1.01	0.91
Stroke	0.19	0.16	0.02
Diabetes mellitus	0.02	-0.37	0.39
Back complaints	0.00	-0.43	0.44
Arthritis	-0.02	-1.22	1.20
Cancer	1.68	0.74	0.94
Other diseases	1.59	0.58	1.02
Disability differences non-attributable to diseases	0.00	-0.82	0.82
Institutions	0.00	-0.49	0.49

Figures are rounded to 2 decimal points.

VI. Discussion

Health expectancies are increasingly being used to monitor population health, as it takes into account not only the length of life (adding years to life), but also the healthfulness of life (adding life to years). This extension of the widely used indicator 'life expectancy', makes health expectancy more useful for monitoring population health than life expectancy for the European Union and its Member States. However, decomposition techniques, as used to analyze differences (between regions, sub-populations or over time) in life expectancy were not yet available for health expectancy.

We developed a method to decompose differences in health expectancies to assist policy makers to understand differences in population health, to do facilitate the definition of priorities and objectives in the field of public health and the assessment of targeted health priorities. This technique decomposes differences in health expectancy (based on the Sullivan method) into the contribution of specific causes of disability and mortality.

We illustrated this new tool by examining male-female differences in life expectancy with and without disability for the Netherlands in 1990-1994. The decomposition showed that most of the extra years women spend with disability was caused by arthritis, 'other diseases', heart disease and cancer. Heart disease, cancer and 'other diseases' also contributed to a longer life expectancy without disability. However, we found that these positive effects on life expectancy without disability were completely nullified by arthritis, back complaints and disability non-attributable to any of the diseases.

Another likely application, not illustrated in this paper for practical reasons, is the decomposition of changes over time. The decomposition will provide information on which part of the observed change in health expectancy reflects a change in mortality and disability. In addition, it provides information on the causes of disability and death behind the changes. Without a decomposition tool, observed changes in health expectancy may even be harder to understand, because less a-priori knowledge is available.

As any tool, the method has some limitations, which should be kept in mind when using it. Some limitations are specific to the data sources used or are related to presenting the model as simply as possible, while others are more fundamental to the method. We will discuss them briefly.

1. Limitations related to the data used

a) Self reported data on diseases

Relying on respondents' self-reports in a health interview containing a checklist of chronic diseases and disability items might bias the results. A golden standard to compare self-reported data on chronic diseases is not

available, but studies reporting the validity of interview data compared with clinical examinations or medical records show considerable discrepancies for some diseases (Jabine 1987; Mackenbach et al. 1996; Schrijvers et al. 1994). The concordance between self-reports and medical registrations depends on a complex combination of factors: homogeneity of diagnostic groups, severity of illness, need for diagnosis and care (Jabine 1987) and level of education (Mackenbach et al. 1996). It is clear that reporting errors in chronic conditions may seriously affect the outcomes. However, because medical registrations in general do not include information on disability and information on the population at risk is incomplete, the deomposition of changes or differences in health expectancy can only be calculated from health interview or health examination surveys.

b) Population living in institutions

In our illustration of the decomposition method for the Netherlands, we used a health interview survey for the population not living in an institution, which has several disadvantages. First, it makes the calculations less transparent. Second, it is based on assumptions about disability in the institutionalised population (i.e. that they are disabled, apart from persons living in homes for the elderly for which an adjustment was made). Last and most important, we could not take into account causes of disability among those living in institutions. We therefore had to include institutionalisation as a separate 'cause' of disability. We strongly recommend including the institutionalised population in the health survey.

c) Comparability of mortality and disability data

Because mortality and disease data are based on different data sources, the disease entities are not entirely comparable. Whereas, in decomposing the mortality effect by cause of death and the disability effect by cause of disability, disease entities in both analyses are analysed separately, in the decomposition of the total effect, the causes of death and disability are added. Classification and analysis of the causes death and disability in a comparable way should therefore receive high priority.

2. Limitations related to the proposed methods

a)Using stock data

The decomposition method is based on the Sullivan method because this is the standard method to calculate health expectancy on a routine basis. The major problem with the Sullivan method is, however, that it integrates prevalence data on disability (i.e. stock data) in a life table which is based on incident data on mortality (i.e. flow data). As a result the Sullivan method generally does not produce a pure period indicator such as (period) life expectancy (Barendregt et al. 1997; Mathers and Robine 1997b; Robine et al. 1992; Robine and Ritchie 1991). Only after all flow variables (i.e. transition rates) have been constant for a long period of time will an equilibrium situation emerge in which the Sullivan method provides a pure period indicator. The deviation from a pure period indicator can introduce bias when the Sullivan method is used to assess whether changes in health expectancy have occurred over time (Barendregt et al. 1995; Barendregt et al. 1997; Mathers and Robine 1997a; Mathers and Robine 1997b; Robine and Ritchie 1991; Van de Water et al. 1995). Biases are expected to occur when, sudden, large changes occur. This implies that theoretically a change in the number of years with or without disability – being the subject of the decomposition technique –may have been caused by prevalence reaching its equilibrium values, in stead of a real change in population health. However, for gradual, small changes over time in underlying transitions that determine the prevalence of disability, the Sullivan method is likely to give a good description. Although no information is available on the potential bias in comparing health expectancies based on the Sullivan method between subgroups, we do not expect large biases in a period of constant or small gradual changes in underlying transitions.

A second consequence of using prevalence data on disability relates to the interpretation of the decomposition by age, as this reflects not the age where differences in disability originate. The difference in the prevalence of disability in a specific age group is the result of a cumulative disability experience over younger ages. For example, higher prevalence of disability in women at age 60, is the result of the disability experiences at all ages up to age 60.

A third consequence of using stock data on disability is that causes of disability had to be reconstructed from cross-sectional data on diseases and disability. Whereas in a situation with incidence data on disability, using a

hazard approach to attribute disability to disease is a logical extension of existing demographic techniques and is intuitively appealing, when using stock data on disability (proportions or probabilities), the choice of using a hazard model in the reconstruction of causes of disability is less straightforward. In the reconstruction, we assumed that diseases present at the time of the survey together with the background risk cause disability in a certain age group, and in doing so act as independently competing causes. This is supported by the literature demonstrating that using independent risks is the exactly the same as additive hazards (i.e. rates) (Manton and Stallard 1984; Namboodiri and Suchindran 1987). Because additive hazards are easy to handle in the presence of more risks, and additive hazard can be used to calculate crude probabilities, adjusted for the presence of other causes, we used a hazard transformation to obtain cause-specific probabilities of disability, adjusted for the presence of other causes.

b) Attribution of disability to disease

The cause of disability is based on statistical associations and not on etiologic information. It is noteworthy that the attribution is a construct and does not necessarily reflect the aetiology of disability. In the attribution, we assumed that the diseases present and the background risk cause disability at the time of the survey. Some conditions, for instance an accident in the past, might not be reported in the survey, while being the cause of disability. This is taken into account implicitly in the background risk. The background risks may thus include (1) the effect of ageing, (2) the effect of diseases and conditions in the past not present anymore (e.g. accident), and (3) the effect of disease(s) present, but not reported by the respondent. The high proportion of disability that cannot be attributed is not an artefact caused by the attribution method. It reflects the high number of persons with disability reporting no disease in the Health Interview Survey. As the background risk increases sharply with age, ageing is likely to play an important role in disability in persons without a specific disease. The high background risk may be partly related to including difficulties in hearing and seeing in the disability indicator.

A second limitation of the attribution method is that to obtain smoothed cause-specific disability proportions the method requires specialised software (GLIM). Limitations related to the use of a simple model for the purpose of illustration

c) Independence of causes of disability

The statistical model used to attribute disability to disease assumes independence of causes of disability in an additive hazard regression model. We used this assumption for transparency reasons and maximise the comparability with the causes of death, but it can be dropped. We suggest testing whether disease-by-disease interactions are statistically significant (at a 5 % level). A stepwise procedure can be used to assist selecting interaction terms to be included in the final model. For our dataset we found significant effects of some disease combinations (men: COPD-other, stroke-other, heart disease-diabetes, back complaints-other; women: arthritis-other, back complaints-arthritis, all positive, indicating additional disability). We suggest including combinations which are either significant for men or women in both models, to guarantee comparability between men and women.

Conclusions:

Decomposition of differences/changes in health expectancy is essential for policy makers for explanation of changes in health expectancy and differences between sub-populations, to do facilitate the definition of priorities and objectives in the field of public health and the assessment of targeted health priorities. This technique decomposes assessment of targeted health priorities. It requires mortality data by cause, which are generally available and disability data by cause, which can be estimated using an attribution method.

Acknowledgements:

Appendix I: Life table decomposition method of differences and changes in health expectancy

The technique to decompose differences (or changes) in health expectancy is based on the Sullivan method and is an extension of the decomposition method already developed by Arriaga for total life expectancy. For the ease of explanation, we explain the technique in terms of changes over time, but the procedure is identical for differences between population groups. First, we describe the method for the decomposition of changes in life expectancy. Then, we move on to the decomposition of changes in health expectancy.

1. Decomposition of changes in life expectancy

The decomposition method developed by Arriaga is a procedure that estimates the number of years added or removed from the life expectancy because of the decrease or increase (respectively) of the central mortality rates in a given age group or by age given cause. This results in the decomposition of changes in life expectancy into the contribution of specific causes of death (and/or age groups). In order words, changes in life expectancy are partitioned into component additive contributions of causes. The method first decomposes the change in life expectancy into the contribution of different age groups (Arriaga 1984) Next, the contribution of each age group is further decomposed by cause of death, assuming that the contribution of a cause of death to the change in life expectancy that can be attributed to an age group is proportional to the contribution of this cause to the change in the central mortality rate in that age group (Arriaga 1989). Finally, in order to avoid that the results of the decomposition depend on whether the first or second time point (or population) is used as reference, the components of the difference between time point 1 and 2 (using 2 as baseline) with the respective components of the difference between time point 2 and 1 (using 1 as baseline) are averaged (Shkolnikov et al. 2001).

a) Decomposition by age

To decompose the change in life expectancy into the contribution of mortality changes in particular age groups, Arriaga distinguishes three types of effects: a direct effect (*DE*), an indirect effect (*IE*) and an interaction effect (*I*). The direct effect on life expectancy is due to the change in person-years lived within a particular age group ($_iL_x$) as a consequence of a mortality change in that age group. The indirect effect consists of the number of years added to (or removed from) a given life expectancy, because the mortality change within a specific age group produces a change in the number of survivors at the end of that age interval. That is, in the presence of unchanged mortality rates at older ages than the age group under consideration, the increase (or decrease) in the number of survivors at the end of the age interval results in an increase (or decrease) in the number of years lived. Both the direct and indirect effect take into account mortality change in a specific age group, independent of the changes in other ages. However, since in general mortality changes occur simultaneously in all ages, in addition, a small part of the change in life expectancy is due to the fact that the gained (or lost) survivors (those responsible for the indirect effect) do not experience unchanged mortality at older ages. The effect of the combination of the changed number of survivors at the end of the age interval and the lower (or higher) mortality rates at older ages is termed the interaction effect (*I*).

Arriaga (Arriaga 1984) expresses the direct effect ($_iDE_x$) that a mortality change between time *t* and *t+n* in an age group *x, x+i* has on life expectancy at age *a* as follows:

$$_iDE_x = \frac{l_x^t}{l_a^t} \cdot \left[\frac{T_x^{t+n} - T_{x+i}^{t+n}}{l_x^{t+n}} - \frac{T_x^t - T_{x+i}^t}{l_x^t} \right] \tag{1}$$

where: l_x^t is the number of survivors at exact age *x* at time *t*, *n* is the difference between the first year and second year of observation, T_x is the number of person years lived after age *x*.. To calculate the indirect effect, first the change in the number of survivors ($_iCS_x$) at the end of the age interval *x, x+i* is calculated as follows:

$$_iCS_x = l_x^t \cdot \frac{l_{x+i}^{t+n}}{l_x^{t+n}} - l_{x+i}^t \tag{2}$$

Next, the indirect effect is the effect that would arise if this changed number of survivors would continue living after age $x+i$ as many years as the rest of the population before the change in mortality (i.e. the life expectancy at age $x+i$ before the change in mortality). Thus, the indirect effect is:

$$_iIE_x = \frac{_iCS_x}{l_a^t} \cdot e_{x+i}^t = \frac{_iT_{x+i}^t}{l_a^t} \cdot \left[\frac{l_x^t \cdot l_{x+i}^{t+n}}{l_{x+i}^t \cdot l_x^{t+n}} - 1 \right] \tag{3}$$

Finally, the interaction effect is calculated as the difference between two components: (1) the number of years added if the additional survivors (*CS*) at age $x+i$ would continue living as many years as the rest of the population after the change in mortality (i.e. the life expectancy at age $x+i$ after the change in mortality) and (2) the indirect effect, being the number of years added if the additional survivors would continue living under the old mortality regime. The first component is called *OE*, and is calculated as follows:

$$_iOE_x = \frac{_iOE_x}{l_a^t} \cdot e_{x+i}^{t+n} = \frac{T_{x+i}^{t+n}}{l_a^t} \cdot \left[\frac{l_x^t \cdot l_{x+i}^t}{l_x^{t+n} \cdot l_{x+i}^{t+n}} \right] \tag{4}$$

The interaction effect ($_iI_x$) is thus:

$$_iI_x = {_iOE_x} - {_iIE_x} \tag{5}$$

The total contribution of a mortality change in each age group x, $x+i$ is calculated by adding the direct, indirect and interaction effect of that age group (although the latter cannot be exclusively allocated to that age). For the open-ended age group, the calculations are different. A morality change in the open-ended age group causes only a direct effect. The formula for calculating the direct effect in the last age group is calculated as follows:

$$_iDE_{x+} = \frac{l_x^t}{l_a^t} \cdot \left[\frac{_iT_{x+}^{t+n}}{l_x^{t+n}} - \frac{_iT_{x+}^t}{l_x^t} \right] \tag{6}$$

b) Decomposition by cause

According to the Arriaga method, the total contribution of a mortality change at each age group x, x+i, is decomposed by cause of death, assuming that the contribution of a cause of death to the change in life expectancy between time t and t+n that can be attributed to an age group is proportional to the contribution of this cause to the change in the central mortality rate in that age group, i.e. ($_iM_x^t$ - $_iM_x^{t+n}$).

The fraction of the contribution of a mortality change attributable to cause k $_iC_{yk}$ is calculated as follows:

$$_iC_{yk} = \left[\frac{R_{yk}^{t+n} \cdot {_iM_y^{t+n}} - R_{yk}^t \cdot {_iM_y^t}}{_iMy_y^{t+n} - {_iM_y^t}} \right] \tag{7}$$

where $_iM_y^t$ is the central mortality rate at age y, $y+i$ at time t, $_iR_{yk}$ is the proportion of deaths from cause k in the total number of deaths in the age group y, $y+i$ and n is the difference between the first year of observation and the second.

2. Decomposition of changes in health expectancy

For the decomposition of changes in health expectancy, the approach is more complex. Whereas changes in life expectancy are caused solely by changes in central mortality rates, changes in health expectancy (calculated with the Sullivan method) might be the result of changes in central mortality rates and changes in the proportion with disability. We first describe the Principles of decomposition of the change in health expectancy into the contribution of each of these components (i.e. the mortality change and disability change), leaving out of consideration different causes of death and disability. Next, we explain how causes of death and disability are incorporated in the decomposition technique.

a) Decomposition by mortality effect and disability effect

Starting point is the Sullivan method for the calculation of health expectancy at age a, with an initial cohort of 1 ($l_{a=1}$). In age group, x, x+i, the number of person years with disability $_i\pi_x \,_iL_x$ is the product of the number of person years lived ($_iL_x$) and the proportion with disability ($_i\pi_x$). A change in the number of person years with disability is thus:

$$\Delta_i \pi_{x\,i}L_x = \left[\left(_i\pi_x + \Delta_i\pi_x\right)\cdot\left(_iL_x + \Delta_iL_x\right)\right] - _i\pi_{x\,i}L_x \tag{8}$$

where Δ is change between the first year of observation (1) and the second (2). Re-expression gives:

$$\Delta_i \pi_{x\,i}L_x = \left(_i\pi_x + 0.5\Delta_i\pi_x\right)\cdot\Delta_iL_x + \left(_iL_x + 0.5\Delta_iL_x\right)\cdot\Delta_i\pi_x \tag{9}$$

or,

$$\Delta_i \pi_{x\,i}L_x = \left[\frac{_i\pi_{x(1)} + _i\pi_{x(2)}}{2}\right]\cdot\Delta_iL_x + \Delta_i\pi_x\cdot\left[\frac{_iL_{x(1)} + _iL_{x(2)}}{2}\right] \tag{10}$$

where 1 refers to the reference year/population and 2 to the year/population of comparison.

Equation 3 shows that a change in $_i\pi_x \,_iL_x$ reflects a change in the number of person years (due to mortality changes) and/or in the proportion with disability. The change in the number of person years with disability is thus the sum of two components:

$$_iMOR_x = \left[\frac{_i\pi_{x(1)} + _i\pi_{x(2)}}{2}\right]\cdot\Delta_iL_x \tag{11}$$

$$_iDIS_x = \left[\frac{_iL_{x(1)} + _iL_{x(2)}}{2}\right]\cdot\Delta_i\pi_x \tag{12}$$

The first component, $_iMOR_x$, is the change in the number of person years with disability due a change in the number of person years lived (ceteris paribus). Since any change in the number of person years lived is caused by a change in mortality, this is termed the 'mortality effect'. The mortality effect is the change in the number of person years with disability that would occur in case only mortality rates would change. A negative $_iMOR_x$, for instance, reflects a decline in the number of person years lived with disability in the age group *x x+i* due to an increase in the mortality in that age group, or in younger age groups. The second component, termed the 'disability effect' ($_iDIS_x$), is the change in the number of person years with disability due to a change in the proportion with disability (ceteris paribus). The disability effect in one age group is the change in the number of person years with disability that would occur if only the proportion with disability would change. A negative $_iDIS_x$ reflects a decline in the number of person years lived with disability in the age group *x x+i* due to a decline in the proportion disabled in that age group. For the decomposition of the change in the number of years without disability, the approach is similar. The only difference is that the proportion without disability (i.e., 1- $_i\pi_x$) rather than $_i\pi_x$ is used in the equations.

Next, we include different causes in the analyses. That is, the mortality effect ($_iMOR_x$) is further decomposed by cause of death and the disability effect ($_iDIS_x$) by cause of disability.

b) Decomposition of mortality effect by cause

To decompose the mortality effect ($_iMOR_x$, see equation 11) by cause, the change in the number of person years lived *(Δ_iL_x)* ,is decomposed into the contribution of specific causes of death by using an adjustment of the Arriaga method. Whereas the original Arriaga method decomposes the change in life expectancy by cause, we decompose the change in the number of person years lived in each age interval by cause. This modification is needed, because in the Sullivan the proportion with disability in a specific age group is multiplied by the number of person years in that age group. For this reason, we re-expressed the Arriaga method. First, we made a distinction between the age group where the mortality change occurs ('age at origin' labeled as *y, y+i*) and the age group where the person years are added to or removed from ('age at destination, labeled as *x, x+i*). Second,

we re-expressed T_x, in terms of $_iL_x$ (i.e., age-specific contribution to T_x). This is possible because the summation of $_iL_x$ over age gives T_x

Similar to the Arriaga method, we define the direct ($_iDE_{xy}$), indirect ($_iIE_{xy}$) and interaction effect ($_iI_{xy}$). The $_iDE_{xy}$, $_iIE_{xy}$, and $_iI_{xy}$, are each arranged in a table with the age group y, $y+i$ where the mortality change originates (i.e. age of origin) presented in the rows, the age groups x, $x+i$ where person years are added (or removed) due to the mortality change (i.e. age at destination) in the columns, and the $_iDE_{xy}$, $_iIE_{xy}$, $_iI_{xy}$, respectively in the cells.

The calculation of $_iDE_{xy}$ (where age at origin y = age at destination x) is identical to the original Arriaga method, since the direct effect is the change in person years within a particular age group as a consequence of mortality change in that age group. The direct effect ($_iDE_{xy}$) of a mortality change in an age group y, $y+i$ between time t and $t+n$ on the number of person years lived between age x, $x+i$ is expressed as follows:

$$_iDE_{xy} = \frac{l_y^t}{l_a^t} \cdot \left[\frac{_iL_x^{t+n}}{l_y^{t+n}} - \frac{_iL_x^t}{l_y^t} \right] \quad (x=y) \tag{13a}$$

$$_iDE_{xy} = 0 \qquad\qquad (x>y) \tag{13b}$$

The indirect effect consists of the number of person years added (or removed) because the mortality change within a specific age group of origin produces a change in the number of survivors at the end of that age interval. The indirect effect is the effect that would arise if the changed number of survivors would continue living after age $y+i$ as many years as the rest of the population before the change in mortality (i.e. the life expectancy at age $y+i$ before the change in mortality).

The adjusted formula for the indirect $_iIE_{xy}$ is:

$$_iIE_{xy} = \frac{_iL_x^t}{l_a^t} \cdot \left[\frac{l_y^t \cdot l_{y+i}^{t+n}}{l_{y+i}^t \cdot l_y^{t+n}} - 1 \right] \qquad (y<x) \tag{14}$$

As in the Arriaga method, the interaction effect ($_iI_{xy}$) is calculated as the difference between two components: (1) the number of person years added (removed) if the additional survivors at age $y+i$ would continue living as many years as the rest of the population after the change in mortality (i.e. the life expectancy at age $y+i$ after the change in mortality) and (2) the indirect effect, being the number of years added (removed) if the additional survivors would continue living under the old mortality regime. The first component is called, $_iOE_{xy}$, and is calculated as follows:

$$_iOE_{xy} = \frac{_iL_x^{t+n}}{l_a^t} \cdot \left[\frac{l_y^t - l_{y+i}^t}{l_y^{t+n} - l_{y+i}^{t+n}} \right] \qquad (x>y) \tag{15}$$

Using equation (7) and (8), the interaction effect ($_iI_{xy}$) is obtained as follows:

$$_iI_{xy} = {}_iOE_{xy} - {}_iIE_{xy} \qquad (x>y) \tag{16}$$

For the open-ended age group, the calculations are different. A morality change in the open-ended age group causes only a direct effect. The formula for calculating the direct effect in the last age group is as follows:

$$_iDE_{xy} = \frac{l_y^t}{l_a^t} \cdot \left[\frac{_iL_x^{t+n}}{l_y^{t+n}} - \frac{_iL_x^t}{l_y^t} \right] \quad (y=x, \text{ open ended age group}) \tag{17}$$

The total contribution of the mortality change at each age group y, $y+i$, to the change in the number of person years lived between age x and $x+i$ ($\Delta_i L_x$) is calculated as follows:

$$_iTOT_{xy} = _iDE_{xy} + _iIE_{xy} + _iI_{xy} \qquad (x \ni y) \qquad (18)$$

$_iTOT_{xy}$ is decomposed by cause of death k, by multiplying $_iTOT_{xy}$ with the contribution of the mortality change in the age group y, $y+i$ attributable to cause k, $_iC_{yk}$. Thus:

$$_iTOT_{xyk} = _iTOT_{xy} \cdot _iC_{yk} \qquad (19)$$

where $_iTOT_{xyk}$ is the contribution of a mortality change due to cause k in age group $y,y+1$ to the number of person years lived between age x, $x+1$ (where y #x). $_iC_{yk}$ is calculated as follows:

$$_iC_{yk} = \left[\frac{R_{yk}^{t+n} \cdot _i M_y^{t+n} - R_{yk}^t \cdot _i M_y^t}{_i M_y^{t+n} - _i M_y^t} \right] \qquad (20)$$

where $_iM_y^t$ is the central mortality rate at age y, $y+i$ at time t, $_iC_{yk}$ is the proportion of deaths from cause k in the total number of deaths in the age group y, $y+i$ and n is the difference between the first year of observation and the second.

The contribution of cause k to the change in the number of person years lived between age x, $x+i$ ($_iTOT_{xk}$) is derived as follows:

$$\Delta_i L_{xk} = \sum_{y=a,x} {}_iTOT_{xyk} \qquad (21)$$

where:

$$\Delta_i L_x = \sum_k \Delta_i L_{xk} \qquad (22)$$

Combining equation 15 and equation 4 gives the mortality effect ($_iMOR_x$) by cause. Summation of $_iMOR_x$ over age x gives the total mortality effect, i.e. the change in health expectancy that would occur if only mortality would have changed.

c) Decomposition of the disability effect by cause

For each age group, in order to decompose the disability effect ($_iDIS_x$) by cause of disability, the change in the proportion with disability ($\Delta_i \pi_x$) needs to be attributed to different causes of disability k. The change in the proportion with disability by cause can be obtained by subtraction of the proportion by cause at time t from that at time $t+n$.

$$\Delta_i \pi_{xk} = _i\pi_{xk}^{t+n} - _i\pi_{xk}^t \qquad (16)$$

where $_i\bullet_{xk}^{t+n}$ is the proportion with disability from cause k in age group x, $x+i$ at time $t+n$, and $_i\bullet_{xk}^t$ is the proportion with disability from cause k in age group x, $x+i$ at time t. And where:

$$\Delta_i \pi_x = \sum_k \Delta_i \pi_{xk} \qquad (16)$$

The proportion of disability by cause can sometimes be obtained directly from health interview surveys or can be estimated from individual information on diseases and disability. Summation of $_iDIS_x$ across ages gives the total disability effect, i.e. the change in health expectancy due to changes in the proportion with disability under the ceteris paribus clause.

d) Decomposition of the total effect by cause

Summation of the mortality and disability effect by cause gives the decomposition of the total change in health expectancy by cause.

Finally, the cause-specific components of the difference between time point 1 and 2 (using 2 as baseline) with the respective components of the difference between time point 2 and 1 (using 1 as baseline) are averaged. That is the mortality effect, disability effect and total effect by cause, obtained with year 2 as baseline and those obtained with year1 as baseline are averaged.

Appendix 2 Attribution of disability to disease

To obtain cause-specific disability proportions for the decomposition method data on disability by cause are needed. In case these are not available, they can be estimated from cross-sectional survey data on diseases and disability for each respondent. Here we explain how to estimate the contribution of each disease to disability from individual survey data on diseases and disability, using an additional hazard model. The method takes into account that: (1) people *without* a (specified) disease can have disability, (2) people can have *more* diseases (co-morbidity), and (3) diseases lead to competing risks of disability. First we explain the general Principles of the method, next we illustrate the method for a simple situation with only two diseases, and finally we explain how using a regression approach can sophisticate the method.

General Principles of the method

Starting point is individual information on age, sex, presence or absence of disability and presence or absence of specific (clusters of) chronic disease(s). Disability in persons *without* a disease is attributed to 'background'. Disability in persons with *one* disease is attributed partly to 'background' and partly to the disease, and disability in persons with *two (or more)* diseases is partly attributed to 'background', partly to each disease and partly to the combination of the two diseases (if co-morbidity is included in the model).

In order to attribute part of the disability to background and part to one or more (combinations of) diseases, we use a hazard transformation to convert the proportion of disability in a hazard of disability. This allows us to make use of the additive property of hazards, which brings along that the sum of all cause-specific hazards of disability for causes that are present and the background hazard equals the total hazard of disability. For instance, the difference between the total hazard in the group without any disease and that in the group with only disease A gives the cause specific hazard of disease A. Each combination of diseases has its own hazard of disability which is a sum of cause-specific and background hazards. For each subgroup we calculate the fraction of disabled persons attributed to a certain cause as the ratio of the cause-specific hazard and the total hazard for disability of the subgroup. Multiplied with the number of persons in this subgroup this gives the number of persons with disability caused by this disease in the group with this combination of diseases. Adding all these cause-specific numbers over all groups where the disease occurs gives the total number of disabled persons by this cause in the total population. The ratio of number of disabled persons by cause and the total number of disabled persons gives the cause of disability ratio. This is similar to the cause-of-death ratio, used in mortality analysis that gives the ratio between the number of deaths from a specific cause and the total number of deaths (in a specific age group).

We illustrate the general principle of the method for two diseases, A and B in one age-sex group (see Table 1). In a situation with disease A and disease B, the total population can be subdivided into four groups: (1) no disease , (2) only disease A, only disease B and (4) both disease A and B.

First, the total proportion of disability (π) is converted into a total hazard of disability, using:

$$\text{hazard (tot)} = - \ln (1-\pi)$$

By definition, this total hazard of disability equals the sum of cause-specific hazards, where both diseases and the background risk are considered as causes, or:

$$\text{hazard (tot)} = \text{hazard (backgr)} + \text{hazard (A)}.X_A + \text{hazard (B)}.X_B + \text{hazard (AB)}.X_A.X_B$$

Second, the cause-specific hazards are obtained by comparing the group with and without the cause (ceteris paribus). In a situation with two diseases and a background risk, there are at most 4 cause-specific hazards:

- hazard(backgr)   = hazard (tot)

- hazard (A)   = hazard(tot)-hazard(background)

- hazard (B)   = hazard(tot)-hazard(background)

- hazard (AB)   = hazard(tot)-hazard(background)-hazard (A)-hazard (B)

where hazard (AB) is additional hazard due to the combination of disease A and B.

Third, the proportion of each cause-specific hazard in the total hazard (i.e., cause-of-disability ratio) is used to divide the total proportion of disability (π) by cause.

- $\pi_{background}$ = π x (hazard (background) / hazard (tot))

- π_A = π x (hazard (A) / hazard (tot))

- π_B = π x (hazard (B) / hazard (tot))

- π_{AB} = π x (hazard (AB) / hazard (tot))

The calculation and interpretation of these cause-specific probabilities is similar to the crude cause-specific probabilities commonly used in mortality research (Manton and Stallard 1984).

The total proportion of disability is sum of cause-specific proportions:

π = $\pi_{background} + \pi_A + \pi_B + \pi_{AB}$

As disability increases rapidly with increasing age, generally age-specific disability proportions are used. Age-specific disability proportions by cause can be obtained by stratifying the population by age, and repeating the above-explained procedure for each group. However, this stratification has some disadvantages. First, hazards may be based on very small groups of people. This may lead to negative contributions if by chance the population with disease A and B has less disability than population group with A (or B). Second, each encountered combination of causes leads to a new hazard, and thus to a cause, irrespective of whether or not the hazard of the combination (here: AB, but with more diseases a large number of combinations exists), differs significantly from zero. These disadvantages can be avoided by using a regression model. Using regression, there is no danger of negative contributions, not all combinations of disease, but only (statistically) significant ones should be modeled, and more stable estimates are obtained, by smooting over age.

Regression model

For one age group and without co-morbidity, the additive hazard model is specified as follows in regression terminology:

$$\hat{Y} = 1 - \exp\left[-\left(\alpha + \sum_{cause} \beta_{cause} \cdot X_{cause}\right)\right]$$

where: $Y^{\wedge}$ is the estimated proportion with disability, α is the background hazard, β_{cause} is cause-specific disability hazard, e.g. hazard (A), X_{cause} is a dummy for the presence of disease.

The cause-specific disability hazard is the additional disability as compared to a person (of the same age) without that disease. For one age group, the regression-based additional hazard model gives identical results as the procedure just described. In this naive regression model, the disabling effect of diseases is same for all ages. Cause-specific hazards are estimated in a maximum likelihood model (with a binominal distribution for Y).

Information as to whether the disabling effect of the diseases generally is the same at all ages is not available from previous research. It is possible that the same disease causes more disability at older age than at younger age because diseases are more severe or individuals more frail.

To avoid the strong assumption that the disabling effect is the same at all ages, we allowed the disabling impact to vary with age. One possibility is to estimate the disabling effect for each disease for each age group. A more parsimonious way is to model the disabling impact by age. That is, rather than, we examined whether we could reduce the number of parameters in the model.

This simplification of the model involved:

1. Using a parameterization of the age pattern of the disabling impact, rather than using separate βs for each age group. The most simple way of parameterization is using a linear change (read: increase) of the disabling effect with increasing age. We used splines, which allow for departure from linearity. This occurs for instance when increase of disabling effect at younger age is less than increase at older ages. We use a quadratic spline with 3 turning points. In the sophistcated regression model β_{cause} is specified as follows:

$$\beta_{cause} = \gamma_0 + \sum_{spline} \gamma_{spline} \cdot A[3]_{spline} \cdot \delta_{cause}$$

2. We examined whether we needed a different parameterization of the age pattern for each disease. In case all diseases follow the same, or a few different age patterns, less parameters are needed to estimate the model.

3. We assumed independence between the causes of disability. However, this is not a necessary assumption. It is possible to add significant disease-by-disease interactions to the model. For the diseases for which an interaction term will be added it should be checked whether in both situations (i.e. disease without the co-morbid disease and with the co-morbid diseases) the overall age pattern(s) of the disabling effect are valid.

Looking at the most parsimonious model involves using a rather complex model structure, as for all diseases the disabling impact increases with age, and in addition for each age the ratio between cause-specific hazards is equal This is handled by using a 'factorial' model. This term is chosen because rather than a matrix with βs for each combination of disease and age, we use on vector for age (modeled with spline) and one vector for cause. Multiplication of the two vectors gives the elements in the matrix.

Output of the regression model

The regression model gives pure hazards by age. The proportion of each cause-specific hazard in the total hazard (i.e., cause-of-disability ratio) is used to divide the total proportion of disability (π) by cause in each age group. These prevalences by cause are used in the decomposition.

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