Selection of a Coherent Set of Health Indicators

Final draft

A First Step Towards

A User's Guide to Health Expectancies for the European Union

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Introduction

Section 1: Background to health expectancies

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Health expectancies provide a means of dividing life expectancy into life spent in various states of good and bad health. These measures represent the increasing focus on indicators of the quality of life lived (life spent in a healthy state) rather than, as previously, on the quantity (life expectancy). Health expectancies extend the concept of life expectancy to morbidity and disability. Health expectancies, in particular disability-free life expectancy, were first developed to address whether or not the lengthening in life expectancy is being accompanied with an increase in time lived in bad health.

The idea of health expectancy had been put forward by Sanders as early as 1964 and a first method of calculation had been proposed by Sullivan in 1971. Since then, health expectancies have been increasingly used in industrialized countries to assess the evolution of the populations' health status, in particular that of older people. Being independent of the size of populations and of their age structure, health expectancies allow direct comparison of the different groups that make up populations: e.g. sexes, socio-professional categories, regions. Thus, by means of health expectancies, countries may estimate health differentials between men and women, between the different socio-economic categories or among regions and over time. The subsequent calculation of potential gains in health expectancy through the simulated elimination of diseases makes it possible to define public health priorities according to the expected effects of this elimination on life expectancy, on disability-free life expectancy and also on life expectancy with disability. In addition the decomposition of differences in health expectancies would make it possible to explain differences between European countries, demographic groups or over time.

Today, estimates of health expectancy (generally disability-free life expectancy) are available for 49 countries (Robine et al, 1999), although direct international comparisons are difficult because of the varying definitions of disability used. When indicators are suitably harmonized across **Europe**, health expectancies will make it possible to not only make comparisons overall between European countries, but also to determine whether differences are due to differential mortality, disability or disease prevalence.

I. A general model of health transitions

Most of the calculations of health expectancy are based on a general model of health transitions that allows a direct assessment of the health consequences of increasing survival (WHO, 1984). It distinguishes between total survival, disability-free survival and survival without disabling chronic disease (Figure 1) and leads to the calculation of life expectancy (LE; area under the 'mortality' curve), disability-free life expectancy (DFLE; area under the 'disability' curve) and life expectancy without chronic disease (DisFLE; area under the 'morbidity' curve). The difference between LE and DFLE measures life expectancy with a disability (LEWD; area between 'mortality' and 'disability' curves); the difference between LE and DisFLE measures life expectancy with at least one chronic disease and the difference between DisFLE and DFLE measures life expectancy with at least one chronic disease but without disability. The sum of complementary health expectancies is always equal to life expectancy (LE), for example, disability-free life expectancy (DFLE), plus life expectancy with disability (LEWD) is equal to total life expectancy (DFLE + LEWD = LE). Health expectancies can also be divided. For instance, the ratio disability-free life expectancy to total life expectancy indicates the part of life expectancy lived without disability (generally expressed as a percentage).

Figure 1: The general model of health transition (WHO, 1984)
The observed mortality and hypothetical morbidity and disability survival curves for females
United States of America, 1980.
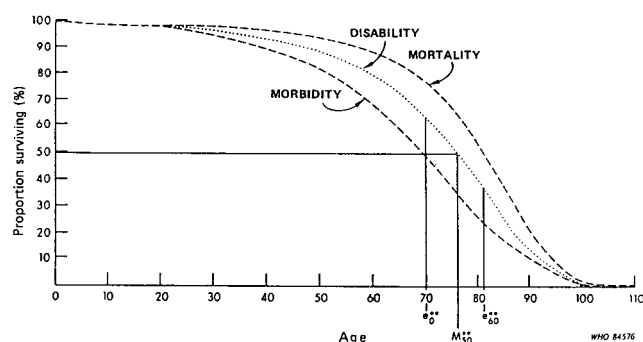
e_0** and e_{60}** are the number of years of autonomous life expected at birth and at age 60, respectively.
M_{50}** is the age to which 50% of females could expect to survive without loss of autonomy.

The relevance of this general model of health transitions lies in its ability to simultaneously assess the evolution of mortality, morbidity and disability and thus to assess the likelihood of different health scenarios which have been proposed: a pandemic of chronic diseases and disabilities (Gruenberg, 1977; Kramer, 1980), a compression of morbidity (Fries, 1980, 1989), contradictory evolutions including the scenario of dynamic equilibrium (Manton, 1982), or a postponement of all morbid events (diseases, disabilities and mortality) at older ages (Strehler, 1975).

Four possible health scenarios were identified by WHO (1984):

(1) rectangularization of the survival curve followed by compression of morbidity and disability in the older age groups - the survival curves without disease and without disability being very close to the total survival curve - corresponding to the compression of morbidity theory (Fries, 1980) - subsequently it has been established that a possible compression of morbidity does not necessarily depend on rectangularization of the survival curve but only on LE increasing less rapidly than DFLE (Palmore, 1987);

(2) only improvement in total survival - extending the life of those with disease and disability as well as extending survival into ages where disease and disability are more likely - corresponding to the pandemic of chronic disease and disability theories (Gruenberg, 1977; Kramer, 1980);

(3) a parallel displacement of the three curves towards the right - illustrating a modification of biological aging in terms of an increase in duration of biological life - corresponding to the theories of Strehler (1975);

(4) the case of relative independence in the evolution of the three curves, medical care or interventions being able, for example, either to delay the appearance of disease or to reduce their disabling consequences.

The first two health scenarios were specified further in 1993 with the following different cases: (1) if the value of life expectancy with disability (LEWD) decreases, there is an absolute compression of morbidity; (2) if the DFLE decreases there is an absolute pandemic of morbidity; (3) if the part of life with disability decreases without the value of LEWD decreasing (it may even increase) there is a relative compression of morbidity; (4) if the part of life without disability decreases without the value of DFLE decreasing (it may even increase) there is a relative pandemic of morbidity; (5) if DFLE/LE is constant there is an equilibrium (Robine and Mathers, 1993). Nusselder (1998) proposed a revised classification distinguishing between absolute compression and absolute expansion according to the change in the number of years lived with disability and between relative compression and relative expansion of disability according to the change in the percentage of years lived with disability. Thus any particular situation can be classified as a combination of absolute compression or expansion, combined with relative compression or expansion. It was only in 1995 after the introduction of severity levels in the model (at least two) that all four health scenarios could be described (Robine et al, 1995). Thus, Manton's (1982) theory of "dynamic equilibrium" corresponds to a scenario where the number of years lived with

disabilities - all levels taken together - increases, while the number of years lived with severe disabilities remains constant or even decreases within life expectancy.

II. Extension of the initial model to different health concepts

Since a health expectancy is in fact the combination of a life expectancy with a health concept, there are as many possible health expectancies as health concepts. From the initial model (WHO, 1984), several improvements have been proposed which increase the health information making up the family of health expectancies. Based on these developments, we can introduce the notions of physical, mental or social well-being (UN, 1946), models of disease consequences (WHO, 1980) and disability processes (Nagi, 1976; Pope and Tarlov, 1991), models of performance for daily living activities (Katz et al., 1963; Lawton and Brody, 1969; Johnson and Wolinsky, 1993) or successful ageing (Rowe and Kahn, 1987), and models of global perceived health (Johnson and Wolinsky, 1993 ; Ware, 1987) into health expectancy calculations. We can even introduce the notion of environment (Fougeyrollas et al., 1998).

We can thus compute indicators like life expectancy "in good perceived health" according to the WHO definition of health, or "disease-free" life expectancy, "impairment-free" life expectancy, "disability-free" life expectancy and "handicap-free" life expectancy according to the ICIDH framework. The "dementia-free" life expectancy, proposed by Ritchie in 1991, is a good example of disease-free life expectancy. In the field of mental health, general indicators of mental health expectancy have also been produced (Gispert et al., 1998; Mutavova et al., 1999). We can compute the life expectancy without loss of independence, known as "active life expectancy", according to the model of performance for daily living activities (ADLs, Katz et al., 1983). We can compute the life expectancy "without significant risk factor damage" (Manton, 1989) or more simply without "risk" (Rowe, 1990) to assess what we call "successful ageing" (Rowe and Kahn, 1997) and we can compute different life expectancies in favorable environment according to the handicap creation process framework (Fougeyrollas et al., 1998). Additional models enable the introduction of concepts such as survival without loss of autonomy (Grimley-Evans, 1983), survival without loss of robustness, or survival without loss of vitality (high functioning level). Furthermore, several levels of severity can be introduced for a single concept as most authors do for disability.

Any other carefully defined health criteria, allowing the partitioning of years lived, can be used, if necessary, to calculate a specific health expectancy. The flexibility of health expectancies makes it possible, for example, to calculate life expectancies within or outside institutions (e.g. nursing home). Using two or three of these indicators simultaneously allows us to check for expected or unexpected effects: for example to check that a decrease in the number or in the proportion of the years lived in nursing home (decrease in life expectancy within institution) is not paid for by an increase in the lifetime spent housebound or in social isolation.

The profusion of possible indicators makes it necessary to decide how to meet the main aim of the Health Monitoring Programme. 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 (see Section 2).

III. Further characteristics of health expectancies

Potential gains: Health expectancies may help public health priorities to be established through recognition of the relationship between elimination of disease and potential gains in, for example, life expectancy, disability-free life expectancy and life expectancy with disability. It has been shown that suppression of certain causes of morbidity, cancer for example, would strongly increase life expectancy without increasing disability-free life expectancy to the same extent and, therefore, would rather strongly increase life expectancy with disability. On the other hand, suppression of diseases that are not lethal, such as arthritis, would strongly extend disability-free life expectancy without changing total life expectancy, and therefore would strongly decrease life expectancy with disability (Nusselder et al., 1996).

Multivariate statistical techniques make it possible, using differing levels of disability severity and of the prevalent morbidity, to calculate the part of disability of a particular severity level, which is explained by a particular pathology (Boult et al., 1996). Thus not only can as many levels of severity as needed be used, but the methods also take into account the problems of co-morbidity. These techniques can be easily integrated into the calculation of potential gains in health expectancies (Nusselder et al., 1996). Decomposition techniques, as used

to analyse differences in mortality (between regions, subpopulations and over time) may be developed in the future for health expectancies.

Weighting system: There is no weighting system in the calculation of health expectancies, except the implicit weighting included in the basic calculation of life expectancy that generates its own age structure (that of the equilibrium population associated with the life table used). However, it is possible to include a weighting system based on severity levels (similar to that of QALYs) into the calculation of life expectancy, thus obtaining a health-adjusted life expectancy (HALE).

International comparisons: The calculations of health expectancies rely on observed data: period life tables together with prevalence of health states obtained from the results of censuses and various surveys (Living conditions, Health, Disability, Labour Force). This explains why, on the one hand, estimations of health expectancies are presently available for about fifty countries and why these estimations are not directly comparable from one country to another. Indeed, the characteristics of different national surveys, in terms of protocol, questionnaire or question formulation make direct international comparisons difficult if not impossible. **This is the major weakness of the present calculation of health expectancies** and justifies this Health Monitoring Programme project "Setting up of a coherent set of health expectancies for the European Union"

Section 2: Common reference framework

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The profusion of health concepts referred to in Section 1 clearly illustrates the multi-dimensional nature of both health and morbidity. The search for the perfect conceptual reference framework, permitting classification and linkage of all health "states" or "conditions" without ambiguity is therefore likely to be illusory. However the profusion of concepts also reflects the varied causes and mechanisms that allow an understanding of the transitions of health and, as a consequence, the means to meet health targets. Nevertheless, it is necessary to aim for a conceptual reference framework with maximum clarification, although imperfections will still exist.

This common framework will be based on 5 points: (I) a life-course definition of health; (II) the acknowledgement of different perspectives on health; (III) the acknowledgement of different approaches to assess health status; (IV) specific conceptual models for each approach; and (V) the acknowledgement of the specificity of the dimension of mental health.

I. A life-course definition of health

In contrast to mortality, notions such as health or morbidity are difficult to define. The **multi-dimensional** nature of health is empirically "defined" by the multiplicity of definitions, some of which are largely perceptual whilst others are largely functional. For example, for the WHO, "Health is a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity" (UN, 1946). Some definitions are more dynamic, for example, Canguilhem (1979) defines being in good health as also "the ability to fall ill and recover".

According to Fanshel and Bush (1970), health is a composite of **current state** and **prognosis** (i.e. the probability of movement to other states) that occurs throughout an individual's life. In this way health is not only, "*the ability to function now, but the outlook for future functional ability*" (Fanshel, 1972). This **life-course definition of health** is the justification for the use of the health expectancies as fundamental health indicators for populations since health expectancies measure the lifetime spent in different health states. In addition the use of multi-state life tables will provide the transitions between states.

But health is not always good or bad and it is well accepted that health is distributed in a **continuum** going from a state of perfect health to death. Each individual makes transitions between health states through his life, passing ultimately to death. This raises problems of norms and thresholds when defining a bad state of health (morbidity in the strict sense of the word) or good health (sometimes referred to as positive health). Negative states of health must be classified to distinguish between the most severe and the most minor. The number of classes will inevitably be a compromise between precision and conciseness. One example of this is health surveys which measure perceived health: "*How is your health in general? Very good, good, fair, bad, very bad*"(de Bruin et al., 1996).

II. Different perspectives on health

The health status of the population can be described in different ways by subjects themselves, researchers, financial administrations, or associations. The basic information - the individual health status - may be perceived, diagnosed or measured by different people before being reported by the individual himself (self-report), a family member (proxy, caregiver), a professional (nurse or doctor) or an administrative clerk. Self-reported morbidity largely corresponds to the morbidity recorded by health interview surveys.

Diagnosed morbidity corresponds to morbidity known by health professionals and testifies to their activity. **Measured** morbidity corresponds to systematic measurements of a representative sample of the population studied through health examination surveys for example. The morbidity **perceived** by the individual himself most closely approaches the idea of need felt by the population. Alongside these three classic levels, **behavioural morbidity** is often mentioned - a concept defined through examples such as absenteeism or the recourse to medical care or medication - which does not integrate well within the classic scheme outlined below.

Perceived morbidity is often qualified by subjective morbidity and measured morbidity by "objective" or "real" morbidity, although it is clear that a report at any level, perception, diagnosis or measurement, may contain a subjective element.

III. Different approaches to health status assessment

In this century the epidemiological framework has changed: from communicable and acute diseases to long-term chronic diseases. This epidemiological trend has affected the approach to diseases and health. Beyond the "**presence or absence of disease**", the classical **bio-medical approach**, health status may be assessed through perceptual, functional or adaptive approaches (Goldberg al, 1979a and b). With the **functional approach**, good health relates to ideas of effective achievement of roles and tasks, the fulfilment of different human activities without difficulty. With the **perceptual approach**, good health relates to ideas such as well-being, a happy attitude to life, or else a full, fruitful and creative life. And with the **adaptive approach** to health, good adaptation testifies to a harmonious relationship with ones environment.

IV. Specific conceptual models for each approach

Each approach to health is defined by one or several conceptual models. We shall now look in more detail at each approach and the conceptual models contained therein. Minaire (1992) observed that in the second half of this century, the notion of health has changed: from "survival", through "freedom from disease" and "individual's ability to perform daily activities" to the current notion of health as "well-being (quality life)".

1. The bio-medical approach

The biomedical health model developed in the late eighteenth century when scientific medicine grew and people trusted completely in the healing power of medicine. The approach found favour with the advances in bacteriology, immunology, surgery, diagnostics and particularly progress in pharmacology. The analytic-descriptive approach to diseases played a key role: diseases were considered as separate items, and expertise was highly specialised and divided to meet the requirements of diseases.

This approach has been criticized for its compartmentalization and oversimplification. In the biomedical approach, the body is the key element, determining health or illness. Psychological and social issues are barely acknowledged although a biopsychosocial model has been proposed to address this (Engel, 1977). Mental illness represents a grey area between physical health and illness. In this model, health is described as an absence of disease. Health-disease are two opposites and not two endpoints of the same whole. The disease develops along a clear cause-effect path, such that health recovery is determined by disease-treatment. Treatment is centred on the disease, while mental, emotional or physiological conditions of the individual are independent. Finally according to this approach only health professionals can heal and recognise diseases (diagnoses) and decide treatment while patients should only passively follow the professional's recommendations. However, defining bad health by the presence of disease worked well when the most common diseases were infectious diseases with known aetiologies.

With epidemiological change and keeping the biomedical model approach to health, biological or physical causes determine disease resulting in a clinical picture, partial or total impairments and/or functional limitation of the individual. This disease/disability model is the basis of the original ICIDH framework (WHO, 1980) and is dealt with in detail in the next section (The functional approach).

2. The functional approach: The consequences of disease and concepts of disability

The functional approach to health is mainly addressed by four models which do not fit together well: the model of disablement process (Nagi, 1991; Jette AM, 1997), the model of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH, WHO, 1980), the model proposed for the revision of the classification, the International Classification of Impairments, Activities and Participation (ICIDH-2, Version beta-2, WHO, 1999), and the model of handicap creation process (Fougeyrollas et al., 1998).

A first conceptual clarification of terms concerning the consequences of disease and disability was proposed by Nagi (1965) with revisions in 1976 and 1991. Nagi distinguishes between four phenomena of which the first is active pathology or disease. Impairments are defined as anatomical, physiological, intellectual or emotional

abnormalities or losses. Nagi noted that if all disease implies an impairment, all impairments do not imply a disease in the sense of active pathology. Functional limitations are limitations in performance at the level of the whole organism or person and comprise three dimensions - physical, emotional and mental. Physical refers to sensory motor functioning of the organism as indicated by limitations in such activities as walking, climbing, bending, reaching, hearing, etc. (Nagi, 1976). Disability concerns inability or limitations in the fulfilment of activities and social roles in relation to work, the family and an independent life (Nagi, 1991). Today, this conceptual model is known as the model of the disablement process (Jette, 1997).

The International Classification of Impairments, Disabilities and Handicaps (ICIDH) of the WHO (1980) (Figure 2) is a classification of the consequences of disease essentially developed by Wood (1975) as a supplement to the International Classification of Disease (ICD). There are four levels - diseases or disorders, impairments, disabilities and handicaps. These distinctions correspond to the succession of events that may occur following disease: (1) an abnormality appears within the individual - the disease; (2) one becomes aware of the fact and exteriorises the pathological state - the impairment(s); (3) the individual's ability to act or behave is altered, the disability reflecting the consequences of impairments in terms of functional performance and activities of the individual - the pathological state is objectivized; (4) the perception of the disability or the alteration of behaviour or functioning which results from it leads to a handicap for the affected individual - the pathological state is socialized by the handicap.

Figure 2: International Classification of Impairments, Disabilities and Handicaps (ICIDH): Integration of concepts (WHO, 1980)

Disease or disorder > Impairment > Disability > Handicap
(Intrinsic situation)   (Exteriorized) (Objectivized) (Socialized)
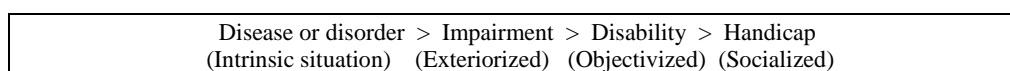
Following the WHO, impairment corresponds to any loss or abnormality of psychological, physiological or anatomical structure or function; disability corresponds to any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being; and handicap or social disadvantage for a given individual results from an impairment or a disability that limits or prevents the fulfilment of a normal role (depending on age, sex and social and cultural factors). Handicap is characterised by discordance between the activity and status of the individual and the expectations of his social environment (WHO, 1980).

In his original work in 1975, Wood clearly introduced a sequence of five levels: (1) disease, disorder or injury, (2) impairment, (3) functional limitation, (4) activity restriction, and (5) handicap. This scheme (Figure 3) is often preferred by those concerned with international comparisons as it has the merit of clarifying the limits between impairment and disability on one hand, and between disability and handicap on the other. Thus, a difficulty concerning actions such as "bending" or "reaching an object" is a functional limitation, while difficulties concerning activities of daily life (dressing or domestic chores) are activity restrictions (European Council, 1990; Chamie, 1990).

Figure 3: Disablement Process, initial diagram by Philip Wood, 1975

Disease > Impairment > Functional limitation > Activity restriction > Handicap
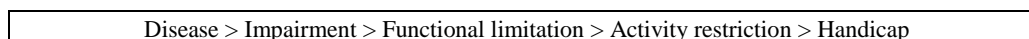
All these boundary difficulties help to justify the revision process of the ICIDH currently being carried out that will end in a new version in 2000/1 (see the special edition of Disability and Rehabilitation, 1995). Within the official revision framework, a particular effort concerns the applicability of concepts of disability to the area of mental health (Ustün et al., 1995). One of the main concerns of the revised ICIDH is that it avoids a false dichotomy between the brain and the body. The current definitions of the different concepts need clarification in terms of their content and their boundaries. Thus impairments apply both to structures and functions (Brandsma et al, 1995). Disability simultaneously concerns abilities and activities; abilities being abstract aptitudes while activities are the observable performances. Finally handicap refers both to "social" circumstances that prevent the individual achieving his activity, and to the individual level (Ustün et al, 1995).

In the present state of revision of the ICIDH-2, now called the International Classification of Functioning and Disability (Beta-2 full version July 1999), "functioning" and "disability" are umbrella terms covering the three new dimensions: (1) body functions and structure; (2) activities at the individual level; and (3) participation in society. The Body dimension comprises two classifications: one for functions of body systems, and one for the

body structure. The Activities dimension covers the complete range of activities performed by an individual, with the chapters organised from simple to complex activities. The Participation dimension classifies areas of life in which an individual is involved, has access to, has societal opportunities or barriers, the domains being organized from simple to complex areas. Functioning and disability are conceived as dynamic interactions between health conditions and contextual factors, the contextual factors including both personal and environmental factors (Figure 4).

Figure 4: International Classification of Functioning and Disability (ICIDH-2)
(WHO, 1999)
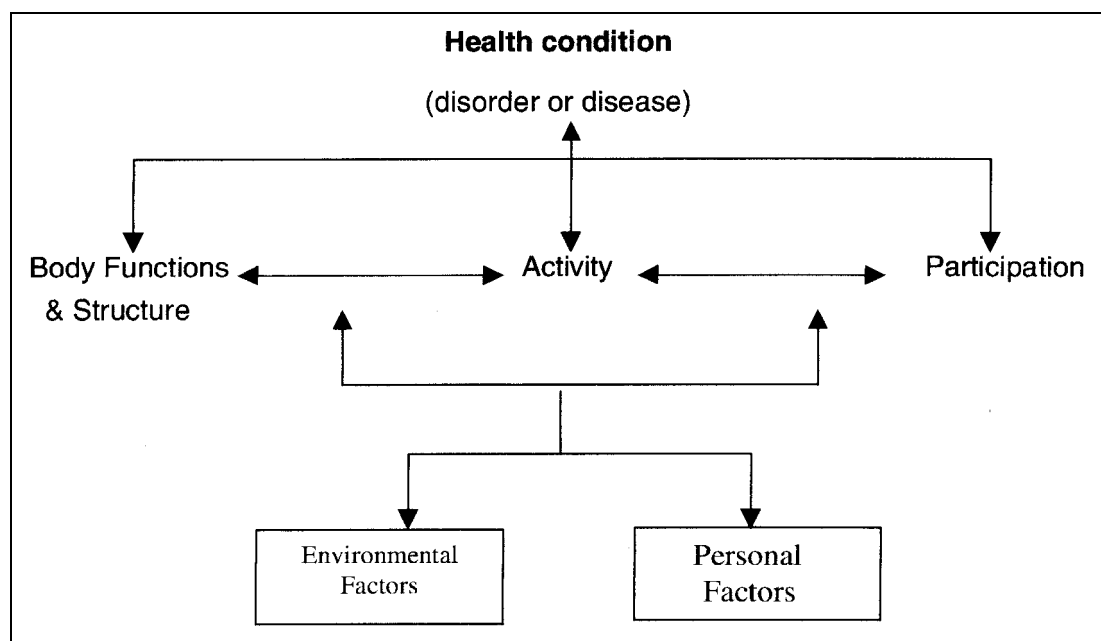
During the revision process, an alternative model was devised, establishing the importance of the environment in the creation of participation or handicap (Fougeyrollas et al., 1998). This model of handicap creation puts the interaction between personal factors (organic systems and abilities) and environmental factors (facilitators or obstacles) at the heart of the model, the result of the interaction being handicap situations (life habits). Risk factors (causes) are associated with personal factors, organic systems go from integrity to impairment and abilities go from ability to disability.

Handicap has often been incorrectly identified with dependence. Physical dependence of old people is an old concept in the field of gerontology (Katz et al, 1963). The current classification of handicaps, WHO (1980) notes that while it is important to have fundamental independence in physical and material activities, the integration of handicap in the term "dependence" obscures the social needs. Grimley Evans (1983) underlined that independence should not be confused with autonomy. Autonomy is the facility to set one's own rules, meaning to decide what one wants to do, while the idea of independence refers to the independent realisation of a whole series of activities. Thus a person dependent on another for his movements can remain autonomous, for example, if he retains the decisions regarding his itineraries. This distinction is essential for surveys regarding disabilities, particularly if mental impairments are to be correctly understood.

In this work, we come back to the distinction proposed by Wood between functional limitations and activity restrictions. Indeed, recent studies have suggested the possibility of using the measurement of the body functional limitations (including the brain) as a predictor of future activity restrictions in daily life; such a "two-step" indicator could be used to screen for potentially disabled people whose functional problems may be solved earlier and perhaps more easily; thus viewing such functional limitations as a "pre-clinical disability" level (Fried et al, 1996; Lawrence and Jette, 1996). Multi-regression models of the determinants of disability (i.e. activity restriction) have clearly shown the importance of functional limitations in the disablement process that leads to the further stage of activity restrictions: an appropriate acknowledgement and care supply for the intermediary

stage of functioning damage could avoid a heavier caring for disability in activities of daily life (Lawrence and Jette, 1996; Fried et al, 1996; Harwood et al, 1998). A step forward in this respect are the results of studies such as those by Lawrence and Jette (1996), which have highlighted the importance of lower body functional limitations, compared to other limitations, in the disablement process. This corroborates the findings of Wolinsky and Johnson (1991), namely that problems with lower body functions generate much more health services utilization than problems with upper body functions. This two-step approach can open research towards new methods of measuring functional health of populations using functional limitation and activity restriction as two levels at which public health action could intervene.

Therefore, functional limitation and activity restriction do refer to different levels of disability leading to different types of consequences in daily life, and towards which different public health actions can be addressed. This distinction is not straightforward, especially because existing measurement instruments are most of the time combining these two levels and rely on apparently similar questions. Clarification is needed at this level.

The activity restriction is assessed by difficulty or impossibility in performing activities which are considered as essential to accomplish a social role in the society, such as, for instance, personal care activities ensuring own minimal independence in daily life (feeding, bathing, dressing...). The functional limitation is located at the level of the body and its functioning. At this level one does not intend to measure the difficulty in the performance of activities that are essential in individual's life, but to test for declining functions that would either prevent individuals who suffer them from normal performance of essential activities or lead them to compensatory strategies for lessening the loss of these functions. In health interview surveys, functional limitations are not tested as they might be in examination surveys. The presence of functional limitations is determined by placing the subjects being interviewed in common situations requiring movements (or actions) that acknowledge specific body functions, and by asking about the ability to perform them: the ability to grab, or to climb stairs, or to turn taps, etc.

Detailed definition of the concepts and measurement instruments for physical and sensory functional limitations and specific activity restrictions (personal care activities) are presented in chapters 1 and 2 in Part 1. In Chapter 3, we present an instrument aiming at targeting the global activity restriction in the population.

3 The perceptual approach

The need to elicit an individual's own assessment of his health has been recognized in the notion of self-perceived health. Although there are several terms that would seem interchangeable it is more relevant to use the terms that emphasise the notion of an assessment coming from the individual and not from anyone outside that individual. Thus the use of the term "self-perceived health" is preferred and it is assumed to be equivalent to terms used by other authors in the same context (self-rated health, self-defined health and self-assessed health). Furthermore, "self-perceived" health has to be clearly distinguished from "self-reported" health. It is known that, in some circumstances, what is perceived (or felt) by the individual and what is reported are not always the same, being influenced by culture, age and gender. This is the case, for example, for the tendency to respond differently by gender due to the accepted traditional "role" for women (in Latin countries) where it is assumed "normal" to have complaints about one's own health although, for men, the opposite is expected.

Although concepts of health and health related quality of life are very different notions (because the models in which those measures developed imply fundamental differences), the ways in which the measures are operationalized have important similarities. We can distinguish between two different approaches to the concept of self-perceived health, one in the context of the model of Consequences of Disease (CoD) and the other, in the framework of Health Related Quality of Life (HRQL).

By the CoD model we refer to further developments of the concept of health based on the bio-medical approach. This approach, described earlier, also supported the first ICIDH classification (Wood, 1975; WHO, 1980; Figure 2) and other conceptualisations about the disablement process. In the CoD model, self-perceived health refers to an extension of the continuum, from disease to the global perception of health through physiological impairment, functional limitations (sensory, mental or physical) and activity restriction (Figure 5). In this case perceived health is a state resulting from other states, reflecting the global health status of the individual. In this scheme, perceived health appears to be a subjective judgement on the overall situation, taking into account disease, functional limitation and activity restriction.

**Figure 5: Consequences of Disease Model
(adapted from Johnson and Wolinsky, 1993)**
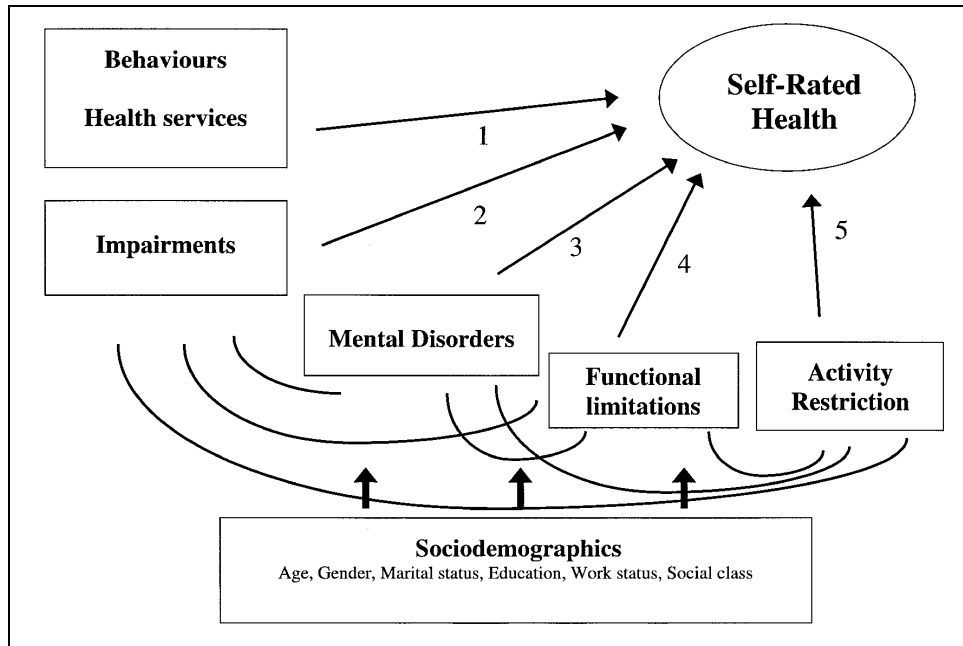
One refinement of this approach establishes that a global self-assessment is based on the assessment (internally by the individual) of specific health problems (including physical functioning, health behaviour, etc.) (Krause, 1994). This is influenced by demographic and cultural variables and by individual expectations. It is not only influenced by functional limitation or activity restriction, but also by "sub-clinical" or symptomatic states, providing a "holistic" approach to the concept of health.

**Figure 6: Theoretical relationships among Health-Related Quality of Life (HRQL) concepts
(Patrick and Bergner, 1990).**
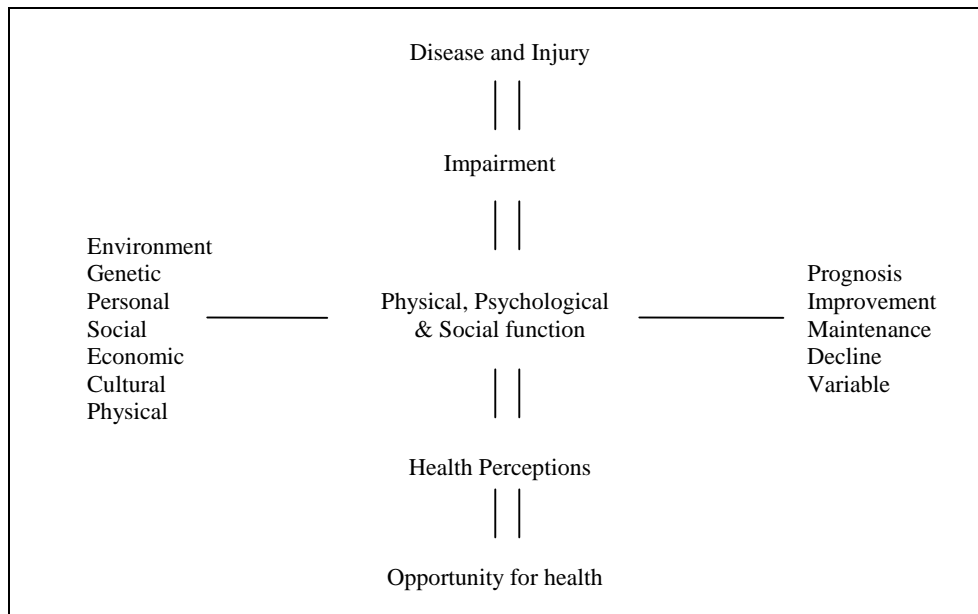
In contrast to this concept of global health status, Health-Related Quality of Life (HRQL) can be defined as the value assigned to the duration of life as modified by the social opportunities, perceptions, functional states and impairments and as influenced by disease and injury (Patrick and Bergner, 1990) (Figure 6). According to this definition covering five broad concepts, the value assigned to the HRQL lies on a continuum anchored at the top

by an optimal value of 1.0 and at the bottom by a minimal value of 0. Specific concepts (opportunity, perception, functional status, impairment and disease) contribute to the value.

In this approach, health perceptions fall between "functioning" and "opportunity for health". Furthermore, in HRQL measures, the items assessing self-perceived health are usually included in a more comprehensive instrument (including other health concepts) providing, in some cases, a single score summarising the HRQL of the individual (for example, EuroQOL, 1990).

Nevertheless, in both approaches, the concept of health perception is measured in a similar way, the most common being the self-assessment by means of one simple question relating to current health, taking into account health expectation and/or comparisons relative to peers. These measures are based on the notion that "your health is what you think it is" (Ware, 1987). Furthermore, the use of self-perceived health items is supported by several arguments: functional performance measures have not shown consistent superiority to self-assessment measures; personal experiences and feelings are not captured by functional items; the measure of limitations or restriction are inherently negative whereas self-perceived health extends the measures to more positive levels of well-being (Ware, 1987). Chapter 4 of Part 1 describes the concepts of this perceptual approach and related measurement instruments of self-perceived health.

V. The specificity of the dimension of mental health

In public health terms, people with mental illness constitute a particularly vulnerable sub-group; they have high rates of dependency and social exclusion, may require that decision-making be assumed for them through legal process, are at increased risk from death due to accidents and other causes, are at increased risk of physical and mental abuse, and engender high rates of morbidity in care-givers. Although mental health has emerged as a prominent problem in health surveys since the 1980's, the monitoring of health status at the population level has been confined almost exclusively to states of physical health largely due to concerns that definitions of mental health states were likely to be particularly problematic. Case detection of mental illness remains a central problem (Kay 1990; 1993). There have been significant advances in recent decades in our understanding of the biological mechanisms underlying mental disorder, however, research designed to isolate specific biological markers remains both inconsistent and inconclusive. At a clinical level competing conceptualizations of mental illness and reliance on non-specific behavioural indicators of dysfunction have led to considerable disagreement at the levels of nosology, differential diagnosis and management. Psychiatric illness in Europe is both under-diagnosed and under-treated.

The World Health Organization and the American Psychiatric Association have recently made significant contributions towards the standardization of nomenclature and diagnostic criteria through the further development of two international classification systems; the International Classification of Diseases (ICD10) and the Diagnostic and Statistical Manual of the American Psychiatric Association (DSM-IV). As a result, research applying these algorithms shows greater consistency even across cultures. The original International Classification of Impairments, Disabilities and Handicaps (ICIDH) has provided a useful international framework for the conceptualisation of disability, however its application to the area of mental health has been problematical due principally to the lack of a conceptual basis for the classification of central nervous system impairments and cognitive limitations. Currently, the U.S. National Institutes of Health and WHO are jointly attempting to better adapt the revised version, ICIDH-2, to the problems of mental illness. The development of cross-cultural population indicators of mental health is now widely considered to be feasible provided workers in this area are prepared to adhere to these common classification systems (Ritchie, 1994; Roelands and Van Oyen, 1994).

Although the World Health Organisation in its influential document "Health For All" published in 1980, has underlined the importance of mental health issues, calling for a "sustained and continuing reduction in the prevalence of mental disorders", this has not been carried over into national policy. Few national health policy documents refer to mental health, and in the few instances where this occurs, this has mainly concerned suicide rates. There are a number of European initiatives beginning in the area of mental health although good co-ordination will be necessary to make these effective. The mental health problems which have been a common focus of research in most western countries are depression and anxiety disorders due to their high prevalence, schizophrenia and other psychotic states which require periods of institutionalization, suicidal behaviour and eating disorders due to their risk of mortality, and substance misuse due to its increasing incidence and its

association with social conditions. Clinical research in psychiatry has given an increasingly important place in recent years to psycho-geriatric disorders that are likely to significantly increase in prevalence in parallel with population ageing.

The senile dementias have been a particular concern since they are likely to reach epidemic proportions as average life expectancy continues to rise. In 1987, Ineichen warned of a "rising tide" of dementia in Britain and predicted a 5 to 17% increase in dementia prevalence by the year 2001. Applying a linear model of the relationship of dementia to age derived from a meta-analysis of epidemiological studies using DSM-III diagnostic criteria to recent population projections, Ritchie and Robine (1994) have shown that, between 1990 and 2020, the French population will increase by 58% but the prevalence of dementia is estimated to increase by 89%. The average life expectancy of an elderly person with early senile dementia is around eight years. This time is spent in a state of progressive dependency for both activities of daily living and decision-making functions (loss of autonomy). Even small changes in the duration of disease will thus have a significant impact on the demand for both domiciliary and institutional services (Ledésert et al., 1994).

Summary

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 European populations (e.g. sexes, socio-professional categories, regions or countries) as well as the estimation of changes over time. The subsequent calculation of potential gains in health expectancy, brought by the simulated elimination of different diseases, gives relevance and definition to public health targets and priorities. The relevance of health expectancy indicators lies in their ability to simultaneously assess the evolution of mortality, morbidity and disability and thus to assess the likelihood of different health scenarios which have been proposed: "a pandemic of chronic diseases and disabilities", "a compression of morbidity", or contradictory evolutions including the scenario of "dynamic equilibrium".

Since health expectancy is in fact the combination of a life expectancy and a health concept, there are as many possible health expectancies as health concepts. The profusion of possible indicators makes it necessary to decide how to meet the main aim of the Health Monitoring Programme. **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.** The calculations of health expectancies rely on period life tables together with prevalence of health states obtained from the results of censuses and various health surveys. Indeed -in practice- the current differences in national surveys make direct comparisons difficult. **This lack of European comparability is the major weakness of the present calculation of health expectancies** and justifies this Health Monitoring Programme project "Setting up of a coherent set of health expectancies for the European Union".

Defining a common reference framework

The profusion of health concepts, clearly illustrating the multi-dimensional nature of health, makes 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 the health expectancies as fundamental health indicators for populations since health expectancies measure the lifetime spent in different health states. The health status of the population can be described from different perspectives: **self-perceived** (approaching the idea of need felt by the population), **diagnosed** (testifying the activity of the health professionals) or **measured** (corresponding to systematic measurements) before being **reported** by the individual himself (self-report), a proxy or a health professional. **Self-reported** morbidity largely corresponds to the morbidity recorded by health interview surveys.

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. The key elements are **impairments** (at the level of organ or system), 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). Impairments and functional limitations characterise the individual health status (physical, sensory or mental) resulting in **global** or **specific** activity restrictions. Current activities in daily life bring together, at the same time, physical, sensory and mental abilities and thus an activity restriction poorly indicates a specific physical, sensory or mental problem. In addition a distinction between **autonomy** (the facility to set one's own rules) and **independence** (the independent realisation of a whole series of activities) is essential if mental health problems are to be correctly understood. The distinction between functional limitations and activity restrictions opens research towards new methods of measuring disability. Functional limitations as a predictor of future activity restrictions allows public health intervention earlier thus preventing the heavier caring burden resulting from activity restriction in daily life. **At present, this is not possible since existing measurement instruments do not make this distinction**.

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 should be clearly distinguished from self-reported health since, what is perceived (or felt) by the individual and what is 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. These may include not only disability, but also sub-clinical conditions, providing a holistic approach to the concept of health. In the context of Health-Related Quality of Life (HRQL), self-perceived health is only one contributor among others and is usually included in a more comprehensive instrument leading eventually to a single score summarising the HRQL. In both cases, the concept of self-perceived health is similarly measured through a single question relating to current health whilst taking into account health expectation and/or comparisons relative to peers. **The use of self-perceived health items is supported by several arguments: being a strong predictor of institutionalization or mortality whilst also capturing personal experiences and feelings**.

Population indicators of **mental health** are currently being developed especially because it is felt that mental disorders in Europe are under-reported, under-diagnosed and under-treated. The mental health problems which have been a common focus of research in most western countries are depression and anxiety disorders due to their high prevalence and psycho-geriatric disorders, such as dementia, that are likely to significantly increase in prevalence in parallel with population ageing.

The remainder of the report is in three parts. Part 1 will focus on the selected instruments (including their policy relevance) corresponding to the perceptual and functional approaches to health, together with a special chapter devoted to the area of mental health. In Part 2 we detail the methods of calculating health expectancies from these instruments. In addition, we present a method to rank the burden of diseases according to the potential gain in health expectancy arising from the elimination of specific disease. Finally Part 3 contains all the alternative instruments examined during the process of selection.

Part 1: Health expectancies for the European Union

Preface

At a superficial level, it could be thought that the health surveys in Europe all cover the same fields and often use the same questions. However a deeper analysis, in conjunction with current scientific research, underlines the significant differences that exist in the wording of the existing questions. We have not found any particular reason why countries choose one form of question over another. Instead we think that the main reason for the variety of question forms 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;

Our proposals acknowledge both these issues. Wherever possible, unless there is confusion with the current concepts of the field, our instruments are based on existing recommendations. This is the case for two of the five instruments proposed: "perceived health" where the question chosen is that already recommended by the WHO-Euro and "mental health" where the chosen instrument is the General Health Questionnaire (12 item version), also already recommended by the WHO-Euro. For these instruments we therefore propose the next step is a validation stage to ensure equivalence in questions between countries. 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. For the general question on disability, we propose the first international standard – a Global Activity Limitation Indicator, or GALI- presented in this volume. In the next volume planned for 2001 we will propose the first international standard on chronic morbidity.

In this volume, we make proposals for five instruments: (1) a general question about functional limitations, (2) a general question about perceived health, (3) a set of specific questions on physical and sensory functional limitations, (4) a set of specific questions on personal care activities and (5) a set of specific questions on mental health. To supplement these we propose six further indicators which will be the subject of the second volume, in 2001, at the end of the second phase of our project (6) a general question about chronic morbidity, (7) a set of specific questions on chronic morbidity, (8) a set of specific questions on cognitive functional limitations, (9) a set of specific questions on household activities, (10) a set of specific questions on other activities of daily living and finally (11) a set of specific questions on perceived health. This will then give us a coherent set of 11 instruments leading to many health expectancies covering the totality of the conceptual framework of the measurement of population health.

This number seems to us 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 countries of the Community, 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 perceived health. For each explored aspect we will attempt to present a global approach and a specific one. The global approach (chronic disease, disability, perceived health) aims to provide an overview of the field, thus capturing all the existing differences on this issue between the countries, whether they are due to " real " health problems, problems of social organization or cultural questions. The specific approach aims to explain the differences between the countries of the Community. 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 between countries.

The publication of this guide will disseminate our proposals and allow them to be discussed as widely as possible. The indicators have been compiled by teams of researchers from all the Community countries and a first consultation with policy-makers underlined the relevance and acceptability of the proposals.

The final, and perhaps the most important, step for these proposals to become European standards for the European Health Monitoring System is that, after acceptance in principle by the Commission, they will need to be validated to pass from a standard in the English language to as many comparable instruments as countries in the Community.

Introduction

The aim of Part 1 is to present and then to justify the recommended instruments we propose to be introduced into the European surveys, to facilitate the calculation of complementary and harmonized health expectancies. Within the conceptual framework outlined in the introductory section, we will focus on body functional limitations, activity restriction, perceived health together with special attention to the area of mental health. We have selected, according to their policy relevance, a set of five instruments corresponding to these concepts: a set of items covering *physical and sensory functional limitations*, a scale of *Personal Care Activities*, a *global activity restriction* indicator, a *global self-perceived health* indicator, and a set of items specifically measuring *mental health*.

Part 1 contains five chapters, one for each instrument, following the same format. First we briefly present the proposed instrument including conceptual and operational definitions, policy relevance and utility, selected descriptors and suggested wording. Secondly, we present, in more depth, the background underlying our choice including, past research and previous recommendations on the instrument and the underlying concept, current practice within Europe through a census of existing instruments and the essential characteristics, for instance wording, for the validity of the proposed instrument.

Current international recommendations:

In addition to the OECD Common Development Effort on Disability Measures (McWhinnie, 1981), as a part of Health for All, the Regional Office for Europe of the WHO has recommended common health instruments that should be introduced into European Health Interview Surveys (WHO-Europe Consultation 1988, 1990 and 1992). These attempts at harmonization have been welcomed although the implementation has been inefficient due to the lack of: guidelines on how to implement the recommendations in a specific country including a lack of any recommendation on the translation process and its validation; follow-up to discuss problems in implementation; any validation of the recommended instruments including peer-reviewed publications in the scientific literature. As a result there has been uncontrolled amendments of the instruments (in question wording, selection of items, change in response categories, etc.) in many countries by professionals who were not made aware of the implications of any changes that they made. However recent scientific work, dealing with the validity of instruments similar to those recommended, has highlighted the importance of these issues and we have benefited from this in selecting our instruments.

Although based on the OECD or WHO-Europe recommendations where possible, our instruments for the Health Monitoring Programme build on the most recent scientific work. However, rather than simply presenting the chosen instruments, this report aims to guide the implementation in the European Union, starting with basic validation of translated instruments in each country. It is only after this validation that the wording of instruments can be finalized and recommended.

National practice within Europe:

Most of the European countries run regular health interview surveys to monitor population health though few produce truly comparable information. The longest established surveys, such as the UK General Household Survey, began before the current desire to harmonize health information within the European Union; as a result the countries with the longest experience are the most reluctant to implement the recommended instruments. Secondly, the relevance of the previously recommended instruments was not always obvious to policy-makers who did however know the utility of their own national instruments. In addition, OECD and WHO-Euro did not recommend specific study designs to contain their instruments, thus producing a further obstacle for comparability of the collected information.

Today, with the growing political force from within countries to compare their population's health with that of their neighbours, the differences between surveys in study design as well as questionnaires is better known. The census of European health surveys conducted by Eurostat has shown the wide variation in response rates (non-respondents are often those with health problems), management of missing data, inclusion/exclusion of institutionalized population, age ranges covered, mode of data collection (face to face, self-administered, by telephone) and selection of respondents (proxies, self respondents, or both). Even with the use of common instruments, differences in any of these issues may produce differences in the prevalence of the health states assessed.

Basic requirements of future recommendations:

Any instrument recommended to facilitate international harmonization, should have relevance for policy-makers at the national level. 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.

Policy relevance and coherence of the proposed set of health expectancies:

During the last few 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. In further examining the individual European surveys, we in Euro-REVES, as others, have been struck by the initial similarity of instruments used. This at least demonstrates a will within Europe to harmonize health surveys, thus recognizing the benefits in making comparisons between counties. The implementation of health policies at the level of country cannot by evaluated using standard evaluative techniques but comparisons between countries can at least help us to learn from each other.

However, although current health surveys appear harmonized at a superficial level, our in-depth analyses show that major differences exist, even when countries have appeared to select the same recommended instruments. These differences stem from the lack of rationale behind the recommended instruments with little obvious reference to the health concepts behind them, together with a lack of guidance to countries in how they should be implemented in surveys. These omissions have important repercussions for policy relevance. If countries cannot see the relevance for health policy of adopting particular recommended instruments for themselves or are not guided as to how to implement them easily in surveys, including the degree to which they can and cannot be altered, harmonization across the European Union will never occur. The instruments we recommend have been firmly anchored to past scientific research and the health concepts behind them, their relevance to policy and guidelines for implementation are explictly made.

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 provide an overview of the field, thus capturing all the existing differences on this issue between the countries, whether they are due to " real " health problems, problems of social organization or cultural questions; secondly, a more specific instrument to explain the differences between the countries of the Community.   At present we have recommended two of the five global indicators and three more specific ones.

In this volume, we make proposals for five instruments: (1) a general question about functional limitations, (2) a general question about perceived health, (3) a set of specific questions on physical and sensory functional limitations, (4) a set of specific questions on personal care activities and (5) a set of specific questions on mental health. To supplement these we propose six further indicators which will be the subject of the second volume, in 2001, at the end of the second phase of our project (6) a general question about chronic morbidity, (7) a set of specific questions on chronic morbidity, (8) a set of specific questions on cognitive functional limitations, (9) a set of specific questions on household activities, (10) a set of specific questions on other activities of daily living and finally (11) a set of specific questions on perceived health. This will then give us a coherent set of 11 instruments leading to many health expectancies covering the totality of the conceptual framework of the measurement of population health. We have thus focussed at present on the broad areas of functional limitations, activity restriction, perceived health and mental health. As well as their inclusion in current health surveys, attesting to their relevance, these broad areas, the instruments recommended and even the reasons for our choice of response categories are defined in terms of their relevance to health policy.

Currently, public health is strongly concerned with the future need for assistance, expected 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. The global instrument we propose provides policy makers with easily obtainable information on the perception of limitations that could result in a need for support. The more specific intruments 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. Measuring activity restriction not only allows us to assess the consequence of health problems (disease or accident, impairment or functional limitation) on daily life activities but also, provides the possibility of preventing activity restrictions by targeting specific functional limitations. Analysed in conjunction with information on functional limitations, activity restrictions allow us: first to describe the disablement process and the mechanism of the transition between health states; second to recognise possible compensatory strategies, and third to shed light on risk factors and health inequalities by differentiating between those with functional limitations who are restricted in activities and those coping with their limitations. It will be possible with the response categories chosen to determine whether differences between countries are due to the extra provision of aids or adaptations, different social structures providing more personal support, or whether there are intrinsic differences in levels of disability.

The area of self-perceived health is important because of its complementarity to 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.

Mental disorders are now recognized as one of the principal causes of disability and consume a significant proportion of the health budget in western countries. The WHO, has already set a series of specific targets for improving health and, in relation to mental health in Europe and a number of individual European countries have also individually set targets for mental health. However, despite these targets, health surveys have not commonly included intruments 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 recommended an instrument with a strong scientific background and use to help overcome some of these problems.

Our choice of domains and instruments provides a coherent yet comprehensive coverage of population health, making it possible at the same time to measure the extent of the differences in health between the countries of the Community, 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 perceived 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 immediate solutions for policy-makers.

Chapter 1: Physical and sensory functional limitations

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Section 1: Definition and presentation of the proposed measurement instrument

1. Defining the concept

Physical and sensory functional limitations are located **at the level of the whole organism or person** (Nagi, 1991) and therefore, must be measured independently of environment. They refer to **sensory-motor functioning of the organism as indicated by limitations** in such actions as seeing, hearing, walking, climbing, bending, reaching, etc. Functional limitations deal with various abilities that may be classified in several ways. The classification used in this work is based on a distinction between physical functional limitations (balance, mobility, agility, strength, and endurance) and sensory functional limitations (seeing and hearing). However, a survey question generally refers to a situation (or action) requiring several functional abilities, for example, walking requires balance, agility, strength, and endurance. Cognitive functional limitations are not studied in this phase of the work.

2. Defining the measure

The 13 selected descriptors of functional abilities provide the basis for the recommended instrument:

　　　　1/ Seeing clearly newspaper print
　　　　2/ Seeing clearly the face of someone from 4 metres (across a road)
　　　　3/ Hearing distinctly what is said in a conversation with one person
　　　　4/ Keeping balance
　　　　5/ Walking 500 metres
　　　　6/ Going up and down a flight of 12 stairs
　　　　7/ Speaking clearly to others
　　　　8/ Biting and chewing on hard foods such as a firm apple
　　　　9/ Reaching out an arm to shake someone's hand
　　　　10/ Using fingers to grasp or handle a small object like a pen
　　　　11/ Turning a tap
　　　　12/ Bending down or kneeling down
　　　　13/ Lifting and carrying a full shopping bag of 5 kilos

Using these descriptors, we propose to collect information on 4 functional hierarchical states:

1) Proportion of individuals having no functional limitations, that is "able to perform all actions under consideration without any difficulty by themselves and without using any special aid".

2) Proportion of individuals having functional limitations but having no difficulty in performing the actions under consideration by themselves because of the use of special aids.

3) Proportion of individuals having functional limitations and unable to perform by themselves without any difficulty or discomfort the actions under consideration, even with the possible use of special aids.

4) Proportion of individuals having functional limitations and totally unable to perform by themselves the actions under consideration, even with the possible use of special aids.

3. Policy relevance and utility

The first category allows us to assess the functional health status 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. Thus we can compare the functional health status of: (i) populations of different countries independently of the level of development of the countries; (ii) different sub-groups of the population within the country independently of social inequalities; and (iii) a population over time independently of technical and social changes.

The second category allows us to estimate the proportion of individuals having no difficulty in daily life according to the situation/action under consideration. The gap between this category and the previous one provides information about the effectiveness and the efficiency of special aids available and used. The

comparison of the gaps between countries, population sub-groups or at different periods within a country will provide meaningful information for targeting public health interventions.

The third category allows us to estimate the proportion of individuals having some difficulties in daily life according to the situations/actions under consideration in spite of the possible use of special aids; i.e. the residual functional limitations giving more direct indication of unmet needs. The comparison of this information between countries, groups of population or at different periods within a country also may help to define areas to target.

The fourth category allows us to estimate the proportion of individuals totally unable to perform the actions under consideration, for reading newspaper print if blind. Together with the earlier categories, this category of the most severe level of functional limitation provides the gradient of a severity scale.

4. Wording

The exact wording of the questions for the data collection needs to be developed in a subsequent phase and will require validation before recommendations can be made. In addition, the wording depends on the mode of data collection used (self-administered questionnaire, face-to-face interview, telephone interview). However, the main thrust of the wording is already indicated below, with two examples, one *on seeing clearly newspaper print* for a face-to-face interview and one on *hearing distinctly what is said in a conversation with one person* for a self-administered questionnaire.

For a face-to-face interview (with possible "Computer Assisted Personal Interview" techniques):

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

1/ Can you see clearly newspaper print without glasses or contact lenses? Yes / No*

If no: **And with your glasses or contact lenses, can you see clearly newspaper print?**

     Yes / No / Have no glasses or contact lenses

* if answer "I'm blind or I cannot see at all", go to question 3/ (skipping other questions on seeing)

For a self-administered questionnaire:

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

3/ Can you hear distinctly what is said in a conversation with one person without a hearing aid? (only tick one box)

□   Yes, I can hear distinctly without a hearing aid

□   No, but I can hear distinctly with my hearing aid

□   No, and I can not hear distinctly even with my hearing aid

□   I cannot hear at all

The two wordings produce the same information. First asking if the person can clearly see or hear distinctly etc., we detect individuals having no functional limitation. In the case of self-administered questionnaires, the person has also the possibility to choose the answers "No, but I can hear distinctly with my hearing aid" (detecting individuals having functional limitations but having no difficulty in daily life because they use special aids) and "No, and I can not hear distinctly even with my hearing aid" (detecting individuals having functional limitations and having difficulty in daily life even with the possible use of special aids; including persons having no special aids). In the case of face-to-face questionnaires, the second question is only asked of people having answered "No" to the first question, distinguishing individuals having functional limitations but having no difficulty in daily life from individuals having functional limitations and having some difficulties in daily life even with the possible use of special aids. Individuals replying, "I have no glasses or contact lenses" are also classified with the individuals having functional limitations and having some difficulties in daily life even with the possible use of special aids. In the case of self-administered questionnaires, the person may tick a fourth choice "I cannot hear at all" if he is deaf, detecting individuals totally unable to perform the action under consideration. In the case of face-to-face questionnaires, spontaneous answers to the first question "I'm blind" or "I cannot see at all" will detect individuals totally unable to perform the action under consideration. Thus the two wordings bring, theoretically, exactly the same required information.

5. Justification of the selection of descriptors

First through the review of the literature and through the analysis of the already existing international recommendations, we have set up a summary classification to map the domain of physical and sensory abilities.

Summary classification

Sensory Functional Abilities:	
* Seeing	- Seeing on a short distance
	- Seeing on a long distance
* Hearing	- Hearing one sound source
	- Hearing several sound sources

Physical Functional Abilities:	
* Balance	
* Mobility	- Walking
	- Going up and down stairs
* Agility	
Global agility	
Head	- Speaking
	- Chewing
Shoulders and Upper limbs	- Reaching
	- Grasping
	- Manipulating
Pelvis and Lower limbs	
* Strength and Endurance	- Strength
	- Endurance

Next, we analysed the Health Interview Surveys (HIS) of the European Union countries and of OECD countries to select, among the already existing questions, the best possible descriptor for each category of our classification. The criteria for this selection were:

- Number of European Union countries using the question;
- Question following OECD or WHO-Europe recommendations;
- Number and type of categories of abilities covered by the question;
- Wording in terms of capacity rather than in terms of performance;
- Relationships with assistance (special aids or human assistance);
- Simplicity and clarity of wording.

According to these criteria, we were unable to find a question covering the category "endurance". We found good descriptors for "Hearing several sound sources" (hearing distinctly what is said in a group of 3 or more persons) and for "Global agility" (bending down and picking up a shoe, when standing, from the floor), but we did not select them to make the instrument shorter. Thus the 13 selected descriptors constitute the shortest list covering the essential functional abilities.

6. Time reference

As we intend to focus only on long-term conditions and since the distinction between short-term and long-term is not always obvious for individuals interviewed, the following introductory sentence is proposed for the draft instrument -*"Think about situations you may face in daily life, please ignore temporary problems"*.

7. Scoring system

Following the classification used, we will explore the possibility of creating scores, first at the fourth category level, gathering for example data on "reaching", "grasping" and "manipulating" to produce a global score of agility of the upper limbs. Then, we will explore the possibility of creating scores at the third level producing for example a global score of agility and at the second level producing for example a global score of physical ability. Since we already know that seeing and hearing abilities vary differently between the sexes, a global score of sensory ability is meaningless, at least for gender comparison purposes. Finally, we will explore the possibility of creating a global indicator of physical and sensory abilities.

Some guidelines for such a scoring system on physical and sensory abilities can already be suggested and some important levels of severity may be provisionally identified.

1- No functional limitations: *able to do without any difficulty by themselves and without using special aid the 13 actions under consideration.*

2- At least one functional limitation, *but no difficulty in daily life for the actions under consideration.*

…

x- At least one difficulty in daily life, *but not unable to do any of the actions under consideration.*

…

x+n- Severe functional limitation, *totally unable to perform at least one action under consideration.*

…

ω- Extreme functional limitation: *totally unable to perform the 13 actions under consideration.*

To proceed further, we need to confirm the hierarchical nature of some categories or sub-categories for which empirical data will be required.

8. Population categories

Applicable to all except very young children.

9. Health expectancies

From this work, we can recommend the calculation of functional limitation-free life expectancy according to the levels of severity identified.

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;*

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.*

Section 2: Background

The use of functional limitation items is widespread in the literature on disability. However they are often used with different meanings because of the numerous models on the disablement process built independently by researchers and practitioners (see Introduction, Section 2). The results of these relatively uncoordinated research efforts are: (1) commonly used instruments to assess disability are poorly related to the conceptual frameworks, (2) the data collected lacks harmonisation both across and within countries and prevents comparisons being made (Robine and Jagger, 1999). Furthermore, the number and the quality of tests on instruments are extremely varied according to the type of instrument. There is much scientific literature published on tests of the validity of generic instruments such as the SF-36 (McHorney, 1996) but few validity tests are applied to instruments recommended by international organisations in this field such as OECD and WHO-Europe.

I. History of the instrument

The first proposal for functional limitation measures was by Nagi, on the basis of his conceptual works (see Introduction, Section 2). In 1976, he established the concept of *Physical Performance*, referring to sensory-motor functioning and described by limitation in activities such as walking, climbing, bending, reaching, hearing, etc. and built a scale for an epidemiological survey, individuals being classified as having none, some or great difficulty in the following (Nagi, 1976):

- Difficulty standing for long periods
- Difficulty lifting or carrying weights of approximately ten pounds
- Difficulty going up and down stairs
- Difficulty walking
- Difficulty stooping, bending, or kneeling
- Difficulty using hands and fingers
- Difficulty reaching with either / or both arms

Many studies and surveys undertaken in the USA are based on this proposal: the Framingham disability survey (Jette and Branch, 1981) with a portion of Rosow and Breslau's Functional Health scale (Rosow and Breslau, 1966); the Established Populations for Epidemiological Studies of the Elderly (EPESE) (Cornoni-Huntley et al., 1993) and the Longitudinal Study of Aging (LSOA) (Harris et al., 1989; Mor et al., 1989) also with additional sensory items on vision and hearing.

On the other hand, functional limitation items have been included in a number of generic instruments: the Sickness Impact Profile (SIP), the Nottingham Health Profile (NHP) and the Short Form Health Survey (SF-36) (Gilson et al., 1975; Bucquet et al., 1990; Ware and Sherbourne, 1992). Among these, the "Physical functioning" module in the SF-36 has often been used in surveys. The items of the SF-36 dealing with functional limitations (lifting, climbing, bending, walking) are described in the annex.

In 1976, based on the concepts contained in a draft report for the future WHO International Classification of Impairments, Disabilities and Handicaps (ICIDH) (Wood, 1975), the Organisation for Economic Co-operation and Development (OECD) proposed an instrument dealing with the functional consequences of disabling health problems and containing 12 (out of 16) questions on functional limitations (McWhinnie, 1981). The limitations covered (vision, hearing, speaking, carrying, walking, cutting toenails, picking up from floor, cutting food, biting/chewing) and the form of the questions are described in the annex.

A few years later, the WHO Regional Office for Europe (WHO-Europe) recommended an instrument based on the ICIDH framework (WHO, 1980) as a consequence of the consultations organised with the Netherlands Central Bureau of Statistics (WHO-Europe, 1988, 1990, 1992). This instrument had, out of a total of 12 items, 3 core items (walking, hearing, vision) and 3 optional items (walking up stairs, picking up from floor, speaking) on functional limitations (de Bruin et al., 1996, p 55-60), described further in the annex.

II. Measuring functional limitations in Europe

We have reviewed the instruments used in European health interview surveys according to the summary classification presented in the first section. The census of existing instruments allows assessment of the

categories covered and the comparability of the questions through an analysis of the descriptors included and the wording used. The comparison has been done with reference to the OECD, WHO-Europe, SF-36 instruments.

Among the most recent European health interview surveys (Hupkens, 1998), we have selected one survey using items on physical and sensory functional limitations for each European country. Where the health interview survey did not include such items, we selected a disability survey.

- Austrian Physical Disabilities Survey, 1995
- Belgian Health Survey, 1997
- British Disability Survey, 1996
- Danish Health and Morbidity Survey, 1994
- Dutch Health Survey, 1995
- Finnish Health Care Survey, 1995/96
- French Health and Medical Care Survey, 1991/92
- German Health Survey, 1997
- Irish Lifestyle Survey, 1997
- Italian Health Conditions Survey, 1994
- Norwegian Health Survey, 1995
- Portuguese Health Survey, 1995/96
- Spanish Health Survey, 1995
- Swedish Living Conditions Survey, 1994
- Swiss Health Survey, 1997

For Greece and Luxembourg, health or disability surveys either do not exist or do not include items on physical and sensory functional limitations.

Most surveys include at least one item on mobility (14/15 surveys) or on vision and hearing (13/15 surveys). Agility is covered in 10 surveys and strength and endurance in 6. Following the international recommendations (OECD, WHO-Europe), the category "agility" is assessed in 6 surveys by a global question (e.g., "Can you (when standing) bend down and pick up a shoe from the floor?").

Sensory Functional Abilities:	
* Seeing	13 / 15 surveys
- Seeing on a short distance	9 / 15 surveys
- Seeing on a long distance	7 / 15 surveys
* Hearing	13 / 15 surveys
- Hearing one sound source	9 / 15 surveys
- Hearing several sound sources	6 / 15 surveys
Physical Functional Abilities:	
* Balance	1 / 15 surveys
* Mobility	14 / 15 surveys
- Walking	13 / 15 surveys
- Going up and down stairs	10 / 15 surveys
* Agility	10 / 15 surveys
Global Agility	*6 / 15 surveys*
Head	*6 / 15 surveys*
- Speaking	4 / 15 surveys
- Chewing	2 / 15 surveys
Shoulders and Upper limbs	*1 / 15 surveys*
- Reaching	1 / 15 surveys
- Grasping	1 / 15 surveys
- Manipulating	1 / 15 surveys
Pelvis and Lower limbs	*3 / 15 surveys*
* Strength and Endurance	*6 / 15 surveys*
- Strength	6 / 15 surveys
- Endurance	1 / 15 surveys

Almost all the European surveys use the OECD and WHO-Europe recommendations as a basis for at least one item (see annexes) and the "Physical functioning" module in the SF-36 serves as a reference for three surveys (Belgian, Danish and German surveys). However, even when following the recommendations, countries are not adhering to these exactly (for instance in terms of wording or selected items), destroying the comparability of the questions used (Cambois, 1997; Gudex et al., 1999).

III. Essential characteristics of the instrument

Previous literature has shown that the prevalence of functional limitation is sensitive to the instrument used in the survey a) the wording of questions, b) the number of response categories and c) the distinction between short and long-term limitations. For this reason, the development of a common instrument for measuring functional limitations is urgently required; this instrument should not only be based on existing recommendations but also on up-to-date research on the reliability and testing of the various wording and scale constructs.

1. Wording

The three main sources of confusion in the wording of functional limitation questions are: formulation in terms of capacity versus performance, absence of any reference to the use of help (technical or human) and rhetoric clarity.

Capacity versus performance: Information on physical and sensory functioning can be obtained from asking respondents to judge their capacity to do a task ("are you *able* to climb stairs") rather than to report their actual performance ("do you climb...."). However, individuals do not necessarily face the situation proposed in the survey (Branch and Meyers, 1987) and, in this respect, it has been proposed to measure functional limitations in terms of abilities whereas activity restrictions in daily life should be assessed in terms of performance, as explained in the chapter following. A physical or sensory functional limitation can be measured through reference to many actions/situations (e.g. loss of agility with fingers can be measured with inability to pick up a shoe, to grasp a cup of tea, etc.); in fact the action/situation used to measure functional limitation is only there to help the respondent, as well as the investigator, assess the level of functioning.

With or without help (technical or human): In addition to human assistance, many types of technical aids are available for people with functional limitations. The level of functional limitation reported will differ if the question (1) does not explicitly specify the use of technical aids or human help; (2) explicitly specifies without help or (3) explicitly specifies with help. Moreover some scientific studies have suggested that the reproducibility varies according to the type of specification (Smith et al., 1990). If the goal is to measure the ability of the individual then the functional limitation should be assessed without the use of aids and assistance.

Rhetoric clarity: All other sources of incomparability present in most of the survey questions arise from the lack of precision on, for example, the number of steps in stairs, the weight of a shopping bag, the length of a block or distance between two crossroads, the nature of a normal conversation, the size or weight of an object, etc.

2. Response categories

Ignoring the use of help, three types of response categories were found: binary responses (Yes / No), qualitative responses (hampered or restricted, a lot or a little, etc.) and responses using metrics (steps, metres, kilos). In addition some surveys allow for the response "don't know" (Picavet and Van den Bos, 1996). No gold standard exists in the scientific literature on the number and type of response categories. However, for the sake of simplicity for respondents, it seems sensible to limit the number of response categories for each item and to apply the same response categories for all items.

3. Temporary and long-term functional limitations

Some reference instruments introduce the notion of time and duration to distinguish temporary and long-term functional limitations (McWhinnie, 1981; Stewart et al., 1988; de Bruin et al., 1996). This distinction may be made in the introduction, the question, or the response categories. For example, the WHO-Europe instrument adds the introductory sentence "Temporary complaints should be ignored" (de Bruin et al., 1996, p 53-55). Despite this distinction being important, it was suggested to drop this distinction on the basis of test-retest

reliability of the OECD instrument due to the misunderstanding of short and long-term by those interviewed (McDowell and Newell, 1996).

IV. Conclusion

The study of a large number of questions on functional limitation found in the literature as well as in European surveys has allowed us to point out the lack of comparability of existing instruments. Sources of incomparability are found in most of the questions and the assessment of the reproducibility of physical function measures has been inconclusive (Smith et al., 1990; Tager et al., 1998). The wealth of questions hides a lack of validated instruments to measure physical and sensory functional limitations. New measures will have to be validated.

The three main reference instruments for the European health surveys ("Physical functioning" in SF-36, OECD and WHO-Europe recommendations) are in fact a mix activity restriction and functional limitation items and cover only part of the physical and sensory functional limitation domains (see annex). Moreover, when adopting the recommended instruments, countries do not adhere exactly.

None of the existing instrument can be recommended without substantial revision. Based on up-to-date scientific work on the wording and the choice of items as well as an analysis of existing reference instruments, we propose the development of a new common instrument (introduced in Section I) with the following characteristics:

- A selection of one descriptor for each category of physical and sensory functional limitation;

- A clear and simple wording based on the capacity ("Can you") without human assistance;

- A clear reference to ignoring temporary problems.

Annex 1: Reference instruments for the measurement of physical and sensory limitations

1. Reference instrument recommended by OECD

Presentation:

<u>Name and year of the instrument</u> : The OECD long-term disability questionnaire (Organisation for Economic Co-operation and Development), 1976

<u>Construction of instrument</u> : Sixteen questions were included, ten of which can be used as an abbreviated instrument and represent a core set of items for international comparisons. For each item, four response categories were proposed to indicate levels of severity: (1) Yes, without difficulty, (2) Yes, with minor difficulty, (3) Yes, with major difficulty and (4) No, not able to. No time specification is attached to these questions to signify long-term. Rather, the interviewer is instructed to ask the respondent what he or she can "usually" do, on a normal day, excluding any temporary difficulties. Within the framework of physical and sensory functional limitations, eleven questions are kept and presented below with the same response categories:

<u>Reference wording</u> (the questions dealing with Activities of Daily Living are not reproduced here):

1) Is your eyesight good enough to read ordinary newspaper print ? (with glasses if usually worn).

2) Is your eyesight good enough to see the face of someone from 4 metres ?

3) Can you hear what is said in a normal conversation with 3 or 4 persons ?

4) Can you hear what is said in a normal conversation with one other person ? (with hearing aid if you usually wear one).

5) Can you speak without difficulty ?

6) Can you carry an object of 5 kilos for 10 metres ?

8) Can you walk 400 metres without resting ?

9) Can you walk up and down one flight of stairs without resting ?

13) Can you cut your toenails ?

14) Can you (when standing), bend down and pick up a shoe from the floor ?

15) Can you cut your own food ? (such as meat, fruit, etc.).

16) Can you both bite and chew on hard foods ? (for example, a firm apple or celery)

Responses to each item:

1. Yes, without difficulty.

2. Yes, with minor difficulty.

3. Yes, with major difficulty.

4. Not, not able to.

<u>Type of used wording</u> : Can you / Is your eyesight good enough to ...

<u>Level of severity</u> : Degree of difficulty (without, with minor, with major, not able to)

Review analysis :

The OECD questionnaire is a survey instrument designed to summarise the impact of ill health on essential daily activities. It was intended to provide measurement techniques common to Member countries (McWhinnie, 1981). In a literature review on the reliability and validity of the instrument, the results are poor. The studies examined all exhibit slight variations in the questions or answer categories; these are only partly attributable to inconsistencies in translation (McDowell and Newell, 1996; Picavet and van den Bos, 1996). Despite the adverse findings, OECD recommendations continue to be used in the most recent European health surveys (Cambois, 1997; Cambois and Robine, 1997).

Related health expectancy :

A set of four recommendations (questions 1, 3, 6 and 8) were used in a clearly modified version in the calculation of "functional limitation-free life expectancies" in Denmark (1987 and 1994) from Danish health surveys (Bronnum-Hansen, 1998). Moreover, two modified recommendations (questions 9 and 14) were used in the calculation of "functional limitation-free life expectancies" in France (Robine et al., 1995).

Conclusions:

This instrument retains a number of desirable qualities compared to the other international references (e.g. it covers more physical and sensory functional limitations than WHO-Europe instrument). However, the studied instrument has a few important sources of confusion (e.g. recommendations are not always clear as to whether the asked action is with or without help) and in addition there is incomplete coverage of the whole of functional limitation fields (mostly on agility).

References :

Bronnum-Hansen H (1998) Trends in health expectancy in Denmark, 1987-1994. *Danish Medical Bulletin* 42 (2):217-221.

Cambois E (1997) *Recommendations for health indicators harmonisation: retrospective and prospective glance*. 3d Euro-REVES general meeting. Fontevraud.

Cambois E, Robine JM (1997) *What do we know about available surveys to adjust them for harmonisation*. 4th WHO-CBS Consultation to develop common instruments for health interview surveys, 26-28 February 1997. Copenhagen.

McDowell I, Newell C (1996) *Measuring health : A guide to rating scales and questionnaires.* Second Edition. Oxford University Press. New-York. 104-106.

McWhinnie JR (1981) Disability assessment in population surveys: Results of the OECD Common development effort. *Revue d'Epidémiologie et de Santé Publique* 29:413-419.

Picavet HSJ, van den Bos GAM (1996) Comparing survey data on functional disability: the impact of some methodological differences. *Journal of Epidemiology and Community Health* 50:86-93.

Robine JMR, Romieu I, Cambois E. (1995) Espérances de santé pour la population âgée de 65 ans et plus: Application des concepts de la classification internationale des handicaps aux calculs d'espérance de santé. *Rapport final de la Convention MIRE*. Equipe INSERM Démographie et Santé. Montpellier.

2. Reference instrument recommended by the WHO-Europe

Presentation :

<u>Name and year of the instrument</u>: The WHO-Europe long-term disability questionnaire (The Regional Office for Europe of the World Health Organisation, 1990).

<u>Construction of instrument</u>: The recommended questionnaire contains ten questions on disability (but only three for physical and sensory functional limitations). Following the recommendation of Council of Europe experts, three questions on other areas of disability (but in the field of physical and sensory functional limitations) can be added; these questions are optional. Each of disability items in the instrument is scored on a three-point scale : (1) No disability = 0, (2) Lower = 1, (3) Higher = 2. The summary score is the highest value assigned for any of the 10 items, and takes a value in the range 0-2. This 10 item summary score is the minimum recommended score that should be calculated. If the three optional items are included, a 13 item summary score can also be used. Within the framework of physical and sensory functional limitations, six items are kept and presented below with various response categories (optional disability items and three disability items):

<u>Reference wording</u> (the questions dealing with Activities of Daily Living are not reproduced here):
Selected disability items :

1) What is the furthest you can walk on your own without stopping and without severe discomfort ?
    1. Only a few steps.   **Higher**
    2. More than a few steps but less than 200 metres.   **Lower**
    3. 200 metres or more.   **No disability**
9) Is your hearing good enough (with a hearing aid, if necessary) to follow a TV programme at a volume others find acceptable ?
    1. Yes   **No disability**
    2. *If no* :
            Can you follow a TV programme with the volume turned up (with a hearing aid if necessary) ?
        1. Yes.   **Lower**
        2. No.   **Higher**
10) Can you see well enough (with glasses or contact lenses, if necessary) to recognize a friend at a distance of four metres (across a road) ?
    1. Yes.   **No disability**
    2. *If no* :
            Can you see well enough (with glasses or contact lenses, if necessary) to recognize a friend at a distance of one metre (at arm's length) ?
        1. Yes.   **Lower**
        2. No.   **Higher**

Optional disability items :

1) Can you walk up and down a flight of 12 stairs without resting ?
    1. Yes.   **No disability**
    2. *If no* :
        Can you do this if you hold on and take rests ?
        1. Yes.   **Lower**
        2. No.   **Higher**
2) Can you (when standing) bend down and pick up a shoe from the floor ?
    1. Yes.   **No disability**
    2. No.   **Higher**
3) Can you speak without difficulty ?
    1. Yes.   **No disability**
    2. No.   **Lower**

<u>Type of used wording</u> : Can you / Is your hearing good enough to ...

<u>Level of severity</u> : Degree of disability (No, Lower, Higher)

Review analysis :

After the example of OECD, the Regional Office for Europe of the WHO has proposed an internationally applicable set of disability items on the basis of an extensive disability questionnaire consistent with the concepts of ICIDH and developed by the British Office of Population Censuses and Surveys (WHO-Europe, 1988, De

Bruin et al., 1996). A first consultation in 1988 has recommended the disability items with a scale of severity for each item (WHO-Europe, 1988). A second consultation in 1990 has proposed adding the optional disability items and the summary score for disability (WHO-Europe, 1990). The third and last consultation in 1992 is a confirmation of previous consultations (WHO-Europe, 1992). A few available studies have shown the use of this instrument as reference in several European health surveys (Robine et al., 1995; Cambois, 1997, Cambois and Robine, 1997).

Related health expectancy:

One slightly modified recommendation (question 1) was used in the calculation of "functional limitation-free life expectancies" in France (Robine et al., 1995).

Conclusions:

Despite the fact that the studied instrument is relatively old (1990) and recommended by the Regional Office for Europe of the WHO, no work on validation of this instrument is published in the scientific literature. Furthermore, this instrument emphasises on activity restrictions rather than functional limitations (only six questions for an instrument endowed with thirteen questions).

References :

de Bruin A, Picavet HSJ, Nossikov A (1996) *Health interview surveys: Towards international harmonization of methods and instruments*. Copenhagen: World Health Organisation. Regional Office for Europe. Voorburg: Statistics Netherlands. (WHO Regional Publications. European Series n°58). 53-60.

Cambois E (1997) *Recommendations for health indicators harmonization : retrospective and prospective glance.* 3d Euro-REVES general meeting. Fontevraud.

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World Health Organization-Regional Office for Europe (1990) *Consultation to develop common methods and instruments for health interview surveys*. Voorburg: NCBS.

World Health Organization-Regional Office for Europe (1992).*Consultation to develop common methods and instruments for health interview surveys*". Voorburg: NCBS.

3. The MOS 36-Item Short-Form Health Survey (SF-36)

Presentation:

Name and year of the instrument: "Physical functioning" module in the MOS 36-Item Short-Form Health Survey (SF-36), 1992.

Construction of instrument: In the module "Physical Functioning", one question introduces ten items. For each item, three response categories are proposed: (1) Yes, Limited a lot; (2) Yes, Limited a little; (3) No, Not limited at all. Within the framework of physical and sensory functional limitations, seven items (c, d, e, f, g, h and i) are kept and presented below:

Reference wording:
The following items ("questions" with the SF-36 version II) are about activities you might do during a typical day. Does your health now limit you in these activities ? If so, how much ?

      c. Lifting or carrying groceries

      d. Climbing several flights of stairs

      e. Climbing one flight of stairs

      f. Bending, kneeling, or stooping

      g. Walking more than a mile

      h. Walking several blocks

      i. Walking one block

      Responses to each seven items:

      Yes, Limited a lot

      Yes, Limited a little

      No, Not Limited at all

Target population and data collection: A 36-item short form (SF-36) was constructed to survey health status in the Medical Outcomes Study. The survey was constructed for self-administration by persons 14 years of age and older, and for administration by a trained interviewer in person or by telephone.

Type of used wording: Does your health now limit you ...

Level of severity: Degree of limitation (not at all, a little, a lot)

Review analysis:

In the field of generic instruments which assess functional status, behavioral disability, emotional well-being, and subjective perceptions of health (such as the Sickness Impact Profile, the Nottingham Health Profile, and the Duke Health Profiles), the SF-36 was designed for use in clinical practice and research, health policy evaluations, and general population surveys (Ware and Sherbourne, 1992). A good literature review on the generic measures shows that the SF-36 is widely used in scientific studies for three reasons : (a) it is the most recent of the family of generic measures; (b) in the few short years since its development, it has become a very widely used measure of health status, in large part because of its brevity; and (c) debate already exists about its use with elderly persons (McHorney, 1996). A more recent literature review indicated the measure has been widely adopted around the world and over 300 articles were published between 1988-95 that included data gained from the SF-36. It has been translated into 40 languages, including English, German, French, Polish, Swedish, Spanish, Icelandic, Japanese, and Portuguese (Jenkinson and colleagues, 1999). But, despite the widespread use of the measure, criticism has been forthcoming concerning the layout and wording of some of the items and its applicability, particularly in this module, for older people (Parker et al, 1998). Consequently, the developers have produced a modified instrument, the SF-36 Version 2 (SF36-II), which is a direct descendent of the SF-36. In this new version, the new module "physical functioning" has been adopted with a single modification (has changed "items" by "questions" in the introduction) (Jenkinson and colleagues, 1999).

Related health expectancy:

No calculation of health expectancies from this instrument.

Conclusions:

Despite its widespread use in scientific studies and a great deal of works of validation, the studied instrument covers few fields of functional limitation (see annexe 4). Moreover, several used questions cover in fact the same field (two items on "stairs" and three items on "walking"). Finally, this instrument has a lot of sources of confusion (e.g. the wording is explained in term of performance).

References:

Jenkinson C, Stewart-Brown S, Petersen S, Paice C. (1999) Assessment of the SF-36 version 2 in the United Kingdom. *Journal Epidemiology Community Health* 53: 46-50.

McHorney CA (1996) Measuring and monitoring General health status in elderly persons: practical and methodoligical issues in using the SF-36 health survey. *The Gerontologist* 36 (5): 571-583.

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Ware JE, Sherbourne CD (1992) The MOS 36-Item Short-Form Health Survey (SF 36): I. Conceptual Framework and Item Selection. *Medical Care* 30 (6): 473-483.

Annex 2: Comparisons between the selected descriptors, international references and the items found in European health interview surveys

Descriptors	OCDE 1976	WHO-Europe 1992	Austria 1995	Belgium 1997	Denmark 1994	Finland 1995/96	France 1991/92	German 1997	Ireland 1997	Italy 1994	The Netherlands 1995	Norway 1995	Portugal 1995/96	Spain 1995	Sweden 1994	Switzerland 1997	United Kingdom 1996
Seeing clearly newspaper print	*				*	*	*				*	*			*	*	*
Seeing clearly the face of someone from 4 metres (across a road)	**	*		*						*	*	*	*	*			
Hearing distinctly what is said in a conversation with one person	*										*						
Keeping balance																	*
Walking 500 metres	*				*	*					*						
Going up and down a flight of 12 stairs	*	**			*		*					*	**				**
Speaking clearly to others	*									*		*	*			*	
Biting and chewing on hard foods such as a firm apple	**			**							**						
Reaching out an arm to shake someone's hand																	
Using fingers to grasp or handle a small object like a pen																	
Turning a tap																	**
Bending down or kneeling down				*	*			*									*
Lifting and carrying a full shopping bag of 5 kilos	*			*	*	*		*			*						*

** very close

* close

<u>Annex 3</u>: Selected descriptors according to criteria of selection

NB: In the shape of a question, each descriptor uses a wording in term of capacity ("Can you") and indicates the level of assistance ("by yourself and not using aids").

	Number of covered categories (in the classification)	Simplicity and clarity of wording	Origins
Descriptors	**One**	**Yes**	
Seeing clearly newspaper print	***Seeing*** on a short distance	*	OECD, 1976
Seeing clearly the face of someone from 4 metres (across a road)	***Seeing*** on a long distance	*	OECD, 1976
Hearing distinctly what is said in a conversation with one person	***Hearing*** one sound source	*	OECD, 1976
Keeping balance	***Balance***	*	British Disability Survey, 1996
Walking 500 metres	***Mobility*** walking	*	OECD, 1976
Going up and down a flight of 12 stairs	***Mobility*** going up an down	*	WHO-Europe, 1990
Speaking clearly to others	***Agility*** Head (Speaking)	*	OECD, 1976
Biting and chewing on hard foods such as a firm apple	***Agility*** Head (Chewing)	*	OECD, 1976
Reaching out an arm to shake someone's hand	***Agility*** Shoulders, and Upper limbs (Reaching)	*	US Longitudinal Survey of Aging (LSOA), 1984-90
Using fingers to grasp or handle a small object like a pen	***Agility*** Shoulders, and Upper limbs (Grasping)	*	US Longitudinal Survey of Aging (LSOA), 1984-90
Turning a tap	***Agility*** Shoulders, and Upper limbs (Manip.)	*	British Disability Survey, 1996
Bending down or kneeling down	***Agility*** Pelvis, and Lower limbs	*	US Longitudinal Survey of Aging (LSOA), 1984-90
Lifting and carrying a full shopping bag of 5 kilos	***St. and End*** Strength	*	US Longitudinal Survey of Aging (LSOA), 1984-90

Annex 4 : Comparisons between the items found in European health surveys and international references

	Descriptors	Indicators	Austria 1995	Belgium 1997	Denmark 1994	Finland 1995/96	France 1991/92	Germany 1997	Ireland 1997	Italy 1994	The Netherlands 1995	Norway 1995	Portugal 1995/96	Spain 1995	Sweden 1994	Switzerland 1997	United Kingdom 1996
Seeing	Eyesight (newspaper print)	OECD			*	*	*				**	*			*	*	*
	Eyesight (from 4 metres)	OECD									*						
	Seeing (D26)	WHO-Europe		*						*		**	**	*			*
	Seeing	OTHERS							≠								
Hearing	Hearing (conversation 3-4)	OECD			*	**					**	*			*	*	
	Hearing (conversation other one)	OECD									**						
	Hearing (D23)	WHO-Europe		*						*	**		**	**	*		*
	Hearing	OTHERS					≠			≠							
Strength	Carrying (5kilos for 10 metres)	OECD			*	*					**						
	Strength	OTHERS		≠	≠			≠									≠
Mobility	Walking (400 metres)	OECD			*	*					*						
	Locomotion (D40)	WHO-Europe		*			**				**	*	*	*		*	
	Walking (stairs)	OECD			*		**				**						
	Stairs (D42)	WHO-Europe									**	*	**				*
	Mobility	OTHERS	≠	≠	≠			≠							≠		
Agility	Cutting (toenails)	OECD				**											
	Speaking	OECD			*						**						
	Speaking (D21)	WHO-Europe											*			**	
	Biting and chewing on hard foods	OECD		**							**						
	Bending down and picking up (shoe)	OECD					**				**	**		*			
	Bending down and picking up (D52)	WHO-Europe															*
	Cutting own food	OECD															
	Agility	OTHERS		≠	≠			≠									≠

*** : strictly identical ** : slight modification * : clearly modified ≠ : really different

Annex 5: Covering of classification by the main reference instruments

NB: items covering several categories are excluded

Classification	*OECD*	*WHO-Europe*	*SF-36 (Physical functioning)*
Seeing on a short distance	Eyesight (newspaper print)		
Seeing on a long distance	Eyesight (from 4 metres)	Seeing (D26)	
Hearing several sound sources	Hearing (conversation 3-4)		
Hearing one sound source	Hearing (conversation other one)	Hearing (D23)	
Balance			
Mobility walking	Walking (400 metres)	Locomotion (D40)	Walking
Mobility going up an down	Walking (stairs)	Stairs (D42)	Climbing
Agility Global Agility	Bending down and picking up (shoe)	Bending down and picking up (D52)	
Agility Head (Speaking)	Speaking	Speaking (D21)	
Agility Head (Chewing)	Biting and chewing on hard foods		
Agility Shoulders, and Upper limbs (Reaching)			
Agility Shoulders, and Upper limbs (Grasping)			
Agility Shoulders, and Upper limbs (Manip.)			
Agility Pelvis, and Lower limbs			Bending, kneeling or stooping
St. and End Strength	Carrying (5kilos for 10 metres)		Lifting or carrying
St. and End Endurance			

Source: McWhinnie, 1981; Ware et al., 1992; de Bruin et al.,

Chapter 2: Activity restriction in daily life (ADL)

Contributors: Emmanuelle Cambois, Carol Jagger, Jean-Marie Robine

Section 1: Definition and presentation of the proposed measurement instrument

1. Defining the concept

According to the conceptual framework of the disablement process, difficulties in performing activities of daily living correspond to the level of activity restrictions (Figure 3, Introduction: Section 2). Activity restriction is the combination of the intrinsic functional status of individuals and what they are expected to do in daily life to ensure a defined social role: such as caring for themselves and ensuring a minimal independence (Activities of Daily Living), or allowing them to live alone in a private household (Instrumental Activities of Daily Living). Here, we concentrate on Activities of Daily Living and propose an instrument measuring **restriction in activities which are considered essential to ensure the minimal independence in personal care**. Such an indicator may be useful for all ages, but is most often applied to those aged 65 years and over.

2. Defining the measure

The aim of the instrument is to collect information on the restrictions and dependence in essential personal care activities and corresponding to the individual's actual performances of these activities (and not on what individuals think they are able to perform).

Five activities are proposed :

- feeding
- transfer (bed)
- dress/undress
- use toilets
- bath or shower

allowing us to collect three different types of information:

- restrictions for personal care activities with different levels of severity,
- the use of (human and/or technical) assistance to perform personal care activities
- the unmet needs for (human and technical) assistance

3. Policy relevance and utility

Currently, public health is strongly concerned with the future need for assistance that is expected to be provided for the growing number of increasingly older individuals, and requiring good data on (i) the number of individuals with and the prevalence of activity restriction and its evolution, (ii) the distribution of these individuals according to severity levels (see scoring system), (iii) the use and the need for (additional) help, providing information both on the dependency of individuals on technical or human assistance for essential personal care activities and on the presence of unmet needs.

Measuring activity restriction not only allows us to assess the consequence of health problems (disease or accident, impairment or functional limitation) on daily life activities but also, gives the possibility of preventing activity restrictions by targeting specific functional limitations. Therefore, analysed in conjunction with information on functional limitations, activity restrictions allows us: first to describe the disablement process and the mechanism of the transition between health states; second to recognise possible compensatory strategies, and third to shed light on risk factors and health inequalities by differentiating between those with functional limitations who are restricted in activities and those coping with their limitations.

4. Wording

For activity restriction, the exact wording of the questions to be asked in surveys in order to collect the relevant information will be developed in a further phase. Indeed, the wording finally adopted for a survey questionnaire largely depends on the administration mode (self-administered / administered; face to face / telephone; computer

assisted/paper form, individual/proxy). Moreover, the recommendation of the wording necessitates in-depth research on reliability and validity of the questions and a case-by-case study of the form of items as well as response categories. At this stage, the choice of items has been made and other technical aspects (reference to the use of assistance, duration, performance vs ability) have been resolved based on existing instruments and the literature review (see Section II). However, a suggestion of wording has been made below to illustrate the direction of the work for specific surveys.

a) Selected items

In everyday life, ignoring temporary problems, do you usually without any difficulty, 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

b) Suggested wording (using feeding as an example)

In the case of administered, face to face questionnaire (with possible Computer Assisted Personal Interview):

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

1/ Do you, usually, feed yourself without any difficulty, on your own and without special aid?   Yes/No*

  [if Yes go to 2/]

  [if No, go to a) and b)]

    a) **Do you use someone's help to feed yourself?**   Yes/No
    b) **Do you** [also]** **use special aid or appropriate equipment*****   Yes/No

  [if Yes to a) and/or b)]

    c) **Do you still have problems to feed yourself**   Yes/No

*   if answer "I am not doing at all" (ex: use toilets) possibility of moving directly to question b)
**   [also] may be inserted if answer YES at the previous question in a "computer assisted" system
*** Can allow collection of or prompt for supplementary information on possible equipment, from light aids to total technical assistance.

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5. Justification of the choice of items

The proposed instrument is based on a selection of items common to 2 well-known scales (Katz et al., 1963 ; WHO-Europe, 1988; de Bruin et al., 1996) and also to the sets of activities currently used in European health surveys. Items have been ordered according to the hierarchical property of such scales, as explained in Section II although further testing of the hierarchy is needed.

We propose using "bathing or showering" rather than WHO-Europe recommended "Washing face and hands". In daily life, washing face and hands is not sufficient for personal self-care, so we prefer "bathing or showering" which may be considered as essential for personal caring. In addition, those restricted in "washing face and hands" are severely restricted, and studies on the hierarchical order of items showed that they are usually the same as those restricted in "feeding". On the other hand, "bathing or showering" targets a population with the least severe level of activity restriction, which would not be taken into account if this item is not included. "Bathing or showering" includes the Chinese concept of "dry bath" (washing whole body, outside shower or bath tub).

Some "ADL" sets include an item dealing with mobility, such as "moving between rooms". Some mobility items can be used to assess specific activity restrictions such as the level of confinement to bed or to the house, physical activity practicies or even leisure-time restrictions through items such as "going for a walk". But further research is required (1) to better define such an instrument and especially the level of the disablement process it should refer to, (2) to propose a core of homogeneous items, and (3) to test for its actual relevance and usefulness. Here, the focus of the instrument is restrictions in *personal care activities*; "mobility between rooms" is neither part of the Katz nor WHO-Europe set of disability items. At this stage of the work, mobility problems

are tested at the level of body functions ("ability to walk", see previous chapter), and are not included in the ADL scale.

6. Time reference

The instrument should focus on long-term disability, ignoring temporary problems. It should depict (1) those having no difficulty / difficulty (including "some" and "a lot") to perform essential personal activities, without (human and/or technical) assistance; the hierarchical order of items, found in all the studies which have tested it, helps in rating severity levels (see Scoring system). Among those with difficulty, the instrument depicts (2) those using (human and/or technical) assistance to perform these activities, giving an idea of possible compensatory strategies and the level of dependence, and also (3) those having remaining problems after using (human and/or technical) assistance; this gives an indication of unmet needs. Distinction is clearly made between difficulty to perform an activity (activity restriction) and the use or the need for help (dependence), which correspond to different information and different public health actions.

7. Scoring system

To be tested with the collected information

<u>a) Activity restrictions level of severity</u>

1- No activity restriction in personal care activities	*having no difficulty in any items*
2- Light activity restriction	*having only difficulty in bathing or showering*
3- Moderate activity restriction	*having difficulty in one (bathing or showering) or several items except feeding*
4- Severe activity restriction	*having difficulty in one or more items including feeding*

<u>b) Functional independence/dependence in personal care activities*</u>

1- Independence on others for personal care activities	*not using someone's help in any items*
2- Independence either on others or on aids for personal care activities	*not using aid or someone's help in any items*
3- Dependence on special aids only for personal care activities	*using aid only, in one or several items*

<u>c) Unmet needs*</u>

1- Not sufficiently helped	*using someone's help or aid and still having difficulties in one or more items*
2- Not helped	*having difficulty in one or more items and not using someone's help or aid*

* in each of these categories can be introduced a level of severity due to the hierarchical property of the items used.

8. Population categories

Although the National Health Interview Survey of the United States have applied ADL-scales to the population aged 3-69 years since 1997, and test of validity made have mostly been performed for those aged 65 years and over, further research is needed to be able to recommend its use to younger populations. At this stage of the work, therefore, the instrument is devoted to older populations. All the proposed scoring systems may be applied to non-institutionalized and institutionalized populations as they refer to personal care for which human assistance is not systematically provided in homes for older people. However, special aids or equipments are often present in such institutions, thus the residential status should be taken into account when reporting or analysing the collected information.

9. Health expectancies

Two main types of health expectancy may be computed: **activity restriction-free life expectancy** and **dependence-free life expectancy** (including or not severity levels).

,The data collected by this instrument makes it possible to measure "net handicap": having difficulty in essential activities and not being helped or sufficiently helped, leading to **net handicap-free life expectancy** (Carrière and Légaré, 1997). With the instrument proposed here this could refer to either technical or human assistance or both.

Section 2: Background

A universal consensus has been reached on the use of scales of elementary activities to assess individual functional capacities (Wiener et al., 1990) and many references exist for assessing the functioning of elderly populations (Branch and Meyers, 1987). This multiplicity of instruments has prevented consistency in information, and comparability from one study to the other. Indeed, the size and the nature of the targeted population and consequently, the magnitude in the resulting observed prevalence largely depend on the scale used.

In 1963, a scale of activities devoted to the assessment of physical or functional independence or dependence of hospital patients was proposed (Katz et al, 1963). The paper identified a set of activities in individuals' daily life which ensure, when performed, "minimum independence" in caring for themselves, or which indicate a high dependence on others when not performed. These activities were :

- feeding,
- dressing/undressing,
- bathing or showering,
- using toilets,
- transferring from bed to chair, and
- continence.

These activities are widely known as the Activities of Daily Living (ADL) and individuals are observed and identified as being independent or as receiving some assistance in these activities or being totally dependent. The definition of independence is: without supervision, direction or active personal assistance, except specifically noted below. This is based on the actual status of individuals and not on ability. A patient who refuses to perform a function is considered as not performing the function, even though he is may be able.

The activities were derived from the parallel made between the order of gaining independence in childhood and the order of lost capacities in chronically ill or aged populations, producing a hierarchy which classifies the population as:

A- independent in feeding, continence, transferring, going to the toilet, dressing and bathing
B- independent in all but one of these functions
C- independent in all but bathing and one additional function
D- independent in all but bathing, dressing and one additional function
E- independent in all but bathing, dressing, going to toilet and one additional function
F- independent in all but bathing, dressing, going to toilet, transferring and one additional function
G- dependent in all six functions
Other- dependent in at least two functions but not classifiable in C, D, E or F

Originally, responses were given by an observer on the objective situation of the individuals; the observer also tested for locomotion and orientation by asking the individual to indicate the bathroom and other objects and rooms.

This index has been used to classify various populations, samples in clinical programmes, patients of specific hospital departments and it compares the physical dependence in these specific populations by the levels independent/receiving partial assistance/dependent.

For each of the areas of functioning listed below, check description that applies (the word assistance means supervision, direction of personal assistance).

Bathing - either sponge bath, tub bath or shower
Receives no assistance (gets in and out of tub by self if tub is usual means of bathing)
Receives assistance in bathing only one part of the body (such as back or a leg)
Receives assistance in bathing more than one part of the body (or not bathed)

Dressing - gets clothes from closets and drawers -including underclothes, outer garments and using fasterners (including braces if worn)
Gets clothes and gets completly dressed without assistance
Gets clothes and gets dressed without assistance except assistance for tying shoes
Receives assistance in getting clothes or in getting dressed or stays partly or completly undressed

Toileting - going to the toilet room for bowel and urine elimination; cleaning self after elimination and arranging clothes
Goes to the toilet room clean self and arrange clothes without assistance (may use object for support such as cane, walker or wheel chair and may manage night bedpan or commode, emptying same in morning)
Receives assistance in going to the toilet room clean self and arrange clothes without or in use of night bedpan or commode

Doesn't go to toilet for the elimination process

Transfer-
Moves in and out of bed as well as in and out of chair without assistance (may be using object for support such as can or walker)
Moves in and out of bed or chair with assistance
Doesn't get out of bed

Continence
Control urination and bowel movement completely by self
Has occasional "accidents"
Supervision helps keep urine or bowel control; catheter is used or is incontinent

Feeding
Feeds self without assistance
Feed self except for getting assistance in cutting meat or buttering bread
Receive assistance in feeding or is fed partly or completely by using tubes or intravenous fluids

Due to the complex scoring system associated with the evaluation of dependence and to its specific construct in being devoted to clinic patients, studies conducted since Katz have amended the instrument. Compared to the original instrument, adapted forms used in health interview surveys vary according to the number and type of items included, or to way of evaluating the level or type of restriction (performance-based vs. ability-based questions; difficulty vs. need for assistance). With the widespread use of such scales in health interview surveys, arises the question of the choice of a "gold standard" to collect comparable information for different populations. International efforts have been initiated since the late 1970's to harmonize the conceptual framework and measurement instruments in the field of disablement. For this purpose, as shown in the previous chapter, OECD have proposed an instrument to assess functional limitations. In this instrument, dedicated to the assessment of body functions, two activities (dressing, transferring) from the Katz scale are mixed with the rest of the items. Although it is a well known reference instrument for functional limitations, owing to its construction, the OECD instrument cannot be taken as a reference for the measurement of activity restrictions.

The WHO Regional Office for Europe(WHO-Europe) proposed the construction and promotion of a common instrument for European health interview surveys (WHO-Regional Office for Europe, 1988 and de Bruin et al., 1996). It proposed a core set of items, to compare the functional health status of populations. As in the OECD instrument, this set of items mixed functional limitations items and activity restrictions but most of the Katz ADL items were included.

I. WHO-Europe recommended instrument

The WHO-Europe set of items and wording corresponding to activity restrictions (i.e. essential activities related to personal care) is:

The following questions refer to what you are normally capable of doing. Temporary complaints should be ignored.

- Transfer   Can you get in and out of bed on your own?
- Transfer   Can you get in and out of a chair on your own?
- Dressing   Can you dress and undress yourself on your own?
- Washing   Can you wash your hands and face on your own?
- Feeding   Can you feed yourself, including cutting up food?
- Toilet   Can you get to and use the toilet on your own?

Response categories   *Without difficulty / With some difficulty / Only with someone to help*

The item on continence was not included due to discussions following the work of Katz on the relevance of this item among essential activities, the consensus being that continence belongs to the domain of impairment and not to activity restrictions. In addition, other amendments to the Katz scale were needed as originally an observer reported the assistance received by a patient to perform the activity. For health interview surveys, people report their own restriction and questions and items had to be adapted to individuals in their environment in which assistance or equipment are not systematically provided, specifically :

Items: - "Transferring" was divided in transferring in/out of bed and in/out of a chair
            - "Washing" is restricted to "face and hands" and not to "bathing/showering"

Wording:-
            - Questions are asked in term of "ability" (can you...) instead of "performance" (do you)
            - In the question, "on your own" expresses independence from others for the activity

II. Measuring activity restriction in Europe

The aim of the census was first to identify the similarities and differences in selected items, wording, response categories in these European instruments in order to assess the level of comparability of the prevalence of the ADL restrictions from the surveys. We took as a reference the WHO-Europe recommended instrument. Among the 16 most recent European health interview surveys listed by the Netherlands Central Bureau of Statistics for Eurostat (Hupkens, 1997): we have selected and analysed 9 recent surveys that use an ADL scale:

- Belgium Health Interview Survey, 1997
- General Household Survey, 1996
- Spanish National Health Interview Survey, 1995
- Portuguese National Health Survey, 1995
- Norway Health Interview Survey, 1995
- Netherlands Health Interview Survey, 1995
- Italian Survey, 1994
- Finish Health Interview Survey, 1993-94
- French Survey on Health and Medical Care, 1991-92

In terms of the construct of the instrument (Annex 2):

⇒ the WHO-Europe recommendations are clearly referred to in 3/9 ;
⇒ long-term problems are referred to in 3/9;
⇒ functional limitation and activity restriction items are not mixed within the same instrument in 2/9
⇒ 7 use questions in term of abilities (can you), 1 uses a mixed performance-ability form (do you usually manage to...), and 1 uses a two-step approach "having difficulty/needing help", 5 specifically refer to the use of human assistance in response categories.
⇒ In terms of the choice of the items to be included (Annex 3): **feeding, dressing, transferring in/out of bed** are included in 8 surveys/9
⇒ washing face and hands are included in 7/9 surveys
⇒ transferring in/out of chair are included in 6/9 surveys
⇒ going and using the toilets are included in 5/9 surveys
⇒ Among the five surveys having additional items compared to WHO-Europe recommendations, 4 have the item "bath or shower", 1 uses "washing whole body".

The use of an ADL set of questions is widespread, and the surveys which were recently initiated (Belgium, Portugal) are based upon the WHO-Europe recommendations, expressing a common will towards

harmonization. Nevertheless, differences in wording and selected items have been found and these prevent comparison of the prevalence of ADL restrictions.

This instrument was the first attempt to harmonize data on functional health in the European region but despite the lack of scientific validation, items have been included in the most recently initiated health interview surveys (Belgium, Portugal) or are partly found in most of the others surveys, indicating a general will for harmonization. The census shows similarity but diversity in the way of measuring activity restriction and physical dependence/independence in the European populations. The instrument to be proposed then, has to build on what is already existing and used in surveys, but, more importantly on what recent scientific research has identified as essential characteristics and pitfalls in this kind of instrument.

III. Essential characteristics of activity restriction measurement instrument

1. Item selection

The original Katz scale was based on the finding that ADLs items can be ordered and used in a hierarchical way providing an indication of different levels of severity of the restriction, going from the most severe to the less severe: *continence, feeding, transferring (bed), going to toilet, dressing, bathing*. Since then many studies have broadly confirmed this hierarchical property of the scale (Lazaridis,1994 ; Finch et al., 1995) ; Ferrucci et al., 1998 ; Spector and Fleishmen, 1998). The latter authors found the item *use of telephone* (classified as IADL item) ranged among ADL items, above *bathing* in term of severity. Lastly, Manton (Manton et al., 1998) presents a model of "disability dimensions" corresponding to profiles of dependent populations with combination of specific ADL, IADL activity restrictions and functional limitations occurring jointly. This study also confirms the hierarchical property of such scale and especially the item *eating* at the top.

The recurrent findings are that the items indicate different levels of severity: (1) *feeding*, at the top end of the increasing severity gradient, (2) *transferring* and *toileting*, (3) *dressing*, and (4) *bathing* at the bottom end. Some authors suggest dropping bathing and in most European sets of questions, the item *washing face and hands* is used and can appear redundant to interviewees. We defend the retention of bathing on the basis that *washing face and hands (or arms)* and *feeding* target similar levels of activity restriction, while the moderate level targeted by *bathing* is not represented by any other item (Ferrucci et al., 1998).

For comparative purposes, the number of items included in the indicator is of prime concern: increasing the number of activities for which individuals have to declare their difficulties leads to an increase in the resulting prevalence of disability (Rodgers and Miller, 1997). However, the choice of items to be included is not straightforward. A core of three items only (walking across a room, feeding and dressing) has been found to provide sufficient information in the sense that only limited additional information came out by asking about the other items (Rodgers and Miller, 1997 ; Ferrucci,1998). As already seen, many scales have been proposed since Katz, and some specific items are sometimes included or dropped without clear justification: the items under discussion, except from continence, are *moving in the house*, *washing face and hands*, *bathing or showering*, *using toilets*. The literature about hierarchy in the scales has indicated the importance of using a set of different items to depict the whole gradient of severity levels of restriction and not focus only on one end or on the middle. Since conciseness will increase the chance of the instrument being used, the number of items to be included in the scale should be minimal, but large enough to target the different levels of severity: i.e. from *feeding* to *bathing and showering*.

As far as possible, the items we have selected are among the most frequently used in existing sets of questions and we propose using: feed, transfer (bed), dress/undress, use toilets, bath or shower.

2. Scale construct

Studies have shown discrepancy among answers for the same item according to the wording used to enquire about the individual's functioning (Jette, 1994; Rodgers and Miller, 1997). Most of the time, the objective in assessing ADL functioning is to evaluate the level of dependence/independence of individuals in their daily life, in order to know the magnitude and trends of disability in our aging societies and to foresee the amount and type of assistance needed. In this respect, questions may satisfy this objective more or less accurately according to the wording used and the construct adopted.

Although self-report is a subjective way of measuring the level of functioning, it appears to be a fairly reliable indicator especially for ADL type of disability (Smith et al., 1990). Furthermore direct measures are not well adapted to ADL type of activity restrictions; discrepancy between self-reported and measured restrictions can be due to the difference between the usual context and "laboratory conditions" for such activities (Reuben et al., 1995; Kempen et al., 1996).

With self reported information, the choice is between asking about performance (do you), abilities (can you), or potential capacities (could you). This has been termed with what he calls the "tenses" of functions, describing different stages and levels of the disablement process, as the information collected differs (Glass , 1998). Indeed, studies have clearly shown a gap between the subjective self-assessment of abilities of respondents and their actual performance (Reuben et al., 1995; Kempen et al., 1996). Here we want to assess dependence in essential activities and we focus on the most essential activities for personal self-care, that individuals face in daily life and <u>have to</u> perform themselves. Their level of dependence does not correspond to what they think they can do but to what they actually do. Therefore, the instrument has to provide information on reported performance (do you...) rather than self-assessed abilities (can you...), to be closer to the actual performance.

The number of response categories as well as the wording and the type (need for help, having difficulty...) may also be responsible for possible differences in the resulting prevalence. Scales can propose several response categories depicting different levels of difficulty (i.e. "some" or "great" difficulty), or the frequency or amount of help received (partly or totally helped). There is a problem in quantifying such notions when self-reporting (Rodgers and Miller, 1997); clear response proposals (such as "any difficulty met", "any help received" or "any equipment used") appear much more efficient and easier to interpret when analysing collected data, especially for comparison between countries or population's groups.

Most questions ask about abilities without someone's assistance and different levels of difficulty are proposed as response categories, ending in the inability to perform without help, called the "rating" of the scale and a large discordance has been found between results coming from "difficulty" scales and "need for human assistance" scales (Jette, 1994). As already explained, activity restrictions scales can lead to two different kinds of indicator: on activity restriction and its severity (through the report of "difficulty in performing"), and on dependence (through the report of "need for help"). Both types of evaluation lead to useful though different information. In order to properly interpret the collected information, the questions have to be asked without any ambiguity.

The WHO-Europe wording is "ability to do on your own" with different levels of difficulty as response-categories as well as the need for someone's help to perform the activity. This instrument gives information on the "need for someone's help", but does not refer to the possible use of technical aids; therefore distinction between those using aids and others cannot be made. A step forward, as suggested in some studies, is to enquire about technical aids (Tager et al., 1998). For clarification of questions and response categories, and to clearly collect information on the use of both human and technical assistance, a solution is therefore to proceed first by evaluating the presence or not of an activity restriction (having or not difficulty in performing, without help, without aids), those having difficulty are then asked about the possible use of help and of aids, and finally, about possible residual difficulties.

Some instruments introduce the notion of time and duration in the questions about the restrictions met: some use a point in time (during last week(s)..., at the time of the survey...), others ask about long-term restrictions only, problems lasting or expected to last over several months. The advantage of the latter option is that it helps in screening disabilities linked to declining functions, excluding temporary limiting consequences of acute health conditions or accidents. Although, it is not proven that this kind of specification is worthwhile or not, especially for an older population for which even temporary health conditions may have more often long term functional consequences, this point should be made to ensure that the collected information from one population to another is based on the same question.

IV. Conclusion

In recent years, efforts have been made towards comparability across Europe, but our census of current surveys demonstrated that there is still some way to go. It seems reasonable at the present time to recommend an existing instrument and to take the opportunity of the current state of "incomparability" to extend the validity of the recommended instrument. Some changes could be made to produce a more powerful instrument but it is

important that any improvements should be made on the basis of scientific research and subsequent validation to reinforce the usefulness and relevance.

In conclusion, the proposed instrument is based on the following aspects that appear to be essential:

- Using a selection of items according to their hierarchical position in term of severity;
- Using wording based on performance ("do you") without assistance and without difficulty;
- Making clear reference to duration in order to avoid temporary difficulties;
- Assessing separately difficulty in performance and the use of technical aids, allowing assessment in part of compensatory strategies that prevents activity restriction despite impairment and functional limitations;
- Eliciting further the assistance received and assistance needed.

These different points have built solid foundations for an instrument to measure activity restriction in older people and we have also suggested a wording to show the future direction we will pursue. However, there is a lack of validity studies on such scales, as demonstrated in the literature review, and further research on validity is strongly recommended before confirming the wording and scale construct.

Together with an indicator of functional limitations, such activity restriction indicators can provide detailed information on the relationship between actual declining functions and daily dependence, shedding light on the potential compensatory strategies or on the effectiveness of basic aids to lessen the consequences of dysfunctions.

Annex 1: Reference instruments for the measurement of restrictions in personal care activities

1. ADL Instrument by Katz

Presentation: The index ADL: A standardized measure of biological and psychosocial function (index developed by the Benjamin Rose Hospital)

Name of the instrument: Index of independence in Activities of Daily Living.

Reference wording (questions) :

Independence means without supervision, direction or active personal assistance, except specifically noted below. This is based on the actual status of individuals and not on ability. A patient who refuse to perform a function is considered as not performing the function, even though he is deemed able. For each of area of functioning listed below check description that applies. (the word assistance means supervision, direction of personal assistance).

Bathing - either sponge bath, tub bath or shower
Receives no assistance (gets in and out of tub by self if tub is usual means bathing)
Receives assistance in bathing only one part of the body (such as back or a leg)
Receives assistance in bathing more than one part of the body (or not bathed)

Dressing - gets clothes from closets and drawers -including underclothes, outer garments and using fasteners (including braces if worn)
Gets clothes and gets completely dressed without assistance
Gets clothes and gets dressed without assistance except assistance for tying shoes
Receives assistance in getting clothes or in getting dressed or stays partly or completely undressed

Toileting - going to the toilet room for bowel and urine elimination; cleaning self after elimination and arranging clothes
Goes to the toilet room clean self and arrange clothes without assistance (may use object for support such as cane, walker or wheel chair and may manage night bedpan or commode, emptying same in morning)
Receive assistance in going to the toilet room clean self and arrange clothes without or in use of night bedpan or commode
Doesn't go to toilet for the elimination process

Transferring- moving in and out of bed
Moves in and out of bed as well as in and out of chair without assistance (may be using object for support such as can or walker)
Moves in and out of bed or chair with assistance
Doesn't get out of bed

Continence-
Control urination and bowel movement completely by self
Has occasional "accidents"
Supervision helps keep urine or bowel control; catheter is used or is incontinent

Feeding
Feeds self without assistance
Feed self except for getting assistance in cutting meat or buttering bread
Receive assistance in feeding or is fed partly or completely by using tubes or intravenous fluids

Data collection: Responses given by an observer on objective situation; the observer tests for locomotion and orientation by asking the individual to show bathroom and an other object and room.

Target population (if any): Population under treatment and prognosis in the elderly and chronically ill.

Wording: observation of performance alone (with technical assistance) or with "human" assistance.

Level of severity: performance with/without assistance

Duration: No reference to duration

Use of technical assistance: Including the possible use of technical assistance for toileting and transferring

Review analysis:

Since Katz, in the field of functional health measurement, a universal consensus has been reached on the use of scales of elementary activities to assess the functional capacities of individuals. As shown in Wiener et al (1990) for instance, such Activities of Daily Living (ADLs) scales are acknowledged as an efficient measurement instrument for clinical experiments (for which they were originally designed by Katz and colleagues), and when adapted, for health surveys (both at specific cohort level and at national level) or for assessment of pension and care system eligibility. Most studies have adapted specific scales to their own objectives, type of population or financial constraints. Many references exist for assessing the functioning of elderly populations (Branch and Meyers, 1987). Nevertheless, the original model remains the reference in the field of dependence, whatever the selected activities of the scale used or the type of evaluation and dependence measurement applied.

Items are commonly used in all studies, except for "continence": studies have validated the importance of the selected items in Katz index in term of the burden of dependence they imply and studies have also validated the hierarchical order defined by Katz to evaluate the severity in functional dependence. The evaluation process goes through the need for assistance or not in the performance of the daily activities and not on abilities. It takes clearly into account the use of technical aids.

Related health expectancy:

Calculation of an "Active life expectancy" has been conducted by Katz using the results of his ADL index. Dealing with a specific population in which he could estimate transition probabilities, he used a multi-decrement method.

Despite the original purpose of the scale being to assess global independence/dependence of the individuals, two indicators can be derived from such scale: one corresponding to activity restrictions, one corresponding to functional dependence/independence.

Limits and justification for non selection:

Evaluation process: Katz's index is devoted to specific populations selected as being chronically ill or patients in hospital. The evaluation process goes through the report by an observer of the patients' capacities in the various situations of daily life. In this original construct, this instrument cannot apply to health interview surveys and should be adapted.

References:

Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW (1963) Studies of illness in the aged. The Index of ADL: A standardized measure of biological and psychosocial function. *JAMA* 185(12):914-919.

2. Reference instrument recommended by WHO-Europe

Presentation: WHO-Euro recommendation for long term disability

Name of the instrument: Long-term physical disability

Set of questions recommended by WHO-Euro for measuring long term physical disability. "Disability items" mix questions about functional limitations and activity restrictions. Other questions inquire separately about "handicap items" (mobility).

Reference wording (questions):

> The following questions refer to what you are normally capable of doing. Temporary complaints should be ignored.
>
> Transfer
> 2   Can you get in and out of bed on your own?
> *without difficulty/with some difficulty/only with someone to help*
>
> Transfer
> 3   Can you get in and out of a chair on your own?
> *without difficulty/with some difficulty/only with someone to help*
>
> Dressing
> 4   Can you dress and undress yourself on your own?
> *without difficulty/with some difficulty/only with someone to help*
>
> Washing
> 5   Can you wash your hands and face on your own?
> *without difficulty/with some difficulty/only with someone to help*
>
> Feeding
> 6   Can you feed yourself, including cutting up food?
> *without difficulty/with some difficulty/only with someone to help*
>
> Toilet
> 7   Can you get to and use the toilet on your own?
> *without difficulty/with some difficulty/only with someone to help*

Data collection: for health interview surveys

Target population (if any): recommended to person aged no less than16.

Wording: can you..... on your own

Level of severity: without difficulty/with some difficulty/only with someone's help

Duration: "temporary items should be ignored"

Use of technical assistance: no reference to the possible use of technical assistance

Review analysis:

Facing a great disparity of information due to the use of different scales and items, WHO-Europe proposed the use of a core set of items in health interview surveys, to be able to compare the health status of the population regarding functional capacities within the European Community.

Items are issued from Katz's index. "Continence" has been removed from the scale and "transferring" has been divided in two items. Katz's scale has been modified to fit with usual health interview survey questionnaires. This has implication for the form of questions to collect the most accurate self-reported limitations and restrictions from respondents.

The tremendous work that has been done in the Consultation to promote the idea of common instrument for Health Interview Surveys is remarkable: the most recent surveys initiated in Europe have adopted the majority of the recommendations.

Related health expectancy:

Health interview surveys are generally designed to be cross-sectional. The calculation of activity restriction-free life expectancy or functionally independent life expectancy is obtained by the Sullivan method.

Two levels can be estimated:

Activity restriction free life expectancy and independent life expectancy.

The characteristics of the instrument:

The literature on testing and validation of activity restriction scales in health interview surveys allows an a-posteriori assessment of the recommended instrument.

The surveys that currently use ADL scales, or even the recommended instrument, show some differences in wording due to translation problems; this points to the feeling of survey makers that these wording or scale construct differences have a limited impact, especially compared to the benefits of the amendments made for the sake of country specific culture or current interests. Nevertheless, it must be stressed that even limited changes in wording may make the resulting prevalence non comparable from one country to another.

In recent years, efforts have been made towards comparability across Europe, but there is still some way to go. It seems reasonable therefore to continue the promotion of a recommended instrument and to take the opportunity of the current state of "incomparability" to extend the validity of the recommended instrument. Some changes could be made to produce a more powerful measurement instrument but any improvements should be made on the basis of scientific validation of such an instrument to reinforce its usefulness and relevance.

References:

WHO Regional Office for Europe, Netherlands Central Bureau of Statistics, Department for Health Statistics, eds. *Consultation to develop common methods and instruments for health interview survey.* Voorburg: NCBS, 1988:82

de Bruin A, Picavet HSJ, Nossikov A (1996) *Health interview surveys: Towards international harmonization of methods and instruments.* Copenhagen: World Health Organisation. Regional Office for Europe. Voorburg: Statistics Netherlands. (WHO Regional Publications. European Series n°58).

Annex 2: Construct of the personal care activities sets of questions in the different European health surveys and sources of problems of comparisons

	BELGIUM (ES, 97)	SPAIN (ENS, 1995)	ITALIA (multi-scopo, 1994)
Face to face (FF) /telephone (T) /self administrated (SA)	FF	FF	FF
Use of proxy	Y		?
Sample size	10 000 indiv (4 500 household)	8 400	60 000 (20 000)
Non-response rate	40%		10%
Age range for ADL questions	60 and over and 15 and over screened	16 and over	6 and over
Institutions included	Nursing homes, homes for elderly	No	No
Introduction to ADL items questionnaire:	N	N	Y
Reference to duration (long term)	N	N	N
Reference to the use of technical assistance	N	N	Y (assessment of limitations with usual assistance used
Mixed items (Functional limitations, IADL, mobility?)	Y	N, Core ADL type of indicator	Y
Other questions about functional status	Y	Y (functional limitations, mobility)	Y (functional limitations, mobility)
Clear reference to WHO/CBS	Y	N	Y
Performance/Ability	Ability, without help	Ability	Ability, alone
Level of disability			
with degrees of difficulty (number of items)	Y (2)+	Y (2)+	Y (2)+
with help (wording used)	Y (always need...)	Y (can only...)	Y (can only...)
human/mechanical assistance specified	Human	not specified	Human
non response item	N	Y (nc)	N
duration	N	N	N

	PORTUGAL (INS, 95)	FRANCE (SSM, 91-92)	UNITED KINGDOM (GHS, 96)
Face to face (FF) /telephone (T) /self administrated (SA)	FF	FF	FF
Use of proxy	?	N	?
Sample size	50 000 (17 400)	21 500 (8 000)	18 000 (9 700)
Non-response rate	27%	6%	15%
Age range for ADL questions	10 and over	65 and over	65 and over having difficulty with stairs
Institutions included	No	No	N
Introduction to ADL items questionnaire:	Y	Y	N
Reference to duration (long term)	Y (prolonged and chronical situation)	Y(expressed for the interviewer)	N
Reference to the use of technical assistance	N	N	N
Mixed items (Functional limitations, IADL, mobility?)	Y	Y	Y
Other questions about functional status	Y (functional limitations, mobility)	Y (functional limitations, mobility, IADL)	Y (functional limitations, mobility, IADL)
Clear reference to WHO/CBS	Y	N	N
Performance/Ability	Ability	Ability, alone	Perf/ability (Do you usually manage to...)
Level of disability			
with degrees of difficulty (number of items)	Y (2) (without help)+	Y(3)+no	N
with help (wording used)	Y (with help)	N	Y(2)+no
human/mechanical assistance specified	N	-	Human
non response item	Y (do not know)	N	N
duration	Y (for some items, question on duration)	N	N

	NORWAY, 95	FINLAND (CATI, 93)	THE NETHERLANDS, (HIS) 95
Face to face (FF) /telephone (T) /self administrated (SA)	FF	T	FF/SA
Use of proxy	?	?	?
Sample size; people (households)	10 248 (5 200)	3 250 (25-79 years old)	9 000 (3 500)
Non-response rate	24%	29,5%	42%
Age range for ADL questions	?	60-79	55 and over
Institutions included	N	N	N
Introduction to ADL items questionnaire:	Y	N (introduction only to general question on disab.)	Y
Reference to duration (long term)	Y (at least 6 months)	N (in the introduction to general disab. 6 months)	N
Reference to the use of technical assistance	N	N	N
Mixed items (Functional limitations, IADL, mobility?)	Y	Y	Y
Other questions about functional status	Y (functional limitations, mobility, IADL)	Y (functional limitations, mobility, IADL)	(functional limitations)
Clear reference to WHO/CBS	N	N	N
Performance/Ability	Ability, without help of others		Ability
Level of disability		Having difficulty/needing help	Having difficulty/needing help
with degrees of difficulty (number of items)	Y(2)+		Y(3)+
with help (wording used)	Y (only with...)		Only with help
human/mechanical assistance specified	Human	Human	Human
non response item	N	Y	N
duration	N	N	N

Annex 3: Wording used to ask for ADL limitations or difficulties in surveys compares to the WHO-Europe

Transfer (bed), transfer (chair), dress/undress, wash, get to and use toilets

WHO/CBS	BELGIUM (ES, 97)	SPAIN (ENS, 1995)	ITALIA (multi-scopo, 1994)
		... if you are able to perform them without, with...	*about difficulty in daily activity, even with mechanical help*
Can you get in and out of bed on your own?	*Can you get up and lie down without help*	*Can go to and get up from bed -*	*Can get to bed and get up from a bed alone*
Can you get in and out of a chair on your own?	*Can you sit in an armchair and get up without help*	*Can sit down and get up from a chair -*	*Can sit and get up from a chair alone*
Can you dress and undress yourself on your own?	*Can you dress and undress yourself without help*	*Can get dressed and undressed -*	*Can get dressed and undressed alone*
Can you wash your hands and face on your own?	*Can you wash your hands and face without help*	*Can wash hands and face -*	*Can wash hands and face alone*
Can you feed yourself, including cutting up food?	*Can you eat without help and cut your food*	*Can eat including cut up food -*	*Can eat alone, including cut food alone*
Can you get to and use the toilet on your own	*Can you go to the toilets without help*		
		Can take a shower or bath alone	*Can have a bath or a shower alone*
Without difficulty	*Yes, without difficulty*	*Without difficulty*	*without difficulty*
With some difficulty	*Yes with some difficulties*	*With difficulty*	*with some difficulty*
Only with someone to help	*I always need someone's help*	*Can only with help*	*Can do it only with someone's help*
		Nc	
WHO/CBS	PORTUGAL (ISQ, 95)	FRANCE (SSM, 91-92)	UNITED KINGDOM (GHS, 96)
			... be able to do on their own, while others may ...
Can you get in and out of bed on your own?	*Are you able to get to and get up from bed*	*Can you go to or get up from bed alone*	*Do you usually manage to get in and out of bed*
Can you get in and out of a chair on your own?	*Are you able to sit and get up from a chair*	*-*	*-*
Can you dress and undress yourself on your own?	*Are you able to get dressed and undressed*	*Can you dress and undress yourself alone*	*Do you usually manage to dress and undress yourself*
Can you wash your hands and face on your own?	*Are you able to wash your hands and face*	*Can you wash alone*	*Do you usually manage to wash your face and hands*
Can you feed yourself, including cutting up food?	*Are you able to eat, cut your food and lift it and drinks to your mouth*	*Can you feed including cutting your food alone*	*Do you usually manage to feed yourself*
Can you get to and use the toilet on your own	*Are you able to go to the toilets and use it*	*Can you get to and use the toilets alone*	*Do you usually manage to get to the toilet*
			Do you usually manage to bath, shower or wash all over
			Do you usually manage to get around the house
Without difficulty	*Without help, without difficulty*	*Yes, without difficulty*	*On your own*
With some difficulty	*Without help, but with difficulty*	*Yes without too much difficulty*	*Only with help from someone else*
Only with someone to help	*With help*	*Yes with a lot of difficulty*	*Or not at all*
	Do not know	*No*	
WHO/CBS	NORWAY, 95	FINLAND, 93	THE NETHERLANDS, 1995
			Now, I am going to... Please indicate... whether you can perform without difficulty.....
Can you get in and out of bed on your own?	*Can you get into and out of a bed without help from others*	*Do you have difficulty getting into or out of bed/ do you need help...*	*- getting in and out of a bed*
Can you get in and out of a chair on your own?	*Can you sit down in and get up from a chair without help from others*		*- getting in and out of a chair*
Can you dress and undress yourself on your own?	*Can you dress and undress yourself -*	*Do you have difficulty dressing or undressing/ do you need help...*	*- dress and undress yourself*
Can you wash your hands and face on your own?	*-*		*- wash your face and hands*
Can you feed yourself, including cutting up food?	*Can you eat by yourself, including cutting up your food*		*- eat and drink*
Can you get to and use the toilet on your own	*-*	*Do you have difficulty using the toilets/ do you need help...*	*-*
		Do you have difficulty washing yourself or bathing/ do you need help	*- Wash your whole body*
			- move towards another room on the same floor
			- leave the house and enter it
			- move along outside the house
Without difficulty	*With no difficulty*	Yes / No	*Without difficulty*
With some difficulty	*With some difficulty*		*With some difficulty*
Only with someone to help	*Only with the help of others*		*With great difficulty*
			Only with help from others

Chapter 3: 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 draft ICIDH-2 an activity is defined as: '*the performance of a task or action by an individual*' and thus activity limitations are defined as '*the difficulties the individual experience in performing an activity*' (World Health Organization, 1999). Within the framework of the ICIDH-2, 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 performance 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 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 - ICIDH-2 Beta 2 draft, (World Health Organization, 1999) - gives us an opportunity to better relate a Global Activity Limitations Indicator to a conceptual framework (see chapter 2, section 1). In the current draft of the revision, activity limitations are defined as the difficulties the individual experiences in performing an activity, due to a health condition. Activity is defined as: '*the performance of a task or action by an individual*'. The activity dimension of the ICIDH-2 gives a profile of an individual's functioning in terms of activities, from simple to complex ones, and deals with the actual 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 ICIDH-2, 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 and a detailed description of these instruments is given in Part III. Table 3 also includes the results of the evaluation of the proposed GALI instrument and the extended GALI instrument against the criteria.

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 (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	+	-	-	-	-	-	-	-	-	-	+	-	-	-	-	-	-	-	-	-	-	-	-	-

Numbers 1 to 22 refer to candidates (for references see Part 3)

Score: see text

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. Within the concept of the ICIDH-2, 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.

*   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.

- 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)

As the proposed indicator is a newly formulated question, it is not yet validated. Validation is foreseen in the next phase of the project (translation, sensitivity, specificity). 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; Kramer, 1980; Fries, 1980; Manton, 1982).

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 4: Perceived health

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Section 1: Definition and presentation of the proposed measurement instrument

1. Defining the concept

In recognition of the need to elicit an individual's assessment of their health and of the considerable advantages of measuring overall health through the use of a single question, the concept of self-perceived health (SPH) has been increasingly used.

In view of the varied interpretations and methodologies in measuring self-perceived health the following framework is suggested. First, it is more relevant to use the term *self-perceived health* (SPH) rather than just *perceived health*. This is to emphasise that the notion is restricted to an assessment coming from the individual 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 relative to their own beliefs and attitudes. In addition, SPH is a global measure that is expected to include the different dimensions of health, i.e. physical, social and emotional function and biomedical signs and symptoms, whereas with specific health indicators we get only a partial indication of health. Hence, the reliance on only a few questions, or ideally one, instead of the battery of questions which is more usual in the assessment of, for example, social functioning and activities of daily living.

2. Defining the measure

Despite its general and subjective character, a single question on self-perceived health brings useful information for public health. The WHO-Europe question on self-perceived health, "*How is your health in general?*", is commonly used in health interview surveys (WHO-Europe, 1996).

3. Policy relevance and utility

The advantage of SPH is that it provides a global approach to health rather than a partial one, leading to a single figure of population health. SPH can easily be measured through a single question that can be administered in all types of surveys and to a population of all ages. In health monitoring, the analysis of regional differences and temporal trends of population health can easily be addressed by using SPH as a global measure of health (Robine et al., 1998).

SPH is associated with a number of other health outcomes and the use of health services (Idler and Benyamini, 1997) and is also an independent predictor of survival in older people (Kaplan et al., 1988). 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.

4. Wording

We conclude from our analyses that there is no reason to change the already recommended SPH question of WHO-Europe (WHO-Europe, 1996).

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

5. Justification of the choice

Among all the reviewed instruments measuring SPH, the WHO-Europe question is one of the best. The question is absolute in that it omits any reference to either an age or time comparison. The WHO argues that the inclusion of such comparisons prevents the monitoring of the average health of a population. The question is not time limited. The reference is to health in general rather than the 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 refers to the different sub-attributes or dimensions of health.

6. Scoring system

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. 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 for any 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.

7. Population categories

In order to provide good estimates of the self-perceived health status of a population, this instrument should be administered to a general population of all ages. For this question a proxy should not be used.

8. Health expectancies

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 (Robine et al., 1998).

According to the present proposal, life expectancy in good self-perceived health could be used as the indicator to monitor progress on perceived health and quality of life throughout the European region.

Section 2: Background

I. History of the instrument

"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)" was the first self-perceived health (SPH) question (Heyman and Jeffers, 1963). Other studies found a significant correlation between SPH and mortality (LaRue et al., 1979; Singer et al., 1976; Mossey and Shapiro, 1982; Kaplan and Camacho, 1983). Since then, a review of 27 studies, confirmed the strong relationship between SPH and mortality, stronger for men than for women (Idler and Benyamini, 1997). SPH shows a better correlation with mortality than many 'objective' measures based on health service use and self-reported morbidity and is independent of other factors like chronic illness, physical functioning, use of health services, education, income, smoking, social networks.

Fewer studies have investigated the relationship between SPH and morbidity. A review of the literature concluded that there is significant correlation between SPH and physical symptoms, chronic illness, functional ability and psychological symptoms (Kristensen et al., 1998). Good SPH has also been shown to be important in elements of adjustment to major illness (Hunt et al., 1980). Poorer SPH is associated with neuroticism as measured with Eysenck Personality Inventory (Blaxter, 1990), greater use of health services (Goldstein et al., 1984) and predicts decline in functional ability among the elderly (Idler and Kasl, 1991) and among the general population (Ferraro et al., 1997). Education, employment, social class, single parenthood and smoking behaviour have all been found to be associated with SPH (Kind et al., 1998; Kristensen et al., 1998; Blaxter, 1990).

Despite the correlation of SPH with mortality and with some aspects of morbidity, the measurement of SPH has been criticised (Bowling, 1991; McDowell and Newell, 1996). 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 multi-dimensional and that only a limited number of response choices are provided. Various attempts have been made to investigate what people are actually answering when they respond to a global question on perceived health (Blaxter, 1990; Van Dalen et al., 1994) Many disabled and/or older people insist on calling their health excellent, even when this seems optimistic, meaning 'is excellent, considering my advanced years' or 'despite my disability'. People prefer to define their own health as good if at all possible. According to Blaxter (1990), those who think their own health is good are more likely to associate health with 'never ill, not diseased' and, especially men, those who think their own health is bad to associate health with '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 bio-medical dimension was dominant in defining both good and poor health. 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, it is worth mentioning more complex, multi-item measures of which the three best known examples are the Health Perceptions Questionnaire (HPQ, Davies and Ware, 1981), the Short Form–36 (SF-36, Ware and Sherbourne, 1992) and the European Quality of Life Scale (EuroQol, McDowell and Newell, 1996). The HPQ, designed as a measure of SPH for use in the evaluation of medical care and assessment of population health status, 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). The Short Form–36 covers eight sub-scales, one of which is general health perception (consisting of five questions) and is widely used as a measure of health status with 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 and 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

The surveys and questions examined for the purposes of this report were identified through a report on the "Coverage of Health Topics by Surveys in the European Union" (Hupkens, 1997). In order to get a more extensive picture of the surveys performed in Western Europe, the main national health surveys of Iceland, Norway and Switzerland are also included. 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 or a similar surveys with a substantial health component.

A total of 37 European surveys containing questions on SPH were identified. However, two surveys include 2 questions, one in a face-to-face questionnaire and one in a self-administered questionnaire. As a result, 39 questions were examined. No information was obtained for Greece or Ireland as neither country's national health survey included a question on SPH.

While a SPH question is commonly used in health interview surveys, there has been little consensus on the wording of the question and response categories and whether or not a reference to age or time should be included**.** A closer examination of the European Health Surveys illustrates this:

 A few surveys (5/37) use an age-related wording, where respondents are asked to make a comparative judgement of their own health with others of the same or similar age (see annex 2).

Almost half (14/37) of the surveys include a reference to time, with the majority asking respondents about their 'present' or 'current' state of health (see Annex 3).

A general wording, where respondents are not specifically asked to compare their health with others of the same age or with their own previous or future health state, is used by half of the surveys (18/37) (see Annex 4). One survey includes two such questions and as a result 19 were examined. While a general wording is recommended by the WHO-Europe, omitting reference to either age or time comparison, the questions found still vary significantly in the wording and in the number and type of response categories. Among the 19 questions using a general wording, 10 followed the WHO-Europe recommendation. In the remaining, the main differences in wording were: the verb used (perceive or say), what respondents have to rate (state of health, general health, physical health or health in general), the context (in general, generally speaking or on the whole).

Major differences also appear in the response categories. The WHO-Europe recommended five response categories are used by 10/37 surveys although a further 17 surveys also include five response categories, with different wording and variation in the number 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 make it impossible to rigorously compare results.

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.

It has been suggested that the pattern of answers to a SPH question can differ considerably between cultures and countries (Eurostat, 1997; Appels et al., 1996; WHO, 1997) although the relationship between SPH and mortality seems to be universal (Idler and Benyamini, 1997). Responses to the question on SPH in the 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. For instance, 53% of the Danish respondents reported 'very good' health compared to only 8% of those from Portugal. It is uncertain to what extent, these findings reflect actual health difference, cultural perception differences, or poor validity.

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

There has been little formal evaluation of the validity of the SPH measurement because of its predictive value, strongly on mortality (Idler and Benyamini, 1997) and less strong on disability (Idler and Kasl, 1991; Wilcox et al.,1996; Ferraro et al., 1997) and self-reported long-standing illness (Blank and Diderichsen, 1996). The consistency of findings with mortality suggests that SPH is an effective summary of the respondents' health regardless of whether it has an independent effect on mortality or not (Manderbacka et al., 1998).

SPH has been compared with more complex, multi-item summary measures of self-reported health suggesting concurrent validity, with the conclusion that SPH provides information that is, at the very least, consistent with more complex measures of self-reported health assessment (Rowan, 1994).

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 reasonable reliability with the weighted kappa values varying between 0.59 and 0.65 and more than 85 percent of the respondents giving similar answers in the initial interviews and in the re-interviews. Similar results were found from two Swedish studies, with reliability of SPH being as good or even better than most of the more specific health questions, and with kappa values of 0.6-0.7 (Manderbacka and Lundberg, 1996).

Response categories such as those used in the proposed instrument to measure SPH, 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 does not use descriptive terms and has been found to have good reliability and validity (Andrews and Withey, 1976). The use of symbols (such as 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 and can also be used with children and others who may otherwise 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. Ladder scales and visual analogue scales may achieve interval level measurement since each point on ladder can be assumed to be equidistant from its neighbours. There have been relatively few studies on the scaling procedures used with the single-item question on SPH. Comparing a five-point category scale (excellent, very good, good, fair and poor) to a visual analogue scale on a range 0 to 100, Badia (Badia et al., 1999) found considerable overlap between the three categories at the upper end of the scale (good, very good and excellent).

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 and Gutierrez Fisac, 1997).

IV. 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 their own health, the notion and measurement of self-perceived health has gained recognition. 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-Europe 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. Europe is made 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. These may include qualitative studies to examine various interpretations of the question and response categories. Statistical techniques such as multivariate analysis and cluster analytical techniques should 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 in the next phase of this project, 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) and external threats (the impact of social and personal life-events). These topics or similar concepts are included in 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 self-perceived 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 those measures. The priorities of further work should be to elucidate current international recommendations covering these topics (if these exist), 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 method1	Frequency	Sample size (persons)2
A01	Austria	Special health survey	1991	FTF	1973, 1983, 1991	67,000
A05	Austria	Consumption of alcohol & psychoactive substances	1993/94	FTF		2015 (quota samples)
B01	Belgium	Health interview survey	1997	FTF & SA	every two years from 1997	10,000
CH01	Switzerland	Swiss health survey	1997	FTF, SA & TEL	1992, 1997	16,000 households
D03	Germany	Deutsch Herz-Kreislauf-Preventionsstudie	1990/91	SA	1984-86, 1987-89, 1990/91	
D04	Germany	Gesundheitssurvey Ost Deutschland	1991/92	SA	1990/91	
D05	Germany	Nationaler Gesundheitssurvey	1997	SA		7,500
D06	Germany	Umwelt, Gesundheit und Gesundheitsversorgung	1994/95	FTF		5,000
DK01	Denmark	Danish health interview survey	1994	FTF & SA	1986/87, 1994	6,000
E01	Spain	National health survey	1995	FTF	1987, 1995	8,400
E02	Spain	Household survey on drug use	1995	FTF & SA	every two years	10,000
F01	France	Enquête sur la santé et les médicaux	1991/92	FTF	every 3 years	
F03	France	Enquête sur la santé et la protection sociale	1995	FTF & SA	annual since 1988	10,000
F06	France	Baromètre santé grand public	1995	TEL	every 3 years	
F08	France	Enquĺte conditions de vie et aspirations des FranÁais	1994/95	FTF	annual	(quota samples)
FIN01	Finland	Survey on health behavior	1994	SA		
FIN04	Finland	Living conditions survey	1994	FTF	irregular since the 1970s	
FIN05	Finland	Health care survey	1995/96	FTF	1968, 1976, 1987, 1995/96	4,000 households
FIN08	Finland	Use of health services and health status	1993/94	TEL		
FIN10	Finland	Family planning services	1994	SA		
FIN12	Finland	Finnish drinking habits survey	1992	FTF	every 8 years	
I01	Italy	Survey on health conditions and use of health services	1994	FTF	every 4 years	75,000
I02	Italy	Aspects of daily life	1994	FTF & SA	annual	
IS01	Iceland	Omnibus survey	1996	TEL	1994, 1996	1,500
L01	Luxembourg	Socio-economic panel Living in Luxumbourg	1996	SA	1995, 1996	8,000
N01	Norway	Health interview survey	1995	FTF & SA	every 10 years	14,000
NL01	the Netherlands	Health interview survey	1995	FTF & SA	annual since 1981	9,000
NL02	the Netherlands	Standard of living survey	1996	FTF	annual since 1989	3,500
P01	Portugal	National health survey	1995/96	FTF	irregular	50,000
S01	Sweden	Survey on living conditions	1996	FTF & TEL	annual since 1975	7,000
UK01	United Kingdom	General household survey	1996	FTF & SA	annual since 1971	18,000
UK02	United Kingdom	Health education monitoring survey	1996	FTF	1995, 1996	4,700
UK03	United Kingdom	Health and lifestyle survey	1991	FTF & SA	1984/85, 1991	5,352
UK04	United Kingdom	Disability survey	1996	FTF		7,000
UK05	United Kingdom	Survey of psychiatric morbidity	1993/94	FTF	irregular	12,500
UK09	United Kingdom	Health survey for England	1995	FTF & SA	annual since 1991	20,000
UK10	United Kingdom	Scottish health survey	1995	FTF	every three years since 1995	7,932

[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 soins médicaux
   Actuellement, compte tenu de votre âge, comment estimez-vous votre état de santé?
   très bon – bon – moyen - médiocr - 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. Switzerland - CH01: Swiss health survey
   Wie geht es Ihnen sur Zeit gesundheitlich?
   sehr gut – gut – mittelmässig – schlecht - sehr schlecht

2. Germany - D03: Deutsch Herz-Kreislauf-Praventionsstudie
   Wie würden Sie Ihren gegenwartigen Gesundheitszustand beschreiben?
   sehr gut – gut – zufriedenstellend - weniger gut – schlecht

3. Germany - D04: Gesundheitssurvey Ost Deutschland
   Wie würden Sie Ihren gegenwartigen Gesundheitszustand beschreiben?
   sehr gut - gut – zufriedenstellend - weniger gut – schlecht

4. Germany - D06: Umwelt, Gesundheit und Gesundheitsversorgung
   Wie wurden Sie Ihren gegenwärtigen Gesundheitszustand beschreiben?
   sehr gut – gut – zufriedenstellend - weniger gut – schlecht

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

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?
   very good – good – fair – poor - very poor

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

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

9. Finland - FIN05: Heath care survey
   Is your present state of health in your own opinion: good, fairly good, average, rather poor or poor?
   good - fairly good – average - rather poor – poor

10. Finland - FIN08: Use of health services and health status
   I should now like to ask about your present state of health. Do you think it is good, fairly good, average, rather bad or bad?
   good - fairly good – average - rather bad – bad

11. Finland - FIN10: Family planning services
   How would you rate your current level of health?
   good - fairly good – middle - fairly poor – poor

12. Finland - FIN12: Finnish drinking habits survey
   What is your opinion of your current state of health?
   excellent - fairly good – average - fairly weak - extremely weak

13. 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

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

Annex 4: Formulation of absolute self-perceived health questions

1. Austria - A01: Consumption of alcohol & psychoactive substances
   Wie beurteilen Sie im allgemeinen Gesundheitszustand?
   sehr gut – gut – mittelmabig – schlecht - sehr schlecht

2. Belgium - B01: Health interview survey
   Comment est votre état de santé général?
   très bon – bon – moyen – mauvais - très mauvais

3. Germany - D05: Nationaler Gesundheitssurvey
   Wie wurden Sie Ihren Gesundheitszustand im allgemeinen beschreiben?
   ausgezeichnet - sehr gut – gut - weniger gut - schlecht

4. Denmark - DK01: Danish health interview survey (self-administered)
   How do you perceive your health in general?
   excellent - very good – good – fair – bad

5. Spain E02: Household survey on drug use
   Would you say your health in general is excellent, very good, good, fair or bad?
   excellent - very good – good – fair – bad

6. France - F03: Enquête sur la santé et la protection sociale
   Pouvez-vous noter, entre 0 et 10, votre état de santé? 0 = en très mauvaise santé, 10 = en excellente santé.

7. Italy - I01: Survey on health conditions and recourse to health services
   Generally speaking, what is your state of health?
   very bad – bad - moderately good – good - very good

8. Italy - I02: Aspects of daily life
   Health-wise, how well are you? Self-score from 1 to 5: 1 is bottom score, and 5 top score.

9. Iceland - IS01: Omnibus survey
   Do you find your physical health to be very good, good, fairly good, fairly bad or bad?
   very good – good - fairly good - fairly bad – bad

10. Luxembourg - L01: Socio-economic panel living in Luxembourg
   Vous sentez-vous en très bonne santé, bonne santé, plus ou moins bonne santé, mauvaise santé ou très mauvaise santé?
   très bonne santé - bonne santé - plus ou moins bonne santé - mauvaise santé - très mauvaise santé

11. 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 or very poor
   very good – good - neither good nor bad / average – poor - very poor

12. the Netherlands - NL01: Health interview survey
    How is your health in general?
    very good – good – fair - sometimes good and sometimes bad – bad

13. the Netherlands - NL02: Standard of living survey
    How is your health in general?
    very good – good – fair - sometimes good and sometimes bad – bad

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

15. Sweden - S01: Survey on living conditions
    In your opinion, how is your state of health? Is it very good, good, fair, poor or very poor?
    very good – good – fair – poor - very poor

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

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

18. United Kingdom - UK09: Health survey for England (self-administered & face-to-face)
    How is your health in general? Would you say it was very good, good, fair, bad or very bad?
    very good – good – fair – bad - very bad
    In general, would you say your health is excellent, very good, good, fair, or poor?
    excellent - very good – good – fair – poor

Chapter 5: Development of a set of mental health indicators

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Section 1: Definition and presentation of the proposed measurement instrument

1. Defining the concept

There is no generally agreed definition of the term mental health. In the founding statement of the World Health Organisation in 1946, 'health' was defined as; "a state of complete physical, mental and social well being and not merely the absence of disease or infirmity" (United Nations, 1946). Following on from this definition, others have developed an equally broad definition of 'mental health'; "Mental health is a positive sense of well-being; a belief in our own worth and the dignity and worth of others; the ability to deal with the inner world of thinking, feeling, managing life and taking risks; the ability to initiate, develop and sustain mutually satisfying personal relationships; the ability of the mind to heal itself after shock or stress" (Health Education Authority, 1997).

While some have welcomed the breadth and vision implicit in these broad definitions of health (Susser, 1987), others have criticised them for being impractical (Callahan, 1995). It has been argued that in legitimizing unlimited demand for health services these definitions detract from the aim of reducing the burden of illness (Saracci, 1997). These two approaches to conceptualising mental illness have led to increasingly divergent views about the relationship between health and illness. While recent publications from WHO continue to assert that 'mental health is not just the absence of mental disorder', others have argued that this is exactly how it should be defined (Kendell,1995).

Defining an outcome is a central element of surveillance. As Susser has noted (1987) 'The way health is defined is a necessary antecedent of the way health is measured'. It is possible to measure mental health using both the broad and narrow definition. A narrow definition is preferable if the aim is to meet international targets to reduce the prevalence of mental disorders (World Health Organisation, 1992). It is also more helpful if the aim is to examine the response of a population to medical interventions. Therefore, for the remainder of this document, **mental health is defined as the absence of mental illness**.

2. Defining the measure

The concept indicator proposed in this document is the twelve item version of the General Health Questionnaire (GHQ-12) (Goldberg, 1972). The GHQ-12 aims to measure the likelihood of psychiatric disorder. In doing so it measures the likelihood that someone is experiencing depression, anxiety and other 'neurotic' mental disorders. To some extent it also measures the likelihood of other mental states associated with psychiatric disorders such as psychosic disorders. Because the GHQ includes items on social functioning the GHQ-12 score also provides a proxy measure of social function and quality of life. The twelve questions included in the GHQ-12 are commonly used in clinical practice.

3. Policy relevance and utility

Mental disorders are now recognized as one of the principal causes of disability and consume a significant proportion of the health budget in western countries. Any attempt to develop a health monitoring system must therefore give careful consideration to the observation of psychiatric disorder. Several 'world' bodies are actively involved in monitoring public health. As part of these efforts the World Health Organization (WHO) has produced estimations on the causes of morbidity and mortality around the world (Murray and Lopez, 1995).These findings were used to support the conclusion that five of the ten leading causes of disability world wide, are mental illnesses and that mental illness contribute to 28% of all years lived with disability. The WHO, has also set a series of specific targets for improving health and, in relation to mental health in Europe, has published the influential document 'Health for all'(WHO-Europe, 1980 ; 1985). This states that;

'By the year 2000, there should be a sustained and continuing reduction in the prevalence of mental disorders, an improvement in the quality of life of all people with such disorders.' (World Health Organization, 1992)

In the treaty of Amsterdam, the commitment to public health was reinforced (van de Water and Herten, 1998). 'Europa' is the web-server for the European Union. It provides a way of identifying and inspecting documents produced by European institutions such as the Parliament, Commission and the Council of Ministers.

Over 1,000,000 documents are available on Europa of which over 27,000 relate to health. A search on Europa for all documents related to mental health revealed only 384 'hits' (i.e. 1.4%). A review of these documents suggested that concern about mental health is increasing. In addition to documents concerned with mental health in non-member countries in Eastern Europe, documents highlighting the importance of mental illness in social exclusion and the effects of mental illness on absence from work are also evident.

Within countries targets for health have also been set, in some these include targets related to mental health. For instance in England and Wales the 'Health of the Nation' document set targets to reduce the national rate of suicide by 15% by the year 2000 along with the more general aim of 'improving significantly the health and social functioning of mentally ill people' (Secretary of State for Health, 1993). Norway, Finland, Sweden, France and the Netherlands have also set up programmes aimed at reducing the national rate of suicide (Taylor et al. 1997). In recognition of the high level of burden associated with mental illness, national and international organisations have become increasingly aware of the need to monitor and reduce the prevalence of mental illness.

4. Wording

The General Health Questionnaire - 12-item version is proposed. The wording of the introductory sentences and items are given below:

Introduction: "We would like to know if you have had any medical complaints, and how your health has been in general, over the past few weeks. Please answer ALL the questions simply by underlining which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you have had in the past". Have you recently:

	Score 0	*Score O**	*Score 1*	*Score 1*
1. Lost much sleep over worry?	Not, at all	No more than usual	Rather more than usual	Much more than usual
2. Felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
3. Been able to concentrate on whatever you are doing?	Better than usual	Same as usual	Less than usual	Much less than usual
4. Felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
5. Been able to face up to your problems?	More so than usual	Same as usual	Less able than usual	Much less able
6. Felt capable of making decisions about things?	More so than usual	Same as usual	Less capable than usual	Much less capable
7. Felt you couldn't overcome your difficulties?	Not at all	No more than usual	Rather more than usual	Much more than usual
8. Been feeling reasonably happy, all things considered?	More so than usual	About the same as usual	Less so than usual	Much less than usual
9. Been able to enjoy your normal day-to-day activities?	More so than usual	About the same as usual	Less so than usual	Much less than usual
10. Been feeling unhappy and depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual
11. Been losing confidence in yourself?	Not at all	No more than usual	Rather more than usual	Much more than usual
12. Been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual

5. Justification of the choices

At a general level it was felt that a set of mental health indicators should address four areas currently considered of primary importance in health care assessment and delivery :

a)   there should be an indicator which monitors the changes in health status which may occur due to alterations in demography and population structure over time, for example changes in dementia prevalence ;

b)   there should be an indicator of general stress which is sensitive to socio-economic change and environmental pressures for example suicide rates ;

c)   there should be an indicator which is sensitive to the status of primary care delivery, for example relating to the prevalence and treatment of depressive symptomatology ;

d)   there should be a measure of general mental well-being which is likely to be sensitive to changes due to all causes (disease incidence, clinical intervention, socio-economic and political change).

Ideally we have sought for a generic indicator of the type d) which would have the possibility of decomposition into a), b), and c) and yet be suitable for widespread population use within the context of a general health survey using non-clinical interviewers. In the first instance an extensive literature search was carried out over the past 30 years using the Medline and Psychinfo data bases to locate all previous population studies of mental health.

The SIGMUND data base provided detailed information of the research design and instruments used in many of these studies. As a result of this study a short list of over 20 possible instruments were located of which four (the Cornell Medical Index, the General Well-Being Schedule, the SF36 MIH5 and the General Health Questionnaire) were considered to constitute generic instruments adapted to the calculation of health expectancies using current methods. Following careful examination of these different possibilities, the work group argued that the GHQ-12 currently provides an indicator of mental disability which has been validated against psychiatric assessment and used throughout Europe. Use may also be made of specific items included in the instrument such as those referring to suicide or depression. The GHQ-12 provides a means of estimating the likelihood that a person suffers from mental illness. It does this by enquiring about the presence or absence of symptoms of mental distress and associated dysfunction. These factors appear to represent experiences common to people experiencing mental distress in a variety of different settings. The GHQ-12 score provides valid and reliable means of detecting the likelihood of mental illness across a variety of different cultural and geographical settings throughout Europe.

6. Scoring system

Three methods have been proposed for the scoring of the GHQ. There seems little difference between different systems of scoring the GHQ but most experience has been with the original 'GHQ score' system in which 0 is given to the first two scoring categories indicating no symptomatology and 1 to the two categories indicating positive symptoms. Cut-off points for GHQ-12 have already been established in several European countries. Further work may need to be carried out in other countries in order to determine the optimal cut off point in the general population and in groups of people of older and younger ages, before large scale population surveys can begin.

7. Population categories

In addition to collecting information from both men and women of all ages, estimates of health expectancies based on the GHQ need to be based on information from a sample that is representative of the whole population. Information should be sought from a random sample of ALL citizens including those who may be isolated from main-stream society. The indicator should be used only with adult populations (over age 18).

8. Health expectancies

The instrument permits principally the calculation of **health expectancy in good or poor mental health**. Individual items may subsequently be used to calculate expectancies such as life expectancy without suicidal ideation or life expectancy without depressive mood ; however these specific calculations should be taken as subjective indicators and not diagnostic categories.

Section 2: Background

I. History of the instrument

The General Health Questionnaire (GHQ) was developed in the UK in the late 1960's in an attempt to; 'devise a self administered questionnaire that would identify respondents with non-psychotic psychiatric illness, by assessing the severity of their psychiatric disturbance' (Goldberg, 1972).

The GHQ was designed to detect psychiatric disorder in community and general medical settings. What is a psychiatric disorder and how does the term relate to the concept of mental illness? The term mental has been defined as 'of the mind' (Hawkins, 1988) while psychiatry has been defined as *'the study and treatment of mental disease'* (Hawkins, 1988). The terms mental illness and psychiatric illness have sometimes been used interchangeably. Others have argued that the term psychiatric is to be preferred because it avoids problems inherent in the Cartesian division of mental and physical. It is suggested that as knowledge of 'mental' and 'physical' illness has increased the two concepts have been demonstrated to have so much in common that they can no longer be seen of as being separate entities (Kendall, 1995). Such authors therefore prefer the term 'psychiatric' as an umbrella term to describe depression, psychosis and other conditions treated by psychiatrists.

While in the general medical literature the terms 'disorder' and 'illness' have sometimes been used interchangeably others, notably medical sociologists, have taken care to consider the differences in the origins and meaning of each concept. Disorder is a broad concept that encompasses all forms of dysfunction or disruption of functioning. Illness is the subjective experience of symptoms (Tuckett, 1976). In relation to psychiatry psychiatric disorders include mental illnesses and a variety of other forms of disorder such as cognitive impairment or problems related to substance misuse. The GHQ was not designed to detect psychiatric illness and is a poor measure of these other forms of disorder (Goldberg and Williams, 1988).

Items chosen for the prototype of the GHQ were drawn from qualitative data from a cross-sectional study conducted in the United Sates of America (Gurin et al. 1960) and combined with items from several existing questionnaires including the Cornell Medical Index (Brodman et al. 1949), the Macmillan Health Opinion Survey (Macmillan, 1959) and Langer's 22 item screening test (Langer, 1962), together with items suggested by the 'clinical experience of several psychiatrists' and thirty items decided by the author. Items that indicated mental distress but were thought to be related to personality traits were excluded. As were some of the items that related to a persons social relationships.

The prototype GHQ consisted of 140 items but, following initial testing among subjects who were and were not experiencing psychiatric distress, this number was reduced to 93. Following principle components analysis a decision was made to exclude 33 items which contributed least to the five factors that were identified. This resulted in a sixty item questionnaire which takes between 10 and 12 minutes to complete. Two other versions of the GHQ, a 12 item version which takes approximately two minutes to complete, and a 30 item questionnaire were developed by excluding items that were endorsed by patients with physical illnesses and a 28 item questionnaire 'scaled' version was developed using principle components analysis (Goldberg and Williams, 1988).

Reliable biological correlates for mental illness have not been identified. Diagnosis of syndromes of mental illness are usually based on the presence of clusters of symptoms and signs and the presence of associated disability or dysfunction. Mental illnesses are non-transmissible. While an important minority are chronic illnesses (such as chronic schizophrenia) the majority are either single episodes of illness or run a relapsing course over many years. While most mental illnesses can not be considered to be fatal, higher rates of suicide have been described among patients with all categories of mental illness compared to those in the general population (Harris and Barraclough, 1997).

What was novel about the GHQ was that it was geared towards identifying the milder 'neurotic' mental disorders at a time when many instruments were aimed at detecting symptoms of severe psychotic illness. In doing so the aim was to develop an instrument that could be used in setting outside psychiatric services in the community and in patients in general medical settings. Since its development the GHQ was increasingly been used as a screening instrument. Both to aid clinicians in identifying those with mental illness and as a 'case finding' instrument in population studies of the prevalence of mental disorder.

In measuring psychiatric disorder, the GHQ measures the likelihood that someone is experiencing depression, anxiety and other 'neurotic' mental disorders. The ability of the GHQ to tap such disorders have been reported. Several studies have examined associations between a patient's GHQ score and their rating on measures aimed at detecting anxiety and depression. These were reviewed by Goldberg and Williams (1988) and ranged from moderate to high (+ 0.54 to + 0.90). While the original aim of the GHQ was to detect non-psychotic disorders, Goldberg and Williams (1988) have argued that all patients with psychiatric illnesses, including patients with schizophrenia and affective psychosis exhibit the 'core neurotic symptoms' that the GHQ is designed to detect. Evidence from community surveys suggests that the GHQ is 'marginally acceptable' at detecting patients with psychotic disorders – with a sensitivity of 49% (Samuels et al. 1994). A 'suicidal ideation score', derived from the GHQ has been proposed as a means of monitoring the extent of suicidal ideation in a population (Goldney et al. 1981). There are strong cross-sectional associations between the extent of suicidal ideation in a population and the extent of suicidal behaviour (Weissman et al. 1999). At the time of an episode of self harm GHQ scores are increased (Newson-Smith and Hirsch, 1979).

Studies that have simultaneously measured mental health using the GHQ and aspects of social functioning have all demonstrated positive correlations. In a review by Goldberg and Williams these ranged from +0.06 for social isolation (Andrew et al. 1977) to +0.74 for role problems checklist (Worsley et al. 1977). In general, moderate levels of association are seen, suggesting that in addition to the likelihood of psychiatric caseness the GHQ provides some indication of the social functioning of a population. Self-report disability was consistently correlated with GHQ-28 scores in all six European centres in a primary care based study of physical disability in primary care – with correlation coefficients ranging from 0.17 in Manchester to 0.37 in Verona (Von Korff et al. 1996). In the absence of specific biological markers for mental illness, diagnostic algorithms refer principally to functional consequences. Disability is thus a strongly linked concept. Hepworth (1980) demonstrated a moderately high positive correlation between GHQ scores and 'life satisfaction' in a population of unemployed men. GHQ scores and general well being scores were highly correlated in general medical patients in a Spanish hospital settings (Badia et al. 1996). The GHQ has been used in studies to indicate the closely related concept of well-being (Vinamaki et al. 1995).

The GHQ was originally designed for use in Britain. As Goldberg and Williams (1988) have pointed out it would be wrong to assume that a questionnaire designed to measure psychiatric disorder in one country will produce valid findings in a different geographical or cultural setting. However studies which have examined the validity and reliability of the GHQ in a range of different cultural settings suggest that the GHQ is a good measure of the likelihood of psychiatric disorder in settings outside the one in which it was originally developed. Goldberg and Williams (1988) go on to argue that this is because 'psychological distress has certain common features in widely different settings'. While there appears to be a high degree of consistency between the symptoms that the GHQ enquires about and the likelihood of psychiatric disorder, the level of symptomatology that leads to a diagnosis of mental disorder appears to differ in different settings. For this reason the 'cut-off point' used to distinguish those who are most likely to be psychiatrically disordered needs to be determined in the different settings that the instrument is used.

The GHQ is now the most widely used instrument for detecting psychiatric disorder. It has been translated into over 40 other languages (Goldberg and Williams, 1988) and the validity and reliability of these versions of the instrument have been widely reported. For these reasons it has been described as offering a 'leading example of how a health measure should be developed' (McDowell and Newell, 1996).

II. Measuring mental health in Europe

Two different methods are commonly used to identify the likelihood of mental illness. These are – the structured interview (e.g. the Present State Examination) and the self-administered questionnaire (e.g. the GHQ). The self administered questionnaire is the preferred method when measuring the general health of a population and as a screening tool in the first stage of more detailed epidemiological surveys. The principle reason for this is that self administered questionnaires are quicker and easier to administer and as a result structured interviews are more costly to conduct. Our research revealed a large number of instruments of which only a small number met the dual criteria of adequate clinical validation and suitability for administration within the context of a general health survey using non-clinical interviewers. In addition to the GHQ, the following instruments were selected for further consideration :

a)   Cornell Medical Index Health Questionnaire (Brodman et al., 1949).

195 questions, binary (yes/no) responses. Includes items on family history of illness and previous illnesses. 51 items relate to emotional disorder. It continues to be used in European population studies but has been used less often over recent decades and its use is no longer recommended (Mann and Murray, 1979) due to poor validity and reliability.

b)   General Well-being Schedule (Dupuy, 1977)

Originally developed as a 68 item self-administered rating scale aimed at measuring 'psychological well-being and distress, the most commonly used form consists of an 18-item version that was used in large scale population surveys in the US (Monk, 1981). The scale has items that measure both *positive* and *negative* feelings – and is more than a measure of mental illness. Its psychometric properties have been widely tested in North American populations, with test-retest reliability of 0.85 and convergent validity (against self assessed ratings of depression) of 0.78. While its use in Europe has been limited, French and Spanish versions (Badia et al, 1996) have been successfully developed. This instrument is, however, principally designed as a means of evaluating overall, subjective mental well-being and is unable to indicate either prevalence of clinical psychopathology or underlying symptomatology.

c)   Mental health dimension of the SF-36 (the MHI-5)

The five questions that form the mental health dimension of the 36 health survey questionnaire (Brazier et al, 1992), have recently been recommended as a brief way to screen for the presence of mental disorder in community samples (McCabe et al, 1996). While the measure is shorter than the GHQ (only 5 items), the instrument was demonstrated to have a high degree of internal consistency (Cronbachs alpha = 0.94), and the results to be highly correlated (0.73) with results from GHQ-12, in a community sample of 3000 residents in Britain. The authors argue that the items avoid a bias that may be present in the GHQ in the identification of cases among elderly subjects. On the other hand a five item questionnaire can only give a general estimate of level of distress and is inadequate as a means of identifying the nature of the underlying symptomatology. Studies using the MHI-5 rely on the GHQ as the 'gold standard'. The SF-36 has been translated into most European languages and studies have been undertaken in Belgium, Denmark, Italy, France, Germany, Netherlands, Norway, Spain, Sweden, Switzerland and UK. The majority have been in medical patients but several large population based studies have been conducted (for example the Dutch general practice survey). While the reliability of the SF-36 has been extensively examined in European studies, attempts to validate the MHI-5 at a population level have not been conducted outside the UK.

It was concluded that the GHQ is the preferred method of assessing mental health in European countries because it is simple to use, has excellent psychometric properties and has been extensively used throughout Europe and other parts of the world. The GHQ has been used in a broad range of epidemiological studies throughout Europe and has been recommended by the Regional Office for Europe of the World Health Organization for use in Health Interview Surveys (de Bruin, 1997). It has been used extensively used in hospital and primary care settings and also in samples of the general population. It has also been used to gather information about the mental health of a populations at a single point in time as well as to obtain longitudinal information about changes in the presence and extent of mental illness over specific periods of time.

Because it may be self-administered and relatively simple to complete it is a relatively inexpensive way of determining the mental health of a population. Because it is short and can be completed quickly, it would be possible to add the GHQ to other health surveys without adding very much to the burden of respondents. As with other self administered questionnaires, it is necessary that potential respondents are literate.

From a census of European surveys of mental health conducted by the Euro-REVES mental health subcommittee, a database called 'SIGMUND' has been compiled (Jagger et al. 1998). SIGMUND includes several studies that have used or are using the GHQ in order to examine the mental health of various populations (see table below).

Table 4: European surveys using GHQ-12 on the SIGMUND database (Jagger et al., 1998)

Nation	Study design	Population	Sample size	Progress
Belgium	Cross-sectional	Young adults	2,000	Completed
Netherlands	Cross-sectional	Older adults (85+)	1,300	Completed
Finland	Cross-sectional	Adults (30+)	7,200	Completed
UK	Cross-sectional	Adults (16-64)	1,200	Completed
UK	Cross-sectional	Adults (16-99)	17,000	Completed
Spain	Cross-sectional	Adults (16+)	800	Completed
Belgium	Longitudinal	Older adults (65+)	1,500	Completed
Netherlands	Longitudinal	Older adults (57-99)	5,000	In progress
Netherlands	Longitudinal	Adults (18-64)	4,000	In progress
UK	Longitudinal	Adults (11-98)	10,000	In progress

The GHQ has been used in several large European population based studies in order to identify the prevalence of psychiatric disorders. It is short and easy to administer and could therefore be simply incorporated into new and existing health surveys. In addition, the GHQ has been used to address several different areas of public health importance within Europe, including : **the identification of psychiatric disorder in high risk groups** - those receiving treatment for a variety of physical illnesses (Jimenez Hernandez, 1996; De Mont-Marin et al. 1993) those exposed to various sorts of trauma (Reijneveld, 1994) and the carers of those with chronic illness (Stengard and Salokangas, 1997) ; **aiding detection and treatment of mental disorder in primary care settings** - (Verhaak and Tijhuis, 1992; Sartorius et al. 1996 ; Ormel et al. 1997 ; Adeyemi et al. 1998; Smith, 1998) ; **Occupational health** - to indicate the prevalence of psychological disorder in various occupational groups including nursing staff and in non-medical settings (Butterworth et al. 1999; Parkes, 1992) ; **identifying the psychiatric needs of a population** – often as the first stage of a two stage survey, in which more detailed examination of 'probable' cases of psychiatric disorder is used in order to identify levels of psychiatric morbidity and measure the health care needs of a population (Bebbington et al. 1997; Shapiro et al. 1985) ; **exploring the aetiology of psychiatric disorders** - as an outcome in studies examining the effects of a variety of exposures implicated in the aetiology of psychiatric disorder (D'Arcy, 1982 ; Vinamaki et al., 1993) ; **measuring change in health over time** (Ormel et al. 1989; Graetz, 1993) ; **measuring the response** to a variety of physical, psychological and social interventions (Iwi, 1998).

Together these studies suggest that the GHQ, while giving a global mental health score referring to current levels of distress, is also sensitive to population and economic change, is able to reflect changes due to therapeutic intervention strategies, and adequately detects the lower levels of dysfunction observed in general practice.

Recently comparisons have been made of mental health expectancies among citizens of two European nations (Catalonia, Spain and Bulgaria) using the GHQ (Gispert et al. 1998). This comparison was based on the findings of estimates of prevalence of mental illness using data derived from cross-sectional population based surveys using the 'Sullivan method' (Sullivan, 1971).

Table 5: Life expectancy (LE), life expectancy in good mental health (MHLE) and life expectancy in good mental health as a proportion of life expectancy (%MHLE/LE) at the age of 65 years in Bulgaria and Catalonia by sex.

	Spain			Bulgaria		
	LE	MHLE	%MHLE/LE	LE	MHLE	%MHLE/LE
Men	16.4	14.1	86.0	12.7	5.1	39.7
Women	20.5	16.5	80.5	15.3	4.3	28.4

III. Essential characteristics of the instrument

In 'The users guide to the General Health Questionnaire', Goldberg and Williams (1988) describe how the GHQ-12 was produced by removing items from the GHQ-60 that had been endorsed by patients with physical illnesses and no mental illness. They also present a re-analysis of the data used to examine the validity of the GHQ-60 in order to examine the validity of the GHQ-12. The relative figures *(GHQ-12 in italics)* are;

> Test-retest reliability *0.76 for GHQ-12* ; 0.73 for GHQ-60
>
> Specificity *87.8 for GHQ-12* ; 78.5 for GHQ-60
>
> Sensitivity *95.7 for GHQ-12* ; 93.5 for GHQ-60

They also review the results of six validity studies that had been conducted up until 1988. In total they included 965 subjects in six different countries (Australia, UK, Yugoslavia, Brazil, India and Italy). The overall sensitivity of the GHQ-12 is reported as 86 (range = 71 to 91) and specificity of 80 (range = 71 to 93). Pooled estimates of the sensitivity and specificity of the GHQ-28 and the GHQ-30 are no higher. Data from the WHO study of mental illness in general health care allowed comparison of the reliability and validity of the GHQ-12 and the GHQ-28 (Goldberg et al, 1997). Validity of the GHQ-28 was no higher than that of GHQ-12 and the authors of the paper concluded that the shorter version was the better choice for prevalence studies. Fewer studies have been conducted using the GHQ-12 compared to longer versions, nonetheless the GHQ-12 has been used in most European countries over recent years (e.g. in Belgium, Finland, France, Germany, Greece, Italy, Netherlands, Spain, UK and Yugoslavia). In addition to this, longer versions of the GHQ have been used in Austria, Czech Republic, Norway, Sweden, and Denmark. Portuguese versions of the GHQ are also available.

Three different methods of scoring the GHQ have been proposed. For each item, respondents are asked to mark one of four categories. This is exemplified in the following item relating to worry.

Have you lost much sleep over worry?

	Not at all	No more than usual	Rather more than usual	Much more than usual
GHQ	0	0	1	1
Likert	0	1	2	3
CGHQ	0	1	1	1

The GHQ score assigns 0 to each of the first two categories and 1 to the latter two. The Likert score assigns 0 to the first response, 1 to the second, 2 to the third and three to the final response. The CGHQ score, recommended by Goodchild and Duncan-Jones (1985) in order to make the GHQ more sensitive to longstanding disorders involves assigning the first category a 0 and the remaining three categories a 1. In their review in 1988, Goldberg and Williams concluded that while there was little difference between Likert and GHQ scoring, the balance of available evidence suggested that adopting the CGHQ scoring system may improve the validity of the measure and resulted in a more normal distribution of scores in population studies.

Since then eight other studies have examined the relative methods of the different scoring systems. Six studies reported that the reliability of the CGHQ scoring system was not superior to the GHQ score. Of the remaining two studies Koeter and colleagues (1989) examined psychiatric complaints among 175 people attending out-patient clinics and concluded that the CGHQ was 'marginally better' than the CGQ score. Huppert et al. (1988) administered the GHQ to 6,317 community residents and reported that the CGHQ scoring system improved the sensitivity of the instrument among people in mid-life. This is the only occasion on which this finding has been reported.

It should be noted that the scoring method is specifically designed for the detection of incident pathology (that is the subject notes a recent change from normal functioning). Cases of prolonged, untreated psychiatric disorder in which the subject has come to consider his state as normal, may thus be missed. These cases are, however, likely to be rare and change little within a large-scale population estimation of general health.

Goldberg and Williams (1988), have presented a strong case for rejecting the use of a predetermined cut-off point. This is based on the findings of 72 validity studies that demonstrated that in different populations different cut-off points produced the best levels of sensitivity and specificity. In relation to GHQ-12, of the five studies they reviewed two had chosen 1/2, two – 2/3, and one – 3/4. They argue that the most important factor in

determining the best cut-off point is the level of physical illness in the population. They also state that there is little evidence for cultural differences in cut-off point. It is suggested that once the best cut-off point has been found in a given population this can then be used in further studies. They recommend that in order to work out the best cut-off point in a new study ROC curves should be plotted in order to display the relationship between the number of false positives and the number of true positives. The cut off point that is associated with the best positive predictive value is that associated with the greatest area under the curve. This approach is coherent with the aim of the present indicator, which is to detect *comparable levels of psychiatric illness* across countries. It is generally accepted that the validity criterion should be standardized clinical interview by a psychiatrist conforming to internationally accepted diagnostic algorithms.

Cut-off points used in European centres during WHO primary care study were as follows :
Greece - 2/3, Germany - 2/3, Netherlands - 2/3, France - 1/2, Italy - 1/2 and UK - 3/4.

European population based studies that have used the GHQ-12 have reported optimal cut off points of:
Netherlands - 2/3, Finland - 2/3, Switzerland (among people 20 years old) - 5/6, Germany (among those over 65) - 3/4.

In summary, a review of published studies suggested that cut off points for the GHQ-12 have been established for general population samples in Belgium, Finland, Germany, Netherlands, Spain and UK. GHQ-12 cut-off points could be calculated from population data and the results of studies using longer versions of the GHQ in France, Italy and Norway. Cut off points in the remaining nations of the European Union may need to be established before the GHQ can be used in population studies. An alternative method of estimating " probability of caseness " has been used in a recent study (Gispert et al. 1998) and this method should be considered as an alternative approach which overcomes some of the misclassification problems related to strict cut-off points.

The addition of a standardized measure of population mental health (such as the GHQ-12) will facilitate international and within-nation comparisons of mental health expectancy.

IV. Conclusion

For all categories of mental illness important prognostic factors have been described and a range of interventions have been extensively evaluated which can effectively alter prognosis and reduce associated disabilities and impairments. It is therefore argued that the identification and proper treatment of mental disorders should result in a decrease in the prevalence of mental illness and in the additional costs associated with reduced functioning among those who are mentally ill.

Mental illness has important damaging effects on a persons' perceived health, often results in a range of functional disabilities and impairs adaptive health. Globally it is estimated that mental illness is responsible for 28% of all years lived with disability (Murray and Lopez, 1995). In European studies mental illness has been demonstrated to impair adaptive health through effecting vulnerability to various different forms of stress and the demands of work (Krupa et al. 1998). As a result mental illness is associated with substantial direct and indirect costs (Croft-Jeffreys and Wilkinson, 1989), and impacts on the psychological health of carers. In conclusion, mental illness is perceived by sufferers as distressing, they result in a range of disabilities and impairments and damage adaptive health. A range of interventions have been successfully developed which can alleviate symptoms of distress and reduce associated functional impairments.

The GHQ-12 has been used in multiple cross-sectional and longitudinal surveys of mental health. It has been repeatedly demonstrated to be a reliable and valid measure of the likelihood of psychiatric disorder in hospital, out-patient and community settings throughout Europe and other parts of the world. As it includes items on social functioning it also provides a proxy measure of social function and quality of life. It consists of twelve questions commonly used in clinical practice to reveal disorder and associated disability. It has already been used in Europe to address a range of public health concerns including measuring the health of populatons, occupational health, identifying treatment needs and measuring changes in health over time. The GHQ is presently the preferred method of assessing mental health in European countries, and is recommended by the World Health Organisation. It has excellent psychometric properties and a considerable body of population data has already been collected. The GHQ has already successfully been used to compare health expectancies in different regions of Europe. Such comparisons have highlighted marked differences in overall health expectancy between countries.

Part 2: Methods of calculation

Introduction: Overview of the methods of calculation and methodological problems

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Part II first gives an overview of the life table methods, which can be used to calculate health expectancy. Three methods are discussed: the prevalence-based life table model (also known as Sullivan method), the multi-decrement life table and the increment-decrement life table (also known as multistate life table). For each of these methods, we pay attention to the historical background, the construction of the life table and its advantages and disadvantages. In Chapter 1, we focus on the most commonly used method, the Sullivan method and provide a step-to-step guide of this method to calculate health expectancy and its standard error. Finally Chapter 2 deals with the potential gains in health expectancy indicator, a tool based on the Sullivan method. This cause-elimination technique can be used to analyse the gain in life expectancy with and without that disability that would occur when one disease would be eliminated. This potential gain indicator provides insight into the relative impact of diseases on health expectancy, identifying the major causes of health losses and thus identifying the potentials for health gains.

The method for calculating life expectancies in a specific health state is based on life expectancy calculation techniques. Basically, the numbers of individuals in each age interval of the life table are partitioned according to the age-specific probabilities of being in each of the studied states.

In theory, the age-specific probabilities of being in a specific health state are derived from the incidence rates of entry into and exit from this status, just as in life expectancy the age-specific probabilities of dying are derived from the registered number of deaths. Thus the probabilities are calculated from *flow* data collected over a definite period, providing information on the number of transitions in and out of the state, associated with the period mortality and morbidity pattern. For the construction of the period life table, the age-specific probabilities of death are applied to a hypothetical cohort of newborns as they age, simulating the development of a fictitious population for which the mortality pattern of the period is assumed to be constant through time and to apply indefinitely to new cohorts, reaching the *equilibrium population*. The period life expectancy gives a picture of the currently prevailing mortality conditions, allowing time comparisons of period mortality conditions. Including probabilities of being in a specific health state enhances the information by referring both to the prevailing mortality conditions and to the morbidity patterns. The population of such an enhanced life table converges towards an *equilibrium distribution* between the studied health states. In each age interval, the distribution in a specific state corresponds to the *period prevalence*, that is, the proportion of the population that would be in the health state, were the current mortality and morbidity patterns and more generally the current conditions of life to hold indefinitely. The table permits the calculation of life expectancy and life expectancy in the health states under consideration.

In practice, the construction of such tables is a difficult process. Data on transitions in and out of the studied states are not collected systematically, unlike data on mortality which are exhaustively registered in most countries. Consequently, transition rates cannot be calculated directly, and the "period prevalence" associated with the states under study must be estimated from available data. The methods that have been developed correspond to different procedures that have been devised for this estimation. They can be classed into three groups: observed prevalence life table methods, multiple-decrement life table methods, and increment-decrement or multi-state life table methods.

The first models of life expectancy applied to a specific state were developed in the 1930s, to study trends in labor force participation, as well as for actuarial studies and public health purposes (Woytinsky, 1938); but the methodology was confusing. Only ten years later, Durand (1948) proposed a calculation of "working life expectancy" based on life table techniques, as described above, proposing an estimation based on the observed prevalence of labor force participation.

I- The observed prevalence life table method

1- Historical background

Durand constructed in 1948 an observed prevalence life table to estimate a "working life expectancy" (Durand, 1948). Deviating from the original purpose and method proposed by Durand, Wolfbein tried to estimate a

working life expectancy only for the workers population (Wolfbein, 1949); strong assumptions, mostly unrealistic, were necessary to lessen the inadequacy of the observed prevalence data of the total population for Wolfbein's objectives. Nevertheless, during the following decades, numerous estimations of workers-based working life expectancy, have been produced relying on Wolfbein's method and assumptions, particularly in the United States. Due to the strong assumptions inherent to the calculation, this method has been increasingly criticised and then dropped in the 1970's when other techniques were developed (Cambois et al., 1999).

In the field of health, Sanders proposed a model combining mortality and morbidity in the same life table (Sanders, 1964). The idea was finally taken up by Sullivan, who constructed the first observed prevalence life table applied to the measurement of health state and computed a disability-free life expectancy, following the method originally presented by Durand (Sullivan, 1971). Known as the 'Sullivan method', it remains the most commonly used in health research for calculations of time series and cross-national trend comparisons.

2. Construction of the observed prevalence life table

The process used to construct an observed prevalence life table for a specific state is a simple one. It consists of modifying the regular life table by applying (t_x) the age (or age group) specific prevalence rate of a specific state, observed in a cross-sectional population survey, to (L_x) the number of persons in each age interval of the table. For each age interval, the table provides (l_x) the survivors of the life table, (L_x) the number of person-years and ($t_x L_x$) the number of person-years in the specific state: this estimates the equilibrium distribution of the population of the table between those being ($t_x L_x$) and not being (($1-t_x)L_x$) in the state under consideration. So, (e_n) the population's life expectancy at age n and (e^j_n) the associated life expectancy in the status j are calculated by:

$$e_n = \sum_{x=n}(L_x)\Big/l_n \qquad \text{and} \qquad e^j_n = \sum_{x=n}(t_x L_x)\Big/l_n$$

For this method, the data on mortality is derived from civil registration and regular life tables. The data related to the state j comes from a cross-sectional survey. The age-specific prevalence rates (t_x) related to the health status are 'stock' data, representing the distribution observed by the survey in each age or age group, that is, the *observed prevalence*, or the proportion of those in the state among the survey population, at a specific moment. This quantity is the result of the transitions in and out of the state, ever lived by the individuals included in the sample of the survey; it therefore reflects the general conditions of life and massive events which may have affected the population health (wars, epidemic...) of the past and which were faced from time to time by different cohorts of the population *up to the survey period*. The "total" life expectancy, being based on flow data collected for a short definite period, provides information on the mortality conditions prevailing *at the moment*: the age-specific death rates and the period life expectancy reflect the current pattern of causes of death of the population and not past ones, despite some cohorts of the population being at risk at those times (i.e. infectious diseases, fatal epidemics, war...).

3- Advantages and disadvantages

The method omits the stage of observation of transitions in and out the health state which permits the calculation of probabilities and the simulation, in the life table, of these transitions to obtain the equilibrium distribution and the period prevalence. The prevalence observed at the survey is applied directly to the population of the period life table. *Observed prevalence thus replaces period prevalence*. As already said, the *observed* prevalence is the proportion of the population, that results from the past and present conditions of life experienced by each cohort represented in the survey. The *period* prevalence is a theoretical proportion, based on the transitions observed during a definite period and taking into account the state occupied at the beginning of the period: this reflects the current morbidity pattern and conditions of life that cause changes in state. The observed prevalence used in the calculation is subject to a global cohort effect (reflecting past events and conditions), and the observed prevalence method only provides an approximation of true period conditions.

The effect of the gap between observed prevalence-based estimates and period estimates has been well described (Crimmins et al., 1993; van de Water et al., 1995; Barendgregt et al., 1995, 1997; Mathers and Robine, 1997). The worst implication can be shown in an example from the field of labor-force participation with trends in activity rates being strongly related to cohorts' history, particularly for women: the observed prevalence life table

method leads to an underestimate of the period indicator of working life expectancy for women, being based on low activity rates in the older cohorts – representing the past labor market history– ; it would not fully take into account the huge increase in women's entry into the labour force during the 1970s, and therefore poorly represents the current period situation of high activity rates for women (Brouard, 1980). However, the effect fades out gradually as these cohorts approach retirement age, and the age specific activity rates become more stable. Indeed, it has been shown that the observed prevalence life table provides good estimate when the studied transition is stable over time, or a good estimate for trends over time when the transition evolves regularly, unlike women's labor force participation. In contrast, when this transition differs markedly cohortwise or undergoes a sudden change, the method should not be used. With health states such as disability, trends in incidence are gradual enough to support the observed prevalence estimate as good a representative for trends over time of the period estimate (Robine and Mathers., 1993; Mathers and Robine, 1997). Nevertheless, the differences between the observed prevalence estimate and the actual period value prevents firm conclusions being drawn on the magnitude of these estimates, especially when focusing on the part of life expectancy spent in rare health states (ie. life expectancy with disability), which account for only a few years and on which this lack of precision has a greater impact.

To study long-term trends, and when the model's conditions are satisfied, the observed prevalence life table method proves very appealing. It requires data which are commonly available: observed prevalence of states are often collected by cross-sectional surveys, sometimes routinely conducted. Life tables are routinely produced by Statistical Institutes with data collected from population registers or censuses. In addition, the model is based on a simple and robust methodology. Such advantages mean that it can be applied in many countries, allowing international trend comparison, when changes in the studied state are gradual over time.

Fifty countries have already produced estimates, and some time series, of "health expectancies": all the calculations (with their references) being compiled and analysed by the International Network on Health Expectancy and the Disability Process (REVES). The REVES network was created in 1989 to standardize the data and facilitate international comparisons of health expectancies[1]. The network still promotes the observed prevalence life table model for the study of *health trends*, due to its more widespread use, while encouraging the collection of longitudinal data and the development of more sophisticated models (increment-decrement models, as described below) to improve the estimation of health expectancy indicators.

II- Multiple decrement life tables

1- Historical background

This methodology was initially devised by actuaries and insurance companies to calculate pensions and contributions on the basis of mean length of life before getting in the insured state, namely, disabled or widowed. In 1952, Jordan described the demographic techniques leading to the construction of multiple decrement tables that could be used in these fields (disability, marital status…) (Jordan, 1952). Referring to previous works on disablement pensions[2], he gave as a practical exercise a table combining mortality and disability, which measured the mean length of life before first disability (or mean *active life*, "active" being a good level of functioning, a term still used today[3]). The model has only been used sporadically since: in 1957, by Spiegelman in a description of demographic methods applicable to disability, marriage or professional activity. This method was also used to calculate an active life expectancy, using longitudinal data. (Katz et al., 1983)

2- Construction of the multiple decrement life table

The multiple decrement life tables consider not only death but also transition towards definite life-states as decrement events for the cohort of the table. In his model, Jordan considers death and disability as "absorbing" states. The years-lived *before getting disabled* in such a multiple decrement life table are equivalent to the years-lived in the life table; while the latter leads to the estimation of life expectancy, the former leads to the estimation of "active" life expectancy expressing the mean duration of life before getting disabled. The model does not

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allow for the possibility of a return to the initial state (that is, the recovery of lost functions). By using a follow-up survey to assess, between two waves of data collection, the number of transitions from the initial state (active) to the absorbing state (death or disability), it is possible to estimate the age-specific probabilities of survival in the initial active state (s_x), to apply this age by age to an hypothetical cohort and construct the active life table of the survey population: at each age, the survivors of the table (l'_x) are active survivors. Being presented with data collected by surveys conducted several times on the same sample, this method produces a period indicator, properly reflecting the current conditions of life and health patterns.

The table provides the active life expectancy which is the mean duration of life without entering disability (e^{act}_x):

$$e^{act}_n = \sum_{x=n} (L'_x)/l'_n$$

3- Advantages and disadvantages

Among the existing estimation method for health expectancy indicators, the multiple decrement life table presented by Katz et al. provides a period indicator from a relatively limited amount of data and a simple methodology. This method has been used in very specific contexts with specific data and therefore there has been no opportunity to either compare properly period conditions over time or to compare the situation from a country to another.

The interest of this method also relies on its calculation of joint probabilities of transition out of the initial health state and into death: therefore, the state based mortality risk is taken into account, unlike when transition probabilities are applied to regular life tables concerning the whole population. Nevertheless, the probabilities of dying are estimated from a limited number of observations (the survey sample) and so are very approximate compared to those from regular life tables (used with the first type of method presented above). Secondly, the indicator derived by this method must be interpreted rigorously, taking into account the fact that any withdrawal from the initial cohort is considered as being definitive. This is due to the structure of the tables which, as we have seen, were originally constructed with specific purposes: a multiple decrement life table was aimed to estimate the number of years spent before entry into one of the states covered by the insurance scheme (widowhood, disability…). For public health studies, it seems inappropriate to ignore the possibility that good health will be regained.

However, it would be of interest for health prevention to construct indicators informing about length of life before the onset of disease, or, in the field of health policy, to evaluate the time between remission and relapse or death (Robine et al., 1992). Finally, this method can be used for cases where there is no possible return to the initial state, for instance senile dementia.

III- Increment-decrement (multi-state) life tables

1- Historical background

As early as the 1970s, various authors began to explore models capable of handling not only transitions out of the initial state (as the multiple decrement model), but also moves back into this state. Increment-decrement life tables were developed to allow transitions of all kinds (Hoem, 1970; Fanshel et al., 1970; Schoen, 1975; Hoem, 1977). Indeed, in 1970 Fanshel and Bush proposed a health index designed to evaluate the impact of a *specific* health programme on the health state of a *population targeted by this programme*. This index led to the development of an increment-decrement (multi-state) life table based on a Markov chain.

The central idea was to measure differences in the functional history of a target population before and after the implementation of a health programme (Fanshel, 1972; Fanshel et al, 1970). For these authors, the concept of 'health' has two dimensions relating the functional history of the population: the immediate state and the prognosis. At any moment in time, the population is partitioned into different classes of functional health and these are related to the corresponding *prognoses* which are the transition probabilities between states; the latter providing the information necessary to calculate the new functional class distribution as it changes over time. In 1971 Bush, Chen and Zaremba examined the possibilities of summarizing a cohort's functional history by the equilibrium distribution of a Markov process. The application, in a stationary Markovian model, of an identical

transition matrix for each period is analogous to the period life table model. This distribution can be used to calculate expected durations in different functional classes for a population subjected to the process. These models, developed to evaluate the impact of health programmes, were initially applied to target sub-populations, and there has so far been no real numerical application at the population level (Chen et al., 1975). They have been taken up since to measure aggregate functional level (relative to health, professional activity…), but only a few states are considered, resulting in a simple increment-decrement model. In the field of health and disability, some studies have been conducted to produce multistate-based health expectancies and discuss methodological issues (Rogers et al., 1989; Guralnik et al., 1993; Land et al., 1994; Crimmins et al., 1994 and 1997; Nusselder, 1998; Gaüzère et al., 1999; Ferrucci et al., 1999)

2- Construction of the increment-decrement life table

As originally presented, the table is constructed from a hypothetical cohort of persons of given age belonging to one of the studied states. By observing transitions between states and towards death, one obtains the age specific incidence of transitions for the studied period, and the related transition probabilities. Knowing the age-specific probabilities of remaining in, leaving, re-entering a state or dying, we can distribute the survivors of the *initial cohort*, age after age, among the considered states. We then have the equilibrium distribution of the population associated with the initial cohort, whether the individuals have never, or have only temporarily, left these states. This is the *period prevalence* associated with these states as a result of the conditions of life and health pattern prevailing during the period. From this, we derive the person-years spent in the states and the corresponding state based health expectancies, for the persons belonging to the initial state cohort. Then, by adding to the transition probabilities, the weights corresponding to the age specific probabilities of being in the different states under consideration, one obtains the increment-decrement life table of the whole population. The weights and transition probabilities are combined in a calculation matrix to obtain the life table. The *period prevalence* of the state for each age group can be derived, for the whole population and for those being in the state, and consequently their life expectancies in the state (population-based indicators and state-based indicators).

3- Advantages and disadvantages

The increment-decrement life table is ideally constructed from data from registers or flow data produced by longitudinal surveys of at least two waves, conducted on a representative sample of population, so as to encompass all transitions. The index obtained in this way, entirely constructed from incidence rates, is a period index of great precision. Unlike the observed prevalence life table method, the constituent data series of the increment-decrement methods are all "period" data, and data on mortality is assessed status-based allowing estimation of the different risks related to the different health states. The wealth of information makes it possible to simulate, from any age, the distribution of a closed stationary population among the different states, under period conditions, and thence to calculate period health expectancies specific to each state or for the whole population.

In theory increment-decrement life tables are so powerful that this method should have supplanted previous ones. However, the lack of appropriate flow data in most countries makes such 'ideal' models virtually unusable. Indeed, the various studies published health expectancies use mostly the same material, the only available longitudinal data series: those from the Massachusetts Health Care Panel Study, the Longitudinal Study of Aging, the Establishment of Populations for Epidemiological Studies of the Elderly, the National Long Term Care Survey. These studies usually propose new methods for the estimation of transition probabilities; they are rather theoretical and the calculations provided are sporadic. To date, they do not permit any regular production of indicators or time series necessary to study trends and make international comparisons.

Second, the theoretical models proposed use increasingly sophisticated methods to estimate the transition probabilities, making it possible to handle a great number of variables which might affect the studied transitions (Land et al., 1994; Laditka and Wolf, 1998). In the usual models, the transitions are assumed to be *independent of each other* and *independent of duration*, both of which are questionable; the states between which one moves may be linked and time might play a part that is not negligible. In this respect, some models have integrated the duration in the different states, as well as the usual demographic and social variables, to estimate the probabilities. The use of longitudinal data also raise some methodological problems. Longitudinal data require complex survey design and the collected data as to be used with caution as regards to the precision of the information on transitions. Furthermore, as transitions are observed in a sample, the estimates are submitted to

variability depending on the size of the sample (generally small in the case of longitudinal surveys): therefore methodologies are also developed in order to clarify the precision of the outcome indicators (i.e. boostraps techniques). Escalating methodological complexity restricts the use of the models. Not only does it compromise their dissemination, it also sets problems for standardizing indicators at the international level. However these models are essential for research on causation and mechanisms (Nusselder, 1998; Ferruci et al., 1999).

Lastly, we note that the development of such models was motivated by a somewhat excessive rejection of the observed prevalence life-table method. Up to the 1970s, many observed prevalence tables were constructed following Wolfbein's proposal, trying to estimate age-specific transition probabilities from observed prevalence data. Assumptions and inherent bias underlying such calculations were not reasonable but were only constrained by an inaccurate use of this method. As this was not correctly addressed by the authors; the result was an unjustified criticism of the method itself. Yet when the ultimate goal is appropriate, observed prevalence life tables are often preferable to increment-decrement life tables, since they permit a regular production of indicators from surveys conducted routinely in most developed countries (Robine et al., 1999).

IV- Conclusion

The three groups of methods presented here have their particular advantages and disadvantages. Deciding which method to use will depend on the aim to be pursued and the data that are available. Broadly, the choice is between a method that gives accuracy but is based on a complex methodology and requires data that are rarely available – multiple-decrement or increment-decrement life tables – and a method that contains more assumptions but is based on a straightforward, robust methodology and requires data that are widely available: observed prevalence life tables. In the latter case, the size of error involved must be weighed against the usefulness of the indicator produced. When only cross-sectional data are available, if the studied phenomenon is sensitive to contextual factors and subject to sharp fluctuations through time, it is a case of deciding whether the information conveyed by the indicator will be relevant enough to proceed with the calculation. If so, then it will be necessary to stress the bias contained in the results and specify its nature. When the first option is preferred, the question is whether, in a case where flow data are available, the studied phenomenon is stable over time and a time series can be built, it is really worthwhile investing systematically in the complex increment-decrement life table methodology and the data that it requires.

However, health expectancy estimates based on increment-decrement life tables are an important supplement to Sullivan-based estimates: despite their heavy data requirements and more complex modelling, the increment-decrement life tables are a very powerful tool in understanding current mortality and morbidity patterns and their implications (and changes therein) for population health. Therefore, while the observed prevalence life table is prefered most of the time due to its possible direct application in most countries, the collection of longitudinal data and the development of improved methods to produce increment-decrement life tables are largely encouraged.

Chapter 1: Prevalence life table method (Sullivan method)

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The previous introduction gave a brief history and overview of the observed prevalence life table method of calculating health expectancies. The Sullivan method (Sullivan, 1971) is the most commonly used method for calculating health expectancy since it requires only the use of mortality data taken from period life tables and data on the prevalence of the health status measure. To date, health expectancies using the Sullivan method have provided health indicators on populations of at least 49 countries (Robine et al., 1999). This chapter will describe the main uses of the Sullivan method, together with a step-by-step guide to calculating the indicator and its standard error. Further examples of the Sullivan method using Microsoft Excel are available in both published form (Jagger, 1999) and on the WWW (http://sauvy.ined.fr/euroreves).

I- Use of health expectancy by the Sullivan method

The main reason for calculating health expectancy is to combine information on mortality and morbidity into a single composite measure. Such a measure of the health status of a population is useful to monitor population health and to make comparisons between countries, within countries over time or between population subgroups, despite any differences there may be in age composition. Comparability is also increased by the calculation of this indicator separately for males and females.

If several measures of health expectancies are to be compared, a number of important points need to be noted :

- The same definitions of health states should be used for each of the health expectancies, since differences between health expectancies calculated for different countries have been explained by differences in the measurement instruments used to collect the prevalence data (Boshuizen and van de Water, 1994).

- The general design of the surveys used to derive prevalence also needs to be the same, as estimates of the prevalence of ill-health are very sensitive to the method by which the data are collected (eg face to face interview, telephone interview, postal questionnaire).

- Health expectancies should preferably be compared on total populations, that is including mortality and morbidity data on people in institutional care as omitting these may produce bias particularly for older populations and certain health conditions associated with admission to institutional care such as dementia (Ritchie et al., 1992). This may be done in one of three ways of which the first two are the most preferable: (1) the prevalence survey may be of a total population including those in institutional care ; (2) a separate survey of those in institutional care may be undertaken to estimate prevalence and combined with the prevalence outside institutions by weighting ; (3) with knowledge of the size of the population in institutions, assumptions are made of the prevalence and these are then combined as in (2) using the appropriate weighting.

- Care should be taken with the last age group as the age distribution of this group may be substantially different between surveys, also affecting the comparability of health expectancies.

II- Data requirements

To calculate a health expectancy, the data required are the age-specific prevalence (proportions) of the population in healthy and unhealthy states (often obtained from cross-sectional surveys), and age-specific mortality information. The Sullivan health expectancy is not very sensitive to the size of the age groups, meaning that an abridged life table[4] may be used. In general, five (sometimes ten)-year age intervals are preferred, since most surveys used to derive the age-specific proportions (prevalence) in healthy and unhealthy states are too small to allow smaller age intervals. This is particularly important at the higher ages and it is usual to include the final age interval as 85 years and over.

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[4] An abridged life table is like a complete life table but has age intervals greater than one year (apart from the first years of life). A typical set of intervals might be 0 to under 1 year, 1 to under 5 years, 5 to under 10 years, 10 to under 15 years, etc.

In the example in the next section we will define health operationally as 'without disability' and will use an abridged life table to calculate a disability-free life expectancy for women in France, with data from a disability survey conducted in 1991.

The morbidity data is therefore the prevalence of disability in women by five year age group. The survey covered only the non-institutionalized population but the prevalences here are a combined prevalence for the non-institutionalized and institutionalized populations. Since the prevalence data relate to 1991, the mortality data need to relate to the same time period. We therefore use the number of deaths and mid-year population estimates, combined into the five year age groups, from the French National Statistics Institute (INSEE).

III- Calculation of the Sullivan health expectancy

The steps in calculating disability-free life expectancy by the Sullivan method, using an abridged life table, are shown in Table 6. We begin with the age groups in column A, noting the open-ended final interval (85+), which we will assume is of length 10 years. We will explain the calculation when the number of deaths and mid-year population estimates are available within age groups. In this case Columns B and C contain the mortality data and column E contains the figures corresponding to the curvature of the true survival curve over the age interval (Chiang, 1984). These are necessary for the adjustment into age bands rather than single years of age and would be assumed to be 0.5 if single years of age were used. An alternative method is to obtain l_x (column G) and $_nL_x$ (column H) from National Statistical Offices. For either method in column K we have the proportion of each age group with disability.

In columns D-J we calculate the total life expectancy (e_x) and the person years lived in the age interval ($_nL_x$), these being the key quantities for calculation of the disability-free life expectancy. The steps are as follows:

a) First we calculate the death rate which is the number of deaths divided by the mid-year population (D = C/B);

b) From the death rates are calculated the probabilities of death in the age interval conditional on having survived to that age, Q_x (column F). By definition the final entry in column F corresponding to 85+ years is 1, F[85+] = 1, since if a person has survived to 85 years of age then they must die sometime in this interval. The other entries are calculated as F = 5*D/(1+(1-E)*5*D) or in algebraic form with n = 5

$$Q_x = \frac{nM_x}{1 + n(1 - a_x)M_x}$$

c) The calculation of the life expectancy continues with the probability of survival to age x, l_x (column G). The first entry G[0 – 4] is by definition 1.0. Then each successive row is calculated as the previous entry multiplied by its corresponding (1-F). Thus G[5 - 9] = G[0 – 4]*(1-F[0 – 4]) or 0.9924 = 1.0*(1-0.00755678). Algebraically this is $l_x = l_{x-1} + (1-Q_x)$.

d) Similarly $_nL_x$, column H, the person years lived **in each age interval**, is given by

$$_nL_x = n(1-a_x)l_{x+1} + na_xl_x$$

where n is the size of the age group. In our example n = 10 for the final age group and 5 for the remainder. Thus for the person years lived in the 30-34 year age group, H[30 – 34], we have n = 5, a_x = 0.538, G[30 – 34] = 0.9840 and G[35 – 39] = 0.9805. Thus H[30 – 34] = 5*0.538*0.9840 + 5*0.462*0.9805 = 4.912.

e) The total number of years lived T_x (column I) if found by adding the $_nL_x$ (the entries in column H) from x to the final age interval (85+). Thus I[65 – 69] = H[65 – 69] + H[70 – 74] + H[75 – 79] + H[80 – 84] + H[85+].

f) The total life expectancy at age x e_x (column J) is given by J = I/G, or algebraically $e_x = T_x /l_x$.

g) We now continue with partitioning this life expectancy into years spent without and with disability, or disability-free life expectancy (DFLE) and life expectancy with disability. To do this we have input in column K, the proportion of those in the age group with disability beginning age x, π_x.

h) To get the person years lived without disability (column L) we multiply the person years lived in the age interval (H) by the proportion of people <u>without</u> disability at that age (1- K) or $(1-\pi_x)*L_x$.

If the survey has a complex design or if the non-response rates are high in the initial sample, π_x (column K) should contain weighted rates, that is to say prevalence rates adjusted for the design characteristics and for the bias introduced in the final sample by the non-response profiles.

π_x should also be adjusted to incorporate the institutionalized population. The most common method of doing this requires data on the proportion of the total population who are in institutions in each age group. These data are usually obtained from Census figures. The assumption made is that all those in institutions are in a particular health state (in our example we assume they all have disability). In this case if we assume the prevalence (proportion) of disability in the <u>non-institutional population</u> is π'_x and the proportion in age group x in institutions in I_x then the prevalence of disability in the total population $\pi_x = (1 - I_x) * \pi'_x + I_x$.

i) The total number of years lived without disability (column M) are found from L in the same way that column I was found from column H above.

j) Similarly the DFLE at each age (column N) is found in the same way as column J, N = M/G. Thus a women aged 65-69 years in 1991 could expect to live 20.02 years of which 12.28 years (61.3%) would be free of disability. Life expectancy with disability is found from subtracting DFLE (column N) from total life expectancy e_x, column J.

IV- Calculation of standard errors

The prevalence of disability by single or five-year age groups shows fluctuation due to sampling variation and mortality rates are also subject to random variation. Since health expectancy combines such mortality and morbidity rates, it too is subject to random variation. However we usually omit the random variation of the mortality rates as they can be considered negligible compared with the sampling variation in the prevalence of disability (Newman, 1988).

To assess the size of the random variation in health expectancy calculated by the Sullivan method, we can calculate the standard error of DFLE for each age interval, using approximations in Mathers (1991). We shall use the previous data for females in France in 1991 to do this and the continuation of the calculations in Table 6 are shown in Table 7. For clarity we have omitted columns B – F from Table 7.

The variance of $DFLE_x$ can be approximated by

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where N_x is the number of persons in the age interval taking part in the survey and S, l, L and π_x are as given previously. We will calculate this in steps in Table 7 using columns P – U as follows:

k) First we input N_x the number of persons in the age interval taking part in the survey (column P). If the survey does not have a complex design and if the non-response rates are not high, then column P contains the denominators used to calculate the prevalence (column K). We will show the calculations necessary if the prevalence figures are weighted up to adjust for the institutional population in l) below.

l) The variance of the prevalence rates (column Q) is given by $S^2(\pi_x) = \pi_x * (1-\pi_x)/N_x$ or in terms of columns in Table 7: Q = K*(1-K)/P. However, if the survey providing the prevalence rates has a complex sampling design then more accurate estimates of the variances of the prevalence rates will be provided by the appropriate Statistical Institute involved in the survey. In case these more accurate estimates are not available, a simple approximation to the calculation of the standard error of DFLE is to use the general formula above but with the weighted prevalence in K and in P the unweighted number of persons in the age interval i.e. the <u>actual</u> number who took part in the survey in the given age interval.

If π_x is a weighted prevalence incorporating the institutional population as described in h) then the variance of the weighted prevalence rate π_x can be approximated by $S^2(\pi_x) = (1-I_x)*\pi'_x*(1-\pi'_x)/N_x$ where π'_x is the proportion of the non-institutional population with disability as before.

m) Next we calculate $L^2S^2(\pi_x)$ in column R by multiplying column Q by column H and by column H again (R = H*H*Q).

n) Column S is found by summing the entries in column R from that age interval to the final age interval (in this case 85+).

o) The variance of the health expectancy is given in column T where in terms of columns T = S/(G*G) and the standard error of the health expectancy in column U is the square root of column T. If required, approximate 95% confidence intervals for the DFLE are given by N - 1.96*U and N + 1.96*U.

Table 6: Calculation of Disability-Free Life Expectancy (DFLE) by the Sullivan method using an abridged life table

A Age group			B Mid-year population	C No. deaths	D Central Death rate	E	F Conditional probability of death in age interval	G Probability of survival to age x	H Person years lived in age interval	I Total number of years lived from age x	J Total Life Expectancy	K Proportion of age group with disability	L Person years lived without disability in interval	M Total years lived without disability from age x	N Disability-free life expectancy
x	-	x+	P_x	D_x	$_nM_x$	a_x	$_nQ_x$	l_x	$_nL_x$	T_x	e_x	π_x	$(1-\pi_x)*L_x$	T_x	$DFLE_x$
0	-	4	1842444	2802	0.001521	0.178	0.00755678	1.0000	4.969	81.057	**81.057**	0.010	4.919	70.111	**70.111**
5	-	9	1873804	313	0.000167	0.477	0.00083483	0.9924	4.960	76.088	**76.667**	0.024	4.841	65.192	**65.688**
10	-	14	1866802	301	0.000161	0.530	0.00080589	0.9916	4.956	71.128	**71.729**	0.026	4.827	60.351	**60.861**
15	-	19	2025249	691	0.000341	0.555	0.00170467	0.9908	4.950	66.172	**66.785**	0.043	4.737	55.524	**56.038**
20	-	24	2120295	975	0.000460	0.517	0.00229666	0.9891	4.940	61.221	**61.894**	0.037	4.757	50.786	**51.345**
25	-	29	2163219	1255	0.000580	0.519	0.00289673	0.9869	4.927	56.281	**57.031**	0.064	4.612	46.029	**46.642**
30	-	34	2158003	1534	0.000711	0.538	0.00354838	0.9840	4.912	51.354	**52.189**	0.040	4.715	41.417	**42.090**
35	-	39	2137312	2028	0.000949	0.524	0.00473358	0.9805	4.891	46.442	**47.365**	0.056	4.618	36.701	**37.431**
40	-	44	2157647	3120	0.001446	0.524	0.00720532	0.9759	4.863	41.551	**42.578**	0.064	4.551	32.084	**32.877**
45	-	49	1531927	3274	0.002137	0.528	0.01063226	0.9688	4.820	36.688	**37.868**	0.088	4.396	27.532	**28.418**
50	-	54	1412383	4312	0.003053	0.531	0.01515654	0.9585	4.759	31.868	**33.247**	0.109	4.240	23.137	**24.138**
55	-	59	1525871	6747	0.004422	0.534	0.02188313	0.9440	4.672	27.109	**28.718**	0.126	4.083	18.897	**20.018**
60	-	64	1544558	10077	0.006524	0.534	0.03213211	0.9233	4.548	22.438	**24.300**	0.156	3.838	14.814	**16.043**
65	-	69	1479532	14908	0.010076	0.534	0.04922552	0.8937	4.366	17.890	**20.019**	0.196	3.510	10.976	**12.281**
70	-	74	974049	16574	0.017016	0.539	0.08186437	0.8497	4.088	13.524	**15.917**	0.286	2.919	7.465	**8.786**
75	-	79	954451	29857	0.031282	0.543	0.14596476	0.7801	3.640	9.436	**12.096**	0.370	2.293	4.547	**5.828**
80	-	84	819903	51059	0.062274	0.529	0.27156185	0.6663	2.905	5.796	**8.699**	0.513	1.415	2.253	**3.382**
85	-	+	684460	11491	0.167891	0.596	*1.00000000*	0.4853	2.891	2.891	**5.956**	0.710	0.838	0.838	**1.727**

Table 7: Calculation of the standard error for DFLE by the Sullivan method using an abridged life table

A	G	H	I	J	K	L	M	N	P	Q	R	S	T	U
Age group	Probability of survival to age x	Person years lived in age interval	Total number of years lived from age x	Total Life Expectancy	*Proportion of age group with disability*	Person years lived without disability in interval	Total years lived without disability from age x	Disability-free life expectancy	*Number in survey in age interval*					Standard error of DFLE$_x$
x - x+n	l$_x$	$_n$L$_x$	T$_x$	e$_x$	π_x	$(1-\pi_x)*$L$_x$	T$_x$	DFLE$_x$	N$_x$	S$^2(\pi_x)$	L^{2}S$^2(\pi_x)$	ΣL^{2}S$^2(\pi_x)$	S^2(DFLE$_x$)	S(DFLE$_x$)
0 - 4	1.0000	4.969	81.057	**81.057**	*0.010*	4.919	70.111	**70.111**	*772*	0.000013	0.000317	0.06919	0.06919	**0.263**
5 - 9	0.9924	4.960	76.088	**76.667**	*0.024*	4.841	65.192	**65.688**	*741*	0.000032	0.000778	0.06887	0.06992	0.264
10 - 14	0.9916	4.956	71.128	**71.729**	*0.026*	4.827	60.351	**60.861**	*745*	0.000034	0.000835	0.06809	0.06925	0.263
15 - 19	0.9908	4.950	66.172	**66.785**	*0.043*	4.737	55.524	**56.038**	*775*	0.000053	0.001301	0.06726	0.06851	0.262
20 - 24	0.9891	4.940	61.221	**61.894**	*0.037*	4.757	50.786	**51.345**	*728*	0.000049	0.001194	0.06596	0.06742	0.260
25 - 29	0.9869	4.927	56.281	**57.031**	*0.064*	4.612	46.029	**46.642**	*805*	0.000074	0.001807	0.06476	0.06650	0.258
30 - 34	0.9840	4.912	51.354	**52.189**	*0.040*	4.715	41.417	**42.090**	*892*	0.000043	0.001039	0.06296	0.06502	0.255
35 - 39	0.9805	4.891	46.442	**47.365**	*0.056*	4.618	36.701	**37.431**	*814*	0.000065	0.001554	0.06192	0.06440	0.254
40 - 44	0.9759	4.863	41.551	**42.578**	*0.064*	4.551	32.084	**32.877**	*824*	0.000073	0.001719	0.06036	0.06339	0.252
45 - 49	0.9688	4.820	36.688	**37.868**	*0.088*	4.396	27.532	**28.418**	*627*	0.000128	0.002974	0.05864	0.06248	0.250
50 - 54	0.9585	4.759	31.868	**33.247**	*0.109*	4.240	23.137	**24.138**	*571*	0.000170	0.003851	0.05567	0.06059	0.246
55 - 59	0.9440	4.672	27.109	**28.718**	*0.126*	4.083	18.897	**20.018**	*603*	0.000183	0.003986	0.05182	0.05815	0.241
60 - 64	0.9233	4.548	22.438	**24.300**	*0.156*	3.838	14.814	**16.043**	*611*	0.000215	0.004456	0.04783	0.05610	0.237
65 - 69	0.8937	4.366	17.890	**20.019**	*0.196*	3.510	10.976	**12.281**	*534*	0.000295	0.005625	0.04338	0.05431	0.233
70 - 74	0.8497	4.088	13.524	**15.917**	*0.286*	2.919	7.465	**8.786**	*380*	0.000537	0.008980	0.03775	0.05229	0.229
75 - 79	0.7801	3.640	9.436	**12.096**	*0.370*	2.293	4.547	**5.828**	*310*	0.000752	0.009964	0.02877	0.04728	0.217
80 - 84	0.6663	2.905	5.796	**8.699**	*0.513*	1.415	2.253	**3.382**	*228*	0.001096	0.009249	0.01881	0.04237	0.206
85 - +	0.4853	2.891	2.891	**5.956**	*0.710*	0.838	0.838	**1.727**	*180*	0.001144	0.009558	0.00956	0.04058	0.201

Chapter 2: Potential gains in health expectancy

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I. Introduction

Calculations of potential gain in life expectancy based on cause-elimination or cause-deleted life tables are well known in mortality research (Manton and Stallard, 1984; Namboodiri and Suchindran, 1987; Tsai et al., 1978). These tools are used to calculate the life expectancy that theoretically would be gained from the complete elimination of a cause of death. For example, these calculations show that eliminating cancer in men would increase life expectancy at age 15 by 3.9 years. Such a comparison of the hypothetical situation without exposure to a specific cause with the observed situation with exposure shows to what extent a specific cause of death affects life expectancy. In addition, it shows the maximum effect on life expectancy that prevention might have.

However what is not known from this calculation is whether or not these extra years lived are spent with disability. In low mortality countries, the change in health expectancy (e.g. life expectancy with and without disability) that would occur from the elimination of a disease is a more informative population health measure. Potential gains in health expectancy were first calculated by Colvez and Blanchet (Colvez and Blanchet, 1983). These calculations have since been made for Australia (Mathers, 1992; Mathers, 1997; Mathers, 1999), the Netherlands (Nusselder et al., 1994; Nusselder et al., 1996) and the United Kingdom (Bone et al., 1995). In these calculations all deaths and disability associated with a particular disease are eliminated. By taking into account the impact of a disease both through their effect on mortality and on disability, this tool is more suitable than the gain in life expectancy to assess the health impact of various diseases and the potential impact of prevention and treatment on population health. Cause-deleted health expectancies have also been used to assess whether elimination of a disease would lead to a compression or expansion of morbidity (Mathers, 1992; Mathers, 1999; Nusselder et al., 1994; Nusselder et al., 1996).

Potential gains in health expectancies can be calculated by extension of the conventional cause-deleted life tables used in mortality research. This extension includes two steps. The first relates to the calculation of cause-deleted disability rates. Since people may have multiple diseases, it is very difficult to assess whether disability would have disappeared if a specific disease was removed as a cause of disability. For mortality, multiple diseases may have caused death, underlying (principal) cause-specific mortality data are available. Although these data have shortcomings regarding the classification and coding of underlying causes of death, in particular for the oldest old, at least these data are based on international coding rules that assist physicians to classify the principal cause of death. For disability, information on the principal cause of disability is often not available, and even if self-reported causes of disability are known, it is not straightforward to identify the principal cause because persons often have (and report) multiple conditions (Bone et al., 1995). The second step relates to the life-table technique, which takes into account simultaneously the effect of mortality reductions and disability reductions on health expectancy. We will discuss these two steps in the next sections.

II. Method to estimate cause-deleted disability rates

Several possible alternatives to estimate cause-deleted disability rates have been described and used in literature (Bone et al., 1995; Colvez and Blanchet, 1983; Mathers, 1992). Bone has summarised four alternatives (Bone et al., 1995):

(a) Eliminate all disabilities in a person with the eliminated disease. This approach was used by Colvez and Blanchet (Colvez and Blanchet 1983), but neglects the fact that some disability might have been caused by diseases other than the one eliminated or by other factors (Nusselder et al., 1996). As a result, this approach largely overestimates the effect of elimination.

(b) Classify each individual who reports a disability according to the first-mentioned disease, assuming that the first-mentioned disease is the one of greatest concern. Next, calculate cause-deleted disability rates based on these cause-specific disability data. This approach was used by Mathers (Mathers, 1992) and Bone (Bone et al., 1995), but may, for some people, result in an overestimate of the health gain, since other conditions will cause residual disability. For other people, this approach will underestimate the health gain, since the health problem

may be causing a proportion of their disability, even if it is not the main cause their disability (Mathers, 1999). This approach can only be used when self-reported information on causes of disability is available.

(c) Delete disability only in those individuals for whom the condition is the sole cause of disablement. This approach has only been considered theoretically and has not been used practically, largely because it underestimates the effect of eliminating a disease on disability.

(d) Develop a statistical model that predicts the probability of disability from any combination of causes, the reduction in expected disability then being predicted from the model. This approach was used by Nusselder (Nusselder et al., 1994; Nusselder et al., 1996) and takes into account that disability might have been caused by diseases (or factors) other than the eliminated disease and also that disability occurs in people without any chronic disease. It can be used when separate information is available on the presence of disability and on the presence of (chronic) diseases in subjects. However, it requires information on chronic diseases in the non-disabled population, which will not occur if only data on (self-reported) causes of disability are available.

One should keep in mind that for comparative studies, the same method to calculate cause-deleted disability rates should be used, because methods differ in the extent to which they under- or overestimate the effect of a disease on disability as a result of co-morbidity. For the Health Monitoring System, which aims at generating comparative indicators, this means that one approach should be selected for all countries of the European Union, depending on the data available. Approaches a) and c) lead to respectively large over- and under-estimations, of the effect of a disease on disability. Approaches b) and d) differ in the data required and the way they take into account co-morbidity. Approach b) requires data on the (self-reported) causes of disability, whereas method (d) requires data on diseases in the non-disabled population. The statistical approach d) is considered the most satisfactory approach (Bone et al., 1995; Mathers, 1992; Mathers, 1999), the major advantage being that it takes into account co-morbidity explicitly.

1. Statistical model to estimate cause-deleted disability prevalence

We focus on the statistical model to estimate cause-deleted disability rates, which takes into account that disability might have been caused by diseases (or factors) other than the eliminated disease and that disability also might occur in persons without any chronic disease. In previous studies, logistic regression was used to calculate cause-deleted disability rates (Nusselder et al., 1994; Nusselder et al. 1996).

Based on the logistic regression model (available in standard software, such as SPSS and SAS), cause-deleted disability prevalence (for men and women separately) can be estimated as follows:

- Estimate a logistic regression model with the presence of one or more disabilities as the dependent variable and age, the selected diseases, and a category of several other diseases as independent variables. For ease of explanation of the method, age-by-disease and disease-by-disease interactions will not be included in the model. However, when needed, these interactions can be included easily.

- Calculate for each subject the estimated probability of having one or more disabilities before elimination by substituting the regression coefficients and the respondents' scores on the independent variables in the regression equation:

$$P = \frac{e^{\beta X}}{1 + e^{\beta X}}$$

  where P is the probability that the person has at least one disability, e is the base of the natural logarithm, and $\beta X = \alpha + \beta_1 X_1 + \beta_2 X_2 + \dots$ the vector of regression coefficients (α, β) and data (X) included in the model as independent variables (age, specified diseases, other diseases).

- Sum up the individual probabilities of disability $(_i\pi_x)$ within the age groups x-$x+i$. This is the expected number of persons with disability by age group. The prevalence of disability based on this expected number of disabled persons should be taken as the baseline to assess the effect of elimination of a disease.

- Simulate the elimination of a disease by deleting the disease in the regression equation, i.e., delete the disease in the regression equation and calculate again for each subject the fitted probability of having one or more disabilities (after elimination of the disease). This approach can also be used in the case where the model includes interaction terms

- Again, sum up the individual probabilities of disability after elimination within the age groups. This gives the expected number of persons with disability after elimination. Calculate cause-deleted prevalence of disability by dividing the number of persons with disability after elimination by the total number of persons in each age group.

The difference between the baseline prevalence of disability and the cause-deleted prevalence of disability is caused by the elimination of the disease. The cause-deleted prevalence of disability is used to calculate cause-deleted health expectancies, as shown in the next section.

2. Life-table method to calculate cause-deleted health expectancies

Colvez and Blanchet presented the first calculations of the potential gain in disability-free life expectancy by eliminating a disease, calculating separately the effect of a mortality reduction on total life expectancy and of a disability reduction on disability-free life expectancy (Colvez and Blanchet, 1983). The effect of mortality reduction on health expectancy was not considered, an important disadvantage, because mortality changes affect health expectancy significantly (Nusselder, 1998). For instance, mortality reductions (ceteris paribus) increase life expectancy with and without disability, and may result in an expansion of morbidity.

Mathers (1992) introduced cause-elimination life tables in combination with the Sullivan method. Hypothetically, if a disease is eliminated, there will be no disability or death from this disease. Assuming independence among causes of death and causes of disability, eliminating a disease leads to a decline in age-specific probabilities of dying, as well as in age-specific prevalence of disability. By combining the cause-elimination life table with the Sullivan method, the effect on life expectancy with and without disability of mortality and disability reductions caused by the (hypothetical) elimination of a disease as a cause of death and of disability are taken into account simultaneously. The same approach was followed by Nusselder et al. (1996) and Bone et al. (1995). We use this method to calculate cause-deleted health expectancies before elimination (baseline situation) according to the Sullivan method as presented in Chapter 1 (Table 6), with $a_x = 0.5$.

Assuming national statistics provide the number of deaths by age group (5 years) and by cause in a given year (as this is the case in the Netherlands), this quantity can be subtracted from the total number of deaths in Table 6 (Column C). Then, following the steps presented in Chapter 1, from Column C to Column J, one can estimate a cause-deleted life table and life expectancy.

Then, the cause deleted prevalence of disability is estimated as previously described in this chapter. By following the process in Table 6 from column K to the end one obtains life expectancy with and without disability after elimination of the disease. Notice that the change in life expectancy and life expectancy without disability due to the elimination of a disease should be greater than or equal to zero, but the change in life expectancy with disability may be positive, zero or negative.

III. Illustration of the calculation of potential gains in health expectancy for the Netherlands

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 multiple years; Tabeau et al., 1994). Population and total mortality data by single year-of-age were used, whereas cause-specific mortality data were only available by 5-year age groups, with age 95 and over as the oldest age group. The distribution among causes of death was assumed to be constant within the five-year age interval. 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 summarised in Table 8.

b) Disability

Cross-sectional data on long-term disability and chronic diseases were obtained from the Netherlands Health Interview Survey 1990-1994 (Statistics Netherlands, 1990-1994). This health interview survey is a random sample among the non-institutionalized population (N=32936). This study used a sub-sample 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 Cooperation 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 and have been detailed in Part 1 Chapter 1 (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 recognise 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. This definition of disability was also used in previous research on health expectancy in the Netherlands (Boshuizen et al., 1994; Boshuizen et al., 1997). This selection was chosen only for the purpose of illustration. When this tool is being applied within the Health Information System, the selection should be based on the proposals of indicators, made in the previous chapters of this guide.

Ideally, people living in institutions should have been included in the health interview survey. However, since the Dutch Health Interview Survey excluded people living in institutions, additional data were collected by TNO-PG for people living in institutions. For institutions covered by the AWBZ (including nursing homes, psychiatric hospitals, homes for the mental deficit), data were 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 (Social and Cultural Planning Office, 1991; Statistics Netherlands, 1984).

c) Chronic diseases

In the Health Interview Survey, 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 people living in institutions no data were available on the chronic diseases. We ignore the changes in disability due to the elimination of a chronic condition among people living in an institution.

Table 8: 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; arthritis	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.

2. Methods and Results

The starting point was the Sullivan life table. Complete life tables were constructed on the basis of mortality and population data by single-year of age. Based on these complete life tables, abbreviated life tables (with five-year age intervals and age 95+ as the oldest open age interval) were derived.

The number of person-years lived per five-year age interval was subdivided into years with and without disability by multiplying the number of person-years by the proportion with disability. Because in the Health Interview Survey 1990-1994, the proportion with disability only relates to the non-institutional population, first the number of person-years was subdivided into the number of years lived outside an institution and inside an institution by multiplying the number of person-years with the proportion of people living outside and inside an institution, respectively. Time spent inside an institution was considered as time with disability, although an adjustment was made for those living in a home for the elderly without disability (see Data section). The number of years lived outside an institution was further subdivided into the years with and without disability.

Cause-deleted probabilities of death were calculated from cause-specific mortality data, as explained in section II.2. By substitution of these cause-deleted probabilities in the life table, we obtained the cause-deleted number of person-years lived per five-year age interval. By multiplying this number by the proportion of persons living outside an institution, we obtained the number of person-years of the non-institutionalized population. The decline in disability due to eliminating the specific disease is assessed for the non-institutionalized population, because no data were on the diseases and disability in the institutionalized population.

Cause-deleted disability proportions (among the non-institutionalized population) were calculated using logistic regression. The regression analysis was based on weighted cases, in order to take into account the stratification in the sample. For the ease of explanation, we did not take into account interaction terms, although the following interactions were statistically significant: back complaints by age (men, women); heart disease by cancer (women), heart disease by back complaints (women) and heart disease by diabetes mellitus (men). In particular, including the interaction of back complaints by age would have affected our results. Table 9 summarises the outcomes of the regression analysis.

Table 9: Beta's for chronic diseases, Odds Ratios, and 95% Confidence Intervals derived from logistic regression analysis, The Netherlands, 1990-1994

	Regression coefficients (β)	Disability Odds ratio	95% Confidence interval
Men			
Chronic Obstr. Lung Disease	0.5866	1.8	1.4-2.2
Heart disease	0.5967	1.8	1.4-2.4
Stroke	1.7750	5.9	3.5-10.1
Diabetes mellitus	0.3467	1.4[b]	1.0-2.0
Back complaints	1.2556	3.5	2.9-4.2
Arthritis	0.7125	2.0	1.7-2.4
Cancer	0.6257	1.9	1.1-3.2
Women			
Chronic Obstr. Lung Disease	0.3154	1.4	1.1-3.7
Heart disease	0.9232	2.5	1.8-3.5
Stroke	1.2944	3.6	2.0-6.6
Diabetes mellitus	1.1949	3.3	2.5-4.3
Back complaints	1.2817	3.6	3.1-4.2
Arthritis	0.9882	2.7	2.4-3.1
Cancer	0.7914	2.2	1.4-3.4

[a]   Controlled for age (five-year age groups) and presence of other diseases.
[b]   Not statistically significantly different from 1.0.

The odds ratios (i.e. e^{β}) show the net effect of the selected chronic disease on the probability of having disability corrected for age and other diseases. Stroke and back complaints have the largest effects on disability (odds ratio 5.9 and 3.5, respectively in men, and 3.6 and 3.5, respectively in women). The contribution of diabetes is not statistically significant in men. The effect of eliminating a disease on the disability prevalence depends not only on the disabling impact of the disease but also on its prevalence. Both are taken into account in the elimination procedure.

Based on the logistic regression model, total and cause-deleted disability proportions were calculated. The difference between the (predicted) total and cause-deleted disability proportion is caused by the elimination of the disease. The deleted disability proportions were used to subdivide the cause-deleted number of person-years (outside an institution) after the elimination of a disease into years with and without disability. According to standard methods, life expectancy with and without disability was calculated. The results were as follows in Table 10.

The baseline situation (no change) is presented for comparison. The sum of the change in life expectancy with and without disability is the change in total life expectancy (first column is the result from the conventional cause-elimination analysis). The second and third columns show the change in health expectancy. Changes in life expectancy (LE) and life expectancy without disability (DFLE) are positive for all diseases. Changes in life expectancy with disability (LED) are positive for some and negative for other diseases.

Regarding the life expectancy free of disability, elimination of cancer (men), heart disease, arthritis (women) and other diseases leads to the greatest gain. The impact of diabetes in men, and COPD and stroke is of medium

effect. For those diseases showing no significant change in total life expectancy (e.g. arthritis and back complaints) the increase in disability-free life expectancy implies a decrease in years with disability. For other diseases the change in life expectancy with disability depends upon the change in disability-free life expectancy as compared to that in total life expectancy.

Table 10: Baseline[a] and Change in Total Life Expectancy (LE), Disability-Free Life Expectancy (DFLE), Life Expectancy with Disability (LED) at age 15 due to Elimination of the Specific Disease, The Netherlands[b], 1990-1994

	Years of		
	LE	**DFLE**	**LED**
Men Baseline[c]	**59.93**	**51.52**	**8.41**
Chronic Obstructive Pulmonary Disease (COPD)	0.53	0.60	-0.07
Heart disease	3.18	2.13	1.05
Stroke	0.67	0.57	0.10
Diabetes mellitus	0.19	0.19	0.00
Back complaints	0.00	0.97	-0.96
Arthritis	0.02	0.68	-0.65
Cancer	3.85	3.10	0.75
Women Baseline[c]	**65.82**	**51.16**	**14.65**
Chronic Obstructive Pulmonary Disease (COPD)	0.27	0.30	-0.03
Heart disease	2.57	1.13	1.44
Stroke	1.02	0.46	0.57
Diabetes mellitus	0.30	0.55	-0.25
Back complaints	0.00	1.36	-1.36
Arthritis	0.07	2.08	-2.01
Cancer	3.37	1.63	1.74

[a]   Baseline figures are based on life tables and on disability prevalence for 1990-1994.
[b]   Figures are rounded to 0.2 years.
[c]   The baseline expectancies are based on the fitted age-specific prevalence.

Table 10 shows that eliminating heart disease, cancer, stroke and other diseases increases life expectancy with disability, i.e. an expansion of morbidity, due to the large mortality reductions from these diseases. In the years saved from dying from these diseases, people are exposed to disability from other diseases and from old age.

3. Discussion

Potential gain indicators provide insight into the relative impact of diseases on health expectancy, identifying the major causes of health losses and thus identifying the potentials for health gains (Mathers, 1999). Using the potential gain indicator, the diseases that cause major losses in years without disability can easily be identified. On the other hand, the indicator also shows which diseases 'avoid' time spend with disability, since people dying from this disease are not exposed to disability from this disease, other diseases or old age. As a consequence, when eliminating lethal diseases, life expectancy with disability may increase. The potential gain indicator of health expectancy also clearly shows these possible side effects. As any tool, the proposed indicator has limitations, some of them being specific to the data sources used or related to presenting the model as simply as possible, while others are more fundamental to the method. We will discuss them briefly.

a)   Limitations related to the data used

Population living in institutions

In our illustration of the potential gain 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 institutionalized population (i.e. that they are disabled). Last and most important, we could not take into account changes in disability due to elimination of a chronic condition among those living in institutions, perhaps introducing an overestimation of the age-specific cause-deleted disability prevalence for the institutionalized population. Although a considerable decline in disability due to elimination of one disease is not likely, because of the advanced age and therefore the likelihood of co-morbidity in this population, we strongly recommend including the institutionalized population in the health survey.

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 gold 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 (Heliovaara et al., 1993; Jabine, 1987; Schrijvers et al., 1994; Van den Bos, 1989) show considerable differences for some diseases (Jabine, 1987; Schrijvers et al., 1994; Van den Bos, 1989). 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; Van den Bos, 1989) 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 potential gain in health expectancy can only be calculated from health interview or health examination surveys.

b)   Limitations related to the use of a simple model for the purpose of illustration

Independence of causes of disability

The statistical model used to estimate cause-deleted disability prevalence assumes independence of causes of disability in a (multiplicative) logistic regression model. As indicated, we used this assumption for transparency reasons, but it can easily 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. With large surveys, there is the possibility that interactions are included as significant, while their effect on health expectancy is negligible. Based on a model with interaction terms, the procedure is identical to the procedure based on a model without interactions. We tested this approach (detailed results not shown) in our dataset, by including the significant interactions (i.e. heart disease by cancer (women), heart disease by back complaints (women) and heart disease by diabetes (men) altered the results little.

Constant effect of disease on disability at all ages

In the illustrated method we did not take into account that different types of diseases included in a single disease cluster might have different implications for disability at different ages. However, as indicated, disease-by-age interactions can be included without problems. We tested for disease-by-age interactions and found that for the Netherlands the interaction between age and back complaints was significant in women. At older ages, the effect of back complaints on disability was less than at younger ages. Including this interaction term would have reduced the effect of elimination of back complaints on the life expectancy with and without disability considerably, but the direction of the effects (increase versus decrease) would not have changed. Again we suggest testing for interactions and to include these in the model, where necessary.

c) Limitations related to the proposed method

Independence of causes of death

As in conventional calculations of the gain in life expectancy, for several reasons the method proposed assumes independence among causes of death. In most European Union countries , like in the Netherlands, multiple-causes-of-death data are not generally available. In addition, the assumption of independence can hardly be avoided until more is known about the exact nature of dependence among various causes of death. Third, modelling dependence between causes of death would make the tool too complex to be used in comparative research. However, since death in particular at more advanced ages tends to result from a number of age- and disease-related degenerative conditions that often act interdependently, and since degenerative diseases are known to share common risk factors, the assumption of independence is likely to be violated (Manton et al., 1991; Olshansky, 1988). Assuming independence among competing risks might have resulted in an over-estimation of the mortality reduction in advanced ages (Fries, 1984; Manton, 1988). By contrast, using underlying cause-of-death data might have resulted in an underestimation of the effect of elimination in some cases because non-underlying causes (e.g. diabetes) can contribute to death from other causes (e.g. stroke) (Manton, 1982).

Ignoring severity of disability

In this illustration we calculated the potential gain in life expectancy with and without disability, including different levels of severity of disability. Mathers (1997; 1999) has used severity weights to calculate severity-weighted disability prevalence, which in turn were used to calculate the gain in Health Adjusted Life Expectancies (HALE). Severity weights cannot easily be included in the statistical model that we have proposed, therefore separate calculations of potential gain indicators for different levels of severity of disability should be made.

Despite these limitations, which should be kept in mind when using it, methods of calculating potential gain are useful in exploring the possible effect of preventing different diseases, and therefore reducing disability, on health expectancy.

Part 3. Examined measurement instruments

1- Charts on physical and sensorial functional limitations

1. Belgian Health Interview Survey, 1997

(IHE= Institut d'Hygiène et d'Epidémiologie)

Presentation:

The studied instrument has three parts. The first one (IL01-IL07) contains one question introducing seven items with three response categories, the second corresponds to one question on walking (IL08) and the third contains five separated questions, of which four (IL09-IL12) with two response categories (yes, no) and one (IL.13) with four response categories. (Van Oyen et al., 1997; Hupkens, 1998).

Reference wording (original and translated versions):

Voici une liste d'activités que vous pouvez avoir à faire dans votre vie de tous les jours. Pour chacune d'entre-elles indiquez si vous êtes gêné(e) en raison de votre état de santé actuel. Si oui, dans quel mesure ? *The following items deal with activities you might have to perform during your everyday life. For each activity, indicate if you are hampered because of your current state of health ? If so, how much ?*

IL.01 Soulever et porter les courses *Lifting or carrying groceries*
- oui, très gêné (e) *yes, hampered a lot*
- oui, un peu gêné (e) *yes, hampered a little*
- non, pas gêné (e) du tout no, *not hampered at all*

IL.02 Monter plusieurs étages par l'escalier *Climbing several flights of stairs*
- oui, très gêné (e) *yes, hampered a lot*
- oui, un peu gêné (e) *yes, hampered a little*
- non, pas gêné (e) du tout no, *not hampered at all*

IL.03 Monter un seul étage par l'escalier *Climbing one flight of stairs*
- oui, très gêné (e) *yes, hampered a lot*
- oui, un peu gêné (e) *yes, hampered a little*
- non, pas gêné (e) du tout no, *not hampered at all*

IL.04 Se pencher en avant, se mettre à genoux, s'accroupir *Bending, kneeling, stooping*
- oui, très gêné (e) *yes, hampered a lot*
- oui, un peu gêné (e) *yes, hampered a little*
- non, pas gêné (e) du tout no, *not hampered at all*

IL.05 Marcher plus d'un km à pied *Walking for more than a kilometre*
- oui, très gêné (e) *yes, hampered a lot*
- oui, un peu gêné (e) *yes, hampered a little*
- non, pas gêné (e) du tout no, *not hampered at all*

IL.06 Marcher plusieurs centaines de mètres *Walking several hundred metres*
- oui, très gêné (e) *yes, hampered a lot*
- oui, un peu gêné (e) *yes, hampered a little*
- non, pas gêné (e) du tout no, *not hampered at all*

IL.07 Marcher une centaine de mètres *Walking one hundred metres*
- oui, très gêné (e) *yes, hampered a lot*
- oui, un peu gêné (e) *yes, hampered a little*
- non, pas gêné (e) du tout no, *not hampered at all*

Si la personne interrogée a répondu OUI à l'une des questions reprises ci-dessus et/ou que la personne interrogée a 60 ans ou plus, passez à la question IL08. Sinon, passez à la question IL09. Les réponses par proxys sont autorisées. *If the selected person answered one of the above mentioned questions with YES and/or the selected person is older than 60 - go to IL08. If not - go to IL09. Answers by proxy are admitted.*

IL.08 Jusqu'où pouvez-vous marcher sans vous arrêter et sans éprouver de gêne importante ? *What is the furthest you can walk without stopping and without severe discomfort ?*
- quelque pas seulement *only a few steps*
- plus de quelques pas mais moins de 200 mètres *more than a few steps but less than 200 metres*
- 200 mètres ou plus *200 metres or more*

Les questions suivantes (IL.09-IL.13) doivent être posées à tout le monde. Les questions IL09 à IL12 seront être posées en tenant compte des capacités des individus avec leurs lunettes et/ou appareils auditifs s'ils en portent d'habitude. *The next questions (IL.09-IL.13) must be asked to everyone older than 15 years. For the questions on hearing and seeing, hearing and seeing aids normally used by the respondent must be taken into account.*

IL.09 Entendez-vous suffisamment bien pour suivre un programme télévisé avec un volume acceptable pour les autres ? *Do you hear good enough to follow a TV programme at a volume others find acceptable ?*
- oui *yes*
- non *no*

IL.10 Pouvez-vous suivre le programme télévisé avec un volume plus élevé ? *Can you follow a TV programme with the volume turned up ?*

<div align="center">- oui *yes*</div>
<div align="center">- non *no*</div>

IL.11 Avez-vous une vue suffisamment bonne pour reconnaître un ami à 4 mètres de distance (de l'autre côté de la rue)? *Do you have an eyesight good enough to recognize a friend at a distance of four metres (across a road)?*

<div align="center">- oui *yes*</div>
<div align="center">- non *no*</div>

IL.12 Avez-vous une vue suffisamment bonne pour reconnaître un ami de 1 mètre de distance (la longueur du bras)? *Do you have an eyesight good enough to recognize a friend at a distance of one metre (at arm's length) ?*

<div align="center">- oui *yes*</div>
<div align="center">- non *no*</div>

IL.13 Etes-vous capable de mordre et de mâcher une nourriture dure comme une pomme dure par exemple ? *Are you able to bite and chew on hard foods as a firm apple for example ?*

<div align="center">- oui, sans difficulté *yes, without difficulty*</div>
<div align="center">- oui, mais avec une certaine difficulté *yes, but with minor difficulty*</div>
<div align="center">- oui, mais avec beaucoup de difficulté *yes, but with major difficulty*</div>
<div align="center">- non, je ne peux pas *no, I can't*</div>

Data collection: Face to face questionnaire

Target population (if any): Respondents aged 15 and over, living in private households, nursing homes and homes for elderly.

Wording: Extremely varied (If you are hampered / Can you / Do you / Are you able ...)

Level of severity: Varying according to questions.

Duration: No reference to duration.

Use of assistance: The use of hearing and seeing aids must be taken into account answering four questions on sensory functional limitations (IL09-IL13).

Limits and justification for non selection:

The large number of questions on functional limitations comes from several reference instruments (the "Physical functioning" module in the SF-36 instrument, OECD recommendations and WHO-Europe recommendations) (Ware et al., 1992; McWhinnie, 1981; De Bruin et al., 1996). Several questions cover the same field of functional limitations (e.g., six questions on mobility) while other fields are not covered (mostly agility). The wording of questions is generally in term of performance rather than capacity. The use of assistance is not always taken into account.

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2. British Disability Interview Survey, 1996
(Department of Health and ONS = Office for National Statistics)

Presentation:

The studied instrument is a set of seventeen questions selected from ninety-seven items on functional limitations in the British Disability Survey (a follow-up of the Family Resources Survey) (Hupkens, 1998). The questions hereunder have been selected according to two main criteria (level of comparison with international recommendations and coverage of the main fields of functional limitations). Except for the four first questions, there are two response categories (yes/no) are proposed.

Reference wording (original version):

1. What is the furthest you can walk on your own without stopping and without severe discomfort ?
    - At least 200 yards / - Less than 200 yards but at least 50 yards / - Less than 50 yards but more than a few steps / - only a few steps
2. How long can you remain standing without having to move around ?
    - Less than 10 minutes / - 10 but less than 30 minutes / - 30 minutes or more
3. Can you walk up and down a flight of 12 stairs on your own ?
    - without holding on and without stopping for a rest / - by holding on but without stopping for a rest / by holding on AND stopping for a rest / - or not at all
4. Do you need to hold on to something to keep your balance ?
    - All the time / - quite often / - only occasionally / - or not at all
5. Can you bend down far enough to touch your knees and straighten up again, holding on if necessary ?
    - Yes / - No
6. Can you bend down and pick something up from the floor and straighten up again, holding on if necessary ?
    - Always / - Sometimes
7. Can you stretch both arms above your head at the same time to reach for something above you ?
    - Yes / - No
8. Do you have great difficulty holding, gripping or turning things ?
    - Yes / - No
9. Can you turn a tap or the control knobs of a cooker …with your right hand ?
    - Yes / - No
10. Can you turn a tap or the control knobs of a cooker …with your left hand ?
    - Yes / - No
11. Can you pick up and carry a 5 lb bag of potatoes ... with your right hand ?
    - Yes / - No
12. Can you pick up and carry a 5 lb bag of potatoes ... with your left hand ?
    - Yes / - No
13. (wearing glasses or lenses ...) Do you have difficulty recognising a friend across the road ?
    - Yes / - No
14. (wearing glasses or lenses ...) Do you have difficulty reading ordinary newspaper print ?
    - Yes / - No
15. (wearing glasses or lenses ...) Can you see well enough to recognise a friend who is an arm's length away ?
    - Yes / - No
16. (wearing your hearing aid ...) Can you follow a TV programme with the volume turned up ?
    - Yes / - No
17. (wearing your hearing aid ...) Can you follow at a volume others find acceptable ?
    - Yes / - No

Data collection: Face to face questionnaire.

Target population (if any): Respondents aged 16 years or older.

Wording: What is the furthest you can / Can you / Do you ...

Level of severity: Sometimes.

Duration: No reference to duration.

Use of assistance: Several questions specify the use of assistance (e.g., "on your own" for the questions 1 and 3 or "wearing your hearing aid" for questions 16 and 17).

Limits and justification for non selection:

The British Disability Interview Survey is rich in questions covering largely the conceptual field of functional limitations. Ten questions follow international recommendations (questions 1, 3, 6, 11, 12, 14, and 15 from WHO-Europe recommendations; questions 9, 10, and 13 from OECD recommendations) (McWhinnie, 1981; de Bruin et al., 1996). Several questions mix functional limitations and actual performances. The wording of

questions is often in term of performance rather than capacity, and the use of an assistance is not always specified.

References:

de Bruin A, Picavet HSJ, Nossikov A (1996) *Health interview surveys: Towards international harmonization of methods and instruments*. Copenhagen: World Health Organisation. Regional Office for Europe. Voorburg: Statistics Netherlands. (WHO Regional Publications. European Series n°58). 53-60.

Hupkens C (1998) *Coverage of health topics by surveys in the European Union.*. University of Maastricht. Dept of Medical Sociology and Statistics Netherlands. (Eurostat Working Papers)

McWhinnie J.R (1981) Disability assessment in population surveys : Results of the OECD Common development effort. *Revue d'épidémiologie et de santé publique* 29: 413-419.

3. Danish Health and Morbidity Interview Survey, 1994 (face to face)

(DIKE, Dansk Institut for Klinisk Epidemiologi)

Presentation:

Question 58 in section "Physical disability" introduces five items with four response categories. The interviewers have to complete themselves the last question on speaking (DICE, 1996; Hupkens, 1998).

Reference wording (original and translated versions):

Kan De normalt uden besvær, med lidt besvær, med meget besvær eller slet ikke gøre følgende? *Are you normally able to do the following with no difficulty, with minor difficulty, with major difficulty, or not at all?*

A   Læse en almindelig avistekst (evtS. med briller, hvis det normalt bruges*) Read ordinary newspaper print? (with glasses, if normally worn)*   - ja, uden besvær *yes, no difficulty*
> - ja, med lidt besvær *yes, minor difficulty*
> - ja, med meget besvær *yes, major difficulty*
> - nej, slet ikke *no, not at all*

B   Høre hvad der bliver sagt under en normal samtale mellem 3 eller flere personer? (evt. med høreapparat, hvis det normalt bruges*) Hear what is said in a normal conversation between 3 persons or more? (with hearing aid if normally worn)*   - ja, uden besvær *yes, no difficulty*
> - ja, med lidt besvær *yes, minor difficulty*
> - ja, med meget besvær *yes, major difficulty*
> - nej, slet ikke *no, not at all*

C   Gå 400 meter uden at hvile *Walk 400 meters without resting?*
> - ja, uden besvær *yes, no difficulty*
> - ja, med lidt besvær *yes, minor difficulty*
> - ja, med meget besvær *yes, major difficulty*
> - nej, slet ikke *no, not at all*

D   Gå op eller ned ad en trappe fra en etage til en anden uden at hvile *Walk up and down a staircase from one floor to another without resting?*
> - ja, uden besvær *yes, no difficulty*
> - ja, med lidt besvær *yes, minor difficulty*
> - ja, med meget besvær *yes, major difficulty*
> - nej, slet ikke *no, not at all*

E   Bære 5 kg? (fx indkøbsposer) *Carry 5 kg (e.g. a shopping bag)?*
> - ja, uden besvær *yes, no difficulty*
> - ja, med lidt besvær *yes, minor difficulty*
> - ja, med meget besvær *yes, major difficulty*
> - nej, slet ikke *no, not at all*

F   (Udfyldes af interviewer) (To be completed by interviewer)
> - tale uden besvær *speaks with no difficulty*
> - tale med noget besvær *speaks with minor difficulty*
> - tale med meget besvær *speaks with major difficulty*

Data collection: Face to face questionnaire.

Target population (if any): 60 years of age or older.

Wording: Are you normally able to ...

Level of severity: Degree of difficulty (no, minor, major, not able at all).

Duration: No reference to duration.

Use of assistance: The use of special aids is specified in items A and B.

Limits and justification for non selection:

The face to face Danish Health and Morbidity Interview Survey uses the OECD recommendations as reference (McWhinnie, 1981). Several questions mix functional limitations and actual performances. This instrument is complementary to the self-administered Danish Health and Morbidity Interview Survey (see chart 4) covering other functional limitations. The use of walking aids is not specified in items C and D.

References:

de Bruin A, Picavet HSJ, Nossikov A (1996) *Health interview surveys: Towards international harmonization of methods and instruments*. Copenhagen: World Health Organisation. Regional Office for Europe. Voorburg: Statistics Netherlands. (WHO Regional Publications. European Series n°58). 53-60.

Danish Institute for Clinical Epidemiology [DICE] (1996) *Questionnaire for the Health Interview Survey 1994 with response-frequencies*. DICE. Copenhagen.

Hupkens C. (1998) *Coverage of health topics by surveys in the European Union.*. University of Maastricht. Dept of Medical Sociology and Statistics Netherlands. (Eurostat Working Papers)

McWhinnie J.R. (1981) Disability assessment in population surveys : Results of the OECD Common development effort. *Revue d'épidémiologie et de santé publique* 29: 413-419.

4. Danish Health and Morbidity Interview Survey, 1994 (Self-administered)

Presentation:

Question 3 introduces seven items on functional limitations with three response categories (DICE, 1996; Hupkens, 1998).

Reference wording (original and translated versions):

De følgende spørgsmål handler om aktiviteter i dagligdagen. Er De på grund af Deres helbred begrænset i disse aktiviteter? I så fald, hvor meget ? (én ring i hver linie) *The following questions are about daily activities. Are you because of your health restricted in these activities. If so, how much? (one ring in each line)*

a   At løfte eller bære dagligvarer *lifting or carrying groceries*
-       ja, meget begrænset *yes, very much restricted*
-       ja, lidt begrænset *yes, a little restricted*
-       nej, slet ikke begrænset *no, not restricted at all*

b   At gå flere etager op ad trapper *climbing several flights of stairs*
-       ja, meget begrænset *yes, very much restricted*
-       ja, lidt begrænset *yes, a little restricted*
-       nej, slet ikke begrænset *no, not restricted at all*

c   At gå én etage op ad trapper *climbing one flight of stairs*
-       ja, meget begrænset *yes, very much restricted*
-       ja, lidt begrænset *yes, a little restricted*
-       nej, slet ikke begrænset *no, not restricted at all*

d   At bøje sig ned eller gå ned i knæ *bending or kneeling-*
-       ja, meget begrænset *yes, very much restricted*
-       ja, lidt begrænset *yes, a little restricted*
-       nej, slet ikke begrænset *no, not restricted at all*

e   Gå mere end én kilometer *walking more than 1 kilometre*
-       ja, meget begrænset *yes, very much restricted*
-       ja, lidt begrænset *yes, a little restricted*
-       nej, slet ikke begrænset *no, not restricted at all*

f   Gå nogle hundrede meter *walking a few hundred meters*
-       ja, meget begrænset *yes, very much restricted*
-       ja, lidt begrænset *yes, a little restricted*
-       nej, slet ikke begrænset *no, not restricted at all*

g   Gå 100 meter *walking 100 meters*
-       ja, meget begrænset *yes, very much restricted*
-       ja, lidt begrænset *yes, a little restricted*
-       nej, slet ikke begrænset *no, not restricted at all*

Data collection: Self administered questionnaire.

Target population (if any): All persons

Wording: Are you restricted ...

Level of severity: Degree of restriction (very much, a little, not at all).

Duration: No reference to duration.

Use of assistance: No reference to assistance.

Limits and justification for non selection:

The self-administered Danish Health and Morbidity Interview Survey Instrument uses a modified version of the "Physical functioning" module in the SF-36 instrument (Ware and Sherbourne, 1992). This instrument is

complementary to the face to face Danish Health and Morbidity Interview Survey (see chart 3) covering other functional limitations. The wording of questions is generally explained in term of performance rather than in term of capacity. The use of assistance is never specified in the questions.

References:

Danish Institute for Clinical Epidemiology [DICE] (1996) *Questionnaire for the Health Interview Survey 1994 with response-frequencies*. Copenhagen: DICE.

Hupkens C (1998) *Coverage of health topics by surveys in the European Union*. University of Maastricht. Dept of Medical Sociology and Statistics Netherlands. (Eurostat Working Papers).

Ware JE, Sherbourne CD (1992) The MOS 36-Item Short-Form Health Survey (SF 36) : I. Conceptual Framework and Item Selection. *Medical Care* 30 (6): 473-483.

World Health Organization (1999) International classification of functionning and disability (ICIDH II-Beta 2), Short version. WHO: Geneva.

5. Dutch Health Interview Survey, 1995

Presentation:

The studied instrument is made of eight questions in part D of the Dutch health interview survey. Each question has four response categories (Hupkens, 1998).

Reference wording (original and translated versions):

1. Kunt u een gesprek volgen in een groep van 3 of meer personen ? (Zo nodig met hoorapparaat) *Can you hear what is said in a group of 3 or more persons ? (with hearing aid if necessary)*

    - Ja, zonder moeite *Yes, without difficulty*

    - Ja, met enige moeite *Yes, but with minor difficulty*

    - Ja, met grote meite *Yes, but with major difficulty*

    - Neen, dat kan ik niet *No, I can't*

2. Kunt u met één andere persoon een gesprek voeren ? (zo noodig met hoorapparaat) *Can you carry on a conversation with one other person ? (with hearing aid if necessary)*

    - Ja, zonder moeite *Yes, without difficulty*

    - Ja, met enige moeite *Yes, but with minor difficulty*

    - Ja, met grote meite *Yes, but with major difficulty*

    - Neen, dat kan ik niet *No, I can't*

3. Zijn uw ogen goed genoeg om de kleine letters in de kraant te kunnen lezen ? (zo nodig met bril of kontaktlenzen) *Is your eyesight good enough to read the small letter in the newspaper ?*

    - Ja, zonder moeite *Yes, without difficulty*

    - Ja, met enige moeite *Yes, but with minor difficulty*

    - Ja, met grote meite *Yes, but with major difficulty*

    - Neen, dat kan ik niet *No, I can't*

4. Kunt u op een afstand van 4 meter het gezicht van iemand herkennen ? (zo nodig met bril of kontaktlenzen) *Is your eyesight good enough to recognise someone's face at a distance of 4 metres ? (with glasses if necessary)*

    - Ja, zonder moeite *Yes, without difficulty*

    - Ja, met enige moeite *Yes, but with minor difficulty*

    - Ja, met grote meite *Yes, but with major difficulty*

    - Neen, dat kan ik niet *No, I can't*

5. Kunt u hard voedsel bijten en kauwen zoals bijvoorbeeld een harde appel ? *Can you bite and chew on hard foods, for instance a firm apple ?*

    - Ja, zonder moeite *Yes, without difficulty*

    - Ja, met enige moeite *Yes, but with minor difficulty*

    - Ja, met grote meite *Yes, but with major difficulty*

    - Neen, dat kan ik niet *No, I can't*

6. Kunt u een voorwerp van 5 kilo, bijvoorbeeld een volle boodschappentas, 10 meter dragen ? *Can you carry an object of 5 kilos for 10 metres, for example a full shopping bag ?*

    - Ja, zonder moeite *Yes, without difficulty*

    - Ja, met enige moeite *Yes, but with minor difficulty*

    - Ja, met grote meite *Yes, but with major difficulty*

    - Neen, dat kan ik niet *No, I can't*

7. Kunt u als u staat, bukken en iets van de grond oppakken ? *Can you, when standing, bend down and pick up something from the floor ?*

    - Ja, zonder moeite *Yes, without difficulty*

    - Ja, met enige moeite *Yes, but with minor difficulty*

    - Ja, met grote meite *Yes, but with major difficulty*

    - Neen, dat kan ik niet *No, I can't*

8. Kunt u 400 meter aan een stuk lopen zonder stil te staan ? (zo nodig met stok) *Can you walk 400 metres without resting ? (with walking-stick if necessary)*

    - Ja, zonder moeite *Yes, without difficulty*

    - Ja, met enige moeite *Yes, but with minor difficulty*

    - Ja, met grote meite *Yes, but with major difficulty*

    - Neen, dat kan ik niet *No, I can't*

Data collection: Self-administered questionnaire.

Target population (if any): All persons aged 16 or more in ordinary households.

Wording: Can you / Is your eyesight good enough to ...

Level of severity: Degree of difficulty (without / with minor / with major / cannot).

Duration: No reference to duration.

Use of assistance: The use of special aids is generally specified in the questions.

Limits and justification for non selection:

The Dutch health interview survey instrument is close to OECD recommendations (McWhinnie, 1981). This instrument is in fact an improved version the OECD recommended instrument as several important sources of confusion have been taken out. It covers almost the same fields than the OECD recommended instrument which seems to be insufficient to get a comprehensive information on functional limitations (mostly on agility). Several questions mix functional limitations and actual performances.

References:

Hupkens C (1998) *Coverage of health topics by surveys in the European Union.* University of Maastricht. Dept of Medical Sociology and Statistics Netherlands. (Eurostat Working Papers)

McWhinnie JR (1981) Disability assessment in population surveys : Results of the OECD Common development effort. *Revue d'Epidémiologie et de Santé Publique* 29:413-419.

6. Finnish Health Care Interview Survey, 1995/96

(Stakes, KELA, KTL, and Tilastokeskus)

Presentation:

The studied instrument is made of five questions on functional capacity in section C9 of the Finnish health care interview survey. The questions have three or four response categories (Hupkens, 1998).

Reference wording (original and translated versions):

Tämä osa kysytään kaikilta 60 vuotta täyttäneiltä (tai vuonna 1996 60 täyttäviltä), työkyvyttömyys eläkkeellä olevilta ja niiltä pitkäaikaissairailta, joilla on jokin toimintakykiä haittaava sairaus joilla c2k5 on 1 tai 2). *For all who are 60 years or older, for all invalidity pensioners, and for chronically ill people who report a disabling chronic disease.*

1 Pystyttekö vaikeuksitta kävelemään ilman mitään apuvälineitä noin 400 metrin pituisen matkan ? *Can you walk without any aids a distance of 400 metres without difficulty ?*

- pystyy vaikeuksitta *yes, without difficulties*

- pystyy, mutta vaikeuksia on jonkin verran *yes, but with minor difficulties*

- pystyy, mutta se on erittäin vaikeaa *yes, but with major difficulties*

- ei pysty lainkaan *not at all*

2 Pystyttekö kantamaan ostoskassia tai muuta, noin 5 kilon painosta taakkaa vähintään 100 metrin matkan ? *Can you bear a shopping bag or some other burden of about 5 kilos at least 100 metres ?*

- pystyy vaikeuksitta *yes, without difficulties*

- pystyy, mutta vaikeuksia on jonkin verran *yes, but with minor difficulties*

- pystyy, mutta se on erittäin vaikeaa *yes, but with major difficulties*

- ei pysty lainkaan *not at all*

3 Pystyttekö leikkaamaan omat varpaankyntenne ? *Can you cut your toenails ?*

- pystyy vaikeuksitta *yes, without difficulties*

- pystyy, mutta vaikeuksia on jonkin verran *yes, but with minor difficulties*

- pystyy, mutta se on erittäin vaikeaa *yes, but with major difficulties*

- ei pysty lainkaan ? *not at all*

4 Pystyttekö lukemaan tavallista sanomalehtitekstiä silmälaseilla tai ilman ? *Can you read ordinary newspaper print with or without glasses ?*

- pystyy vaikeuksitta *yes, without difficulties*

- pystyy, mutta vaikeuksia on jonkin verran *yes, but with minor difficulties*

- ei pysty lainkaan ? *not at all*

5 Pystyttekö vaikeuksitta kuulemaan, mitä usean henkilön välisessä keskustelussa sanotaan (kuulolaitteen avulla tai ilman) ? *Can you hear what is said in a conversation between several people (with or without a hearing aid) ?*

- pystyy vaikeuksitta *yes, without difficulties*

- pystyy, mutta vaikeuksia on jonkin verran *yes, but with minor difficulties*

- ei pysty lainkaan ? *not at all*

Data collection: Face to face questionnaire.

Target population (if any): All respondents 60 years or older, all invalidity pensioners, and chronically ill people living in ordinary households

Wording: Can you ...

Level of severity: Degree of difficulty (without, with minor, with major, not at all).

Duration: No reference to duration.

Use of assistance: The use of special aids is specified in questions 1, 4, and 5.

Limits and justification for non selection:

The Finnish health care interview survey is close to the OECD recommendations (McWhinnie, 1981). This instrument is in fact an improved version the OECD recommended instrument as several important sources of confusion have been taken out. However, it covers less fields than recommended. Several questions mix functional limitations and actual performances.

References:

Hupkens C (1998) *Coverage of health topics by surveys in the European Union.* University of Maastricht. Dept of Medical Sociology and Statistics Netherlands. (Eurostat Working Papers)

McWhinnie JR (1981) Disability assessment in population surveys : Results of the OECD Common development effort. *Revue d'Epidémiologie et de Santé Publique* 29:413-419.

7. French Health and Medical Care Interview Survey 1991/92.

(INSEE = Institut National de la Statistique et des Etudes Economiques and CREDES = Centre de Recherche d'Etude et de Documentation en Economie de la Santé),

Presentation:

The studied instrument contains five questions in paragraph 52 (questionnaire on disabilities in household) of the French Health and Medical Care Interview Survey. The questions have three or four response categories (Hupkens, 1998).

Reference wording (original and translated versions):

1. Quelle est la plus longue distance que vous pouvez parcourir en marchant seul(e), sans vous arrêter et sans être gravement incommodé(e) ? *What is the furthest distance you can walk on your own without stopping and without severe discomfort ?*

     - Quelques pas seulement *Only a few steps*

     - Plus de quelques pas, mais moins de 200 mètres *More than a few steps, but less than 200 metres*

     - 200 mètres ou plus *200 metres or more*

2. Pouvez-vous monter et descendre un étage d'escalier d'une traite ? *Can you walk up and down one flight of stairs without resting ?* - Oui, sans difficulté *Yes, without difficulty*

     - Oui, sans trop de difficulté *Yes, without too many difficulties*

     - Oui, mais avec beaucoup de difficulté *Yes, but with a lot of difficulties*

     - Non *No*

3. Pouvez-vous, quand vous êtes debout, vous courber pour ramasser un objet tombé par terre ? *Can you (when standing) , bend down and pick up an object from the floor ?*

     - Oui, sans difficulté *Yes, without difficulty*

     - Oui, sans trop de difficulté *Yes, without too many difficulties*

     - Oui, mais avec beaucoup de difficulté *Yes, but with a lot of difficulties*

     - Non *No*

4. Voyez-vous suffisamment bien (avec vos lunettes) pour lire un livre ou un journal ou faire des mots croisés ? *Do you see good enough (with your glasses) to read a book or a newspaper or to make crossword ?*

     - Oui, sans difficulté *Yes, without difficulty*

     - Oui, sans trop de difficulté *Yes, without too many difficulties*

     - Oui, mais avec beaucoup de difficulté *Yes, but with a lot of difficulties*

     - Non *No*

5 Pouvez-vous habituellement suivre une conversation téléphonique ? *Can you habitually follow a phone conversation ?*

     - Oui, sans difficulté *Yes, without difficulty*

     - Oui, sans trop de difficulté *Yes, without too many difficulties*

     - Oui, mais avec beaucoup de difficulté *Yes, but with a lot of difficulties*

     - Non *No*

Data collection: Face to face questionnaire.

Target population (if any): All respondents aged 65 years or more living in ordinary households

Wording: What is the furthest / Can you / Do you ...

Level of severity: Degree of difficulty (without, without too many, but with a lot of, no) except in question 1.

Duration: No reference to duration.

Use of assistance: The use of special aids is only specified in question 4.

Limits and justification for non selection:

The French Health and Medical Care Interview Survey Instrument uses several OECD recommendations, reference for questions 2, 3, and 4 (McWhinnie, 1981). Question 4 mixes functional limitations and actual performances. Many categories of functional limitations are not covered by this instrument. The wording is likely to lead to lack of precision (e.g., no reference to hearing aid in question 5).

References:

Hupkens C (1998) *Coverage of health topics by surveys in the European Union.* University of Maastricht. Dept of Medical Sociology and Statistics Netherlands. (Eurostat Working Papers)

McWhinnie J.R. (1981) Disability assessment in population surveys : Results of the OECD Common development effort. *Revue d'Epidémiologie et de Santé Publique* 29:413-419.

8. German Health Interview Survey, 1997
(RKI = Robert Koch Institut)

Presentation:

The studied instrument is made of one question introducing seven items: question 23 in section "General Health Status" of German Health Interview Survey. The questions have three response categories (Hupkens, 1998).

Reference wording (original and translated versions):

Im folgenden sind einige Tätigkeiten beschrieben, die Sie vielleicht an einem normalen Tag ausüben. Sind sie durch Ihren derzeitigen Gesundheitszustand bei diesen Tätigkeiten eingeschränkt? Wenn ja, wie stark?

The following passage is about activities you might do during a typical day. Are you limited in the performance of these activities by your current health condition ? If so, how much ?

a. Einkaufstasche heben oder tragen *Lifting or carrying a shopping bag*
- Ja, stark eingeschränkt *Yes, limited a lot*
- Ja, etwas eingeschränkt *Yes, limited a little*
- Nein, überhaupt nicht eingeschränkt *No, not limited at all*

b. Mehrere Treppenabsätze steigen *Climbing several flight of stairs*
- Ja, stark eingeschränkt *Yes, limited a lot*
- Ja, etwas eingeschränkt *Yes, limited a little*
- Nein, überhaupt nicht eingeschränkt *No, not limited at all*

c. Einen Treppenabsätz steigen *Climbing one flight of stairs*
- Ja, stark eingeschränkt *Yes, limited a lot*
- Ja, etwas eingeschränkt *Yes, limited a little*
- Nein, überhaupt nicht eingeschränkt *No, not limited at all*

d. Sich beugen, knien, bücken *Bending, kneeling, or stooping*
- Ja, stark eingeschränkt *Yes, limited a lot*
- Ja, etwas eingeschränkt *Yes, limited a little*
- Nein, überhaupt nicht eingeschränkt *No, not limited at all*

e. Mehr als 1 Kilometer zu Fußgehen *Walking more than one kilometre*
- Ja, stark eingeschränkt *Yes, limited a lot*
- Ja, etwas eingeschränkt *Yes, limited a little*
- Nein, überhaupt nicht eingeschränkt *No, not limited at all*

f. Mehrere Straβenkreuzungen weit zu Fuβ gehen *Walking along several crossroads*
- Ja, stark eingeschränkt *Yes, limited a lot*
- Ja, etwas eingeschränkt *Yes, limited a little*
- Nein, überhaupt nicht eingeschränkt *No, not limited at all*

g. Eine Straβenkreuzung weit zu Fuβ gehen *Walking to one crossroads*
- Ja, stark eingeschränkt *Yes, limited a lot*
- Ja, etwas eingeschränkt *Yes, limited a little*
- Nein, überhaupt nicht eingeschränkt *No, not limited at all*

Data collection: Self-administered questionnaire

Target population (if any): Respondents aged between 18 and 80 years.

Wording: Are you limited ...

Level of severity: Degree of limitation (a lot, a little, not at all).

Duration: No reference to duration.

Use of assistance: No reference to assistance.

Limits and justification for non selection:

This instrument is the close to the "Physical functioning" in the SF-36 instrument (Ware and Sherbourne., 1992). Therefore, it has the qualities and shortcomings of SF-36: several types of functional limitations are not covered (mostly sensory), items explained in term of performance rather than capacity, no reference to assistance

References:

Hupkens C (1998) *Coverage of health topics by surveys in the European Union.* University of Maastricht. Dept of Medical Sociology and Statistics Netherlands. (Eurostat Working Papers)

Ware JE, Sherbourne CD (1992) The MOS 36-Item Short-Form Health Survey (SF 36): I. Conceptual Framework and Item Selection. *Medical Care* 30 (6):473-483.

9. Italian Survey on health conditions and recourse to health services, 1994.

(ISTAT = Instituto Nazionale di Statistica)

Presentation:

The studied instrument is made of eight questions (part II of the family questionnaire of the Survey on health conditions and recourse to health services). Some questions are screened by a previous one (Hupkens, 1998).

Reference wording (original and translated versions):

1. Qual è la distanza più lunga che può percorrere camminando da solo senza fermarsi e senza stancarsi troppo ? *What is the furthest can he/she walk on his/her own, without stopping and without getting too much tired ?*

    - 200 metri o più *200 metres or more*

    - più di qualche passo ma meno di 200 metri *more than a few steps, but less than 200 metres*

    - qualche passo soltanto *only a few steps*

2. Può scendere o salire da solo una rampa di scale senza fermarsi ? *Can he/she walk up and down a flight of stairs on his/her own without stopping ?*

    - Si, senza difficoltà *Yes, without difficulty*

    - Si, con qualche difficoltà *Yes, with some difficulty*

    - Si, con molta difficoltà *Yes, with great difficulty*

    - No, non è in grado *No, he/she is not able to do this*

3. Quando sta in piedi è in grado di chinarsi per raccogliere una scarpa da terra ? *Can he/she when standing bend down and pick up a shoe from the floor ?*

    - Si, senza difficoltà *Yes, without difficulty*

    - Si, con qualche difficoltà *Yes, with some difficulty*

    - Si, con molta difficoltà *Yes, with great difficulty*

    - No, non è in grado *No, he/she is not able to do this*

4. Sente abbastanza per seguire una trasmissione televisiva ad un volume che non disturbi gli altri considerando l'uso eventuale di apparecchi acustici ? *Does he/she hear good enough to follow a TV programme at a volume that does not disturb others (take into account a hearing aid if normally used)*

    - Si *Yes*

    - No *No*

        Se NO, riesce a seguire una trasmissione televisiva alzando il volume ? *If no, can he/she follow a TV programme with volume turned up*

        - Si *Yes*

        - No *No*

5. Vede abbastanza da riconoscere un amico a 4 metri di distanza (dall'altro lato della strada) considerando l'uso eventuale di occhiali o lenti a contatto ? *Does he/she see good enough to recognise a friend at a distance of 4 metres (across a street) (take into account glasses or contact lenses if normally used)*

    - Si *Yes*

    - No *No*

        Se NO, vede abbastanza da riconoscere un amico a 1 metro di distanza (alla distanza di un braccio) ? *If no, does he/she see good enough to recognise a friend at a distance of one metre (at arm's length) ?*

        - Si *Yes*

        - No *No*

6. Riesce a parlare senza difficoltà ? *Can you speak without difficulty ?*

    - Si, senza difficoltà *Yes, without difficulty*

    - Si, con qualche difficoltà *Yes, with some difficulty*

    - Si, con molta difficoltà *Yes, with great difficulty*

    - No, non è in grado *No, he/she is not able to do this*

Data collection: Face to face questionnaire.

Target population (if any): Respondents and family members aged 6 years or more living in ordinary households

Wording: What is the furthest he/she can / Can he/she / Does he/she ...

Level of severity: Varying according to questions.

Duration: No reference to duration.

Use of assistance: The use of assistance is specified in questions 1, 2, 4, and 5.

Limits and justification for non selection:

This instrument uses a combination of OECD (questions 2, 3, and 6) and WHO-Europe modified recommendations (questions 1, 4, and 5) (McWhinnie, 1981; de Bruin et al., 1996). Several questions mix functional limitations and actual performances. Some categories of functional limitations are not covered (e.g., strength). No reference to walking aids in question 1.

References:

de Bruin A, Picavet HSJ, Nossikov A (1996) *Health interview surveys: Towards international harmonization of methods and instruments*. Copenhagen: World Health Organisation. Regional Office for Europe. Voorburg: Statistics Netherlands. (WHO Regional Publications. European Series n°58). 53-60.

Hupkens C (1998) *Coverage of health topics by surveys in the European Union*. University of Maastricht. Dept of Medical Sociology and Statistics Netherlands. (Eurostat Working Papers)

McWhinnie JR (1981) Disability assessment in population surveys : Results of the OECD Common development effort. *Revue d'Epidémiologie et de Santé Publique* 29:413-419.

10. Norwegian Health Interview Survey, 1995.

(Statistik sentralbyr**åå**)

Presentation:

The instrument is made of seven questions from section "Vision and Hearing (five first items) and from section "disability" from the Norwegian health interview survey (Hupkens, 1998).

Reference wording (original and translated versions):

1 Kan du uten vansker, eventuelt med bruk av briller, se vanlig teskt i aviser ? *Can you without difficulty, or wearing glasses if need be, see ordinary sized newsprint ?*

         - Ja *Yes*   - Nei *No*

2 Kan du se godt nok, eventuelt med bruk av briller, til å gjenkjenne en venn på fire meters avstand ? *Can you see well enough, wearing glasses if need be, to recognise a friend at a distance of 4 metres ?*

         - Ja *Yes*   - Nei *No*

3 Kan du uten vansker, eventuelt med bruk av høreapparat, høre hva som blir sagt i en normal samtale med minst to andre ? *Can you without difficulty, or wearing a hearing aid if need be, hear what is said during the course of a normal conversation with at least two other people ?*

         - Ja *Yes*   - Nei *No*

4 Er hørselen din god nok, eventuelt med bruk av høreapparat, til å følge et TV-program på et lydnivå andre synes er akseptabelt ? *Is your hearing good enough, wearing a hearing aid if need be, to follow along with a TV programme with the sound at a level others find acceptable ?*

         - Ja *Yes*   - Nei *No*

5 Kan du følge et TV-program hvis lyden er skrudd høyere opp ? *Can you follow along with a TV programme if the sound is louder ?*

         - Ja *Yes*   - Nei *No*

6 Kan du gå i trapper opp og ned en etasje uten å hvile ? *Can you walk up or down one flight of stairs without resting ?*

         - Ja *Yes*   - Nei *No*

7 Hva er det lengste du kan gå uten hjelp av andre, uten å stoppe og uten vansker ? På vei og på tørt føre *What is the furthest you can walk without help from others, without stopping and without difficulty ? On a road in dry weather*

         - Bare noen steg *Just a few steps*

         - Mer enn noen få steg, men mindre enn 200 meter *more than a few steps, but less than 200 metres*

         - 200 meter eller mer *200 metres or more*

Data collection: Face to face questionnaire.

Target population (if any): All respondents linving in ordinary households

Wording: What is the furthest you can / Can you / Is your hearing good enough to ...

Level of severity: Varying according to items.

Duration: No reference to duration.

Use of assistance: The use of assistance is specified in questions 1, 2, 3, 4.

Limits and justification for non selection:

This instrument uses a combination of OECD (questions 1 and 3) and WHO-Europe modified recommendations (questions 2, 4, 5, 6, and 7) (McWhinnie, 1981; de Bruin et al., 1996). Several questions mix functional limitations and actual performances. Categories of functional limitations are not covered (mostly agility). No reference to walking aids in question 7.

References:

de Bruin A, Picavet HSJ, Nossikov A (1996) *Health interview surveys: Towards international harmonization of methods and instruments*. Copenhagen: World Health Organisation. Regional Office for Europe. Voorburg: Statistics Netherlands. (WHO Regional Publications. European Series n°58). 53-60.

Hupkens C (1998) *Coverage of health topics by surveys in the European Union*. University of Maastricht. Dept of Medical Sociology and Statistics Netherlands. (Eurostat Working Papers)

McWhinnie JR (1981) Disability assessment in population surveys : Results of the OECD Common development effort. *Revue d'Epidémiologie et de Santé Publique* 29:413-419.

11. Portuguese Health Interview Survey, 1995/96.

(Ministério da Saúde)

Presentation: The studied instrument is made of six questions in the paragraph on long-term disabilities of the Portuguese health interview survey (Hupkens, 1998).

Reference wording (original and translated versions):

1 Que distância consegue andar, em sítio plano, sem parar e sem grande desconforto ? *How far are you able to walk on the flat without major discomfort ?*

- 200 metros ou mais *200 metres or more*

- mais que uns passos, mas menos do que 200 metros *more than a few steps, but less than 200 metres*

- apenas uns poucos passos *only a few steps*

- não consegue andar, mas desloca-se sozinho em cadeira de rodas *cannot walk, but can move to wheelchair by myself*

- não consegue andar *cannot walk*

2 Consegue subir e descer um lanço de escadas de 12 degraus (um 1° andar) ? *Are you able to go up and down a flight of 12 stairs (i.e. one floor) ?*

- sem descansar *yes, without stopping to rest*

- parando para descansar *yes, if I stop to rest*

- não consegue mesmo parando para descansar *no, not even if I stop to rest*

3 Quando está em pé, consegue apanhar, por exemplo, um sapato do chão ? *When standing, can you pick up an object (such as a shoe) from the floor ?*

- sozinho, sem dificuldade *yes, without help and without difficulty*

- sozinho, mas com dificuldade *yes, without help, but with difficulty*

- só com ajuda *only with help*

4 Consegue ouvir um programa de tv ou de rádio ? (sem ou com aparelho auditivo) *Are you able to listen to a tv or radio programme (with or without a hearing aid) ?*

- num volume que náo incomode as outras pessoas *yes, at a volume which does not disturb others*

- só com o volume alto *yes, but only at high volume*

- não consegue ouvir mesmo com volume alto *no, not even at high volume*

5 Consegue ver de forma a reconhecer um amigo ? (sem ou com óculos ou lentes de contacto) *Can you see well enough to recognise a friend (with or without spectacles or contact lenses) ?*

- a uma distância de 4 metros, digamos, do outro lado da rua *yes, at a distance of 4 metres (e.g. across the street)*

- a uma distância de 1 metro *yes, at a distance of one metre*

- não consegue mesmo à distância de 1 metro *no, not even at one metre*

6 Tem dificuldades a falar ? *Do you have difficulty in speaking ?*

- sim *yes*

- não *no*

Data collection: Face to face questionnaire.

Target population (if any): All persons aged 10 or more, living in ordinary households

Wording: How far are you able to / Can you / Are you able to ...

Level of severity: Varying according to questions.

Duration: No reference to duration .

Use of assistance: The use of assistance is specified in the response categories (items 1 and 3) or in the wording of questions (questions 4 and 5).

Limits and justification for non selection:

This instrument is the close to WHO-Euro recommendations (de Bruin et al., 1996). On particular questions, survey instrument seems to improve the wording of the WHO-Euro recommendations. Nevertheless, several questions mix functional and actual performances (question 5 for instance). Many categories of functional limitations are not covered by this instrument (e.g., strength). No reference to walking aid in the question 1).

References:

de Bruin A, Picavet HSJ, Nossikov A (1996) *Health interview surveys: Towards international harmonization of methods and instruments*. Copenhagen: World Health Organisation. Regional Office for Europe. Voorburg: Statistics Netherlands. (WHO Regional Publications. European Series n°58). 53-60.

Hupkens C. (1998*) Coverage of health topics by surveys in the European Union*. University of Maastricht. Dept of Medical Sociology and Statistics Netherlands. (Eurostat Working Papers)

12. Spanish Health Interview Survey, 1995

(Ministerio de Sanidad y Consumo)

Presentation:

The studied instrument is made of three items and five questions. (Hupkens, 1998).

Reference wording (original and translated versions):

1. ¿ Oye Vd. un programa de televisión a un volumen que otros consideran aceptable ? *Can you hear a television programme at a volume which other people consider acceptable ?*

    - Si *Yes (go to 36)*

    - No *No (go to 35a)*

        P.35a ¿ Puede oirlo al aumentar el volumen ? *Can you hear it if the volume is turned up ?*

          - Si *Yes*

          - No *No*

2. ¿ Ve Vd. suficientemente bien como para (con gafas o sin gafas o lentillas) reconocer a un amigo a una distancia de cuatro metros (al otro lado de la calle) ? *Do you see well enough to recognise (with or without glasses or contact lenses) a friend at a distance of four metres (on the other side of the street) ?*

    - Si *Yes (go to 37)*

    - No *No (go to 36a)*

        P.36a ¿ Puede Vd. reconercelo a una distancia de un metro ? *Can you recognise him or her at a distance of one metre ?*

          - Si *Yes*

          -No *No*

3. ¿ Cuanto puede Vd. caminar sin pararse y sin ninguna molestia ? *How far can you walk without stopping and without any discomfort ?*

    - No puede caminar solo/a *cannot walk unaided*

    - Sólo unos pocos pasos *only a few steps*

    - Más de unos pasos, pero menos de 200 metros *more than a few steps but less than 200 metres*

    - 200 metros o más *200 metres or more*

Data collection: Face to face questionnaire.

Target population (if any): All respondents

Wording: How far can you / Can you / Do you ...

Level of severity: Varying according to the items.

Duration: No reference to duration.

Use of assistance: Specified in the response categories (item 3) or in the wording of questions (item 2).

Limits and justification for non selection:

This instrument uses the WHO-Europe recommendations as reference (de Bruin et al., 1996). Item 2 mixes functional limitations and actual performances. Some categories of functional limitations are not covered (mostly agility). No reference to walking aids in item 3; wording in term of performance rather than capacity in item 1.

References:

de Bruin A, Picavet HSJ, Nossikov A (1996) *Health interview surveys: Towards international harmonization of methods and instruments*. Copenhagen: World Health Organisation. Regional Office for Europe. Voorburg: Statistics Netherlands. (WHO Regional Publications. European Series n°58). 53-60.

Hupkens C (1998) *Coverage of health topics by surveys in the European Union*. University of Maastricht. Dept of Medical Sociology and Statistics Netherlands. (Eurostat Working Papers)

13. Swedish Living Conditions Interview Survey, 1995.

(SCB Statistiska Centralbyrån)

Presentation:

The studied instrument is made of four questions with two response categories (Hupkens, 1998).

Reference wording (original and translated versions):

1. Kan Du utan svårighet höra vad som sägs i samtal mellan flera personer (med eller utan hörapparat)? *Can you hear what is said without difficulty in a conversation between several persons (with or without a hearing aid)?*
> - Ja *Yes*
> - Nej *No*

2. Kan Du utan svårighet läsa vanlig text i dagstidning (med eller utan glasögon)? *Can you read ordinary text in a newspaper without difficulty (with or without spectacles)?*
> - Ja *Yes*
> - Nej *No*

3. Kan Du gå i trappor utan besvär? *Can you climb stairs without difficulty?*
> - Ja *Yes*
> - Nej *No*

4. Kan Du ta en kortare promenad på säg 5 minuter i någorlunda rask takt? *Can you take a short walk, say five minutes, at a fairly brisk pace ?*
> - Ja *Yes*
> - Nej *No*

Data collection: Face to face questionnaire.

Target population (if any): All respondents.

Wording: Can you ...

Level of severity: Degree of ability (yes / no).

Duration: No reference to duration.

Use of assistance: The use of special aids is specified in questions 1 and 2.

Limits and justification for non selection:

This instrument uses the OECD recommendations as reference for questions 1 and 2 (McWhinnie, 1981). Several questions mix functional and actual performances (question 2 for instance). Several categories of functional limitations are not covered (mostly agility), no reference to walking aids in question 4.

References:

Hupkens C (1998) *Coverage of health topics by surveys in the European Union*. University of Maastricht. Dept of Medical Sociology and Statistics Netherlands. (Eurostat Working Papers)

McWhinnie JR (1981) Disability assessment in population surveys : Results of the OECD Common development effort. *Revue d'Epidémiologie et de Santé Publique* 29:413-419.

14. Swiss Health Telephone Interview Survey, 1997.

(Bundesamt für Statistik)

Presentation: The studied instrument is made of four questions with four response categories for three of them and two response categories for question 3 (Hupkens, 1998).

Reference wording (original and translated versions):

1 Voyez-vous suffisamment bien pour lire un livre ou un journal ? Avec des lunettes, respectivement des lentilles de contact si vous en portez d'habitude. *Do you see good enough to read a book or a newspaper ? With glasses or contact lenses if you usually wear it.*

- oui, sans difficulté *yes, without difficulty*

- oui, sans trop de difficulté *yes, without too many difficulties*

- oui, mais avec beaucoup de difficulté *yes, but with a lot of difficulties*

- non *no*

2 Pouvez-vous suivre une conversation à laquelle participent au moins deux autres personnes ? (avec un appareil auditif) *Can you follow a conversation with at least two other persons ?*

- oui, sans difficulté *yes, without difficulty*

- oui, sans trop de difficulté *yes, without too many difficulties*

- oui, mais avec beaucoup de difficulté *yes, but with a lot of difficulties*

- non *no*

3 Pouvez-vous parler sans difficulté ? *Can you speak without difficulty ?*

- oui, *yes*

- non, *no*

4 Sur quelle distance pouvez-vous marcher seul (e) (sans aide), sans vous arrêter et sans être fortement incommodé (e) ? *Which distance can you walk on your own (without help), without stopping and without severe discomfort ?*

- 200 mètres ou plus *200 metres or more*

- plus de quelques pas, mais moins de 200 mètres *more than a few steps, but less than 200 metres*

- seulement quelques pas *only a few steps*

- ne peut pas me déplacer *I cannot walk*

Data collection: Telephone interview

Target population (if any): All respondents aged between 15 and 74 years living in ordinary households

Wording: can you walk / Can you / Do you ...

Level of severity: Varying according to questions.

Duration: No reference to duration.

Use of assistance: The use of assistance from persons or devices is specified in questions 1, 2, and 4.

Limits and justification for non selection:

This instrument uses the OECD recommendations (questions 1 and 2) and the WHO-Europe recommendations (questions 3 and 4) as references (McWhinnie, 1981, de Bruin et al., 1996). Several questions mix functional limitations and actual performances (question 1 for instance). Several categories of functional limitations are not covered (mostly agility), no reference to walking aids in the question 4.

References:

de Bruin A, Picavet HSJ, Nossikov A (1996) *Health interview surveys: Towards international harmonization of methods and instruments*. Copenhagen: World Health Organisation. Regional Office for Europe. Voorburg: Statistics Netherlands. (WHO Regional Publications. European Series n°58). 53-60.

Hupkens C. (1998) *Coverage of health topics by surveys in the European Union*. University of Maastricht. Dept of Medical Sociology and Statistics Netherlands. (Eurostat Working Papers)

McWhinnie JR (1981) Disability assessment in population surveys : Results of the OECD Common development effort. *Revue d'Epidémiologie et de Santé Publique* 29:413-419.

2- Charts on Difficulty in daily living beyond age 65

1. Belgian Health Interview Survey, 1997

Presentation:

Set of questions related to the Activities of Daily living, part of a more general scale measuring Long term physical disability (Incapacité physique de longue durée) with other items from WHO recommendations. ADL-indicator based on WHO/CBS recommendation with slight modifications in the wording of some questions (feeding, transfer, toilets): "can you... without help" instead of "can you... on your own", or answer item "always need someone's help" instead of "only with someone to help"

Reference wording (questions) :

IL.15　Pouvez-vous vous lever et vous coucher sans aide? Can you get up and lie down without help ?
　　oui, sans difficulté. *Yes, without difficulty*
　　oui, avec une certaine difficulté. *Yes with some difficulties*
　　j'ai toujours besoin de l'aide de quelqu'un pour me lever et me coucher. *I always need someone's help to get up and lie down*

IL.16　Pouvez-vous vous asseoir dans un fauteuil et vous lever sans aide? *Can you sit in an armchair and get up without help*
　　oui, sans difficulté. *Yes, without difficulty*
　　oui, avec une certaine difficulté. *Yes with some difficulties*
　　j'ai toujours besoin de l'aide de quelqu'un pour m'asseoir et me lever d'un fauteuil. *I always need someone's help to sit in an armchair and get up*

IL.17　Pouvez-vous vous habiller et vous déshabiller sans aide? *Can you dress and undress yourself without help*
　　oui, sans difficulté. *Yes, without difficulty*
　　oui, avec une certaine difficulté. *Yes with some difficulties*
　　j'ai toujours besoin de l'aide de quelqu'un pour m'habiller et me déshabiller. *I always need someone's help to dress and undress myself*

IL.18　Pouvez-vous vous laver les mains et le visage sans aide ? *Can you wash your hands and face without help*
　　oui, sans difficulté. *Yes, without difficulty*
　　oui, avec une certaine difficulté. *Yes with some difficulties*
　　j'ai toujours besoin de l'aide de quelqu'un pour me laver les mains et le visage. *I always need someone's help to wash my hands and face*

IL.19　Pouvez-vous manger sans aide et couper votre nourriture? *Can you eat without help and cut your food*
　　oui, sans difficulté. *Yes, without difficulty*
　　oui, avec une certaine difficulté. *Yes with some difficulties*
　　j'ai toujours besoin de l'aide de quelqu'un pour manger et couper la nourriture. *I always need someone's help to eat and cut food*

IL.20　Pouvez-vous aller aux toilettes sans aide? *Can you go to the toilets without help*
　　oui, sans difficulté. *Yes, without difficulty*
　　oui, avec une certaine difficulté. *Yes with some difficulties*
　　j'ai toujours besoin de l'aide de quelqu'un pour aller aux toilettes. *I always need someone's help to go to the toilet*

Data collection: Health interview survey based face to face questionnaire/on private households/nursing homes and homes for elderly

ADL target population (if any) : Respondents over age 60 and over age 15 but screened by a prior question on functional limitations. Proxy respondent is allowed.

Wording: can you... without help

Level of severity: degree of difficulty (without, with some, needing someone's help)

Duration: no reference to duration

Use of technical assistance: no reference to the possible use of technical assistance

Review analysis:

The Belgian survey is one of the most recent ones. In the field of disability, it follows the recomendations from the WHO-Europe consultation.

Limits and justification for non selection:

It follows WHO-Europe recommendations, the same comments can be made. Especially on the use of abilities rather than performance. Furthermore, the modification in the wording of the questions ("can you.... without help" instead of the recommended "can you.... on your own") can bring some problems of confusion in answers, as shown in literature (see chapter). The notion of "help" may be misunderstood, especially for cognitively

impaired: it may be interpreted as "human" as well as "technical assistance" and it is noteworthy that the help of spouse, children or clos relatives is sometime not acknowledged as being external "help"...

2. Spanish National Health interview survey (Encuesta nacional de salud, 1995)

Presentation:

Set of questions related to the Activities of Daily living, (dificultad para activitad cotidianas); instrument part of other instrument recommended by WHO (functional limitations...); based on WHO-Europe recommendations with modification in the selected activities (shower and bath question added; question on toilets missing); modifications in the structure of the scale (text in an introductory question: to be able to perform these activities without difficulty, with difficulty, only with someone's help, the activities are listed after the introductory question); in questions' wording (feeding); a question on no-answer is added.

Reference wording (questions) :
39   Voy a harcerle unas preguntas sobre algunas actividades cotidianas de cualquier persona y querria saber si es Vd. capaz de realizarlas sin dificultad, con dificultad o si solo puede hacerlo con ayuda: *I am now going to ask you a few questions about certain common daily activities, and I would like to know if you are able to perform them without difficulty, with difficulty or only with help:*

Puede acostarse y levantarse de la cama *can go to and get up from bed*
        sin dificultad *without difficulty*
        con dificultad *with difficulty*
        Solo puedo harcelo con ayuda *can only with help*
        nc
Puede sentarse y levantarse de una silla *can sit down and get up from a chair*
        sin dificultad *without difficulty*
        con dificultad *with difficulty*
        Solo puedo harcelo con ayuda *can only with help*
        nc
Puede vestirse y desnudarse *can get dressed and undressed*
        sin dificultad *without difficulty*
        con dificultad *with difficulty*
        Solo puedo harcelo con ayuda *can only with help*
        nc
Puede lavarse las manos y la cara *can wash hands and face*
        sin dificultad *without difficulty*
        con dificultad *with difficulty*
        Solo puedo harcelo con ayuda *can only with help*
        nc
Puede comer includo cortar la comida *can eat including cut up food*
        sin dificultad *without difficulty*
        con dificultad *with difficulty*
        Solo puedo harcelo con ayuda *can only with help*
        nc
Puedo ducharse o bañarse sola/a *can take a shower or bath alone*
        sin dificultad *without difficulty*
        con dificultad *with difficulty*
        Solo puedo harcelo con ayuda *can only with help*
        nc

Data collection: Face to face questionnaire

Target population (if any): Respondents over age 16.

Wording: can do....

Level of severity: without/with difficulty (without, with, can only with help), an item for no answer

Duration: no direct reference to duration, but is close to other question about long-term disability

Use of technical assistance: no reference to the possible use of technical assistance

Review analysis:

The Spanish survey has developed its own instrument for assessment of both disability and dependence with the recommendations from WHO-Europe. The additional non-response item makes it difficult to interpret when compared with surveys without it.

Nevertheless, this kind of activity restriction indicates a severe level of disability for which responses should be clear and should not lead to no answer. This item might help towards reallocating a part of the usual missing data.

Limits and justification for non selection:

It follows WHO-Europe recommendations, the same comments can be made. Especially on the use of abilities rather than performance.

References:

Ministerio de Sanidad y Consumo. *Encuesta Nacional de Salud de Espana 1995*. Ministerio de Sanidad y Consumo: Madrid, 1996:244

3. Italian survey (Indagine statistica multiscopo sulle famiglie : condizion de salute e ricorso ai servizi sanitari; anno 1994 (ISTAT)

Presentation:

Set of questions related to Activities of Daily living, (difficolta nelle attivita quotidiane) part of a more general set of questions based on the WHO recommendations measuring also functional limitations and mobility restriction; ADL-indicator is based on WHO/CBS recommendations with modification in selected activities (shower and bath question added; question on toilets missing). An introductory text describes what is disability (consequence of...) and questions on the degree of difficulty met by the family components to perform a set of activities (answer on the degree of difficulty to perform activity with the mechanical assistance usually used).

Reference wording (questions) :
Segue Scheda familiare (parte seconda):
Le chiedo ancora un po' di tempo per sottoporle alcuni quesiti che riguardano l'eventuale esistanza di difficultà ad effetuare le activià della vita quotidiena. A volte, infatti, per problemi di salute legati a malattie chroniche o a quelche forma di invalidità, puo accedere che una persona trovi difficolta ad effetuare azioni che fanno parte della vita di tutti i giorni. Facendo riferimento distintamente a ciascun componente familiare, puo indicare l'eventuale grado di difficoltà ad effeture ciascuna delle seguenti attività della vita quotidiena? Se utiliza bastoni, sedie a rotelle, protesi, occhiali o altri apparecchi, consideri il grado de difficultà che incontra in ciascuna attività, pur con l'aiuto degli apparecchi stessi:

9- Puo mettersi a letto e alzarsi dal letto da solo *Can get to bed and get up from a bed alone*
       senza difficolta *without difficulty*
       con qualche difficolta *with some difficulty*
       Puo mettersi a letto e alzarsi dal letto solo con l'aiuto di qualcuno *Can.... only with someone's help*

10- Puo sedersi e alzarsi da una sedia da solo *Can sit and get up from a chair alone?*
       senza difficolta *without difficulty*
       con qualche difficolta *with some difficulty*
       Puo sedersi e alzarsi da una sedia solo con l'aiuto di qualcuno *Can.... only with someone's help*

11- Puede verstirsi e spogliarsi da solo *Can get dressed and undressed alone?*
       senza difficolta *without difficulty*
       con qualche difficolta *with some difficulty*
       Puo farlo solo con l'aiuto di qualcuno *Can do it only with someone's help*

12- Puo farci il banio o la doccia da solo *Can have a bath or a shower alone?*
       senza difficolta *without difficulty*
       con qualche difficolta *with some difficulty*
       Puo farlo solo con l'aiuto di qualcuno *Can do it only with someone's help*

13- Puo lavarsi li mani e il viso da solo *Can wash hands and face alone?*
       senza difficolta *without difficulty*
       con qualche difficolta *with some difficulty*
       Puo farlo solo con l'aiuto di qualcuno *Can do it only with someone's help*

14- Puo mangiare da solo, anche tagliando il cibo da solo *Can eat alone, including cut food alone?*
       senza difficolta *without difficulty*
       con qualche difficolta *with some difficulty*
       Puo farlo solo con l'aiuto di qualcuno *Can do it only with someone's help*

Data collection: Face to face

Target population (if any): All the family members aged over 6

Wording: can...

Level of severity: without difficulty/with some difficulty, can... with someone's help (includes the use of mechanical assistance and only refers to someone's help)

Duration: No reference to duration

Use of technical assistance: Including the possible use of technical assistance

Review analysis:

The Italian survey has developed its own instrument for assessment of both disability and dependence with the recommendations from the WHO-Europe. This scale is preceded by an introductory speech explaining the subsequent questions and referring to technical aids which should be taken into account when reporting about abilities.

Limits and justification for non selection:

As it follows the recommendations, the same limits appear according to what the literature shows in this field, especially about reporting on abilities instead of performances.

4. Portugese national health survey (Inquérito Nacional de Saùde, Q95)

Presentation:

Set of questions related to the Activities of Daily living, (difficolta nelle attivita quotidiane), part of a more general set of questions based on the WHO recommendations measuring also functional limitations and mobility restriction; ADL-indicator is based on the WHO-Europe recommendations with modifications in the structure of the scale (text in an introductory question: are you able to perform these activities? without help, without difficulty, with help, only with someone's help, the activities are listed after the introductory question); in the wording of questions (feeding); an answer item for no-answer is added.

Reference wording (questions) :

4.10 [...] consegue deitar-se e levantar-se da cama? Are you able to get to and get up from bed
    Sozinho, sem difficuldade Without help, without difficulty
    Sozinho, mas com difficuldade Without help, but with difficulty
    So com ajuda, With help
    No sabe, Do not know

4.11 [...] consegue sentar-se e levantar-se da de uma? Are you able to sit and get up from a chair
    Sozinho, sem difficuldade Without help, without difficulty
    Sozinho, mas com difficuldade Without help, but with difficulty
    So com ajuda, With help
    No sabe, Do not know

4.12 [...] consegue ir a retrete e utiliza-la? Are you able to go to the toilets and use it?
    Sozinho, sem difficuldade Without help, without difficulty
    Sozinho, mas com difficuldade Without help, but with difficulty
    So com ajuda, With help
    No sabe, Do not know

4.16 E consegue vestir-se e despir-se? Are you able to get dressed and undressed?
    Sozinho, sem difficuldade Without help, without difficulty
    Sozinho, mas com difficuldade Without help, but with difficulty
    So com ajuda, With help
    No sabe, Do not know

4.19 [...] consegue lavar as mãos e a cara? Are you able to wash your hands and face?
    Sozinho, sem difficuldade Without help, without difficulty
    Sozinho, mas com difficuldade Without help, but with difficulty
    So com ajuda, With help
    No sabe, Do not know

4.20 E consegue comer (cortar a comida, levar os alimentos e bebidas à boca)? Are you able to eat (cut your food and lift it and drinks to your mouth)?
    Sozinho, sem difficuldade Without help, without difficulty
    Sozinho, mas com difficuldade Without help, but with difficulty
    So com ajuda, With help
    No sabe, Do not know

Data collection: Face to face; questions 4.13 and questions 4.14, 4.17 and 4.18 (not shown) ask about the origin of the difficulty if the answer of the previous questions is "with difficulty"; they also ask about the duration of the problem ; question 4.15 asks about a functional limitation item (pick up a shoe from the ground).

Target population (if any): Population over age 10.

Wording: Are you able to... ?

Level of severity: without help, without difficulty/without help, but with difficulty, yes... with help, do not know

Duration: not explicit but is part of a part of the questionnaire on long-term consequences of health problems.

Use of technical assistance: no reference to the possible use of technical assistance.

Review analysis:

The Portuguese survey is one of the most recent ones. In the field of disability, it follows the recomendations from the WHO-Europe consultation. The additional non-response item makes it difficult to interpret when compared with surveys whithout it.

Nevertheless, this kind of activity restrictions indicates a severe level of disability for which responses should be clear and should not lead to no answer. This item might help towards reallocating a part of the usual missing data.

Limits and justification for non selection:

It follows the WHO-Europe recommendations, the same comments can be made. Especially on the use of abilities rather than performances.

5. French survey on health and medical care (Enquête sur la santé et les soins médicaux), 1991-92

Presentation:

Set of questions related to the Activities of Daily Living, part of a more general set of questions on disability partly based on the WHO recommendations measuring also functional limitations and mobility restrictions; the ADL-indicator is based on the WHO/CBS recommendations with modifications in the structure of the scale: items missing (transfer chair); change in the wording (washing); answer items (number and wording)

Reference wording (questions) :

8.3   Pouvez-vous vous coucher ou vous lever du lit seul(e)? *Can you go to or get up from bed alone?*
       oui, sans difficulté. *Yes, without difficulty*
       oui, sans trop de difficulté. *Yes without too much difficulty*
       oui, avec beaucoup de difficulté. *Yes with a lot of difficulty*
       Non, vous ne pouvez pas vous coucher ou vous lever du lit sans aide. *No, you can't go to or get up from bed without help*

8.7   Pouvez-vous vous habiller et vous déshabiller seul(e)? *Can you dress and undress yourself alone?*
       oui, sans difficulté. *Yes, without difficulty*
       oui, sans trop de difficulté. *Yes without too much difficulty*
       oui, avec beaucoup de difficulté. *Yes with a lot of difficulty*
       Non. *No*

8.8   Pouvez-vous faire votre toilette seul(e)? *Can you wash alone?*
       oui, sans difficulté. *Yes, without difficulty*
       oui, sans trop de difficulté. *Yes without too much difficulty*
       oui, avec beaucoup de difficulté. *Yes with a lot of difficulty*
       Non. *No*

8.9   Pouvez-vous vous rendre et utiliser les toilettes seul(e)? *Can you get to and use the toilets alone?*
       oui, sans difficulté. *Yes, without difficulty*
       oui, sans trop de difficulté. *Yes without too much difficulty*
       oui, avec beaucoup de difficulté. *Yes with a lot of difficulty*
       Non. *No*

8.11   Pouvez-vous vous nourrir et couper vos aliments seul(e)? *Can you feed including cutting your food alone*
       oui, sans difficulté. *Yes, without difficulty*
       oui, sans trop de difficulté. *Yes without too much difficulty*
       oui, avec beaucoup de difficulté. *Yes with a lot of difficulty*
       Non. *No*

Data collection: Face to face/ household survey; questions 8.3 only for those who declare not being beddridden; 8.4-8.6 ask about functional limitations and mobility ; question 8.10 asks about a functional limitation item (pick up something from the ground).

Target population (if any): population over age 65 living in ordinary households

Wording: can... alone

Level of severity: without difficulty/without too much difficulty/with a lot of difficulty/no

Duration: explicitly refers to long-term health problem

Use of technical assistance: no reference to the possible use of technical assistance

Review analysis:

The French survey has developed its indicators in accord with the various research done in this field.

Limits and justification for non selection:

As in most surveys, the questions are asked in term of abilities rather than performances. The 4 response categories on the one hand offers the opportunity to work on several severity levels but on the other hand could be confusing for the interpretation of responses, as the divisions between these different levels are unclear. As in most surveys, gains should be obtained by distinguishing the questions on mobility, functional limitations, and activity restrictions.

References:

Robine JM, Romieu I, Cambois E. *Espérances de santé pour la population agée de 65 ans et plus: Application des concepts de la classification internationale des handicaps aux calculs d'espérance de santé: France, début des années 1990 : Rapport final de la convention MIRE*. Laboratoire d'Epidémiologie et d'Economie de la Santé, Montpellier, 1995.

Robine JM, Romieu I, Cambois E. Espérances de santé pour la population âgées de 65 ans et plus. *Mire Info* 1996;(35):14-18.

6. English General Household Survey, 1996

Presentation: Set of questions related to the Activities of Daily Living with some questions on mobility; ADL items are partly compatible with the WHO/CBS recommended items but the wording is a performance wording.

Reference wording (questions) :

If respondent finds stairs difficult, needs help or cannot manage them at all: "Now I'd like to ask you about a few tasks that some people may be able to do on their own, while others may need help, or not do them at all. As I read out each task, I'd like you to look at this card and tell me whether you usually manage to do it on your own, only with help from someone else, or not at all"

4   Do you usually manage to get to the toilet
5   Do you usually manage to get in and out of bed
6   Do you usually manage to dress and undress yourself
7   Do you usually manage to feed yourself
-                  on your own
-                  only with help from someone else
-                  or not at all?

All adults aged 65 and over
8   Do you usually manage to bath, shower or wash all over ...
-                  on your own
-                  only with help from someone else
-                  or not at all?

If manages without help
9   Do you find it ...   very easy
                             fairly easy
                             fairly difficult or
                             very difficult to do this on your own?

If respondent finds bathing difficult, needs help or cannot manage at all
10 Do you usually manage to wash your face and hands ...
-                  on your own
-                  only with help from someone else

Data collection: Face to face

Target population (if any): 65 and over having difficulties with stairs

Wording: Do you usually manage to....

Level of severity: on your own/only with help/not at all

Duration: no reference to duration

Use of technical assistance: no reference to the possible use of technical assistance

Review analysis:

The English survey has developed its indicators according to the various research work in the field. In this scale, some questions are screened by functional limitations questions. The question on Bathing/showering" is asked to all the 65 years old and over. As seen in the literature the "bathing/showering" item targets a population with a moderate level of disability compared to the other ADL. This two step indicator can lead to interesting analyses in term of various levels of disability.

Limits and justification for non selection:

This scale construct is a little complex in the prospect of proposing a module to include in health or social surveys. It is also less close to the WHO-Europe recommendations in this form. Questions are asked in term of abilities but using the word "usually", making it more an inquiry about actual competences in daily life. The response category "not at all" is problematic when looking at such essential activities; inquiring about degrees of difficulty of performing and only performing with help or assistance, as in the WHO-Europe recommendations seems more accurate in this field.

7. Norwegian Health Interview Survey – Helseundersokelsen, 1995

Presentation:

Set of questions related to the Activities of Daily Living with some questions on functional limitations and mobility and questions on IADL; ADL items are partly compatible with the WHO/CBS recommended items.

Reference wording (questions) :

The following questions apply to more long-term problems, in other words, they do not apply to any temporary problems you may be experiencing at the moment. THE TERM LONG-TERM REFERS TO A PROBLEM THAT HAS LASTED OR IS EXPECTED TO LAST AT LEAST SIX MONTHS.

IF YOU ANSWERED 200 METRES OR MORE TO QUESTION 24, GO TO QUESTION 27. OTHERS MAY GO TO QUESTION 25.

25.   Can you sit down in and get up from a chair without help from others?
1   with no difficulty
2   with some difficulty
3   only with the help of others

26.   Can you get into and out of a bed without help from others?
1   with no difficulty
2   with some difficulty
3   only with the help of others

PEOPLE WHO HAVE RESPONDED YES TO QUESTIONS 27 AND 28, GO TO 32.

29.   Can you dress and undress yourself?
1   with no difficulty
2   with some difficulty
3   only with the help of others

30.   Can you manage to attend to your own personal hygiene?
1   with no difficulty
2   with some difficulty
3   only with the help of others

WHERE WITH NO DIFFICULTY WAS THE RESPONSE TO 29 AND 30, GO TO 32. WHERE THE RESPONDENT HAD LONG-TERM ILLNESSES IN QUESTIONS 11 - 13. OTHERS (I.E. THOSE WITHOUT LONG-TERM ILLNESSES) MAY GO TO QUESTION 39.

31.   Can you eat by yourself, including cutting up your food?
1   with no difficulty
2   with some difficulty
3   only with the help of others

Data collection: Face to face

Target population (if any): those screened according to answers given to previous questions

Wording: can you... without help from others

Level of severity: with no difficulty/with some difficulty/only with help of others

Duration: Explicit reference to problems that have lasted or are expected to last at least 6 months

Use of technical assistance: no reference to the possible use of technical assistance

Review analysis:

The Norwegian survey uses an indicator for activity restriction close to the WHO-Europe recommendation. It is based on a succession of screening tests to go through the different activities of the scale.

Limits and justification for non selection:

This scale construct is a little complex in the prospect of proposing a module to include in health or social surveys. The wording and answer categories have the same limitations as those raised with the WHO-recommended instrument (abilities/performance). The questions ask about abilities to do the activity "by yourself" or "without the help of others", which is a positive point, as this seems precise enough to avoid the confusion of the usually used "without help".

8. Finnish health survey - Terveystutkimus 1993, CATI-Tutkimuslomake

Presentation:

Set of questions related to the Activities of Daily Living among other questions on functional limitations, mobility and IADL restrictions; only some of the recommended ADL items are included. The questions are organised in two steps : having difficulty or not / needing help or not.

Reference wording (questions) :

117.   Onko Teillä vaikeuksia WC:n käyttämissessä? *Do you have difficulty using the toilet?*
Kyllä, Ei *Yes, No*
Ei osaa sanoa *Don't know/No answer*

118.   Tarvitsetteko siinä apua? *Do you need help?*
Kyllä, Ei *Yes, No*
Ei osaa sanoa *Don't know/No answer*

119.   Onko Teillä vaikeuksia peseytymisessä tai kylpemisessä? *Do you have difficulty washing yourself or bathing?*
Kyllä, Ei *Yes, No*
Ei osaa sanoa *Don't know/No answer*

120.   Tarvitsetteko siinä apua? *Do you need help ?*
Kyllä, Ei *Yes, No*
Ei osaa sanoa *Don't know/No answer*

121.   Onko Teillä vaikeuksia pukeutumisessa tai riisuuntumisessa? *Do you have difficulty dressing or undressing?*
Kyllä, Ei *Yes, No*
Ei osaa sanoa *Don't know/No answer*

122.   Tarvitsetteko siinä apua(pukeutumisessa tai riisuuntumisessa)? *Do you need help (dressing or undressing)?*
Kyllä, Ei *Yes, No*
Ei osaa sanoa *Don't know/No answer*

123.   Onko Teillä vaikeuksia vuoteeseen asettumisessa tai nousemisessa? *Do you have difficulty getting into or out of bed?*
Kyllä, Ei *Yes, No*
Ei osaa sanoa *Don't know/No answer*

124.   Tarvitsetteko siinä apua (vuoteeseen asettumisessa tai nousemisessa)? *Do you need help (getting into or out of bed)?*
Kyllä, Ei *Yes, No*
Ei osaa sanoa *Don't know/No answer*

Data collection: Telephone interview

Target population (if any): 60-69 years

Wording: do you have difficulty / do you need help

Level of severity: having or not difficulties in performing / needing or not help to perform

Duration: no direct reference to duration in the questions related to ADL restrictions. Some introductory questions enquire about general disability and restrictions of activity compared with other people of the same age, and then enquire about possible changes in capacity over the last six mounths.

Use of technical assistance: no reference to the possible use of technical assistance

Review analysis:

The Finish survey uses an indicator based on the items of Katz's scale. It is based on difficulty or not in the performance more than on the need or not for help. It uses yes/no response categories with a non-response item. Such a two-step evaluation of the nature of the activity restriction is interesting especially for a module which could be long or short.

Limits and justification for non selection:

The answer categories of this indicator are limited if one wants to look at different degrees of severity or difficulty. The two-step approach could be enhanced by inquiring about the difficulty met by the respondent for performing the activity "on his own" (with response categories "no difficulty" "some/great difficulty" or "not performing alone"), followed by the assessment of the met/unmet need for help according to the level of difficulty.

3- Charts on Global Disability Indicator

1. Austria: Living conditions of persons aged 60 years or more (June 1998)

Presentation :

Reference wording (questions) or standardised examination (conditions)

Original language

Frage 1:

Können Sie folgende Tätigkeiten normalerweise jeweils ohne Hilfe anderer Personen (unter Umständen mit Benützung eines Hilfsmittels) – nur mit Hilfe anderer Personen – oder überhaupt nicht (mehr) ausüben:

> *Aufstehen, Zubettgehen*
> *sich waschen, anziehen*
> *Essen, Trinken*
> *in der Wohnung gehen*
> *Stiegen steigen*
> *leichte Hausarbeit*
> *schwerere Hausarbeit*
> *Einkaufen*
> *Ausgehen, Besuche machen?*

English translation

Question 1:

Are you able to carry out the following activities without help of other persons (auxiliary material like wheel chair possible) – only with help of other persons – not at all:

> *Getting in and out of bed*
> *washing, dressing oneself*
> *eating, drinking*
> *moving within the flat, house*
> *climbing up stairs*
> *(physically) easier housework (f.e. sweeping)*
> *(physically) harder housework (f.e. cleaning windows)*
> *shopping*
> *going out, making visits.*

Review:

Number of questions : 1

Longstanding limitations : not considered

Health related problems : not considered

Usual activities : not considered

Range of severity : 3 categories

No preceding screener : yes

All ages : no specific age groups specified

Causes included : not considered

Use of assistance : personal assistance, no devices

Activity description : specific activities are proposed

Reference:

B. Wiederhofer (1998) Soziale Fragen: Senioren: Unterstützung durch Angehörige, Freunde, Soziale Dienste. Ergebnisse des Mikrozensus-Sonderprogramms

2. Belgium: Health Interview Survey, 1997

Presentation:
Reference wording (questions) or standardised examination (conditions)

Original language
Vraag 1:
Hebt u last van één of meerdere langdurige ziekten, aandoeningen of handicaps ? Ja, Nee → naar vraag X

Vraag 2: Indien ja
Van welke langdurige ziekte(n), aandoening(en) of handicap(s) hebt u last ? ….

Vraag 3:
Bent u vanwege deze ziekte(n), aandoening(en) of handicap(s) belemmerd in uw dagelijkse bezigheden? Voortdurend, Af en toe, Niet of zelden

Vraag 4:
Bent u als gevolg van deze ziekte(n), aandoening(en) of handicap(s) bedlegerig? Voortdurend, Af en toe, Niet of zelden

English translation
Question 1:
Do you suffer from one or more longstanding illnesses, chronic conditions or handicaps ? Yes, No → go to question X

Question 2:
From which longstanding illness(es), chronic condition(s) or handicap(s) do you suffer?

Question 3:
Are you restricted in you daily activities due to this (these) illness(es), chronic condition(s) or handicaps? Continually, At intervals, Not or seldom

Question 4:
Are you bedridden due to this (these) illness(es), chronic condition(s) or handicaps? Continually, At intervals, Not or seldom

Review :

Number of questions : 4

Longstanding limitations : not considered, reference is made to longstanding illness, conditions or handicap

Health related problems : specified in broad domains

Usual activities : daily activities, not specified

Range of severity : more than 3 categories of severity can be defined

No preceding screener : no, there is a selection for people with longstanding illness, conditions or handicap

All ages : no specific age groups specified

Causes included : there is an open question

Use of assistance : not considered

Activity description : not considered

Reference:

H. Van Oyen, Scientific Institute of Public Health (1997) *Belgian Health Interview Survey*. Bruxelles: SIPH

3. Canada: National Population Health Survey (NPHS), restriction of activities part

Presentation:
Reference wording (questions) or standardised examination (conditions)
Original language (a French version exists): Age => 12

The next few questions deal with any health limitations which affect ... daily activities. In these questions, "long-term conditions" refer to conditions that have lasted or are expected to last 6 months or more.
Question 1:
 Because of a long-term physical or mental condition or a health problem, are/is ... limited in the kind or amount of activity you/he/she can do:
 at home?
 at school?
 at work?
 in other activities such as transportation to or from work or leisure time activities? Yes, No, Not applicable

Comments

Note by L. Verbrugge: The two global items differ slightly from their predecessors in the Census, HALS 1, and HALS2.

With marginal different wordings or with less additional questions this GDI candidate is almost the same as NPHS, 94-95, Canadian Census of Population 1986, Canadian Health and Activitry Limitation Survey 1986-1987, Canadian Health and Activitry Limitation Survey 1991, Global disability items of the National Population Health Survey Canada 1994-1995, The Filter-questions Canadian Health and Activity Limitation Survey 1986 and 1991and the proposed Filter-questions Canadian Health and Activity Limitation Survey 2001.

Note by the authors: the initial indicator question is followed by questions about disabilities and handicaps, causes and personal assistance or assistive devices used.

Review :

Number of questions : 4

Longstanding limitations : not considered, reference is made to longstanding illness, conditions or handicap

Health related problems : specified in broad domains

Usual activities : specified in four life situations

Range of severity : no

No preceding screener :there is no screener

All ages : no specific age groups specified

Causes included : not considered

Use of assistance : not considered

Activity description : not considered

References

Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362

4. Great Britain: General Household Survey for Great Britain (2000)

Presentation :

Reference wording (questions) or standardised examination (conditions)

Original language
Question 1:
Do you have any long-standing illness, diability or infirmity? By long-standing, I mean anything that has troubled you over a period of time or that is likely to affect you over a period of time? Yes, No.

Question 2:
What is the matter with you?

Question 3:
How many longstanding illnesses or infirmities does respondent have?

Question 4:
Does this illness or disability (Do any of these illnesses or disabilities) limit your activities in any way? Yes, No.

Review :

Number of questions : 4

Longstanding limitations : not considered, reference is made to longstanding illness, conditions or handicap

Health related problems : specified in broad domains

Usual activities : not specified: your activities

Range of severity : no, dichotomous

No preceding screener : no, there is a selection for people with longstanding illness, conditions or handicap

All ages : no specific age groups specified

Causes included : not considered

Use of assistance : not considered

Activity description : not considered

5. International: REVES Harmonisation Committee

Presentation :

Reference wording (questions) or standardised examination (conditions)

Original language:

Because of your health, are you usually limited in your daily activities, apart from personal care?
    Fully able to perform any activity (apart from personal care),
    Severely limited in daily activities,
    Slightly limited in daily activities,
    Not limited in daily activities.

Comment

Note by L. Verbrugge: The International Network on Health Expectancy (dubbed REVES) is a collection of researchers engaged in methodological and analytical studies of disability. A committee has worked to develop brief questions about functional domains. Two forms of the proposed question on occupation (role) disability are shown (Chamie 1990).

Review :

Number of questions : 1

Longstanding limitations : not considered

Health related problems : holistic approach, not specified

Usual activities : not specified: daily activities

Range of severity : yes, in four categories

No preceding screener : there is no preceding screener

All ages : no specific age groups specified

Causes included : not considered

Use of assistance : not considered

Activity description : not considered

References

Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

6. International: European Community Health Panel

Presentation :

Reference wording (questions) or standardised examination (conditions)

Original language

Question 1:
    Do you have any chronic physical or mental health problem, illness or disability? Yes, No.
Question 1a: If Yes:
    Are you hampered in your daily activities by this physical or mental health problem, illness or disability? Yes, No.

Comment

Note by L. Verbrugge: A panel study is being conducted in 15 European countries. The global disability item is a followup Q for persons with chronic health problems broadly stated.

Review :

Number of questions : 2

Longstanding limitations : not considered

Health related problems : specified in broad domains

Usual activities : not specified: daily activities

Range of severity : no, dichotomous

No preceding screener : no, there is a selection for people with longstanding illness, conditions or handicap

All ages : no specific age groups specified

Causes included : not considered

Use of assistance : not considered

Activity description : not considered

References

Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

7. The Netherlands: Permanent Onderzoek Leefsituatie (POLS) (first version)

Presentation :

Reference wording (questions) or standardised examination (conditions)

Original language
Belemmeringen Kind (alleen als leeftijd <12 jaar)
   Vraag 1:
   Heeft het kind een langdurige ziekte, aandoening of handicap die hem of haar beperkt bij activiteiten op school, het spelen of andere activiteiten die normaal zijn voor een kind van zijn of haar leeftijd? ja, nee, weigert/weet niet

Leeftijd >12 jaar
   Belemmeringen Thuis
   Vraag 1:
   Bent u, als gevolg van een langdurige ziekte, aandoening of handicap belemmerd bij het uitvoeren van dagelijkse bezigheden thuis? ja, nee, weigert/weetniet

   Belemmeringen Werk (alleen gevraagd indien aantal werkuren >11 of als opleiding _voltijd)
   Vraag 2:
   Bent u, als gevolg van een langdurige ziekte, aandoening of handicap belemmerd bij het uitvoeren van dagelijkse bezigheden op school of op het werk? ja, nee, weigert/weet niet

   Belemmeringen Anders
   Vraag 3:
   Bent u, als gevolg van een langdurige ziekte, aandoening of handicap belemmerd in uw vrijetijdsbesteding, bij het sporten of het reizen? (zoals van en naar werk of school gaan) ja, nee, weigert/weet niet

   Langdurige Aandoeningen
   Vraag 4:
   Heeft u last van één of meer langdurige ziekte(n), aandoening(en) of handicap(s)? ja, nee, weigert niet
   (na het eventueel vermelden van 1-4 langdurige aandoeningen)

   Belemmeringen dagelijkse bezigheden
   Vraag 5:
   Bent u als gevolg van deze ziekte(n), aandoening(en) of handicap(s) belemmerd in de dagelijkse bezigheden?
   Voortdurend, met tussenpozen, niet of zelden, weigert niet

English translation (by RP)

   Limitation children (age <12 only)
   Question 1:
   Has the child one or more longterm disease, disorders or handicaps that limits him or her in activities at school, in playing or other activities, normal for a child of his or her age? Yes/no?

   Limitations at home
   Question 1
   Are you, due to a longterm disease, disorder or handicap limited in your daily activities at home? Yes/no

   Limitations at work (only asked when working hours > 11 per week, or if full-time education)
   Question 2:
   Are you, due to a longterm disease, disorder or handicap limited in your daily activities at work or at school? Yes/no

   Limitations other activities
   Question 3
   Are you, due to a longterm disease, disorder or handicap limited in leisure time activities, in sporting or traveling (to and from work, school?) Yes/no

   Longterm disorders:
   Do you have one or more longterm diseases, disorders or handicaps? Yes/no

   (after mentioning 1 to 4 longterm disorders):
   Limitations daily activities:
   Are you because of this/these disease(s), disorder(s) or handicap(s) limited in your daily activities? always, sometimes, (almost) never

Review :

Number of questions : 5 (to estimate acivity limitations)

Longstanding limitations : not considered, reference is made to longstanding illness, conditions or handicap

Health related problems : specified in broad domains

Usual activities : specified in broad life situations (school, work, household)

Range of severity : no, dichotomous

No preceding screener : no preceding screener included

All ages : different questions for different age groups

Causes included : not considered

Use of assistance : not considered

Activity description : not considered

References

Ooijendijk WTM, Geurts J (1998) *De ontwikkeling van een globale beperkingen indicator*. Manuscript.

8. The Netherlands: Permanent Onderzoek Leefsituatie (POLS) (second version)

(will be included in the Dutch new Permanent Survey on the Life Situation (including health) (januari 2001)

Presentation :

Reference wording (questions) or standardised examination (conditions)

Original language

Als leeftijd <12 jaar:
Vraag 1: Heeft uw kind last van één of meer langdurige ziekte(n), aandoening(en) of handicap(s)? ja, nee, weigert/weet niet
Vraag 2: Indien ja:
In welke mate wordt uw kind hierdoor belemmerd bij activiteiten op school, het spelen of andere activiteiten die normaal zijn voor een kind van zijn of haar leeftijd? sterk belemmerd, licht belemmerd, niet belemmerd

Als leeftijd >= 12 jaar:
Vraag 3: Heeft u last van één of meer langdurige ziekte(n), aandoening(en) of handicap(s)? (ook ouderdomsklachten of specifieke ouderdomsziekten tellen mee) ja, nee, weigert/weet niet
Vraag 4: Indien ja:
In welke mate wordt u hierdoor belemmerd bij het uitvoeren van dagelijkse bezigheden thuis? sterk belemmerd, licht belemmerd, niet belemmerd, weigert/weet niet
Vraag 5: In welke mate wordt u hierdoor belemmerd bij het uitvoeren van dagelijkse bezigheden op school of op het werk? sterk belemmerd, licht belemmerd, niet belemmerd,weigert/weet niet
Vraag 6: In welke mate wordt u hierdoor belemmerd in uw vrije tijdsbesteding, bij het sporten of het reizen ? (zoals van en naar werk of school gaan)? sterk belemmerd, licht belemmerd, niet belemmerd, weigert/weet niet

English translation (by RP)
If age < 12:
Question 1: Does your child suffers from a longterm disease, disorder or handicap? Yes, no
Question 1a: if yes:
How much is your child limited by this in activities at school, in playing or other activities, that are normal for a child of his of her age? very limited, a bit limited, not limited

If age >= 12
Question 2: Do you suffer from one or more longterm disease(s), disorder(s) or handicap(s) (also due to old age or age related diseases): yes no
Question 2a: If yes:
How much are you limited by these in your daily activities at home? very limited, a bit limited, not limited
Question 2b: How much are you limited by these in your daily activities at school or at work? very limited, a bit limited, not limited
Question 2c: How much are you limited by these in your leisure time activities in sporting or travelling (to and from work or school)? very limited, a bit limited, not limited

Review :

Number of questions : 6 (to estimate acivity limitations)

Longstanding limitations : not considered, reference is made to longstanding illness, conditions or handicap

Health related problems : specified in broad domains

Usual activities : specified in broad life situations (school, work, household)

Range of severity : yes, in three categories

No preceding screener : no, there is a selection for people with longstanding illness, conditions or handicap

All ages : different questions for different age groups

Causes included : not considered

Use of assistance : not considered

Activity description : not considered

9. The Netherlands: Peilingen WVG

Presentation :
Reference wording (questions) or standardised examination (conditions)

Original language
    Ernst belemmeringen
    In welke mate bent u belemmerd bij het uitvoeren van dagelijkse bezigheden thuis?
    Gaat het: met enige moeite, met grote moeite, alleen met hulp van anderen

    Duur belemmeringen
    Hoe lang bent u inmiddels belemmerd bij het uitvoeren van dagelijkse bezigheden thuis?
    Minder dan 6 maanden, van 6-12 maanden, van 1-3 jaar, van 3-5 jaar, langer dan 5 jaar

    Inclusief psychische problemen
    Bent u als gevolg van langdurige lichamelijke en/of psychische problemen, aandoeningen of handicaps belemmerd bij het
    uitvoeren van ....

English translation (by RP)
    Severity of limitations
    Question 1
    How much are you limited in your daily activities? Is it:
    with some trouble
    with a lot of trouble
    only with help of others

    Question 2
    Duration of limitations
    How long are you limited in your daily activities?
    less than 6 months
    6 months – 1 year
    1 year – 3 year
    3 year – 5 year
    more than 5 years

    Question 3
    Inclusion of mental problems:
    Because of a longterm physical and /or mental problem, disorder or handicap, are you limited in activities…..

Review :

Number of questions : 3

Longstanding limitations : Yes, in 5 categories from short term to more then 5 years

Health related problems : No reference to health related problems

Usual activities : not specified: daily activities

Range of severity : yes, in three categories

No preceding screener : no preceding screener included

All ages : no specific age groups specified

Causes included : not considered

Use of assistance : not considered

Activity description : not considered

References

Ooijendijk WTM, Geurts J (1998) *De ontwikkeling van een globale beperkingen indicator*. Manuscript.

10. USA: National Health Interview Survey U.S. (NHIS)

Presentation :

Reference wording (questions) or standardised examination (conditions)

Original language

For Ages <5
Question 1: Is ... able to take part at all in the usual kinds of play activities done by most children ... age? Yes, No.
Question 2: If Yes:
Is ... limited in the kind or amount of play activities ... can do because of any impairment or health problem? Yes, No.
Question 3: If No:
Is ... limited in any way in any activities because of an impairment or health problem? Yes, No.

For Ages 5-17
Question 4: Does any impairment or health problem now keep ... from attending school? Yes, No.
Question 5a to c: If No:
[There are three further Qs about attending special school, needing to attend special school, or limited in school attendance.]
Question 6: If No to all four questions (4 and 5a to c):
Is ... limited in any way in any activities because of an impairment or health problem? Yes, No.

For Ages 18-69
Question 7: If Keeping house:
Does any impairment or health problem now keep you from doing any housework at all? Yes, No.
Question 8: If No:
Are you limited in the kind or amount of housework you can do because of any impairment or health problem? Yes, No.

Question 7:If Working:
Does any impairment or health problem now keep ... from working at a job or business? Yes, No.
Question 8: If No:
Is ... limited in the kind or amount of work ... can do because of any impairment or health problem? Yes, No.

Question 7: If Keeping house, going to school, something else:
Does any impairment or health problem keep you from working at a job or business? Yes, No.
Question 8: If No:
Are you limited in the kind or amount of work you could do because of any impairment or health problem? Yes, No.

Question 9: If No to all questions asked:
Are you limited in any way in any activities because of an impairment or health problem? Yes, No.

For all persons ages 60+ AND persons ages 5-59 who are limited in main or secondary activity:
Question 10:
Because of any impairment or health problem, does ... need the help of other persons with personal care needs, such as eating, bathing, dressing, or getting around this home? Yes, No.
Question 11: If No and also age 18+:
Because of any impairment or health problem, does ... need the help of other persons in handling routine needs, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes? Yes, No.
Question 12: If No and also Age 70+:
Is ... limited in any way in any activities because of an impairment or health problem? Yes, No.

Comment

Note by L. Verbrugge:

-"an" impairment or health problem instead of "any".

-NHIS annually has a set of questions about limitations in principal role (called major activity) and other activities (called secondary activities). A respondent's age and stated major activity determine which limitation questions are asked. From this diverse questioning approach, a single analytic variable with four categories is created that applies to everyone: unable to carry on major activity, limited in kind or amount of major activity, limited in secondary activities only, not limited in major or secondary activities. Here, we have condensed the question set (see copy of NHIS for actual sequence). The survey is being redesigned (new format 1996) and the questions may change.

-Definition of Main Activity: Persons ages 18+ are asked What was ... doing most of the past 12 months: working at a job or business, keeping house, going to school, or something else? This is called the person's major activity. It determines which limitation questions are asked and their sequence. For children ages <5, major activity is assumed to be play; for children ages 5-17, school.

Definition of Secondary Activities: Persons all ages who report no limitation in major activity are then asked about limitation in any other activities. These are called secondary activities.

Review :

Number of questions : 12

Longstanding limitations : Not considered.

Health related problems : Not specified, holistic

Usual activities : specified in broad life situations (work, school, household)

Range of severity : no

No preceding screener : no preceding screener included

All ages : specific questions for specific age groups

Causes included : not considered

Use of assistance : one question directed at personal assistance.

Activity description : only as examples.

References

Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

11. USA: Disability questions in U.S. Census of Population 1990

Presentation :

Reference wording (questions) or standardised examination (conditions)

Original language

Question 1
Does ... have a physical, mental, or other health condition that has lasted for 6 or more months and which:
   Limits the kind or amount of work ... can do at a job? Yes, No.
   Prevents ... from working at a job? Yes, No.

Question 2:
Because of a health condition that has lasted for 6 or more months, does ... have any difficulty:
   Going outside the home alone, for example, to shop or visit a doctor's office? Yes, No.
   Taking care of his or her own personal needs, such as bathing, dressing, or getting around inside the home? Yes, No.

Review :

Number of questions : 4

Longstanding limitations : Not considered, reference is made to longstanding health problem.

Health related problems specified in broad concepts.

Usual activities : specified in broad life situations (work, personal care).

Range of severity : no.

No preceding screener : no preceding screener included

All ages : the questions refer to work/job, so children are not included.

Causes included : not considered

Use of assistance : not considered

Activity description : yes: work, job, going outside, taking care of persomal needs.

References

Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

12. USA: National Health and Nutrition Examination Survey III (NHANES III)

Presentation :

Reference wording (questions) or standardised examination (conditions)

Original language
Question 1:
What were you doing most of the past 12 months:
   working at a job or business,
   retired,
   keeping house,
   going to school,
   or something else?
Question 1a: If Working:
   Are you limited in the kind or amount of work you can do because of any impairment or health problem? Yes, No.
Question 1b: If Keeping house or retired:
   Are you limited in the kind or amount of housework you can do because of any impairment or health problem? Yes, No.
Question 1c: If Going to school or something else Or if no to above Q about Work/Housework:
   Are you limited in any way in any activities because of an impairment or health problem? Yes, No.

Question 2: If Yes to any of above Q's:
   Have you ever changed your job, stopped working, or made any changes in your housework because of a disability or health problem? Yes, No.

Comment

Note by L. Verbrugge: An increasing number of surveys take the NHIS limitations questions as their model, but modify them into shorter versions.

Review :

Number of questions : 3

Longstanding limitations : Not considered.

Health related problems: holistic approach.

Usual activities : specified in broad life situations.

Range of severity : no.

No preceding screener : no preceding screener included

All ages : no specific questions for specific age groups

Causes included : not considered

Use of assistance : not considered

Activity description : not considered.

References

Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

13. USA: Survey of Income and Program Participation 1984 (SIPP)

Presentation :

Reference wording (questions) or standardised examination (conditions)

Original language

For Ages 16-67
Question 1:
Does ... have a physical, mental, or other health condition which limits the kind or amount of work ... can do?
Question 1a: If Yes:
Does ...'s health or condition prevent ... from working at a job or business? Yes, No.
Question 2:
For Ages 68+ or If No to initial question (Ages 16-67):
Does ... have a physical, mental, or other health condition which limits the kind or amount of work ... can do around the house? Yes, No.
Question 2a: If Yes:
Does...'s health or condition completely prevent ... from doing work around the house? Yes, No.
Question 3:
For Ages < 6
Because of a physical, learning, or mental health condition, do any of ...'s children under 6 years of age have any limitations at all in the usual kind of activities done by most children their age? Yes, No.
Question 3a: For No, there is a follow-up Q about receipt of medical services for developmental needs.
Question 4:
For Ages 6-21
Because of a physical, learning, or mental health condition, do any of ...'s children between the ages of 6 and 21 have limitations in their ability to do regular school work? Yes, No.
Question 4a: For No, there are two followup questions about ever use and current use of special education services.
Question 5:
For Ages 3-14
Do any of ...'s children between the ages of 3 and 14 have a long lasting condition that limits their ability to walk, run, or use stairs? Yes, No.

Comment

Note by L. Verbrugge: The 1984 SIPP used NHIS as a model. Note the greater emphasis on children than in NHIS. There are complex checkpoints for these questions; we show their basic format.

Review :

Number of questions : 5

Longstanding limitations : Not considered.

Health related problems: specified by broad concepts.

Usual activities : specified in life situations for different age groups.

Range of severity : no.

No preceding screener : no preceding screener included

All ages : specific questions for specific age groups

Causes included : not considered

Use of assistance : not considered

Activity description : for age group 3 to 14 some specific activities mentioned.

References

Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

14. USA: National Medical Expenditure Survey. 1987 (NMES)

Presentation :

Reference wording (questions) or standardised examination (conditions)

Original language

Question 1
Does your health keep you from working at a job, doing work around the house, or going to school? Yes, No.

Question 2
Are you unable to do certain kinds or amounts of work, housework, or schoolwork because of your health? Yes, No.

Comment

Note by L. Verbrugge: The NMES questions have dual virtues of brevity and scope by combining job, housework, and school in one question. The item is from the self-administered questionnaire. Both Qs are asked for persons of all ages.

Review :

Number of questions : 2

Longstanding limitations : Not considered.

Health related problems: holistic approach.

Usual activities : specified in broad life situations

Range of severity : no.

No preceding screener : no preceding screener included

All ages : no specific questions for different age groups

Causes included : not considered

Use of assistance : not considered

Activity description : not considered

References

Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

15. USA: Behavioral Risk Factor Surveillance System (BRFSS), 1995 Quality of Life/Functional Status (QOL/FS) Optional Module

Presentation :

Reference wording (questions) or standardised examination (conditions)

Original language

Question 1:
Are you limited in any way in any activities because of any impairment or health problem? Yes, No.

Question 1a: If Yes:
For how long have your activities been limited because of your major impairment or health problem? Interviewer records respondent's statement of years/ months/days. [Question is preceded by a query about the "major" cause of limitation.]

Question 2:
Because of any impairment or health problem, do you need the help of other persons with your personal care needs, such as eating, bathing, dressing, or getting around the house? Yes, No.

Question 3:
Because of any impairment or health problem, do you need the help of other persons in handling your routine needs, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes? Yes, No.

Comment

Note by L. Verbrugge:

-Uses "any" impairment or health problem, whereas NHIS uses "an". Same in all instances of this Q below.

-In Activity Limitation Module developed in 1993-94. Questions are worded closely to the NHIS activity limitations items.

-CDC has taken a lead in developing global disability items. BRFSS is a telephone interview of adults conducted by all U.S. states. It has a Core questionnaire and optional modules. #14 was introduced into the Core in 1993 and continues to be there (Centers for Disease Control and Prevention 1994, Hennessy et al. 1994).

Review :

Number of questions : 4

Longstanding limitations : Yes, (open question).

Health related problems: holistic approach.

Usual activities : holistic approach.

Range of severity : not considered.

No preceding screener : no preceding screener included

All ages : no specific questions for different age groups

Causes included : not considered

Use of assistance : yes

Activity description : not considered

References

Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

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

Presentation :

Reference wording (questions) or standardised examination (conditions)

Question 1:
Now thinking about your health, do you have any physical or mental condition that limits you in any way, and that has lasted for 6 or more months? Yes, No.

Question 2: *[For Ages 18-69:]*
What were you doing most of the past 12 months: working at a job or business, keeping house, going to school, or something else? Working at a job or business, Keeping house, Going to school, Something else.
Question 2a: If Keeping house:
Does any impairment or health problem now keep you from doing any housework at all? Yes, No.
Question 2aa: If No:
Are you limited in the kind or amount of housework you can do because of any impairment or health problem? Yes, No.
Question 2b: If Working:
Does any impairment or health problem now keep you from working at a job or business? Yes, No.
Question 2bb: If No:
Are you limited in the kind or amount of work you can do because of any impairment or health problem? Yes, No.
Question 2c: If Keeping house, going to school, something else:
Does any impairment or health problem keep you from working at a job or business? Yes, No.
Question 2cc: If No:
Are you limited in the kind or amount of work you could do because of any impairment or health problem? Yes, No.

Question 3: If No to all questions asked:
Are you limited in any way in any activities because of any impairment or health problem? Yes, No.

Question 4: *[For Ages 60+:]:*
Question 4:
Because of any impairment or health problem, do you need the help of other persons with personal care needs, such as eating, bathing, dressing, or getting around this home? Yes, No.
Question 4a: If No:
Because of any impairment or health problem, do you need the help of other persons in handling routine needs, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes? Yes, No.
Question 4aa: If No and also age 70+:
Are you limited in any way in any activities because of any impairment or health problem? Yes, No.

Review :

Number of questions : 8

Longstanding limitations : not considered.

Health related problems: holistic approach.

Usual activities : specified in broad life situations.

Range of severity : not considered.

No preceding screener : no preceding screener included

All ages : specific questions for different age groups

Causes included : not considered

Use of assistance : for specific age groups included.

Activity description : only considered as examples

17. USA: Behavioral Risk Factor Surveillance System (proposed)

Presentation :

Reference wording (questions) or standardised examination (conditions)

Original language

Question 1:
Because of a physical, mental, emotional, or communication-related condition, have you been limited for the past 12 months in your activities at home, school, work, or in the community? Yes, No, Not sure/don't know, refused.

Question 2:
Do you use any kind of equipment or devices such as a hearing aid, wheelchair, cane, artificial limb, or do you use assistance from other people to carry out your activities at home, school, work, or in the community? Yes, No, Not sure/don't know, refused.

Review :

Number of questions : 2

Longstanding limitations : yes, 12 months.

Health related problems: specified in broad concepts.

Usual activities : specified in broad life situations.

Range of severity : not considered.

No preceding screener : no preceding screener included

All ages : no specific questions for different age groups

Causes included : not considered

Use of assistance : yes included.

Activity description : not considered

18. USA: National Health Interview Survey, Disability Supplement 1994-95

Presentation : Reference wording (questions) or standardised examination (conditions)

Original language

Question 1:
Do you consider yourself (or anyone in your family) to have a disability? Yes, No.

Question 2
Would other people consider you (or anyone in the family) to have a disability? Yes, No.

After specific questions about emotional/cognitive problems:
Question 3: If Yes to any:
During the past 12 months, did any of these problems seriously interfere with ... ability to work or attend school or to manage ... day-to-day activities? Yes, No.

After specific questions about emotional/cognitive problems and mental conditions:
Question 4: If Yes to any and also age 18+:
Because of (this/these) mental or emotional problem(s), is ... unable to work or limited in the kind or amount of work ... can do? Yes, No.
Question 4a: If No:
Because of (this/these) mental or emotional problem(s), does ... have trouble finding or keeping a job or doing job tasks? Yes, No.

For Ages 2-17
Question 5:
Because of a physical, mental, or emotional problem, do(es) ... now have any difficulty participating in strenuous activity, such as running or swimming, compared to other children their age? Yes, No.
Question 5b: If Yes:
Has the problem or condition which causes ... to have difficulty participating in strenuous activity been going on or is it expected to go on for at least 12 months? Yes, No.

For Ages 2-17:
Question 6:
Because of a physical, mental, or emotional problem, do(es) ... now have any difficulty playing or getting along with others their age? Yes, No.
Question 6a: If Yes:
Has the problem or condition which causes ... to have difficulty getting along with others been going on or is it expected to do on for at least 12 months?

Comment

Note by L. Verbrugge: The 1994-95 National Health Interview Survey had a Disability Supplement (NHIS-Disability) with two phases. Phase One has questions asked about all household members; it is conducted at the same time as the NHIS core questionnaire. Phase Two is for persons who screen-in as having disabilities; it is conducted several months later. NHIS-Disability has many detailed questions but only a few global ones. They are in Phase One and for All Ages except where stated. Note there are global questions related to mental (emotional & cognitive) problems, but none related to physical problems. Phase Two has no global items.

Review :

Number of questions : 5

Longstanding limitations : reference is only made to a time period of the past 12 months, not to duration.

Health related problems: specified in broad concepts.

Usual activities : specified in broad life situations.

Range of severity : not considered.

No preceding screener : no preceding screener included

All ages : specific questions for different age groups

Causes included : not considered

Use of assistance : for specific age groups included.

Activity description : not considered.

References

Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

19. USA: Medical Outcomes Study Short-form Health Survey (MOS-20)

Presentation :

Reference wording (questions) or standardised examination (conditions)

Original language

Question 1:
Does your health keep you from working at a job, doing work around the house or going to school?
Yes for more than 3 months;
Yes for 3 months or less;
No.

Question2:
Have you been unable to do certain kinds or amounts of work, housework or schoolwork because of your health?
Yes for more than 3 months;
Yes for 3 months or less;
No.

Comment

Note by L. Verbrugge: Shown here are the MOS-20 items for the concepts role functioning (#36; no skip pattern; both questions asked of all persons) and social functioning (#37). References for MOS20: Stewart et al. 1988; Ware, Sherbourne, and Davies 1992.

Review :

Number of questions : 2

Longstanding limitations : yes, but restricted to 3 months or more.

Health related problems: holistic approach.

Usual activities : specified in broad life areas.

Range of severity : not considered.

No preceding screener : no preceding screener included

All ages : no specific questions for different age groups

Causes included : not considered

Use of assistance : for specific age groups included.

Activity description : not considered.

References

Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

20. USA: International Center for the Disabled Survey 1985 (ICDS)

Presentation :

Reference wording (questions) or standardised examination (conditions)

Original language

Question 1:
   Does a health problem, handicap or disability now keep you from participating fully in school, work, housework, or other activities? Yes, No.
Question 1a: If No:
   Have you ever been limited in any way in your activities for a year or more because of a handicap, impairment, or health problem?
   Yes-limited now,
   Yes -limited in past,
   No.
Question 1b: If Limited In Past:
   Do you still have a disability or health problem, or not?
   No longer have it (screens out),
   Still have it.
Question 1c: If No:
   Do you:
  Question 1ca:
   Have any learning disability of any kind, or not? Yes (questions stop at first Yes), No (screens out if No to all).
  Question 1cb:
   Have an emotional or mental disability, or developmental disability, or not?
  Question 1cc:
   Have a physical disability or handicap, or not? Yes (questions stop at first Yes), No (screens out if No to all).
  Question 1cd:
   Have any talking, hearing, or visual disability, except for ordinary eyeglasses, or not? Yes (questions stop at first Yes), No (screens out if No to all).

Comment

Note by L. Verbrugge. A first-stage screen for disability was done in a national telephone sample. Persons with long-term role limitations, certain long-term impairments, or self-perceived status as a "disabled or handicapped person" were selected. Screened-in persons were then contacted for an interview; the second-stage began with a check for disability status (#41; some persons screened out at that point). De last set of Qs shows three questions asked later in the second-stage interview. Reference: Louis Harris and Associates, Inc. 1986.

Review :

Number of questions : 4

Longstanding limitations : not considered.

Health related problems: holistic approach.

Usual activities : specified in broad life situations.

Range of severity : not considered.

No preceding screener : no preceding screener included

All ages : no specific questions for different age groups

Causes included : not considered

Use of assistance : not considered.

Activity description : not considered.

References

Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

21. USA: Baltimore Longitudinal Study of Aging Followup

Presentation :

Reference wording (questions) or standardised examination (conditions)

Original language

> Question 1: Would you describe your overall level of functioning as: excellent, good, fair, poor, don't know?
> > Excellent
> > Good
> > Fair
> > Poor.
>
> Question 2:
> Has your ability to function or take care of yourself changed in the last 2 years? No, Yes.
> Question 2a: If Yes:
> > Has your ability to function or take care of yourself improved or declined? Improved, Declined.
>
> Question 3:
> Does your health allow you to do everything you would like to do? No, Yes, Uncertain.
> Question 3a: If No Or Uncertain:
> > What are you unable to do for yourself that you would like to do? [Interviewer writes respondent's description.]

Comment

Note by L. Verbrugge: BLSA is a life-long study of adults who have medical exams and questionnaires every two years. It is conducted by the Gerontology Research Center, National Institute on Ageing. Reference: Shock et al. 1984. The items are from a telephone follow-up on dropouts (had not returned for biennial exam) conducted in 1989.

Review :

Number of questions : 3

Longstanding limitations : not considered.

Health related problems: holistic approach.

Usual activities : refers to functioning in general.

Range of severity : yes, in four categories.

No preceding screener : no preceding screener included

All ages : no specific questions for different age groups

Causes included : not considered

Use of assistance : not considered.

Activity description : not considered.

References

Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

22. USA: Pilot Study on Subjective Health, NCHS

Presentation :

Reference wording (questions) or standardised examination (conditions)

Original language

> Question 1:
> Is there anything about your physical condition-that is, your health and the amount of energy you have- that makes it hard for you to do your usual (work/activities)? Yes, No.
>
> Question 1a: If Yes (Ask Both Below):
> Would you say it is hard or very hard for you to do your usual (work/activities)? Hard, Very hard.
>
> Question 1b
> What are some of the things you have trouble with? [Interviewer writes responses.]

Comment

Note by L. Verbrugge: The items come from a small-scale pilot study (Subjective Health: Perceptions of Health Status and Health Care) conducted by Charles Cannell and colleagues for the National Center for Health Statistics in 1975. No publications.

Review :

Number of questions : 3

Longstanding limitations : not considered.

Health related problems: holistic approach.

Usual activities : usual activities.

Range of severity : yes, 3 categories: not limited, hard and very hard.

No preceding screener : no preceding screener included

All ages : no specific questions for different age groups

Causes included : not considered

Use of assistance : not considered.

Activity description : not considered.

References

Verbrugge LM (1997) A global disability indicator. *Journal of Aging Studies* 11 (4):337-362.

4- Charts on self-perceived health

1. The Age comparative questions to measure self-perceived health

Presentation:

Five of the questions in the European Community's health surveys use an age-comparative format to measure self-perceived health. These questions ask respondents to make a comparative judgement of their own health with others of the same or similar age.

Instruments and reference wording:

Austria: Konsum von Alkohol und psychoaktiven Stoffen 1993/94
   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

France : Enquête sur la santé et les soins médicaux 1991/92
   Actuellement, compte tenu de votre âge, comment estimez-vous votre état de santé?
   très bon – bon – moyen – médiocre - franchement mauvais

France : Baromètre santé grand public 1995
   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

France : Enquête conditions de vie et aspirations des Français 1994/95
   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

United Kingdom : Health and lifestyle survey 1991
   Would you say that for someone of your age your own health is generally excellent, good, fair or poor?
   excellent – good – fair - poor

Review analysis

Many studies have measured self-perceived health with an age-comparative question. A typical question is "How would you rate your health compared to other people of your age?" or "Would you say that for someone of your age your own health is excellent, good, fair or poor?" The number and wording of response categories varies, but the questions all contain some reference to age.

Fienberg et al. (1985) have suggested that the assessment of one's health involves a comparison process, but it is not clear what points of reference are used. Possible points of reference include one's previous health, the health of age peers and the health of socially similar others. Few, if any studies however, have systematically examined the points of reference used in self-ratings, although the results obtained are likely to be dependent on the points of reference used by the respondents (Manderbacka 1998).

In their recommended question on self-perceived health, however, the WHO omits any reference to an age comparison arguing that it would prevent the monitoring of progress in the average health of a population (WHO 1996).

Limits and justification for non selection:

Until future studies are able to more systematically examine the points of reference that respondents use when rating their health, we propose the question recommended by the WHO - a single-item question without a specific reference to an age comparison.

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2. The time-limited questions to measure self-perceived health

Presentation:

Thirteen of the questions in the European Community's health surveys use a time-limited format to measure self-perceived health. These questions refer to a specific period in time when asking respondents to rate their own health. Most commonly used in the surveys was the use of the word 'present' or 'current' when referring to health. Also used, is the phrase 'over the last 12 months'.

Instruments and reference wording:

Switzerland : Schweizerische Gesundheitsbefragung 1997
   Wie geht es Ihnen sur Zeit gesundheitlich?
   sehr gut – gut – mittelmässig – schlecht - sehr schlecht

Germany : Herz-Kreislauf-Praventionsstudi 1990/91
   Wie würden Sie Ihren gegenwartigen Gesundheitszustand beschreiben?
   sehr gut – gut – zufriedenstellend - weniger gut - schlecht

Germany : Gesundheitssurvey Ost Deutschland 1991/92
   Wie würden Sie Ihren gegenwartigen Gesundheitszustand beschreiben?
   sehr gut - gut – zufriedenstellend - weniger gut - schlecht

Germany : Umwelt, Gesundheit und Gesundheitsversorgung 1995
   Wie wurden Sie Ihren gegenwärtigen Gesundheitszustand beschreiben?
   sehr gut – gut – zufriedenstellend - weniger gut - schlecht

Denmark : Danish health interview survey, Sundhed og sygelighed i Danmark 1994
   How do you rate your present state of health in general?
   excellent – good – fair – bad - very bad

Spain : National health survey, Encuesta nacional de salud 1995
   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?
   very good – good – fair – poor - very poor

Finland : Survey on health behavior, Finbalt health monitor 1996
   What is your own assessment of your present state of health?
   good - reasonably good – average - rather poor - poor

Finland : Living conditions survey, Elinolotutkimus 1994
   Which of the following alternatives best describes your present state of health: very good, good, moderate, poor or very poor?
   very good – good – moderate – poor - very poor

Finland : Health care survey, Terveydenhuollon vaestotutkimus 1995/96
   Is your present state of health in your own opinion: good, fairly good, average, rather poor or poor?
   good - fairly good – average - rather poor – poor

Finland : Use of health services and health status 1994
   I should now like to ask about your present state of health. Do you think it is good, fairly good, average, rather bad or bad?
   good - fairly good – average - rather bad - bad

Finland : Family planning services 1994
   How would you rate your current level of health?
   good - fairly good – middle - fairly poor - poor

Finland : Finnish drinking habits survey 1992
   What is your opinion of your current state of health?
   excellent - fairly good – average - fairly weak - extremely weak

United Kingdom : General household survey 1996
   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

United Kingdom : Disability survey 1996
   To help people say how good or bad their health is, we have drawn a scale (rather like a thermometer) on which the best state of health you can imagine is marked by 100 and the worst state of health you can imagine is marked by 0.
   We would like you to indicate on this scale how good or bad your health is today, in your opinion. Please do this by showing me the point on the scale which indicates how good or bad your current health is.

Review analysis:

In addition to the above, self-perceived health can also be measured with a question referring to a dimension of time. This may be a specific time-comparative question, such as "Compared to one year ago, how would you rate your health in general now"? It might be argued that the question "I expect my health to get worse" is also a time-comparative

In their recommended question on self-perceived health, however, the WHO omits any reference to time, as the question is not intended to measure temporary health problems (WHO, 1996). In addition, the WHO recommended question does not ask respondents to compare their health with their own previous or future health state. The rationale is the same for why they do not recommend an age-comparative question. They argue that the inclusion or either a time dimension of any sort would prevent the monitoring of progress in the average health of a population.

Limits and justification for non selection:

All of the above questions contain a reference to time, whether specifically asking respondents to consider a previous or future health state, or more simply, including a time-limiting word or phrase (e.g. 'present' or 'current'). Therefore, they are not well suited for the monitoring of progress in the average health of a population.

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