

# **Measurement of physical functioning in comprehensive national health surveys**

**- ICF as a framework**

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HEALTH SURVEYS IN THE EU:  
HIS AND HIS/HES EVALUATIONS AND MODELS  
Phase 2, Subproject 4



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## **ABSTRACT**

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Information about the population's physical functioning is increasingly important. Its measurement in national health surveys has a long tradition. Despite of numerous recommendations there are few valid and practical measurement methods for large population surveys. Current methods comprise self-reports and performance-based measures. The comparability of the results obtained is relatively poor.

The aim of this study is to describe and analyze current measurement of physical functioning in comprehensive national health interview (HIS) and health examination (HES) surveys. The information was drawn from the most recent European health survey database (version 2002). The search was limited to the latest 5-year period (1998 - 2002) and the evaluation was limited to surveys including questions and/or examinations on physical functioning. Altogether 46 of the 57 health interview surveys included at least some physical function topics. However, the number of topics on physical functioning varied greatly between surveys. There were also huge differences in the contents of questions and their wording. National health examinations including surveys with an examination component added to national health interview surveys have been carried out in only two European countries (three surveys). The range of the measurement included has been from a few tests to a comprehensive clinical examination. The most comprehensive health examination survey is the Finnish Health 2000.

The results of this study have been presented in terms of the new International Classification of Functioning, Disability, and Health, ICF. This study served as an example for linking the questions on physical functioning to the codes of the ICF with the help of linking rules. Most of the physical functioning items of current surveys could be linked to ICF. This new classification system should be also used in the HIS/HES-database.

ICF is a potential solution for harmonising survey methods in the area of physical functioning. International collaboration is needed to develop further already existing instruments and to assess the need for new instruments. Future development of measurement methods should use ICF as a starting point. In the future it is probably best to assess physical functioning by a combination of interview and questionnaire data with performance based test data. Both performance-based tests and questions for interviews need to be developed for national health surveys. To improve current methods and specially their international comparability requires intense international collaboration.

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# 1 INTRODUCTION

## 1.1 The measurement of physical functioning

Within the next 20 years, the proportion of people over 65 years of age will increase considerably, with the fastest growing population in most countries being those who are very old (i.e. aged 80 years and over). (Healthy ageing home: Product design 2002). Eighteen out of the 20 countries in the world with the highest percentages of older people are in WHO's European region. In these countries between 13.2% and 17.9 % of the population are over 65 years old. The number of the elderly is growing since life expectancy at age 65 shows a steady increase in EU countries (WHO 2001b). With the continuing growth of elderly populations in modern societies, information on functional status is becoming increasingly important (WHO1998).

Assessing functioning is particularly important in the elderly, as the prevalence of functional disability increases with age. Growing interest is emerging in different aspects of functioning. Adequate physical function plays a prominent role in maintaining independence of older adults. Declining physical functioning associated with increasing age and chronic diseases, contributes to the need of assistance in performing basic tasks and to increased rates of institutionalisation (Salive et al 1994).

Measures of functional ability, mobility, and physical activities are frequently used in population surveys because they are socially relevant and interpretable (Bowling 1997). In addition, measuring the functional level offers a convenient way to compare the impact of different types of disease on different populations at different times (McDowell & Newell 1996). The measurements can also provide important information about the need for assistance in personal care, ability to live independently and prognosis (Reuben & Sui 1990). From the public health perspective knowing the health and functional status of the ageing population is important so that interventions can be targeted towards the right population groups (Malberg et al 2002).

Since the 1950s there has been an expansion in the development of functional assessment measures for clinical, survey and research application (Brooks 1995, McDowell & Newell 1996). Most instruments have relied either on patient self-report, or on direct observation of the individual performing a variety of tasks, or on performance based measures. Although there is widespread agreement that screening for functional status in older person is important, the preferred method is still uncertain. Evidence of reliability and validity is still inadequate for a large number of measures (McDowell & Newell 1996). Moreover, it is unclear whether self-report and performance based measures can be used interchangeably (Sherman & Reuben 1998).

The development of functional assessment measures has been criticised for being uncoordinated. One reason for this is the lack of a clear theoretical or conceptual framework (Haley & Langmuir 2000). From the national population health survey perspective this hinders international comparisons of the results (de Bruin et al 1996).

Striving for unification of the assessment and measurement procedures WHO (2001a) has approved the International Classification of Functioning, Disability and Health, ICF. A need has emerged to further explore the practical use of the ICF in epidemiological research. Grimby and Smedby (2001) emphasise the need to explore how to link already established instruments with identified psychometric characteristics to the codes in the ICF. The Final Report of the European Disability Measurement project (de Kleijn-de Vrankrijker & Bonet 2002) suggests that the European health survey database (HIS/HES database) could be a good starting point for listing the reference instruments and instrument questions in order to mapping the existing items, instruments and instrument questions to the ICF framework.

## **1.2 Health surveys in the EU: HIS and HIS/HES evaluations and models**

The aim of the project "Health Surveys in the EU: HIS and HIS/HES evaluations and models" is to facilitate comprehensive and comparable health measurement by Health Interview Surveys (HIS) and Health Examination Surveys (HES). The project has been carried out by three institutes, in close co-operation: The Finnish National Public Health Institute (KTL), the Belgian Scientific Institute of Public Health, and Statistics Netherlands, and a core group of experts from seven countries (Hupkens & Swinkels 2001, Koponen & Aromaa 2001).

During the first phase of the project, overviews of previous, current and planned national health interview and examination surveys were made. KTL produced an overview of information on Health Examination Surveys in the EU/EFTA Member States (including description of the HES part of combined HIS/HES) (Koponen & Aromaa 2001). Statistics Netherlands developed the health survey HIS-database and made an overview of information on HIS (including HIS questionnaires of combined HIS/HES) (Hupkens & Swinkels 2001, Hupkens 1998). The database shows the methods and contents of existing and planned HIS and combinations of HIS/HES in the EU Member States (MS) and in all countries of the European Free Trade Association/European Economic Area (EFTA/ETA) where national comprehensive health surveys have been or were known to be implemented.

Under the main project several subprojects were carried out during the phase 2. One of these subprojects was this project focusing on the measurement of physical functioning (Aromaa et al 2003a, 2003b).

## **1.3 Objectives and outcomes**

The aim of this study is to describe the current situation of measurement of physical functioning in comprehensive national health surveys. The conceptualisation and measurement of physical functioning is discussed. Currently used instruments on physical functioning are evaluated from the viewpoints of international comparability through systematic review of the methods and

instruments. In addition description and analysis of the conceptual framework are performed through literature review. A summary of recommendations will be made from the viewpoint of comparability.

This study aims to list questions, instruments (health interview methods) and examination measurements (health examination methods) on physical functioning based on the information recorded in the European health surveys (HIS/HES) database. The results will be presented in terms of International Classification of Functioning, Disability and health, ICF (WHO 2001a).

One of the main outcomes of this subproject is to serve as an example of using the HIS/HES database to make comparison of instruments/questions and linking these to the codes of ICF. The specific aim is to develop ICF linking rules for the database questions by using the items on physical functioning as an example. Preliminary experiences suggest that linking already established instruments to the codes in the ICF is possible at least for a number of commonly used instruments (Grimby & Smedby 2001, Cieza et al 2002). Finally conclusions concerning the current situation and on the needs for further development will be made.

## **PART I BACKGROUND AND REVIEW OF LITERATURE**

The first part of this report discusses the conceptualisation and measurement of physical functioning. A review of the literature was performed to identify conceptual and methodological issues that needed to be addressed when measuring physical functioning in national health survey settings. Several search strategies and combinations of search terms were experimented with and searches were carried out mainly through PubMed (Annex 1). Further documentation concerning the international harmonisation of research methods was obtained from international agencies such as WHO, OECD, EUROSTAT etc. Also Google, a search engine of Internet, was used to obtain information about ongoing projects on international harmonisation in the domain.

The theoretical framework and the coding scheme, International Classification of Functioning, Disability and Health, ICF is described. The information obtained from the 3<sup>rd</sup> Nordic-Baltic conference on ICF: "ICF in practice" (Helsinki September 2002), helped to better understand the use of ICF in practice. In addition to the conference and recent literature, the participation in the evaluation process of the pilot version of the Finnish translation of ICF made it possible to go more deeply into the terms and approaches of ICF.

## **2 THE CONCEPT OF PHYSICAL FUNCTIONING**

### **2.1 Concepts of functioning and terms**

Gerontologists and policymakers are increasingly becoming interested in functioning as the number of elderly people increases. However, the concept itself is not unambiguous. For example, from the viewpoint of gerontological research functioning is usually described as a dynamic concept that is modified by the process and changes of ageing (Heikkinen et al 1990).

Usually physical functioning has been described as a subcategory of health status. Disability, the inability to function normally, psychologically or physically, is a

fundamental health status measure (Lan et al 2002). The term disability has become nearly synonymous with the concepts of functioning and functional status (McDowell & Newell 1987). Functional status, on the other hand, has been defined as the degree to which an individual is able to perform socially allocated roles free of physically related limitations (Aromaa et al 1999).

Physical functioning has been defined as one component of functional capacity. Functional capacity is seen to include physical, psychological, and social components, closely related to life circumstances (Bowling 1997, Kivinen et al 1998). Several definitions have been presented. Guralnik and Lacroix (1992) divide functional capacity into physical, psychological, social, cognitive and sensory functions whereas Branch and Jette (1981) state, that functional capacity consists of physical, emotional, mental and social components. As a whole, good functional capacity means the ability to cope with ordinary activities of everyday life (Crees 1997, Hervonen et al 1998). Impaired functional capacity, on the other hand, increases with age and it may have various social consequences, at it's worst permanent incapacity for work or institutionalisation (Aromaa et al 1999).

In addition to the terms functional status and functional capacity the term functional ability has been used. Heikkinen et al (1990) see that this term (functional ability) is often used to describe the part of functional capacity that relates to the ability, capacity and opportunity to perform activities of daily living (ADL). Thus, person's functional ability is ability to act and participate in society as a fully active member of society and fulfil ones roles. It can be divided into three main areas: physical, psycho-cognitive and social ability (Heikkinen et al 1990, Hervonen et al 1998).

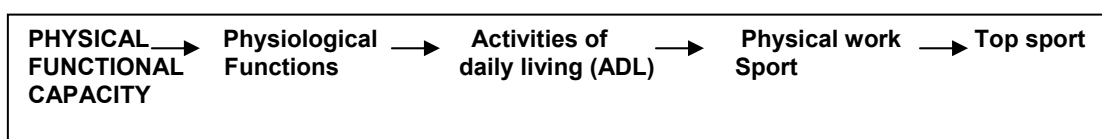
In conclusion, physical functioning is one part of the main concept of functional status, ability or capacity. It is the most and longest explored area of the different components of functional status, ability or capacity (Katz & Stroud 1989, McDowell & Newell 1996). This has been explained mainly by the biological principles and mechanisms of ageing: Impaired functional capacity increases with age and the consequences of ageing can be seen most clearly in the physical area of functioning (Katz & Stroud 1989).

However, when evaluating functioning the comprehensiveness of the concept can not be by-passed. All the components, physical, social and psychological interact. In addition, environmental factors must be taken into account. Thus, functional limitations may be due to impairments and disabilities or environmental factors or both. To improve functioning, actions can be directed either towards enhancing functioning or towards improving the working and living environments or both. Also, personal aids and mechanical devices can improve functioning (Heikkinen 1990).

## 2.2 Models of physical functioning

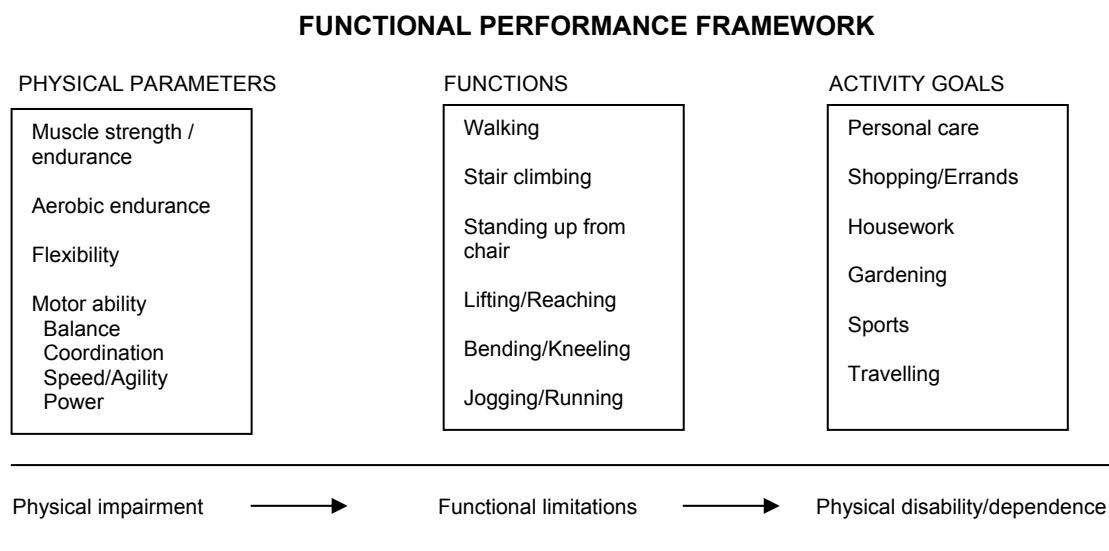
Physical functioning is a series of increasingly integrated steps, beginning with several basic components and progressing to more integrated functions (figure 2.1). At the highest level of physical function are the so-called advanced activities of daily living, including the fulfilment of societal roles or recreational activities. The basic components of strength, balance, co-ordination, flexibility, and endurance are the necessary building blocks allowing the performance of more integrated functional tasks (Heikkinen 1986, Dipietro 1996). A hierarchical model of functional capacity (Hervonen et al 1998, Heikkinen et al 2000) presents human physical dimensions (as well as mental and social dimensions) from a functional perspective. At the lowest level are the vital, simple basic functions such as breathing, and at the highest level is the capacity to carry out the most demanding, complex tasks (e.g., physical capacities enabling participation in top sport).

**Figure 2.1** A hierarchical model of functional capacity (Hervonen et al 1998, Heikkinen 2000).



Rikli and Jones (1997) have introduced the functional performance framework (figure 2.2). It indicates also a progressive relationship between physiological performance, functional performance, and activity goals. Common activity goals (e.g. personal care, shopping, and travelling) require the ability to perform functions such as walking and stair climbing). Functions (walking and stair climbing) on the other hand require physical strength, endurance, flexibility, and motor ability. The model has been linked to the progression leading to disability and dependence.

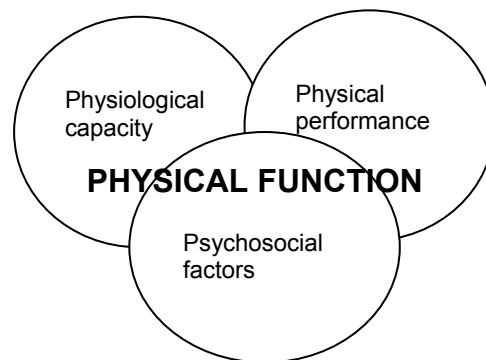
**Figure 2.2** A physical performance framework (Rikli & Jones 1997).



Cress et al (1996) have represented a Venn diagram, a conceptual model of physical and psychological spheres affecting physical function (figure 2.3). According to this model the physiological capacities of the cardiovascular, musculoskeletal, and neuromuscular systems are primary determinants of function. Physiological capacity refers to the basic cellular and anatomic function such as muscle strength. Physical performance, on the other hand, is the ability to integrate these physiological systems into co-ordinated, efficient movements to achieve optimum physical function. Physical function is influenced by psychosocial factors such as confidence, motivation, perceived ability, depressive symptoms and social roles. As a whole physical function can be seen to be the integration of physiological capacity and physical performance influenced by psychosocial

factors. However, environmental factors affecting physical functioning have not been taken into account in this model.

**Figure 2.3** A Venn diagram illustrating the relationship between the components of physical function (Cress et al 1996).



### **2.3 Physical functioning – a sensory motor function**

In the literature the physical part of functioning has been generally seen to include sensomotor and also psychomotor functions (Nagi 1979, Jette & Branch 1985, Heikkinen et al 1990). According to Nagi (1976) physical refers to sensory motor functioning of the organism as indicated by limitations in activities such as walking, bending, climbing, reaching, and hearing and seeing. Also Jette and Branch (1985) state that physical function includes both sensory and motor functions. They define physical function as the sensory motor performance of an individual including fundamental and complex activities of daily living (Jette & Branch 1985).

Several population-based studies have shown that sensory impairments are strongly associated with physical disability among older adults (Stuck et al 1999). Persons aged 65 years and older reporting visual impairment have been found to have difficulty with activities of daily living (ADL) (Jette & Branch 1985, Rudberg et al 1993). Especially in men visual impairment had the greatest influence on dependence in ADL (Sonn 1996). Poor self-reported vision is associated with an

increased risk of functional status decline (Stuck et al 1999). Persons with several visual impairments had three-fold higher odds for incident functional status decline compared to those with better visual function (Salive et al 1994).

However, some studies suggest that progression of sight and hearing impairments is not associated with change in physical disability (Jette et al 1990). Hearing impairment has not been found to be significantly or independently associated with disability (Stuck et al 1999). Hearing impairment is directly related to age (Rudberg et al 1993, Rubin & Salive 1995). An explanation for the poor association between hearing and functional status is the fact that most studies use crude measures of hearing impairment (single item questions), or they combine deafness and hearing troubles without taking into account the functional consequences of hearing impairment (Stuck et al 1999). It has also been argued that older persons are quite able to compensate for sensory impairments in maintaining the independence of their daily life activities (Jette et al 1990). Still, together with visual impairment, hearing impairment has been found to be a significant risk factor for balance problems and falls, especially in older women (Rudberg et al 1993, Greson et al 1998).

In contrast to sensory impairments, physical impairments and functional limitations have a considerable impact on dependence in daily life activities. The basic motor functions, such as bending, lifting and walking, are prerequisites for performing daily activities (Winograd et al 1994, Guralnik et al 1995). For example, Sonn (1996) argued that persons dependent in ADL had lower maximal walking speed, grip strength, knee extensor strength, stair-climbing capacity and forward reach than those independent in ADL. The results of Avlund et al (1995) showed that subjects reporting "tiredness" in activities of daily living or in mobility were more likely to need help five years later. Thus, limitations in activities of daily living are early indicators of functional decline (Stuck et al 1999).

Mobility disability is also often an early manifestation of the disablement process and is highly predictive of disability progression (Fried & Guralnik 1997). Relatively minor deficits in musculoskeletal domains (strength, range of motion) may add to the overall burden of impairment and lead to functional decline. For example,

decreased hip motion has been associated with decreased ability to use public transportation and climb stairs, and restricted knee motion with increased difficulty in toileting, transfers, bathing and climbing stairs (Bergstrom et al 1985). In particular, loss of strength in the lower extremity has been linked with increased time to rise from chair, climb stairs, and walk (Bassey et al 1992). On the other hand the consequences depend on the changing environment. A good example is the introduction of low-floor vehicles in public transport.

Both upper and lower extremity functions have an impact on functional outcomes (Tinetti et al 1995). Lawrence and Jette (1996) found that lower extremity functional limitations were stronger determinants of subsequent disability as compared to upper extremity functional limitations. In addition, lower extremity functions have been shown to predict increased mortality, nursing home admission, and further disability in community-dwelling older adults (Guralnik et al 1994).

## **2.4 Physical functioning and the models of health and disability**

Assessing physical functioning and functional status of individuals requires an understanding of the progression leading to loss of function (Rikli & Jones 1999). For several decades, the predominant conceptual scheme for functioning has been the disability model. The disability models explain the pathway from pathology to loss of function. The understanding of this pathway is important since the development of the measurement of functioning has been related to disability models (Verbrugge & Jette 1994, McDowell & Newell 1996).

Various conceptual models of functioning have been proposed. These may be expressed in a dialect of “medical model” versus “social model” (WHO 2001a). The two most often used medical models to describe the consequences of disease and chronic injuries are the World Health Organization (WHO) classification system known as the International Classification of Impairments, Disability, and Handicap (ICIDH) (WHO 1993) and Nagi’s model (Nagi 1991). These models share a common perspective of a continuum of functioning ranging from minimal

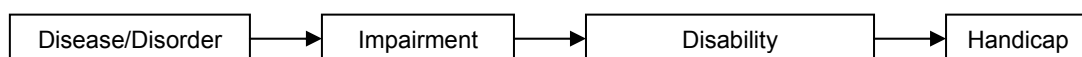
tissue or organ level deviations from normal bodily functioning to major functional limitations, where the individual's overall ability to perform various activities is limited, and ultimately to what can be referred to as disability or handicap status.

The best-known social model of disability is Verbrugge and Jette's model of the disablement process (1994). The World Health Organization's (WHO) new classification system known as the International Classification of Functioning, Disability and Health, ICF, uses a "biopsychosocial" approach integrating the medical and social models into one (WHO 2001a).

#### **2.4.1 The International classification of Impairments, Disabilities, and Handicaps, ICIDH**

The ICIDH model (WHO 1993) identifies three concepts or levels of disablement-impairment (organ level), disability (person level) and handicap (societal level). Impairment is defined as any loss, or abnormality of psychological, physiological, or anatomical structure or function (figure 2.4.1). Disability is defined as any restriction or lack (resulting from impairment) or ability to perform an activity in the manner or within the range considered normal for the human being. Handicap on the other hand is defined as a disadvantage for a given individual, resulting from an impairment or disability limiting or preventing the fulfilment of a role normal for that individual (depending on age, sex, and social and cultural factors). The three concepts are considered to be related, yet independent. In other words, an individual could have an impairment without disability, a disability without handicap et cetera.

**Figure 2.4.1** Disability Model by WHO (WHO 1993).

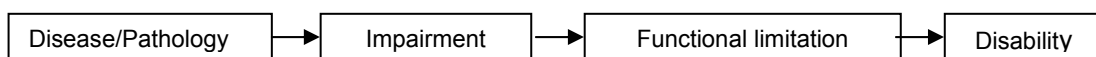


### 2.4.2 Nagi's model

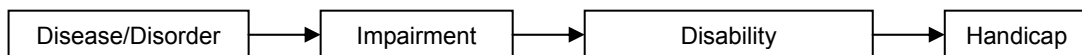
The disablement process of Nagi (Nagi 1991) describes a progression leading to loss of function from pathology (presence of disease) to impairments (anatomical and structural abnormalities) to functional limitations (restriction in basic physical and mental actions or performances) to disability (difficulty in doing basic and instrumental activities of daily life (ADLs) and other social roles, figure 2.4.2). Disability concerns the fulfilment of activities and social roles in relation to work, the family and independent life.

**Figure 2.4.2** Differences in traditional disability models.

Disability Model by WHO (WHO 1993):



Disability Model by Nagi (Nagi 1991):



The conceptual framework of this model is basically consistent with the ICIDH. Although there are similarities the terminology of ICIDH and Nagi's model differs. The ICIDH uses the terms "disability" and "handicap" where as Nagi uses "functional limitations" and "disability". Both of these models (figure 2.4.2) share a common perspective of a continuum of functioning ranging from minimal, tissue or organ-level deviations from normal bodily functioning [referred to as pathology (Nagi 1991) or disease (WHO 1993)] to major functional limitations, where the individual's overall ability to perform various activities is limited, and ultimately to what has been referred to as disability (Nagi 1991) or handicap (WHO 1993).

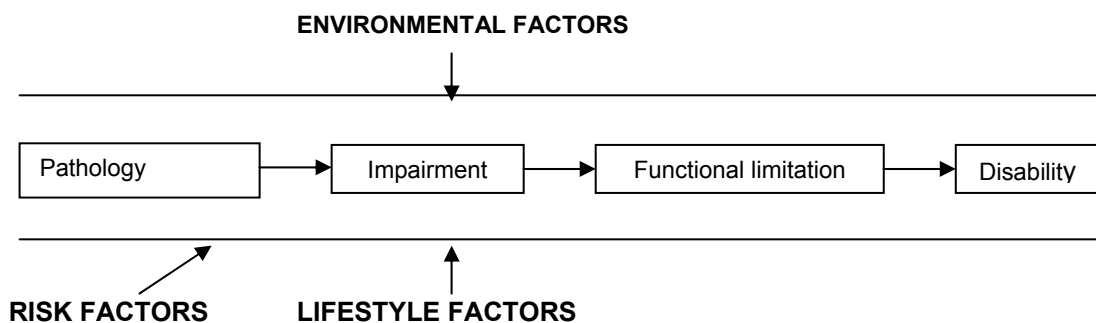
The disablement model of Nagi can give information on aspects requiring public health actions. An important application of the disablement process model is its use in identifying health states predictive of future disability and responsive to

interventions that can prevent or delay the onset and progression of disability and loss of independence with increasing age (Guralnik et al 1995, Ferrucci 1996, Lawrence & Jette 1996).

### 2.4.3 Verbrugge and Jette's model of the disablement process

Although traditional models, such as ICIDH and Nagi, indicate that all disability originates directly from disease or pathology (with disease leading to impairment, impairment to functional limitation, and functional limitation to disability), the current understanding is that also other factors can be equally responsible for the physical decline leading to disability. Compared to WHO's (1993) and to Nagi's (1991) traditional models, the disablement process as described by Verbrugge and Jette (1994) progresses from pathology through impairments to functional limitations and disability, but it describes also the personal and environmental factors that speed or slow disablement, namely, risk factors, interventions and exacerbation (figure 2.4.3).

**Figure 2.4.3** Disability Model by Verbrugge and Jette (Verbrugge and Jette 1994).



In this model (Verbrugge & Jette 1994) disability is defined as perceived difficulty in performing activities in any domain of life due to a health or a physical problem. Disability is not a personal characteristic, but it is instead a gap between personal capability and environmental demands. Disability refers to the expression of functional limitation in a social context, while functional limitations refer to

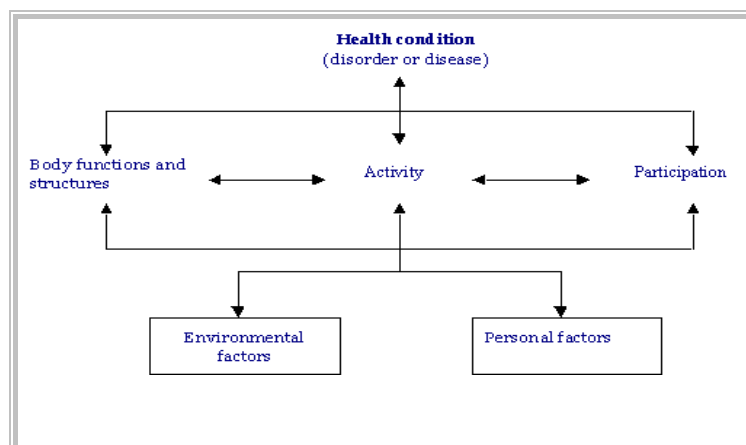
individual capability without reference to situational requirements. Functional limitations, on the other hand, are restrictions in performing fundamental physical (and mental) actions used in daily life.

#### 2.4.4 International Classification of Functioning, Disability and Health, ICF

By using a “biopsychosocial” approach, ICF attempts to achieve a synthesis, in order to provide a coherent view of different perspectives of health from a biological, individual and social perspective. ICF has moved away from being a "consequences of disease" (ICIDH) classification to become a "components of health" classification. ICF identifies the constituents of health, whereas its predecessor, ICIDH, focuses on the impacts of diseases and other health conditions that may follow as a result. It provides a multi-perspective approach to the classification of functioning and disability as an interactive and evolutionary process (WHO 2001a).

In ICF (WHO 2001a), the terms “Body Functions and Structures”, and “Activities and Participation”, replace the formerly used terms “impairment”, “disabilities” and “handicap”. The diagram presented in figure 2.4.4 visualises the current understanding of the interaction of components of the ICF. The interactions of the components in the model are in two directions, and interventions affecting in one component can potentially modify one or more of the other components.

**Figure 2.4.4** Interaction between the components of ICF (WHO 2001a).



According to ICF (WHO 2001a), an individual's functioning is an interaction or a complex relationship between the health condition and environmental and personal factors (contextual factors). There is a dynamic interaction among these entities and the interaction works in two directions. The contextual factors, environmental and personal factors, have an important role in the process. These factors interact with the individual's health condition and determine the level and extent of the individual's functioning. ICF is described in detail in chapter 7.

### **3 MEASUREMENT OF PHYSICAL FUNCTIONING IN NATIONAL HEALTH SURVEYS**

#### **3.1 National health survey settings**

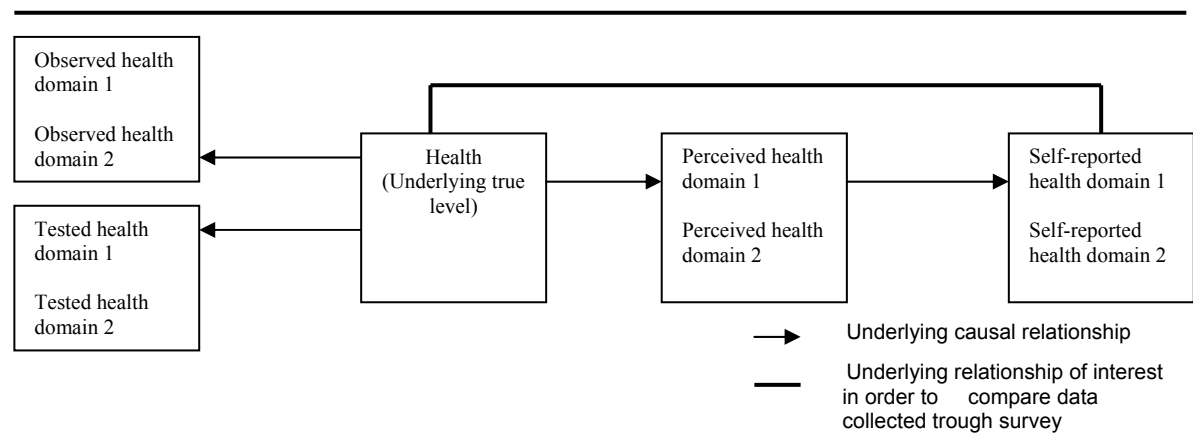
A population's true level of health may vary in a variety of domains, such as physical functioning. Information on the population's health is usually obtained through official records or population surveys (Armitage 1976, Sadana et al 2002b). **National health surveys** typically include measures of a variety of a domains of health and the target population comprises all persons living in a certain country (Picavet 2001). Usually a small proportion of the total population, representing the target population, is interviewed in a systematic and structured way (Evers 1993, de Bruin et al 1996).

According to Sadana et al (2002b) the current empirical approaches to assess health in population surveys are based on the model presented in Figure 3.1. The population's true level of health may be assessed by tested health, observed health or perceived health. Tested health is measured through laboratory or functional tests while observed health is based on professionals' clinical assessments or other ratings. Perceived health is based on individuals' knowledge and beliefs referring to self-reported health.

There are three main categories of sources of health information (Armitage 1976). In **health interview surveys, HIS**, information is obtained from members of the

general population by a health questionnaire (self-reported). In **health examination surveys, HES**, doctors, nurses, or other qualified persons perform a clinical examination or carry out tests (tested or observed health). In addition there are also **official records** such as records of morbidity. Furthermore, special registrations of diseases and use of care have been developed in many countries. An advantage of health survey data over most statistical records and sources that they allow associations between different health variables to be studied (Sadana 2002a). At least as important is that surveys are not selective in the sense of being based on users of services or beneficiaries of social security only.

**Figure 3.1** Empirical model for assessment of health status (Sadana et al 2002b).



### 3.1.1 National health interview surveys, HIS

Health interview surveys (HIS) can be carried out by face-to-face interviews, telephone interviews, mail questionnaires or a combination of methods (de Bruin et al 1996, Picavet 2001). They may also contain health examination components (de Bruin et al 1996). Health interview surveys are especially relevant for health indicators that can not be collected by means of statistical records, like indicators on health status, lifestyle and medical consumption (Hupkens et al 1999).

In Europe national health interview surveys have been conducted at intervals for perhaps the last half-century: in the UK the Survey of Sickness ran from 1943 to

1952, and has been followed since 1971 by the health section of the General Household Survey (Armitage 1976). In Finland, a series of health security surveys was initiated in 1964 (Purola 1968). Until now national health interview surveys are being performed in most European countries. Exceptions are Greece (only regional surveys), Luxembourg, Ireland and Iceland (only multipurpose surveys). Regular health interview surveys had been carried out in 14 of the 18 EU/EFTA Member States until 2001. Especially in France, Finland and in the UK many health surveys have been executed (Aromaa et al 2003a, 2003b).

Outside Europe well known examples include the health interview surveys in the United States, undertaken continuously since 1957, health interview surveys in Japan, in progress since 1953, and the disability surveys conducted by Statistics Canada since 1953 (Armitage 1976, de Bruin et al 1996). In addition to national health interview surveys, there is also an increasing number of ad hoc surveys carried out by research institutions, and university and health departments (Bowling 1997).

### **3.1.2 National health examination surveys, HES**

Surveys comprising e.g. a physical examination, functional assessment of lungs and heart, laboratory measurements of blood and urine are generally called health examination surveys (HES). Although most of the topics usually included in a health survey can be investigated using traditional structured questions in a personal interview (health interview survey), the scope for including additional measurements and tests is increasing (de Bruin et al 1996). Clinical measurement is needed to obtain valid information on many chronic conditions, functional limitations and disabilities and several key health determinants (Aromaa et al 2003a, 2003b). Such information can only be obtained by carrying out health examination surveys or by supplementing a health interview survey by a health examination survey (de Bruin et al 1996, Koponen & Aromaa 2001, Aromaa et al 2003b). The health examination and health interview are complementary, and thus data from interview and examination surveys should ideally be collected as part of the same survey (de Bruin et al 1996).

One of the best known examples of national health examination surveys is the United States National Health and Nutrition Examination Survey (NHANES) started in the late 1950s. It is now conducted on a continuing basis (Thomas & Frankenberg 2002). Japan has instituted continuous health surveys involving physical examinations, clinical and laboratory tests and various other technical measurements (Armitage 1976). In Europe, population based, national, HESs have been conducted at regular or irregular intervals, until 2001, in five countries: Finland, Germany, Ireland, The Netherlands and the UK (Aromaa et al 2003b). The most comprehensive of these have been the Finnish National Health Examination Surveys (The Mini-Finland survey 1978-80 and the Health 2000 survey 2000-2001) to be carried out in future at an interval of ten to fifteen years (Aromaa & Koskinen 2002). In addition to national comprehensive surveys, many focused, local and regional surveys have been carried out. In fact, focused and geographically limited HES surveys have been conducted in almost all EU/ETA countries. For example in Spain, Catalonia, a large regional HES survey has been conducted (Koponen & Aromaa 2001). Often regional surveys have been the national contribution to international research studies such as the Seven Country Study (Kromhout et al 1993) and the Nora study (Heikkinen et al 1997).

## **3.2 Physical functioning and national health surveys**

### **3.2.1 The evolution of measurements**

Measurement of physical functioning has a long history (Brooks 1995) partly due to its political and social importance. Information about functional status was obtained in health interview surveys in Europe and in the United States as early as in the late 1800s and early 1900s. More systematic measurements of functioning were developed and used after the Second World War in the United States, where various indices were developed to assess the ability of war veterans to cope independently in the community (McDowell & Newell 1996, Laukkanen et al 2001).

At first, satisfactory theories on which to base functional assessments were not available and the development of the measurement instruments was not

coordinated. Theoretic insight and the precision of measurements improved through research (Katz & Stroud 1989). The early development of disability indicators concentrated on measuring basic functional ability, with a focus on limitations in activities of daily living (ADL). Katz et al (1963) were the first to develop a theory and an index of activities of daily living, ADL. Later (during the 1960s), Lawton & Brody (1969) introduced the notion of Instrumental Activities of Daily Living (IADL) to cover a broader range of activities, including activities required to live independently (such as the ability to manage personal finances, do housework and shopping etc.).

One of the most influential landmarks in the development of measurement of physical functioning has been the publication of the International Classification of Impairments, Disabilities and Handicaps, ICDH, in 1980 (WHO 1993). It was partly developed to provide a framework for the study of disablement (WHO 2001a). Since the publishing of ICDH the development of measurement of physical functioning has been related to the concepts of impairment, disability and handicap (Brooks 1995, McDowell & Newell 1996).

Over the last 40 years numerous instruments to measure ADLs and IADLs have been developed (McDowell and Newell 1996). More recently, there has been a strong development of more generic health measurement instruments containing disability-related components along with items on physical and psychological health. These instruments are referred to either as “generic health status measures” or as “measures of health-related quality of life”. Prime examples of such generic instruments include the SF-36 questionnaire (and its abbreviated versions, such as SF-12), and the EuroQol-instrument. These generic health measurement instruments are increasingly used in national surveys to measure health and activity limitations, either as a complement or as a substitute to disability-specific instruments (Gaudex & Lafortune 2000).

Concerns about the reproducibility, ability to capture the spectrum of disability, precision, and sensitivity to change of self-report scales have led to the development of performance based instruments (Reuben et al 1995). Over the past years measurement protocols have been developed, including also detailed

assessment of physical performance (Guralnik et al 1994, Rikli & Jones 1997). Usually these instruments measure physical function such as balance and strength and functional tasks either real or simulated quantitatively (Reuben et al 1995). Examples of the test items designed to assess physical performance functioning in independent older adults are those included in the National Institute of Aging, Established Populations for Epidemiologic Studies of the Elderly (EPESE) project, such as chair stand and walking speed tests (Guralnik et al 1994).

### **3.2.2 Requirements for measurements**

The first step in any study is to decide what actually should be investigated or measured. The second step is to analyze the construct or constructs chosen to be the target of measurement (de Bruin et al 1996, McDowell & Newell 1996). From the national health survey perspective it is advantageous to select a commonly used measurement technique (McDowell & Newell 1996). Both interview (self-reported) and examination (performance-based) methods should be valid and in the international context they should yield comparable results (Aromaa et al 2003b).

When a potentially suitable measure or measures (interview and/or examination method) has been identified, the validity of the measure should be reviewed and evaluated (McDowell & Newell 1996, Jette et al 1999). The validity of an instrument refers to the extent to which the instrument or the score measures what it is supposed to measure. The validity of a measure in the health field has most often been evaluated by means of *content*, *construct*, and *criterion validity*. (McDowell & Newell 1996).

In addition to ensure validity of the survey as a whole and of all measures also reliability must be considered. Reliability, or consistency, is concerned with error in measurement. This refers to the consistency or stability of the measurement process across time, patients, or observers. Repeatability means that if the

measurement is repeated (twice or more), the score reported should agree (McDowell & Newell 1996).

### *3.2.2.1 Interview methods*

In population studies for reasons of simplicity and costs most measures of functional disability or capacity are based on self-report methods (de Bruin et al 1996, McDowell & Newell 1996, Bowling 1997, Kivinen et al 1998, Fenny 2002). They are relatively low in cost and easy to administer (Cress et al 1995, de Bruin et al 1996).

The questions to be included in the survey are determined by the purpose of the survey and the analysis plan that has been devised in advance (de Bruin et al 1996). For international comparison one of the key determinants is culturally valid translation and formulation of question. Mainly formulation, adaptation and translation of question influence validity. In general, there is some loss of standardisation in questions when different languages are used (the meaning of the words and phrases differs). Furthermore, the significance of health and health-related problems differ substantially between different cultures.

### *3.2.2.2 Performance-based methods*

Indicators of performance based physical functioning should fulfil also the demands of test-rest reliability, both with respect to intra-individual variation, and to differences in condition of measurements and between observers (Era & Rantanen 1995). The performance based measures should be acceptable, understandable and motivating to the individual. The social acceptability of a test may vary according to a person's age, gender, economic level, and ethnic and cultural background. For the purpose of population surveys tests should be relatively easy to administer and score, safe for participants and they should require minimum equipment, time and space (Rikli and Jones 1997).

If the same measurements are used in studies including a wide spectrum of age or functional abilities, ceiling or floor effects in the measures may occur (Era & Rantanen 1995). If the test is too difficult for a large proportion of the subjects a floor effect may occur. A ceiling effect, on the other hand, occurs when a test is too easy for a large part for the population of interest (Rikli & Jones 1997). For example the 10-second tandem balance test in the EPESE and MacArthur Successful Aging studies was too easy 40% or more of the target populations receiving perfect scores (Guralnik et al 1994, Seeman et al 1994). Rikli and Jones (1997) propose that in some cases, a simple adjustment in testing protocol can eliminate a potential floor or ceiling effect improving the discriminative power of the test.

## **4 SELF-REPORT MEASURES**

### **4.1 Instruments of self-reported measurement**

In studies of older adults, physical function and disability are usually assessed in terms of self-reported difficulty or inability to perform specific tasks of daily life across a range of functions:

- 1) Activities of daily living (ADLs) such as bathing, dressing, eating, and toileting (Katz et al 1963) or
- 2) Instrumental activities of daily living (IADLs) such as shopping, telephone use, meal preparation, and money management (Lawton and Brody, 1969), and
- 3) Mobility, upper extremity function, and exercise tolerance-demanding tasks (Nagi 1976).

Most surveys measure physical functioning through ADLs and IADLs. However, the distinction between ADL and IADL instruments is not straightforward. Some of the instruments include both IADL and ADL questions (McDowell & Newell 1996). In addition to ADLs and IADLs, a wide variety of other measures of self-reported functional status have been developed, in which the assessment of mobility is often used (Guralnik et al 1989). Some measures focus simply on basic

functioning (e.g. mobility), but more commonly they include also items of instrumental, or extended, activities of daily living (Bowling 1997). In addition general health status measures or measures of health-related quality of life may cover the physical (ADL, IADL and mobility items) as well as cognitive dimension of health (McDowell & Newell 1996, Bowling 1997).

In this section the self-reported instruments of physical functioning mainly developed or used in population surveys are presented. ADL and IADL instruments, and some other common instruments on physical functioning are discussed. In addition, general health status instruments (measures of health-related quality of life) are dealt with in a separate chapter from the physical functional perspective. The most often used and common instruments developed for survey settings are listed in table 4.1. The validity and reliability of these instruments has been based on published information (McDowell & Newell 1996). *Thoroughness* of reliability and validity testing means what kind of tests and how many, and how many studies have reported reliability and validity results. Zero means that there is no reported evidence of reliability or validity and three plus that all major forms of reliability and validity tests have been carried out. Because the thoroughness of testing may be independent of results obtained, *results* (in table 4.1) of the reliability and validity summarise the results obtained (from 0=no numeric results obtained to +++= excellent reliability and validity).

**Table 4.1** Physical functioning measurements for population survey settings (Adapted from McDowell & Newell 1996).

Measurements	Scale	Number of items	Application	Administered by (time)	Studies using methods	Reliability		Validity	
						Thoroughness	Results	Thoroughness	Results
<b>ADL scales</b>									
Index of ADL (Katz 1963)	ordinal	6	clinical	staff	many	+	+	++	++
Physical Self Maintenance Scale (Lawton 1969)	Guttman	6	survey	self-, staff	few	+	++	+	++
MOS Physical Functioning Measures (Stewart 1992)	ordinal	14	survey	self	few	+	+	+	++
<b>IADL scales</b>									
Functional Activities Questionnaire (Pfeffer 1982)	ordinal	10	survey	lay information	few	+	+	++	++
Lambeth Disability Screening Questionnaire (Patric 1981)	ordinal	25	survey	self	few	+	?	++	++
Disability Interview Schedule (Bennett 1970)	ordinal	17	survey	interviewer	few	+	+	+	+
OECD Disability Quest. (McWhinnie 1981)	ordinal	16	survey	self	many	++	+	++	+
WHO-Europe Long-term disability Questionnaire (de Bruin et al 1996)	ordinal	10+3	survey	self	few	+	?	+	?
<b>General health status measurements</b>									
McMaster Health Index Questionnaire (Chambers 1976)	ordinal	59 / 9 phys.func.	survey clinical	self (20 min)	several	++	++	++	+
Multilevel Assessment Instrument (Lawton, 1982)	ordinal	147 / 16 ADL & 3 mobility	survey	interviewer (50 min)	few	++	++	++	++
Sickness Impact Profile (Bergner 1976)	interval	136 / 12/ 3 phys.func.	survey research	self, interviewer (20 - 30 min)	many	+++	+++	+++	+++
Nottingham Health Profile (Hunt 1981)	Interval	45 / 8 phys.func	survey clinical	self (10 - 15 min)	many	++	++	++	++
Short-Form-36 Health Survey (Ware 1990)	ordinal	36 / 10 phys.func.	survey	self (5 - 10 min)	many	+++	+++	+++	+++
<b>Quality of life measurements</b>									
EuroQol Qulaity of Life Scale (EuroQol Group, 1990)	ratio	5 / 3 physical	research	self	few	+	++	+	++
Quality of Well-Being Scale (Bush & Kaplan, 1973)	ratio	18 / phys.func.	research	interviewer (7 min)	many	++	+++	+++	++

#### 4.1.1 ADL instruments

Activities of daily living (ADL) refer to basic personal care tasks of everyday life. These mean a set of tasks necessary to function independently and to attend to personal care needs (Wiener et al 1990, Rodgers & Miller 1997). It has been claimed that ADL items on walking or bathing offer pure measures of physical (as well as cognitive) function (McDowell & Newell 1996). In addition, studies have identified ADLs as significant predictors of admission to a nursing home, use of paid home care, use of hospital and physician services, living arrangements, insurance coverage, and mortality (summarised in Wiener et al 1990).

Historically, the measurement of ADLs has occurred in outpatient and rehabilitation settings (Sager et al 1992). As a consequence, most ADL questions reflect relatively severe levels of disability, relevant mainly to institutionalised patients and the elderly and so are insensitive to variations at the upper levels of functioning, where most people score. Therefore, it is claimed that ADL scales are unlikely to be suitable for health surveys, for they are not sensitive to minor deviations from complete well-being (McDowell & Newell 1996). However, a number of national surveys measuring ability of elderly people to perform the ADLs have been implemented (Wiener et al 1990).

Katz (1963) created the basic direction for ADL measurement. He created The Activities of daily living Scale, Index of ADL, which assesses if personal assistance is received in eating, bathing, dressing, transferring, using the toilet, and continence (Katz 1963). It is one of the few ADL instruments to provide theoretical justification for the topics included: Katz noted that the loss of functional skills occurs in a particular order so that the most complex functions are being lost first (McDowell & Newell 1996). The Index of ADL was originally developed as an observational dichotomous scale, but it was adapted over time to survey self-reports of performance (Rodgers & Miller 1997). The Katz scale has been used as a reference instrument for example in the OECD long-term disability questionnaire (McWhinnie 1981) and in the recommendations of the WHO-Europe Long-term disability instrument (de Bruin et al 1996).

Over the years, a number of measures of physical functioning covering tasks similar to the Katz ADL scale have been introduced. One review identified 43 different clinical and survey indices of ADL (Feinstein et al 1986). However, the development of most of these instruments has been uncoordinated and there is not yet consensus about the best way to measure ADL limitations (McDowell & Newell 1996). McDowell and Newell (1996) have listed ADL instruments suitable for use in survey settings. The classification of these authors has been based on what appears to be the primary orientation of the scale and the evidence of reliability and validity of the instruments has been stressed. According to McDowell & Newell (1996) Physical Self-Maintenance Scale (Lawton & Brody 1969) and Medical Outcome Study Physical Functioning Measures (Stewart 1992) are pure (include only ADL questions) measures of ADL, which can be used in survey settings.

The Physical Self- Maintenance Scale, PSMS, includes six ADL items: toileting, feeding, dressing, grooming, physical ambulating, and bathing ranging in five point rating scales from total independence to total dependence (Lawton & Brody 1969). The scale records activities similar to those included in Katz's Index of ADL. PSMS is a reliable and valid ADL scale for survey research application (as well as clinical application). However on its own PSMS has not been widely reported in the literature, but is known as a component of other general health status instruments such as the Multidimensional Health Status Questionnaire and the Multi Level Assessment Instrument (McDowell & Newell 1996, see chapter 4.1.4.5).

The situation is somehow similar in the Medical Outcome Study Physical Functioning Measures, MOS. On its own it is not widely used but its ten ADL (physical functioning) items appear in the well-known Short-Form-36 (see chapter 4.1.4.3). The MOS instrument includes items sensitive to variation at relatively high levels of functioning. Thus, it is suitable for use in health surveys and also in relatively healthy populations (McDowell & Newell 1996).

#### 4.1.2 IADL instruments

Wiener et al (1990) argue that as useful as ADL measures are, they do not measure the full range of activities necessary for independent living in the community. In contrast, instrumental activities of daily living (IADL) measure the ability to live independently in the community and the ability to perform household activities, including functioning in the social world and the world outside home. Terms like extended ADL, social ADL and domestic ADL are also commonly used in the literature (Ward et al 1998).

IADLs include activities such as shopping, housekeeping, doing laundry, using transportation, taking medications, handling money, and using the telephone (Lawton & Brody 1969). These are not pure measures of physical function, namely activities such as cooking, shopping, and cleaning reflect both social roles and physical capacity. IADL items reflect a higher level of functioning and are sensitive to lower levels of disablement. Thus, IADL scales are commonly used in less severely handicapped populations and often as survey methods for general population studies (McDowell & Newell 1996).

There are many IADL assessments suitable for use in measures of disability in populations. In 1998 Ward and his colleagues (1998) made a review of IADL assessment used in studies of older people. They reported findings from 14 instruments (Ward et al 1998). Robine et al (2002) up-dated the review of Ward et al (1998) with three new instruments. These scales (altogether 17) and the coverage of their domains are listed in table 4.1.1.

Although several IADL scales have been developed, only few are suitable for use in population surveys. McDowell & Newell (1996) have listed four IADL-instruments designed for use in surveys and/or research settings (see table 4.1.1). They have emphasised the importance of reliability, validity and theoretical basis in their reporting of IADL instruments.

The Functional Activities Questionnaire, FAQ, is a screening tool for assessing independence in daily activities designed for community studies of normal ageing (Pfeffer et al 1982). Although the FAQ measures daily activities of normal ageing there are still some drawbacks compromising its use in population surveys. The FAQ is not self-administered but is completed by lay information, such as by a relative or a close friend. In addition it measures mainly social functioning rather than physical (McDowell & Newell 1996).

The Disability Interview Schedule is one of the few disability instruments designed for survey use. It was designed to measure the prevalence and severity of disability in epidemiological surveys for planning health and welfare services (Bennett et al 1970). However, McDowell & Newell (1996) argue that the instrument is quite old and lacks sufficient validity testing. Therefore the OECD instrument should be considered as an alternative.

The OECD (Organisation for Economic Co-operation and Development) Long-term Disability Questionnaire (McWhinnie 1981) is a survey instrument summarising the impact of ill health on essential daily activities. It contains 16 questions. The items cover vision, hearing, speaking, carrying, walking, and cutting toenails, picking up from the floor, cutting food and biting/chewing. It has been used in several population studies in Europe (Klaukka 1981, Raymond et al 1981, Van Sonsbeek 1981), in the USA (Wilson & McNeil 1981) as well as in Canada (McDowell 1981) and Japan (McDowell & Newell 1996). Although it has been widely used, there are problems with the scale. The instrument is designed as a survey instrument but the questions cover relatively severe levels of disability. Therefore the questions are most relevant to people over 65. In addition, reliability and validity results are poor. The instrument is narrow in scope compared, for example, to the Lambeth questionnaire (McDowell & Newell 1996).

**Table 4.1.1** Coverage of domains by current IADL assessment (Robine et al 2002).

IADL scale/author	Cooking	House work	Transport	Social/Leisure	Laundry	Shopping	Financial	Work	Medicine	Telephone
Lawton & Brody (1969)	√	√	√		√	√	√		√	√
Northwick Park (Benjamin, 1976)	√									
ORAS (Fillenbaum, 1978)	√	√	√			√	√		√	√
Sheikh et al (1976)	√									
Whiting & Lincoln (1980)	√	√	√		√	√	√			
Fortinsky et al (1981)	√	√			√	√				
Klein & Bell (1982)										√
Frenchay (Holbrook & Skilbeck, 1983)	√	√	√	√	√	√		√		
FIM (Hamilton et al 1987)				√						
Yerax et al (1988)	√	√	√	√	√		√	√		
Sonn & Asberg (1991)	√	√	√			√				
ALSAR (Williams et al 1991)	√	√	√	√	√	√	√		√	√
Byres & Parker (1992)	√	√			√	√				
EADL (Lincoln & Gladman, 1992)	√	√	√	√	√	√	√			
COPM (Law et al, 1994)	√	√	√	√	√	√	√	√		
AMPS (Fisher, 1994)	√	√		√	√					
GARS (Kempen et al 1996)	√	√			√	√				
TOTAL	15	13	9	7	11	11	7	3	3	4

See references from Robine et al 2002

The OECD questionnaire was the first attempt to develop an internationally applicable set of disability items (McWhinnie 1981). A few years later the WHO Regional Office for Europe, WHO-Europe, made recommendations for standardised instruments to measure both short-term and long-term disability. The WHO-Europe “long-term disability list” (de Bruin et al 1996) is designed to measure disability through IADL-type limitations, covering the key basic activities related to mobility, self-care and communication. The instrument has not been widely tested and it is likely to prove to be most relevant in measuring relatively severe levels of disability more frequently found in the population 65 and over (Gudex & Lafortune 2000). Despite this criticism it has been used with good results in 1978-80 in the first Finnish national health examination survey (Aromaa et al 1989).

### **4.1.3 Other instruments**

In addition to ADLs and IADLs, a wide variety of other measures of self-reported functional status have been developed. The assessment of mobility has been found to be an especially important part of functional evaluations. Mobility can be evaluated by self-report using a hierarchical approach, starting with simple mobility tasks such as transferring from bed to chair and progressing through walking short and longer distances and climbing stairs (Guralnik 1997).

Nagi (1976) was first to propose a scale for physical functional limitations measurement. In 1976 he established the concept of physical performance, referring to sensory motor functions and designed a scale for epidemiological surveys. This scale classified individuals as having no, some, or great difficulty in the seven domains: 1) standing for a long time, 2) lifting or carrying weights of approximately ten pounds, 3) going up and down stairs, 4) walking, 5) stooping, bending or kneeling, 6) using hands and fingers, and 7) reaching with either one or both arms. The proposals of Nagi (1976) have been used in many studies and surveys in USA (McDowell & Newell 1996).

### **4.1.4 General health status measurement**

A growing number of health measurements combines physical as well as social and psychological themes in one instrument. It has even been estimated that the present ADL and IADL scales may be replaced by these broader-ranging general measurement methods. Some of the general health status instruments have been widely used in population surveys and have even documented validity and reliability results (McDowell & Newell 1996).

#### *4.1.4.1 The Sickness Impact Profile (SIP)*

The Sickness Impact Profile, SIP, is one of the general health status measures used in population surveys. It is broad in scope and is intended for use in measuring the outcomes of care in health surveys, in programme planning and policy formation

(Bergner et al 1979). The SIP was adapted for use in England and renamed the Functional Limitations Profile, FLP. The FLP is the version of SIP normally used in British studies (McDowell & Newell 1996).

SIP measures health status by assessing how sickness affects daily activities and behaviour. It is composed of statements such as “ I do not walk at all”, each describing the change in behaviour and specifying the extent of limitation (McDowell & Newell 1996). The scale comprises in total 136 statements in 12 categories in which three form the physical dimension of the scale; ambulation, mobility and body care and movement. The 12 categories may be scored separately or two dimension scores may be formed, a psychosocial score and a physical score (formed from ambulation, mobility and body care and movement items, Bergner et al 1981). The scale can be administered either by interview in 20 to 30 minutes or it can be self-administered. The SIP has been translated into Dutch, Spanish, French, and Swedish and also into other European languages (McDowell & Newell 1996).

According to McDowell & Newell (1996) the SIP has several advantages. First, it is well established and has been extensively used. Secondly it is appropriate where a comprehensive assessment is required, since it is applicable to many countries, to all age groups, and to any medical conditions (McDowell & Newell 1996). In addition, the reliability of SIP is good, and it appears valid as a discriminative method (Berner et al 1981).

#### *4.1.4.2 The Nottingham Health Profile (NHP)*

The Sickness Impact Profile has influenced the design and content of The Nottingham Health Profile, NHP (McDowell & Newell 1996). NHP was designed to give a brief indication of perceived physical, social and emotional health problems (Hunt et al 1985). NHP includes eight items of physical abilities. In addition to physical abilities it includes pain, sleep, social isolation, emotional reactions and energy level. It is self-administered and takes approximately 15 minutes to complete (Hunt & McEwen 1980).

NHP has been translated into most European languages (McDowell & Newell 1996). Although it was originally suggested that NHP could be used in health surveys, Hunt & McKenna (1992) suggested that NHP should not be used as a survey instrument. They argue that NHP is suitable as a survey tool only in populations, such as the elderly, where there are likely to be people with significant disability (Hunt & McKenna 1992).

#### *4.1.4.3 Short Form of the Medical Outcomes Study questionnaire (SF-36)*

Despite its limitations, The Nottingham Health Profile was one of the most popular instruments in Europe until the advent of the SF-36 (McDowell & Newell 1996). There are several versions of SF measures (SF-36, SF-20, SF-12), and the number of their items is indicated by the name of the measure (Gandek et al 1998). The 36-item short form of the Medical Outcomes Study questionnaire, SF-36, was derived from the work of the Rand Corporation of Santa Monica during the 1970s and was designed as a generic indicator for use in population surveys and evaluative studies of health policy (Stewart et al 1989). Currently, a short SF scale for survey purposes, SF-8, is in development. The SF-8 was constructed to replace the SF-36 and SF-12 in population health surveys in the U.S. and internationally. Accordingly, it has been translated and linguistically validated for use in more than 30 countries and languages. The development and the validation of the new SF-8 Health Survey is documented in a manual by John E. Ware, Mark Kosinski, James E. Dewey and Barbara Gandek: "How to Score and Interpret Single-Item Health Status Measures: A Manual for User of the SF-8 Health Survey", Quality Metric, Inc., Lincoln RI, USA (in press).

The most frequently used version SF-36 taps eight domains of functioning and well being. The ten physical functioning items in SF-36 are similar to the MOS, Medical Outcome Study Physical Functioning Measures (see chapter 4.1.1). The physical activity items focus on gross activities such as walking, bending, and kneeling. In addition to these there are four items on role limitations resulting from physical health problems. SF-36 and SF-20 may be found in McDowell & Newell 1996.

The SF measures have been translated into many languages and they have been extensively used. They may be self-administered or used in personal or telephone interviews. The questions take approximately five to ten minutes to complete (McDowell & Newell 1996). SF measures have been widely and cross-culturally validated (McHorney et al 1993, McHorney et al 1994, Sullivan et al 1995, Bullinger et al 1998, Gandek et al 1998, , Ware et al 1998). It is even estimated that the SF-36 will become one of the standard measures in the field (McDowell & Newell 1996).

#### *4.1.4.4 Quality of Life Scales*

In addition to these general health status measurements some quality of life measurements (QOL) cover also the physical dimension of health. Usually the quality of life measures combine several well-being and health-related themes in one instrument and cover physical, emotional, and social dimensions of health (McDowell & Newell 1996). For example The European Quality of Life Scale, EuroQol, is intended for use in evaluative studies and policy research (not for national health surveys) and the measure expresses health status in a single index score (Brazier et al 1993). EuroQol includes only core functional status questions and no questions on symptoms. It comprises five dimensions of health: mobility, self-care, role (or main) activity, pain, and mood. Within each dimension, the respondent chooses one of three alternatives, indicating 'no problems', 'some problems', and 'severe problems' in this dimension (McDowell & Newell 1996). The EuroQol is well suited for measuring health in populations with major morbidity (Anderson 1993). The index is available in many European languages (such as Dutch, English, Finnish, Norwegian, and Swedish, McDowell & Newell 1996).

Quality of Well-being scale, QWB (formerly the Index of Well-Being), on the other hand, is intended to be used as an outcome indicator and in estimating present and future need for care. It is applicable for individuals as well as populations and can be used with any type of disease. The coverage of QWB is oriented strongly toward physical problems: the mobility dimension concentrates on ability to get around or transport oneself. Of the Quality of life scales the QWB is the most widely used. Its

advantages lie in its clear conceptual approach, attention to scaling, and widespread use (McDowell & Newell 1996).

A one hundred item scale, WHOQOL, covers many dimensions of everyday life (not included to the table 4.1). The original WHOQOL with 100 items is not applicable for surveys, while the WHOQOL-BREF, the abbreviated version with 24 items, may be usable. WHOQOL produces a multi-dimensional profile of scores across six domains and 24 sub-domains of quality of life (The WHOQOL Group 1998, WHOQOL Group 1995). The domains are 1) physical domain (including pain and discomfort, energy and fatigue, sexual activity, sleep and rest, sensory functions), 2) psychological domain 3) level of independence (mobility, activities of daily living, dependence on medication or treatments, dependence on non-medical substances, e.g., alcohol, tobacco, drugs, communication capacity, working capacity), 4) social relationships, 5) environment 6) spirituality/religion/personal beliefs (The WHOQOL Group 1998). Its reliability and validity have been extensively evaluated in international collaborative fieldwork. Even whole 24 item scale is probably too long for surveys a short version of only eight items is under development.

#### *4.1.4.5 Other general health status instruments*

Some of the general health status measures cover physical functioning but they have not been widely used. One of these is the McMaster Health Index Questionnaire, MHIQ, providing a profile of scores describing physical, emotional and social function. It is intended for use in clinical research, principally with persons living in the community (i.e. non-institutionalised). An equal number of items (altogether 59) cover physical, emotional and social functioning. The physical items cover physical activities, mobility and self-care (as described by Katz), and communication (McDowell & Newell 1996).

The questionnaire can be used in self-completed mode (20 minutes) or via personal or telephone interviews. The MHIQ has mainly been used in studies at the McMaster University in Canada. However, one factor hindering a wider use of this instrument is

the lack of information on reliability and validity hinders the wider use of this instrument (McDowell & Newell 1996).

Another general health status measurement that lacks the reliability and validity information is the Multilevel Assessment Instrument, MAI (Lawton 1982). It covers health problems, activities of daily living (ADL) skills, as well as psychological well being, environment and social interaction. MAI has altogether 147 items. The instrument is administered in a home interview taking on an average of 50 minutes to complete. According to McDowell and Newell (1996) the scale shows potential but lacks adequate documentation and validity analysis.

There are also some new measures of well-being and functioning. For example the 15D is a generic, comprehensive, 15-dimensional, standardised, self-administered measure of health-related quality of life (HRQoL) that can be used both as a profile and single index score measure (Sintonen 2001, not included to the table 4.1). It includes items on physical and sensory functioning and usual activities. As a profile measure on roughly comparable dimensions the 15D performs equally well as the Nottingham Health Profile (NHP) and SF-20, in some respects even better, and clearly better than EuroQuol (-5D) (Sintonen 1994, 2001). The 15D scores are shown to be highly reliable, sensitive and responsive to change, generalisable at least in Western societies, and particularly valid for deriving quality-adjusted life years (QALYs) gained for resource allocation purposes. The instrument is recommended by the Washington Panel and is available in several languages for clinical economic evaluation and population studies (Sintonen 2001).

## **4.2 Characteristics of the items and the instruments**

Instruments measuring physical functioning vary greatly. For example in a comparison of 11 national surveys, sources of variation in ADL instruments included 1) which items were measured; 2) scaling classification by level of difficulty and type of assistance; 3) use of mechanical aids, and 4) duration of problems (Wiener et al 1990).

## 4.2.1 Differences in items

### 4.2.1.1 ADL items

Although numerous self-report instruments have been developed to assess self-care or basic activities of daily living, none has become the standard in the field (Guralnik et al 1989). In health interview surveys the topics or items of ADL vary according to the number and type of items included, or the way of evaluating the level or type of restriction (Wiener et al 1990, Robine et al 2002). In 1981, eleven ADL-scales were compared and only three activities; eating, dressing, and bathing were common in all scales (Hendric et al 1981). In a comparison of 22 scales only three activities, transfer, dressing and eating, were present in 90% of all instruments reviewed (Unsworth 1993).

Although the actual list of ADL tasks varies somewhat by surveys, most surveys include a list of eating, dressing, bathing, transferring, and toileting (Wiener et al 1990, Sonn 1996). Mobility measures, such as walking and going out, are also often included (Rodgers & Miller 1997). The choice of items to be included in ADL instruments is not straightforward. Also the more ADL tasks are included, the larger will be the number of people with ADL disabilities (Wiener et al 1990, Rodgers & Miller 1997). On the other hand, many of the items are strongly intercorrelated suggesting that it may not be necessary to inquire about all of these, certainly not for many research purposes.

It has been suggested that a core of three items; walking across a room, feeding and dressing, provide sufficient information and only limited additional information is gained by asking about the other items of ADL (Rodgers & Miller 1997, Ferrucci et al 1998). These three items have been estimated to be most applicable for policy and research contexts where an individuals ADL functioning is used as a predictor for service use, living arrangements, morbidity, or mortality. The more comprehensive ADL indices may be appropriate for estimates of need for different types of services, insurance coverage, and placement decisions (Rodgers & Miller 1997). Wiener et al (1990) confirm this by describing that public policy has focused on five ADLs: eating, toileting, transferring, dressing and bathing. These five items have been proposed for

use in determining eligibility for benefits in several insurance programmes (Wiener et al 1990).

The use of different sets of items is essential to depict the whole spectrum of severity level of restriction. Findings of Ferrucci et al (1998) provide strong evidence for this. They found that at the population level, decrements in functional ability progress from activities that required dynamic balance, agility and muscular strength down to the activities performed using only the upper extremities (Ferrucci et al 1998). Survey estimates of physical ADLs suggest that difficulty in bathing is the least severe level of ADL disability, followed by dressing, toileting, transferring, and feeding (Lazaridis et al 1994, Rodgers & Miller 1997).

#### *4.2.1.2 IADL items*

The situation is quite similar in the field of IADL. Even if numerous self-report instruments have been developed to assess instrumental activities of daily living, none has become the standard in the field (Guralnik et al 1989). In addition, there is not yet consensus about the activities to include in the assessment of IADL (Ward et al 1998).

The activities most often included in the assessments are cooking, housework, social activities / hobbies, transport, laundry, shopping, and financial activities. The use of telephone, work and medication are the most rarely covered ones in the scales (table 4.1.1., Ward et al 1998). Although the list of items can be extensive, Fillenbaum (1985) identified five items (getting to a place beyond walking distance, shopping for groceries or clothes, preparing own meals, doing housework, and handling money) as essential for determining the need for services. The ability to perform these activities without personal assistance is the implied criterion of independence.

One source of variation in the scales may be that the IADL scales vary from culture to culture since the content of IADL measure often reflects specific cultural concerns (Fillenbaum 1985, McDowell & Newell 1996). For example, British measures frequently included items on making tea and carrying a tray, whereas Dutch scales

include making the bed, and the New Zealand scale covers gardening ability (Fillenbaum 1985). In fact, some differences may also be environmentally determined depending on differential introduction of changes in building communication and technology in different societies. Ward et al (1998) argue that as IADL is culturally and environmentally determined it seems that no one assessment will ever meet the needs of all populations.

One characteristic for IADL, as well as for ADL items, is that different items of IADL describe different levels of disability. Studies have found a gradient severity for IADLs together with a combined ordering for IADL and ADL items together. Finch et al (1995) found that of the IADL items meals preparation and taking medicine were the most severe levels of IADL limitations while shopping and cleaning the house were the least severe.

#### **4.2.2 Differences between instruments**

In addition to the variation in items, the content of instruments varies significantly. Hupkens (1998) reviewed the coverage of the 78 national health interview surveys and specific questions in a subset of 52 surveys conducted in the European Union. The comparability was assessed in terms of the wording of the questions across surveys. Of the ten most often included questions in the 52 surveys only questions related to height and weight were considered comparable (Hupkens 1998). Rasmussen and colleagues (1999) documented variations among questions, such as recall periods, definition of terms, response categories or qualifications. The authors reviewed 16 national health surveys conducted within 11 European countries and concentrated specifically on the questions addressing aspects of health status, such as limitations in daily activities and functioning. Most questions appeared not to be comparable primarily due to differences in recall periods. Skip patterns, where only a subset of individuals was asked questions (e.g. those with chronic illnesses or not), the types of limitations included, and the response scales were common differences among ADL question series (Rasmussen et al 1999).

Already seemingly minor differences in response categories and in the wording of the questions cause major differences in estimated disability prevalence (Picavet & van den Bos 1996, Rodger & Miller 1997). The impacts of these differences are discussed in the following sections.

#### *4.2.2.1 Response categories*

The response scales are usually a yes/no dichotomy, a series of graded adjectives or a numeric rating scale with points (McDowell & Newell 1996). Scales to rate individual ADL and IADL activities take basically three standard forms: 1) The degree of difficulty in performing certain activities (how hard is it to perform an activity); 2) the degree of assistance or dependence (whether or not a person uses or needs assistance to perform an activity); and / or 3) whether or not the activity is performed or can be performed (Jette 1994).

In the difficulty measures respondents are asked to estimate the degree of difficulty in different scales for example, little difficulty, some difficulty or a lot of difficulty (Crawford et al 1997). A widely used example of the difficulty rating approach is Nagi's physical performance scale (Nagi 1979).

In survey scales assistance can be defined in a number of different ways. A measure of dependency can either assess if a person needs assistance or whether she or he uses assistance (Jette 1994, Crawford et al 1997). "Need" scales include persons who receive assistance along with those with unmet need, whereas "use" scales exclude those with need for assistance that has been unmet (Jette 1994). According to Wiener et al (1990) assistance can include human help or mechanical help. Mechanical assistance includes such devices as grab bars or special beds to facilitate transferring (Wiener et al 1990). In some dependence scales assistance is defined to include both human and mechanical help (Jette 1994). The most frequently used ADL measure employing a dependence rating scale is the Katz Activities of daily living scale (Katz 1969).

Some assessments allow the use of an aid or equipment, while others do not consider the person independent if equipment is used (Ward et al 1998). However the greatest concern in scaling methods is that the different disability rating scales can have a dramatic impact on prevalence estimates of disability in older populations (Jette 1994, Rodgers & Miller 1997). Jette (1994) found that measures of difficulty gave estimates for special ADLs from 1.2 to 5 times greater than scales asking about assistance from others. The effects of scaling methods varied substantially across ADLs. Walking and bed/chair transfer disability occurred four to five times more often using the “difficulty / does not do” scale than the “human help / does not do” scale. Differences across scaling methods were much smaller in self-care areas such as dressing and eating (Jette 1994).

Similar patterns of variations were reported in the National Long Term Care Survey (Wiener et al 1990) and in the research of Rodgers and Miller (1997). The only certain way to compare different disability estimates is to use the same scaling methods across studies (Jette 1994). As far as this is not possible one ought to keep in mind the impact of scaling methods.

Guralnik et al (1989) argue that without precise guidelines by which to assess the level of disability, it may be problematic for subjects to report whether they have little, some or a lot of difficulty with a particular activity. However, Rodgers and Miller (1997) found that clear response proposals (questions about whether any difficulty is experienced, any help is received, or any equipment is used) convey sufficient information for many purposes. The more qualitative questions (about the amount of difficulty, the frequency with which help is received, or the type of equipment used) do not necessarily offer any additional information (Rodgers & Miller 1997).

#### *4.2.2.2 Duration of disability*

In addition to variations in the response categories, the scales may differ according to the duration of the disability. The scales may use different reference periods such as “during the last month” or “yesterday” (Wiener et al 1990, Reuben et al 1995). The distinction between whether the question concerns long-term or short-term disability

can be made in the introductory part of the question, in the question itself or in the response categories (Robine et al 2002).

The different emphasis on long- or short-term disabilities reduces the comparability of the scales (Wiener et al 1990). In addition, as is the case with the OECD Long-term Disability Questionnaire, the distinction between long- and short-term disabilities may not have been adequately explained to the respondent, which may lead to bias of the results (McDowell & Newell 1996).

#### *4.2.2.3 Capacity versus Performance*

One important conceptual issue in self-reported methods is the framing of questions (McDowell & Newell 1996, Young et al 1996). Self-report instruments of physical functioning usually ask whether the persons are capable of performing a task or whether they actually perform the task (Reuben & Sui 1990, Young et al 1996). The distinction between a person's physical capacity and his actual performance in managing his life in the face of physical limitations has been widely discussed (Branch & Meyers 1987, McDowell & Newell 1996, Young et al 1996, Bowling 1997).

Performance is what a person "does do" in usual circumstances of everyday life, and capability is what a person "can do" in a defined situation apart from real life (McDowell & Newell 1996). The performance wording implies a concrete set of real world circumstances (if the action queried has not been done the answer is no), where-as capacity does not link the circumstances to the real world but rather the persons capability to do the activity (hypothetical) (McDowell & Newell 1996, Young et al 1996). Thus, capacity can be seen to refer to the environmentally adjusted ability of the individuals. To assess the full ability of the individual, one would need to have a "standardised" environment to neutralise the varying impact of different environments on the ability of the individual (WHO 2001a).

There is some evidence that the capacity wording may substantially under-estimate the true prevalence of disability in populations (Glass 1998), since people tend to be optimistic about their capabilities. Despite this, the capacity wording is often used in

IADL items (McDowell & Newell 1996, Glass 1998). According to Robine et al (2002) also physical and sensory functioning can be obtained from asking the respondent to judge their capacity to do the task (“are you able to / could you climb stairs”) rather than to report their actual performance (“do you climb...”) This may well be a good choice since the performance wording has also considerable drawbacks as many people do much less in their everyday life than they are capable to. However, the most recent ADL indices favour the performance approach for ADL items. The performance approach may be better suited for ADL than IADL activities since everybody can be expected to need to manage ADL activities daily or almost daily.

For ADL items an intermediate phrasing has also been used as “do you have difficulty with...” (McDowell & Newell 1996). This formulation of questions has met critique as well. The wording of “ do you have difficulty with” seems to lie between capacity and performance, thus it does not tell whether the person does or does not do the activity in question, or whether he cannot (McDowell & Newell 1996). However, this form of questioning has been used for example in the Lambeth Disability Screening Questionnaire (McDowell & Newell 1996) and in the OECD Long-term Disability Questionnaire (McWhinnie 1981).

## **5 PERFORMANCE BASED MEASURES**

### **5.1 Definition of performance-based measures**

The second category of measures of physical functioning is performance-based measures (Reuben & Sui 1990, McDowell & Newell 1996, Bowling 1997, Hoeymans et al 1997). Methods based on laboratory or diagnostic tests are generally termed “objective measurements” (McDowell & Newell 1996). An "objective" physical performance measure is one in which an individual is asked to perform a specific task in a standardised manner and is evaluated in a uniform manner using predetermined criteria, often including the time to completion or counting of repetitions (Guralnik et al 1989). It requires the co-operation of the patient /individual and the presence of an examiner (Reuben & Sui 1990).

In population studies performance-based assessments of functional capabilities have not been as widely used as self-reported measures (Branche & Meyers 1987, Hoeymans et al 1996, McDowell & Newell 1996, Young et al 1996, Bowling 1997, Kivinen et al 1998). However, a variety of performance tests have been developed for use in institutions (Gerety et al 1993, Winograd et al 1994) and also among community-dwelling older persons (Williams & Hornberger 1984, Tinetti 1986, Tinetti & Ginter 1988, Reuben & Siu 1990, , Williams et al 1990, Weiner et al 1992, Guralnik et al 1994). The limitation of many of the current instruments is that physical impairments often are not detected until late in the disability process. Thus, such instruments are not suitable for younger people e.g. high functioning (Rikli & Jones 1999).

Several fitness tests (treadmill and cycle ergometer tests, bench step tests etc.) have been developed and validated for describing physical capacity of younger people. However many of them are inappropriate for older adults (too difficult or even risky). In addition, these protocols often require expensive equipment or extensive training for test technicians and have therefore been judged not to be feasible for use in clinical or population survey settings (Rikli & Jones 1999). On the other hand, there are at least some examples of large scale population surveys having successfully employed such methods (Aromaa & Koskinen, 2002).

There are still only a few standardised tests for assessing physical performance in large populations (Rikli & Jones 1997). There is, however, some evidence validating performance measures of functioning as true measures of physical health status in non-disabled elderly people (Guralnik et al 1994). Due to the current limitations only tests and test batteries designed to describe physical functioning of community dwelling older adults (suitable also for large populations) are presented here. In recent years, these measures have been increasingly employed in studies of functional status and disability in old age (Guralnik 1997, Guralnik et al 2000).

## **5.2 Performance assessment instruments**

In general, performance based tests may be categorised by either the domain of functioning they assess (e.g., upper extremity versus lower extremity) or the complexity of the functioning they assess (more basic physiologic abilities, such as grip strength, versus more complex tasks, such as putting on a blouse). Myers et al (1993) have categorised performance tests into four main groups: tests of motor capacity, manual ability, self-care abilities, and more complex or instrumental abilities (Myers et al 1993).

In this section performance instruments will be presented in three basic categories: 1) tests of lower extremity, 2) tests of manual ability and 3) tests of sensory functioning (seeing and hearing). The focus of this section is on 4) physical performance batteries suitable for health surveys. Attention is focused on instruments of mobility (area of physical functioning) developed for clinical or population-based research and highly structured to permit uniform data collection from a number of participants.

### **5.2.1 Tests of the lower extremities**

Good lower extremity functioning is necessary for mobility and is thus a critical element of independence in the community. Tests of gait speed, standing balance and time to rise from a chair have been used to evaluate lower extremity function (Guralnik et al 1994). These tests accurately predict disability across populations (Guralnik et al 2000). In addition they have been found to predict mortality and nursing home admission in representative samples of older adults (Guralnik et al 1994) and indicate disability in non-disabled persons over age 70 years (Guralnik et al 1995). They have the additional advantage of being quite independent of changing environmental conditions.

### 5.2.1.1 Gait speed

Gait speed has been shown to have a graded relationship with mobility and activity of daily living disability in the non-disabled population (Guralnik et al 1995). It predicts further nursing home admission, morbidity and mortality (Guralnik et al 1994). Sonn (1996) proved that women and men who stayed independent when aged over 70's had significantly higher maximal walking speed than those who became or already were dependent. Further-more lower body function is strongly associated with incidence of falling: usual walking speed of less than 0.6 meters/ second is associated with increased risk of falls (Nevitt et al 1989). A subject's ability to increase or decrease walking speed above or below a comfortable pace suggest a potential to adapt to varying environments and task demands (Steffen et al 2002).

Gait speed is measured over a relatively short distance and its measurement does not include endurance as a factor (Steffen et al 2002). The walking distance in the assessment of gait speed varies greatly between surveys. Myers et al (1993) have summarised the variance of methods across walking tests. Distances ranged from walking 2 and 12 steps, walking 12 feet, 50 feet, 30 meters or approximately 98 feet (Myers et al 1993). In some surveys the distance of 6.1 meters has been used (Fiatarone et al 1994). For the assessment of gait speed over a short distance Guralnik et al (2000) believe that a 4-meter walk is a good distance because it has been demonstrated to be feasible in the home as well as in the clinical settings and that a longer distance may (only) improve measurement accuracy.

Regardless of the measurement method, gait speed measurements are considered highly reliable in people without known impairments that should affect gait (Steffen et al 2002). Gait speed is a simple performance measure, easily assessed and interpreted (Cress et al 1995, Guralnik et al 2000). It is a well-established performance measure of mobility function in population surveys, because of its relatively high and stable intra-rater (test-rest) reliability. Hoyemans et al (1997) have reported the correlation of retest reliability for gait speed to be 0.90 and Jette and colleagues (1999) reported that the intraclass correlation coefficient (kappa) for 8-foot walk was 0.76.

As gait speed is easy to measure and may be done quickly in the clinical as well as in research settings (Cress et al 1995, Guralnik et al 2000). Guralnik et al (2000) evaluated whether measuring gait speed alone may capture the predictive power of a more comprehensive physical performance battery. The findings indicated that gait speed alone is nearly as good a predictor of disability outcomes as a full performance battery of the lower extremity (see chapter 5.2.4.2). In addition it has been stated that walking tests are more reliable than other performance based measures in elderly people, such as timed chair stand and weight lift (Jette et al 1999).

#### *5.2.1.2 Walking – endurance*

An adequate level of aerobic endurance during ageing is necessary in order to perform many everyday tasks such as walking, shopping, or performing recreational or sport. The time to carry out the walking tests may vary from 2 minutes to, 6-minutes or 12 minutes (Myers et al 1993). It has been suggested that the 2-minute walking test may not discriminate well enough, but the 12-minute test may be unnecessarily long (Guyatt et al 1984). However, most community-dwelling elderly persons can quickly and safely perform the 6 -minute walking test (Enright et al 2003).

The purpose of the test is to see how far the participant can walk in six minutes (Enright et al 2003). The 6-minute walk test has been found to be reliable and valid in relation to other performance and self-reported indicators of physical functioning (Harada et al 1999). It is easy to conduct and it can provide reasonably reliable and valid information of physical endurance in older adults. The results moderately reflect overall physical functional performance (Rikli & Jones 1998).

#### *5.2.1.3 The chair stand – muscle strength*

The assessment of rising from the chair gives information valuable in understanding the pathway from disease to disability (Verbrugge and Jette 1994). Poor performance in chair stand tests is associated with adverse health outcomes in older persons (Guralnik et al 1994, 1995, Tinetti et al 1995). The chair stand test assesses lower

body strength (Guralnik et al 1994). Lower body muscular strength has been well established as a major factor in maintaining functional mobility and preventing or delaying the onset of disability (Guralnik et al 1994, 1995, Lawrence & Jette 1996).

Csuka and McCarty (1985) developed a timed-stand test. It involves recording the amount of time required to stand up 10 times. Modifications of this test have been developed. Five-chair stands test is a well-established performance measure of mobility function in population surveys. It has a relatively high and stable intrarater (retest) reliability. However it has been found to be too difficult for a great proportion of an elderly target population. Over 20% of the participants were unable to complete the test (Guralnik et al 1994). Rikli and Jones (1999, 140) have changed the protocol to the 30-s chair-stand to enhance the test. The 30-s chair-stand test involves counting the number of times within 30 seconds that an individual can rise to a full stand from a seated position (Rikli & Jones 1999).

The Timed Up and Go Test (TUG) was originally developed as a clinical measure of balance in elderly people. The test measures the time it takes a subject to stand up from an armchair, walk a distance of 3 meters, turn, walk back to the chair, and sit down. The original test has been modified by timing the task and it has been proposed to use it as a short test of basic mobility skills for frail community-dwelling elderly. In addition the test is quick and does not require special equipment or training (Podsiadlo & Richardson 1991).

#### *5.2.1.4 Balance*

Balance is required to maintain a position, remain stable while moving from one position to another, perform acts of daily living, and move freely in the community. Balance can be measured either by laboratory tests or performance-based tests. Laboratory tests usually record the postural sway of subjects while they stand on a force platform. Laboratory assessments present logistic difficulties with routine use (Berg et al 1992).

Besides laboratory tests many functional assessment tests (performance-based) have been developed (Berg et al 1992). However, there are no generally accepted ways of performing the actual balance test, or analysing data even in the simplest static tests. Era et al (1996) have listed differences between tests. There are discrepancies in recording periods from a few seconds up to several minutes, different standards for positions of the feet and arms, and different practices in the use of fixed marks for visual stabilisation, among others (Era et al 1996).

Because of such differences, comparisons across studies or between subjects tested in different laboratories have been difficult. From the viewpoint of national health surveys the measures of balance (especially functional test of balance compared to the force platform method) have advantages of ease of administration, and low cost, and they are also functionally relevant (Berg et al 1992).

One of the best known functional balance tests is the Berg Balance Scale (Berg et al 1992). It was developed as a performance-oriented measure of balance in elderly individuals. The BBS consists of 14 items scored on a scale of 0 to 4. A score of 0 is given if the participant is unable to do the task, and score of 4 is given if the participant is able to complete the task (maximum score of the test is 56). The items include simple mobility tasks (e.g. transfers, standing unsupported, sit-to stand) and more complex tasks (e.g. Tandem standing, turning 360 degree, single-leg stand).

Guralnik et al (1994) developed a test battery specifically to assess mobility in older adults (see chapter 5.2.4.2). The test battery comprises a short set of items to measure balance. The test of standing balance includes tandem, semi-tandem, and side-by side stand for 10 seconds (Guralnik et al 1994). The test has been found to be reliable and valid, but it was too easy to discriminate among many individuals, with nearly half of the subjects obtaining perfect scores (Guralnik et al 1994, Seeman et al 1994). Despite these drawbacks the test is widely used (see chapter 5.2.4.2).

### 5.2.2 Manual ability

Although impairments in lower body function have been found to be stronger predictors of the initial onset of disability, both lower body and upper body impairments are associated with dysfunction in later years (Jette et al 1990, Lawrence & Jette 1996). Upper body function is important in executing many normal everyday activities such as household chores (Williams et al 1982, Jette et al 1990, Lawrence & Jette 1996). Since many of the ADL skills require manual proficiency, measures of manual ability could add useful information to multidimensional assessments by indicating possible reasons for individuals' difficulty in performing ADL tasks (Williams et al 1982). Jette et al (1990) found that advanced age and the progression of hand impairment and impaired upper extremity functions were related to increasing basic ADL disability.

Performance tests of upper extremity function are an important marker of functional dependency (Williams et al 1990). Older individuals who perform poorly on tests of manual dexterity tend to use more health care resources (Williams et al 1982, Scholer et al 1990), including intermediate and long-term care (Williams & Hornberger 1984, Williams 1987). Fine motor control is needed to do many of the basic ADLs such as dressing, bathing, and eating instead of complex, strenuous activities like shopping and housekeeping (Jette et al 1990).

Jebsen et al (1969) have developed an objective and standardised test of hand function. The test items include writing a short sentence, turning over 3 by 5 inch cards, picking up small objects, stacking checkers, simulated eating, moving empty large cans, and moving weighted large cans. The test for both hands takes approximately 15 minutes.

A dynamometer is used to measure handgrip strength in many surveys. The measurement protocol usually includes both the left and right sides and is reported as the sum of three trials on both hands (Cress et al 1999). In some surveys only the highest value from the participant's dominant hand has been used for analysis (Enright et al 2003). The validity and reliability of the results depends on the instrument, and the instructions used (Cress et al 1999).

Keitel et al (1971) and his co-workers have proposed an index intended to reflect the degree of functional limitations of the joints. The items were developed as a clinical tool in rheumatology. The test assesses the functional capacity of the extremities and vertebral column. The test is called Functional Test, FT (Keitel et al 1971). The test gives an overall picture of functional limitations. In addition it can easily be performed in 10 to 15 minutes and does not require any special instruments (Eberl et al 1976). Jette et al (1990) have adapted parts of the test in community dwelling elderly. The joint function test conducted in a Finnish national health examination survey has also been adapted from the field of rheumatology (Aromaa et al 1985).

### **5.2.3 Sensory functions**

Hearing and seeing function have been assessed in many health surveys. The tests have been developed mainly in clinical practice settings.

Hearing ability is usually measured with an audiometer. Audiometry has to do with an individual's sensitivity (see threshold of hearing) or tolerance (see threshold of pain). It also concerns discrimination levels (see differential threshold), the ability to distinguish speech from background noise (see cocktail party effect), or the ability to recognise pitch. In general, audiometry can measure the results of some types of hearing loss (NHANES 2001). For example the hearing component in NHANES tested a half-sample of adults aged 20-69 using pure tone audiometry and tympanometry. Pure tone audiometry thresholds were obtained in both ears at 500, 1000, 2000, 3000, 4000, 6000, and 8000 Hz. The measurement took approximately 16 minutes. Of the European national health surveys the Finnish Health 2000 survey has tested hearing function (Aromaa & Koskinen 2002). The tests were performed in those over 30 years. Hearing was tested by audiometry (Micromate) in both ears at 500, 1000 and 2000 Hz in a quiet room. The smallest stimulation given was 5dB. The hearing test is easy and quick to conduct and there are no known risks associated with the hearing examination.

Seeing function has been tested extensively in international studies (World Health Survey Home Page 2003). Both distance and near vision have been evaluated by

standard card or chart in national survey settings (Aromaa & Koskinen 2002). Although the measurement technique is quite easy, a correct technique is a prerequisite for correct results.

In both hearing and seeing tests environment and equipment (calibration) may affect the results obtained. Those responsible for conducting the examination must be trained experts. Good instructions help the subjects to perform as intended. Instruments must be calibrated to yield correct readings.

#### **5.2.4 Physical performance test batteries**

Several physical performance test batteries have been designed for the assessment of physical functioning or functional performance. Although walking speed alone can predict physical functioning quite well (see chapter 5.2.1.1), the full battery of lower extremity tests is likely to be a better instrument by which to assess performance and change over time. More accuracy may be gained by using the full battery because measuring a specific construct with multiple measures increases reliability (Guralnik et al 2000). In this section some of the best known and most often used performance batteries designed for the community dwelling elderly population and adults are presented.

##### *5.2.4.1 Physical Performance Test, PPT*

Reuben & Sui (1990) developed the Physical Performance Test (PPT). The test assesses several domains of physical functioning, using observed performance of tasks stimulating activities of daily living of various degrees of difficulty. The tasks include upper body strength and dexterity, mobility, balance, co-ordination, and endurance. The test includes specific ADL activities (eating, transferring, dressing) and IADL activities (upper extremity strength necessary to perform laundering; climbing stairs essential in using public transportation).

The tasks of the PPT test can be administered and scored by a layperson with minimal training and the test can be completed in less than 10 minutes and requires only a few simple props (Reuben & Sui 1990). The test includes writing a sentence, simulated eating, turning 360 degrees, putting and removing a jacket, lifting a book and putting it on a shelf, picking up a penny from the floor, a 50-foot walk test and climbing stairs (scored as two items). The PPT can be also completed by a seven-item test (does not include stairs). PPT was found to be reliable and demonstrated concurrent and construct validity when compared to other measures of functional status. The test may be useful as a clinical and a research instrument. It may be useful for screening for functional impairment, monitoring change in functional status and subsequent functional decline.

#### *5.2.4.2 A short lower extremity battery- EPESE*

A short lower extremity battery- EPESE (Established Populations for Epidemiologic Studies of the Elderly) is a test developed specifically to assess mobility in older adults (Guralnik et al 1994, Guralnik et al 2000). The test battery includes a short battery of items to measure strength, balance and gait speed. The total time to perform these tests takes from 10 to 15 minutes (Guralnik et al 1994). The test of standing balance includes tandem, semi-tandem, and side-by-side stand for 10 seconds. The walking speed test is performed over an 8-feet (2,44 meters) distance. The ability to rise from the chair includes five rises without the help of the arms.

Good to excellent test-retest reliability of these tests has been demonstrated (Seeman et al 1994, Ferrucci et al 1996). The test battery has been shown to have good test-retest reliability over a wide range at least in a fairly old population (Jette et al 1999). The battery has been successful in classifying large populations of community-dwelling older adults into broad categories by functional status, but still there are some problems with the instrument. The problems of balance tests have been already discussed (see chapter 5.2.1.4) In addition to these problems it was found that approximately 22% of the target population could not complete a 5-time chair-stand test of lower body strength (Guralnik et al 1994).

In spite of these floor and ceiling effects the test battery has been widely used (Guralnik et al 1994, Hoeymans et al 1996, Hoeymans et al 1997, Guralnik et al 2000, Simonsick et al 2001). It has been used as a reference battery for example in NHANES (Guralnik et al 1989).

#### *5.2.4.2 Health-related fitness test battery, HRFTB*

The health –related fitness test battery has been developed by the UKK Institute in Finland. The battery is designed for middle-aged adults, but it has been proven to be safe also for older adults with minor changes in the test protocol (Malmberg et al 2002). The test includes the walking test for cardiorespiratory fitness (2-km Walk Test), four muscular strength and endurance tests (leg muscular power [jump and reach]), leg strength [one-leg squat], upper-body strength [modified push-ups], and trunk muscular endurance [static back extension]), and two flexibility tests for musculoskeletal fitness (trunk side-bending, knee extension range of motion), a balance test for motor fitness (one-leg standing), and measures of weight and height to calculate body mass index (BMI) (Sunni et al 1999).

The battery has been evaluated systematically for its reliability, safety, feasibility, and validity. The interrater intraclass correlation coefficients (kappa) for one-leg balance, trunk side bending, push-up strength, leg power, and leg strength have been found to be good ranging from .89 to 1.00. and the mean test-retest differences ranged from small to moderate, varying from 0.6% to 12.1 % (Sunni et al 1996). In addition test-retest correlation coefficients have been found to be high for dynamic back extension and the 2-km walking test (Oja et al 1991). The test has been designed to measure health related fitness of individuals and populations in order to evaluate the amount and type of physical activity needed to promote health.

#### *5.2.4.3 Functional Fitness Test Battery*

Rikli and Jones (1999) have developed a functional fitness test battery. The complete battery consists of six tests (and one alternative) designed to assess physiologic parameters associated with independent functioning and physical mobility in older

adults. The items of the battery cover lower and upper body strength, aerobic endurance, lower and upper body flexibility and agility/dynamic balance. The body mass index is also included in the test battery to estimate body composition.

The lower body strength is measured by a 30-s chair-stand-test. The 30-second time limit makes it possible for all individuals to receive a score (compared to 5 stand chair test). The arm-curl test measures upper body strength and involves determining the number of times a hand weight (5lb for women, 8lb for men) can be curled through a full range of motion in 30 seconds. The 6-minute walk test is used to determine the distance that can be walked in 6 minutes. A 2-minute walk test (the 2-min step in place) can be used as an alternative. In addition to these tests, the flexibility of the lower body is measured through chair sit- and reach test and the upper back scratch test measures the shoulder range of motion. The modified timed up-and-go test measures the mobility and balance. The distance has been changed to 8 feet. The tests of this battery have been shown to be feasible and safe to complete. The content validity of each test has been demonstrated by literature review and expert opinion (Rikli & Jones 1999).

#### *5.2.4.4 The Groningen Fitness Test for the elderly (GFE)*

The Groningen Fitness Test for the Elderly has been developed for field-based assessment of fitness in healthy people over 55 years of age (Lemmink et al 1995). The battery consists of six test items for objective measurement of fitness and a questionnaire for subjective evaluation of fitness. It includes measures of walking, strength, flexibility, reaction power, and manual dexterity. The test can be used in studies concerning the relationships between fitness and physical activity, health, and performance in instrumental activities of daily living (IADL). In a pilot study the correlation between instrumental activities of daily living and objective fitness was .52. It can be concluded that the GFE is a valid contributor of performance of IADL.

#### *5.2.4.5 Continuous-Scale physical functional performance test (CS-PFP)*

Continuous-Scale physical functional performance test (CS-PFP) is an instrument designed to measure physical function reflecting abilities in several separate physical domains (Cress 1995). The test consists of a battery of 15 everyday tasks, ranging from easy to demanding, that describe the physical domains of upper and lower body strength, upper body flexibility and, balance and co-ordination, and endurance. Tasks include carrying a pan of water a distance of one meter and carrying and then pouring from a jug of water into a cup. In addition to tasks of basic instrumental activities of daily living the tasks include walking as far as possible in six minutes.

Continuous-Scale physical functional performance test is a valid, reliable measure of physical function, applicable to a wide range of functioning. It has minimal floor and ceiling effects and it is suitable for both research and clinical purposes (Cress 1995).

### **5.3. Characteristics of performance-based measures**

#### **5.3.1 Advantages of performance measures**

Performance measures have several advantages (table 5.3.1). Ordinarily, both measures, self-report and performance tests, give valid and important information about physical functioning (Cress et al 1995, Hoeymans et al 1997). It has been estimated that performance measures may provide more accurate and reliable information than self-report or proxy report (Reuben & Sui 1990). It is generally approved that performance measures complement the information obtained from self-report because self-report and performance-based measures assess a different concept of functional status (Guralnik et al 1994, Guralnik 1997, Guralnik et al 2000).

**Table 5.3.1** Theoretical advantages and disadvantages of performance versus self-report measures of physical functioning (Guralnik et al 1989).

<b>Advantages</b>
Face validity clear for task being performed Better reproducibility Greater sensitivity to change Usual activity vs. maximal capacity Influenced less by poor cognitive functioning Influenced less by culture, language, and education
<b>Disadvantages</b>
More time consuming Adequate space and special equipment needed Special training of examiners Modifications necessary for home surveys Potential injuries Simple tests may not reflect performance on complex tasks or adaptation to environment in daily life

Performance measures executed in an identical way each time offer the potential for greater reproducibility and greater sensitivity for detecting change. However, empirical evidence for this is limited. Performance measures of functioning, especially those, which time an activity or count repetitions within a specific time interval, may offer real advantages over self-report measures in the evaluation of change (Guralnik et al 1989, Cress 1997).

A particular value of physical performance tests is that they are excellent measures of functional limitations, such as gait limitations, problems with climbing stairs, and difficulty in grasping (Guralnik 1997). Thus, performance measures can capture a hierarchy of functioning in non-disable persons and even in those who are high functioning (Guralnik et al 1994). In addition, in non-disabled persons performance measures have been shown to predict the incidence of disability (Guralnik et al 1994, 1995).

The use of performance-based measures offers a supplemental approach also to obtaining valid data on physical functioning in cognitively impaired persons if their cognitive abilities are adequate for understanding and following the instructions of the tests. In addition to cognitive impairments, performance tests are less influenced by culture, language, and education level compared to self-report methods. Thus, the use of objective performance measures in cross-cultural and international studies has obvious advantages. In these studies, cultural, language, and social differences

between populations may greatly limit the validity of comparisons of self-reported functioning and disability (Guralnik 1989). Performance based measures have also major advantages for time trend estimation since these findings are independent of environmental changes (Aromaa et al 2003a).

### **5.3.2 Disadvantages of performance measurements**

The use of performance based tests offers an alternative for comparisons of functional levels among different populations by using the standardised tests (Guralnik 1989). However, comparison of existing performance measures may be difficult. There are great variations in content, methods of assessment, and scoring procedures. Myers et al (1993) have listed examples of several methods used to quantify observations, including assistance needed, observed difficulty, accuracy, ability to complete the task, timing, and the various combinations of the above.

In addition to methodological differences there are some characteristic features of performance tests affecting the test results. Theoretical disadvantages of performance measures have been listed in table 5.3.1 (Guralnik et al 1994). Performance measures may be limited by their dependence on the subject's motivation to participate in the test (Kivinen et al 1998). Myers et al (1993,) found that if persons perceived themselves as incapable of doing these activities (on the questionnaire), they were less likely to take part in the performance segment of the study. On the contrary, patients may be more motivated to perform a task in a clinical or research setting when being observed (Reuben & Sui 1990).

As a consequence of motivational and environmental factors, performance based tests may provide very little information about how a person copes in his or her own home environment (Reuben & Sui 1990, Kivinen et al 1998). Thereby, performance tests may reflect performance only at a single point in time (Kivinen et al 1998) and be closer to maximum than average performance (what can you do as opposed to what do you do). Despite this criticism, observed performance of everyday activities

should be highly correlated to self-reports, provided that the tests have been suitably selected.

Most people have some experience in filling in questionnaires or forms; few, however, are used to having their behaviour observed or timed using a stopwatch. People may have difficulties to concentrate in the test situation. For example, Myers et al (1993) found that it was difficult for the subjects to complete the tasks without pauses to comment or laugh nervously (regardless of instructions). In addition, the presence of a stopwatch appeared to fluster many subjects (Myers et al 1993).

One drawback of performance-tests may be that some of the measures of physical function may be risky (Guralnik et al 1989, Reuben & Sui 1990). However, Guralnik et al (1989) reported that in two large studies injuries were not a problem; there were no injuries in nearly 1 400 persons examined in the Massachusetts health care panel study and only one minor injury in more than 7000 participants in a multicenter study of fractures and falls. Those administering the tests must be trained in methods of reducing potential injuries and dealing with them if they occur. Trained examiners are the best way of reducing the risk of injuries (Rikli and Jones 1997).

#### **5.4 The association between self-reported and performance-based measurement**

The preferred method to measure physical functioning is still uncertain. Moreover, it is not clear in which circumstances and to what extent self-report and performance-based measures can be used interchangeably (Sherman & Reuben 1998).

Previous studies comparing different measures of functional status assessment have found a good but not perfect correlation between self-reported and performance-based measurements. The association between self-reported and performance-based indices of functioning ranges from weak (Kelly- Hayes 1992, Sager et al 1992, Kempen et al 1996) to moderately good (Myers et al 1993, Guralnik et al 1994, Cress et al 1995, Hoyemans et al 1996, Sherman & Reuben 1998).

The reason for this less-than-perfect agreement is not clear. One possibility is that the scales measure different aspects of functioning (Kelly-Hayes et al 1992, Guralnik et al 1994). It has been stated that a self-report measure assessing more highly integrated activities (such as shopping) may not correlate highly with a performance-based measure assessing specific movements (such as picking up a penny). They are assessing different levels of functioning (Sherman & Reuben 1998).

Also capability, motivation and perception affect the correlation between self-report and performance-based measurements (Sherman & Reuben 1998). How subjects answer or perform is affected by what they can do (capability), what they want to do (motivation), and what they feel to do (perception). Thus two measures assessing the same level of functioning may still not correlate highly if one is more influenced by motivation or by perception (Sherman & Reuben 1998).

It has been even estimated that functioning is too complex to be measured precisely with a questionnaire or short performance assessments, or that the method of assessment is responsible for the differences (Glass 1998). Only Kempen et al (1996) have examined why performance-based measures and self-report measures are not highly correlated in a sub-sample of the population-based Groningen Longitudinal Aging Study. They found that subjects with more depressive symptoms and those with lower levels of perceived physical competence were more likely to "under estimate" their self-reported functioning when compared to the results of performance-based assessment (Kempen et al 1996).

Physical functioning is complicated and can be best assessed by multiple methods (Reuben et al 1995). If performance tests are used alone without self-reports vital information such as perceptions of pain and reasons of disability are obscured. Some researchers suggest that functional performance tests should not be viewed as superior to questionnaire measures (Myers et al 1993), but rather confirming the validity of self-report and proxy-report assessment (Guralnik et al 1989, Reuben & Sui 1990). Thus, it has been generally agreed that performance measures supplement, rather than replace, self-reports of disability (Myers et al 1993, Cress et al 1995, Kivinen et al 1998, Guralnik et al 2000).

However, there is a conceptual difference between self-reports and other measures since perception can only be measured by asking the person concerned. Therefore, it is futile to expect complete agreement. Finally, the major benefits of using several types of measures are that a comprehensive picture can be obtained.

## **6 INTERNATIONAL COMPARABILITY**

The possibility to compare between different studies enhances the usefulness of the data obtained. In particular, health policy benefits from the understanding of the relative health status in one country compared to others. However, international comparison of survey data has posed problems owing to differences in the methods and instruments used (de Bruin et al 1996, Hupkens et al 1999, Aromaa et al 2003a, 2003b).

### **6.1 Efforts to improve common methods**

There have been some efforts to improve common methods for national health surveys (de Bruin et al 1996). It has been pointed out that methodological differences such as sampling frames and data collection methods affect the comparability of survey data (Wiener et al 1990, Picavet & van den Bos 1996, Hupkens et al 1999, Picavet 2001).

The use of common methods of data collection (interviewer administered techniques, self-completion, or both, and whether to use proxies) is essential, since these may substantially influence results and response rates. For some disability indicators it is known that systematically higher prevalence is found using self-administered questionnaires compared to interviews (Picavet & van den Boss 1996). For example, the scores for SF-36 were significantly less favourable among older persons completing it by mail (self-administered) than by telephone (interviewer) (McHorney et al 1994). However, for many health topics carefully designed mailed surveys are probably an equally good alternative to the –much more expensive- interview surveys (Picavet 2001). It is generally thought that response rates are better for interview surveys than for mail surveys. For example in a research concerning the data

collection effects to the SF-36 in old person response rates were better when data was collected through interview (Mallinson 1998).

In addition the data collection method, also the sampling frame and year the survey has been conducted may influence the comparability of the results. Especially the sample design can have a major impact on the prevalence of disability as a result of unequal probabilities in selecting the sample unit (Wiener et al 1990). Most sampling frames for health surveys exclude people living in institutions, which implies the exclusion of a group of probably severely disabled elderly (de Bruin et al 1996, Picavet & van den Bos 1996). This should be taken into account when data from a survey excluding institutionalized people is compared with a survey including people in institutions. More detailed information on the effects of methodological differences is provided by Koponen & Aromaa (2003).

## **6.2 Efforts to improve common instruments**

A number of different approaches have already been used to improve comparability of self-reported data both across and within countries (Koponen & Aromaa 2001, Iburg et al 2002). Most efforts have focused on the comparability of surveys, in terms of health topics covered, the specific wording and the types of the wording (de Bruin et al 1996, Hupkens 1999, Gudex & Lafortune 2000, Sadana 2002a). For example WHO and OECD have produced reference instruments and/or recommendations for instruments to be used in national health surveys (Hupkens et al 1999). In addition a series of projects have been funded by the European Commission (Aromaa et al 2003a, 2003b). The most recent recommendations and efforts (of some EU projects and projects under the WHO organisation) to improve the comparability of questions and items on physical functioning are listed in table 6.2.

One of the first attempts to standardise disability measures across countries was undertaken by OECD in the late 1970s (see chapter 4.1.2). This effort led to the so-called "OECD long-term disability list" (McWhinnie 1981). The main objective of the OECD instrument was to allow better international comparisons of disability across countries, through its implementation in national surveys. The instrument was

implemented, for a period of time at least, in 8-10 OECD countries (Gudex & Lafortune 2000).

**Table 6.2** Recent recommendations/proposed instruments on physical functioning.

Recommendation's /project's name /reference	Organisation/project responsible for the recommendation (and co-ordinator)	Year	Included in the HIS/HES database	Topic/Content (name of instrument tested, proposed and/or recommended)
OECD (McWhinnie 1981)	OECD	1981	Yes	Long Term Disability Questionnaire (vision, hearing, speaking, carrying, walking, cutting toenails, picking up a shoe from the floor, cutting food, biting/chewing)
WHO (de Bruin et al 1996)	WHO Copenhagen/ Statistics Netherlands	1996	Yes	Long term disability (physical: mobility, locomotion, transfer, dressing, washing, feeding, toileting, continence, hearing, seeing)
Euro-REVES (Robine et al 2000, Robine et al 2002)	HMP/Euro-REVES (INSERM, Montpellier, France)	2002	No	ADL (feeding, transfer [bed], dress/undress, use toileting, bathing or showering)  IADL (using telephone, shopping, preparing meals, doing light housework, heavy housework, laundry, handling finances)  Physical and sensory functional limitations (seeing, hearing, walking, climbing stairs, speaking, biting/chewing, arm use, fine arm use, bending/kneeling, lifting/ carrying)  GALI= Global Activity Limitations Index
EDM (de Kleijn-de Vrankrijker & Bonet 2002)	HMP (TNO, the Netherlands)	2002	No	Recomotends common items and relies on recommendations of Euro-REVES

HMP= Health Monitoring Programme  
EDM= European Disability measurement

A more recent attempt to standardise disability measures was undertaken by The Regional Office for Europe of WHO, WHO-Europe, in collaboration with Statistics Netherlands, as part of an effort to standardise methods and instruments in health interview surveys (de Bruin et al 1996). The WHO-Europe "long-term disability questionnaire" has been incorporated in some surveys in European countries, such as Belgium, The Czech Republic, and Portugal as well as in the 1995 Health Survey for England with some adjustments (Gudex & Lafortune 2000).

The Euro-REVES Network, (Robine et al 2000, 2002) with support from the European Commission, recently released a set of recommendations for ten survey instruments to be used in European health surveys. Five of these concern either

functional limitations (physical, sensory and cognitive) or activity restrictions (ADL/IADL). In the area of disability, Euro-REVES has proposed to break down the WHO-Europe “long-term disability list” into two components: some of the questions to be used to measure “physical and sensory functional limitations”, while the other questions should be used to measure “ADL restrictions”. This distinction has been justified on the grounds that functional limitations and activity restrictions refer to different levels of disability. This leads to different types of consequences in daily life, and differences in problems to which different public health actions should be addressed. Euro-REVES recognises however that “the distinction” between functional limitation and activity restriction is not straightforward, especially because existing measurement instruments are most of the time combining these two levels and are relying on similar questions.

The Euro-REVES network (Robine et al 2000, 2002) proposes to include four severity levels in functional and ADL limitations (as opposed to three for most of the WHO-Europe questions), by making a clear distinction in the ability to function or carry out basic activities of daily living with or without special aids (such as glasses or hearing aids). In addition, the Euro-REVES network proposes a global (single) question on disability in usual activities, which can be administered to a population of all ages.

The European Disability Measurement (EDM) project (de Kleijn-de Vrankrijker & Bonte 2002) aimed at consistent disability statistics in Europe with the development of a minimum set of items, with reference questions and the collection of data by 2006. This project emphasises the need for common disability items rather than for a common instrument. A distinction can be made between a reasonable short list of core items, which should be available at regular intervals in all Member States and at EU level. The EDM-report relies on recommendations of Euro-REVES for the three general disability/health items but it emphasises the need for further work in the development of relevant instruments and questions.

In addition to the efforts of three international governmental organisations (WHO, OECD, EU) and their projects there have also been a number of academic initiatives to promote the use of common generic health measurement instruments

internationally in health surveys. The best example of attempts to minimise differences in items in health surveys is probably the adaptation of the SF-36 questionnaire to more than 40 countries (Ware 2000).

The most recent work of WHO includes the continuing development of summary measures of population health (Murray et al 2002), a critical review of the validity and comparability of existing population based survey data on health status (Sadana et al 2002b), the publication of the International Classification of Functioning, Disability and Health (ICF, WHO 2001a), and the implementation of the WHO Multi-Country Survey Study on Health and Responsiveness 2000-2001 (WHO Multi-Country Survey Study, Üstün et al 2001) as well as the World Health Survey (World Health Survey Home Page 2003).

However, it has been estimated that due to differences in culture and language the emphasis to improve international comparability should not be on common instruments only. Rather development should concentrate on common items and on agreement related to reference questions or instruments (de Kleijn-de Vrankrijker & Bonet 2002). In fact a number of significant national reports have called for common data frameworks and definitions in disability field (de Kleijn-de Vrankrijker & Bonet 2002, Aromaa et al 2003a, 2003b).

### **6.3 Efforts to improve performance based instruments**

Already in the 1970's the possibilities for collaborative action between European countries in conducting health examination surveys were discussed (Armitage 1976). International recommendations for performance-based tests have been given for example for the measurement of blood pressure, body weight and height (Tolonen et al 2002). However, international recommendations on physical functioning related tests have not been given. On the other hand many components of test batteries for physical and sensory functioning are such that international guidelines exist for clinical work.

## 7 Theoretical framework - ICF

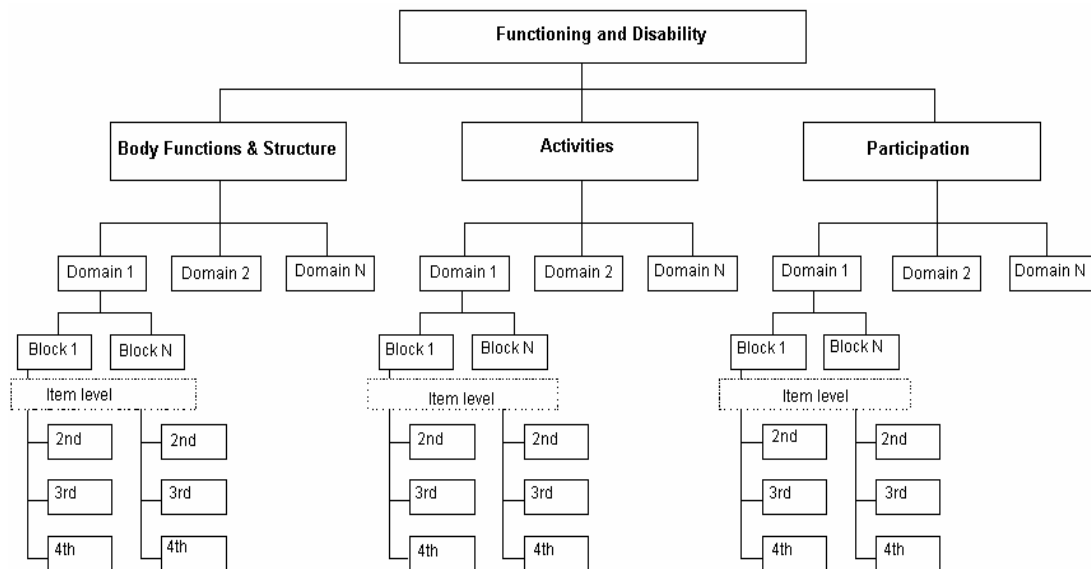
ICF (WHO 2001a) is regarded by the World Health Organization as one of the two core international classifications for health and health-related information, the other being the International Classification of Diseases and Related Health Problems (ICD). Health conditions (diseases, disorders, injuries etc.) are generally classified using ICD-10 comprising diagnoses of diseases, disorders or other health conditions; and functioning and disability associated with health conditions are classified by using ICF. The WHO family of international classifications provides a framework and language for information about health and functioning, to enable communication about health and health care in common terms, across various disciplines and between countries.

### 7.1 The structure of ICF

In order to understand the overall classification of ICF, it is important to understand its structure. Classification is the overall structure and universe of ICF and at the same time it is the top term in the hierarchy. In ICF, a person's functioning or disability is conceived as a dynamic interaction between health conditions and environmental and personal factors (WHO 2001a, figure 2.4.4).

ICF has a hierarchical structure (figure 7.1.1). It has **two parts**, each containing two separate **components** (figure 7.1.2). Part 1 covers Functioning and Disability and includes the components: 1. Body Functions (b) and Structures (s) and 2. Activities and Participation (d). Part 2 covers Contextual Factors and includes the components: 1. Environmental Factors (e) and 2. Personal Factors. Each component consists of various domains and, within each domain, categories, which are the units of classification.

**Figure 7.1.1** Hierarchy of classification in the ICF (WHO 2001a).



Each component of the classification is organised into chapters and domains and domain headings and under them are common categories or specific items. Each component can be expressed in both positive and negative terms. For example **functioning** is an umbrella term encompassing all body functions, activities and participation. While its negative term, **disability**, serves as an umbrella term for impairments, activity limitations or participation restrictions (figure 7.1.2). ICF components and domains are listed in annex 2, together with examples of some of the contents of each domain.

The categories of ICF are arranged so that a lower level category shares the attributes of the higher-level categories of which it is a member. The categories are mutually exclusive, i.e. no two categories at that same level share the same attributes. In the ICF classification, the letters b, s, d, and e referring to the component of the classification, are followed by a numeric codes starting with the chapter number (one digit) followed by the second level (two digits), and the third and fourth level (one digit each).

**Figure 7.1.2** An overview of ICF (WHO 2001a).

<b>Parts</b>	<b>Part1: Functioning and Disability</b>		<b>Part 2:Contextual factors</b>	
Components	Body Functions and Structures	Activities and participation	Environmental factors	Personal factors
Domains	Body functions Body structures	Life areas (Tasks, actions)	External influences on functioning and disability	Internal influences on functioning and disability
Constructs	Change in body functions (physiological) Change in body structures (anatomical)	Capacity Executing tasks in a standard environment	Facilitating or hindering impact of features of the physical, social, and attitudinal world	Impact of attributes of the person
Positive aspects	Functional and structural integrity	Activities Participation	Facilitators	Not applicable
	<b>Functioning</b>			
Negative aspects	Impairment	Activity limitation Participation restriction	Barriers/ hindrances	Not applicable
	<b>Disability</b>			

Domains are at chapter level (e.g. mobility) in the classification and consist of facets or blocks (e.g. specific mobility functions) within which are nested groups of second, third, and sometimes fourth-level categories (table 7.1.3). Generally the more detailed fourth level version is intended for special services (e.g. rehabilitation outcomes, geriatrics, or mental health) whereas the two-level classification can be used for surveys and health outcome evaluation. Blocks are not part of the classification and are not used for coding purposes (table 7.1.3).

**Table 7.1.3** Classification within components in ICF: an example

<b>Component</b>	<b>Body Functions</b>	<b>Activities</b>
First-level item /chapter	Sensory functions and pain (Chapter 2)	Mobility (Chapter 4)
Facet/Block	Seeing and related functions (b210 –b229)	Carrying, moving and handling objects (codes d430–d449)
Second-level item	Seeing function (b210)	Lifting and carrying objects (d430)
Third-level item	Quality of vision (b2102)	Putting down objects (d4305)
Fourth-level item	Contrast sensitivity (b21022)	–

## **7.2 ICF and the measurement of physical functioning**

WHO recommends that the member states should use ICF in several areas (WHO 2001a). The principles of ICF are useful for a broad spectrum of different applications, for example population surveys at local, national and international level. ICF aims to provide a scientific basis for understanding and studying health and health-related states, outcomes and determinants and to permit comparison of data across countries, health care disciplines, services and time. It aims to provide also a systematic coding scheme for health information systems. It may be used as a statistical tool- both in the collection and recording of data and as a research tool just as its trial version ICIDH.

ICF is an excellent classification system for functional items providing standard operational definitions of functioning and disability related conditions. These definitions describe the essential attributes of each domain (qualities, properties and relationships) and contain information as to what is included and excluded in each domain. These inclusion and exclusion terms are provided as a guide to the content of the category. In addition, ICF offers a scientific categorisation of items related to functioning and disability. Finally, ICF includes codes across the domains of the components of the classification (WHO 2001a).

Methods of assessing particular aspects of disability should be located within the ICF framework, thereby clarifying which aspects they do, and do not, attempt to measure (Üstun 2002). It is estimated that from now on health status will be evaluated by current and existing instruments and also by instruments and terms based on ICF (Cieza et al 2002, Lollar 2002, Stuci et al 2002, Weigl et al 2003). It is therefore important to understand the relationship between these two concepts (measures and classification). There are already some experiences of linking the codes of ICF to general health status measurement (Cieza et al 2002, Weigl et al 2003, see chapter 8.3.2).

### 7.3 Physical functioning in this study

The concept of physical functioning is created by using the terms and aspects of ICF. ICF can be seen as a language providing building blocks for users who can create models and study different aspects of functioning (WHO 2001a).

In this study **physical functioning** refers to **activities** and **participation** of an individual denoting the positive aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors). In addition the negative aspect of functioning, disability, is included by referring to **physical problems or impairments** as the source of **activity limitation and participation restriction** (WHO 2001a).

In this study, **physical** refers to **sensory motor functioning** of the organism as indicated by possible limitations in activities such as walking, bending, climbing, reaching, hearing and seeing (Nagi 1976). **Physical functioning is seen as the sensory motor performance and /or capacity of an individual including fundamental and complex activities of daily living.**

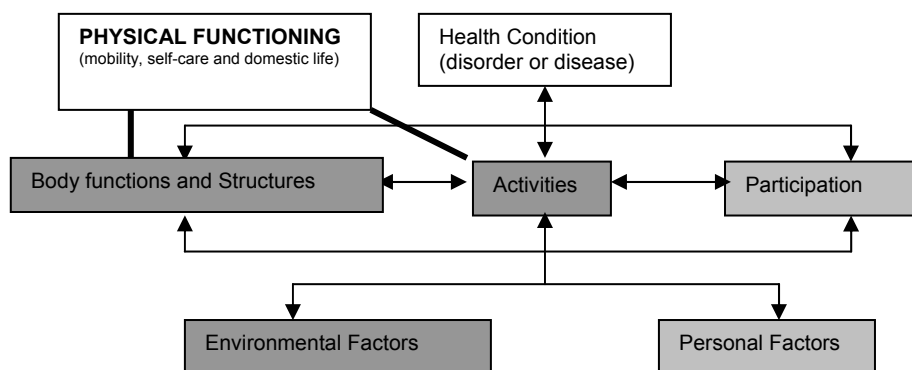
The main focus of this definition of physical functioning is on two dimensions of ICF; body functions and activities. **Body functions / structure dimension** (impairment) covers basic human senses such as the seeing and hearing function and also the movement-related functions (sensory-motor functions). **The activity dimension**, on the other hand encompasses the performance and tasks or actions performed by an individual. It includes items and tasks from mobility, self-care and domestic life, among others.

The activity dimension represents the individual's perspective on functioning (WHO 2001a). It is constructed from concepts of capacity and performance. In the ICF **performance** is described as what an individual does in his or her current environment. **Capacity** describes an individual's ability to execute a task or an action, and aims to indicate the highest probable level of functioning that a person may reach in a given domain at a given moment. The gap between capacity and performance reflects the difference between the impacts of current and uniform

environments (WHO 2001a). However it may also be a reflection of the impact of motivational factors (Sherman & Reuben 1998).

As a whole the definition of **physical functioning** (figure 7.3.1) encompasses the dimension of **body functions and activities** (negative aspect impairments and activity limitations). The aspects of **environment are also taken into account**. The consideration of environment is essential for the measurement of physical functioning. To assess the full ability of the individual, one needs a 'standardised' environment to neutralise the varying impact of different environments on the ability of the individual. In ICF this 'standardised' environment has been defined to be (a) an actual environment commonly used for capacity assessment in test settings; or (b) in cases where this is not possible, an assumed environment that can be thought to have a uniform impact (WHO 2001a). However, one should not forget that actual performance (functioning or activity) in an individual's usual everyday surroundings is decisive. Investigating capacity in a test setting makes it possible to understand why a person's actual performance may be better or worse than his/her capacity.

**Figure 7.3.1** Definition and components of physical functioning in this study.



By using the terminology of ICF physical functioning is discussed here in terms of:

- 1) **Body Functions/Structures and Activities** (sensory motor (mobility) functions),
- 2) **Self-care Activities** (activities of daily living (ADLs) such as bathing, dressing, eating, and toileting etc.), and
- 3) **Domestic life Activities** (instrumental activities of daily living (IADLs) such as shopping, telephone use, meals etc.).

## **PART II CURRENTLY USED MEASURES AND LINKING TO ICF**

The aim of the second part of this report is to describe the current state of measurement of physical functioning in comprehensive national health surveys. This is done by listing the questions, instruments (health interview methods) and examination measurements (health examination methods) on physical functioning as recorded in the European health surveys (HIS/HES) database. The objective is to provide a systematic and standardised approach for linking the HIS/HES database items to the ICF. We will also present the ICF linking rules for the database.

In order to develop health monitoring in the EU, already used instruments on physical functioning are evaluated from the viewpoint of international comparability and further development of the measurements. The evaluation is performed with the help of existing recommendations in the area. The recommendations will be summarised and evaluated from the viewpoint of international comparability.

## **8 MATERIAL AND METHODS**

### **8.1 Source of information - European Health Surveys Database**

Health Surveys in the EU: the HIS and HIS/HES Evaluations and Models project has made an inventory of health interview and/or health examination surveys in 18 Western European countries as well as in Canada, Australia and the USA. The data have been recorded in a database called "European Health Surveys Database". This was first set up in Access and distributed on CD ROM, but it has been more recently be made available trough directly the Internet (The HIS/HES Group 2003, see <https://www.iph.fgov.be/hishes>).

The database includes information about the methods, questions and examination protocols used in the health interview (HIS) and health examination (HES) surveys. Information on survey design, mode of data collection, target population, sampling frames and procedures as well as sample size, non-response, survey personnel and their training, quality assurance and control have been entered into the health survey

database together with the recommended instruments and protocols. The database covers all interview questions, both in the original language and in English, and examination protocols.

To be included in the database the surveys must be based on nationally representative population samples, they must be repeated at more or less regular intervals, and they must be comprehensive. This means that they may not be disease or topic specific, or restricted to a narrow age group (such as only the elderly). The current (January 2003) version of the database includes 90 HISs (with a total of 13809 questions) and 16 HESs (with a total of 221 test/examination protocols) in EU and EFTA Countries, and in Australia, Canada and USA. (The HIS/HES Group 2003, see <https://www.iph.fgov.be/hishes>).

In the database health survey questions and examination protocols have been classified using specific topic codes, which can be used as search criteria in the database. For the time being the HIS questions have been coded following a classification of European Community Health Indicators (ECHI, Kramers et al 2001). ECHI-indicators and the current database topic codes are listed in Annex 3. The list of HES topic codes is partly based on the ICF- classification, and it is divided into 17 areas, sensory function as well as physical function and physical fitness, among others. The HES topic codes are listed in Annex 4.

Questions and examinations of the database are coded (either primarily, secondarily or thirdly) as belonging to one or several topic-codes. Questions are coded primarily to belong under one topic-code and if necessary secondarily to another etc. (table 8.1.1). One coded question may include one independent question or questions with further sub-questions and/or be part of an instrument or a series of questions. In the database some series of questions have been separated and thus coded as independent questions while others have been coded as one unit.

**Table 8.1.1** An example of the coding system from the database

Survey	Country	Question	At_code	AT_code2	At_code3
National Health Interview Survey	Portugal	2. Are you (is she/he) sitting on a chair (not a wheel chair) all day (except at night), unable to walk even with someone's help?	211	212	
			Primary	Secondary	

The topic-codes and the present classification system of the database related to questions on physical functioning (HIS-methods) are somewhat overlapping. For example the category of limitations of functional ability: physical, and the category of mobility include similar questions. Thus there has appeared a need to complement the health topic codes currently used in database. It has been estimated that the use of the ICF classification may allow refining the searching procedure and enhancing the possibilities of comparisons between the different surveys (Minutes of Core Group Meeting 2002).

## 8.2 Topics of this study

In order to generate an overview of national comprehensive health interview and examination surveys in the area of physical functioning, information on the methodology and questionnaires has been collected from the European Health Surveys Database, Version 25102002 (Access2000 format, The HIS/HES Group 2002). National comprehensive health surveys from the time period 1998 to 2002 are most accurately recorded in the European Health Survey Database. All the questionnaires of year 2000 were not available yet by the end of 2002 and could therefore not be included in the HIS/HES database. Ten surveys out of the 21 from year 2002 had already been included in the database.

Altogether 57 national health interview surveys (HIS) from European countries were included. Out of the 57 HISs ten included also examination procedures. In addition to these ten surveys two British surveys conducted between 1998 – 2002 included examination procedures. The main characteristics of each survey are reviewed briefly in the Annexes 5 (HIS components) and 6 (HES components).

This study was limited only to those national comprehensive surveys including questions and/or examinations on physical functioning. Of the 57 HISs 46 had at least some questions related to physical functioning. Of the 12 HIS/HESs only two Finnish surveys and one Dutch survey comprised an examination of physical functioning. Thus the more detailed evaluation of this study concerns 46 health interview surveys and three surveys combining health interview and health examination protocols.

The instruments, questions and examinations related to physical functioning from the 46 HIS and three HIS/HES were included in the analyses and comparisons. Altogether 548 questions (table 8.3.1) and 3 different examination procedures (covering several tests) were analysed. However, the coverage of items related to physical functioning noted in this study should be viewed as a minimum, since other methods than interview or examination (such as self-completed questionnaire) may also have been used in national health surveys. This study relies on the English translations of questions and examination procedures as described in the database. In addition to English, of the original languages, only Finnish, Swedish and French have been taken into account when necessary.

## **8.3 Methods**

### **8.3.1 Use of the database**

Questions and instruments (HIS methods) as well as examination measurements (HES methods) related to physical functioning were retrieved from the database by using procedures of the Access2000 program. The search was limited to the 5-year period and only surveys from European countries were included. International HISs and recommendations were excluded.

Methods related to health interview surveys are listed in the database under the area code health status (2). The topic-codes between 207-208 and 210-214 were comparable with the definition of physical functioning and they were thus included in

this work. These codes belong in the following under area 2, Health Status (see annex 3) and include items concerning:

<b>Topic</b>	<b>Codes</b>
Limitations of functional ability: sensory	(207)
Limitations of functional ability: physical	(208)
Access limitations	(210)
Mobility	(211)
Limitations of activities of daily living (ADL): personal	(212)
Limitations of activities of daily living (ADL): household and	(213)
Limitations of activities of daily living (ADL): others	(214).

All questions between topic-codes 207- 208 and 210-214 were retrieved from the database by using the primary, secondary and also the tertiary topic-code. The overlapping of the codes was taken into account so that the same question has been evaluated only once.

Because of the present classifying system of the database, the number of question listed by using topic-codes does not give real picture of the current situation of the number of questions included in the surveys. This is due to that one coded question may be either an independent question or part of a series of questions and/or be an instrument. The separation of each question from the series of questions and instruments to be independent questions were essential:

- 1) to get an accurate picture of the current situation of the coverage of physical functioning measurements,
- 2) to make it possible to analyse the contents of the questions, and
- 3) to test the linking of the questions to the ICF.

For this purpose the retrieved list of questions from the database was transcribed to Excel-table. The questions from the series of questions and instruments were taken apart and rewritten each as an independent question (see the ICF linking rules in table 8.3.2.1). The total number of the questions analysed and reclassified by using ICF codes is thus larger (548) than the number of questions retrieved from the database (399) by using the topic-codes (table 8.3.1).

**Table 8.3.1** The total number of questions on physical functioning included in this study.

Topic code	Number of questions / items through database search	Number of independent questions
207	71	99
208	70	72
210	44	48
211	15	28
212	103	183
213	38	61
214	37	37
Others*	20	20
<b>Total =</b>	<b>399</b>	<b>548</b>

\* Others refers to the search on topic codes 207 – 208 and 210 – 214 results obtained through topic code 2 and 3.

In the database the examinations related to measurements on physical functioning are classified under the area code (22) sensory function, physical function and fitness (see annex 4). Methods related to the examinations on physical functioning were listed by using relevant topic codes and all examinations related to physical functioning were identified. Three different examination procedures (covering several tests) were retrieved.

### **8.3.2 Analysis of the questions and examination procedures**

To test the linking of the questions on physical functioning to the ICF, the content of the questions was analysed. ICF was used as a guidebook according to which different questions on physical functioning were mapped to certain categories of ICF and coded with the help of ICF codes. The analyses units were the questions (n= 548) and examination procedures (n= 3) on physical functioning.

To guarantee an accurate coding some linking rules were developed. The ICF linking rules of Cieza et al (2002, annex 7) were adapted to the needs of this study. Cieza et al (2002) have tested and developed 10 linking rules concerning the mapping of health-status questions to the categories of ICF. The linking rules were tested by applying them to the four generic and four specific health status instruments: SF-36, Sickness Impact Profile, EuroQol (EQ-5d), The World Health Organization Disability

Assessment Schedule II (WHODAS II), Pain Disability Index, Lumbar Spine-Baseline, Self-Rating Depression Scale and Hamilton Depression Scale. Two health professionals linked these instruments independently to the codes of ICF. Due to the high agreement between the two health professionals in all questionnaires studied, the authors encouraged to use the linking rules established in this study in other settings too. It was stressed that the linking rules developed allow the sound linking of items from health-status-measures to the ICF.

In developing the linking rules for this study, the principles of the current database classification were also taken into account. The current classification is based on six principles:

- 1. Clarity:** The list of topics (or keywords) should be clear and easy to understand. Users of the database should have no problem in finding the keyword they are looking for.
- 2. Complete and concise:** The list of topics should cover a broad range of health aspects, including health status, health determinants, medical consumption, health prevention and other variables associated with health.
- 3. Reliability:** The topic list should be highly reliable. Two persons searching for the same information should obtain the same results using the health topics list.
- 4. Limited number of levels:** To structure the topic list a hierarchical system is necessary, e.g. categories that are split up into subcategories. Again, these subcategories may be split up in sub-subcategories etc. However, if there are more than 2 or 3 levels, it will be too complicated to use the list as a search tool.
- 5. Mutually exclusive topics:** It is easier to find the proper questions if the topics do not overlap. To achieve this topics are mutually exclusive. However, for some subjects both a general topic and some more detailed topics can be used.
- 6. Questions may refer to more than one topic:** Questions may contain more than one topic. Therefore, the possibility exists that one question refers to one, two or a maximum of three topics (Aromaa et al 2003b).

ICF fulfils the first five current principles of the database.

So far ICF linking rules (Cieza et al 2002) have been developed only for health interview methods (questions). Linking rules for the performance-based method do not exist but they are under progress (Smolander et al 2003: Cieza personal communication). As far as common and internationally recommended rules for performance-based measures do not exist the linking rules of performance-based measurements of this study should be regarded as indicative and simultaneously as a contribution to their development. From the viewpoint of the database the

performance-based test are linked to the codes of ICF according to the main purpose of the test. For example the measurement of back extension endurance is mainly designed to measure the strength and endurance of back muscles. Thus, the test should be coded to belong to the category of muscle endurance function (b740, body functions and structure).

Altogether ten ICF linking rules (table 8.3.2.1) were developed for this purpose and used for reclassifying the selected items and analysing the content of questions and examination procedures. The first three ones concern the database and its formulation. The remainder give instructions about the use of ICF-classification.

**Table 8.3.2.1** ICF Linking rules for questions related to physical functioning in the European Health Survey Database (Adapted from Cieza et al 2002).

Number	The linking rules
1	All database questions should be classified as <b>independent questions</b> . Each item in the series of questions or instruments must be rewritten to be independent before reclassifying.
2	Sub-questions do not have to be separated of the main ones, if they give only further information about the same subject as the main question.
3	The reclassification can be done independently for each topic-code.
4	Before one links HIS/HES items and questions to the ICF categories, one should have acquired good knowledge of the conceptual and taxonomical structure of ICF. One should know the chapters, domains and categories of the detailed classification, including definitions.
5	Each single question or a question and its sub-question should be linked to the most <b>precise</b> ICF category. If the response options of the questions give further information and if they refer to a additional construct, they are to be taken into consideration. Also the introductory text has to be noted.
6	Questions may contain more than one ICF code (topic). If a single question encompasses different constructs, the information in each construct should be linked. Therefore, the possibility exists that one question refers to one, two or a maximum of three ICF codes.
7	Because of the nature of the present classification of the database and the nature of the use of database, too accurate classification of questions is not feasible in this study. In the ICF the two level classification (three digit, b210) is recommended to be used for surveys and it may also be adequate to describe precision (WHO 2001a, 220). Thus the two-level (three digit) classification is used as the most detailed level for classifying questions of the database. However if the content of the question is more general than

the corresponding ICF category (b210), then the code of the higher level is linked (b2).

- 8 If the information provided by the question is not sufficient for making a decision about the ICF category to which the item should be linked, or if the information of the question is not contained in the ICF, this question should be assigned to **not** (not definable or not covered in the ICF).
- 9 Performance based tests are linked to the codes of ICF according to main purpose of the test. Linking work is performed at the tow-level (three digit, d450, walking).
- 10 The linking of this study has been performed at question level and with two-level classification of ICF. However the main categories for the database classification are recommended to be constructed according to the main domains of the ICF (see table 11.3.1).

### 8.3.3 Further analysis of questions

Further analysis of the questions was made after mapping questions to ICF. The evaluation was performed from the viewpoint of international comparability and further development of the measurements in the area. The questions included were compared to the recently given international recommendations and reference instruments (see table 6.2). Detailed information about the instruments is offered in annexes 8 - 11. As the evaluation of the questions (n=548) was performed in terms of ICF, also the recommended questions were mapped to the codes of ICF.

The questions will be analysed according to recent findings on barriers to international comparability:

1. qualifiers and scales,
2. question formulation,
3. population coverage (concerns only some age group / skipped if) of questions,
4. in the combination of items (Wiener et al 1990, Rasmussen et al 1999, Sadana 2002a).

## **9 RESULTS**

### **9.1 ICF linking**

#### **9.1.1 Linking the questions to the ICF**

The number of linked questions according to primarily marked ICF codes is listed in table 9.1.1. One question may contain one or a maximum of three ICF codes.

41 % (225) of the linked questions on physical functioning concerned primarily mobility. 18 % (98) of the questions were linked to the codes on self-care, 15.6% (86) to sensory functions and 11 % (60) to the codes on domestic life. 34 questions on IADL related functions were linked primarily to the codes of general task and demands. 12 questions concerned the major life areas such as employment, work, leisure and recreation, and economic life.

The database search (using topic codes) found out also questions concerning emotional functioning (N=1), pain (N=1), speaking (N=4) and conversation (N=7), and family relationship (N=1, see table 9.1.1 marked with \*). These questions could be linked to the codes of ICF but they were regarded as not belonging to the area of physical functioning (according to definition of this work see chapter 7.3). Thus, no further analysis of these questions was performed.

The next chapters give more detailed examples of the ICF categories and of the concrete linking work. Annex 12 provides examples of the questions and linked codes.

**Table 9.1.1** Number of questions linked to the specific ICF codes.

Code	ICF category	Number of question coded	Component of ICF	Main domain of ICF
b152	Emotional functions	3*	Mental functions	Body functions
b210	Seeing functions	47	<b>Sensory functions and pain</b>	
b230	Hearing functions	36		
b240	Sensations associated with hearing and vestibular functions	2		
b280	Sensation of pain	1*		
b510	Ingestion functions (biting and chewing)	6	Functions of the digestive, metabolic and endocrine systems	
d230	Carrying out daily routine	34	General tasks and demands	Activities and participation
d330	Speak	4*	Communication	
d350	Conversation	7*		
d360	Using communication devices and techniques	5		
d410	Changing basic body position	10	<b>Mobility</b>	
d415	Maintaining a body position	1		
d430	Lifting and carrying objects	11		
d440	Fine hand use	9		
d445	Hand and arm use	3		
d450	Walking	28		
d455	Moving around	38		
d460	Moving around in different locations	35		
d470	Using transportation	21		
d475	Driving	7		
d498	Mobility, other specified	62		
d510	Washing oneself	27	<b>Self-care</b>	
d520	Caring for body parts	7		
d530	Toileting	11		
d540	Dressing	20		
d550	Eating	21		
d560	Drinking	2		
d570	Looking after one's health	4		
d598	Self-care, other specified	6		
d610	Acquiring a place to live	3	<b>Domestic life</b>	
d620	Acquisition of goods and services	12		
d630	Preparing meals	11		
d640	Doing housework	33		
d660	Assisting others	1		
d760	Family relationships	1*		
d859	Work and employment, other specified and unspecified	4	Major life areas	
d879	Economic life, other specified and unspecified	6		
d899	Major life areas, unspecified	1		
d920	Recreation and leisure	1		
e155	Design, construction and building products and technology of buildings for private use	2	Products and technology	Environmental factors
e110	Drugs	1*	Support and relationships	
e399	Support and relationships unspecified	4		
		<b>548</b>		

\* Not included in the definition of physical functioning

### *9.1.1.1 Sensory functions (and pain)*

Questions on seeing and hearing functions were mainly mapped to the codes of 1) seeing functions (b210) and 2) hearing functions (b230, WHO 2001a). Seeing functions include sensory functions relating to sensing the presence of lights and sensing form, size, shape and colour of the visual stimuli. It includes both the distance and near vision functions. Hearing functions relate to sensing the presence of sounds and discriminating the location, pitch, loudness and quality of sounds.

Seeing and hearing functions represent the component of body functions in the ICF. In addition to body function, the activities and participation component of ICF includes activities related to using the seeing and hearing sense (functions) intentionally e.g. purposeful sensory experiences. The watching (d110) category includes the intentional use of the sense of seeing to experience visual stimuli, such as watching a sporting event or children playing. Correspondingly, the listening (d115) category contains listening for example to the radio, music or a lecture. Also these codes were used (secondarily) if relevant.

In addition to the codes of body functions (b210, b230) and activities and participation (d110, d115), some codes from environmental factors such as light (e240) and sound (e250) were used if the question included some terms to describe lighting or sound conditions. Also hearing aids and glasses (e125) e.g. products and technology for communication were marked if relevant.

In some surveys (FIN03, D05, F09) questions were asked related to specific eye diseases and the treatment of these. Diseases are not classified in ICF and thus these questions can not be directly mapped to any of the ICF codes. Questions on problems with hearing and vestibular functions such as tinnitus and wheezing/whistling were mapped to the code of sensations associated with hearing and vestibular functions (d240).

### 9.1.1.2 Mobility

Mobility items represent the activities and participation domain in the ICF. Mobility related items are divided into five main groups (blocks):

- 1) Changing and maintaining body position (d410 – d429)
- 2) Carrying, moving and handling objects (d430 – d449),
- 3) Walking and moving (d450 – d469),
- 4) Moving around using transportation (d470 – d89).

In addition there is a large proportion of questions on

- 5) Other mobility related items (d498 – d499).

All of these codes were used in the coding work. The codes and categories of mobility are quite straightforward. However, there were few cases in which it was difficult to find a relevant code. For example, questions related to ability to move from chair or bed are usually seen to give information about personal care activities. According to ICF these questions were linked to the mobility area (d498, mobility other specified, see Cieza et al 2002). Similarly, questions on transportation are usually part of some Instrumental Activities of Daily Living (IADL) question series (table 4.1.1). In the ICF this topic represents the mobility topics.

### 9.1.1.3 Self-care

Questions on 1) washing, 2) caring for body parts, 3) toileting, 4) dressing, 5) eating and drinking (here combined together), 6) looking after one's health, and 7) other self-care items were mapped to the codes of self-care activities.

The codes were basically straightforward and the mapping of a question could be done without difficulties. However, in some questions more than one code was used. For example the questions on difficulties or abilities in the use of toilet were directly mapped to toileting (b530) whereas questions including activities related to excretion had to be mapped to the codes of body functions (b610, b525). Similarly eating and drinking related questions could be directly mapped with corresponding codes whereas biting and chewing hard food was linked to the ingestion related functions (b510).

Questions related to looking after one's medication have been generally seen to belong to the persons ability to manage instrumental activities of daily living (IADL, see table 4.1.1). In this work the ability to take medication has been regarded to belong to the ability to follow medical and other health advice as described in the ICF. Questions related to medication in general or drugs (e110) are not included in the comparison of questions.

#### *9.1.1.4 Domestic life*

In terms of physical functioning IADL related questions can be discussed by domestic life, general tasks and demands, and major life area domains. Questions on carrying out domestic and everyday actions and tasks such as shopping (d620), preparing food (d630) and doing housework (d640) etc. were mapped to the codes of domestic life. Questions on carrying out the tasks and actions required to engage in education (d810 – d839), work and employment (d859) and to conduct economic transactions (d879) represent the major life area (WHO 2001a).

Usually the ability to use a telephone has been part of the IADL questions (see table 4.1.1). From the functional perspective it belongs to the area of communication and the ability to use communication devices and techniques (d360).

General questions on coping with every day tasks and demands were coded to the ICF domain of general tasks and demands. Carrying out daily routine (d230) includes managing and completing the daily routine as well as managing one's own activity level (WHO 2001a, Cieza et al 2002).

### **9.1.2 Linking the examination procedures to ICF**

The performance tests on physical functioning were also linked to the codes of ICF. The coded tests are listed in table 9.1.2. Vision, hearing, reaction time, muscle strength, parts of joint function (upper extremity parts), and back extension tests were classified to belong to the body functions (b) part of ICF. On the contrary stair-mounting ability, walking test and other parts of joint function test (walking, squatting and upstairs walking) were regarded representing activities and participation (d, mobility). Balance tests that assess the ability to stand in different positions were coded to the activities and participation part while balance test assessing the sway of body's gravity centre (computer based meter) was linked to the functions of relevant parts of body structures and functions.

**Table 9.1.2** The coverage of health examinations on physical functioning and the relevant ICF codes.

Survey name English	Survey year	Survey code	Country	HES code	Topic text	Examination description	ICF CODE
Health 2000	2000	FIN03	Finland	2210	Other measurements of sensory or physical function	For those aged 55 and over: Chair stands (time to rise from a chair and return to the seated position 5 times)  For those aged less than 55: Musculoskeletal fitness test: back extension for the endurance capacity of the trunk extensor muscles (the endurance time of the task up to 4 minutes)	d410  b740
Health 2000	2000	FIN03	Finland	2208	Muscle strength	Hand grip strength measured from the dominant hand with the electrical grip strength meter, repeated twice	b730
Health 2000	2000	FIN03	Finland	2207	Standing balance and/or sway of body's gravity center	Measured with a computer based meter with the subject standing 30 sec. with open eyes and with eyes shut, and 20 sec. in a semi-tandem and tandem position	d415 b235
Health 2000	2000	FIN03	Finland	2206	Stair-mounting ability	For those aged 55 and over	d455
Health 2000	2000	FIN03	Finland	2205	Reaction time	Psychomotor reaction time (computer assisted measurement)	b760 b147
Health 2000	2000	FIN03	Finland	2204	Walking speed	For those aged 55 and over: timed 6,1 meter walk	d450
Health 2000	2000	FIN03	Finland	2203	Joint function	Walking on even ground, walking on tiptoes, upstairs walking, squatting,  Elevation of the upper arms, extension of the elbow joints, flexion of the elbow joints, volar flexion of the wrists, flexion of the fingers to the palm, opposition of the thumbs (for those aged 55 and over)	d450, d455, d410  b710
Health 2000	2000	FIN03	Finland	2202	Hearing tests	Audiometry: 500, 1000 and 2000 Hz (with Micromate 304 device) special sound proof cabin: No	d230
Health 2000	2000	FIN03	Finland	2201	Vision tests	Procedure: 40 cm board and 4 meter board (in at least 350 lux and 9-11 lux lightning) Tested with own glasses	d210
Finrisk 2002	2002	FIN07	Finland	2209	Physical fitness test	Subsample only – database do not include any future information about the content of test battery	*
Netherlands Health Examination Survey	2001	NL01	The Netherlands	2203	Joint function	Walking on even ground, walking on tiptoes, upstairs walking, squatting,  Elevation of the upper arms, extension of the elbow joints, flexion of the elbow joints, volar flexion of the wrists, flexion of the fingers to the palm, opposition of the thumbs	d450, d455, d410,  b710

\* Database do not include any precise information of the test battery and thus the ICF linking could not be done.

## **9.2 Current state of the measurement of physical functioning in national surveys**

The coverage of questions on physical functioning varies greatly in the national health surveys in Europe. All the 57 European Health Interview surveys over the last 5 years (1998-2002) and their items in the area on physical functioning are listed in annexes 13 and 14. The same information is summarised by country in Table 9.2.1.

Altogether 46 of the 57 Health Interview Surveys included at least some of the physical functional topics. The two French disability surveys (F02, F05) and the Spanish disability survey (E04) were the most comprehensive from the physical functional perspective (see annexes 13 and 14). These three surveys are disability surveys (annex 5) and thus the disability and functional items are naturally well represented. Also Belgium (B02), Germany (D02), The Netherlands (NL02), Norway (N01) and Sweden (S01) have surveys covering all the relevant items on physical functioning. In addition several surveys cover almost all the topics related to physical functioning (Finland, Italy and United Kingdom).

19% (11 surveys) of the European health surveys do not include any questions on physical functioning (see annexes 13 and 14). Most of these surveys are multipurpose surveys such as the Eurobarometer. Austria and Iceland have included a very limited number of physical functioning topics. Greece is the only country that has no surveys including questions on physical functioning (table 9.2.1).

Compared to interview surveys health examination surveys including physical functional measurements are rare in Europe (table 9.1.2). Measurements of sensory functions have been conducted only in Finland (FIN03). Physical functional measurements have been included in Finland (FIN03 and FIN07) and in The Netherlands (NL01). The Finnish Health2000 (FIN03) survey is the only European survey covering both comprehensive health interviews and examinations of physical functioning (both sensory and mobility items) (See annex 13 – 14 and table 9.1.2 ).

**Table 9.2.1** Physical functioning topics covered in national surveys in Europe according to database.

Country	Sensory functions	Mobility	Self-care	Domestic life	(IADL) Others
Austria			HIS		HIS
Belgium	HIS	HIS	HIS		HIS
Denmark	HIS	HIS			HIS
France	HIS	HIS	HIS	HIS	HIS
Finland	HIS/HES	HIS/HES	HIS	HIS	HIS
Germany	HIS	HIS	HIS	HIS	
Greece					
Iceland		HIS	HIS	HIS	HIS
Ireland	HIS	HIS	HIS		HIS
Italy	HIS	HIS	HIS	HIS	HIS
Luxembourg	HIS	HIS			HIS
Norway	HIS	HIS	HIS	HIS	HIS
Portugal	HIS	HIS	HIS		
Spain	HIS	HIS	HIS	HIS	HIS
Sweden	HIS	HIS	HIS	HIS	HIS
Switzerland	HIS	HIS	HIS		
The Netherlands	HIS	HIS/HES	HIS	HIS	HIS
United Kingdom	HIS	HIS	HIS	HIS	HIS
Number of countries	15	16	15	10	14

HIS= health interview surveys

HES= health examination surveys

### 9.3 Current situation by items in HIS

The current situation on physical functional topics in HISs is presented in terms of ICF. Four main categories (headings): Sensory functions, Mobility, Self-care activities and Domestic-life activities were coded according to ICF. Sensory functions represent the component of body functions whereas Mobility, Self-care and Domestic life represent the activities and participation component of ICF (see tables 9.2.1). In addition to these four main categories, an additional category was created. This category includes mainly IADL related items, which could not be mapped under the domestic life category (comprise several items from different ICF domains).

### **9.3.1 Sensory functions**

46 % (26) of the European surveys include questions on sensory functions. Altogether 15 countries have gathered information on hearing or seeing functions by health interview surveys. Only Austria, Greece and Iceland have not included these items in their health interview surveys (table 9.2.1).

Of the international recommendations both OECD and WHO Long-term disability questionnaire as well as the more recent recommendation of Euro-REVES have recommended questions on seeing and hearing (annex 8).

#### *9.3.1.1 Seeing function, ICF-code b210 and/ or d110*

24 surveys (14 countries, altogether 47 questions) have gathered information on seeing functions. Information on seeing has been obtained by asking the respondents to judge their capacity to see (“are you able to see” or “can you see”) rather than to report their actual performance (“do you see”). Most of the European HISs covering seeing related items have included both seeing on a short and long distance.

Both the recommendations of the OECD and WHO have been utilised in European health surveys. Most of the questions (16/47) follow the recommendations of OECD “Is your eyesight good enough to read ordinary newspaper print” and “Is your eyesight good enough to see the face of someone from a distance of 4 meters?”. Questions recommended by WHO-Europe have also been used (8/47 questions) but not as often as questions recommended by OECD. Even when the surveys have used the recommended questions the wording has been modified. The wordings of these two sets of recommendations have even been mixed together by changing for example the response scales.

The Eurobarometer October 2002 (INT06) has followed the recommendations of Euro-REVES “Can you clearly see newspaper print without glasses or any other aids/devices?” and “Can you clearly see the face of someone 4 metres away (across a road) without glasses or any other aids/devices?”. The Eurobarometer October

2002 has been used as a pilot survey to test some of the questions recommended by Euro-REVES (see also chapter 9.3.2).

The Finnish Health 2000 (FIN03) survey included a question where environment and the lightning conditions (ICF code, e240) have been taken into account: “Does your sight restrict your moving about: only in the dim, to some extent also in good lightning, very much also in a good lightning or not at all?”. In addition to combining lightning conditions, this is the only survey question relating the seeing function to the ability to move (mobility items). In some surveys (FIN03, D05, F09) questions have been asked concerning specific eye diseases and their treatment. Four surveys (CH02, F11, F07, F03) have questions related to use of glasses or contact lenses (ICF code, e125).

One main source of incomparability present in most seeing related questions arises from the lack of precision in distances. For example, the long distance varies from one to four meters (four yards). The object to see varies from recognising a face, recognising a friend, some one you know or, to see the text of television. For example in a Finnish survey (FIN03) the question on seeing a long distance has been formulated: “Are you able to read TV text (with glasses) from the normal watching distance (about 3 metres)?”. There is not such a variance in questions on seeing at a short distance. These questions are usually formulated by using “reading the newspaper print”.

Almost none of the questions in the European health surveys are identical with the recommendations. There is at least some modification in the wording of questions. Also population coverage may differ. For example in Eurobarometer 2002, the seeing related questions have not been presented if the respondent has been blind.

#### *9.3.1.2 Hearing function, ICF-code b230*

Questions on the hearing function have been included in 22 surveys (15 countries, altogether 38 questions). Information on hearing (as well as seeing) has been obtained by asking the respondents to judge their capacity to hear (“are you able to

hear” or “can you hear”) rather than to report their actual performance (“do you hear”). Still the performance wording has been utilised. One survey (FIN03) has used the performance wording when inquiring about hearing in noisy surroundings: “How do you hear talk/speech in a noisy or sonorous surrounding?” Environmental perspective (ICF, code e250) in the wording of hearing related questions, as described in this example, has not been commonly used in European surveys (only FIN03 and IRL01). Of the very recent studies also the French survey (F05/ 2001) has used the performance wording: “Do you hear what is said in a conversation (using hearing aid if necessary)”.

The OECD recommendation or its modifications are common within European health surveys (11 questions), although strictly identical wording with the recommendation is quite rare. The use of the recommendation of WHO-Europe has also been common (10 questions). Generally the wording of these has been modified from the recommended form. The Eurobarometer October 2002 is the only European survey including and also piloting the questions on hearing as recommended by Euro-REVES.

Questions of general hearing functions or hearing problems are not common in European health surveys. For example hearing problems (“When did you start having hearing problems”) have been asked in four countries (UK07, P03, E04, D05). Straight questions related to use of hearing aid (ICF-code, e125) are rare (CH02). Only few surveys (FIN03 and E04) have questions on ear diseases affecting hearing. The Finnish (FIN03) and the English survey (UK13) have questions on tinnitus and wheezing/whistling (ICF-code d240).

The lack of precision in the wording causes incomparability between questions on hearing functions. The most critical variations in the wording concern the number of people within a conversation. The number of people in the questions varies from one to four people. In addition some surveys use a general definition such as “conversation between several people”. In some surveys questions on hearing have not been asked from the deaf.

### 9.3.2 Mobility

Mobility related questions are the most frequently included questions on functioning. 61 % (35) of the surveys over the last 5 years include this item (altogether 16 countries). Austria and Greece have not included any of the mobility items in their HIS.

Of the international recommendations the OECD and the WHO Long-term disability questionnaires as well as the more recent recommendation of Euro-REVES have recommended questions on mobility. In addition, the general health status questionnaire, SF-36 includes a series of questions on mobility (see annex 9).

#### 9.3.2.1 *Changing and maintaining body position, ICF-code d410 – d429*

Questions on changing and maintaining body position have been asked in eleven surveys (8 countries, 11 questions). Surveys have mainly utilised either the OECD or the WHO-Europe recommendations. These recommendations on changing basic body position (d410) differ only in response categories (OECD- difficulty and WHO yes/no). Of the European countries The Netherlands (NL02, NL03), Portugal (P03), German (D02), Italy (I01), France (F02, F05) and The United Kingdom (UK12, the only one using the yes/no- response category) have utilised the recommended formulations. However slight modifications in the wording are quite common. For example, the term “shoe” has been replaced by using the term “something from the floor” or “ an object from the floor”.

Only two surveys, the Belgian (B02) and the German (D05), have used the mobility related questions from SF-36 as a reference. The Spanish disability survey (E04) is the only survey inquiring about maintaining body position (d415) and getting up, sitting down, and maintaining a standing or seated position.

#### 9.3.2.2 *Carrying, moving and handling objects, ICF-code d430 – d499*

Altogether 14 surveys from 9 countries (altogether 23 questions) have gathered information about carrying, handling and moving objects. Ten surveys from seven countries (Belgium, Denmark, Finland, France, Germany, Luxembourg, and The

Netherlands) have included questions on lifting and carrying objects (d430). Most of these have used the question recommended by OECD (annex 9). However, there are enormous variations in the wording and in the content of questions compared to the recommended form. For example, in the two Finnish surveys (FIN03 and FIN09) the distance to carry an object of 5 kilos has been changed from 10 meters to 100 meters. In addition some questions use precisely ten meters while others have formulated the distance "over ten meters". In one case (DK02), the distance has not been defined at all. The most recent recommendation of Euro-REVES does not define the distance (annex 9). The Eurobarometer October 2002 (INT06) has tested the Euro-REVES recommendation. The Belgian (B02) and German survey (D05) have used the question from SF-36 "Lifting and carrying groceries".

The Euro-REVES recommends questions on fine hand use "Using fingers to grasp or handle a small object like a pen" and "Turning a tap" (annex 9). These have not been used strictly identically in any of the surveys. Only the French survey (F02) has inquired about the ability to turn a tap. Questions about fine hand use (handling small objects, d440) have been asked in two French (F02, F05) and Spanish (E02, E04) disability surveys. The French disability survey from 1999 (F02) has been the most comprehensive with six questions related to hand use and carrying and handling objects. The respondents have been inquired: "Can you specify which of the following gestures are hard or impossible for you to make: opening and closing the door, turning a tap on and off, using scissors, using pen and buttoning the clothes", also a more common form of question: "Can you use your hands and fingers?" has been used.

Information about hand and arm use (d445) has been inquired in three surveys (E04, B02, D05). Belgium (B02) and Germany (D05) have utilised the questions from SF-36 concerning moderate activities such as moving a table, pushing a vacuum cleaner, bowling or playing golf. The question relates the hand and arm use to recreational and household activities.

The OECD recommendation is the most often used reference instrument in questions related to carrying objects. None of the surveys has included the question recommended by Euro-REVES. There appear variations in the wording as well as in

the population coverage. For example, some questions have been posed only to children (E04).

### *9.3.2.3 Walking and moving, ICF-code d450 – d469*

The most often asked mobility item concerns the ability to walk and move around. Altogether 15 out of the 18 countries (29 surveys, altogether 101 questions) have included these items in their surveys. The questions concern walking (d450, 28 questions), moving around (d455, mainly running and going up and down of stairs, 38 questions, d455) as well as moving around in different locations (d460, 35 questions, d460).

13 countries (20 surveys) have included questions related to walking (d450). Most of the surveys have used some of the recommended questions (see annex 9). The recommendation of OECD has been used only in the Netherlands (NL02, NL03). The recommendation of WHO-Europe has been utilised more often: Seven surveys have used it or a modification of it. Modifications in the wording and in the response scales are quite common. For example, in some cases (F02, F05) the ordinary response scale has been replaced with an open question. Eurobarometer 2002 (INT06) has used the recommendation of Euro-REVES. The Belgian (B02) and German (D05) surveys have used the questions from the SF-36.

All of these recommended forms and also their modifications appear in health surveys in European countries. Also other forms of asking about walking have been used. For example in the Finnish surveys (FIN03, FIN01, FIN07) the ability to walk about half a kilometre without stopping and the ability to walk two kilometres (FIN03) were included with response scale without difficulty, with minor difficulties, with major difficulties, and not at all. Both Swedish surveys (S01, S02) have included a question: "Can you take a short walk, say five minutes, at a fairly brisk pace?".

A main source of incomparability in questions on walking is the variation in distances. The distances vary between 100 and 400 meters, and between one half and two kilometres (one block/several blocks). In addition some questions do not specify a distance at all, mentioning only a time limit for walking (S01, S02). The great

variability of questions is perhaps not surprising, since also the recommendations on this area differ greatly

The variation in the wording and contents of the questions resembles (as in questions on walking) that in the questions on the ability to move around (d455, 23 surveys from 14 countries). Questions on moving around can be divided into questions concerning running (12 questions) and going up and down the stairs (26 questions).

Only OECD has produced recommendations concerning running (annex 9), but this has not been used. The SF-36 served as a reference in German (D05) and Belgian (B02) surveys. Most of the surveys use some other forms than the recommended ones when inquiring about running.

One main source of incomparability present in questions on running arises also from the variation in distances. The distance to run varies between 100 (F06, S01, S02) and 400 meters (D02). In addition some questions mention terms to describe the situation when running ("if you are in hurry" (S01, S02) while others have no descriptions. The Finnish surveys (FIN01, FIN03, FIN07) offer a good example of the diversity of questions. All of these three surveys have asked about the ability to run a short (100m) and a long distances (half kilometre). However although the wording of these questions is quite similar the response scales differ between the surveys: "FIN01: yes/no, FIN03: without difficulties/ with minor difficulties/ with major difficulties/ not at all, and FIN07: I can not/ I can with difficulty/ I can without difficulty".

OECD, WHO-Europe as well as Euro-REVES group have proposed a question on climbing stairs. Also the SF-36 includes questions on climbing several flights and one flight of stairs. The question of Euro-REVES has served as a reference for Eurobarometer 2002 (INT06) and the questions of SF-36 for Belgian (B02) and German (D05) surveys. Other surveys have used mainly the modifications of either OECD or WHO recommendations.

The main source of incomparability in questions on climbing arises from variation in flights or number of stairs. Differences in the wording include: from one floor to

another (DK02), more than one floor (D02), a flight of stairs (I01, F05), stairs without difficulty (S01, S02, F06), a flight of 12 stairs (P03, UK12), go up ten stairs (E02), and walk up and down stairs (NL03). In addition the response scales vary from being yes/no to difficulty and ability scales. The great variability in the wording and in the contents makes the replies non-comparable.

Questions on moving around in different locations (d460) such as moving around within the home and other buildings than home as well as moving outside the home and other buildings have been asked quite often in the European health surveys (in 16 surveys from 9 countries, 35 questions). In health surveys in Europe questions have been asked concerning the ability to move inside the home (9 questions) for example from one room to another and get around inside the home. The recommendation of OECD “Moving between rooms” has been used as a reference. In addition there are questions inquiring information about difficulties in leaving and entering home (11 questions) as well as questions on the ability to move outside the home (11 questions) such as walking along the street and going out unaided. Some questions (4) gather more general information about moving around.

#### *9.3.2.4 Moving around using transportation, ICF-code d470 – d480*

Questions on the ability to move around using transportation are the most rarely asked questions related to mobility. Only seven European countries include questions on moving around using transportation (d470, 21 questions 9 surveys) or driving a car (d475, 7 questions in 3 countries).

There are no recommendations on transportation, but some general health status measurements, such as the McMaster Health Index Questionnaire (McDowell & Newell 1996, 425) and the Quality of Well-Being Scale (McDowell & Newell 1996, 485) include questions on the use of transportation and on the ability to drive a car. However, these have not been utilised in national health surveys. Most of the questions on transportation ask about the ability to use public transport or difficulties in using public transport due to health-related problems. Some of the questions concern the use of specific forms of transportation due to health problems or disabilities. The second bigger area of transportation questions concerns the ability to

drive a car (FIN03, F02, E04) or whether the respondent has a valid driver's licence (FIN03, F02).

The questions on transportation are so rare and variable that comparison between countries in Europe is not possible. Since the utility to use transportation is so essential in modern society it is surprising that not more interest has been shown to it.

#### *9.3.2.5 Other mobility related items*

General or global questions on the present mobility situation are quite common in European countries. Altogether 22 surveys from 12 countries include them. Most of these questions (35) concern the ability to transfer (move from bed or chair). The recommendations of OECD or WHO have been used as a reference (annex 9). The use of the recommendation of OECD is more common than WHO-Europe: only the Belgian (B02), Portuguese (P03) and Italian (I01) surveys have used the WHO-Europe questions as a reference. In addition to these recommendations there have been several other forms of questions related to general mobility. For example the Irish surveys (IRL01, IRL03) have used a question from the EuroQol Quality of Life Scale (Mobility: I have no problems in walking about, I have some problems in walking about, I'm confined to bed).

**Table 9.3.1** Mobility topics covered in the national health surveys in Europe categorised according to ICF.

Country	Changing and maintaining body position d410 – d429	Carrying, moving and handling objects d435 – d449	Walking and moving d450-d469	Moving around using transportation d470 –d489	Other mobility related items d498-d499
Austria					
Belgium	HIS	HIS	HIS		HIS
Denmark		HIS	HIS		
France	HIS	HIS	HIS	HIS	HIS
Finland	HES	HIS /HES	HIS / HES	HIS	HIS
Germany	HIS	HIS	HIS		HIS
Greece					
Iceland			HIS		
Ireland					HIS
Italy	HIS	HIS	HIS	HIS	HIS
Luxembourg		HIS	HIS		
Norway			HIS	HIS	
Portugal	HIS		HIS		HIS
Spain	HIS	HIS	HIS	HIS	HIS
Sweden			HIS	HIS	HIS
Switzerland			HIS		HIS
The Netherlands	HIS	HIS /HES	HIS / HES		HIS
United Kingdom	HIS		HIS	HIS	HIS
Number of countries	9 *	9	15	7	12

\* 8 HIS and 1 HES

### 9.3.3 Self-care activities

40% (23) of European health surveys include questions on self-care activities (ADL items). Only Greece, Denmark and Luxembourg have not included these items in their surveys.

Of the international recommendations OECD, WHO-Europe and Euro-REVES have recommended questions on self-care. In addition SF-36 includes a reference question on problems with self-care (see annex 10).

#### 9.3.3.1 Washing , ICF-code d510

Questions on washing have been asked in eleven countries in 18 surveys (altogether 27 questions). The recommendation of WHO-Europe has been used in 9 surveys. The recommendation of Euro-REVES has not been used identically in any survey but the content of the question, bathing and showering, has been included in three surveys (I01, S02, E02). The Belgian (B02) and the German (D05) surveys have

used the question from SF-36 where bathing and dressing are combined under the same question. The Belgian survey (B02) has modified the original form of SF-36 by including also the term “showering” to the question.

Most of the surveys (11) have own forms of asking about the ability to wash oneself. Examples on the variations of the wording include: washing oneself completely or overall, washing or dressing, washing and taking care for body parts, washing and bathing, and washing up. Usually the questions inquire about the need of assistance, assistance received, or difficulties in performing the task.

#### *9.3.3.2 Caring for body parts, ICF-code d520*

Questions related to taking care of body parts have not been widely asked in Europe. Only six surveys from four countries (altogether seven questions) have included the question "Can you cut your toe nails" as recommended by OECD". Slight modifications in the wording are common. In addition to cutting toenails, one survey (E02) has inquired about the ability to do hair (women) and shave (men). The Spanish disability survey (E04) has one question concerning both bathing and taking care of body parts.

#### *9.3.3.3 Toileting, ICF-code d530*

Nine surveys from six countries (altogether 11 questions) have included questions on the use of toilet or activities related to excretion (b610, b525). Most of the surveys have followed the recommendations of WHO-Europe: “ Can you get to and use the toilet on your own?”. Only one survey has used the formulation of the actual performance as recommended by Euro-REVES (“Do you usually, use toilet yourself without any difficulty, without human /technical help?”). None of the surveys have included the related question recommended by WHO-Europe “Do you ever lose control of your bladder”. Incontinence may have been included in questions on chronic diseases and thus not evaluated in this study.

#### *9.3.3.4 Dressing, d540*

Altogether 18 surveys from 12 countries (altogether 20 questions) have included questions related to dressing or undressing. Both OECD and WHO-Europe have recommended almost similar questions on dressing “Can you dress and undress (yourself on your own)?” (see annex 10). Most of the surveys use the recommended forms with slight modifications mainly in response categories. The two French surveys (F02/F05) have used a question almost similar to the recommendation of Euro-REVES “Do you usually, dress and undress yourself without any difficulty, completely on your own?”.

The Spanish disability survey (E02) has used an exceptional wording, combining the term “choose clothes” under the question on dressing ability. Few surveys (E04, FIN07) have asked about dressing without inquiring information about the ability to undress. In two surveys (D05, B02) the question on dressing has been combined with bathing according to SF-36.

#### *9.3.3.5 Eating and drinking, ICF-code d550 – d560*

Eating and drinking questions have been presented in 17 European surveys (12 countries, 23 questions). The WHO-Europe recommendation or its modification has been used in seven surveys. Only the Belgian (B02) and the English (UK12) surveys have followed the recommendation strictly. Most of the surveys have replaced the term “feed” with the term “eat”. The recommendation of OECD “Can you cut your own food (such as meat, fruit etc.)” has not been strictly used. In some surveys, however, there are separate questions concerning the ability to cut up food (D02, I01).

OECD has recommended a separate question for the ability to bite and chew on hard food such as apple or celery. Five European countries (6 surveys) have included the question on biting and chewing hard food. The Netherlands (NL02/NL03), Germany (D02) and Belgium (B02) have followed the recommendation of OECD and Finland (FIN09) and Italy (I01) have modified the wording.

Besides the recommendation on eating/feeding many surveys have used some other forms of questions on eating and/or drinking. Some of the surveys include questions concerning only eating (IS02, FIN03, FIN09), while others include questions on both eating and drinking (E02, F02, F05, NL01, NL02, NL03). In two French surveys (F02, F05) the questions are worded, "Once the food is ready, do you (does he/she) eat and drink without any assistance?". These two surveys are also the only ones asking about the ability to drink in a separate question. In other surveys eating and drinking items have been combined into the same question.

The recommendation of Euro-REVES "Do you usually feed yourself without any difficulty, and completely on your own?" has not been used in any surveys but the French surveys (F02, F05) have used the performance wording as recommended by Euro-REVES.

#### *9.3.3.6 Looking after one's health, ICF-code d570*

Questions on looking after one's health in terms of functioning are rarely included in European health surveys. The ability to take medication without any help has been inquired in 4 surveys only (annex 14).

#### *9.3.3.7 Self-care other, ICF-code d589 – d599*

Self-care is covered in five countries by general questions. The Irish surveys (IRL01, IRL03) have utilised the problem approach following the EuroQol (I have no problems in self-care...some problems with self-care, I am unable to wash and dress myself). The Norwegian survey (N01) has inquired about the ability to manage one's personal hygiene and the Austrian survey (A01) the ability to carry out important personal functions. The Icelandic (IS01) survey included a question concerning the assistance needed in eating, dressing or moving around at home.

**Table 9.3.2** Self-care topics covered in the national surveys in Europe categorised according to ICF.

Country	Washing d510	Caring for body parts d520	Toileting d530	Dressing d540	Eating and drinking d550/d560	Looking after one's health d570	Self-care other d589-d599
Austria							HIS
Belgium	HIS		HIS	HIS	HIS		
Denmark							
France	HIS	HIS	HIS	HIS	HIS	HIS	
Finland	HIS	HIS	HIS	HIS	HIS		
Germany	HIS	HIS		HIS	HIS		HIS
Greece							
Iceland				HIS	HIS		HIS
Ireland							HIS
Italy	HIS			HIS	HIS	HIS	
Luxembourg							
Norway				HIS	HIS		HIS
Portugal	HIS		HIS	HIS	HIS		
Spain	HIS	HIS	HIS	HIS	HIS	HIS	
Sweden	HIS						
Switzerland	HIS		HIS	HIS	HIS		
The Netherlands	HIS			HIS	HIS		
United Kingdom	HIS		HIS	HIS	HIS		
Number of countries	11	4	7	12	12	3	5

### 9.3.4 Domestic life Activities

37 % (20) of the European surveys (from 10 countries) included questions on domestic life activities (IADL Instrumental activities of daily living). 40 % (23) of the surveys (from 11 countries) inquired about general tasks and demands (other IADL questions, mainly the global questions). The current state of questions in this area is summarised in table 9.3.4.

The only recommendation on domestic-life questions comes from the Euro-REVES (see annex 11). In addition there are at least 17 different kinds of common IADL-instruments some of which are also used as a reference in national health surveys. However, none of these have been generally recommended as reference instruments.

#### *9.3.4.1 Shopping, ICF-code d620*

Shopping related questions have been asked in 12 surveys (from 9 countries, altogether 12 questions). The wording of the questions varies greatly. For example the question in the Norwegian survey (N01) assesses self-reported ability "Can you manage to do your shopping without help from others?" whereas questions from the two French surveys (F02, F05) assess self-reported performance "Do you do the daily shopping on your own or with the help of somebody". The most recent recommendation (Euro-REVES) uses the performance wording for the IADL-questions: " Do you, usually, do all the shopping without any difficulty on your own?". This formulation has not, so far, been used in any surveys.

In addition to differences in the wording of questions, there are also differences in the contents. For example, in the Spanish survey (E02) buying food and clothes have been combined under the same question whereas a Swedish survey has asked simply about buying food (S01). Also more common terms for buying such as shopping (I01), household shopping (UK02) or daily shopping (NI01, NL02) have been utilised. Most of the shopping related questions include the assessment of the level of difficulty or the assistance needed.

#### *9.3.4.2 Preparing meals, ICF-code d630*

The ability or the actual performance to prepare meals has been asked in ten surveys (6 countries, altogether 11 questions). The questions on preparing meals assess mostly self-reported abilities "Can you prepare you own meals unaided?" (F05). The Euro-REVES recommends to use the performance wording but the proposed form has not yet been used in practice.

Most of the questions include the assessment of the degree of difficulty or amount of assistance needed. A main source of poor comparability in the questions on preparing meals is the variation of the content of the questions. It varies from preparing food, hot meals, cooking, taking care of meals, and preparing breakfast etc.

#### *9.3.4.3 Doing housework, ICF-code d640*

Questions related to cleaning or doing the laundry have been asked in 13 surveys (8 countries, altogether 33 questions). Most of the surveys include at least two questions on the topic. Norway (N0), Italy (I01), France (F02/ F05) and Iceland (IS02/IS03) have only one question on the topic per survey. These concerned the ability or performance of doing the housework in general such as common house chores (IS03), taking care of the home (I01) and handling household work (IS02).

A major source of poor comparability is the variation in the content of questions. Differences comprise the ability to make ones' bed, to clean and to do the laundry. Also more general terms have been utilised; do light housework and/or heavy housework (FIN09). The Spanish survey (E02) has been most comprehensive by asking a series of questions on cleaning a stain on the floor, cleaning the house or flat (washing the floor, sweeping), washing clothes by hand, using the washing machine, washing plates and making the bed. The Netherlands (NL01, NL02) has included a very specific task: the ability to do jobs requiring kitchen steps / stepladder.

In general, both the performance and the capacity wording have been utilised in questions on doing housework. So far, none of the surveys have used the recommendations of Euro-REVES. It proposes two questions for housework duties and one for the ability to do the laundry. These questions on housework include both routine light housework and periodic heavy housework "Do you usually do the periodic housework without any difficulty and completely on your own?".

#### *9.3.4.4 Domestic-life other*

In the French (F02) and Spanish (E04) surveys there were questions related to acquiring a place to live (d610). The questions concerned the necessity to move for health reasons (F02) or as a result of suffering from a disability (E04). The Spanish survey (E04) is the only one asking about assisting other household members (d660).

### **9.3.5 Other items**

#### *9.3.5.1 Major life areas - finance (d860) and work (d845)*

Only five surveys from four countries (annex 11) included questions on managing finances. The two French (F02, F05) surveys inquired “Do you at present fill in simple forms (cheques or sickness forms)?” and in Italy (I01) “Is he/she usually able to manage his/her own finances”. Difficulties to manage money, banking and office duties were asked in one Finnish (FIN03) and one Spanish survey (E02).

Managing finances is covered in seven current IADL–instruments (table 4.1.1). Euro-REVES recommends to include a question on managing financial matters. The recommendation proposes the performance wording: “Do you, usually, take care of/ manage your financial matters.

Questions related to ability to work or handle one's work were asked only in four surveys (annex 11). Questions on working conditions and work force participation have been categorised under work force participation of disabled people (nine surveys including this topic) in the European health survey database and thus not all of the work related questions are evaluated in this study.

#### *9.5.3.2 Community, social and civic life - social life (d910) and leisure (d920)*

Only two surveys (N01 and IS03) have included questions concerning social life and leisure from the perspective of participation restrictions. The Norwegian survey (N01) has asked about trouble in participating in recreational activities and the Icelandic survey (IS03) inquired “Has health failure caused you to have less independence or participation in society?”. The Finnish Health 2000 survey, on the other hand, inquired about participation in a very large number of leisure activities.

#### *9.5.3.2 Communication – use of telephone (d360)*

Five surveys from four countries have included questions related to the ability to use a telephone. The French survey (F02) used a wording almost similar to the

recommendation of the Euro-REVES “Do you, usually, use the telephone without any difficulty and completely on your own?”. Basically the countries have utilised difficulty approaches (do you have any difficulty...) in questions on telephone use. No surveys have taken into account the ability to use a mobile phone, however.

#### *9.5.3.3 General tasks and demands - Global approach- carrying out daily routine (d230)*

Eleven countries (23 surveys) inquired about limitations in usual activities by using global questions. Most of the questions referred to usual activities in general and only a few referred to specific life situations such as leisure-time, school and work. Most of the questions used in national surveys referred to health-related problems (most commonly health in general, some to physical or mental health) as a source of activity limitations. In addition most of the questions refer to health in general and only some refer to specific health concepts such as physical or mental health as a source of activity limitations.

For example the question “Does this illness or disability (Do any of these illnesses or disabilities) limit your activities in any way?” has been included in six different surveys in The United Kingdom. In some surveys the questions have been asked only for those having some long-term disability or handicap (UK11, UK09, UK02). Only few surveys use the age limit. In the Netherlands (NL01) and in the United Kingdom the questions have been asked only from those aged 65 years and older (NL01, UK02).

Various forms of generic questions on the limitations have been utilised. There has been an initiative to develop a Global Activity Limitation Indicator (Robine et al 2002, 67). The indicator, GALI, has not yet been evaluated but it has been translated into all European languages. The recommended question “For at least the past 6 months or more have you been limited in activities people usually do because of health problems?” has been used only in one national survey (B02). One French survey (F09) has also used the time limit of six months, but the wording of the question differs from the recommendation.

**Table 9.3.4** Domestic-life and major life area topics covered in the national surveys in Europe categorised according to ICF.

ICF	Domestic-life				(IADL) others				
					Major life area		Community	Communication	General tasks and demands
Country	Shopping d620	Preparing food d630	Doing housework d640	Domestic life other d660-d699	Finance d860	Work d845	Social and leisure	Telephone d360	Global questions
Austria									HIS
Belgium									HIS
Denmark									HIS
France	HIS	HIS	HIS	HIS	HIS			HIS	HIS
Finland	HIS	HIS	HIS		HIS	HIS		HIS	HIS
Germany	HIS								
Greece									
Iceland			HIS			HIS	HIS		
Ireland									HIS
Italy	HIS	HIS	HIS		HIS			HIS	
Luxembourg									HIS
Norway	HIS		HIS			HIS	HIS		HIS
Portugal									
Spain	HIS	HIS	HIS	HIS	HIS			HIS	HIS
Sweden	HIS	HIS	HIS			HIS			
Switzerland									
The Netherlands	HIS	HIS	HIS						HIS
United Kingdom	HIS								HIS
Number of countries	9	6	8	2	4	4	2	4	11

## **9.4 Current situation by items in HES**

### **9.4.1 Examination procedures for sensory functions**

The Finnish Health 2000 (FIN03) survey is the only survey including both health interview and health examination on seeing and hearing functions. Seeing was tested at short and long distance in different lightning conditions (in at least 350 lux and 9-11 lux lightning). Hearing was measured by audiometers (in 500, 1000 and 2000 Hz). The test was conducted for those over 30 years. The test protocols are listed in table 9.1.2.

### **9.4.2 Examination procedures for mobility related items**

Three of the European surveys have included examination procedures related to mobility (table 9.1.2). In the two Finnish HES (FIN03, FIN07) and in the Dutch HES (NL03) there has been a similar joint function test (walking on even ground, walking on tiptoes, upstairs walking, squatting, elevation of the upper arms, extension of the elbow joints, flexion of the elbow joints, volar flexion of the wrists, flexion of the fingers to the palm, opposition of the thumbs). In Finland the test was performed only for those over 55 years and over whereas in the Netherlands there were no age limits. In the Finnish Health 2000 survey (FIN03) also a 6.1 meters walking test, stair-mounting ability, and chair stands (time to rise from a chair and return to the seated position 5 times) was performed in the population aged over 55.

Health 2000 is the most comprehensive health examination survey in Europe in the area of physical functioning. In addition to the tests mentioned above psychomotor reaction time (computer assisted measurement), the standing balance and/or the sway of body's gravity center was measured. The balance was measured with a computer-based meter with the subject standing 30 seconds with open eyes and with eyes shut, and 20 seconds in a semi-tandem and tandem position. Also, handgrip strength was measured with a computer-based instrument. All of these tests were performed in those aged 30 years and older. In addition, a musculoskeletal fitness test: back extension for the endurance capacity of the trunk extensor muscles (the

endurance time of the task up to 4 minutes) was included in the survey protocol for those aged under 55 years.

#### **9.4.3 Comparability of methods**

A main source of poor comparability of the HES protocols is in the differences in instruments and survey methods. The test protocols vary in the scope and in the meanings of the tests. In addition to instruments used there are differences in the sample and examination protocols between surveys (see annex 5).

The Dutch survey (NL01) and one of the Finnish surveys (FIN07) were undertaken at normal health care facilities. The average duration of examination was 30 minutes (including all the examinations performed, of which the joint function test takes on average 5 minutes) for the Dutch survey and for the Finnish 90 minutes. The Finnish Health 2000 survey differs from the two others. It was undertaken both in clinical settings and in the subject's home. An average duration of the examination was 240 minutes, of which 30 minutes concerned the physical functional examination.

In all three surveys (FIN03, FIN07, NL01) including performance-based tests on physical functioning quality assurance was performed by training the personnel (by supervisors), calibrating of the equipment and observing during the examination. In addition the Finnish survey (FIN03) used pilot runs, repeated measurements during one clinic or home visit, repeated measurements with different equipment and /or protocols. Also, the monitoring findings reported by observers were taken into account.

### **9.5 Future development of the database**

#### **9.5.1 HIS and ICF**

Based on the experience of the linking work and on the principles of the database classification new topic codes (for physical functioning topics) are proposed to be created according to the main domains of ICF as described in the table 9.5.1. For the

topic list of the database a hierarchical system is necessary, e.g. categories that are split up into subcategories. Again, these subcategories may be split up in sub-subcategories etc. However, if there are more than two or three levels, it will be complicated to use the list as a search tool. This means that a too accurate and multi-level classification system for the database is not feasible. Thus for the purpose of the database the main domains of the ICF offer useful topics.

**Table 9.5.1** Proposal for the new database topics on physical functioning items in HIS.

<b>Present Database topic</b>	<b>Present Database codes</b>	<b>New Main Topic (domain/chapter)</b>	<b>Items included: Specific topic (blocks)</b>	<b>Questions (codes)</b>
Limitations of functional ability sensory	207	Sensory functions and pain	Seeing and related functions	b210-b229
			Hearing and vestibular functions	b230-b249
			Additional sensory functions	b250-b279
			Pain	b280-b289
Limitations of ADL:others	214	General tasks and demands	(topics such as undertaking a single/ multiple tasks etc.)	d210-d299
Limitations of functional ability physical	208	Mobility	Changing and maintaining body position	d410-d429
Access limitations	210		Carrying, moving and handling objects	d430-d449
Mobility	211		Walking and moving Moving around using transportation	d450-d469 d470-d489
Limitations of ADL: personal	212	Self-care	(Topics such as washing oneself, caring for body parts, toileting, dressing, eating, drinking, looking after one's health)	d510-d599
Limitations of ADL: household	213	Domestic life	Acquisition of necessities	d610-d629
			Household tasks Caring for household objects and assisting others	d630-d649 d650-d669
Limitations of ADL: household	213	Major life area	Education Work and employment Economic life	d810-d839 d840-d859 d860-d879
Limitations of ADL: household	213	Communication	Communication –receiving Communication – producing Communication and use of communication devices and techniques	d310– d329 d330-d349 d350-d369

## 9.5.2 HES and ICF

For the purpose of the database the examinations are proposed to be linked to the ICF codes according to the main purpose of the surveys (table 9.5.2). As the present classification system for HES components are good, there is no compulsory need to change it. One could, however, use the ICF to mark whether the test represents body function or activities and participation part. If the HES topics will, however, be changed, the main topics could be derived from the main domains of ICF:

**Table 9.5.2** Proposal for the new database topics on physical functioning items in HES.

Present Database topic	Present Database codes	New Main Topic (domain/chapter)	Items included: Specific topic (blocks)	Questions (codes)
Musculoskeletal function and diseases (area 21)	2102 - 2104	Neuromusculoskeletal and movement related functions	Functions of the joints and bones  Muscle functions Movement functions	b710-b729  b730-b749 b750-b789
Sensory function, physical function and fitness (area 22)	2201- 2202	Sensory functions and pain	Seeing and related functions Hearing and vestibular functions	b210-b229 b230-b249
Sensory function, physical function and fitness (area 22)	2203 - 2210	Mobility	Changing and maintaining body position  Carrying, moving and handling objects Walking and moving	d410-d429  d430-d449 d450-d469

Linking performance-based measures is more complicated compared to self-reported methods. A good example of the complexity is the chair stand test. Chair stand is a complex test in which several physiologic components, including muscular strength, balance, co-ordination, joint range of motion, and exercise tolerance, contribute to the overall performance. From the functional point of view, the task may be described as the ability to transfer the body from one posture to another, with the second posture requiring a higher level of energy and more effective functioning of the systems involved in maintaining balance. (Guralnik et al 1994, 1995; Tinetti et al

1995). Even if the test includes several physiologic components (muscular strength, balance, coordination, joint range of motion, exercise tolerance), which could be linked to the codes of ICF, the test was linked in this study to the ICF according to the main purpose of the measurement. As the chair stand test describes the ability to transfer the body from one posture to another it was linked to the code of activities and participation - changing basic body position (d410).

## **PART III DISCUSSION AND CONCLUSIONS**

The third part of this report summarises the main findings of this study and discusses future issues. Conclusions on the present situation on physical functioning in national health surveys are also presented and some suggestion for the future are made.

### **10 DISCUSSION**

#### **10.1 Measurement of physical functioning**

An individual's health fundamentally includes the capacity to carry out the full range of actions, activities and tasks required to fully engage in all areas of human life. The measurement of these items is becoming an increasingly important research and clinical topics. Information about functioning is needed in order to appreciate the full picture regarding the health of an individual and a population. Research and actions in all areas of health and social policy, at all levels, need valid and reliable data about functioning (functional status) in order to make informed conclusions and decisions.

In response to the increasing need of information, a plethora of both self-report and performance-based measures of physical functioning have been developed for multiple purposes. Despite the wide application of many current instruments of physical functioning, there remains a need for improvements in instruments. Most of the current measurements of physical functioning are relevant for the population 65 and older (McDowell & Newell 1996, Gudex & Lafortune 2000). In addition the development of indices has been guided to the large degree by the needs of health care (McDowell & Newell 1996). Instruments designed to obtain information related to specific diseases and treatments, to plan placement decision, to describe the stage and severity of chronic diseases, and to determine benefits and estimating demand for long-term care services do not necessarily discriminate among groups of healthy older adults in population based studies. In particular, most patient groups are much more severity restricted than population of a similar age. Further research is needed to develop measures for population based surveys. The recent work of the

Euro-REVES is a good example of new initiatives (Robine et al 2000, Robine et al 2001).

## **10.2 Challenges in international comparability**

Besides the great progress over the past three decades in international harmonisation the comparability of survey data is problematic. However, in order to understand differences between populations' health the comparability of health survey data is essential. The idea of internationally standardised scales is commendable, but it has not been fully achieved. Both WHO-Europe (DeBruin et al 1996) and OECD (McWhinnie 1981) have recommended common instruments for health interview surveys. Both of these instruments are likely to be most relevant in measuring relatively severe levels of disability more frequently found in the population 65 and over (Gudex & Lafortune 2000). In addition, validity and reliability results are poor (McDowell & Newell 1996). Validation of these instruments has often been focused on their application at national level. Less attention has been given to validation for harmonisation of data collection at international level.

Despite of the deficiencies, the use of these recommended instruments has been widespread in Europe. However, the wording of questions in different surveys varies greatly. The development of standardised instruments, such as OECD, WHO-Europe or Euro-REVES, is a dynamic process and takes usually a long time. Some of the European surveys have included questions being under development. Thus the questions may differ from those in the final version of the instrument. Another source of incomparability arises from the history of the surveys. Countries with the longest experience want to keep time trends by continuing to use the questions they have been used to.

Cultural, environmental and linguistic differences are great challenges for the comparability and for the development of a reference instrument. In all languages there are usually several ways the question may be worded. It is possible that some of the apparent wording differences (performance versus capacity wording) may not have any major impact on the findings. If so, this needs to be demonstrated. In some

instances the differences in wording may not introduce any bias, in others they do. A still large bias can be introduced by the relatively large non-response in many surveys (see annex 5), which has rarely been given the weight it deserves. Reduced non-response is clearly as important as developing measurement.

It can not be assumed that people of different cultural and environmental backgrounds will interpret the questions identically. Responses of individuals may vary by country or by population sub-groups due not only to real differences in the quantity of interest but also differences in norms and expectations, or cognitive processing of survey questions. Although most weight has been put to equal conceptual and linguistic construction of questions and scales, little attention has been given to true differences between countries and population groups. These are probably of minor relevance in regard of basic ADLs but e.g. environments and demands put on functioning of older people may be quite different in different types of housing.

Any instrument recommended to facilitate international harmonisation should have relevance for policy-makers both at the international and at the national level. More attention should be paid to testing recommendations in practise and to evaluation at a regular basis. In fact all new measurements should only become recommended ones when their performance has been adequately investigated. For example, the Euro-REVES list needs further development and validation since some of the items are not equally applicable to all countries: turning the tap question, among others, is becoming an irrelevant question in the Nordic countries. Improving comparability of health interview survey instruments and methods requires scientific co-operation between countries. Evaluation and development of the present recommendations is needed. Also, the role of the functional performance tests needs to be taken into account.

### **10.3 Wider use of performance based measures**

The use of performance measures in cross-cultural and international studies is not common but it still has obvious advantages (Guralnik 1989). Cultural, language, and social differences between populations may greatly limit the validity of comparisons of self-reported functioning and disability. Cognitive impairments, culture, language and education have much less influence on performance tests, compared to self-report methods. Furthermore, they are essential for understanding time trends in functional capacity. In addition tests on physical functioning are quite safe to conduct. For example, in the Finnish Health 2000 survey of 7000 subjects there were no injuries.

However, there are only a few standardised tests suitable for assessing physical performance in large populations (Rikli & Jones 1997), but evidence of validity of performance measures of functioning in non-disabled elderly persons exists (Guralnik et al 1994). Further efforts are needed to find out new and more wide-ranging methods suitable for national health survey settings. On the other hand, many components of the test batteries for physical and sensory functioning are such that international standards exist for clinical work. When applicable survey instruments should take such recommendations into account. A more extensive literature review is needed to find out all the methods widely tested and suitable for national health survey setting. Also experiences of already existing health examination surveys (Aromaa & Koskinen 2002, NHANES 2003) are valuable.

International research collaboration is required to develop new methods and recommendations for performance based tests of physical functioning. A development of a reference laboratory for testing and evaluating performance based measurements would be a good starting point. Such testing should also be used to develop questions and scales by comparing them to tests and observations. Attention should be paid for evaluating the most suitable test for elderly persons as well as for working age persons. From the public health, working ability and pension security polices perspective the functional capacity of the working population is essential and more attention should be paid to its assessment in the future.

Methodological research is also needed to assess how best to combine self-report and performance measures. Self-report and performance-based measures are often not highly correlated (Kelly- Hayes 1992, Sager et al 1992, Myers et al 1993, Guralnik et al 1994, Cress et al 1995, Hoyemans et al 1996, Kempen et al 1996, Sherman & Reuben 1998). One reason for this not high correlation may be that they measure different levels of functioning. Self-reports measure more highly integrated activities such as working or shopping where as performance-based measures assess specific movements such as picking up a penny. However, two measures assessing the same level of functioning may still not correlate highly if the respondent is more influenced by motivation or perception.

There is already some evidence that self-reported and performance-based methods complement each other (Myers et al 1993, Cress et al 1995, Kivinen et al 1998, Guralnik et al 2000). Performance based methods are particular useful as they provide results independent of environmental differences. Also in some cases such as for vision, hearing and muscle strength they can be seen to provide easily standardized objective findings. On the other hand interview questions are more feasible to assess ADLs and relatively complex functions: it is likely that their assessment would benefit from adding observations and assessments of some complex findings.

#### **10.4 The impact of the new classification system**

A major problem in the development of measures of physical functioning has been the lack of a clear theoretical or conceptual framework. Over the years several theories have been proposed on which current measures have been based on. The publication of the International Classification of Functioning, Disability and Health, ICF, may harmonise the definitions and the measurements of physical functioning. Being an international classification, ICF makes it possible for the data collection and analyses to be comparable around the world.

The use of ICF in the field of public health is widely recommended (WHO 2001a). However, to become the real conceptual framework in the field requires a lot of

practical work. It is important to note that for the classification to be useful the development of comparable survey instruments closely related to the classification is required. Until such tested measurement methods have been put together and their international comparability has been ensured, ICF is useful mainly as a conceptual background. It is important to note, however, that the WHO has already developed a new instrument WHO-DASII based on the ICF (Dahl 2002, 204).

It has been estimated that from now on most of the measurement of functioning, e.g. physical functioning will be done using current instruments and ICF. Simultaneous application of ICF and health-status measures demonstrates the usefulness of ICF in creating a common language for research settings, among others (Cieza et al 2003, Weigel et al 2003). Thus it is very important to understand the relationship between these two. The basis for this understanding is the linkage of individual items of the current instruments to the ICF. The results of the linking process conducted in this study reflect the structure and relationship of the questions used in European national health surveys in the area of physical functioning showing that the ICF can become main reference for existing health status measure.

## **10.5 The current situation in Europe**

The choice of what measurement to use in assessing functioning should be based on the objectives of the research and on the study population. In national health surveys self-reported methods are much more commonly used than performance-based assessment – certainly because of ease of administration. At present, almost all countries in Europe implement national health interview surveys. The number of topics on physical functioning varies greatly within European surveys. Some of the surveys covered all the items concerned relevant while others had none. The coverage of topics depends partly on the nature of the surveys. Disability surveys are usually comprehensive from the perspective of functioning while the multipurpose surveys such as Eurobarometer may include no items.

The long-term disability questionnaires of both OECD and WHO-Europe recommend questions on seeing and hearing. The use of these has been wide spread in Europe.

However, even when the recommendations were followed the wording was modified or different items were selected. Research is needed to establish the most valid way to measure sensory functions by interviews and questionnaires. Existing recommendations must be taken into account. In view of the rather straightforward way in which seeing and hearing can be tested it should also be considered whether testing should be introduced for all national surveys.

Almost all European surveys used either the OECD or the WHO-Europe recommendations as a basis for mobility questions. The SF-36 (physical part) was included in two surveys (German and Belgium). However, even when the recommendations were followed in principle, the wording was modified or only some of the items were selected. The recommendation of Euro-REVES aims to improve the comparability of surveys within Europe by producing new reference questions/instruments. However, these questions/instruments have to be tested and validated before they can be recommended for wider use.

Most of the mobility questions (as well as sensory related questions) ask respondents' capacity rather than actual performance. However, there is already some evidence that capacity wording may substantially underestimate the true prevalence of disability in populations (Glass 1998). The formulation of questions on physical functioning is not straightforward. The environment and its requirements may make different demands for different persons. Thus, the person may have different kinds of experiences and beliefs on his actual performance or capacity. On the other hand, even if the environment is uniform, not all people have experienced all of the activities inquired in questions. The relevance and impact of the use of performance or capacity wording need to be discussed and assessed particularly since it is not clear when these wording differences have an impact on the results and when they don't.

Most of the surveys including self-care questions were based on the WHO-Europe recommendations (long-term disability questionnaire). However, there were differences in wording and in the selection of items. It is reasonable to recommend this quite widely used instrument also in future. Scientific research is still needed to validate and develop ADL instruments for use in population surveys since most of the

ADL-instruments have been developed for institutionalised persons. The proposals of Euro-REVES can be seen as a starting point for this development.

Existing European questions on domestic life are far from comparable. There is no definitive reference instrument that could have been recommended in comprehensive health surveys, and countries have chosen different instruments. Euro-REVES (Robine et al 2002) recommended both an instrument for IADL and a Global Activity Limitations Indicator (GALI). The GALI has not yet been evaluated but it has been translated into all European languages. The development work of GALI is important since the indicator can be linked to the codes of ICF. The results of this development are to be taken in to consideration when giving the recommendations on the instruments of IADL.

National health examinations or at least examination components added to national health interview surveys have so far been carried out in a small number of countries. Only two countries have included examinations on physical functioning (sensory and mobility items). The range of the measurement included has been considerable from a few tests to a comprehensive clinical examination. At the present, the most comprehensive health examination survey in the Europe is the Finnish Health 2000. It combines a health interview (90 minute) and a health examination (4,5 hour). The examination procedure included both sensory and mobility related tests. Since test based assessment of functioning have clear advantages of their own, future development in this field is clearly needed.

## **10.6 Generalisation of this study**

The European health survey database is the only source where information on population based national health surveys has been extensively collected under the same context. Thus, it is reasonable to use it when comparing health interview and examination methods used in the Europe.

However, when making conclusions on the present situation of European national health surveys, the limitations of this study and the database must be taken into

consideration. First, only the health interview and examination surveys from the past five years as described in the database were included in this study. The database covers the health interview forms and examination protocols of the surveys. The surveys included may also have had; for example; mailed questionnaires, and they have not included in this study since they are not yet available from the database.

In addition several regional and/or topic specific surveys have been carried out in most European Countries, but this study considers only national comprehensive surveys. Therefore, the national coverage of measures noted in this study may not be comprehensive since physical functioning may have been surveyed in other studies.

### **10.7 The development of the database**

Linking already used questions to the codes of ICF is feasible as far as physical functioning related questions are concerned. The ICF classification system fulfils almost all the principles of the current database classification (clarity, reliability, limited number of levels, mutually exclusive topics, questions may refer to more than one topic). In fact ICF offers a list of topics (or keywords) that are clear and easy to understand. As ICF includes a hierarchical classification with definitions (what are included /excluded), it enable the systematic linking of items to the specific codes. Clear categories with inclusion and exclusion terms enables that one topic includes only the relevant questions.

ICF does not include any rules for linking the health status measures to the codes of ICF. However WHO has been aware of the need for common linking rules and has co-ordinated the work of Cieza et al (2002). The ICF linking rules developed and tested (Cieza et al 2002) can be adapted for wider use and also for the needs of the database. ICF Linking rules for the performance-based method do not yet exist but they are under preparation (Smolander et al 2003). As far as common and internationally recommended rules for performance-based measures do not exist the linking rules for performance-based measurements of this study should be viewed as indicative.

The network of experts and topic specific experts could be the best ones to perform the linking work. Changes of the topic in the database codes would lead to considerable amount of work. However, by changing the coding scheme of the database to be congruent with the ICF for suitable topics, the database could serve its user with an "internationally common language" e.g. ICF codes. As the ICF offers an international common language for classifying functioning, disability and health, the use of it enables the uniformity and usability of the database around the world.

From the viewpoint of the database, the only limitation of ICF is perhaps that it does not cover a broader range of health aspects. The ICF classifies health and functioning, but it does not classify diseases (classified through ICD-10). Thus when linking the ICF one may encounter difficulties, one of the most important of which may be linking items that ask about one's health in general or items related to specific diseases. International collaboration and discussion is needed also to decide how the performance-based measures are to be linked to the codes of ICF – Are the main principal, the main purpose of the test or are the tests wanted to be seen from the broader perspective. At the moment and from the viewpoint of the HIS/HES database the performance-based tests are recommended to be linked according to the main purpose of the test.

In addition to revising the coding and classification system of the database, this study revealed another important target for development of the database. The database includes a considerable amount of questions. Questions are basically either individual instruments or part of some instruments. The database includes information about the instruments (recommendation or reference instruments) and questions used in each survey. However the link between the reference instruments or recommendations used and a single question does not exist. To be able to check out from which instruments the questions come from, the user of the database needs to know each instrument at question level.

For the database to be useful in a wider context and usable for users within different backgrounds, the link between instruments and single questions is essential. This link could be useful also from the perspective of international harmonisation. The information about which countries have used a certain instrument is not sufficient.

From the viewpoint of comparability information on instruments used at question level provide possibilities to compare the wording and possible modifications of questions from a certain instrument.

## **11 CONCLUSIONS**

The concepts of physical functioning, and classifications based on them, are rather advanced. Most of them are based on the idea of deterioration of functioning due to diseases and impairments. Also, most measurement methods concern deterioration of functioning and are therefore mainly suited for measurement in older age groups.

In principle, the concepts would allow for better than average performance ("positive health") to be recorded. However, there are no practical measurement methods for this for large population surveys. Yet, it would be important to be able to follow the physical condition of healthy and sick persons in addition to those with various degrees of disability. Unfortunately, there is currently not a close tie between concepts and measurement methods used. In particular, there is also a lack of suitable measurement methods for population surveys for the newest classification system, the ICF.

Despite the above, it was possible to link most of the physical functioning items of current surveys to ICF thus improving the possibilities for comparison. Current measurement methods of population based health surveys comprise self-reports on perceived functional limitations and performance-based measures including also observations. Whereas interview surveys on health and functioning have been carried out in many countries health examination surveys comprising physical functioning measurements are still rare. The most commonly applied physical functioning measures in national health surveys include interview scales designed to assess the ability to perform ADL and IADL. The majority of these measures reflects body functions and activities. Body structures and contextual factors (personal and environmental) have not been widely encompassed. However, hardly any attempt has been made to separate the contextual (environmental) and the participation dimensions of these measures. Thus, the potential utility of these instruments in

future research on the role of environment and participation in the understanding of disability is relatively limited. International collaboration is needed to develop further existing instruments and to assess the need for and the potential to develop new high quality instruments.

Measurement of functioning, healthy life expectancy and disability-free life expectancy are important both for national and international health information systems. However, the international comparability of self-report measures is not satisfactory. To improve comparability it is important to take care that the translations are linguistically valid and equivalent. But it is even more important to make sure that the questions are equivalent conceptually. A question or method intended for international use should measure the same concepts and phenomena in all countries. Some advances will probably result from adopting common measures and instruments as well as from the ongoing development work. However, it is clear that further joint efforts are needed to achieve comparability.

One step toward improvement is adoption both of self-report measures and performance based measures in national and international surveys. Many of these measures are interrelated but they provide also different information. Serious consideration should be given to including at least measured eyesight and hearing in more countries, since it is a rather quick way to gain valid information about actual sensory performance. Experience suggests that a combination of questions and tests is the best way to gather information on sensory performance. A combination of self-report measures and performance-based measures is probably the best way to gain insight into physical functioning in populations. In particular, performance based measures are important for comparison between population groups, countries and points in time.

Interviews of physical functioning need largely to be based on current used survey instruments and performance-based measurement on the experiences of the few health examination surveys employing them so far. When agreement has been reached on common concepts and contents manuals and training protocols must be developed and joint quality assurance must be arranged. The best future option is probably to combine interview and questionnaire methods with performance based

tests. Thus both self-reported and performance based measures need to be developed further. This requires joint efforts of population survey experts and of experts in measurement of functioning.

The ICF framework is promising and a large number of countries have expressed interest in using it as a common framework. Their representatives have also expressed the view that ICF is relevant for rehabilitation and public health. For functional topics ICF seems to be an ideal classification system. Using it also in the HIS/HES-database should be considered. Future development of measurement methods should use the concepts and classifications of ICF as a starting point. The development of valid and comparable survey instruments closely related to the classification is a must.

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## **Annex 1. Search procedures.**

### **(Pubmed)**

- 1)** ("physical performance" OR "performance tests" OR "performance test" OR performance task OR performance tasks) AND (functional ability OR functional abilities OR motor task OR motor tasks OR "motor control" OR motor skill\* OR movement impairment\* OR activities of daily living OR disabled OR disability OR health status OR physical functioning) \*
- 2)** (disabled OR disability OR functional ability OR functional abilities OR health status) AND (motor task OR motor tasks OR "motor control" OR motor skill\* OR movement impairment\* OR activities of daily living OR physical functioning)
- 3)** AND (assessment OR measure\* OR instrument\* OR screening OR rating scale OR rating scales OR discriminat\* OR indices OR index OR test\*)
- 4)** NOT (child OR children)
- 5)** NOT (anatomy[MESH] OR surgery OR surgical OR neurosurg\* OR drug OR drugs OR "drug therapy" OR heart function OR lung function OR gastric OR internal medicine OR "spinal cord injury" OR athletic injuries)
- 6)** NOT (toxicology OR neurotoxicology OR pathogenesis OR autopsy OR pathology OR pharmacology OR manipulation OR massage OR "gene therapy" OR "brain mapping" OR "brain stimulation" OR "electric stimulation" OR "action potential" OR PET OR SPET OR SPECT)
- 7)** NOT (biomechanics[MESH] OR sport rehabilitation OR sports rehabilitation OR arthroplasty OR dental OR HIV OR Alzheimer\* OR mental retarded OR schizophrenia OR colorectal OR "colonic resection")
- 8)** NOT (case studies OR case study OR editorial\* OR letter\* OR voice training OR "diagnostic imaging" OR depression scale OR depression scales OR "emotional functioning")
- 9)** NOT (stroke OR MS OR Parkinson's disease OR rheumatoid arthritis OR cancer)

\* vision OR hearing

\* health survey, Europe, comparability

\* interview

\*examination

## Annex 2. ICF components and domains, with examples of contents.

Component	Domains/Chapter headings
Body Function	<p>Mental functions e.g. memory function, intellectual functions</p> <p><b>Sensory functions and pain e.g. hearing function, seeing function, sensation of pain</b></p> <p>Voice and speech functions e.g. articulation functions</p> <p>Functions of the cardiovascular, haematological, immunological and respiratory systems e.g. blood pressure functions, respiratory muscle functions</p> <p>Functions of the digestive, metabolic and endocrine systems e.g. injection functions, endocrine gland functions</p> <p>Genitourinary and reproductive functions e.g. menstruation functions</p> <p><b>Neuromusculoskeletal and movement-related functions e.g. mobility of joint functions</b></p> <p>Functions of the skin and related structures e.g. repair functions of the skin</p>
Body Structures	<p>Structures of the nervous system e.g. spinal cord and related structures</p> <p>The eye, ear and related structures e.g. structure of eyeball, structure of inner ear</p> <p>Structures involved in voice and speech e.g. structure of mouth</p> <p>Structures of the cardiovascular, immunological and respiratory systems</p> <p>Structures related to the digestive, metabolic and endocrine systems e.g. structure of intestine, structure of gall bladder and ducts</p> <p>Structures related to the genitourinary and reproductive systems e.g. structure of pelvic floor</p> <p>Structures related to movement e.g. structure of head and neck region</p> <p>Skin and related structures e.g. structure of skin glands</p>
Activities & Participation	<p>Learning and applying knowledge e.g. learning to read, solving problems</p> <p>General tasks and demands e.g. carrying out daily routine</p> <p>Communication e.g. speaking, conversation</p> <p><b>Mobility e.g. getting around inside or outside home</b></p> <p><b>Self-care e.g. washing oneself, dressing</b></p> <p><b>Domestic life e.g. preparing meals, acquiring a place to live</b></p> <p>Interpersonal interactions and relationships e.g. relating with strangers, formal relationships</p> <p><b>Major life areas e.g. work and employment</b>, remunerative employment</p> <p>Community, social and civic life e.g. recreation and leisure, religion and spirituality</p>
Environmental Factors	<p>Products and technology e.g. products and technology for communication</p> <p>Natural environment and human-made changes to environment e.g. physical geography</p> <p>Support and relationships e.g. immediate family, health professionals</p> <p>Attitudes e.g. individual attitude of friends, individual attitude of health professionals</p> <p>Services, systems and policies e.g. social security services, systems and policies</p>

**Bold** = domains included to this study

**Annex 3.** List of HIS topic codes.

**SUMMARY : 2002 HIS-classification Access database**

Date last update: 17.10.2002

**Area 1 Demographic and socio-economic factors**

<b>Topic Code</b>	<b>Topic</b>
101	Age
102	Sex
103	Marital status
104	Household composition
105	Pregnancy status
106	<b>Income</b>
107	Education
108	Employment status
109	Population subgroup
110	Nationality; country of birth
111	Geographical information
199	other demographic and socio-economic factors

**Area 2 Health Status**

<b>Topic Code</b>	<b>Topic</b>
201	self assessed/perceived health
202	quality of life (QOL) measures
203	limitations of activity: short term/temporary
204	bed-days as consequence of (short term) limitations
205	long-standing illness/chronic conditions/disabilities
206	disease specific morbidity
207	limitations of functional ability : sensory
208	limitations of functional ability : physical
209	limitations of functional ability : cognitive
210	access limitations
211	mobility
212	limitations of activities of daily living (ADL): personal
213	limitations of activities of daily living (ADL): household
214	limitations of activities of daily living (ADL): other
215	health related absenteeism from work, work loss, etc.
216	accidents/injuries
217	general mental health
218	aspects of mental health (stress, nervous, anxiety, etc.)
219	positive mental health (self-esteem, mastery, coherence, self-efficacy)
220	sleeping disturbances
221	social health (social support, - adjustment and life events)
222	dental formula
223	dental prosthesis
299	other health status items

**Area 3 Personal factors**

Topic Code	Topic
301	blood pressure
302	serum cholesterol
303	body height and weight
304	birth length and weight
399	other personal factors

**Area 4 Life style factors**

Topic Code	Topic
401	Smoking: general (incl. present)
402	former smoking
403	passive smoking
404	stop/reduce smoking
405	alcohol use and abuse
406	alcohol-related problems
407	diet/nutrition
408	consumption of fresh fruit
409	consumption of vegetables
410	consumption of butter, oil, etc.
411	daily activities
412	physical activity (incl. vigorous)
413	leisure time activities (excl. Physical exercise)
414	breastfeeding
415	(il)licit drug use
416	knowledge of (un)healthy life styles
417	risk factors of cancer (excl. Smoking, drinking, diet)
418	sexual behaviour
499	other life style factors

**Area 5 Living and working conditions**

Topic Code	Topic
501	occupation
502	working conditions
503	work force participation of disabled people
504	workplace exposure (carcinogenic/dangerous substances, etc.)
505	external environment (air/water/other pollution/noise, etc.)
506	type of dwelling
507	housing conditions
599	other living and working conditions

**Area 6 Prevention, health protection and promotion**

Topic Code	Topic
601	Screening for breast cancer
602	Screening for uterus/cervix cancer
603	Screening for other cancers (prostate, etc.)
604	Contraception
605	Hormone Replacement Therapy
606	Vaccinations (incl. influenza)
607	Campaigns or programmes : general
608	Campaigns or programmes : smoking
609	Campaigns or programmes : alcohol use

610	Campaigns or programmes : physical activity
611	Campaigns or programmes : diet
612	Campaigns or programmes : safe sex
699	Other prevention, protection and promotion items

**Area 7 Health and social services**

<b>Topic Code</b>	<b>Topic</b>
701	Use of services: general
702	general practitioner
703	specialist
704	physiotherapist
705	dentist
706	alternative practitioners
707	hospitalisation
708	operations
709	maternal and child health care
710	mental health care
711	physical examinations or check ups
712	medication: general
713	medication: prescribed
714	medication: non-prescribed/over the counter
715	medication: use of specific groups
716	use of technical/medical aids
717	Home care
718	Rehabilitation
719	Health insurance
720	Recognition of disability
721	expenditures on health and social services
799	other health and social services

**Area 8 Other factors: not classified**

<b>Topic Code</b>	<b>Topic</b>
999	not classified

**Topics to consider**

Area 2	suicide
Area 4	alcohol related problems
Area 6	attitudes towards health policies
Area 7	Accidents & Emergency Unit
Area 7	Day care Unit

#### Annex 4. HES health status components and health topics lists 2002.

<b>Area 10</b>	<b>Risk factors</b>
1001	Anthropometric measurements: Body height
1002	Anthropometric measurements: Body weight
1003	Anthropometric measurements: Skinfold
1004	Anthropometric measurements: Waist and hip circumference
1005	Anthropometric measurements: Demi-span
1006	Other anthropometric measurements
1007	Blood samples: Triglycerides
1008	Blood samples: Total cholesterol
1009	Blood samples: HDL cholesterol
1010	Blood samples: LDL cholesterol
1011	Blood samples: Other blood lipids
1012	Blood samples: Smoking indicators
1013	Saliva sample: Smoking indicators
1014	Other risk factor measurements

<b>Area 11</b>	<b>Cardiovascular function and diseases (CVD)</b>
1101	Blood pressure
1102	Electrocardiography (ECG)
1103	Clinical physical examination: CVD
1104	Non-invasive measurements
1105	Blood samples: Measurements related to blood clotting
1106	Other measurements related to cardiovascular function

<b>Area 12</b>	<b>Respiratory function and respiratory diseases</b>
1201	Spirometry/PEF
1202	Clinical physical examination: respiratory
1203	Other measurements related to respiratory function

<b>Area 13</b>	<b>Diabetes mellitus (DM) and other metabolic functions and diseases</b>
1301	Blood samples: Glucose
1302	Blood samples: Insulin
1303	Blood samples: Other indicators used in diabetes surveillance
1304	Urine sample: Glucose
1305	Other measurements of metabolic functions

<b>Area 14</b>	<b>Kidney, urinary tract and thyroid function and diseases</b>
1401	Blood samples: Indicators of kidney function
1402	Urine samples: common basic tests
1403	Blood samples: Hormones reflecting thyroid function
1404	Other measurements of kidney, urinary tract and thyroid function

<b>Area 15</b>	<b>Liver, gallbladder, stomach and pancreas functions and diseases</b>
1501	Blood samples: Gamma-GT and similar tests
1502	Blood samples : Other enzymes
1503	Other measurements of liver, gallbladder, stomach and pancreas function

<b>Area 16</b>	<b>Haematological system functions and diseases</b>
1601	Blood samples: Blood count
1602	Other measurements of haematological system function
<b>Area 17</b>	<b>Infections and inflammations</b>

1701	Blood samples: general markers of infection
1702	Blood samples: Markers of specific infectious agents
1703	Urine samples: Bacterial culture and comparable
1704	Other measurement of infections

<b>Area 18</b>	<b>Allergy</b>
1801	Blood samples: Immunoglobulins
1802	Skin prick test
1803	Other measurements of allergy

<b>Area 19</b>	<b>Cancer</b>
1901	Blood samples: cancer markers
1902	Urine samples: metabolites of carcinogens
1903	Other screening for malignancies

<b>Area 20</b>	<b>Reproductive functions</b>
2001	Blood samples: Sex hormones
2002	Other measurements of reproductive functions

<b>Area 21</b>	<b>Musculoskeletal function and diseases</b>
2101	Bone density
2102	Non-invasive radiological and other joint measurements
2103	Clinical physical examination: locomotor system
2104	Other measurements related to musculoskeletal function

<b>Area 22</b>	<b>Sensory function, physical function and fitness</b>
2201	Vision tests
2202	Hearing tests
2203	Joint function
2204	Walking speed
2205	Reaction time
2206	Stair-mounting ability
2207	Standing balance and/or sway of body's gravity center
2208	Muscle strenght
2209	Physical fitness test
2210	Other measurements of sensory or physical function

<b>Area 23</b>	<b>Mental disorders, mental and cognitive functions</b>
2301	Diagnostic measurement of depression
2302	Diagnostic measurement of psychosis
2303	Diagnostic measurement of alcohol/drug dependence
2304	Diagnostic measurement of other mental disorders
2305	Cognitive function tests
2306	Other measurements of cognitive function

<b>Area 24</b>	<b>Dental health</b>
2401	Clinical dental examination
2402	Radiological dental examination
2403	Other measurements of dental health

<b>Area 25</b>	<b>Nutritional status</b>
2501	Blood samples: Vitamins
2502	Blood samples: Minerals and trace elements
2503	Blood samples: Markers of physiological metabolic processes
2504	Urine samples: Minerals and trace elements
2505	Other measurement of nutritional status

<b>Area 26</b>	<b>Other health components</b>
2601	Blood samples: determination of medicaments and their metabolites
2602	Other analyses of blood samples
2603	Urine samples: Metabolites of medicaments
2604	Other analyses of urine samples
2605	Other analyses of saliva samples
2606	Any analysis of stool samples
2607	Any analysis of fat and tissue samples
2608	Other unclassified measurements

**Annex 5.** European health surveys (HIS and HIS/HES) from 5 years period (1998 - 2002) included to this study.

Survey name English	Survey code	Year	Country	Type of survey	Frequency	Inst.	Age restriction	Type of sample	% non resp.
Microcensus	A01	1999	Austria	HIS	irregular	no	no restriction	households	17,8 (i)
General Socio-Economic Survey 2001	B03	2001	Belgium	multi purpose survey	once	yes	no restriction	all citizens	
Health Interview Survey	B02	2001	Belgium	HIS	4-yearly	yes	no restriction	households	37,7 (h)
Health and Morbidity in Denmark	DK02	2000	Denmark	HIS	6-7 yearly	yes	16+	individuals	25,8 (i)
The European Community Household Panel Survey	FIN08	2001	Finland	standard of living survey	yearly	no	16+	households	6 (h)
Health Behaviour Survey among the elderly population	FIN09	2001	Finland	HIS	irregular	yes	65-84	individuals	81 (i)
Health Behaviour Survey among the Adult Population	FIN06	2001	Finland	HIS	yearly	yes	15-64	individuals	70 (i)
Health 2000	FIN03	2000	Finland	HIS/HES	irregular	yes	18+	individuals	11,2 (i)
Survey on health behaviour	FIN01	2000	Finland	other	yearly	yes	15-64	individuals	30 (i)
The National Finrisk Study	FIN07	2002	Finland	HIS/HES	5-yearly	no	unknown	individuals	35 (i)
Health and Social Protection Survey	F09	2002	France	HIS	2-yearly	no	no restriction	individuals	
Continuous survey on households living conditions	F07	2000	France	other	yearly	no	15+	households	28 (h)
The INSEE Survey on Handicaps, Disabilities and Dependency	F05	2001	France	disability survey	10-yearly	yes	no restriction	individuals	21,9(i)
Survey on households living conditions	F 11	2001	France	standard of living survey	yearly in 3 waves	no	15+	households	32 (i)
French survey on living conditions and aspirations	F12	2001	France						
French survey on living conditions and aspirations	F08	1999	France	multi purpose survey	yearly	yes	18+	individuals	
Health Barometer	F06	1999	France	HIS	3 yearly	no	12-75	households	25 (h)/6(i)
Health and Social Protection Survey	F03	1998	France	other	2 yearly	no	no restriction	individuals	34 (h)
Handicaps, Disabilities and Dependency Survey	F02	1999	France	disability survey	unknown	yes	no restriction	individuals	31 (i)
Survey on living conditions, health and environment	D02	1998	Germany	multi purpose survey	irregular	no	minimum age 45	individuals	42,9 (i)
German National Health Examination and Interview Survey	D05	1998	Germany	HIS/HES	6-7 yearly	no	18-79	individuals	38,6 (i)
Questions on Health	D01	1999	Germany	HIS	4 yearly	yes	no restriction	households	9 (i)
National Greek Survey: Psychosocial factors and Health	EL02	1998	Greece	HIS	5-yearly	no	12 to 64 only	individuals	19,7 (i)
Health and lifestyle of the Icelandic population									
Health and lifestyle	IS03	2001	Iceland	multi purpose survey	yearly	no	20-80	individuals	48 (i)
Health and Living Conditions in Iceland	IS02	89/99	Iceland	HIS	irregular	no	18-75	individuals	31 (i)
Living in Ireland Survey, 2001	IRL04	2001	Ireland	multi purpose survey	yearly	no	16+	households	16 (h)
Living in Ireland Survey	IRL02	2000	Ireland	standard of living survey	yearly	unkno wn	no restriction	households	11(h/9(i))
Survey of Lifestyle, Attitudes and Nutrition (SLÁN)	IRL01	1998	Ireland	HIS/HES	4 yearly	yes	18+	individuals	37,8 (i)
Survey of Lifestyle, attitudes and nutrition (SLAN)	IRL03	2002	Ireland	HIS/HES	4-yearly	no		individuals	36,8 (i)

Survey name English	Survey code	Year	Country	Type of survey	Frequency	Inst.	Age restriction	Type of sample	% non resp.
Aspects of daily living	I03	2000	Italy	multi purpose survey	yearly	no	no restriction	households	
Aspects of daily living	I04	2001	Italy	multi purpose survey	yearly	no	no restriction	households	14,2
Health Conditions and the Use of Health Services	I01	99/00	Italy	HIS	4 yearly	no	no restriction	households	10(h)/10(i)
Eurobarometer	INT07	98/99	Luxembourg	multi purpose survey	twice a year	no	aged 15 & over	individuals	
Socio-Economic Panel Living in Luxembourg	L02	2001	Luxembourg	multi purpose survey	yearly	no	no restriction	households	19,2(h)/ 19,2(i)
Eurobarometer October 2002	INT06	2002	Luxembourg	multi purpose survey	twice a year			individuals	
European Community Household Panel	INT05	2001	Luxembourg	standard of living survey	yearly	no	16+	households	30 (h)
European Community Household Panel	INT02	2000	Luxembourg	multi purpose survey	yearly	no	15+ years	households	
2002 LFS ad hoc module employment of disabled people	LFS01	2002	Luxembourg	other	continuous	yes	16-64	households	
Survey on Living Conditions	N01	1998	Norway	multi purpose survey	3-4 yearly	no	16+	individuals	27,3(i)
General Census 2001	P04	2001	Portugal	other					
National Health Interview Survey	P03	98-99	Portugal	HIS	irregular	no	no restriction	households	19,8 (h)
Impairments, Disabilities and Health Status Survey	E04	1999	Spain	disability survey	irregular	no	no restriction	households	
National Health Survey	E02	2001	Spain						
Living Conditions Survey	S02	2001	Sweden	standard of living survey	yearly	yes	16-84	individuals	23 (i)
Living Conditions Survey	S01	1999	Sweden	multi purpose survey	yearly	yes	16-84	individuals	23,3 (i)
Swiss Health Survey 2002	CH02	2002	Switzerland	HIS	five yearly	no	15 years & ove	households	
Continuous Quality of Life Survey	NL03	2001	The Netherlands	HIS/HES	continuous	no	no restriction	individuals	45 (i)
Patient survey - Second Dutch National Survey of General Practice	NL02	2001	The Netherlands	HIS	irregular	no	no restriction	individuals	35 (i)
Continuous Quality of Life Survey	NL01	1998	The Netherlands	HIS/HES	continuous	no	no restriction	individuals	37,7 (i)
Census 2001	UK15	2001	United Kingdom						
The General Household Survey	UK11	2001	United Kingdom	multi purpose survey	continuous	no	no restriction	households	28 (h)
General Household Survey	UK07	2002	United Kingdom	multi purpose survey	continuous	no	no restriction	households	
General Household Survey	UK01	2000	United Kingdom	multi purpose survey	continuous	no	16+	households	12 (h)
The Scottish health survey	UK13	1998	United Kingdom	HIS/HES	irregular	no	2-74	households	23 (h)
The Health Survey for England	UK12	2000	United Kingdom	HIS/HES	continuous	yes		households	25 (h)
Health Survey for England	UK09	1998	United Kingdom	HIS/HES	continuous	no	2+	households	26(h)/31(i)
Health Education Monitoring Survey	UK02	1998	United Kingdom	other	irregular	No	16+	individuals	29 (1)

Inst. = Institutionalised included% and non resp = % of non response either individuals (i) or household (h)

**Annex 6.** 12 European surveys including health examinations, HES, in the time period 1998 – 2002.

Survey name English	Survey code	Year	Country	Type of survey	Frequency	Inst.	Age restriction	Type of sample	%non resp.
Finrisk 2002	FIN07	2002	Finland	HIS/HES	5 yearly	yes	25-74	individuals	
Health 2000	FIN03	2000	Finland	HIS/HES	irregular		30+	individuals	15,1 (i)
German National Health Interview and Examination Survey	D05	1998	Germany	HIS/HES	5-7 yearly	no	18-79	individuals	38,6 (i)
Survey of Lifestyle, Attitudes and Nutrition (SLAN)	IRL03	2002	Ireland	HIS/HES	4 yearly		18+	individuals	
Survey of Lifestyle, Attitudes and Nutrition (SLÁN)	IRL01	1998	Ireland	HIS/HES	4 yearly		18+	individuals	45 (i)
Netherlands Health Examination Survey*	NL01 (NL03)	2001	The Netherlands	HIS/HES	continuous		age 12 and over	individuals	75 (i)
Continuous Quality of Life Survey	NL01	1998	The Netherlands	HIS/HES	continuous	no	no restriction	individuals	37,7 (i)
The Scottish Health Survey	UK13	1998	United Kingdom	HIS/HES	3-4 yearly	no	2-74	households	23 (h)
Health Survey for England	UK12	2000	United Kingdom	HIS/HES	yearly	yes	2+	households	25 (h)
Health Survey for England	UK09	1998	United Kingdom	HIS/HES	yearly	no	2+	households	26 (h)
Health Survey for England *	UK16	2002	United Kingdom	HIS/HES	yearly	no	no restriction	households	
Health Survey for England *	UK08	1999	United Kingdom	HIS/HES	yearly		2+	households	

\* Surveys has been coded as NL03 (Continuous Quality of Life Survey) to the list of 57 HIS surveys in annex 1, the performance-part of the survey has received own code (NL01)

Inst. = Institutionalised included

% non resp. =% of non response either individuals (i) or household (h)

**Annex 7.** Linking rules for health-status measures with examples developed by Cieza et al (2002).

Number	Rule	Example
1	Before one links health-status measures to the ICF categories, one should have acquired good knowledge of the conceptual and taxonomical fundamentals of ICF, as well as chapters, domains and categories of the detailed classification, including definitions.	
2	Each item of health-status measure should be linked to the most precise ICF category	Item C4 of <i>West haven-Yale Multidimensional Pain Inventory</i> "Play card and other games" is linked to d2200 "Play" and not to d920 "Recreation and leisure".
3	If a single item encompasses different constructs, the information in each construct should be linked.	In item 4 the <i>Oswestry Low Back Pain Disability Questionnaire</i> "Pain doesn't prevent me from walking any distance" <i>pain</i> as well as <i>walking any distance</i> will be linked.
4	All constructs of the item to be linked have to be highlighted (e.g. bold).	Item 8 of the <i>Million Visual Analogue Scale</i> "Does your <i>pain</i> interfere with your ability to <i>stand still</i> ?".
5	To response options of an item are linked if they refer to additional constructs.	Item 3 of the Backill Measure: "Walking" - I am able to <i>walk any distance</i> . - Discomfort prevents me from <i>walking more than a 1 mile</i> - Discomfort prevents me from <i>walking more than a 1/2 mile</i> - Discomfort prevents me <i>from walking more than a 1/4 mile</i> - I <i>walk only a limited distance</i> or use a cane, crutches, or a walker - I am <i>in bed most of the time</i> or I use a wheelchair
6	If the content of an item is not explicitly named in the corresponding ICF category, then the "other specified" option at the third and fourth coding level of the ICF classification is linked. The additional information not covered by the ICF classification is documented. Two special cases are to be distinguished within this rule:  a) When the "other specified" option in the two level classification is not available, then the "other specified and unspecified" option is linked. The additional information not covered by the ICF will be documented.  b) When the content of an item is not explicitly named in the corresponding ICF category, but at the same time is included in the category, then the item is linked to this ICF category and the additional information not explicitly named by the ICF is documented.	Item 17 of the <i>Stait-trait Anxiety Inventory (STAI)</i> "I am <i>worried</i> " is linked to b1528 "Emotional functions other specified" and the additional information "worried" is documented.  Item 6 of the <i>Functional Abilities Confidence Scale (FACS)</i> "We would like to know how <i>confident</i> you are that you get <i>in and out of the car or bus</i> " is linked to d469 "Walking and moving around, other specified and unspecified. "Get in and out of the car" and "Get in and out of the bus" is additionally documented.  Item 5.1 of the <i>Aberdeen low Back Pain Scale</i> " <i>In your right leg do you have pain in the foot/ankle</i> " is linked to b28015 "pain in lower limb" and the information "in a lower limb is documented.
7	In the content of an item is more general than the corresponding ICF category, then the code of the higher levels is linked.	Item 14 of the <i>Dallas Pain Questionnaire</i> "How much do you think your <i>pain</i> has changed your <i>relationship with others</i> " is linked to d7 "Interpersonal Interactions and relationships"
8	If the content of an item is more general than any ICF category but otherwise the item specifies by examples partial aspects of the concept contained in one or more ICF categories, the "unspecified" option of the ICF classification is linked (Code 99 for the second coding level, code 9 for third and fourth coding levels). A statement or part of an item will be considered an example when it is introduced with "e.g." appears between parentheses, is introduced with "for example", or with "such as"	Item 2 of the Dallas Pain Questionnaire – 16 "How much <i>pain</i> interfere with your <i>personal care (getting out of bed, teeth brushing, dressing etc.?)</i> " is linked to b280 "Sensation of pain" d599 "self care, unspecified" and " d499 mobility, unspecified".
9	If the information provided by the item is not sufficient for making a decision about which ICF category the item should be linked to, this item is assigned <i>nd</i> (not definable).	Item 1 of the Brief Psychiatric Rating Scale "Degree of concern over present bodily health"
10	If an item is not contained in the ICF classification, then this item is assigned <i>nc</i> (not covered in ICF).	Item 3 of the Beck Depression Inventory "I do not feel like a failure"

**Annex 8.** Comparison of the sensory items and questions of the most often used or generally recommended instruments.

References for sensory functions				
ICF code		OECD (1981, 417) (*Long term disability 10 items minimum core set)	WHO-Euro (1996, 57 -58)	Euro-REVES (2002, 5)
		<p>"What can you "usually" do, on a normal day, exclude any temporal problems."</p> <p>"Is your... " / "Can you ....."</p> <p>coded as: yes without difficulty/ yes, with minor difficulty/ yes, major difficulty /no, unable (not able) to do.</p>	<p>"The following questions refer to what you are normally capable of doing. Temporary complaints should be ignored"</p> <p>"Can you ....." ;</p> <p>coded as yes/no</p>	<p>"Think about situation you may face in daily life. Please ignore temporary problems."</p> <p>"Can you,.....without aids / devices?"</p> <p>Coded YES/NO If No: "With your aids/devices, can you.....?" YES/NO/ Have no aids/ devices</p>
<b>b210</b> (d110)	<b>Seeing function</b>	<p>1.Is your eyesight good enough to read ordinary newspaper print (with glasses if usually worn) <sup>2*</sup></p> <p>2. Is your eyesight good enough to see the face of someone from 4meters<sup>2*</sup></p>	<p>10. Can you see well enough (with glasses or contact lens, if necessary) to recognize a friend at a distance 4meters (across a road) IF NO</p> <p>Can you see well enough (with glasses or contact lens, if necessary) to recognize a friend at a distance 1 meters (at arms length)</p>	<p>1. Can see clearly newspaper print without glasses or contact lenses?</p> <p>With your glasses or other aids/devices, can you clearly see ....</p> <p>2. Can you see clearly the face of someone from 4 meters (across a road)</p> <p>With your glasses or other aids/devices, can you see clearly....</p>
<b>b230</b> (d115, e250)	<b>Hearing function</b>	<p>3. Can you hear what is said in a normal conversation with 3or 4 other persons (with hearing aid if usually wear one)</p> <p>4. Can you hear what is said in a normal conversation with one other person (with hearing aid if usually wear one)</p>	<p>9. Is your hearing good enough (with hearing aid if necessary) to follow a TV programme at a volume others find acceptable? IF NO</p> <p>Can you follow a TV programme with the volume turned up (with hearing aid if necessary)?</p>	<p>3. Can you hear distinctly what is said in a conversation with one person without hearing aid?</p> <p>With your hearing aid or other aids/devices, can you hear distinctly....</p>

**Annex 9.** Comparison of the mobility items and questions of the most often used or generally recommended instruments.

References for mobility					
ICF code	Nagi (1979, 442)	OECD (1981, 417) (*Long term disability 10 items minimum core set)	WHO-Euro (1996, 57 -58)	Euro-REVES (2002, 5)	SF-36 (1990)
	"Do you have any difficulty.....";  coded as: no difficulty/ some difficulty/ great difficulty	"What can you "usually" do, on a normal day, exclude any temporal problems."  "Can you ....." ;  coded as:yes without difficulty/ yes, with minor difficulty/ yes, major difficulty /no, unable (not able) )to do.	"The following questions refer to what you are normally capable of doing. Temporary complaints should be ignored" /  "Can you ....."  coded as yes/no	"Think about situation you may face in daily life. Please ignore temporary problems."  : "Can you,.....?"  Coded YES/NO If No: : "With your aids/devices, can you.....?" YES/NO/ Have no aids/ devices	" The following items are about activities you might do during a typical day. Does your health now <b>limit you in</b> these activities? If so <b>how much?</b>  Coded: Yes, limited a lot/ Yes, limited a little / No, not limited at all
d415	Standing for long periods				
d430	Lifting or carrying weights of approximately ten pounds	6. Carry an object of 5 kilos for 10 meters*		12. Lifting and carrying a full shopping bag of 5 kilos	c. Lifting and carrying groceries
d455	Going up and down stairs	9. Walk up and down one flight of stairs without resting*	Walk up and down a flight of 12 stairs without resting	5. Going up and down a flight of 12 stairs	d. Climbing several flights of stairs e. Climbing one flight of stairs
d450	Walking	8. Walk 400 meters without resting*	What is the furthest you can walk on your own without stopping and without sever discomfort? (Only few steps/ more than a few steps but less than 200m/200 meters or more)	5. Walking 500 meters	g. Walking more than a mile h. Walking several blocks i. Walking one block
d410	Stooping, bending or kneeling	14. Bend down (when standing) and pick up shoe from the floor	Bend down and pick up a shoe from the floor	11.Bending down and kneeling down	f. Bending, kneeling, or stooping
d440	Using hands and fingers			9. Using fingers to grasp and handle small object like a pen 10. Turning a tap	b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf
d445	Reaching with either/or both arms			8.Reaching out of arm to shake someone's hand	
d455		7. Could you run 100 meters			a. vigorous activities, such as running, lifting heavy objects, participating in strenuous sports
d460		10. Move between rooms*			
d498	Transferring (from bed and chair) Katz (1963, 95)	11. Get in and out of bed*	2. Get in and out of bed on your own 3. Get in and out of chair on your own	2. Transfer in and out of bed	
			1. Are you permanently confined to bed even tough there may be help to get you up? 2. Do you sit in a chair (not a wheel chair) all day even if there may be help to for you to walk 3. Are you confined to your house/flat and garden?		

**Annex 10.** Comparison of the self-care items and questions of the most often used or generally recommended instruments.

References for self-care activities (ADL)					
ICF code	Katz (1963, 95)	OECD (1981, 417) (*Long term disability 10 items minimum core set)	WHO-Euro (1996, 57 - 58)	Euro-REVES (2002, 7)	SF-36 (1990)
	"Do you perform ....."  without supervision/ direction of personal assistance.	"What can you "usually" do, on a normal day, exclude any temporal problems."  "Can you ....." ;  coded as yes without difficulty/ yes, with minor difficulty/ yes, major difficulty /no, unable (not able) )to do.	"The following questions refer to what you are normally capable of doing. Temporary complaints should be ignored"  "Can you ....." ; coded as without difficulty/ with some difficulty/ only with someone to help.	"Think about activities in your everyday life. Please ignore temporary problems. "Do you, usually,.....without any difficulty, and completely on your own? Coded YES/NO  IF no a) Does someone help you.... and b) Are you satisfied with the help received or are there problems you still need help with? YES/NO*	"The following items are about activities you might do during a typical day. Does your health now limit you in these activities? Is so how much?"  Coded: Yes, limited a lot/ Yes, limited a little / No, not limited at all
d510	<b>Bathing</b>		5. Wash hands and face on your own	5. Bath or shower yourself	j. Bathing or dressing your self
d540	<b>Dressing</b>	12. Dress and undress*	4. Dress and undress yourself on your own	3. Dress and undress yourself	
d530	<b>Going to toilet (toileting)</b>		7. Get to and use the toilet	4.use toilets	
	<b>Continance</b>		8. Do you ever loss control of your bladder? (No/ Yes If Yes at least once a week/ Less than once a week but at least once a month/ less than once a month)		
d550 d560	<b>Feeding</b>	15. Cut your own food (such as meet, fruit etc.)*	6. Feed yourself, including cutting up food	1 Feed yourself	
b510		16. Bite and chew on hard foods		7. Biting and chewing on hard foods such as a firm apple	
d520		13. Cut your toenails			

\* **For general surveys:** Think about your personal care activities in everyday life, for example feeding yourself, getting in and out of bed, dressing, bathing, using toilets, taking medication. Please ignore temporary problems: "Do you, usually, perform such activities without any difficulty and completely on your own?" YES/NO "Does someone help you to perform your personal care activities?" If YES "Are you satisfied with the help received or are there problems you still need help with?" YES/NO

**Annex 11.** Comparison of the domestic life items and questions of the most often used or generally recommended instruments.

<b>References for domestic life</b>		
<b>ICF code</b>	<b>Lawton &amp; Brody (1969, 181)</b>	<b>Euro-REVES (2002, 38 - 39)</b>
	Ability to carry out activity. Coded independent/ with assistance/ dependent or unable to do	Think about your household and other routine activities of daily living. Please ignore temporary problems: <b>“Do you usually...without any difficulty and completely on your own”</b> coded: Yes, without difficulty and completely on my own/ No, with difficulty but completely on my own/ No, not completely on my own/ Do not... <b>a) “Could you do it on your own without any difficulty if you had to or wanted to”</b> Yes/No  <b>b) “Do you require (more) help in getting...to your satisfaction”</b> Yes/No *
d360	Ability to use telephone	Use the telephone
d620	Shopping	Do all the shopping
d630	Food preparation	Prepare meals
d640	Housekeeping	Do routine light housework  Do periodic light housework
d640	Laundry	Do the laundry
	Mode of transportation	
	Responsibility for own medication	
d879	Ability to handle finance	Take care of/manage your financial matters

\* For general surveys: Thinking about your household and other routine activities in everyday life such as shopping, preparing meals, doing housework, doing the laundry, taking care of financial matters or using telephone. Please ignore temporary problems:  
**“Do you, usually, perform such activities without any difficulty and completely on your own?”** Yes without difficulty and completely on my own/ No, with difficulty but completely on my own/ No, not completely on my own/ Do not such activities

## Annex 12. ICF linking examples.

Questions on sensory functions	ICF_code1	ICF_code2	ICF_code3	ICF domains
Can you <b>read ordinary text</b> in a newspaper without difficulty (with or without <b>spectacles</b> )? Yes / No	b210	e125		Sensory functions and pain Products and technology
Are you able <b>to read TV text (with glasses)</b> from the normal watching distance (about 3 metres)? can read without difficulties can read but with difficulties can not read at all	b210	d110	e125	Sensory functions and pain Learning and applying knowledge Products and technology
Does your <b>sight restrict</b> your <b>moving</b> about: only in the <b>dim</b> to some extent also in <b>good lightning</b> very much also in a good lightning not at all?	b210	e240	d455	Sensory functions and pain Products and technology Mobility
Can you tell when <b>the volume</b> has been <b>increased</b> ? Yes/ No/ Don't know	b230	e250		Sensory functions and pain Natural environment and human made changes to environment
Can you <b>follow a TV program</b> with <b>the volume</b> turned up? Yes / No	b230	d115	e250	Sensory functions and pain Learning and applying knowledge Natural environment and human made changes to environment
Do you ever have any difficulties with your <b>hearing</b> even when you're <b>wearing an aid</b> ? Yes / No	b230	e125		Sensory functions and pain Products and technology

<b>Questions on mobility functions</b>	<b>ICF_code1</b>	<b>ICF_code2</b>	<b>ICF_code3</b>	<b>ICF domains</b>
Can you, when <b>standing, bend down</b> and <b>lift</b> something from the floor? Yes, without any problem / Yes, with some difficulty Yes, with great difficulty / No, I can't	d410	d430		Mobility
Can you without difficulty <b>lift and carry</b> a full shopping bag of 5 kilos ? Yes / No	d430			Mobility
Can you use your <b>hands and fingers</b> without difficulty? (to open a door, turn on a tap, hold a pencil, use scissors, etc.) Yes, without any difficulty / Yes, but with some difficulty....	d440	d445		Mobility
<b>Walk for one hour</b> without stopping I can manage without help / I can manage with help I can't manage it / Don't know	d450	b455		Mobility (Functions of the respiratory systems)
<b>Run</b> for 400 metres without a break Without any difficulty / With slight difficulty With considerable difficulty /Can't do this	d455	b455		Mobility (Functions of the respiratory systems)
<b>Climb steps for more than one floor, without a break</b> Without any difficulty / With slight difficulty With considerable difficulty / Can't do this	d455	b445		Mobility (Functions of the respiratory systems)
<b>Moving around outside the home</b> without difficulty / with some difficulty with great difficulty /only when aided by someone else	d460			Mobility
Are you <b>able to travel by train, bus or tram</b> ? without difficulties / with minor difficulties / with major difficulties /not at all	d470			Mobility
Do you <b>drive a car</b> ? Yes, regularly / Yes, occasionally / No, not any more /Does not know	d475			Mobility
Do you (he/she) <b>get in and out of bed</b> without any <b>assistance</b> ? Yes, without any difficulty / Yes, but with some difficulty....	d498	e		Mobility Environment

..

<b>Questions on self-care functions</b>	<b>ICF_code1</b>	<b>ICF_code2</b>	<b>ICF_code3</b>	<b>New Database categories (ICF domains)</b>
Can he/she <b>bath or shower</b> without help? without difficulty / with a little difficulty / he/she can only do it with the help of someone	d510			Self-care
The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? <b>Bathing or dressing yourself</b> Yes, limited a lot / Yes, limited a little / No, not limited at all	d510	d540		Self-care
Can you <b>cut your toenails</b> unaided? Yes, without any difficulty / Yes, but with some difficulty ....	d520			Self-care
Can you [she/he] <b>go to the toilet/WC and use</b> it? alone, easily / alone, but with some difficulty only with help / Don't know	d530			Self-care
Can he/she <b>get dressed and undressed</b> without help ? without difficulty / with a little difficulty he/she can only do it with the help of someone	d540			Self-care
Can you <b>eat</b> by yourself, including <b>cutting up your food</b> ? with no difficulty / with some difficulty / only with the help of others	d550			Self-care
Can you <b>bite and chew on hard foods</b> , for instance a firm apple? Yes, without difficulty / Yes, but with minor difficulty Yes, but with major difficulty /No, I can't	b510	d550		Self-care
Do you <b>take medicine</b> prescribed by your doctor unaided? Not applicable: does not take any medicine / Yes, I take it unaided without difficulty / Yes, I take it unaided but with some difficulty / Yes, I take it unaided but with great difficulty	d570			Self-care
Can you manage to attend to your <b>own personal hygiene</b> ? with no difficulty / with some difficulty / only with the help of others	d598			Self-care

<b>Questions on domestic-life functions and others</b>	<b>ICF_code1</b>	<b>ICF_code2</b>	<b>ICF_code3</b>	<b>ICF domains</b>
Have you (you or the household) <b>had to move</b> for health reasons? Yes / No / Will not answer / Does not know	d610			Domestic life
Can you manage to do your <b>shopping</b> without <b>help form others</b> ? Yes / no	d620			Domestic life
Can you <b>prepare you own meals</b> unaided? Yes, without any difficulty / Yes, but with some difficulty ...	d630			Domestic life
Can you manage <b>to clean</b> your dwelling/flat without help from others? Yes / no	d640			Domestic life
<b>... taking care of well-being of household members</b> yes/no	d660			Domestic life
Do you have difficulty coping with <b>everyday chores, job tasks or other demands of everyday life</b> ? no difficulty coping / slight difficulty coping/ a great deal of difficulty coping / I cannot cope....	d230	d8		General tasks and demands Major life areas
Does this illness or disability (do any of these illnesses or disabilities) limit your activities in any way? Yes / No	d230			General tasks and demands
Can you <b>use the telephone</b> unaided? Yes, I call and answer alone without any difficulty / Yes, I use it unaided but I only call very few numbers ....	d360			Communication
Owing to permanent health problems or disabilities, have you: <b>had trouble doing your job</b> not possible / extremely difficult / somewhat difficult / not difficult	d859			Major life areas
Is he/she usually able <b>to manage his/her own finances</b> ? Yes, he/she manages his/her own financial matters (plans the shopping, fills in checks, pays the rent and bills, goes to the bank )collects money and keeps accounts ...	d879			Major life areas

**Annex 13.** The coverage of questions/ items on sensory function and mobility in 57 European health surveys.

Survey code	Survey year	Country	SENSORY FUNCTIONS		MOBILITY				
			Seeing	Hearing	Body position	Handling objects	Walking and moving	Using transportation	Mobility other
A01	1999	Austria							
B02	2001	Belgium	√	√	√	√	√		√
B03	2001	Belgium							
CH02	2002	Switzerland	√	√			√		√
D01	1999	Germany							
D02	1998	Germany	√		√	√	√		√
D05	1998	Germany	√	√	√	√	√		
DK02	2000	Denmark	√	√		√	√		
E02	2001	Spain	√	√		√	√	√	√
E04	1999	Spain	√	√	√	√	√	√	√
EL02	1998	Greece							
F 11	2001	France	√				√		
F02	1999	France	√	√	√	√	√	√	√
F03	1998	France	√				√		
F05	2001	France	√	√	√	√	√	√	√
F06	1999	France					√		
F07	2000	France	√				√		
F08	1999	France							
F09	2002	France	√						
F12	2001	France							
FIN01	2000	Finland					√		
FIN03	2000	Finland	√	√		√	√	√	√
FIN06	2001	Finland							
FIN07	2002	Finland					√		
FIN08	2001	Finland							
FIN09	2001	Finland	√	√		√	√		√
I01	99/00	Italy	√	√	√	√	√	√	√

Survey code	Survey year	Country	SENSORY FUNCTIONS		MOBILITY				
			Seeing	Hearing	Body position	Handling objects	Walking and moving	Using t transportation	Mobility other
I03	2000	Italy							
I04	2001	Italy							
INT02	2000	Luxembourg							
INT05	2001	Luxembourg							
INT06	2002	Luxembourg	√	√		√	√		
INT07	98/99	Luxembourg							
IRL01	1998	Ireland		√					√
IRL02	2000	Ireland							√
IRL03	2002	Ireland							√
IRL04	2001	Ireland		√					√
IS02	89/99	Iceland					√		
IS03	2001	Iceland							
L02	2001	Luxembourg							
LFS01	2002	Luxembourg					√		
N01	1998	Norway	√	√			√	√	
NL01	1998	The Netherlands					√		√
NL02	2001	The Netherlands	√	√	√	√	√		√
NL03	2001	The Netherlands	√	√	√	√	√		√
P03	98-99	Portugal	√	√	√		√		√
P04	2001	Portugal							
S01	1999	Sweden	√	√			√	√	√
S02	2001	Sweden	√	√			√		√
UK01	2000	United Kingdom						√	√
UK02	1998	United Kingdom							
UK07	2002	United Kingdom		√					
UK09	1998	United Kingdom							
UK11	2001	United Kingdom							
UK12	2000	United Kingdom	√	√	√		√		√
UK13	1998	United Kingdom							
UK15	2001	United Kingdom							
<b>Number of surveys</b>			<b>24</b>	<b>22</b>	<b>11</b>	<b>13</b>	<b>29</b>	<b>9</b>	<b>22</b>

**Annex 14.** The coverage of questions/items on self-care, domestic life and major life area items in 57 European health surveys.

Survey code	Survey year	Country	Self-care							Domestic-life			IADL-other		
			Washing	Care body parts	Toileting	Dressing	Eating and drinking	Look after health	Self-care other	Shopping	Meals	House-work	Tele-phone	Finance Work Leisure	General task/demands
A01	1999	Austria							√						√
B02	2001	Belgium	√		√	√	√								√
B03	2001	Belgium													√
CH02	2002	Switzerland	√		√	√	√								
D01	1999	Germany													
D02	1998	Germany		√		√	√		√	√					
D05	1998	Germany	√												
DK02	2000	Denmark													√
E02	2001	Spain	√	√	√	√	√	√		√	√	√	√	F	
E04	1999	Spain	√		√	√	√			√	√	√			√
EL02	1998	Greece													
F 11	2001	France													
F02	1999	France	√	√	√	√	√	√		√	√	√	√	F	
F03	1998	France	√												
F05	2001	France	√	√	√	√	√	√		√	√	√	√	F	
F06	1999	France													√
F07	2000	France													
F08	1999	France													
F09	2002	France													√
F12	2001	France													
FIN01	2000	Finland													
FIN03	2000	Finland	√	√	√	√	√			√	√	√	√	F W	
FIN06	2001	Finland													√
FIN07	2002	Finland	√			√									
FIN08	2001	Finland													√
FIN09	2001	Finland	√	√	√	√	√				√	√		F	
I01	99/00	Italy	√			√	√	√		√	√	√	√	F	
I03	2000	Italy													
I04	2001	Italy													
INT02	2000	Luxembourg													√

Survey code	Survey year	Country	Washing	Care body parts	Toileting	Dressing	Eating and drinking	Look after health	Self-care other	Shopping	Meals	House-work	Tele-phone	Finance Work Leisure	General task/ demands
INT05	2001	Luxembourg													
INT06	2002	Luxembourg													
INT07	98/99	Luxembourg													
IRL01	1998	Ireland							√						√
IRL02	2000	Ireland													√
IRL03	2002	Ireland							√					L	√
IRL04	2001	Ireland													√
IS02	89/99	Iceland				√	√		√			√		W	
IS03	2001	Iceland										√			
L02	2001	Luxembourg													
LFS01	2002	Luxembourg													
N01	1998	Norway				√	√		√	√		√		W	√
NL01	1998	The Netherlands	√			√	√			√	√	√		L	√
NL02	2001	The Netherlands	√			√	√			√	√	√			√
NL03	2001	The Netherlands	√			√	√								
P03	98-99	Portugal	√		√	√	√								
P04	2001	Portugal													
S01	1999	Sweden													
S02	2001	Sweden	√							√	√	√		W	
UK01	2000	United Kingdom													√
UK02	1998	United Kingdom								√					√
UK07	2002	United Kingdom													
UK09	1998	United Kingdom													√
UK11	2001	United Kingdom													√
UK12	2000	United Kingdom	√			√	√								√
UK13	1998	United Kingdom													√
.	2001	United Kingdom													
<b>Number of surveys</b>			<b>18</b>	<b>6</b>	<b>9</b>	<b>18</b>	<b>17</b>	<b>4</b>	<b>6</b>	<b>12</b>	<b>10</b>	<b>13</b>	<b>5</b>	<b>11</b>	<b>23</b>



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