Selection of a Coherent Set of Health Indicators

A First Step Towards a User's Guide to Health Expectancies for the European Union

Edited by J-M Robine, C. Jagger and V. Egidi

Executive Summary

Although health state expectancies are currently available for 49 countries worldwide, their direct comparability is impossible due to the differing definitions, survey and analytic methodologies. The project Euro-REVES 2, "Setting up of a coherent set of health expectancies for the European Union", was begun in 1997 under the European Health Monitoring Programme with the aim of selecting a concise set of instruments from which a comprehensive set of health state expectancies can be produced.

In addition to the OECD Common Development Effort on Disability Measures, as a part of Health for All, the Regional Office for Europe of the WHO has recommended common health instruments that should be introduced into European Health Interview Surveys. Most of the European countries run regular health interview surveys to monitor population health and the longest established surveys, such as the United Kingdom General Household Survey, began before the current desire to harmonize health information within the European Union. As a result:

- countries with the longest experience tend to be the most reluctant to implement the recommended instruments;
- the relevance of previously recommended instruments was not always obvious to policy-makers who did however know the utility of their own national instruments;
- instruments were rarely accompanied by recommendations on the specific study designs to contain them, thus producing a further obstacle for comparability of the collected information;
- countries were not made aware of the implications when they amended the instruments (through question wording, selection of items, change in response categories).

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

Since health state expectancies are the combination of a life expectancy and a health concept, there are as many possible health state expectancies as health concepts. The profusion of possible indicators made it necessary for us to decide how to meet the main aim of the European Health Monitoring Programme, since **too many indicators may divert attention; too few indicators may hide the possible trade-off between the different facets of health as well as the effects.** We therefore decided that it was important to define, at the outset, the conceptual framework for health we would work to and the selection of the domains in which we would develop instruments within the Euro-REVES 2 project. The current project did not aim to be completely comprehensive in the domains covered, but that subsequent work would complete this task.

Design of Euro-REVES 2

Euro-REVES 2 is made up of 7 research teams from six countries (Denmark, France, Italy, the Netherlands, Spain, United Kingdom) and the multi-disciplinarity, consisting of psychologists, statisticians, social scientists, demographers, epidemiologists, brings different strengths and approaches to the project. After the initial

meetings to choose and refine the common reference framework and domains, through discussion, the group split into the 7 teams to cover the main domains. The remit for each team was to:

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

After the initial scoping of instruments and related research, each team presented their preliminary recommendations to the whole group and then to invited policy-makers from a range of countries for further input and consensus. The format of the final report, presenting the recommendations, was given particular thought by the group with each team presenting their work to a standard format.

The common reference framework and chosen domains

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

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

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

Mental disorders are now recognized as one of the principal causes of disability and consume a significant proportion of the health budget in western countries. The World Health Organization has already set a series of specific targets for improving health in relation to **mental health** in Europe and a number of individual European

countries has also individually set targets for mental health. However, despite these targets, health surveys have not commonly included instruments to measure the mental health of their populations, partly due to difficulty but also to the stigma of mental illness perceived by individuals. We hope that an instrument such as the General Health Questionnaire (GHQ) with a strong scientific background and use will help overcome some of these problems.

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

Conclusions

During the last few years a number of inventories of European health surveys have been made by several international organizations, including the WHO Regional Office for Europe, Eurostat, the European Health Monitoring Program and the OECD. At a superficial level, it could be thought that the health surveys in Europe all cover the same fields and often use the same questions. However a deeper analysis, in conjunction with current scientific research, underlines the significant differences that exist in the wording of the existing questions. We think that the main reason for the variety of question forms is the absence of two factors: firstly the absence of a rationale behind the questions clearly demonstrated in the recommendations; secondly the absence of the science behind specific questions forms, more particularly the effect of changes in the wording on the responses;

Any instrument recommended to facilitate international harmonization, should have relevance for policy-makers at the national level as there seems little point in recommending instruments that do not substantially improve upon current recommendations where they exist. Any recommendation should be accompanied by a plan of implementation as well as regular evaluation of the number of countries using the instrument and the quality of the information collected. A further stumbling block to the adoption of recommended instruments by countries is the need to retain questions to protect the calculation of trends over time. To address this issue we intend, ultimately, to provide two types of each indicator: one at a **global** level, therefore being concise and requiring little room and time in surveys, to **describe** all the existing differences on this issue between the EU countries, whether they are due to " real " health problems, problems of social organization or culture; secondly, a more **specific** instrument to **explain** the differences between these countries. The central point of this set of indicators is that an increase in the life expectancy with at least one chronic disease or with functional limitations does not necessarily imply an increase in life expectancy with activity restrictions. Between these two, lies the response of the health system in the broadest sense, with its successes and its failures, and this set of indicators aims also to measure these gaps between countries.

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

In this current project we have made proposals for five instruments:

(1) a general question about activity restrictions,

(2) a general question about perceived health,

(3) a set of specific questions on physical and sensory functional limitations,

(4) a set of specific questions on personal care activities and

(5) a set of specific questions on mental health.

To supplement these we propose six further indicators, to be the subject of the second volume, in 2001, at the end of the second phase of the project

(6) a general question about chronic morbidity,

(7) a set of specific questions on chronic morbidity,

(8) a set of specific questions on cognitive functional limitations,

(9) a set of specific questions on household activities,

(10) a set of specific questions on other activities of daily living and finally

(11) a set of specific questions on perceived health.

Ultimately we will provide a coherent set of 11 instruments leading to many health state expectancies covering the totality of the conceptual framework of the measurement of population health. This number seems to us a good compromise between too little and too many, making it possible at the same time to measure the extent of the differences in health between the European Union countries, to appreciate the causes, to specify the profile of each country and the differences between the various concepts of health: chronic disease, functional limitations, activity restrictions, mental health and perceived health. We also recommend for the present, before the full complement of 11 instruments are prepared, three global instruments to be known as the Minimum European Health Module, comprising the GALI (developed by Euro-REVES for the European Health Monitoring Programme), the WHO-Euro perceived health question and the Chronic Disease question developed by ISTAT for EuroHIS. These are listed at the end of this summary.

Proposed Instruments

Functional limitations. The 13 selected descriptors of functional abilities provide the basis for the instrument:

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

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

1- Life expectancy free of any functional limitation;

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

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

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

Activity restriction. In everyday life, ignoring temporary problems, do you usually without any difficulty, without (human / technical) help: 1/ feed yourself
2/ transfer in and out of bed
3/ dress and undress yourself
4/ use toilets
5/ bath or shower yourself.

In addition the use of personal help or aids or adaptations are collected separately allowing two main types of health expectancy to be computed: activity restriction-free life expectancy and dependence-free life expectancy (including or not severity levels).

Global Activity Limitations Indicator. The wording of the proposed instrument is:
For the past 6 months or more have you been limited in activities people usually do because of a health problem ? Yes, strongly limited / Yes, limited / No, not limited.

An Activity Limitation Free Life Expectancy maybe calculated and the introduction of three response categories (not limited, limited and strongly limited) will allow testing of the plausibility of the scenario of a dynamic equilibrium (Manton, 1982).

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

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

Self-perceived health has already been used in health expectancy calculations in several countries including the United States, Australia and throughout Europe, including the Netherlands, Denmark, Sweden, Finland, Spain and the UK.

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

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

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

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

Minimum European Health Module

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

2. Do you suffer from (have) any chronic (long-standing) illness or condition (health problem)? Yes/ No.

3. For the past 6 months or more have you been limited in activities people usually do because of a health problem ? Yes, strongly limited / Yes, limited / No, not limited.