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Session 4 – Invited paper

RESULTS OF TRANSLATION AND TESTING

Submitted by Eurostat[*]

I. The context: The European Health Survey System (EHSS) and its European Health Interview Survey (EHIS) of the European Statistical System and Eurostat

1. In September 2002, the European Parliament and Council adopted a new Programme of Community Action on Public Health (2003-2008)[1]. One of the three main pillars of the new programme is "to improve health information and knowledge for the development of public health". This is to be done by "developing and operating a sustainable health monitoring system to establish comparable quantitative and qualitative indicators at Community level". In this view the existing work and accomplished results will constitute the basis. The information that is necessary to be collected, analysed and disseminated should be comparable and compatible for age and gender. The interest is for "specific information on human health at Community level, concerning health status, health policies and health determinants, including demography, geography and socio-economic situations, personal and biological factors, health behaviours such as substance abuse, nutrition, physical activity, sexual behaviour, and living, working and environmental conditions, paying special attention to inequalities in health". In particular, the new Programme of Community Action on Public Health states that "the statistical element of the system will be developed, in collaboration with Member States, using as necessary the Community Statistical Programme[2] to promote synergy and avoid duplication".

[*] Paper prepared by Didier Dupré.

[1] Decision No 1786/2002/EC of the European Parliament and of the Council of 23 September 2002 adopting a programme of Community action in the field of public health (2003-2008), OJEC L 271/10

[2] Decision 2367/2002/EC of the European Parliament and the Council of 16 December 2002 on the Community statistical programme 2003 to 2007

2. In general, the aim of producing comparable data can be achieved only by means of surveys that make use of common instruments. The Health Interview Survey (HIS) or other household surveys are widely accepted instruments that could provide comparable data for health topics (health status and its determinants, use of medical services, etc.) in relation with the personal characteristics of the population. In this way, the differences between population groups in relation with the above mentioned health topics could be better reflected.
At the European level, the process of producing comparable data in the area of public health statistics by means of surveys was realised in several steps.

3. The first achievement in the development of a HIS in a co-ordinated way across Europe was a small module on health in the European Community Household Panel (ECHP 1994-2001). This was the first attempt at harmonised annual HIS data collection in the EU with the same questions in all the MS. Although the same questions may not ultimately be measuring the same underlying health concepts, the results of these surveys were the starting point for extra efforts to achieve better comparable EU wide data health and disability and their results have been widely published.

4. The second step was the collection by Eurostat of 12 (now 18) items on health from national surveys (on self-perceived health, chronic conditions, present and former smoking, physical activity, in patient care, out patient care, etc.). The latest round was carried out in 2004. However the frequency and completeness of the data are not the same in the Member States.
The third step (in 2002) was a module on disability related to working conditions that was included in the European Labour Force Survey (LFS) and analysis of this is still ongoing.
A fourth major step forward was a decision to include the Minimum European Health Module (MEHM) in the annual European Union Statistics on Income and Living Conditions survey (SILC)[3], which began in 2003, 2004 or 2005 depending on the Member States. This small module providing a general indicator for perceived health and for disability has been developed with cross-national comparability specifically in mind. Because of its brevity it can easily be included in other topical surveys, e.g. on labour or income, when supporting variables on health are needed.

5. Finally, the fifth step was represented by the proposal of the Task Force on Health and health related survey data (TF/HIS) to have a framework for a regular collection of harmonised data by means of surveys and/on survey modules on health, named the European Health Survey System (EHSS). This framework was endorsed by the Working Group on Public Health Statistics (WG/PH) and welcomed by the meeting of the European Directors of Social Statistics.

6. The aim of an EHSS is to anticipate the health information needs of the Member States and of the EU in the mid-term (2003-2008), including the needs arising from the new Community public health programme and other EU programmes. It should coordinate the efforts on HIS, avoiding unnecessary overlap and incompatibility and fill gaps existing in health information.

7. The EHSS is a comprehensive and co-ordinated but flexible set of surveys, allowing inter country comparisons, and built around an essential core survey, according to flexible and modular implementation.

[3] Commission Regulation (EC) No 1983/2003 of 7 November 2003 implementing Regulation (EC) No 1177/2003 of the European Parliament and of the Council concerning Community statistics on income and living conditions (EU-SILC) as regards the list of target primary variables (OJ L 298, 17.11.2003, p.34).

8. The EHSS consists of three parts:

- An European Core Health Interview Survey (ECHIS): this core survey should respond to the basic information needs and demands and should be further developed by the European partnership on health statistics in the European Statistical System, as a follow-up of the ongoing HIS activities in Eurostat (within the new EU programme of public health it is stated that the statistical elements should be developed under the EU statistical programme);
- A complementary set of special surveys (ESHIS): these surveys address specific demands and the national institutes of public and research groups could play a central role in their development;
- A database of certified standard and recommended reference instruments: this is an ongoing database of "off-the-shelf" instruments for use in different types of HIS.
- The ECHIS consists of two parts:
- The annual MEHM which is included in the SILC (the 7 variables on health in the SILC are presented in annex 1) and is already being implemented in 2003 for pilots and will be carried out from 2004-2005 onwards on a routine basis;
- An European HIS (EHIS) to be held every five years and including the following modules: a module on health status (EMHS), a module on health care (EHCM), a module on health determinants (EMHD), and a module on background variables (EBM).

9. The EHSM is already developed (by EuroReves for Eurostat in 2003) and being tested. The other modules of the EHIS are currently developed by the Belgium Scientific Institute of Public Health and the Hungarian Central Statistical Office for Eurostat and will be ready and already translated and tested in 6 languages by mid-2006.

10. These modules will be conducted together in all EU25 Member States, EFTA and Candidate Countries every 5 years, with a first implementation mainly in 2007 or 2008 depending on the Member States (few countries will already start in 2006). The second round will take place during the same year for all countries (year to be defined, 2012 or 2013). The modules may be grouped in one separate national survey, though they may also be included in existing national surveys (i.e. national health interview survey, labour force survey, other household survey) – in some cases more than one national survey may be used. In such a way Member States will have the maximum flexibility for implementation though across the EU the same data are collected and become available at the same time.

11. The complementary surveys may be further developed in the framework of EU public health and related programmes. They might address different topics or subject groups, e.g. nutrition, adolescents, mental health. However, for reasons of comparability and to strengthen coordination, these surveys should at least include the MEHM and preferably one module of the EHIS.

II. The development and translation of the EHIS modules

12. A document « Guidelines for the development and criteria for the adoption of Health Survey instruments » was developed for the EHSS by a Task Force of the Eurostat Partnership

for Public Health statistics in 2004[4] and published in the series of the Working Papers of Eurostat.

13. The guidelines provide recommendations according to the following structure:

Basic Information on the phenomenon under study:
- Policy relevance and utility
- Justification of the inclusion of the module in the survey
- Description of the concept
- Description of the measure and the instrument
- Indicators;

Development of the instrument
- History of the measurement
- Review of the instruments
- Description of the instrument
- Characteristics
- Stability;

Quality evaluation of the source instrument
- Critical review of the questions
- Pre-testing (simple testing, cognitive testing, behaviour coding, special probing, expert panel, comparison of pre-testing methods)
- Reliability
- Validation
- Pilot testing (field testing).

In practice, the developments for the EHIS modules refer:
- For the justification and utility to the European policy and indicators needs, in particular the European Community Health Indicators (ECHI);
- For the instruments selection to the projects developed at international level and within the Health Monitoring Programme and Community Action on Public Health (DG SANCO - Health and Consumer Protection) and to the HIS/HES database developed by BE and FI and hosted by the Belgium Scientific Institute of Public Health (financing: SANCO and Eurostat);
- For the quality evaluation to cognitive/laboratory and field testing.

14. The modules are originally developed in English. For the translation into all other 20 official languages of the EU25 and additional languages of the EFTA and Candidate Countries, a detailed translation protocol has been developed. This protocol describes the actions that have to be performed for ensuring comparability between the national versions. The protocol includes conceptual translation cards for each part of the module that have been prepared in order to help the translators to understand and translate the underlying health concepts. In a first step, translators working in field of health, having an understanding of the health concepts used and having the target language as mother tongue and English as working language are chosen. After the initial translation, checkers with the same characteristics as translators judge the adequacy of the translation with reasons through completion of a questionnaire. Finally, the checkers views and the initial translation are brought together in a final translation.

[4] These guidelines were developed by Dr. Jean Tafforeau (coordinator, BE), Montserrat Lopez Cobo (ES), Hanna Tolonen (FI), Christa Scheidt-Nave (DE) and Alessandra Tinto (IT) and improved on the basis of the comments received from Arpo Aromaa (FI), Herman Van Oyen (BE), Jozsef Vitrai and Erzebet Stokker (HU)

15. After translation, the modules are also pre-tested (cognitive) and tested (field-testing, pilots) nationally. For countries sharing the same language a coordination process is established.

III. Other tools for ensuring high quality and comparability at EU level

16. A second Task Force of the Eurostat Partnership for Public Health statistics was set up in 2005 and is developing recommendations on survey designs for the EHSS[5]. It will be finalised during the first half 2006 and also published in the Eurostat Working Papers series. It covers :

- Survey methodology ad implementation, data collection (interviewers, type of interview, survey arrangement, etc.)
- Sampling (sample size, sampling design and methods, participation, proxys, etc.)
- Data management (missing values, estimations, etc.)
- Quality insurance

17. Moreover, as for the SILC above, the implementation and quality of the EHIS will be reinforced by a legal basis. Its first implementation will probably, at least for the countries implementing it in 2007, based on a gentlemen agreement, for time schedule issues. But a Proposal for a Regulation of the European Parliament and of the Council concerning Community statistics on public health and health and safety at work will be submitted to the Statistical Programme Committee of the European Statistical System by the end of November 2005 in order to be adopted by the European Commission early in 2006. When adopted later by the European Parliament and the European Council via co-decision procedure, an implementing regulation will be issued on the EHIS for adoption by the European Commission (only).

18. In addition, it should be noted that in 2005 a European Statistics Code of Practice was adopted and presented by a Commission Regulation, defining principles for promoting the application of best statistical principles, methods and practice by all producers of European Statistics and to improve trust and confidence in the credibility and quality of the statistics produced and disseminated.

IV. The MEHM and the EHSM : translation, testing and first implementation

19. The EHMS covers the following subjects, the 3 first ones being the MEHM:

- self-perceived health (global);
- limitations at least the past 6 months due to health problems (global);
- chronic conditions (global and detailed);
- physical and sensory functional limitations;
- personal care activities;
- household care activities;
- other daily activities;
- psychological distress and well-being.

20. The MEHM was implemented first in the SILC. In this context, though the SILC is a EU-wide pre-harmonised survey, the translation protocol defined above was not yet used but the usual testing procedure were used. Actually the main point is that the SILC being defined legally by a Regulation published in all official EU languages, all questions are available on a

[5] « Guidelines and quality criteria for population healt hsurvey design and method », Gunilla Davidson (coordinator, SE), Stefaan Demarest (BE), Hanna Tolonen (FI), Claudia De Viitis (IT), Paola Primatesta (UK), Lucian Agafitei (Eurostat).

compulsory basis. However, the regulation contents actually variables and not questions. Consequently some weaknesses are identified. Moreover, it appears that the national questionnaires implemented do not fully respect the concepts defined by the regulation and are sometimes different among countries sharing the same language. For this purpose, as the MEHM is exactly the set of the 3 first questions of the EHSM currently translated by health specialists using the translation protocol (see below), it will be required now that in each language the national SILC questionnaires use the questions as translated under the EHIS project. This activity has started and the national SILC responsible people were contacted and will be provided with the MEHM-EHSM questions as soon as available.

21. Actually, the 2003 SILC results are available for 6 Member States – BE, DK, EL, IE, LU, AT – and NO. These results can be compared with all EU health survey data available previously which were not pre-harmonised (either partially harmonised as ECHP or post-harmonised as the 18 HIS items). The data comparison for the question on the general self-perceived health is presented in annex 2.

22. Concerning the EHSM, the translation, testing and some first implementation in pilot surveys was launched by Eurostat and the Member States, EFTA and Candidate countries in 2004 and 2005 via two grant actions and 2 Phare-Transition Facilities projects (new Member States). For the Phare-Transition Facilities the actions were also supported by experts (seminars, visits in the countries, etc.) under a call for tender. In total, about 1 million € was provided by the Commission for this process. The actions were based on the use of the translation protocol and cognitive/laboratory and field testing as defined above, as well as first pilot surveys under Phare projects. The time schedule is attached in annex 3. Finally, as a way to allow all countries to benefit each others from their experience during this work and to identify remarks for improvement and final decision on the contents of the official EHIS modules for implementation from 2007 onwards, web newsgroups were implemented in the HIS Circa site. The 3 first pages of the current summary of questions-answers from these newsgroups is presented as an example in annex 4.

23. At the end of the action, each country provides Eurostat with a report including the linguistic version of the EHSM, the protocol used in the process of translation, as well as the problems encountered in the translation process or, when it is the case, results and documentation on the coordination with other countries sharing the same language. Moreover, the report will present the methodology (including any special instructions or guidelines for the interviewers referring to the questions of the module, in case such instructions were used) and organisation of the field test, the problems encountered in the field operationalisation, the conclusions derived from the field testing and possible proposals, comparisons with existing results in the area.

24. As indicated in the time schedule, the latest results and reports will be available in May-June 2006. They will be analysed into details and a special meeting of the Technical Group HIS will take place on 25-27/09/2006 in order to define on this basis the final contents of the modules (including the EHDM, EHCM and EBM to be also available in 6 languages by mid-2006) and all other elements for their implementation, such as minimum requirements for the survey which will host them, etc.

V. More information:

25. See the Eurostat Public Health statistics Circa web site http://forum.europa.eu.int/Public/irc/dsis/health/library.

Annex 1 - Eurostat F3 & F5 – EU-SILC – Health-related variables

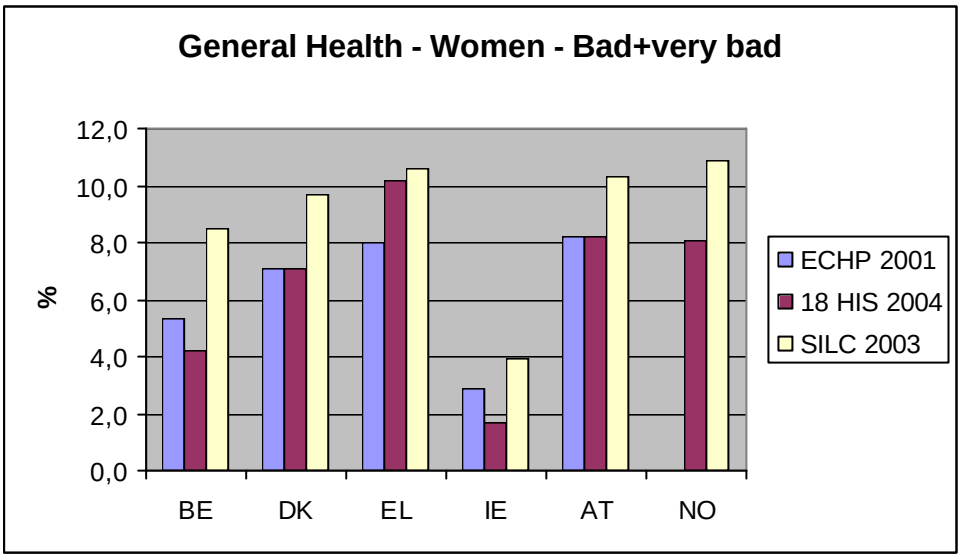
Code	Target variable
	Health, including health status and chronic illness or condition
	General health
1	Very good
2	Good
3	Fair
4	Bad
5	Very bad
	Suffer from any chronic(long-standing) illness or condition
1	Yes
2	No
	Limitation in activities people usually do because of health problems for at least the last 6 months
1	Yes, strongly limited
2	Yes, limited
3	No, not limited
	Access to health care
	Unmet need for medical examination or treatment during the last 12 months
1	Yes, there was at least one occasion when the person really needed examination or treatment but did not receive it
2	No, there was no occasion when the person really needed examination or treatment but did not receive it
	Main reason for unmet need for medical examination or treatment
1	Could not afford to (too expensive)
2	Waiting list
3	Could not take time because of work, care for children or for others
4	Too far to travel/no means of transportation
5	Fear of doctor/hospitals/examination/ treatment
6	Wanted to wait and see if problem got better on its own
7	Didn't know any good doctor or specialist
8	Other reasons
	Unmet need for dental examination or treatment during the last 12 months
1	Yes, there was at least one occasion when the person really needed dental examination or treatment but did not receive it
2	No, there was no occasion when the person really needed dental examination or treatment but did not receive it
	Reason for unmet need for dental examination or treatment
1	Could not afford to (too expensive)
2	Waiting list
3	Could not take time because of work, care for children or for others
4	Too far to travel/no means of transportation
5	Fear of doctor/hospitals/examination/ treatment
6	Wanted to wait and see if problem got better on its own
7	Didn't know any good doctor or specialist
8	Other reasons

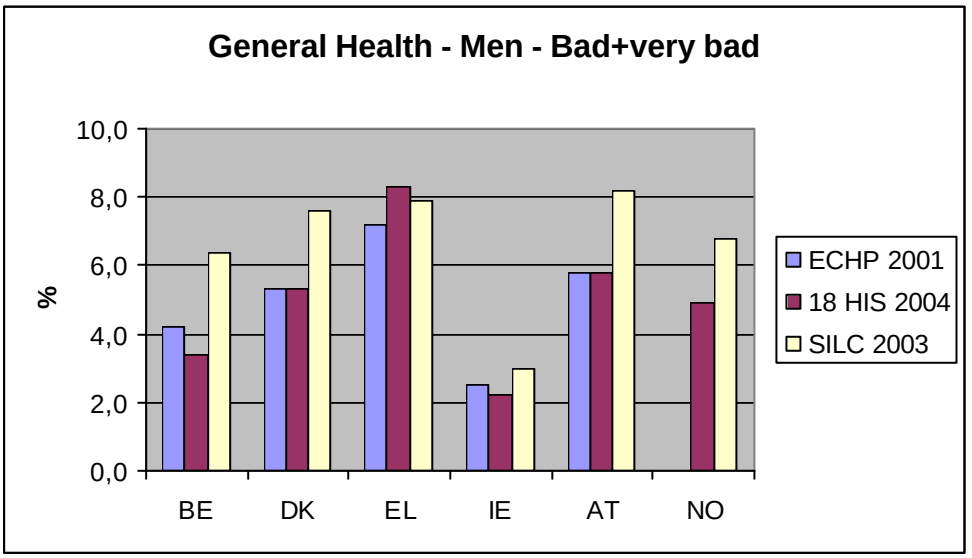
Annex 2 – Comparison: ECHP 2002 – 18 HIS items 2004 round – SILC 2003

ECHP 2001 – self-perceived health

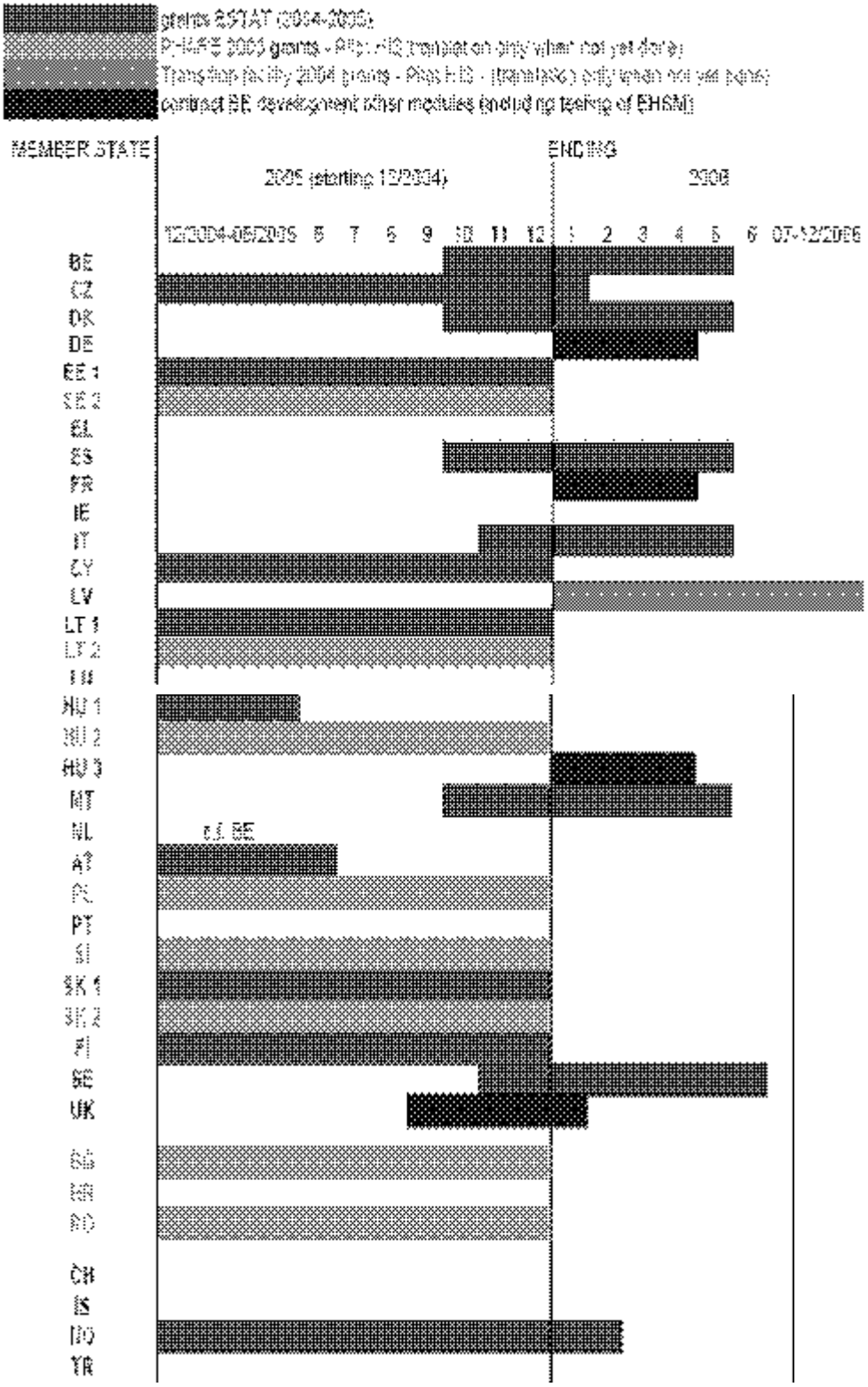
18 HIS items round 2004 – "how is your health in general"

SILC 2003 : "how is your health in general"





Annex 3 – EHSM Time schedule : translation and testing



Annex 4 – EHIS translation newsgroups implemented in the HIS Circa site: summary of questions-answers

HIS newsgroups on CIRCA

General considerations

Two newsgroups exist in the Health Interview Survey group on Circa. They have the role to help the experts involved in the process of the implementation of the European Core Health Interview Survey (ECHIS). The first one[1], "Health status module", is a forum dedicated to discussion and share of experiences for the ongoing translation of the Health Status Module of the ECHIS. It is open to the TG HIS members and national project managers. The second newsgroup[2], called "HIS-forum", is a place to discuss and ask questions to experts and colleagues about the implementation of the ECHIS and other HIS related matters, e.g., the Minimum European Health Module (MEHM) implemented in the SILC. It is now open to all the participants of the Technical Group HIS.

After the last TG HIS meeting in late 2004, comments and questions concerning the health status module and its translation were received from Austria, Czech Republic, Poland, Spain and UK via the newsgroups or by e-mail. Some of these comments and questions are based on recent national experiences.

In January 2005, a revised English version of the module was provided to Eurostat by the team who developed the module. Compared to the version that was discussed in the last Technical Group HIS meeting, this one is more adequate to be used in an interview (i.e. is not just a set of questions). Although it is recognised that improvements are still necessary, no further changes will occur in this revised version before knowing the issues faced in the translation process and field testing.

The comments and questions presented in this paper were made on the version of the module that was presented in the October 2004 TG HIS meeting (i.e. not on the January 2005 revised English version) and therefore some of them are not of actuality. In text box is presented the answer prepared by Eurostat with the support of the Core Group HIS (in particular, Dr. Jean Tafforeau) to the problem raised, taking into consideration the new questionnaire version.

Comments and questions referring to the content of the module

The issues raised in the messages refer to the need for clarifying some concepts or other aspects and to disagreements and suggestions to change some elements in the module. A part of these comments were already taken into account in the revised English version of the module[3].

Needs for clarification on concepts or other aspects

Longstanding illness or health problem

- The duration of the "longstanding" should be explained more precisely and in detail. It is appreciated that longstanding illness or health problem should last at least 6 months or longer, similar to the duration of limitation.

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[1] http://forum.europa.eu.int/Members/irc/dsis/healthtf/newsgroups?u=europa.dsis.healthtf.health-status-module
[2] http://forum.europa.eu.int/Members/irc/dsis/healthtf/newsgroups?u=europa.dsis.healthtf.his-forum
[3] The comments and suggestions received from Howard Meltzer are not included in this paper, as he contributed to the revised English version of the module.

There are conditions that you have for all your life as soon as you suffer from it, such as ischemic heart disease by example. Even if you got the diseases only two weeks ago, it will last for more than six months or even for the rest of the life.

Limitation for at least 6 months

- It is understood that the limitation must last for the whole 6 months, the duration of the underlying health problem being irrelevant. Thus, limitation for e.g. 4 months out of the last 6 implies the answer "not limited".

Yes

- As concerns the wording "activities people usually do" is not understood if it refers to the usual activities of the concerned person or to the activities performed by the people of the same age group. The activities performed by a person usually depend on age and sex. Only basic self-service activities are common for all people. For young persons usually activities mean school education, for adults mean work and for non-working women mean housekeeping.

A list of activities was purposively not included as they would perhaps vary from country to country and it is not intended to put in an age reference in keeping with the self-perceived health. Also others have found this not wise. Below is the reasoning from the team who prepared this question on the choice of the phrase 'people usually do':
People with long-standing limitations due to health problems, have passed through a process of adaptation. This may result in a selection or reduction of the set of activities they do. In order to identify the existing limitations a reference is necessary. Although some instruments include an explicit external reference to the age-group of the subject, this is not preferred. Therefore the activity limitations are assessed against a generally accepted population standard, relative to cultural and social expectations by referring only to activities people usually do. This is consistent with the self-perceived health instrument (see next chapter) and gives no restrictions by culture, age, gender or the subjects own ambition. It seems to have been acceptable in its use so far though we obviously need to do further testing.

Chronic diseases

- The meaning of the question - "Have you had …….in the last 12 months?" is not clearly explained. Does somebody who has taken any medicines and doesn't have symptoms of the disease (e.g. hypertension) have the disease or not?

The new English version of the module answers to this question: both questions on having the health problem and taking medicines in the last 12 months are asked.

Physical and sensory functional limitation

- It should be known in the questions referring to walking up and down a flight of stairs whether using a banister is regarded as a device. The need to determine clearly what means "flight of stairs" (8-9 stairs or half of floor) is also mentioned.

The new English version of the module answers to this question.

- It should be known in the question referring to bending and kneeling down whether using any support (e.g. back of the chair) is regarded as a device.

The new English version of the module answers to this question.

Personal care activities

- It is not clear if the answer "I do it with help" refers to the help of a person or special equipment (device). Also, the meaning of "on your own" is not clear. The instruction specifies that it means without the help of another person. In this case, is not clear how is considered the use of special equipment or devices. If a person uses special equipment only, can he/she say -- "Yes, I do it on my own"?

The new English version of the module answers to this question (see footnote 2 on page 5 of the module).

Household care activities

- It is necessary to determine strictly which type of activities is covered, as the same activity could be performed in different ways. Therefore, some clues are necessary. For instance, going to a shop on foot and carry a heavy bag back home is different from shopping in supermarket and then going back by car. Also, cleaning the windows for a young woman can be a light housework, but for an older woman is a heavy work. Doing the laundry could be done by hand or using washing machine and so on.

Yes, but the car doesn't necessarily bring everything inside the house and even it is a shorter way, still heavy load should be carried moreover, age being a background variable, it will be possible to analyse the results by age groups.

Examples of heavy housework: walking with heavy shopping for more than 5 minutes, moving heavy furniture, spring cleaning, scrubbing floors with a scrubbing brush, cleaning windows, or other similar heavy housework.

Examples of light housework: cooking, washing dishes, ironing, child care.

- The intention of the question "To what extent do you, usually, prepare meals on your own?" is not clear. Suggestion for wording: "Could you …… if you had to or wanted to?".

The new English version of the module answers to this question.

Other daily activities

- The wording "going where and when you want to go" is not understandable as well as the question "Are there any remaining problems in doing your usual school/work activities to your satisfaction that you require (more) help with?".

In the revised version, these questions have been reworded.

Mental health

- The difference between the wordings "feel full of pep" and "have a lot of energy", respectively "feel worn out" and "feel tired" is not distinguished.

Etc. …