



Post-Emergency, Multi-Hazard Health Risk Assessment in Chemical Disasters PEC

D.E.5

Guidelines for Population Survey



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1. INTRODUCTION

The main objective of a general population health survey is to provide a description of the health status of the population. In the case of natural disasters, the purpose is to obtain information on how people experience their health, to what extent they make use of health care facilities, how their health was affected by the natural disaster and how they look after their health. More specifically, the goals of health surveys after natural disasters can be summarized as follows:

- Identification of specific health problems of the local population related to the natural disaster
- Description of the health status and health needs of the population
- Measurement of the health status of the population
- Collection of data on health determinants
- Analysis of social (in)equality in health and access to health services

A health survey provides the channel through which such information can be obtained. On the basis of such surveys, assessing a large variety of personal, social and material characteristics, life habits and conditions, determinants for public health can be traced and monitored. The ultimate goal of a health survey is to provide an integrated instrument in decision-making when health policy is framed. This makes it possible to fix priorities in policy development and to monitor the progress of the health of the populations for a **specific timeframe after the natural disaster**.

This is a generic document in the sense that it can be applied to any health survey instrument. Although most of the concepts used could probably also be applied to health examination surveys, the present guidelines are however for the moment more specifically focused on the health interview surveys, and is specifically adjusted for cases after natural disasters.

Different steps are described here; it is suggested that experts who are developing or recommending instruments to be applied in population health survey in European Community member states may follow each of those steps to produce comprehensive documentation together with the instrument proposed.

It is also suggested that those experts who are using the recommended instruments should verify exactly that all the criteria proposed in the present guidelines are met before adopting a (new) instrument.

The guidelines are subdivided into five chapters:

- **Basic information**, outlining the background information to be provided
- **Development**, describing all the steps to be followed to design the survey protocol (instrument)



- **Translation process**, with clear recommendations on how to ensure the comprehensive translation of the instrument from the source (English) to the target European languages
- **Quality evaluation** describing the minimal requirements concerning validation of the instrument
- **Implementation**, with a description of the content of the users' manual to be provided with the (new) instrument.

Each of those topics is briefly described here but the reader is also strongly recommended to study the corresponding information available in the scientific literature.

1.1 Definitions

The term “Health Survey” will be used here as a generic expression to label any kind of survey including health related topics.

The term “Population Survey” is used to indicate surveys implemented on a representative sample of the population.

The term “Health Interview Survey” refers to a population survey specifically designed to investigate health topics; data collection is achieved by means of survey questionnaires without performing any kind of physical examination or biological testing.

The term “Health Examination Survey” refers to a population survey specifically designed to investigate health topics; data collection is achieved by means of survey questionnaires and by performing physical examination and/or biological testing.

The term “instrument” refers to one or several questions included in the survey questionnaire and aiming to investigate a specific subject matter (by example, smoking behaviour, self-perceived health, etc.), in this case we aim to the health status of the local population after a natural disaster.

The term “measure” refers to the outcome of the instrument, that is the results obtained from one or several questions on a specific topic.

The term “module” refers to one or several instruments included in the survey questionnaire; together these instruments permit the investigation of a general area related to the health of the population such as health status, health behaviour, health care consumption, etc.

2. CONTENT OF HEALTH SURVEYS

In population health surveys, data are collected by means of interviews in a representative sample of the population.

Most European member states conduct surveys exclusively oriented towards health (status and



consumption) and its determinants. In some countries such as Germany and the UK (and more recently in the Netherlands with the “POLS”) there are multipurpose surveys with a specific module on health. However specific health surveys usually allow more in-depth and broader study of health-related issues than general surveys with health modules, as there is no competition with other areas of investigation (4).

Most health surveys are performed via interviews only (Health Interview Surveys – HIS). The potential advantages of examinations coupled with the interview must be analysed in detail due to the increased cost and complexity of such an investigation. Such health examination surveys (HES) are thus not discussed here.

Five main areas are usually considered in the conceptual framework of the Health Interview Surveys (HIS):

- Health Status
- Health behaviour
- Disease prevention
- Health consumption
- Health and society

These can be related to the classification proposed in the framework of the European Community Health Indicators – ECHI:

ECHI classification	HIS domains
1. Demographic and socio-economic factors 1.1 Population 1.2 Socio-economic factors	Health and society
2. Health status 2.1 Mortality 2.2 Morbidity, disease-specific 2.3 Generic health status 2.4 Composite health status measures	Health Status Health Status Health Status
3. Determinants of health 3.1 Personal and biological factors 3.2 Health behaviours 3.3 Living and working conditions	Health behaviour Health and society



<p>4. Health systems</p> <ul style="list-style-type: none"> 4.1 Prevention, health protection and promotion 4.2 Health care resources 4.3 Health care utilisation 4.4 Health expenditures and financing 4.5 Health care quality/performance 	<p>Disease prevention</p> <p>Health consumption</p> <p>Health and society</p>
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3. HEALTH STATUS

Attention to the health status of the population is necessary under the WHO definition of health and the global approach of health problems. Indeed, measuring health consumption only is no longer sufficient, and an instrument such as HIS is essential to complement the information usually collected by health care providers, registries and vital statistics.

HIS allows measurement of the health status of the population in general and not only in relation with specific health problems. This is referred to in the literature as the distinction between ‘health status’ and ‘state of the health’ (6).

Even if health is the prevailing subject of the survey and despite the positive approach of health recommended by WHO, most of the domains investigated in HIS will be concerned with ill-health and diseases. A positive conceptual framework was effectively considered when designing the HIS but it has unfortunately not been possible to implement the concepts due particularly to the lack of available instruments (7;8).

One of the main characteristics of the health survey comes from the fact that most of the information gathered is provided by the individuals themselves with all the potential subjectivity involved. Their experience and their sensitivity in relation to their own health status plays a major role. However it is possible to differentiate relatively more objective questions (height and weight for example) from purely subjective ones (self-perceived health). Most of the topics investigated in HIS lie between these two extremes.

Another basic concept of HIS is the different approach towards medically diagnosed diseases on one side and their consequences on the functional status of the individual on the other side. Here medical diagnoses refer to the declaration of the person answering the question “Has a doctor ever told you that you have?” without any objective verification by medical records.

The measurement of the health status of the population is mainly focused on chronic conditions; due to their long duration these conditions have a bigger impact on health expenditures and they represent a higher burden at the population level.

Not only the conditions are considered but also their impact on the functional status of the respondents: functionality and disability are thus also important problems that are investigated



here.

3.1 Health behaviour

Lifestyles are intrinsic components of the daily lives of individual people. They are closely linked to the values and the priorities of each person, as well as to the opportunities and constraints inherent in culture and socio-economic status. Lifestyles are in fact shaped by the social acquirements and interpersonal interactions. It is thus wrong to believe that a specific behaviour is determined only by a simple personal decision to adopt or reject health-related life styles (deterministic approach).

Lifestyles are, however, health determinants: some aspects of daily life contribute to the preservation of a good state of health, the prevention of specific conditions and the improvement of psychological well-being. Equally, specific behaviours may be harmful to health especially if they are excessive or chronic.

Better lifestyles are the main potential source of improvement in the health of the population, probably to an even greater extent than medical progress. This is why health promotion is one of the most important components of the public health programmes especially the Health for All initiative of the WHO aimed at improving individual health-related behaviours.

It should be kept in mind that a reverse effect may also occur, for example people might give up smoking because of health problems, and not only to adopt a healthy behaviour.

For public health decision makers, as well as for the institutions in charge of the implementation of health-promotion programmes, it is essential to measure regularly the prevalence of specific health-related behaviours and their trends at population level and in specific population subgroups. See for example the Surf – NCD InfoBase of the World Health Organisation with estimates of national prevalence for each risk factor and Member State¹.

Such measurement is imperative for the evaluation of programmes and policies. Health surveys cannot be used to prove the relationship between a programme and a specific trend but they are however useful tools for the monitoring of health-related behaviours.

4. DISEASE PREVENTION

The advantages of preventive medicine have become more and more apparent during the last 30 to 40 years. This new approach modifies deeply the way to solve problems such as infectious diseases (with immunisation programmes for example). Early disease detection has also become an essential component of preventive medicine with striking results as far as morbidity and mortality are concerned (9).

¹ http://www.who.int/ncd_surveillance/infobase



Public health policies have progressively been enlarged from the management of health care expenditures to the development of strategies aimed at improvement of the health of the population. Such an approach involves specific actions at the level of the biological factors, the physical and social environment, and the individual behaviour but also at the level of the health services in their curative and preventive components (10).

The WHO Health for All targets published in 1985 explicitly mention health promotion and diseases prevention programmes as priority programmes. From a conceptual point of view, three areas can be mentioned in the field of preventive medicine (10):

- Primary prevention: actions aimed at eradicating the cause of a disease in order to prevent emergence of new cases
- Secondary prevention: early detection and treatment of a specific disease before the appearance of the clinical symptoms and the complications
- Tertiary prevention: it is not strictly speaking prevention of diseases but rather trying to limit its consequences such as disability and chronic pain.

Some modules in the HIS investigate specific action in the primary and secondary prevention. Several methods have been used to select the priority actions in the area of preventive medicine. The frequency of the disease but also the importance of the problem at the individual and societal level, and the efficacy of the preventive methods are taken into account.

5. HEALTH CARE CONSUMPTION

Information on health care consumption is an essential part of the health information system in order to assign necessary resources to the population. This covers three main topics: ambulatory care, institutional care and medical drugs consumption.

Different methods are usually available to measure health care consumption: routine services statistics (including hospital discharge), health expenditures and their reimbursements by the social security system, and health surveys.

It is generally admitted that health services statistics are more reliable than information coming from health surveys. This is due to the recall bias as well as the lack of medical knowledge of the individuals participating in health surveys.

However, health surveys are the main source of information where data can be collected concurrently on different health related aspects, making it possible to analyse:

- The level of health consumption in correlation with several determinants such as health status, lifestyles or socio-demographic characteristics
- The relation between different types of health care use

Health survey data permit the comparison of the health needs and health consumption and thus



make it possible to explore the concepts of vertical and horizontal equity in health care.

Health surveys are also sometimes used to measure patient satisfaction.

6. HEALTH AND SOCIETY

The concept of health has enlarged over time including progressively non-medical components and has become a social issue.

The health status and the social level of the individual are known to be closely linked: social status is a powerful determinant of health in the population. This can be studied through the accessibility to health care but also through the detailed analysis of the determinants of health inequalities.

In addition, environmental (physical and social), as well as familial and professional parameters have to be considered, as well as income inequalities, social capital, social support, as they may interfere with the health of the population.

Health surveys are also used more and more frequently to investigate such problems as injuries, violence or gender inequalities. Ethnicity and geographical regions are important factors to be taken into account.

7. BASIC INFORMATION ON THE PHENOMENON UNDER STUDY

7.1 Policy relevance and utility

The general aim of population health surveys is to acquire information about the state of the population with regard to health condition and its determinants, as far it is perceived. This knowledge is utilised to elaborate public health policies at the national and supranational levels, and to provide information to the population. Thus, any health survey or instrument to be developed needs to serve this purpose.

It is important to have clearly defined the main and specific objectives of the instrument to be developed. Only after we have defined what we want to know and how we want to get it, can we develop the instrument that provides us with the data to reach the predefined target.

In the process of selecting and designing an instrument, it is essential to justify the necessity of it, as well as to explain the future or expected use of the provided data. A list of potential users of the intended instrument could be provided.

In general, the utility of the data is not restricted to a single feature. A variety of factors can be involved, such as:

- The extent to which the predefined objectives of the survey and of a specific instrument have been reached.



- The possibility to compare the results at the geographical level (national and international) as well as the evolution over time.
- The possibility to compute the expected indicators, preferably those recommended internationally. Microdata are non-sense if these are not used to provide indicators, which summarise the information.
- The satisfaction of the largest number of possible users: local, national and supranational governments, which will benefit from the data in order to establish specific health policies (assistance, prevention, services, etc.). Non-Governmental Organisations, such as patients' organisations, may need to know the magnitude and geographical distribution of a disease or a disability, in order to better apply resources and maximise social benefits. Other probable data consumers are companies in charge of the supply of health products and services.

The utility of the data may arise from an urgent need for information about a particular problem. In that case, the introduction of a new instrument in a survey may make it possible to quantify the dimension of the problem and to measure the determinants; this will allow the planning of prevention strategies.

An example that combines political interest and production of internationally comparable indicators is the 2003 declaration of *the European Year of People With Disabilities*, and the ongoing activities in this context throughout the world and in particular in Europe.

In conclusion, the policy relevance and the utility of the instrument proposed have to be explained in detail in the manual that will be prepared for the potential users.

7.2 Justification of the inclusion of the module in the survey

The expert developing the instrument should justify why it should be included in a population survey (health or general survey). Is this the best source of data on the phenomenon under study? Are there any specific conditions to be fulfilled to include such an instrument in a population survey?

For example, the widespread instrument on self-perceived health, “*How is your health in general?*” is often included in population surveys, since this single question provides information about how people feel their own health, giving clues on unmet needs, health services, etc. In addition, interview surveys are the only way to collect such information from the population. Due to its simple wording, it may be included in both a general and a specific health survey. Recent studies (still to be published) have however shown a lack of intercultural comparability of this instrument.

On the other hand, an instrument to measure the prevalence of low birth weight is probably not adapted for inclusion in a population health survey. Indeed, due to the relatively small sample size of a generic survey, the number of newborns included would be fairly small and would not



allow computation of valid estimates. In this case other data sources such as birth registries would probably be preferable.

7.3 Description of the concept

For each instrument it should be explained what exactly will be measured.

The concept needs to be defined in the most complete and clear way, specifying what is meant to be included and what to be excluded in the study. It is usually necessary to complement this definition with other concepts related or included in an explicit or implicit way, also adding explanatory nuances: duration of the process, time reference indicating the period to which the instrument restricts, fulfilment of administrative conditions, etc.

For example:

A specific concept was adopted in 1992 entitled: “*health-related physical activity*” or “*health-enhancing physical activity*”. It is defined as any body movement produced by striated muscles leading to a significant increase of energy expenditure when compared with the rest status (Bouchard et al, 1994). This concept covers the entire spectrum of activities including leisure-time physical activities, exercises, competitive sports, occupational activities and daily tasks.

Interviewees will thus be asked if they performed any type of physical activity. Intensity as well as frequency of the effort will be taken into account. This will not be done through direct measurements but it will rather be based on the declaration on the individuals, with all the subjectivity that this may entail.

7.4 Description of the measure and the instrument

Once the meaning and coverage of the concept under study is appropriately delimited, it is necessary to describe the instrument selected in order to have the health issue measured. The range of measures that will be obtained must also be delimited, that is the results that will fulfil the requirements of information in the area being considered (Detailed information on criteria to be considered for the selection of the instrument is provided in chapter 3).

It is important also to explain what is the linkage or proximity between what it is really being measured and the concept defined *a priori*. For instance, in a module on chronic condition what it was aimed to measure is the prevalence of some chronic diseases but in interview surveys the respondent is asked if a doctor ever told him that he was suffering from some illnesses. This is thus only an indirect estimation.

7.5 Indicators

The International Institute for Sustainable Development (<http://www.iisd.org/>) gives a definition for ‘indicator’: "An indicator quantifies and simplifies phenomena and helps us understand



complex realities. Indicators are aggregates of raw and processed data but they can be further aggregated to form complex indices." Thus, an indicator is a quantification of a measure.

Additional readings about the concept of health indicators and their role in the management of public health programmes can be found in the literature (12-17).

An Interesting website on indicators used in Canada is also available:

<http://www.statcan.ca/english/freepub/82-221-XIE/free.htm>.

More specifically, health indicators can be defined as quantitative measures chosen to reflect the health status of the population or to represent how well a health system is performing. By means of health indicators, the level and change in community health and in health system performance are judged.

The selected indicators must summarise the wide range of information given by the survey/instrument and fulfil its objectives. The instruments have to be such that they allow these indicators to be computed.

Several classifications of indicators exist:

- Classification of WHO's HFA by the Year 2000 strategy
- Classification by WHO for managerial process for national health development
- Classification for monitoring the European Regional strategy of WHO
- Classification of UN Statistical Office
- OECD list of health indicators

Three levels of indicators are usually proposed:

1. Indicators associated with the health status of persons and populations in a given area
2. Indicators related to physical environmental conditions having a more or less direct bearing on the health status of the area under review
3. Indicators concerned with health services and activities directed to the improvement of health conditions

8. DEVELOPMENT OF THE INSTRUMENT

It is essential for the potential users to understand clearly in which context the instrument has been developed and adopted. A literature review should thus be conducted with a view to answering the following questions:

- What are the most important underlying concepts and what is the public health relevance of the domain investigated?
- How was the measurement considered here performed in the past in either specific or



general population health surveys?

- Who proposed the instruments used in the past (give the exact bibliographic references)?
- To what extent have those instruments effectively been used, in which surveys (give some examples of surveys with exact references)?

An inventory of the health surveys performed in Europe is available (<https://www.iph.fgov.be/hishes>). The questions used in those surveys are also available on the same website together with a translation into English. This inventory provided a good opportunity to evaluate the Health Surveys in the European Union (18;19).

An example of such a detailed description is the Euroreves report “Selection of a coherent set of health indicators” (20); this document is available on the website of the European Commission - DG Sanco:

http://europa.eu.int/comm/health/ph_projects/1998/monitoring/monitoring_project_1998_full_en.htm#3

Other examples can also be found in the manuals of some widely used instruments such as the SF-36 Health Survey module (21), the SCL-90-R symptom checklist (22) or the users’ guide for the General Health Questionnaire (23).

Such an inventory should be complemented by a short review of the validity of each of the instruments used in the past: were the instruments developed successful in collecting valuable data? Did they effectively measure what they intended to measure? What were the results of the test-retest reliability checks? Has a standard been defined (independent source of information such as a register by example) and have the data from health surveys been compared with this standard?

It is important to understand how far the instruments used to measure a particular health concept or phenomenon (such as tobacco consumption, for example) have been progressively replaced by others. If different instruments have been used over time, the rationale behind such an evolution should be explained: is it because the new instruments provide a better measure of the same construct or is it because the concept behind the measurement evolved over time?

Was the measurement always separated in a specific instrument or was it included in a generic instrument such as the Sickness Impact Profile (SIP), the Nottingham Health Profile (NHP) or the Short Form Health Survey (SF-36)?

8.1 Description of the instrument

If the instrument proposed is new, a detailed description on how it was designed should be given:

- How was the decision process organised as far as the content of the instrument is concerned?



- How were the concepts integrated in the design of the instrument?
- What are the important issues that have been considered?
- What are the important problems that have been faced in the design of the instrument and how have those been solved?
- How many questions have been included and why?
- What is the potential for comparability between different cultures?

An example of such a description of the construction of a new instrument can be found in the Euroeves report “Selection of a coherent set of health indicators, phase II” (26); this document is available on the website of the European Commission - DG Sanco:

http://europa.eu.int/comm/health/ph_projects/2000/monitoring/monitoring_project_2000_full_en.htm#3

Whether the instrument is new or old, it is necessary in any event to provide the detailed characteristics of the instrument: what is measured and how is this achieved? The same holds true if an existing instrument is modified (i.e. if a list of chronic conditions is extended or to adapt the questions on health consumption to better fit health care delivery characteristics).

8.2 Quality evaluation of the source instrument

This section discusses the quality evaluation of the instrument in the source language. After the instrument in the source language has gone through the quality evaluation, it will be translated to the target languages. If there is any doubt whether the quality evaluation in source language is sufficient, the quality evaluation should be redone for the instrument after it has been translated to the target languages.

The quality evaluation is a process during which the reliability and the validity of the instrument is assessed. Each step of the evaluation should be documented and made publicly available, i.e. preferably published.

From now on, the instrument is referred as questions.

8.3 Critical review of the questions

After the preparation of questions is finished, the team who have prepared the questions should fill in the questions themselves to see if they can answer all the questions without any problems. If the team members do not find any problems with the questions, a number of colleagues/family members/friends are asked to answer the questions and report any difficulties. Usually, the biggest problems with the questions are picked up during this process, which does not cost much and is fast to conduct.



When the questions have passed this critical review by colleagues/family members/friends, the actual pre-testing of the questions can be planned and conducted.

8.4 Pre-testing

During the pre-testing, the questions are studied from the respondents' point of view. The clarity, comprehensiveness and acceptability of the questions are tested (27;28):

- *Clarity:* Do respondents understand questions correctly?
- *Comprehensiveness:* Are the words/terms used in the questions known by all the respondents? Are all the response alternatives clear and unequivocal for the respondent? Are all required response alternatives listed? Is the question reasonable and is it really needed? Is the length of recall period feasible?
- *Acceptability:* Are questions ethically and morally approved, i.e. are questions not too sensitive? Do questions affect privacy? Is the respondent's burden acceptable?

The required number of subjects for the pre-testing is somewhere between 25 and 75. Persons selected for the pre-test should have the same background profile as the target population of the survey (27;29;30). The interviewers used in pre-testing should not solely be top professionals but preferably range from professionals to beginners. The top professional interviewers may not reveal all shortcomings of the questions due to their high experience which can compensate some problems related to the questions (30).

8.5 Conclusion

Quality evaluation of questions is done to ensure that the results obtained are reliable and valid. It is recognized that pre-testing and validation of the questions are time consuming and expensive processes but nevertheless they form an important part of the question development. To ensure at least the minimum level of reliability and validity of new questions, a pre-testing should be conducted using the most appropriate method for the questions taking into account the financing available.

The reliability and validity of question should be evaluated. If the validity cannot be measured against a "gold standard", it should be done at least against one other data source. In cases where new questions are planned to replace already existing ones, they should always be validated against the existing questions.

Pilot testing can be left to the survey organizer to test the question(s) in the context of the survey design and the complete questionnaire.



9. GUIDELINES FOR TRANSLATION PROTOCOL DEVELOPMENT

9.1 Introduction

The aim of translation guidelines is to assure the technical, linguistic and conceptual equivalence of health interview questions used in comparative multi-lingual survey research. This 'Ask-the-Same-Question (ASQ)' approach is relevant to international surveys as well as to inter-cultural studies within a given country. The original instrument and all translated versions are expected to 'capture' a particular phenomenon in the specific target populations with consistent reliability and validity. Otherwise the comparability of data collected is not achieved, and the validity of conclusions drawn from the study results will be compromised.

Standardized procedures are needed for the translation process as well as quality assessment of the translated instruments. Translation has to consider linguistic subtleties (e. g. semantic or lexical ambiguity) as well as differences in cultural background in order to avoid misunderstanding. Evaluation procedures need to assess both quality of translation and quality of instrument performance in the translated version and respective target populations.

The aim of this chapter is to provide an overview of existing translation guidelines and protocols developed in previous multi-lingual studies for comparative health assessment. Recommendations for the translation protocol development process will be based on the best available evidence, existing resources will be identified, and controversial / unsettled issues will be discussed.

The end result at this stage will be the translation from a source language to one or more target languages. The source will usually be in English. However, because an expert can hardly develop any valid instrument except in his own mother tongue, the original source language could in fact be any European language.

The present chapter is based on the assumption that a “brand new” instrument has been developed. Nowadays, the general situation is that various established measures exist and possible new ones must build on them.

In fact, when an instrument is proposed, it has frequently already been used in some settings. A preliminary step consists thus in verifying where it has been applied and if any translation procedure has already been performed. Where that is the case, the quality of the translation process should be verified.

9.2 Approach to the translation procedure

There is no 'gold standard' on how to proceed as evaluation studies dealing with the problem of multi-lingual survey research are scarce and different studies have very different needs (43); see also the website of LE et al. <http://latino.rcm.upr.edu/spantran.pdf>.



The most commonly cited approach to the design of a multi-lingual survey instrument is translation from a source language to one or more target languages (43). In this case, a set of unequivocally phrased questions in the source language has to be already worked out and accepted by all national coordinators represented in the project steering group (43;44). Furthermore, the group of national investigators has to agree on the source language (e.g. English) and a set of target languages. A complete inventory of target languages needs to be taken. The selection of target languages depends on (a) the official language(s) of participating countries, and (b) the decision to include within-country minority populations who do not speak the first official language(s).

As an alternative to the source-to-target approach, a multi-lingual survey instrument could be developed using an in parallel design (43). For instance, in the annual Eurostat social survey on Statistics on Income and Living Conditions (SILC), current practice is to provide members with a concept definition of each question (and answer), but the actual wording of the questions is left to their own discretion.

Specific recommendations relate to countries that share a main language, such as German for Germany, Switzerland, Austria or English for the U. K. and Ireland.

To conserve resources and render the translation process efficient, a split translation approach and joint translation process referred to as harmonization has been suggested (44;45). This means that countries sharing a first language appoint one translator each to translate part of the instrument. A common protocol for the conduct and documentation of the translation, review and adjudication steps is worked out with the overall aim to agree on one final version that accommodates input from all countries.

With either approach, it is mandatory to have worked out and to agree upon the concepts of health that are to be measured in the survey (see chapter 2).

10. IMPLEMENTING THE INSTRUMENT IN THE SURVEY AND PROCEDURES FOR ANALYSIS

10.1 Introduction

Implementing a specific instrument in a survey involves various considerable tasks. The potential users should be provided with all the necessary technical information for an effective and correct use of the proposed instrument, including details on:

- data collection method
- training for interviewers
- response rate
- data entry procedures
- data management phases



- data analysis and reporting.

These technical guidelines should take the form of a *User's Manual*. The items to be covered in such a manual are described here in detail.

The User's Manual should include information related to three main phases: the data collection on the field, the data entry and management, and the data analysis and reporting.

10.2 Field data collection

The choice of how to administer the questionnaire needs to be considered carefully, as different **data collection methods** may produce different results, and the instrument used in a self-completed questionnaire may not be completely identical to the one that should be used in a face-to-face interview, for instance.

The different techniques that can be used in a Health Survey are, in particular: *self-administered* (by post, internet or with the presence of a researcher), *face-to-face* (Computer Assisted Personal Interview-CAPI or Paper and Pencil Interview-PAPI), and *telephone interview* (of which the most common type is the Computer Assisted Telephone Interview - *CATI*).

The list of advantages and disadvantages for each technique presented in Table 6.1 may be useful to assist in the choice of the most appropriate data collection method (52).

If the instrument to be implemented requires strict rules about the data collection method to be used, these should be described in detail in the User's Manual together with the reasons why these rules should be followed carefully. As an example, the SCL-90-R symptom checklist (22) recommendations indicate that it can only be administered through a self-completed questionnaire (paper and pencil or on-line).

Other modules may have less strict requirements regarding the type of data collection method. In this case, or when the survey is composed by different parts using different techniques, indications should be given in the User's Manual about the best way to administer the questions. This will depend on:

- the nature and the purpose of the study;
- specific recommendations related to the instrument (for example if the questions include predominantly delicate matters, then it would be more advisable to use a self-completed questionnaire);
- characteristics and needs of the respondents: it is crucial that the participants to the survey remain interested and cooperative throughout the whole interview, understand the questions in an univocal way and that they receive the appropriate support during the completion of the questionnaire;
- resources available (both in terms of funds and skills);



- time constraints.

10.3 Data entry and data management

As entering, checking and cleaning the data is an extremely delicate phase, it is important that details are given to the users on the main steps to follow in order to have the data as 'clean' as possible.

Data entry

The system for performing data checking, cleaning, and recoding should be planned from the beginning, and it should be universally agreed and understood by all researchers involved in the study and be well documented. In the **data entry phase** all individual answers from the questionnaire should be entered in the data file according to the values that respondents or interviewers recorded in the questionnaire. It could happen, though, that the value to be registered is not so easily identifiable. It is thus important to supply in the User's Manual any useful specifications on how to deal with these situations. In the case of the SF-36 Health survey module, for instance, a set of rules were identified (21):

- if the respondent chose two adjacent response categories, the value of one of the two, randomly selected, should be recorded.
- if the respondent chose two nonadjacent response categories for the same question, a missing value should be recorded.
- if the respondent chose three or more response categories for the same question, a missing value should be recorded.
- If the respondent wrote the answer instead of circling the chosen answer category, then the value should be recorded as if the response had been circled.

Recoding

An important phase that follows data entry is the **recoding of the responses**, which allows the user to have the values needed for the calculation of the scores. The first step of this process is to verify whether there is any question with **out-of-range response values**. These are values lower or higher than the minimum and maximum threshold value determined for that specific question. If the problem is not due to a data entry error, it is necessary to give advice on how to deal with it, for example give instructions that these out-of-range values should be changed into missing values. Such instructions should be provided in the User's Manual and each change done to the original data should be well documented.

If the instrument involves a **scoring system** to build synthetic indicators, it is important to give extremely clear and detailed instruction on how to calculate those scores, and on the characteristics and use of the different indicators that, in certain cases, can be produced.



Examples on this can be found in the manual of the SF-36 Health Survey module (21), or the SCL-90-R symptom checklist (22) or the users guide for the General Health Questionnaire (23).

If appropriate, the issue of licence/copyright for the scoring and/or analysis procedures should be also mentioned in the User's Manual.

Item non-response

Item non-responses occur when only part of the information related to a specific unit is missing. This happens, for instance, when the interviewer forgets to ask or record the answer to a question or when the interviewee is not able or does not want to answer to a specific question. This kind of non-response has to be carefully considered. In particular it is important to understand the possible underlying mechanism determining the item non-response, which can be related to the questions of interest.

If any question in the proposed instrument is more likely to induce such a problem, this should be mentioned in the User's Manual, together with potential solutions to possibly reduce the specific item non-response rate.

There are various methods which can be used to reduce the bias of the final survey estimates resulting from items non-response. Advice should be given on the best technique to be used for the specific instrument or on the advantages and disadvantages related to the different methods that are available. It is particularly important to give all the detailed instructions on this matter especially when a score has to be built.

A method commonly used is **imputation**. It consists in assigning substitute values to the missing data, to be able to restore the complete data matrix (58;59). Some researchers (60) believe that the multivariate nature of statistical surveys, in which any variable could potentially present a missing value, justify the use of imputation in order to reduce the bias due to item non-response in the estimates and to have a complete data set. In any case, the possible disadvantages of imputation need to be considered, and it is necessary to provide detailed instructions on when imputation is suggested, on the method to be used together with the best software to be used to apply this method.

The literature suggests several imputation methods for items non-response, which can generally be grouped into three categories:

- *deductive methods*, the imputed value is deduced from known information or relations;
- *deterministic methods*, repeated imputations for units with the same characteristics always produce the same imputed values;
- *stochastic methods*, repeated imputations for units with the same characteristics could produce different imputed values; they are characterised by the presence of an aleatory component (residual), corresponding to a probabilistic scheme associated with the chosen imputation method.



The impact of the item non-responses on the building of scores and indices should also be mentioned.

10.4 Data analysis and reporting

The set of questions included in a specific instrument is usually aimed at the construction of a specific set of **indicators or indices** rather than at the analysis of each of the single questions. If this is the case, detailed information should be provided in the User's Manual on how to use the collected data and produce the indicators. Something should also be mentioned about the treatment of outliers.

For instance, height and weight are measured in the population to build the Body Mass Index, a composite index commonly used to measure body composition. For the sake of international comparability, the formula to calculate the BMI (Kg/m^2) has to be clearly explained, together with the cut-off values used to classify the population as obese or overweight should be provided, and appropriately referenced. Instructions on how to deal with outliers are also advisable.

Before anyone starts working on the dataset, the **statistical methods** to be used for the analysis should also be agreed on. Even if several packages usually yield similar results, it is important to verify if they make it possible to take adequate account of the survey / sample design and the weighting factors in order to produce correct estimates and variances. Here is a non exhaustive list of such packages: SAS, SUDAAN, StatA, R and Spss (V12 and higher).

In addition, when joint / European publications are considered, details should be given on how data should be analysed and presented

- which are the basic tables to be reported
- how the variables or indicators built for the specific instrument should be categorised
- which background variables such as age, gender, education income, ...) should be taken into account.

All those points are important for obtaining comparability.



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