Epidemiological Survey

Handicap International – France
2006

Patrick JULLIEN
Technical Adviser on Epidemiology
Handicap International
14 avenue Berthelot 69007 LYON
Tel: 00 33 (0)4 78 69 79 60
E-mail: pjullien@handicap-international.org
Introduction ............................................................................................................................................... 5
What is an epidemiological survey?
- Why do it?
- How and when should the survey be carried out?
- Who should do it?

Ethics ................................................................................................................................................ 6
- Things to think about
- Why? How?
- Deontology

A concept: Handicap Creation Process (HCP) ...................................................................................... 8

Creating a survey

Stage One: the preliminaries

Defining the objectives: .......................................................................................................................... 9
- What do we want to know?
- About which population?

Collecting existing data - do the following already exist: ................................................................. 10
- Answers concerning this or another population?
- Known confounding factors?

Survey feasibility ..................................................................................................................................... 11
- Feasibility?
- Funding?

Terms of reference: .............................................................................................................................. 12
- The principle
- Provisional and definitive terms of reference
Stage Two: the preparation

Chose a survey method:
- experimental or « quasi-experimental» .............. 14
- observational .............................................. 15

Choose the reference population .................... 16

Define the indicators

Define the risk factors

Draw up an analysis plan .................................. 17

Design the questionnaire .................................. 18

Develop the survey plan .................................. 19 and the coding

Population information .................................. 20

Choose the protocol for collecting data

Select and train people to carry out the survey

Plan logistics and budget ......................... 21

Stage Three: the testing

Testing the survey ........................................... 22

Stage Four: the survey

Quality control of data .................................... 23

Recording questionnaires ............................... 23

Checking the representativeness of the sample 24

Analysing the data ........................................... 24

Stage Five: the results

Communicating the results ............................. 25

Bibliography ................................................. 26

Example surveys ........................................... 27
Introduction

What is epidemiology?
On its simplest level, epidemiology is the statistical understanding of epidemics. It is the understanding of health events and all the health characteristics of a given population, including the disabled. It is also the evaluation of techniques, procedures and programmes designed to prevent disease and incapacity or their consequences.

Principles of evaluation or surveying

Why carry out a survey?
- Prior to a project: to establish a clear picture of and understand the extent of a situation or phenomenon.
- During or after the activity: to evaluate the effectiveness of the intervention and changes to the situation by comparing results from before and after the intervention.

It is important to convince others, and maybe even oneself, of the quality of a project. In general an evaluation makes it possible to see if the project’s objectives have been attained, to highlight any errors, to correct these and diffuse the methodology.

Where no serious evaluation takes place, two extreme situations can be imagined:
- The project is of an extremely high quality but this cannot be proven. It is even possible that the quality of the project cannot be seen if the population’s health deteriorates. Without the project this deterioration would have been worse but nobody knows this. We cannot publicise this project.
- The project is of poor quality: with the same approach we will reproduce the same mistakes in another project. The results may have been harmful or catastrophic but we will never know. Finally, if, despite the project, the population’s health is good, we may think it is thanks to our project.

When should we carry out a survey?
An evaluation should be planned right at the beginning of the definition of the project.
- during a search or capitalisation to validate a hypothesis,
- prior to a project in order to better understand its context,
- during an intermediate or final evaluation to correct, show, diffuse and reproduce.

Example: During the analysis phase, a causal tree will have shown possible causes (lack of transport). An epidemiological survey will confirm and quantify the problems (number of people concerned, distance to be covered, places to benefit).

How to carry out a survey?
An epidemiological survey will obtain numbers, rates and quantative data. A sociological survey will obtain qualitative results.

These two types of surveys are complementary. Together or separately they can provide answers to many questions.

Sociological studies, are also scientifically based but rarely provide numerical data. They show trends, generalities and major concerns. They are used in different situations and answer different questions. They are not dealt with in this document.

Examples:
- The causal tree helps establish what the population or its representatives see as a priority: access to healthcare. The objective of the project is to meet this expectation. A focus group will evaluate the situation both prior to and following the project. The results are therefore measured on people’s word.
- In a dangerous zone it can be difficult to find a representative sample in the field. A meeting with representatives of the population can be sufficient to bring to light the major concerns.
Who creates the survey?
An epidemiological survey should be carried out by two people “a project manager and an epidemiologist”. An epidemiologist alone is not capable of fully understanding the key factors affecting the area in which the survey is carried out. A field worker with no knowledge of epidemiology is not capable of employing the methodology necessary to produce an in-depth analysis.

The association of two specialists helps avoid drawing hazy conclusions which cannot be validated.

Ethics
“Primum non nocere”: First do no harm; as if that was easy.

The outcome of controversial research programmes (Cameroon or the Amazonian rainforest) should make us vigilant. The ethical approach is all the more complicated as it depends on the cultural approach. Who can or should give their consent? The individual, the family, the group, the village headman? Who do the raw materials (the data) and the ensuing results belong to?

Should the multitude of different national customs and rights be added up, averaged out or differentiated between in order to find the right path? In terms of respecting laws and traditions the rule of maximum constraint (the sum of all constraints) should apply.

Example: Handicap International is an association governed by French law. A survey in Somalia (written law non-existent or non-operational) should respect both traditional Somali law and French written law. The use of any other approach must be justified and justifiable in all circumstances.

Good faith is not sufficient as a shield to protect populations from us. On the one hand there is aggressive interventionism (or even hygienism) which leads to all kinds of abuses and on the other the attitude of blind neutrality in which the causes are no longer taken into consideration. Should we offer healthcare to people against their will, according to standards which are not their own? Should we respect their wishes and acts without condition, so they do not reject us, and thus can allow us to take action?

Ethics: Why? How?

The usefulness of the approach:
"You must find information to make decisions" Stufflebeam, 1967.

Before carrying out any survey it is important to answer some general questions, notably:
What will we do with what we find? Who will this help? For which action? For which beneficiaries? Is the survey helpful for a population, a government, an organisation? Can the results be used for or against the population?

The money and energy spent on a study should be weighed up against these considerations.
Deontology

It is impossible to cover all the "good practices" which should govern any epidemiological survey with the main principles summarised here. Those who wish to do so should refer to the "Guide to deontology and good practices in epidemiology" (bibliography).

Free consent and informed consent

Anybody should be able to access comprehensive information concerning the survey, its objectives, its protocol and any possible side effects. Anybody should have the right to refuse to participate or stop their participation at any moment during the survey without any negative consequences.

Side effects:
In a cohort survey (page 19), the negative effects of being exposed to a risk factor, or the positive effects of being exposed to a protection factor (awareness campaign) should be considered before they are applied.

For example, it is impossible to envisage testing a new treatment against a placebo if an effective treatment already exists. The testing should be carried out against the treatment already in use. In another example, a mine awareness campaign cannot be compared to the absence of an awareness campaign in a similar population. It would however be possible to compare two awareness campaigns to find out which is the most effective.

If an intermediate evaluation has been planned (in certain statistical conditions), and the results prove a treatment is effective or toxic, the testing or observation should be stopped to allow everyone to benefit from the "good" treatment.

Protecting participants:
The safety of each participant is a priority which outweighs the potential advantages the survey could offer to the population. People cannot be "sacrificed" to carry out an experiment.

Confidentiality:
All data will remain confidential and cannot be used to the detriment of any person. No personal information will be diffused or made accessible to a third party.

Personal data: "Any data, in any form, which makes it possible to directly or indirectly identify the physical person to which it pertains."

Or, if a piece of information makes it possible to identify a person directly or through its use in conjunction with other pieces of information, it is considered to be personal data. If collecting such information is necessary it should be protected against misuse or being used for any purpose other than that of the survey or the database.

Potential referral:
Anybody requiring so should be able to be referred to a competent healthcare or rehabilitation provider without any false promises being proffered during the survey concerning this care.

Communicating the results (see also “the results”, page 25):
Everybody should know who the results are destined for. Anybody should be able to obtain the results on request.
An example of concept: Handicap Creation Process (HCP)

Social participation is a permanent individual goal. A person’s disability is the result of personal and environmental factors and can change.

The evaluation of an individual or a group should therefore be based on:

1. measurement of the initial living conditions,
2. measurement of the personal and environmental situation

The project will be constructed on this basis and evaluated using precise indicators and either continuous, periodic or final assessment through:

3. measurement of the precise results of the project on the personal and environmental factors
4. then measurement of the effects of the project on the people’s social participation

The same tools (and their indicators) will be used to measure on the one hand stages 2 and 3 and on the other stages 1 and 4. Any validated comparisons between these stages will make it possible to prove the findings of an evaluation.

---

Potential measuring tools:
- for social participation: "Measure of life habits" (MLH)\(^a\)
- environmental factors: "Measure of the Quality of the Environment" (MQE)\(^a\)

---

a [http://www.ripph.qc.ca/instmes.htm](http://www.ripph.qc.ca/instmes.htm)
Notes on the results and effects:

**The results:**
These are directly linked to the projects' objectives:
- build a bridge, create an adapted access
- improve the general public's perception of disability,
- improve access to a service,
- produce prosthesis
- train technicians,
- etc.

**The effects:**
These are the consequences of the results on people's lives:
- people's satisfaction,
- to be able to move around town,
- to find employment
- to assume familial or financial responsibilities,
- etc.

HCP is just one of the existing concepts concerning disability. The existence of other concepts with varying degrees of similarity to HCP must also be acknowledged.

- The *International Classification of Functioning, Disability and Health (ICF)* belongs to the World Health Organisation's (WHO) family of classifications. In the WHO's international classifications, health status is recording according to the ICD-10 (International Classification of Diseases 10th revision). ICD-10 and ICF are therefore complementary.

- Amartya Sen's concept of capability states that "the capacity (or capability) of a person defines the different combinations of functions he is able to execute". The contribution of A. Sen is to differentiate between the possibility of being and doing (the 'capacity' of the individual) and what the individual has been able to do and be (the actions he has carried out and the things he has achieved).

In all these concepts the physical and social environment is considered as an essential factor for understanding disability.

Before any survey it is worth considering which concept (or concepts) should be used to deal with disability. The creation of the survey will follow on logically from this. A round table or training seminar will help the creators of the survey to think about its meaning.
Defining the objectives

What we want to know:
The exact questions to be asked. It is important not to try to answer too many questions with any one survey. The simpler the object, the better the chances of obtaining clear, usable results.

Example: Is the mine risk education (MRE) project effective? Are the messages understood, learned, retained, and do they lead to a change in behaviour? Are the amputees satisfied with their prosthesis? How long will the prosthesis last? Which zones are the worst-affected by lymphatic filariasis? How much more autonomy do the beneficiaries of microcredits have? How dependent are the elderly?

Target population:
This is the population that interests us and that concerned by the results of the survey. It could be children aged 5 and under, women, all inhabitants, people undergoing treatment, etc.

Source population (or sampling frame)
This is the population for which we have basic data (list of names and addresses, geographic dispersal, age, gender etc.) and which provides the sample. The results always concern this population. The target and the source population are not always identical. In a best case scenario they should be, however we do not always dispose of as much data as we would like.

Example 1:
We want to question people aged 60 and over, living in France: target population.
No comprehensive list of all these people exists or is accessible, we will therefore take a sample of people aged 60 and over, registered on the electoral roll: source population.

All the people in the target population are not registered to vote, particularly immigrants. We can estimate that the majority of this age range is registered and the (selection) bias is acceptable. In a country where registering to vote is obligatory, the two populations (target and source) are almost the same.

Example 2:
We want to establish a clear picture of disability in Sierra Leone. The target population will be all disabled people likely to want to go into the town centre. No data concerning the source population exists, except an approximate total of inhabitants in the region. The methodology will have to be adapted with a limited census taking place at the same time as the survey.
Collecting existing data

At this stage it is useful to conduct a bibliography search for existing survey results.

Are there already answers for this population?
A study may already exist and be used as a reference. However any comparison must be made cautiously and validated epidemiologically.

In order to compare two studies on the same population the conditions for collecting data must be exactly the same (population, sampling, environment, risk factors, health indicators etc.) Only the risk or protection factor studied can be different as this is the purpose of the comparison.

There is no ideal situation apart from so-called experimental studies. We can therefore accept the differences between the two studies as long as there is sufficient justification.

Are there already answers for another population?
The same kind of study or one with a similar approach can provide results. It is rare to have absolutely no comparable elements. We can glean ideas from, or use the reference data. If the prevalence is known it can be used as the basis for the sample calculation necessary for a new survey.
Biases or confounding factors can be found in preliminary documentation.

Prevalence:
This is the measurement of the frequency of a disease at a given moment T or after a lapse of time. It is the proportion of new cases and old cases still ill within the total population.

Calculating the sample:
It is useful to know the expected prevalence (P), even approximately, as the number of persons to be questioned in a survey depends on P according to the formula: \( n = \frac{1.96^2 \times P \times (1-P) \times D}{0.05} \) where D (design effect) is equal to 1 if the sampling is individual and random and higher than 1 for a cluster sampling.

It is possible to confirm by calculation that the further the prevalence rate from 0.5 (50%), the larger the sample must be. If we ignore the prevalence, we must choose the least favourable hypothesis ie. P = 0.5.

Bias (of the selection or the classification):
Due to poor sampling.

Selection bias: There is a discrepancy between the target and the source population or a discrepancy between the source population and the sample.

Classification bias: Individuals are incorrectly classified as being exposed or unexposed (to the risk factor) or as diseased and not diseased.

In both cases the picture given by the sample is distorted and cannot be corrected through analysis.

Confounding factor:
A confounding factor leads to bias in the perception of the relationship between the exposure (the factor being studied) and the disease (or the result measured). It is brought about by a third factor linked both to the exposure and the disease (or the result). It changes the estimation of the strength of the link sought, independently of the exposure concerned by the survey. The phenomenon exists in the source population as well as the sample.

The confounding factor can be taken into account during analysis in order to correct it, as long as it is known about and measured.

For example, two-wheeled vehicles are involved in more accidents than cars. The former are more often used by young adults and young people have more accidents than older people. Age is the confounding factor in the link between two-wheeled vehicles and accidents. To rectify the problem we can adjust the results concerning age (by stratification or other methods).
Feasibility of the survey

Feasibility:
Is it acceptable or socially or logistically possible to look for certain pieces of information? For example, is it really possible to find out the number of Down syndrome children killed at birth in Afghanistan, or the weight/(height²) ratio of child soldiers during the Sierra-Leone conflict?

Funding:
The budget has an impact on how the survey is carried out, the methodology, logistics, records etc. It should therefore be estimated prior to the survey in order to decide what kind of survey to use and to what extent, even if it has to be modified later. The scientific quality of the survey is not directly proportional to the amount of money spent. Limited objectives can often give a sufficient amount of information if the methodology is rigorous.

Funding and methods:
Choosing a prospective cohort study (page 15) for a rare situation and following a cohort over three years requires a large sample and considerable human resources. This will provide a lot of information and will be expensive.
Choosing a case-control study (page 15) for an easily measured event will be less expensive.

Funding and data collection logistics:
Carrying out a survey across the whole of a country with difficult access will cost more than conducting the survey in a zone which is accessible on foot all year round.

Funding and data entry:
Having one general secretary enter data from questionnaires will be cheaper and less efficient than double data entry performed by two members of staff trained to this purpose, using adapted software with automatic data entry checks. Automatic data entry using a scanner requires more means and will be quicker.
Terms of reference

The principle:
Essentially the terms of reference (TR) should make it possible to define the objectives. They are fixed by the client (the person or the team which has requested the survey). They have the same framework as other projects but have some particularities.
The TR can be defined in two phases: The provisional TR are drawn up by the team and submitted to the epidemiologist and the definitive TR are the result of the exchange between the team and the epidemiologist.

Provisional terms of reference:
- Introduction and context
  These elements are used to situate the environment of the proposed survey. The political, sociological, geographic and logistical aspects can be outlined. The project for which the survey will be conducted is explained here. If they exist previous studies can be summarised (bibliography). The partnership, compulsory or optional, will also be analysed.

- Subject of the study:
  What is the study about: an action, a population. It is necessary to portray the all the known elements both past and predicted and to describe in detail the intermediate and final objectives set.

- Objectives of the study:
  Exactly what we want to know: no more, no less.

  This is the most difficult part. These objectives should, otherwise indicated, be operational targets. What do we want to do with the results of the study? Extensive and ambitious enquiries ("Find out everything about all forms of disability within a working area") are rarely carried out by humanitarian organisations and demand means. We cannot emphasise strongly enough that the more detailed and limited the objectives the more relevant, efficient and cost-effective the survey.

  The criteria to be measured can be outlined through they may have to be modified on the epidemiologist's advice.

  It is often necessary to revise the objectives several times before the survey.

- Justification:
  Why do the objectives make sense in the given context? Is there another study which can already provide some of the answers? What more can a new study offer, taking into account the costs which will be incurred? What use will it really be and for whom? Why not do without it?

- Proposed methodology
  This is just a proposal and can be fine-tuned or modified. Demographic information, a census or a known survey base may guide the choice of methodology. The epidemiologist or the survey team will provide any further information required (study population, control population, sampling frame, number of subjects required, sampling technique etc.).

  If the survey takes the form of a questionnaire, this will be chosen or written in collaboration with all those involved (at the very least the field team and the epidemiologist).

  The reference population will be chosen according to the type of study.

  The criteria for judgement (primary and secondary indicators) will be defined according to the objectives and existing references (previous studies, bibliography etc.).

  Other elements such as the right to access data and the conditions for the publication and diffusion of the results can also be defined.
• Expected results – Analysis Plan
   Defining the expected results prior to the survey makes it easier to define the objectives and other elements (judgement criteria, number of subjects necessary etc.). The expected results often provide a starting point for creating the analysis plan which must be set up before the survey is carried out.

   The analysis plan covers the treatment and statistical tests. It is the epidemiologist’s responsibility.

• Report - Restitution
   The form and use of the publication report will be detailed along with the conditions of restitution.

• The expert’s profile
   What are the essential or desirable skills should the person or team possess? Number, profiles. National experts should be given preference if they have same level of skills. A mixed team of local and "imported" members can also be effective.

   It is also possible to let the evaluating body make its own proposal according to the other elements.

• Schedule
   Gives the start date and the duration of the mission.

• Budget
   A budget proposal can be produced from the basis of the TR.

• Practicalities
   Who is going to do what? It can be helpful to formalise the delegation of roles and responsibilities.

**Definitive terms of reference:**
These are defined by the "project worker and epidemiologist" pairing through a series of exchanges.

They represent the synthesis, the moral or formal contract linking the *service provider* (epidemiologist or the team responsible for the survey) and the *client* (the person or the team who has requested the survey). They are defined using the same form.
Stage Two: the preparation

Experimental or “quasi-experimental” surveys

These surveys allow us to show the links of cause and effect.

Randomised testing or the experimental survey:
This consists of a cohort study where the exposed and the unexposed (or the beneficiaries and non-beneficiaries of a project) are determined by drawing lots. The exposure factor (risk or protection) is therefore the only element which distinguishes one group from another. The comparison between the two groups is therefore less susceptible to biases. This is the reference method. However its disadvantages and constraints (ethical, financial, prevalence) make it difficult to use.

The before and after survey:
Survey of one population carried out before the intervention and again after. In this case the investigator decides who benefits from the intervention. Once both surveys are completed a statistical comparison can be made and the results of the intervention measured.

- Both parts of the survey must be carried out using the same methodology and under the same conditions.
- The relationship of cause and effect between MRE activities and the population’s understanding is not certain as other causes (media, local organisations, spontaneous learning) may interfere. This should be taken into account.

Example: MRE (mine risk education) activities in a population would be completed with two surveys into people’s understanding of and attitudes towards mines. We could therefore measure any change.

The here and there survey:
Two comparable, separate populations, are surveyed at the same time. The statistical comparison can demonstrate the interest of the action evaluated. Once again the investigator decides who benefits from the intervention.

- Both parts of the survey must be carried out using the same methodology and under the same conditions.
- Ideally both populations should be comparable in every way excluding the intervention. This is rarely the case and the limitations of this comparison should be acknowledged and taken into account.

Example: MRE activities in a population can be evaluated ex post facto in a population which has benefited from the intervention and one which has not. We can use statistical comparison to measure the effectiveness of the MRE.
Observational surveys

Before-and-after and here-and-there surveys can also be observational. In this case the investigator does not decide (by drawing lots) who benefits from the intervention.

The cohort study:
The investigator adopts either a prospective or retrospective position vis à vis the population. He selects people according to their exposure to the intervention (the risk or protection factor), and then compares if they become diseased or not. He is therefore able to form a picture of the intervention in terms of relative risk.

Example: Are those receiving social accompaniment better integrated than others? The relative risk is positive (protection factor) if they benefit from the guidance. If there is no statistical difference the intervention is perhaps inefficient.

The case-control study:
The investigator arrives after the intervention and selects people according to their status as a 'case' or a 'control'.

A case is someone who manifests the positive or negative result we are looking to obtain or avoid. A control is someone who does not manifest the result sought.

Examples:
- The cases are people suffering from the disease which may be linked to the exposition being studied, the controls are not suffering from the disease.
- The cases are people whose economic situation has improved and we are looking for a link between this and the guidance project for professional autonomy. The controls are people for whom there has been no economic improvement.

Statistical comparison between cases and controls allows us to calculate an odds ratio which can demonstrate a significant link between the exposure (action) and the disease (result).

The cross-sectional survey:
The investigator arrives after the intervention but does not select his sample according to exposure (or the intervention) nor disease (or the benefit). The people making up the sample are drawn at random and represent the entire population. The exposed / unexposed are analysed in relation to the diseased / not diseased in the sample.

This comparison allows us to calculate the relative risk.
The reference population

We can also settle for finding the frequency of an event in the population studied. We can also compare this frequency to that of a reference population which is either the same population before the intervention or a comparable population, or the general population from which the population studied is taken.

The population studied (the cases or the exposed) is therefore compared to the reference (the controls or the unexposed). This is the only approach which makes it possible to establish a relationship, a statistical link, between the intervention and the evolution, the exposure and the disease, the project and the results.

Ideally the unexposed or control group should be identical in every way to the exposed or case group except for the existence of the intervention, disease or project.

In an experimental situation a good means of deciding who will be exposed to or benefit from project and who will not is to draw lots with people or groups from a coherent grouping (in which nothing distinguishes one from another).

Indicators to be measured

The indicators must be directly linked to the objectives, inspired by bibliographic research and then defined in detail.

Example:
In a study seeking to identify the environmental factors of perinatal risk, the indicators might be prematurity (possible definition: birth before 37 weeks), hypotrophy (definition: birth weight less than 2500g) and prenatal mortality (definition: death in utero after 28 weeks from amenorrhea or death during first 7 weeks of life).

The risk factors

A survey should allow us to establish a statistical link between a health event and one or more risk factors. As for the indicators it is therefore important to define the measuring of risk factors in detail.

Example 1: Establish the link between prematurity and smoking (20 cigarettes a day for at least 1 year or number of packets x number of years).
Example 2: Establish the link between the onset of a debilitating disease and visits to certain agricultural areas.

It is possible to replace the notion of a risk factor with that of a protection factor. The factor becomes the element we are looking to promote in order to improve health. The statistical link between the health indicator and the protection factor is analysed in the same way.
Analysis plan

It is preferable to define from the beginning, how the results will be analysed.

- Definition of classes: A health (or protection) indicator or a risk factor can be exploited continuously or in classes.

- Sequential sorting: This makes it possible to visualise the distribution of the data obtained, to understand how the participants are distributed and to group together different classes. It also allows us to obtain the number of non-responses and to spot any discrepancies.

- Cross checking data: As far as possible relevant cross checks will be carried out. An empty cross tabulation will outline the expected data.

  Warning: Interpreting a cross tabulation requires statistical analysis (for example $\chi^2$ test to compare percentages).

- representativeness checks (page 24) will also be planned at this stage.

- We may also want to adjust data due to a confounding factor (page 10), which must be introduced here in order to measure its influence.
Questionnaire

The questionnaire may already exist or can be created for the occasion.

A pre-existing questionnaire can be used for two reasons:
- a questionnaire adapted to the objectives already exists. The survey costs and analysis time will be reduced.
- we want to compare between here and there or before and after. In this case even a flawed survey can be used to make a comparison.

In both cases the questionnaire must correspond to the objectives of the survey and be as well-adapted as possible to:

- the survey situation. There are as many different situations as there are methods of preparation and implementation.
  
  **Examples:**
  - survey in a tropical region with rainy season,
  - survey in a war zone,
  - survey in partnership with a corrupt administration,
  - survey where anonymity is impossible,
  - survey requested by a highly-active social government.

- to the people concerned, who manifest the characteristics to be taken into consideration. Just try for example to question Corsicans about murder or Jordanians about honour killings etc.

  **Examples:**
  - illiteracy ⇒ no self-completed written questionnaire
  - few telephones ⇒ no telephone survey
  - participants absent ⇒ adapt survey times
  - low rate of participation ⇒ preparation, information
  - acceptability ⇒ compatible with customs

- to the investigators (page 20), the data entry (page 23) and the analysis (page 24)

The questions asked must correspond to the objectives of the survey. No more, no less. It is tempting to try to find out information about different, complementary aspects. However this risks affecting the quality of the results of the survey.

The questionnaire should be built on the imperatives established by the analysis plan. A cut-and-paste questionnaire from another survey is unlikely to correspond to the objectives.

Its content should:
- reiterate the instructions for the investigators on the first page (presentations, support, conclusion).
- include the criteria for identifying the person questioned (often useful for the representativeness checks - page 24)
- followed by the main body of the questionnaire (the questions themselves).

**Types of questions:**
There are two common types of questions:
- open-ended questions. They allow for freely given answers but are difficult to exploit.
- closed-ended questions, easier to exploit. All hypotheses must be envisaged prior to the survey (interest of the test - page 22).
Drawing up a survey plan

A survey is necessary because it is not often possible to question or measure a factor in all the population. Indeed this would require too much time and money. Questioning a representative sample (page 24) of the source population (the survey base) is therefore sufficient. The possibility of extrapolating this to the whole of the general population depends on the quality of this sample taken.

The best sampling methods are random sampling and systematic sampling. Cluster sampling and stratified sampling require special statistical consideration.

It is important to calculate the number of people questioned and apply the methodology rigorously in order to ensure representativeness.

Random sampling:
Lots must be drawn from a box or a list of names including all the people in the sample. In this way everyone has an equal chance of being questioned.

Systematic sampling:
Using a comprehensive list with the names from the source population from which x people must be taken, the first number is chosen at random (from a table of numbers of a banknote number). The pitch is determined (total number / x) and then all those positioned on the pitch from the first number are selected. This method is more practical than random sampling and holds the same statistical value. However in either case it is rare to have an up-to-date list.

Coding

Coding the data facilitates the data entry and exploitation.

The coding should be simple to reduce the margin for error.

Whole number coding (1,2,3,4,5, etc) to define the number of children is obviously better than coding such as:
- "1 child" = a
- "2 children" = b
- "3 children" = c
- etc.

The coding allows certain calculations to be made.

Coding of the type
- "from 1 to 3 children"
- "from 4 to 6 children"
- etc.

is poorly adapted, not instinctive and allows no calculation to be made.

The coding of the question:
“How satisfied are you?“:
- "a little satisfied": 1
- "averagely" 2
- "very satisfied": 3
permits no calculation to be made. The best solution is to encode the qualitative variables with qualitative codes (A,B,C,etc.) and to use this for the analysis.

Be careful with qualitative classes coded with whole numbers. There is a lot of temptation to make calculations with this data (average etc.). Though it might seem obvious, it is important to avoid this type of mistake.

If possible the questionnaires will be encoded by the investigator rather than the person responsible for entering the data. This helps to reduce the margin for error.
Population information

Although the feasibility should have already been thought about in the first stage checks (page 11), the population and its representatives should be prepared and informed in the field prior to the survey. This is not just out of politeness but also to improve the acceptability of the survey. A well-understood and well-accepted survey will be more reliable with less refusals or inaccurate answers.

Data collection protocol

The means of selecting the people to be questioned should be transparent both for the population and the investigators. The investigator should have no choice in the matter to limit biases.

The protocol should state:
- which areas to visit and which households to question,
- how the investigator should introduce himself (who he works for, to what purpose, what are their policies).
- who makes up the sample (population, age bracket, gender etc.)
- how to replace someone who refuses to participate, is absent or does not meet the defined criteria.
- etc.

If the sampling is to take place in the field, the investigator should know exactly how to select the people to be questioned. Where should he go to begin? Which direction should he take? Which household should he stop at? Who should he question? Where should he go when he leaves?

If the investigator finds himself at a house with a closed door, he needs to know if he should come back an hour later or the next day, or if he should continue to the next household, the first on the right or left or on the next floor.

If the first member of the household selected refuses to reply, should the investigator ask another member of the same household with the same selection protocol or should he go directly to the next household etc.?

Choosing and training the investigators

There are often two solutions for choosing investigators. Either local, not necessarily professional, investigators; or professional, not necessarily local, investigators.

Professional, non-local investigators will be more familiar with survey procedure and more rigorous in applying it. They will accept more easily the idea of quality control (page 23). They will be less susceptible to pressure (emotional or social). Training will be quicker.

Local, non-professional investigators will have a better understanding of the culture, language, acceptability problems and the optimal application conditions for the survey. They will be better placed to adapt to different people and ensure participation. Their intervention will cost less (compensation, travel, skills).

The choice will be made according to the situation. Local investigators are often favoured and require more intensive training if they have never participated in a survey.
Logistics and budget

These two aspects need to be defined at the same time as the other parts of the preparation.

Planning specific logistics for the survey:
- bibliography
- preliminary meetings
- trips
- stationary and small equipment
- printing questionnaires
- training investigators
- salaries and allowances
- computer hardware and software
- printing and diffusion of the results (trips)
- restitution seminars
- etc.

Planning the budget:
The protocol and logistics have an impact on the budget. It is important to frequently balance the total budget and its allocation to different logistical elements.
Stage Three: the testing

Testing the survey

This stage is of major importance as any flaws in the planning of the survey should, logically, come to light at this point.

Testing should be carried out to ensure that all aspects of the survey (logistics, finance, questionnaire, investigator training, data entry and analysis) are ready. This test may be carried out using a few questionnaires (10-20), but other aspects should be tested as for the real thing. The test should take place in exactly the same way as the survey.

Ideally it will involve a population which is not affected by the survey but which is similar in every way to the population concerned. If the test takes place within the same population it is important to have as little contact as possible with the people involved in the real survey (at the very least those questioned in the test should not be questioned again in the survey).

It should be possible to modify any element of the survey after the test. The investigators, the population and its representatives and the data entry workers will also be able to help modify the survey.
Stage Four: the survey

Quality control

It is necessary to provide tools for checking the questionnaires with the people questioned. Investigators should be found to do this.

We can:
- randomly select a certain number of questionnaires and check their validity with the people questioned in person or by telephone. The check may cover the whole questionnaire or just certain key questions
- to draw up statistical comparisons between the results of different investigators. If the dispersal of the questions is too varied further, more detailed checks may be carried out.
- to check the internal consistency of the questionnaires.

Examples of internal consistency checks:
- The investigator is unaware that a pathology or incapacity exists in certain people or certain age brackets (he will have recorded sequels of filariasis in a newborn).
- The duration of an illness or the recovery period may be too long or too short and therefore suspicious.

Recording the questionnaires

This task should be integrated into the design of the paper questionnaire.

A wide variety of softwares exists for this kind of task (Excel, Access, Modalisa, SPSS, Epi-Info).\footnote{Epi-Info is a collection of free reference software for field epidemiology:}

There are several options for efficient data entry:

- **The data entry form** should have a similar appearance to the questionnaire. The chronology of the questions, their titles, the position of the answer box and the method of answering (text, tick box, yes/no answer) should be the same.

- **The coding** should be done before the data entry. It can be carried out by the investigator or another person.

- Open-ended questions will either be interpreted by the investigators according to pre-defined, common criteria or by one single person.

- **On-line data checks** avoid the entry of impossible data.

- Each questionnaire should be saved using **double data entry** performed by two different people or one person over two different sessions. The comparison of two data entry files make it possible to correct the inevitable data entry errors (it is unlikely that the same error will occur twice). Double data entry with correction is therefore a good measure of quality. Some software offers this option and produces a report comparing the two files (Epi-Info for example).

- **Sequential sorting** (page 17) sometimes avoids data entry discrepancies.

\footnote{Epi-Info 6.04d works in a DOS interface and is not very user-friendly but is very powerful and very small. It can be used in conjunction with Epi-Data for data entry in Windows.  
Epi-Info 2002 (and subsequent versions) works with Windows, it is bigger (64 Mo to download) but more user-friendly (Windows with mouse and classic interface).  
For downloads: EpiConcept (http://www.epiconcept.fr) or CDC (http://www.cdc.gov/epiinfo)
Representativeness of the sample

This is an indispensable stage.

The question we must ask ourselves is: “Is my sample representative of the source population?”

It is impossible to state this with absolute certainty. However the accumulation of several elements may support such a statement. For example, if we cannot find any significant statistical differences in age, gender and area of residence, between the source population and the sample, this is strong evidence of representativeness.

Conditions for checking the sample:
- There must be representativeness indicators for the source population available.
  
  Age, gender and address are often used. Others may be chosen.

- The sample should not be selected according to the chosen representativeness factors. The best sampling is random.

  Deciding that the sample must be made up of 50% men and 50% women makes any verification of representativeness according to gender impossible.

- Information concerning the factors chosen to check representativeness should be collected in the questionnaire.

Data analysis

This apparently simple stage requires a statistical approach.

At the very least the following should be carried out:
- A verification of the sample’s representativeness compared to the source population.

  Example:
  The gender ratio is 0.45 in the general population and 0.54 in the sample (random sample of 100 people).
  Can we demonstrate a significant difference?
  Answer: we cannot demonstrate a difference (p > 0.05; risk \( \alpha = 5\% \)). The sample can therefore be considered representative.

- A verification of the “no response” or “unexploitable” groups to see if their exclusion has created a bias.

  No response and unexploitable:
  By their absence these two categories can lead to bias if their characteristics are statistically linked to the intervention or the results.
  Different techniques can facilitate this verification, such as looking for differences in general characteristics between this group and those who replied (gender, age, address, etc.).

  Example:
  The general population of country X contains 1.7% of amputees. The local sample contains 2.5%. Is the difference significant for a random sample of 1000 people?
  Answer: we cannot demonstrate the difference (p > 0.05; risk \( \alpha = 5\% \)). The sample does not make it possible to prove a difference in the proportion of amputees.

- then the planned comparisons with the reference population.
Stage Five: the results

Communicating the results

The quality of your survey should be reflected in its diffusion.

Verbal and written communication should follow strict rules.

Finally, remember that public health and epidemiology are highly politicised fields. In dealing with these subjects all the necessary ethical precautions should be taken concerning the interests of those affected and uncontrollable and difficult situations avoided.
Bibliography

9. « Evaluation des soins en obstétrique » B. Blondel, F. Goffinet, G. Bréart. Editions MASSON, 2001. (about epidemiology of the evaluation, as the title does not show it…)
Example surveys

These surveys were carried out by Handicap International and Steps consulting. They vary in quality and illustrate the results and limitations of a survey.

<table>
<thead>
<tr>
<th>Surveys</th>
<th>Strengths</th>
<th>Weaknesses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kosovo - <a href="#">Analysis report of the situation of people with disabilities in Kosovo - 2002</a></td>
<td>• Survey based on HCP (MQE) (<a href="#">page 7</a>)</td>
<td>• Flawed sampling and statistical methods</td>
</tr>
</tbody>
</table>
| Bangui, Central African Republic – Evaluation of first micro-projects programme for disabled people in the Central African Republic - 2004 | • Survey based on HCP (MQE and MLH) ([page 7](#))  
• Speed of set-up (1 month)  
• Inexpensive | • Methodology lacking in rigour (high level of biases) |
| Morocco - National Disability Survey – 2005 ([Steps consulting](#)) | • National survey based on the concept of the ICF ([page 8](#)), with the deficiency and restriction of activities as a point of entry.  
• Local demand (Moroccan government).  
• Rigorous methodology  
• Detailed results for each region | • Expensive |
| Afghanistan – National Disability Survey in Afghanistan (in progress) | • Survey based on the concept of Armartya Sen ([page 8](#)).  
• Local demand (Afghan government).  
• Rigorous methodology  
• Detailed results for each region | • Expensive |