

SECTION 9

DESIGNING SURVEYS TO MEASURE INEQUALITY

9.1 Introduction

Next to the thermometer, probably the most widely used instrument for measuring health status in the U.K. is the following Census question:

“Do you have any long-term illness, health problem or disability which limits your daily activities or the work you can do?”

The development and use of health status questionnaires has now reached impressive proportions. Broadly speaking there are four classes of instruments:

- ◆ Portmanteau questionnaires on health and lifestyle intended for home-based interviews (and sometimes supplemented with physiological measurements).
- ◆ General health status questionnaires intended either for use in the general population, or for periodic use in healthcare settings.
- ◆ Specialised questionnaires relating to symptoms and various aspects of the life of people with medical conditions.
- ◆ Single questions or short batteries of items that are included in non-health questionnaires. These items are often taken from longer health status questionnaires.

The characteristics of the instruments have been reviewed in [Section 4](#). The focus here is on their potential for use in population surveys.

The Portmanteau and general health status questionnaires are routinely used in population surveys.

Specialised questionnaires and short batteries of items are mainly intended for use with patients in medical settings. The dramatic increase in the number of such instruments largely can be explained by the developing

interest in obtaining standardised patient reports of the outcomes of care. Despite their clinical focus, some examples of the last two groups are suitable for the mapping of health inequalities with population surveys.

9.2 Surveys and Their Limitations

Regardless of the choice of questionnaire, the validity of the results of a survey will depend to a considerable extent on the sampling strategy and design, details of which can be found in texts on sampling techniques and on questionnaire design. The purpose of this section is to focus on the particularity of surveys for elucidating inequalities in health in your area.

9.2.1 *Advantages and Disadvantages*

Advantages

- ◆ Self-report information can only be obtained from the people concerned, e.g. by asking them (although there are sometimes attempts to solicit proxy information for children and older people).
- ◆ Surveys of health provide insights into unmet need and into differences in unmet need between different population groups, because they can collect supporting information on socio-economic characteristics and lifestyle that are rarely kept in medical records.
- ◆ With current data systems, surveys may be the best source of information on some types of health service use, especially on aspects of community health services and general practice. This may change as improve.

Disadvantages

However, as a source of information on population morbidity, household or individual surveys have a number of limitations compared with data derived from healthcare administrative systems:

- ◆ Survey data (like all data) are subject to a range of errors, including sampling, non-response, coverage and measurement error, which can make results at the small area level statistically unreliable. To avoid this problem, synthetic estimation procedures based on relationships established in the sample have to be used to produce small area estimates [214].
- ◆ Surveys cannot collect information that is not related to the characteristics of the respondent (only partial data from the individual's perspective can be collected to measure neighbourhood characteristics such as the extent of community support or social control). It is, however, possible to attach or attribute some geo-demographic information to individual cases if postcoded information on the sample respondents is available.

- ◆ Survey assessments of need do not easily translate to potential services or requirements [215]. In some cases, surveys do not even attempt to measure the extent of actual individual need, but simply assess individual service utilisation. These problems could, in principle, be overcome by the use of more sophisticated sampling designs, incorporating some form of independent needs assessment or improved measurement instruments.
- ◆ Surveys are generally expensive and time consuming. They cannot anticipate the future; and therefore do not tell us about the characteristics of those who are about to enter hospital, nursing or residential homes.
- ◆ It is difficult to obtain valid information for some groups. For example, undertaking a survey to measure children's and families' need for health and family and child care services would be both practically and methodologically difficult. The direct interviewing of children about family and child care problems, within a household or school survey, would pose logistical and ethical problems.
- ◆ Unless a survey is accompanied by a medical examination (as in the British Dental Surveys) all evidence on health and health status will be self-reported, complicating any comparisons with the results of surveys with, for example, medically generated incidence data that may use standard-clinical-systems for classifying symptoms and conditions.

In the context of health inequalities, two issues are particularly important:

- ◆ Nearly all surveys are of households or of individuals and therefore omit those living – whether permanently or temporarily – in institutions or on the street. Such persons are more likely to be ill, so that one is likely to underestimate overall prevalence. If the purpose is to make comparisons between areas, the problem is compounded because such institutions or the incidence of street living are not distributed equally between areas.
- ◆ Non-responses are particularly important in this context because the non-responders may well be the most ill. It is important to compare the sample breakdowns with the Census in terms not only of socio-demographic characteristics but also with the expected percentage reporting a limiting long-term illness (LLTI).

When used for measuring inequalities, results from surveys of health will often be presented as rates, such as the numbers with certain symptoms or poor self-report health per 1000 of the population. Because of the strong associations with age (and often sex) results will frequently need to be standardised by age or by both age and sex (Section 6).

9.2.2 When Not to Do a Survey and the Alternatives

When not to do a survey

Even small surveys can be expensive in time, money and other resources. Surveys that fail to achieve their objectives also incur other costs – they may have inspired false hopes or opened up issues better kept closed. There are often methodological reasons why surveys fail to produce the hoped-for results [216]. Careful design and preliminary checks should help avoid such failures.

Even the most conclusive of surveys is wasted if the report is unread, the proposals rejected or quietly filed. Ensuring that the style, length and presentation of the report is appropriate for the intended readership is one important factor, but if local conditions are unfavourable, it may not be worth starting a survey. Surveys should be avoided if:

- ◆ There are insufficient technical and staff resources to conduct the research effectively, especially the analysis and reporting stages.
- ◆ The timescale is too tight.
- ◆ The data are likely to be inconclusive and no proposals will result.
- ◆ The data, or a near equivalent, are already available from official sources or other studies.

Alternatives to surveys

An over-emphasis on the details of survey technique sometimes leads to less formal and less technical research methods being devalued. In academic work, formal methods are used at a late stage in the research, after various sorts of exploratory studies. Obviously, there are times when quantitative data collected by formal methods is essential, but you should be aware of the wide variety of other methods that are available.

Informal data sources

An inequality may become noticeable because of reports in the media, for example, about food poisoning or pollution that has traced back to a particular retailer or factory pollution. In some circumstances, systematic monitoring of the media could substitute for an expensive and potentially inconclusive survey.

Drawbacks of formal methods

Expensive and inconclusive results are not the only reasons for exploring alternatives. One of the great assets of survey research – people's

considerable willingness to fill in self-completion questionnaires – hides one of its main drawbacks, that you only get their replies to a series of pre-set questions, not their spontaneous views. Once the fieldwork is over, there is a considerable temptation to forget that what you are confidently describing as your respondents' views are only their replies to your questions, and not necessarily their own interests and priorities. If health service policy has been steered by providers' perceptions and definitions of good practice, should this also hold for consumer research? If one is to emphasise the patients' agenda, how should this be done?

Evidence-based policies need information

There is no such thing as a perfect piece of research. Whilst academic researchers frequently end their report with a plea for further research, they also typically draw attention to how much can be learnt by their approach. The latter is the more appropriate emphasis in this context. The point is to recognise the often fragile information base for present policies, and therefore to realise the scope for improvement. Whilst this does not mean that any information is better than none, it does mean that a wide variety of approaches to collecting information will provide a useful addition to what is known.

9.2.3 *Doing a Survey*

Here we outline the steps one should pay attention to in designing and executing a survey (Table 9.1).

Table 9.1. Steps to designing and executing a survey

<i>Step</i>	<i>Comments</i>
Specification of Objectives	
Are these clear and potentially answerable by survey?	<i>If not, return to peer group who suggested survey – DO NOT PROCEED.</i>
Specify precise aims of survey	<i>If not, return to objectives</i>
Propose rough timetable	
Preliminaries	
What do we already know about the situation?	<i>If enough is known to formulate policy, WHY A SURVEY?</i>
Look at reports of similar studies	
Pre-piloting, finding out which kinds of questions will be appropriate	<i>If this is not done, statistics will not save you</i>
Draw up a sampling plan	
Will any of the analysis require technical input?	

(Continued)

Table 9.1. (Continued)

Step	Comments
<p><i>Survey design to include:</i> whether interview or self-completion; sampling plan and rough size of sample (this might be as simple as a choice of clinics and a number of days); length and style of questionnaires; proposed staff and training; plan for fieldwork (crucially proposed dates, times and proposed location of staff); preparations for coding, data entry; plan for analysis; rough timetable for survey.</p>	<p><i>If you will need statistical/technical advice get it now</i></p>
<p>Seeking agreement on sampling points from floor management</p>	
<p>Re-examine design of survey for technical inputs</p>	
Questionnaire Design	
<p>Produce first draft of questionnaire. Circulate to interested parties. Try it on friends.</p>	<p><i>Remember the potential respondents are at best patient, probably long- suffering, and may not read or speak English fluently. Do not make it worse by asking them to answer an incomprehensible question</i></p>
<p>Piloting, trying out the draft questionnaire on small number of the potential respondents</p>	
<p>Analyse the responses from the pilot</p>	<p><i>If it looks as if you would not get the answers you need, DO NOT PROCEED</i></p>
<p>Final approval from colleagues</p>	
<p><i>Return to examine aims of research and whether design is appropriate</i></p>	
Setting up	
<p>Choosing staff for interviewing</p>	<p><i>Good interviewers are rare; they need to be insistent, but extremely pleasant with it</i></p>
<p>Choosing staff for clerical work</p>	
<p>Finalise fieldwork plan (dates, times and location of staff)</p>	<p><i>Although much of work is clerical, accuracy is obviously very important</i></p>
Execution	
<p>Data Collection</p>	<p><i>Regular spot visits by you to see how things are going</i></p>
<p>Running record of progress</p>	
<p>Coding and data entry</p>	<p><i>Compare with sampling plan</i></p>
<p>Analysis</p>	<p><i>If possible, arrange for checking</i></p>
<p>Report writing</p>	<p><i>Refer repeatedly to original aims of survey</i></p>
<p>Discuss proposed draft with peer group and management</p>	
<p>Formal report for action</p>	
<p>Monitor effectiveness</p>	

9.3 Assuming You Have Decided on a Survey

9.3.1 Getting Your Objectives Clear: What Do You Want to Find Out?

Information is only useful when your objectives are clear. Many studies fail to reach tangible conclusions simply because they fail to define their aims beyond “wanting to find out about the distribution of limiting long-standing illness”. It is often difficult to reach policy relevant conclusions with a general purpose questionnaire.

What will be the nature of your results?

You should realise that, with most surveys, the results are broadly predictable. They are unlikely to tell you anything new, only to provide you with quantitative estimates of the relative importance of the various factors. Indeed, the most likely surprises are that certain factors are NOT as important as you thought they were.

The need for comparisons

Secondly, very little can be done with absolute percentages. Suppose you find limiting long-term illness levels in your area is between 15 and 20%, does this mean things are going well or badly? Answering inequality-type questions requires comparative data. This could come from the same study, when you might be comparing results from several different units, or from previous studies done either in your area or elsewhere.

The need for comparisons raises three further points:

- ◆ There should be greater standardisation in the questions asked. There are a large number of examples of how different dimensions of inequality can be measured ([Section 2](#)), and a wide range of scales have been developed for measuring different aspects of health ([Section 3](#)).
- ◆ It is difficult to make effective comparisons with results from weak questions, e.g. when the wording tends to get the same response from most informants.
- ◆ Even if percentage differences show that some groups report more limiting long-term illness than others, they do not tell you causation or etiology.

Making recommendations based on your survey

The potential effectiveness of a survey should be tested by running a trial analysis on your pilot data and checking that it is capable of informing the sort of recommendations you want. Do not forget to record open-ended comments as these are often very useful in illustrating the discussion of your findings.

9.3.2 Research and Academic Criteria

How important is it to observe the technical criteria, what the 'research methodologist' says you should do? There is a tendency for non-academic authors to distance themselves from 'research'.

The notion that one set of criteria applies to health service surveys and another for academic research is unsound. Health service surveys may pay more attention to questions of effectiveness, and may be more descriptive than hypothesis testing but, they still benefit from good design. A survey which has only a 30% response rate will have expended considerable resources trying unsuccessfully to reach the other 70%. It will have no way of telling whether policy based on the views of that particular minority is likely to be acceptable to the other 70%, though one suspects that with such a low response rate, certain groups will be systematically under-represented. One should automatically be suspicious of a questionnaire giving such low response rates; for example, were the questions incoherent or irrelevant such that many respondents gave up?

There are some very technical forms of data analysis and accuracy estimation that are unlikely to be relevant for many surveys, but the vast majority of methodological criteria, are really just ways of ensuring conclusive and cost-effective surveys.

9.3.3 Research Aims

Surveys will normally have one or more of the following purposes:

- ◆ *Explanatory studies.* These would usually be the first stage of any research where one is uncertain of the issues. They can include literature searches, and interviews with 'experts' and others in the area. Exploratory studies may either be a preliminary to developing more formal methods, such as a pre-coded questionnaire, or may be worthwhile exercises in themselves in developing knowledge of a little known area.
- ◆ *Descriptive studies.* These are the type most often used in patient-feedback studies. Their aim is usually to collect data, which can influence or evaluate policy. Although descriptive, they should still have well-defined objectives, e.g. one should be precisely sure what range of data is needed and how it might lead to specific recommendations.
- ◆ *Hypothesis testing surveys.* These are widely used in socio-medical research. A typical study might aim to explore links between dietary patterns and a particular medical condition. They differ in two main respects from the descriptive model. First, their sampling strategy will require some sort of control group. Second, their analysis is unlikely to stop at basic frequency counts and cross-tabulations, and will include various forms of multi-variate analyses. Though less

common than descriptive studies, hypothesis testing is also used in patient-feedback research, especially when the project sets out to test the effects of a specific change.

- ◆ *Other motives.* Finally, there are a variety of studies for which data collection is a secondary aim. Their intentions differ, but are usually either some form of public relations, or some attempt to demonstrate research activity.

9.4 Different Types of Survey

Cross-sectional surveys or 'snapshot' approach is the most common, but surveys of health may often benefit from other designs. They are the most common form of feedback research, though one also finds examples of panel, quasi-panel and standing-panel models.

9.4.1 Cross-Sectional Studies Versus Longitudinal Surveys

Cross-Sectional Surveys are simply surveys conducted at a single point in time. If they aim to be explanatory or test some hypothesis, they require a control group. If they are mainly descriptive, a control may not be necessary. A well-designed cross-sectional study can be as valid or 'scientific' as a longitudinal study.

At the same time, there are situations in which one would have much more confidence in inferences based on repeated observations over time on a set of variables for the set of persons belonging to the survey. An important constraint on the design of a longitudinal survey is the specification of the purposes the survey is to serve and to identify their operational and budget constraints. Choosing the most appropriate survey design requires assessing the benefits of the different sorts of information provided and the different costs required to derive them.

9.4.2 Obtaining Longitudinal Data through Health Surveys

There are four main ways of deriving these repeated observations on the same people through a survey:

- ◆ *Retrospective:* wherein respondents are typically interviewed only once and they are asked about the past.
- ◆ *Record linkage:* in which responses from the sample respondents are linked to their health service records.
- ◆ *Quasi-panel surveys:* in which the responses from a before group are compared with those of an after group.
- ◆ *Panel (or longitudinal) surveys:* wherein the same sample of persons (a 'panel') is followed over time, and data are collected from a sequence of interviews ('waves').

Retrospective surveys

In retrospective surveys, respondents are typically interviewed only once and they are asked about the past as well as the present in order to provide two (or more) observations on the same person. The advantages of this method are its simplicity and cheapness (because there is only a single interview: respondents do not have to be tracked), and the immediate availability of longitudinal information (since one does not have to wait for a second interview to measure change). The principal disadvantages are that information about the past is typically dependent on respondents' recall of events, and the accuracy of this is questionable for some variables of policy interest. People are unlikely, for example, to remember very well their income beyond the immediate past,⁸ or may do so in a biased way. On the other hand, the dates of significant, low frequency, lifetime events such as getting married or divorced, having a child, or changes in one's main job, are more likely to be remembered with reasonable accuracy. These latter events have been the focus of retrospective social surveys.

Record linkages

Another important approach is to link together information from diverse sources, for example, from respondents and from their health service records. The Data Protection Act, however, often precludes this sort of linkage. Even when it is acceptable, it is rather difficult because of the different ways in which the crucial identification variables have been constructed in the different sources.

Nevertheless, where it is possible, often very important information can be obtained. A study carried out by the National Primary Care Research and Development Centre interviewed respondents about their visits to surgery and asked for permission to approach their GPs for access to their records. The study showed that there were significant discrepancies in the respondents' recall of diagnosis and what had been recorded in their General Practitioners' files.

Quasi-panel surveys

The presumption here is that the current before group can be compared to a current after group as if they were identical. Though not normally providing valid comparisons, and therefore not recommended, the quasi-panel method is frequently used. In the health survey context, we frequently compare the results, for example, of the GHS across several years without paying as much attention as we should to issues of comparability of the samples in different years.

⁸ One estimate is that the recall of small items of household expenditure 'decays' by nearly 3% a day!

Panel surveys

Panel surveys are ones in which a sample of informants ('the panel') are contacted more than once to find if they, their experiences and opinions, have changed over time. Perhaps, the most famous British panel studies are the birth cohort studies conducted on large samples of all children born in single weeks in 1946, 1958 and 1970.

The simplest panel design interviews an individual both before and after a course of treatment. There are many possible variations, but the main distinction is between surveys comprising a single panel of indefinite life, and surveys comprising multiple overlapping panels of fixed life, also known as rotating panel surveys. A second distinction refers to the sampling unit and the population that the survey aims to represent – whether the focus is entirely at the individual level, or on individuals within their household context. This distinction helps define the rules about who comprises the panel beyond the initial sample: which people in the original panel are followed over time, and how (if at all) new panel members might replenish survey numbers. The issue is quite complex ([Appendix to Section 9](#)). A third distinction refers to the types of longitudinal information collected by the panel survey, in particular, the extent to which data are collected about life prior to the first interview wave and about life between waves.

9.5 Summary

Advantages

- ◆ You can only get self-report information from people by asking them.
- ◆ Surveys can provide insights into unmet need.
- ◆ With current data systems, surveys may be the best source of information on some types of health service use.

Disadvantages

- ◆ Survey data (like all data) are subject to a range of errors, including sampling, non-response, coverage and measurement error.
- ◆ Surveys can only collect information related to the characteristics of the respondent.
- ◆ Survey assessments do not easily translate to potential services or requirements.
- ◆ Surveys are expensive and time consuming.
- ◆ It is difficult to obtain valid information for some groups.
- ◆ Nearly all evidence on health and health status will be self-reported, complicating any comparisons with the results of surveys with medically generated incidence data.

In the context of health inequalities, there are two other issues that must be remembered:

- ◆ Nearly all surveys are of households, and therefore omit those living in institutions or on the street.
- ◆ The importance of accounting for non-responses because the non-responders may well be the most ill.

Main types of design

- ◆ Cross-sectional surveys.
- ◆ Retrospective surveys.
- ◆ Record linkage surveys.
- ◆ Quasi-panel surveys.
- ◆ True panel surveys.