Survey Design and Methodology in National Health Interview and Health Examination Surveys
Review of literature, European survey experiences and recommendations

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HEALTH SURVEYS IN THE EU:
HIS AND HIS/HES EVALUATIONS AND MODELS
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Contents

ABSTRACT ................................................................................................................ 3

1. INTRODUCTION .................................................................................................... 4

2. AIMS....................................................................................................................... 5

3. METHODS.............................................................................................................. 6

4. REVIEW OF LITERATURE .................................................................................... 8

4.1. Sampling 8
  4.1.1. Target populations and sampling frames ......................................................... 8
  4.1.2. Sample selection............................................................................................... 9

4.2. Recruitment and informed consent in health surveys 10
  4.2.1. Recruitment methods....................................................................................... 10
  4.2.1.1. Type of contacts ........................................................................................... 10
  4.2.1.2. Number of contacts and difficult-to-recruit respondents ............................ 13
  4.2.2. Informed consent ............................................................................................ 15
  4.2.2.1. Effect of informed consent ............................................................................. 16
  4.2.2.2. Informed consent and minors or cognitively/mentally impaired persons ......... 17

4.3. Factors supporting or reducing response and participation in health surveys 19
  4.3.1. Public attitudes towards medical research ....................................................... 19
  4.3.2. Reasons for refusal to participate ................................................................... 20
  4.3.3. Promoting and motivating participation: Acceptance, awareness and access .... 21
  4.3.4. Effect of survey protocols and incentives ....................................................... 23

4.4. Non-response bias 24
  4.4.1. Defining response rates .................................................................................. 24
  4.4.2. Differences between respondents and non-respondents ............................... 26
  4.4.3. Proxy respondents ......................................................................................... 29

5. CONCEPTUAL FRAMEWORK FOR SURVEY PARTICIPATION .................... 30

6. REPRESENTATIVENESS AND PARTICIPATION IN NATIONAL HEALTH
   SURVEYS IN EUROPE ............................................................................................. 34

6.1. Sampling 35
  6.1.1. Target population and sampling frame ............................................................ 35
  6.1.2. Sampling procedures, stratification and over-sampling .................................... 38
  6.1.3. Some details on sampling procedures ............................................................. 39
  6.1.4. Age limits and sample size ............................................................................ 43

6.2. Recruitment and informed consent 44
  6.2.1. Recruitment letters and type of contact ........................................................... 44
  6.2.2. Informed ........................................................................................................ 45
  6.2.3. Number of contacts ...................................................................................... 47
  6.2.4. Informed consent ......................................................................................... 48
  6.2.5. Incentives ....................................................................................................... 50
6.3. Response
6.3.1. Refusals, eligibility and not contacted ................................................................. 51
6.3.2. Selection of new respondents and proxy interviews ........................................ 54
6.3.3. Collection of information on non-respondents .................................................. 56
6.3.4. Reasons for non-participation ............................................................................ 57

6.4. Data collection and fieldwork procedures
6.4.1. Survey design and mode of data collection ......................................................... 59
6.4.2. Place of examinations and survey personnel ..................................................... 61
6.4.3. Information on results ....................................................................................... 63
6.4.4. Quality assurance during fieldwork .................................................................. 64

7. RECOMMENDATIONS: HOW TO IMPROVE REPRESENTATIVENESS AND
PARTICIPATION IN NATIONAL SURVEYS?.......................................................... 66

8. DISCUSSION AND CONCLUSIONS ................................................................... 68

REFERENCES ........................................................................................................ 71

ANNEX 1. HES METHODOLOGICAL QUESTIONNAIRE........................................ 82

ANNEX 2. HIS METHODOLOGICAL QUESTIONNAIRE FOR INFORMATION ON
SAMPLE AND PARTICIPATION .............................................................................. 99

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ABSTRACT

As one of the subprojects of the second phase of the HMP project "Health surveys in the EU: HIS and HIS/HES evaluations and models" this study aims to review and evaluate sampling frames and survey protocols in European Health Surveys. It aims to describe differences between surveys and to propose recommendations for sampling and fieldwork procedures to minimise non-response.

A review of literature was carried out on survey representativeness and participation. The HIS/HES database provided details on methodology in national surveys carried out during the period of 1998-2002 (43 HIS and 12 HIS/HES). Information on target populations, sampling procedures and participation rates in these surveys was obtained from the database. For a more detailed analysis on sampling and participation, a questionnaire on methodological aspects of health surveys was mailed to the contact persons for five latest national HIS/HESs in EU/EFTA countries. A shorter questionnaire on factors affecting participation was mailed to contact persons for two selected national HISs.

The most frequently used survey design in the national surveys was cross-sectional without follow-up. Samples were drawn from population registers or address files of households or individuals, most commonly by multistage probability sampling, stratified by geographic areas. Nearly half of the surveys had no age limit. When applied, the lower limit varied from 2 to 30 years, and the upper limit from 64 to 84 years. Institutionalised persons were included in 15 surveys from 7 countries.

Sample sizes varied from fewer than 2000 individuals to 79 000 households and non-response rates from 5% to 48% for HISs and from 15% to 75% for HESs. The high non-response rates can be explained e.g. by the large number of people not contacted in some countries, linked to the level of accuracy in sampling frames. Further explanations for the low response rate in some HESs are the fact that only those who were first interviewed were invited to the examinations in two surveys, restrictions in available appointment times, and poor feedback to the participants about their personal test results in one survey.

There were also differences e.g. in the place of the examinations (home or clinic), in the data collection methods, in the professional background of survey personnel, and in their training before and during fieldwork. More than one mode of data collection was applied in most HISs, e.g. both face-to-face interviews and self-administered questionnaires.

Due to the small number of surveys included in our detailed analysis, it is not possible to evaluate the specific effect of different recruitment and fieldwork procedures on response rates. However, there seems to be no evidence that any one single element in the survey process would increase or decrease response. There is an obvious need for further analysis of non-participation in national health surveys in Europe. International comparisons of sampling, recruitment and participation, and reasons for non-participation are needed in the evaluation of comparability of survey results. Analysis of the recruitment process and the effects of non-response should be a central issue in developing survey designs and fieldwork protocols.
1. INTRODUCTION

Health Interview Surveys (HIS) and Health Examination Surveys (HES) in Europe were reviewed and evaluated during the first phase of the project 'Health surveys in the EU: HIS and HIS/HES evaluations and models' (Koponen and Aromaa 2001). Several differences in the design and fieldwork phase were found to limit the comparability of results of the surveys. Important differences were identified in the sampling frames. Non-response for HES varied from 20 to 49 percent. It was assumed that these differences in response rates are to a large extent due to different sampling frames and differences during fieldwork procedures, especially recruitment. In some countries low response rates may also be due to factors outside the survey organisers' control. One example may be survey fatigue among the population. The proliferation of various kinds of surveys may well lead to resistance to participate (Clarke et al 1990). In most countries it is becoming increasingly difficult to achieve high response rates (Groves & Couper 1998).

At the end of the first phase of the HIS/HES project, we concluded that the health survey protocols must be improved, in particular to obtain representative samples and to achieve higher response rates. However, attitudes towards surveys at the population level and the whole social environment for surveys needs also to be taken into account (Groves & Couper 1998).

Non-participation is typically higher in health examinations (HES) than in interviews (HIS). The problems associated with low response rates and increasing refusal rates have been well documented (e.g. Kessler et al 1995). To perform valid comparisons among different countries when response rates vary, the problem of possible selection bias must be considered (de Marco et al 1994). Also, it is important to note that selection bias may be different at different ages and its effect may depend on the phenomena studied. The potential for health related selection bias is particularly critical in studies involving persons aged 65 or older because this age group has greater heterogeneity in health status and disease burden than any other (Carter et al 1991).
Even when the response rate is high, bias may be important when respondents and non-respondents differ systematically with respect to survey measures (Kessler et al 1995, Novo et al 1999). Effects of non-response should be a central issue in developing the survey design and fieldwork. Procedures need to be developed for respondent recruitment, survey administration, and collection of data on both respondents and non-respondents.

Recruitment remains one of the most challenging and underestimated phases in the research process (Brown et al 2000, Riedel-Heller et al 2000). The efforts made to enhance comparability of survey results through the use of common standardised instruments should be complemented by more attention paid to recruitment issues and the potential bias due to non-participation. More understanding is needed on willingness and unwillingness to participate in research (Carter et al 1991, Hartge 1999). Communication on recruitment issues is essential to improve the validity of study outcomes (Riedel-Heller et al 2000).

This report presents the results of one subproject, carried out during the second phase of the project 'Health surveys in the EU: HIS and HIS/HES evaluations and models' (see Aromaa et al 2003). This subproject aimed to review and evaluate sampling frames and survey protocols to understand differences between surveys and to propose recommendations for sampling and fieldwork procedures.

2. AIMS

The specific aims of this subproject were to:

1) Review methodology in current health surveys in EU Member States and in EFTA countries: sampling frames and designs, participation rates and implementation from the point of view of representativeness.

2) Identify characteristics and consequences of selective samples and non-participation.
3) Compare recruitment: methods used to approach and contact subjects, to invite subjects and to motivate participation. Whenever available, the reasons for refusal will also be compared.

4) Compare methods used to follow up non-respondents and information collected on them.

5) Evaluate design and implementation features to improve representativeness and to reduce non-participation.

6) Suggest recommendations on practical methods to be used in national HIS/HES to increase representativeness and to motivate participation.

3. METHODS

A review of literature was carried out concerning survey representativeness and participation. The MEDLINE was searched for articles using the following terms: Health survey and recruitment or participation or response bias or informed consent. Original articles on surveys using population samples, and review articles were selected. Reports of surveys of specific patient groups were included if they focused on factors supporting or restricting survey participation. The review focuses on interviews and health examinations, but mail surveys are also referred to since questionnaires may be used as the first contact to participants in HIS or HES, or questionnaires are used in addition to interviews and/or examinations.

Inventories of national HIS and HIS/HES in EU and EFTA Member States were carried out and updated during the first and second phase of the HIS/HES project (Hupkens et al 1999, Hupkens & Swinkels 2001, Koponen & Aromaa 2001). The collection of information about previous, ongoing and planned surveys as well as on methods used relied on literature reviews, personal communication, and a systematic postal survey covering all EU/EFTA Member States, and methodological questionnaires (see annex 1.) sent to contact persons of identified surveys. Only one institute (one HIS) refused to fill in the methodological questionnaire. Information from the methodological questionnaires was entered into the HIS/HES database.
The inclusion criteria for HIS and HES in the database were: the surveys must be based on nationally representative population samples, they must be repeated at more or less regular intervals, and they must be comprehensive health surveys (not disease/topic specific or restricted to a narrow age group, e.g. only children or the elderly).

The January 2003 version of the database included 88 HIS (with a total of 13695 questions) and 16 HES (with a total of 221 test/examination protocols) in EU/EFTA Member States, and in Australia, Canada and USA. The database is directly available through Internet at https://www.iph.fgov.be/hishes/.

The database was searched for information on national surveys carried out during the period of 1998-2002 (43 HIS and 12 HIS/HES). Information on target populations, sampling procedures, participation rates and fieldwork protocols in these surveys was obtained from the database.

For a more detailed analysis on sampling and participation, a new questionnaire on methodological aspects of health surveys was mailed in May-June 2002 to the contact persons for the latest HIS/HES in five EU/EFTA countries (see annex 1.). Compared to previous methodological questionnaires for the HIS/HES project, new questions on participation were included. A shorter questionnaire on factors affecting participation was mailed to two selected contact persons for national HIS (see annex 2.). All contact persons returned the questionnaires. They also returned, if feasible and available, the following letters, brochures, leaflets and manuals/protocols:

- Document(s) describing the sampling process
- Invitation letter(s) and reminders
- Brochure(s)/leaflet(s) sent/given to subjects
- Informed consent form(s)
- Forms, letters etc. given to subjects concerning their test/examination results (HES)
- Other document(s)/publication(s)/web-pages where the design, methods and procedures of the survey have been described.
This material was returned in the national language(s), and concerning the documents from the Netherlands also as translated into English.

4. REVIEW OF LITERATURE

4.1. Sampling

4.1.1. Target populations and sampling frames

The target population has to be defined taking into account practical limitations in the availability of sampling frames. A sampling frame, the list or register of the population elements from which the sample is drawn, often includes additional information on the structure of the population (Lehtonen & Pahkinen 1995). In some countries representative up-to-date population registers are not available and household samples are selected for national health surveys, even though it is recognised that these exclude those not independently living in private households. Especially to make comparisons on functional abilities between studies from different countries meaningful, the inclusion of institutionalised individuals is crucial (Riedel-Heller 2000).

The representativeness of study results may be jeopardised by any sampling method systematically excluding certain segments of the population (Carter et al 1991). For health surveys the most complete register including the persons defined as target population of the survey can be chosen among population registers, electoral lists, census lists or public health registers. The availability of an adequate sampling frame differs between European countries and the use of different types of registers, which are up-dated at different intervals may lead to differences in study populations (Riedel-Heller 2000). When the sampling frames include a large number of ineligible persons (moved away or died between time of sampling and survey) and there is no way to identify such individuals, the response rate will be under-estimated (Wolf et al 1998).
The European Health Risk Monitoring Project (EHRM) recommends that the target population for a health risk monitoring survey comprises all residents in a specified age group in a geographically defined population (Tolonen et al 2002). However, the concept of resident can be ambiguous. It has to be defined if the target population includes only permanent residents or also temporary residents. If any exclusions apply, such as leaving out institutionalised persons or prisoners from the target population, they have to be carefully documented.

4.1.2. Sample selection

Different sampling techniques can be applied in national health surveys, either using a particular method or a combination of methods (Lehtonen & Pahkinen 1995). These techniques include:

- Simple random sampling, applied when no auxiliary information on the population is used.
- Systematic sampling, where auxiliary information is used in the form of the list order of population elements in the sampling frame.
- Sampling with probability proportional to size, used when an auxiliary variable is assumed to measure the size of a population element.
- Stratified sampling, where the population is first divided into non-overlapping sub-populations called strata, and sampling is executed independently within each stratum.
- Cluster sampling, where the population is assumed to be readily divided into naturally formed subgroups called clusters. A sample of clusters is drawn from the population of clusters.

To ensure representativeness it would be preferable to take a systematic sample of the total population. Practical reasons, however, lead to multistage samples in national health surveys. The EHRM project recommends the use of probability sampling and a single-stage sampling scheme (Tolonen et al 2002). If analyses for specific population subgroups or geographical areas are anticipated, stratification is recommended to guarantee sufficient representation of the subgroups in the survey.
If multi-stage sampling is used, the statistical precision is smaller than when using single stage sampling, but this reduction in precision can be limited by careful planning.

4.2. Recruitment and informed consent in health surveys

In addition to subject variables (e.g. socio-economic and health status) research design characteristics affect study participation. For example, the context in which a request for participation takes place, the type and quality of interaction at first contact, the persuasion used in recruitment, and the skills of the research staff may be relevant (Edwards Neumark et al 2001).

4.2.1. Recruitment methods

4.2.1.1. Type of contacts

Methodological research on recruitment is rare and very little is known about different fieldwork procedures or the demands that surveys or clinical trials put on fieldwork personnel and participants. In a feasibility study of a clinical trial for prostate testing for cancer and treatment Donovan et al (2002) used qualitative research methods to investigate the process of recruitment. The study included interviews with participants, and audio-taped recruitment appointments and follow up interviews. Early findings were used to devise recruitment strategies. Documents were circulated to the study centres with examples of presentation of information, and an intensive training programme was developed and delivered to the recruiters. This resulted in an increase of the rate of consent to randomisation from 30-40% to 70%. Changes were made to the content and delivery of information. The study suggests that qualitative methods could be used in feasibility and pilot phases in order to understand recruitment and to maximise participation.

Different recruitment strategies have been used in clinical studies to motivate and attract potential participants. Some of these experiences could be applied to health
survey settings. In clinical studies mass media campaigns have appeared to be the best strategy for recruitment of participants (Löfdahl et al 1998). Advertisement and articles in newspapers have been used. These studies show that a sufficient number of telephone lines and personnel have to be available after mass media campaigns. After the first contact by telephone a quick appointment for the first screening may also be essential to promote enthusiasm in the future participant. In community studies it seems crucial to prepare the study involving community leaders and key persons such as GPs and other local health professionals followed by newspaper articles (Ritchie & Dennis 1999, Riedel-Heller 2000, Bermejo et al 2001).

The more personal the contact, the more likely is successful recruitment (McDonald 1998). Several studies have confirmed that face-to-face or other personal contacts result in higher response rates than invitation by letter, especially for those with lower education (Eastwood et al 1996, McDonald 1998, Barriball & White 1999, Sitzia & Wood 1998, Hellard et al 2001, Riedel-Heller et al 2001). The response is higher if several contact modes are used (Stang et al 1999). The effectiveness of recruitment with personal contacts improves when it is used in combination with media (McDonald 1998). Successful recruitment depends on reaching the target population and persuading them to participate. Multiple recruitment strategies may be necessary, especially for older adults. In the recruitment of older adults, there are good experiences from sending easily understandable letters in large print, mailed together with a handout giving study details and a photo of the interviewer with a personal hand-written note before the face-to-face contacts (Riedel-Heller et al 2000).

Five sets of "input" or independent variables have been identified that may be manipulated in communication campaigns to promote participation in health promotion programs: source, destination, message, receiver, and channel (McDonald 1999). These may be applicable to recruitment in health surveys. Source variables refer to the characteristics of the person or group sending a message (e.g. credibility, attractiveness and power). Destination factors refer to the type of behaviour that the communication is aimed at (e.g. behaviour vs. attitudes). Message factors include how the message is delivered and organised (e.g. length, pace, repetition). Channel
factors are the methods by which messages are transmitted (interpersonal and mass media). Receiver factors concern the extent to which the communication is consistent with the characteristics of the intended audience.

In health surveys phone interviews have been reported to be a feasible method for reaching those not wishing to participate in personal interviews or examinations, and to get at least some information from these persons (Santariano et al. 1998, Reidel-Heller et al 2000). When the effects of ageing on physical functioning among non-institutionalised individuals aged 55 and over were studied, an additional home visit to those who did not respond by mail or by telephone identified only subjects quite similar to those identified by mail (Santariano et al 1998). In their review of population-based case-control studies in Germany Stang et al (1999) found that the use of home visits in addition to letters and phone calls did not have much effect on the response proportions. In contrast to these, differences were found in the prevalence of disability between early and late respondents when a home visit to collect questionnaires from non-responding households was conducted in a survey in UK (Locker et al 1981).

Several randomised controlled trials of strategies to influence the response to a postal questionnaire have been carried out (Edwards et al 2002). Less is known about strategies to influence the response in surveys with personal interviews and/or examinations. A few studies indicate that relatively simple interventions like an explanatory letter before the first telephone contact (Kessler et al 1995, Smith et al 1995, Edwards et al 2002), a reminder postcard or other follow-up contacts (Perneger et al 1993, Asch et al 1997, Carter et al 1999, Hartge 1999, Edwards et al 2002) can significantly improve participation rates.

In a report on recruitment during the EC Respiratory Health Survey in Oregon (USA) the use of a preliminary "announcement postcard" before questionnaire mailings did not improve participation (Vollmer et al 1994). Telephone contacts, conducted after five unsuccessful mailings resulted in good completion rate for the questionnaires. However, these hard-to-reach subjects were much less likely to participate in the clinical evaluation (HES) part of the study than the easy-to-recruit subjects.
In studies conducted with several data collection phases and several questionnaires, regular contact with the participants and informing the participants of the study’s progress e.g. via newsletters seem to be successful methods to maintain a high level of participation (Hellard 2001).

In a telephone survey of older adults (Verboncoeur et al 2000) participants were first sent a letter informing about the survey with an enclosed preaddressed and stamped postcard if they did not want to be contacted. The use of these refusal postcards greatly increased the refusal rates without offering any advantage in the recruitment process. It was concluded that the use of a refusal postcard precluded individuals from making fully informed decisions about participating.

4.2.1.2. Number of contacts and difficult-to-recruit respondents

According to several studies there is a positive correlation between recruiting effort and response rate (Cottler et al 1987, Kalantar & Talley 1999). The intensity of recruitment effort can lead to a considerable increase in response rate with relatively low cost per late respondent (Rodes et al 1990). Several studies have shown differences between early respondents and late respondents, some of which influence population estimates (Locker et al 1981, Cottler et al 1987, Rodes et al 1990).

In a psychiatric epidemiologic study of the US population, the largest number of contact attempts was required by persons with current alcohol abuse and dependence disorder (Cottler et al 1987). Other characteristics independently associated with a high number of contact attempts needed were being young, black, male, urbanised, well-educated, and full-time employed. In this study those with current alcohol disorders were more difficult to contact initially, more likely to refuse when contacted, and more difficult to convert once they refused.

Cottler et al (1987) recommend early and rapid assignment to a refusal converter when a respondent with characteristics of low response first shows signs of reluctance. This refusal converter can be another member of the survey personnel
who contacts those refusing or hesitating participation after the first contact. In a Spanish survey (Bermejo et al 2001) a supervisor intervened to seek co-operation if a subject repeatedly refused. The assistance of a local physician, other subjects who have been examined previously or other local volunteers facilitated recruitment in surveys with older adults (Tell et al 1993, Bermejo et al 2001). Contacts with a family caregiver (Edwards Neumark et al 2001) and allowing family members or friends to participate in the health examination (Tell et al 1993) have also been found to facilitate recruitment of older individuals.

The study of response over time, wave analysis, has proved a useful way of investigating the nature of non-response (Tennant & Badley 1991). In most surveys the late respondents and individuals who are difficult to recruit (several contacts needed) have had similar characteristics as the non-respondents. Several studies have shown that younger individuals and urban dwellers are relatively difficult to recruit (Rodes et al 1990). Late respondents have had lower socio-economic status, longer unemployment periods, and lower levels of education (Novo et al 1999).

In most studies the prevalence of many diseases is higher in late respondents and in those who are difficult to recruit compared to early respondents (Cottler et al 1987). The late respondents have also had higher risk factor levels than early respondents, e.g. higher levels of smokers (de Marco et al 1994) and higher alcohol consumption (Novo et al 1999). In a psychiatric epidemiologic survey Cottler et al (1987) found that prevalence rates of five common psychiatric disorders could be estimated correctly only after eight or nine contact attempts per case. The prevalence of current alcohol disorders increased with the number of contact attempts up to 6-10 contacts.

In a mailed health survey in Switzerland only physical health and not mental health (assessed by the SF 36) was related to early response (Etter & Perneger 1997). Those with better physical health, but also those who had used health services, responded earlier. This survey in a population of young adults and middle-aged persons indicates that a low response rate may result in overestimating the utilisation of health services. On the other hand, surveys in elderly populations have shown that
more non-participants than participants had been hospitalised one year before the survey (Osler & Schroll 1992, Paganini-Hill et al 1993).

In the EC Respiratory Survey in Italy the easy-to-recruit subjects (aged 20 to 44 years) reported a slightly higher prevalence of asthma than the hard-to-reach subjects, but there were no significant differences with respect to reported asthma symptoms (de Marco et al 1994, Vollmer et al 1994). In Spain those reporting at least one respiratory symptom responded earlier by mail and current smokers later (Galobardes et al 1998). In Italy the rate of attendance in the examination was significantly higher for early responders to the questionnaire than for late responders, and for those with greater symptom prevalence (de Marco et al 1994). The effect of different response rates on bias was evaluated. The results show that bias increases rapidly as response rate decreases (de Marco et al 1994). Correspondingly, a higher prevalence of disability was found in early respondents compared to late respondents of a disability survey in England (Locker et al 1981).

A higher level of cognitively impaired persons was found in the initial non-respondents in a community survey of cognitive status in the elderly in USA (Norton et al 1995). In a mailed survey in UK the estimated prevalence of disability remained similar throughout the survey for those aged 65 years and over (Tennant & Badley 1991). For those aged 16-64 years the cumulated prevalence of disability fell as a greater proportion of the survey was returned, indicating a tendency of those with disabilities to reply sooner.

4.2.2. Informed consent

Ethical guidelines for biomedical research (CIOMS 2002) oblige voluntary informed consent of the prospective subject or, in the case of an individual who is not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law. As a general rule, in health research the subject should sign a consent form. A documented consent will also be required by the Council of Europe, in the draft additional protocol to the convention of human rights
and biomedicine, on biomedical research (CDBI 2001). There is no general agreement when a signed consent should be obtained in population based surveys and also the practices vary in HISs and questionnaire surveys. Most ethical guidelines and studies in subject's abilities to give consent refer to clinical trials. In HESs the subjects undergo clinical examinations and give biological specimens and therefore an informed consent must always be obtained. However, any possible risks are minimal also in HESs compared to clinical trials and this simplifies ethical issues.

4.2.2.1. Effect of informed consent

Consent forms used in clinical studies are often overly complex (Cook Gotay 2001, Cox 2002, Peduzzi et al 2002). The participants may be frightened by the informed consent form, if it includes detailed warnings of possible rare adverse outcomes of assessment procedures (Ritchie & Dennis 1999). Some study participants may not later recall reading the consent form or remember someone explaining the form (Cook Gotay 2001). Several studies show that signing a consent form and discussing the study with members of the research team/survey fieldworkers does not imply that subjects are adequately informed about the study. The readability of consent forms and other information on the study is essential (Sugarman et al 1998, Cox 2002, Peduzzi et al 2002). The organisation of the material, writing style, layout, typography as well as cultural appropriateness needs to be assessed. There is some evidence that developing the consent documents in collaboration of the investigators and a focus group of potential participants may be beneficial (Peduzzi et al 2002).

Requiring written authorisation (signed consent) has been found to be associated with lower participation in some population based surveys (Woolf et al 2000, Pokorny et al 2001), whereas no effect has been seen in other studies (Sugarman et al 1999). There is also some evidence that survey participants giving consent to the use of medical records differ in important characteristics from those who do not (Woolf et al 2001). Seeking consent to access medical records did not reduce response rates to a mailed health survey among older people in UK when subjects were randomly assigned to receive questionnaires with or without a consent form (Shah et al 2001). In this survey refusal to access records was also low (13%). In study in USA the
refusal rate to use medical records was much higher (25%), and patients who gave consent were older, less educated, included fewer women and African Americans, and reported poorer physical function than those who did not give consent (Woolf et al 2000). Visits for certain reasons were also associated with lower consent rates. In Finland a recent effort to ask consent to link records to the mailed questionnaire data reduced the response rate by 10 % (Uutela, personal contact 2003).

Very little is known about people's willingness to give consent to genetic and other future research on their own samples many years after the samples were taken, even though this is a typical situation in most epidemiologic studies and HESs. In Sweden most (93%) of the participants in a previous MONICA survey gave consent for their blood to be used for academic genetic research, provided that the ethics committee had approved the research (Stegmayr & Asplund 2002). These persons were contacted by mail 11 years after they had participated in the cardiovascular screening. Of those who gave consent, 22 % wanted to be informed about, and give new consent for, each new genetic project. The rest gave a general consent to genetic research.

In student surveys active parental consent procedures have resulted in low rates of participation (Pokorny et al 2001). Adolescents with active parental consent (written, signed permission to participate) have been more likely to be younger, female, report lower rates of lifetime tobacco use or other negative health behaviours, and have parents who are more involved with them (Pokorny et al 2001, Moolchan & Mermelstein 2002).

4.2.2.2. Informed consent and minors or cognitively/mentally impaired persons

The pressure to participate in research can be characterised as existing on a continuum potentially raising ethical concerns (Brody & Waldron 2000, CIOMS 2002). On one end of this continuum is persuasion, where participants are offered rational arguments to convince them of the benefits of research participation. On the other end is coercion, where participants have virtually no option but to agree to
participate. The difference between persuasion and coercion is especially problematic for those with lower decision-making competence. Obtaining informed consent to research includes ensuring that the individual is competent to decide, receives full disclosure of relevant information and acts voluntarily in the consent process (Cox 2002, CIOMS 2002).

Whether children and adolescents, psychiatric patients, cognitively or mentally impaired persons and other vulnerable persons have adequate capacities to consent to research is a question worth specific attention in the ethical guidelines (CIOMS 2002). The cognitive-developmental needs of the target groups in surveys have to be carefully considered and information and forms may need to be tailored appropriately (Zinner 1995, Moolchan & Mermelstein 2002).

In most countries written parental consent is legally required for studies involving children and adolescents under the age 18. Ethically, investigators should determine also the children's/adolescent's competency and capacity to give consent within the context of the interplay of parental and other influences (Brody & Waldron 2000, Moolchan & Mermelstein 2002, CIOMS 2002). The rights of both the minor as well as that of parents/guardians have to be recognised. The issue of confidentiality is important in research when e.g. teenagers may not readily disclose information on their health and health behaviour to parents (Moolchan & Mermelstein 2002). Zinner (1995) points out the ethical issues rising from parental consent because this excludes the child from making a decision based upon his or her unique personal beliefs, values and goals. She suggests a shift of emphasis from age to competence. Emotional factors (e.g. perceived control over one's life and anxiety) have also been found to be related to children's and adolescents' understanding of research participation in clinical situations (Dorn et al 1995).

Consent-related abilities have been studied with specific competence assessment tools in clinical studies involving psychiatric patients (Appelbaum et al 1999) and persons with Alzheimer's disease (Kim et al 2001). It has been found that even mild Alzheimer's disease significantly impairs consent-giving ability (Kim et al 2001). However, there were no differences in willingness to participate between the persons
suffering from Alzheimer's disease and healthy comparison subjects (Kim et al 2002). A study of outpatients with major depression showed only a few impairments in their decision-making capacities related to research (Appelbaum et al 1999).

Sugarman et al (1998) carried out a literature review of empirical research on informed consent with older adults. Diminished understanding of informed consent information was associated with older age and fewer years of education. Strategies to improve understanding included a variety of novel formats (e.g. simplified forms, using a larger typeface, videos) and procedures (e.g. use of health educators, quizzing subjects, multiple disclosure sessions, multiple individuals providing information).

4.3. Factors supporting or reducing response and participation in health surveys

4.3.1. Public attitudes towards medical research

Empirical literature on public attitudes regarding participation in medical research in virtually non-existent and refers to clinical trials (Trauth et al 2000). Negative beliefs and lack of knowledge about research have been identified as barriers to participating in studies (Sugarman et al 1998, Brown et al 2000). Other factors found to inhibit study participation include perceptions that the costs of participating are greater than potential gains, concerns about time constraints and inconvenience, interference with work/family responsibilities, and desire to control decisions affecting personal health and well-being (Brown et al 2000). Altruism and the desire to foster the progress of medical research facilitate participation. However, general support for the use of humans in medical research does not necessarily translate into individual willingness to participate (Trauth et al 2000).

The general trend towards decreasing response rates in national health surveys has been reported in several European countries. E.g. in the annually conducted Finnish survey on health behaviour and health among adult population, the response rate for the mailed questionnaires decreased quite steadily from 84% at the end of 1970s to
65% in 2002 (Helakorpi et al 2002). The reasons for this trend have not been studied and they may be very difficult to study, but many changes in lifestyle and living conditions may contribute in addition to changes in public attitudes and in the number of studies (Groves & Coupier 1998).

### 4.3.2. Reasons for refusal to participate

In a few studies feedback questionnaires have been used to find out reasons for participation or non-participation. Conducting focus groups may also be a useful tool to identify effective recruitment methodologies (Ritchie & Dennis 1999, Brown et al 2000). Studies have shown that the belief that the study is important and interesting is a strong motivator (Hellard et al 2001). When reasons for refusal to participate in health surveys have been documented they have comprised factors related to own health status and age, personal interests, attitudes, and lack of time. Often the following reasons have been listed for non-participation: not interested, too ill or infirm, no time, invasion of privacy, too old, poor language skills, seeing own doctor regularly, seeing too many doctors and general antipathy to surveys (Clarke et al 1990).

In studies of older adults the main reasons for refusal have also included caregivers or family members who try to protect the elderly from any potential harm (Ritchie & Dennis 1999). In some cultures fear of crime may lead to unwillingness to open doors to strangers which restricts personal interviews and examinations during home visits (Cottler et al 1987).

In a mental health survey in Australia respondents were asked if the questionnaire had made them feel distressed or depressed, and if it had been an intrusion on privacy (Jacomb et al 1999). Only a small number (5% or less) reported negative effects, while over one-third reported that the questionnaire made them feel good about themselves. Those reporting some distress from the interview tended to be younger and have higher education. They also reported less social support and higher anxiety and depression. Those who felt that some of the questions were
intruding on their privacy also showed similar characteristics, plus a higher level of alcohol consumption. It is possible that the characteristics of persons becoming distressed during participation are similar to the characteristics of those refusing to take part.

4.3.3. Promoting and motivating participation: Acceptance, awareness and access

By synthesising data from literature reviews, focus groups, surveys, one-to-one interviews and direct experience from recruiting diverse populations of women for research, Brown et al (2000) developed a conceptual model. This model outlines the interplay of three factors found to be relevant to the recruitment of diverse populations into research studies: awareness, acceptance, and access.

**Awareness** is defined as an understanding of the importance of research, the procedures during the research process, and the value of the individual's participation (Brown et al 2000). These can be supported by the development of educational materials and through personal contacts of possible subjects with study recruiters. Recruiters' communication skills and their ability to relate to subject populations are essential. Barriball and White (1999) suggest that conveying the importance and usefulness of the study is the factor which most influences a respondent's decision to participate. The interviewers and other survey personnel need to be sensitive to the individual, social and historical concerns of the participants (Kessler et al 1995, Ritchie & Dennis 1999). Successful interviewers seek to engage the person in conversation in an effort to obtain cues about potentially useful persuasion messages before asking for an interview (Kessler et al 1995). Groves and Coupier (1998) name this as tailoring, and consider it as an essential part of interviewer's skill's.

**Acceptability** is defined as social support for participation, reflected in the messages disseminated by community leaders and through media (Brown et al 2000). Media campaigns, newsletters, fliers and brochures can be used to highlight the importance of research participation. Researchers should obtain an understanding of what is of
value to the community. The salience and interest of the survey topic for the respondent is a powerful determinant of response rate (Clarke et al 1990). It is also important that research findings are disseminated in a manner accessible to communities. Some form of reciprocity may be necessary to improve relationships between research institutions and the communities (Brown et al 2000). It is essential to inform other persons in addition to the subjects themselves. E.g. objections by the subject's physician or a family member have been found to be common reasons reported for non-participation of older adults (Carter et al 1991). Clarke et al (1990) recommend energetic consultation before the survey, both with community representatives and with powerful people who can influence the community's perception of the survey.

Promoting access means reducing the practical barriers to participation, e.g. through transportation, understandable consent forms, translation services in multilingual populations, and financial remuneration (Brown et al 2000). Transportation may be especially crucial for older adults (Tell et al 1993).

In health examinations the treatment of subjects at the examination site is essential. The absence of waiting, the immediacy of receiving the results of the measurements, as well as positive atmosphere at the study centre and the manner of the staff may motivate participation (Clarke et al 1990, Hertge 1999). Personal benefits promote participation. These may include acquisition of new knowledge about health and rapid feedback to the participants regarding their test results and assessments (Clarke et al 1990, Ritchie & Dennis 1999).

Different motivations related to satisfaction with health care can play a role in the decision to participate in a health examination survey (Rodes et al 1990). Regimented and rushed attention, and lack of privacy may cause frustration in participants, and lead to future negative attitudes towards surveys. To avoid this, local volunteers have been used as hostesses or hosts at the field centre to attend to the participants' needs and provide company (Tell et al 1993).
4.3.4. Effect of survey protocols and incentives

The effect of different survey protocols on response rate has mainly been studied in mailed surveys. A randomised mail survey in Switzerland showed that a prior letter informing of the results of previous surveys and announcing the future survey neither improved nor decreased participation (Etter et al 1998). In this study a professional layout (with e.g. various colours and fonts) reduced the response rate, while other studies (e.g. Edwards et al 2002) have indicated increased response when using coloured ink. The response rate has not been related to the length of the questionnaire in some studies (Asch et al 1997, Hoffman et al 1998), while other studies have shown that shorter questionnaires increase response rates (Kalantar & Talley 1999, Edwards et al 2002). Some studies indicate that sensitive questions are not as readily answered by telephone or by face-to-face interview as by mail or self-administered questionnaires (Siemiatycki et al 1984).

According to ethical guidelines, subjects may be reimbursed for lost earnings, travel costs and other expenses incurred in taking part in a study (CIOMS 2002). They may also be paid or otherwise compensated for inconvenience and time spent. Many health researchers are reluctant to use monetary incentives (Wedeen 2000, Smeeth & Fletcher 2002), since the payments may raise questions of both equity and autonomy. Undue inducement, coercion, selection bias towards the poor, and distortion of the researcher-subject relationship are cited by critics of financial incentives in medical research (Wedeen 2000).

Monetary or lottery incentives have increased response in studies using mailed questionnaires (Perneger et al 1993, Asch et al 1997, Kalantar 1999, Martinson et al 2000, Roberts et al 2000, Shaw et al 2001, Edwards et al 2002) and especially among subjects with least interest in the subject of the survey (Roberts et al 2000). The use of direct payments seems to be more effective than lotteries (Roberts et al 2000). No studies were found on the effect of incentives on participation in health examinations. A review of literature on recruitment for community based quit smoking programs suggested that use of incentives is not associated with the success of recruitment (McDonald 1998).
Some researchers question the relative importance of financial inducements, especially if the study is conducted with several data collection phases and methods (Hellard et al 2001). In such studies other factors like the nature of contacts between the survey personnel and the participants may be of more importance. When monetary incentives are used, it is important to understand what subjects perceive as an adequate amount for their effort involved (Kessler et al 1995, Brown et al 2000). Incentives can sometimes lead to lower response rates, either because people believe that the value of the incentive indicates that their time is undervalued or because the incentive undercuts the motivation of people who believe that social utility should be the reason for participation (Kessler 1995).

4.4. Non-response bias

4.4.1. Defining response rates

Careful documentation of the recruitment process is needed to show response rates in a comparable way. A recent review of randomised, controlled trials identified sporadic and incomplete reporting of the recruitment process (Gross et al 2002). This seems to be true for many health surveys as well. In some studies response rates are reported based on the number of individuals sampled while others report response rates of eligible individuals (Riedel-Heller 2000). The comparison of response rates is difficult as there is no uniformly applied definition of eligibility (Asch et al 1997).

In principle, it should be easy to agree that non-response is calculated from the number of persons sampled after removing those not belonging to the target population, i.e. those who had died and those who do not live in the country/area any more. However, investigators do not agree on how to deal with the categories of "too ill" and "never reached" when calculating response (Stang et al 1999). Uncertainty about the definitions used in some study centres and inconsistency of the participation rate information from different sources of data was identified even in a survey using common manuals for the definition and calculation of eligibility and non-respondents (Wolf et al 1998). Slattery et al (1995) suggest that when those with
unknown eligibility and verified noneligibility are excluded from the denominator, the term co-operation rate should be used rather than response rate.

To promote comparability of response rates, first, the target population has to be defined, i.e. location and characteristics of potentially eligible persons. This represents the population to which the survey's results are expected to apply. Second, the eligibility fraction shows the proportion of potential participants who are eligible to participate. Typically the individuals selected in the original sample who died or moved out of the area before the survey are called ineligibles. Third, the enrolment fraction defines the proportion of people who are eligible for participation and who can be contacted. Finally the recruitment fraction shows the proportion of potential participants who actually participate. (Gross et al 2002).

Slattery et al (1995) use the terms contact, co-operation and response proportion. The contact proportion shows the effect of those not contacted because inability to locate a telephone or address or unable to reach subject, including people who moved away and those who died, and the co-operation proportion the effect of those refusing participation. Stang et al (1999) introduce recruitment efficacy proportion excluding from the response proportion non-participating subjects who died, moved away, or were too ill. Unfortunately the last category introduces bias to health surveys.

Three types of non-response in surveys can be defined at different stages of the study process (Barriball & White 1999). During sample selection non-coverage can occur when the sampling frame omits some units of the survey population either accidentally or deliberately. During recruitment unit non-response may be due to refusal or non-contact. During data collection item non-response may occur when the subject is unable to answer a particular question or the interviewer fails to ask the question by mistake.

Due to the differences in sample selection and recruitment and the lack of common eligibility criteria it is very difficult to define a simple figure representing an acceptable response rate. The EHRM project recommends that the response rate should be at
least 70% for all population sub-groups of interest (Tolonen et al 2002). Multi-centre studies conducted in several European countries have shown that participation rates differ a lot by country and by local study centre (O’Neil et al 1995, European Community Respiratory Health Survey 1996, Wolf et al 1998). Lower response rates have been typically reported in southern Europe and higher in northern countries. Differences in response rates have been explained by cultural factors, but there may also have been some differences in recruitment and fieldwork procedures, even though the survey protocols have been similar in broad outline.

4.4.2. Differences between respondents and non-respondents

Register linkages, audition of medical records, questionnaires mailed to non-respondents (abbreviated versions if needed for these non-participant surveys), and brief telephone or face-to-face contacts are typical sources of information about individuals declining to participate or unable to participate. For surveys where data is collected in several phases, information from the subjects attending the first phase, typically a mailed questionnaire or interview, has been compared to the data of subjects attending the next phase, e.g. the examination. Also the results of other surveys conducted with the same target population have been used to compare the observed prevalence of some health status characteristics and risk factors to the corresponding results from another recent survey in the same population (e.g. Manjer et al 2001).

A simple comparison of the characteristics of responders with known population characteristics, e.g. their age and sex, says little or nothing about the characteristic under study. It may lead to unjustifiable confidence about the lack of bias (Tennant & Badley 1991).

Most studies, both HISs and HESs, have found significant differences between the participants and the non-participants. The participants have been of higher socio-economic status (Bergstrand et al 1983, Carter et al 1991, Pullen et al 1992, Davies et al 1994, Pietilä et al 1995, Hoeymans et al 1998, Boeing et al 1999, Freudenstein

In most surveys the participants have had fewer sickness benefit days (Bergstrand et al 1983, Goldberg et al 2001), a lower prevalence of disabilities (Tell et al 1993, Hoeymans et al 1998) and better health status (Tell et al 1993, van't Hof et al 1996, Hoeymans et al 1998, Boeing et al 1999, Manjner et al 2001) than the target population or than the non-respondents. Especially the prevalence of substance abuse and other psychiatric diagnosis has been higher among non-respondents than among respondents (Rosengren et al 1987, Kessler et al 1995, Pietilä et al 1995, Goldberg et al 2001, Hansen et al 2001). Cognitive impairment has also been identified as a determinant of non-response in community surveys of older adults (Norton et al 1994, Riedel-Heller 2000). In contrast to most findings, the prevalence of disabilities, symptoms or diseases was higher among participants (those completing the interview and clinical phase) in an oral health survey (Locker 1993).

The participants have fewer risk factors (e.g. more non-smokers and non-obese) than non-participants (Pullen et al 1992, Tell et al 1993, Goldberg et al 2001). However, some studies have not found any significant differences (Davies et al 1994, Weinheil et al 1998, Manjer et al 2001). In a few studies with mailed questionnaires health service use was more abundant among respondents (Etter & Perneger 1997, Freudenstein et al 2001). In contrast, in a local HES in Sweden most of the non-participants (middle-aged men) had recent contacts to health care either as high-consumers of health care, or because they had attended a health examination at work (Persson et al 1994). In a Canadian survey especially the very elderly non-
respondents used more medical services than responders, and had a higher number of hospital admissions, and longer average lengths of stay (Rockwood et al 1989).

A review of participation of older adults in health programmes and research showed that persons with lower incomes and education as well as smokers consistently participated less frequently (Carter et al 1991). This review indicated that health status, social support, obesity, drinking habits, and recent medical care use may or may not be related to participation, depending on the programme or study.

Several studies have shown biased estimates of morbidity rates, disabilities and risk factors due to non-response (Hoeymans et al 1998), but there are some exceptions where no major bias has been reported (Cottler et al 1987, Andersen et al 1998). In a review of prevalence studies of dementia Riedel-Heller et al (2000) found that cognitively impaired individuals are likely to be underrepresented in most community studies. Excluding individuals who can not be examined or tested due to fragility and sensory impairment results in a healthier and positively biased sample.

Non-response has also been shown to cause bias in the associations between diseases and disabilities and self-rated health (Hoeymans et al 1998). The direction and magnitude of this bias may vary according to type of disease and health outcome and is therefore difficult to predict.

Prospective studies have shown that mortality rates among participants have been lower than in the whole sample, or lower than among non-participants (Rosengren et al 1987, Bengtsson et al 1997, Andersen et al 1998, Goldberg et al 2001, Manjer et al 2001). Excess mortality among the non-participants has been found to be due to diseases directly related to high alcohol use and smoking, life-style related cancers, cardiovascular diseases, accidents, and suicides (Rosengren et al 1987, Goldberg et al 2001, Manjer et al 2001).

In a few surveys information from other sources, e.g. from medical records, has been included in the data collection to reduce non-response. In a Spanish survey on the
prevalence of dementia, Parkinson’s disease and stroke (Bermejo et al 2001) the examination non-participation rate was reduced from 34 % to 2% by also including as participants the persons who were not examined but for whom there was adequate diagnostic information (e.g. from local physicians). A national Finnish survey on dementia took into account findings on the 90% of health examination participants and added to this data from abstracted hospital records on both participants and non-participants resulting in what was believed to be a complete count of persons with severe dementia in the sample (Sulkava et al 1985).

It is important to obtain the same additional information also on the total sample and not only on the non-respondents since it has been recognised a long time ago that information from medical records can be different from interview or examination data from the same persons (Madow 1967).

### 4.4.3. Proxy respondents

The validity of proxy responses has been questioned in several studies, both for the elderly (Hoeymans et al 1998, Neuman et al 2000, Ball et al 2001), for children (Rajmil et al 1999) and for the general adult population (Siemiatycki et al 1984, Clarridge & Massagli 1989, Grootendorst et al 1997, Todorov & Kirchner 2000). It has been shown that proxies consistently under-report morbidity and health care utilisation (Siemiatycki et al 1984, Clarridge & Massagli 1989, Grootendorst et al 1997), systematically underestimate the health status of the respondent (Hoeymans et al 1998), and report poorer function than the older patients themselves (Ball et al 2001).

There may be differences in the validity of proxy reports by the type of proxy, and their relationship with the subject, by age of subject and by type of disease or disability. In the US National Health Interview Survey on Disability proxies underreported disabilities for people aged 18 to 64 years but over-reported them for people 65 years and older (Todorov & Kirchner 2000). A review of clinical studies using proxy replies as a source of information about older adults showed fairly good agreement between subjects and proxies in assessments of functioning, physical...
health, and cognitive status and fair to poor agreement in assessments of psychological well-being (Neuman et al 2000). Several studies have found larger differences between self and proxy responses for subjective psychosocial dimensions than for more observable and chronic physical dimensions (Clarridge & Massagli 1989, Grootendorst et al 1997, Dewey et al 2000, Todorov & Kirchner 2000). Proxy respondent's characteristics such as their age, sex and relationship with the subject can influence responses to health surveys (Rajmil et al 1999, Dewey et al 2000).

5. CONCEPTUAL FRAMEWORK FOR SURVEY PARTICIPATION

The components of survey participation to be taken into account when evaluating surveys carried out in different countries and at different times are summarised in the conceptual framework presented in Figure 5.1. Some of these characteristics are mainly outside researcher control while others can be directly controlled. However, while the social environment may be mostly out of researcher control, use of media and contacts with community leaders and support received from them may have an impact to public attitudes towards surveys in general and towards a specific survey.

Factors related to the social environment affect e.g. the social responsibility received by the subject. The legitimacy of organisations responsible for the survey, the perceived legitimacy of surveys in general and the number of surveys conducted in a society (the "over-surveying" effect), as well as factors related to urbanicity affect survey response (Groves & Couplier 1998). Urbanicity is internationally one of the most universal correlates of survey participation. It is related to fear of crime, faster pace of life and looser ties between persons in the community.

Characteristics of the individual subject and/or household affect survey co-operation by producing a set of personal pre-dispositions affecting the decision. Feelings of efficacy or social isolation and moods of depression or anger are affected by these characteristics.
Factors related to the social environment and characteristics of the individual subjects or households affect contactability and willingness to participate in surveys. Contactability is a function of physical impediments to access, at-home patterns, and the timing and number of contacts.

Attributes of the survey design and fieldwork affect the potential benefits or discomfort of the survey to the individual respondent. Evoking authority in mailed advance letters before interviewer contact and emphasising the value of the respondent are examples of procedures aiming at high participation.

Attributes of the interviewer are reflected on the subject-interviewer interaction. These may be the interviewers' ability to adapt their approach to build a personalised approach with most respondents. While standardisation in the measurement phase is a basic requisite of validity and reliability, it has no proven value at the recruitment phase (Groves & Coupier 1998). The interviewers and other survey personnel need information on all potential characteristics related to participation to be able to tailor and customise approaches during recruitment. Tailoring is also needed in HIS/HESs during the examination phase. Even though it is essential that the measurements are carried out strictly according to the standardised protocols, the interaction between the survey personnel and the subject may be tailored. E.g. the general introduction about what is going to happen during the examination may be tailored as well as the information about the subject's personal test results. There should be a common proven good recruitment practice around which tailoring and individualisation should take place.

Important aims in the subject-interviewer/survey personnel interaction during recruitment are to promote awareness of the survey protocols and the value of participation (in general and personally), acceptability as social support for participation, and access as removed practical barriers to participation (Brown et al 2000). Especially in HIS/HESs including several phases of data collection (e.g. interview before examination and/or different tests/measurements carried out by several persons during the examination) the subject-interviewer or subject-survey
personnel interaction is essential during the whole data collection, not only during the first contact when consent to participation is sought.

The significance of all factors included in the conceptual framework has not been proven and there are conflicting results concerning some factors' effects on participation. However, there is at least some practical evidence on all factors in the framework indicating that they should be taken into account in survey planning, implementation and evaluation.

The conceptual framework shows that understanding survey participation requires attention to very practical features of the whole study process. The factors that influence the survey participation decision are a function of a dynamic social communicative process. The decision to co-operate or refuse is also affected by several random factors. These are e.g. that the subject is contacted and interrupted at a bad moment. Thus the decision is not always a result of rational reasoning, but it is rather based on several ad hoc influences.
Figure 5.1 A conceptual framework for health survey co-operation (adapted from Groves & Coupier 1998)

- **Mainly out of researcher control**
  - **SOCIAL ENVIRONMENT**
    - Survey-taking climate (public attitudes)
    - Economic conditions
    - Neighbourhood characteristics
    - Support from community leaders
  
  - **SUBJECT/HOUSEHOLD**
    - Marital status, age and sex/household structure
    - Socio-demographic characteristics (education, socio-economic status etc.)
    - Psychological predisposition and personal attitudes
    - Social activity and social support
    - Health status
    - Health behaviours
    - Use of health care

- **Mainly under researcher control**
  - **SURVEY DESIGN AND FIELDWORK**
    - Topic
    - Mode of administration
    - Respondent selection
    - Recruitment
    - Fieldwork procedures
  
  - **INTERVIEWER/SURVEY PERSONNEL**
    - Socio-demographic characteristics
    - Experience and expectations
    - Communication skills
    - Training received

- **SUBJECT-INTERVIEWER/SURVEY PERSONNEL INTERACTION**
  - Promoting
    - acceptability
    - awareness
    - access

- **DECISION TO COOPERATE OR REFUSE**
6. REPRESENTATIVENESS AND PARTICIPATION IN NATIONAL HEALTH SURVEYS IN EUROPE

This section includes results based on the HIS/HES database and detailed information (questionnaires and documents) collected from national health surveys from six EU countries:

- Finland, the Health 2000 Survey (HIS/HES)
- Germany, the National Health Interview and Examination Survey 97/99 (HIS/HES)
- The Netherlands, the Regenboog survey 1998-2001 (HIS/HES)
- UK, the Health Survey for England in 1999 and in 2000, and the Scottish Health Survey in 1998 (HIS/HES)
- Italy, the Health Conditions and Use of Health Services in 1999/2000 (HIS)
- Belgium, the Health Interview Survey in 2001 (HIS).

All five national HIS/HESs carried out in EU countries were selected since it was acknowledged that it is more difficult to achieve high participation in health examinations than in interviews. The two HISs were selected as different examples from the point of view of sampling and participation. The Italian HIS represents a survey with one of the largest sample sizes in Europe and high participation. The Belgian survey represents a survey with an average sample size in European countries and a relatively high non-response rate. If detailed information on response and refusals was not available from these latest surveys, reported data from previous rounds of these surveys was used.

Results based on information from the database will be presented separately for the national HISs (43) and the HIS/HESs (12) or, when necessary separately for the interviews (50 HISs including the HIS parts of HIS/HES) and for the examination (12 HES). This is to show differences in the response for the interview and for the examination part of the survey.

The period 1998-2002 was examined although the database includes also previous surveys from several countries. However, not all earlier surveys from all countries are
included. When the survey methodologies in different countries are compared, it has to be taken into account that there may be other previous surveys not taken into account in the present report. Therefore it is e.g. impossible to say that e.g. children or the elderly have not been included in the health surveys in some of the countries, as there may be other previous surveys including these age groups. In addition, there may be other age-group specific surveys not meeting the inclusion criteria for the HIS/HES database.

6.1. Sampling

6.1.1. Target population and sampling frame

Information from the database shows that both household and individual samples were used in the national surveys. Household samples were used for 20 HISs and 6 HIS/HESs, and individual samples in 20 HISs and 6 HIS/HESs (Table 6.1).

Household samples were used in HISs in seven EU/Efta countries and individual samples in seven countries. For HIS/HESs individual samples were used in all countries (DE, FI, IE, NL), except UK. Several HISs with both individual and household samples were carried out in four countries (DE, FR, IE, UK). If household samples were used, all persons in the household were included in the survey (16 surveys), or a limited number of persons (7 surveys, selecting 2-4 persons for the survey and 3 surveys selecting only one person). In case of individual samples also some or all other members in the household were included in three surveys. Information on sampling was missing or unknown in the database for three surveys.

In the seven surveys chosen for detailed analysis a sample of individuals was used in all surveys, except for the Belgian, UK and Italian surveys using household samples (Annex Table 1.). The samples were selected from a national registry of the population in Belgium, Finland, Germany and the Netherlands. The municipality registry was used in Italy and address files were used in UK.
In Belgium up to four persons in the selected households were interviewed, the reference person selected from the National Register and his/her partner, and two other persons selected by the “Birthday rule” (the persons who have their birthday coming up first after the interview). In Scotland one adult and up to two children aged 2-15 years were selected at random from the household. In England all adults and up to two children were selected at random. In England the 1999 survey sample was split into two: the usual general population sample of households and the ethnic minorities boost (Black Caribbean, Indian, Pakistani, Bangladeshi, Chinese and Irish). In the ethnic groups boost up to four adults and three children were selected at random. The sample of the year 2000 survey in England included a care home sample in addition to the private household sample.

Table 6.1 Target population and type of sample in the 55 national surveys in EU/EFTA countries (number of surveys during period 1998-2001).

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<th>Household</th>
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<th>Institutionalised included</th>
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<td>1 HIS**</td>
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<tr>
<td>BE</td>
<td>1 HIS</td>
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<td>2 HIS**</td>
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<td>5 HIS</td>
<td>3 HIS</td>
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<td>DE</td>
<td>1 HIS</td>
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<td>2 HIS</td>
<td>2 HIS, 1 HES</td>
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<td>NL</td>
<td>3 HIS, 1 HES</td>
<td></td>
<td></td>
<td>3 HIS, 1 HES</td>
</tr>
<tr>
<td>NO</td>
<td></td>
<td></td>
<td></td>
<td>2 HIS</td>
</tr>
<tr>
<td>PT</td>
<td>1 HIS</td>
<td></td>
<td></td>
<td>2 HIS**</td>
</tr>
<tr>
<td>ES</td>
<td>1 HIS</td>
<td></td>
<td></td>
<td>2 HIS</td>
</tr>
<tr>
<td>SE</td>
<td>2 HIS</td>
<td>2 HIS</td>
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<td>2 HIS</td>
</tr>
<tr>
<td>CH</td>
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<td></td>
<td></td>
<td>1 HIS</td>
</tr>
<tr>
<td>UK</td>
<td>3 HIS, 6 HES</td>
<td>1 HIS</td>
<td>1 HIS, 1 HES</td>
<td>5 HIS**, 6 HES</td>
</tr>
<tr>
<td>Total</td>
<td>20 HIS, 6 HES</td>
<td>20 HIS, 6 HES</td>
<td>13 HIS, 4 HES</td>
<td>43 HIS**, 12 HES</td>
</tr>
</tbody>
</table>

* HIS= General HIS, disability surveys, health education/lifestyle or living conditions surveys etc. with a specific health module/section. HES= Combination of HIS and HES, surveys including a health examination to all/some participants of HIS
** HIS including health modules within a "Microcensus", General Census or a General socio-economic survey to all citizens
Institutionalised persons were included in the sampling frame of 13 HISs and 3 HIS/HESs. There may be separate surveys carried out in institutions, specific disability surveys or surveys on psychiatric morbidity including these persons. Institutionalised persons were included in at least one survey in seven EU/Efta countries. If institutionalised persons were included it was most common to include persons living in homes for the elderly (12 HIS and 3 HIS/HES) or in nursing homes (11 HIS and 4 HIS/HES). These institutionalised elderly persons were included in eight EU/Efta countries. Persons living in psychiatric institutions (10 HIS and 2 HIS/HES), in institutions for the mentally handicapped (8 HIS and 2 HIS/HES), or in boarding schools (8 HIS and 2 HIS/HES) were included in five countries. Those living in convents and monasteries (7 HIS and 2 HIS/HES in four countries), and those in prisons (9 HIS and 2 HIS/HES) were included in four countries. Special surveys among homeless and in prisons were planned in France.

In the surveys selected for the detailed analysis all residents were included only in the Finnish survey (Annex Table 1.). In other surveys some or all institutionalised persons were excluded. In year 2000 the English survey included an additional sample of elderly people aged 65 and over in nursing homes and in homes for the elderly. In Belgium persons living in homes for the elderly and in nursing homes were included, but those in prisons and in monasteries and cloisters were excluded. In Italy people living in homes for the elderly for less than two years and people in prisons for less than five years were included.

In the Netherlands, Germany and UK residents not fluent with survey languages were excluded. As an exception to this the 1999 survey in England included the minority ethnic groups and seven foreign languages were used in addition to English (Hindi, Gujarati, Punjabi, Urdu, Bengali, Mandarin and Cantonese). Non-citizens (e.g. refugees) were excluded in Belgium, Italy and in UK. In Scotland about 90 inhabited islands with very small populations were also excluded from the sampling frame.
6.1.2. Sampling procedures, stratification and over-sampling

Multistage probability sampling was used in most surveys (Table 6.2.1) and in all countries except in Iceland, Luxembourg and Sweden. Simple probability sampling was not used as often (in six countries). Other sampling procedures were rare (two countries). Other procedures included one-stage cluster sampling, a sample based on former health surveys and screening in one disability survey.

**Table 6.2.1** Sampling procedure in national HIS and HIS/HES surveys in EU/EFTA countries (number of HIS and HIS/HES carried out 1998-2002).

<table>
<thead>
<tr>
<th>Sampling procedure</th>
<th>HIS (Total 43)</th>
<th>HIS/HES (Total 12)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multistage probability</td>
<td>29</td>
<td>11</td>
</tr>
<tr>
<td>Simple probability</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Unknown/missing</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Stratification by</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Geographic area</td>
<td>27</td>
<td>10</td>
</tr>
<tr>
<td>Degree of urbanisation</td>
<td>12</td>
<td>2</td>
</tr>
<tr>
<td>Age</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Sex</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Other variables</td>
<td>7</td>
<td>7</td>
</tr>
</tbody>
</table>

In multistage probability samples stratification by geographic area was most common (in 14 countries). Stratification by degree of urbanisation (in seven countries), and by age (in six countries) was also common. Stratification by sex (in four countries) was rare. Other stratification variables were used in seven countries, including variables such as household size, size of building, size of municipalities, city blocks, severity of impairment/disability or responses to the screening survey (in disability surveys), occupation and other socio-economic indicators.

Over-sampling for certain groups of persons was applied in eight HISs and in five HESs in seven European countries. This meant over-sampling of certain geographic areas (e.g. certain provinces or sparsely populated areas), of certain age groups
(children, adolescents, or the elderly), of severely disabled persons (disability survey) or of specific ethnic groups.

6.1.3. Some details on sampling procedures

In Belgium stratification by region was applied with fixed sample size (3000-3500) for three regions (Van Oyen et al 1997, Renard et al 1998, Burzykowski et al 1999, Demarest et al 2001). The second stratification was at the level of the provinces with the sample size proportional to the population size of the province (12 strata). Over-sampling was applied for the city of Brussels, the German community and four provinces. In 2001 the provinces were encouraged to make extra funds available, enabling province-specific analysis. Four provinces (out of ten) agreed to pay for this over-sampling. In the third stratification the primary sampling units (municipalities) were selected within each stratum by a weighted systematic sampling procedure (total 178). The population density was ranked from large to small. Larger municipalities had a greater probability to be selected. In the fourth stratification stage, the secondary sampling units, households were selected after ranking them hierarchically by statistical sector, household size and age of the reference person. Three replacement households living in the same (or near by) statistical sector, having the same household size and age of the reference person were selected for each household. In the last step the individuals were selected within the household (up to four persons).

In Finland 80 clusters were selected in the first sampling phase (Aromaa & Koskinen 2002), 16 in each research region (five University Hospital regions). These 80 areas were local health centre districts, covering 160 municipalities. 15 areas/clusters with the highest number of inhabitants were forced into the sample, and for the rest (65 areas/clusters) the probability to be included was proportional to the number of inhabitants. The number of people sampled was proportional to size in the first 15 areas, and equal within the research centre district in the other 65 areas. The sampling plan was developed in Statistics Finland and in the Social Insurance Institution drawing the sample from the national registry of population. The total
population was considered the target population, only a few small island municipalities on the coastline were excluded from the sampling plan. The aim was to select 10,000 persons aged 18 and over and the final sample consisted of 8,028 persons aged 30 and over (invited to the HIS/HES), and 1,894 persons aged 18-29 years (HIS only). Finally an additional sample of 1,260 persons from seven municipalities was taken from the participants in the previous national HIS/HES, the 1978-80 Mini Finland Survey (for a follow-up study of those aged 50 and over). Over-sampling was applied to those aged 80 and over. For these persons the probability to be included in the sample was twice as high as for persons aged under 80.

**In Germany** 120 samplepoints (municipalities) were first selected, second the city areas/electoral districts were selected, and third the persons were selected from resident registries (Bellach et al 1998). Over-sampling for inhabitants of the former GDR was applied (40 samplepoints in the west and 80 in the eastern part of the country).

**In Italy** the sample was drawn using a two-stage design with stratification of the primary sampling units (municipalities). The country is divided in 20 regions. Municipalities of each region were divided into the following groups: 1) metropolitan areas, 2) municipalities close to metropolitan areas, and 3) other municipalities stratified by population size and altitude. The municipalities of each group were classified as Self Representative units (SR) and Non Self Representative units (NRS) according to a threshold based on demographic size: a SR municipality was itself a stratum, whereas NRS units were stratified in strata of approximately equal size in terms of resident population. Municipalities were selected with probability proportional to size, while households (secondary sampling units) were selected with equal probability. In the 1999-2000 survey, the sample consisted of 60,110 households selected from 1464 municipalities.

**In England** ethnic groups were over-sampled in 1999 and those aged 65 and over in 2000. For the 1999 Health Survey for England the general population sample was about half the size of previous years. The survey included three independently designed samples. For the **general population sample**, a random sample of 6,552
addresses was selected from the Postcode Address File. Before selection postal sectors were stratified by Health Authority and then listed in order of percentage of households with a head of household in a non-manual occupation (taken from the 1991 Census of Population). First 312 postcode sectors were selected systematically as primary sampling units, with each postcode sector being given a probability of selection proportional to its total number of addresses. 21 addresses were selected within each sector. The minority ethnic boost sample of 26 528 addresses was selected from another 408 postcode sectors. Before selection all postcode sectors in England were assigned to one of eight strata based on the proportion of residents (taken from the 1991 Census of Population) in the sector who were Black Caribbean, Indian, Pakistani, Bangladeshi or Irish. All the sampled addresses were fully screened. At these addresses, only persons from the specified minority ethnic groups were eligible. A further 37 632 adjacent addresses were covered by focused enumeration, by asking neighbours to identify members of minority ethnic groups living in adjacent addresses. The boost sample of Chinese informants was obtained by following addresses (569) found to contain Chinese households in a previous study.

For the English care home sample in 2000, five categories of care homes were chosen, as these were most likely to contain older residents. The eligible categories were public (local authority) residential homes, private nursing homes, dual registered homes, private residential homes, and private small residential homes. 677 care homes were selected and 604 care homes were eligible for the survey. In each care home, up to six residents aged 65 and over were selected for the survey.

In the English surveys indicators of the socio-economic status of the population were used in the stratification. These were proportion of the population aged 16 and over with limiting long-standing illness, proportion of households with head in non-manual occupation, proportion of households with no cars, and proportion of population non-white.

To allow regional comparisons in Scotland seven ‘regions’ were defined for the purposes of the survey aggregating (mainly) contiguous Health Boards. The two least
populated regions were slightly over-sampled. Within each region the selection of postcode sectors was carried out separately, in general with probability proportional to size (the number of addresses). Indicators of the socio-economic status in the population used in the stratification were overcrowding, male unemployment, low social class and households with no private car (the Carstairs index for deprivation). All postcode sectors were first ordered by region and by the Carstairs index, and then 312 of the sectors were systematically selected. Within these sampling points (sectors), addresses (46/section) were selected from the Postcode Address File (PAF). At each residential address up to three households were selected randomly by interviewers using specially designed random number tables (computer-generated selection digits). However, selection of more than one household was rare. Within each household, one person aged 16-74 and up to two children aged 2-15 were selected randomly to be included in the survey.

In The Netherlands the HIS (POLS) sampling frame was based on the 'Municipal Administration' (Gemeentelijke Basisadministratie (GBA)). A two-stage design was applied. First, municipalities were sampled proportional to their size (number of citizens). Secondly, within these municipalities individuals were sampled. The number of individuals from each municipality depended on the size of the municipality. As background information was not included in the sampling frame, names and addresses as well as information on sex, date of birth and marital status was requested from the municipalities. This information was needed to contact the respondents and to allow analyses of non-response.

The Dutch HES sample was based on the HIS sample. For the HES two additional selection criteria were applied. First, individuals aged 12 years or more were selected (whereas no age limits were applied for the HIS). Secondly, the selection of municipalities was in 2001 restricted to 39 GGD regions out of a total of 43 regions in the country (Gemeentelijke Gezondheidsdienst/Municipal Health Authority/Health centre regions). This was based on the decisions made in the health centres to join the project. No over-sampling for certain groups of persons was applied in the Netherlands.
For the HES phase only those first interviewed were invited in the Netherlands and in UK. In UK the participants also filled in self-administered questionnaires during/after the interview phase. In Finland all belonging to the sample, i.e. even those who had not participated in the interview were invited to examinations and if needed (and if the participant agreed) a short version of the interview (and self-administered questionnaires) was conducted during the clinic/home visit for examination. In Germany there was no interview phase before the examination. The German participants filled in self-administered questionnaires before or during the examination and there was a medical interview with questions on illnesses and use of medicines, carried out by a physician during the examination.

6.1.4. Age limits and sample size

No age-restriction or age limits were applied in 20 HISs and 2 HIS/HESs (at least one survey with no age limits in ten countries). If age limits were applied, the lower limit ranged from 2 years (UK) to 20 years (IS) for HIS and from 2 years (UK) to 30 years (FI) for HES. Children under the age of 15 were included in 24 HISs and in 6 HESs. The upper age limit ranged from 64 to 84 years.

The household sample size (the net/crude sample) for HIS in EU/EFTA countries ranged from 2431 (LU) to 79 000 (E). The mean household sample size for HIS was 16 375. The household sample size for HES ranged from 6343 (UK/E) to 15332 (UK/S). The individual sample size in HIS ranged from 1010 (IE) to 400 000 (DE). In proportion to the population size, the differences in sample sizes were minor. E.g. the sample equalled 0.7% of the population in Iceland and 0.5% in Germany. The individual sample size for HES ranged from 1035 (IE) to 13 500 (FI). In proportion to the population size the sample sizes for HES varied between 0.002% in Ireland and 0.2% in Finland.

Details of the samples sizes in the seven surveys selected for the detailed analysis are shown in Annex Table 1. In these surveys the minimum age ranged from 2 to 30, and the maximum age from 74 to no upper age limit. In the two HISs no age limits
were used. The (annual) sample size for HES ranged from 3646 to 13222 individuals or to 15332 households.

6.2. Recruitment and informed consent

6.2.1. Recruitment letters and type of contact

Information on the recruitment process was collected only from the seven surveys selected for detailed analysis. Invitation letters and reminders were used in all these seven surveys. In addition, all surveys, except the Italian one, utilised brochures or leaflets informing about the purpose of the survey and the nature of the interviews and examinations. Telephone contacts (prior to interviewer visit) were also used in almost all surveys (not UK), but other personal contacts (home visits) were not used in The Netherlands.

In the Netherlands the interviews were carried out by different organisation (CBS carrying out the POLS/GEZO survey) than the examinations (RIVM in collaboration with the local health centres carrying out the Regenboog survey). In the interview phase the participant gave permission to send his/her name and address to the local health centre. When this information was received at the health centre the nurse could make an appointment with the participant for the examination. In UK and in Finland the interviews and the examinations were organised and carried out jointly by two institutes. In Finland the survey personnel (examination teams and personnel from the central office) contacted also those not previously contacted or who had refused to participate during the initial contacts with the interviewer.

In all seven surveys the invitation letters were signed by the person(s) responsible for the survey and/or the directors of the institutes responsible for the survey. In Italy another letter of the major of the municipality of the sampled household was also mailed to selected households. Both letters in Italy included telephone numbers for further queries. In Belgium the name of a contact person and his telephone number, and an Internet address was given for further queries. In Finland the name of the interviewer who would first contact the person, was also given in the invitation letter.
All invitation letters described the purpose of the survey, the institutes responsible for the survey, confidentiality and the choice of participants. Survey methods were also mentioned briefly (e.g. the length of the interview). The importance of participation of all selected persons or households was stressed.

In Germany and in Finland the invitation letters also stressed the benefits of receiving the examination results, and the importance of participation of all invited persons, even though the person had had regular or recent medical care. In Germany the time and place of the interview and examination were also given in the invitation letter and the participant was asked to return a card to confirm the appointment or to ask for another appointment time. Instructions for the participants were given concerning fasting and not using alcohol, and taking their glasses and medicines with them to the examination. In Finland the participants received another letter confirming the time of the interview (after the interviewer's first contact by phone) and the time of the examination (after the interview during which the appointment for the examination was made). Instructions for the participants concerning fasting etc. were given in these letters. A free-phone service number was given for change of appointment times and another number, liable for charge, was given for other queries.

6.2.2. Informing

To motivate participation national media was used in Belgium, Finland and Germany, and regional media in all other countries except in UK and in Italy, where only personal contacts were used to inform the target population about the survey.

Information leaflets or brochures were used in all surveys, except in Italy. These were mailed to the participants together with the invitation/recruitment letter, or the interviewers or other survey personnel gave these to the participants during personal contacts. Most information leaflets were written completely or partly in a question and answer style.
The information leaflets for the Health Survey for England briefly listed the institutes responsible for the survey, described the purpose of the survey, why the households have been selected, the survey protocols (interview, nurse visit) and the measurements (why and how they are conducted). By layout the leaflets were simple, without any pictures. Questions on confidentiality, implications for insurance cover, voluntary participation and personal benefits were also dealt with. Contact persons and their addresses and telephone numbers were given. Two leaflets were used in UK: one handed out by the interviewers and describing the survey in general and the purpose of the interview, and another which the nurses handed out describing the measurements carried out during the nurse visit.

The information leaflets in Belgium, Finland and Germany covered most of the same issues as in UK. In Germany also brief information on the financing of the survey was given. The layout was very simple (no pictures). Participation was motivated by personal benefits, i.e. getting the cost free health examination and receiving results from the blood tests and other examinations for personal use.

In Finland a survey logo was used and the information leaflet was three coloured. Some words about the positive support from employer organisations were also included (recommending to attend the examination during working time if possible/needed). The Internet address for further information, and the survey information telephone number (liable to charge) were given. Two leaflets were used in Finland, one for the main sample (those aged 30 and over), and another for young adults (18-29 years) since the survey protocols differed. The leaflet for young adults also included pictures and an e-mail address to the physician in charge of fieldwork.

A web-site, e-mail address, names and telephone number of contact persons for further information were also given in Belgium, and a list of ministers by whose initiative the survey was carried out. The Belgian information-leaflet was three coloured and humorous with cartoon type pictures.

The information leaflet in The Netherlands was multi-coloured and included several pictures. It described the purpose of the survey, the content of the interview and the
examination, and gave a brief description on the protection of privacy. The use of data only for statistics is given as the reason for not sending the participants the results of their blood samples. The needs to get information on the health status of Dutch people are described to motivate participation. In addition to the information leaflet the participants received a list of all health centres in the Netherlands (with addresses and phone numbers) where the examination phase would be carried out.

In Italy a free-toll phone number has been considered essential for the success of the surveys (Sabbadini et al 2000). It is considered to be especially effective in reassuring the households about the importance of the survey and in offering guarantees about confidentiality. The percentage of telephone calls made during Italian surveys has been between 1-2% of the letters sent, but it is anticipated that it also creates a more positive attitude to the interview, even if the person decides not to call.

6.2.3. Number of contacts

In all of the seven countries the non-respondents were contacted on average three to five times. In Belgium at least five contact attempts were to be undertaken within each two-week interval (3 intervals, max. six weeks). These attempts were preferably done using different modes (face-to-face, at doorstep, telephone), at different times of the day and on different days of the week (also at weekend). The first contact (attempt) was preferably at doorstep.

In Finland special attention was paid to contacting and motivating the study subjects. If the subject refused to participate when first contacted by the interviewer, he/she was re-contacted by another interviewer. No time limit to contacting the subjects was set, and if needed contact attempts were made during the whole fieldwork period. If the interviewers were not able to contact the subject, contact was later attempted by the examination teams, and also by the survey “central office” at KTL. If no interview was obtained or the subject refused the appointment to the clinic examination, the subjects were contacted from the survey "central office" by telephone and by mail to
re-invite them to the examination. In case of no attendance at the clinic examination, nurses made home visits. A specific "home visit nurse" was employed in each fieldwork team to carry out these visits. All interviewers and other members of the fieldwork personnel had written instructions on how to motivate participation, including "model" answers to different questions indicating participant hesitation and to respond to potential reasons given for refusal.

6.2.4. Informed consent

The signed informed consent was obtained during the interview phase before the examination and/or during the clinic or home visit for the examination. In Finland and in UK two consent forms were signed; the first during the interview phase and the second at the examination site or during the home visit. No signed informed consent was used in the HISs in Italy and in Belgium.

In the consent forms the participant declares and agrees that:

- He/she received the information and understands what the survey participation means what the survey includes (FI, DE, NL)
- Knows that the data is treated strictly confidentially (FI, DE, NL)
- Gives permission to store a part of the blood sample for future studies (FI, DE, NL)
- Knows he/she will not receive personal results of the blood samples (NL)
- Knows he/she participates entirely voluntarily and will be free to withdraw any time (FI, NL)
- Knows that the data from the interview will be used together with the data from the examination (NL)
- Agrees that information from the death certificate may be used in case of his/her death (DE)
- Agrees that the information can be linked to information from other sources (several registers listed in FI, statistics on disease and cause of death in UK)
In the Netherlands the participants also answered separately yes/no to following:

- Agrees that the investigators in future receive their address information
- Agrees that the investigators in future get information from the national cancer registry
- Agrees that the investigators in future get information from other national medical registries
- Agrees that he/she can be contacted again once within two years for complementary studies linked to the current survey/project

In both consent forms in Finland the participant agreed to the linkage of his/her interview or examination data to register data on health and its determinants from different sources (e.g. registers kept by the Central Pension Security Institute, the Social Insurance Institution, and the National Centre for Research and Development on Social Welfare and Health, i.e. registers on pensions, prescribed medicines, hospital use, cancer and causes of death). The two consent forms were similar, but the information pages differed so that the first was less detailed and in the other (used at the beginning of the examination) the tests and measurements and their use for research purposes was described in more detail. This included a statement that the samples will be stored and that they may in the future be analysed for other research purposes, including genetic studies on heredity of diseases.

In UK written consent was obtained at the interviewer’s visit to link the informant’s name and date of birth to the statistics on disease and cause of death. In the consent booklets filled in and signed during the nurse visit the subject gives a signed consent to each measurement (separately) and a specific consent for informing his/her GP on the measurement results. A separate consent is also signed for blood samples to be stored for future analysis. The permission to interview children aged 13-15 was first obtained from the child's parent or guardian. The parent or guardian was present in the home throughout the interview. Information about younger children was collected from a parent in the presence of the child. Those aged 8-15 years also filled in a short self-completion questionnaire on topics such as drinking and smoking, to fulfil the child's need for privacy. Verbal agreement from the child's (aged 15 and under) parent or guardian was obtained before the measurements carried out by the nurse.
For the blood sample written consent was obtained from the 11-15 year old and counter-signed by their parent or guardian, who had to be present during the nurse visit.

6.2.5. Incentives

No financial compensation, reimbursement or lotteries for participants were used in Belgium, UK and Italy. Travel expenses were reimbursed for selected participants in Finland and in Germany. In Germany the travel expenses could be covered if requested and the subject could be picked up from home by the survey "travel service" if needed. In Finland the interviewers were instructed to offer compensation for travel expenses (e.g. taxi fares) if this seemed to be necessary to motivate or help the subject to participate in the examination. This could be due to illness or restricted mobility, or also due to lack of public transport or private car. The interviewers could arrange the transportation to the examination site, if needed.

Gift-vouchers (6,78 Euro) were used in the Netherlands. A lottery among the young adults (18-29 years of age) was conducted in Finland to motivate participation in the interview (the prices were e.g. a bike, a mobile phone and several others of smaller value). Participation in the lottery was linked to returning the self-administered questionnaire after the interview.

In Belgium a summary of the general survey results was sent to the participants after the survey, and in Finland, Germany and UK a summary of personal survey results such as laboratory examinations. In Finland the summary explained the findings and was accompanied by recommendations for further action, if needed.

6.3. Response

The reported percentage of non-response for the interviews in the 43 HISs ranged from 6% (IE) to 38% (BE) for households and from 6% (FR, FI) to 48% (IS) for individuals. For the 12 HIS/HESs the household non-response for the interview in UK
ranged from 23% to 26% and the individual non-response for interviews in other countries ranged from 11% (FI) to 45% (NL). For the examinations the individual non-response ranged from 15% (FI) to 75% (NL).

The detailed analysis from seven surveys showed that due to inconsistencies in the calculation the response rates cannot be compared. The exact refusal rate was not available for all surveys, but it ranged from 5% (FI/HIS) to 36% (NL/HES) (see Annex table 1.). In Finland only 1.4% of the persons in the original (eligible) sample were not contacted, while 20% were not contacted in the Netherlands. For the Italian HIS, the refusal rate was 6% of the households and only 7% of the households could not be contacted, while in Belgium the refusal rate was 38% and 26% of the households could not be contacted.

6.3.1. Refusals, eligibility and not contacted

The accuracy of the sampling frame is reflected in the number of ineligible persons or households. In Finland only those who were deceased before the survey fieldwork began were considered ineligible (0.6% of the original sample). Those having moved were invited to participate, even though they no longer lived in the sampled municipalities (health centre districts). In Germany 12% of the persons in the original sample were ineligible (deceased or moved). In Belgium 28% of the households and 5% of individuals were considered ineligible in 1997 (deceased, removed, not known in the address or non-citizens). The response rate was reported only at the household level in Belgium (62% in 2001) and this was calculated from all households invited to participate and contacted (the replaced and the replacement households were taken into account). In the surveys with an interview phase before the examination, the response rates varied in different phases of data collection, in different measurements and by different population groups.

In the 1997 survey in Belgium 29% of the originally contacted households refused to participate and 31% (26% in 2001) of the households could not be contacted (Burzykowski et al. 1999). The fact that these households could be replaced (using
the three replacement households, see the chapter on sampling above) restricts the comparability of response rates in Belgium with the response rates in other countries. The probability of household level non-participation and non-availability was analysed using information from the National Registry of the population in Belgium. The probability of household level non-participation was higher in the Brussels region, in females, in non-Belgian reference persons, and in larger households. The probability of household level non-availability (problems with contacting the household) decreased with household size and age of the reference person, and it also depended on the region.

The influence of item-level non-response has also been reported in Belgium (Burzykowski et al 1999). The percentage of missing data for any of the items never exceeded 11%. No important differences were found between available-case and multiple-imputation based results. The influence of item-level missing data on the HIS results was negligible.

In the UK the denominator of the individual response rate (the total number of adults in the sampled households) is not known and must be estimated. No information at all was obtained from a small proportion of households. Participation rates were calculated by assuming that this group includes the same proportion of eligible households and individuals as the rest of the sample. Estimated 'set' samples of individuals were used in the calculation of response rates. In the English general population sample in 1999, 10% of the addresses were ineligible (no private households) and 76% of the households responded to the interview. The response to the interview was higher among women than among men, highest among men and women aged 65 and over and lowest among men aged under 25 years (Erens et al 2001).

In the minority ethnic boost sample 4% of the addresses were ineligible due to them not being private households, and 9% of the households were eligible (minority ethnic groups screened). There were differences in the response rates of the ethnic minority groups. Based on estimated eligibles, 67% of the households and 60% of the adult individuals responded to the interview and 41% to the nurse visit. In the
Chinese sample 76 % of the households responded to the interview. Based on the estimated 'set sample' the adult response to interviews differed from 66 % in Bangladeshi population to 55% in the Black Carribbean population. The lowest response rates were for blood samples in the Bangladeshi population (24%).

In the general population sample of 2000, based on the estimated set sample, 69% of adults were interviewed and 58% had a nurse visit (examination). In the care home sample (aged 65 and over) 34 % were interviewed in person and 36 % by proxy, 28% had a nurse visit.

In Scotland the total number of eligible households (those with someone aged 2-74) selected for the survey is not known exactly because no information at all was obtained from a small proportion of households. Participation rates were calculated by assuming that this group includes the same proportion of eligible households as the rest of the sample. On this basis, at least one interview was conducted in 77 % of the eligible households.

In Scotland the response rates were slightly higher for men than for women. Response was reported separately for each survey phase (interview and examination) and for each measurement (Shaw et al 2000). The lowest response rates were for blood samples in the youngest age group for female adults (53% of women aged 16-24).

In Germany the subjects were considered participants if they had the blood pressure measurements, weight and height measurements, and urine samples taken, and at least two of the following: questionnaire, medical interview and/or blood samples (Thefeld et al 1999). The lowest response rates in Germany were reported for men aged 20-29 (56,5%) and for women aged 70-79 (50,4%).

In Finland the response rate for the interview was 87% and for the examination 85%, although a complete data set (interview, examination and all self-administered questionnaires) was received from 68% of the eligible persons. The response for the HIS/HES was highest for women aged 45-64 (90%), and lowest for women aged 85
and over (Aromaa & Koskinen 2002). Only 38% of women in this oldest age-group participated in the examination at the clinic and an additional 31% had the condensed examination at home (or institute), while 50% of men in this age group took the clinic examination and 16% had the examination at home. Major differences in disability rates were identified between persons attending the clinic examination and those visited at home. Participation in different parts (tests/measurements) of the examination varied from 84% (laboratory/blood samples) to 75% (the CIDI mental health interview).

In the Netherlands the reasons for non-response in the HIS were recorded only until year 1996, and no data is available from 1997 onwards. Until 1996 about 25% refused, about 10% were not contacted (not at home), and about 5% were not able to answer (e.g. because of language problems).

6.3.2. Selection of new respondents and proxy interviews

In most national health surveys in Europe a non-respondent is not replaced. In case of non-response new respondents/households were selected if the respondent/household could not be contacted in two HISs, in case of refusal in one survey, and in both cases in five surveys. E.g. in Belgium three replacement households were selected for each sampled household (see chapter 6.1).

Proxy interviews for children were allowed in 26 surveys (table 6.3.2) in twelve countries. Proxy interviews for adults not able to reply and for adults not at home have also been commonly used (in 11 countries. Proxy interviews have not been allowed at all in a minority of surveys (seven countries).
**Table 6.3.2** Use of proxies in national HISs in Europe (50 surveys carried out 1998-2002, including HIS part of HIS/HES).

<table>
<thead>
<tr>
<th></th>
<th>Number of surveys (total 50)</th>
</tr>
</thead>
<tbody>
<tr>
<td>For children</td>
<td>26</td>
</tr>
<tr>
<td>For adults not able to respond</td>
<td>28</td>
</tr>
<tr>
<td>For adults not at home</td>
<td>22</td>
</tr>
<tr>
<td>No proxies allowed</td>
<td>13</td>
</tr>
</tbody>
</table>

In the seven surveys selected for detailed analysis proxy interviews for adults not able to reply (e.g. cognitively impaired, not able to communicate clearly) were allowed in Belgium, Finland (HIS part of the survey), Italy and for the institutionalised elderly in England in 2000. In Germany no proxies were allowed and in the Netherlands proxies were allowed only for children.

When interviewing residents in care homes in year 2000, the interviewers in **England** first attempted to complete a memory questionnaire. If the resident did not appear to have any memory problems a personal interview was completed. If the resident was judged to be incapable of completing a full interview, either on the basis of the memory test, or according to the assessment of the care home staff, or the interviewer's judgement, interviewers tried to carry out a proxy interview. About half (51%) of the care home residents were interviewed by proxy. The proxy informant was usually a member of the care home staff. The proxy interview was a shortened version and did not include any examinations.

In **Finland** no formal pre-testing of the ability to respond was used. The interviewers reported that 5% of all interviews were carried out with a proxy. Most of these proxy informants were family members and relatives. In **Italy** proxy interviews for adults at home were carried out for 3% of the interviews.

Proxy interviews for also adults not at home were allowed in Belgium (23% of interviews with proxies in 1997) and in Italy (23% of the interviews were proxy interviews for adults not at home). In **Belgium** proxies were used for those aged
under 15 years (71% of all proxy interviews in 1997), and for persons too sick or mentally disabled (Burzykowski et al 1999, Demarest et al 2001). By default proxies (household members, nurses or other caretakers) were also allowed for an elderly person living in an institution but with his/her official address within a noninstitutional household. In addition, proxies were also allowed for persons who could not be reached for an extended period (al least 1 month, 17% of all proxy interviews in 1997), and for persons refusing an interview but not refusing proxy use. For nearly half (46%) of the individuals who refused the face-to-face interview (within a participating household) a proxy was used in 1997. One third of the proxy interviews in Belgium was due to non-participation of the individual (irrespective of reasons).

6.3.3. Collection of information on non-respondents

Some information on non-respondents is available from nine HISs and from 8 HIS/HESs (four countries). This information is unknown or missing in the database for seven HISs and the type of this information is not available from all surveys. Short mailed questionnaires or telephone interviews, and registers were used to collect data on non-respondents.

Information on non-respondents is available from all the surveys selected for detailed analysis. Short mailed questionnaires or telephone interviews were used in Finland. Basic register based information will be available for all non-respondents, as well as all respondents, on socio-demographic factors, use of hospital care and entitlements to the most important social insurance benefits. These will be analysed later. Abbreviated or adapted examinations and interviews were also carried out at home, if needed. Short telephone interview or questionnaire data only is available of 6.6% of the original (eligible) sample. A short telephone interview was obtained from 6% of the main HIS/HES sample (46% of non-respondents aged 30 and over), and a short mailed questionnaire from an additional 1% (6% of non-respondents). For 6.5% of the persons aged 30 or over, and for 9% of the persons aged 18-29, no information was obtained despite the telephone contacts and short mail questionnaires.
For all sampled persons in The Netherlands information on sex, age and marital status was available from the municipal administration. HIS data for some of the non-respondents in HES is also available in the Netherlands. In UK some information on the non-respondents of HES was available when at least one subject in the household agreed to take part in the survey (interview) otherwise no information from non-respondents was collected. Register information on the size of the household was available in Italy. Information on household size, nationality, age, sex and residency was available from the National Registry of Population in Belgium.

In Germany 16% of the non-respondents filled in a short questionnaire (Thefeld et al 1999). Based on the questionnaire data the non-respondents had lower levels of education and lower BMI than the respondents. There were no significant differences in smoking and perceived health between non-respondents and respondents.

### 6.3.4. Reasons for non-participation

The reasons for non-participation were reported in different ways or not reported or listed at all. In Germany the following reasons for non-participation were given (Thefeld et al 1999): not contacted (15.4%), health reasons (10.4%), content of the survey (9.0%), time-table (7.7%), travelling (5.0%), confidentiality (2.7%) and other (7.7%). On 42.1% of the non-participants no reasons for non-participation were available.

In Belgium (2001) there were 3472 refusals at the household level. In 22% of these the people said they didn't have the time, in 38% that they were not interested, 7% of the people felt they were too old, 6% gave other reasons, and for 27% the reason for refusal is unknown.

No reasons for refusal were asked in UK and in Italy. In the other seven surveys the reported main reasons for refusal were:

- Illness (DE, FI)
- The subject considers that she/he is too old (BE)
Has no interest (BE, DE, FI, NL)
Lack of time (BE, DE, NL, FI)
Other practical difficulties in participation, e.g. family circumstances (NL)
Not receiving results of the blood analyses (NL)

Based on the experience of the experts carrying out the surveys, the following reasons causing non-response/non-participation were listed:

- General "survey fatigue", people feel they are answering questions all the time for a lot of surveys (UK)
- People may feel suspicious that data are collected for other purposes than those stated (UK)
- Low confidence in the institution (IT)
- People are worried about confidentiality (UK), sensitivity of the questions (BE)
- Interviewers living in same area, people feel that they are too close or even know the interviewer personally (BE)
- Insecurity, e.g. too frightened of strangers to allow interviewers in their home (BE)
- Time needed (FI, DE, NL, IT), length of the questionnaire (BE)
- Not getting a convenient time for the examination (restricted opening times of the health centre, people wanting to go in the evening or on Saturday) (NL)
- No interest in the survey subject or in surveys in general (DE, NL, FI, IT)
- Does not think that has something to say about health (BE)
- Has enough information on one's own health, good occupational health care or primary health care and recently participated in other health examinations, or a chronic disease well in control (FI)

As motivating factors the following were listed:

- People are motivated to take part in HES if they feel there is some personal advantage for them, like receiving their personal results of their examination (FI, DE, UK, NL), or getting information on the survey results in general (BE)
- The survey covers a disease meaningful for the subjects and/or their relatives (UK, NL)
- People want to help and support science, and participate for public interest (NL)
• Good coverage in the national and local media in a media campaign for the survey (BE, FI) or a media campaign for the statistical institute responsible for the survey stressing the importance of official national statistics (IT)
• Recommendation from employer organisations to allow participation during working hours (FI)
• Ability to motivate decision makers (BE)
• A letter signed by the institute's president (IT), and survey organised by official research institute (BE)
• Motivated by own general practitioner (BE)
• Several contacts from the survey personnel (FI)
• Free telephone number for queries (IT)
• Well trained and experienced personnel (FI, IT)

In Finland a specific "feedback questionnaire" was also given to a sub-sample of the participants after the health examination. They were asked to rank the most positive and the most negative experiences during their survey participation. The most common positive experiences included the polite and friendly behaviour of the survey personnel, good professional skills of the survey personnel, personalised treatment of the subjects, comprehensive and thorough examinations, and getting new knowledge about own health. The most common negative experiences included difficulties in answering all questions, long waiting times and queuing at the examination site, and the interviews and examinations taking too much time.

6.4. Data collection and fieldwork procedures

6.4.1. Survey design and mode of data collection

The survey design was cross-sectional without follow-up in most surveys (Table 6.4.1). A follow-up was included in the cross-sectional design in HISs in four countries and in HESs in two countries. Panel studies and combinations of cross sectional and panel-designs were rare; these were living condition surveys in six
countries, and health and social protection surveys in one country. The follow-up was based on registers, mailed questionnaires, and/or repeated examinations.

Table 6.4.1 Survey design in national HISs and HIS/HESs surveys in EU/EFTA countries (number of HISs and HIS/HESs carried out 1998-2002).

<table>
<thead>
<tr>
<th>Survey Design</th>
<th>HIS (Total 43)</th>
<th>HIS/HES (Total 12)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cross-sectional without follow-up</td>
<td>22</td>
<td>6</td>
</tr>
<tr>
<td>Cross-sectional with follow-up</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Panel</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Combination of panel and cross-sectional</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Unknown/missing</td>
<td>6</td>
<td>0</td>
</tr>
</tbody>
</table>

The data was collected by face to face interviews in most surveys (Table 6.4.2), in 19 surveys this was the only method. Telephone interviews (in two surveys this was the only method), and self-administered questionnaires (in nine surveys as the only method) were also commonly used. Most surveys applied several methods, e.g. both face to face interviews and self administered questionnaires (one or several) were used in twelve surveys. In surveys using household samples the interviews typically consisted of short household questionnaires and longer individual questionnaires. In many surveys the questionnaires were adapted for different age-groups with special questions e.g. to young adults or to the elderly.

Computer assisted interviews (CAPI, CATI) were applied in half of the surveys (see Table 6.4.2, in eight countries) and also the examination part was computer assisted in nine HESs (in two countries).
Table 6.4.2 Mode of data collection for national HISs in Europe (50 surveys carried out 1998-2002, including HIS phase of HIS/HES).

<table>
<thead>
<tr>
<th>Method</th>
<th>Number of surveys (Total 50)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Face-to-face interview</td>
<td>43</td>
</tr>
<tr>
<td>Telephone interview</td>
<td>14</td>
</tr>
<tr>
<td>Self-administered questionnaires</td>
<td>28</td>
</tr>
<tr>
<td>Computer assisted interview</td>
<td>30</td>
</tr>
<tr>
<td>Computer assisted examination</td>
<td>9</td>
</tr>
</tbody>
</table>

In the seven surveys, the average length of the interview ranged from 35 minutes to 1 hour 30 minutes and the average length of the examination from 30 minutes to 4 hours (Annex Table 2.). In addition to face-to-face interviews (and examinations) the surveys in Belgium, Finland and UK included one or several self-administered questionnaires.

In Finland three self-administered questionnaires were used at different phases of the survey: one given at the end of the interview and returned at the examination site (checked by the fieldwork personnel), another filled in during the examination, and a third given at the end of the examination and returned by mail. The response rates to these questionnaires varied from 81% for the first questionnaire to 80% for the second and 79 % for the third. In addition 75 % of the sampled persons returned a specific nutrition questionnaire in Finland.

6.4.2. Place of examinations and survey personnel

No information is available concerning the place of interviews, but it can be assumed that they are mostly carried out in the participants' homes or for institutionalised persons in the institution. In Finland the interview could be carried out in the participants’ place of work or in some other public place if the subject requested. In most HESs the examinations were carried out at normal health care organisations or facilities. Other rented rooms or stationary clinics were also used in Germany and in Finland (when needed).
In UK the examinations were carried out in the participants' homes. Home visits (or visits to the institution) were also made in Finland if the participant was unable or unwilling to come to the examination site (5% of the main HIS/HES sample). An abbreviated protocol was used for these examinations. As one way of supporting participation the subjects in Finland were offered the possibility to come to the examination at another examination site if they could not attend the examination where they had originally been invited (e.g. due to travelling, working or studying at another part of the country).

In 41 surveys (out of the 60 HISs or HIS/HESs) the interviewers received a general interview training before fieldwork and/or in 32 surveys a special training concerning the survey topics/questions. In all HESs the fieldwork personnel received both a general training and a specific training for the measurement techniques. In addition repeated training during fieldwork was arranged in nine HESs.

Nurses carried out the examinations in all surveys. Other personnel groups employed were physicians (FI, DE), dentists and dental hygienists (FI), laboratory technicians (FI), and medical-technical assistants or receptionists (DE, NL). In UK nurses carried out most of the examinations, but interviewers were trained to measure height and weight. Specific survey personnel was employed in all HESs, except in the Netherlands were regular health care personnel (in local health centres) was used.

All survey materials (invitation letters, questionnaires etc.) were available in all official languages used in the country (e.g. in Belgium in French, Dutch and German, and in Finland in Finnish and Swedish). In the English 1999 survey with ethnic minorities, all survey materials and questionnaires were translated into seven languages. Interviewers who could speak and read these languages were recruited. The same interviewer accompanied the nurse for the examination visit. In Finland interpreters were used, if necessary, for people of other nationalities.
6.4.3. Information on results

The results of the examination were explained to the participants during and/or at the end of the examination, and the informants were given a form with results of the measurements. In Finland the participants also received copies of their ECG, spirometry and bio-impedance recordings, and the x-ray-picture (ortopantomography). They also received a written dentist’s statement of the findings of the clinical dental examination. If some need for further examinations and treatments was found in the clinical examinations, the survey physicians and dentists wrote a referral to the local hospital (or health centre), if needed.

In UK informants were later sent (if they wished) the results of their blood sample analyses, and the results of their measurements (BP, ECG and blood samples) were mailed to the participant's own doctor/GP (with the consent from the subject). In UK the nurses were instructed to read exactly the written information on the BP results appearing on the computer screen (after the computer calculated the result). In case of severely raised blood pressure the nurses were instructed to contact the Survey Doctor at the earliest opportunity who would inform the respondent’s GP. The nurses were instructed not to comment on values of the lung function tests.

In Germany and in Finland the participants received a detailed letter/form on their results comparing them with the reference values of each blood or urine test and other measurement (those not already given at the end of the examination). In the invitation letter in Germany the participants were promised that they receive the results within about four weeks after the examination. In Finland the participants received the mailed results within a few months. In Germany the letter on examination and test results was signed by a doctor and included a general statement if it was considered necessary or useful that the person would seek further medical advice based on the results. Also in Finland the letter included recommendations for further action, if needed.

In The Netherlands the participants did not receive any results from the blood samples, only weight, height, waist circumference and BP results were given in the
feedback forms (for the adults aged 18 and over with explanations on reference/normal values).

In Belgium a summary of the general survey results was sent to the participants after the survey. In this leaflet the director of the institute responsible for the survey and the survey co-ordinators thanked the families for their participation. The most important results were presented with a few figures, e.g. the most prevalent health problems and symptoms, health behaviours, and the use of medicines, preventive and other health services. The use of the survey results in future research projects was described, and an Internet and e-mail address as well as the name and telephone number of the contact person for further information was given.

6.4.4. Quality assurance during fieldwork

There are standard procedures for quality control in laboratories, but they will not be described here. Only procedures having consequences from the point of view of the survey participants are presented. For other measurements than laboratory samples, external quality control by another organisation (external observers during examinations) was organised in Germany, while all other examination surveys used internal quality control, i.e. observers from the organisation implementing the survey. All surveys reported training of survey personnel and the use of written instructions. In addition, several other quality assurance and control procedures were used. Repeated measurements of the same subjects were carried out in the German and the Finnish HIS/HESs. In all countries the findings reported by observers (survey personnel) were monitored at regular intervals. Calibration of equipment was also used as part of quality assurance in all HESs. Some examples of other quality assurance methods/systems are presented below, based on the information available from the seven surveys selected for detailed analysis.

Pilot runs of the examinations were reported in Finland, in the Netherlands and in UK. In Finland two full-scale pilot surveys tested the feasibility of survey protocols and developed guidelines and manuals for the survey. The performance of the
fieldwork staff was observed by those responsible for the survey planning, preparation of manuals and training of survey personnel. The main method for quality assurance was that the health examination fieldwork included "quality assurance days". Some measurements (with the consent of the participants) were repeated with different techniques (e.g. different BP-devices) or the same measurements were carried out by two observers. Data were recorded into laptops and the programmes had built-in checks for non-permissible values.

In Germany standardised site visits from an external organisation were carried out using specific checklists for each measurement (Winkler et al 1998).

In Belgium a sub-sample of the households was re-contacted later by phone to verify some information given during the interview. A specific Quality Control Board acted as a critical reflection chamber in the Belgian survey, giving advice to the director of the survey. During data collection the progress of data entry and data consistency checks were reviewed. The interviewers’ performance was reviewed by e.g. progress report forms with information on the number of realised interviews and the number of refusing households.

In Italy supervisors attended some of the interviews during the pilot surveys to identify the difficulties in understanding and administering the questionnaires (Sabbadini et al 2000). The day after the interview during the actual fieldwork phase, some households chosen at random were contacted again by telephone by ISTAT (institution responsible for the survey) staff. The household was thanked for their collaboration and a rapid check on the interview was conducted on all its parts. Each day a monitoring group analysed reports from the interviewers and the notifications given to the free-phone number.

In UK recalls to check on the work of both interviewers and nurses were carried out in 10% of participating households (Erens et al 1999). The computer program used by interviewers had in-built checks, including messages querying uncommon or unlikely answers. At the end of each survey month, the measurements made by each interviewer and nurse were inspected. E.g. if a nurse had obtained a number of
abnormally low measurement values, the supervisors discussed these with the nurse.

7. RECOMMENDATIONS: HOW TO IMPROVE REPRESENTATIVENESS AND PARTICIPATION IN NATIONAL SURVEYS?

Improving representativeness in health surveys starts from choosing an adequate sampling frame. The most complete register comprising all residents should be selected and all efforts should be made to cover the whole population, i.e. not excluding the institutionalised population. The sample selection should be carefully documented.

To reduce the non-response rate the complex relationships existing between different characteristics of non-response and participation must be addressed (Groves & Couper 1998, Barriball & White 1999). Decisions made throughout the study process have an accumulating effect upon the different sources of non-response. Several methods have been developed to reduce non-response bias by the use of statistical models. However, statistical adjustments cannot control for the many independent factors that affect non-response. These models treat all non-respondents as a homogenous group, even though several studies suggest that this is rarely appropriate (Etter & Perneger 1997). Thus analysis of personal and health status characteristics of non-respondents is essential.

All surveys should attempt to achieve as high participation rates as possible. Efforts that can be taken to minimise non-response are:

- using several publicity and recruitment strategies, and giving potential participants several options for obtaining further information (media, Internet, mail, telephone, personal visit)
- enhancing readability of consent forms, invitation letters and information leaflets on the study
- providing intensive training to fieldwork personnel, playing attention to recruitment strategies and "tailoring" of interaction with the subjects
using several persons to contact subjects if needed (e.g. a different interviewer or a supervisor re-contacting those who refuse to participate during the initial contact)

- emphasising the importance of the participation of every individual, whether extremely healthy, unhealthy or anything between

- avoiding proxy use as far as possible and using proxies only in well-determined conditions, if needed, due to problems in the validity of proxy reports found in several studies

- analysing the validity of proxy reports and collecting at least a minimum set of basic data from the proxy respondent him/herself (e.g. age, sex, relationship to the subject) to evaluate different patterns of response (see Rajmil et al 1999).

- using compensations or incentives for participation (financial or other) and securing easy access to examination sites, and arranging also examinations at home or in institutions if needed

- emphasising personal benefits to the participants and making sure that they are received quickly, e.g. rapid feedback on examination and test results

- collecting a minimum data set from the non-respondents

Actual numbers should be reported, with the following details: size of the original sample, number of eligible households/persons, number of households/persons effectively contacted, number of households/persons who refused to participate and number of individuals who were interviewed and/or examined. Attention should also be given to the calculation of response rates in a comparable way, taking into account the use of proxies and selection of new respondents in case of non-contact or refusal. Eligibility needs to be defined in comparable ways, and the number of different groups of in-eligible persons (died, moved out) needs to be reported. It is also useful to record and report in detail all reasons for non-participation and refusal. Allowing replacement is likely to introduce health related bias. If replacements are used, their selection and the replacement process should be carefully documented.

The design of all surveys should include some mechanism to collect data on non-respondents to facilitate analysis of non-response bias. Understanding the consequences of non-response bias is an essential precondition of international
comparisons of survey data since the effect of non-response may be different in each country, reflecting different cultural and social attitudes (de Marco et al 1994).

8. DISCUSSION AND CONCLUSIONS

There seems to be no evidence that any single element in the survey process would decisively increase or decrease the response rate. However, the type of contact, number of contacts, type of information given to the potential participants, consent forms, incentives and feedback received on survey/examination results seem to effect participation. Recruitment and motivating participation are closely linked to survey ethics and obtaining informed consents. This is especially important in the case of health examination surveys. The possible benefits and discomfort caused by participation have to be documented and described to the subjects in a manner allowing fully informed decision making. On the other hand no undue hesitation or even fear should be provoked.

Previous research on survey participation has mainly focused on subject or household characteristics related to non-participation. Less is known on characteristics of the interviewers and other survey personnel, and very little is known about the effect of different social environments. The effect of different survey designs and fieldwork procedures on response rates has mainly been studied from the point of view of mailed questionnaires, pointing out the importance of technical aspects such as questionnaire length and typography. However, complex qualitative characteristics of the subject-interviewer/survey personnel interaction should be taken into account when developing HIS and HES methodology.

Quality assurance methods are essential in the efforts to achieve high response and participation. Detailed information on training of survey personnel should be collected and compared, and standardised training modules and programmes should be developed for European health surveys. Feasibility, as well as the costs and benefits of different quality assurance methods should be evaluated, including e.g. re-contacts with interviewed persons, repeated measurements during examinations,
and observation of staff performance during fieldwork. It can be assumed that all these quality assurance methods have mainly positive effects on participation, e.g. by ensuring smooth execution of interviews and examinations. Survey protocols that may be inconvenient from the participant's point of view should be identified as well as any difficulties in understanding the information received.

Based on the literature, non-respondents are often found to be quite different from respondents also when the response rate is high. Most studies have found significant differences in the health status, health related behaviour, socio-economic background and mortality of participants and non-participants. The differences between participants and non-participants have been more explicit in surveys with physical examinations (HES) than in mailed surveys or interviews. The questionnaire or interview respondents consenting to health examinations differ from those not consenting. There is some evidence for these differences in European national health surveys but detailed analyses are still lacking or their findings have not been reported.

Non-participation seems to be selective: in the younger age-groups people with addictive behaviours or problematic life situations, in the middle-aged persons those with higher disease risk and in the elderly those with chronic diseases and/or disabilities are less likely to participate. The effects of disease and disability on response rates seem to differ by age and by type of disease or disability. When surveys focus on specific disabilities, symptoms or diseases those with personal interests or experiences in the content of the survey are more likely to reply. This may apply especially for the younger age groups and middle-aged persons. In general health surveys persons with several health problems or disabilities are less likely to respond, but the effect of health status on participation may differ by type of disease/disability also in elderly age groups.

There is an obvious need for further analysis of non-participation in national health surveys in Europe, particularly to understand its impact on validity and comparability. International comparisons of non-participation rates and reasons for non-participation are also needed in the evaluation of comparability of survey results. More attention
should be given to the recruitment process and to comparable methods for calculating and reporting response rates.

Methodological work on the implementation of surveys should be carried out to make sure that samples are more comparable and participation rates improve. Experiences should be shared and an international work force should be established to design modules for training and quality assurance and for helping with setting these up.
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Annex Table 1. Sample and response in national surveys.

<table>
<thead>
<tr>
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<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Sampling frame</td>
<td>National registry</td>
<td>National registry</td>
<td>National registry</td>
<td>Municipality registry</td>
<td>Municipal registry</td>
<td>Address file</td>
<td>Address file</td>
</tr>
<tr>
<td>Sample type</td>
<td>Households</td>
<td>Individuals</td>
<td>Individuals</td>
<td>Households</td>
<td>Individuals</td>
<td>Households</td>
<td>Households</td>
</tr>
<tr>
<td>Institutionalised</td>
<td>Those living in institutions for elderly included, others excluded</td>
<td>Excluded</td>
<td>Included</td>
<td>Those living in homes for the elderly for less than 2 years, those in prisons for less than 5 years</td>
<td>Excluded</td>
<td>Excluded, specific sample of people living in the homes for the elderly and in nursing homes, aged 65 and over</td>
<td>Excluded</td>
</tr>
<tr>
<td>Other groups excluded</td>
<td>No</td>
<td>Not fluent in survey languages</td>
<td>No</td>
<td>No</td>
<td>Not fluent in survey languages, Those in sample of previous surveys</td>
<td>Not fluent in survey languages, Non-citizens</td>
<td>Not fluent in survey languages, Non-citizens</td>
</tr>
<tr>
<td>Min. age</td>
<td>no</td>
<td>18</td>
<td>18 (HIS) 30 (HIS/HES)</td>
<td>No</td>
<td>No (HIS) 12 (HES)</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Max. age</td>
<td>no</td>
<td>79</td>
<td>79</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>74</td>
</tr>
<tr>
<td>Original sample (N)</td>
<td>10 000 (base sample) 12 455 households (including extra oversampling paid by 4 provinces) (12769 persons)</td>
<td>13 222</td>
<td>1894 (aged 18-29) 8028 (aged 30+)</td>
<td>60 111 households</td>
<td>15 664 (HIS) 6797 (HES)¹</td>
<td>6840 households + 677 care homes</td>
<td>15332 households</td>
</tr>
</tbody>
</table>

* HIS only, for other surveys information on sample and response concerning HES

¹ from participants in HIS
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Eligible</td>
<td>9026 households (12105 persons)</td>
<td>11601</td>
<td>1894 (18-29) 7977 (30+)</td>
<td>55382 households</td>
<td>15664 (HIS) 6797 (HES)²</td>
<td>6343 households 11684 individuals (estimate) 604 care homes</td>
<td>11836 adults 5059 children (estimate)</td>
</tr>
<tr>
<td>Response (%) of eligible</td>
<td>9026 (62%)</td>
<td>7124 (61%)</td>
<td>1504 (79%, HIS 18-29) 6986 (87%, HIS 30+) 6770 (85%, HIS/HES 30+)</td>
<td>52332 (94%)</td>
<td>9676 (62% HIS) 1748 (26% HES)</td>
<td>7988 adults (68%) + 2493 persons in care homes (75%)</td>
<td>7455 adults aged 16-74 (63%)</td>
</tr>
<tr>
<td>Non-response (%)</td>
<td>38%</td>
<td>39%</td>
<td>15% (HIS/HES)</td>
<td>6%</td>
<td>38% (HIS) 75% (HES)</td>
<td>32%</td>
<td>37%</td>
</tr>
<tr>
<td>Not contacted (%)</td>
<td>replaced</td>
<td>15%</td>
<td>1% (HIS/HES)</td>
<td>7%</td>
<td>10-20%</td>
<td>See below</td>
<td>Not known/reported</td>
</tr>
<tr>
<td>Refused (%)</td>
<td>38%</td>
<td>Not known/reported</td>
<td>5% (HIS/HES)</td>
<td>6%</td>
<td>25% (HIS) 36% (HES)</td>
<td>Not contacted or refused the interview 15% of adult men and 7% of adult women</td>
<td>6 % (of the interviewed adults and children refused the nurse visit)</td>
</tr>
<tr>
<td>Not able to participate (e.g. illness, timetable) (%)</td>
<td>replaced or proxy used</td>
<td>Not known/reported</td>
<td>0,4 % (HIS/HES, e.g. those abroad)</td>
<td>1%</td>
<td>About 5% for previous years, Not known for 2001</td>
<td>Not known/reported</td>
<td>Not known/reported</td>
</tr>
</tbody>
</table>

* HIS only, for other surveys information on sample and response concerning HES

² from participants in HIS
## Annex Table 2. Fieldwork procedures.

<table>
<thead>
<tr>
<th></th>
<th>BE*</th>
<th>DE</th>
<th>FI</th>
<th>IT*</th>
<th>NL</th>
<th>UK/E</th>
<th>UK/S</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average length of interview</td>
<td>60 min</td>
<td>60 min</td>
<td>90 min</td>
<td>50 min</td>
<td>40 min</td>
<td>60 min</td>
<td>50 min</td>
</tr>
<tr>
<td>Average length of examination</td>
<td>-</td>
<td>30 min</td>
<td>4 hours</td>
<td>-</td>
<td>30 min</td>
<td>40 min</td>
<td>35 min</td>
</tr>
<tr>
<td>Place of examination</td>
<td>Interview at home or institution</td>
<td>Rented rooms/Temporary clinics</td>
<td>Health centres and rented rooms</td>
<td>Interview at home</td>
<td>Health centres</td>
<td>Home</td>
<td>Home</td>
</tr>
<tr>
<td>Type of personnel</td>
<td>Interviewers with specific training</td>
<td>Specific survey personnel employed</td>
<td>Specific survey personnel employed</td>
<td>Interviewers with specific training</td>
<td>Regular health care personnel</td>
<td>Specific survey personnel employed</td>
<td>Specific survey personnel employed</td>
</tr>
<tr>
<td>Information on examination results</td>
<td>No examinations</td>
<td>Explained at the examination and mailed later to the participant</td>
<td>Explained at the examination and mailed later to the participant</td>
<td>No examinations</td>
<td>Explained at the examination</td>
<td>Explained at the examination and mailed later to the participant and his/her GP (with specific consent)</td>
<td>Explained at the examination and mailed later to the participant and his/her GP (with specific consent)</td>
</tr>
</tbody>
</table>

* HIS only, for other surveys information on sample and response concerning HES
QUESTIONNAIRE CONCERNING METHODOLOGICAL ASPECTS OF HEALTH EXAMINATION SURVEYS

Survey name:
Survey year:
Survey code:
Institute:
Country:

This project is financially supported by the European Commission
This page contains information related to previous information collected during phase I of the HIS/HES project. Since it is a few years ago, some of these data may be outdated or inadequate. Please make additions and/or corrections. If options are mentioned, then we would like you to make a choice from these alternatives.

Survey name : 
Survey name in English : 

Institute mainly responsible for this survey and the contact person:
Institute : 
Department : 
Name contact person : 
Telephone number : 
Fax : 
E-mail : 

Other institutes involved in this survey (please state their role):

Institutes or organisations financing the survey:

Type of the above-mentioned survey:
-  ☐ national HIS/HES
-  ☐ national HES
-  ☐ regional HIS/HES
-  ☐ regional HES
-  ☐ pilot for a planned national HIS/HES or HES
-  ☐ other, specify:

Coverage of the health survey:
-  ☐ Broad/multipurpose health survey
-  ☐ Focused health survey (e.g. cardiovascular)
-  ☐ Other, specify.

The frequency of the survey:
-  ☐ Continuous
-  ☐ Yearly
-  ☐ __ Yearly
-  ☐ Irregular
-  ☐ Other, specify:

The years in which the survey has been carried out (incl. this year if applicable):

The next year(s) the survey is expected to be carried out:
Survey design:
Follow-up
☐ no
☐ yes, to all
☐ yes, to subsample(s), namely….

Follow-up based on
☐ registers
☐ questionnaires and/or interviews
☐ examinations

The mode of data collection used for the survey:
☐ One phase only
☐ Interview phase before health examinations
☐ Interview phase after health examinations
☐ Self-completed questionnaires
☐ Additional phases/examinations after screening/selection (please specify criteria)

Survey structure:
☐ Core survey supplemented with different modules each time the survey is conducted
☐ Core survey supplemented with specific modules for certain subpopulations
☐ No major differences between years and subpopulations
☐ Other, specify:

Language(s) used during interviews and examinations:
### Health status components (body functions and impairments) covered in the examinations

Please indicate if any component was included for certain sub-groups/sub-samples only

<table>
<thead>
<tr>
<th>Component</th>
<th>Year(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Functions of the cardiovascular system/cardiovascular diseases</td>
<td></td>
</tr>
<tr>
<td>Respiratory functions/diseases</td>
<td></td>
</tr>
<tr>
<td>Diabetes mellitus and metabolic functions/diseases</td>
<td></td>
</tr>
<tr>
<td>Kidney and urinary tract function/diseases</td>
<td></td>
</tr>
<tr>
<td>Functions/diseases of liver, gall bladder, stomach and pancreas</td>
<td></td>
</tr>
<tr>
<td>Musculoskeletal diseases</td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td></td>
</tr>
<tr>
<td>Infections</td>
<td></td>
</tr>
<tr>
<td>Immunization</td>
<td></td>
</tr>
<tr>
<td>Allergy</td>
<td></td>
</tr>
<tr>
<td>Psychiatric disorders</td>
<td></td>
</tr>
<tr>
<td>Hematological system functions/diseases</td>
<td></td>
</tr>
<tr>
<td>Reproductive functions</td>
<td></td>
</tr>
<tr>
<td>Hearing functions</td>
<td></td>
</tr>
<tr>
<td>Seeing/visual functions</td>
<td></td>
</tr>
<tr>
<td>Movement and mobility function (e.g. muscle power, joint function)</td>
<td></td>
</tr>
<tr>
<td>Cognitive function and memory</td>
<td></td>
</tr>
<tr>
<td>Other mental function</td>
<td></td>
</tr>
<tr>
<td>Dental health</td>
<td></td>
</tr>
<tr>
<td>Nutrition</td>
<td></td>
</tr>
<tr>
<td>Risk factors and health behaviour</td>
<td></td>
</tr>
<tr>
<td>Alcohol use</td>
<td></td>
</tr>
<tr>
<td>Smoking</td>
<td></td>
</tr>
<tr>
<td>Blood lipids</td>
<td></td>
</tr>
<tr>
<td>Other, specify:</td>
<td></td>
</tr>
<tr>
<td>Other, specify:</td>
<td></td>
</tr>
</tbody>
</table>
Measurement/methods (e.g. laboratory and other tests) used (add year if needed)
Please indicate if any measurement was used for certain sub-groups/sub-samples only

- Anthropometric measurements:
  - height
  - weight
  - skinfold
  - waist circumference
  - hip circumference
  - demi-span
  - other, specify:

- Blood samples
  Fasting status:
  - Fasting ____ hours
  - non-fasting
  Analysis:
  - in the field laboratory
  - sent to external/centralised laboratories
  - samples stored for future analysis (specify temperature____°C)

- Blood samples tested for:
  - Triglycerides,
  - Total Cholesterol
  - HDL Cholesterol
  - Glucose
  - Gamma-GT
  - Cotine
  - Other, specify

- Urine samples
  Type of sample:
  - Dipstick
  - spot sample
  - urine collection overnight
  - urine collection 24 hour
  Urine samples tested for:
  - Glucose
  - Albumin
  - Other, specify

- Blood pressure
  number of measurements:
  type of device:
  - Automated
  - Manual
  - Simple mercury sphygmomanometer
  - Random zero sphygmomanometer
  - Other, specify

Length of resting before measurements:
Time interval between measurements:
Cuff sizes used (length/width):
ECG
Protocol:
- 12 lead
- other, specify:
Classification:
- Minnesota code
- other
Classification type:
- Automatic
- manual

Respiratory function/Spirometry
Type/name of device:
Measurements:
- FVC
- FEV₁
- PEF

Allergy test
- Skin prick test
- Other, specify

Bone density measurement
- Ultrasound
- Other, specify
Location (calcaneus, trochanter, radius etc.):
Type/name of device:

x-ray:
- Chest
- Other, specify

Vision
Procedure:
- 40 cm board
- 4 meter board
- Other, specify
Tested:
- With own glasses
- Without glasses
Hearing
- Audiometry Hz
  - special sound proof cabin
    - Yes
    - No
    - whisper
    - Other, specify

Musculoskeletal and movement-related function
- Joint function
- walking speed
- reaction time
- stair-mounting ability
- standing balance and/or sway of body’s gravity center
- muscle strength:
  - Hand grip strength
  - Other, specify
- Other tests, specify

Cognitive function assessment /tests
- MMSE
- CERAD neuropsychological measures
- CAMDEX
- Other, specify

Diagnostic mental health interview:
- CIDI, specify the version:
- Other, specify

General mental health measures
- Symptom Check-List-90 (SCL90) and Brief Symptom Inventory (BSI)
- General Health Questionnaire (GHQ); specify the version:
- Other, specify:

Depression measures
- Center for Epidemiological Studies depression Scale (CES-D)
- Beck Depression Inventory (BDI)
- Self-Rating Depression Scale (SDS)
- Other, specify:

Quality of life measures
- WHO Quality of Life Assessment (WHOQOL)
- Short-Form Health Survey (SF-36, SF-20, SF-12, SF-8, specify the version)
  - EuroQol quality of life scale
  - Other, specify:

Measures of psychosomatic concepts
- The Toronto Alexithymia Scale (TAS-26, TAS-20)
- Other, specify
- Occupational health measures
  - The Maslach Burnout Inventory (MBI, MBI-GS)
  - Other, specify

- Social health measures
  - Social adjustment measure
  - Social support measure
  - Life event measure
  - Other, specify

- Positive mental health measures
  - Self-esteem measure
  - Sense of mastery measure
  - Sense of coherence measure
  - Self-efficacy measure

- Other diagnostic and/or symptom questionnaires
  - Rose questionnaire
  - MRC respiratory questionnaire
  - Edinburgh claudication questionnaire
  - Other, specify

- Clinical dental examination
  Description of main topics:

- Clinical physical examination
  Description of main topics:

- Other measurements/tests, specify

If available, please enclose copy of document(s) describing measurement protocols including equipment and references to methods
PLEASE ANSWER THE FOLLOWING QUESTIONS:

1. In general two types of sample are possible. Which of these was used the last time the survey was carried out?

   □ A sample of households
   □ A sample of individuals

   (If available please enclose a copy of a document describing the sampling procedure)

2. Target population

   □ All residents included
   □ Excluding institutionalised
   □ Excluding temporary residents (e.g. students)
   □ Excluding residents not fluent with survey languages
   □ Excluding non-citizens (e.g. refugees)
   □ Excluding other, specify

3. Which of the following institutionalised groups were included in the survey? (tick more than one answer if necessary)

   Persons living in:
   □ Homes for the elderly
   □ Nursing homes
   □ Psychiatric institutions
   □ Institutions for the mentally handicapped
   □ Boarding schools
   □ Convents/monasteries
   □ Prisons
   □ Others, namely

4. Sampling frame (the lists from which the sample is selected)

   □ National registry of population (e.g. civil registry)
   □ Address File, list of addresses
   □ Census lists
   □ Electoral registry/lists
   □ Primary Health Care/Public health registry/lists
   □ Other, specify

5. If a household sample was drawn: which persons of the household were examined in the survey?

   □ Only one person
   □ A limited number of persons of the household, namely ...... persons
   □ All persons of the household of a certain age
   □ All persons of the household

   If a limited number of persons of the household were selected, how was the person(s) selected?
6. If a sample of individuals was drawn: were other persons belonging to the household examined as well?

- Yes, all members of the household were selected
- Yes, some members of the household were selected
- No other persons were examined

7. What kind of sampling procedure was applied?

- A multistage probability sample → go to question no. 8
- A simple probability sample → go to question no. 10
- Other procedure, namely
  ...
  go to question no. 10

8. If a multistage probability sample was taken: which variables were used for the stratification? (tick more than one answer if necessary)

- Age
- Sex
- Marital status
- Geographic area
- Degree of urbanisation
- Other, specify

9. If a multistage probability sample was taken: was oversampling applied for certain groups of persons?

- Yes, namely for ………
- No

10. In the case of a HIS preceding the HES, where all sampled persons invited to health examinations?

- Yes, all persons were invited
- No, only a sample of those who were interviewed or returned a questionnaire were invited
- No, but all those who were first interviewed or returned a questionnaire were invited
- No, only those who filled the following criteria were invited
  Specify criteria:
11. Is there any difference in questions or examinations (tests, measurements) among institutionalised groups from those among the general population (household or individuals)?

○ No
○ Yes

If yes, please specify

12. Was there a specific need to request permission to conduct the survey if the person was living in:

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homes for the elderly</td>
<td>□</td>
</tr>
<tr>
<td>Nursing homes</td>
<td>□</td>
</tr>
<tr>
<td>Psychiatric institutions</td>
<td>□</td>
</tr>
<tr>
<td>Institutions for the mentally handicapped</td>
<td>□</td>
</tr>
<tr>
<td>Boarding schools</td>
<td>□</td>
</tr>
<tr>
<td>Convents/monasteries</td>
<td>□</td>
</tr>
<tr>
<td>Prisons</td>
<td>□</td>
</tr>
<tr>
<td>Others, namely</td>
<td>□</td>
</tr>
</tbody>
</table>

If yes, whose permission?

13. The data obtained from institutionalised groups were (will be) reported:
   a. Separately from the general population (non-institutionalised persons)

   ○ Yes
   ○ No

   b. Together with the general population (non-institutionalised persons)

   ○ Yes
   ○ No

   c. Other, specify:

14. Was the survey restricted to certain age groups?

○ Yes: minimum age: maximum age:
○ No: all age groups were included
15. What size was the sample (those invited to the examinations) the last time the survey was carried out? (net sample size, i.e. *exclusive of non-response*).

Number of households in the original sample:
Number of households in the sample after exclusion of ineligible (e.g. not meeting age criteria, deceased):
Number of persons in the original sample:
Number of persons in the sample after exclusion of ineligible (e.g. not meeting age criteria, deceased):

16. What was the overall percentage of non-response for the health examinations the last time the survey was carried out?  
(Number of examined households or individuals / Number of sampled and eligible households or individuals)

Percentage non-response: .............% (households)
Number of respondents (households)
Percentage non-response: .............% (individuals)
Number of respondents (individuals)

17. Specification of non-response:
    Percentage not contacted
    Percentage refusal
    Percentage not able to participate (e.g. because of time-table, illness)
    Other, specify

18. In the case of non-response: was basic information on the non-respondents collected by any means?

☐ Yes by means of a shortened examination protocol (e.g. home visit if no attendance for a clinic visit)
☐ Yes by means of a short mailed questionnaire
☐ Yes by means of a short telephone interview
☐ Yes, from registers, specify…
☐ No

19. In case of non-response/non-participation: how many times were the subjects re-contacted

On average ____ times by telephone/letter/home visit

20. How were the subjects contacted, invited/ and motivated to participate?

☐ invitation letter and reminders (please enclose a copy)
☐ brochure/leaflet (please enclose a copy)
☐ telephone contact(s)
☐ personal contact(s) (visit)
21. How was the target population informed about the survey
   □ Personal contacts (letters, telephone contacts, visits)
   □ National media (newspapers, radio, TV)
   □ Regional media (newspapers, radio, TV)

22. How/when was informed consent obtained?
   □ No signed informed consent
   □ During interview phase before examinations
   □ During clinic/home visit for examination
   □ Other, specify
   If available, please enclose copies of informed consent form(s)

23. Were reasons for refusal asked?
   □ No
   □ Yes, please list main reasons:

24. Did participants receive any financial compensation/reimbursement
   □ No
   □ Yes, of travel expenses to all participants
   □ Yes, of travel expenses to participants with certain criteria
   □ Yes, other specify
   Please, specify criteria for reimbursement/compensation:

25. Were other means used to motivate participation
   □ No
   □ Yes, lottery among participants
   □ Yes, other means, specify:

26. List up to five reasons you feel are most important factors motivating response/participation (willingness to participate in the survey)?

27. List up to five reasons you feel are most important factors causing non-response/non-participation in this survey?

28. Please indicate below in which months the examinations were conducted the last time the survey was carried out?
   (tick all months that apply)
   □ January □ May □ September
   □ February □ June □ October
   □ March □ July □ November
   □ April □ August □ December
29. Average duration of survey per participant (total)
   Interview phase _______ hours _____ minutes
   Examination phase _______ hours _____ minutes

30. Where were the field health examinations mainly carried out?
   □ At the participants home
   □ At a mobile clinic
   □ At normal health care organisations/facilities (health centres or hospitals)
   □ At stationary clinic(s) set up for the examinations
   □ Other____________________________________________________

31. Was specific survey personnel employed to carry out the examinations?
   □ No, regular health care personnel was used
   □ No, specific survey personnel had been employed before and was used to carry out this survey
   □ Yes, specific survey personnel/teams was employed for this survey

32. What kind of personnel groups carried out the examinations? (tick several, if necessary)
   □ Nurses
   □ Physicians
   □ Psychologists
   □ Dentists
   □ Dental hygienists
   □ Laboratory technicians
   □ Medical-technical assistants
   □ Trained/lay interviewers
   □ Other_________________________________________________

33. What kind of training did the personnel receive before and/or during fieldwork? (tick several, if necessary)
   □ A general training before fieldwork
   □ A special training for some/the following methods/instruments________________________________________
   □ Repeated training/briefing during fieldwork
   □ Other

34. Were the examination results entered in a computer file already at the field examination?
   □ Yes
   □ No, recorded mainly on paper and entered afterwards elsewhere
35. Were previously standardised or recommended procedures were followed during the fieldwork?

- No such procedures followed
- Cardiovascular survey methods recommended by WHO
- Blood pressure measurement according to MONICA protocol
- Blood pressure measurement according to EHRM recommendations
- Anthropometric measurements according to MONICA protocol
- Anthropometric measurements according to EHRM recommendations
- Blood collection according to MONICA protocol
- Blood collection according to EHRM recommendations
- Other, specify:

36. How were the participants informed about examination results? (tick several if necessary)

- The results were explained to them during and/or at the end of the examination
- The results were explained in a mailed letter to the participant
- The results were mailed to the participant’s own doctor, GP or other professional

(if available, please enclose copies of forms, letters etc. given to subjects concerning their test/examination results)
37. Was external quality control performed during fieldwork (other than laboratory tests)?

☐ Yes, by ____________________________ name of the institute(s)
☐ No, only internal quality control by research team
☐ Other ________________________________

38. What type of quality assurance and control procedures were used during fieldwork (other than laboratory tests)?

☐ Training (and retraining) of personnel
☐ Pilot runs
☐ Calibration of equipment at regular intervals
☐ Internal observation during examinations (including supervision, videos etc.)
☐ External observation during examinations (including supervision, videos etc.)
☐ Repeated measurements of the same subjects by two or more observers during one clinic/home visit
☐ Repeated measurements of the same subjects at two or more occasions, e.g. at home and at the clinic
☐ Repeated measurements with different equipment and/or protocol (e.g. automatic and manual devices)
☐ Analyses of standard/control samples
☐ Monitoring findings reported by observers
☐ Other ________________________________

39. Was a reference laboratory used?

☐ No
☐ Yes, specify

40. Are the micro-data (i.e. data on the level of the individual) from the survey available (in principle) for research by other institutes?

☐ Yes
☐ No

41. Publications: Please, give a list of major publications where the design, methods and procedures of this survey have been reported (Please enclose copies, if available)
SOME QUESTIONS ABOUT OTHER HEALTH EXAMINATION SURVEYS IN YOUR COUNTRY

If you know of any other health examination surveys in your country that would be of interest to us, please fill in the next section. Please inform us also of surveys at an advanced planning stage.

Please note that any survey to be included should meet the following criteria:

1. The survey should contain a substantial health monitoring component.
2. The survey uses national population-based samples or representative regional samples.
3. The survey should not be restricted to a specific part of the population (e.g. children, occupational groups, patients or prisoners)
4. The survey should not be restricted to one specific health component/disease (e.g. nutrition, asthma or AIDS)
5. Preferably there should be plans to repeat the survey later unless it already has been repeated. You can record also once-only surveys if there are no repeated surveys.

Name of the survey : ................................................
Name of the survey in English : ................................................
Type of survey (National /regional) : ................................................
Institute responsible for this survey : ................................................
Contact person for this survey : ................................................
Address : ................................................
Telephone number : ................................................
Fax : ................................................
E-mail : ................................................

THANK YOU FOR ANSWERING THE QUESTIONS.

Please return this questionnaire, and, if applicable, the above mentioned letters, brochures, leaflets, manuals/protocols to:

National Public Health Institute (KTL)
Department of Health and Functional Ability
Päivikki Koponen
Mannerheimintie 166
FIN-00300 Helsinki
Finland
e-mail: paivikki.koponen@ktl.fi
Annex 2. HIS methodological questionnaire for information on sample and participation

European Health Surveys Database
HIS/HES project phase II

QUESTIONNAIRE CONCERNING METHODOLOGICAL ASPECTS
OF HEALTH INTERVIEW AND EXAMINATION SURVEYS

Survey name:
Survey year:
Survey code:
Institute:
Country:

This project is financially supported by the European Commission
This page contains information related to previous information collected during the HIS/HES project. Please make additions and/or corrections if needed. If options are mentioned, then we would like you to make a choice from these alternatives.

Survey name : 
Survey name in English : 

Institute mainly responsible for this survey and the contact person:
Institute : 
Department : 
Name contact person : 
Telephone number : 
Fax : 
E-mail : 

Other institutes involved in this survey (please state their role):

Institutes or organisations financing the survey:

Type of the above-mentioned survey:
☐ national HIS/HES
☐ national HES
☐ national HIS
☐ regional HIS/HES
☐ regional HES
☐ pilot for a planned national HIS/HES or HES
☐ other, specify:

Coverage of the health survey:
☐ Broad/multipurpose health survey
☐ Focused health survey (e.g. cardiovascular)
☐ Other, specify.

The frequency of the survey:
☐ Continuous
☐ Yearly
☐ ____Yearly
☐ Irregular
☐ Other, specify:

The years in which the survey has been carried out ( incl. this year if applicable):

The next year(s) the survey is expected to be carried out:
Survey design:
Follow-up
☐ no
☐ yes, to all
☐ yes, to subsample(s)
Follow-up based on
☐ registers
☐ questionnaires and/or interviews
☐ examinations

The mode of data collection used for the survey:
☐ One phase only or interview with self-completed questionnaires
☐ Interview phase before health examinations
☐ Interview phase after health examinations
☐ Self-completed questionnaires
☐ Additional phases/examinations after screening/selection (please specify criteria)

Survey structure:
☐ Core survey supplemented with different modules each time the survey is conducted
☐ Core survey supplemented with specific modules for certain subpopulations
☐ No major differences between years and subpopulations
☐ Other, specify:

Language(s) used during interviews:
PLEASE ANSWER THE FOLLOWING QUESTIONS:

1. **In general two types of sample are possible.** Which of these was used the last time the survey was carried out?
   - □ A sample of households
   - □ A sample of individuals

   (If available please enclose a copy of a document describing the sampling procedure)

2. **Target population**
   - □ All residents included
   - □ Excluding institutionalised
   - □ Excluding temporary residents (e.g. students)
   - □ Excluding residents not fluent with survey languages
   - □ Excluding non-citizens (e.g. refugees)
   - □ Excluding other, specify

3. **Which of the following institutionalised groups were included in the survey?** (tick more than one answer if necessary)
   - Persons living in:
     - □ Homes for the elderly
     - □ Nursing homes
     - □ Psychiatric institutions
     - □ Institutions for the mentally handicapped
     - □ Boarding schools
     - □ Convents/monasteries
     - □ Prisons
     - □ Others, namely

4. **Sampling frame (the lists from which the sample is selected)**
   - □ National registry of population (e.g. civil registry)
   - □ Address File, list of addresses
   - □ Census lists
   - □ Electoral registry/lists
   - □ Primary Health Care/Public health registry/lists
   - □ Other, specify

5. **If a household sample was drawn: which persons of the household were examined in the survey?**
   - □ Only one person
   - □ A limited number of persons of the household, namely ….. persons
   - □ All persons of the household of a certain age
   - □ All persons of the household

   If a limited number of persons of the household were selected, how was the person(s) selected?
6. If a sample of individuals was drawn: were other persons belonging to the household examined as well?

- Yes, all members of the household were selected
- Yes, some members of the household were selected
- No other persons were examined

7. What kind of sampling procedure was applied?

- A multistage probability sample → go to question no. 8
- A simple probability sample → go to question no. 10
- Other procedure, namely
  …………………………………………….
  ……………………………………………. → go to question no. 10

8. If a multistage probability sample was taken: which variables were used for the stratification?
   (tick more than one answer if necessary)

- Age
- Sex
- Marital status
- Geographic area
- Degree of urbanisation
- Other, specify

9. If a multistage probability sample was taken: was oversampling applied for certain groups of persons?

- Yes, namely for ……..
- No

10. Was the survey restricted to certain age groups?

- Yes: minimum age:
  maximum age:
- No: all age groups were included

11. What size was the sample (those invited to the examinations) the last time the survey was carried out? (net sample size, i.e. exclusive of non-response).

   Number of households in the original sample:
   Number of households in the sample after exclusion of ineligible (e.g. not meeting age criteria, deceased):
   Number of persons in the original sample:
   Number of persons in the sample after exclusion of ineligible (e.g. not meeting age criteria, deceased):

12. What was the overall percentage of non-response for the health interviews the last time the survey was carried out?
   (Number of examined households or individuals / Number of sampled and eligible households or individuals)

   Percentage non-response: …………..% (households)
   Number of respondents (households)
   Percentage non-response: …………..% (individuals)
   Number of respondents (individuals)
13. Specification of non-response:
   Percentage not contacted………
   Percentage refusal……….
   Percentage not able to participate (e.g. because of time-table, illness)…….
   Other, specify…….

14. In the case of non-response: was basic information on the non-respondents collected by any means?
   □ Yes by means of a short mailed questionnaire
   □ Yes by means of a short telephone interview
   □ Yes, from registers, specify…
   □ No

15. In case of non-response/non-participation: how many times were the subjects re-contacted
   On average ____ times by telephone/letter/home visit

16. How were the subjects contacted, invited/and motivated to participate?
   □ invitation letter and reminders (please enclose a copy)
   □ brochure/leaflet (please enclose a copy)
   □ telephone contact(s)
   □ personal contact(s) (visit)

17. How was the target population informed about the survey?
   □ Personal contacts (letters, telephone contacts, visits)
   □ National media (newspapers, radio, TV)
   □ Regional media (newspapers, radio, TV)

18. How/when was informed consent obtained?
   □ No signed informed consent
   □ During interview phase
   □ Other, specify
   If available, please enclose copies of informed consent form(s)

19. Were reasons for refusal asked?
   □ No
   □ Yes, please list main reasons:
20. Did participants receive any financial compensation/reimbursement?

- [□] no
- [□] yes, of travel expenses to all participants
- [□] yes, of travel expenses to participants with certain criteria
- [□] yes, other compensation, specify

Please, specify criteria for reimbursement/compensation:

21. Were other means used to motivate participation?

- [□] No
- [□] Yes, lottery among participants
- [□] Yes, other, specify:

22. List up to five reasons you feel are most important factors motivating response/participation (willingness to participate in the survey)?

23. List up to five reasons you feel are most important factors causing non-response/non-participation in this survey?

24. Average duration of survey per participant (total)

   Interview _______ hours _____ minutes

25. What kind of training did the personnel (interviewers) receive before and/or during fieldwork? (tick several, if necessary)

   - [□] A general training before fieldwork
   - [□] A special training for some/the following methods/instruments_____________________________________________
   - [□] Repeated training/briefing during fieldwork
   - [□] Other _________________________________________________________

26. What type of quality assurance and control procedures were used during fieldwork?

   - [□] Training (and retraining) of personnel
   - [□] Pilot runs
   - [□] Internal observation during interviews (including supervision, videos etc.)
   - [□] External observation during interviews (including supervision, videos etc.)
   - [□] Repeated interviews (questions) of the same subjects by two or more interviewers
   - [□] Monitoring results by interviewers
   - [□] Other__________________________________________________________

27. Publications: Please, give a list of major publications where the design, methods and procedures of this survey have been reported (Please enclose copies, if available)
THANK YOU FOR ANSWERING THE QUESTIONS.

Please return this questionnaire, and, if applicable, the above mentioned letters, brochures, leaflets, manuals/protocols to:

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