



Toolkit for the development and implementation of epidemiological surveys in small populations



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Toolkit for the development and implementation of epidemiological surveys in small populations

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1. Preface

This toolkit is published by the Islands and Small States Institute of the University of Malta as part of its work carried out as WHO Collaborating Centre on Health Systems and Policies in Small States. Under the coordination of **Dr. Natasha Azzopardi Muscat**, the WHO Collaborating Centre carries out activities that support the development of frameworks and policies for strengthening the resilience of health systems in small state.

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2. Aim of toolkit

The aim of this toolkit is to illustrate the epidemiological theory underlying the conduction of health surveys in small states or regions.

3. What is a health survey?

A health survey is usually the collection of new health-related data as part of an observational research study that is conducted to measure the prevalence of health problems, risk factors, health behaviours, as well and other determinants of health (such as socioeconomic status within a specific population). Such a survey can have an analytical (exposure-outcome relationship), as well as a purely descriptive aim. The carrying out of such a study requires close attention to: the study design, case definition, the participants' selection, the inclusion of controls, valid tools of measurement, the measurement of exposure/s, outcome/s and potential confounders, along with robust data analysis ¹.

There are different types of observational studies. The more common type is the cross-sectional study with a strong descriptive element, while the case-control and longitudinal cohort studies have a more analytical scope.

- A cross-sectional study collects information at one point in time from a defined population. Such a study can provide useful descriptive information in the form of prevalence rates (frequency of exposure/outcome). It could also provide analytic information, where an association between the outcome and potential exposures are investigated. This type of study is relatively easy to conduct and repeat in small populations. Regular cross-sectional randomised studies at a population level can provide invaluable health information on trends of exposure and outcomes. However, selection bias can occur, and temporal relationships cannot be assessed given the retrospective nature of data collection.
- A case-control study explores retrospectively the exposure between a cohort with a disease (cases) and (ideally matched) individuals from the same population without the disease (controls). However, selection bias can occur, and temporal relationships between the exposure and outcome cannot be assessed. Confounding bias can often be accounted for in this study, as long as all potential confounding factors are known and measured. Additionally, this methodology lends itself to various forms of information bias, prominent among which is recall bias.
- A longitudinal cohort study measures the incidence rate of a particular exposure/disease by following up a selection of a population over a period of time. This requires a baseline measurement (and exclusion of the outcome condition at the onset of the study) with a follow up for new incident cases of outcome/s over the specified period of time. Such studies can explore temporal relationships between the exposure and the outcome. However, these are expensive and take a long time to be completed with expected participants withdrawal throughout the follow-up period. These limitations can seriously threaten the survey feasibility and validity

The type of survey conducted will depend on the intended outcome (descriptive/analytical) and other practical considerations, such as available resources and time.

4. Preparation for the health survey

2.1 Survey team

A team should be put together to assume responsibility of the health survey. The core members of the team should be composed as follows:

- Project leader – Planning and overall coordination of the survey from beginning to end.
- Epidemiological support and advice – May be provided on an ad hoc basis.
- Statistical officer – Sampling of the survey population, analysis of the survey data and drawing up of reports
- Financial officer – Preparation of the initial budget and financial management
- Administrative staff – Coordination of interviewers and supervisors during the fieldwork period
- Interviewers – Responsible for the collection of data from interviewees using the validated tool
- Supervisors – Monitor the interviewer's work and aid them as required. Usually there can be up to 10 interviewers per one supervisor

2.2 Budgeting and sponsorships

Budgeting for health surveys should be performed at the early phases in order to ensure adequate funding from sponsorships. A detailed budget should be drawn up alongside a Gantt chart. The budget should include, but is not limited to²:

- Staff costs (individualised by skill and per time unit spent)

- Interviewer and supervisor costs (typically defined per successfully completed questionnaire)
- Telephone costs
- Communication, dissemination and publicity of the health survey
- Printing costs of forms, questionnaires and reports
- Hardware & software costs, including electronic survey tool (if any), scanner/mark reader software (if any) & statistical package e.g. SPSS, R, STATA, SAS.
- Laboratory investigation costs (if health examination survey)
- Equipment – e.g. Weighing scales; sphygmomanometers; peak-flow meters, etc. (if health examination survey)
- A 10% addition for incidental expenses that is usually used to the full

In order to promote participation, small incentives are sometimes provided to the respondents who completed the survey. Such incentives, such as discount vouchers for goods or services, small items such as dried fruit portions or toiletries, may be provided by sponsors in sufficient quantities to cover the whole sample population. Larger items, such as flights or weekend breaks, can be used as lottery prizes. These incentives act as a token of appreciation to the respondents. However, lottery prizes may require regulatory clearance and may be subject to taxation in certain countries³.

2.3 Defining the population

2.3.1 Target population

The target population for health examination surveys among adults typically includes the country's permanent residents between the ages of 25 and 64 years. This age group is the most amenable to interventions intended to prevent future disease and disability. On the other hand, health interview surveys typically include all adults above the age of 18, including the elderly especially when assessing functional capacity². Health information on children is also important, in which case the health

survey tool and methodology typically need to be modified extensively to cover this sub-population, which is most amendable to preventive activities. In this case using school-based surveys may also be more efficient.

2.3.2 Sample population

Health surveys conducted in small countries or regions need to cover a greater proportion of the population to ensure enough statistical power for the survey to produce accurate estimates, as this depends on the number of actual respondents³. Unfortunately, this presents a challenge for small countries as it results in a higher cost per capita to conduct a national survey. However, in small countries a single-staged sampling procedure is utilised, unlike in larger countries where two-stage sampling is required to keep the survey geographically feasible. When a single-stage sample (randomly stratified by age, gender and locality) is drawn and used, the survey will be able to cover the entire population without major logistic difficulties. The sample size required would be smaller than that of the two-stage sampling, since the latter is subject to a design effect of 1.5⁴. The country's expected response rate needs to be taken into consideration when calculating the required sample population size from national registers. If the expected response rate is low, it is suggested to enhance the resources to increase the response rate, rather than increase the total sample size. When an elderly population is to be included in the sample population, it is recommended to increase the sample probabilities of this sub-group. This applies also to other small population groups of interest, such as migrants⁵. The European Health Examination Survey (EHES) provides a specific sampling application tool that can be used to estimate the population sample size required for a health examination survey (ehes.info/rc/tools/tools.htm). Obviously, any differential probability sampling would require weighting to be applied before carrying out any analysis. The possibility of serious respondent bias is always present and seriously undermines validity when the response rate is low.

2.3.3 Inclusion and exclusion criteria

The inclusion and exclusion criteria are dependent on the country. It is, however, suggested that the sample population should be representative of the whole residents (more than 6 months residency) of that country. Where possible, institutionalised persons and immigrants should be included in the national survey. Whilst their numbers are unlikely to be large enough to allow the analysis of their replies as a subgroup, some prevalence estimates can be materially affected. Ethical and practical issues may be present for institutionalised persons, since these are usually elderly with limited cognitive functioning, requiring certain questions to be omitted for institutionalised individuals⁶. In such cases, special protocols or extra resources (e.g. provision of interpreters or home visits) may be required⁵. Difficulties may arise in some countries when sampling non-citizens living permanently in that country, such as major language barriers. Other linguistic versions of the questionnaire may have to be prepared. In this case, what is typically recommended by most health survey guidelines is conceptual translation⁷. Females happening to be pregnant at the time of the survey are typically excluded from participating in health examination surveys since the anthropometric and biological parameters may be altered from the norm.

2.4 Survey preparation

Health surveys provide tangible benefits to a country by identifying the needs for targeted actions and thus enable the utilization of resources efficiently³. Information at population-level is crucial for evidence-based health policy decisions and research⁸. Health surveys should be planned and standardized between small countries in order to enable comparisons of health risks and health information.

Health surveys can be classified into two types, namely, health interview surveys (HIS) and health examination surveys (HES). Data collection for HIS is carried out through self-reported questionnaires, whether self-administered or interview-based, and can measure health behaviours, health status and diseases that are known to the

respondent. Unlike HES, HIS cannot provide any information on undiagnosed conditions and is prone to report bias, especially when covering factual questions, such as weight and height, leading to inaccurate obesity prevalence. HIS is also subject to culture-based preferences when reporting on health problems ^{2,9}. A health examination survey is composed of a health examination for different anthropometric and biological parameters, including the collection of biological samples, and is accompanied with a questionnaire for socio-demographic data. Health interview surveys are much cheaper to conduct than health examination surveys, since the latter require more personnel training and specialist clinical investigations ¹⁰.

2.4.1 Questionnaire

Health surveys should be based on validated questionnaires in the native language of the population under study. There are a number of validated questionnaires covering a range of health-related topics that can be adapted to other populations. One example is the European Health Interview Survey that can be used to collect data on health status, health care use and health determinants

(ec.europa.eu/eurostat/web/products-manuals-and-guidelines/-/KS-RA-13-018),

while the demographic health survey (DHS) can be used to collect demographic data (dhsprogram.com), especially in countries wherein there are no birth or death registries.

The World Health Organization (WHO) also provides a step-by-step questionnaire (STEPS) that can be used for risk factor surveillance of non-communicable diseases (who.int/ncds/surveillance/steps/instrument/en/).

The European community respiratory health survey II provides validated questions covering respiratory health (ecrhs.org/Quests/ECRHSIImainquestionnaire.pdf).

The global adult tobacco survey (GATS) is a WHO validated tool used for surveys covering tobacco habit (who.int/tobacco/surveillance/tqs/en/) while the global physical activity questionnaire (GPAQ) is a tool for measurement of physical activity

(who.int/ncds/surveillance/steps/resources/GPAQ_Analysis_Guide.pdf).

The Katz Index of independence in activity of daily living

(chroniccare.rehab.washington.edu/westernwa/geriatrics/resources/katzindeptest).

pdf) can be used to measure the ability of the participant's ability to perform independently daily living activities. The European School Survey Project on Alcohol and Other Drugs (ESPAD) tool is used to collect data on substance use among 15 – and 16-year-old students (espad.org), while the Health Behaviour in School-aged Children (HBSC) tool is used to collect data on 11-, 13- and 15- year boys' and girls' health and well-being, social environments and health behaviours (hbsc.org). The WHO European Childhood Obesity Surveillance Initiative (COSI) tool is used to measure overweight and obesity among primary school aged children (euro.who.int/en/health-topics/disease-prevention/nutrition/activities/who-european-childhood-obesity-surveillance-initiative-cosi).

It is important that the questionnaire is acceptable and shows sensitivity towards LGBTIQ individuals and any minorities, both in the way traditional gender questions are formulated and, even more importantly, in sexual health modules.

Sensitive questions, such as sexual related questions, should be self-administered by the respondent in an anonymous manner. Such sensitive questions may include the use of alcohol, smoking and any illicit drugs. Also, any questions that may cause any embarrassment to the respondent and are therefore at risk of desirability bias should be included in a self-administered tool, such as questions of a financial nature that request information on salary and financial standing. A minor word of note – in a number of populations, such as in the Maltese population, asking about income using income deciles or quintiles generated from another source resulted in a higher response rate than simply asking the respondent to provide a value for income.

Questionnaires are usually available in the English language. Translation to the native language may be required but the tool needs to be conceptually equivalent to the original form. Specific guidelines on how to construct such translations are outlined by EUROSTAT for the European health interview survey report ⁷. In this case back translation and cultural adaptation are usually considered.

2.4.1.1 Mode of delivery

The questionnaire can be conducted in various modes including dissemination through mail, online, through telephone interviews and face-to-face interviews. In both the telephone and face-to-face interview modes the questions are delivered by trained interviewers with support from both coordination and technical personnel. Face-to-face interviews are customarily conducted at a place of convenience for the participant, including their place of residence. It is important that a unique code is provided for each questionnaire, which code may be linked to one's personal details and be accessible to the project leader.

2.4.2 Health examination

Health examination surveys (HES) are required to establish accurate physical health information data as well as to assess undiagnosed conditions. A standardized protocol across countries is required in order to provide accurate and comparable HES results. Such surveys require standardised measurement protocols and devices as well as training of survey personnel along with adequate quality control⁹. Utilising common definitions of indicators would enable comparisons between countries and benchmarking^{11,12}. Standardization should also be implemented to the seasonal and diurnal timings of the health survey. The timing of the examination is known to affect not only participation rates but also physical examination results. Ideally health surveys should cover all seasons and last at least a year to avoid seasonal bias. Appointment flexibility throughout the week for participation in the health examination survey increases the respondents response rate¹³. A national representative survey conducted in the small European country of Malta reported that appointments scheduled during the weekends were for some even more acceptable by the participants. Furthermore, early appointments (between 7am and 8am) were favoured by over 50 years respondents, while later appointments (8.30am to 9.30am) were favoured by the younger population¹⁴. Additionally, in most countries, conducting the health survey fieldwork during the summer holidays may lower the

response rate as would fieldwork conducted during the Christmas period, mostly because of unavailability of respondents in their usual place of residence.

2.4.2.1 Health exam protocol

The European Health Examination Survey (EHES) provides a detailed manual on such a measurements' protocol, including examples of validated tools of measure (julkari.fi/handle/10024/131503)¹³. Similarly, the WHO provides a protocol for non-communicable risk surveillance (WHO Stepwise approach) that can be adopted by countries¹⁵.

According to the EHES, the core physical measurements that should be included in health examination surveys are height, weight, waist circumference, blood pressure, blood lipids, fasting blood glucose and glycated haemoglobin (HbA1C) apart from a questionnaire capturing self-reported information. These core measurements contribute to major chronic disease risk factors and are not readily available from other sources unless physically measured⁹. It is imperative that the trained measurers follow a standardised protocol when measuring and recording physical measurements, such as recording blood pressure accurately and not rounding up to the nearest whole number. Such protocols are detailed in the EHES manual¹³.

2.4.2.1.1 Setting a health examination site

A single or multiple health examination site/s should be set up in close residential proximity to the randomly selected sample population. In small countries these sites are easier to set up when compared to larger countries as the total number required is typically small and such sites may be under the control of a central authority. Getting access to some office space within primary care centres in the community could be an example. It was reported that establishing satellite hubs within all the towns of the

small state of Malta led to a good response rate¹⁴. The EHES manual provides details on selection of examination sites¹³.

2.4.2.1.2 Tools of measurement

The tools of measure (such as sphygmomanometer) should be validated tools, as outlined within the EHES manual¹³. These tools should be mobile to enable transportation from one hub to another if multiple hubs are to be set up. If a number of trained fieldworkers are recruited, simultaneous health examination sessions could be set up at different localities. In this case a number of identical validated tools of measurements are required. The tools need to be calibrated and tested prior to initiation of the health examination sessions and repeated subsequently.

2.4.2.1.3 Sequence of examination

The health examination survey should follow a specified standardised sequence for accurate data collection. Informed consent should be the initial step followed by the questionnaire. This will ensure that the respondent builds trust with the interviewer/examiner and is relaxed. Stressful procedures such as bloodletting should be left to the last especially if blood pressure measurement is part of the protocol¹³.

When blood samples are collected during the survey, it is imperative that a number of critical issues are considered ranging from the actual procedure of blood taking to storage and transport to the laboratory¹³. In small countries there is, most likely, a short distance between the examination site and the laboratory. In this case, the survey team may decide to use appropriate blood tubes for blood collection, store under ice and transfer to the laboratory within an appropriate timeframe to avoid denaturation of the blood sample. If this is not possible, then an on-site centrifuge would need to be present to separate the serum of the blood sample and then ensure refrigerated storage. The detailed procedure can be found in the EHES manual¹³.

2.4.2.2 Laboratory standardisation

In small countries, accredited laboratories are few. It is essential that such laboratories are identified and permissions obtained to use these facilities for analyses of the core sample measurements. Standardised protocols and cut-off points for the examined core samples need to be in place between countries to enable comparisons.

2.4.2.3 Data inputting

Data collected during the health survey needs to be in an appropriate electronic format for analysis later on. The collected data can either be immediately inputted electronically during the fieldwork or else a paper-based inputting system is used and the information inputted electronically later on. However, implementing a computer-assisted personal interviewing (CAPI) system instead of a paper-and-pencil interviewing (PAPI) system would reduce the burden of human resources and costs when conducting healthy surveys¹⁶. In addition, CAPI presents the option of having validation routines applied at source, a feature that is not available on PAPI.

2.4.3 Permissions and ethical approval

A number of permissions need to be sought out and granted prior to initiating the health survey along with ethical approval of the survey's protocol. Permissions include but are not limited to data protection clearance for obtaining a randomised population sample, permissions to use the laboratory, permissions to access any laboratory software and permissions to set up examination sites. Informed consent forms with a detailed explanation of the aim and outcomes of the health survey along with information about storage of personal information, measurements and, if included, tissue or serum samples need to be prepared. In the case of health examination surveys, the researcher may have to decide whether to communicate the results back to the respondents, not just as a gesture of thanks for participating, but also in order for the respondent to follow up on the results, especially deranged results. One way of

doing this is to communicate results to the respondents in the form of a letter addressed to their GP, highlighting any out of range values. This depends on whether the results are clinically useful or not. Certain research genetic markers may not yet have any clear clinical interpretation and the respondent may consent that they do not wish to have access to them.

A unique coding system is required, where the identifiable personal data is only accessible by the project leader. In self-administered questionnaires the unique code needs to be linked with the remaining survey measurements. This is usually performed by having the same unique code printed on all questionnaire material prior to dissemination. The self-administered questionnaire could then be detached from the face-to-face component and once the respondent finishes, the questionnaire is placed in a blank envelope, sealed and placed in a deposit box. Later on, the data is linked through the unique code. In this manner, the identifier used cannot be linked back to the respondent, but nonetheless allows linkage of the different components of the survey data. Lab results can be linked in a similar manner, once available. Nonetheless, the researcher may opt to keep it an identifiable manner, if the respondent requests to have these results sent to them.

2.5 Fieldwork preparation

2.5.1 Pilot survey

A pilot survey evaluates the survey process and ascertains that it is sustainable, as well as identifying any problems prior to the actual health survey. This is also the ideal time for the fieldworkers to practice and reduce inter-observer bias in a controlled environment. The pilot study is usually conducted on a convenient sample of around 50 individuals that were purposely selected to represent all socio-economic sectors. This is important to ensure that the questionnaire is easily understood by all the population society. Feedback from the invited participants further evaluates the

survey process. Following the pilot study, amendments to the questionnaire and/or the examination protocol may be required.

2.5.2 Recruitment and training

Fieldworkers need to be competent and motivated as their characteristics can influence the response as well as the survey data validity and reliability. Proficiency in the native language/s is another requisite. Furthermore, the fieldworkers need to be competent in carrying out the clinical measurements, where applicable. Different countries will have different legislations concerning recruitments, especially of medical professionals for health surveys. Details on fieldworkers recruitment are provided in the EHES manual ¹³.

Fieldworkers should be provided a manual listing all their requirements and expectations, along with a copy of the questionnaire. Training sessions need to be held few weeks prior to the pilot study and repeated following the pilot study. In the absence of a formal pilot study, interviewers should nonetheless carry out a trial run of the questionnaire between sessions in order to bring forward any issues. If there are any recesses in the fieldwork, it would be worth repeating the training towards the end of the recess. The measurers need to practice using the validated tools prior to the fieldwork and externally evaluated by an expert third-party.

2.5.3 Marketing

A multipronged marketing approach should be adopted that includes marketing of the health survey through newspaper adverts, billboards, television adverts (ideally during prime airtime) and online, although this will depend on availability of funds. In small countries, it may be relatively easy to access the secretariat of the Minister for Health. Ministries typically have access to regular radio or television talk-show slots, and they might be willing to allow the researcher to use some of these to enhance the visibility

of the survey, if such a survey is considered as aligned with the vision of the Ministry. Securing a launch event in the presence of the Minister for Health would typically ensure media attention and a dedicated reference in news bulletins and reporting. This could be very effective marketing with specific tiers of the population. The marketing should be initiated a few weeks before the start of the fieldwork and kept on-going especially during each new-wave participants' recruitment phase. Such marketing could be crucial to achieve acceptable response rates, particularly in the elderly subgroup. If the marketing is successful, one would typically start getting phone calls from volunteers who want to join the study, who would obviously be kindly turned down and explained that for the study to be valid and representative it has to restrict itself to a randomised sample.

2.6 Fieldwork

Invitation letters are to be sent out to randomly selected participants by mail at least two weeks prior the appointment or start date. The invitation letter should consist of detailed information about the health survey and its importance in providing valuable new information, how the data will be collected (through questionnaires and/or physical measurements), how the participants were selected, the confidentiality of personal details obtained during the survey as well as contact information (mobile number and e-mail) of the fieldworkers or project leader. The employed participants should also be notified that a note of absence from work would be provided to the respondents⁸. Offering a flexible appointment (time and date) enhances the response rate^{8,14}. Participants should be encouraged to contact the survey team with their decision to accept or reject the invitation for logistic purposes. The reason/s for non-response should be noted, if such information is available. In cases where the participants do not make contact with the survey team within an appropriate time frame, the fieldworkers should try to contact them by phone, provided a contact number is available. If a contact number is not available, a second invitation letter may be sent out. In case of health interview surveys, the fieldworkers may attempt to try to contact the participant at their home residence, although this is subject to cultural

norms. Obtaining a simple answer as to why a participant opts out of the survey can be very useful to assess selection bias between respondents and non-respondents and may thus assist with the validity of the collected data. The participants' recruitment process is outlined by the EHES manual¹³.

If a paper-based inputting system is used, the data sheets should be referred back to the coordinator immediately. Data inputting is to be done concurrently with the fieldwork to reduce the timescale of the survey. Back checking with a short phone call on approximately 15% of the respondents of successfully completed questionnaires is suggested, to monitor the conduct of the survey.

Data security is an important principle that needs to be in place throughout the fieldwork as well as after, as discussed in detail in the EHES manual¹². During the fieldwork external quality assessment should be considered for quality assurance^{11,12}.

5. Extraction of data

Data gathered during the health surveys (both HIS and HES) need to be in electronic format for data analysis and reporting. The electronic data needs to be validated prior to analysis in order to ensure that the data is "clean" and does not contain inappropriate data, such as weight exceeding 200Kg. Weighting for each respondent should be calculated based on the response rate in different age-gender-locality strata prior to reporting.

6. Reporting

Reporting of small countries health survey results may prove challenging due to small populations. Confidentiality needs to be a priority when reporting results on sub-groups, since these might easily lead to identification of the respondent.

Reports outlining the health survey outcomes should be targeted according to the audience it is being distributed to. In order to enhance visibility of the health survey results, it is essential that reports are easily accessible to researchers and the public alike. Furthermore, enrolling ministerial bodies to the launching of the survey's results will boost the visibility of such reports. Selective health survey results can be presented through activities on specific public health awareness days, such as Obesity Day, Diabetes Day etc. Such activities increase the awareness of the particular risk factor¹¹. Such results can simply be infographics that are easily and quickly shared through social media.

Ways to improving response rate:

- Continuous marketing throughout fieldwork of the health survey on the media, especially before sending out a batch of invitation letters.
- Contacting participants through mail and telephone
- Conducting interviews at the participants' house
- Setting examination hubs in each town
- Flexible appointments
- Early appointments times for elderly participants, later appointments for the younger participants
- Incentives to respondents
- SMS message prior to appointment

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