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Integrated population-based surveillance of NCDs

as part of the
National Action Plan for Prevention and Control of
Non- Communicable Diseases and Health Promotion in Pakistan

Survey Protocol



Heartfile

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National Action Plan for the Prevention and Control of
Non-Communicable Diseases in Pakistan

1. BACKGROUND

1.1 Survey Institution

Heartfile, Pakistan (under its program: *National Action Plan for the Prevention and Control of NCDs* in collaboration with the Ministry of Health, Government of Pakistan)

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1.2 Context

Non communicable diseases accounted for an estimated 33.4 million deaths worldwide in the year 2002; of these, 72% occurred in the developing countries.ⁱ NCDs and injuries are amongst the top ten causes of mortality and morbidity in Pakistan;ⁱⁱ estimates indicate that they account for approximately 25% of the total deaths within the country.ⁱⁱⁱ NCDs contribute significantly to adult mortality and morbidity and impose a heavy economic burden on individuals, societies and health systems.^{iv} In most cases, it is the economically productive workforce that bears the brunt of these diseases. South Asia has one of the highest rates of CAD compared to any throughout the world.^v Existing population-based morbidity data on NCDs in Pakistan show that one in three adults over the age of 45 years suffers from high blood pressure.^{vi} The prevalence of diabetes is reported at 10% whereas 40% men and 12.5% women use tobacco in one form or the other.^{vii,viii} Karachi reports one of the highest incidences of breast cancer for any Asian population.^{ix} In addition, estimates indicate that there are one million severely mentally ill and over 10 million individuals with neurotic mental illnesses within the country.^x Furthermore, 1.4 million road traffic crashes were reported in the country in the year 1999. Of these, 7000 resulted in fatalities.^{xi}

Against this background, the **National Action Plan for the prevention and control of non communicable diseases and health promotion in Pakistan** (Action Plan) is the first opportunity to develop and implement a National Plan of Action aimed at preventing and controlling these diseases in Pakistan. The Action Plan was officially released on May 12, 04 in a ceremony held in Islamabad, Pakistan. This program is a collaborative initiative of the Ministry of Health, Pakistan; the WHO Pakistan office and Heartfile. This public-private partnership has been mandated to develop and implement a long-term national strategy for prevention and control of NCDs and health promotion in Pakistan. The terms of this partnership, stipulated in an official agreement, placed the onus of responsibility on Heartfile to provide national leadership to develop and implement the National Action Plan.

Based on the priority areas identified in the Integrated Framework for Action of the National Action Plan, the first phase of its implementation has already commenced. The First Phase of implementation of the National Action Plan includes surveillance and a behavioral change communication component.

A necessary prerequisite for effective planning, implementation and evaluation of NCD prevention programmes is access to reliable and timely information on mortality, morbidity, risk factors and their socio-economic determinants. In Pakistan, lack of comprehensive databases for NCDs presents an obstacle to effective priority setting, targeting of programmes

to various population groups, evaluation of process-related activities and long-term evaluation of preventive interventions. The adoption of practical and economical systems to meet these needs have, therefore, been recognized as part of the Action Plan. There is some potential for strengthening and upgrading conventional data sources such as those that presently exist within administrative systems, public health and primary healthcare structures, individual files, death records and hospital data within the healthcare system in Pakistan. These data sources, however, suffer several limitations. These include lack of systematic data collection systems and population-based data on NCDs; lack of data for population subgroups with heterogeneous health characteristics; relatively small sample sizes in cross-sectional surveys; lack of longitudinal studies; and self-selection bias in sampling methods. By and large, existing data sources in Pakistan do not serve the purpose of monitoring population parameters, which this Action Plan aims to impact. For this reason, a more comprehensive, integrated, systematic and sustainable population-based data collection infrastructure needs to be established, maintained and expanded over time. This can then be supplemented by facility-based data collection systems and stand-alone data sources wherever applicable.

A surveillance process conforming to all these parameters is being established at Heartfile – this will be a sequential process and will begin with conducting a cross sectional survey with a sample of sufficient size with a power to detect changes in population level of the risk factors and NCDs over time. Appropriate linkages have also been established with institutions such as the Pakistan Medical Research Council (PMRC), which can provide sustainable support for surveillance activities.

2. OBJECTIVES

1. To estimate the prevalence of NCDs and also the distribution of risk factors, as a first step in a sequential process that aims to establish and maintain a comprehensive, integrated, systematic and sustainable population-based data collection system as part of the National Action Plan for the Prevention and Control of Non-communicable diseases in Pakistan.
2. To establish baseline levels of population level of the risk factors for NCDs.
3. To establish baselines for process evaluation of interventions.

3. STUDY DESIGN

3.1 Design

A cross sectional survey with a sample of sufficient size with a power to detect changes in population level of the risk factors for NCDs and selected NCDs will be conducted. A common population surveillance mechanism for all NCDs (with the exception of cancer) has been developed. The model includes population surveillance of main risk factors that predict many NCDs and combines modules on population surveillance of injuries, mental health and stroke. Guidance has been sought from the WHO STEPwise approach. Optional STEPS modules on mental health, injury and stroke have also been included in the surveillance model. The model has also incorporated components from the BRFSS module. In addition, it has been adapted for programme evaluation; this will enable it to track implementation processes using appropriate indicators, facilitating an assessment of how interventions work and which components contribute most to success. This will enable the surveillance model to measure outcomes and evaluate processes both qualitatively and quantitatively. Efforts will be made to build on similar data that have already been collected in Pakistan.

3.2 Inclusion criteria:

Males and females between 25-65 years of age (inclusive), who are willing to participate and also the permanent residents of the study area are being included in the study.

3.3 Exclusion criteria:

Individuals in institutionalized settings e.g. in hotels, motels, hospitals, nursing homes and other institutions and also the temporary residents of the study are being excluded from the study.

4. SAMPLING DESIGN**4.1 Sampling Frame:**

Rawalpindi District has been selected as the surveillance site. Both urban and rural areas of this district have been included. The District has a total population of 3.4 million according to the 1998 census; of this 58% is rural whereas 42% is urban. Sample size has been divided into urban and rural sub-samples according to the rural-urban distribution of the population. The sampling frame consists of the entire population of Rawalpindi District including urban as well as rural.

4.2 Sampling Plan:

The sampling strategy is multi-stage cluster sampling with stratification; rural and urban areas are being considered as two different strata. Each urban and rural area has been further divided into clusters. In urban areas these clusters (blocks) consist of 200-250 structures (houses as enumerated by the Federal Bureau of Statistics) and in rural areas these clusters will be villages/dehs/mouzas. At the first stage, clusters from urban and rural areas have been randomly selected proportionate to the population size of the two strata from the list of clusters. At the second stage a random sample of the households is being selected from each stratum using systematic sampling technique; assistance from the Federal Bureau of Statistics (FBS) has been sought for this technique. Representatives of the FBS are accompanying the field team for identification of households. An eligible respondent will be randomly selected from the list of eligible respondents in the selected household by using the lottery method.

4.3 Sample size estimation:

We assumed that prevalence of NCDs is ranging between 5% to 30% in Rural and Urban Rawalpindi, with 95% confidence level, 3% precision, and design effect of 2.5 after allowance for incomplete responses and population distribution will need a minimum of 2243 respondents (1301 respondents from Rural and 942 respondents from Urban Rawalpindi). 43 clusters need to be identified in the rural areas and 31 in the urban areas.

The requirement of augmenting the survey sample size to adjust for estimated non-response is necessary to ensure that we have adequate persons in the sample to have the power to make precise estimates. This does not, however, account for the bias that is created by non-response, since non-responders are often different from responders with respect to key variables that are linked to the domains under study in the survey. All effort, therefore, will be made to minimize non-response, and to interview as many people in the survey sample as possible.

5. DATA COLLECTION**5.1 Data collection and questionnaire design:**

The WHO Stepwise approach to surveillance has been adopted to develop this surveillance structure, with a focus on the core behavioral risk factors as outlined within the framework of STEP 2.

Respondents from the households are being identified using the lottery method. A respondent will be contacted 3 times – during different hours of the day, before deciding to code it as

“non-interview”? Data will be collected through face-to-face interviews with the help of a structured questionnaire. Informed consent will be taken from the respondents before each interview. Self-administered questionnaires will not be used, since they require a certain level of skill and education on part of the respondent, and as our study participants are likely to have low literacy level, that would not be the preferred approach. In the face-to-face interview, the interviewer will be able to maintain the respondent’s interest, and will be able to allay anxiety if it is aroused. The questionnaire has been translated into *Urdu* and back translated ensuring consistency in phrasing of questions so that the responses would not generate a bias. Respondents will not be receiving any incentives to participate – enticing participation by offering incentives tends to generate a bias as respondents in poor urban and rural areas tend to respond in the affirmative, assuming that such replies would be linked to rewards. Our previous experience with community interviews is encouraging and our culture where hospitality is a norm makes us feel strongly against incentives as part of such initiatives

5.2 Components of the questionnaire

Components of the questionnaire have been compiled with the use of previously validated questions included in previous studies.

Table 5.1 components of the questionnaire; their methodology and sources

Domain	Method	Source
Age	Date of birth. If unavailable, estimation of age with reference to an index event	Modified RISKCORN methodology ^{xii}
Education and work status	Based on the level of education and work status relevant in Pakistan	As above
Socio-economic status	Education, occupation and income	As above
Physical activity	Work activity, leisure time	STEPS/NCD V1.41 ^{xiii}
Smoking	Frequency and quantity Duration of exposure Past status Environmental tobacco smoke	As above INTERHEART ^{xiv}
Diet	Dietary patterns	As above
History of high blood pressure and diabetes	Screening for blood pressure Compliance with therapy	As above
History of angina	Symptom based	Rose Angina Questionnaire ^{xv}
Stroke	History of Stroke or Transient Ischemic Attack	STEPS S – RF ^{xvi}
Injury	Seat belt and helmet use Prevalence of injury Type of injury	WHO Injury module ^{xvii}
Mental Health	Personal and family history of mental disorder Somatic symptoms indicative of underlying disease	WHO Mental Health V 0.7 ^{xviii} Bradford Somatic Inventory ^{xix}
KAP modules	As indicated in the Integrated Framework for Action of the NAP ^{xx}	BRFSS questionnaire V1.5e ^{xxi} Heartfile Methodology ^{xxii}

A series of consultations were used to fully develop and refine the tool of assessment. The questionnaire will be piloted and modified as necessary. It was ensured that all questions have face validity; questions are clear, non-ambiguous and fair. Most questions have been designed to have fixed alternative responses for greater uniformity and simplicity of analysis.

Some however, have open-ended responses so as not to lose valuable information. These will be subsequently coded.

5.3 Quality assurance procedures:

Will be used to ensure consistency of interviewing and good quality data (i.e. random checks by field supervisor, principal investigator and re-interviewing the important questions from 10 percent of the respondents by different interviewer); in addition double data entry of the whole data will be done. Verification checks on 5% of the sample will be conducted after double entry if the error in the double entry will be <5 per thousand then the whole data will be re-entered. Measures will be taken to attain complete reliability and to reduce variation to reasonable limits. To this end, clearly defined standardized procedures will be developed; questions will be asked in a standard manner and the wording and the order of the questions will be decided well in advance. Particular attention will also be paid to reproducibility or the extent to which similar information is supplied when the question is asked more than once, so as not to generate a bias and to minimize variability of responses. Questions will be asked in a neutral manner without showing a preference for a particular response; it will be made sure that the respondents understand them in the same way.

5.4 Data Management:

Data will be edited, coded and double entered on a daily basis using software EPIDATA (version 3.2). Confidentiality of data will be ensured.

5.5 Data Analysis: data will be analyzed using SPSS (version 11.0). Adjustment for multiple sampling levels, editing for response errors and inconsistencies, weighted to reduce bias and provide representative prevalence estimates will be done.

6. SELECTION OF INTERVIEWERS

6.1 Selection:

A group of 25 interviewers (graduate in social sciences/above the age of 25/both sexes) have been selected for conducting the interviews. One member of the field team has been identified as a leader. Experienced data collectors with previous research experience have been selected in consultation with the Pakistan Medical Research Council.

6.2 Training of interviewers:

All data collectors have been extensively trained in taking informed consent, administering the questionnaire, and interview procedures. Details have been given in the section describing the questionnaire. In addition lectures have been given on the background of NCDs. Special attention has been given to the KAP modules. A Two day in house training on June 21 and 22 has been followed by extensive training in the field. A detailed field manual has been developed and is provided to the field officers.

7. CONFIDENTIALITY

Confidentiality will be maintained by incorporating this element as a clause into the short-term assignment contracts of the interviewers. A commitment to confidentiality will be ensured in the consent forms and training exercise. In addition, data entry will be done on the same day; questionnaires will be taken from the field staff and stored away safely on a daily basis. Heartfile systems are password protected.

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