
Integrated Population-Based Surveillance of Noncommunicable Diseases

The Pakistan Model

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Abstract: The escalating burden of noncommunicable diseases (NCDs) worldwide warrants an urgent public health response. Resource constraints and other factors necessitate an integrated and concerted approach to the range of NCDs. A necessary prerequisite for effective planning, implementation, and evaluation of NCD prevention programs is access to reliable and timely information on mortality, morbidity, risk factors, and their socioeconomic determinants. However, there is limited experience in the setting up of integrated NCD surveillance models in low-resource settings.

As part of the National Action Plan for the Prevention and Control of NCDs in Pakistan, an integrated, systematic, and sustainable population-based NCD surveillance system is being established, and will be maintained and expanded over time. This is a common population surveillance mechanism for all NCDs (with the exception of cancer). 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. In addition, the model has been adapted for program 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 paper outlines the first activity in this sequential process, including its merits and limitations.

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Introduction

Noncommunicable diseases (NCDs) accounted for an estimated 33.4 million deaths worldwide in the year 2002; of these, 72% occurred in the developing countries.¹ South Asia has one of the highest prevalence of coronary artery disease (CAD) compared to other world regions.² In Pakistan, NCDs and injuries are among the top ten causes of mortality and morbidity.³ Estimates indicate that they account for approximately 25% of total deaths.⁴ One in three adults aged >45 years suffers from high blood pressure.⁵ The prevalence of diabetes is reported at 10%, whereas 40% of men and 12.5% of women use some form of tobacco.^{6,7} Karachi reports one of the highest incidences of breast cancer among Asian populations.⁸ In addition, estimates indicate that there are 1 million severely mentally ill and >10 million individuals with neurotic mental illnesses.⁹ Furthermore, 1.4 million road traffic crashes were reported in the country in 1999. Of these, 7000 resulted in fatalities.¹⁰

Against this background, the National Action Plan for Prevention and Control of Noncommunicable Diseases and Health Promotion in Pakistan (NAP-NCD) is the first concerted approach to develop and implement a national program aimed at preventing and controlling these diseases in Pakistan.¹¹ This program is a collaborative initiative of the Pakistani Ministry of Health, World Health Organization (WHO) Pakistan office, and nongovernmental organization Heartfile, described as a public–private partnership, mandated to develop and implement a long-term national strategy for the prevention and control of noncommunicable diseases and health promotion.¹²

The plan, officially released on May 12, 2004, defines NCDs in an extended context. By convention, the term “noncommunicable” disease refers to major chronic diseases inclusive of cardiovascular diseases, diabetes, cancer, and chronic respiratory diseases and their risk factors. As part of this initiative, however, the chronic conditions of mental illnesses and injuries have also been grouped alongside the conventional ones, as country requirements necessitated that these be addressed through synchronized public health measures within a combined strategic framework. Based on the priority areas identified in the Integrated Framework

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Table 1. Variable in questionnaire: methodology and sources

Domain	Method	Source
Age	Date of birth. If unavailable, estimation of age with reference to an index event	Modified RISKCORN methodology ^{17,18}
Education and work status	Based on level of education and work status relevant in Pakistan	As above
Socioeconomic status	Education, occupation, and income	As above
Physical activity	Work activity, leisure-time activity	STEPS/NCD V 1.41 ¹⁵
Smoking	Frequency and quantity Duration of exposure Past status Environmental tobacco smoke	STEPS/NCD V 1.41 ¹⁵ Interheart ¹⁷
Diet	Dietary patterns	STEPS/NCD V 1.41 ¹⁵
History of high blood pressure and diabetes	Screening for blood pressure	STEPS/NCD V 1.41 ¹⁵
History of angina	Compliance with therapy	
Stroke	Symptom based History of stroke or transient ischemic attack	Rose Angina Questionnaire ¹⁹ STEPS S-RF ²⁰
Injury	Seat belt and helmet use Prevalence of injury Type of injury	WHO Injury module ²¹
Mental health	Personal and family history of mental disorder Somatic symptoms indicative of underlying disease	WHO Mental Health V 0.7 ²¹ Bradford Somatic Inventory ²²
KAP modules	As indicated in the Integrated Framework for Action of NAP	BRFSS questionnaire V1.5e ¹⁶ Heartfile methodology ²³

BRFSS, Behavioral Risk Factor Surveillance; KAP, Knowledge, attitudes, and practices; NAP, National Action Plan; NCD, noncommunicable disease; RISKCORN, Study of Coronary Heart Disease in a Pakistani Population; STEPS, Stepwise; V, version; WHO, World Health Organization.

for Action,¹³ the first phase of its implementation has already commenced. As part of this, **the setting up of a surveillance process is the first step.** This paper discusses the surveillance methodology adopted and its strengths and weaknesses.

Study Design

A common population surveillance mechanism for all NCDs (with the exception of cancer) has been developed.¹⁴ 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. To develop this surveillance structure, guidance has been sought from the WHO Stepwise (STEPS) approach to surveillance,¹⁵ and the Behavioral Risk Factor Surveillance (BRFSS) model of the Centers for Disease Control and Prevention (CDC).¹⁶ Optional STEPS (WHO) modules on mental health, injury, and stroke have also been included in the surveillance model. The model has also incorporated knowledge related components from other sources (Table 1). In addition, it has been adapted for program evaluation, which will facilitate tracking of implementation processes using appropriate indicators, and assessing how interventions work and which components contribute most to success. The linkage of this surveillance model with the NAP-NCD Integrated Framework for

Action provides the framework for program evaluation.¹²

The objective of this activity is to establish and maintain a comprehensive, integrated, systematic, and sustainable population-based data collection system for NCDs. This will be a sequential process; the index activity will be a cross-sectional survey with a sample of sufficient size with a power to detect changes in population level of risk factors and NCDs over time.

For the initial survey, Rawalpindi District has been selected as the surveillance site. The district, located in northeastern Pakistan, has an area of 2010 square miles and a total population of 3.4 million, according to the 1998 census; 58% is rural and 42% urban. The sampling frame consists of the entire population of the district. The district sample was divided into urban and rural subsamples according to the rural-urban population distribution. There were a total of 68 primary sampling units; of these, 33 were in rural areas and 35 in urban areas.

With the assumption that the prevalence of NCDs ranges between 5% to 30% in rural and urban Rawalpindi, with a 95% confidence level, 3% precision, and design effect of 2.5, and after allowance for incomplete responses and population distribution, a sample size of 2243 has been calculated (1301 respondents from rural areas and 942 respondents from urban areas). Males and females aged 25 through 65 years,

who are willing to participate and are permanent residents of the study area, will be included in the study, whereas individuals in institutionalized or temporary settings, and those who do not consent to participate will be excluded from the study.

Data Collection

A series of consultations were used to fully develop and refine the assessment tool. The study questionnaire collects data on demographic factors, risk factors, selected NCDs and knowledge-related factors. Components of the questionnaire have been compiled with the use of previously validated questions included in previous studies (Table 1). The questionnaire has been translated into Urdu, and back-translated to ensure consistency in phrasing of questions so that the responses would not generate bias. The questionnaire has been piloted and field tested in 50 individuals.

An eligible adult respondent will be randomly selected from each household. Respondents will be contacted three times at different times of the day before the case is coded as “non-interview.” Data will be collected through face-to-face interviews. Informed consent will be obtained from each respondent before the interview. Questions have been evaluated for face validity, and results indicate that they are clear, unambiguous, 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 the opportunity to collect valuable information outside fixed responses. Respondents will not receive any incentives to participate.

Training of interviewers has stressed measures to ensure consistency of interviewing and high-quality data. Measures have been taken to attain complete reliability and to reduce variation to reasonable limits. To this end, clearly defined standardized procedures have been developed, and field operation manuals provided to the data collection staff. Questions will be asked in a standard manner, and the wording and the order of the questions have been decided in advance. Particular attention has been 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 preference for a particular response; interviewers will attempt to ensure that the respondents understand them in the same way. Verification checks will be conducted on 5% of the sample.

Data will be stored on a daily basis using SPSS, version 11 (SPSS Inc., Chicago, 2003). Double data entry will be performed. Confidentiality will be maintained by incorporating this element as a clause into the short-term assignment contracts of the interviewers.

Questionnaires will be taken from the field staff and stowed away safely on a daily basis. In addition, data systems will be password protected.

Discussion

The NAP-NCD attempts to bridge the gap between academic researchers and policymakers and administrators engaged in planning evidence-based strategies for bringing about an improvement in health outcomes. Several research dimensions have been flagged as priority areas as part of this Action Plan. These research areas emphasize the need to move away from the sole focus on risk factor and etiologic research toward surveillance and health systems and policy research to facilitate assessment of the effectiveness of current policies, disease trends, and future health needs.

A necessary prerequisite for effective planning, implementation, and evaluation of NCD prevention programs is access to reliable and timely information on mortality, morbidity, risk factors, and their socioeconomic determinants. This approach has been validated in several settings: WHO STEPS, the BRFSS, and the use of various database sources such as the WHO Global NCD InfoBase and those used as part of WHO's regional programs Countrywide Integrated Noncommunicable Disease Intervention (CINDI) and Conjunto de Acciones para Reduccion Multifactorial de Enfermedades No Transmisibles (CARMEN). In Pakistan, lack of comprehensive databases for NCDs presents an obstacle to effective priority setting, targeting of programs to specific population groups, evaluation of process-related activities, and long-term evaluation of preventive interventions. The adoption of practical and economically efficient systems to meet these needs have, therefore, been recognized as part of the NAP-NCD.

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 Pakistani healthcare system. These data sources, however, suffer several limitations, such as 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 NAP-NCD 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 wher-

ever applicable. A population-based NCD surveillance process conforming to all these parameters has been established by Heartfile and its partners as an entry point to NCD prevention activities—with appropriate linkages with institutions such as the Pakistan Medical Research Council (PMRC)—which can provide sustainable support for surveillance activities, have been established as part of this activity.

With the exceptions of cancer and stroke, disease surveillance is not appropriate for Pakistan, as deaths are not registered. Nevertheless, the feasibility of establishing a mortality sentinel site must be assessed; such data sources can provide adequate information to generate reasonable estimates of mortality in large populations. However, in view of the limited resources that are available for surveillance monitoring, the Integrated Framework for Action has developed a common population surveillance mechanism for all NCDs (with the exception of cancer). 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, which offers standardized methods and materials for country-specific information on adult populations. 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 program evaluation, which 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 have been made to build on similar data that have already been collected in Pakistan.¹⁷

Owing to the limited available resources, there are several limitations of this baseline survey. First, in such studies a broadly representative sample should be sought; however, resource constraints have necessitated a more selective approach. The total size of the sample size in this study is 2243, which will not permit analysis of subgroups other than age and gender. Second, it was not possible to augment the sample size, which would have allowed analysis of rural and urban differences. Third, inclusion of diabetes in the surveillance process entails adding information obtained from blood samples, which is not feasible in the short term. As an alternative, the physical measurement of waist circumference has been used as a proxy for the risk of diabetes. In a recently conducted case-control study on patients with angiographically defined CAD versus controls with no evidence of disease, waist circumference was strongly associated with the risk of developing CAD and diabetes.¹⁶ However, future efforts in upgrading the surveillance system should be structured to allow a

more comprehensive assessment, expanding this approach to include laboratory assessments.

This surveillance system also incorporates modules on stroke, CAD, injuries, and mental health. Collecting mortality and morbidity data on stroke in populations conventionally necessitates the setting up of population-based stroke registries; this is fraught with logistic and methodologic issues, making it an impractical approach in Pakistan over the short term. Therefore, risk factor burden (hypertension) has been used as a proxy for stroke burden. In addition, a module for estimating stroke prevalence has been incorporated in the surveillance system. However, it is recognized that stroke-related population measures do not fit well in population surveys.

Injury surveillance is a key component of an injury prevention program, and therefore surveillance of injuries has been integrated with this system. However population data need to be supplemented by multiple data sources (facility-based data, reliable police and newspaper reports, and data from other appropriate sources).

This surveillance process will also develop linkages with other continuous population-based data sources. A recent surveillance effort introduced in Pakistan is the Global Youth Tobacco Survey (GYTS). Focusing on adolescents aged 13 to 15 years, this school-based survey provides an insight into students' knowledge, attitudes, and behaviors as these relate to tobacco, inclusive of issues pertaining to access and availability, exposure to passive smoke, tobacco use cessation, media advertising, and school curricula.

Efforts have been ongoing as part of National Program for Mental Health,⁹ in Pakistan to include a uniform recording system for key mental illnesses into the Health Management and Information System (HMIS). As an initial step, appropriate indicators have been developed and integrated with the HMIS in five districts as part of a pilot intervention (K. Saeed, Rawalpindi Medical College, Rawalpindi, Pakistan, personal communication, 2003). This arrangement provides facility-based data, and must be continued and supported as planned. However, it is also essential to monitor trends through a population-based surveillance mechanism. Within this context, studies done to date are important with regard to any future attempts since they can serve as a baseline.

Ideally, chronic respiratory diseases (CRD) surveillance should be part of a comprehensive NCD surveillance system to facilitate mapping of CRDs and their determinants. However, due to issues inherent to surveillance of CRD, this has not been included in the NCD surveillance system in Pakistan. Tobacco use can be used as a proxy for the magnitude of chronic obstructive pulmonary disease (COPD) in populations.

There are several issues in assessing the magnitude of the CRD burden in general and COPD in particular within populations. Mortality data under-represents

CRD, as it is under-diagnosed and often not listed either as a primary or a contributory cause of death. Few countries have good population-based data on CRD due to lack of a uniform set of diagnostic criteria. In addition, there are issues with estimating the prevalence of CRD accurately, for which measurement of airflow obstruction is necessary. These considerations explain the paucity of population-based data on CRD in Pakistan. Within this context, it is necessary to partner with global efforts to assist with the development of globally acceptable criteria for the diagnosis of CRDs and inexpensive methodologies to monitor COPD that are suitable for use in the developing countries.

Notwithstanding that there are several limitations of this model, it offers the best use of the available limited resources for NCD surveillance in Pakistan. Baseline data will act as an entry point for activities related to the prevention of NCDs, and serve the purpose of monitoring population parameters, which this Action Plan aims to influence. We hope that standardized epidemiologic information greatly facilitates comparative analysis and ongoing modification of interventions.

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