A role for INDEPTH Asian sites in translating research to action for non-communicable disease prevention and control: a case study from Ballabgarh, India

Anand Krishnan*, Baridalyne Nongkynrih, Suresh Kumar Kapoor and Chandrakant Pandav
Centre for Community Medicine, All India Institute of Medical Sciences, New Delhi, India

Background: The International Network of field sites with continuous Demographic Evaluation of Populations and Their Health (INDEPTH) has 34 Health and Demographic Surveillance System (HDSS) in 17 different low and middle-income countries. Of these, 23 sites are in Africa, 10 sites are in Asia, and one in Oceania. The INDEPTH HDSS sites in Asia identified chronic non-communicable diseases (NCDs) as a neglected area of attention. As a first step, they conducted NCD risk factor surveys within nine sites in five countries. These sites are now looking to broaden the agenda of research on NCDs using the baseline data to inform policy and practice.

Methods: A conceptual framework for translating research into action for NCDs at INDEPTH sites was developed. This had five steps – assess the problem, understand the nature of the problem, evaluate different interventions in research mode, implement evidence-based interventions in programme mode, and finally, share knowledge and provide leadership to communities and countries. Ballabgarh HDSS site in India has successfully adopted these steps and is used as a case study to demonstrate how this progress was achieved and what factors were responsible for a successful outcome.

Results: Most of the HDSS sites are in the second step of the process of translating research to action (understand the problem). The conduct of NCD risk factor surveys has enabled an assessment of the burden of NCD risk together with determinants in order to understand the burden at the population level. The experience from Ballabgarh HDSS exemplifies that the following steps – pilot testing the interventions, implementing activities in programme mode, and finally, share knowledge and provide leadership – are also possible in rural settings in low-income countries. The critical success factors identified were involvement of a premier medical institution, pre-existing links to policy makers and programme managers, strong commitment of the HDSS team and adequate human resource capacity.

Conclusion: All INDEPTH HDSS sites now need to strengthen their links to health systems at different levels and enhance their capacity to engage different stakeholders in their respective country settings so as to translate the current knowledge into actions that can benefit the health of the population they serve and beyond.

Keywords: non-communicable diseases; surveillance; policy; translational research

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The World Report on Knowledge for Better Health in 2004 laid strong emphasis on translating knowledge into action to improve health, thereby bridging the gap between what is known and what is actually done (1). Initiatives are needed to facilitate interaction between researchers and policy makers to foster greater use of research findings and evidence in policy making and to narrow the know-do gap (2). Thailand’s Health System Research Institute suggests the need for mediating mechanisms especially those of governments and civil society agencies (3). The International Network of field sites with continuous Demographic Evaluation of Populations and Their Health (INDEPTH) could be one of the potential
The first step is the use of existing information sources to identify a new public health problem. In the case of NCDs in HDSS sites, this includes mortality surveillance data which demonstrate that NCDs are a significant and major contributor to deaths in their population.

The second step is to develop a better understanding of the problem by undertaking additional data collection to measure changes in the burden and determinants of NCD risk factors using both quantitative (surveillance) and qualitative methods.
The third step is to evaluate the feasibility and effectiveness of different interventions related to NCDs. These are primarily in two domains – health promotion interventions directed at the whole population (prevention) and health systems interventions directed at individuals at high risk (treatment). This step requires close co-operation with the local health system and other stakeholders. The activities undertaken in a research mode provide key results to be shared with relevant stakeholders at higher levels.

In the fourth step, the activities related to NCD surveillance, prevention and control that are found to be feasible and cost-effective in research mode would be implemented in a regular routine programme mode to ensure sustainability.

In the final step, the HDSS sites share knowledge and provide leadership in their own communities, countries and region by supporting advocacy, encouraging capacity building and providing technical assistance in the development of NCD related policies, programmes and guidelines.

The Ballabgarh HDSS: a case study
This section traces the progress of the Ballabgarh HDSS site over the five steps listed above and draws lessons for implementation elsewhere.

The Comprehensive Rural Health Services Project (CRHSP) in Ballabgarh was started in 1965 by the All India Institute of Medical Sciences (AIIMS), New Delhi, and is situated in the state of Haryana in Northern India. The CRHSP is run in active collaboration with the State Government of Haryana. The Intensive Field Practice Area (IFPA) of the project comprises of 28 villages catering to a population of 85,552 in 2008. CRHSP Ballabgarh has been part of INDEPTH Network since 2003. Unlike most other HDSS sites, the primary responsibility of CRHSP Ballabgarh is training of medical and nursing students, as well as delivering health care services patterned on national norms.

CRHSP conducts demographic surveillance on an ongoing basis. Routine data (births, deaths, in-migration, out-migration) is collected on a monthly basis and a yearly census is also conducted in the month of December. The demographic database has been stored electronically since 1991. Every individual in the project area has been assigned a unique identification number that is present in all the files and which is used to link all the databases. The computerised database is updated and revised to accommodate the needs of the users and introduction of new national programmes. Verbal autopsy is carried out for all deaths in the area by the health workers and the cause of death is determined by the Medical Officer. This platform was used to conduct NCD surveillance, prevention and control activities at Ballabgarh. This setup is similar to other INDEPTH sites except that the managers of the site are also the health care providers for the population. Its link to AIIMS, a
The analyses of mortality data for the years 2002–2007 show that the proportion of deaths due to NCDs among the population 15 years and over was 56% (61% of deaths in males and 52% in females); the remaining deaths were due to injury or infectious diseases; about 17% of deaths could not be classified by verbal autopsy. All INDEPTH sites generate this information on mortality using verbal autopsy tools in a regular and sustainable way and help in establishing the mortality burden of NCDs.

**Step 1: Identify the problem**

Step 2: Understand the problem

Qualitative and quantitative studies can be used in measuring the burden and understanding the determinants of disease. As a first step, Ballabgarh HDSS site was involved in the pilot testing of the WHO STEPwise approach to Surveillance (STEPS) (http://www.who.int/chp/steps/en/) and in the validation of the physical activity tool (22). Subsequently, Ballabgarh HDSS has been a part of a nationwide multicentre survey for behavioural and anthropometric NCD risk factors surveillance using the WHO STEPS methodology in 2003 that included urban, urban slum and rural areas (23). In 2005, in a sub-sample of the population, assessment of the biochemical risk factors (Step 3 of WHO STEPS) was also carried out. These studies provided valuable insight into the practical aspects of carrying out community-based surveillance activities, especially in Step 3 where quality assurance in handling and processing of blood samples was of utmost importance (24). The results of these surveys have been published and widely disseminated nationally (25–28).

A second risk factor survey was carried out in 2006 in the same population using the same WHO STEPS instrument to allow an assessment of the trend of risk factors in the absence of any active intervention. The results show that the risk factor levels are more or less stable (unpublished data). There was no specific ongoing intervention in the villages for NCD prevention and control during this time period. A third measure is required in order to determine trends in the population levels of risk; this is planned for 2010.

Most of HDSS sites have completed only the baseline or first round of risk factor surveys and will need to ensure that these are repeated in the same populations using the same methodology.

**Step 3: Evaluate feasible and cost-effective interventions**

As a part of the WHO’s efforts to generate local evidence, Ballabgarh has been involved in the demonstration project of community-based intervention in urban Ballabgarh (29). One of the faculty members (SKK) went on a training visit to North Karelia for this purpose. Again, the process and results of this exercise are being disseminated and shared regularly with national and regional policy makers and programme managers. Recently this programme was evaluated and the results are in the process of being published.

Currently, Ballabgarh is also implementing a programme for management of chronic diseases under the primary health care system in rural Ballabgarh funded by the Department of Health Research, Ministry of Health and Family Welfare (MOHFW), Government of India. This ongoing research work looks at operational issues like cost and impact on workload of adding NCD work to health workers. A weekly NCD clinic was started in 2001. The experience of managing these diseases at secondary level hospital has been published (30). A tobacco cessation clinic has been started at the hospital with support from the National Ministry of Health and Family Welfare and WHO India. These activities demonstrate close collaboration of the site with the Central Ministry of Health.

These activities have been possible largely due to the high credibility of Ballabgarh and AIIMS as an academic institution among a spectrum of stakeholders ranging from international agencies to local community, a physical location near New Delhi (capital of India), existing links to WHO and Ministry of Health, and the presence of a good team of epidemiologists and social workers. Many of the sites in Asia have strong links to academic institutions.

**Step 4: Implement activities in programme mode**

Currently, Ballabgarh HDSS has integrated and included in its routine programme mode, activities related to surveillance, prevention and control. In 2002, ‘Surveillance for Demographic, Environment and Health Information (SUDEHI)’ was initiated at the HDSS with the objective of collecting information on human behaviour which predisposes the population to both common communicable diseases and NCDs, and to ascertain health care seeking behaviour. It also included questions on NCD risk factors such as tobacco use, alcohol consumption, consumption of excess fats and oils, and leisure time physical activities in the past week, mean number of days of consumption of vegetables and fruits, soft drinks, fried food, sweets and whether or not blood pressure had been measured in the last year. A comparison of the result of SUDEHI using routine health workers in surveillance mode with the result of the STEPS NCD risk factor surveys showed that similar results were obtained (31). This experience shows that it is possible for HDSS sites to integrate a few core elements of a larger NCD risk factor survey into its routine surveillance activities without imposing an excessive burden.
burden on the existing system, though this restricts the number of questions.

All the health system interventions (risk screening by health workers, management of the at-risk population at primary health centres and in an NCD clinic) have been integrated with the system and are currently funded by the regular budget of the site. This was largely possible because each institution is also responsible for health service delivery to the population. For other HDSS sites, this step calls for a much stronger link with the health care delivery system in their community. Similarly NCD issues, especially tobacco use, are discussed in all community-based activities.

**Step 5: Share knowledge and provide leadership**

The capacity of Ballabgarh to carry out NCD prevention and control activities has been strengthened over these years by its team members being formally trained (WHO STEPS methodology, community-based intervention in a community setting) as well as informally trained through involvement in planning and implementation of different NCD-related activities. Ballabgarh is now in a position to provide guidance and assistance to others. The list of extramural activities of Ballabgarh HDSS and the different partners that it works with for capacity building, advocacy and technical support, is at both national and international level as shown in Table 1. At the international level, the staff of the site was involved in the Regional STEPs training workshop for member countries of the SEA Region. One of the authors (KA) of this paper has also been involved in providing technical support to other countries of the South-east Asian region including Nepal, Maldives, Bhutan and DPR Korea. A workshop in WHO STEPS methodology was organised for participants from INDEPTH – Asia HDSS, after which NCD risk factor surveillance activities were initiated in their respective sites. The outcome of these efforts have been the conduct of multiple risk factor surveys in the countries of this region with more than 100 people being trained in the WHO STEPwise approach to NCD surveillance.

At a national level, WHO in-country fellows were trained in different aspects of NCD prevention and control activities. A workshop for sensitising the state health departments and faculty from various medical colleges in NCD prevention and control activities was carried out in 2003. The team members have participated in numerous efforts to sensitisie different stakeholders in NCD prevention and control. It is very difficult to quantify the outcomes of these efforts. Suffice to say, that this teams’ contribution in creating a paradigm for a shift in thinking of different stakeholders to a health agenda which is inclusive of NCDs, is well recognised. It is only because of this that formal recognition by the Government of India has come its way. Ballabgarh HDSS has been designated as a resource centre for training and monitoring the NCD surveillance component of the Integrated Disease Surveillance Project. Ballabgarh HDSS is also contributing to the National Programme for Prevention and Control of Diabetes, Cardiovascular Diseases and Stroke that was launched in India in January 2008 through technical assistance input and by providing a platform for training (http://www.mohfw.nic.in/D4.htm).

**Lessons for other sites**

This paper focuses on the activities of Ballabgarh HDSS and consequently the role that it is playing in national and international efforts to strengthen NCD prevention and control activities. Based on our experience at Ballabgarh HDSS, the possible roles that HDSS sites can play in NCD prevention and control include the following:

- A demographic surveillance system provides a unique platform on which a range of health, social, economic and behavioural studies can be carried out through community-based, longitudinal follow up of populations. Ideally this is what a surveillance system requires—a system where populations can be followed up to monitor trends and identify action points for intervention. HDSS can provide a platform for carrying out surveillance of NCD risk factors to measure trends in population risk in the absence of such information at national level. A study from three INDEPTH sites (Ethiopia, Vietnam and Indonesia) has reported that combining WHO STEPS with HDSS activities can address epidemiologic questions on NCDs (32).

- Since all HDSS conduct regular demographic surveillance activities for census purposes, the potential of including a few selected key core questions related to risk factor surveillance in the surveillance activity of the HDSS sites in a cyclical manner is innovative. This approach reduces the need for repeated separate cross-sectional surveys for NCD surveillance in HDSS sites, although some measures do require full surveys.

- The HDSS sites included in this series differ in the prevalence of these risk factors that needs further exploration. These differences need to be studied in the context of differences in the stage of epidemiological transition as well as socio-cultural differences between the sites. These differences provide opportunities for understanding the social determinants of risk better so as to formulate appropriate policies. As these sites also measure socio-economic status of individuals and families, these sites can provide valuable evidence to raise the issue of equity. Reports from other INDEPTH sites, particularly in Africa, have brought out the potential of HDSS sites to measure mortality and morbidity differentials, thus addressing the issue
of equity (33). These can be done for NCDs as well and will help in dispelling the myth that these diseases are confined to wealthy countries and wealthy people within those countries.

- Because of the fact that HDSS represent different socio-cultural and national identities, they can help develop and test/validate standard tools and protocols for measurement of different NCD risk factors as has been done with physical activity and diet (22).

- HDSS sites can be used as places for research and training of public health experts. HDSS sites attract professionals from diverse backgrounds. Highly qualified demographic, epidemiologists, sociologists, clinicians and economists enable a continuum of research and a multi-faceted examination of health problems and provide an ideal environment for training of research professionals.

- HDSS sites can also spearhead involvement in planning, implementing and evaluating intervention against NCDs. Many of these sites are involved in doing the same for communicable diseases and reproductive health issues. It is only logical to take this forward to include non-communicable issues.

However, the role of HDSS sites will keep evolving as they move ahead on the road of translational research. For example, the Ballabgarh HDSS site now needs to focus on issues of quality of care/intervention and evaluation. The activities would include process evaluation of community-based intervention to economic evaluation of different interventions, assessing quality of different activities like counselling, training, etc.

The way forward
In order to carry out this agenda, the HDSS sites would need to address issues at multiple levels.

- Sites need to strengthen their capacity to conduct research in NCDs and develop leadership skills. Currently, the capacity varies widely between the sites. While some have strength in social sciences, others have more expertise in epidemiology. Each site will have to look at the role it can play depending upon its own current strengths and limitations while working on a longer term strategy for strengthening its capacity. The network needs to identify partners who can support such capacity-building initiatives.

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**Table 1. Summary of extramural NCD prevention and control activities in Ballabgarh HDSS**

| Role | Activities | Partner agencies |
|------|------------|------------------|
| Advocacy/ sensitisation | Supported over 25 regional meetings of WHO with national programme managers of SEAR countries | World Health Organization (WHO) |
| | Support to different national level meetings for policy makers and programme managers | Ministry of Health and Family Welfare (MOHFW) |
| Capacity building | Training for STEPs surveys in SEARO countries (Maldives, Nepal, Bhutan) | WHO |
| | India – Regional Resource Centre for NCD surveillance under Integrated Disease Surveillance Programme (IDSP) | Indian Council of Medical Research (ICMR), MOHFW Government of India |
| | Training in survey methodology for INDEPTH HDSS investigators | INDEPTH |
| | Regional centre for NPDCS | MOHFW |
| | WHO Fellowship Programme in NCD surveillance prevention and control | MOHFW/WHO |
| | Capacity strengthening modules for programme managers – development and implementation of the course for countries in SEAR | WHO |
| Technical support to guideline/tool/ manual development | Pilot testing of STEPs approach | WHO |
| | Validating instruments for physical activity | WHO |
| | Development of planning and monitoring manual for community-based intervention | WHO |
| Policy, programme development | Advisory – member of the technical advisory group for NCD Surveillance under IDSP | ICMR, MOHFW |
| | Member Steering Committee – National Programme for Prevention and Control of Diabetes, Cardiovascular Diseases and Stroke (NPDCS) | MOHFW |
- Secondly, in order for sites to influence policy and help translate research to action at national level, they need to improve links to national ministries of health. They need to be able to demonstrate leadership to the local and national health authorities so that national governments will be encouraged to support and invest in HDSS (34).

- The sites also need to engage more closely with the health care delivery system of the population under surveillance.

- Finally, as a part of a network, these sites can develop cross-site activities, including research proposals which build on the strengths of the network. This also takes care of capacity weaknesses at site level as one site’s weakness in an area can be compensated by other site’s strengths in that area. The international research agenda is shifting to large-scale multicentre studies. INDEPTH HDSS have the potential to support such research by demonstrating versatility, fresh ideas and new approaches (35).

Conclusions

In the past, HDSS sites have made significant contributions to national efforts in dealing with infectious diseases such as HIV/AIDS, malaria and maternal child health issues. These need to be expanded to cater for emerging health problems such as NCD and the risk factors which predict them. They are uniquely positioned to elucidate issues related to measuring shifts in population distribution of risk factors and measuring effectiveness of prevention programmes. They need to leverage their strengths to influence policy makers and programme managers in their own countries so as to translate the current knowledge into actions that can benefit the health of people.

Conflict of interest

The authors have declared no conflict of interest.

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*Anand Krishnan
Centre for Community Medicine
All India Institute of Medical Sciences
Ansari Nagar, New Delhi 110029, India
Tel: +91 11 26594253
Email: kantaridyev@yahoo.com