

# The Indian Health and Demographic Surveillance System Network: Opportunity to Generate Evidence for Public Health Policy

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## Abstract

The Health and Demographic Surveillance System (HDSS) is a valuable longitudinal cohort study that tracks the health and demographic changes of a geographically defined population, serving as a platform for research and evidence-based policymaking. In India, there are nearly 20 HDSS sites covering diverse areas and populations totaling around two million. To foster collaboration, the Indian HDSS Network (IHN) was formed, comprising 19 sites from 16 institutes, covering a population of 1.5 million. The IHN aims to standardize data collection processes while allowing site-specific autonomy, generating high-quality longitudinal health, and demographic data. To ensure effective coordination, a governance structure with a rotating secretariat and working committee was proposed. The IHN envisions conducting robust multicentric research, supporting data-driven efforts to improve population health, and promoting research-policy synergy. The network's outcomes have the potential to optimize health research funding, generate epidemiological data, and provide evidence for public health policy. Collaboration within the IHN strengthens HDSS sites in newer technologies and community-based research, fostering capacity building. Seed funding is being sought to formalize and support the day-to-day functioning of the network, which holds promise for advancing population health and informing policymaking in India.

**Keywords:** Evidence-based public health policy, HDSS, India

Health and Demographic Surveillance System (HDSS) is a dynamic cohort of the population residing in geographically defined area which is followed longitudinally for their health and demographic changes. HDSS is a valuable resource to obtain robust longitudinal demographic data for a dynamic cohort in a defined geographic population.<sup>[1,2]</sup> The HDSS can provide platforms for conducting translational and implementation research, which could address critical gaps in the information and generate evidence to inform policy.<sup>[3,4]</sup> The first HDSS was established in the 1940s in South Africa<sup>[5]</sup> and since then has become a crucial tool to evaluate public health interventions in low- and middle-income countries (LMICs).<sup>[6]</sup>

In 1998, the International Network for the Demographic Evaluation of Populations and Their Health (INDEPTH) was established which has brought together 49 sites from 42-member health research centers in 19 countries in Africa, Asia, and Oceania as of 2018.<sup>[7]</sup> Recently, seven sites from five

Asian countries have collaborated to form the Asian HDSS Network.<sup>[8]</sup> The HDSS network has the potential to help in harmonization, sharing best practices among each site and data standardization making it sharable.<sup>[9]</sup>

Over the last few decades, nearly 20 HDSS were established or are planned in India, by both public and private organizations. These HDSSs are not only geographically widely dispersed but also cover around two million population in India. The administration and management of these HDSSs vary as is the funding and sustenance mechanism.<sup>[10-12]</sup>

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Earlier, in January 2015, Vadu HDSS attempted to bring the Indian HDSS together to inform the policymakers and researchers about the importance of HDSS and to discuss how HDSS across India could support policy-relevant research. This meeting was attended by more than 50 researchers and government representatives of Maharashtra, Delhi, and West Bengal states. It further led to discussions on the formation of the Indian Network of HDSS. During all these interactions a need for a consensus-building meeting was raised, the meeting aimed at bringing stakeholders to the same platform and making a general consensus on the structure and function of networks of HDSSs in India.

This article will document the formation of this nationally important and relevant network by reporting a brief proceeding of meetings held on April 19<sup>th</sup>, 2022, which was jointly organized by Armed Forces Medical College, Pune (AFMC), and KEM Hospital Research Centre, Pune (KEMHRC).

All Indian HDSS, active, or planned were invited to the meeting as it aimed to bring different stakeholders together for the formation of an IHN. The response received was remarkable as all HDSS were represented at the discussion, planning, and preparation of the network. The sessions were planned to discuss network nomenclature, aims, and activities for the network.

The network now includes 19 HDSS sites from 16 institutes (both public and private) across India covering 1.5 million population. We achieved several key outcomes. All agreed to name it “Indian HDSS Network (IHN)” unanimously. Further, the meeting outcomes highlight the plans for standardization efforts, data quality consensus, collaborative ideas, as well as the establishment of an effective governance structure. It was agreed that coming together of HDSS would be beneficial to the newer HDSS wherein they may learn from the experience of established HDSS. The established HDSS will provide technical expertise and share their experiences with newer ones. The data collection process would be standardized; however, besides these common variables each site would have the autonomy to collect context and site-specific data.

The IHN envisions “to provide a platform for collaborative research and data sharing for generating timely, exemplary, high-quality, longitudinal health, and demographic data in compliance with ethical principles for supporting evidence-based policymaking and progress towards achieving sustainable development goals in India.” The mission of this network is “to develop a sustainable pan-India collaborative network of demographic surveillance sites that can generate timely, high-quality, policy-relevant, longitudinal health and health-related data, in compliance with ethical principles that are available and accessible to all, towards improving population health, fostering synergy in research, tracking progress, and supporting evidence-based policymaking in the country.”

To ensure effective coordination and decision-making, the meeting participants discussed the formation of a governance structure for the HDSS network. This structure will serve as a framework for guiding the network’s activities, allocating resources, and facilitating collaboration. It was agreed that the

governance structure would consist of a rotating secretariat and working committee with members representing diverse HDSS sites and stakeholders. Vadu HDSS run by KEMHRC Pune was declared as the first Secretariat of the IHN.

Membership eligibility criteria were also deliberated upon. Two categories of membership were proposed: associate members and full members. Associate members will have access to available resources and contribute to the network’s activities, while full members, determined by minimal criteria set by the governance structure, will have voting rights and additional privileges. The eligibility criteria were established to encourage active participation and ensure the network’s growth and effectiveness.

Moreover, recognizing the importance of effective communication and coordination, each HDSS designated a contact person. This contact person will serve as a focal point for communication, ensuring smooth information exchange and facilitating collaborative efforts among the network members.

The IHN aims to fulfill the below objectives-

- To bring the major HDSS sites in India on a common platform and build an effective collaborative structure
- To standardize the tools and processes for data collection across the IHN sites for achieving uniformity and high quality in data collection
- To conduct robust and relevant multicentric research leveraging the longitudinal data collection while ensuring national research ethics principles and local community needs
- Support data-driven efforts towards improving population health, tracking progress in health indicators, and policymaking.

Capacity building and strengthening of HDSS-sites in newer technology, skills for conducting community-based research in India through collaborative research projects.

The output of the network of HDSS could improve the use of health research funds and help to produce epidemiological data for understanding the disease burden as well as for generating evidence for public health policy in a timely manner. The IHN spread across geographies in India and covering a large population creates opportunities to conduct research in real-life settings which may be generalizable to the entire Indian population. Data on maternal and newborn health, infectious diseases, and non-communicable diseases may be collected besides collecting data on demography and trend. This information would help create robust estimates with uncertainty intervals at the national and sub-national levels, identify common determinants of health, enable shared learnings and challenges, and increase the strength of evidence for presentation to policymakers. These data can guide policymakers in the prioritization of health issues.

The multicentric project at different HDSS may help in the development of co-operative feeling and cement the collaboration within network and beyond. It was proposed

that any member HDSS site (principle site) may propose the multicentric project. The required protocol, data collection tools, training, and funding if required may be provided by the principle site. Some sites may also be specific to particular domain of research depending on the demography. The multiple sites can come together and write protocols and seek funding from agencies like ICMR and DBT. The national funding agencies may also exploit the HDSS network to address the issue of evidence generation for health policy needs of the country as it provides access to large heterogeneous population.

The network is currently not funded, and the network will collectively look out to generate seed funding which can support the formalization and day-to-day functioning of the network. The network is in nascent stage at present; however, good beginning is half done.

### **Name of IHN network\* (In alphabetical order)**

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### **Conflicts of interest**

There are no conflicts of interest.

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