HEALTH SURVEYS IN INDIA:
REVIEW AND RECOMMENDATIONS

Final Report
(Strictly confidential)

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Final Report
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Disclaimer

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“We recognise that a reliable evidence base is essential for informing the planning, implementation and monitoring of health programmes and of systems strengthening. Data are also critical to facilitate timely responses to health risks. Yet health data often remains unavailable, inaccessible, of poor quality, fragmented, not well protected and are often not used appropriately. We therefore encourage support for data system strengthening to improve health data availability, disaggregation, quality, systems interoperability, data transparency, sharing and the protection of personal data, and the use of data on a national, regional and international level, while respecting privacy and other human rights with regard to all collected health data.”

Berlin Declaration of G20 Health Ministers (2017)

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Abstract

As part of a country’s health information system (HIS), health surveys cater to a variety of national and international data needs on a periodic basis. In the context of weak administrative health data systems, the independent, population-based estimates provided by health surveys become all the more significant. Nevertheless, it is also important to periodically review these surveys – themselves instruments for reviewing a country’s health policies and programs – to ensure that they continue to cater to a country’s evolving health data requirements in a smart, efficient and coordinated way.

This study undertakes a review of major health surveys in India, with a special focus on the National Family Health Survey (NFHS), based on extensive desk research – covering major ongoing health surveys in 3 countries as well (US, Canada, UK) – and key stakeholder / expert interactions in New Delhi as well as 6 states, covering various geographical regions of the country. Based on this desk and field research, it offers a set of recommendations for India’s health survey strategy as well as a thematic and methodological framework for 6 health surveys it proposes as part of the strategy – the India Health Survey (HIS), the India Health Measures Survey (IHMS), the Maternal and Child Health Survey (MCHS), the ongoing Sample Registration System (SRS) and Cause of Death Survey (CDS), and a COVID-19 Impact Survey (CIS). Kindly refer to the table in the conclusions for details.

The report is organized thus. Chapter 1 sets the conceptual context for the discussions on health surveys that follow. It briefly refers to the notion and determinants of health, WHO’s health systems approach to monitoring and evaluation, the policy context of health systems and health information systems thinking in India, and whether health surveys should pursue a purely quantitative or mixed methodology. The chapter is followed by 3 sections.

Section 1 has 5 chapters. Chapter 2 provides an overview of major health surveys in India since independence, with a special focus on the NFHS and SRS, and discusses their comparative scope. Chapters 3 to 6 assess the scope of NFHS vis-à-vis health policies, programs, health-related SDGs and the emerging area of health technology assessment (HTA) respectively at the national level.

Section 2 shares the perspectives of respondents vis-à-vis NFHS as well as other health surveys.

Section 3 provides an overview of major health surveys in selected countries (US, Canada and UK) and draws lessons for India. Several chapters end with recommendations, marked with ®. The key recommendations, emerging from our desk and field research, are listed in the concluding chapter. The chapter also includes a table which characterizes the potential respective features and themes of the 6 national health surveys that we propose.

Key terms

Term	Definition / description	Source
Health	Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.	WHO 1946 / 2020
Epidemiology	The study of the distribution and determinants of health-related states or events (including disease).	WHO[2]
Verbal autopsy (VA)	An established health surveillance method that provides information on levels and causes of death in populations where medical death certification is weak or absent.	Thomas, D'Ambruoso and Balabanova 2018: 1
Health system	All the organizations, institutions, resources and people whose primary purpose is to improve health.	WHO 2010: vi
Health information system (HIS)	A well-functioning health information system is one that ensures the production, analysis, dissemination and use of reliable and timely health information by decision-makers at different levels of the health system, both on a regular basis and in emergencies. It involves three domains of health information: on health determinants; on health systems performance; and on health status. To achieve this, a health information system must: • Generate population and facility based data: from censuses, household surveys, civil registration data, public health surveillance, medical records, data on health services and health system resources (e.g. human resources, health infrastructure and financing);	WHO 2007: 18-19

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[2] https://www.who.int/topics/epidemiology/en/ (15/10/2019, 12:40 hours).

Term	Definition / description	Source
	• Have the capacity to detect, investigate, communicate and contain events that threaten public health security at the place they occur, and as soon as they occur; • Have the capacity to synthesize information and promote the availability and application of this knowledge.	
Health management information system (HMIS)	An information system specially designed to assist in the management and planning of health programmes, as opposed to delivery of care.	WHO 2004: 3
Administrative data	Data from the records maintained by agencies, institutions, commercial entities and governments, where the records are used for administrative purposes or for providing services. Examples include hospital and other health facility data, claims data, occupational injuries data, and police data.	Global Health Data Exchange (GHDx)[3]
Civil registration and vital statistics (CRVS)	A well-functioning CRVS system registers all births and deaths, issues birth and death certificates, and compiles and disseminates vital statistics, including cause of death information. It may also record marriages and divorces.	WHO[4]
Public health surveillance	The continuous, systematic collection, analysis and interpretation of health-related data needed for the planning, implementation, and evaluation of public health practice. Such surveillance can: ▪ serve as an early warning system for impending public health emergencies;	WHO[5]

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[3] http://ghdx.healthdata.org/about-ghdx/data-type-definitions (8/3/2020, 1:01 hours).

[4] https://www.who.int/healthinfo/civil_registration/en/ (8/3/2020, 1:01 hours).

[5] https://www.who.int/topics/public_health_surveillance/en/ (9/10/2019, 10:55 hours).

Term	Definition / description	Source
	- document the impact of an intervention, or track progress towards specified goals; and - monitor and clarify the epidemiology of health problems, to allow priorities to be set and to inform public health policy and strategies.	
Surveillance system	The critical components in the definition of a surveillance system include the ongoing collection, analysis, and use of health data. Demographic or health information systems (for example, registration of births and deaths, routine abstraction of hospital records, health surveys in a population) that are not linked to specific prevention and control programs, do not constitute a surveillance system.	WHO 2003: 3
Surveillance sources	Surveys (population-based data), disease registries (incidence and case fatality), hospital activity data (morbidity and health service use indicators), administrative data (births, deaths, insurance claims, medication use, health systems performance, hospital audits), aggregate consumption data (per capita consumption) and economic activity data (economic indicators).	WHO 2003: 4
Interoperability	The ability to access and process data from multiple sources without losing meaning and then integrate that data for mapping, visualization, and other forms of representation and analysis. Interoperability enables people to find, explore, and understand the structure and content of data sets. In essence, it is the ability to 'join-up' data from different sources to help create more holistic and contextual information for simpler, and sometimes automated analysis,	Collaborative on SDG Data Interoperability, Global Partnership for Sustainable Development Data[6]

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[6] http://www.data4sdgs.org/initiatives/interoperability-data-collaborative (17/10/2019, 11:29 hours).

Term	Definition / description	Source
	better decision-making, and accountability purposes.	
Health technology	The application of organized knowledge and skills in the form of medicines, medical devices, vaccines, procedures and systems developed to solve a health problem and improve quality of life.	WHO[7]
Health technology assessment (HTA)	The systematic evaluation of properties, effects, and/or impacts of health technology. It is a multidisciplinary process to evaluate the social, economic, organizational and ethical issues of a health intervention or health technology. The main purpose of conducting an assessment is to inform a policy decision making.	

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[7] https://www.who.int/medical_devices/assessment/en/ (14/10/2019, 12:57 hours).

Introduction

India's National Family Health Survey (NFHS) has been an enormously valuable source of reliable, representative and richly disaggregated population-level data on family planning, selected aspects of health, nutrition as well as related determinants. It has been all the more valuable in the context of a weak health information system (HIS), including the civil registration and vital statistics (CRVS) systems. With its round 1 (1992-93) hailed as a 'landmark in the history of collection of demographic data through surveys' (Visaria and Rajan 1999: 3002), 4 more NFHS rounds have been conducted so far – 1998-99, 2005-06, 2015-16 and 2019-20 – under the stewardship of India's Union Ministry of Health & Family Welfare (MoHFW), with the International Institute for Population Sciences (IIPS), Mumbai, as the nodal agency for its conduct and coordination. Modelled on the lines of USAID's Demographic and Health Surveys (DHS)[8] – 400 rounds of which have been conducted in over 90 developing countries since 1984[9] – NFHS has received international financial support from USAID and other agencies, and international technical support from the ICF International. As such, not only has the NFHS itself been instituted as a widely reputed and referenced health survey, it has instituted what we could refer to as a 'health survey culture' in the country, nationally, if not yet in the states. However, even at the national level, the institution / progress of NFHS has not been linear or smooth.

Over time, there have been certain growing realizations in central / state governments that have had implications for the scope of NFHS, other health surveys as well as the broader HIS landscape. The foremost realization is that 'severe fragmentation, compounded by market failures and governance challenges, is the key driver of India's underperforming health system' (Kumar 2019: 6-7). This, *inter alia*, has not only meant 'fragmented data capture by multiple stakeholders', but that 'governments, central and state alike, do not have reliable and complete data for policy analysis and evidence-based interventions' (MoHFW 2020: 6). More generally, there is a realization that 'certain systemic deficiencies continue to exist in the statistical system' (MoSPI 2018: 32), and that it 'needs to be revamped, modernised and get aligned with the statistical system in the world'.[10] Secondly, there has been a growing realization that, despite 'an irreversible process of fertility decline' even around the NFHS-2 period (Visaria and Rajan 1999: 3007), which is now 'close to the replacement level at the national level and well below it in many states' (Kulkarni 2020: 70) – and non-communicable diseases (NCDs) emerging as the leading cause of death, disease and disability across the country – our health programs and data systems continue to excessively focus on reproductive and child health (RCH). Thirdly, with India's growing economic and political influence at the global level, the country has become more assertive and less accepting vis-à-vis international agencies. Likewise,

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[8] https://bit.ly/2w1adpK (25/2/2020, 11:58 hours).

[9] https://dhsprogram.com/Who-We-Are/About-Us.cfm (25/2/2020, 11:58 hours).

[10] https://bit.ly/2Vy0PEQ (29/2/2020, 13:13 hours).

external donor funding for health declined from 2.3% of total health expenditure during 2004-05 to an insignificant 0.3% by 2013-14 (NHA 2018: 10).

What have been the implications of these broad realizations / trends for the NFHS as well as other health surveys in the country? As far as fragmentation is concerned, there have been calls for an integrated health survey. The GoI reportedly decided to even discontinue the NFHS in April 2012, as it wanted to 'integrate all the existing surveys into one', and obtain 'data at the district level, so that action can be taken accordingly'. A National Health Survey (NHS) was proposed instead, to be fully funded by MoHFW.[11] With backlash from several quarters, the decision was shortly reversed, and it was decided that the District Level Household and Facility Survey (DLHS) would instead be subsumed under the NFHS and the latter would provide district-level data with 3-year periodicity.[12] The Annual Health Survey (AHS) was also discontinued in 2013, paving way for NFHS-4 to be conducted as an integrated health survey and serve as the benchmark for the fifth and subsequent rounds.[13] The Office of the Registrar General (ORGI), Ministry of Home Affairs (MHA) – responsible for conducting AHS – was asked to provide district-level infant and under-five morality rates (IMR and U5MR) and maternal mortality ratio (MMR) with a 3-year periodicity.[14] This is yet to materialize.

Last year, in a meeting of the Cabinet Committee on Economic Affairs (2/1/2019), chaired by the Prime Minister, it was mentioned that 'the NFHS provides valuable data for policy and programmes right up to the district level' and, for the future, 'the target for NFHS is to provide reliable data on all health indicators'. Schematically, NFHS is one of the 2 sub-components of the 'Health Surveys and Research Studies' (HSRS) component – the other sub-component being Rural Health Statistics (RHS) – of MoHFW's 'Umbrella scheme for family welfare and other health interventions' (Umbrella scheme, also referred to as 'Family welfare schemes' in the Union Budget 2019-20). The scheme is seen as 'crucial for attaining the goals and objectives' of National Health Policy (NHP) 2017 and international commitments under Sustainable Development Goals (SDGs). Its HSRS component is expected to 'assist in keeping a tab on the progress of entire set of health programmes/schemes run by Government of India, assisting in timely course corrections'.[15]

As far as the second realization is concerned, while NFHS is still predominantly RCH-oriented, it now covers NCDs too in some ways (table 2.4). Finally, as far as the third realization is concerned, one of the key respondents during our field research, who has been involved with the NFHS data collection in several states, shared that USAID and ICF International will not be involved with NFHS sixth round onwards, and it will be completely funded and managed domestically by the MoHFW.

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[11] Bhattacharya, Pramit. 'Government to discontinue National Family Health Survey'. Mint, 11/4/2012.

[12] Shrinivasan, Rukmini. 'National health survey not nixed'. The Times of India, 30/7/2012.

[13] 'Conducting the NFHS/Annual Health Surveys'. PIB, 2/7/2019. https://bit.ly/2T9X6dE (25/2/2020, 17:05 hours).

[14] Krishnan, Vidya. 'Govt discontinues annual health survey'. Mint, 25/7/2013.

[15] 'Cabinet approves Continuation of Umbrella scheme for "Family Welfare and Other Health Interventions" during 2017-18 to 2019-20'. PIB, 2/1/2019. https://bit.ly/2AHbNMz (6/10/2019, 00:34 hours).

Study objectives

Since no independent assessment of the HSRS had been envisioned or commissioned so far vis-à-vis its objectives, the GoI mandated the NITI Aayog to get it done through a third-party institution. ICRIER was selected for this purpose. In this context, the present study aims to –

1) Assess the scope of NFHS in the light of the data requirements for the fulfilment of objectives, achievement of goals, monitoring of progress vis-à-vis – 1) NHP 2017 and other health policies, 2) health programs, 3) NITI Aayog's dashboard for monitoring of health outcomes,[16] 4) SDGs;[17]
2) Assess the scope of NFHS vis-à-vis other health surveys;
3) Assess the NIMS (ICMR)-WHO study to validate Verbal Autopsy (VA) tools;[18]
4) Assess health surveys of selected countries to draw lessons for India; and
5) Provide recommendations based on above assessments.

Study methodology

The study is based on extensive desk and field research involving key informant interviews in New Delhi, selected states and districts between 2/12/2019 and 25/1/2020. Kindly refer to Annexure A for the list of interviewees.

One state was selected from each NFHS region on the basis of IMR (NFHS-4) – Rajasthan from North, Uttar Pradesh from Central, Bihar from East, Assam from the Northeast, Maharashtra from West and Kerala from South India. Union territories (UTs) were not considered. The first 4 had the worst IMR in their respective regions, the latter 2 the best. Such a selection strategy was adopted not only to capture perspectives on the NFHS from various geographical regions of the country, but also from both good- and bad-performing states vis-à-vis an outcome (IMR) that has long been the focus of health policy and programs in the country since independence.

Within these states, we also tried to meet district-level health and statistical authorities in the state capitals as well as in cities with a Population Research Centre (PRC) outside of the state capital – in Udaipur (Rajasthan) and Pune (Maharashtra). Like NFHS, PRCs not only fall under the ambit of the Umbrella scheme and are managed by the Statistics Division of MoHFW, they were involved

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[16] The dashboard – http://social.niti.gov.in/hlt-ranking (19/10/2019, 11:56 hours) – presents data from NITI Aayog's Health Index (NAHI). As such, we will look at the scope of NFHS vis-à-vis NAHI.

[17] The Union Ministry of Statistics and Programme Implementation (MoSPI) developed the National Indicator Framework (NIF) for SDGs, and brought out a report identifying the data sources of various indicators in 2019 and version 2.0 in 2020. On its part, the NITI Aayog has brought out 2 SDG India Index reports so far, a baseline report in 2018 and one in 2019. We have referred to both versions of their reports in the assessment of the scope of NFHS vis-à-vis the SDGs.

[18] Despite several efforts, we were not able to obtain this study and could not, therefore, include its assessment here.

with the NFHS earlier, and many of them are now involved with the monitoring of annual district Program Implementation Plans (PIPs) of the National Health Mission (NHM). Strengthening survey research capabilities of the PRCs was one of the objectives of the NFHS (NFHS-1 national report).

As part of desk research, we –

1) Analyzed health surveys and institutional data requirements based on government documents and websites –
    a. Health surveys conducted / commissioned by the MoHFW, MHA and MoSPI;
    b. Institutional health data requirements were assessed vis-à-vis MoHFW's health-related policies and schemes, health-related SDGs, NITI Aayog's Health Index, etc. The scope of NFHS vis-à-vis the above was tabulated;
2) Conducted thematic mapping of health survey indicators to assess their comparative scope;
3) Reviewed health surveys in selected countries (US, Canada and UK) to draw lessons for India.

As part of field research, we tried to –

1) Fill in the information gaps identified during desk research;
2) Understand institutional health data requirements at the state and district levels, and the extent to which NFHS and other health surveys helped in meeting those requirements;
3) Elicit the views and suggestions of respondents regarding the NFHS and other health surveys.

Challenges

Let alone any assessment of institutional health data requirements, one of the biggest challenges was the availability of basic information about health policies and programs, especially in the states. Either the list of health policies and programs is not available in the public domain or not presented systematically – the output and outcome indicators of schemes included in the Union budget being the only exception that came to our rescue. Despite health being a state subject, states tend not to have their own health policies. If they did – as in the case of Kerala (2013, 2018 and 2019 in the recent past) and UP ('The Uttar Pradesh Health Policy, 2018' (draft), which was somehow available on the Government of Madhya Pradesh's rather than Government of UP's website)[19] – quantifiable targets against which the relevance of NFHS could be assessed were not available. In most cases, states also did not have their own health schemes; instead, they had either modified some aspects or renamed the central ones. And once again, their quantitative targets were not available against

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[19] https://bit.ly/2A3wG81 (8/6/2020, 19:40 hours).

which to assess the relevance of NFHS. Officials were generally very supportive, but tend to have piecemeal information, and that too only vis-à-vis their work profile. They keep getting transferred, and institutional memory is generally very weak. Given these challenges, we decided to confine ourselves to the central government for assessing the scope of NFHS vis-à-vis institutional health data requirements.

Organization of the report

Chapter 1 sets the conceptual context for the discussions on health surveys that follow. It briefly refers to the notion and determinants of health, the dichotomy of complex vision, but RCH-oriented action in India, data that the government should collect, the policy context of health systems and health information systems thinking in India, WHO's health systems approach to monitoring and evaluation and whether health surveys should pursue a purely quantitative or mixed methodology. Section 1 has 5 chapters. Chapter 2 provides an overview of major health surveys in India since independence, with a special focus on the NFHS and SRS, and discusses their comparative scope. Chapters 3 to 6 assess the scope of NFHS vis-à-vis health policies, programs, health-related SDGs and the emerging area of health technology assessment (HTA) respectively at the national level. Section 2 shares the perspectives of respondents vis-à-vis NFHS as well as other health surveys. Section 3 provides an overview of major health surveys in selected countries (US, Canada and UK) and draws lessons for India. Several chapters end with recommendations, marked with ®. The key recommendations, emerging from our desk and field research, are listed in the concluding chapter. The chapter also includes a table which characterizes the potential respective features and themes of the 6 national health surveys that we propose.

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1. Conceptual framework

Before we move into a dense discussion of health surveys at national, state and international levels, it is important to briefly discuss some of the key concepts from the perspective of health statistics.

Statistics is usually considered the domain of statisticians – and increasingly of IT experts who are expected to help organize statistics from a wide range of sources into an integrated, user-friendly framework to support decision-making. In fact, there is so much fascination with leveraging IT now in the Central government – thanks to the 'Digital India' initiative – as well as in states like Rajasthan that statisticians might worry that they no longer hold a position of privilege as they once did. The private sector – not least India's global success in IT – have played their part in stoking the public sector's fascination with IT. A top leader of the Indian pharmaceutical industry even argued that – 'I truly believe that technology can solve many of the daunting challenges of poverty and primitive living standards that we face as a country' (Shaw 2018: 49). In a meeting with one of us (Ali Mehdi) in 2016, senior officials from the US Centers for Disease Control and Prevention (CDC) exhorted that India should lead the world in health surveillance, given its globally recognized IT credentials.

However, if you talk to any leading statistician or IT expert, she will tell you that conceptual clarity and domain expertise are foremost, and statistical or IT tools are what they are – 'tools'. It seems that concepts are rarely invoked, while it is largely bureaucrats that we have in the name of domain (health) expertise in the context of health data ecosystems in the country. It is, at best, rare to find any public health academic / epidemiologist – let alone philosopher / social scientist with expertise on health issues – involved even in any of the surveys, not to talk of administrative data systems. For example, NFHS-4 had 4 committees – Technical Advisory, Project Management, Administrative & Financial Management and a Steering Committee. There were also several project coordinators, officers and consultants involved with the survey. While many of them are reputed domain experts, only one member of its Steering Committee (Dr A K Shiva Kumar) was a development economist, who has been writing on health from a broader social scientific and philosophical perspective. He too was there, not as an independent expert, but as member of the Mission Steering Group (MSG) of the National Rural Health Mission (NRHM) and that of the erstwhile National Advisory Council.

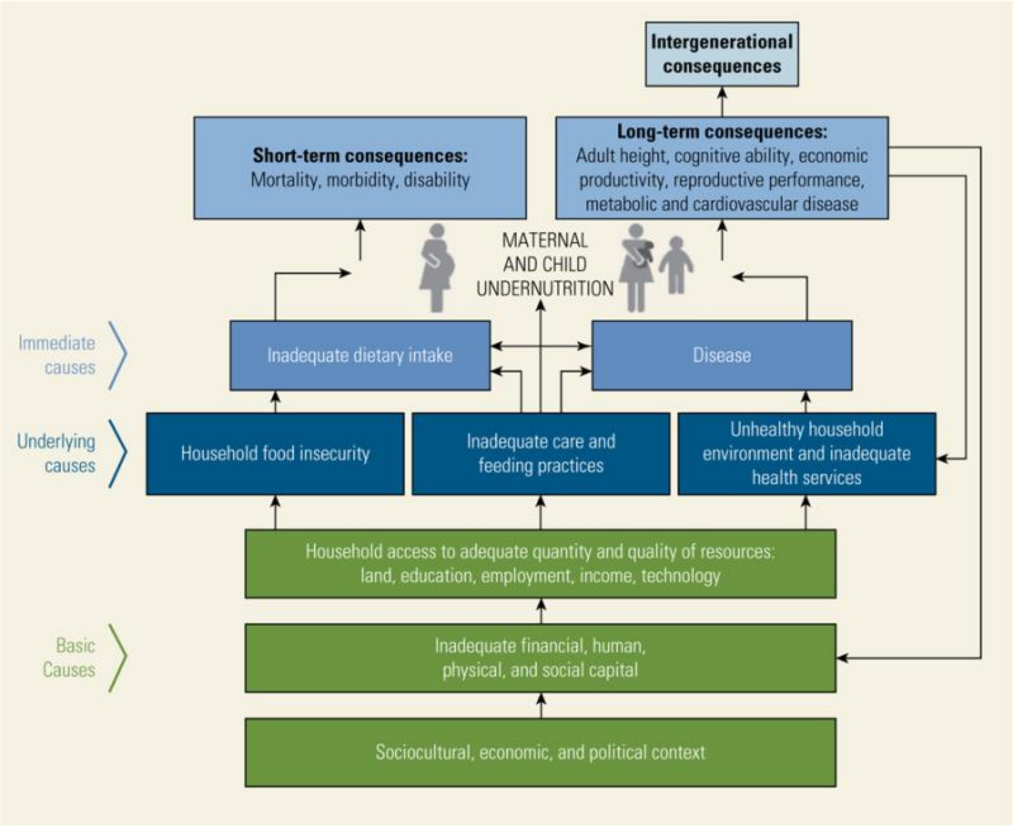
The notion and determinants of health

Health, generally, is a highly complex notion in terms of its dimensions (physical, mental and social – as defined by the WHO), determinants and distribution in a population (by individual, household, social, political, economic and physical environmental characteristics). It acquires added layers of complexity in a country as comprehensively diverse as India, with a federal structure of general /

health governance,[20] fragmented system of health care financing (figure 1.10) and, not least, multiple medicinal systems with their own notions of health, disease classifications and service providers.[21]

Like health more generally, maternal and child health (MCH) – one of the key focus areas of health policies and programs in India – is determined by a wider set of factors than by health care alone. Figure 1.1 provides a conceptual framework, figures 1.2 and 1.3 empirical evidence from 146 low- and middle-income countries on socioeconomic determinants of child and maternal mortality over two decades. One important lesson here is – data collection as well as monitoring and evaluation (M&E) have to be sensitive to this framework and evidence. In other words, we need interoperable data on these factors from health / related sectors to analyze the determinants of health. Program M&E has to keep such wider factors and data into consideration while analyzing the precise impact of health care policies and programs, which have a limited role to play vis-à-vis health outcomes.

Figure 1.1: Determinants and consequences of maternal and child undernutrition



Source: UNICEF 2013: 4.

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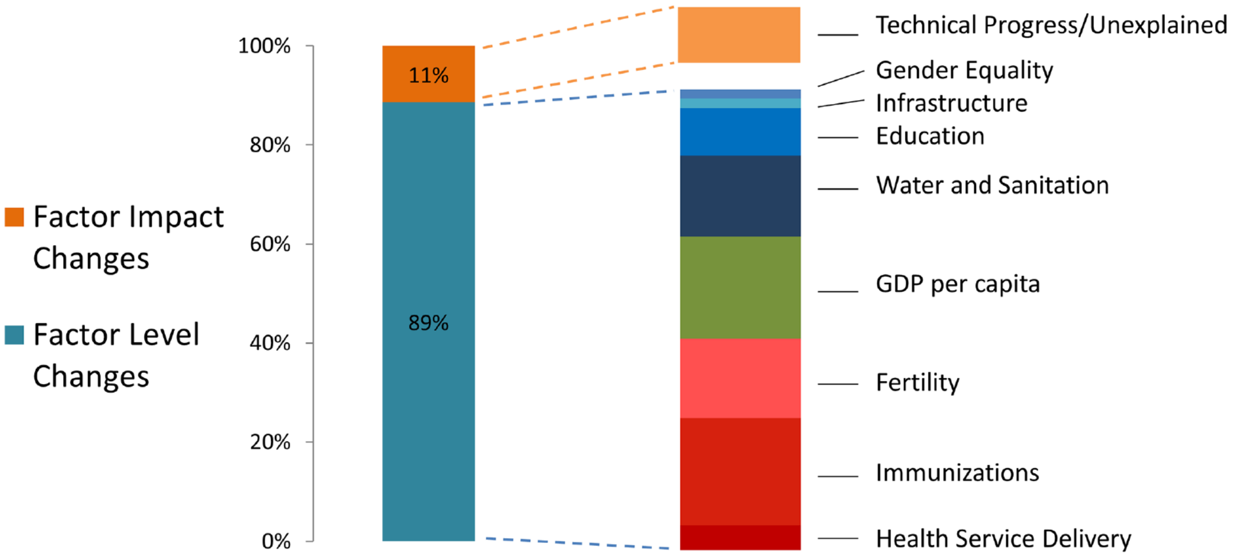
[20] According to the NHP 2017, 'one of the most important strengths and at the same time challenges of governance in health is the distribution of responsibility and accountability between the Centre and the States' (27).

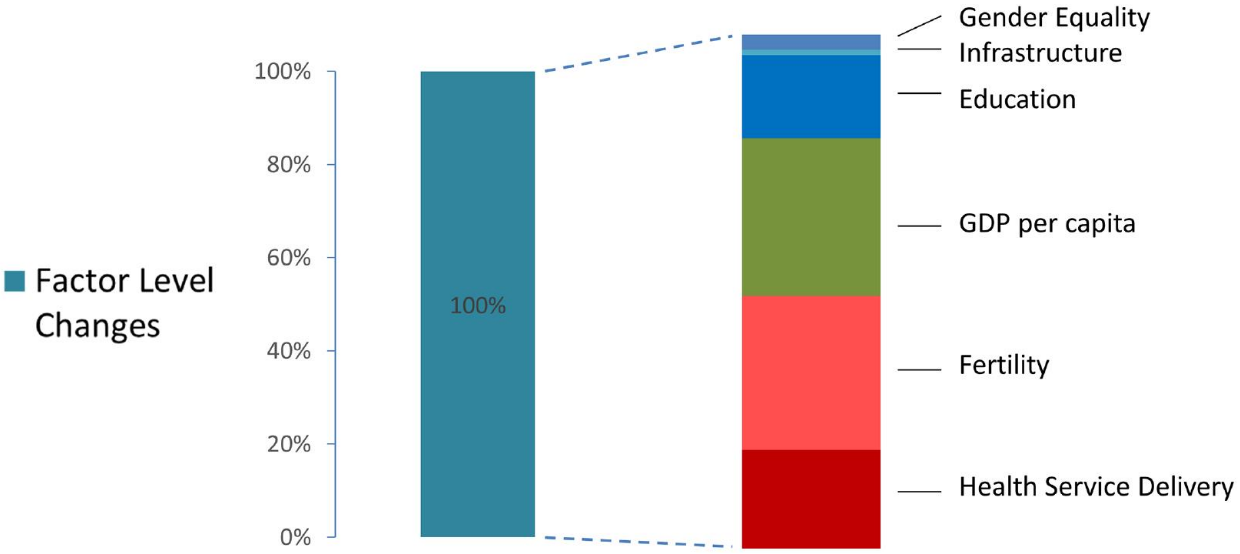
[21] Ayurveda, Siddha and Unani have their own morbidity codes. Refer to the NAMASTE (National AYUSH Morbidity and Standardized Terminologies Electronic) portal. http://namstp.ayush.gov.in/#/index (27/2/2020, 16:35 hours).

Figure 1.2: Contribution of changes in the levels of determinates of health (health interventions, social and environmental determinants) to reductions in U5MR, in 146 LMICs,1990-2010



Source: Bishai et al 2016: 9.

Figure 1.3: Contribution of changes in the levels of determinates of health (health interventions, social and environmental determinants) to reductions in MMR, in 146 LMICs,1990-2010



Source: Bishai et al 2016: 10.

The dichotomy of complex vision and RCH-oriented action in India

There has been due recognition of the general complexity of health and the willingness to address it as such in the national discourse. Around the same time as WHO's constitution and definition of health (1946), the Bhore Committee Report (BCR) argued that 'the term health implies more than an absence of sickness in the individual and indicates a state of harmonious functioning of the body and mind in relation to his physical and social environment, so us [*sic*] to enable him to enjoy life to the fullest possible extent and to reach his maximum level of productive capacity'. However, it felt that 'data regarding positive health are more-difficult to collect than those relating to sickness and mortality' (Vol. 1: 7). The first NHP 1983 started out with a reference to the constitutional vision for 'the establishment of a new social order based on equality, freedom, justice and the dignity … the elimination of poverty, ignorance and ill-health … raising the level of nutrition and the standard of living … improvement of public health'. The NHP 2017 'envisages as its goal the attainment of the highest possible level of health and well-being for all at all ages, through a preventive and promotive health care orientation in all developmental policies'. It calls for addressing the 'social determinants of health' through 'an empowered public health cadre' and 'developmental action in all sectors'; 'achieving convergence among the wider determinants of health' for urban health; the strengthening of Panchayati Raj Institutions (PRIs) so they can 'play an enhanced role at different levels for health governance, including the social determinants of health'. It argues that 'maternal and child health is a mirror that reflects the entire spectrum of social development'; and makes a case for 'research on social determinants of health'. From a programmatic perspective as well, 'intersectoral convergence' has been seen as a 'key to the success of the NHM',[22] India's flagship health program. 'The thrust of the mission is on establishing a fully functional, community owned, decentralized health delivery system with inter-sectoral convergence at all levels, to ensure simultaneous action on a wide range of determinants of health such as water, sanitation, education, nutrition, social and gender equality'. To achieve it, 'the District/City Health Action Plan is an important institutional structure for enabling decentralization, convergence, and integration, and is also the vehicle for promoting equity and prioritizing the needs of the most socially and economically vulnerable groups in a district'.[23] On its part, the NFHS provides richly disaggregated data on the wider determinants and distribution of MCH as well as some aspects of general health.

Yet, in terms of program operationalization, financing and actual practice, the integration of 'health' and 'family welfare' (HFW) has meant that the focus of HFW has predominantly been on population control / stabilization / FW / RCH / MCH rather than on health *per se*, even on its physical, let alone its mental and social dimensions. India's population has been viewed as problematic since colonial

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[22] https://nhm.gov.in/index1.php?lang=1&level=2&sublinkid=1084&lid=149 (28/2/2020, 13:40 hours).

[23] https://nhm.gov.in/images/pdf/NHM/NHM_more_information.pdf (28/2/2020, 14:21 hours).

to present times.[24] 'India was the first country in the world to have launched a National Programme for Family Planning in 1952' (MoHFW Annual Report 2015-16: 81). Despite starting out on a highly visionary note, NHP 1983 argued – 'irrespective of the changes, no matter how fundamental, that may be brought about in the over-all approach to health care and the restructuring of the health services, not much headway is likely to be achieved in improving the health status of the people unless success is achieved in securing the small family norm'. Despite being one of the most visionary programs as far as conceptualization is concerned, 63.1% of total expenditure under NHM between 2005-06 and 2015-16 was on its RCH component (NRHM-RCH flexible pool) vis-à-vis 4.5% under its flexible pool for communicable disease control programmes and 1.4% under its flexible pool for non-communicable disease (NCD) programmes (figure 2.8), despite the fact that during the same period (2005-16), 6.7% of total deaths in the country were due to maternal and neonatal disorders, 26.8% were due to communicable diseases and 55.6% due to NCDs – the remaining being due to nutritional deficiencies (0.7%) and injuries (10.2%) (Global Burden of Disease / GBD).[25] Yet, despite all the prioritized focus and allocations for RCH, and all the progress, India continues to be the world's leading contributor to child deaths since 1960, and managed to become the second largest contributor to maternal deaths in 2008 (World Development Indicators / WDI, The World Bank).[26] And, despite NFHS providing richly disaggregated data, its focus (RCH) seems to have been inspired more by health program funding and practice than the broad vision of health which inspired health policy and program documents. As recently as 20/12/2019, NITI Aayog held a national consultation, 'Realizing the vision of population stabilization: Leaving no one behind'.[27] At least, RCH is not going to be left behind any time soon, so it seems. External funding for health may be miniscule, influence at least vis-à-vis population concerns does not seem to be.

What data should the government collect?

As is evident from the above discussion, there has been a disconnect between the government's understanding and vision for health (complex) on the one hand, and its programs and funding for health (RCH-oriented) on the other. The relevant question is – should its data collection be guided by the former or the latter?

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[24] 'India came to be imagined, both by Indians and in the West, as an overpopulated place. Beginning in the nineteenth century and continuing into the twentieth, fears of overpopulation haunted Indian political culture, thereby shaping state policy and civil society debates', and inspiring 'the colonial management of famine in the nineteenth century; debates on contraception and reproductive technologies in the early twentieth century; and policies of population control in the post-independence period' (Sreenivas 2010). 'In more recent years, some in the United States and Europe have argued that this large population poses a global threat, as Indians consume an ever-increasing portion of the world's resources' (Sreenivas 2009).

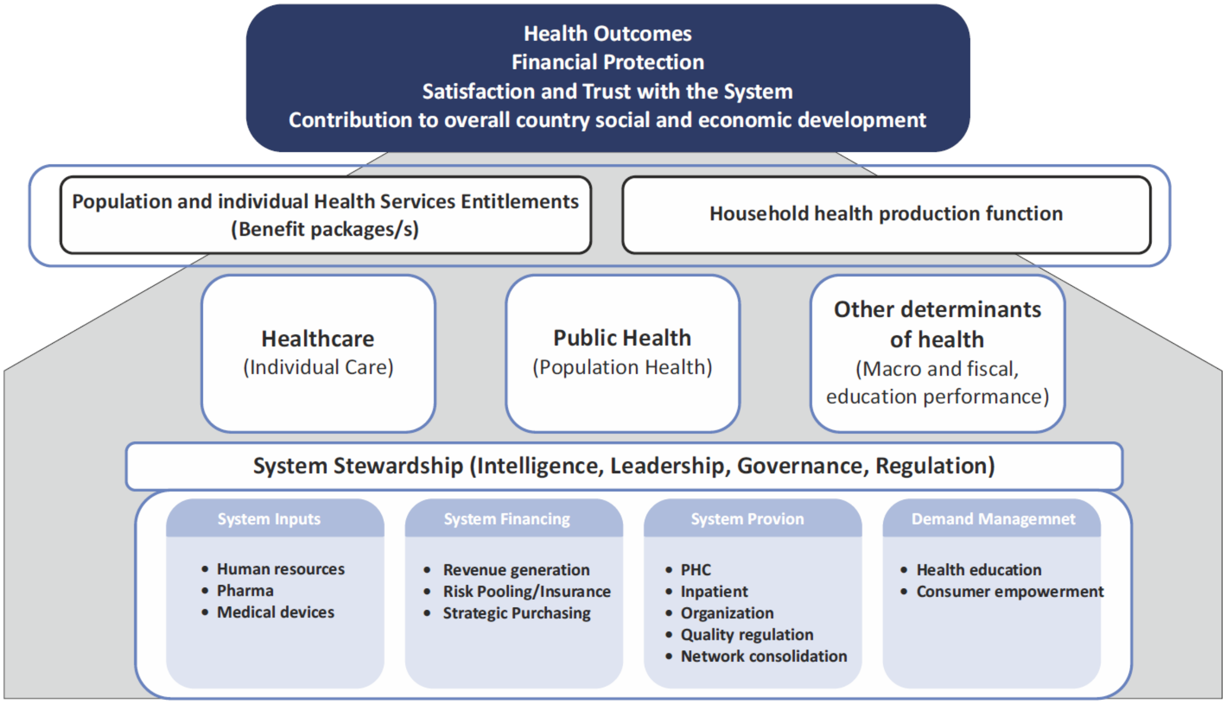
[25] http://ghdx.healthdata.org/gbd-results-tool (27/2/2020, 16:17 hours).

[26] A total of 936,338 under-five child and 35,000 maternal deaths were recorded in the year 2017 (WDI).

[27] https://pib.gov.in/newsite/PrintRelease.aspx?relid=195978 (1/3/2020, 11:34 hours).

In its “Three-year Action Agenda (2017-18 to 2019-20)”, the NITI Aayog suggested a ‘stewardship role’ for the government, which involves – 1) ‘setting and enforcing rules / incentives to guide the behaviour of the health system’, 2) ‘a data-driven and more decentralised approach to designing health systems’, 3) increases in government health expenditure ‘to cover screenings for the entire population, active case detection and disease surveillance including from the private sector’, 4) ‘availability of credible population-level data on the prevalence of risk factors and complete health outcome data at frequent intervals’, and 5) ‘evidence-based preventive health interventions’ (NITI Aayog 2017: 144-145). In a more recent document of NITI Aayog, there is a reference to ‘systems approach to health’, ‘the stewardship function of the health system’ as ‘typically the core mission of the national health authorities’, and efforts to take ‘a comprehensive view, impacting the multiple determinants of health’ (Kumar 2019: 3,4,12). Figure 1.4 depicts the proposed system stewardship function for the central government, with ‘intelligence’, notably, being the first of its 4 components.

Figure 1.4: Proposed health systems framework



Source: Kumar 2019: 12.

Clearly, the NITI Aayog’s thinking as well as general efforts toward data integration, as referred to earlier, make it clear that GoI as well as some states like Rajasthan wish to go beyond their specific health funding and programs, and take a comprehensive health systems’ view based on data from various sources to increasingly play a stewardship role vis-à-vis the entire range of processes and outcomes than merely be funders and providers of selective health care for selective populations.

This would also imply redefining the scope of government-sponsored administrative data sources as well as surveys. More population-based data is being collected through administrative sources through door-to-door surveys and mass screening of eligible persons. The scope of NFHS too has broadened over the years. We will discuss this in detail in the next section. However, let us quickly highlight that a health systems thinking is not new and has been reflected in various health policies.

The policy context of health systems and health information systems thinking in India

A health systems' thinking has been there since India's first National Health Policy. The NHP 1983 called for the establishment of a decentralized, 'well dispersed network of comprehensive primary health care services', together with 'a well worked out referral system', and 'services and support' of the private health sector to be 'utilised and intermeshed with the governmental efforts, in an integrated manner'. It had a dedicated section on 'Management information system' (MIS), where it argued that 'appropriate decision making and programme planning in the health and related fields is not possible without establishing an effective health information system. A nation-wide organisational set-up should be established to procure essential health information. Such information is required not only for assisting in planning and decision making but to also provide timely warnings about emerging health problems and for reviewing, monitoring and evaluating the various on-going health programmes. The building up of a well-conceived health information system is also necessary for assessing medical and health manpower requirements and taking timely decisions, on a continuing basis, regarding the manpower requirements in the future'. What we are trying to do now had been proposed in a broad sense 37 years earlier itself.

NHP 2002 recognized that 'unsatisfactory health indices' were 'an indication of the limited success of the public health system' (PHS). Noting 'distortion' in PHS of vertical implementation structures, it envisaged 'gradual convergence of all health programmes under a single field administration', 'full operationalization of an integrated disease control network', a 'public health surveillance network', which will include 'information from private health care institutions and practitioners'. With reliable data on 'incidence of various diseases, the public health system would move closer to the objective of evidence-based policy-making'. In its aftermath, NRHM was launched in 2005 'to strengthen the Rural Public Health System',[28] with a dedicated component of 'health systems strengthening',[29] getting the highest share within NHM budget – 39% of total approved NHM outlay in Union budget 2018-19 and 29% in 2019-20. 'Strengthening data capturing, validity / triangulation' is one of the imperatives under the program, involving complete registration of births and deaths under the CRS, recording births in private facilities, data collection on key performance indicators, rationalization of HMIS indicators and ensuring reliability of health data by means of triangulation.

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[28] https://nhm.gov.in/index1.php?lang=1&level=2&sublinkid=971&lid=154 (18/10/2019, 16:42 hours).

[29] http://164.100.154.238/nrhm-components/health-systems-strengthening.html (18/10/2019, 16:42 hours).

A lesser known fact is the collection of cause of death (CoD) data as part of NHM's maternal and infant death reviews at facility and community levels.[30] We will discuss this in some detail shortly.

NHP 2017 has taken a step further compared to NHPs 1983 and 2002 by focusing more explicitly on HIS. It has specific quantitative goals and objectives under 3 broad themes, one of them being health systems strengthening (HSS). There are 3 indicators under each of the 3 sub-components of HSS, one of the latter being health management information (HMI), whose goals are – 1) ensure district-level electronic database of information on HS components by 2020; 2) strengthen 'health surveillance system and establish registries for diseases of public health importance by 2020'; 3) 'establish federated integrated health information architecture, Health Information Exchanges and National Health Information Network by 2025'. It talks of 'an integrated health information system' with 'private sector participation in developing and linking systems into a common network/grid which can be accessed by both public and private healthcare providers'. It talks of strengthening post-marketing surveillance (PMS) for drugs, etc. as well. And most relevant from the perspective of the present study, it calls for extending 'the scope of health, demographic and epidemiological surveys to capture information regarding costs of care, financial protection'. It also suggests 'rapid programme appraisals and periodic disease specific surveys to monitor the impact of public health and disease interventions using digital tools for epidemiological surveys'. Another unique aspect of NHP 2017 is its commitment to 'development of institutional framework and capacity for Health Technology Assessment' (HTA), with its own set of implications for data collection in the country. The Health Technology Assessment in India (HTAIn) in MoHFW's Department of Health Research has already been established. We will discuss it in some detail in chapter 6.

This overview demonstrates that a health system and health information system thinking has been there at least at the policy level. There has been piecemeal operationalization of the vision of NHPs in this regard, and it is now time to do so in an organized and integrated manner. However, most importantly, we need to keep in mind that statistical and IT experts can only offer the tools for this endeavor; a comprehensive vision and conceptual framework needs to be developed beforehand.

WHO's health systems approach to monitoring and evaluation

In the context of the broadening scope of administrative data sources and surveys, it has become imperative for GoI as well as state governments to develop / adopt a health systems approach to monitoring and evaluation (M&E) too. Let us quickly discuss the work of World Health Organization (WHO) in this regard and draw some lessons for the Indian context.

In 2007, the WHO presented its health system framework with 6 'building blocks' (BBs), including one on information. Focused on health systems' performance, health determinants and outcomes,

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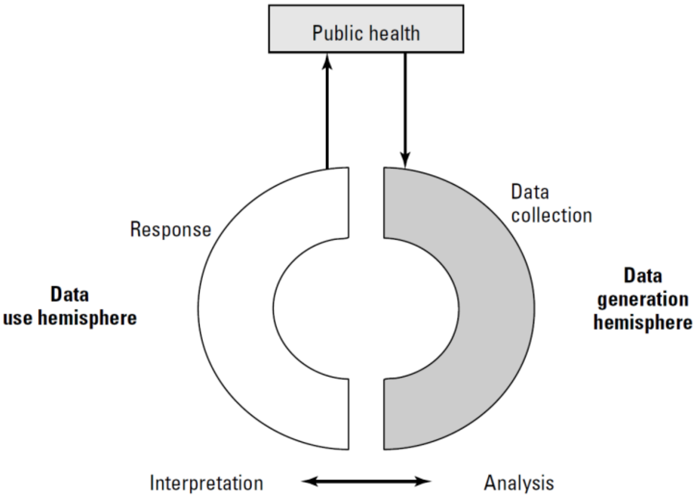
[30] http://www.nrhmhp.gov.in/content/reporting-formats-child-health (2/3/2020, 20:23 hours).

a well-functioning information BB or HIS ‘ensures the production, analysis, dissemination and use of reliable and timely health information by decision-makers at different levels of the health system’ (WHO 2007: 18). It is important to note the word ‘use’ here – without it, the collected data becomes useless. Data ‘collection and analysis should not be allowed to consume resources if action does not follow’ (Foege, Hogan and Newton 1976: 29-30). In a 1956 address, titled ‘Statistics must have purpose’, P C Mahalanobis, the architect of modern statistical methods in the Indian sub-continent (Ghosh et al 1999), argued that ‘before starting to collect any new statistics it is useful to pause and enquire, “for what purpose?” When a statistician is requested to collect some statistics his first responsibility is to ask the person or authority making the request to explain as clearly as possible the purposes for which the information would be used’ (Mahalanobis 1956: 3). Figure 1.5 highlights the data cycle with a data use hemisphere, involving data interpretation and subsequent response from a public health perspective. When we discuss the scope of NFHS, we would also refer to its data use hemisphere because if it is not actually used for some reason, its scope gets limited in a practical sense, which would also have implications for its data collection in the first place. Another critical thing to note in WHO’s description of information BB is ‘production, analysis, dissemination and use’ at ‘different levels of the health system’. Those below are not just supposed to collect and share statistics upwardly – the entire data cycle is supposed to be operationalized at various levels of the health system. This is also an integral part of the data use hemisphere.

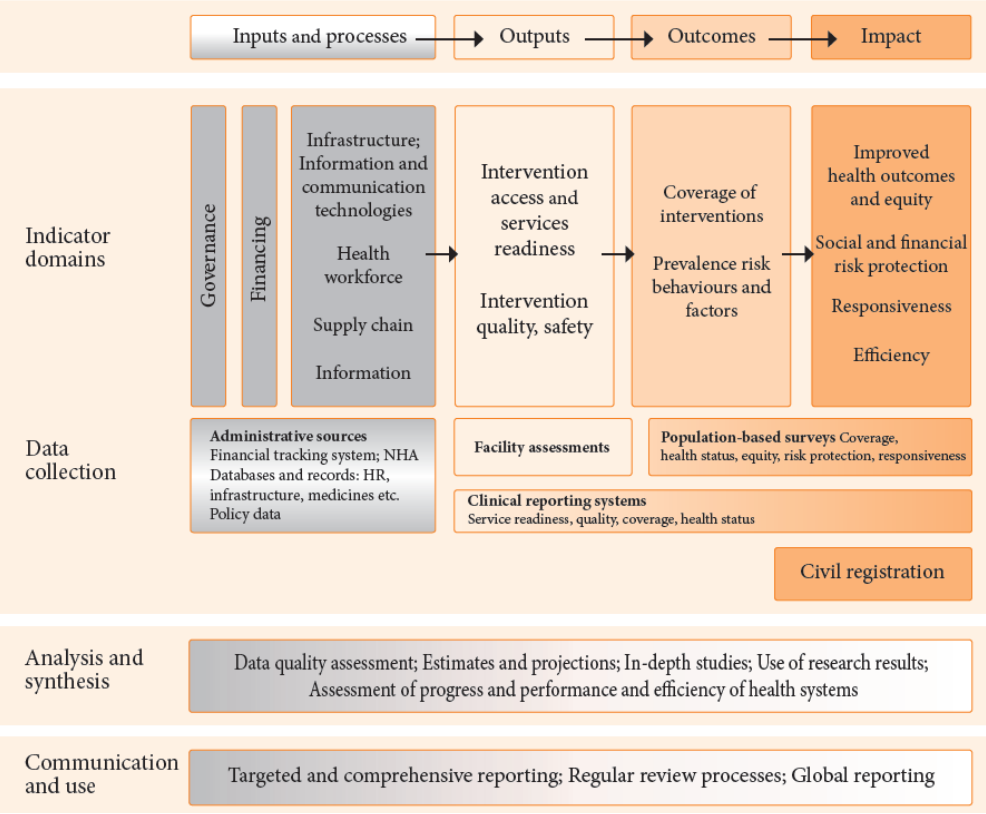
Figure 1.5: Data cycle



Source: World Bank 2006: 1001.

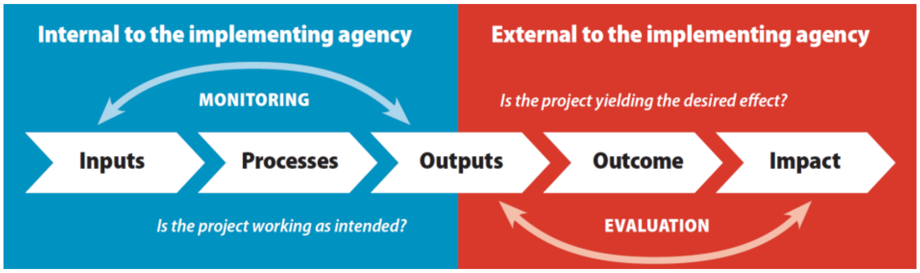
In 2010, WHO put forth a data strategy for health system M&E (figure 1.6), involving a variety of data collection sources pertaining to different health system BBs. The idea that administrative sources / surveys / registries / Electronic Health Records (EHR) would be sufficient seems naïve in the light of this M&E framework. Figure 1.7 makes a further distinction between internally-driven monitoring and externally-driven evaluation – monitoring should ‘be carried out internally by the implementing agency and focus on linkages between inputs, processes and outputs', while 'evaluation efforts to determine an intervention's effect on health outcomes and impact may be conducted' externally by an independent agency and / or program's 'intended clients or beneficiaries' (WHO 2016: 10). Figure 1.8 is WHO's Global Reference List (GRL) of 100 core indicators for harmonized monitoring of health systems from the perspective of various international agencies.

Figure 1.6: WHO's health systems monitoring and evaluation framework



Source: WHO 2010: viii.

Figure 1.7: Internal and external monitoring and evaluation



Source: WHO 2016: 10.

Figure 1.8: WHO's Global Reference List of 100 core health indicators (including health-related SDGs)

Inputs and processes → Output → Outcome → Impact

Inputs and processes

Health financing

- Total current expenditure on health as % of gross domestic product *(Also: total capital expenditure on health as % of current + capital expenditure on health)*
- Public domestic sources of current spending on health as % of current health expenditure *(Also: private)*
- External source of current spending on health (% of current expenditure on health)
- Total net official development assistance to medical research and basic health sectors [SDG 3.b.2]

Health workforce

- Health worker density and distribution [SDG 3.c.1]
- Output training institutions

Health infrastructure

- Health facility density and distribution *(Also: access to emergency surgery)*
- Hospital bed density

Health information / governance

- Birth registration [SDG 16.9.1]
- Death registration [SDG 17.19.2]
- Completeness of reporting by facilities *(Also: completeness and timeliness for notifiable diseases)*
- Existence of national health sector policy/strategy/plan

Output

Service access and availability

- Outpatient service utilization *(Also: inpatient admissions and surgical volume)*
- Service-specific availability and readiness
- Access to a core set of relevant essential medicines [SDG 3.b.3]

Service quality and safety

- Perioperative mortality rate
- Obstetric and gynaecological admissions owing to abortion
- Institutional maternal mortality ratio
- Maternal death reviews
- ART retention rate
- HIV test results for TB patients
- TB notification rate
- TB treatment success rate

Health security

- International Health Regulations (IHR) core capacity index [SDG 3.d.1]

Outcome

Coverage of interventions

- Demand for family planning satisfied with modern methods [SDG 3.7.1]
- Contraceptive prevalence rate
- Antenatal care coverage
- Births attended by skilled health personnel [SDG 3.1.2] *(Also: institutional delivery – overall and in "baby-friendly" institutions)*
- Postpartum care coverage – women
- Postnatal care coverage – newborn
- Care-seeking for symptoms of pneumonia
- Coverage of diarrhoea treatment
- Vitamin A supplementation coverage
- Immunization coverage rate by vaccine for each vaccine in the national schedule [SDG 3.b.1]
- People living with HIV who know their status
- Prevention of mother-to-child transmission
- Antiretroviral therapy (ART) coverage
- HIV viral load suppression
- Coverage of treatment for latent TB infection (LTBI)
- HIV-positive new and relapse TB patients on ART during TB treatment
- Drug susceptibility testing coverage for TB patients
- TB treatment coverage
- Treatment coverage for drug-resistant TB
- Intermittent preventive therapy for malaria during pregnancy (IPTp)
- Use of insecticide treated nets (ITNs)
- Treatment of confirmed malaria cases
- Indoor residual spraying (IRS) coverage
- Number of people requiring interventions against neglected tropical diseases [SDG 3.3.5]
- Coverage of preventive chemotherapy for selected neglected tropical diseases
- Cervical cancer screening
- Coverage of services for severe mental health disorders
- Treatment coverage for alcohol and drug dependence [SDG 3.5.1]
- Coverage of essential health services [SDG 3.8.1]

Risk factors and behaviours

- Exclusive breastfeeding rate 0–5 months of age
- Early initiation of breastfeeding
- Incidence of low birth weight among newborns
- Children under 5 years who are stunted [SDG 2.2.1]
- Children under 5 years who are wasted [SDG 2.2.2]
- Children aged under 5 years who are overweight [SDG 2.2.2]
- Anaemia prevalence in children
- Anaemia prevalence in women of reproductive age *(Also: severe anaemia)*
- Prevention of HIV in key populations
- Population using safely managed drinking-water services [SDG 6.1.1]
- Population using safely managed sanitation services [SDG 6.2.1a/6.2.1b (forthcoming)] *(Also: population with handwashing facility with soap and water)*
- Population with primary reliance on clean fuels and technologies [SDG 7.1.2]
- Air pollution level in cities [SDG 11.6.2]
- Total alcohol per capita (age 15+ years) consumption [SDG 3.5.2]
- Tobacco use among persons aged 15+ years [SDG 3.a.1] *(Also: adolescents)*
- Raised blood pressure among adults
- Overweight and obesity in adults *(Also: school-age children and adolescents)*
- Raised blood glucose/diabetes among adults
- Salt intake
- Insufficient physical activity in adults *(Also: adolescents)*
- Intimate partner violence prevalence [SDG 5.2.1]
- Non-partner sexual violence prevalence [SDG 5.2.2]
- Prevalence of female genital mutilation/cutting [SDG 5.3.2]
- Sexual violence against children [SDG 16.2.3]
- Early marriage [SDG 5.3.1]
- Frequency rates of occupational injuries [SDG 8.8.1]

Impact

Health status

- Life expectancy at birth
- Adolescent mortality rate
- Adult mortality rate between 15 and 60 years of age
- Under-five mortality rate [SDG 3.2.1]
- Infant mortality rate
- Neonatal mortality rate [SDG 3.2.2]
- Stillbirth rate
- Maternal mortality ratio [SDG 3.1.1]
- TB mortality rate
- AIDS-related mortality rate
- Malaria mortality rate
- Premature noncommunicable disease (NCD) mortality [SDG 3.4.1]
- Mortality from household and ambient air pollution [SDG 3.9.1]
- Mortality from unsafe water, unsafe sanitation and lack of hygiene [SDG 3.9.2]
- Mortality from unintentional poisoning [SDG 3.9.3]
- Suicide rate [SDG 3.4.2]
- Death rate due to road traffic injuries [SDG 3.6.1]
- Number of deaths, missing persons and persons affected by disaster per 100 000 people [SDG 1.5.1, 11.5.1, 13.1.1]
- Mortality rate due to homicide [SDG 16.1.1]
- Adolescent birth rate [SDG 3.7.2]
- Total fertility rate
- New cases of vaccine-preventable diseases
- New cases of IHR-notifiable diseases and other notifiable diseases
- HIV prevalence rate
- HIV incidence rate [SDG 3.3.1]
- Hepatitis B surface antigen prevalence
- Hepatitis B incidence [SDG 3.3.4]
- Sexually transmitted infections (STIs) incidence rate
- Congenital syphilis rate
- TB incidence rate [SDG 3.3.2]
- Malaria parasite prevalence among children aged 6–59 months
- Malaria incidence rate [SDG 3.3.3]
- Cancer incidence, by type of cancer

Finanical risk protection

- Proportion of the population with impoverishing health expenditure
- Proportion of the population with large household expenditure on health as a share of total household consumption or income [SDG 3.8.2]

Source: WHO 2018: 16.

Health surveys – quantitative or mixed methods?

Finally, a note on the desirable methodology of health surveys.

We tend to think of surveys in particular, data collection activities in general, in quantitative terms. Among the dictionary meanings of 'survey' are – 1) 'a general view, examination, or description of someone or something'; 2) 'an investigation of the opinions or experience of a group of people, based on a series of questions' (Oxford);[31] 3) 'an examination of opinions, behaviour, etc., made by asking people questions' (Cambridge).[32] None of these definitions seem to restrict the meaning of the term 'survey' to the quantitative. On the contrary, one could argue that they convey a much broader analytical as well as descriptive impression. The pre-independence 'Heath Survey and Development Committee (1943-46) – widely known as the Bhore Committee – as well as the post-independence 'Health Survey and Planning Committee' (1959-61) – widely known as the Mudaliar Committee – both established by GoI, were of this nature, as we shall briefly highlight, before we move on to discuss the better known health surveys. Both these surveys as well as the National Mental Health Survey (NMHS), conducted during NFHS-4 period (2015-16), used a mixed method approach. The former two included detailed analytical reports on health and health care situations of their times and discussion of wider determinants of health; the NMHS had a sociodemographic information proforma and included socioeconomic impact assessment of the mental health burden.

Even the DHS Program – in which global DHS surveys, including NFHS, are anchored – also designs and supports qualitative / mixed method surveys and research for understanding social and cultural dynamics related to health, population and nutrition. 'By using a qualitative approach to examine the social and cultural contexts of daily life, The DHS Program works to increase the validity and reliability of its surveys, to expand the information available for monitoring and evaluation, and to contribute original qualitative research in the fields of anthropology, demography, and public health. The capability to collect data through qualitative as well as quantitative methods provides a unique opportunity to learn and demonstrate how quantitative and qualitative approaches can be linked to expand our understanding of social and cultural dynamics related to health, population and nutrition around the world'. RCH, child nutrition and HIV/AIDS are among the topics covered by DHS through qualitative research, using 'observations, participation, rapid assessment procedures, various types of individual or group interviews, personal narratives, focus group discussions, and content analysis of medical records and other documents'.[33]

Let us conclude this discussion here by a reference to the famous libertarian economist, Friedrich August von Hayek. In his lecture, 'The pretence of knowledge', delivered on receiving 1974 Nobel

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[31] https://www.lexico.com/definition/survey (11/3/2020, 9:54 hours).

[32] https://dictionary.cambridge.org/dictionary/english/survey (11/3/2020, 9:55 hours).

[33] https://dhsprogram.com/What-We-Do/Survey-Types/Qualitative-Research.cfm (11/3/2020, 12:02 hours).

Memorial Prize in Economic Science, he argued that 'unlike the position that exists in the physical sciences, in economics and other disciplines that deal with essentially complex phenomena, the aspects of the events to be accounted for about which we can get quantitative data are necessarily limited and may not include the important ones. … social sciences … have to deal with structures of *essential complexity* … whose characteristic properties can be exhibited only by models made up of relatively large numbers of variables. …. the superstition that only measurable magnitudes can be important has done positive harm in the economic field' (Hayek 1974). Health is surely one of the 'essentially complex phenomena' – as borne out by WHO's definition of health as well as references to 'well-being' in our own NHP 2017. Likewise, aspects of health 'about which we can get quantitative data are necessarily limited and may not include the important ones'. In this context, the obsession with 'measurable magnitudes' of health surveys is actually quite paradoxical, given that their comparative disadvantage lies in not being able to assess physical health beyond a limited scope (self-reported morbidity / biomarkers), while they tend to ignore their comparative advantage in focusing on more subjective dimensions of health, given their opportunity to interact with people, an opportunity they seem oblivious of. A definition and operationalization of the notion of health may help in reorienting health surveys as well as health policy and practice more broadly towards health *per se* and closer to people's day-to-day sufferings. Health, suffering, pain, etc. are more subjective regular issues, and rarely one-time events (birth, death, hospitalization, etc.). The shift in focus toward chronic diseases has been taken to mean biomarkers, etc., while the fact that 'chronic' also means prolonged suffering, with several subjective health issues (related to mental health or more regular aches – lower back, neck, etc.) and a major bearing on one's quality of life, seems to have been largely ignored. And it is precisely in these subjective contexts of chronic diseases that traditional and complementary systems of medicine (TCSM), especially Yoga, have gained enormous worldwide popularity. According to US National Health Expenditure 2007 data, Americans spent USD 33.9 billion out-of-pocket on TCSM. According to the NIH's National Cancer Institute, 'just as cancer affects your physical health, it can bring up a wide range of feelings you're not used to dealing with. It can also make existing feelings seem more intense. They may change daily, hourly, or even minute to minute'.[34] These are not random, hypothetical issues which do not merit attention – they are at the core of what we as human beings feel on a daily basis. The health narrative in general, India's in particular, has been sorely deficient from this perspective. If health surveys capture such themes, they may not necessarily remain so and make more sense to their primary stakeholders – the people of India.

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[34] https://www.cancer.gov/about-cancer/coping/feelings (26/10/2019, 13:16 hours).

Recommendations

- In the context of India’s health transition, the GoI should adopt / develop a definition of health[35] which should guide the design and assessment of all health-related activities, including health information systems. Although this may seem basic / academic / unnecessary, one could argue that it is, *inter alia*, due to the absence of a publicly articulated / guiding definition that health has historically come to mean population stabilization / fertility / mortality / RCH in India. Efforts should also be made to operationalize a positive notion of health beyond the negative death / disease / disability oriented notion, which should not be difficult in a country where local health traditions / traditional systems of medicine have adopted a positive, holistic approach to health.

- In line with India’s health transition, health data collection should also shift from a demographic to a predominantly health orientation – according due importance to the population dimension. At the same time, we need to ensure that the emergent health orientation is not exclusively / predominantly biomedical, and is sufficiently focused on the wider determinants of health. As such, GoI should involve experts from all health-related disciplines, including social scientists, ethicists and others working on health issues for administrative data as well as health surveys.

- None of the NFHS committees has independent experts or state representatives. Health survey committees should also include independent experts from public health, epidemiology, social sciences, etc. working on health issues to enhance the domain and conceptual underpinnings of the survey as well as representatives from state / UT governments to enhance the sense of ownership at the subnational level. For instance, NHM’s Mission Steering Group (MSG) has 9 public health professionals as well as health secretaries of the high-focus states as members.[36]

- GoI should develop a National Health Data Policy (NHDP) and a National Health Data Advisory Committee (NHDAC) with members from relevant ministries / departments of central and state / UT governments (health, statistics, planning); national organizations like IIPS, ICMR, National Institute of Mental Health and Neuro-Sciences (NIMHANS) and Indian Council of Social Science Research (ICSSR); international organizations like the UN Statistical Commission, WHO, UNDP, UNFPA, UNICEF and the World Bank; leading international health statistics agencies like NCHS from the US, Statistics Canada and NHS Digital from the UK; leading national and international health scholars; industry and civil society representatives.

- The NHDAC should develop a health systems framework and health-related goals, targets and indicators with timelines like SDGs – a National Reference List (NRL) of core health indicators,

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[35] India is a signatory to WHO’s constitution, and it could be argued that it affirms the definition of health enshrined in it. https://bit.ly/32mZWjR (24/2/2020, 14:55 hours). If that is the case, it too should be spelt out clearly rather than assumed.

[36] https://nhm.gov.in/index1.php?lang=1&level=1&sublinkid=1293&lid=193 (28/2/2020, 13:06 hours).

like the WHO’s GRL, which is periodically revised to incorporate emerging concerns. For every indicator, there should be a rationale, standardized definition, numerator, denominator, method of measurement and estimation, disaggregation, frequency, preferred and other data sources, baseline value, etc. State / UT governments should, likewise, develop SHDPs, SHDACs and SRLs. NRLs and SRLs should guide interoperable data collection through a variety of sources.

- The NRL / SRL should be developed vis-à-vis core indicators of national / state health policies and programs, international data reporting requirements (including health-related SDGs) and WHO’s Family of International Classifications (WHO-FIC). The entire health information system should be revised according to the above.

- Figure 1.6 shows that various data sources are required for monitoring various health system building blocks, and there is a preferred respective role for each of them. In India, surveys like SRS and NFHS are seen as compensating for weaknesses of administrative sources, including the civil registration system. The latter need to be strengthened. However, strengthening them would not imply that surveys are no longer required – as a high-ranking health official in a state argued. Surveys have their own role to play, in periodically monitoring ‘outcomes’ and ‘impact’ of not just specific policies and programs, but more generically. It is not necessary that surveys provide data in real-time or much more frequently, as some policymakers and experts expect, although their periodicity should be annual / biennial at the most (as in US, Canada and UK – kindly refer to section 3 for details).

- Health surveys should focus on monitoring the vision / goals / objectives of health policies and programs to periodically ensure that they are being fulfilled. Program MIS / other mechanisms (ground assessments by DGHS Regional Offices, PRCs, review missions, local communities, etc.) should be strengthened for regular program monitoring and evaluation. Surveys should not be expected to help in MIS data validation beyond a few core indicators. Where there is an expectation from surveys to help validate MIS data, indicator definitions, population coverage, etc. should be harmonized. At the moment, their definitions, numerators, denominators, etc. do not necessarily match and validation cannot be done in a strict sense. In fact, data from 2 surveys also does not match precisely due to these as well as several methodological reasons. That does not automatically make one data source inferior, the other superior, based on overall perceptions rather than case-specific assessments of data quality of the concerned sources.

- No independent, systematic and exhaustive review of India’s public health surveillance system has been conducted. GoI should commission an independent review urgently, especially given the widespread prevalence – and, therefore, particularly from the perspective – of COVID-19.

- The division of labor between the 4 relevant ministries could be the following. MHA looks after all population-related indicators through census (decennial), CRVS (continuous) and the SRS (annual enumeration-cum-survey) – as it already does. MoHFW should look after public health surveillance – as it already does. However, it should be Department of Health Research (DoHR) in MoHFW, rather than its Department of Health and Family Welfare (DoHFW) – as is presently the case – which should lead and coordinate all public health surveillance activities, with the exception of policy- and program-based MIS. DoHFW, being the operational wing of MoHFW, should manage various MIS in an integrated, consistent and coordinated manner. The MHA and MoHFW could collaborate for a cause of death survey, given that it requires domain expertise which the MHA lacks. DoHR / ICMR institutions should be involved in this case. MoSPI should oversee all health surveys in consultation with MoHFW and MHA. All statistical activities should strictly be conducted under its statistical guidance, coordination and supervision – and, in the case of health, under the domain-related guidance of the DoHR (MoHFW). MoSPI, in its turn, should play a more proactive rather than a passive role as far as statistical coordination and regulation is concerned – both at the Central and state / UT levels. For this, MoSPI needs to be independent, both from political interference and IAS-led bureaucracy. There is a serious conflict of interest that the DoHFW, which manages various health schemes, also commissions and manages the *independent* NFHS, conducted by an agency (IIPS) which itself 'is under the administrative control' of MoHFW.[37] Not only this, the MoHFW's Statistics Department, which manages the HMIS, also manages the NFHS. These are very serious conflicts of interest which should be addressed immediately. If need be, the DoHR should be renamed as the *Department of Health Research and Surveillance (DoHRS)* – research and surveillance go hand in hand – and all health surveillance activities, including surveys, should be carried out under its domain supervision and MoSPI's statistical supervision. Budgets and staff in both these organizations need to be enhanced accordingly. The DoHR / ICMR already has a network of leading centers across the country, which can be leveraged for this purpose. However, at the same time, DoHR needs to go beyond its 'biomedical'[38] approach – with ICMR as only one network of institutions – and adopt a much more broad-based approach to health – with another network of public health and health-related social scientific institutes developed / supported by it. COVID-19 has already put DoHR in the lead. It is time that its role be expanded as we reorient for the future.

- ® While data collection is important, analysis is also part of data generation hemisphere, followed by interpretation and response under the data use hemisphere (figure 1.5). All four data-related frameworks need to be strengthened at the central / state / local-most levels – it cannot be the exclusive prerogative of researchers / statisticians on sidelines (DES, NIHFW / SIHFWs, PRCs, etc.) or at the top (ICMR, IHME, etc.) to analyze / interpret data. Central / state / local capacities need to be strengthened and IT tools leveraged for the entire data life-cycle. In fact, those who

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[37] http://iipsindia.org/about.htm (15/6/2020, 11:53 hours).

[38] https://dhr.gov.in/about-us/about-department and https://main.icmr.nic.in/ (15/6/2020, 11:58 hours).

collect data at local levels can sometimes contextualize and contextually analyze it better than those who do not know / understand the local context in which the data was collected. This is also in keeping with the spirit of decentralization inherent in the conceptualization of the NHM – India's leading public health program.

- There has to be a clearly defined framework for data collection, processing, synthesis, analysis and use for the design and assessment of policies and programs as well as course-correction. In the absence of such a framework – despite humongous data collection and 'reporting' within the system as part of MIS and accountability of various functionaries – data 'use' for the design and assessment of policies and programs as well as course-correction is not seen as important and becomes an arbitrary / whimsical activity. Statisticians and IT can provide the tools, but it is eventually the domain officials who have to use the data from a policy / program perspective. This is seriously missing across the country – from the national to the local levels, including in states like Kerala (field interactions).

- Ease of data use should be facilitated for policymakers as well as other stakeholders. This is a huge challenge at the moment. The STATcompiler customization tool for DHS surveys[39] / the visualization hub of GBD data on causes of death are 2 excellent examples.[40] A Kolkata-based organization, Riddhi, has developed spatial visualization tools for NFHS-4 and Census data.[41] A senior health official in Kerala found the NFHS-4 tool helpful for promptly accessing data – he said reports are bulky and one needs to collate data from different reports for comparisons. There are a few efforts in this direction within the government system as well. For e.g. the NITI Aayog's National Data and Analytics Platform (NDAP) 'aims to democratize access to publicly available government data'.[42] However, we need a dedicated platform for ease of data use for policy purposes for various levels of officials, which goes beyond visualization dashboards and helps in using data to develop policies and programs and monitor / course-correct the latter.

- A mixed methods approach should be adopted to health surveys in the country. For guidance, we could refer to health surveys conducted in India pre- and post-independence and The DHS Program,[43] of which the NFHS is a part, for instance. The richness of the notion and experiences

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[39] https://www.statcompiler.com/en/ (7/3/2020, 12:50 hours).

[40] https://vizhub.healthdata.org/gbd-compare/ for global data / https://vizhub.healthdata.org/gbd-compare/india for India and state data (7/3/2020, 12:53 hours).

[41] http://nfhs4.indiagis.org/nfhs4/ and http://www.censusgis.org/india/ (7/3/2020, 13:09 hours).

[42] https://pib.gov.in/PressReleaseIframePage.aspx?PRID=1600370 (7/3/2020, 13:12 hours).

[43] 'The DHS Program supports qualitative research to produce informed answers to questions that lie outside the purview of a standard survey approach to understanding issues in health, population, and nutrition … to increase the validity and reliability of its surveys, to expand the information available for monitoring and evaluation … The capability to collect data through qualitative as well as quantitative methods provides a unique opportunity to learn and demonstrate how

of health, well-being and health care utilization and satisfaction can best be captured by means of qualitative methods. Qualitative information could also imbue the otherwise dry quantitative data with an intimate, human sense and help in making health systems more people-oriented.

- The DHS Program also has several types of surveys and not just the standard DHS, according to which the NFHS has been modelled. Beyond the standard DHS surveys – with large sample sizes, typically conducted every 5 years, to allow comparisons over time – 'interim DHS' focus on select indicators, are conducted between standard DHS, have shorter questionnaires and sample sizes, but are nationally representative. There is also 'continuous DHS', as part of which data is collected and reported annually by a permanent DHS office and field staff.[44] There are 'in-depth DHS' and 'mini DHS'[45] too. India should adopt a dynamic approach to health surveys, and consider the various options available in the light of its requirements.

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quantitative and qualitative approaches can be linked to expand our understanding of social and cultural dynamics related to health, population and nutrition around the world'. https://bit.ly/30IXsgE (15/6/2020, 11:22 hours).

[44] https://bit.ly/3cZvrUB and https://bit.ly/2Bd0TBq (15/6/2020, 12:21 hours).

[45] For a list of various types of DHS conducted so far, kindly refer to – https://bit.ly/3e43qwr (15/6/2020, 12:21 hours).

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SECTION 1 –

HEALTH SURVEYS AND THE SCOPE OF NFHS AT THE NATIONAL LEVEL

2. Health surveys in India

In this chapter, we will discuss health surveys in India in a chronological order, with a special focus on the NFHS and SRS. Towards the end, we will highlight their comparative / respective coverage and offer recommendations towards India's health survey strategy.

Heath Survey and Development / Bhore Committee (1943-46)

This is the first official 'survey of the whole field of public health and medical relief', 'a broad survey of the present position in regard to health conditions and health organisation in British India and to make recommendations for future development', commissioned by the GoI in 1943 (BCR 1946, Vol. 1: 1). Given its broad mandate, it not only provided data on life expectancy, death rate, infant and under-10 child deaths, maternal mortality, deaths due to epidemic diseases and other causes, but also on 'the social background of ill-health', on the 'causes of the low level of health in India' – e.g. insanitary conditions, social customs, people's outlook, nutrition, education, unemployment and poverty. The authors of the report argued that 'our survey of the causes of ill-health in India will not be complete without drawing attention to the profound influence that these factors exert on the health of the community' (ibid.: 17). Six decades before the Michael Marmot-led 2005 WHO Commission on Social Determinants of Health (CSDH) that held 'a toxic combination of poor social policies, unfair economics, and bad politics' responsible for ill-health, the BCR highlighted the role of the broader determinants of health,[46] unlike the narrow focus of health surveys of our time, with limited exceptions, NFHS being one of them.

National Planning Committee (NPC) – National Health Sub-Committee Report (1948)

Appointed by Jawaharlal Nehru in 1938, under the chairmanship of Col S S Sokhey (also known, therefore, as the Sokhey Committee Report), the NPC had 29 sub-committees, with one being on population and another on health. 'Investigation into the volume and causes of infant mortality, as well as mortality among women', 'compilation of vital statistics' were among the terms of reference of the national health sub-committee. Noting that 'India is very poor in statistical information of all kinds', it proposed 'vital statistics accurately taken and maintained for statistics and research' as one of the 'preventive measures' and a village survey with the following scope and methodology, inspired by a comprehensive view of health and its determinants like the Bhore Committee earlier.

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[46] In Britain, vast differences in life expectancy across occupational groups were reported by Edwin Chadwick in his 'Report on the sanitary condition of the labouring population and on the means of its improvement' way back in 1842, which became the basis for the first Public Health Act there in 1848. So, there was a background even to what the Bhore Committee was referring to. See Mehdi (2019) for further discussion on this. Likewise, universal health coverage, too, had a background in pre-independence India and Britain, in terms of provisioning it for the working class, to begin with.

No definite programme can successfully be made with out a through survey of the local conditions. This survey must include all the necessary data needed for future planning and expansion.

For the general health of a community is dependent on the topography, soil formation, productivity, industry, water supply, drainage, population (man and cattle), weather conditions, education and economical or cultural backgrounds of a community, therefore the survey must include all these items.

Besides the survey of the society and its surroundings one must possess intimate knowledge of the individual's mental and physical health this makes it imperative to make study of not only each family, but every individual.

This survey must be done on card system by school teachers who may be provided with questionnaire; and they may not only survey once and be done with them, but keep them up-to-date by checking and rechecking on them for many years. Students have proved useful in gathering information of this kind of survey work.

This survey will give us information of the success or failure of a programme, therefore though monotonous, dry and statistical in outlook, it has to be carried out with scientific precision.

The survey schedule, with the following components, was also included in the report –

1) Basic details (name, district, province, name of villages in north, south, east and west)
2) General topography, quality of soil, area
3) Sources of water supply, drainage, sewage, garbage
4) Household population characteristics (male, female, under 5 and 5-16 years, occupation)
5) Kinds of produce and trade
6) Dairy products
7) Animals, animal fodder and sheds
8) Tree surveys
9) Housing
10) Family survey (with details of the head of the household– for e.g. caste, race, gender, age, occupation, income, economic and housing status and details, family diet)
11) Family health survey (name, gender, age, illness in past 12 months and duration, treatment (home, dispensary, private), cost of medical care, details of physician, dispensary, hospital)
12) Morbidity survey (communicable and chronic diseases, disease names, number of cases, average number of days / person, whether epidemic / endemic / quarantine, cases traced)
13) Vital statistics
14) Individual's detailed medical history (with socioeconomic characteristics)

15) Detailed physical examination by physician (with socioeconomic characteristics)
16) School survey with attendance and health record
17) Population survey

Truly an inspiration on the scope of health surveys from the perspective of WHO's definition and social determinants of health.

National Sample Survey (NSS, 1952-)

Given the poor status of health statistics at the time of independence, health was one of the focus areas for the NSS since its inception in 1950. IMR from as far back as its 2nd (1952), 14th (1958-59) and 17th to 20th rounds (1961-62 to 1965-66) are available. Its estimates were, however, not considered reliable (Chandrasekhar[47] 1972: 141-142). As per RGI (1989), population surveys were 'an integral part' of annual rounds of the NSS during 1958-68, after which they were discontinued. 'Comprehensive survey on population, fertility, family planning and mortality' was reintroduced in its 28th round (1973-74), with the second one conducted in its 39th round (1984). These 'surveys conducted by NSS since 1958 have provided comprehensive data on all aspects of population covering size, structure and composition of population, marital status, births, deaths and migration' (1). NSS has conducted 4 health surveys since the 1990s – during its 52nd (1995-96), 60th (2004), 71st (2014) and, most recently, 75th round (2017-18), covering 113,823 households (NSO 2019).

The NSS conducted 'exploratory' surveys on morbidity, starting with the 7th round (1953-1954), followed by three subsequent rounds (11th-13th rounds, 1956-58). A pilot survey was conducted in its 17th round (1961-1962) 'to examine alternative approaches of morbidity reporting'. Based on the experience of these surveys, a 'full-scale' survey on morbidity was conducted in the 28th round (1973-1974). Subsequently, no separate morbidity surveys were undertaken, and morbidity became part of 'decennial surveys on social consumption'. The first national social consumption survey (SCS) – household schedule 25.0 on 'Social Consumption: Health' – was carried out during its 35th round (1980-81) – covering the public distribution system, health services (including mass immunisation), family welfare, etc. The second SCS 25.0 was carried out during the 42nd round (1986-1987), and included problems of the aged. The third SCS 25.0 was carried out during the 52nd round (1995-1996), dropping utilisation of the public distribution system and family planning services since the former was covered during the 50th round (1993-94), the latter in NFHS-1. The fourth SCS 25.0 was conducted in the 60th round (2004), covering morbidity, health care and the problems of the aged on MoHFW's request. The fifth SCS 25.0 was conducted after a gap of 10 years during the 71st round (2014), covering self-reported morbidity and hospitalisation, childbirth and maternity health care services and condition of the aged, including the extent of use and cost

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[47] S Chandrasekhar was Health Minister in Indira Gandhi's cabinet. https://bit.ly/2MLUeSr (25/10/2019, 13:04 hours).

of treatment of AYUSH for the first time. It also provides information on proportion of ailing persons per 1,000 for acute and chronic ailments by age, residence, gender and quintile. However, unlike other rounds, 60th and 71st rounds were 6-month surveys with smaller sample size and, therefore, could not provide even nationally representative data (NSO 2019). The sixth SCS 25.0 survey was conducted during the 75th round (2017-18). Data on outbreak of certain communicable diseases, immunisation status and related expenditure was also collected. Table 2.9 offers a comparative overview of major themes covered in the latest NSS and NFHS.

NSS has been conducting disability surveys too. The first attempt to gather information on physical disability was during its 15th round (1959-60), and subsequently in the 16th (1960-61), 24th (1969-70) and 28th (1973-74) rounds, all of which were exploratory in nature, and provided data only on the number of persons suffering from type of physical disabilities in India. A comprehensive survey on disability was carried out in the 36th round (1981), followed by the 47th round (1991), with the objective of developing a database on the prevalence and incidence of disability in the country. It provided data on all types as well as the particulars of physical disabilities, like degree of disability, cause, age, etc. along with demographic characteristics of households. In the 58th round (2002), along with physical, data on mental disability was also collected. The latest disability survey was conducted during the 76th round (2018), covering 7 disability types – locomotor, visual, hearing, speech and language, mental retardation / intellectual disability, mental illness other disabilities.

NSS has also been conducting quinquennial (5-yearly) household Consumer Expenditure Surveys (CES) since its 27th round (1972-73) to generate the 'estimates of household monthly per capita consumer expenditure (MPCE), its distribution over households and persons, and its break-up by commodity group, at national and State/UT level, and for different socio-economic groups'. These estimates help assess the population's standard of living, nutrition (energy, protein and fat intake), poverty, inequality as well as certain indices related to the national economy. Latest available data is from the 9th quinquennial survey in the series conducted in its 68th round (2011-12), that of the 10th CES survey, conducted during its 75th round (2017-18), was not released due to 'data quality issues'. Two back-to-back CES surveys were under consideration for 2020-21 and 2021-22.[48] We should highlight that while these surveys provide data on nutrition, they are 'not specially designed to serve the needs of a nutrition survey' ('Nutritional Intake in India, 2011-12', 68th round report).

It also needs to be noted that, over different rounds, sample size and selection, classifications and the definitions of variables have changed. Until the 60th round, only ailments treated by medical personnel were considered to be treated, which changed since the 71st round. With growing self-medication in India, the 71st and 75th rounds consider use of over-the-counter (OTC) drugs too as treatment. The definition of disability also changed since 71st round, with pre-existing disability

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[48] Seshadri, Suresh. 'What is Consumer Expenditure Survey, and why was its 2017-2018 data withheld?'. The Hindu (24/11/2019). https://bit.ly/2wVJ5sA (15/3/2020, 18:24 hours).

considered as chronic ailment only when it is under treatment. Further, classification of ailments and nature of treatment has also changed with more categories being added. Therefore, caution needs to be exercised while analyzing, comparing and interpreting data over the rounds. Further, it is to be noted that the data pertaining to ailments is self-reported, and not diagnosed, except for few chronic diseases like cancers, tuberculosis, HIV/AIDS, diabetes, etc. In all the other ailments, prevalence was reported by respondents or diagnosed on the basis of symptoms, which may lead to wrong reporting / classification of ailments. Another issue has been the presentation of data on medical services received from modern and traditional systems of medicine (AYUSH) – the report provides percentage of ailments treated by allopathy and AYUSH, which adds up to 100 percent, despite the fact that people tend to use various systems of medicine in a 'complementary' rather than an 'alternative' manner, and so their use should not add up to 100 percent. This is one of the classic examples of how the lack of domain expertise can lead to errors in providing estimates. Of course, people can use raw data and calculate absolute rather than relative use, but the ability to use raw data is quite limited among policymakers as well as other relevant stakeholders. We have pointed out later that in one of the Kerala reports, a statistician in the state Department of Health Services totaled the IMR for different districts to provide state IMR! Another case which highlights need for domain and statistical experts to work together for data collection, tabulation and analysis.

Another limitation is that NSS 'still does not give reliable district-level estimates for most indicators. … experts fear that over the last two decades, developments like cuts in staff strength, change in recruitment practices, and the creation of a 'centralised' Subordinate Statistical Service have resulted in a shortfall of experienced field investigators, which may have compromised the quality of data being collected by the NSSO. … considerable resources are also spent to collect what is known as the 'state sample', which covers at least a matching number of respondents in each state. Pooling of central and state samples will enhance the policy relevance of NSS data, as these can then be used to arrive at district-level estimates' (Kurian 2016: 10-11). The SRS was instituted 'when the inadequacy of the National Sample Survey became obvious', (Jeffery 1988: 23), when NSS proved not 'to be reliable due to the effect of non-sampling errors, which are only too obvious in the results' (Chandrasekhar 1972: 74).

Health Survey and Planning Committee (1959-61)

Sixteen years later, the government of independent India appointed a 'Health Survey and Planning Committee' in June 1959 to review the 'developments that have taken place since the publication' of the Bhore Committee Report, and 'formulate further health programmes for the country in the third and subsequent five-year plan periods' (Mudaliar Committee Report 1962,[49] Vol. 1: 7). The

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[49] Subsequent committee reports – Chadha (1963), Jungalwalla (1967), Mukerji (1968), Kartar Singh (1973), Shrivastav (1975) and Bajaj (1986) – were sectoral in nature, focusing on specific aspects, rather than a comprehensive survey.

Mudaliar Committee adopted a mixed methods strategy – eliciting 'information and views' through 907 questionnaires (receiving 665 responses), visit to 'representative institutions', 'interviews with representatives of organizations' as well as with other individuals, listening to 'views, experiences and suggestions' of foreign participants at the 1961 World Health Assembly in India, and 'scrutiny of memoranda received from various sources' (ibid.: 11). Like the Bhore Committee Report, it also referred to the social determinants of health – 'the most essential conditions for promotion of health are good housing, adequate and whole some food, abundant supply of potable water, proper disposal of sewage, free perflation of air, prevention of overcrowding and clearing of slum areas, supply of pure milk, particularly to children', not least, 'the development of sanitary conscience in the community' (ibid: 64). Its report referred to NSS data on the distribution of doctors and hospital services in rural areas and out-of-pocket expenditure on health care (ibid: 74, 79).

Model Registration System (MRS, 1965-81), Survey of Causes of Death (SCD), Rural (1981-98)[50]

India introduced the world's first VA-based CoD reporting in 1965 to get CoD data from rural areas as part of the MRS, and subsequently the SCD. In January 1999, the SCD was also discontinued, and a CoD component was added to the SRS. MRS and SCD have been discussed in some detail elsewhere (RGI 1988; Mahapatra and Rao 2001; Mahapatra 2002; Chattopadhyay and Agnihotram 2004; Mahal, Karan and Engelgau 2010), so we will leave it here.[51] However, let us point out that both the MRS and SCD were designed to get rural CoD data from a sample of villages, given lack of a robust CRVS system. Like the SRS, both of them were based on continuous enumeration as well as half-yearly verification by a PHC statistician. It seems that because of the similarity in their approaches, the SCD was discontinued and CoD for the entire country subsumed under the SRS.

Sample Registration System (SRS, 1971 –)

Given the challenges of the CRVS system, the ORGI initiated the sample registration of births and deaths scheme as 'an interim measure' in the 1960s (Mahapatra 2017: 2) so as to provide regular, reliable and representative vital statistics (birth and death rates). It was piloted in a few states during 1964-65, launched across the country during 1969-70 and has regularly been providing data since 1971. Table 2.1 shows the indicators and background characteristics for which it currently provides data at national level, state level for smaller states and NSS natural division level[52] for major states.

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[50] We could find the years of these surveys only in Colaco (2016).

[51] For a robust discussion on CoD in India, kindly also refer to http://www.ihs.org.in/BurdenOfDisease/CauseofDeath.htm (13/3/2020, 19:11 hours).

[52] NSS natural divisions are 'classified group of contiguous administrative districts with distinct geographical and other natural characteristics' (SRS Statistical Report 2017: 2).

Table 2.1: SRS indicators and background characteristics, 2017

Indicators	Disaggregation
Annual estimates	
Percentage distribution of estimated population	Age-group, residence, gender, marital status
Fertility	Age-group, residence, mother's educational level
Percentage distribution of live births	Birth order, residence, gender, birth interval
Percentage distribution of deaths	Age-group, residence, gender
Death rate	Age-group, residence, gender
Child mortality (all levels from SBR to U5MR)	Residence, gender
Medical attention received at delivery (mothers) and before death at public / private facilities	Residence
Three-yearly estimates	
Sex ratio at birth (3-yearly)	Residence
Cause of death	2 state groupings – EAG + Assam and other states By major ICD codes at the national level (by age-group, residence, gender) By 4 major ICD cause groups and top 10 causes for state groupings (by residence, gender) By top 10 causes for age-groups (by state groupings, residence, gender)
Maternal mortality ratio and rate, lifetime risk	Age-group
Five-yearly estimates	
Life expectancy	Age-group, residence, gender

Source: Developed by author from various SRS reports.

SRS is based on a dual record system, beginning with a baseline survey, involving preparation of a notional map of areas to be surveyed, house numbering / listing and filling of household schedule with the residential status and other demographic characteristics of each individual residing in the household – identification code, name, sex, date of birth, age, educational / marital status, etc. List of all women in reproductive age-group, along with their pregnancy status, is also prepared during the baseline survey. The second phase involves continuous enumeration of births and deaths in sample villages and urban blocks by resident part-time enumerators – usually *Anganwadi* workers and teachers. The third phase is independent and retrospective half-yearly surveys (HYS) by SRS supervisors belonging to the statistical cadre of State Census Directorates. While carrying out the HYS survey, supervisors do not have access to birth and death records of enumerators for same periods, which are withdrawn from the field before supervisor's visit for the HYS survey. The fourth phase involves matching data from two sources – i.e. continuous enumeration and HYS survey – while the fifth phase involves verification in the field of the unmatched and partially matched events 'to get an unduplicated count of correct events'. In the sixth phase, verbal autopsy (VA) forms are filled for finalized deaths to obtain CoD estimates. Table 2.2 lists the SRS forms and the information collected as part of them, while figure 2.1 depicts the entire SRS process.

It is interesting to note that 'for ensuring complete netting, the enumerator uses different sources to get information of the occurrence of vital events in the sample unit. These include the help of the village priest, barber, village headman, midwife and such other functionaries. The enumerators maintain contact with these informants at frequent intervals and collects information about the occurrence of births and deaths. On being informed about the occurrence of an event, the enumerator visits the concerned household and records the prescribed particulars. The enumerator also keeps in touch with other socially important persons and visits local or nearby hospitals, nursing homes, cremation or burial grounds, at frequent intervals to keep updated about the occurrence of events. Besides, enumerator maintains and updates a list of all women in the reproductive span along with their pregnancy status, which helps in better netting of all the births. Despite all these efforts, the enumerator may miss information about some of the events and is, therefore, required to visit all the households once a month in urban area and once in a quarter in rural areas so as to ensure that all the events have been recorded'.[53]

The infant mortality rate is taken as the decisive indicator for estimation of sample size. HYS 2017 was conducted in 8,853 sample units, covering about 7.9 million sample population. SRS sampling frame is revised every 10 years based on results of the latest Census. While changing the sample, modifications in sampling design, wider representation of population, overcoming limitations in the existing scheme, meeting additional requirements, etc. are taken into account. First sampling frame replacement was done in 1977-78, the latest in 2014. Given its sample design, the SRS is the only panel household health-related survey in the country that can potentially help in tracking changes in vital statistics at the individual / household level. Given its sample size, it claims to be the world's 'largest demographic survey'. To add more feathers to its cap, SRS data has been used to conduct Census Evaluation Studies (CES) 'to estimate the extent of misreporting of age at younger ages

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[53] http://censuskarnataka.gov.in/SRS%20Introduction.pdf (11/3/2020, 13:35 hours).

in the census', with 'ages recorded' in the SRS 'taken to be the true ages'. The CES, along with the census PES, have highlighted 'the constraints in data collection in a large operation like the census', helping improve 'future census operations' (CES 1996: iii). At the same time, its data has also been used to check under-enumeration in CRS. SRS vital rates are much more widely used than those of the NFHS or other sources.

The NFHS has a major rival in the SRS – its sample design and size, continuous enumeration and bi-annual independent retrospective survey methodology, periodicity, validation potential vis-à-vis the census and CRS, ability to canvass CoD surveys and provide data not only on a higher range of vital statistics (for e.g. MMR and life expectancy as well), but also on the whole range of diseases as per ICD-10, being an independent source of data from within the government system, etc. give SRS a massive advantage over the NFHS. However, the NFHS also has an edge over the SRS on certain parameters – it is coordinated by a group of professional and independent demographers with the best international support as far as vital statistics are concerned; provides data on a wide range of background characteristics that SRS usually does not (for e.g. religion, caste/tribe, wealth index, etc.); is able to provide at least some data up to the district level (though not vital statistics). However, as far as background characteristics are concerned, the ORGI did commission 3 special SRS surveys – in 1978, 1984 and 1997 – 'to throw light on inter-relationship of fertility and mortality indicators with various socio-economic factors' (RGI 1989), providing data by caste, religion, etc. As far as district level data is concerned, the ORGI did contemplate in 2012 'a massive increase by adding 46,000 sample units for the year 2015-16'. Given the 'prohibitive costs and operational difficulties', however, the idea was not taken any further (Mahapatra 2017: 6). The sample size of NFHS-4 was instead expanded so that it could provide data at the district level.

SRS CoD (VA) surveys

The SCD was integrated with the SRS on 1st of January 1999 (MHA Annual Report 2003-04: 118). Four rounds of SRS CoD surveys have been conducted ever since – 2001-03, 2004-06, 2007-09 and 2010-13 – covering 455,460 deaths.[54] SRS forms 10A to 10D are meant for these surveys. Figure 2.1 illustrates the process. However, given the limited sample size, only 3-yearly estimates are possible; that too, only for 2 groupings of all states; and, more importantly, even at the national level, we do not have data for each ICD-10 code, rather several codes have to be lumped together to provide estimates for broader categories (table 2.1). So, lumping of samples, states as well as ICD codes. And the latest available estimates are almost a decade old. Although SRS CoD surveys have been a silver lining, there is still a lot of darkness out there as far as regular, representative data on causes of death in the country is concerned. In this context, there have been attempts to fill in the gaps through the Global Burden of Disease and National Burden Estimates (NBE, Menon

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[54] https://bit.ly/2WgRH5J (26/10/2019, 13:58 hours).

et al 2019) by researchers affiliated with the ICMR. The ORGI has been making efforts not only to revamp the CRVS system, but also to boost up the VA-CoD statistics.[55] Both are urgently needed.

'Recent studies suggest that VA can provide cause of death information that, at the population level, is similar to death certification in high-quality hospitals', argues Dr Chattopadhyay, Director of All India Institute of Hygiene and Public Health.[56] However, it has also been argued that the VA method assumes that 'most causes of death can be recognized by trained physicians based on descriptions of signs and symptoms provided by a close relative of the deceased. Identification is simple for causes of death with distinct symptoms such as tetanus and injuries but can be difficult to distinguish in cases which have symptoms common to many diseases, such as of the fever during malaria'. Furthermore, VA is 'not very useful in identifying causes of death in persons over 70 years of age'.[57] Strengthening of MCCD should be a top priority for improved CoD data quality.

Table 2.2: SRS forms and their respective data points

Form No.	Form Name	Data points
1	House list	Building number, name and status of household head, house (residential, etc.) and household (migration, etc.) over 4 HYS
2	Household schedule	Name and identification code (used in most forms) of household members, relationship to head, gender, DOB, date of first marriage, total number of children (born alive, surviving), status over 5 HYS (age, educational status, residential status, marital status, reason of migration – work, education, marriage, etc.)
2A	Morbidity, personal habits and socio-economic status	Identification details, self-reported morbidity (name of the disease – codes 1 to 9 are given, the last being 'Others (specify)' – duration of disease, source of treatment), behavioural risk factors for persons aged 15+ years (tobacco, smoking, alcohol)
2B	Maternity history and family planning practices schedule (currently married women aged up to 49 years)	Identification details Woman – age, age at marriage, number of children born and surviving, awareness and use of contraceptives by type Children – gender, DOB, surviving / dead

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[55] https://causeofdeathindia.com/ (13/3/2020, 19:39 hours). An MoU was signed between RGI and AIIMS Delhi in March 2017 to provide technical support to RGI for SRS-based VA. AIIMS developed an online platform, the Minerva (Mortality in India established through Verbal Autopsies), for this purpose. https://bit.ly/32HLXUW (25/10/2019, 13:37 hours). Future data on CoD using VA will come from this source. 'Assigning most-probable underlying cause of death for nearly 50,000 deaths identified annually under the SRS all over the country' is its target.

[56] https://bit.ly/32HLXUW (25/10/2019, 13:37 hours).

[57] https://causeofdeathindia.com/background/ (25/10/2019, 13:53 hours).

Form No.	Form Name	Data points
3	Pregnancy status of women	Identification details, pregnancy status, expected month and outcome of pregnancy (live births / still births / abortions), remarks
4	Outcome of pregnancy recorded by enumerator	Identification details, residential status, age, details of outcome of pregnancy (place of delivery, outcome and date, birth multiplicity, gender, birth weight), type of attention at delivery / abortion, details of sterilization of husband and wife
5	Deaths recorded by enumerator	Identification details, particulars of the deceased (identification details, place of death, residential status, date of death, gender) age at death, type of medical attention at the time of death
6	Monthly report of outcome of pregnancy	Identification details of household head and pregnant woman, details of outcome of pregnancy (place and date of live births / still births / abortions, gender)
7	Monthly report of deaths	Identification details of household head and the deceased, place and date of death, residential status, gender, age at death
8	Unit-wise consolidated monthly report	Sample unit code, population as on 1st January / July, live births, still births, abortions, deaths, infant deaths, remarks
9	Outcome of pregnancy recorded by supervisor	Identification details (including age and level of education of the pregnant woman), details of outcome of pregnancy, details of previous child, order of current live birth, birth interval, type of attention at delivery / abortion, sterilization, matching remarks (code: fully matched – 1, partially matched – 2, unmatched – 3), reverification remarks
10	Deaths recorded by supervisor	Identification details, place and date of death, residential status, gender, death registration (yes – 1, no – 2, not known – 3), age at death, order of birth in case of infant death, type of medical attention at the time of death, matching and reverification remarks
11	Finalized list of outcome of pregnancy	Identification details, residential status, age, level of education, type of attention at delivery / abortion, details of outcome of pregnancy (including birth registration status), details of previous birth, birth interval, sterilization
12	Finalized list of deaths	Identification details and particulars of the deceased, type of medical attention at the time of death
13	Results of the Half Yearly Survey on	Gender, live births, still births, abortions, remarks

Form No.	Form Name	Data points
	outcome of pregnancy	
14	Results of the Half Yearly Survey for deaths	Gender, deaths, infant deaths
15	Distribution of usual resident population of the sample unit by age, sex and marital status	Age-group, marital status by gender
16	Distribution of total female population by broad age-group, sex and level of education	Age-group, level of education
17	Number of females who got married by age at effective marriage	Age at effective marriage, number of females
SRS – Verbal Autopsy Form (2011 versions)		
10A	Neonatal death (28 days or less of age)	Name of the head of the household, full name of deceased, name of mother of the deceased, identification codes of the head, deceased and mother of the deceased, unique form number, SRS unit number, year *Section 1* Respondent – name, relationship with deceased, lived with the deceased during the events that led to death, age, gender, education, religion of the head of the household, identification code of the respondent Details of deceased – gender, age, relationship of the deceased with the head of the household, date of birth, date of death, house address of the deceased, PIN, place of death, HH-reported cause of death *Section 2* Death details – • Death due to injury or accident

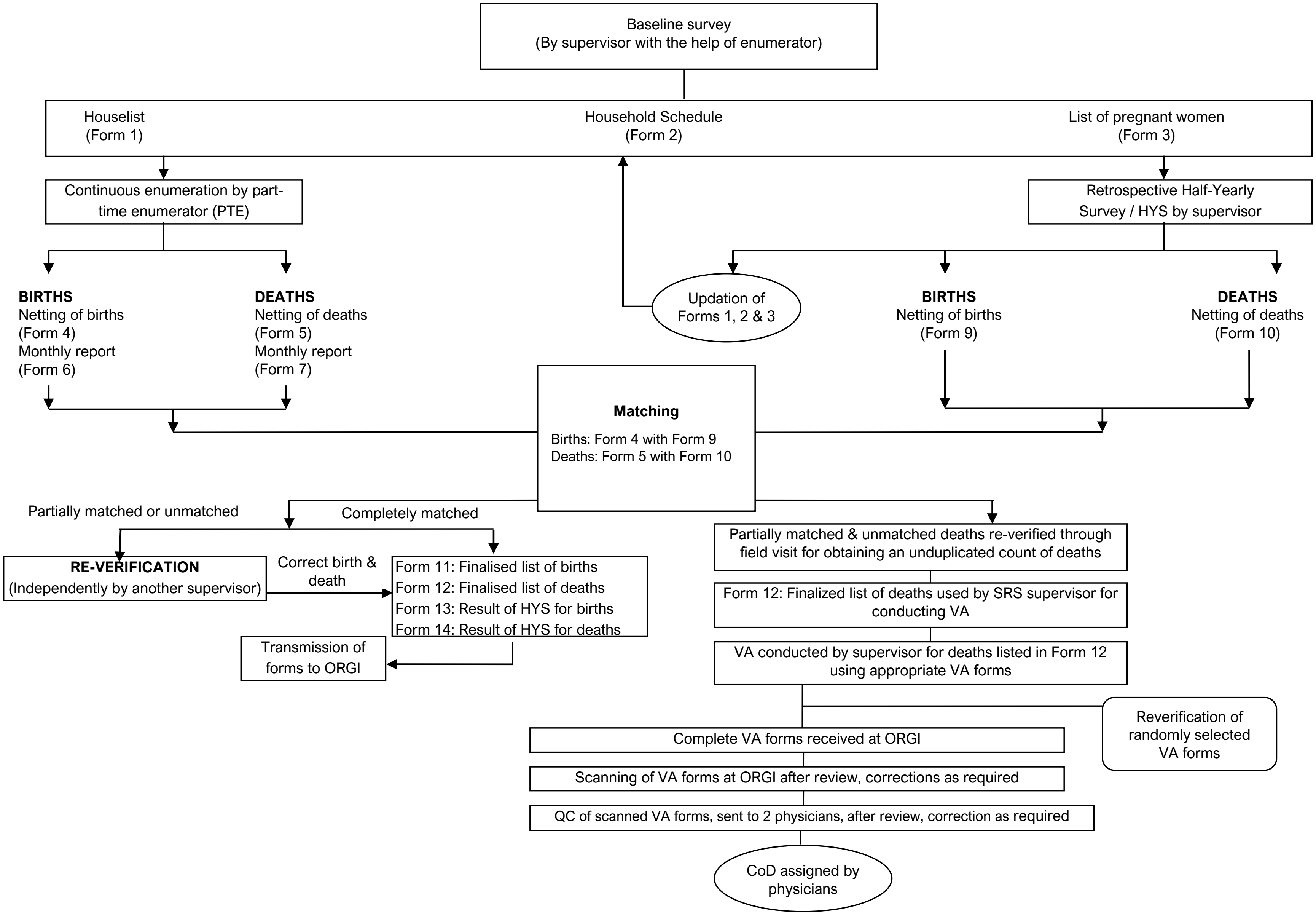
Form No.	Form Name	Data points
		• Details of pregnancy and delivery – duration of the pregnancy, immunization during pregnancy, complications, single / multiple birth, place of delivery, medical attention at birth • Details of baby after birth – signs of a live birth, birth weight, child's size at birth vis-à-vis other children in that area, breast-feeding details • Details of sickness at the time of death – fever, diarrhoea, breathing issues, cough, spasms or fits ○ Physical symptoms – for instance, yellow eyes or skin, cold body, discolored hands / legs / lips, redness around umbilical cord stump *Section 3* Written narrative in local language – description of symptoms in order of appearance, doctor consulted or hospitalization and history of similar episodes
10B	Child death (29 days to 14 years)	Name of the head of the household … *Section 1* Respondent – name, relationship with deceased, lived with the deceased during the events that led to death, age, gender, education, religion of the head of the household, identification code of the respondent Details of deceased – gender, age, relationship of the deceased with the head of the household, date of birth, date of death, house address of the deceased, PIN, place of death, HH-reported cause of death *Section 2* Death details – • Death due to injury or accident • Details of baby after birth – premature, duration of pregnancy, child's size at birth vis-à-vis other children in that area, breastfeeding details, child's size at birth, birth weight • Details of sickness at the time of death – multiple illnesses along with symptoms, consumption of antibiotics, immunization received (BCG, DPT, polio, measles), growth of children vis-à-vis other children of the same age, details of fever, diarrhoea ○ Disease symptoms – for instance, stiffness of body / neck, breathing issues, convulsions or fits, blood in stools, cough, abdominal pain, vomit, skin rash, red eyes, yellow eyes /

Form No.	Form Name	Data points
		skin, weight loss, swelling of hands / feet / abdomen, lack of blood *Section 3* Written narrative in local language – description of symptoms in order of appearance, doctor consulted or hospitalization and history of similar episodes
10C	Adult death (15 years or older)	Name of the head of the household … *Section 1* Respondent – name, relationship with deceased, lived with the deceased during the events that led to death, age, gender, education, religion of the head of the household, identification code of the respondent Details of deceased – gender, age, relationship of the deceased with the head of the household, education, occupation, date of death, house address of the deceased, PIN, years deceased lived at this address, place of death, HH-reported cause of death *Section 2* Past medical history of the deceased – hypertension, heart disease, stroke, cholesterol, diabetes, tuberculosis, HIV/AIDS, cancer, asthma and other chronic illness, medications taken regularly by the deceased during the last five years Behavioural risk factors (tobacco, smoking, alcohol, dietary habit) of the deceased and the respondent In case of death of a female aged 15-49 years: known or suspected to be pregnant or within 42 days of delivery or abortion. Description of key symptoms – fever, breathlessness, cough, diarrhoea, chest pain, paralysis, urinary problems, jaundice, etc. *Section 3* Written narrative in local language – description of symptoms in order of appearance, doctor consulted or hospitalization and history of similar episodes
10D	Maternal death (females aged 15-49 years)	Name of the head of the household … *Section 1* Duration of pregnancy, pregnancy history, antenatal care, duration between delivery / abortion and death, place of delivery / abortion, medical attention at delivery, caesarean delivery, complications during delivery – prolonged labour, excessive bleeding at the

Form No.	Form Name	Data points
		beginning of labour pain / after delivering the baby, difficulty delivering the placenta, fever after birth, etc. *Section 2* Written narrative in local language – description of symptoms in order of appearance, doctor consulted or hospitalization and history of similar episodes

Source: Forms 10A-10D – https://bit.ly/2IF86ef; rest – https://bit.ly/2TZHfi5 (11/3/2020, 20:34 hours). Developed by Priyanka Tomar.

Figure 2.1: The SRS process, including VA CoD survey



Source: Adapted by Priyanka Tomar, Divya Chaudhry and Rajesh Chaudhry from SRS Statistical Report 2017, RGI and AIIMS 2017.

National Family Health Survey (NFHS, 1992 –)

We had offered a brief overview of the NFHS at the beginning. Let us now discuss it in some detail.

Objectives

Why exactly was the NFHS launched, and what is the purpose that it was expected to serve earlier and now? Since SRS was already providing data on selected vital statistics for two decades before the NFHS was launched, some justification for the latter should have been provided in the context of the former. However, no such justification vis-à-vis SRS in particular / health information system in general has been provided (table 2.3). This is particularly surprising given the demographic / RCH focus of both the SRS and the NFHS. One could ask – couldn't the additionally required indicators been included in the SRS instead of launching a separate survey altogether, especially given the relative strengths of SRS vis-à-vis NFHS, some of which we highlighted in the write-up on SRS?

Nevertheless, let us discuss the objectives of the NFHS, as put forth on NFHS website and national reports of its various rounds (table 2.3). Despite some commonalities, it seems the objectives of NFHS have also changed over the rounds. Let us start with the commonalities. The NFHS website as well as most national reports highlight that providing data for policy and program purposes was one of its key reasons. In chapters 3 and 4, we will assess the scope of NFHS vis-à-vis all health-related policies and programs of MoHFW, and in section 2 vis-à-vis that of the selected states. For now, let us look at 2 related email responses from the IIPS Director (16/10/2019, with some others from IIPS and ICF International involved with NFHS copied on the email – henceforth 'IIPS email') –

1) 'Before each round of NFHS, there is detailed consultation with different programme divisions of MoHFW and other ministries on their data requirements. Accordingly, indicators are finalised and questions are added or aligned to SDG health indicators'. We will also review the scope of NFHS vis-à-vis SDG 3 (health) in chapter 5.

2) 'There are enough evidence of using NFHS data for policy and programme in India, starting from using it as inputs in different Five year plans to recently launched national nutrition mission. Ministry of Health and Family Welfare has used NFHS results as scientific evidence for various policy decisions including adopting target free approach in 1996, setting goals for the national population policy 2000, framing of different national health policies, etc. Notable policy or programme changes have also been based on NFHS results in areas such as domestic violence, child marriage, menstrual protection, sanitation, and C-section deliveries. In addition, various states have brought out state-specific population and health policies and programmes based on state level findings of various rounds of NFHS'.

This is quite remarkable as far as inputs for 'design' of a series of policies and programs at national and state levels is concerned. However, several references in table 2.3 indicate that NFHS is also expected to help in their M&E. MoHFW's Annual Report 2017-18 states that 'the Ministry has been conducting large scale survey periodically to assess the level and impact of health interventions - National Family Health Survey (NFHS)' (22). There is also reference to 'effective management' of HFW programmes and monitoring of their 'key process indicators' using NFHS data in table 2.3. Assessment of a few 'impact' and 'process indicators' within a broad framework through NFHS is fine, but there are serious challenges if we try to get more nuanced from a program perspective or try to use NFHS data to validate that of the MIS. For instance –

1) With a few exceptions, NFHS and MIS data are not comparable largely because –
    a. Their data points / indicators have not been harmonized;
    b. NFHS offers population-level data, while MIS largely has facility / beneficiary data, which does not include data from the private sector and is, therefore, not representative. There is also no claim of population-level completeness / representativeness vis-à-vis MIS data, although the severely over-worked and statistically under-competent ASHAs and ANMs are expected to collect community-based data as well, conduct surveys, etc. Comparing data collected by frontline health workers with data from a professional survey like NFHS is asking for too much. With all its weaknesses, the MIS data helps the service delivery system to function and fulfil its reporting requirements at various levels. But that is it;
2) MIS data is available on real-time / daily / monthly basis and is used as such for M&E purposes. NFHS national reports have been released with a gap of 10 to 22 months (table 2.4), although preliminary data / fact sheets have been made available earlier to the programme managers.[58] Nevertheless, it is not clear how a programme manager could hold functionaries accountable based on data which is several months old or plan for the future precisely for the same reason. Health outcome data could be relevant, but the same cannot be said about process indicators. However, even vis-à-vis outcome indicators (fertility, mortality, etc.), both the Centre and the states tend to use SRS data anyways rather than the NFHS due to some of the reasons spelt out earlier (periodicity, from the government system, etc.). Furthermore, the Centre (MoHFW and NITI Aayog) is conducting annual assessments of state performance, states like Rajasthan are doing so for their districts on a monthly basis. There is still some room for annual estimates of the SRS in such assessments. NFHS does not seem too helpful for regular M&E purposes.

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[58] Vaccination coverage is one of the key and most widely used indicators of the NFHS. However, 2 different figures on 'all age appropriate vaccinations' are available from 2 versions of the NFHS-4 national report. According to one version – https://bit.ly/2TO8iyg – it is 27.4% for India; according to another – https://bit.ly/39UxVml (DHS), https://bit.ly/2TWvlWc (NFHS) (13/3/2020, 20:40 hours) – it is 42.9% (a difference of 15.5%)! And both reports have the December 2017 date! If any revision was made subsequently, the dates of the reports should have been changed and this should have been indicated in the initial pages itself. Policymakers, researchers, media and others tend to predominantly use the reports rather than the raw data, and such changes in key indicators can lead to general confusion. In a bid to make the reports available quickly, data accuracy should not be compromised. We have only pointed out one instance. One might assume that there could potentially be other instances too, which may impinge on the overall credibility of published NFHS data.

Let us clarify that this is not necessarily a reflection on NFHS *per se*, and even as far as periodicity is concerned, it is a matter of debate whether an independent survey should be conducted once in 3 or 5 years. After all, there is a government survey (SRS) which provides annual estimates on RCH / demographic indicators. Why do we need an independent survey also to provide data with a similar periodicity? Let us also clarify that NFHS data is used at times by policymakers for regular M&E as well, but to hold their subordinates accountable – they do not usually like it when they are held accountable using it, hence, the outrage of some senior state officials against NFHS in some of the not-so-well performing states.

Let us now turn to another NFHS objective, which was listed in the first place in its round 1 national report and in the NFHS-5 bid document too – strengthening 'survey research capabilities' of PRCs (round 1) and 'Indian institutions' (NFHS-5). As far as PRCs are concerned, all 18 of them were involved in NFHS-1, then only 6 in NFHS-2 and -3, 3 in NFHS-4 and, eventually, none in NFHS-5. On the other side, 'increased involvement of commercial agencies for data collection' has been a matter of concern from the perspective of data quality (Srinivasan and Mishra 2020: 40). Neither the survey research capabilities of PRCs seem to have neither been leveraged nor strengthened in any significant way vis-à-vis the NFHS. As far as 'Indian institutions' are concerned, we do not know for which institutions or in what ways have their capabilities been strengthened by the NFHS. As far as use of NFHS data by researchers is concerned, it has been argued that 'the four rounds of the NFHS have produced an enormous quantity of data, which regrettably have been subjected to only inadequate critical scrutiny by Indian scholars', even as 'the opposite is true of researchers outside the country' (Rajan 2020: 39). This is not necessarily a reflection on the NFHS itself, but it should be explored as to what could be done to enhance the use of NFHS data for policymakers, researchers and other stakeholders. On its website, NFHS highlights 'worldwide media coverage' of NFHS-4. The DHS Program website lists 24 analytical publications on the NFHS over a 20-year period (May 1999 to July 2019).[59] This seems to be a gross under-estimation. On a quick check, the Google Scholar shows around 21,600 results (search: "National Family Health Survey NFHS").

Let us end this section by highlighting that its objective of providing 'information in the context of related socioeconomic and cultural factors' (NFHS-2 introduction) seems to have been well-served – even if from the limited perspective of RCH and a few other indicators – since NFHS is the only data source in India providing richly disaggregated data by various background characteristics as well as for households, status of women, etc. It is also the only source which provides data in such a professional and transparent manner – government data sources, with the limited exception of the NSS – are seriously lacking on this front. Even SRS forms were accidentally found online, and we have never seen SRS' raw data, for instance. None of this would, probably, have been possible without regular involvement – both technically and financially – of relevant international agencies.

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[59] https://bit.ly/3cS3r6p (12/3/2020, 21:16 hours).

Table 2.3: Objectives of NFHS as outlined on NFHS website and in national reports of various rounds

Round	Source(s)	Objectives
	NFHS website[60]	'Each successive round of the NFHS has had two specific goals' – a) 'To provide essential data on health and family welfare needed by' MoHFW 'and other agencies[61] for policy and programme purposes'; b) 'To provide information on important emerging health and family welfare issues'.
1	Multiple, in the national report	*Foreword by K B Pathak (Director, IIPS)* – a) The NFHS is 'an important component' to strengthen survey research capabilities of the PRCs (the PRC project of MoHFW); b) 'Undertaken with the principal objective of providing state-level and national-level estimates of fertility, infant and child mortality, the practice of family planning, maternal and child health care and the utilization of services provided for mothers and children'; c) 'Another important objective of the NFHS was to provide high quality data to academicians and researchers for undertaking analytical research on various population and health topics'; d) 'I do hope that it will contribute to the knowledge of researchers and analysts in India and that programme administrators and policymakers will find it useful for policy development and implementation of the family welfare programme'. *Chapter 2 (survey design and implementation)* – a) 'The primary objective of the NFHS is to provide national-level and state-level data on fertility …'; b) 'This information is intended to assist policymakers, administrators and researchers in assessing and evaluating population and family welfare programmes and strategies'.
2	Multiple, in the national report	*Preface by T K Roy (Director, IIPS)* – a) NFHS-1 created 'an important demographic and health database in India'. NFHS-2 'is designed to strengthen the database further and facilitate implementation and monitoring of population and health programmes in the country'; b) 'As in the earlier survey, the principal objective of NFHS-2 is to provide state and national estimates of fertility …'; c) 'We hope that the report will provide helpful insights into the changes that are taking place in the country and will provide policymakers and

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[60] http://rchiips.org/nfhs/ (12/3/2020, 14:09 hours).

[61] The NFHS-4 steering committee had representations from MoSPI, RGI, Ministries of Women & Child Development and Drinking Water & Sanitation in addition to MoHFW and its erstwhile Department (now Ministry) of AYUSH from GoI.

		programme managers with up-to-date estimates of indicators that can be used for effective management of health and family welfare programmes, with an emphasis on reproductive health dimensions'; d) The report should also contribute to the knowledge of researchers and analysts in the fields of population, health, and nutrition'. *Introduction –* e) 'Another important objective is to examine this information in the context of related socioeconomic and cultural factors'.
3	Multiple, in the national report	*Foreword by Naresh Dayal (Secretary, MoHFW) –* a) NFHS has provided 'newer set of evidences of the ground realities' to help in policy- and program-making; b) NFHS-3 has provided baseline information on RCH, nutrition, lifestyle and HIV/AIDS related indicators in the context of RCH-2 and NACP-3; c) 'I hope' NFHS-3 'would further strengthen India's demographic and health database'. *Preface by S Lahiri (Officiating Director, IIPS) –* a) NFHS is designed to be / 'has emerged as a nationally important source of data on population, health, and nutrition for India and its states'; b) 'The basic objective of releasing fact sheets within a very short period … was to provide immediate feedback to planners and programme managers on key process indicators'; c) 'We hope that the report will provide helpful insights into the changes that are taking place in the country and will provide policymakers and programme managers with up-to-date estimates of indicators that can be used for effective management of health and family welfare programmes, with an emphasis on both the reproductive and nutritional health of the population'; d) 'The report should also contribute to the knowledge of researchers and analysts in the fields of population, health, and nutrition'. *Introduction –* a) The MoHFW 'initiated the NFHS surveys to provide high quality data on population and health indicators. The three NFHS surveys conducted to date are a major landmark in the development of a demographic and health data base for India'; b) NFHS-2 'was an important step in strengthening the database for implementation of the Reproductive and Child Health (RCH) approach adopted by India after the International Conference on Population and Development (ICPD) in 1994 in Cairo'.
4	Multiple, in the national report	*Message by Preeti Sudan (Secretary, MoHFW) –*

		a) NFHS ‘indicators are more needed now than ever before to monitor the progress of a number of flagship programs launched by the Government of India in the recent past’; b) ‘The NFHS-4 also brings to the forefront a number of emerging issues that will occupy central place in the near future’; c) ‘I hope’ NFHS data ‘will immensely help policy makers and programme managers in planning focused policies and programmes’; d) ‘I also hope that this report will be of great help to all those who are working in the area of population and health’. *Foreword by Manoj Jhalani (Additional Secretary & Mission Director, NHM) –* a) NFHS has ‘played a crucial role in providing the Government of India with reliable evidence on the success of its flagship programmes as envisioned in the National Health Policy that aim to improve’ RCH ‘and the health care delivery system in the country’; b) NFHS-4 ‘will serve as a benchmark’ for government initiatives to achieve SDGs by 2030; c) ‘Over the years, the NFHS has expanded its scope and coverage to fill the gap in the data required by the government, NGOs, and researchers in the field of population and health’; *Message from Laishram Ladusingh (Officiating Director, IIPS) –* a) ‘These indicators available at the national, state and district levels shall serve not only as benchmark for guiding the trajectory of health for all but also as process indicators for a number of ongoing health programmes’. *Introduction –* a) The main objective of NFHS-4 ‘is to provide essential data on health and family welfare, as well as data on emerging issues in these areas’; b) It is ‘intended to assist policymakers and programme managers in setting benchmarks and examining progress over time in India’s health sector. Besides providing evidence on the effectiveness of ongoing programmes, NFHS-4 data will help to identify the need for new programmes in specific health areas’.
5	Request for Proposal: Bid document[62]	a) ‘The main objectives of the NFHS programme have been to strengthen India’s demographic and health database by providing information that is both reliable and relied upon’; b) ‘To strengthen the survey research capabilities of Indian institutions to provide, analyse, and disseminate high quality data’; c) ‘To anticipate and meet the country’s needs for data on emerging health and family welfare issues’.

Source: Developed by author.

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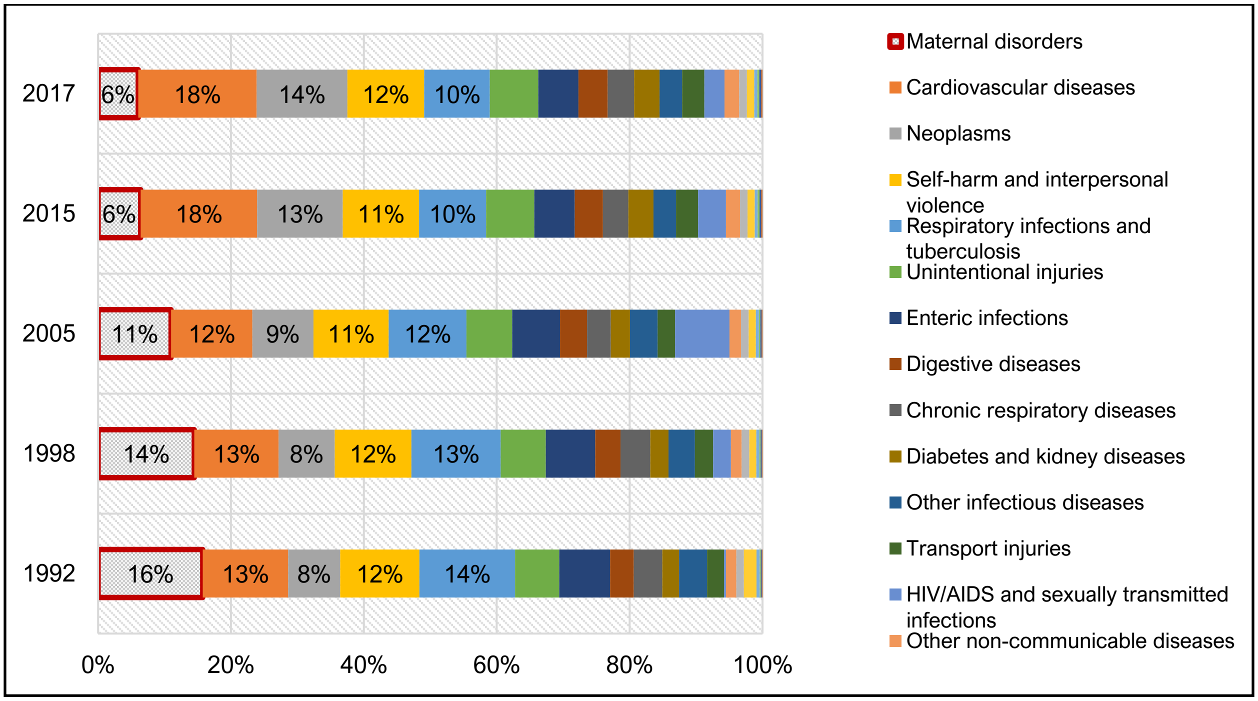
[62] http://rchiips.org/NFHS/NFHS5/pdf/Final%20RFP-Packer%20&%20Movers-NFHS-5.pdf (12/3/2020, 14:12 hours).

Scope

Table 2.4 highlights the logistical, respondent and thematic scope of various rounds of the NFHS. Expectations from it have increased considerably over the years, and so has its scope and sample size. The expectation to provide district-level data led to five- / six-fold increases in its sample size, which has only been enough to develop district fact sheets with 93 indicators, covering population and household profile, family planning, maternal and child health (including maternal and delivery care, female examinations (breast, cervix, oral cavity), child immunization / disease prevalence / treatment / feeding practices), nutritional status of children and adults, blood pressure and glucose among adults. However, crucial RCH indicators such as IMR and TFR cannot be calculated, given small NFHS sample size at the district level. Obviously, no district reports can be developed. The increase in sample size has, nevertheless, meant that the duration from fieldwork to national report increased from close to 2 years in the case of NFHS-2 and -3 to 3 years for NFHS-4, when district level data was expected. Most importantly, it is not clear whether any assessment was done as to what sort of data is required at the district, or central and state, levels before deciding the sampling strategy. We will come to more on this in the section on methodology. The use of CAPI and geo-referencing is said to have helped in monitoring of data collection and reducing turn-around time.

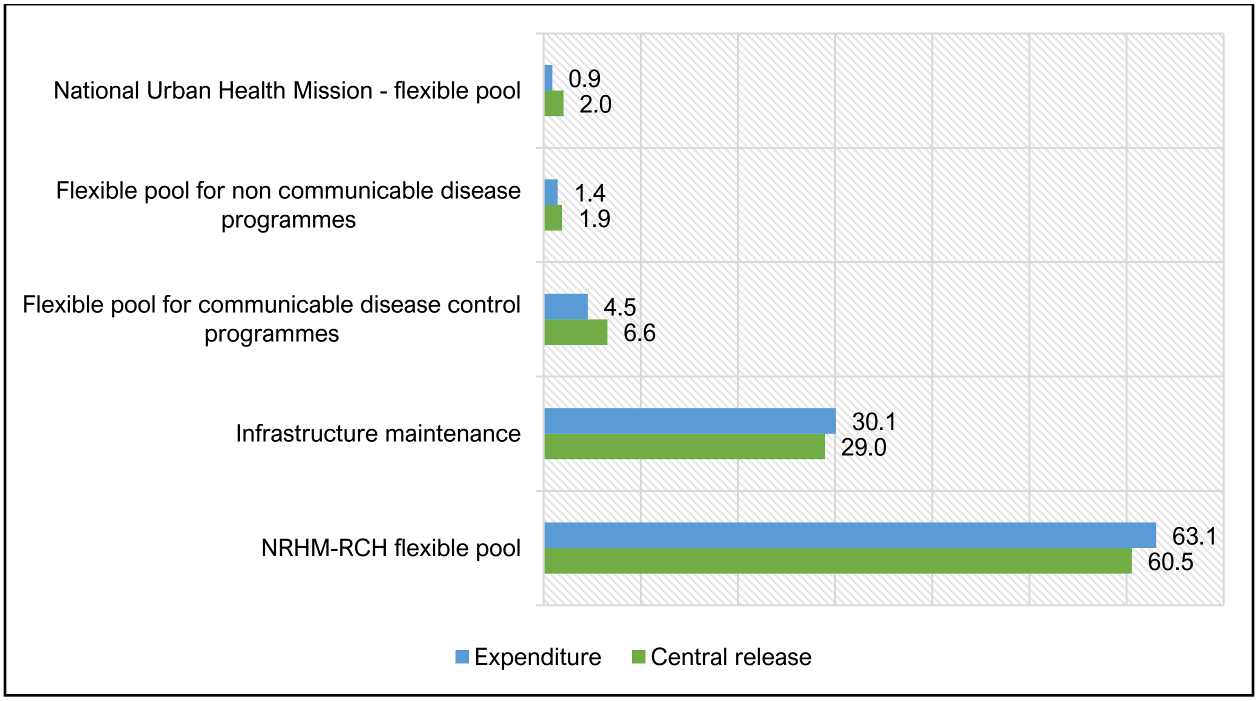
As far as the thematic scope of NFHS is concerned, it has been 'designed to provide information on sexual behaviour; husband's background and women's work; HIV/AIDS knowledge, attitudes, and behaviour; and domestic violence' (NFHS-4 national report: 1) and other RCH-related themes. Men were included NFHS-3 onwards – but their sample size has gone down from 60% of female sample size in NFHS-3 to 16% in -4 and 14% in -5. So much for gender equality, on a lighter note! So, although the proportion of MCH questions has gone down from 99.2% in NFHS-1 to 92.3% in -4, the MCH orientation of NFHS in terms of its sample size seems to have become stronger over time. Yet, NFHS-4 'did not capture data for most known risk factors and commonly recommended interventions for the improvement of newborn and maternal outcomes throughout the continuum of care from pregnancy to the neonatal period, due to which, it was inadequate to inform relevant policy and program (Dandona and Kumar 2019: 563-564). Further, maternal and neonatal causes have only been one of the many health issues for women aged 15-49 years – their scope vis-à-vis causes of death for this group declined from 16 to 6% during NFHS rounds (figure 2.2). In 2040, according to a forecast, maternal and neonatal disorders would only be responsible for 0.79% of all deaths in the country (Foreman et al 2018). True, that NFHS now covers their NCD risk factors and self-reported status as well, but the proportion of NCD-related questions has only increased from 0.8% in NFHS-1 to 4.7% in -4. But why blame NFHS alone for a predominant RCH orientation – only 1.9% of the central release and 1.4% of total national expenditure under NHM was for NCDs between 2005-06 and 2015-16 (figure 2.3). Communicable diseases weren't treated much better. It has been proposed that, with declining fertility rates, NFHS should focus on issues like infertility, early menopause, rise in hysterectomies, children, adolescents and senior citizens (Rajan 2020).

Figure 2.2: Causes of death among females 15-49 years in India during NFHS rounds (1992-2017)



Source: GBD. Developed by author.

Figure 2.3: Central Release and expenditure under NHM, India, 2005-06 to 2015-16 (% of total)



Source: MoHFW. https://bit.ly/2O9ctBI (29/1/2020, 12:06 hours). Developed by Divya Chaudhry and Ali Mehdi.

Let us end the discussion here by pointing out that although questions are added or removed over time as per the prevailing requirements, it is important to ensure that comparability over its rounds vis-à-vis core indicators in particular is not compromised so that we are able to track progress on them. NFHS has had problems in this regard. Single NFHS reports provide comparable data, but users need to be cautious while collating data from reports of various rounds.[63] This is a challenge since policymakers, researchers, media-persons and others may not have the statistical capacity to use raw data. Thankfully, the DHS Program offers online data visualization tools – for instance, the STATcompiler – that help get comparable data over various rounds, and even other countries. Cross-country comparisons is one of the major distinguishing features of the NFHS, which is rarely used within India, with the exception of a few researchers. However, the STATcompiler does not provide data on India-specific characteristics – for instance, caste / tribe and religion – or districts. Neither the IIPS nor MoHFW have developed any user-friendly, online visualization tool to facilitate access to comparable NFHS data. We had mentioned an online tool privately developed for NFHS data at the national / state / district level, which one of the NHM officials in Kerala uses for ease of access. He also said that it is very cumbersome to search for data in bulky NFHS reports.

Table 2.4: Selected characteristics of various rounds of NFHS

Details		NFHS-1	NFHS-2	NFHS-3	NFHS-4	NFHS-5
Logistics						
Geographical coverage	States / UTs / Districts (marked 'D')	25	26	29	36, 640 (D)	36, 707 (D)
Fieldwork duration	Month / Year	04/1992-09/1993	11/1998-12/1999	11/2005-08/2006	01/2015-12/2016	06/2019-06/2020
	Months (numbers)	18	13	10	24	13
National report dated	Month / Year	08/1995	10/2000	09/2007	12/2017	N/A
Time taken from fieldwork to national report	Months (numbers)	24	10	13	12	N/A
Survey mode	Paper	Yes	Yes	Yes		
	CAPI				Yes	Yes

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[63] For instance, U5MR went 'up' for 'others' in the caste / tribe category from 63.4 in NFHS-2 to 70.4 in -3, while it went down from 81.5 to 46.6 during this period for SCs, in West Bengal (state reports). West Bengal was the only state in the country where SCs had a lower U5MR than others as per the NFHS-2 and -3 state reports, which is difficult to fathom, and could lead to skewed priority-setting in the state. It seems there are issues with NFHS data presentation in reports.

Details		NFHS-1	NFHS-2	NFHS-3	NFHS-4	NFHS-5
GPS / geo-referenced					Yes	Yes
Respondents						
Households	Sample size	88,562	92,486	109,041	601,509	609,120
Females	Group category	Ever married		All		
	Age-group	13-49[64]	15-49			
	Sample size	89,777	90,303	124,385	699,686	668,622
Males	Age-group			15-54 (married / unmarried)		
	Sample size			74,369	112,122	91,200
Themes						
Disease- / condition-specific questions	Number	246	294	694	868	N/A
	Maternal and child health (%)	99.2	97.3	93.3	92.3	
	NCDs (%)	0.8	1.7	3.2	4.7	
	Injuries (%)	0	1	3.5	3	
Abortion		Yes	Yes		Yes	
Alcohol consumption			Yes	Yes	Yes	
Anemia	Question (Q)		Yes	Yes	Yes	
	Test (T) – child (C), men (M), women (W)		Yes	Yes	Yes	Yes
Anthropometry (waist and hip circumference also in NFHS-5)	Measurement (MT) – C, M, W	Yes	Yes	Yes	Yes	Yes
Asthma			Yes	Yes	Yes	

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[64] The DHS Program website mentions that although data was collected for women aged 13-49 years during NFHS-1, indicators were calculated for women aged 15-49 years, like the later rounds.

Details		NFHS-1	NFHS-2	NFHS-3	NFHS-4	NFHS-5
Birth registration				Yes	Yes	
Blood glucose (random testing in NFHS-4, Hba1c in NFHS-5 through DBS)	Q			Yes	Yes	
	T – M, W				Yes	Yes
Blood pressure	MT – M, W				Yes	Yes
	Q				Yes	
Causes of death		Yes	Yes			
Child labor			Yes	Yes		
Cooking fuel		Yes	Yes	Yes	Yes	
Disability						Yes
Domestic violence			Yes	Yes	Yes	Yes
Health expenditure			Yes	Yes		
Health insurance				Yes	Yes	
HIV	T (DBS / dried blood samples) – M, W			Yes	Yes	
HIV behavior				Yes	Yes	
HIV knowledge		Yes	Yes	Yes	Yes	
Iodine salt test			Yes	Yes	Yes	
Lead testing			Yes			
Malaria (testing to help assess the burden of malaria and antimalarial drug resistance)	T (DBS)					Yes
	Q			Yes	Yes	
Maternal mortality		Yes	Yes			
Micronutrients		Yes	Yes	Yes	Yes	

Details		NFHS-1	NFHS-2	NFHS-3	NFHS-4	NFHS-5
Service availability		Yes				
Social marketing (contraception)			Yes	Yes		
Tobacco use			Yes	Yes	Yes	
Tuberculosis	Q	Yes	Yes	Yes	Yes	
Verbal autopsy			Yes			
Vitamin A	Q	Yes	Yes	Yes	Yes	
Vitamin D3	T					Yes
Women's examination (cervix, breast, oral cavity)	Q				Yes	
Women's status			Yes	Yes	Yes	

Source: The DHS program website; Dandona, Pandey and Dandona 2016. Developed by author.

Table 2.5: NFHS-5 schedules

Schedule	Themes
Household	1) All members of the household 2) Household characteristics a. Drinking water b. Sanitation c. Ownership of assets d. Cooking fuel e. Mosquito net ownership and use f. Hand washing facilities g. Salt iodization 3) Socio-economic characteristics a. Type of residence b. Caste / tribe c. Religion

	d. Literacy / education e. Employment / occupation
Women	1) Background characteristics 2) Gender issues, including domestic violence 3) Marriage and sexual activity 4) Family planning knowledge and use 5) Fertility and fertility preferences 6) Media exposure 7) Information on reproductive outcomes in calendar 8) Maternal / reproductive health (antenatal, delivery and postnatal care) 9) Nutrition (infant and young child feeding practices, micronutrient intake) 10) Beneficiaries of national GoI programs (for e.g. ICDS, JSY and JSSK) 11) Infant and child mortality 12) Child health (immunizations, prevalence of diarrhoea, fever, ARI and their treatment seeking behaviour) 13) HIV/AIDS knowledge, stigma and discrimination, previous HIV testing 14) Tuberculosis 15) Non-communicable diseases 16) Medical injections 17) Smoking / drinking 18) Health insurance coverage
Men	1) Background characteristics 2) Gender issues, including domestic violence 3) Marriage and sexual activity 4) Family planning knowledge and use 5) Fertility and fertility preferences 6) Reproductive health 7) Infant and child mortality 8) HIV/AIDS knowledge, stigma and discrimination, previous HIV testing 9) Tuberculosis 10) Non-communicable diseases 11) Medical injections

	12) Smoking / drinking 13) Health insurance coverage
Biomarkers	Measurement – 1) Height / length, weight, waist and hip circumference 2) Blood pressure Testing – 3) Anemia 4) Blood glucose / HbA1C 5) Malaria (parasites and antimalarial drug resistance) 6) Vitamin D3

Source: NFHS-5 bid document.

Sample design

The NFHS follows a two-stage stratified sampling method. The Census 2011 formed the sampling framework for selection of Primary Sampling Units (PSUs) during its 4th round, with the Census Enumeration Block (CEB) in urban areas and villages in rural areas forming the PSUs. Each district was stratified into rural and urban stratum. Rural substratum was further divided into smaller strata, taking into account the village population as well as the percentage of scheduled population in the village. Within each explicit rural sampling stratum, a sample of villages were chosen as the PSUs. These PSUs were sorted according to the literacy rate of women aged above 6 years before their selection. In urban areas, CEBs were sorted according to the percentage of SC / ST population, and, thereafter, a sample of CEBs were selected through Probability Proportional to Size sampling. In the second stage, 22 households per cluster were selected from the newly created list of households living in the selected PSUs.

Sampling and non-sampling errors

We have highlighted sampling and non-sampling challenges of NFHS raised by our respondents in the relevant sections, but let us discuss some of them here, starting with non-sampling errors.

NFHS includes sensitive themes (sexual activity / health, domestic violence, etc.), getting reliable information on which is difficult. Interviewer are supposed to maintain privacy while interviewing the respondents on such questions, but it has been noticed that household head as well as several others are present during interviews. This is particularly a problem in rural areas, from where 71% of respondents were in NFHS-4. Further, recall error and age-heaping are some of the major non-sampling errors (Srinivasan and Mishra 2020; Rajan and James 2008), which is a serious problem, once again, in rural areas. One of us was in one of the villages in Western Uttar Pradesh, wherein he asked for the age of an old man. After ‘negotiation’, the old man settled on 70 years, down from 140 years! Respondents with higher educational levels are more likely to provide correct answers compared to those with little or no education (Rajan and James 2004). As per NFHS-4, only 13.7% of female and 20% of male respondents had 12 or more years of education at the national level. These figures were lower in BIMARU states that have a much higher proportion of NFHS sample. This also critically highlights the limits to capturing self-reported information in population surveys in a predominantly rural and uneducated country like India, which is a particularly serious problem from the perspective of health. Some questions on MCH pertain to 5 years preceding the survey, increasing the possibility of recall errors. Answers are also often found to be affected by individual / social bias of the respondents or wrong interpretation of questions by respondents / interviewers. It is difficult to statistically assess non-sampling errors or their effect on data quality. Due caution needs to be exercised in the type of information that we wish to obtain through population surveys, given the characteristics of potential respondents. It is not clear whether this was a consideration for schedule / sampling design of the NFHS. One of our respondents said that during an interaction with the NFHS team, the Chief Statistician of India said that he can understand that the team would have taken due precautions vis-à-vis potential sampling errors, but what the non-sampling errors? It is the latter that he said he is more concerned about as far as quality of NFHS data is concerned.

Another related concern has been the continuous disengagement of PRCs from the NFHS sphere, despite its foremost objective being to strengthen their survey research capabilities, as highlighted earlier, and the implications it potentially had on the quality of the data collected. ‘Assigning data collection to consulting agencies that had no capacity building agenda by trained demographers resulted in making the survey more of a money-making exercise than one focusing on delivering reliable data. The biggest shortcoming in hiring private consulting agencies is the presence of insufficient number of poorly trained and poorly paid field agents to collect data who receive little logistical support and work under harsh conditions that lead to the violation of labour laws. Many consulting agencies were operating without a local base in the states. This affects the quality of data collection’ (Rajan 2020: 38). 4 field investigators also died (Karpagam and Sathyamala, 2015).

Sampling errors can be assessed statistically, involving complex formulas. The variance estimates for important variables are provided by NFHS to evaluate the reliability of data. As its key focus is to generate estimates on MCH, the sample selection criteria is based on characteristics of women, which can lead to errors in information collected about men / other indicators. Further, NFHS also collects information on alcohol, smoking, NCDs, etc., but its sample does not include institutional populations in hostels, hospitals, etc. which are more prone to them. Some experts we interacted with argued that a different sample strategy is required for different health concerns, while NFHS’ sampling is largely done from an RCH perspective. The discussion in the scope of NFHS section is relevant here as well.

Length of the questionnaire

With each round, along with increase in sample size, the length of the questionnaire also increased due to the expansion in the scope of the survey. There is a general consensus among researchers that lengthy questionnaires result in poor quality of data due to hastening of the process to reduce the time (Rajan 2020). From 610 questions in NFHS-1 (women schedule), the number of questions has risen to more than 948 questions in NFHS-5. Inclusion of new areas along with elaboration of particular topics have led to increase in its length. Further, wide variations in time taken to interview respondents was also noticed across the states. While the average time taken was 86 minutes in Tamil Nadu, it was 45 minutes in Haryana, for NFHS-3 women's schedule (Rajan and James 2008). NDQF has also argued that lengthy questionnaires and sensitive questions leading to non-response or skipping of questions are important factors affecting data quality. Further, it is to be noted that many of the questions may not be applicable to all the household as it depends on the occurrence of events, like births, immunizations, etc. during five years preceding the survey. The involvement of too many ministries / stakeholders has meant that everyone wants their questions included, and there is little scope for independent assessment regarding the feasibility / rationality of questions to be included – everyone has to be satisfied. Some of the same set of stakeholders will also pull up NFHS organizers if the data it throws up does not match their 'expectations' or is inconvenient.

Data validation

Let us end the discussion of the NFHS here with a comparison of data on some of the indicators from NFHS-4 and HMIS (2015-16), which matches with the periodicity of NFHS-4. Table 2.6 offers data on some of the rare NFHS-4 and HMIS indicators which are broadly comparable. Once again, Kerala's figures match perfectly as far as home and institutional deliveries are concerned, hinting toward a potential correlation between the robustness of administrative data and health outcomes. These are major divergences as far as other, particularly health-backward, states are concerned, adding more weightage to the correlation. In the case of C-section deliveries, however, while India and Rajasthan figures match quite closely, there are substantial divergences in the case of other states, including Kerala. In the case of TT injections, divergence in the case of Kerala is the highest, while figures for India, Rajasthan, Uttar Pradesh and Maharashtra are close by. Does the potential correlation stand nullified? Given some of the challenges vis-à-vis quality of NFHS data highlighted above, it is difficult to say. Nevertheless, harmonizing the definitions of some of the core indicators of NFHS and HMIS would help in more robust and extensive comparisons and may help both data sources and their organizers to be more vigilant vis-à-vis data quality.

Table 2.6: Data comparison of selected indicators from HMIS (2015-16) and NFHS-4 (2015-16)

Source	Indicator	India	Rajasthan	Uttar Pradesh	Bihar	Assam	Maharashtra	Kerala
HMIS	Home deliveries to total reported deliveries (%)	11.1	3.8	22.3	22.1	14.1	1.3	0.2
NFHS-4	Home deliveries (%)	20.8	15.8	31.8	35.9	29.2	9.6	0.1
HMIS	Institutional deliveries to total reported deliveries (%)	88.9	96.2	77.7	77.9	85.9	98.7	99.8
NFHS-4	Births delivered in a health facility (%)	78.9	84	67.8	63.8	70.6	90.3	99.8
HMIS	C-section deliveries to reported institutional deliveries (%)	17.3	9.9	4.2	2.9	18.5	14.8	41.4
NFHS-4	Births delivered by caesarean section (%)	17.2	8.6	9.4	6.2	13.4	20.1	35.8
HMIS	Women received TT2+ TT Booster to total ANC registration (%)	82.8	82.3	83	88	90.8	84	81.3
NFHS-4	Women received two or more TT injections during the pregnancy (%)	83	81.9	81.4	81.5	83.6	81.4	94.8

Source: HMIS and NFHS reports. Developed by Priyanka Tomar.

District Level Household and Facility Survey (DLHS, 1998-2013)

DLHS was initiated by MoHFW – with IIPS as the nodal agency – to provide RCH data at the district level. After 4 rounds – 1998-99, 2002-04, 2007-08 and 2012-13 – it was discontinued due to reasons highlighted in the introduction. It also generated data on utilization of health services and people's perception about the quality of the services provided. It was the only survey which provided data on the quality of government health facilities.

The 1st round was conducted in 2 phases and the key objective was to gather information on ANC and immunization services, deliveries, contraceptive use, awareness about RTI/STI, HIV/AIDS, family planning, utilization of government health services, user satisfaction, incidence / prevalence of malaria, leprosy, tuberculosis, information on childbirth, maternal health, unmarried adolescents' counselling by ANMs on reproductive health issues and the management of anaemia. It covered 529,817 households, 474,463 currently married women aged 15-44 years and 257,245 men aged 20-54 years in 504 districts. Providing district-level data and covering men were both firsts for an RCH survey in the country, both of which were incorporated in the NFHS subsequently.

DLHS-2 was conducted across 593 districts, covering 620,107 households, 507,622 women aged 15-44 years and 330,820 husbands of eligible women. Beyond DLHS-1, it also collected data on iodine intake through testing of cooking salt used by households, biometric and anthropometric measures (measurement of weight of children, assessment of anaemia levels through blood tests of children, adolescents and pregnant women), and had 3 additional questionnaires – husband's, village and health – in addition to household and women's questionnaires canvassed in DLHS-1.

Inputs from DLHS-2 helped in the design of NRHM, launched in 2005-06. In order to monitor and assess its impact, the third round of DLHS was launched in 2007-08 to collect data on utilization of various health care services, accessibility to health services, effectiveness of ASHA and JSY in improving the health scenario in the country and condition of health infrastructure along with usual information. It also tried to assess the linkages between RCH indicators and health facilities. Some major changes were also introduced in the third round. In the last two rounds, the survey covered currently married women and men, while in the third round, ever married women in the age group of 15-49 years and unmarried women in the age group of 15-24 years were interviewed. A total of 720,320 households, 643,944 ever-married women and 166,620 unmarried women across 601 districts 34 states / UTs were covered in the third round using 5 questionnaires – household, ever married women's, unmarried women's, village and health facility questionnaires, the latter covering all CHCs and district hospitals at the district level and all SCs and PHCs expected to serve selected primary sampling unit (PSU) populations.

The fourth and final round did not cover Empowered Action Group (EAG) states (Bihar, Rajasthan, Madhya Pradesh, Jharkhand, Chhattisgarh, Uttarakhand and Uttar Pradesh) and Assam since they were covered under RGI's Annual Health Survey. The discontinuation of DLHS in 9 states meant it could not provide national estimates. At the state level as well, it only provided fact sheets rather than reports as earlier. DLHS was discontinued and the scope of NFHS-4 was expanded to provide RCH data up to the district level.

Global Youth Tobacco Survey (GYTS, 2000-)

Three rounds of GYTS have been carried out in the country as part of Global Tobacco Surveillance System (GTSS) from 2000-05 at the state level, and in 2006 and 2009 at the national level. IIPS was appointed as the nodal agency by MoHFW for GYTS-4, using the Unified-District Information on School Education (U-DISE) 2017-18 database for its sampling. A school-based survey, GYTS uses a standardized instrument – developed by WHO, UNICEF and CDC – to collect information on tobacco use among school going children aged 13-15 years, studying in grades 8 to 10.[65]

During 2003-05, individual surveys were carried out in 28 states / UTs. Data was compiled from all the states, applying weights to independent samples to produce a weighted national estimate. For the 2006 phase, while the sampling procedure remained the same, samples were drawn from 6 independent geographical regions consisting of contiguous states, to save time and budget. The 2009 survey also followed the same sampling method with minor modifications. Uttar Pradesh and Rajasthan were included in the Central region to mirror the composition of Global Adult Tobacco Survey, which was also carried out in the same year. The sample size of the survey was 11,768 students. Questionnaire for all the three surveys were self-administered and collected information on prevalence of tobacco use (smoke and smokeless), access and availability of tobacco products, perceptions and attitudes about tobacco, exposure to second-hand smoke and smoke-cessation.

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[65] https://bit.ly/2TPp0x3 (15/3/2020, 22:35 hours).

National Behavioural Surveillance Survey (NBSS, 2001-06)

Behavioural surveillance is one of the important tools to understand the levels of knowledge and awareness about HIV/AIDS, sexual behaviours and attitudes. Therefore, to provide a baseline for the interventions of National AIDS Control Program (NACP), a behavioral surveillance survey was conducted by the National AIDS Control Organization (NACO) and UNICEF in 2001, covering the 15-49 year population. However, data for 15-24 years, which was disaggregated from the survey, did not have a sufficient sample size for representative estimates and, therefore, NBSS-2 (2006) had a separate sample of 15-24 year-olds beyond general population. NBSS-2 aimed to measure changes in the knowledge and attitudes of the youth vis-à-vis NBSS-1 and help in the expansion of interventions to reduce transmission. It covered a sample of 97,240 respondents (15-49 years) from 2,434 PSUs across 25 states, with smaller states and UTs merged with the larger ones. In each selected PSU, a sample of 40 respondents (20 male and 20 female) was interviewed for the general population along with additional 20 respondents (10 male and 10 female) in the age group of 15-24 years for the youth survey. The total sample covered for the youth was 78,916 – 30,791 from the general population survey and 48,125 additionally covered. With inclusion of knowledge and awareness about HIV/AIDS in NFHS-3, NBSS was discontinued.

Global Adult Tobacco Survey (GATS, 2009-)

GATS is a nationally representative survey of persons aged 15 years and above, using a standard protocol across countries to monitor adult tobacco use and key tobacco control indicators. GATS is supposed to enhance technical capacity of countries in designing, implementing and assessing the impact of tobacco control initiatives. It also captures socio-economic determinants influencing tobacco use, and its data is considered useful for making projections about tobacco-related health and economic consequences. Further, GATS has enabled countries in achieving their obligations under WHO’s Framework Convention on Tobacco Control (FCTC) to generate comparable data within and across countries. Such features have made GATS one of the most powerful instruments that countries can deploy to support tobacco cessation programs and curtain tobacco use (GATS 2016-17, 2010). As India is world’s third largest tobacco producer and second largest consumer, GYTS and GATS have been critical for the country. The first round of GATS was implemented in 2009-10 in 31 states / UTs, covering a sample of 69,296 adults, the second in 2016-17 in 32 states / UTs, with a sample size of 76,500 adults.

Annual Health Survey (AHS, 2010-13)

While DLHS was unique in covering districts, men and health facilities, the AHS was conceived in 2005 and launched in 2010-11 to provide annual estimates on RCH as well as other indicators for 284 districts of EAG states and Assam. These were high-priority states, which together accounted for around – 50% of India's population, 61% of births, 71% of infant deaths, 72% of under-5 deaths and 62% of maternal deaths. AHS was the world's largest household sample survey, covering 4.1 million households in its first round (2010-11), 4.2 million in the second (2011-12), 4.3 million in the third (2012-13) and a population of nearly 18 million. Despite its RCH-orientation – presenting a district-level index of maternal and child health deprivation – it collected data on the prevalence of chronic and acute illness, disability, injury as well as health care utilization (AHS report, Vol. 1). It also had a clinical, anthropometric and biochemical (CAB) component in a sample of 1.8 million population in 360,000 households – height / weight of all members of the household, women, men and children 1 month and above; Hb estimation of women, men and children aged 6 months and above; fasting blood glucose and blood pressure of all members of household aged 18 years and above and household salt testing for iodine content.[66]

National Anti-TB Drug Resistance Survey (NATDRS, 2014-)

Although India has achieved significant gains in the treatment of TB, it contributes 27 percent to the global burden of tuberculosis (TB). Roughly, 2.79 million new TB cases are reported annually. Moreover, rapidly emerging evidence of drug-resistant (DR) strains of TB pathogen is jeopardizing the national progress achieved in TB control. Patients with DR-TB fail to respond to *rifampicin* – the most effective first-line drug therapy for TB. MDR-TB is another form of TB infection in which the pathogen is resistant to at least two of most powerful anti-TB drugs (*rifampicin* and *isoniazid*). Further, extensively drug-resistant TB (XDR-TB) is an extreme form of MDR-TB that is resistant to isoniazid and rifampicin, at least one fluoroquinolone (antibiotics used to treat or prevent bacterial infections) and at least one of three injectable second-line anti-TB drugs (*amikacin*, *capreomycin*, *kanamycin*) (WHO 2017). While prevalence of XDR-TB is currently low worldwide, the estimated prevalence of MDR-/rifampicin resistant (RR)-TB in India is 147,000 – accounting for a quarter of the global burden of MDR-/RR-TB.

In order to investigate the epidemiology of DR-TB and estimate the prevalence of DR among TB patients in India, the first ever NATDRS was conducted by MoHFW and WHO India between July 2014 and July 2015. This is the world's largest DR survey ever conducted and first ever to include drug-susceptibility testing for 13 anti-TB drugs, making use of the automated liquid culture system and mycobacteria growth indicator tube (MGIT) 960. A total of 5,280 sputum smear+ pulmonary TB patients diagnosed at designated microscopy centres (DMCs) of RNTCP between August 2014 to July 2015 were enrolled in the survey. Despite these merits, the NATDRS had a major limitation – patients treated in the private sector who did not seek care in public health facilities during their treatment course remained out of the scope of the survey, and hence, accurate prevalence rates of DR-TB could not be estimated (MOHFW, WHO and USAID 2014-16).

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[66] https://bit.ly/2voCZAH (15/3/2020, 21:06 hours).

National Mental Health Survey (NMHS, 2015-16)

Given the historical focus on fertility and mortality, and recently on physical health / NCDs – not unjustified in the context of poverty, population growth and the enormous burden of premature, especially child, mortality in the country – mental health has long been a neglected area, and it is only since 2014 that some serious, yet limited, efforts have been made to deal with it. The National Mental Health Policy – themed ‘New Pathways, New Hope’ – was released in October 2014. Soon thereafter, the first National Mental Health Survey, 2015-16 was commissioned to address the lack of reliable and comprehensive data on mental health. The prestigious National Institute of Mental Health and Neurosciences (NIMHANS), Bengaluru undertook the survey across 12 selected states – 1) to estimate prevalence and burden of mental health disorders in a representative population, 2) to identify current treatment gap, health care seeking and service utilisation patterns, disability status and impact of mental disorders, and 3) assess mental health care facilities, resources and systems in the surveyed states for planning and strengthening of mental health services.[67] Its total sample size included 39,532 individuals across 720 clusters from 80 talukas in 43 districts of 12 states. Employing both quantitative and qualitative methods, all individuals 18 years and above in selected households were interviewed. The qualitative component of the survey included questions related to drug use / abuse characteristics, region- / state- / area-specific mental health problems, stigma towards mental health problems and mental health care-seeking patterns, etc. No second round of the survey is being planned. While the sample size consists of individuals above the age of 18 to ensure correctness of information, survey of adolescents (13-17 years) was also carried out alongside in the states of Gujarat, Uttar Pradesh, Jharkhand and Tamil Nadu. The tools used in the survey consisted of Mini International Neuropsychiatric Interview Schedule (MINI), jointly developed by European and American psychiatrists, a socio-demographic questionnaire, tobacco use and dependence questionnaire, screeners for epilepsy, intelligence deficiency and autism spectrum disorders, pathways to care and disability assessment schedule (Gururaj & Collaborators 2016). . A salient feature of the NMHS is the collection of data according to ICD-10 classification which renders its analysis useful in global context. Further, it included all types of mental disorders (including epilepsy) which are of public health importance along with substance abuse. The NMHS not only provides information about the extent and patterns of mental disorders / substance abuse, but also service utilization patterns and gaps in infrastructure and manpower. While the first round provides robust nationally representative data, the second phase should be conducted across all states for representative data at the state level as well.

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[67] http://indianmhs.nimhans.ac.in/Docs/Report2.pdf (25/10/2019, 16:38 hours).

Comprehensive National Nutrition Survey (CNNS, 2016)

Launched in 2016 to collect reliable data on various domains of nutritional health for the age group of 0-19 years, the CNNS was conducted in 30 states, covering a sample of 112,316 children and adolescents under the stewardship of MoHFW, in collaboration with UNICEF and the Population Council. The surveyed population was divided into three age groups of pre-schoolers (0-4 years), school-going children (5-9 years) and adolescents (10-19 years) – with a sample size of 38,060, 38,405 and 35,856 respectively. For children below 10 years, the respondents were the heads of the households or parents of the child; those aged 10-19 years were themselves the respondents. Along with information on anthropometric status, anemia and iron deficiency, it also provided data on micronutrient consumption, infant and young child feeding practices and risk factors for NCDs – like glucose concentration, lipid profile and physical fitness – becoming the first survey to provide such data for its age-groups. Unlike NFHS-4, in which random blood glucose samples were tested, CNNS used fasting plasma glucose and glycosylated hemoglobin (HbA1c) (MoHFW, UNICEF and Population Council 2019). The survey also has some limitations despite its comprehensive nature and robust data quality. Data is available only at the state level. Furthermore, the most important limitation of the survey is that disaggregated analysis cannot be conducted, limiting the ability to understand the underlying causes. Overcoming these limitations in phase 2 should be considered.

Longitudinal Ageing Study in India (LASI, 2016-)

Even though adult health and ageing have garnered significant attention in international discourse, there is a serious dearth of comprehensive and comparable survey data on the economic, social, and public health implications of ageing in India. In order to address this lacuna, the pilot wave of LASI was launched in India in 2010. The MoHFW appointed IIPS as nodal agency for conducting LASI surveys in India. LASI team in IIPS has collaborated with the Harvard School of Public Health (HSPH) and University of Southern California for technical support. The most important aspect of LASI is its longitudinal character which will enable researchers to analyze the dynamics of India's ageing population and inform policy decisions. Like NFHS, despite India-specific characteristics, LASI has been developed to be consistent with other international ageing surveys – for instance, the Health and Retirement Study, the Chinese Health and Retirement Longitudinal Study, the Japanese Study on Aging and Retirement and the Korean Longitudinal Study of Aging[68] – with the expectation that 'it will contribute to scientific insights and policy development in other countries' as well and vice-versa. Its survey instrument is, therefore, internationally harmonized. The pilot

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[68] http://iipsindia.org/research_lasi.htm (25/10/2019; 13:00 hours).

phase of the survey was supported by a grant from the National Institute on Aging (NIA), National Institutes of Health (NIH), Health and Human Services Department, US government.[69]

The LASI pilot study was carried out in 4 Indian states – Punjab, Rajasthan, Karnataka and Kerala – with a targeted sample of 1,600 non-institutionalized Indian residents aged 45 or older and their spouses (irrespective of age). LASI survey instrument comprises of a household survey (one per household collected by interviewing a selected key informant), an individual survey (one for every age-eligible respondent of at least 45 years of age and their spouse) and a biomarker module (one for every consenting age-eligible respondent and spouse). In addition to recording demographic composition of the household, the household survey has questions on residential history, physical and social characteristics of neighbourhood, household consumption, assets and debt, income of all household members from all sources and coverage under public and private health insurance schemes. The individual survey is more detailed, comprising elaborate modules on demographics, family and social welfare networks, awareness and utilization of social security schemes, health (overall health, specific diseases, functional health, family medical history, mental health, including cognition and depression, etc.), health care access and utilization, work, retirement and pension. There is a biomarker module in the health section of the individual survey that collects information on anthropometrics, blood pressure, dried blood spots and performance measures like gait speed, grip strength, balance, lung function and vision.[70]

LASI's first full-scale, nationally representative survey was launched in 2016, covering a sample size of 60,250 eligible individuals in 36 states / UTs. The results of the survey are still awaited. The LASI team will follow these individuals over time and survey them once every 2 years (Onur and Velamuri 2018). It is aimed to continue the survey at this scale for the next 25 years. Although LASI is the first of its kind, a number of challenges are yet to be addressed. For instance, problems like lack of documentation, self-production and consumption, limited number of transactions in market contexts, etc. make it virtually impossible to estimate income or assets. Furthermore, some people may be reluctant to share certain information with surveyors. For instance, women often hesitate to reveal information about their savings because they fear that their husband / children / sons-in-law might claim it.[71]

National NCD Monitoring Survey (NNMS, 2017-)

With the passing of the World Health Assembly resolution 66.10, India became the first country to develop its National NCD Monitoring Framework with country-specific 10 targets and 21 indicators to be achieved by 2020 / 2025. In consultation with all the relevant stakeholders, MoHFW further

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[69] https://www.hsph.harvard.edu/pgda/major-projects/lasi-2/ (24/10/2019, 10:35 hours).

[70] https://www.ncbi.nlm.nih.gov/books/NBK109220/; http://iipsindia.org/research_lasi.htm (25/10/2019, 13:00 hours).

[71] https://www.ncbi.nlm.nih.gov/books/NBK109220/ (25/10/2019, 13:05 hours).

developed National Multisectoral Action Plan (NMAP) for prevention and control of common NCDs (2017-22). To monitor progress on India's NCD targets and indicators, NNMS has been conducted by ICMR's National Center for Disease Informatics and Research (NCDIR), Bengaluru with support from MoHFW.[72] The first round of the survey was initiated in 27 states in October 2017, with 2010 treated as baseline to evaluate progress made. It covered primary and secondary health facilities, and 1 adult (18-69 years) and all adolescents (15-17 years) from selected households. The survey included questions on NCD risk factors – tobacco consumption (smokeless and smoking), harmful consumption of alcohol, dietary habits, salt intake, physical measurements, activities, body mass index, fasting blood sugar and blood pressure. Not much is known about it at this stage since its results / report have not been made public so far – allegedly, pending government clearance. This would be the first full-fledged NCD survey in the country.

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[72] http://ncdirindia.org/ncd_dashboard/documents/AboutNNMS_2017_18.pdf (25/10/2019, 16:35 hours).

Table 1.7: An overview of active population health surveys in India

Survey (initiation year)	Coordinating Ministry	Population covered and sample size (latest round)	Representativeness (latest round)	Disaggregation (latest round)	Periodicity	Rounds completed
National Sample Survey (1952)	MoSPI	Social Consumption: Health (SCH) – 75th round (2017-18) – 113,823 households, 555,115 persons Disability – 76th round (2018) – 118,152 households, 576,569 persons Household Consumer Expenditure Survey (CES) – 68th round (2011-12) – 101,662 households	National, state	Gender, rural / urban, age groups, education, religion, caste, quintile class, occupation, marital status	SCH and disability – Non-periodic CES – Quinquennial	SCH – 6 Disability – 4 CES – 9 (data of 10th CES was not released)[73]
Sample Registration System (1971)	MHA	2017 – 7,925,000 persons	National, state (major)	Gender, rural / urban, broad age groups, education, marital status	Annual / 3-yearly / 5-yearly	N/A
National Family Health Survey (1992)	MoHFW	NFHS-4 (2015-16) – 601,509 households, 699,686 women (15-49 years), 112,122 men (15-54 years)	National, state, district (selected)	Gender, rural / urban, education, religion, caste / tribe, wealth index, occupation, marital status	Non-periodic	4

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[73] 'In view of the data quality issues, the Ministry has decided not to release the Consumer Expenditure Survey results of 2017-2018. The Ministry is separately examining the feasibility of conducting the next Consumer Expenditure Survey in 2020-2021 and 2021-22 after incorporating all data quality refinements in the survey process'. https://pib.gov.in/Pressreleaseshare.aspx?PRID=1591792 (1/6/2020, 11:52 hours).

Survey (initiation year)	Coordinating Ministry	Population covered and sample size (latest round)	Representativeness (latest round)	Disaggregation (latest round)	Periodicity	Rounds completed
Global Youth Tobacco Survey (2000)	MoHFW	2009 – 10,112 students (13-15 years, in grades 8-10)	National, state	Gender, age, grade	Non-periodic	4 (4th round, 2017-18, data not released)
Sample Registration System – cause of death survey (2001)	MHA	2010-13 – 182,827 deaths	National, 2 state groupings	Gender, rural / urban, broad age groups, education, religion, occupation	Non-periodic	4
Global Adult Tobacco Survey (2009)	MoHFW	GATS-2 – 33,772 men and 40,265 women (15+ years)	National, state	Gender, rural / urban, age groups, education, religion, caste / tribe occupation, marital status	Non-periodic	2 rounds
National Anti-Tuberculosis Drug Resistance Survey (2014)	MoHFW	5,280 sputum smear-positive pulmonary TB patients diagnosed at the designated microscopy centres (DMCs) of RNTCP between August 2014 to July 2015	Unknown	Gender, age	Unknown[74]	1
National Mental Health Survey (2015)	MoHFW	39,532 (18+ years, including 13-17 years in 4 states)	National, 12 states – Assam, Chhattisgarh, Gujarat, Jharkhand, Kerala, Madhya Pradesh, Manipur,	Gender, rural / urban, age groups, education, occupation,	Unknown	1

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[74] We have written 'non-periodic' against those surveys for which more than 1 round has been conducted and the periodicity is not fixed / clear, and 'unknown' against those where periodicity is not know since only 1 round has been conducted so far.

Survey (initiation year)	Coordinating Ministry	Population covered and sample size (latest round)	Representativeness (latest round)	Disaggregation (latest round)	Periodicity	Rounds completed
			Punjab, Rajasthan, Tamil Nadu, Uttar Pradesh, West Bengal	marital status, income quintile		
Comprehensive National Nutrition Survey (2016)	MoHFW & UNICEF	112,316 children and adolescents (0-19 years)	National, state	Gender, rural / urban, age groups, mother's age and schooling, religion, caste / tribe, wealth index, occupation, marital status	Unknown	1
Longitudinal Aging Study in India (2016)	MoHFW	60,250 individuals (45+ years)	National, state	Gender, rural / urban, education, religion, caste, wealth index, occupation, marital status	Unknown	1 (data not released)
National Non-communicable Disease Monitoring Survey (2017)	MoHFW	300 urban and 300 rural PSUs – 1 adult (18-69 years) and all adolescents (15-17 years) eligible from a household	National, state	Rural / urban	Unknown	1 (data not released)

Source: Developed by Ali Mehdi, Priyanka Tomar and Divya Chaudhry.

Table 2.8: Thematic mapping of selected population health surveys (latest rounds) in India

Themes		Population covered	NFHS	SRS	SRS CoD	NNMS	NMHS	GATS	CNNS	LASI	NSS	NATDRS
Demographics	Birth record (live births)		🟦	🟦							🟦	
	Birth record (non-live births)[75]		🟦	🟦							🟦	
	Fertility indicators[76]		🟦	🟦								
	Death record	Child[77]	🟦	🟦	🟦						🟦	
		Maternal	🟦	🟦	🟦						🟦	
		Others	🟦	🟦	🟦					🟦	🟦	
	Mortality indicators	Child[78]	🟦	🟦								
		Maternal		🟦								
		Others[79]	🟦	🟦								
Disability[80]			🟦				🟦			🟦	🟦	

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[75] NFHS: non-live births include abortion, miscarriage or stillbirth. SRS: still birth and abortion.

[76] NFHS: CBR, TFR, ASFR, age at birth of first child, wanted fertility rate, birth order and birth interval. SRS: CBR, general fertility rate, ASFR, TFR, gross reproduction rate, general and total – marital fertility rates, mean age at effective marriage for females, birth order and birth interval.

[77] SRS CoD: neonatal death (28 days or less), child death (29 days to 14 years).

[78] All types of child mortality rates.

[79] NFHS and SRS: CDR, ASDR. NFHS also provides adult mortality rates in two categories – deaths due to non-medical reasons (accidents, violence, poisoning, homicides or suicides) and deaths due to other reasons.

[80] NSS: locomotor, visual, hearing, speech and language, mental retardation / intellectual disability, mental illness, other. NFHS-5: hearing, speech, visual, mental, locomotor, other. NMHS: intellectual, self-reported disability across work, social and family life. LASI: self-reported 'difficulty with at least one activity of daily life (ADL)'.

Themes		Population covered	NFHS	SRS	SRS CoD	NNMS	NMHS	GATS	CNNS	LASI	NSS	NATDRS
Cause of death	Verbal Autopsy				🟦							
	HH-reported[81]		🟦		🟦					🟦		
Morbidity[82]	Communicable diseases[83]	Children, men, women	🟦	🟦	🟦					🟦	🟦	🟦
	NCDs[84]	Adolescents, men, women	🟦	🟦	🟦				🟦	🟦	🟦	
	Mental health						🟦			🟦	🟦	
	Injuries				🟦					🟦	🟦	
	Maternal disorders[85]		🟦		🟦						🟦	
Determinants of health (A)												
	Residence (rural / urban)		🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	

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[81] NFHS: maternal, injuries.

[82] SRS CoD captures morbidity of the deceased, as reported by the household respondent.

[83] NFHS: under-5 children (self-reported – acute respiratory infections, fever, diarrhoea), men and women (testing – HIV, self-reported – tuberculosis). SRS: jaundice, HIV/AIDS, tuberculosis (SRS Form No. 2A: morbidity, personal habits and socio-economic status). SRS CoD: diarrhoea, cough, measles and other sickness at the time of death (SRS VA Form 10A and 10B for child), past history of HIV/AIDS and tuberculosis' (SRS VA Form 10C for adult). NATDRS: MDR-TB/XDR-TB among new and previously treated TB patients.

[84] NFHS: diabetes, hypertension, chronic respiratory diseases including asthma, goitre or any thyroid disorder, any heart disease, cancer, any chronic kidney disease. SRS: diabetes, asthma, hypertension, cancer, coronary heart diseases, others (SRS Form No. 2A: morbidity, personal habits and socio-economic status). SRS CoD: past history of hypertension, heart disease, stroke, cholesterol, diabetes, cancer, asthma and other chronic illness (SRS VA Form 10C for adult).

[85] NFHS: abortions, convulsions, vision problem, swelling, post-partum complications (self-reported). SRS CoD: excessive bleeding, prolonged labour, fits or loss of consciousness during pregnancy / during labour or after labour, fever after birth, foul smelling discharge.

Themes		Population covered	NFHS	SRS	SRS CoD	NNMS	NMHS	GATS	CNNS	LASI	NSS	NATDRS
Socioeconomic determinants (A1)[86]	Education[87]		🟦	🟦	🟦		🟦	🟦	🟦	🟦	🟦	
	Marital status		🟦	🟦			🟦	🟦	🟦	🟦	🟦	
	Religion		🟦		🟦			🟦	🟦	🟦	🟦	
	Caste / tribe		🟦					🟦	🟦	🟦	🟦	
	Wealth index / household expenditure or income quintiles		🟦				🟦		🟦	🟦	🟦	
	Drinking water facilities		🟦						🟦	🟦	🟦	
	Sanitation facilities		🟦						🟦	🟦	🟦	
	Occupation / employment status		🟦		🟦		🟦	🟦	🟦	🟦	🟦	
	Ownership of agricultural land, house and farm animals		🟦						🟦	🟦		
	Health insurance		🟦						🟦	🟦	🟦	
	Out-of-pocket[88]		🟦				🟦			🟦	🟦	
Individual risk factors (A2)												

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[86] CNNS also includes type of mother's diet (vegetarian, vegetarian with egg, non-vegetarian).

[87] SRS: women's level of education.

[88] NFHS: average out-of-pocket cost paid for delivery. NMHS: amount spent for care and treatment of mental disorders.

Themes		Population covered	NFHS	SRS	SRS CoD	NNMS	NMHS	GATS	CNNS	LASI	NSS	NATDRS
Metabolic risk factors (A2.1)	Anthropometric indicators	Child	🟦						🟦			
		Adolescents	🟦			🟦			🟦			
		Men, women	🟦			🟦				🟦		
	Haemoglobin	Child	🟦						🟦			
		Adolescents	🟦						🟦			
		Men, women	🟦							🟦		
	Blood pressure	Child										
		Adolescents	🟦			🟦			🟦			
		Men, women	🟦			🟦				🟦		
	Blood glucose	Child							🟦			
		Adolescents	🟦			🟦			🟦			
		Men, women	🟦			🟦				🟦		
Behavioral risk factors (A2.2)	Tobacco consumption / smoking		🟦	🟦	🟦	🟦	🟦	🟦		🟦		
	Alcohol consumption		🟦	🟦	🟦	🟦	🟦			🟦		
	Level of physical activities					🟦				🟦		
	Dietary habits	Child	🟦						🟦			

Themes		Population covered	NFHS	SRS	SRS CoD	NNMS	NMHS	GATS	CNNS	LASI	NSS	NATDRS
		Overall[89]			■	■				■		
Access to health care (A3)	RCH		■	■	■						■	
	Communicable diseases		■								■	
	NCDs										■	
	Mental health						■				■	
	Injuries										■	
	General		■	■					■	■	■	

Source: Developed by Priyanka Tomar and Ali Mehdi.

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[89] SRS CoD: diet of deceased (pure vegetarian or not).

Table 2.9: Thematic mapping of NSS health survey (75th round, 2017-18) and NFHS-4 (2015-16)

Sn.	Indicators	NSS (75th round, 2017-18)	NFHS-4 (2015-16)
1	Proportion of ailing persons	▨	
2	Ailments	▨	▨
3	Treatment-seeking behaviour	▨	▨
4	Proportion of in-patient treatment	▨	
5	Nature and characteristics of in-patient treatment	▨	
6	Average out-of-pocket expenditure		
a	In-patient treatment	▨	
b	Other ailments	▨	▨
7	Expenditure on childbirth by		
a	Type of hospital	▨	▨
b	Nature of delivery	▨	▨
c	Household expenditure class	▨	
9	Childbirths involving surgery	▨	▨
10	Children receiving any vaccination	▨	▨
11	Fully immunized children (0-5 years)	▨	▨
12	Average expenditure on immunization	▨	
13	Condition of the aged (living arrangements, physical mobility)	▨	
14	Health insurance	▨	▨
15	Household and socioeconomic characteristics	▨	▨

Notes: NFHS collects data on selected ailments, treatment-seeking behavior and out-of-pocket expenditure, while NSS collects comprehensively.

Source: Developed by Priyanka Tomar.

Recommendations

- ® Even if we do not agree with the Bhore Committee Report's self-description as 'a broad survey', a similar report could be brought out annually / biennially by DoHR. The CBHI's National Health Profile does provide a broad range of statistics on an annual basis, but it has almost no analysis and certainly no 'recommendations for future development' of the health system / HIS. DoHR is capable of doing this. The fragmentation of the health system / HIS is reflected in discussions as well. The proposed report might help develop a health systems approach, even if notionally, to begin with. Like the Bhore and Sokhey Committee Reports, it should take a comprehensive view of health and its determinants and go beyond health systems / HIS vis-à-vis its approach, evidence and recommendations.

- ® NSSO was the pioneer in health statistics in the country. It still continues to provide some very helpful health statistics (tables 2.7 and 2.8). Beyond the health-related data that it collects, the NSO should focus on the coordination and consistency of health data collection at the national and state / UT levels. This would be a far bigger service than the data that it produces. To lead by example, it should not collect any data which is already being collected through any existing source (tables 2.8 and 2.9). For health-related data that it still collects, it should consult health experts to ensure that there are no conceptual or methodological issues with its data. Among the examples where it has faltered is vis-à-vis its data on the utilization of different systems of medicine as part of its 71st round ('Key indicators of social consumption in India: Health'. NSS 2014). Since people use these systems of medicine more on a complementary rather than an alternative basis, we should not ask about their utilization in exclusive terms. Not surprisingly, AYUSH stakeholders have not been too happy with these statistics, especially because this is the only national survey data that exists on this issue. MoSPI also refused to entertain a request from Ministry of AYUSH to conduct a survey for it (respondent), and the latter was desperately looking for alternatives. Both statistical and domain expertise needs to come together for high-quality statistics in the country. MoSPI needs to play its part much more proactively.

- ® Table 2.8 highlights the thematic overlaps in the major health surveys in the country. The SRS and NFHS have major overlaps in the sphere of demographic / population / vital statistics. And there is preference for SRS data in this regard at the central and state levels primarily due to its annual periodicity and being from within the government system. The major advantage that NFHS has over the SRS in this regard is the background characteristics by which it offers this data. However, table 2.2 shows the extensive nature of data and the background characteristics that the SRS collects. The SRS should put its entire data in the public domain – at the moment, it only puts out a fraction of what it collects. Secondly, it should do so in a more organized and professional manner. These are 2 areas in which the SRS can learn from the NFHS. If it actually does so, there will be no need for the NFHS to waste its respondents' precious time and GoI's limited resources on duplication. We recommend that vital statistics should only be collected by SRS by incorporating from the NFHS all that it presently lacks so that there is no net loss of data in the system, duplication is avoided and resources are rationalized.

- RGI should give up the SRS cause of death survey, for which a more specialized agency like the ICMR is better suited. It can support it with its death statistics from the CRVS, MCCD, SRS, etc. The ICMR should enhance the sample size for the CoD survey to yield representative data at the national and state / UT levels. The frequency of this survey, like others, should preferably be annual (for better respondent recall) or biennial at the most. In some senses, this survey is the backbone of the country's health system / HIS inasmuch as it is / would be the only robust source of data based on which the massive burden of premature mortality in the country can be addressed. India has been the leading contributor to premature deaths at all levels in the world, and reduction in premature mortality is part of both the national and international health agenda. The GoI should no longer let this critical source of data remain underutilized with RGI. According to the *World Health Statistics 2019*, 'monitoring of 11 health-related SDG indicators relies on good-quality cause-of-death data from countries' (WHO 2019: 50).

- Not just survey schedules, but fact sheets, at least, should also be prepared in local languages. They should be made available as well as painted on the walls of SCs, PHCs, CHCs and district hospitals in local languages. This can also be done for key indicators from non-survey sources. This would not only help in the democratization of official data, but also enhance accountability.

- As NFHS data is most professionally and transparently organized and disseminated, especially as done through the DHS Program, the latter's template of data dissemination and visualization should be adopted by all surveys at the national and state / UT levels. The NHDAC should lay down guidelines for the same, ensure that they are religiously followed and develop a common visualization platform that should be accessible to policymakers as well as the public. A mobile phone app should also be developed for the visualization. The support of DHS Program, WHO, UNICEF and the World Bank could be sought in this regard.

- Kindly refer to the table in the concluding chapter for the proposed health survey strategy and health surveys at the national level.

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3. Scope of NFHS vis-à-vis MoHFW's policies

Tables 3.1 and 3.2 show how NFHS presently contributes to MoHFW's vision, mission, objectives and policies. It does not necessarily have to contribute to them completely – as we have pointed out, surveys like the NNMS and NMHS have been conducted for NCD and mental health policies. This and subsequent tables are quite detailed and self-explanatory, and we will only highlight some of the key aspects in this and subsequent discussions.

There are certain aspects on which NFHS cannot contribute due to the fact of being a population survey, and we have marked them 'not applicable' (N/A). 'Yes' is mentioned against themes where it contributes at the moment and 'no' / 'partially' against those where it could potentially contribute. Obviously, this is a matter of interpretation. Let us provide a few examples here, however, to justify our case regarding potential coverage in a population health survey of themes which may not look so on the surface. A thorough exercise is required to identify themes of various policies / programs that could be covered in population health surveys.

1) NFHS contributes partially to certain aspects of the vision, mission and objectives of MoHFW, and not at all to other aspects. One can argue about its potential to shed light on establishment of 'comprehensive primary healthcare delivery system', and its well-functioning linkages with secondary and tertiary care, very important from the perspective of the management of NCDs. One could argue that this should be covered under a facility rather than a population survey. Very true. However, a population survey can also ask beneficiaries whether this is actually the case, which would be more important from the perspective of increasing focus of GoI on health sector performance and strengthening, in comparison to the structural-operational information that a facility survey or study would generate, which too is important. There are socioeconomic inequities too in accessing health systems, and they would also come out through a population rather than a facility survey.

2) UHC has emerged as, perhaps, the most important theme in both the national and international health narrative and trajectory – it is MoHFW's vision. Yet, NFHS is of little help in this regard, either from the perspective of service coverage, financial risk protection or health technology assessment. NSS is also a population survey, but has been providing OOP data for a long time. Not that NFHS should necessarily collect it – just pointing out the possibilities.

3) With respect to Mission 4 of MoHFW, NFHS could shed light on the regulatory status of health service delivery and rational use of pharmaceuticals. In fact, antimicrobial use (AMU) is widely used as a proxy of antimicrobial resistance (AMR) in countries where data on the latter is weak.

4) Self-reported questions about specific diseases yield inaccurate information at the population level and do not serve any major purpose, except awareness (if there is parallel clinical testing and comparison being done). Instead, as per WHO's definition of health as well as MoHFW's

vision and NHP 2017's goal related to well-being, the NFHS could ask questions about mental, emotional and social well-being. These are huge issues generally, especially for women during pregnancy and motherhood as well as for people suffering from chronic conditions, especially pain, or even the more concrete ones like diabetes, cancer, etc. Mental and musculoskeletal disorders are huge dimensions and drivers of disability and lack of well-being which are rarely covered in health surveys despite their massive day-to-day implications for the living. From a demographic point of view, the topics of interest are fertility, birth, death, marriage, migration, etc. Regular life and its challenges do not mean much. From health and well-being perspective, though, they are core concerns, and should be so for public policies, programs, surveys, etc.

Table 3.1: Summary of NFHS-4's scope vis-à-vis MoHFW's vision, mission and objective statement and relevant policies

Institutional context	Themes / indicators	Completely	Partially	Scope (%)
Vision, Mission and Objective Statement for MoHFW (24.4.2019)	7	0	4	57
NHP 2017	31	16	5	68
NPP 2000	16	6	7	81
NVP 2011	0	0	0	N/A
NPC-AMR 2011	0	0	0	N/A
NAP-AMR 2017	2	0	0	0
National Multisectoral Action Plan for NCDs (2017-22)	22	9	2	50
NMHP 2014	14	0	0	0
EHR 2016	2	0	1	50

Source: Developed by Priyanka Tomar and Divya Chaudhry.

Table 3.2: Assessment of NFHS-4' scope vis-à-vis MoHFW's vision, mission and objective statement and relevant policies (our comments on NFHS coverage in bold within [] brackets)

Document	Goals / Vision / Mission	Objectives	Related indicators
'Vision, Mission and Objective Statement for MoHFW' (24.4.2019)	Vision: Attainment of highest possible level of health and well-being for all, through preventive and promotive health care and universal access to good quality health services without anyone having to face financial hardship as a consequence **[Partially – see NHP 2017 goal below for details]** Mission: 1. Ensure availability of quality healthcare on equitable, accessible and affordable basis across regions and communities with special focus on under-served population and marginalized groups **[Partially]** 2. Establish comprehensive primary healthcare delivery system and well-functioning linkages with secondary and tertiary care health delivery system **[No]** 3. Develop the training capacity for providing HRH (medical, paramedical and managerial) with adequate skill mix at all levels **[N/A]** 4. Regulate health service delivery and promote rational use of pharmaceuticals in the country **[No]**	1. Improve health status of the people through concerted action **[Partially]** 2. Expand preventive, promotive, curative, palliative and rehabilitative services provided through public health sector with focus on quality **[No]** 3. Progressively achieve universal health coverage **[Partially]**	Not available

Document	Goals / Vision / Mission	Objectives	Related indicators
National Health Policy 2017	1. Attainment of the highest possible level of health and well-being for all at all ages **[Partially]** 2. Pivotal importance of SDGs **[See SDG section in this chapter]**	Improve health status through concerted policy action in all sectors and expand preventive, promotive, curative, palliative and rehabilitative services provided through the public health sector with focus on quality 1. Progressively achieve UHC a. Assuring availability of free, comprehensive primary health care services (CPHCS) **[Partially]** b. Ensuring improved access and affordability of quality secondary and tertiary care services **[No]** c. Achieving a significant reduction in OOPE **[See 3.a.iii in next column]** 2. Reinforcing trust in public health care system **[No]** 3. Align the growth of private health care sector with public health goals (including enabling private sector contribution to making health care systems more effective, efficient, rational, safe, affordable and ethical) **[No]**	Specific quantitative goals and objectives under NHP 2017: 1. Health status and programme impact a. Life expectancy and healthy life i. Life expectancy at birth (LEB) **[Can be estimated]**[90] ii. Disability-adjusted life years (DALY) **[NFHS-5 has questions on disability; DALYs can be calculated together with disability data from SRS, NSS and Census]** iii. TFR **[Yes]** b. Mortality by age and / or cause i. Under-five mortality rate (U5MR) **[Yes]** and maternal mortality ratio (MMR) **[No]** ii. Infant mortality rate (IMR) **[Yes]** iii. Neonatal mortality rate (NNMR) **[Yes]** and still birth rate (SBR) **[Yes]** c. Disease prevalence / incidence i. HIV / AIDS **[Yes – knowledge, prevalence; No – sustained antiretroviral therapy (ART) or viral suppression]** ii. Leprosy, Kala-Azar and Lymphatic Filariasis **[No]** iii. Tuberculosis (TB) – cure rate in new sputum positive patients and incidence reduction **[No – only prevalence of TB covered]** iv. Blindness **[No]** v. Premature mortality from cardiovascular diseases, cancer, diabetes or chronic respiratory diseases **[No]**

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[90] For instance, Mohanty and Ram (2010) estimated LEB among poor and non-poor by caste and religion in India using NFHS. More recently, Asaria et al (2019) estimated socioeconomic disparities in LEB combining data from NFHS and SRS.

Document	Goals / Vision / Mission	Objectives	Related indicators
			2. Health systems performance a. Coverage of health services i. Utilization of public health facilities **[Yes – only for delivery / birth covered]** ii. ANC **[Yes]** and skilled attendance at birth **[Yes]** iii. Newborn fully immunized by one year of age **[Yes]** iv. Met need of family planning **[Yes]** v. Known hypertensive and diabetic individuals maintaining controlled disease status **[No – only prevalence and medicine intake covered]** b. Cross-sectoral goals related to health i. Prevalence of tobacco use **[Yes]** ii. Prevalence of stunting of under-five children **[Yes]** iii. Access to safe water and sanitation **[Yes]** iv. Occupational injury among agricultural workers **[No – only injury due to spousal violence covered]** v. National / State level tracking of selected health behaviour **[Yes – covered only in the context of HIV/AIDS and fertility]** 3. Health system strengthening a. Health finance i. Government health expenditure as % of GDP **[Not applicable / N/A]** ii. State health spending as % of their budget **[N/A]** iii. Proportion of households facing catastrophic health expenditure **[Partially – only out-of-pocket expenditure (OOPE) in the case of delivery for the most recent live birth in**

Document	Goals / Vision / Mission	Objectives	Related indicators
			public and private health facilities covered] b. Health infrastructure and human resource **[N/A – RHS, the other data source under HSRS, provides information on these aspects]** c. Health management information **[Partially – only a few MIS indicators can be validated through NFHS data]**
National Population Policy (NPP) 2000		1. Immediate objective: Address unmet needs for contraception, health care infrastructure, and health personnel and to provide integrated service delivery for basic RCH care **[Partially – excluding infrastructure and integrated service delivery]** 2. Medium-term objective: Bring the TFR to replacement levels by 2010 through vigorous implementation of inter-sectoral operational strategies **[Partially – TFR status only]** 3. Long term objective: To achieve a stable population by 2045, at a level consistent with the requirements of sustainable economic growth, social development and environmental protection **[No]**	Relevant indicators based on national socio-demographic goals (NSDG) under NPP 2000: 1. Unmet needs for basic RCH services, supplies and infrastructure **[Partially – excluding infrastructure]** 2. Free and compulsory school up to age 14, dropout reduction at primary and secondary school levels **[Partially – school attendance, educational attainment, reasons for dropout covered]** 3. IMR **[Yes]** 4. MMR **[No]** 5. Universal immunization of children against all vaccine preventable diseases **[Yes]** 6. Girls' age at marriage **[Yes]** 7. Institutional deliveries, by trained persons **[Yes]** 8. Access to information / counseling and services for fertility regulation and contraception with a wide basket of choices **[Yes]** 9. Registration of births, deaths, marriage and pregnancy **[Partially – only birth registration covered]** 10. Spread of AIDS **[No – HIV prevalence covered]**

Document	Goals / Vision / Mission	Objectives	Related indicators
			11. Prevention and control of communicable diseases **[Partially – see footnote 38 above]** 12. Integrated Indian systems of medicine (ISM) for reproductive and child health (RCH) services and household outreach **[Partially – no household outreach]** 13. Promotion of small family norm **[Yes]**
National Vaccine Policy (NVP) 2011	The Policy document provides – within the overall framework of NHP – broad policy guidelines and framework to guide the creation of evidence base to justify the need for R&D, production, procurement and quality assessment of vaccines for the Universal Immunization Program (UIP) in India. It also addresses the broad issues of strengthening the institutional framework, processes, evidence base and framework required for decision making for new vaccine introduction, addresses vaccine security and program management, regulatory issues and product development **[N/A]**	Not available	Not available 'The overarching goal of vaccine use is to reduce morbidity and mortality due to vaccine preventable diseases (VPD)' (NVP 2011: 5). **- While NFHS provides data on vaccination, it could also include questions which can help assess their impact on morbidity, mortality as well as other relevant outcomes.** 'Presently, the efforts to collect data on childhood infectious diseases of public health importance are fragmented and there is a need for reliable and comparable data to establish baseline information, monitor trends of infectious diseases, and monitoring the impact of existing interventions' (NVP 2011: 22). **- NFHS should consider tackling this problem.** Surveys like the NHFS should 'create data sets on baseline demography', which are of 'utmost importance in interpreting disease burden data, results of clinical trials or when an adverse events following any intervention has to be investigated and causal linkages established' (NVP 2011: 23). **- NFHS should consider this. It can also ask respondents about related adverse events.**
National Policy for Containment of Antimicrobial		The Policy is the report of a task force constituted with following terms of reference:	Not available While hospital-based sentinel surveillance was recommended in the report and more generally,

Document	Goals / Vision / Mission	Objectives	Related indicators
Resistance (AMR) 2011		1. Review the current situation regarding manufacture, use and misuse of antibiotics in the country **[N/A]** 2. Recommend the design for creation of a national surveillance system for antibiotic resistance **[N/A]** 3. Initiate studies documenting prescription patterns and establish a monitoring system for the same **[N/A]** 4. Enforce and enhance regulatory provisions for use of antibiotics in human, veterinary and industrial use **[N/A]** 5. Recommend specific intervention measures such as rational use of antibiotics and antibiotic policies in hospitals **[N/A]** 6. Diagnostic methods pertaining to antimicrobial resistance monitoring **[N/A]**	NFHS can include questions on awareness and attitudes towards AMR, antimicrobials and their use (AMU), sources of information, prescription behavior, prevalence and causes of self-medication, antibiotic use in agriculture, etc.
National Action Plan on Antimicrobial Resistance (NAP-AMR) 2017	1. To effectively combat AMR in India, and contribute towards the global efforts to tackle this public health threat **[N/A]** 2. To establish and strengthen governance mechanisms as well as the capacity of all stakeholders to reduce the impact of AMR in India **[N/A]**	1. Define the strategic priorities, key actions, outputs, responsibilities and indicative timeline and budget to slow the emergence of AMR in India and strengthen the organizational and management structures to ensure intra and inter sectoral coordination with a One Health approach **[N/A]** 2. Combat AMR in India through better understanding and awareness of AMR, strengthened surveillance, prevention of emergence and spread of resistant bacteria through infection prevention and control, optimized use of antibiotics in all sectors and enhanced investments for AMR activities, research and innovations **[No]**	M&E indicators: 1. Level of awareness and knowledge about AMR in different social and professional groups **[No]** 2. Number of IEC resources developed for awareness / behaviour change communication campaign on AMR and AMU **[N/A]** 3. Revised curricula for health professionals and for professionals in animal health, food industry and agriculture **[N/A]** 4. Terms of reference for National Coordinating Centre, National Reference Laboratories, Infection Prevention and Control Coordinating Unit and Multidisciplinary Antimicrobial Stewardship Committees **[N/A]** 5. Establishment of a quality management system for the medicines supply chain **[N/A]**

Document	Goals / Vision / Mission	Objectives	Related indicators
		3. Enable M&E of the NAP-AMR implementation based on the M&E framework **[N/A]**	6. Engagement with relevant experts to identify research topics on AMR **[N/A]**
National Multisectoral Action Plan for Prevention and Control of Common Noncommunicable Diseases (2017-22)[91]	Goal: Promote healthy choices, reduce preventable morbidity, avoidable disability and premature mortality due to NCDs in India **[Partially – only selected healthy choices covered]** Vision: All Indians enjoy the highest attainable status of health, well-being and quality of life at all ages, free of preventable NCDs and premature death **[Partially – see footnote 38 above]**	1. Priority accorded and resources allocated to the prevention and control of NCDs in the national agenda and policies **[N/A]** 2. National capacity to lead multisectoral partnerships to accelerate and scale-up national response to NCDs **[N/A]** 3. Capacity of individuals, families and communities to make healthier choices by creating healthy environments that promote health and reduce the risk of NCDs **[No]** 4. Health systems provide accessible and affordable good quality care to all people with disease or risk factors through primary health care approach **[No]** 5. Sustainable surveillance, monitoring and evaluation systems for programme development and monitoring that promotes evidence-based policy and programme development **[N/A]**	1. Probability of dying between ages 30-70 from cardiovascular disease (CVDs), cancer, diabetes, or chronic respiratory disease (CRDs) **[No]** 2. Cancer incidence by type of cancer **[Yes – self-reported cancer, no information about type]** 3. Alcohol consumption (aged 18+ years) **[Yes – only for covered age groups]** 4. Obesity (adolescents and aged 18+ years) **[Yes – only for covered age groups]** 5. Blood glucose / diabetes **[Yes]** 6. Physical activity (adolescents and aged 18+ years) **[No – sexual activity covered]** 7. Blood pressure (aged 18+ years) **[Yes – only for covered age groups]** 8. Mean population intake of salt per day in grams (aged 18+ years) **[No – presence of iodized salt in household and ORS (oral rehydration salt) covered]** 9. Tobacco use (smoking and smokeless) (adolescents and aged 18+ years) **[Yes – only for covered age groups]** 10. Households using solid fuels as a primary source of energy for cooking **[Yes]** 11. Adults consuming less than 5 servings of fruit and vegetables per day **[Yes – only for covered age groups]**

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[91] The NNMS, conducted by ICMR's NCDIR (Bengaluru), is meant to take care of India's data reporting requirements for this Plan.

Document	Goals / Vision / Mission	Objectives	Related indicators
			12. Adults receiving drug therapy and counselling to prevent heart attacks and strokes **[No]** 13. Availability and affordability of quality, safe and efficacious essential NCD medicines including generics and basic technologies in both public and private facilities **[No]** 14. Access to palliative care assessed by morphine-equivalent consumption of strong opioid analgesics per death from cancer **[No]** 15. Vaccination coverage against hepatitis B virus monitored by number of third doses of Hep-B vaccine administered to infants **[Yes]** 16. Women aged 30-49 screened for cervical cancer at least once **[No]**[92] 17. Women aged 30 and above screened for breast cancer by clinical examination by trained health professional at least once **[No]** 18. High risk persons (using tobacco, smoking and smokeless and betel nut) screened for oral cancer by examination of oral cavity **[No]**
National Mental Health Policy (NMHP) of India 2014[93]	Goals: 1. To reduce distress, disability, exclusion morbidity and premature mortality associated with mental	1. To provide universal access to mental health care **[No]** 2. To increase access to and utliisation of comprehensive mental health services	Not available

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[92] NFHS-4 had a question (number 727) in the women's schedule, which asked them – 'have you ever undergone: a) a cervix examination, b) breast examination, c) an oral cavity examination?'. It does not mention cancer and contrary to assumption in some quarters, this is not about cancer screening in particular, but rather about general screening. There are 2 other questions about cancer – number 253 which asks whether hysterectomy, if done, was due to cancer; and number 723 which asks whether the woman has cancer (as well as other diseases like diabetes, asthma, goiter or any other thyroid disorder or heart disease)?

[93] The National Mental Health Survey, 2015-16, was meant to provide data for this policy.

Document	Goals / Vision / Mission	Objectives	Related indicators
	health problems across life-span of the person **[No]** 2. To enhance understanding of mental health in the country **[No]** 3. To strengthen the leadership in the mental health sector at the national, state and district levels **[No]** Vision: to promote mental health, prevent mental illness, enable recovery from mental illness, promote destigmatization and desegregation, and ensure socio-economic inclusion of persons affected by mental illness by providing accessible, affordable and quality health and social care to all persons through their life-span within a rights-based frame work **[No]**	(including prevention services, treatment and care and support services) **[No]** 3. To increase access to mental health services for vulnerable groups including homeless person(s), person(s) in remote areas, difficult terrains, educationally / socially / economically deprived sections **[No]** 4. To reduce prevalence and impact of risk factors **[No]** 5. To reduce risk and incidence of suicide and attempted suicide **[No]** 6. To ensure respect for rights and protection from harm of person(s) with mental health problems **[No]** 7. To reduce stigma related to mental health problems **[No]** 8. To enhance availability and equitable distribution of skilled human resources for mental health **[No]** 9. To progressively enhance financial allocation and improve utliisation for mental health promotion and care **[No]** 10. To identify and address the social, biological and psychological determinants of mental health problems and to provide appropriate interventions **[No]**	
Electronic Health Record (EHR) Standards for India 2016	1. Promote interoperability and where necessary be specific about certain content exchange and vocabulary standards to establish a path forward toward semantic interoperability **[No]** 2. Evolution and timely maintenance of adopted standards **[N/A]**	Not available	Not available

Document	Goals / Vision / Mission	Objectives	Related indicators
	3. Technical innovation using adopted standards **[N/A]** 4. Participation and adoption by all vendors and stakeholders **[N/A]** 5. Implementation costs as low as reasonably possible **[N/A]** 6. Consider best practices, experiences, policies and frameworks **[Partially]** 7. To the extent possible, adopt standards that are modular and not interdependent **[N/A]**		

Source: Developed by Priyanka Tomar and Ali Mehdi.

4. Scope of NFHS vis-à-vis MoHFW's schemes

Regular monitoring and data reporting of schemes happens through their MIS, some of which were discussed in chapter 2. It is interesting to note that in one of the MoHFW's quarterly HMIS national report[94] (30/6/2019), there were 8 indicators from SRS,[95] 5 from the erstwhile DLHS[96] and only 3 from NFHS.[97] There is a tendency in government documentation – both at the Central and state levels – to use vital indicators from the SRS and only a few service / impact indicators from NFHS. Surprisingly, despite being discontinued 7 years back, DLHS data continues to be used even now.

Table 4.1: Summary of the scope of NFHS-4 vis-à-vis MoHFW schemes

Schemes	Themes / indicators	Completely	Partially	Scope (%)
Central sector schemes				
Pradhan Mantri Swasthya Suraksha Yojana	2	0	0	0
National AIDS and STD Control Programme	2	1	0	50
Family Welfare Schemes	2	1	1	100
Establishment and strengthening of NCDC branches and health initiatives…	2	0	1	50
Pharma co-vigilance Programme of India	1	0	0	0
Development of Nursing Services	1	0	1	100
Health sector disaster preparedness and response…	1	0	0	0
National Organ Transplant Programme	2	0	0	0
Setting up of nationwide network of laboratories for managing epidemics	1	0	0	0

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[94] https://nhm.gov.in/New_Updates_2018/Quarterly_MIS/June-2019/National_Overview.pdf (24/10/2019, 14:34 hours).

[95] TFR, CBR, life expectancy at birth, CDR, NNMR, IMR, U5MR and MMR.

[96] Contraceptive prevalence rate, children under 3 years breastfed within one hour of birth (%), children age 0-5 months exclusively breastfed (%), children age 6-35 months exclusively breastfed for at least 6 months (%) and children age 6-9 months receiving solid / semi-solid food and breast milk (%).

[97] Unmet need for family planning (%), institutional deliveries (%) and fully immunised children (%).

Schemes	Themes / indicators	Completely	Partially	Scope (%)
Development of infrastructure for promotion of health research	1	0	0	0
Human resource and capacity development	1	0	0	0
Development of tools / support to prevent outbreaks of epidemics	2	0	0	0
Centrally sponsored schemes				
National Rural Health Mission	49	15	1	33
National Urban Health Mission	8	4	2	75
Human resources for health and medical education	5	0	3	60
Ayushman Bharat – Pradhan Mantri Jan Arogya Yojana	7	0	3	43
Tertiary Care Programs	14	2	0	14

Source: Developed by Priyanka Tomar and Divya Chaudhry.

Tables 4.1 and 4.2 convey a similar impression about the scope of NFHS vis-à-vis various schemes of the MoHFW as did tables 3.1 and 3.2 earlier. We have only included the outputs, outcomes and their respective indicators against schemes from the Union Budget 2019-2020 Output Outcome Framework that are relevant from the perspective of a population health survey like the NFHS. It is largely the MIS indicators of NHM – that too primarily of its RMNCH+A component – which are available on MoHFW's Statistics Division's website. The MIS indicators of other schemes, we were told, are with the respective program managers, and not available in the public domain. Below are 2 illustrative comments – the tables otherwise are detailed and self-explanatory.

1) For the PMSSY scheme, in the light of what we said above, the NFHS could ask people about the availability as well as accessibility of AIIMS and AIIMS-like institutes in particular and about availability of affordable / reliable tertiary care in general.
2) It can also provide data on the efficiency of disease surveillance programs by asking questions about disease symptoms, their risk factors, etc. – if not on diseases themselves. For diseases where rapid diagnostics are available and could be leveraged, it could also consider collecting disease prevalence data. Similarly, for the pharmacovigilance programme, it could ask people whether any adverse drug reactions (ADRs) happened, etc.

Table 4.2: Assessment of the scope of NFHS-4 vis-à-vis MoHFW schemes (outlay, outputs and outcomes and their indicators relevant from a population survey perspective taken from Output Outcome Framework with the Union Budget of India 2019-20)

Sn.	Name of the scheme (relevant MoHFW department)	Outlay (INR crores)	Relevant outputs	Relevant outcomes
CENTRAL SECTOR (CS) SCHEMES				
1	Pradhan Mantri Swasthya Suraksha Yojana (Department of Health and Family Welfare / DoHFW)	4,000	1. Increased accessibility to AIIMS and AIIMS-like institutes **[No]** 2. Availability of affordable / reliable tertiary care **[No]**	Not applicable (N/A)
2	National AIDS and STD Control Programme (DoHFW)	2,500	N/A	1. People living with HIV who know their HIV status **[Yes]** 2. … and are on ART (antiretroviral therapy) **[No]**
3	Family Welfare Schemes (DoHFW)	700	N/A	1. To achieve family planning (FP) 2020 goal **[Partially]**[98] 2. Increase in awareness level **[Yes]**
4	Establishment and strengthening of NCDC branches and health initiatives, inter-sectoral coordination for preparation and control of zoonotic diseases and other neglected tropical diseases, National Viral Hepatitis Surveillance Programme, and Anti-Microbial Resistance Containment Programme (DoHFW)	49	1. Improved capacity of states and district level manpower for prevention and control of zoonosis diseases **[No]** 2. Surveillance systems for hepatitis and AMR **[Partially – hepatitis B vaccination for children covered]**	N/A

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[98] NFHS is the source of 13 out of 18 FP 2020 core indicators (indicators 1-9, 14, 16-18). Source: FP Core Indicator Summaries (2018). https://bit.ly/31AETYX (22/10/2019, 12:10 hours). It could also collect data on indicator 15 (women provided with information on FP during recent contact with a health service provider).

Sn.	Name of the scheme (relevant MoHFW department)	Outlay (INR crores)	Relevant outputs	Relevant outcomes
5	Pharma co-vigilance Programme of India (DoHFW)	12	N/A	To create a nationwide system to report ADRs for patient-safety **[No]**
6	Development of Nursing Services (DoHFW)	15	N/A	Availability, knowledge and skills of nurses **[Partially – partial performance covered]**
7	Health sector disaster preparedness and response and human resources development for emergency medical services (DoHFW)	130	N/A	Doctors, nurses and paramedics trained in emergency life support **[No]**
8	National Organ Transplant Programme (DoHFW)	41	Increase awareness on organ donation **[No]**	Organ donation rate **[No]**
9	Setting up of nationwide network of laboratories for managing epidemics and national calamities (Department of Health Research / DoHR)	80	N/A	Timely diagnosis of epidemics and availability of trained viral research and diagnostic professionals at medical colleges, state and regional level laboratories **[No]**
10	Development of infrastructure for promotion of health research (DoHR)	73	N/A	Outcome indicator Increase in transfer of new technologies for improving the quality of health services to rural population **[No]**
11	Human resource and capacity development (DoHR)	87	N/A	Outcome indicator Number of evidence-based guidelines issued on Health Technology Assessment (HTA) **[No]**
12	Development of tools / support to prevent outbreaks of epidemics (DoHR)	7.35	Providing diagnostics for non-viral infectious pathogens **[No]**	Research activity for preparedness and to generate quality and uniform pan-India data **[No]**

Sn.	Name of the scheme (relevant MoHFW department)	Outlay (INR crores)	Relevant outputs	Relevant outcomes
CENTRALLY SPONSORED SCHEMES (CSS)				
13	National Rural Health Mission (DoHFW)	27,039	See scheme components below	See scheme components below
13(1)	Health systems strengthening under NRHM		1. Expanded basket of primary care services provided by Health & Wellness Centers (HWCs) **[No]** 2. Implementation of NHM Free Diagnostics Services Initiative at public health facilities **[No]**	1. Improved utilization of primary care services and screening & management of NCDs **[No]** 2. Increased availability of drugs and diagnostics at public health facilities **[No]** 3. Improved utilization of public health facilities **[Yes – only for delivery / birth covered]** 4. Improved access to emergency obstetric care services **[Yes – caesarean section delivery]** 5. Patients receiving free dialysis care **[No]** <u>Outcome indicators</u> 1. Number of total 30+ population screened for NCDs **[No – see footnote 38 above]** 2. Reduction in OOPE on health in public health facilities (proxy – childbirth) **[Yes]**
13(2)	RCH Flexipool (including Routine Immunization Programme, Pulse Polio Immunization Programme, National Iodine Deficiency Disorders Control Programme, etc.)		<u>Output indicators</u> 1. Percentage of pregnant women who received 4 ANCs (antenatal care) **[Yes]** 2. Percentage of SBA (skilled birth attendant) deliveries to total ANCs registered **[Yes]** 3. Full immunization coverage **[Yes – mother and child]**	<u>Outcome indicators</u> 1. MMR **[No]** 2. U5MR **[Yes]** 3. TFR **[Yes]**

Sn.	Name of the scheme (relevant MoHFW department)	Outlay (INR crores)	Relevant outputs	Relevant outcomes
			4. Use of modern methods of contraception **[Yes]**	
13(3)	National Iodine Deficiency Disorders Control Programme		<u>Output indicator</u> Availability of adequately iodized salt **[Yes]**	N/A
13(4)	Disease Control Programme		N/A	N/A
13(4-A)	National Vector Borne Diseases Control Programme		1. Malaria: Reduction in number of cases **[No]** 2. Kala-azar: Reduction in PKDL (diagnosis of post Kala-azar dermal leishmaniasis) cases **[No]** 3. Japanese Encephalitis (JE) / Coverage of JE in routine immunization at the national level **[No]** 4. Lymphatic Filariasis (LF): Protect the population by Mass Drug Administration in LF endemic districts **[No]**	N/A
13(4-B)	National Viral Hepatitis Control Programme		N/A	1. Free treatment of hepatitis C available **[No]** 2. Free treatment of hepatitis B available **[No]** 3. Enhanced coverage of birth dose hepatitis B vaccine **[Yes]** <u>Outcome indicators</u> 1. Number of new patients completed treatment of HCV **[No]** 2. Number of patients who put on treatment continuing on treatment **[No]**
13(4-C)	National Leprosy Eradication Programme		N/A	Grade II disability (G2D) due to leprosy **[No]**

Sn.	Name of the scheme (relevant MoHFW department)	Outlay (INR crores)	Relevant outputs	Relevant outcomes
13(4-D)	Revised National Tuberculosis Control Programme		Output indicator Percentage increase in TB case notification (public & private) **[Yes – TB prevalence covered]**	Increased detection of drug resistant TB cases **[No]** Outcome indicator 1. Percentage of patients whose outcomes are successful **[No]** 2. Percentage increase in drug resistant TB cases **[No]**
13(4-E)	Integrated Disease Surveillance Programme (IDSP)		Improved capacity of districts to detect and respond to disease outbreaks **[Partially – very limited coverage of IDSP diseases under surveillance in NFHS]**	N/A
13(5)	Non Communicable Disease Programme		See sub-scheme components below	See sub-scheme components below
13(5-A)	National Programme for prevention and control of Cancer, Diabetes, Cardiovascular diseases and Stroke		1. Additional NCD clinics to be set up at CHCs and district hospitals **[No]** 2. Screening for high blood pressure & high blood sugar **[No – see footnote 38 above]**	1. Relative reduction in overall mortality from cardiovascular diseases (CVDs), cancer, diabetes, chronic respiratory diseases (CRDs) **[No]** 2. Early detection of high blood pressure & high blood sugar **[Yes – see footnote 38 above]**
13(5-B)	National Mental Health Programme		Provision of mental health services under District Mental Health Programme **[No]**	Improved coverage of mental health services **[No]**
13(5-C)	National Blindness Control Programme		Eye care services under NPCB&VI provided at primary, secondary at district and below level **[No]** Output indicator Cataract surgeries **[No]**	Improvement in surgical skills and quality **[No]** Outcome indicator Reduction in prevalence of blindness **[No]**
13(5-D)	National Programme for Health Care of Elderly		Provision of primary, secondary and tertiary geriatric health care services at district hospital and below **[No]**	N/A

Sn.	Name of the scheme (relevant MoHFW department)	Outlay (INR crores)	Relevant outputs	Relevant outcomes
			Output indicator 1. District hospitals with physiotherapy and laboratory services **[No]** 2. CHCs with geriatric OPD and geriatric physiotherapy services **[No]**	
13(5-E)	Tobacco Control Programme & Drug De-addiction Programme		1. Increase in availability of tobacco cessation services **[Yes]** 2. Increase in facilities for treatment of drug addiction **[No]**	1. Improved access for tobacco cessation services **[Yes]** 2. Improved access to drug dependence treatment services **[No]**
14	National Urban Health Mission – Flexible Pool (DoHFW)	950	Output indicators 1. UPHCs and UCHCs providing comprehensive primary health care services with adequate staff **[Partially – covered under source of health care, modern contraceptive methods and emergency contraceptive pills]** 2. Women getting at least 4 ANCs **[Yes]** 3. Children getting full immunization **[Yes]** 4. UHNDs (Urban Health & Nutrition Days) outreach conducted by UPHCs **[No]**	1. Improved access to quality healthcare in urban India **[Partially – among reasons for not using government health care and reasons for not delivering the most recent live birth in a health facility]** 2. Increased utilization of public health facilities **[Yes – only for delivery / birth covered]** Outcome indicators 1. MMR **[No]** 2. IMR **[Yes]**
15	Human resources for health and medical education (DoHFW)	4,250	See scheme components below	See scheme components below
15(1)	District hospitals – Upgradation of state government medical colleges (PG seats)		N/A	Availability of specialist doctors **[No]**
15(2)	Strengthening of government medical colleges (UG seats) and central government health institutions		N/A	Availability of doctors **[Partially – RCH services provided by doctors covered]**
15(3)	Establishment of new medical colleges (upgrading district hospitals)		N/A	Output indicator Tertiary level services **[No]**

Sn.	Name of the scheme (relevant MoHFW department)	Outlay (INR crores)	Relevant outputs	Relevant outcomes
15(4)	Upgradation / strengthening of nursing services (ANM / GNM)		N/A	Nurses for healthcare **[Partially – partial performance covered]**
15(5)	Setting up of state institutions of para-medical sciences in states and setting up of colleges of para-medical education		N/A	Availability of allied health professionals **[Partially – partial performance covered]**
16	Ayushman Bharat – Pradhan Mantri Jan Arogya Yojana (DoHFW)	6,400	1. Hospital admissions **[No]** 2. Beneficiary identification **[No]** Output indicator Public and private hospitals empaneled **[No]**	Reduction in health expenditure **[Partially – only OOPE in the case of delivery for the most recent live birth in public and private health facilities covered]** Outcome indicators 1. Proportion of households incurring catastrophic health expenditure **[No]** 2. Percentage of out-of-pocket health expenditure incurred by beneficiaries **[Partially – only OOPE in the case of delivery for the most recent live birth in public and private health facilities covered]** 3. Average out-of-pocket expenditure incurred by beneficiaries **[Partially – only OOPE in the case of delivery for the most recent live birth in public and private health facilities covered]**
17	Tertiary Care Programs (DoHFW)	550	See scheme components below	See scheme components below
17(1)	National Mental Health Programme		Improved coverage of mental health services **[No]**	Improved availability of mental health professionals **[No]**
17(2)	Assistance for capacity building of trauma centres (1. trauma centres, 2. prevention of burn injury)		N/A	Strengthened trauma care facilities and burn units for enhanced quality care to trauma and burn victims **[No]** Outcome indicator

Sn.	Name of the scheme (relevant MoHFW department)	Outlay (INR crores)	Relevant outputs	Relevant outcomes
				Provision of quality services to the victims of trauma and burn injuries by reducing deaths and disabilities **[No]**
17(3)	National Programme for Health Care of Elderly		Provision of tertiary geriatric care services **[No]**	N/A
17(4)	National Programme for Control for Blindness		Sensitization training sessions for trachoma elimination in previously endemic states for trachoma **[No]**	Trained eye surgeons, SPOs and ophthalmologists **[No]**
17(5)	Tele medicine		Doctors for specialist consultation **[No]**	N/A
17(6)	Tobacco Control & Drugs De-addiction Programme		1. Increase in availability of tobacco cessation services **[Yes]** 2. Increase in facilities for treatment of drug addiction **[No]**	1. Improved access for tobacco cessation services **[Yes]** 2. Improved access to drug dependence treatment services **[No]**
	National Programme for prevention and control of Cancer, Diabetes, Cardiovascular diseases and Stroke		<u>Output indicator</u> Drug treatment with OPD services **[No]**	Increase in availability of radio therapy machines **[No]**

Source: Union Budget of India 2019-20. Developed by author.

5. Scope of NFHS vis-à-vis health-related SDGs

The SDG indicator frameworks are a bit complex, so let us start with a brief overview of the global and national historical contexts.

Global context

On 25 September 2015, the United Nations General Assembly (UNGA) adopted the 2030 Agenda for Sustainable Development (Resolution 70/1). 'A plan of action for people, planet and prosperity', it is 'integrated', 'indivisible' and balances the 'economic, social and environmental' dimensions of sustainable development. Its 'integrated' nature is considered of 'crucial importance' for realizing its 'purpose' by means of 'collaborative partnership' between 'all countries and all stakeholders'. The Agenda envisages 'a world free of poverty, hunger, disease and want, where all life can thrive', 'where physical, mental and social well-being are assured', where 'all human beings can fulfil their potential in dignity and equality and in a healthy environment'. It sees poverty eradication 'in all its forms and dimensions' as 'the greatest global challenge' as well as 'an indispensable requirement for sustainable development'.

A total of 17 SDGs with 169 targets, to be achieved between 2015 and 2030, were included in the 2015 UNGA (Resolution 70/1). On 6 July 2017, the UNGA adopted the Global Indicator Framework (GIF) with 244 indicators – 232 excluding the ones repeated under different targets[99] – developed by the Inter-Agency and Expert Group on SDG Indicators (IAEG-SDG) and accepted by the United Nations Statistical Commission (UNSC) at its 48th session (7-10 March 2017). The 2017 UNGA referred to GIF 'as a voluntary and country led instrument that includes the initial set of indicators to be refined annually and reviewed comprehensively' by the UNSC at its 51st session (2020) and 56th session (2025), and to be 'complemented by indicators at the regional and national levels' to be developed by the member states. The decision on National Indicator Framework (NIF) is to be driven by national priorities, but aligned with SDG-GIF as much as possible.[100] 'Targets are defined as aspirational and global' and each government has to set 'its own national targets guided by the global level of ambition but taking into account national circumstances'. Recognizing gaps in data availability, a 'call for increased support for strengthening data collection' was made (UNGA 2015), and SDG target 17.18 ('data, monitoring and accountability') was included. SDG indicator 17.18.1 is about the 'proportion of sustainable development indicators produced at the national level with

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[99] Repeated SDG indicators (9) – 1) 8.4.1/12.2.1, 2) 8.4.2/12.2.2, 3) 10.3.1/16.b.1, 4) 10.6.1/16.8.1, 5) 15.7.1/15.c.1, 6) 15.a.1/15.b.1, 7) 1.5.1/11.5.1/13.1.1, 8) 1.5.3/11.b.1/13.1.2, 9) 1.5.4/11.b.2/13.1.3. The official indicator list, with periodic refinements agreed by the UN Statistical Commission, is available at – https://bit.ly/2oKA41P (16/10/2019, 10:51 hours). Total SDG indicators remain 244 after annual refinements in 2018 (E/CN.3/2018/2) and 2019 (E/CN.3/2019/2).

[100] https://bit.ly/35CJ0Hd (16/10/2019, 13:03 hours).

full disaggregation when relevant to the target, in accordance with the Fundamental Principles of Official Statistics'. The UNGA 2015 called for 'data which is high-quality, accessible, timely, reliable and disaggregated by income, sex, age, race, ethnicity, migration status, disability and geographic location and other characteristics relevant in national contexts'.

The IAEG-SDG has classified the 232 indicators into 3 tiers 'based on their level of methodological development and the availability of data at the global level' (table 5.1).[101]

Table 5.1: Tier classification criteria of SDG indicators

Tier	Classification Criteria	Number of SDG indicators (as on 26 Sep 2019)
1	Conceptually clear, internationally established methodology, standards available, data regularly produced by at least 50% of countries and of the population in every region where the indicator is relevant.	104
2	Conceptually clear, internationally established methodology, standards available, but data not regularly produced by countries.	89
3	No internationally established methodology or standards available, but being (or will be) developed or tested.	33
Multi-tier (different components of indicator classified into different tiers)		6

Source: United Nations Statistics Division. https://bit.ly/2jbOWzA (16/10/2019, 14:59 hours).

Given one's interpretation of determinants of health, beyond the direct 27 health indicators under SDG 3, one can add other SDG goals / targets / indicators to one's list of health-related SDGs. For instance, according to figure 5.1, SDG target 3.4 (NCDs) alone is linked with 8 SDG goals from the lens of social determinants of health (SDH). SDGs are 'integrated', and such interconnections are encouraged from conceptual as well as operational perspectives. In World Health Statistics 2019, the WHO tracks 43 health-related SDG indicators. Of them, 36 have unique indicator numbers in the official list of SDG indicators. Apart from SDG 3 indicators, WHO includes SDG 1.a.2 (domestic government health expenditure), 2.2.1 (child stunting), 2.2.2 (child wasting), 2.2.3 (child obesity), 5.1.2 (intimate partner violence), 6.1.1 (safe drinking water), 6.2.1 (safe sanitation), 6.a.1 (water sector ODA), 7.1.2 (clean energy coverage), 11.6.2 (fine particulate matter in urban areas), 16.1.1 (homicide) and 17.9.2 (cause of death data completeness). With the exception of 2 indicators under SDG 3 – SDG 3.5.1 (Tier 3) and SDG 3.b.3 (Tier 2) – all other SDG 3 indicators in the GIF have been classified as Tier 1 indicators (classification revised until 26 September 2019).[102]

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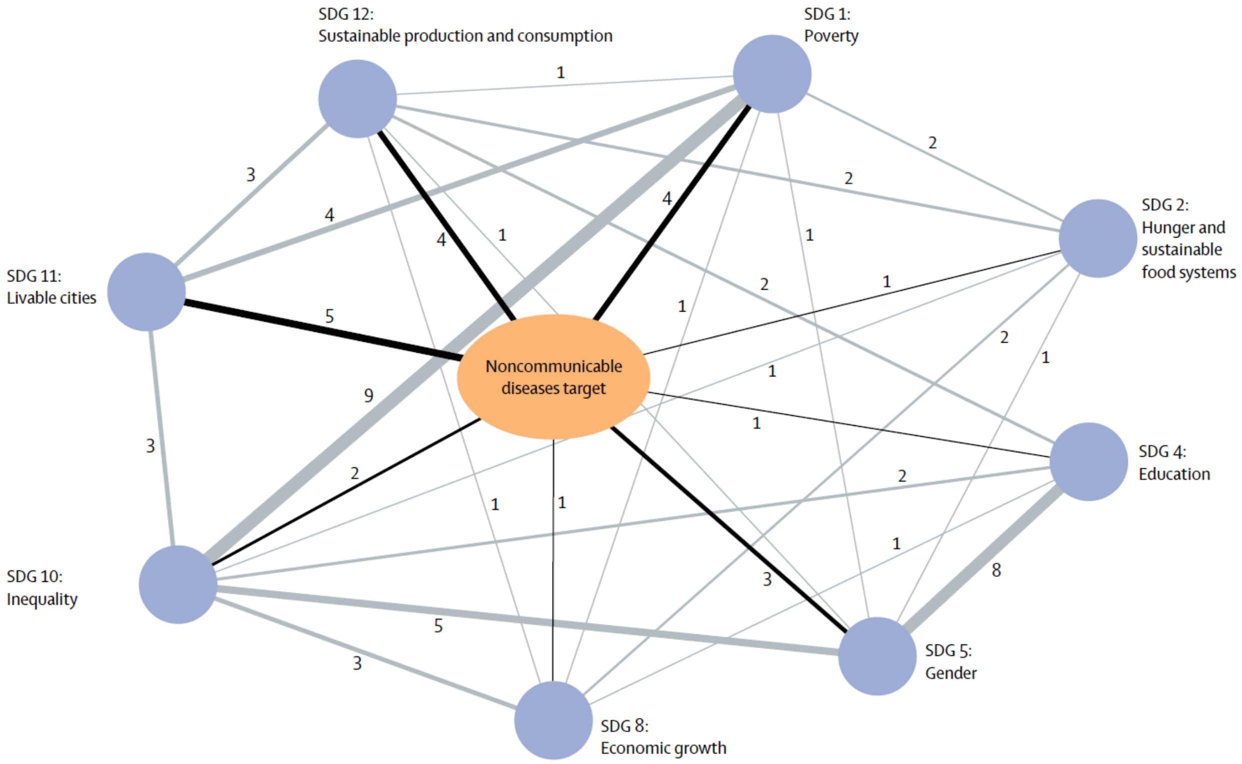
[101] https://unstats.un.org/sdgs/iaeg-sdgs/tier-classification/ (16/10/2019, 14:57 hours).

[102] https://unstats.un.org/sdgs/iaeg-sdgs/tier-classification/ (24/10/2019, 22:32 hours).

Figure 5.1: Interlinkages between SDG 3.4 (NCDs) and other SDGs



Source: Nugent et al 2018: 3.

Indian context

In India, MoSPI and the NITI Aayog have been involved at the central level for monitoring progress vis-à-vis the SDGs.

In consultation with Union government ministries / departments, states, UN, civil society and other stakeholders, MoSPI developed a National Indicator Framework (NIF) in the light of the global SDG indicators, and released a baseline report in March 2019 (version 1.0). A year later, in March 2020, it brought out an SDG progress report based on a revised list of NIF (version 2.0). NIF version 1.0 had a total of 306 indicators, while version 2.0 had 297. Of these, SDG 3 on health had the highest number of indicators in both versions – 41 and 42 respectively. NFHS was identified as the source of 30 SDG-NIF indicators in version 1.0 (9.8% of all NIF indicators) and 27 in version 2.0 (9.1%).[103] For SDG 3, NFHS was identified as the source of 14 (34.1%) and 16 (38.1%) indicators respectively.

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[103] Version 1.0 indicators with NFHS as the source – 1.3.1, 1.3.5, 1.4.3, 2.1.1, 2.2.1, 2.2.2, 2.2.3, 2.2.4, 2.2.5, 3.1.2, 3.1.3, 3.1.4, 3.2.3, 3.5.3, 3.7.1, 3.7.2, 3.7.3, 3.8.1, 3.8.4, 3.8.5, 3.8.7, 3.9.2, 3.a.1, 5.2.6, 5.3.2, 5.6.1, 5.6.2, 5.6.3, 6.2.1 and 7.1.1. Version 2.0 indicators with NFHS as the source – 1.3.1, 2.1.1, 2.2.1, 2.2.2, 2.2.3, 2.2.4, 2.2.5, 3.1.2, 3.1.3, 3.1.4, 3.2.3, 3.5.1, 3.5.3, 3.7.1, 3.7.2, 3.7.3, 3.7.4, 3.8.4, 3.8.5, 3.8.6, 3.8.7, 3.9.2, 3.a.1, 5.2.6, 5.3.2, 5.6.2 and 5.6.3.

On its part, the NITI Aayog has also developed 2 versions of the SDG India Index (SII). SII version 1.0 was released in December 2018 with 62 National Priority Indicators (NPIs) from MoSPI's NIF version 1.0 – out of which, there were 5 SDG 3 indicators, with NFHS identified as the data source for 10 indicators overall (16.1% of all SII indicators), including 3 SDG 3 indicators (60% of SDG 3 SII indicators). SII version 2.0 was released in December 2019 with 100 indicators[104] – out of which, there were 8 SDG 3 indicators, with NFHS identified as the source for 6 indicators overall (6% of all SII indicators), including 2 SDG 3 indicators (25% of SDG 3 SII indicators).[105]

NFHS' significance has relatively reduced vis-à-vis MoSPI's NIF as well as NITI Aayog's SII SDG indicators over their 2 versions, with the exception of SDG 3 NIF indicators in MoSPI's version 2.0. However, it needs to be pointed out that there are certain indicators for which the NFHS provides the data, but the SRS or another source has been identified. And, if those were also included, the NFHS tally would be much higher.

At the same time, it is worth referring to what the SII version 1.0 report stated regarding the issue of data availability: 'the preparation of the index has highlighted data gaps related to the SDGs', and 'the need for India to develop its statistical systems at the national and State levels', and 'increase the capacity and capability of data collection' (NITI Aayog 2018: 4). SII version 2.0 report restated that the 'incomplete coverage of targets remains a partially resolved issue' (NITI Aayog 2019: 7). Health surveys in the country should try to provide data on all health-related SDGs to facilitate an independent assessment of India's progress, at least, at the national and state / UT levels. Likewise, states / UTs should design their health surveys so that they could potentially offer data on all health-related SDGs at the state, district and sub-district levels.

A related challenge is that of data interoperability, considering the 'integrated' nature of the SDGs. The Economic Survey of India 2018-19 states that 'data collection in India is highly decentralised. For each indicator of social welfare, responsibility to gather data lies with the corresponding union ministry and its state counterparts. Consequently, data gathered by one ministry is maintained separately from that gathered by another'. Since 'these datasets are unconnected, each ministry only has a small piece of the jigsaw puzzle that is the individual / firm. However, if these different pieces could be put together, we would find that the whole is greater than the sum of parts' (Vol. 1: 85). Within ministries, there are jigsaw puzzles, and the idea of an integrated and interoperable HIS appears to be a far cry in the given situation, not to talk of interoperability across GoI or at the national level. Thankfully, there is a realization, and steps are being taken to address the problem.

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[104] While 68 were taken from MoSPI's NIF, 20 were 'modified or refined for the sake of data availability across all States/ UTs. 12 indicators which are not part of NIF were identified in consultation with line ministries' (NITI Aayog 2019: 7).

[105] Version 1.0 indicators with NFHS as the source – 1.3.1, 1.3.5, 2.2.1, 2.2.4, 3.2.1, 3.2.3, 3.8.8 (NFHS does not provide data for this indicator ['total physicians, nurses and midwives per 10,000 population'] – MoSPI identified DGHS / MoHFW and not NFHS as the source for this indicator), 5.2.3 (MoSPI identified NCRB, not NFHS, as the source for this indicator), 5.6.1 and 7.1.2. Version 2.0 indicators with NFHS as the source – 1.3.1, 1.3.5, 2.2.4, 3.2.1, 3.7.1 and 5.2.6.

Recommendations

- The ‘integrated’ nature of Agenda 2030, and the ‘collaborative partnership’ required to realize its ‘purpose’, has led to international discussions on data interoperability to leverage traditional and new sources of data for monitoring progress on SDGs.[106] The MoHFW released the EHR standards (version 1 in 2013 and version 2 in 2016) aimed at ‘achieving syntactic and semantic interoperability of health records’ of individuals. MoSPI, NITI Aayog, MoHFW and others should coordinate to develop a plan of action for data interoperability at the population health level, and suggest syntactic and semantic changes for various health data sources. Simply mapping data sources / schemes / ministries would not be enough to realize the ‘integrated’ nature of the SDGs. The Intersecretariat Working Group on Household Surveys (ISWGHS), established in 2015 by the UNSC ‘to foster coordination and harmonization of household survey activities’, can also possibly be consulted. MoSPI has already been participating in UNSC’s SDG activities.

- Interoperability will help in understanding the social determinants of health, syndemics[107] as well as the social *implications* of health (how pursuit of health impacts other sectors and concerns), in the spirit of the 2030 Agenda. A One-Health approach for the surveillance of antimicrobial resistance (AMR) – involving humans, animals, food and the environment – is already widely accepted internationally, and there has been some renewed focus on syndemics. A syndemic and comprehensive One-Health approach (beyond the narrow focus on AMR) to public health surveillance should be developed by DoHR (MoHFW), MoSPI, MEITY, NITI Aayog and others.

- ‘Collaborative partnership’ between all stakeholders implies that data for monitoring progress on SDGs should be sourced from as well as shared with various stakeholders, and not just the governmental. Given that 71.7% spells of ailment in rural India and 78.8% in urban India were treated in the private sector (NSS 71st round),[108] we need a plan to access and integrate this

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[106] Data interoperability in the context of SDGs has emerged as a key theme in international discussions since the 47th session of UNSC in March 2016. The Cape Town Global Action Plan for Sustainable Development Data, launched at the first United Nations World Data Forum (UNWDF) in January 2017, and adopted at the 48th UNSC Session in March 2017, calls on countries to modernize their statistical standards, to ‘define and implement standardized structures for the exchange and integration of data and metadata on the social, economic and environmental pillars of sustainable development’ at the global, regional, national and sub-national levels, and ‘promote interoperability of these systems to facilitate such integration’ (strategic area 2, objective 2.2). The Plan also called for increasing ‘the integration of data from different sources: surveys, administrative data and new sources’ (strategic area 3, objective 3.1). Interoperability of SDG data continued to be discussed during the 49th (2018) and 50th (2019) sessions of UNSC as well as UNWDF 2 (2018), where ‘Data interoperability: A practitioner’s guide to joining up data in the development sector’ was launched.

[107] ‘Specifically, a syndemics approach examines why certain diseases cluster (ie, multiple diseases affecting individuals and groups); the pathways through which they interact biologically in individuals and within populations, and thereby multiply their overall disease burden, and the ways in which social environments, especially conditions of social inequality and injustice, contribute to disease clustering and interaction as well as to vulnerability’ (Singer et al 2017: 941).

[108] NSS. 2015. ‘Key indicators of social consumption in India: Health’. NSS 71st Round (January-June 2014). MoSPI.

data from the private sector – and possibly private personal data, with paramount priority given to individuals' consent and confidentiality in particular – for monitoring national health policies, programs as well as health-related SDGs. Government-funded health insurance programs are one mechanism through which data sharing by the private sector and individuals can be made mandatory – again, with utmost importance assigned to the confidentiality of the data sources.

® The 2030 Agenda talks about poverty in all its forms as the greatest global challenge. However, it is the notion of 'income poverty' that is most prevalent. Even in terms of health, SDG indicator 3.8.2 (proportion of population with large household expenditures on health as a share of total household expenditure or income) is motivationally concerned with impoverishment, but of an income / expenditure type, arising from access to health care. We should consider developing the notion of and a composite index for 'health poverty', primarily focused on health outcomes, but also access to efficacious, safe and quality health care. NITI Aayog's Health Index can be an inspiration for a 'Health Poverty Index' (HPI). The Multidimensional Poverty Index (MPI) – developed by the Oxford Poverty & Human Development Initiative (OPHI) and the UNDP, with 10 indicators for 3 dimensions of poverty (health, education, living standards) – is great, but is multisectoral. We need one specifically for health as well. The World Bank has one for 'learning poverty' – why not have one for health poverty too?

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6. Data for Health Technology Assessment (HTA)

With India's increasing commitment to universal health coverage, especially following the launch of Ayushman Bharat, the necessity for the establishment and strengthening of HTA frameworks and capacities has increased in the country. Our journey in this direction has just begun, and it is the right time to incorporate HTA as well in our discussion of institutional data requirements in the country. We referred to NHP 2017's commitment to the development of an institutional framework and capacity for HTA in chapter 1. As a follow-up, DoHR in MoHFW set up the Medical Technology Assessment Board (MTAB) in January 2017, later renamed as the Health Technology Assessment in India (HTAIn),[109] with the following objectives[110] –

1) Maximize health and minimize out-of-pocket (OOP) expenditures and inequities in health care services;
2) Assess new / existing health technologies vis-à-vis safety; cost and clinical efficiency; budget impact; ethical, social and political feasibility to ensure rational allocation of limited resources for access to quality and equitable health care;[111]
3) To collect and analyze data in a systematic and reproducible manner, ensuring its accessibility and usefulness to inform health policy;
4) Support central and state level health care decision-making;
5) Disseminate findings and related policy decisions to educate and empower the public to make better informed decisions for health.

The HTAIn is not only responsible for collating, but also generating evidence wherever needed.[112] The Health Technology Assessment Board Act, 2019 is in public domain for comments.[113] A DHR-HTA National Database will also be freely available to the public in the near future. As of now, data sources available for HTA-relevant information and assessment are captured in table 6.1 below. It has been argued that there is 'marked absence' of certain types of 'data necessary for informing HTA, particularly data relating to cost, service use, and quality of life' in the Indian context (Downey 2019: 1). As we can see, NFHS is the source of very limited information from an HTA perspective.

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[109] HTAIn Secretariat. 2019. 'A compendium of health technology assessment in India (2017-18)'. DoHR (hereafter 'HTA compendium').

[110] https://dhr.gov.in/about-mtab (4/10/2019, 15:36 hours).

[111] This is particularly helpful as India progressively moves towards universal health coverage (UHC). सर्वे: सन्तु निरामयाः (let all be healthy) is inscribed in HTAIn's logo, expressing its commitment to UHC. https://bit.ly/2LIP09o (4/10/2019, 15:36 hours). HTAIn has been working with Ayushman Bharat to review the packages offered by it ('HTA compendium').

[112] http://htain.icmr.org.in/ (4/10/2019, 15:52 hours).

[113] https://bit.ly/2MbdZRL (4/10/2019, 15:44 hours).

Table 6.1: Key national data sources for HTA in India (as on 17 May 2019)

HTA-related information	Data source	Commissioning body	Equity-relevant information
Epidemiology (communicable disease)	IDSP	MHFW	Geographic location
Epidemiology, service use, health expenditure	HMIS	MHFW	Gender, geographic location
Epidemiology, service use, OOP spending (for institutional delivery only)	NFHS-4	MHFW	Location, gender, ethnicity, age, marital status, contraception use, HIV status, health insurance, water/ sanitation access, literacy, female parity
Epidemiology	SRS, Census 2011	MHA	Location, gender, religion, education, occupation, caste/tribe, language, socio-economic status
Health and service use/utilization for RMNCH indicators	DLHS-3	MHFW	Accessibility of services to women and children in rural villages
Epidemiology, service use, OOP spending	NSS	MS	Location, socioeconomic status, gender, rural/urban, age
Safety, efficacy, clinical comparator(s)	ICMR Clinical Trials Registry	ICMR	No
Epidemiology - Cancer	ICMR Cancer Registry Program	ICMR	Location, gender, rural/ urban, age
Health expenditure	National heath Accounts (2014/2015)	MHFW	Public and private sector expenditure
Billing/Price	Database of Indian Health Benefit Packages		
Health Benefit Packages	WHO India Country Office	Database listing service packages and rates across 22 GFHIS	
Billing/Price	Central Government Insurance Scheme Rates information	CGHS	No
Billing/Price	RSBY package reimbursement rates	RSBY	No
Equity	Socio-economic and Caste Census (2011)	MRD	Socio economic status, caste, religion, living conditions, source of income

Source: Downey, Laura et al. 2018. 'Identification of publicly available data sources to inform the conduct of Health Technology Assessment in India'. F1000Research 7:245.

SECTION 2 –

PERSPECTIVES FROM THE FIELD

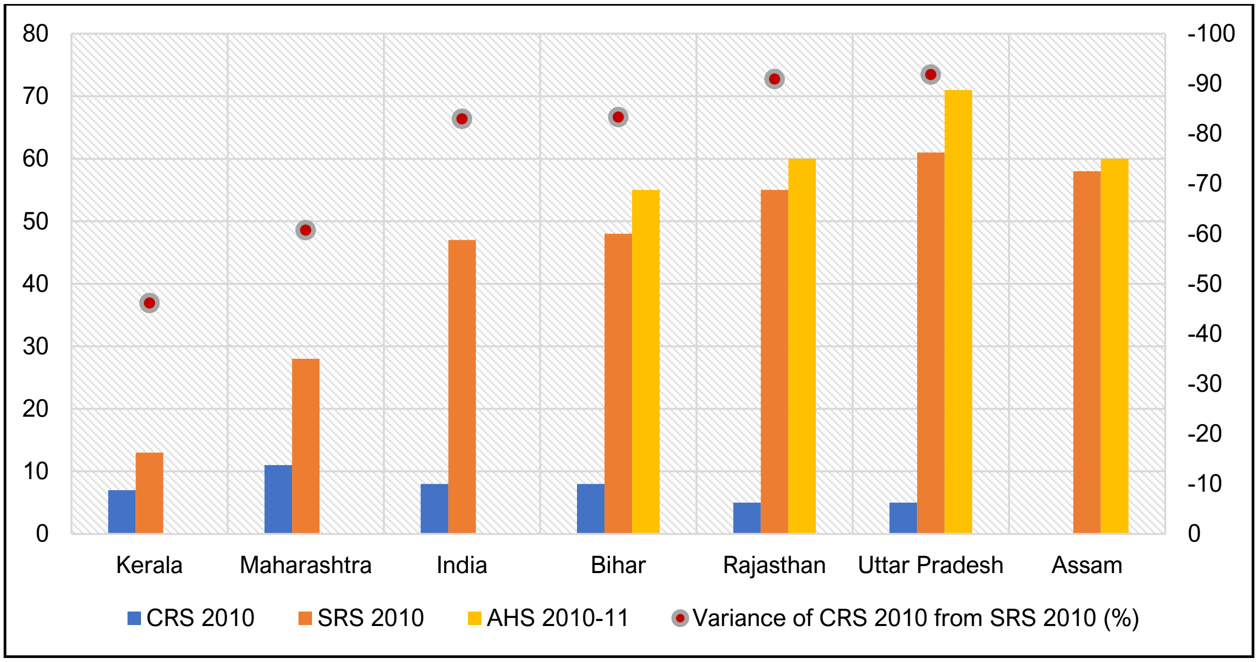
7. Overview of selected states

As part of our field research, we conducted interactions with key stakeholders and experts in New Delhi and 6 states. The rationale for state selection is discussed in the study methodology section of the introduction. In the next chapter, we will share the perspective of respondents (kindly refer to Annexure A for their list) largely on the NFHS by broad themes, but also on other surveys / health data sources. As one can see, their perspectives are, quite naturally, divergent on several themes. Our effort has been to share them objectively from our side for readers' consideration, irrespective of our own views. This is the reason why we did not try to put them out in a narrative / paragraph format, rather as points, which also helped us in presenting them in a focused and concise manner.

Let us start out with a brief overview of selected states. Table 7.1 below highlights the importance of independent data on health through representative population surveys. To begin with, selected states represent various population sizes – from large (UP) to medium (Maharashtra and Bihar) to the smaller ones (Assam and Kerala). However, it is interesting to note that, though Assam's share of national population as well as deaths was similar (2.6% each), Rajasthan, Bihar and Maharashtra had lower shares of deaths vis-à-vis their national population shares, with UP and Kerala – states usually at two different ends of the human development spectrum in the country – had higher death shares. India had the world's largest share of deaths between 1990 and 2013 (with the exception of 2004), with China taking a major lead since 2014, thanks to the latter's ageing population. If one looks at the pattern of under-70 year deaths, there is a huge variation between the two – with India being at the top by a huge margin and China recording massive declines between 1993 and 2007 (GBD). So, although India has recently become the world's second rather than the top contributor to deaths, India's share of premature deaths is much higher than China's, which is the worrisome part from a health perspective. Reductions in premature mortality have been part of international commitments, including SDG 3. And this is where UP is of utmost concern – out of the 5.9 million premature deaths (under 70) in India in 2017, more than a fifth (1.2 million) were in UP alone (GBD).

If we look at the causes of death, although a substantially higher percentage of deaths within Kerala and Maharashtra were due to NCDs, number of NCD deaths was substantially higher in UP, given its much larger share of total deaths. The proportion of deaths due to the traditional communicable, maternal, neonatal and nutritional diseases was anyways substantially higher in Bihar, UP as well as Assam and Rajasthan – the health-backward states in our selection. No wonder life expectancy was also lower in these states, with Bihar's performance being surprisingly better than its peers. We have taken IMR from 2 sources – SRS for 2016 and NFHS-4 for 2015-16. Almost all respondents in Kerala referred to differentials in their IMR from these sources. Since the NFHS-4 IMR matched with IMR from their HMIS (2015-16, 2016-17) and CRS (2016) data – 5.6, 6 and 5.59 respectively – they felt that the quality of the NFHS-4 data is, *therefore*, suspect – the quality of HMIS and CRS data seen as *essentially* suspect and that of the SRS beyond doubt. We also see huge differentials between the IMR of other states – most spectacularly, UP's – from the 2 sources, Rajasthan being the only exception. Coming back to Bihar, we see that, while it did best among its peers as far as the SRS data was concerned, it was behind Rajasthan and Assam as far as IMR from NFHS-4 was concerned. Figure 7.1 shows that there could be substantial variations in IMR from 3 data sources (CRS, SRS and AHS – the latter 2 being surveys) from the same agency (Registrar General of India, Ministry of Home Affairs). It needs to be noted that data variations from different sources does not automatically imply superiority of one or inferiority of the other, as data integrity measure indicator of the NITI Aayog's Health Index hints at. While differences in concepts and methodology explain differences in data from various sources, the imperative of relying on a particular data source for the purposes of policy and program design and evaluation implies that a through investigation is needed on the source of differentials on a case-by-case basis which can help select a data source to rely on for critical matters of priority-setting and resource allocation, for instance. Nevertheless, it is interesting to note in figure 7.1 that differentials in data are lesser in better-off states like Kerala and Maharashtra compared to the health-backward states. So, one could possibly argue that the quality of the administrative health data (CRS) is relatively better in the former set of states – which also hints at a correlation between their IMR and the robustness of their administrative health data.

Figure 7.1: IMR for India and selected states from CRS 2010, SRS 2010 and AHS 2010-11



Source: ORGI 2013 and AHS 2010-11 (variance is mapped on the secondary / right axis).

The less robust the administrative health data, the more the reliance on independent survey data should be. Nevertheless, we observed a far greater sense of keenness vis-à-vis the NFHS in Kerala than in the health-backward states. In Rajasthan, a very high-ranking health official was absolutely against the conduct of health surveys and humiliatingly argued that the era of surveys is over and they should be done away with, and the Government of India should rather support administrative data – this at a time when the nationally infamous Kota child deaths were happening. This not only reflects an antipathy toward data in general, independent data in particular, but one of the reasons for persistent backwardness vis-à-vis a primordial health outcome like IMR.

Coming over to treatment source, we see that the reliance on government / public hospitals is the highest in Kerala and lowest in UP. Nevertheless, out-of-pocket health care expenditure is high in Kerala, but still lower than Bihar and UP. Given that the latter two had a much high proportion of their population below the poverty line than Kerala – 33.7%, 29.4% and 7.1% respectively (2011-12, Tendulkar methodology) – such expenditure may not be as catastrophic as it would be in the latter two states. People in Kerala prefer going to specialists even for small health care concerns vis-à-vis states like UP and Bihar (field research), which explains its high out-of-pocket expenditure. As far as level of registration of births is concerned, there is a huge differential between the NFHS-4 and CRS figures in the case of Rajasthan, which may be a partial cause of the Rajasthan official's anger against the NFHS. As far as level of registration of deaths is concerned, the figure is again high for Rajasthan, especially vis-à-vis its peers, but since there is no independent data available, we cannot be sure about it. It is very high in health-advanced states vis-à-vis the other 3 -backward states (Bihar, UP and Assam). Difference in the level of registration of births and deaths in health-backward states is also quite significant, which is not the case in health-advanced states.

From the perspective of this study, as we said at the beginning of this chapter, all these data points highlight the importance of population-wide estimates from independent surveys, especially in the health-backward states. Low population coverage of government facilities and high out-of-pocket expenditures (largely made in private facilities) mean that states are not able to capture population-wide data as part of their administrative health data systems. With private sector data still largely not shared with governments, the only way to have population-wide estimates – with the exception of extrapolations, which are not usually preferred – is through population sample surveys – not to mention poor quality and highly fragmented capture of administrative data, which further enhance the need for high-quality population-wide survey data. As we said at the beginning of the report, this is one of the major reasons why NFHS has become eminently important in the Indian context. Despite administrative data being the currency which policymakers across various levels deal with on a routine basis, survey data is largely invoked for policy- / program-making and accountability purposes on a random rather than a systematic basis. Among surveys, preference is widely given to the government's own survey (SRS) vis-à-vis the NFHS, coordinated and conducted by external agencies. Inasmuch as this is the case, the governmental system continues to be caught up in the socialist mindset of yesteryears, with the nongovernmental seen as suspicious. However, it should be acknowledged that, despite this, the NFHS has received a lot of respect within, and particularly outside, the government – at least, centrally, if not in the states, particularly in the health-backward.

Table 7.1: Overview of selected states

State	Source	India	Rajasthan	UP	Bihar	Assam	Maharashtra	Kerala
Projected population (% of national, 2016)	MoHFW	1.3 billion	5.8	16.7	8.8	2.6	9.2	2.7
Total deaths (% of national, 2017)	GBD	9.9 million	5.5	18.1	7.5	2.6	8.8	3.1
Cause of death (COD, 2017) - NCDs		63.5	59.7	54.4	52.6	59.8	70.6	81.9
CoD - Communicable, maternal, neonatal and nutritional diseases		26.7	31.8	35.9	38.5	32.2	19.8	8.8
CoD - Injuries		9.9	8.5	9.7	9.0	8.1	9.6	9.4
Life expectancy at birth (2011-15)	SRS	68.3	67.9	64.5	68.4	64.7	72	75.2
IMR (2016)		34	41	43	38	44	19	10
IMR (2015-16)	NFHS-4	40.7	41.3	63.5	48.1	47.6	23.7	5.6
Ailments treated on medical advice by source: government / public hospital (%, 2017-18)	NSS 75th round	30.1	39.8	14.1	18.5	43	25.2	47.5
Out-of-pocket health expenditure (% of total health expenditure, 2015-16)	NHA	60.6	56.4	76.5	79.9	55.1	58.9	71.3
Children (0-4 years) whose births were reported registered (%, 2015-16)	NFHS-4	79.7	66.6	60.2	60.7	94.2	95.1	97.7
Level of registration of births (%, 2016)	CRS	86	100	60.7	60.7	100	94	97.1
Level of registration of deaths (%, 2016)		78.1	93.3	40.2	28.3	59.8	93.7	94.3

8. Perspectives on the NFHS and other surveys[114]

Objective (PRCs)[115]

1) One of the initial objectives of the NFHS was to strengthen the survey capabilities of Population Research Centres (PRCs) of the MoHFW.[116] Earlier, PRCs were involved with NFHS. However, with their subsequent exclusion from the NFHS landscape, the quality of NFHS has deteriorated – as has the relevance of the PRCs.
2) There is now a weak link between the PRCs and the government as well. There are no regular interactions with policymakers. At least, one quarterly meeting should be conducted. 'It is not clear to what extent, and in what form is our research being used in policymaking. PRCs have published a lot of research, undertaken several government projects. But there is no feedback on our work. We are not aware if any actions have been taken based on our recommendations'.
3) It was thought that since PRCs would not be able to conduct the NFHS alone due to shortages in their manpower, skills, etc., private consulting agencies (CAs) were identified for each state. It was decided that data collection will be done by the PRCs and CAs together. Capacity-building of PRC staff was also done. However, after NFHS-1, the role of PRCs was significantly reduced.
4) Earlier, the role of the Pune PRC, in particular, was quite substantial. During the first round of the NFHS, a workshop was organized by it, in which all the questionnaires were finalized from their DHS templates. It has also given inputs for NFHS training of the trainers of the field staff.
5) PRC Lucknow was involved in NFHS-4. Due to several issues, it had to withdraw from NFHS-5. According to rules, payments are made to third parties / government institutes on the basis of the number of schedules covered by them – agreement happens on a per unit rate. If there are any savings, they are used for infrastructural development. 'We have always been allowed to retain them. That is how institutions like the PRCs develop further. There were certain issues in the fourth round also despite the written agreement – the last tranche of payment was not released to us. So, in this round, I raised a question – if we will have savings, what will happen to them? Private institutions were allowed to keep these savings, but the same was not allowed for the PRCs! In fact, the IIPS discouraged the PRCs to take up the NFHS. It was an extremely unfortunate thing! The message I got from somewhere else was that the IIPS feels that private

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[114] Field interactions in New Delhi were conducted by the author, Priyanka Tomar (1), Divya Chaudhry (2) and Nilanjana Gupta (3). The author conducted field interactions in Rajasthan and Kerala; 1 and 2 in Maharashtra and Uttar Pradesh; and 3 in Bihar and Assam. Transcriptions were done by 1, 2 and 3; coded and prepared for this chapter by the author.

[115] For details about the PRCs, see – https://bit.ly/3dYjQGB and https://bit.ly/3d4VKsM (13/6/2020, 17:03 hours).

[116] http://rchiips.org/NFHS/nfhs1.shtml (13/6/2020, 17:05 hours).

parties should get involved in the NFHS and PRCs / government institutes should not be. So, eventually, we decided not to go for the bid. The agreement we had for NFHS-4 has not been fulfilled. If it was framed in a manner saying that PRCs were handed over the studies on a cost basis, we would have had no issues on that. But once you are going into an agreement – firstly, the agreement should be honored; secondly, government institutions should be more favored vis-à-vis private parties. It should not happen the other way round. We do so many studies and much of government funding is on the lines of cost basis. We do not have a problem with that'.

6) Since 2012, PRCs have been extensively involved with the monitoring and evaluation of NHM Programme Implementation Plans (PIPs) and quality monitoring of HMIS data. They regularly review and validate HMIS data. 'When we started, the quality of data was very poor – only 20-30 percent was reliable. But now, we can say that nearly 70 percent of the data is reliable'.

7) Given serious shortages of funding and manpower, PRC in Guwahati is almost defunct. During NFHS-1 in Assam, it played a prominent role as the NFHS field survey agency (FSA) of Assam.

8) Currently, the PRC Kerala monitors all PIPs for Assam and few other northeastern states / UTs. PRC Kerala is also looking after Odisha.

9) PRC Kerala is involved in conducting vulnerability analysis and primary health surveys in urban areas, which would form the basis for deciding the location of urban health centres in the state.

10) PRCs should, once again, be involved in the NFHS. Several PRCs were also involved in DLHS. 'Given the fact that we have more than 25 years of field-related research experience, experts at PRCs can play a crucial role in the conduct of NFHS. We understand the nuances of such surveys, and are equipped to deal with field-related challenges. Involving PRCs in the exercise would definitely improve the data quality of the NFHS and other surveys'.

Thematic scope

1) The issue of multiple health surveys versus one health survey has been extensively discussed, especially in 2012. Consolidating all health surveys into one could have addressed the problem of differences in sample design / frame, which could have helped in linking several indicators.

2) NFHS should be as comprehensive as it could be. It is not possible to plan such a large-scale survey for different themes as it is extremely resource-intensive. For households too, it is not possible to spare time again and again for different surveys. NSS schedules are also elaborate, and have expanded overtime. NFHS should follow the same trajectory.

3) NFHS needs to evolve in the light of the changing demographic and epidemiological profiles.

4) The scope of NFHS may be revised to cater to the data requirements of NHP 2017.

5) NFHS-5 covers a total of 29 out of 44 SDG health-related indicators. The number of indicators covered will be different depending on whether the calculation is based on the standard global SDG indicators or the India-specific SDG indicators.

6) It is not reasonable to have one health survey that provides all required data / indicators.

7) If NFHS questionnaires are expanded further, more data collection will happen, but the quality of data will suffer. After 1 or 1½ hour of interview, it is very difficult to maintain the respondent's attention and interest. Besides, from an ethical point of view, it is not justified to ask so many questions, especially when respondents are not being paid / offered any reward / incentive for providing their valuable time.

8) In view of differences in objectives, design and periodicity of different surveys (such as SRS, NSS, NMHS, etc.), mapping of indicators across the surveys may not yield the desired results.

9) NFHS should continue to focus on its primary strength (RCH) and drop all other questions. There should be other surveys to cover other aspects of health on a regular basis.

10) In data collection, the traditional approach is to collect everything possible. However, it defeats the very purpose for which data is being collected. This approach has also been applied in the design of the NFHS in recent years. It should continue to focus on its primary strength (RCH).

11) IIPS has its expertise in demography. They tend to push their own agenda in the NFHS.

12) While certain international sponsors wanted to include adolescent health in NFHS-3 and -4, IIPS was reluctant to do so. It influences the Technical Advisory Committee (TAC), which is the nodal body responsible for the design and implementation of NFHS. It knows how to go around and get things done as it wishes.

13) ICMR is too biomedical and is not social scientific. If NFHS was to be conducted by them, its social scientific dimension will be affected.

14) Surveys like the NFHS also need to provide morbidity statistics.

15) Although the scope of NFHS is being broadened to include NCDs and other emerging health-related challenges, it is necessary to conduct cost-benefit analyses before augmenting the scope of large-scale surveys such as the NFHS.

16) We need better mechanisms to capture the prevalence of NCDs / their risk factors in surveys.

17) NFHS-5 will provide estimates on 5 types of disabilities.

18) NCDs and disabilities should not be included in the NFHS.

19) Indirect estimation of DALYs is possible using the NFHS data.

20) Indicators to monitor performance of national health programs should be included in NFHS.

21) Only a few crucial health outcome indicators should be prioritized and measured regularly.

22) It is better to restrict the number of questions and focus on key aspects. Rather than increasing the size of questionnaires, emphasis should be on getting complete and accurate information.

23) NFHS does not collect information on causes of death (CoD) in detail. In large-scale household surveys, it is not feasible to canvas modules based on CoD.

24) NFHS indicators are not mapped to WHO's ICD.

25) Under NFHS-5, data on biomarkers is being collected from children aged 0-5 years, women aged 15-49 years and men aged 15-54 years.

26) It has been decided to conduct HIV testing in every alternate round of NFHS. In NFHS-4, HIV testing was done. HIV testing will now be done in NFHS-6.

27) As incidence of mental health issues (depression, anxiety, etc.) is rising rapidly, it is important to conduct a separate survey on mental health. Further rounds of NMHS should be conducted. Further, in order to destigmatize mental health, it is important to mainstream its evidence.

28) It is difficult for NFHS to include questions on socially sensitive issues such as mental health.

29) As communicable diseases like kala-azar are endemic to a few states / districts, questions related to them should be avoided in national health surveys. Alternatively, conducting local surveys can significantly contribute to the understanding of determinants and estimating the incidence of such diseases. However, questions related to certain communicable diseases which are of public health importance at the national level (malaria, dengue, etc.) should be covered in the national surveys.

30) NFHS should also include indicators like out-of-pocket health care expenditures.

31) As migration is one of the three components of demography, NFHS should include questions to evaluate the proportion of population which has migrated (within or across states) and the kind of health concerns being faced by it. There is substantial migration from the backward districts of Maharashtra to cities like Mumbai and Pune, for instance. There should be focus on migrant health as well. The Maharashtra health department is trying to address the health challenges being faced by sugarcane farmers, who are mostly intra-state migrants, for instance. Due to non-adherence of treatment, incidence of drug-resistant tuberculosis is rising among this section of the population.

Geographical scope

1) Health is a state subject. There are different state health requirements, and sometimes national surveys cannot cater to these state-specific requirements.

2) A data strategy is needed for Centre, states and districts as well as for different kinds of health conditions / diseases.

3) It is possible for states to design and conduct their own health surveys. However, unlike NFHS, inter-state comparisons would be difficult through such surveys.

4) State-specific surveys may be conducted to complement the NFHS. NFHS state samples may be used to address the problem of inter-state comparability and national aggregation.

5) States must be consulted in the design and implementation of NFHS. This is important from the perspective of highlighting the burden of certain state-specific health challenges in a large-scale health survey such as the NFHS.

6) It is good to have state- / district-level health surveys in addition to one national health survey. It is impossible to include everything in a national health survey. Maharashtra and Tamil Nadu conduct independent health surveys, for instance, as part of which they collect data up to the block level. Such surveys could be designed based on the epidemiological profile of the states.

7) Customized surveys at the state level would be a better strategy. For instance, in Maharashtra, RCH issues are not as worrisome as micronutrient deficiency issues like stunting. Hence, from a policy perspective, we should channelize more resources for dealing with stunting and other nutritional concerns vis-à-vis RCH. National surveys will be useful to compare the performance of the states / UTs.

8) It is important to understand the data requirements of every state – for instance, illicit drug use is very high among women in northeast states which also has severe implications for the health of children. But, due to lack of data, we have very limited understanding on this issue. Similarly, there are several other important factors which are not being captured in the NFHS that have a bearing on maternal and child health in Assam.

9) From the perspective of estimating the burden of NCDs, state-level data is sufficient. However, within each state, there can be a lot of heterogeneity. Based on whether the population is tribal / non-tribal and topography of the state, there can be certain pockets where the prevalence of modifiable risk factors – such as tobacco and alcohol consumption, physical activity, etc. – is higher vis-à-vis others.

10) NFHS should also provide data on mortality indicators at the district level as there is no reliable source for it at the moment.

11) Due to small sample size, NFHS cannot provide district-level TFR, IMR, U5MR, etc. estimates.

12) NFHS consists of state and district-level modules. Out of 114 indicators, district-level estimates are provided for 93 indicators.

13) We need SRS data at the district level as well.

14) Districts should be the data units. They have their data needs. Presently, local data collection happens for higher requirements. Local data requirements are neither assessed nor taken into consideration. Even the HMIS is designed for central government's data requirements.

15) Another challenge is that small-big town differences are not taken into consideration in NFHS as city estimates are difficult to calculate – one cannot calculate estimates for cities with less than 10 lakh population. Smaller cities should not be ignored as these are the ones which are providing services in rural areas.

16) Although we are focusing on districts now, we should focus on agro-climatic zones, as districts are administrative, not natural, units. Interventions can be similar in similar agro-climatic zones. For states like UP, data by agro-climatic zones would be a huge enabler.

17) There is a need for local level data. In Kerala, a lot of health-related activities are happening at the panchayat level. Administrative data is not very reliable. Therefore, local population-based surveys / studies would be helpful.

18) It is important to devise a strategy for better use of health data. Before data collection, it is vital to consider local data requirements and educate local experts about the use value of this data.

19) Population health surveys should also try to cover the impact of local determinants on health. For instance, if shopkeepers in a locality sell non-iodized salt, people there would be at risk of goitre. Similar problems can arise when soil in a region does not have adequate salt content.

20) It is difficult to customize in large-scale sample surveys. Customization of questions related to HIV was done during NFHS-2. Different questions could be included for different NFHS zones. Collecting data on same parameters across the country offers a comparable view, but misses out on region-specific issues. For instance, the entire dynamics change across regions in UP – the factors that could be responsible for a particular outcome in Lucknow, for instance, would be very different for Eastern UP. Nevertheless, while desirable, customization of questionnaires would make the entire process very tedious and data quality may be at stake.

Periodicity

1) A major issue vis-à-vis health surveys in India is their frequency. There should be a mechanism to conduct health surveys annually. Countries in Africa are already designing / implementing mini-DHS – of which NFHS has been a part – to capture critical health data at shorter intervals.

2) Beyond health, frequency of other surveys / estimates should also be improved. For instance, unit-level data from the 2011 Census is not yet available in the public domain; the latest poverty estimates are available for 2011-12, so on and so forth.

3) A periodicity of 3-4 years should be fixed for the NFHS. Availability of data from other sources such as the Census should be expedited.

4) Due to its periodicity in particular, NFHS data does not contribute much to state-level planning in the health sector.
5) For policy purposes, there is a need for real-time data, which the NFHS does not provide. Lack of availability of quality survey data at regular intervals negatively affects the quality of regular policymaking and program monitoring and evaluation in the country.
6) Small / region-specific / special surveys should be conducted between 2 NFHS rounds.
7) One national health survey must be conducted independently at regular intervals. In addition, local health surveys may be conducted on the basis of local requirements.
8) Annual estimates of key outcome indicators like IMR and MMR are not needed as interventions to tackle them take time to materialize. Annual estimates put undue pressure on states to show improvement in their performance. During the design of NFHS-4, involved experts had several rounds of discussion on this issue. A consensus was reached to capture such critical outcome indicators at intervals of 5 or 10 years. However, annual estimates of input or access indicators are indeed worthwhile.

Sample design

1) The concept of village is different in North vis-à-vis South India, especially Kerala. The sample design and house-listing of the NFHS needs to be accordingly revised.
2) Household mapping was not done properly for NFHS-4 and -5. Kerala's IMR data from NFHS-4, therefore, should be taken with a pinch of salt.
3) Backward areas were selected in Rajasthan for the NFHS, leading to skewed data for the state.
4) There are practical challenges with NFHS sample design – for example, accessibility in tribal / remote areas.
5) NFHS sample size does not permit obtaining reliable data on indicators like MMR. We need to find ways to bridge such data gaps in the NFHS.
6) NFHS sample design is primarily oriented towards RCH issues – an alternate sample design is needed to cover other health issues in the NFHS.
7) Selecting a sample for demographic estimates and selecting a sample for estimating the NCD burden are two different things. For demographic estimates, there are no issues with the NFHS methodology, but for NCD-related indicators, there are problems with its sample design. There are statistical techniques to tackle such challenges – for instance, assigning weights. However, it is preferable to have different sampling strategies for such varying health themes.
8) It is unnecessary to include men in all rounds of the NFHS.

9) Adolescents are not being covered under NFHS, which is another major concern. NCD burden is quite high among adolescent age-groups as well.

10) Due to its large sample size, NFHS is vulnerable to data quality issues.

11) NFHS sampling is such that after a point, you start getting similar responses.

Questionnaires

1) Although the NFHS predominantly follows the DHS questionnaire template, it has undergone substantial revisions based on Indian requirements.

2) NFHS questionnaires are finalized by IIPS in discussion with the central ministries. State health departments are not consulted.

3) NFHS questionnaires are extremely lengthy, which commonly leads to respondent fatigue and reduced probability of obtaining responses, especially to questions towards the end.

4) After an hour, it is impossible to hold the attention of the respondent. Besides, from an ethical point of view, it is not justified to ask so many questions to a respondent, especially when they are not paid or given any kind of reward / incentive for providing their valuable time.

5) In an extensive survey like NFHS, questions on important / thrust areas should be asked first.

6) Though context-specific questions should be included in the NFHS to capture context-specific data, length of NFHS questionnaires cannot be further increased. Covering everything under a single survey is not suitable either from a survey design, fieldwork or data quality perspective.

7) It is difficult to customize in large-scale sample surveys. Customization of HIV questions was done during NFHS-2. Additional questions can be added for different NFHS zones. However, collecting data on same parameters across the country helps in offering a comparable picture, but misses out on specific issues relevant for various regions. For instance, dynamics change across regions in such a large state as UP – factors which could be responsible for a particular outcome in one region might be very different for another. Nevertheless, although desirable, customization of questionnaires would make the process very tedious and data quality might be affected.

8) In-depth view is not emerging from health surveys like the NFHS.

9) There is limited local autonomy and no scope for innovations in the questionnaires. You cannot enter challenges to health that you observe during the fieldwork or respondents' views in the questionnaires.

10) Qualitative observations of the field staff / respondents should be enabled in the questionnaires and included in the survey reports. Larger surveys in India are deprived of qualitative research

component. Qualitative assessments should be made a part of all health surveys. In diseases such as tuberculosis, such assessments play a vital role in ensuring treatment adherence.

11) However, if we want to capture qualitative data, then only key, specific themes / higher disease burden regions should be covered – it will not be feasible to cover the entire country / states. The qualitative dimension should also be very focused / specific.

12) Another challenge is that field investigators may not be able to get the right kind of information for qualitative components. Government officials are better suited for conducting focus group discussions. Supplementary survey reports can cover such discussions. IIPS can collaborate with states for undertaking such an exercise.

Biomarkers

1) Although estimating the prevalence of risk factors is important, collecting data on biomarkers as part of sample surveys is not desirable and reliable as results can be affected by immediate factors – for instance, blood glucose by sugary food consumption. Asking people about their immediate consumption might not necessarily be helpful in low literacy / awareness contexts. Rather than trying to estimate point prevalence of risk factors – as cross-sectional surveys like the NFHS do – it is desirable to have estimates of period prevalence.[117] Longitudinal surveys could still help. Even doctors ask for several readings taken at different points of time to assess the incidence of diabetes or hypertension, for instance.
2) People in urban areas are more reluctant for biomarker assessments; in rural areas, they are much more willing to share their personal information as well as undergo biomarker tests.
3) Adequate treatment facilities and referral mechanisms should be available to respondents who test positive in biomarker tests as part of surveys.

Field staff

1) Extensive training should be provided to the field staff. The survey capabilities of many are not up to the mark.
2) Training provided to NFHS field staff is of differential quality – so is the NFHS data quality.
3) Surveys are generally conducted by students who are not motivated enough due to temporary nature of the job. At the same time, many students quit the surveys after completion of training to go for better avenues. This is one of the biggest challenges for field survey agencies (FSAs).

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[117] *Point prevalence* refers to prevalence measured at a particular point in time. *Period prevalence* refers to prevalence measured over an interval of time. It is the proportion of persons with a particular disease or attribute at any time during the interval. https://www.cdc.gov/csels/dsepd/ss1978/lesson3/section2.html (12/6/2020, 23:10 hours).

4) Skills of field enumerators (FEs) are crucial in data collection and quality. The manner in which a question is being asked makes a lot of difference in the kind of response that the enumerator gets during interviews. 'It is important to build a rapport with the interviewees; only skilled FEs know how to do that. During one of the NFHS rounds, I realized that, even in a city like Mumbai, women are ready to share more if the interview is done properly. I got a lot of useful information about aspects of women's health – for instance, mental health during menopause and due to domestic violence. However, there were no options in the NFHS questionnaire to capture these aspects of women's health. If interviewees are assured that their data is anonymized and will not be shared, they are more willing to discuss issues in detail'.

5) The sheer volume of NFHS questionnaires makes field work a daunting task for data collectors. Using IT has substantially reduced their burden, but there are challenges which they still have to deal with. For instance, they have to be trained in IT tools, and it becomes difficult to check errors in cases where the data has been wrongly entered. Field Checked Tables (FCTs) allow entering data on smartphones within a particular limit. There are more than 10,000 fields in a questionnaire. FCTs are embedded in questionnaires. Through this method, however, only key questions can be verified. Further, even though a majority of present-day surveys make use of geo-tagging, this feature often results in providing inaccurate location coordinates.

6) FEs should be compensated properly. It is extremely difficult to find well-qualified enumerators who are willing and motivated enough to work at such low salaries as the NFHS offers.

7) The accommodation and security of FEs, especially females, is a major concern that needs to be taken care of in a better way by the FSAs.[118]

8) Low FE incentives and limited FSA accountability adversely affect the quality of NFHS data.

9) Government rather than private agencies should be involved in the conduct of NFHS as they not only have greater expertise, experience and integrity, but better logistical and manpower arrangements for conducting such large-scale surveys.

10) Like NSO, local field investigators should be involved. Government agencies can do that, given their vast local networks.

Field work

1) When NFHS-1 was conducted, completing 2½ questionnaires a day, on average, was the norm for FEs. Now, questionnaires are much lengthier and FEs are under enormous pressure to fill more number of questionnaires a day. FSAs involved are completely profit-making companies

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[118] There have been some serious allegations vis-à-vis violation of the rights of the NFHS field staff. https://bit.ly/2ztZSod and https://bit.ly/2UFZDOc (13/6/2020, 17:11 hours) is one set of writings that has raised a number of issues.

and do not care much about data quality – they want to finish the survey in the least possible time and with minimal resources.

2) NFHS-1 FEs in Bharatpur (Rajasthan) did not even go to the field, filling out responses at home.
3) Unemployed students are hired to conduct the NFHS field work in Rajasthan – they sit at home and fill out the responses.
4) It is extremely difficult to collect data in metropolitan cities – people are not willing to participate in surveys. Response rate is quite low in these cities. Some incentive mechanisms need to be developed. They are more reluctant for biomarker tests / measurements. People in rural areas, on the other hand, are much more willing to respond as well as undergo tests / measurements.
5) Given its geographical and cultural complexities, data collection in Assam is very challenging. For instance, people come from different cultures and speak different dialects, so canvassing the survey in one language leads to poor understanding of questions and, therefore, poor data quality. Furthermore, political turmoil and fragility makes it difficult to reach out to respondents. NFHS FSAs are not conducting surveys in Assam as per stipulated norms.
6) The biggest operational challenge vis-à-vis the conduct of the NFHS is that respondents do not agree to respond to many of the questions. Its high overall response rate is misleading.
7) There is respondent-fatigue in NFHS; questionnaires are too long; people give socially desirable responses; there is little respondent privacy – sometimes, the whole village is standing when people are responding.
8) There are various provisions to ensure respondent privacy in the NFHS. If there is no privacy, FEs are told to skip sensitive questions.
9) ANMs' help is sought for conducting NFHS in very critical situations.
10) There have been difficulties in conducting NFHS-5 in some places due to fears related to the CAA (Citizenship Amendment Act) and NRC (National Register of Citizens). These fears would continue to pose problems for any survey-related field work as well as the quality of responses.

Data quality

Data quality-related issues have been highlighted under several themes above. Let us highlight a few more here.

1) Kerala's IMR as per NFHS-4 became a huge issue in the state. No one was willing to believe it. The state government as well as academics believed that IMR in Kerala has not gone below 10 – as reported by the SRS in 2016 (NFHS-4 reported it as 5.6). This made people suspicious of NFHS-4 data more generally. They felt that the SRS is more reliable.

2) With 5 lakh births and 2,700 infant deaths in Kerala,[119] reliable estimates of IMR are difficult.

3) IIPS is very particular about data quality – they try their best to ensure it.

4) Data fudging is not possible under NFHS – use of CAPI eliminates the need for separate data entry, and there are data consistency checks as well as GPS to ensure data quality.

5) Quality varies even if the same agency is managing the NFHS fieldwork in different states. FEs would be different anyways, for instance.

6) Timely dissemination of survey data is essential; otherwise, it pertains to a period which is no more relevant from a program perspective.

7) Survey data can also be wrong; why only distrust HMIS data? There should be a methodology to tackle the variance between HMIS and survey data.

Stakeholder involvement – National

1) Before each round of NFHS, there is detailed consultation with different programme divisions of MoHFW and other ministries on their data requirements. Accordingly, indicators are finalised and questions are added or aligned to SDG health indicators.

2) State level health authorities have never been consulted for the design and conduct of NFHS.

3) States like Rajasthan do not take interest in the design of NFHS. Some states represent states as a whole. There is proactive participation, for instance, from Kerala and Tamil Nadu.

4) States must be consulted in the design and implementation of NFHS. This is important from the perspective of highlighting the state-specific disease burdens and health challenges in a large-scale survey such as the NFHS.

5) Consultation workshops and extensive meetings with relevant state-level government officials and other stakeholders should be done before NFHS is canvassed in the states.

6) Since achieving consensus with states is almost impossible, the National Statistical Institute in Mexico does not consult states in the design of surveys, and this is completely justified. States should be consulted only from the perspective of implementation of health surveys.

7) The National Centre for Disease Informatics and Research (NCDIR) / ICMR provided questions on NCDs for NFHS-4 – they were subsequently modified.

8) ICMR is proactively involved in the design of NFHS-6, and will be for its conduct as well.

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[119] To be precise, there were a total of 496,292 births and 2,774 infant deaths in Kerala in 2016 (Annual Vital Statistics Report – 2016. Vital Statistics Division, Department of Economics and Statistics, Government of Kerala, Trivandrum). https://bit.ly/3e0OU8G (13/6/2020, 21:34 hours).

Stakeholder involvement – International

1) When the first round of the NFHS was conducted, IIPS and MoHFW had a much bigger role to play as there were not many international donor agencies – only USAID was involved then.
2) Give money and your questions will be included in the NFHS – it very donor-driven.
3) With respect to the design of NFHS, the CDC model has been replicated in India, which has not been modified as per Indian requirements. Funding agencies prioritize their own agenda.
4) NFHS is conducted independently and is not driven by the DHS model.
5) ICF is not involved in the process of selection of indicators for NFHS.
6) For NFHS-5, technical and financial support is being provided by ICF and USAID respectively.
7) Some international donors wanted to include the component of adolescent health in NFHS-3 and -4. IIPS was reluctant to do it. It knows how to go around and get things done as it wishes.
8) USAID will not fund the NFHS next time. Along with it, ICF will also go. IIPS largely manages NFHS-related logistics and training – it is Fred Arnold and his team at ICF who provide the more valuable technical guidance – for instance, how to frame questions, which requires a high level of technical expertise and experience. If they are not included, the NFHS survey design and data quality would be seriously affected as we do not have that sort of expertise in the country. Nearly 90% of pass-outs from the prestigious Indian Statistical Institutes (ISIs) go abroad.

Data dissemination

1) Since dissemination of the final NFHS data takes a lot of time, it would be useful if some interim data is made available to states before final data is released. Efforts should also be made to disseminate the final data as early as possible.
2) All NFHS data should be put out in the general public domain in a user-friendly manner to promote transparency and generate public accountability (senior Rajasthan district official).
3) Data curation needs to be done from the perspective of various stakeholders. A lot of countries are doing that. India is also trying, but things are still at a preliminary stage.

Data analysis

1) Data analysis is very preliminary within the government system at both central and state levels. We need separate teams for data analysis and data feedback to government departments. We cannot expect government officials to themselves search for / use relevant data on their own.

The entire data cycle – design, data collection, dissemination, analysis and use – needs to be seen as a continuum and carefully developed at both the central and state government levels. Otherwise, wasting resources on just data collection through multiple sources does not make sense. We need to have the entire package from the beginning till the end. Simply collecting raw materials for food does not help – we also need to cook and serve the food in a palatable manner. Right now, we have random raw materials from a variety of sources. Focus needs to shift to properly cooking and serving the food.

2) In addition to simply collecting and disseminating data, we have to improve data analysis so as to strengthen health intelligence. Currently, a substantial proportion of human resources in the health sector are engaged in routine administrative work and have little time for analysis of data which is being collected. There is shortage of human resources even in National AIDS Control Organization (NACO) and the ORGI / MHA, where data is extensively analyzed.
3) Training institutes are being developed for data analysis and quality checks, with funding from the Centre.

Data use

1) There is enough evidence of NFHS data use for policy and program purposes in India, as input in the erstwhile five year plans to the recently launched National Nutrition Mission. The MoHFW has used NFHS data as scientific evidence for various policy decisions – including for adoption of a target-free approach in 1996, setting goals for the National Population Policy 2000, framing of different national health policies, etc. Notable policy and program changes have also been based on NFHS data in areas such as domestic violence, child marriage, menstrual protection, sanitation and caesarean-section deliveries. In addition, various states have brought out state-specific population and health policies and programs based on state-level findings of various rounds of NFHS.
2) NFHS has significantly contributed to the formulation of MCH policies in the country.
3) NFHS has contributed to generating valuable baseline data and showcasing impact of health policies and programs on health outcomes. The fact that NFHS provides data by background characteristics also makes it an important source of health data.
4) Governments refer to SRS and NFHS data for the formulation of health policies and schemes.
5) NFHS and SRS are also used for developing government proposals, planning and evaluation.
6) NFHS and SRS are being referred to, but we cannot totally rely on national surveys since the situation in Kerala is quite different.
7) NFHS is never used by the Directorate of Economic and Statistics (DES) in Kerala; it uses data collected at the local level.

8) As survey data cannot show the impact of health programs on health outcomes, it is impossible to evaluate health programs on the basis of health surveys.

9) Surveys should be able to show policy implications. More often than not, surveys digress from this objective and only focus on generating factsheets and conducting additional rounds.

10) NFHS is being used rigorously for research purposes.

11) Data use is problematic – too much useless data is being collected.

12) Instead of collecting more data, the focus should be on making the best use of available data.

13) For planning purposes, there is a need for real-time data, which the NFHS does not provide.

14) The usability of NFHS data for planning and monitoring purposes is limited.

15) NFHS and other national health surveys have limited relevance in state-level health planning. Although its data is used for the verification of data generated from state-level sources, state planning decisions are mostly based on data from HMIS and other government sources. Due to periodicity, NFHS data does not contribute much to state-level planning in the health sector.

16) Use of NFHS data is limited in Assam. Sometimes, NFHS factsheets are used while deciding on state level schemes and programs. Lack of availability of NFHS data on a regular, periodic basis is one of the major reasons for its limited use.

17) In Assam, administrative data sources like HMIS and disease registries are being extensively used. There is a high dependence on HMIS data, especially for monitoring the implementation of health schemes / programs, and analyzing emerging data trends at district and block levels.

18) Despite the DLHS being discontinued, it is still being widely used by policymakers in Assam.

19) Using voluminous NFHS reports is a challenge for government officials, especially if they have to refer to different state reports for comparisons. Presenting data in a user-friendly style has to be prioritized to enable ease of data use. ‘I use a spatial visualization tool based on NFHS data developed by a private agency, Riddhi. It is very convenient’ (senior Kerala NHM official).

20) In order to make data more self-explanatory, efforts should be made to make it available in a more useable format.

21) Policymaking is largely politically- rather than evidence-driven.

22) Governments do not take data seriously.

23) Central and state governments do not give sufficient importance to data. Most officials do not appreciate the importance of data.

24) Fear of accountability hinders government officials from using independent data and promotes the collection of low quality data within the system. If, somehow, we could delink accountability

and data collection / use, it would not only lead to more reliable administrative health data, but also greater use of survey data from the NFHS and other sources (senior Kerala NHM official).

25) It is important to devise a strategy for better use of health data. Before data collection, it is vital to consider local data requirements and educate local experts about the use value of this data.

26) Sensitizing government officials, capacity-building and -strengthening for data use is essential.

27) Capacity to use data for decisions needs to be developed (senior Rajasthan official).

28) Data use training was given to health department officials in Rajasthan. ‘Trainers got the money; trainees got time-off from regular work and refreshments; everything remained as usual’.

29) Concerted efforts need to be made to enhance the usability of survey and administrative data in health-related planning.

30) All bureaucrats say survey data like the NFHS has issues. Surveys help in checks and balances on the activities of relevant departments.

31) NFHS and SRS data is used by Rajasthan state government officials for internal accountability and monitoring purposes. State and district officials take NFHS data seriously.

32) NFHS data is very useful (senior Rajasthan district official).

33) Officials in the Directorate of Health Services in Pune use NFHS to verify HMIS data.

34) While one can use NFHS data as a tool to validate the HMIS data, it is technically inappropriate to have such an expectation from population health surveys.

35) Surveys have population-based sampling; their data will never match with the HMIS data, which is largely government facility-based. It is wrong to use survey data to validate the HMIS data.

36) After NFHS estimates, it was realized that HIV prevalence is not as high as it was reported by administrative data – the same patient was being counted as HIV-positive in every hospital he was seeking treatment in, leading to overestimation of the HIV burden. In this way, NFHS has helped policymakers in Maharashtra to understand the true burden of HIV.

37) The IDSP unit in Pune also occasionally refers to indicators from NFHS, including those related to child health, vaccination coverage, tuberculosis and household characteristics like drinking water source and indoor air pollution.

38) A unique and strong dimension of population health surveys like the NFHS is that they provide respondent level data – ‘in a moment, you can get the entire *kundali* (horoscope) of a person’. And a lot of disaggregated information is made available by background characteristics. Even census gives data at state, district, block, village and ward level, but it is impossible to get the complete set of information about an individual through census data.

Other health surveys

1) The SRS data is of no relevance to RGI / MHA; it is only conducted to independently assess the impact of health policies. This is precisely the reason why there is no coordination between the MHA and MoHFW vis-a-vis the SRS.
2) There was a proposal to bring SRS under the administrative scope of MoHFW. However, since SRS is managed by Indian Statistical Service (ISS) officials, they do not want SRS to slip away from their authority.
3) The RGI / MHA is very sensitive about SRS and does not make raw data available to the public.
4) Although SRS collects data by background characteristics like religion and caste, it does not publicly disseminate its data by these characteristics. It should do so.
5) The data quality of the SRS is very good – it is the most reliable health data source.
6) The SRS was initiated with a view to generate reliable and continuous data on vital indicators – birth rate, death rate, IMR and TFR. And for these indicators, its data is more robust than the NFHS since it comes from government sources and focuses on estimation of only 4 indicators.
7) Compared to the NFHS, SRS is much more widely used because SRS data is made available at shorter intervals.
8) Government of India has mandated the use of SRS for core outcome indicators / vital statistics.
9) MMR data in general, including that of the SRS, is not quite reliable. There are issues with the reporting of maternal deaths – it may legally implicate the husband's family, for instance. And collection of data on such a sensitive theme by a government agency – that too the MHA / RGI – makes it more complicated.
10) Sometimes, SRS FEs take data from PHCs rather than collecting it from the field on their own.
11) SRS is based on a sample of 1 percent of the Census population, which is why the SRS can, at best, provide estimates.
12) SRS should also provide data at the district level.
13) Since proportion of medically certified deaths in India is very low, the RGI developed a sample frame (based on previous Census, followed for a period of 10 years) to conduct verbal autopsy (VA) surveys. The primary objective of VA surveys is to build up a statistical database on the most probable causes of death for rural and urban areas using lay diagnosis reporting method (VA). However, since there is usually a considerable time-lapse between the occurrence of death and the SRS-CoD surveys, the problem of recall bias is quite pervasive in these surveys.
14) In collaboration with RGI, the Million Death Study (MDS) was undertaken by Centre for Global Health Research (CGHR), Canada, between 2004 and 2013. Any deaths that occurred in the

nationally representative households in this duration were assigned a probable cause on the basis of VA. For adequacy of sample size, CoD data for 3 years was combined.

15) Since 2015, Dr Anand Krishnan, AIIMS Delhi, has been given charge of the SRS-CoD surveys. Apparently, things are not progressing according to the expectations.

16) HMIS reports are still using DLHS, mostly for facility-level data which is not being captured by NFHS. 'I don't think there is any difference in data quality of NFHS and DLHS. We are not very comfortable using the HMIS data. ANMs are worried about achieving their targets, that's where a lot of data gets corrupted. In some cases, incentives work in another direction – for instance, there are cases where a borderline malnourished child is declared severely malnourished just to meet the targets'.

17) The National NCD Monitoring Survey (2017) was developed on the basis of WHO's STEP-wise approach to surveillance (STEPS). Modules have been given to certain states for customizing and implementing the survey at the state level.

18) A Kerala Information Residents Association Network (KIRAN) survey was conducted to collect data vis-à-vis NCDs – on lifestyles (dietary habits, physical activity, etc.) as well as disease and treatment patterns – by the Kerala Directorate of Health Services and Achutha Menon Centre for Health Science Studies (AMCHSS), Trivandrum. All 14 districts were covered and with the use of electronic tablets, data was available in real-time to these agencies.

19) The Kerala DES' NSS Division has been proactively engaged in conducting NSS with matching samples to provide sub-state estimates, which is not possible through the national sample. As part of 71st round (January-June 2014), a report titled 'Health in Kerala' was published by the DES on the basis of the state sample data on health-related consumption.

20) No health survey is being conducted by the UP government at the moment. Some proposals are being developed within Department of Health and discussions are ongoing for conducting one. As part of NHM activities, 2 surveys – the Annual Family Survey (AFS) and Annual Survey on NCDs (under the Health and Wellness Centers initiative of GoI) – are being conducted. The principal objective of the latter survey is to undertake screening of household members above 30 years of age for NCDs and related risk factors. A Community Based Assessment Checklist (CBAC) questionnaire has been developed for NCD screening, including questions to assess family history and associated risk factors. Scores are assigned and high-risk cases are referred to nearby government health facilities. However, based on these surveys, no reports are being published. Both the surveys are being conducted by the ANMs and ASHAs.

21) Household surveys are being conducted by CARE India as part of the Bihar Technical Support Unit (BTSU) activities, covering all districts and blocks in the state. 'In these surveys, our main priority is to focus on households with 0-23 month old children. Sample size for each population

group is 15,000 to 16,000 households in all rounds. Apart from basic demographic indicators, maternal and child health, immunization and family planning are covered in every round'.

22) While challenges in Bihar's health data ecosystem are similar to those observed in other states, there are certain key differences. Firstly, several development partners are working in different regions of the state to strengthen delivery of health care services. Though a number of surveys and data collection activities are carried out by the agencies, no attempts have been made to integrate their data. Data usability in terms of planning and health-related decision-making has, thus, remained limited. Secondly, as a significant share of population is located in remote and isolated regions of the state, it is difficult for surveyors to include them in the surveys. Thirdly, due to low literacy levels, survey respondents are often not aware of ongoing health programs and schemes, which often renders certain evaluation and survey exercises futile.

Miscellaneous

1) Government of India should allow WHO and UNICEF to conduct health surveys in the country.
2) A comprehensive sampling frame should be developed by nodal statistical agencies to ensure some degree of uniformity across surveys. Due to variations in sampling design / frame across surveys, interoperability in health survey data is limited.
3) Data extrapolation and data integration exercises should be undertaken to facilitate evidence-based policymaking.
4) Monitoring and evaluation of various health programs is not organised, and a lot of work needs to be done on this front. Independent evaluations of health programs constitute a major lacuna in the health sector. Health survey data can be used by independent agencies for this purpose.
5) There seems to be a lot of focus / fascination with IT. However, IT cannot compensate for weak statistical capacity and recognition of importance of data for evidence-based decision-making within the system. It was paradoxical that, despite so many MIS portals, a focus on data is seen as something which is at odds with a focus on service delivery, indicating that the importance of using data for evidence-based decision-making and service delivery is not realized. Several senior statistical officers also point out that data use is weak. The MIS data is used to develop reports / bureaucratic reporting purposes. IT can help in this regard too through user-friendly data visualizations / dashboards, but ultimately people in the system – from top to the bottom – have to realize the importance of data and evidence-based decision-making. There has to be a focus on developing capacities at various levels for data use.
6) 'A data culture is missing in India' (senior multilateral agency official in New Delhi) – that needs to be developed.

SECTION 3 –

HEALTH SURVEYS IN THE UNITED STATES, CANADA AND UNITED KINGDOM

9. United States

The history of sample health surveys in the US goes back to the first National Health Survey (NHS), carried out during 1935-36 by nearly 6,000 unemployed welfare recipients, who collected data on chronic diseases and disability from approximately 2.8 million people in 737,00 urban households across 19 states (Weisz 2011). Subsequently, a series of health survey methodology experiments were carried out and the institutional framework for health statistics was laid down. In 1949, the US Congress established the National Committee on Vital and Health Statistics (NCVHS) to serve as – 1) the statutory review and advisory body to the Secretary, Department of Health and Human Services (DHHS) on national health information policy; 2) a forum for stakeholder interactions on health data to inform DHHS, state as well as private sector health data decision-making.[120] In 1956, the National Health Survey Act was signed into law to enable a series of continuous health surveys. The NHS founders did not envision a single, but 'a program of surveys, using different approaches' and with different objectives as data techniques and needs evolve. In 1957, what is now known as the National Health Interview Survey (NHIS) – the principal source of health data on the US civilian, non-institutional population – was launched with interviews in 36,000 households (Haywood 1981: 195).[121] In 1960, the National Center for Health Statistics (NCHS) – federal government's principal health statistical agency[122] – was established, becoming a part of the Centers for Disease Control and Prevention (CDC), DHHS in 1987. NCHS aims 'to provide statistical information that will guide actions and policies to improve the health of the American people' through its elaborate structure of offices and divisions (table 9.1), with a budget of USD 160.4 million in the financial year 2016.[123]

Table 9.1: Organizational structure and functions of the National Center for Health Statistics (NCHS)

Office / Division	Functional areas
Core	
Classifications and Public Health Data Standards Staff	Data standards – classification systems and terminologies (e.g., ICD, ICF, SNOMED), message formats (e.g., HL-7, ANSI X12, NCPDP), identifiers (provider, plan, individual), implementation guides, core data sets (vital statistics, hospital discharge data),

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[120] https://ncvhs.hhs.gov/about/ (28/4/2020, 18:16 hours).

[121] https://www.cdc.gov/nchs/nhis/about_nhis.htm (28/4/2020, 18:59 hours).

[122] The US federal statistical system has 13 principal statistical agencies, with the Chief Statistician, Office of Information and Regulatory Affairs (OIRA), Office of Management and Budget (OMB), as their coordinator. The NCHS is the principal federal statistical agency, responsible for collection and dissemination of vital and health statistics. https://bit.ly/2y6NBp5 (28/4/2020, 20:22 hours).

[123] https://www.cdc.gov/nchs/about/budget.htm (28/4/2020, 20:15 hours).

	privacy and security; demographic standards and collection of socioeconomic status data in DHSS surveys, comparisons and integration of disparate data systems, data exchange between clinical and population-based data systems
Division of Research and Methodology	Collaborating Center for Statistical Research and Survey Design, Collaborating Center for Questionnaire Design and Evaluation Research, Research Data Center
Division of Analysis and Epidemiology	Health promotion statistics, measures research and evaluation, data linkage methodology and analysis, population health reporting
Division of Vital Statistics	Data acquisition classification and evaluation, mortality statistics, reproductive statistics, IT
Division of Health Interview Statistics	Data production and systems, survey planning and special surveys, data analysis and quality assurance
Division of Health and Nutrition Examination Surveys	Planning, operations, informatics, analysis
Division of Health Care Statistics	Ambulatory and hospital care statistics, long-term care statistics, technical services
Managerial	
Office of Planning, Budget and Legislation	Planning, budget and legislation
Office of Management and Operations	Operations and services, logistics, workforce and career development
Office of Information Services	Information design, dissemination, publishing
Office of Information Technology	IT solutions and services

Source: https://www.cdc.gov/nchs/about/organization.htm (28/4/2020, 19:52 hours).

It is interesting to note that NCHS is not only responsible for DHSS' population health and provider surveys, but also vital statistics. Coordinating with state agencies, its National Vital Statistics System (NVSS) offers monthly / quarterly / yearly provisional statistics of births and deaths – and, as part of its public health surveillance activities, daily / weekly COVID-19 death data by demographic and geographic characteristics. The NVSS mortality data, stored in its centrally computerized National Death Index (NDI), helps in ascertaining death, causes of death, drug overdose, characteristics of the deceased, life expectancy, maternal mortality, etc. Several NCHS surveys are linked with NDI to help study factors associated with mortality in detail. A dedicated National Mortality Followback

Survey (NMFS) was initiated in 1961 to gather additional information on the deceased's life history from next of kin / a related person. The sixth, and the last, NMFS (1993) collected data on disability, socioeconomic differentials in mortality, associations between risk factors and the cause of death, access and utilization of health care facilities in the last year of life and data to assess the reliability of information in the death certificate.[124]

Let us now briefly discuss some of the key data collection systems of the NCHS.

National Vital Statistics System (NVSS)

One of the oldest data collecting organizations, the NVSS is also the most successful example of inter-governmental health data sharing in the US. The recording of vital events dates back to 1632 when a registration law was passed in Virginia. With a few changes, the law was also enacted by Massachusetts in 1639, with a modern vital registration system launched there in 1842 (Gutman 1958). During the late 19th century, decennial censuses included questions on vital events, which, however, proved to be deficient in providing mortality statistics. Accordingly, when the US Bureau of Census was established as a permanent agency in 1902, it started collecting data on vital events from statistical offices in states and cities with a proper registration system annually. By 1933, all states and cities registered vital events with acceptable coverage and shared information with the Bureau to generate national estimates (NCHS 2013).

The legal authority to register vital events (marriages, divorces, births, induced abortions, deaths, fetal deaths) in the US lies with 57 registration areas – 50 states, 5 territories of Puerto Rico, Guam, American Samoa, US Virgin Islands and Commonwealth of the Northern Mariana Islands, and the cities of Washington, DC and New York – involving nearly 6,000 local registers around the country. While some states have centralized vital record offices, most of them have local offices. In 1933, the National Association for Public Health Statistics and Information System (NAPHSIS) was formed to represent state vital records and public health statistical offices in the US, and serve as a forum for discussion and research to solve problems related to the collection and documentation of vital statistics. NAPHSIS plays a key role in ensuring quality, confidentiality and usage of vital statistics (Schwartz 2009). It, *inter alia*, co-organizes vital record courses for newcomers with the NVSS.[125]

Periodic revision of NVSS' 'U.S. Standard Certificates and Reports' takes place every 10-15 years in collaboration with state vital statistical offices, NAPHSIS and experts. 'Making these changes is in keeping with a long history of rigorous evaluation of the quality and usefulness of data generated by the vital statistics system and efforts to improve these data' (DHSS Secretary).[126]

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[124] https://www.cdc.gov/nchs/nvss/nmfs.htm (29/4/2020, 14:27 hours).

[125] https://www.naphsis.org/vital-records-and-their-administrat (29/4/2020, 14:06 hours).

[126] https://bit.ly/2W8n56L. For details on the evaluation process and recommendations for the latest 2003 revision, kindly refer to https://bit.ly/3bMqHSp (29/4/2020, 14:13 hours).

Table 9.2: An overview of major health surveys in the US

Survey / coordinating / conducting agencies	Features	Inception	Frequency	Methods	Sample	Representative	Major themes
National Health Interview Survey (NHIS) / NCHS / US Census Bureau	Primary source of data on health of the US population – widely used by DHHS to track the nation's health and progress towards national health objectives, health policies, programs	1957	Continuous	Personal interviews	~ 87,500 persons in 35,000 households a year	National, states (by combining data years)	Health status (diseases and conditions) - health care access and utilization (incl. doctor visits) - functioning, disability, chronic impairments - health behaviors - health insurance
National Health and Nutrition Examination Survey (NHANES) / NCHS and others[127]	Program of studies conducted as a series of surveys on various groups / health topics to assess health and nutritional status of adults and children in the US	1959	Continuous	Personal interviews – health tests / examinations by highly trained medical staff in mobile centers and during doctor visits – the higher the age, the more extensive the examination	~ 5,000 persons a year – oversampling of persons aged 60+ years, Black, Hispanic and Asian	National	Selected diseases and conditions - sexual behavior, reproductive history - environmental and metabolic risk factors - nutrition - dietary supplement use - children's growth - healthy behaviors - hearing and balance - cognitive functioning - prescription drug use

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[127] US federal agencies that collaborate with NCHS for NHANES are – within the DHSS (Food and Drug Administration, National Institutes of Health, Health Resources and Services Administration, National Institute of Occupational Safety and Health, Agency for Toxic Substances and Disease Registry), Department of Agriculture, Environmental Protection Agency, Social Security Administration. https://bit.ly/3aObUp8 (29/4/2020, 18:52 hours).

Survey / coordinating / conducting agencies	Features	Inception	Frequency	Methods	Sample	Representative	Major themes
National Survey of Family Growth (NSFG) / NCHS / several DHSS agencies[128]	Major source of information on reproductive-age US women since 1973 and men since 2002	1973	Continuous (2006-)	Personal interviews by female interviewers - sensitive questions answered privately (self-administration)	~ 5,000 men and women aged 15-49 years a year - Blacks, Hispanics and teens oversampled	National	Family planning - teenage sexual activity and pregnancy - infertility - adoption - breastfeeding - marriage, divorce, cohabitation - father's involvement - HIV risk behavior
Behavioral Risk Factor Surveillance System (BRFSS) / several CDC centers and federal agencies / All 50 states	The BRFSS is considered as the gold standard in behavioral surveillance – collaborative project between all US states, participating territories and the CDC – collects data on health-related risk behaviors, chronic health conditions and use of preventive services	1984	Monthly (states) Annual (CDC)	Mail - telephone	400,000+ adults (18+ years) a year	National, state, local	Health status - healthy days / health-related quality of life - health care access -exercise - sleep - chronic health conditions - oral health - tobacco and alcohol use – falls - immunization - seat belt use - drinking and driving - breast, cervical, prostate and colorectal cancer screening - HIV/AIDS knowledge - emerging health issues

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[128] https://www.cdc.gov/nchs/nsfg/about_nsfg.htm (29/4/2020, 19:04 hours).

Survey / coordinating / conducting agencies	Features	Inception	Frequency	Methods	Sample	Representative	Major themes
National Immunization Surveys (NIS) / National Center for Immunization and Respiratory Diseases (NCIRD), CDC / NORC, University of Chicago	A group of phone surveys used to monitor vaccination coverage among children and teens	1994	Annual	Telephone - mail Parents / caregivers as respondent	~ 25,000 children (2 years) and 20,000 teens (13-17 years) (2018)	National, state, other areas	Vaccinations as recommended by the CDC's Advisory Committee on Immunization Practices (ACIP)
State and Local Area Integrated Telephone Survey (SLAITS) / NCHS and sponsor (public or private)	Supplements national data by providing in-depth state and local area data to meet various program and policy needs - - quick data for evaluating programs at subnational levels, etc. - data specific to certain populations	1997	Periodic	Telephone	Variable (uses NIS sampling frame)	National, state, local	Variable

Survey / coordinating / conducting agencies	Features	Inception	Frequency	Methods	Sample	Representative	Major themes
National Survey of Children's Health (NSCH) / Maternal and Child Health Bureau, DHHS / US Census Bureau	Provides rich data on multiple, intersecting aspects of children’s (0-17 years) lives - including physical and mental health, access to quality health care, their family, neighborhood, school and social contexts	2003	Annual	Mail - web - paper - telephone Parents / caregivers as respondent	30,530 children (2018) - children with special health care needs and 0-5 years of age oversampled	National, state	Physical and emotional health - factors related to well-being, including medical home, family interactions, parental health, school experiences and safe neighborhoods
Household Pulse Survey (HPS) / US Census Bureau	A 20-minute online survey to evaluate how the COVID-19 pandemic is affecting households across the country from a socioeconomic perspective	2020 (23 April)	Weekly	Random selection from the Census Bureau’s Master Address File (MAF) - sample households contacted via email and/or SMS - longitudinal - each household interviewed thrice - data collection for 90 days - release on a weekly basis	1,048,950 households (first 2 weeks respondents)	State, 15 largest Metropolitan Statistical Areas (MSAs)	Employment status - spending patterns - food security – physical and mental health - access to health care - housing - educational disruption

Source: NCHS and other sources. https://www.cdc.gov/nchs/index.htm (25/5/2020, 20:42 hours). Developed by author.

Table 9.2 above provides an overview of some of the key health surveys in the US. It is interesting to note the mix of health survey strategies – for instance, while the 3 major NCHS surveys (NHIS, NHANES and NSFG) are continuous and nationally representative, others play a complementary role by providing annual / periodic and state / locally representative data as well. The BRFSS is a collaborative effort between the federal and state governments inasmuch as it is conducted by all 50 US states even as the CDC coordinates with them to ensure standardization and puts together national data. The 3 NCHS national surveys also provide a good mix of extensive (NHIS), focused (NSFG) and intensive (NHANES) data. Let us discuss these 3 surveys here in some detail as their combination appears to be quite relevant for the Indian context. Before we do that, let us make a quick reference to the 20-minute online Household Pulse Survey (HPS), conducted by US Census Bureau, to measure the social and economic impacts of the COVID-19 pandemic on households – another example for the Government of India to consider. It is also worth highlighting here that IPUMS[129] Health Surveys harmonizes data from 2 key health surveys – NHIS (1963-present) and Medical Expenditure Panel Survey (MEPS)[130] (1996-present).

National Health Interview Survey (NHIS)[131]

The NHIS is the principal source of information on the health of the civilian noninstitutionalized US population, and is one of the major data collection programs of the NCHS. The National Health Survey Act of 1956 provided for a continuing survey and special studies to secure accurate and current statistical information on the amount, distribution, and effects of illness and disability, and services rendered for or because of such conditions. The survey referred to in the Act, now called the National Health Interview Survey, was initiated in July 1957. Since 1960, the survey has been conducted by NCHS, which was formed when the National Health Survey and the National Vital Statistics Division were combined.

NHIS data is used widely by DHHS to monitor trends in illness and disability and progress towards achieving national health objectives. It is also used by the public health research community for

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[129] IPUMS provides, free of charge, census and survey data from around the world harmonizes and integrated across time and space, making ‘it easy to study change, conduct comparative research, merge information across data types, and analyze individuals within family and community contexts’. https://ipums.org/ (29/4/2020, 23:12 hours).

[130] Starting in 1996, MEPS, sponsored by DHSS’ Agency for Healthcare Research and Quality (AHRQ), ‘is a set of large-scale surveys of families and individuals, their medical providers, and employers’, and ‘is the most complete source of data on the cost and use of health care and health insurance coverage’ in the US. https://www.meps.ahrq.gov/mepsweb/ (29/11/2020, 23:03 hours). Something for the Ayushman Bharat to consider.

[131] While the authors have developed survey tables providing an overview, all descriptions of health surveys, henceforth, have been reproduced from the original country sources (referenced in footnotes) with minor changes only. This has been done to ensure the accuracy and originality of descriptions, paraphrasing which did not seem to be of any value, especially in the context of budgetary and time constraints of the study. A critical review of international health surveys from existing literature was also not undertaken due to these constraints. https://bit.ly/2Slj5yS (30/4/2020, 12:46 hours).

epidemiological / policy analysis of such timely issues as characterizing those with various health problems, determining barriers to accessing and using appropriate health care and evaluating federal health programs.

The NHIS also has a central role in the ongoing integration of household surveys in DHHS. The designs of two major DHHS national household surveys have been or are linked to the NHIS. The National Survey of Family Growth – which we will discuss shortly – used the NHIS sampling frame in its first five cycles, while the Medical Expenditure Panel Survey currently uses half of the NHIS sampling frame. Other linkages include linking NHIS data to death certificates in the NDI.

While the NHIS has been conducted continuously since 1957, the content of the survey has been updated about every 10-15 years. In 1996, a substantially revised NHIS questionnaire began field testing. This revised questionnaire, described in detail below, was implemented in 1997 and has improved the ability of the NHIS to provide important health information.

Purpose and scope

The main objective of NHIS is to monitor the health of US population through the collection and analysis of data on a broad range of health topics. A major strength of this survey lies in the ability to display these health characteristics by many demographic and socioeconomic characteristics. It covers the civilian noninstitutionalized population residing in the US at the time of the interview. Because of technical and logistical problems, several segments of the population are not included in the sample or in the estimates from the survey. Examples of persons excluded are patients in long-term care facilities, persons on active duty with the armed forces (although their dependents are included), persons incarcerated in the prison system and US nationals in foreign countries.

Sample design

NHIS is a cross-sectional household interview survey. Sampling and interviewing are continuous throughout each year. The sampling plan follows an area probability design that permits the representative sampling of households and noninstitutional group quarters (college dormitories, for instance). The sampling plan is redesigned after every decennial census. The current sampling plan was implemented in 2016. Clusters of addresses were defined within each state; the sizes of the clusters correspond generally to the size of an interviewer's workload over the course of the sample design period. Each cluster is located entirely within a county, a small group of contiguous counties, or a metropolitan statistical area. The current sampling plan is a sample of these clusters of addresses.

The current NHIS sample design is not oversampling any race / ethnicity groups at the household level. For the sample adult selection stage, persons aged 65 or older who are Black, Hispanic or

Asian had a higher chance to be selected than other adults in the family. This was an oversampling feature of the previous sample design that continued in the current sample design until 2018.

As with previous two sample designs, the NHIS sample is drawn from each state and the District of Columbia. While NHIS sample is too small to provide state-level data with acceptable precision for each state, selected estimates for most states may be obtained by combining data years.

In the previous three sample designs, most sample addresses came from lists which were created by field-listing operations. In the current sample design, field-listing is being done on a limited basis. The main source of sample addresses is a commercial address list that is updated periodically.

There was a separate sampling mechanism for college dormitories in 2016-2017. This mechanism was discontinued in 2018 due to low response rates. Changes were made in survey questionnaire for 2018 to ask if there are any people who usually live at the sampled address, but are currently living away at school in on-campus housing. If so, the household respondents are asked to include them in the household roster for their ‘home’ address (for e.g., parents’ home).

The total NHIS sample is subdivided into 4 separate panels, or sub-designs, such that each panel is a representative sample of the US population. This design feature has a number of advantages, including flexibility for total sample size. With 4 sample panels and no sample cuts or augmentations, expected NHIS sample size (completed interviews) is nearly 35,000 households, 87,500 persons. The annual response rate of NHIS is approximately 70% of the eligible households in the sample.

Questionnaires

The NHIS questionnaire that was used from 1982-1996 consisted of 2 parts – 1) a set of basic health and demographic items (the ‘core questionnaire’), and 2) one or more sets of questions on current health topics. The core questionnaire remained the same over that time period, while the current health topics changed depending on data needs. The core questionnaire, while collecting data on health conditions and utilization, did not collect any information on insurance, access to health care or health behaviors. In addition, much of the interview time in the core questionnaire was devoted to collecting detailed information on events, such as doctor visits and hospitalizations rather than on information that would better characterize the individual. The 1997 revision of the NHIS questionnaire tried to address these and other shortcomings.

The revised NHIS questionnaire, implemented since 1997, has core questions and supplements. The core questions remain largely unchanged from year to year and allow for trends analysis and for data from more than one year to be pooled to increase sample size for analytical purposes. The core contains 4 major components – household, family, sample adult and sample child.

The household component collects limited demographic information on all of the individuals living in a particular house; family component verifies and collects additional demographic information on each member and collects data on topics including health status and limitations, injuries, health care access / utilization, health insurance, income and assets. The family core component allows the NHIS to serve as a sampling frame for additional integrated surveys, as needed.

From each family in the NHIS, one sample adult and one sample child (if any children are present) are randomly selected and information on each is collected with the sample adult core and sample child core questionnaires. Because some health issues are different for children and adults, these two questionnaires differ in some items, but both collect basic information on health status, health care services and health behaviors.

The supplements are used to respond to new public health data needs. As with the previous NHIS supplements, the questionnaires are sometimes fielded only once or repeated, as needed. These questionnaires may be used to provide additional details on a subject already covered in the core or on a different topic not covered in other parts of the NHIS. The first supplement from the current questionnaire design was fielded in 1998, and focused on data needed to track the Healthy People 2000 and 2010 objectives. Other topics covered in the supplements include cancer screening, complementary and alternative medicine, children's mental health and health care utilization.

Questionnaire redesign

The content and structure of the NHIS are updated in the redesign to better meet the needs of data users. Aims of the redesign are to improve the measurement of covered health topics, reduce respondent burden by shortening the length of the questionnaire, harmonize overlapping content with other federal health surveys, establish a long-term structure of ongoing and periodic topics, and incorporate advances in survey methodology and measurement. Public comments received are instrumental in determining the survey content for the redesigned NHIS.[132]

Data collection procedures

Data are collected through a personal household interview, conducted by interviewers employed and trained by the US Census Bureau, according to procedures specified by the NCHS.

For the family core component, all adult members of the household 17 years of age and over, who are at home at the time of the interview, are invited to participate and to respond for themselves. Beginning in 1997, data were collected for active duty military personnel, provided there is one civilian in family. However, these persons were not weighted for analytical purposes. For children or adults not at home during interviews, information can be provided by a responsible adult family member, 18 years of age and over, residing in the household. For the sample adult questionnaire,

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[132] The 2020 as well as previous questionnaires, instrument flowchart and the field representative manual are available at – https://www.cdc.gov/nchs/nhis/data-questionnaires-documentation.htm (30/4/2020, 13:41 hours).

one civilian adult per family is randomly selected. Generally, this adult must self-report responses to questions in this section. Information for the sample child questionnaire is obtained from a knowledgeable adult in the household, usually a parent.

The US Census Bureau, under a contractual agreement, is the data collection agent for the NHIS. Nationally, NHIS uses about 600 interviewers, trained and directed by health survey supervisors in each of the 6 Bureau regional offices. The supervisors are career civil service employees, while the interviewers are part-time employees, selected through an examination and testing process. Interviewers receive thorough training in basic interviewing procedures and in the concepts and procedures unique to the NHIS.

The revised NHIS questionnaire, fielded since 1997, uses the CAPI mode – the interviewers enter responses into the laptop during the interviews, ensuring timeliness of data and improved quality.

Early Release (ER) Program

The ER Program of NHIS provides estimates, analytical reports and preliminary microdata files on an expedited schedule. NHIS data users have access to timely estimates, reports and microdata files without having to wait for the final annual NHIS microdata files by selected characteristics. The first 2019 NHIS ER estimates were available in early 2020.[133]

National Health and Nutrition Examination Survey (NHANES)

The NHANES is a program of studies designed to assess the health and nutritional status of adults and children in the US. It is unique in that it combines interviews and physical examinations.

The NHANES program began in the early 1960s and has been conducted as a series of surveys focusing on different population groups or health topics. In 1999, the survey became a continuous program with a changing focus on a variety of health and nutrition measurements to meet emerging needs. The survey examines a nationally representative sample of about 5,000 persons each year, located in counties across the US, 15 of which are visited a year. Interviews includes demographic, socioeconomic, dietary and health-related questions. Examinations consist of medical, dental and physiological measurements and laboratory tests conducted by highly trained medical personnel.

Findings from the survey are used to determine prevalence of major diseases and risk factors as well as assess nutritional status and its association with health promotion and disease prevention. Its findings are also the basis for national standards for such measurements as height, weight and blood pressure; its data is used in epidemiological studies and health sciences research that help develop sound public health policy, direct and design health programs and services, etc.

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[133] https://bit.ly/3d7Pm4G and https://bit.ly/3caCSaZ (30/4/2020, 13:45 hours).

Purpose and scope

The purpose of NHANES is to –

- Estimate the number / percentage of persons in the US population and designated sub-groups with selected diseases and risk factors
- Monitor trends in the prevalence, awareness, treatment and control of selected diseases
- Monitor trends in risk behaviors and environmental exposures
- Analyze risk factors for selected diseases
- Study the relationship between diet, nutrition and health
- Explore emerging public health issues and new technologies
- Establish a national probability sample of genetic material for genetic testing for liver health

As in past health examination surveys, data is collected on prevalence of chronic conditions in the population. Estimates for previously undiagnosed conditions, and those known to and reported by respondents, are produced in the survey. Such information is a strength of the NHANES program.

Risk factors are examined – smoking, alcohol consumption, sexual practices, drug use, physical fitness and activity, weight and dietary intake are studied. Data on certain aspects of reproductive health such as use of oral contraceptives and breastfeeding practices are also collected. Diseases / medical conditions / health indicators studied include – cardiovascular diseases, diabetes, kidney and respiratory diseases, osteoporosis, oral health, eye diseases, hearing loss, infectious diseases, sexually transmitted diseases (STDs), reproductive history and sexual behavior, obesity, nutrition, anemia, physical fitness / functioning and environmental exposures.

Sample design

NHANES uses a complex, multistage probability design to sample the civilian noninstitutionalized population residing in the 50 states and D.C. Sample selection followed these stages, in order –

1) Selection of PSUs, which are counties or small groups of contiguous counties
2) Selection of segments within PSUs that constitute a block / group of blocks containing a cluster of households
3) Selection of specific households within segments
4) Selection of individuals within a household

In 2015-2016, 15,327 persons were selected for NHANES from 30 different survey locations. Of those selected, 9,971 completed the interview and 9,544 were examined.

To facilitate oversampling of the Asian population, survey materials were translated into Mandarin Chinese (traditional / simplified), Korean and Vietnamese. Recorded and written translations were also posted on the NHANES participants' webpage, which included a short video that explained what was involved for the participant when participating in the survey. This video was designed to promote interaction and show participants some of the benefits of participating in the survey. The video was also available in Amharic, French, Haitian Creole, Hindi and Spanish languages.

The staff participated in cultural competency training to help them recognize and respect cultural differences. Local interpreters were hired when necessary and provided with translated glossaries of terms, hand cards and exam scripts to minimize interpretation errors. In addition, a professional medical interpreter phone service was available to assist with any needs not otherwise provided.

Beginning in 1999, NHANES oversampled low-income persons, adolescents aged 12-19, persons aged 60 and over, Black or African American persons and persons of Mexican origin The sample for data years 1999-2006 was not designed to give a nationally representative sample for the total Hispanic population residing in the US. Starting with 2007-10 data collection, all Hispanic persons were oversampled, not just persons of Mexican origin; adolescents were no longer oversampled In 2011-14, the sampling design was changed and following groups were oversampled – Hispanic and non-Hispanic Black and Asian persons; non-Hispanic white and other persons at / below 130% poverty; and non-Hispanic White and other persons aged 80 and above. In 2015-16, the sampling design was revised again, changing the cut-point for low-income oversampling from at / below 130% poverty to at / below 185% poverty.

For NHANES 1999-2000 to NHANES 2011-12, number of persons selected ranged from 12,160 to 13,431. The percentage who were interviewed ranged from 73% to 84%, while the percentage who were examined ranged from 70% to 80%. For NHANES 2013-14, a total of 14,332 persons were eligible, of which 71% were interviewed and 68% completed health examination component. For NHANES 2015-16, a total of 15,327 persons were eligible, of which 61% were interviewed and 59% completed the health examination component.

Survey process

In each location, local health and government officials are notified of upcoming NHANES survey. Households in the study area receive a letter from the NCHS Director to introduce the survey. Local media may feature stories about the survey.

Selected persons are invited to take part in the survey by being interviewed in their households. Household interview data is collected via CAPI and includes demographic, socioeconomic, dietary and health-related questions. Upon interview completion, sample persons are asked to participate in a physical examination conducted in a specially equipped / designed Mobile Examination Center (MEC). The MEC is composed of 4 trailers, and houses all the state-of-the-art equipment for the physical exams and tests conducted. The trailers are divided into rooms to assure the privacy of each study participant during the examination and interview. This examination includes a physical examination conducted by a physician, measurements like height, weight, laboratory tests, bone density scans and other health measurements (including laboratory analysis of blood, urine and other tissue samples) and interviews conducted by highly trained health professionals. In general, the older the individual, the more extensive the examination. Medical examinations and lab tests follow very specific protocols and are standardized as much as possible to ensure comparability across sites and providers. Study teams are largely bilingual (English / Spanish), and consist of a physician, medical and health technicians as well as dietary and health interviewers. NHANES is designed to facilitate and encourage participation. Transportation is provided to / from the mobile center if necessary. Participants receive compensation and a report of their medical findings.

An advanced computer system using high-end servers, desktop PCs and wide-area networking collect and process all NHANES data, nearly eliminating need for paper forms and manual coding operations. This system allows interviewers to use notebook computers with electronic pens. The staff at the mobile center can automatically transmit data into databases through such devices as digital scales and stadiometers. Touch-sensitive computer screens let respondents enter their own responses to certain sensitive questions in complete privacy. Survey information is available to NCHS staff within 24 hours of collection, enhancing the capability of collecting quality data and increasing the speed with which results are released to the public.

Questionnaires

NHANES has 2 screener modules, a family and a sample person questionnaire. Screener module 1 is administered on the doorstep to determine if anyone in the household is eligible to be in the sample. Screener Module 2 establishes the relationship of everyone in the household to everyone else in the household. The family questionnaire has the following sections – consumer behavior, demographic background, family questionnaire handcards, food security, housing characteristics, income, salt sample selection and smoking. The sample person questionnaire has these sections – acculturation, audiometry, blood pressure, cardiovascular disease, demographic, dermatology, diabetes, diet behavior / nutrition, dietary supplements / prescription medication, early childhood, functioning, health insurance, hepatitis, hospital utilization and access to care, immunization, infant formula questionnaire, kidney condition, medical conditions, occupation, oral health, osteoporosis, physical activity and physical fitness, respondent selection section, sample person questionnaire handcards, sleep disorders, smoking and tobacco use, standing balance and weight history.

Data uses

NHANES information is made available through an extensive series of publications and articles in scientific and technical journals. For data users and researchers throughout the world, survey data are available on the internet and on easy-to-use CDs. Research organizations, universities, health care providers and educators benefit from its information. Primary data users are federal agencies that collaborated in the design and development of the survey. The NIH, FDA and CDC are among the agencies that rely upon NHANES to provide data essential for implementation and evaluation of program activities. The US Department of Agriculture and NCHS cooperate in planning and reporting dietary and nutrition information from the survey. Partnership with the US Environmental Protection Agency allows continued study of many important environmental influences on health. Past surveys have provided data to create the growth charts used nationally by pediatricians to evaluate children's growth. The charts have been adapted and adopted worldwide as a reference standard and are updated using the latest NHANES data.

Because NHANES is an ongoing program, information collected contributes to annual estimates in topic areas included in the survey. For small population groups and less prevalent conditions / diseases, data must be accumulated over several years to provide adequate estimates.

Data release and access policy

This policy addresses when, to whom and in what form the Division of Health Examination Surveys (DHANES) should disseminate NHANES data and outlines dissemination procedures. The policy is consistent with CDC and NCHS policies, including the guiding principles of making high quality data available –

- As widely as practicable
- As soon as possible after data collection
- In as much detail as possible
- While maintaining survey participant confidentiality

Various mechanisms of data release and access are used to follow the principles, including public data release as well as limited data access arrangements.

Since NHANES 1999-2000, public use data releases have been and continue to be made on a bi-annual basis. Due to voluminous nature of NHANES and the large amount of post data-collection processing, release of all data from 2 years of data collection does not occur at a point in time. An initial data release occurs approximately 9 months after completion of each 2-year data collection cycle and intermittent releases follow as remaining data is processed, until all releasable data are available for public use.

Whenever new data items are developed using physical samples from NHANES surveys, such as stored sera, DNA or imaging studies, these items are made publicly accessible under either public use or RDC access, depending on nature of the derived data item and disclosure risk. If requested data are not currently collected or available in NHANES, a proposal to obtain (and fund) the new data items can be submitted via email to NHANES Biospecimen Program. The NHANES Project Officer and a technical panel evaluate all proposals for scientific merit. The NCHS Human Subject Contact and Ethics Review Board (ERB) then review the proposal for any potential human subjects concerns and the NCHS Confidentiality Officer for disclosure risk. Any data developed under this mechanism are made accessible under either public use, or RDC access to appropriate recipients as noted above.[134]

National Survey of Family Growth (NSFG)

The NSFG gathers nationally representative data – not for individual states – on family life, marriage and divorce, pregnancy, infertility, use of contraception, general and reproductive health. The first NSFG surveys were conducted as periodic cycles by NCHS in 1973, 1976, 1982, 1988 and 1995, based on personal interviews conducted in the homes of a national sample of women 15-44 years of age in the civilian, noninstitutionalized population of the US. Later changes to the NSFG include addition of an independent sample of men in 2002, shift from being a periodic survey to continuous interviewing in 2006, and shift in age range to 15-49 years in 2015. Under continuous interviewing, fieldwork takes place continually (48 weeks / four 12-week quarters each year) in a smaller number of areas in the US than is the case for periodic interviewing. In each interviewing year, over 5,000 interviews have been completed. Significant oversampling of Blacks, Hispanics, teens aged 15-19 years and a slightly higher sampling rate for females is observed. The samples for different time intervals could be combined. Like periodic interviewing, all interviews are conducted in person by female interviewers (CAPI), with some of the more sensitive questions answered privately using audio-computer assisted self-interviewing (Audio-CASI / ACASI) through self-administration. In this procedure, respondents answer questions on the laptop either by reading them or listening to pre-recorded questions read over headphones and enter their answers directly into the computer.

The NSFG responds to the Congressional mandate for NCHS to collect and publish reliable national statistics on “family formation, growth, and dissolution” (Sec. 306 (a and b), paragraph 1(H) of the Public Health Service Act) as well as vital statistics on births and deaths, and a number of aspects of health status and health care. The NSFG collects and publishes the most reliable – in most cases the only – national data on such major topics as adoption, unplanned births, contraceptive use and effectiveness, infertility and use of infertility services, pelvic infection and sexually transmitted

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[134] https://bit.ly/35kHVEk; https://bit.ly/2zL4K8j; https://bit.ly/3c2UBSs; https://bit.ly/2ZFbgbv; https://bit.ly/3aNq4qF and https://bit.ly/2TI1rWy. For details on NHANES Biospecimen Program – https://bit.ly/3d2SxtS (30/4/2020, 22:03 hours).

disease, sterilization, expected future births, the sexually active population, and the use of and need for family planning services. The NSFG aims at providing time series data on these variables through continuous interviewing, while improving sample sizes at an affordable cost.

Purpose and scope

The primary purpose of the survey, particularly since the inclusion of a sample of men, has been to produce reliable national estimates of –

- factors affecting pregnancy, including sexual activity, contraceptive use and infertility
- the medical care associated with contraception, infertility and childbirth
- factors affecting marriage, divorce, cohabitation and family building
- adoption and caring for non-biological children
- father involvement with their children
- use of sexual and reproductive health services
- attitudes about sex, childbearing and marriage

No clinical or examination data are collected from survey participants. Only one survey participant is selected from each sample household. Socioeconomic variables include income and poverty, education, employment status (full-time or part-time), source of payment for delivery and selected health services, and receipt of public assistance.

Sample design

The NSFG sample is designed to meet a number of key objectives, including –

- minimizing the overall design effects for women and men
- controlling the costs of both screening and interviewing
- obtaining overall sample size of at least 5,000 interviews per year
- providing for oversamples of Blacks, Hispanics and teens aged 15-19 years

The NSFG survey population consists of all noninstitutionalized women and men aged 15-49 years as of first contact for the survey, whose usual place of residence is the 50 United States or District of Columbia. The NSFG is based on a stratified multi-stage area probability sample using probability proportionate to size (PPS) selection with 5 stages of sample selection –

- selection of PSUs

- selection of secondary sampling units (SSUs)
- listing and selection of housing units within SSUs
- selecting one of the eligible persons within each sampled household
- two-phase sampling for non-response[135]

Each year, about 15,000 households are contacted in order to get approximately 5,000 interviews. Each year of data is an independent national sample, but the desired sample size and precision for several key estimates and statistics are attained after about 4 years of interviewing. In addition, despite each year of fieldwork being designed to yield nationally representative data, sample weights are only constructed for 2 years of data, which is the minimum timespan for NSFG public use file releases that permit statistically reliable estimates to be made.

Survey process

Fieldwork for 2015-2017 NSFG was conducted from September 2015 through September 2017, based on a survey protocol and informed consent procedures approved by the NCHS Research Ethics Review Board. After a sample respondent per household was selected based on screening interviews in NSFG sample households, in-person interviews were conducted with 5,554 women and 4,540 men 15-49 years of age for a total sample size of 10,094. Signed parental permission and minor assent were obtained for all minor respondents aged 15-17 years. Adult respondents could provide consent without signature. For 2015-2017, the interviews for female respondents averaged 73.0 minutes in length, and the interviews for male respondents averaged 49.9 minutes, both within the limits of 80 minutes for females and 60 minutes for males approved by the Office of Management and Budget. Respondents in Phase 1 of data collection were offered a $40 token of appreciation in cash. Those adult respondents screened in Phase 1 and selected into Phase 2 for a main interview were offered an additional $40 (total of $80) as a prepaid token of appreciation for completion of the survey. Households selected for Phase 2 that were not yet screened in Phase 1 were also sent a $5 prepaid token of appreciation for completion of the screener.

Respondent burden for the NSFG is kept to a minimum through the use of sampling procedures that permit generation of statistically valid national estimates for roughly 149 million people 15-49 years of age with about 20,000 interviews over 4 years of interviewing; keeping the length of the questionnaires under the approved 80 minutes for women and 60 minutes for men, and by using faster and more efficient laptops and the latest edition of BLAISE CAPI software. CAPI reduces burden for the respondent because it collects data using a laptop computer, along with a highly skilled interviewer. The computer customizes the questionnaire and question wording for the

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[135] Further details on sample selection are available at – https://bit.ly/3e8f2OI (22/5/2020, 18:40 hours).

respondent, based on answers given during the administration of the instrument. A portion of the NSFG interview (around 15-20 minutes) is conducted using ACASI. However, only material that is sensitive and fairly simple to ask and answer is collected in ACASI. Respondents often report that they enjoy the ACASI part of the interview because they can control the pace of the interview themselves and be more active participants in it. Despite its appeal, however, it is not practicable to use ACASI to conduct the entire survey as much of the questionnaire material is too complex to be self-administered.

Questionnaires

The questions in the NSFG questionnaires may be divided into 2 categories – (1) questions that have generally been asked in some form in the NSFG since the 1970s – including demographic characteristics like education and marital status and behaviors like contraceptive use, marriage, divorce and unmarried cohabitation; and (2) more sensitive questions that are asked in ACASI and have mostly been asked since 2002 (Incarceration, drug use, on-voluntary sexual experience, behavior, identity and attraction, same-sex sexual activity, sexually transmitted diseases, income).

There are 4 NSFG questionnaires – the household screener questionnaire, female questionnaire, male questionnaire and verification questionnaires – as well as an interviewer observation form.[136]

Data uses

NSFG provides data for major areas of *Healthy People 2020*, and is the primary source of data for family planning objectives. In addition, NSFG is an important contributor of data for objectives in the areas of HIV, STDs, maternal, infant and child health. NSFG data has been used to brief the DHHS Secretary, Surgeon General as well as others. One of the NSFG-based objectives (receipt of reproductive health services in the past 12 months) was selected as one of 26 leading health indicators for the nation. NSFG data are used by many DHHS agencies; for instance –

- The Office of Population Affairs uses NSFG data to estimate the characteristics of women who use *Title X*-funded clinics for family planning and related health services and for research on factors affecting contraceptive use, unintended pregnancy, teenage sexual activity and use of medical services for family planning and reproductive health. The data on men's reproductive behavior are also used to improve family planning and related health services targeting men.
- Population Dynamics Branch, NICHD, NIH, uses the data from men and women as a resource for intramural and extramural research on marriage, cohabitation, fertility and infertility, contraceptive use, sexually transmitted infections and breastfeeding in the United States.

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[136] NSFG questionnaires are available at – https://bit.ly/2LZtYTe (22/5/2020, 17:41 hours).

- The Children’s Bureau has a special research interest in data collected on children in foster care, fertility and family formation behaviors of adults who experienced foster care as children.
- The Administration for Children and Families in the Office of Planning, Research and Evaluation relies on NSFG data on fatherhood, marriage and teen pregnancy risk behaviors for planning programs to improve the economic and social well-being of children and families.
- Division of HIV/AIDS Prevention, CDC, undertakes research based on NSFG data on behaviors that affect the risk of transmission of HIV – including condom use, numbers of sexual partners, etc.
- Division of Cancer Prevention and Control, CDC, uses NSFG data on screening for cervical cancer, human papillomavirus (HPV) and breast cancer, which can be analyzed in relation to the NSFG’s extensive data on pregnancy histories, sexual behavior and reproductive health. It has also supported recent questionnaire additions to evaluate adherence to revised cancer screening guidelines.
- Division of Reproductive Health, CDC, uses NSFG data for surveillance of reproductive health outcomes and research on teen pregnancy prevention, sexual activity and contraceptive use. DRH also uses NSFG data for their work on establishing recommendations for family planning services, including contraceptive services.
- Within CDC’s National Center for Chronic Disease Prevention and Health Promotion, the NSFG has long been supported by the Divisions of Cancer Prevention and Control and Reproductive Health. Since 2016, Division of Nutrition Monitoring, Physical Activity and Obesity has begun co-sponsoring NSFG to support overall data collection on fertility and infant feeding practices, including breastfeeding, as well as nutrition-related counseling that mothers of young children receive from health care providers and other sources.
- The Division of Birth Defects and Developmental Disabilities, CDC, uses estimates of number and characteristics of women at risk of an alcohol-exposed pregnancy that could lead to Fetal Alcohol Syndrome.[137]

Lessons for India

The GoI / state / UT governments should consider the following lessons from the US context –

- Develop a national / state health information policy / Act.
- Establish –

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[137] https://bit.ly/3bS69aA, https://bit.ly/2XitqgE, https://bit.ly/3gdyw6w; https://bit.ly/36xCGBH; https://bit.ly/3c8dF0S and https://bit.ly/36khpeH (22/5/2020, 17:41 hours).

  - National Vital Statistics System (NVSS)-type agency with Centre-state coordination;
  - National / state committees on vital and health statistics (like the NCVHS) that function as statutory, advisory and monitoring bodies for vital and health statistics;
  - National / state centers for vital and health statistics (like the NCHS) that function as principal health statistical agencies (much like the DES at a broader level).

- We should consider a mixed health survey strategy – for e.g., 3 major surveys (NHIS, NHANES and NSFG) are continuous and nationally representative, while others play a complementary role by providing annual / periodic and state / locally representative data. These 3 surveys also offer a good mix of extensive (NHIS), focused (NSFG) and intensive (NHANES) data. In India, the SRS is already continuous – we can easily learn from its experience, while acknowledging / addressing its limitations / challenges.
- Continuous surveys could have a smaller sample size and be representative at national and state / UT level. For smaller population groups / districts, there should be the option of pooling data over a few years to get representative estimates.
- At least, some of the health surveys should be linked up with vital statistics for follow-up data collection. This is particularly important for death and cause of death statistics as well as RCH. India should consider mortality follow-up surveys. The SRS-CoD survey is already doing that. However, we need to have a much bigger sample size for these surveys – and for that, linkage with / follow-up on the CRVS mortality data is needed, as in the US.
- All vital and health statistics should be interoperable. An IPUMS-type agency should be set up for this purpose, under the administrative control and supervision of the NSO.
- A survey on the health and socioeconomic impact of COVID-19 on households (like Household Pulse Survey) should be developed that could provide data by background characteristics like the NFHS to assess the differential impact of the pandemic on different population groups.

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10. Canada

Statistics has been a federal responsibility in Canada since its creation in 1867. The Statistics Act, 1918 created the Dominion Bureau of Statistics, which came to be known since 1971 as Statistics Canada (StatCan), the country's central statistical office – functioning under the Canadian Ministry of Innovation, Science and Economic Development. Both the Ministry and StatCan are headed by persons of Indian origin – Navdeep Bains and Anil Arora (Chief Statistician of Canada). With over 6,000 employees across the country, StatCan conducts more than 350 surveys around almost all aspects of public life (31 themes) as well as population and agriculture censuses quinquennially.

According to the Statistics Act (current to 17 May 2020), StatCan's duties are to –

1) Collect, compile, analyse, abstract and publish statistical information relating to the commercial, industrial, financial, social, economic and general activities and condition of the people;
2) Collaborate with departments of government in the collection, compilation and publication of statistical information, including statistics derived from the activities of those departments;
3) Take the census of population of Canada and the census of agriculture of Canada as provided in this Act;
4) Promote avoidance of duplication in the information collected by departments of government; and
5) Generally, to promote and develop integrated social and economic statistics pertaining to the whole of Canada and to each of the provinces thereof and to coordinate plans for the integration of those statistics.

In functional terms, StatCan has 2 main objectives –

1) To provide statistical information and analysis to help:
    a. improve public and private decision-making;
    b. develop and evaluate public policies and programs;
2) To promote sound statistical standards and practices by:
    a. using common concepts and classifications to provide better quality data;
    b. working with provinces and territories for higher efficiency in data collection, including reducing duplication as well as respondent burden through greater use of data sharing agreements (for e.g. employee payroll, tax and customs records);
    c. improving statistical methods and systems through joint research studies and projects.

The agency collaborates with various departments and levels of the governments as well as public and private agencies, academics and others to develop surveys based on Canada's priorities and requirements. StatCan maintains close relationships with key federal departments / agencies to foster awareness of each other's needs / priorities. The Federal-Provincial-Territorial Consultative Council on Statistical Policy and its subcommittees comprise a network of 13 provincial / territorial official representatives, who collaborate with StatCan to determine data requirements, consult on current statistical activities and coordinate dissemination of StatCan's products to provincial and territorial governments. There are 3 special initiatives, in the areas of health, education and justice statistics. StatCan's priorities in health are developed with the assistance of the Board of Directors of Canadian Institute for Health Information (CIHI). The Board comprises senior federal, provincial and private sector representatives, including the Chief Statistician.[138]

A set of advisory groups offer impartial and independent advice to StatCan vis-à-vis overall quality of the national statistical system (Canadian Statistics Advisory Council), continuous review of the Agency's statistical outputs and helping set priorities and foster program relevance (a network of professional advisory committees in major subject areas), data access, privacy, data governance to maintain and support data needs (Advisory Council on Ethics and Modernization of Microdata Access), developing common approaches for collection of vital statistics, sharing information and facilitating problem-solving through sharing experiences, research findings and expertise among various jurisdictions (Vital Statistics Council for Canada). All this is seen as critical to the fulfilment of StatCan's mission – 'serving Canada with high-quality statistical information that matters'.[139]

StatCan's Health Statistics Program (HSP)

In Canada, StatCan and CIHI jointly produce national health data and indicators related to health. The distinction in their roles is – CIHI is mandated to lead the development and maintenance of comprehensive and integrated health information which enables sound policy and effective health system management, while StatCan (HSP) provides information about the health of the Canadian population, the determinants of health and the use of Canada's health care resources. HSP could be compared to the NCHS in the US – only that the former functions under a much broad-based agency (StatCan) than the latter does (CDC).

HSP's aim is to provide reliable, timely and relevant information about the health of Canadians. Its Health Statistics Division (HSD), in collaboration with the Health Analysis Division (HAD), provides statistical analysis and information about the health of the population, the determinants of health, the scope / use of Canada's health care resources. This information is used to assist and support health planners and decision-makers at all levels of the government, to sustain demographic and

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[138] https://www.statcan.gc.ca/eng/about/relevant (3/6/2020, 15:42 hours).

[139] https://www.statcan.gc.ca/eng/about/about?MM=as (3/6/2020, 15:48 hours).

epidemiological research and to report to the Canadian public on their collective health and health care system performance.

HSD works in partnership with provincial and territorial vital statistics registrars, cancer registries as well as data providers and users at the federal level – Health Canada and Public Health Agency of Canada (PHAC) – with the provincial ministries of health and health regions. It also works with many other partners, including CIHI, to provide statistical information and undertake research and analysis on the health status of Canadians and the health care system.

HAD's mandate is to provide high-quality, relevant and comprehensive information on the health status of the population and on the health care system to a broad audience – health professionals, researchers, policymakers, educators and students. A significant part of HAD's research program is undertaken in collaboration with various partners – federal ministries, health organizations and universities. HAD brings out *Health Reports*, a peer-reviewed and indexed journal of population health and health services research, publishing original and timely analyses of surveys as well as national / provincial administrative databases. HAD analysts also regularly publish in other journals.

HAD's program of work involves data development, development of methods and modelling, and research in 5 broad-based health themes – maternal, child and youth health; ageing; vulnerable populations; health and the environment; behaviors, chronic disease and cancer – using a number of analytical lenses, including determinants, outcomes, mortality / morbidity, heath care utilization, international comparisons and longitudinal as well as person-oriented focuses. Research is based on StatCan's comprehensive suite of data on the health of Canadians and the functioning of the health system, including census, vital statistics, administrative health data, population, post-censal and special surveys. Its record linkage activities[140] deserve special mention. Various projects have combined census, vital statistics, cancer, population health surveys as well as other data to avoid duplication / burden in data collection and to help better understand the health of Canadians and the functioning of the health system. Survey respondents are notified of planned linkages before / during the survey. If any respondent objects to the linking of their data, their objection is recorded and no data linkage happens. Income information obtained from income tax records, for instance, is provided to federal, provincial and territorial agencies only after the respondents' consent.[141]

Microdata linkages

Linking of separate records from different sources can be a very useful and cost-efficient technique in the design, production, analysis and evaluation of statistical data, leading to important savings in cost, time and respondent burden, and, in some cases, it may be the only feasible way to obtain

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[140] 'Record linkage is the process of bringing together 2 or more records relating to the same entity (e.g., person, family, event, community, business, hospital or geographical area)'. https://bit.ly/304k1fm (3/6/2020, 16:12 hours).

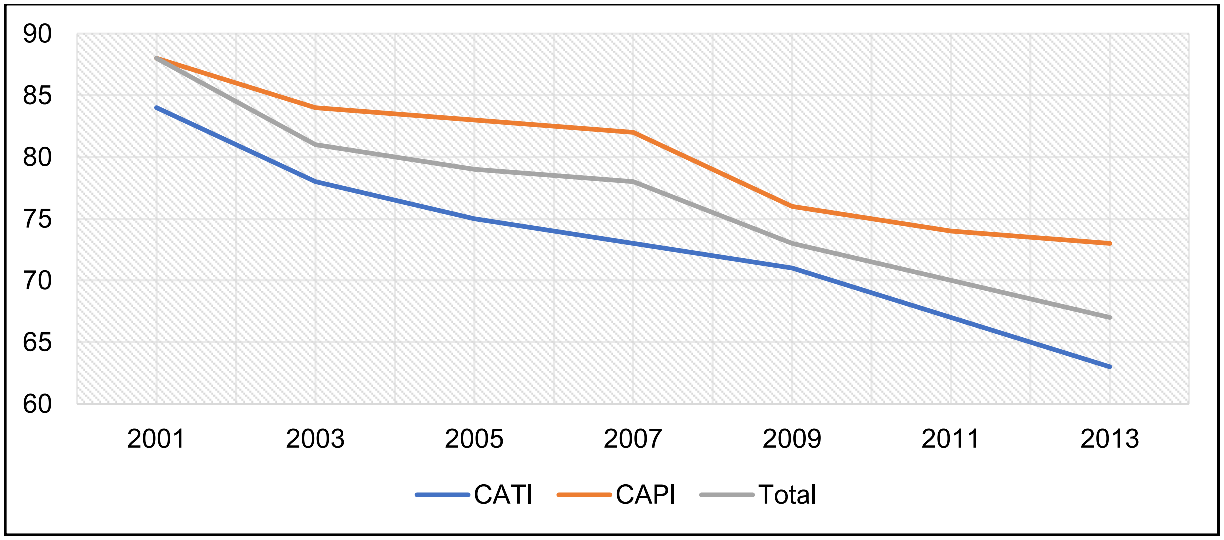
[141] https://bit.ly/36UHAJ4 and https://bit.ly/2TNML8n (3/6/2020, 16:15 hours).

important statistical information. When possible, instead of conducting additional surveys, StatCan uses information that individuals, businesses and institutions have already provided to the Agency or other government departments for methodological purposes, data enhancement and subject-matter studies. When health survey and administrative data are combined through record linkage, relationships between social determinants and health outcomes could be analysed in more depth.

Microdata linkages are conducted in accordance with StatCan's Directive on Microdata Linkage, in place since 1986. StatCan performs microdata linkages – a) to support the design, maintenance, evaluation, research and redesign of ongoing data collection / methodological studies in StatCan; b) provide statistical information in aggregate or anonymous format in support of research studies. StatCan has pre-approved specific types of microdata linkages where privacy risks and situations of potential conflict of interest are low and where procedures to mitigate risk to confidentiality and privacy are in place. All other microdata linkages must undergo a prescribed review and approval process, which involves submission of documented proposals to senior management. When such linkages include personal information, a summary of the approved microdata linkage is posted on StatCan's website.[142]

Before we move on to provide an overview of major active health surveys in Canada (table 10.1) and discuss some of them, let us highlight the issue of declining responses rates in health surveys in the country. Figure 10.1 illustrates this vis-à-vis a leading Canadian health survey. It is important to note that telephonic interviewing (CATI) has become less favourable than personal interviewing (CAPI), with the differentials in response rates between the two modes increasing over the years.

Figure 10.1: Response rates of Canadian Community Health Survey, 2001-2013



Source: https://www.statcan.gc.ca/eng/about/er/hspfr (3/6/2020, 17:54 hours).

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[142] https://bit.ly/3eJv2Xz; https://bit.ly/3duU90g; https://bit.ly/2U7Kipp and https://bit.ly/30aQBw6 (3/6/2020, 16:25 hours).

Table 10.1: An overview of major active health surveys in Canada

Survey	Objective	Inception	Frequency	Methods	Sample	Representative	Major themes
Canadian Community Health Survey (CCHS) - Annual component	A cross-sectional, flexible survey for data at sub-provincial levels (health region / combined health regions)[143] on health status, health care utilization and determinants – single data source for research on small populations and rare characteristics	2000	Annual (2007-), Biennial (2001-05)	Instrument with 3 components: common (core and theme), optional (unique provincial and territorial data needs), rapid response (data on an emerging or specific issue) - computer-assisted personal and telephone interviews (CAPI and CATI)	12+ year olds living in all the 10 provinces and 3 territories - 65,000 respondents annually (2007-), 130,000 biennially (2001-05)	Health region level on a biennial basis - data years can be combined to study small populations / rare characteristics	Diseases and health conditions - health care services - lifestyle and social conditions - mental health and well-being - record linkages
Canadian Health Measures Survey (CHMS)	A cross-sectional survey to assess extent of chronic and infectious diseases, lifestyle characteristics and environmental exposures as well as help explore emerging public health issues	2007	Biennial	2 questionnaires: household (HH) interview and physical examination in a mobile clinic (as in NHANES, US)	3-79 year olds in 10 provinces - 6,361 HHs, 7,944 persons, 5,786 physical examination	National	Diseases and health conditions - environmental factors - lifestyle and social conditions

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[143] 'Health region' refers to administrative areas defined by the provincial ministries of health. For details, kindly refer to https://bit.ly/2ZLRjzO (28/5/2020, 20:46 hours).

Survey	Objective	Inception	Frequency	Methods	Sample	Representative	Major themes
Canadian Health Survey on Children and Youth (CHSCY)	A cross-sectional survey to paint a portrait of health and well-being of children and youth and the factors influencing their physical and mental health	2017	Occasional	Questionnaire: online (self) / phone (StatCan interviewer)	1-17 year olds in 10 provinces, 3 territories - 92,170 raw units	National, provincial, territorial	Chronic conditions - nutrition - injuries - physical activity - time spent in school and extracurricular activities - use of electronic devices - social environment (family, friends, and communities)
Childhood National Immunization Coverage Survey (CNICS)	A cross-sectional survey to assess child immunization in accordance with the immunization schedules for publicly-funded vaccines, parental knowledge, beliefs attitudes about vaccines	2011	Biennial	CATI with the person most knowledgeable (PMK) about the child's immunizations, child's vaccine history from child's health care provider(s)	Children aged 2, 7, 14 and 17 years in 10 provinces, 3 territories - 14,960 units	National, provincial, territorial	Child immunization - knowledge, attitudes and beliefs - education - income - ethnicity - immigration status
Survey on Maternal Health (SMH)	A random, cross-sectional survey to monitor maternal health (pregnancy and postpartum experiences) and improve the health and wellness of women	2018	One-time	Electronic questionnaire (EQ) / CATI	Biological mothers who gave birth (1 Jan to 30 Jun 2018) in 10 provinces - 13,000 initial sample	Provincial	Maternal health and well-being - pregnancy and postpartum experiences

Survey	Objective	Inception	Frequency	Methods	Sample	Representative	Major themes
Longitudinal and International Study of Adults (LISA)	To improve the understanding of what is happening in the lives of Canadians - how people's lives change over time - causality between major life experiences and their impact on the educational, employment and financial outcomes - to help assess what services are suitable for them	2011	Biennial	In-person CAPI interview (StatCan) - record linkages from other surveys or administrative data sources	15+ years - ca. 10,000 households in 10 provinces (1 eligible person per household)	Provincial	Education and training - labour market activities and job characteristics - work schedules - income, pensions and finances - life satisfaction - life after retirement and planning for it - family and relationship status homelessness - caregiving - health (child, self-reported, mental, work-related, disability)
Canadian Health Survey on Seniors (CHSS)	A supplement to the CCHS (annual component), this cross-sectional survey aims to help better understand what contributes to healthy aging and help policymakers to make informed decisions about health care, social services and support programs for the seniors	2019	Occasional	Computer-assisted interviewing (CAI)	65+ seniors - 10 provinces (oversample in 8 provinces to achieve the sample target) - ca. 25,000 respondents a year	National, provincial	Diseases and health conditions - lifestyle and social conditions - mental health and well-being - health care services

Survey	Objective	Inception	Frequency	Methods	Sample	Representative	Major themes
Canadian Survey on Disability (CSD)	A cross-sectional survey to provide information about Canadian youth and adults whose everyday activities are limited due to a long-term condition / health-related problem	1986	Quinquennial	Self-reported / interviewer-led methods: questionnaire completed directly by the respondent on-line (rEQ) / conducted by the interviewer over telephone (iEQ) (2017-)	15+ disabled - 10 provinces, 3 territories - 50,000 persons	National	Type and severity of disability - use of aids and assistive devices - daily help received or required - therapy and social service supports use - educational attainment - labour force participation - accommodations at school / work - experience of being housebound - internet use - methods used to access government services - sources of income
Impacts of COVID-19 on Canadians	Collects data on the current economic and social situation as well as people's physical and mental health to assess needs of communities and implement suitable support measures during and after the pandemic	2020 (24 April)	Weekly	Electronic questionnaire - participant self-completion	All from 10 provinces, 3 territories - no sampling - crowd-sourcing initiative - 46,000 respondents (24 Apr - 11 May 2020) for mental health component	Not known	Health - mental health and well-being - disability - economic accounts - income and expenditure accounts

Source: Statistics Canada and other sources. https://bit.ly/3dhpdAx (28/5/2020, 20:33 hours). Developed by author.

Let us now discuss some of the major surveys in some detail. Let us reiterate that we have adopted the description of these surveys from official sources and referenced them, with minimal changes / rephrasing from our side, given the resource constraints. However, we have tried to put together information from a variety of sources to provide a fuller overview of the surveys described below.

Canadian Community Health Survey (CCHS) – Annual Component

In 1991, the National Task Force on Health Information highlighted a series of challenges with the country's health information system. StatCan, CIHI and Health Canada came together to create a Health Information Roadmap to address these challenges. CCHS was one of the key outcomes.

The CCHS is a cross-sectional survey that collects information related to health status, health care utilization and health determinants for Canadian population. It is offered in both official languages. It has a large sample of respondents, designed to provide reliable estimates at the health region level every 2 years. The CCHS produces an annual microdata file and a file combining 2 years of data. Collection years can also be combined by users to study populations or rare characteristics.

The CCHS has the following objectives –

1) Support health surveillance programs by providing health data at the national, provincial and intra-provincial levels;
2) Provide a single data source for health research on small populations and rare characteristics;
3) Timely release of information easily accessible to a diverse community of users;
4) Create a flexible survey instrument that includes a rapid response option to address emerging issues related to the health of the population.

The survey began collecting data in 2001 and was repeated every two years until 2005. Starting in 2007, data for the Canadian Community Health Survey (CCHS) were collected annually instead of every 2 years. While a sample of approximately 130,000 respondents were interviewed during reference periods of 2001, 2003 and 2005, the sample size was changed to 65,000 respondents each year starting in 2007 (data collection period: January to December).

In 2012, CCHS began work on a major redesign project that was completed and implemented for the 2015 cycle. The objectives of the redesign were to review the sampling methodology, adopt a new sample frame, modernize the content and review the target population. Consultations were held with federal, provincial and territorial share partners, health region authorities and academics.

Target population

The CCHS covers the population 12 years of age and over living in 10 provinces and 3 territories, with certain exclusions.

Instrument design

Each component of the CCHS questionnaire is developed in collaboration with specialists from StatCan, other federal and provincial departments and / or academic fields. CCHS questions are designed for computer-assisted interviewing (CAI) – as questions were developed, the associated logical flow into and out of the questions was programmed. This includes specifying the type of answer required, the minimum and maximum values, on-line edits associated with the question and what to do in case of item non-response.

The CCHS content is comprised of 3 components – 1) common content (core content and theme content), 2) optional content, and 3) rapid response content. The core content is collected from all survey respondents and remains relatively unchanged over several years. The theme content, also collected from the entire sample, varies from year to year. The optional content fulfils the unique data needs of each province and territory, and may vary from year to year. The rapid response component is offered to organizations interested in national estimates on an emerging or specific issue related to population health. Provincial estimates may be derived from the rapid response component; however, they may be of limited quality. A rapid response component may be added to the survey in each 3-month collection period. Data is released about 6 months after the collection period through an announcement in *The Daily*.[144]

It also needs to be noted that, until the 2015 redesign, CCHS had cycles. In addition to the main cycles, CCHS had special surveys on specific themes – cycle 1.2 on mental health (2002), cycle 2.2 on nutrition (2004) and cycle 4.2 on healthy aging (2008).[145] A decade later, a pilot CCHS – Nutrition (CCHS-N) was conducted in 2014, followed by a survey with a desired sample of 24,000 respondents in 37,694 selected dwellings, aged 1+ years, living in 10 provinces.[146]

New modules and revisions to existing CCHS content are tested using different methods. Qualitative tests using individual cognitive interviews or, more rarely, focus groups are used to ensure that questions and concepts are appropriately worded.

The computer application for data collection is extensively tested in-house each time changes are made. The objective of these tests is to identify any errors in the program flow and text before the start of the main survey.

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[144] *The Daily* (TD) is StatCan's official release bulletin, its first line of communication with the media and the public. TD issues news releases on current social and economic conditions and announces new products, offers a comprehensive overview of new information available from StatCan. It is released at 8:30 am Eastern time each working day, has been published since 1932 and posted on the internet since 1995. https://bit.ly/3glX4V0 (3/6/2020, 21:08 hours).

[145] https://www150.statcan.gc.ca/n1/pub/91-549-x/2009001/par7-eng.htm (4/6/2020, 11:19 hours).

[146] https://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&Id=201486 (4/6/2020, 11:27 hours).

Sampling

CCHS is a sample survey with a cross-sectional design.

To provide reliable estimates at the health region (HR) level, a sample of 130,000 respondents is required on a 2-year basis – 120,000 respondents to cover the population aged 18 and over and 10,000 respondents to cover the population aged 12 to 17 years.

Since 2015, a multi-stage sample allocation strategy has been used to give relatively fair sample distribution to HRs and provinces. For each age group (18 and over, 12 to 17), the sample is first allocated among the provinces using a power allocation of 0.75 according to the size of their respective population. Each province’s sample is then allocated among its HRs using a power allocation of 0.35 according to the size of the population in each HR.

From 2015 onwards, the CCHS sample is selected using 2 different frames – an area frame and the Canada child benefit (CCB) frame. Using the area frame, a sample of dwellings is selected to target the population aged 18 and over. During collection, all members of the dwelling are listed and a person aged 18 years or over is automatically selected using various selection probabilities based on age and household composition. The CCB frame is used to sample persons aged 12 to 17 years. One child is then pre-selected to complete the survey.

The area frame is mainly designed to serve the Labour Force Survey (LFS). Thus, the sampling plan of the LFS must be considered in selecting the CCHS dwelling sample. The LFS plan is a complex 2-stage stratified design in which each stratum is formed of clusters. The LFS first selects clusters using a sampling method with a probability proportional to size (PPS), and then the final sample is chosen using a systematic sampling of dwellings in the cluster. For CCHS, LFS clusters are grouped in each HR. Then, a sample of clusters and systematic dwellings are selected in each HR. The process maximizes overlaps between clusters selected by both surveys and ensures that the same dwelling is selected only once.

For the CCB frame, an HR is assigned to each child in the target population based on the address. The CCB frame is then stratified by HR. A simple random sample (SRS) of children aged 12 to 17 is selected within each HR.

The size of the sample is enlarged during the selection process to account for non-responses and units outside the coverage.

Data sources

Data are collected directly from survey respondents.

Data are collected using CAPI and CATI software. Cases from the area frame are collected using a combination of both modes, while CCB cases are collected exclusively by telephone interview.

In both cases (area frame and CCB), proxy reporting is allowed, although certain questions may be skipped.

Respondents are initially offered to complete the interview in either English or French. To remove language as a barrier to conducting interviews, each StatCan Regional Office recruits interviewers with a wide range of language competencies. If necessary, cases are transferred to an interviewer with the language competency needed to complete an interview.

The average time to complete the survey was 50 minutes.

The information collected during 2018 CCHS was linked to tax records of respondents and that of all household members. Household information (address, postal code, and telephone number), respondent's information (social insurance number, surname, name, date of birth / age, sex) and information on other members of the household (surname, name, age, sex and relationship to respondent) are key variables for the linkage.

Respondents are notified of the planned linkage before and during the survey. Any respondent who objects to the linkage of their data have their objections recorded and no linkage to their tax data takes place. Income information obtained from income tax records will also be provided to federal, provincial and territorial share partners only with respondents' consent.

Error detection

Most editing of data is performed at the time of interview by CAI application. It is not possible for interviewers to enter out-of-range values and flow errors are controlled through programmed skip patterns. For example, CAI ensures that questions that do not apply to a respondent are not asked. In response to some types of inconsistent / unusual reporting, warning messages are invoked but no corrective action is taken at the time of the interview. Wherever appropriate, edits are instead developed to be performed after data collection at the Head Office. Inconsistencies are usually corrected by setting one or both of the variables in question to 'not stated'.

Imputation

Household income data in 2018 CCHS is imputed. Missing values due to either respondent refusal or respondent's lack of knowledge of household income was replaced using a nearest neighbour imputation method based on a modeled household income.

Quality evaluation

Throughout the data collection process, control and monitoring measures are put in place and corrective action is taken to minimize non-sampling errors. These measures include response rate evaluation, reported / non-reported data evaluation, on-site observation of interviews, improved collection tools for interviewers and others. Subsequently, 3 data validation steps are undertaken. A validation program is run in order to compare estimates for the health indicators taken from the common content with previous years. This validation is performed at various geographical levels as well as by age and sex. Significant differences are examined further to find any anomalies in data. The work of analysts who use CCHS data allows for an in-depth look at many variables of the survey and represents a very effective way to find errors.

Key themes in CCHS 2020

- Activity limitation
- Biking
- Body mass index
- Breastfeeding initiation
- Chronic disease
- Citizenship and immigration status
- Colorectal cancer screening
- Contact with health professionals
- Difficulties accessing health information or advice
- Disability
- Drinking status
- Exclusive breastfeeding
- Food insecurity of households and persons
- Fruit and vegetable dietary practices
- Functional health status
- Health-adjusted life expectancy
- Health care received
- Household total income
- Influenza immunization
- Injury
- Leisure-time physical activity level
- Life satisfaction
- Life stress
- Mammogram
- Mood disorder diagnosis
- Neurological condition
- Pain or discomfort
- Pap smear
- Perceived health and mental health
- Quality rating of health care services received
- Regular family physician
- Sense of belonging to local community
- Smoking[147]

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[147] https://bit.ly/2z5Go9o and https://bit.ly/2U7kauY (3/6/2020, 20:42 hours).

Canadian Health Measures Survey (CHMS)

Launched in 2007, CMHS collects key information related to the health of Canadians by means of direct physical measurements like blood pressure, height, weight and physical fitness. In addition, the survey collects blood, urine, saliva and hair samples to test for chronic and infectious diseases, nutrition and environment markers – storing blood, urine and DNA samples at the CHMS Biobank for future health research projects. Through household interviews, it gathers information vis-à-vis nutrition, smoking and alcohol use, medical history, health status, sexual behaviour, lifestyle and physical activity, environmental, housing, demographic and socioeconomic characteristics.

This information is supposed to create a national baseline data on the extent of such major health concerns as obesity, hypertension, cardiovascular disease, exposure to infectious diseases and environmental contaminants. Additionally, the survey provides clues about illness and the extent to which many diseases might be undiagnosed among Canadians. It helps to determine linkages between disease risk factors and health status as well as highlights emerging public health issues.

The CHMS data are representative of the population, whether they are healthy or not, and provide a picture of the actual health of Canadians. Following are some of the measures that it covers –

Physical measures

- Anthropometry (standing height, weight, waist circumference, neck circumference)
- Cardiovascular health and fitness
- Musculoskeletal health and fitness
- Physical activity (accelerometry)
- Vision (visual acuity, visual field, retinal photography, intraocular pressure)

Blood measures

- Nutritional status (for e.g., Vitamin B12, Vitamin D, ferritin)
- Diabetes (for e.g., glucose, glycated hemoglobin A1c)
- Cardiovascular health (for e.g., apolipoprotein A1 and B, lipid profile)
- Musculoskeletal health
- Environmental exposure
- Infection marker (toxoplasmosis)

Urine measures

- Environmental exposure
- Nutritional status (for e.g., iodine, sodium, potassium)
- Infection marker (chlamydia trachomatis)

Saliva measures

- DNA extraction for future health research projects

Hair measures

- 25 metals and trace elements (e.g., lead, cadmium, mercury)

The CHMS team works closely with the Health Canada and PHAC Research Ethics Board and the Office of the Privacy Commissioner of Canada in order to address privacy issues and to implement proper laboratory procedures.

Target population

The target population for CHMS consists of persons 3 to 79 years of age living in the 10 provinces, with approximately 4% of the target population excluded.

Instrument design

Two questionnaires were used for cycle 5 (January 2016 to December 2017) of the CMHS.[148]

Household questionnaire

The household questionnaire content was developed with input from stakeholders (Health Canada and PHAC) as well as from the external experts who participated as members of various advisory committees. Prior to finalizing questions, one-on-one qualitative test interviews were conducted to look at specific questionnaire content, particularly the content new to cycle 5. As a result of this testing, improvements were made to questionnaire wording, instructions and the flow of questions.

Clinic questionnaire

Development of the clinic questionnaire proceeded in much the same way as that of the household questionnaire. Its content was developed by means of a comprehensive consultation process, and multiple iterations of collection application were generated. Each iteration was assessed on flow within the mobile examination center (MEC) for both the respondent and staff. Quantity and quality of data collected was also assessed. The clinic questionnaire includes a set of self-reported health questions similar to the type of questions asked within the household questionnaire. The questions included at MEC are related to medication use, fish / shellfish consumption and vision. In addition,

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[148] CHMS cycle 5 questionnaires are available at – https://bit.ly/2BnX64r (4/6/2020, 12:21 hours).

the questionnaire includes introductory text / instructions, screening and administrative questions related to the physical measures tests conducted at the MEC.

Sampling

This is a sample survey with a cross-sectional design.

The CHMS uses a stratified 3-stage sample made up of 1 or 2 selected respondents from each dwelling selected in a sampled collection site.

The sampling unit at the first stage is a collection site. A collection site is a geographical unit limited to a radius of about 50 km in urban areas and up to 75 km for rural areas. The sampling unit at the second stage is the dwelling and at the third stage, the sampling unit is the person.

The CHMS consists of a full sample and several sub-samples.

For the full sample, at the first stage, a sample of 16 collection sites was required. The sites are allocated by region: Atlantic (2), Quebec (4), Ontario (6), Prairies (2) and British Columbia (2). Within each region, sites are sorted according to the size of their population and whether or not they belonged to a census metropolitan area. Within the Prairies and Atlantic regions, they were first sorted by province. Sites are then randomly selected using a systematic sampling method with probability proportional to the size of each site's population.

The sample size determination and allocation for the second and third stage are done together. The target sample size for cycle 5 was 5,700 respondents for the clinic component of the survey, which works out to approximately 356 respondents per collection site. To determine the number of dwellings to sample in each collection site to reach this target, previous response rates were used from both the CHMS and the CCHS. The CHMS and CCHS are both used to calculate –

- The expected probability that a dwelling would be eligible for the CHMS (the eligibility rate)
- The expected probability that a roster of all occupants of the household would be completed (the roster rate)
- The expected probability that a selected person would respond to the household questionnaire (the questionnaire rate)

Finally, rates from the previous CHMS sites are used to calculate the expected probability that a household questionnaire respondent would also be a respondent to the clinic (the clinic rate).

The sample is allocated amongst the 6 age group strata (3-5, 6-11, 12-19, 20-39, 40-59 and 60-79), with a small portion of the sample going to an "other" stratum. A maximum number of 35 dwellings per site is selected in this stratum, with fewer being selected for sites that had fewer dwellings in the stratum. This stratum size helped to prevent extreme dwelling sampling weights.

The allocation of the dwelling sample to each of the age group strata is done to allow for the best chance of meeting the age and sex clinic respondent targets for cycle 5 without going too far over. Where possible, the sample is allocated in a way that emphasized the strata where more sample was required to meet the targets.

Once the sample of dwellings is in the field, when the household interviewer makes contact with a sampled dwelling, the goal is to create a roster for the household. A roster is a list of all persons residing in the household and includes pertinent information such as age, sex and whether the individual works full-time for the Canadian Forces. With this information, the computer application randomly selects one or two persons to take part in the remaining part of the survey, including the questionnaire and the clinic visit. The number of persons selected depends on the composition of the household –

- If there is at least one child between the ages of 3 and 11, two people are selected: one child between the ages of 3 and 11 and one other person between the ages of 12 and 79
- If there are no children between the ages of 3 and 11, only one person in the 12 to 79 age group is selected
- If there are no one eligible for the survey, no one is selected. This includes households where all in-scope persons are under the age of 3, over the age of 79 and / or are full-time members of the Canadian Forces

When the roster is completed, the computer application assigns a sampling factor to each eligible member of the household and this information is used to determine the probability of selection. The sampling factor assigned to each individual is based on their age group and sex and the factors vary between groups in order to do a better job of reaching the clinic targets for each age group by sex. In households where two people are selected, the selection of the child (aged 3-11) is done independently of the person aged 12 to 79.

Data sources

Data are collected directly from survey respondents.

Collection includes a combination of a personal interview using a CAI method and, for the physical measures, a visit to an MEC specifically designed for the survey.

CHMS collects data in 16 sites across the country. The collection sites are located in 7 provinces. Collection is scheduled so that each region is distributed in the 2-year collection period, between seasons and in a way which tries to minimize the movement of staff and equipment between sites. The MEC stays in a site for 5-7 weeks, collecting measures from nearly 350 respondents per site.

First step: personal interview at the household

The first contact with respondents is a letter sent through mail. The letter informs people living at the sampled address that an interviewer will visit their home to collect some information about the household. At home, the application randomly selects one or two respondents and the interviewer conducts a separate health interview with each of them. The interview takes 45 to 60 minutes per respondent. The interviewer then assists the respondent in setting an appointment for the physical measures at the CHMS MEC.

Second step: visit to the CHMS MEC

MECs are used to conduct physical measures portion of the survey. Similar MECs have been used successfully for years for NHANES in the US (as discussed in the previous chapter).

The MEC consists of 3 trailers (side by side), linked by enclosed pedestrian walkways. One trailer serves as a reception and administration area, the second has a laboratory and physical measure room, while the third contains additional physical measure rooms.

For each respondent, a complete visit to MEC lasts for about 2 hours. This is an approximate time since each respondent is assessed for their suitability for each measure and tested accordingly.

For children under 14 years of age, a parent or legal guardian has to be present at the MEC and has to provide written consent for the child to participate in the tests.

At the end of their visit to the MEC, respondents are provided with a waterproof activity monitor. This small device is worn for a week at all times except when sleeping – even when swimming or bathing. It records information about normal physical activity patterns without respondents having to do anything special.

Respondents are also provided with materials to send a second urine sample from home to a laboratory for nutritional analysis.

Error detection

Most editing of the data is performed at the time of the interview by the CAI application. It is not possible for interviewers / HMS to enter out-of-range values and flow errors are controlled through programmed skip patterns. For example, CAI ensures that questions that did not apply to the respondent were not asked. Edits requiring corrective action were incorporated in CAI application to deal with inconsistent responses. In addition, warnings not requiring corrective action were also included to identify unusual (i.e., improbable rather than impossible) values as a means of catching potential errors and allowing correction at source. At head-office, the data undergoes a series of processing steps that results in some of the data being adjusted. As a final validation step, the CAI edits are re-applied to the processed data. As a result, final data are complete and contain reserve codes for responses of ‘less than limit of detection’, ‘valid skip’, ‘don’t know’, ‘refusal’, ‘not stated’.

Imputation

Questions on personal and household income were not asked in cycle 5 – instead, respondents were asked permission to use administrative files to obtain their income. The process involved finding personal income on administrative files for all members of the respondent’s household and then to sum their income to derive the household income. However, in certain cases, the personal income was not obtained for all members of the household because either the permission to use administrative files was not given or it could not be linked / found for those who gave permission. In these cases, the personal income was imputed.

- The personal income was set to zero for people aged 0-19 who gave permission, but for whom no income was found on the administrative files
- For people aged 15-19 years old who did not give permission and people 20-39 years old who refused or could not be found on the administrative files, their personal income was imputed as the median revenue of their imputation class based on age, sex and collection site
- For people 40+ years old who did not give permission or could not be found, their personal income were imputed using the median, but with imputation classes based on 5-year age groups, sex and collection site

The personal income of all household members, whether found / linked / imputed, is then added to derive the household income of the respondent. The personal income of the respondent is also kept on the file.

Quality evaluation

One of the unique features of the CHMS is that 3 different sets of data are collected for the same respondent – household interview data, physical measures data and laboratory results data. Each set of data has to be processed on its own. Yet, they cannot be completely separated from each other because, at various points during processing, the 3 sets of data have to be used together.

The processing of the household interview data was performed in a manner similar to that of other health surveys at StatCan. The data are validated first at the record level, then at individual variable level, followed by detailed top-down editing. During data collection, processing takes place on a daily basis. The household interview responses have to be processed quickly in order for the data to be available at the MEC in time for the respondents’ visit to the MEC.

Similarly, the processing of the physical measures data begins with the data being validated first at the record level, then at individual variable level, followed by detailed top-down editing. Also, because the laboratory tests are determined based on responses received at the MEC, the MEC data are used to generate a file containing a list of tests for which laboratory results are expected to be received. This laboratory control file is used in processing the laboratory results data.

The processing of laboratory data involves significant file manipulation due to the fact that several different file types are received from the MEC and the various reference laboratories. As with the household and physical measures data, the laboratory data are validated at the record level, then at the individual variable level and several new variables are subsequently derived. The laboratory data are processed as quickly as possible so that any results that have been identified as outside of a normal range at the reference laboratories and the MEC are available in a timely fashion for reporting to respondents.

Non-sampling errors

Much time and effort were devoted to reducing non-sampling errors in CHMS. Quality assurance measures were applied at each stage of data collection and processing cycle to control the quality of the data. In cycle 5 of CHMS, there was little partial non-response, since once the questionnaire began, respondents tended to complete it. There was total non-response when the person selected to participate in the survey refused to do so or could not be contacted by the interviewer. Cases of total non-response were taken into account during weighting by correcting weights of persons who responded to the survey in order to compensate for those who did not respond.

Response rates

In all, 8,539 dwellings were selected within the scope of CHMS cycle 5. Of these dwellings, 6,361 agreed to provide information on the composition of the household (response rate - 74.5%). From respondent households, 8,847 persons were selected (1 or 2 persons a household) to participate in the survey, of whom 7,944 responded to the questionnaire (response rate - 89.8%). Of these persons, 5,786 then reported to the MEC for physical measurements (response rate - 72.8%). At the national level, a combined response rate of 48.5% was observed.

Some respondents who attend the MEC are unable / unwilling to participate in the blood and urine components. A response rate is derived for each of these components, which are supposed to be done on the full sample respondents. The response rates for these measures use the full sample response rates up to the MEC and derive the rest as follows – of 5,786 participants who reported to the MEC for physical measurements, 5,482 participants provided blood and 5,688 urine. The combined response rate for blood draw was 46.3%, for urine 47.7%. Likewise for other measures.

Canadian Health Survey on Children and Youth (CHSCY)

CHSCY explores issues that have an impact on physical and mental health of children and youth. It is used by StatCan, Health Canada, PHAC, provincial and territorial health ministries as well as other federal and provincial departments to monitor, plan, implement and evaluate programs to improve the health of children and youth. Researchers from various fields are also interested in the survey data and use it to conduct research into various factors that affect the health and well-being of children and youth in Canada.

Target population

The 2019 CHSCY covers population aged 1 to 17 as of 31 January 2019, living in the 10 provinces and 3 territories, covering at least 98% of the total target population in all provinces and 96% in all Northern territories.

Instrument design

The survey content was developed based on consultation across Canada with key experts and federal and provincial stakeholders. The goal of the consultation was to provide advice to StatCan on what survey content would be relevant for programs and policies, and fill data gaps related to children and youth. The questionnaire was developed by StatCan with PHAC and Health Canada.

Qualitative test by StatCan's Questionnaire Design Resource Centre using face-to-face interviews and focus groups was conducted during 2014-18.

Sampling

CHSCY is a sample survey with a cross-sectional design. Its sampling frame is the Canadian Child Tax Benefit file. Sampling units are children and youth aged 1 to 17 years as on 31 January 2019.

In terms of geography, the sample is primarily stratified by province, and further into 3 age groups – children aged 1 to 4 years, 5 to 11 years and youth aged 12 to 17 years. The sample size for the survey was 92,170 raw units.

Data sources

Data was collected directly from the survey respondents. Respondents are given the opportunity to complete an e-questionnaire. If it was not completed by 31 March 2019, a StatCan interviewer called and asked the respondent to complete the questionnaire over the telephone.

Error detection

Some data editing was performed at the time of the interview within the electronic questionnaire. The questionnaire had built-in checks for out-of-range or extreme values that prompt respondents and interviewers to verify the recorded answer. Flow errors were controlled in the application via programmed skip patterns – for e.g., questions that did not apply to a respondent were not asked.[149]

Survey on Maternal Health (SMH)

The main objective of SMH is to collect information from biological mothers about their pregnancy and postpartum experiences. Results from the survey are used by researchers and policymakers to monitor and improve the health and wellness of women.

Target population

The target population for the survey is the set of biological mothers who have given birth between 1 January and 30 June 2018 in the 10 provinces. Persons living in institutions or on an Indigenous reserve were excluded.

Instrument design

Content for the electronic questionnaire was drafted in consultation with PHAC. The questionnaire underwent cognitive testing in the form of in-depth interviews in both official languages, conducted by StatCan's Questionnaire Design Resource Centre.

Sampling

SMH is a random, cross-sectional, targeted respondent survey. Its frame was stratified by province and a simple random sample of mothers was selected independently in each province. Sufficient sample was allocated to each of the provinces so that the survey could produce provincial level estimates. An initial sample of 13,000 mothers was selected and sent to collection.

Data sources

Data was collected from the survey respondents either through an electronic questionnaire (EQ) or through CATI (computer-assisted telephone interviewing).

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[149] https://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=5233 (4/6/2020, 16:08 hours).

Response rate

The response rate for SMH 2018-19 was 54.74%.[150]

Canadian Health Survey on Seniors (CHSS)

The CHSS is a supplement to CCHS – Annual component. It collects information related to health status, health care services, supports as well as social and health determinants of population aged 65 and above. Its objectives are to –

1) Better understand what contributes to healthy aging by collecting data on the health and well-being of seniors, including their use of health care services and supports, social, demographic, geographic and economic determinants;
2) Produce estimates on the health of seniors aged 65 and over at the provincial, and for seniors aged 85 and over at the national, levels;
3) Produce a cross-sectional dataset on the health of seniors that permits analysis on a range of research questions and surveillance activities;
4) Evaluate changes on certain aspects of health from CCHS - Healthy Aging, 2008-09 survey.

The data collected in the survey will be used by StatCan, Health Canada, PHAC, provincial health ministries as well as federal and provincial health planners across the country. The CHSS will help policy makers, researchers and planners to make informed decisions regarding health care, social services and support programs for the ageing population, which will affect all Canadians.

Target population

The CHSS covers the population 65 years of age and over living in the 10 provinces, with certain exclusions.

Instrument design

Its instrument was developed in collaboration with Health Canada, PHAC and an expert advisory group. The questions are designed for CAI – as questions were developed, the associated logical flow into and out of the questions was programmed. This includes specifying the type of answer required, the minimum and maximum values, on-line edits associated with the question and what to do in case of item non-response. In collaboration with StatCan's Questionnaire Design Resource

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[150] https://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=5283 (4/6/2020, 16:38 hours).

Centre, the questionnaire was subjected to qualitative testing in 2018, which consisted of one-on-one interviews. The objective was to evaluate respondent reactions to, and understanding of, the survey as well as their willingness to respond to the questions.

Sampling

The CHSS is a sample survey with a cross-sectional design, a combination of the CCHS – Annual component respondents from all provinces who are at least 65 years old along with an oversample in all provinces, except Ontario and Quebec – no oversample was required to achieve the sample targets in these provinces. The CHSS oversample is selected from a list frame of dwellings with a valid telephone number that have at least one occupant aged 65 years or older.

Both the CCHS – Annual component for respondents 18+ and CHSS oversample for respondents 65+ have dwelling as the sampling unit. Once contact with the household has been established, a roster of household members is taken, from which one person is randomly selected to complete the survey. The CCHS oversample for CHSS purposes is stratified by province – 10,000 dwellings a year. When combined with the CCHS – Annual component sample (15,000), it is estimated that, overall, there will be approximately 25,000 respondents to the CHSS per year.

Data sources

Data is collected directly from survey respondents using CAPI and CATI software. Proxy reporting is allowed, although some modules are skipped in that case. Respondents are initially offered to complete the interview in either English or French. To remove language as a barrier to conducting interviews, StatCan regional offices hire interviewers with a wide range of language competencies. The average time to complete the survey is 15 minutes.[151]

Canadian Survey on Disability (CSD)

CSD started out as Health and Activity Limitation Survey: Household Component (HALS) in 1986, was renamed Participation and Activity Limitation Survey (PALS) in 2001, and finally CSD in 2012.

The purpose of CSD is to provide information about Canadian youth and adults (15+ years) whose daily activities are limited due to a long-term condition or health-related problem. This information is used to develop and evaluate policies, programs and services for those living with disabilities to help enable their full participation in society. In particular, information on adults with disabilities is essential for the effective development and operation of the Employment Equity Program. Data

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[151] https://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=5267 (4/6/2020, 16:51 hours).

on disability are also used to fulfill Canada's international agreement relating to the United Nations Convention on the Rights of Persons with Disabilities. CSD information is used by all levels of the government, associations for persons with disabilities as well as researchers working on disability.

The survey collects information on type and severity of disability, use of aids and assistive devices, daily help received or required, use of various therapies and social service supports, educational attainment, labour force participation details, requirements and unmet needs for accommodations at school or work, the experience of being housebound, veterans of the Canadian Armed Forces with disabilities, internet use, methods used to access government services and sources of income.

Target population

The population covered by the CSD was composed of all persons aged 15 and over (as of 10 May 2016 – Census Day) who reported difficulty 'sometimes' / 'often' / 'always' to one of the Activities of Daily Living questions on the 2016 Census of Population long form. This included persons living in private dwellings in the 10 provinces and 3 territories, with some exceptions.

Instrument design

The questionnaire was developed with Employment and Social Development Canada (ESDC). A content review of the 2012 CSD was conducted with subject matter experts and stakeholders to identify any potential data gaps. Input was obtained from ESDC's Technical Advisory Group (TAG) on disability, consisting of representatives from various community associations across Canada. Specialized consultation was also provided by Veterans Affairs Canada and Service Canada.

New questions were added to the 2017 CSD, including 7 new modules in the areas of episodic disabilities, general health, use of various therapies and social services supports, the experience of being house-bound, veterans of the Canadian Armed Forces, internet use and accessibility of government services. Two age-related questions were introduced for each of the 10 disability types. The first asked respondents at what age they began having difficulty with a health-related problem or condition; the second determined at what age the difficulty or condition began to limit their daily activities. Also in 2017, CSD underwent transformation from a CATI to an EQ mode. The labour force activities component of the questionnaire also underwent modifications to better reflect standard employment indicators found in labour surveys by StatCan (harmonized content). The 2017 questionnaire was tested in both official languages. Qualitative content testing was conducted by Questionnaire Design Resources Centre at StatCan and in several off-site locations across Canada. The EQ application underwent qualitative testing by the Centre along with ESDC. An in-depth review of 2016 Census variables was undertaken for potential record linkage with the CSD dataset, leading to addition of nearly 300 Census variables covering 15 subject areas linked to the final CSD data files for 2017.

Sampling

CSD has a cross-sectional, stratified two-phase design based on the 2016 Census. The first phase is the Census itself, corresponding to the sample of households selected to receive the long form, with about 1 out of 4 households systematically selected across Canada. Phase 2 corresponds to the sample of persons who reported having difficulty on the Activities of Daily Living questions on the long form Census. Sampling unit for phase 1 (Census) is the household, phase 2 the person. The total sample size for CSD 2017 was 50,000 persons. The sample was drawn using systematic sampling with the frame being sorted by collection unit to minimize the chance of selecting more than one person per household.

While CSD did not cover persons who responded ‘no’ difficulties or conditions on the Activities of Daily Living questions on the Census questionnaire, a sample of these individuals (called the NO sample) was nonetheless included in the final CSD data files. These people are all considered to be people without a disability. This sample allows the computation of disability rates, which require estimates for the entire population, not just persons with a disability.

An additional sample of nearly 5,000 persons was also drawn as part of a methodological research project. This sample of persons was also drawn among persons who did not report any difficulties or conditions on the Activities of Daily Living questions on the Census. The Disability Screening Questions were asked of these persons to see if they had a disability or not to allow methodologists to determine the extent to which new questions on the Census covered persons with a disability.

Data sources

Data were collected directly from survey respondents and also linked from the 2016 Census. Data collection for CSD was done using an EQ, involving 2 types of collection methods – a self-reporting method with the questionnaire completed directly online by the respondent (rEQ), an interviewer-led method conducted via telephone (iEQ). All respondents received an invitation to participate in the survey by mail, with the rEQ respondents receiving a link to the EQ and a secure access code, while the iEQ respondents were informed that they would be contacted by telephone. Reminder letters were sent to rEQ respondents nearly 2 weeks apart for the duration of collection. Collection for rEQ and iEQ were done in parallel for the first part of collection, with all rEQ non-respondents were transferred to iEQ for follow-up. Overall, nearly 40% of respondents completed the rEQ and 60% the iEQ. All survey responses were kept highly secure through industry-standard encryption protocols, firewalls and encryption layers. Proxy interviews were allowed under some conditions. The EQ was available in English and French. Interviews lasted about 35 minutes on average. To reduce interview time, StatCan combined information from CSD with selected data from the 2016 Census. Data from other surveys or administrative data sources may be added later.

Error detection

All responses to the 2017 CSD questions were captured directly in the EQ application, both for iEQ and rEQ components. For some questions, data underwent a preliminary verification process when respondents were completing the survey. This was accomplished by means of a series of edits programmed into the EQ. That is, where a particular response appeared to be inconsistent with previous answers or outside of expected values, the interviewer or self-reporting respondent was notified with an on-screen warning message, providing them with an opportunity to modify the response. Once survey responses were transmitted to the head office, more extensive data processing for CSD began. This involved a series of steps to convert the questionnaire responses from their initial raw format to a high-quality, user-friendly database, involving a comprehensive set of variables for analysis. A series of data operations were executed to clean files of inadvertent errors, remove duplicate records, edit the data for consistency, code open-ended questions, create useful variables for data analysis, and finally to systematize and document the variables for ease of analytical usage.

Imputation

For CSD, discrepancies, logical inconsistencies and missing information were resolved, wherever possible, by means of automatic, customized deterministic editing rules or manual interventions.

Quality evaluation

Quality assurance measures were implemented at each collection and processing step. Measures included recruitment of qualified interviewers, training provided to interviewers for specific survey concepts and procedures, observations of training of interviewers as well as interviews to correct questionnaire design problems / instruction misinterpretations, procedures to ensure that coding errors were minimized and edit quality checks to verify the processing logic. Data were verified to ensure internal consistency and were also compared to other sources when available.

For 2017, the CSD included the full implementation of the Disability Screening Questions (DSQ) used for identifying persons with disabilities. In 2016, the Activities of Daily Living question on the Census, which serves to create the sampling frame for CSD, was replaced by new filter questions taken from the DSQ framework. Qualitative and quantitative testing have shown that the new filter questions allow for better coverage overall of persons with disabilities, and especially of persons with less visible disability types (for e.g. pain-related disabilities, memory, learning, development and mental health). One important consequence of this full implementation is that the disability rates observed in the 2017 CSD are not comparable to those of the 2012 CSD, but are very much consistent with what was expected and observed during testing.

Response rates

CSD 2017 had an overall response rate of 69.5%. Response rates for the provinces ranged from 66.5% for New Brunswick to 78.5% in Quebec; in territories, from 51.5% in Nunavut to 65.6% in the Yukon; and by age group, from 62.1% among 15-24 year olds to 77% among 65-74 year olds.[152]

Lessons for India

GoI / state / UT governments should consider the following lessons from the Canadian context –

- Although India does have a central statistical agency (MoSPI), it needs to be independent and proactive like Statistics Canada to develop a rational, systematic and well-coordinated system of data collection in the country. Fragmentation of India's statistical landscape, leading to non-essential data collection and wastage of precious limited resources, is a challenge that cannot be tackled without doing so. MoSPI needs to step up to its mandate and act 'as the nodal agency for planned development of the statistical system in the country'.[153] It should seek assistance from Statistics Canada in this regard, if needed – the presence of 2 persons of Indian origin at the helm of the relevant Ministry and the agency should make it easier, even if not necessary. Nevertheless, given the firmly entrenched federal system of governance in the country as well as health being a state subject, MoSPI should facilitate – rather than take over – development of rational, systematic and well-coordinated systems of data collection in the states / UTs too. However, linkages between state Directorates of Economics and Statistics (DES) in particular with MoSPI should be made more formal and organized than it is at the moment. MHA should also consider yielding its own statistical ground to MoSPI. In any case, MoSPI at the central and DES at the state level do send their statistical staff to various ministries. Why not have a formally organized, coordinated system of data collection which is proactively led by them?
- Like StatCan, MoSPI and DES should be supported by a set of advisory groups which should offer impartial and independent advice to them vis-à-vis various aspects of data collection as well as review their performance from time to time.
- Beyond program MIS – which departments and ministries can manage internally, with MoSPI / DES oversight – all data collection should be supervised and quality checked by MoSPI / DES. Right now, the DES', in particular, are largely data aggregators without any statistical authority.
- Data linkage is one of the biggest lessons for India from the Canadian context. In order to avoid enormous duplicity of data collection in the country and the resultant wastage of precious and limited resources, this is something that MoSPI, DES as well as all government departments

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[152] https://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&Id=321555 (4/6/2020, 16:54 hours).

[153] http://www.mospi.gov.in/about-ministry-0 (4/6/2020, 20:39 hours).

and ministries should seriously undertake. However, citizen consent and confidentiality of their data needs to be paramount, another count on which India is hugely lacking. Public perception and trust around consent and data confidentiality needs to be systematically built up through positive action. Again, this is not possible without strong and independent central coordinating statistical agencies both at the Central and state / UT levels.

- When India was liberalizing its economy in 1991, Canada was developing a Health Information Roadmap (HIR) to tackle challenges with its health information system (HIS), highlighted by its National Task Force on Health Information. It is time India consider establishing its own HIR to address the manifold challenges with its HIS.
- If continuous surveys are not feasible (as many health surveys in the US are), India should at least consider annual / biennial periodicity as in Canada (and also in the US).
- Improving survey response rates is something that Canada can learn from India. Nevertheless, survey techniques adopted by Canada to ensure data validity, quality and representativeness offer lessons for India.
- India should consider designing flexible surveys like the CCHS – Annual component with fixed, variable and rapid content components, taking into cognizance the continuing and changing needs of various stakeholders. Neither programs nor statistical instruments seem to have this sort of flexibility, despite India being such a diverse and federal nation.
- India needs to consider developing specialized and dedicated surveys for various population groups / themes like Canada (and the US). Rather than trying to broaden the scope of NFHS, its focus should be sharpened and other health surveys included. With data linkages, we can arrive at integrated views of health and its social determinants from a health-in-all perspective. For this, even non-health surveys should include certain health components. A good place to begin with would be a periodic survey of Employees State Insurance Schemes (ESIS), which provides 6 social security benefits, including health, to its beneficiaries. A similar survey should also be considered for beneficiaries of other social / government-sponsored health insurance.
- With an array of health surveys – and states doing their own set of surveys – there is no need to have bloated sample sizes for a few surveys. Survey sampling needs to be smarter in order to achieve representative data in the most focused, equitable and economically efficient style.
- The CCHS is somewhat like NFHS in terms of its broad population and geographical coverage. However, what NFHS can learn from it is the breadth of thematic coverage – more importantly, the flexibility of its instrument.
- India should consider developing a longitudinal survey like LISA, which would help study how health and its determinants – as well as other aspects of adult life – change over time. It should also consider developing instruments for comprehensive tracking of COVID-19 as in Canada.

11. United Kingdom

Like Canada, the UK has a central UK Statistics Authority (UKSA) – ‘an independent body at arm’s length from government’. Its objective is to promote and safeguard the production and publication of official statistics that ‘serve the public good’ – a) informing the public about social and economic matters; b) assisting the development and evaluation of public policy; and c) regulating the quality and publicly challenging the misuse of statistics. Its overall mission is to mobilize the power of data to help the UK make better decisions.

The UK statistical system (UKSS) comprises the –

1) Board of the UK Statistics Authority (BUKSA) – responsible for oversight of the UKSS
2) Office for Statistics Regulation (OSR) – the regulatory arm of the UKSA
3) Office for National Statistics (ONS) – UK’s National Statistical Institute and the largest producer of official statistics in the country
4) Government Statistical Service (GSS) – a community of all those involved in the production of official statistics in the country

The majority of official statistics are produced by statisticians operating under the umbrella of GSS – working in either the ONS, UK’s government departments and agencies, or one of the 3 devolved administrations (Northern Ireland, Scotland and Wales). Every public agency with a significant GSS presence – vis-à-vis statisticians involved in the production or use of official statistics – has its own Head of Profession for Statistics (HPS), while the 3 devolved administrations have their own Chief Statisticians. The HPS and their staff in each agency are accountable to the National Statistician.[154]

Health statistics in the UK

UK’s health statistical system is decentralized, with several agencies collecting and publishing data. Some of the leading sources of health statistics in England are – ONS, NHS England, NHS Digital, Department of Health & Social Care, Public Health England, Care Quality Commission, Ministry of Defence, Department for Education and the Department for Work & Pensions.

Special mention needs to be made here of the NHS Digital, which is responsible for standardizing, collecting and publishing data and information from across the health and social care system in England. It has a National Indicator Library – the official hub of health and social care indicators in England, with the methodology and other details for each indicator specified. It has a collection of

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[154] https://bit.ly/2MwqCaC and https://bit.ly/3gW33pH (5/6/2020, 11:44 hours).

over a thousand datasets for clinical indicators – covering a wide variety of subjects, ranging from quality to population health and outcome of treatments – supporting clinical staff, commissioners, researchers and others who need evidence to help with decision-making in health and social care. Its Clinical Commissioning Group Outcomes Indicator Set (CCG OIS) is an important part of NHS England's systematic approach to quality improvement. Its NHS Outcomes Framework (NHS OF) provides national level accountability for the outcomes the NHS delivers. Its Seven-day Services are experimental statistics to help in effectively measuring both improvement and variation in care provision across the week. Its Summary Hospital-level Mortality Indicator (SHMI) reports mortality at trust level across NHS England, using a standard and transparent methodology. And finally, its *Compendium of Population Health Indicators* is a wide-ranging collection of over 1,000 indicators designed to provide a comprehensive overview of population health at the national, regional and local levels[155] – somewhat like our own annual National Health Profiles, brought out by the Central Bureau of Health Intelligence (CBHI), Ministry of Health and Family Welfare, Government of India.

However, not surprisingly, given the colonial legacy, both UK and India seem to be struggling from a set of similar challenges as far as organization of their health statistical systems are concerned. However, there are lessons that can be learnt in the way the UK is trying to diagnose and address those challenges as well as from its existing health statistical system. In 2016, the UKSA convened a roundtable of leaders from England's health and care system to discuss how health statistics can be better organized to facilitate evidence-based decision-making. Following were some of the major conclusions of the roundtable –

1) Nearly 250 sets of health statistics are produced by 10 organizations, available on a 'variety of different websites, in different formats, with no single portal'. Lacking an effective coordinating mechanism, the decentralised health statistics system in the UK is incoherent and inconsistent;
2) There are huge opportunities in combining administrative data from different sectors;
3) Data collection is significantly costly, burdensome for providers and bodies who produce data;
4) There is duplication of data collection between and within bodies;
5) The health statistical landscape is data-rich, but information-poor – the importance of analysis has been neglected, as has been the support for analysts and researchers;
6) There are delays in data analysis and publication;
7) Although a coordinated system-wide approach is needed, there is no 'magic bullet' to address these challenges;
8) An independent review of the state of health statistics should be commissioned.

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[155] https://bit.ly/30ciCnc and https://bit.ly/3gXXLK7 (5/6/2020, 13:41 hours).

Table 11.1: Major health surveys in the UK

Survey / coordinating / conducting agencies	Objective	Inception	Frequency	Methods	Sample	Representative	Major themes
Health and Lifestyle Survey (HALS) / Health Promotion Research Trust / Social and Community Planning Research	To assess self-reported health, measured health, cognitive function, psychological well-being and lifestyle of adults in all areas of Great Britain - changes in health and circumstances of the surviving respondents	1984	Occasional	Random sample (England, Wales and Scotland) - longitudinal / panel / cohort - face-to-face interviews - self-completion - psychological and clinical measurements	HALS 2 (1991-92): 25+ years surveyed in HALS 1 (1984-1985) - 5,352 interviews - 3,871 self-completion - 4,483 measurements	National	Demographic, working, social circumstances - self-reported health - physical measures - cognitive functioning - dietary habits – exercise, work, leisure - alcohol - smoking - beliefs and attitudes about disease / health
Health Survey for England (HSE) / NHS Digital / NatCen Social Research	To monitor changes in health and lifestyles - prevalence of specific health conditions - policy development - planning services - monitoring and evaluating policy	1991	Annual	Household interview - individual interview (at home) - paper self-completion - nurse visits	Around 8,000 adults (16+ years) and 2,000 children (0-15 years)	England	Physical and mental health and well-being - physical measures (nurse) - lifestyle behaviours - social care

Survey / coordinating / conducting agencies	Objective	Inception	Frequency	Methods	Sample	Representative	Major themes
National Study of Health and Wellbeing – Children and Young People / NHS Digital / NatCen, ONS	To look at how common different kinds of health, developmental, emotional disorders are - factors associated with good and poor health, well-being and development - to inform policy decisions about the need for child and adolescent mental health services - to help with planning services	1999	Occasional	Home interview (parent / self)	10,500 children and young people (2-19 years) in England	England	Health – well-being and development – emotional / conduct / hyperkinetic / autism spectrum disorders - social media use – bullying
English Longitudinal Study of Ageing (ELSA) / US National Institute on Aging (NIA), etc. / NatCen	Part of international longitudinal survey of ageing and quality of life (for e.g. LASI in India and LISA in Canada) which explores the dynamic relationships between health, functioning, social networks, participation and economic position as people plan for, move into and progress beyond retirement	2002	Biennial	Longitudinal / panel / cohort - multi-stage stratified random sample - face-to-face interview (CAPI) - self-completion (PAPI) - nutrition questionnaire - bio-measures (nurse)	50+ year HSE respondents - 18,000+ respondents since 2002	England	Household and individual characteristics - physical health and activity - psychosocial health - social participation - work & pensions - income and assets - housing - cognitive function

Survey / coordinating / conducting agencies	Objective	Inception	Frequency	Methods	Sample	Representative	Major themes
Health Survey Northern Ireland (HSNI) / Department of Health, Northern Ireland / Central Survey Unit, Northern Ireland Statistics and Research Agency (NISRA)	To provide a picture of the health of the Northern Ireland population - to monitor the extent to which government health targets are being met - to help authorities effectively plan local health services	2010	Annual	Systematic random sample - CAPI - computer-assisted self-interviewing (CASI)	16+ years - 2,866 households, 3,593 interviews	Northern Ireland	Health - activity - experience of health & social care - diets - food security - child health - well-being scale - mental and sexual health – smoking - drinking - measurements
Scottish Health Survey (SHeS) / Scottish Government Health Directorates / ScotCen Social Research, ONS	To estimate prevalence and monitor trends in certain health conditions - associated risk factors and health behaviours - cardiovascular disease and related risk factors remains the principal focus - health inequalities - help monitor progress towards health targets	1995	Annual	Multi-stage stratified random sample - cross-sectional - face-to-face CAI - self-completion PAPI - core questions - rotating modules - clinical, physical measurements	3,899 households - 6,793 respondents: 1,983 children (0-15), 4,810 adults (16+), 1,204 adults completed biological module	Scotland, Health Board and Local Authority level (4-year period)	General, mental and respiratory health and well-being - CVD - diet - physical activity - obesity alcohol - smoking

Survey / coordinating / conducting agencies	Objective	Inception	Frequency	Methods	Sample	Representative	Major themes
National Survey for Wales (NSW) / Welsh Government / ONS	Brings together 5 surveys previously commissioned by the Welsh government (including the annual Welsh Health Survey, 2003-15) - a key source of information for the Welsh government, public sector organisations and academics on the views and circumstances of people in Wales	2016	Annual	One-stage stratified or systematic random sample - cross-sectional - 45-minute face-to-face interview	16+ year olds - 11,922 respondents	Wales	Demographics - health status - mental well-being - risk factors - NHS - social care - material deprivation – education and qualifications - democracy – culture
COVID-19 Infection Survey (CIS) / Department for Health and Social Care, ONS, University of Oxford / IQVIA UK, The National Biosample Centre	To understand how many people of different ages across the UK have already had COVID-19 - help the government work out how to manage the pandemic better moving forwards and protect the NHS from being overwhelmed	2020	2020-21	Household (HH) invites - HH can call IQVIA for an appointment - questionnaire - nose and throat swabs, blood samples - 16 home visits (15-30 mins - once / weekly 4 times / monthly 11 times) by health workers, nurses	ONS survey respondents (age 2+ years) who agreed to be contacted again - phase 1: ca. 11,000 households in England - next year: 132,000 households across the UK	UK (by age, geography)	Antibody tests - symptoms - contact - gender - ethnicity - occupation - date of birth - general physician (nose and throat swab results will be sent to them) - linkages with ONS and NHS data records

Source: UK Data Service and ONS websites as well as other sources. https://www.ukdataservice.ac.uk/ (6/5/2020, 21:58 hours). Developed by author.

The English Health Statistics Steering Group (EHSSG) was formed in 2016 as a remedial measure. In 2018, it was handed over the responsibility to improve the coherence and accessibility of health and social care statistics in England by removing the duplication of statistical releases, harmonizing definitions and methodologies, increasing user engagement and aligning publication dates. To do so, it collaboratively produced a Work Plan 2019-24, established several theme groups that cover the breath of the health and care statistical system and developed the 'Health and Care Statistics Landscape for England', providing an overview as well as links to all key official health and social care statistics to help users find relevant statistics on specific topics and cross-cutting themes in one central place.[156]

Table 11.1 above provides an overview of key health surveys in the UK, including a recent one on COVID-19. One leading survey from each administration (England, Northern Ireland, Scotland and Wales) is discussed in detail below.

Health Survey for England (HSE)

Among the evidence provided to the Sir Donald Acheson-led 'Committee of Inquiry into the Future Development of the Public Health Function' in England (1988), 'the most important … was a lack of co-ordinated information on which to base policy decisions about the health of the population at national and local levels'.[157] Consequently, a Central Health Monitoring Unit was established in the Department of Health in 1989, and an annual survey on health and nutrition was commissioned to fulfill the purpose. The survey, which initially focused on cardiovascular disease and associated risk factors, came to be known as the HSE. Started in 1991, HSE is a series of annual surveys, the 2018 survey being the 28th one. It provides regular information that cannot be obtained from other sources about public's health and health-related behaviour. Each round includes core questions covering general health, hypertension, diabetes, social care and health-related behaviours as well as measurements such as blood pressure, height and weight measurements and analysis of blood and saliva samples. Additionally, there are modules on specific issues that vary from year to year. Sometimes, the core sample is augmented by additional samples from a specific population sub-group such as minority ethnic groups, older people or children.

HSE provides information on children (0 to 15 years) and adults (16 and above), living in private households in England. It consists of an interview in person, followed by a visit from a nurse, who takes a number of measurements and samples. A total of 2,072 children and 8,178 adults were interviewed in the 2018 survey – of them, 1,103 children and 4,825 adults had a nurse visit. The sample is designed to represent the whole population within practical constraints (time, cost, etc.).

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[156] https://bit.ly/2XB9tTx, https://bit.ly/3h2tWbk, https://bit.ly/2BLqkYc, https://bit.ly/2UeI7AD (26/10/2019, 19:49 hours).

[157] https://api.parliament.uk/historic-hansard/lords/1988/apr/27/public-health-in-england (6/6/2020, 14:57 hours).

Sample design

HSE 2018 had a multi-stage, stratified, random probability sample, designed to be representative of the population living in private households in England. Those living in institutions (such as care homes) were outside the scope of the survey. The sampling frame was the small user Postcode Address File (PAF). The very small proportion of households living in addresses not on PAF (less than 1%) was not covered. The sample consisted of 9,612 addresses selected at random in 534 postcode sectors. All HSE surveys cover the adult population aged 16 and over (up to a maximum of 10 adults per household). From 1995, the survey has included children aged 2 to 15, and from 2001, infants aged under 2. Up to 4 children a household were interviewed (up to 2 aged between 0 and 12, up to 2 aged between 13 and 15). Where there were 3 or more children in an age band, 2 of the children were selected at random to limit the respondent burden for parents.

Data collection

Data collection involved both interviews and self-completion.

The household interview included questions on household size, composition and relationships; type of dwelling, tenure, and the number of bedrooms; car ownership; smoking within the home; the economic status and occupation of the household reference person; and household income.

Adults were asked to participate in a face-to-face interview which included a self-completion questionnaire. The contents of the self-completion booklets varied by age – young adults aged 16 to 17 were asked about smoking and drinking behaviour as well as other questions. Interviewers also had the option of using this booklet for those aged 18 to 24 if they felt that it would be difficult for anyone in this age group to give honest answers to questions face-to-face with other household members present.

Children aged 0 to 15 years were also interviewed, and were eligible for a nurse visit. During the interview, those aged 13 to 15 answered themselves, while parents answered on behalf of children aged 0 to 12. In addition, children aged 8 and over answered questions on some sensitive topics within a self-completion questionnaire.

Self-reported longstanding conditions among adults and children were examined using data from the 2017 and 2018 surveys. Participants were asked – ‘Do you have any physical or mental health conditions or illnesses lasting or expected to last 12 months or more?’. If the answer was positive, it was further asked – ‘What is the matter with you?’ and their answers for up to 6 conditions were recorded verbatim. These were grouped into 14 categories of WHO’s ICD-10, covering infectious and non-communicable diseases of the body and mind.

Interviewers also measured the weight of all participants and the height of everyone aged 2 and over. In 2018, for the first time, only a proportion (89%) of addresses were eligible for nurse visits.

In these households, nurse visits were offered to all participants who were interviewed (both adults and children). The nurse visit included questions about prescribed medicines and, for adults, folic acid and nicotine replacement products. Nurses took waist and hip measurements for those aged 11 and over and measured the blood pressure of those aged 5 and over. Adults were also asked to provide non-fasting blood samples for the analysis of total cholesterol and HDL cholesterol, and glycated haemoglobin. Samples of saliva were taken from children aged between 4 and 15 for the analysis of cotinine (a derivative of nicotine, showing recent exposure to tobacco / smoke).

Table 11.2: Content of interview (including self-completion questionnaires) by age group (in years)

Theme	0-1 y	2-4 y	5-15 y	16-64 y	65+ y
General health, long-standing illness, limiting long-standing illness	🟩	🟩	🟩	🟩	🟩
Diagnosed hypertension and diabetes				🟩	🟩
Breathing problems	🟩	🟩	🟩	🟩	🟩
Receipt of social care					🟩
Fruit and vegetable consumption			🟩	🟩	🟩
Smoking, e-cigarettes, etc.				🟩	🟩
Exposure to second-hand smoke	🟩	🟩	🟩	🟩	🟩
Drinking alcohol				🟩	🟩
Economic status and occupation				🟩	🟩
Educational attainment				🟩	🟩
National identity				🟩	🟩
Ethnic origin	🟩	🟩	🟩	🟩	🟩
Height and weight measurements		🟩	🟩	🟩	🟩
Consent to link data to health records				🟩	🟩

Source: HSE 2018 Quick Guide. https://bit.ly/375Mvad (6/6/2020, 16:44 hours).

Table 11.3: Content of self-completion booklets by age group (in years)

Theme	8-12 y	13-15 y	16-17 y	18+ y
Smoking	🟩	🟩	🟩	
E-cigarettes	🟩	🟩	🟩	
Other nicotine delivery products		🟩	🟩	
Exposure to second-hand smoke	🟩	🟩	🟩	
Drinking alcohol	🟩	🟩	🟩	
EQ-5D[158] (general health)			🟩	🟩
General Health Questionnaire		🟩	🟩	🟩
Gambling behaviour			🟩	🟩
Physical activity (IPAQ)			🟩	🟩
Sexual orientation			🟩	🟩
Religion	🟩	🟩	🟩	🟩

Source: HSE 2018 Quick Guide. https://bit.ly/375Mvad (6/6/2020, 16:44 hours).

Response rate and interview time

A household response rate of 59% was achieved, with an individual response rate of 54% of adults and 60% of children in all eligible households. Average interview time for an adult was 40 minutes, while nurse visit for adults who took part in all measurements averaged 32 minutes. When children were interviewed without adults (aged 8 to 15), average interview time was 14 minutes and nurse interview was 16 minutes.[159]

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[158] EQ-5D is a widely known and used instrument in population health surveys. It is a standardised instrument for the measurement of a person's health status and has 2 parts – a descriptive system and a visual analogue scale (EQ VAS). The descriptive system consists of 5 dimensions – mobility, self-care, usual activities, pain or discomfort, and anxiety or depression. In the original version, each dimension has 3 severity levels – having no problems, some problems or severe problems. To increase sensitivity to changes in health, a new version with 5 levels was developed (HSE 2018: Methods). https://bit.ly/3eVxFWp (6/6/2020, 15:55 hours).

[159] https://bit.ly/2Ubhf4r and https://bit.ly/375Mvad (6/6/2020, 15:53 hours).

Health Survey Northern Ireland (HSNI)

The HSNI is a Department of Health survey that runs every year on a continuous basis. The survey covers a range of health topics that are important to the lives of people in Northern Ireland. It has been conducted since 2010/11 with separate modules for different policy areas in different years. HSNI is the single source of a range of population-based health and social care data, and is used to inform a wide range of Department of Health's strategies and indicators. Outside the department, key users include the Public Health Agency, Health and Social Care trusts, other departments and Arm's Length Bodies, local government and the voluntary sector. Additionally, its statistics are of interest to the local media, academics and the general public. It is sometimes used to compliment the administrative data sources, and does not capture the same information collected elsewhere. Department data needs are established on an annual basis during the questionnaire development phase. This involves a series of meetings to enable policymakers to share their requirements.

Steps are taken to maximise usefulness of the data whilst mindful of the burden on respondents. The department participates in the survey control process whereby surveys are assessed in terms of the burden they place on respondents vis-à-vis time taken to complete the survey. Additionally, any new survey which is proposed is considered within the context of the health survey and other existing surveys, in attempt to reduce duplication and increase the re-use of existing data sources.

HSNI follows ONS guidance on harmonized standards for social surveys; where possible, includes questions that have been agreed as standard in other UK countries (for e.g. on physical activity). Further, recognized scales / instruments are used to allow comparisons to be made more readily. Nevertheless, though steps are taken to encourage standardization and commonality in approach across surveys, differences in sampling, weighting, etc. make it broadly rather than fully comparable.

The 2018/19 HSNI included questions on general health, mental health and well-being, antibiotics, obesity, smoking, drinking alcohol and sexual health. It had a sample size of 3,593 individuals aged 16 and above. It had a systematic random sample of addresses from the Northern Ireland Statistics and Research Agency (NISRA) Address Register (NAR). The NAR is developed within NISRA, and is primarily based on the Land and Property Services (LPS) POINTER database. A total of 6,240 addresses were selected for interview. From an eligible sample of 5,448 addresses, 53% or 2,866 households participated. In each household, everyone aged 16 or over was selected to participate. Measurements of height and weight were sought from individuals aged 2 and over in participating households – data was obtained from 501 children (2-15 years) and 2,723 adults (16 and above).

The survey first results report and trend tables are published within a year of fieldwork completion, most typically within 7-8 months. The date is preannounced on the department's statistical release calendar. In the majority of cases, the target publication date is met.[160]

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[160] https://bit.ly/3cHW4gG and https://bit.ly/2UhSK5B (6/6/2020, 18:25 hours).

Scottish Health Survey (SHeS)

The SHeS has been carried out annually since 2008 – earlier, it was carried out in 1995, 1998 and 2003. The 2018 survey was the 14th in the series. Commissioned by Scottish Government Health Directorates, it provides regular information on aspects of public health and related factors which cannot be obtained from other sources. The SHeS series was designed to –

1) estimate the prevalence of particular health conditions in Scotland;
2) estimate the prevalence of certain risk factors associated with these health conditions, and to document the pattern of related health behaviours;
3) look at differences between regions and sub-groups of population in the extent of their having these particular health conditions or risk factors, and to make comparisons with other national statistics for Scotland and England;
4) monitor trends in the population's health over time;
5) make a major contribution to monitoring progress towards health targets.

Each survey in the series includes a set of core questions and measurements (height and weight, blood pressure, waist circumference and saliva sample) and modules on specific health conditions and risk factors that vary from year to year. Each year, the sample is augmented by an additional boosted sample for children. Since 2008, NHS Health Boards[161] (HB) also have the opportunity to boost the number of adult interviews.

Cardiovascular diseases (CVDs) and related risk factors remain the principal focus of the survey. The main components of CVD are ischemic heart disease (IHD) or coronary heart disease (CHD) and stroke, both of which are clinical priorities for NHS Scotland. Many of the key behavioural risk factors for CVDs are of special interest to health policymakers and NHS on their own. For example, smoking, poor diet, lack of physical activity, obesity and problematic alcohol use are all the subject of specific strategies at improving health in Scotland. SHeS has detailed measures on all of them.

Topics covered in the 2018 to 2021 surveys were agreed following a consultation carried out in 2017. Many of the topics and questions included in earlier years of the survey were included again to continue the time series. The 2018 survey included the same rotating topics as 2016 and 2014 surveys, although in 2018, a number of questions were removed or made less frequent to shorten the survey and reduce the respondents' burden. Some questions were added to the 2018 survey; nevertheless, like earlier surveys, it continued to have a focus on CVDs and associated risk factors.

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[161] NHS Scotland consists of 14 regional NHS Boards – responsible for protection and improvement of their population's health and the delivery of frontline health care services – 7 Special NHS Boards and 1 public health body which support regional NHS Boards through a range of specialist and national services. https://bit.ly/2UeMXxu (6/6/2020, 20:07 hours).

Table 11.4: Contents of the 2018 SHeS survey

CORE SAMPLE – Main interview outline	
Version A	**Version B**
Household questionnaire including household composition	
General health (0+ years) including caring (4+)	
Respiratory symptoms 16+	-
General CVD (16+)	
Use of health services (0+)	
Asthma (0+)	
Asthma additional 16+	-
Physical activity adults (16+) and children (2-15)	
Sedentary activity adults (16+) and children (2-15)	
Additional physical activity questions 2+	-
Eating habits adults 16+	-
Eating habits children (2-15)	
Fruit and vegetable consumption (2+)	
Smoking and drinking (16+) [16-19 through self-completion]	
Dental health (16+)	
Economic activity (16+)	
Education (16+)	
Ethnic background, religion and country of birth (0+)	
Self-completion (13+ and parents of 4-12 year olds)	
Height and weight (2+)	
Data linkage and follow-up research consent (0+)	
-	Biological module (16+)

Source: SHeS 2018: Volume 2 – Technical Report. https://bit.ly/2Y6Lomx (6/6/2020, 20:46 hours).

Main interview

Information was collected at both the household and individual level. Table 11.4 summarizes the content of individual interviews – the topics covered for a participant depended on their age and the sample type to which their address had been allocated. Version A households accounted for 67% of the main (core) sample – their questionnaire included the core questions and the questions included in Version A rotating module. Version B households accounted for the remaining 33% of the main (core) sample – only core questions were asked during main interview, with participating adults also eligible to complete the biological measures module.

Sample design

The survey is designed to yield a representative sample of the general population living in private households in Scotland every year.

Since 2008, the sample has been designed to be representative of adults – and since 2012 of the population – at the HB level and since 2018 for adults at Local Authority (LA) level as well, following 4 years of data collection. HBs and LAs with sufficiently large sample sizes may be able to analyze their data with fewer years of data collection.

In 2018, the SHeS design was coordinated with the designs of the Scottish Household Survey and the Scottish Crime and Justice Survey as part of a survey efficiency project to allow the samples of the 3 surveys to be pooled for further analysis.

In 2018, a random sample of 6,080 addresses was selected from the Postcode Address File (PAF), using a multi-stage stratified design. If an address was found to have multiple dwelling units, 1 was randomly selected; if multiple households were found at a dwelling unit, 1 was randomly selected. Each person in a selected household was eligible for inclusion. If there were more than 2 children in a household, 2 were randomly selected to limit burden on households. Individuals interviewed at these addresses formed the main sample. At each selected household in the main sample, all adults and a maximum of 2 children were eligible for interview. Two further samples were selected for the 2018 survey – a child boost sample (5,448 addresses) in which up to 2 household children were eligible to be interviewed, but adults were not, and a HB boost sample (224 addresses) for HBs that opted to boost the number of adults interviewed.

Data collection

A letter stating the purpose of visit was sent to each sampled address in advance of the interviewer visit. Interviewers sought the permission of each eligible adult in the household to be interviewed, and both parents' and children's' permission to interview up to 2 children aged 0-15 years.

Interviewing was conducted using a combination of CAI and self-completed paper questionnaires. Adults and children aged 13-15 completed interviews themselves. Parents of children aged 0-12 completed the interview on behalf of their child.

Those aged 13 and over were also asked to complete a short paper self-completion questionnaire on more sensitive topics during the interview. Parents of children aged 4-12 selected for interview were also asked to fill in a self-completion booklet about the child's strengths / difficulties designed to detect behavioural, emotional and relationship difficulties.

Towards the end of the interview height and weight measurements are taken from those aged 2 and above. In a household sub-sample, interviewers seek permission from adults to participate in an additional biological module. Participants are asked questions by specially trained interviewers about prescribed medication, anxiety, depression, self-harm and suicidal attempts. In addition, the interviewer takes participants' blood pressure, saliva sample and measures weight. Data from the biological module is reported every second year to allow 2 years of survey data to be combined.

Response rates

In 2018, interviews were held in 3,899 households with 1,980 children (949 as part of main sample and 1,031 as part of the child boost sample) and 4,810 adults. Of these, 1,204 adults completed the biological module.

For the combined main and HB boost sample, 57% of all eligible households responded, with all individual interviews complete at 45% of households. For the child boost sample, around 3/4ths of the households were ineligible as they did not contain any children. In eligible households, 64% responded, with all individual interviews complete at 64% of households.

Adult response rate was 47% for men, 53% for women, 50% total. There was a further differential. For both men and women, younger age-groups had a lower response rate (51% for men and 71% for women aged 16-24 years) vis-à-vis the elderly (92+% for men and 95+% for women over 65). Response rates were highest among children aged under 11 years (93-99% for boys and 95-99% for girls), while the response rate for children aged 11-15 years was slightly lower at 92% for boys and 91% for girls.[162]

National Survey for Wales (NSW)

NSW is conducted by the Welsh Government (WG), succeeding 5 surveys earlier commissioned by WG and 3 of its sponsored bodies – including the Welsh Health Survey, which was discontinued in 2015. Before the survey was launched in 2016, a large-scale pilot survey and a small-scale field

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[162] Scottish Health Survey 2018: Vols. 1 and 2. https://bit.ly/3dLnxzC and https://bit.ly/2Y6Lomx (6/6/2020, 21:39 hours).

test on the final questionnaire were conducted. The survey is designed to be representative of all adults aged 16 and above, in private households in Wales. The annual sample is, therefore, set up as a stratified, single-stage random selection of addresses across Wales.

In its third round (2018-19), carried out by ONS, a sample of 24,762 addresses was initially drawn from the Royal Mail Small Users Postcode Address File. The sample was stratified by 22 Welsh LAs, with survey effort approximately proportional to the LA population size and oversampling to ensure a minimum effective sample size of 250 in smaller LAs and 750 in Powys. It involved 11,922 interviews – the number of interviews achieved in each LA ranging from 312 in Isle of Anglesey to 1,057 in Cardiff and 1,394 in Powys. Respondents received a £10 shopping voucher as a 'thank you' for taking part in the survey, which was sent to them after the interview.

Face-to-face interviews were conducted using portable computers for 73 main modules to cover the entire range of topics specified by WG and its sponsored bodies. Key themes included –

- Health
- Childcare and child education
- Climate change and environmental action
- Visits to the outdoors, participation in arts events and sports activities
- Use of / satisfaction with public services
- Material deprivation and income
- Well-being and loneliness
- Use of / attitudes towards the use of the Welsh language
- Internet access and use
- Tax devolution

Health and social care questions were focused on the following themes –

- BMI
- Diet
- Alcohol
- Smoking and e-cigarettes
- Physical activity
- Child screen time
- Mental well-being
- Hearing impairment
- Eye care
- Use of / satisfaction with GP and hospital services
- Use of / satisfaction with out of hours GP services
- Overall satisfaction with health services
- Views on social care services

The survey questionnaire and supporting materials were available as standard in both Welsh and English (pilot and mainstage surveys), with interviews also offered in other languages with the help of interpreters, if required. Furthermore, for some topics, sub-sampling was used to collect robust estimates at the national level as efficiently as possible.

Questionnaire

The survey design is based on a single questionnaire administered to one randomly selected adult aged 16 and above in each sampled household. The questionnaire content was developed by WG and the 3 sponsored bodies. Annual questionnaire review and stakeholder consultation is carried out by WG to determine new policy needs and the questionnaire content for the new survey year. Further, a feedback questionnaire is sent to interviewers to get their views on how well the survey process worked in the field, whether there were any specific issues with the questionnaire content or flow and whether there is room for improvement. WG had considered the interviewer feedback during the development of the 2018-19 questionnaire. A small scale pilot survey was conducted by ONS in January 2018 to test the questionnaire and fieldwork processes.

In 2016-17, questions for the survey were largely taken from the 5 predecessor surveys, with some questions also taken from other large-scale surveys. Changes for consecutive years include small updates to individual questions which were continued from year to year, discontinuing or pausing certain questionnaire modules that do not need to be asked every year as well as introducing new questionnaire modules and individual questions.

Response rate and interview time

The planned response rate for 2018-19 was 56%, based the previous year’s achievement and the additional measure put in place to increase response. The final response rate at the national level was 54.2%. The number of interviews achieved was at / above target only in 9 LAs.

ONS closely monitored the progress of survey response performance over the course of fieldwork period and applied very strict performance management measures to ensure that targets are met. Performance at the start of the survey year was a little volatile across LAs, potentially influenced by short-term capacity issues (e.g. sick leave, annual leave, mentoring for new interviewers) being addressed inconsistently. However, performance became stronger and more consistent from the second quarter onwards.

However, despite 73 main modules, median interview length was around 46.6 minutes, with 50% of interviews lasting between 35 and 60 minutes.[163]

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[163] https://bit.ly/2Yc7ZOu and https://bit.ly/2AbUoPp (6/6/2020, 22:27 hours).

Lessons for India

- The UK Statistics Authority (UKSA) is ‘an independent body at arm’s length from government’. The Statistics Wing of MoSPI – the National Statistical Office (NSO) – should also be the same. Independent, high-quality data has a critical role to play in a democracy, and statistical offices should be answerable to the public at least as much as they are to elected governments. The NSO, like the UKSA, should, first of all, aim at informing the public about social and economic status and development, and then at assisting the development and evaluation of public policy and programs as well as statistical coordination and regulation. One could also argue that the independence and quality of a country’s statistical system is a core indicator of the strength of its governance and democracy. In all the 3 countries included in this study, statistical systems are focused on / answerable not just to governments, but also citizens. In India, no need seems to be felt to make data user-friendly and accessible to citizens, and even researchers have to struggle to access it and make sense of it. Data collection and dissemination in general, in the sphere of health in particular, should function with a democratic ethos, be citizen-oriented and -friendly. Only then will mechanisms such as community-based monitoring of health services, as envisaged under schemes like the NHM, be realistically possible.
- The CBHI (MoHFW) should try to model its annual National Health Profile reports on the lines of NHS Digital’s ‘Compendium of Population Health Indicators’, with a wide range of indicators (and not just numbers) to provide a comprehensive overview of population health and care in the country in a citizen-friendly manner so that it can be used by ordinary citizens to hold their elected governments accountable.
- The UK statistical system suffers from several challenges similar to India’s – for e.g. duplication of data collection, fragmented / incoherent / inconsistent / data-rich, information-poor statistics (without much analysis to help citizens or governments) and dissemination delays. India could learn from the remedial initiatives of the English Health Statistics Steering Group (EHSSG) and even partner with it in addressing its own challenges.
- Given the NHS, a number of surveys in the UK support the evaluation of health care utilization, quality and satisfaction. Certain health surveys in India, including the NFHS, provide general evidence regarding the utilization of certain aspects of public and private health care, but there is very limited scheme-specific evidence from their side to directly evaluate their performance. Health surveys should gather more policy- and scheme-specific as well as general evidence (both quantitative and qualitative), not just on health care utilization, but also on the quality of health services and, most importantly, people’s satisfaction and expectations to enable action towards making health systems in the country increasingly citizen-centric and -accountable.
- Health surveys in UK as well as in the other countries studied here also collect information on mental health and well-being of the population. Only one round of the National Mental Health

Survey in India has been conducted in India so far, with no further round being planned (until our meeting in October 2019 with NIMHANS, Bengaluru, which conducted the first round). If not a dedicated survey, India should incorporate questions on mental health and well-being in existing / proposed health surveys, especially given widespread coronavirus-instigated anxiety and distress. A young population, ridden with personal and professional identity crisis, makes a focus on mental health and well-being critical even more generally. ‘National Study of Health and Wellbeing – Children and Young People’ survey is an example to consider.

® India needs to consider having a longitudinal / panel / cohort health survey, even if with a very limited sample size, to be able to track changes in health and health care services over time in an in-depth manner. It has LASI focused on health as well as other themes for adult / ageing population, but one is needed focused on health for a broader age-group. It can be occasional in its periodicity like HALS in the UK.

® Once again, we see that most health surveys are either of annual / biennial periodicity. SRS is the only health survey in India with annual periodicity. However, it offers rudimentary birth and death data only. All health surveys in India should be of preferably annual or maximum biennial periodicity, with data dissemination within a maximum of 6 months. Smart sample size should be considered, which is representative at the national and state / UT level. States / UTs should conduct their own health surveys which are representative at state / district / sub-district levels, with similar periodicity and dissemination timeframe. However, there should be consistency in survey definitions, methodologies, etc. to ensure comparability, even if broadly and selectively.

® All the 3 countries studied here have multiple health surveys. An integrated health survey – or for that matter, an integrated general survey – is only possible in small geographies like Wales. Indian UTs could consider the Welsh survey model and have one integrated survey – but with annual periodicity – which focuses on health as well as other themes. This would also help in studying the social determinants of health (SDH). In fact, the inclusion of health themes in non-health specific surveys should be encouraged to have SDH evidence. However, the demands of comparability / interoperability need to be met.

® Surveys should have computer-assisted field investigator interviews as well as self-completion instruments for sensitive questions. Pictorial computer-assisted instruments can be developed for the less literate / illiterate populations. Work done on obtaining informed consent for clinical trials for such population groups could be referred to for this purpose.

® Likewise, children should be directly interviewed, wherever possible, to know from them about them. Their parents / guardians can still respond to more complex questions related to them.

® Disease-related questions / tests in surveys should be designed such that they can be mapped to ICD-10. The Health Survey for England (HSE) does that to some degree. Mapping of survey questions with WHO Family of International Classifications (FIC) should be ideally considered. At the moment, only SRS-CoD survey does ICD-10 mapping.

® UK's COVID-19 Infection Survey framework should be considered by India. US and Canadian surveys appear more desirable since they focus on the social and economic impact of COVID-19 as well, which is important given its widespread impact. Nevertheless, the UK has adopted a robust, long-term testing strategy as part of its survey, which should be considered by India, given that COVID-19 seems to be here to stay. At least, its health and wider impacts would be.

® The fieldwork model followed by the NFHS, involving a range of different private agencies for different rounds, should be completely done away with. There should be a dedicated unit and teams for conducting health – as well as other – surveys. Where external agencies have to be involved, there should, first of all, be sufficient internal regulatory / monitoring capacities within the parent organization and only agencies (including research organizations / universities) that can deliver high-quality data should be involved. A UK-like system of ONS, NatCen, ScotCen, etc. should be developed in India, with NSO in the lead from a statistical perspective and DoHR from the domain perspective. There are huge conflicts of interest involved in the way the NFHS is organized at the moment – neither should DoHFW, which manages MoHFW's schemes, be coordinating the survey nor should an external agency (IIPS) be in the lead, involving several private agencies, whose primary motive is profit rather than data rigor and quality. Dedicated surveyors need to be trained and employed – temporary arrangements should be disbanded.

12. Conclusions

Let us conclude the study with key recommendations and a table which characterizes the potential respective features and themes which the 6 national health surveys that we propose could cover.

- ® The Government of India (GoI) should adopt a definition of health,[164] which can guide the design and assessment of all health-related activities, particularly its health information system (HIS).
- ® In line with India's health transition, health data collection should also shift from a demographic to a predominantly health orientation – according due importance to the population dimension. At the same time, we need to ensure that the emergent health orientation is not exclusively / predominantly biomedical, and is sufficiently focused on the broader determinants of health.
- ® GoI should develop a National Health Data Policy (NHDP) and a National Health Data Advisory Committee (NHDAC) with members from relevant ministries / departments of central and state / UT governments (health, statistics, planning); national organizations (ICMR, IIPS, NIMHANS, ICSSR, etc.); multilateral agencies (UNSC, WHO, UNDP, UNFPA, UNICEF, World Bank etc.); leading international health statistical agencies like the NCHS (US), Statistics Canada and NHS Digital (UK); national / international health experts; industry and civil society representatives.
- ® The NHDAC should develop a health systems framework and health-related goals, targets and indicators with timelines like SDGs – a National Reference List (NRL) of core health indicators, like the WHO's GRL, which is periodically revised to incorporate emerging concerns. For every indicator, there should be a rationale, standardized definition, numerator, denominator, method of measurement and estimation, disaggregation, frequency, preferred and other data sources, baseline value, etc. State / UT governments should, likewise, develop SHDPs, SHDACs and SRLs. NRLs and SRLs should guide interoperable data collection through a variety of sources.
- ® The NRL / SRL should be developed vis-à-vis core indicators of national / state health policies and programs, international data reporting requirements (including health-related SDGs) and WHO's Family of International Classifications (WHO-FIC). HIS should be revised accordingly.
- ® HIS comprises a variety of data sources, and they are all required for monitoring various health system components, with a preferred respective role for each. In India, since surveys are seen as compensating for the weakness of administrative sources, there are high expectations from them. All data sources should be strengthened in order to have rational expectations from each.

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[164] India is a signatory to WHO's constitution, and it could be argued that it affirms the definition of health enshrined in it.

- Health surveys should focus on monitoring the vision / goals / objectives of health policies and programs to periodically ensure that they are being fulfilled. Program MIS / other mechanisms (ground assessments by DGHS Regional Offices, PRCs, review missions, local communities, etc.) should be strengthened for regular program monitoring and evaluation. Surveys should not be expected to help in MIS data validation beyond a few core indicators; indicator definitions, population coverage, etc. should be harmonized in such cases.

- The division of labor between the 4 relevant ministries could be the following. MHA looks after all population-related indicators through census (decennial), CRVS (continuous) and the SRS (annual enumeration-cum-survey) – as it already does. MoHFW should look after public health surveillance – as it already does. However, it should be Department of Health Research (DoHR) in MoHFW, rather than its Department of Health and Family Welfare (DoHFW) – as is presently the case – which should lead and coordinate all public health surveillance activities, with the exception of policy- and program-based MIS. DoHFW, being the operational wing of MoHFW, should manage various MIS in an integrated, consistent and coordinated manner. The MHA and MoHFW could collaborate for a cause of death survey, given that it requires domain expertise which the MHA lacks. DoHR / ICMR institutions should be involved in this case. MoSPI should oversee all health surveys in consultation with MoHFW and MHA. All statistical activities should strictly be conducted under its statistical guidance, coordination and supervision – and, in the case of health, under the domain-related guidance of DoHR (MoHFW). For this, MoSPI needs to be independent, both from political interference as well as from the IAS-led bureaucracy.

- There is a serious conflict of interest that the DoHFW, which manages various health schemes, also commissions and manages the *independent* NFHS, conducted by an agency (IIPS) which itself 'is under the administrative control' of the MoHFW. Not only this, the MoHFW's Statistics Department, which manages HMIS, also manages the NFHS. These are very serious conflicts of interest which should be addressed immediately. If need be, the DoHR should be renamed as the *Department of Health Research and Surveillance (DoHRS)* – research and surveillance go hand in hand – and all health surveillance activities, including surveys, should be carried out under its domain supervision and MoSPI's statistical supervision. Budgets and staff in both these organizations should be enhanced accordingly. The DoHR / ICMR already has a network of leading centers across the country, which could be leveraged for this purpose. However, it should go beyond its biomedical – and adopt a much more broad-based – approach to health.

- While data collection is important, analysis is also part of data generation hemisphere, followed by interpretation and response under the data use hemisphere (figure 1.5). All four data-related frameworks need to be strengthened at the central / state / local-most levels – it cannot be the exclusive prerogative of researchers / statisticians on sidelines (DES, NIHFW / SIHFWs, PRCs, etc.) or at the top (ICMR, IHME, etc.) to analyze / interpret data. Central / state / local capacities need to be strengthened and IT tools leveraged for the entire data life-cycle. In fact, those who collect data at local levels can sometimes contextualize and contextually analyze it better than those who do not know / understand the local context in which the data was collected. This is also in keeping with the spirit of decentralization inherent in the conceptualization of the NHM.

® There has to be a clearly defined framework for data collection, processing, synthesis, analysis and use for the design and assessment of policies and programs as well as course-correction. In the absence of such a framework – despite humongous data collection and 'reporting' within the system as part of MIS and accountability of various functionaries – data 'use' for the design and assessment of policies and programs as well as course-correction is not seen as important and becomes an arbitrary / whimsical activity. Statisticians and IT can provide the tools, but it is eventually the domain officials who have to use the data from a policy / program perspective. This is seriously missing across the country – from the national to the local levels, including in states like Kerala (field interactions).

® Ease of data use should be facilitated for policymakers as well as other stakeholders. This is a huge challenge at the moment. The STATcompiler customization tool of DHS surveys and the visualization hub of GBD data with causes of death are two excellent examples.

® Not just survey schedules, but fact sheets, at least, should also be prepared in local languages. They should be made available as well as painted on the walls of SCs, PHCs, CHCs and district hospitals in local languages. This can also be done for key indicators from non-survey sources. This would not only help in the democratization of official data, but also enhance accountability.

® A mixed methods approach should be adopted to health surveys in the country. For guidance, we could refer to health surveys conducted in India pre- and post-independence and The DHS Program, of which the NFHS is a part, for instance. The richness of the notion and experiences of health, well-being and health care utilization and satisfaction can best be captured by means of qualitative methods. Qualitative information could also imbue the otherwise dry quantitative data with an intimate, human sense and help in making health systems more people-oriented.

® The DHS Program also has several types of surveys and not just the standard DHS, according to which the NFHS has been modelled. Beyond the standard DHS surveys – with large sample sizes, typically conducted every 5 years, to allow comparisons over time – 'interim DHS' focus on select indicators, are conducted between standard DHS, have shorter questionnaires and sample sizes, but are nationally representative. There is also 'continuous DHS', as part of which data is collected and reported annually by a permanent DHS office and field staff. There are 'in-depth DHS' and 'mini DHS' too. India should adopt a dynamic approach to health surveys, and consider the various options available in the light of its requirements.

Proposed surveys

- ® All the 3 countries studied here have multiple health surveys. An integrated health survey – or for that matter, an integrated general survey – is only possible in small geographies like Wales. Indian UTs could consider the Welsh survey model and have one integrated survey – but with annual periodicity – which focuses on health as well as other themes. This would also help in studying the social determinants of health (SDH). In fact, the inclusion of health themes in non-health specific surveys should be encouraged to have SDH evidence. However, the demands of comparability / interoperability need to be met.

- ® Table 12.1 below outlines a health survey strategy with 6 surveys and their major characteristics that we recommend GoI should adopt at the national level. A similar strategy can be developed for the states / UTs for representative data at the state, district and subdistrict levels. However, there should be consistency in survey definitions, methodologies, etc. to ensure comparability, even if broadly / selectively, between surveys conducted at the national and state / UT levels.

- ® Once the challenge of COVID-19 diminishes, the CIS could be dropped. However, the template of an emergency survey which reflects the health as well as its broader socioeconomic impact should be kept for the future. The CIS will also enable us to monitor potential future pandemics in a better way. With CIS / like being an emergency survey, we have a total of 5 regular surveys.

- ® The IHS would be the comprehensive health survey providing an overview of the health of the nation. The IHMS would be an in-depth survey, with a smaller sample size, aimed at collecting clinical information from physical and biomedical tests and measurements – like the NHANES in the US and CHMS in Canada. Such tests and measurements should not be appended to an existing survey (as has been done in the case of NFHS) since testing and measurements need to be done much more professionally and with much more caution than the general field work investigators can possibly ensure. The MCHS would be exclusively focused on maternal and child health in a broader – unlike the typical traditional RCH – framework. SRS will continue to be the same, but with added features and professional dissemination practices of the NFHS. It will be the only survey source of vital statistics. RGI should give up the cause of death survey, for which a more specialized agency like ICMR is better suited. It can support it with its death statistics from the CRVS, MCCD, SRS, etc. The ICMR should enhance the sample size for the CoD survey to yield representative data at the national and state / UT levels. The frequency of this survey should be annual for better respondent recall.

- ® The proposed surveys cover major data points which health surveys should provide, including the core indicators of health policies to monitor progress on them. Many of the core indicators of health policies overlap with those of health programs, hence we have not included the latter here. In any case, the table below is more illustrative, to provide a potential blueprint of a health survey strategy at the national level. The proposed NHDAC / SHDACs can work out the details.

- India should consider designing flexible surveys like the Canadian *CCHS – Annual component* with fixed, variable and rapid content components – taking into cognizance the continuing and changing needs of various health sector stakeholders. Neither health programs nor statistical instruments have this sort of flexibility, despite India being such a diverse and federal country.

- With an array of health surveys – and states doing their own set of surveys – there is no need to have bloated sample sizes for a few surveys. Survey sampling needs to be smarter in order to achieve representative data in the most focused, equitable and economically efficient style.

- Health surveys in US, Canada and UK are either continuous or of annual / biennial periodicity. India should adopt a mixed strategy – with continuous surveys or annual / biennial periodicity (see table 12.1 below for details).

- Data linkage is one of the biggest lessons for India from the Canadian context to avoid enormous duplicity of data collection and resultant wastage of precious and limited resources. However, as in Canada, citizens' consent / confidentiality should be paramount – no data linkage should happen without their explicit consent and with utmost care to keep it confidential.

- Surveys should have computer-assisted field investigator interviews as well as self-completion instruments for sensitive questions. Pictorial computer-assisted instruments can be developed for the less literate / illiterate populations. Work done on obtaining informed consent for clinical trials for such population groups could be referred to for this purpose.

- Likewise, children should be directly interviewed, wherever possible, to know from them about them. Their parents / guardians can still respond to more complex questions related to them.

- The fieldwork model followed by the NFHS, involving a range of different private agencies for different rounds, should be completely done away with. There should be a dedicated unit and teams for conducting health – as well as other – surveys. Where external agencies have to be involved, there should, first of all, be sufficient internal regulatory / monitoring capacities within the parent organization and only agencies (including research organizations / universities) that can deliver high-quality data should be involved. A UK-like system of ONS, NatCen, ScotCen, etc. should be developed in India, with NSO in the lead from a statistical perspective and DoHR from the domain perspective. Dedicated surveyors need to be trained and employed – temporary arrangements should be disbanded.

Table 12.1: Proposed national health surveys and themes

Survey characteristics	India Health Survey (IHS)	India Health Measures Survey (IHMS) – IHS sample	Maternal and Child Health Survey (MCHS) – IHS sample	Sample Registration System (SRS)	Cause of Death Survey (CDS) – SRS sample	COVID-19 Impact Survey (CIS) – IHS-SRS samples
Design and logistics						
Conducting / coordinating agency	NSO	ICMR	IIPS	ORGI	DoHR	ICMR, NSO
Target age-groups (in years)	6+	6+	0-5 children, 15-49 women	0+	0+	15+
Representativeness (data pooling for lower level representativeness)	National, states / UTs					National
Research design	Mixed methods	Quantitative	Mixed methods	Quantitative	Mixed methods	Mixed methods
Survey design	Cross-sectional	Panel	Cross-sectional	Panel	Cross-sectional	Panel
Oversampling	Vulnerable and under-served populations					
Survey mode (CAPI: Computer-assisted personal-interviewing; CASI: … self-interviewing; CATI: … telephone-interviewing)	CAPI, CASI	CAPI, physical examinations	CAPI, CASI	CAPI	CAPI	CAPI, CATI (follow-up)
Periodicity	Biennial	Annual	Biennial	Annual	Annual	Continuous
Duration – Interview	1 hour	45 minutes	1 hour	30 minutes	1 hour	15-30 minutes
Duration – Data collection (in months)	12	6	12	6	12	Continuous
Duration – Data dissemination (in months, following data collection)	6	3	6	3	6	Quarterly
Duration – Final report (in months, following data dissemination)	6	3	6	3	6	Biannual

Survey characteristics	India Health Survey (IHS)	India Health Measures Survey (IHMS) – IHS sample	Maternal and Child Health Survey (MCHS) – IHS sample	Sample Registration System (SRS)	Cause of Death Survey (CDS) – SRS sample	COVID-19 Impact Survey (CIS) – IHS-SRS samples
Local area characteristics (local area questionnaire – to be filled in by the area survey team based on documentation, observation and interactions)						
Type of area (rural / urban)	🟦			🟦		
Physical infrastructure (including from a physical activity perspective)	🟦					
Social infrastructure (health care, public health, educational facilities)	🟦					
Environmental characteristics (pollution, WASH, etc.)	🟦					
Economic and employment characteristics	🟦					
Health facility characteristics (health facility questionnaire – to be filled in by the area survey team based on documentation, observation and interactions)						
WHO health system building blocks (availability and quality)	🟦					
Household characteristics						
Local area score (based on local area characteristics)	🟦	IHS scores can be used by all surveys				
Health facility score (based on health facility characteristics)	🟦					
Housing characteristics (cooking fuel, electricity, drinking water, sanitation, ventilation, number of rooms, etc.)	🟦			🟦		
Household economic status (including asset ownership)	🟦			🟦		
Social characteristics of the household (caste / tribe, religion, etc.)	🟦			🟦		
Household composition (relation, age and gender)	🟦			🟦		🟦

Survey characteristics	India Health Survey (IHS)	India Health Measures Survey (IHMS) – IHS sample	Maternal and Child Health Survey (MCHS) – IHS sample	Sample Registration System (SRS)	Cause of Death Survey (CDS) – SRS sample	COVID-19 Impact Survey (CIS) – IHS-SRS samples
Respondent characteristics						
Demographic characteristics	🟦	🟦	🟦	🟦 Both of living and deceased	🟦	🟦 Both of living and deceased
Civil registration (births and deaths, Aadhar / PAN / BPL card, etc.)	🟦					
Educational characteristics	🟦					
Employment characteristics	🟦					
Health practices and behaviors (sanitation, physical activity, dietary patterns, salt intake, tobacco and alcohol consumption, etc.)	🟦					
Exposure to mass media	🟦					
Respondent's health status						
NHP 2017 – 'Attainment of the highest possible level of health and well-being for all at all ages'						
General health and well-being – physical, mental and social[165] (self-reported) – incl. musculoskeletal, sense organ diseases, disabilities	🟦					🟦
Disease, disability, risk factor prevalence (measurements / tests)[166]		🟦				🟦
COVID-19 prevalence (symptoms and tests)						🟦
Maternal and child health and nutrition			🟦			

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[165] Health as defined in WHO's constitution; social health and well-being as defined at https://www.nhp.gov.in/social-health_pg (9/6/2020, 17:35 hours).

[166] List of health measurements and tests included in the NHANES (US) – https://bit.ly/2XMsKS8 – and CHMS (Canada) – https://bit.ly/2MKjOq0 (9/6/2020, 17:42 hours) – surveys.

Survey characteristics	India Health Survey (IHS)	India Health Measures Survey (IHMS) – IHS sample	Maternal and Child Health Survey (MCHS) – IHS sample	Sample Registration System (SRS)	Cause of Death Survey (CDS) – SRS sample	COVID-19 Impact Survey (CIS) – IHS-SRS samples
Cognitive and emotional health			🟦			
Adverse drug reaction (ADR)		🟦				
Fertility				🟦		
Mortality				🟦	🟦	🟦
Injuries (transportation, falls, poisoning, self-harm and violence, etc.)	🟦					
Respondent's views on health system performance (public and private)						
NHP 2017 – 'Expand preventive, promotive, curative, palliative and rehabilitative services provided through the public health sector with focus on quality'						
Coverage of essential health services (SDG 3.8.1 tracer indicators – 'service capacity and access' indicators to be covered under health facility questionnaire above)	🟦	🟦	🟦			
Financial protection when using health services (SDG 3.8.2)	🟦					🟦
Accessibility / affordability / utilization of safe, efficacious and quality preventive, promotive, curative, palliative and rehabilitative services	🟦		🟦			🟦
Accessibility / affordability / utilization of comprehensive primary health care (CPHC), including Health and Wellness Centres (HWCs)	🟦		🟦			🟦
Access / affordability / utilization of secondary and tertiary health care and linkages with CPHC	🟦		🟦			🟦
Accessibility / affordability / utilization of various systems of medicine	🟦		🟦			🟦

Survey characteristics	India Health Survey (IHS)	India Health Measures Survey (IHMS) – IHS sample	Maternal and Child Health Survey (MCHS) – IHS sample	Sample Registration System (SRS)	Cause of Death Survey (CDS) – SRS sample	COVID-19 Impact Survey (CIS) – IHS-SRS samples
Maternal and child immunization			🟦			
Access to / utilization of health insurance and public health schemes	🟦		🟦			🟦
Access to free drug and diagnostic services through public facilities	🟦		🟦			🟦
Screening and management of noncommunicable diseases (NCDs) – facility- and community-based (including interlinkages / referrals)	🟦					
Patient safety and system to report adverse drug reactions (ADRs)	🟦		🟦			🟦
Performance and attitudes of health care and public health staff	🟦		🟦			🟦
Awareness and attitudes towards antimicrobial resistance (AMR) and antimicrobial use (AMU), self-medication, AMU in agriculture	🟦					
IEC for small family norm			🟦			
IEC for healthy choices	🟦					
Trust in public and private health care facilities	🟦		🟦			🟦
Interface of public and private health care facilities	🟦		🟦			🟦
Health care satisfaction and expectation	🟦		🟦			🟦
Child care, training and soft skill development			🟦			
Out-of-pocket health care expenditure (especially catastrophic)	🟦		🟦			🟦
Socioeconomic impact of poor health	🟦		🟦			🟦

Survey characteristics	India Health Survey (IHS)	India Health Measures Survey (IHMS) – IHS sample	Maternal and Child Health Survey (MCHS) – IHS sample	Sample Registration System (SRS)	Cause of Death Survey (CDS) – SRS sample	COVID-19 Impact Survey (CIS) – IHS-SRS samples
Specific outcomes / outcome indicators (MoHFW's policies)						
NHP 2017 (general), NPP 2000, National Multisectoral Action Plan for Prevention and Control of Common NCDs, 2017-22 (NMAP-NCDs), SDG 3 (wherever specified)						
Life expectancy at birth				🟦		
Disability-adjusted life years (DALYs) (together from IHS, IHMS, SRS)	🟦	🟦		🟦		
Total fertility rate (TFR)				🟦		
Maternal and child mortality (stillbirth, neonatal, infant under-5, MMR)				🟦		
Prevalence of stunting among under-5 children			🟦			
Premature mortality from cardiovascular diseases, cancer, diabetes or chronic respiratory diseases – probability of dying between ages 30-70 from these 4 diseases and cancer incidence by type of cancer (NMAP-NCDs)					🟦	
Disease prevalence / incidence (HIV/AIDS; leprosy, kala-azar and lymphatic filariasis in endemic pockets; tuberculosis; blindness) – preventable morbidity, disability and mortality due to NCDs (NMAP-NCDs); malaria, neglected tropical diseases, hepatitis, water-borne, other communicable diseases (SDG 3.3)		🟦			🟦	
Risk factor prevalence / incidence (blood pressure, blood sugar, tobacco use, etc.) – alcohol consumption, obesity, physical activity, salt intake, cooking fuels, fruit and vegetable consumption (NMAP-NCDs); substance abuse, including narcotic drug abuse (SDG 3.5)	🟦	🟦				
Occupational injury among agricultural workers – deaths and injuries from road traffic accidents (SDG 3.6)	🟦				🟦	

Survey characteristics	India Health Survey (IHS)	India Health Measures Survey (IHMS) – IHS sample	Maternal and Child Health Survey (MCHS) – IHS sample	Sample Registration System (SRS)	Cause of Death Survey (CDS) – SRS sample	COVID-19 Impact Survey (CIS) – IHS-SRS samples
National Vaccine Policy 2011						
Morbidity and mortality due to vaccine-preventable diseases (VPDs)		🟦			🟦	
Childhood infectious diseases of public health importance		🟦			🟦	
Impact of existing interventions		🟦			🟦	
National Mental Health Policy of India 2014						
Distress, disability, exclusion, morbidity and premature mortality associated with mental health	🟦				🟦	
Prevalence and impact of risk factors related to mental health	🟦					
Risk and incidence of suicide and attempted suicide	🟦					
Respect for rights and protection from harm of person(s) with mental health problems	🟦					
Stigma related to mental health problems	🟦					
Other outcome indicators						
Fertility indicators (including birth rates and sex ratios)				🟦		
Mortality indicators (including death rates)				🟦		
Cause-specific morbidity and disability (WHO-FIC)		🟦				
Cause-specific mortality (WHO-FIC)					🟦	

Survey characteristics	India Health Survey (IHS)	India Health Measures Survey (IHMS) – IHS sample	Maternal and Child Health Survey (MCHS) – IHS sample	Sample Registration System (SRS)	Cause of Death Survey (CDS) – SRS sample	COVID-19 Impact Survey (CIS) – IHS-SRS samples
Specific processes / process indicators (MoHFW policies)						
NHP 2017 (general), NPP 2000 (specified)						
Antenatal care coverage			🟦			
Skilled attendance at birth – institutional deliveries by trained persons (NPP 2000)			🟦			
Newborns fully immunized by one year of age – universal immunization of children against all vaccine preventable diseases (NPP 2000)			🟦			
Met need of family planning – unmet needs for basic RCH services, supplies and infrastructure as well as access to information / counseling and services for fertility regulation and contraception with a wide basket of choices (NPP 2000)			🟦			
Registration of births, deaths, marriage and pregnancy (NPP 2000)				🟦		
Prevention and control of communicable diseases (NPP 2000)		🟦				
Hypertensives and diabetics maintain ‘controlled disease status’		🟦				
Integrated Indian systems of medicine (ISM) for reproductive and child health (RCH) services and household outreach (NPP 2000)			🟦			
NMAP-NCDs						
Adults receiving drug therapy and counselling to prevent heart attacks and strokes		🟦				

Survey characteristics	India Health Survey (IHS)	India Health Measures Survey (IHMS) – IHS sample	Maternal and Child Health Survey (MCHS) – IHS sample	Sample Registration System (SRS)	Cause of Death Survey (CDS) – SRS sample	COVID-19 Impact Survey (CIS) – IHS-SRS samples
Availability and affordability of quality, safe and efficacious essential NCD medicines including generics and basic technologies in both public and private facilities		■				
Access to palliative care assessed by morphine-equivalent consumption of strong opioid analgesics per death from cancer		■				
Vaccination coverage against hepatitis B virus monitored by number of third doses of Hep-B vaccine administered to infants			■			
Women aged 30-49 screened for cervical cancer at least once		■				
Women aged 30 and above screened for breast cancer by clinical examination by trained health professional at least once		■				
High risk persons (using tobacco, smoking and smokeless and betel nut) screened for oral cancer by examination of oral cavity		■				
Capacity of individuals, families and communities to make healthier choices by creating healthy environments that promote health and reduce the risk of NCDs	■					
Accessible and affordable good quality care to people with disease or risk factors through primary health care approach	■					
National Mental Health Policy of India 2014						
Enhanced understanding of mental health	■					
Universal access to quality health and social care for mental health (including prevention services, treatment, care and support services) throughout the lifespan within a rights-based framework	■					

Survey characteristics	India Health Survey (IHS)	India Health Measures Survey (IHMS) – IHS sample	Maternal and Child Health Survey (MCHS) – IHS sample	Sample Registration System (SRS)	Cause of Death Survey (CDS) – SRS sample	COVID-19 Impact Survey (CIS) – IHS-SRS samples
Access to mental health services for vulnerable groups, including homeless persons, persons in remote areas, difficult terrains, educationally / socially / economically deprived sections	🟦					
Enhanced availability and equitable distribution of skilled human resources for mental health	🟦					
Enhanced financial allocation and improve utliisation for mental health promotion and care	🟦					
Identify and address the social, biological and psychological determinants of mental health problems	🟦					
Electronic Health Record (EHR) Standards for India 2016						
Promote interoperability and where necessary be specific about certain content exchange and vocabulary standards to establish a path forward toward semantic interoperability	🟦	🟦	🟦	🟦	🟦	🟦

Source: Developed by author.

Annexure A – List of interviewees

Sn.	Name	Designation	Division / Department / Ministry / Organization	Government of
NEW DELHI				
1	Dr Nivedita Gupta + Team	Chief Director (Statistics)	Statistics Division, Department of Health and Family Welfare (DoHFW), Ministry of Health and Family Welfare (MoHFW)	India
2	Ms Anjali Rawat	Director (HMIS)	Statistics Division, DoHFW, MoHFW	India
3	Mr Birendra Kumar Mishra	Deputy Director	Central Bureau of Health Intelligence (CBHI), Directorate General of Health Services (DGHS), DoHFW, MoHFW	India
4	Ms Anu Nagar + 1	Joint Secretary	Department of Health Research (DoHR), MoHFW	India
5	Dr D K Shukla	Consultant; Former Director In-charge	National Institute of Medical Statistics (NIMS), Indian Council of Medical Research (ICMR), DoHR, MoHFW	India
6	Dr Harpreet Singh	Scientist 'E' & Head	Informatics, Systems & Research Management Cell, ICMR, DoHR, MoHFW	India
7	Dr Ashoo Grover	Scientist 'F' & Head	Research Methodology Cell, ICMR, DoHR, MoHFW	India
8	Ms Sandhya Singh	Deputy Registrar General	Vital Statistics Division, Office of the Registrar General of India, Ministry of Home Affairs	India
9	Dr Ashutosh Ojha + Team	Deputy Director General	Social Statistics Division, Ministry of Statistics and Programme Implementation	India
10	Ms Shruti Pandey	Assistant Director (P&E)	Planning and Evaluation Division, Ministry of AYUSH	India
11	Dr Harshad P Thakur + 1	Director	National Institute of Health and Family Welfare (NIHFW), MoHFW	India

Sn.	Name	Designation	Division / Department / Ministry / Organization	Government of
12	Dr Ved Prakash Yadav	National Consultant (Health Systems)	WHO (Country Office)	
13	Mr Jorge Coarasa + 1	Program Leader (Human Development)	The World Bank (India)	
14	Mr Luigi D' Aquino	Chief of Health	UNICEF (India Country Office)	
15	Mr Venkatesh Srinivasan + 1	Assistant Representative	UNFPA (Country Office)	
16	Ms Suneeta Krishnan + 1	Country Lead (Measurement, Learning & Evaluation)	Bill and Melinda Gates Foundation (India Country Office)	
17	Ms Moutushi Sengupta	Director	MacArthur Foundation (India)	
18	Prof Lalit Dandona	Distinguished Research Professor	Public Health Foundation of India (PHFI)	
19	Dr Bhaswati Das	Associate Professor	Centre for the Study of Regional Development, School of Social Sciences, Jawaharlal Nehru University	
UDAIPUR				
20	Dr B L Nagda	Former Joint Director	Population Research Centre (PRC) Udaipur (Mohanlal Sukhadia University)	India
21	Dr Pooran Mal Yadav	Additional Charge	PRC Udaipur	India
22	Dr Julfikar Kazi	Joint Director (Udaipur Zone)	Department of Medical, Health and Family Welfare (DoMHFW)	Rajasthan
23	Dr G S Rao	District Program Manager (Udaipur)	DoMHFW	Rajasthan
24	Mr Pratap Singh	District Monitoring and Evaluation Officer (Udaipur)	DoMHFW	Rajasthan

Sn.	Name	Designation	Division / Department / Ministry / Organization	Government of
25	Mr Punit Sharma	Deputy Director (Udaipur)	Directorate of Economics and Statistics (DES)	Rajasthan
JAIPUR				
26	Dr Deepak Saxena + Team	Senior Regional Director	Regional Office of Health and Family Welfare (RoHFW), DGHS, DoHFW, MoHFW	India
27	Ms Seema Mishra + 1	Deputy Director	CBHI, DGHS, DoHFW, MoHFW	India
28	Shri Rohit Kumar Singh + 1	Additional Chief Secretary	DoMHFW	Rajasthan
29	Shri Naresh Kumar Thakral	Special Secretary & Mission Director (NHM)	DoMHFW	Rajasthan
30	Dr R S Chhipi	Director (Family Welfare / FW)	DoMHFW	Rajasthan
31	Dr K K Sharma	Director (Public Health) and Commissioner (Food and Safety)	DoMHFW	Rajasthan
32	Mr Sujan Kumar Saha	Assistant State Programme Manager	State Programme Management Unit (SPMU, NHM), DoMHFW	Rajasthan
33	Mr Raushan Kumar Jha	State Data Manager	SPMU (NHM), DoMHFW	Rajasthan
34	Mr Vikas Meena + 1	Demographer (FW)	DoMHFW	Rajasthan
35	Dr Ramesh Chandra Gupta	Project Director	National AYUSH Mission, Department of Ayurved and Indian Medicine (DoAIM)	Rajasthan
36	Dr Renu Bansal + 2	Director	Homeopathy Chikitsa Vibhag, DoAIM	Rajasthan
37	Dr Joga Ram	District Collector (Jaipur)		Rajasthan
38	Dr Mamta Chauhan + 1	Associate Professor	State Institute of Health and Family Welfare (SIHFW)	Rajasthan

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39	Dr Shiv Dutt Gupta + 1	Chairman	Indian Institute of Health Management Research (IIHMR)	
40	Dr Arindam Das	Associate Professor	IIHMR	
41	Dr Ruchit Nagar + 1	CEO	Khushi Baby	
LUCKNOW				
42	Dr Krishan Kumar Mittra + 1	Senior Regional Director	RoHFW, DGHS, DoHFW, MoHFW	India
43	Prof Arvind Mohan	Director	PRC Lucknow (University of Lucknow)	India
44	Ms Jasjit Kaur + 3	Additional Mission Director & Additional Executive Director	NHM & State Innovations in Family Planning Services Project Agency (SIFPSA)	Uttar Pradesh
45	Dr Vikasendu Agarwal	Joint Director (IDSP)	Directorate of Medical and Health Services	Uttar Pradesh
46	Mr Arvind Kumar Pandey	Director	DES	Uttar Pradesh
47	Dr Narendra Agarwal + 1	Chief Medical Officer (Lucknow)	DoMHFW	Uttar Pradesh
48	Mr Satish Kumar	District Program Manager (Lucknow)	DoMHFW	Uttar Pradesh
49	Dr Mahesh Nath Singh	Assistant Professor	SIHFW	Uttar Pradesh
50	Prof Nomita Kumar + 1	Assistant Professor	Giri Institute of Development Studies (GIDS)	
51	Mr Waseef Naqvi + 1	Senior Research Analyst	Academy of Management Studies (AMS)	

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PATNA				
52	Shri Manoj Kumar	Mission Director	NHM	Bihar
53	Mr Ranjan Kumar	Assistant Director (HMIS and MCTS)	NHM	Bihar
54	Dr Tabrez Akhter Lari	State Programme Officer	Bihar AYUSH Society	Bihar
55	Mr Banshidhar Mishra	Joint Director	DES	Bihar
56	Dr Hemant Shah	Chief of Party (Bihar Technical Support Program)	CARE India	
57	Dr Sanchita Mahapatra	Epidemiologist	Centre for Health Policy (CHP), Asian Development Research Institute (ADRI)	
GUWAHATI				
58	Dr Parthajyoti Gogoi	Regional Director	RoHFW, DGHS, DoHFW, MoHFW	India
59	Ms Mallika Medhi	Director	Directorate of Health Services (Family Welfare)	Assam
60	Dr Lakshmanan S	Mission Director	NHM	Assam
61	Mr Rahul Dev Chakraborty	State MIS Manager	NHM	Assam
62	Dr Jyotirmoy Choudhury	Consultant	Directorate of AYUSH	Assam
63	Dr R M Dubey	Professor and Head	Centre for Sustainable Development Goals (CSDG)	Assam
64	Dr Madhulika Jonathan	Chief	UNICEF India (Guwahati Field Office)	

Sn.	Name	Designation	Division / Department / Ministry / Organization	Government of
65	Dr Ashoke Roy	Director	Rural Resource Centre for North Eastern States	
66	Dr Joydeep Borua	Associate Professor	O K D Institute of Social Change and Development	
PUNE				
67	Dr V L Gokak	Senior Regional Director	RoHFW, DGHS, DoHFW, MoHFW	India
68	Dr Madhuri Thakar	Scientist 'F'	Immunology and Serology (I&S), National AIDS Research Institute (NARI), ICMR	India
69	Dr Ashwini Shete	Scientist 'D'	I&S, NARI, ICMR	India
70	Dr Vini Sivanandan + Team	Assistant Professor	PRC Pune (Gokhale Institute of Politics and Economics / GIPE)	India
71	Dr Nitin Bilolikar + Team	Deputy Director of Health Services (Pune Region)	Public Health Department (PHD)	Maharashtra
72	Dr Pradip Awate	State Surveillance Officer (IDSP)	PHD	Maharashtra
73	Mrs P P Telkhade	District Statistical Officer (Pune)	DES	Maharashtra
74	Dr Anjali Radkar	Professor	GIPE	
THIRUVANANTHAPURAM				
75	Dr Ali Manikfan Abdullage + 1	Senior Regional Director	Regional Office of Health and Family Welfare, Directorate General of Health Services	India
76	Team		PRC Thiruvananthapuram (University of Kerala)	India
77	Dr Rathan U Kelkar	Mission Director / Secretary	NHM / Department of Agriculture Development and Farmers' Welfare	Kerala

Sn.	Name	Designation	Division / Department / Ministry / Organization	Government of
78	Dr Sreehari M	State Nodal Officer (Child Health and RBSK)	NHM	Kerala
79	Dr Raju V R + 1	Additional Director (FW, Planning and e-health)	Directorate of Health Services (DHS)	Kerala
80	Mr Preeth	State Data Officer / Demographer	Health Information Cell, DHS	Kerala
81	Mr V Ramachandran + Team	Director	DES	Kerala
82	Dr K S Shinu + 3	In Charge / Executive Director	Kerala SIHFW / State Health Systems Resource Centre (SHSRC)	Kerala
83	Dr Preetha + Team	District Medical Officer (Thiruvananthapuram)	DHS	Kerala
84	Mr Anish Kumar B	Deputy Director (Thiruvananthapuram)	DES	Kerala
85	Dr Sankara Sarma P	Professor and Head	Achutha Menon Centre for Health Science Studies, Sree Chitra Tirunal Institute for Medical Sciences and Technology	
86	Prof Irudaya Rajan + 1	Professor	Centre for Development Studies (CDS)	
87	Prof K R Thankappan	Professor	Department of Public Health and Community Medicine, School of Medicine and Public Health, Central University of Kerala	
OTHERS				
88	Prof K S James + NFHS Team	Director and Senior Professor	International Institute for Population Sciences (IIPS) – Mumbai (email interaction)	India
89	Dr Prashant Mathur	Director	National Centre for Disease Informatics and Research (NCDIR), ICMR, DoHR, MoHFW – Bengaluru	India
90	Dr B N Gangadhar + Team	Director	National Institute of Mental Health and Neuro-Sciences (NIMHANS) – Bengaluru	India