DEVELOPMENT OF NATIONAL AND SUB-NATIONAL ELECTRONIC HEALTH RECORDS TO ENABLE HEALTH DATA EXCHANGE FOR IMPROVED MATERNAL HEALTH SERVICE DELIVERY AND PROGRAM: THE CASE OF A TERTIARY CARE STATE GOVERNMENT HOSPITAL IN INDIA

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ABSTRACT

Manish Kumar: Development of National and sub-National Electronic Health Records to Enable Health Data Exchange for Improved Maternal Health Service Delivery and Program: The Case of a Tertiary Care State Government Hospital in India
(Under the direction of Javed Mostafa)

Despite the fact that understanding stakeholders and their health information needs, health data systems, and workflows are essential for the development of electronic health records to enable inter-organizational health data exchange for decision-making, there is limited research evidence about how to enable inter-organizational health data exchange in India. A qualitative case study focused on a tertiary care state government hospital in India was conducted. The study aimed to identify factors that favor or hampered development of electronic health records, document and describe stakeholder, their health information needs, data systems and workflows associated with maternal health, and proposed a health data exchange model for improving maternal health services and programs at hospital, state, and national levels. The study applied purposive sampling to identify and collect data from twenty key informants using key informant interview technique. Inductive analysis was conducted.

The findings suggested that leadership support and coordination, budgetary constraint, centralized decision-making authority, siloed data collection and reporting systems, shortage of workforce, gaps in health information technology education and training, and poor system design affected development of health data exchange. The findings showed national level agencies were driving adoption and use of electronic health records, provision of financial incentives, program development and had limited engagement of the state and hospital level stakeholders. Both electronic and paper-based data collection, storage, and data sharing systems and the processes and the workflows were complex and ad-hoc.

Following an iterative design process and based on the essential requirements suggested by the key informants an interorganizational health data exchange model was developed. The proposed model leverages electronic heath records to enable use of data for patient care, and reuse of data to support management and administrative decisions at hospital, state, and national levels. The model shows how to balance inter- and intra-organizational data exchange needs. The study also offers five recommendations to facilitate the operationalization of the health data exchange model. The study adds to the current knowledge base and calls for additional research focused on strengthening use and reuse of data for clinical and public health decision making at different health system levels.

To my wife and son, I could not have done without your love and support.
To my father who inspired and motivated me to pursue my personal and academic journey in the United States.
I know you must be proud and celebrating this accomplishment in heaven.

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

API	Application Programming Interface
BMGF	Bill and Melinda Gates Foundation
CDC	Centers for Disease Control and Prevention
COVID	Corona Virus Disease
DFID	Department for International Development
Digital REACH	Digital Regional East African Community Health
DME	Department of Medical Education
DMHFW	Department of Medical Health and Family Welfare
EHR	Electronic Health Record
EMR	Electronic Medical record
FHIA	Federated Health Information Architecture
HDX	Health Data Exchange for Decision-Making
HIC	High-Income Country
HIE	Health Information Exchange
HIS	Health Information System
HIT	Health Information Technology
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome
HMIS	Health Management Information System
ICD	International Classification of Diseases
IMR	Infant Mortality Rate
IRB	Institutional Review Board
IT	Information Technology
JSY	Janani Suraksha Yojana
KII	Key Informant Interview
LMIC	Lower- and Middle-Income Country
MCTS	Mother and Child Tracking System
MDG	Millennium Development Goal
MEIT	Ministry of Electronics and Information Technology
MHR	MyHealth Record

MMR	Maternal Mortality Ratio
MoHFW	Ministry of Health and Family Welfare
NDHB	National Digital Health Blueprint
NDHM	National Digital Health Mission
NHA	National Health Authority
NHM	National Health Mission
NIC	National Informatics Center
NIHFW	National Institute of Health and Family Welfare
NMC	National Medical Commission
OpenMRS	Open Medical Record System
ORS	Online Registration System
PEPFAR	President’s Emergency Plan for AIDS Relief
PMJAY	Pradhan Mantri Jan Arogya Yojana
PRISM	Performance of Routine Information System Management
RCH	Reproductive and Child Health
RHIS	Routine Health Information System
SDG	United Nations Sustainable Development Goal
SHA	State Health Agency
SHM	State Health Mission
TB	Tuberculosis
TSGH	Tertiary Care State Government Hospital
UHC	Universal Health Coverage
UHID	Unique Health Identification
UNAIDS	Joint United Nations Program on HIV/AIDS
US	United States
USAID	United States Agency for International Development
WHO	World Health Organization
NHSRC	National Health Systems Resource Center
ERP	Enterprise Resource Platform
OPD	Out-Patient Department

IPD	In-Patient Department
LDC	Lower Division Clerk
MRD	Medical Record Department
HIMS	Hospital Information Management System
MCH	Maternal and Child Health
DIT	Department of Information Technology
eHIS	Electronic Hospital Information System
AIIMS	All India Institute of Medical Sciences
RADT	Registration, Admission, Discharge, Transfer
DISHA	Digital Information Security in Health Care Act
C-Section	Cesarean Section
MDS	Minimum Data Set

CHAPTER I: INTRODUCTION

Introduction

The newly released global strategy on digital health of the World Health Organization (WHO) calls for developing a national digital information technology (IT) infrastructure that enables seamless exchange and processing of health data-which is primarily generated by the healthcare providers- for use by the healthcare providers, the public health authorities, teaching, and research institutions (WHO, 2020b). Data exchange across different health data systems and among different healthcare organizations is essential to meet the diverse data needs of healthcare providers, public health administrators, program managers, policymakers, and researchers at the national, sub-national, and hospital levels (M. Kumar et al., 2018). The interorganizational data exchange would allow providers to generate, capture, share, analyze and use clinical data to improve both patient health outcomes and the quality of public health monitoring data. The development of an interorganizational data exchange would require a federated health data system which caters to the specific data needs-such as clinical care, care coordination, program management, hospital operations, cost effectiveness- at national, sub-national, and hospital levels and will depend on the adoption and use of standardized electronic health records (EHRs) for patient care. A data exchange model that enables providers and public health decision makers do exist in high-income country (HIC) settings (McMurry et al., 2007). However, these are needed in the decentralized and heterogeneous health systems of the lower-and middle-income countries (LMICs) (Moodley et al., 2012). Hence, there was a felt need to conduct research and propose a health data exchange model that can enable service delivery and program management decision-making at the various levels of the healthcare system in a LMIC such as India. For the purpose of this study, *health data exchange for decision-making (HDX) refers to sharing of health data among different healthcare organizations delivering and managing clinical, administrative, program, policy, and research services*. This definition of HDX is different from how health information exchange (HIE) is defined in high-income countries. For example, in the United States, *HIE is the process of electronically exchanging clinical information across organizational boundaries to overcome fragmentation of patient records. This HIE supports health mobility, allowing patients to move from one location to another and still allowing them and their providers the ability to have access essential health information* (Eden et al., 2017).

The recently launched national digital health mission (NDHM) of India provides a necessary impetus to develop HDX at national, state, and local levels (Ministry of Health and Family Welfare et al., 2020). The national digital health blueprint (NDHB) outlines the vision and operational aspects of the NDHM and has articulated the principles of federated architecture (Table 1) to enable HDX across facility, state, and national level health care organizations (Ministry of Health and Family Welfare, 2019). EHRs are one of the four pillars of the federated architecture proposed under the NDHM and essential for the HDX and can enable capture, analysis, use, and reuse of patient-level data for both clinical care, population health, and program management. Availability and sharing of electronic health information is an essential criterion to enable HDX across healthcare organizations to support healthcare service delivery and program management decision-making (Payne et al., 2019). Yet, data exchange capabilities are very weak especially in LMICs (Oderkirk, 2017) and health system research on health information in India is very limited (Rao et al., 2014). Further, the global evidence on HDX among LMICs is weak or limited (Oderkirk, 2017; Payne et al., 2019). Based on the findings of this qualitative study, a model was proposed that allows interorganizational HDX to support use and reuse of data to improve maternal health service delivery and program decision-making at local (hospital), state, and national levels.

Table 1. Principles of federated architecture, national digital health blueprint

1. All Health Data and Applications are held at 3 levels – National, State and Local (Facility) levels
    a. following the Principle of Minimality at each level
2. Patient Data is held at the Point of Care or closest to it
3. Systems of Record shall hold the primary data and all others will have access to it only through links
    a. subject to the applicable permissions and consent.
4. Large Facilities and Government Health Departments shall be Data Fiduciaries
    a. small facilities which do not have the capacity/ infrastructure can take the services of Licensed Health Data Repositories
5. The Data Fiduciary holding the data shall be responsible for all the data protection obligations and compliances.

Source: Ministry of Health and Family Welfare, Government of India. 2019. National Digital Health Blueprint.

In this study, EHR refers to electronic collection of documents (or database entries) containing health information about a person/patient and national and sub-national levels refer to public administrative units. For example, Indian public administrative structure consists of national, state, district, block, and village level administrative units.

This chapter provides a general overview of the dissertation study. First, an introduction to the current state of EHRs in LMICs such as India with a focus on maternal health service delivery and program management is presented. Second, it examines the problem of limited development and use of electronic health information across organizations in LMICs specifically at the local and state level for delivery and management of healthcare services. Third, the significance of the study is discussed, and how it aims to address the existing gaps in research literature. Fourth, the theoretical models and conceptual frameworks that guided this study are presented and discussed. Finally, this chapter concludes with the study aims and research questions posed in this dissertation, and a discussion of how the study contributes to the field of health informatics.

1.1 Background

Development of national and sub-national EHRs in LMICs is vital for health information sharing and supporting use and reuse of data for realizing a country's health goals and contribute to achieving the United Nations Sustainable Development Goal (SDG) of ensuring healthy lives and promoting well-being for everyone at all ages (WHO, 2020b). It is important to note that almost all the countries that have a health information system (HIS), digital health or eHealth policy/strategy also make a reference to EHRs and clearly describe the importance of collecting, sharing, and using patient level data for achieving improved health outcomes (WHO, 2016a). Since the global and national focus had been primarily on population health issues (emanating from the Millennium Development Goals (MDGs) and now, SDGs of the United Nations) and regional and global health reporting, the LMICs prioritized development of national HIS for collecting, sharing, and using aggregated health services data. Interestingly, most of these data are aggregated from patient-level data captured in paper-registers at the point-of-care. Overall, LMICs have made significant progress in the development of national HIS though these countries have multiple HIS linked with vertical disease programs such as human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS), tuberculosis (TB), and malaria. This siloed approach has led to duplication of financial, technological, human resources, and fragmentation of individual healthcare data. Development of EHRs has the potential to enable HDX among diverse systems and address data quality issues associated with aggregated healthcare data. Further, it can reduce duplication of data collection and maximize use of limited resources through creation of shared technology infrastructure and delivery of integrated health care services through the life cycle of individuals.

1.2 Problem Statement

Globally, there is a general consensus that EHRs can enable capture, analysis, use, and exchange of patient-level data for both patient care and population health management (Jawhari et al., 2016; Syzdykova et al., 2017) and digital health technologies could prove beneficial. However, the uptake of EHRs has been minimal given the fact that the WHO published its EHR manual for LMICs more than a decade ago (WHO, 2006b). While national EHRs are a high priority in the HIC and there is broad adoption of EHRs across different levels of health care delivery, development and use of modern EHR systems in LMICs are still in a nascent stage or even non-existent (WHO, 2016b). Even when countries are using EHRs or other sub-systems, at least in the HIV domain, only a few countries- India (Ministry of Health & Family Welfare, 2016b), Kenya (Ministry of Health Kenya, 2014b) and Tanzania (The United Republic of Tanzania, Ministry of Health, Community Development, Gender, 2016) seem to have published guideline standards for EHRs. The fact that the spare and minimal use of EHR systems, where they are deployed in LMICs, do not adhere to data quality, and assessment metric standards make it challenging to leverage EHRs for improved health care service delivery and effective program management. As a result, LMICs are struggling to deal with critical health care challenges, particularly fragmentation of information, difficulty in tracking services, and consequent gaps in safety and quality of health care. Lack of availability of and access to patient level data has slowed down the pace of controlling disease epidemics (e.g., HIV/AIDS) and limited the health system's ability to deliver health care services through the life cycle of a patient. A recent report by the United Nations Children's Fund highlights the issue of limited or no data exchange capabilities in LMICs. The report states, "Investments in country information systems, including coordination across the information systems in different sectors and across different levels of the system (community, district, national, regional and global) is core to progress and accountability. These investments must support strengthening country ability to collect, analyze and use data for decision-making and civil society's ability to use data to demand high-quality services for all women, children, and adolescents." (WHO and UNICEF, 2020). The EHRs are considered as an essential foundation of the health services oriented digital health framework (Liaw et al., 2020) to harness digital tools that strengthen health systems and improve access, equity, safety, and quality of health services.

Increasingly, international donors and governments are prioritizing investments to support use and reuse of patient data captured in EHRs for both patient care and program management. For instance, the NDHB of the government of India describes the vision to develop a digital infrastructure that will facilitate collection, exchange, and use of healthcare data across the country (Ministry of Health and Family Welfare, 2019). However, the evidence required to enable HDX at the national and sub-national levels to support use of data for health care service delivery and program management in India is lacking. Despite the fact that understanding stakeholders and their health information needs, health data systems, and workflows are essential for the development of EHR to enable inter-organizational HDX (M. Kumar et al., 2018), there is limited research evidence about how to enable inter-organizational HDX to support use and reuse of patient data for healthcare service delivery and program management at national and sub-national levels in India (Manish Kumar & Mostafa, 2019)(M. Kumar & Mostafa, 2019).

1.3 Significance

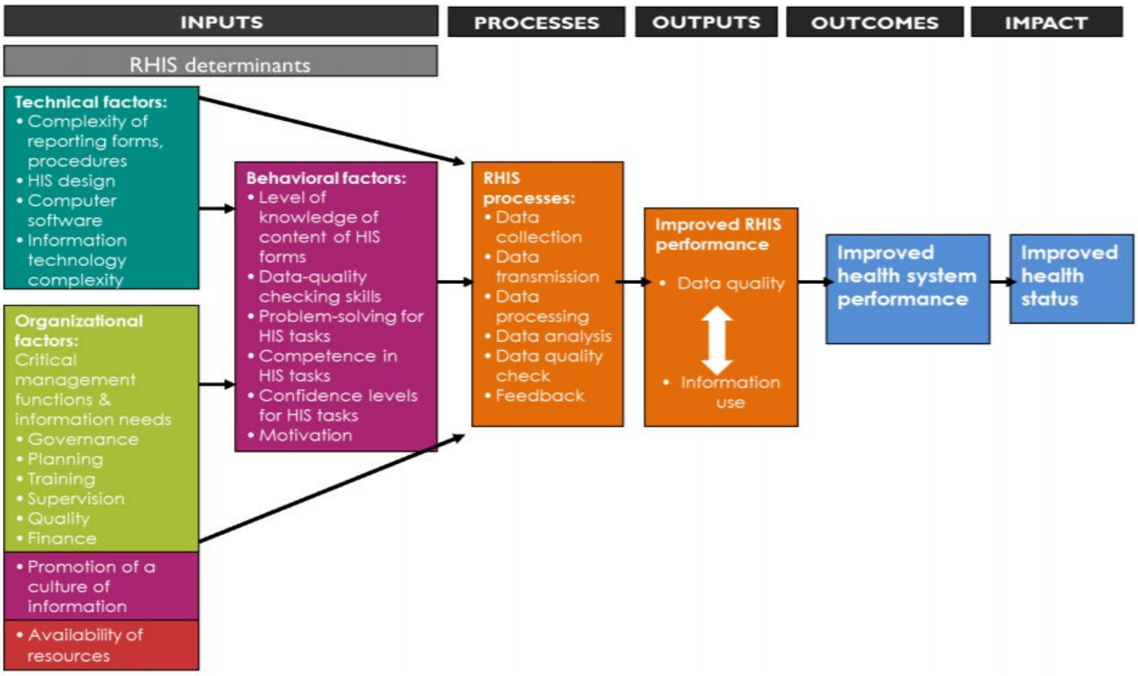
To the best of my knowledge this is the first study aimed at development of national and sub-national EHRs to enable HDX for improved maternal health service delivery and program management in India. Also, this study offers evidence-based insights to operationalize federated health information architecture (FHIA) proposed in the NDHB of India to support HDX. Given that the NDHB was finalized in 2019, there is a lack of evidence on how to develop interorganizational HDX. Together, Aim 1 and 2 of this study were focused on identifying factors that favored or hampered development of EHRs and described various stakeholders and their health information needs, electronic health data systems, and workflows associated with maternal health service delivery and program management decision-making across different organizations at hospital, state, and national levels (M. Kumar & Mostafa, 2019). Given the global and country level focus on optimizing collection and use of patient level data at the point of care and all other levels of the health system, this dissertation research is not only timely but also fills an important evidence gap concerning how to enable interorganizational HDX in India and similar other settings. Aim 3 of this dissertation research resulted into a proposed HDX model appropriate to the Indian context and other similar contexts in LMICs. The results will also enable researchers to validate and/or modify the model for developing interorganizational HDX and guide future research in this domain.

1.4 Theoretical Frameworks

The dissertation study is guided by two theoretical frameworks: (1) Performance of Routine Information System Management (PRISM) framework (Aqil et al., 2009) (MEASURE Evaluation, 2018); and (2) Social-technical model for studying health information technology (HIT) in complex adaptive healthcare systems (Sittig & Singh, 2010). These two frameworks describe organizational, people, technology, and process related factors affect HIT or routine health information system (RHIS) performance in terms of using data for clinical and program management decision-making.

The PRISM RHIS framework which was developed in the healthcare context of LMICs and focused on aggregate health data systems states that systems collecting data at period intervals (less than a year) - performance are affected by processes, which in turn are affected by technical, behavioral, and organizational determinants (Figure 1). It shows that behavioral determinants have a direct influence on RHIS processes and performance which is measured in terms of data quality and data use. Technical and organizational determinants can affect processes and performance directly or indirectly through behavioral determinants. According to the framework, technical determinants are the most obvious determinants of RHIS performance. Technical determinants include a standard set of indicators, data collection form design, form completeness, technologies for data analysis, transfer, and presentation, and user friendliness to enable data use. The organizational determinants include the context of data management, culture of data use, technology, financial, and human resources. The behavioral determinants are related to people involved in data collection, management, and use. The performance of a RHIS is influenced by people's motivation, commitment, skill, and perception about the value of data use.

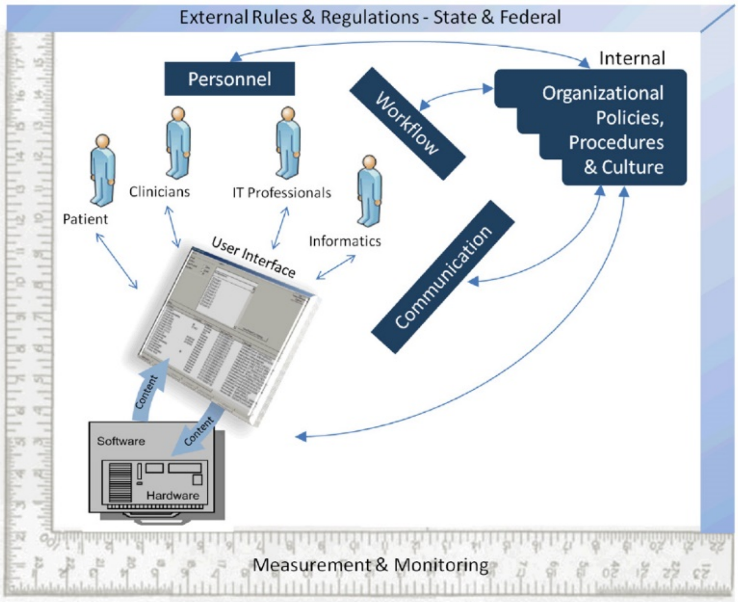
Figure 1. Performance of routine information system management framework



Source: MEASURE Evaluation, 2018

The social-technical model for studying HIT in complex adaptive healthcare systems (Figure 2) provides a more comprehensive model to integrate specific technological and measurement dimensions of health information technology with other socio-technical dimensions in a clinical setting. Sittig and Singh's model consists of eight dimensions- hardware and software, clinical content, human computer interface, people (those interacting with system), workflow and communication, internal organizational features, external organizational features, and measurement and monitoring both intended and unintended consequences of HIT implementation and use- related to people, processes, technology, and organizational aspects. This model has addressed limitations of other social and technology innovation models such as Rogers' diffusion of innovations theory, Venkatesh's unified theory of acceptance and use of technology, and Norman's 7-step human-computer interaction model by incorporating a full range of factors influencing the design, development, implementation, use, and evaluation of HIT interventions even though it is grounded in the healthcare context of HICs.

Figure 2. Illustration of the complex inter-relationships between the eight dimensions



Source: Sittig and Singh, 2010. A New Socio-technical Model for Studying Health Information Technology in Complex Adaptive Healthcare Systems.

The eight dimensional socio-technical model for studying HIT in complex adaptive healthcare systems is specifically designed to address the socio-technical challenges involved in design, development, implementation, use, and evaluation of HIT in healthcare settings that are dynamic (e.g. changes in patient record forms will affect upstream data reporting and sharing, and can cause disruption in how indicators are calculated and used in decision making), distributed, and consist of interrelated subsystems such as health care workforce, supply chain, laboratory, and pharmacy systems. Similar to the composition of complex adaptive healthcare systems the socio-technical dimensions are also interrelated and interdependent. For example, the hardware and software are used to support and operate clinical and administrative applications whereas clinical content is collected, stored, shared, and used through the clinical applications. The human computer interaction allows providers, administrator , and patients to access and use relevant information. The workflow and the communication processes influence the design and function of HIT. Interactions among different dimensions are enabled or obstructed by organizational policies and regulations. To continuously monitor and guide improvement efforts requires establishing standard matrices associated with the eight dimensions in the sociotechnical model.

The PRISM framework and the social-technical model together informed the research aims and associated research questions which are discussed in the next subsection in addition to guiding the study design, methods, and development and testing of data collection instruments.

1.5 Study Aims and Research Questions

The purpose of this study was to enable HDX among healthcare organizations for improved maternal health service delivery (antenatal care, childbirth, and post-natal care) and program management at hospital, state, and national levels. The study aimed to identify factors that favored or hampered development of national and sub-national EHRs, to document and describe stakeholder, stakeholder's health information needs, health data systems, and workflows associated with maternal health service delivery and program management decision-making. The study aimed to propose a HDX model for improved maternal health service delivery and program management at hospital, state, and national levels. Table 2 summarizes the study aims, research questions, and data collection methods.

Table 2. Overview of study aims, research questions, and data collection methods

Study aims	Research questions	Data Collection Methods
To identify factors that favor or hamper development of national and sub-national EHRs to enable HDX for improved maternal health service delivery (antenatal care, childbirth, and post-natal care) and program management.	R1	• In-depth interviews • Review of documents and artifacts
To document and describe stakeholder, health information needs, health data systems, and workflows associated with maternal health service delivery and program management.	R2 through R4	• In-depth interviews • Review of documents and artifacts
To propose a HDX model for improved maternal health service delivery and program management at hospital, state, and national levels.	R5 through R6	• In-depth interviews • Review of documents and artifacts • User feedback

AIM 1: To identify factors that favor or hamper development of national and sub-national EHRs to enable HDX for improved maternal health service delivery (antenatal care, childbirth, and post-natal care) and program management.

R1: What are the perceived drivers of and barriers to the design, implementation, and maintenance of EHRs required for improved maternal health service delivery and program management?

AIM 2: To document and describe stakeholder, health information needs, health data systems, and workflows associated with maternal health service delivery and program management.

R2: Who are the stakeholders engaged in development of EHRs, maternal health service delivery, and program management?

R3: What are the stakeholders' health information needs?

R4: What health data systems and processes are used to collect and use data for decision-making?

AIM 3: To propose a HDX model for improved maternal health service delivery and program management at hospital, state, and national levels.

R5: What are the essential design and development requirements?

R6: How will the model enable HDX to support use and reuse of data for improved maternal health service delivery and program management at hospital, state, and national levels?

1.6 Conclusions

The following chapters present a comprehensive survey of literature that describes who are the key stakeholder, how data is collected, shared, and used, and what are the factors affecting the development of EHRs to enable HDX for improved service delivery and program management at national and sub-national levels in the LMICs Next, the research methods used for data collection and analysis are discussed. Finally, the results of this study are presented, key findings are discussed, and the implications of the findings for researchers, clinicians, and managers involved in the development and use of HDX to improve maternal health service delivery and program management are highlighted.

CHAPTER 2: LITERATURE REVIEW [1]

Introduction

The newly released WHO four-year global strategy on digital health aims to "improve health for everyone, everywhere by accelerating the adoption of appropriate digital health" (WHO, 2020b) and clearly underscores the value of EHRs to enable HDX for achieving its aim (Jawhari et al., 2016; Syzdykova et al., 2017) . Further, EHRs are an essential tool to strengthen health systems and improve access, equity, safety, and quality of health services (Liaw et al., 2020). Development of national and sub-national EHRs that enables HDX in the healthcare systems of the LMICs are also vital for achieving the United Nations SDG of ensuring healthy lives and promoting well-being for everyone at all ages.

The uptake of EHRs has been minimal given the fact that the WHO published its EHR manual for LMICs more than a decade ago (WHO, 2006a). While national EHRs are a high priority in the HICs and there is broad adoption of EHRs across different levels of health care delivery, development and use of modern EHR systems in LMICs is still in a nascent stage or even non-existent (WHO, 2016a). As a result, LMICs are struggling to deal with critical health care challenges, particularly fragmentation of information, difficulty in tracking services, and consequent gaps in safety and quality of health care. The fact that the spare and minimal use of EHR systems, where they are deployed, do not adhere to data quality, and assessment metric standards make the aforementioned challenges even more intractable. The development of digital infrastructure such as national EHRs to enable HDX for supporting all the health system building blocks of the health care system is a multidimensional challenge requiring a significant investment of time and money (Aminpour et al., 2014) and involves diverse stakeholders with varying, often competing, health information needs. The WHO has recently released the Digital Health Investment Guide to inform the digital health investment efforts of private and bi-lateral donors and host country governments (WHO, 2020a) such as India.

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[1] The content of this chapter was adapted from the previously published article in the Library Hi Tech Journal. The original citation is as follows: Kumar, Manish, & Mostafa, J. (2020). Electronic health records for better health in the lower- and middle-income countries: A landscape study. Library Hi Tech, 38(4). https://doi.org/10.1108/LHT-09-2019-0179

2.1 India Context

While India has made good progress in improving its health infrastructure, human resources for health, health financing, regulation, medical technologies and supplies, and health information systems, significant gaps exist in the national and state health systems (Gudwan, A., Mitra, P., Puri, A., and Vaidya, 2012; Ministry of Health and Family Welfare, 2017) . Continued reliance on large periodic surveys to gather data for policy and program formulation and assessment is a bottleneck to the development of a dynamic health system which can respond to the diverse health care needs of the population. Growing health disparity and slow pace of progress among the most populated and less developed states like Bihar, Madhya Pradesh, Rajasthan and Uttar Pradesh continues to hamper India's overall health indicators (Gudwan, A., Mitra, P., Puri, A., and Vaidya, 2012).

The rising burden of non-communicable diseases like diabetes, cancer and cardiovascular problems are challenging the Indian health system which is oriented towards infectious and communicable diseases (Ministry of Health and Family Welfare, 2017).

Increasingly, the burden of non-communicable diseases (39.1%) and injuries (11.8%) have increased as compared to communicable diseases which contribute to 24.4% of the entire disease burden (Ministry of Health and Family Welfare, 2017). However, national health programs for non-communicable diseases are very limited in coverage and scope. The situation is further aggravated by growing health inequity among rural and urban population in terms of health outcomes and access to health care services. For example, about 69 % of childbirth in rural areas happened in public hospitals as compared to about 21 % in private hospitals. In urban areas, public and private hospitals, each accounted for about 48% of childbirth (Ministry of Statistics and Program Implementation, 2019). Further, the Maternal Mortality Ratio (MMR) of India has declined to 113 in 2016-18 from 122 in 2015-17 but is still more than the MMR of 70 needed to achieve the United Nations sustainable development goals for health (Office of the Registrar General, 2020). The IMR for the country has come down to 32 in 2018 from 40 in 2013. The corresponding decline in rural IMR has been from 44 in 2013 to 36 in 2018 and in urban IMR from 27 in 2013 to 23 in 2018. Despite the decline in IMR, one in every 31 infants at the National level, one in every 28 infants in rural areas and one in every 43 infants in urban areas still die within one year of life (Office Of The Registrar General and Census Comissioner, 2018). The high IMR is further aggravated by the high (60%) out of pocket expenditure on health services (Ministry of Health and Family Welfare, 2017).

Recently, India has launched the NDHM that aims to create and use digital health infrastructure, with an EHR as one of the foundational components. The NDHM aims to address the challenges confronting the health systems in the country and to accomplish its health policy objectives of assuring universal availability of free, comprehensive primary health care services, as an entitlement, for all aspects of reproductive, maternal, child and adolescent health and for the most prevalent communicable and non-communicable diseases in the population (National Institute for Transforming India, 2018). However, there is limited evidence, globally and locally, to inform the development of EHRs in India that support both service delivery and program management at national and sub-national levels. A screening of abstracts of 226 EHR related review papers (https://ehrlmic.unc.edu/), especially systematic reviews, from PubMed and Web of Science databases yielded only two relevant review papers from the LMIC perspective. Moreover, these papers were focused on EHR implementation challenges in the context of LMICs. Therefore, a comprehensive survey and analysis of available literature (scientific and gray) was conducted to answer the following specific questions:

- Who are the key stakeholders influencing the development of national and sub-national EHRs?
- What are the health data systems and processes used to collect, share, and use data for service delivery and program management at national and sub-national levels?
- What are the factors affecting the development of national and sub-national EHRs to enable use and reuse of data for improved service delivery and program management?

To answer the above questions, the literature review was focused on the following dimensions: stakeholders, health information architecture including data flow, information need, and data systems, and factors affecting development of EHRs to enable HDX. For the purpose of this review EHRs referred to electronic collection of documents (or database entries) containing health information about a person/patient. The electronic medical record (EMR) refers to electronic patient records meant for clinical purposes.

2.2 Methods

2.2.1 Search Strategy

The methodology was designed to align with the scope of this systematic survey of literature while acknowledging the fact that limited scientific publications are available in scientific databases and mostly available as gray literature. For conducting this review of peer-reviewed literature, a comprehensive survey of literature was conducted using scientific electronic databases – PubMed, SCOPUS, Web of Science, Global Health, and curated lists of publications shared by two international digital health experts at the InterAmerican Development Bank and the Asian Development Bank, respectively.

The country-focused gray literature search included electronic repositories and consultation with international and country-based experts.

2.2.1.1 Peer- reviewed literature search and review

A two-pronged strategy was adopted to conduct a comprehensive, yet focused search of peer-reviewed literature. First, the author conducted an electronic search across four scientific databases: PubMed, Web of Science, SCOPUS, and Global Health. Search terms used for each database are provided in Table 3. These search terms were finalized based on inputs from scholars participating in the meeting of the Laboratory of Applied Informatics Research and after consultations with an EHR expert and a health informatics librarian from the University of North Carolina at Chapel Hill. The electronic search did not use publication period or geography to limit search results in order to obtain a broad sample of literature, but it did limit the focus to English language publications.

Table 3. Scientific database search terms

#	Database	Search terms	#Results
1	SCOPUS	TITLE-ABS-KEY (“delivery of health care” OR “Healthcare Delivery” OR “Health care Delivery” OR “healthcare system” OR “health care system”) AND TITLE-ABS-KEY (hospitals OR hospital) AND TITLE-ABS-KEY (“Electronic Health Records” OR “Medical Records Systems” OR “Medical Informatics” OR “Personal health records” OR “Health Information Systems” OR “Hospital Information Systems” OR EHR OR EHRs OR EMR OR EMRs OR PHR OR PHRs OR “Electronic Medical Records” OR “Electronic Medical Record” OR “Computerized Medical Records”) AND TITLE-ABS-KEY (“developing country” OR “Developing Countries” OR “low resource” OR “limited resource” OR “low resources”)	116
2	Web of Science Core Collection	TS 5 (“delivery of health care” OR “Healthcare Delivery” OR “Health care Delivery” OR “healthcare system” OR “health care system”) AND TS 5 (“hospital*”) AND TS 5 (“Electronic Health Record*” OR “Medical Records System*” OR Medical Informatics OR Personal health record* OR Health Information System* OR Hospital Information System* OR EHR OR EHRs OR EMR OR EMRs OR PHR OR PHRs OR “Electronic Medical Record*” OR “Computerized Medical Record*”) AND TS 5 (“developing countr*” OR “low resource*” OR “limited resource*”)	72
3	PubMed	(“delivery of health care” [MeSH] OR “healthcare delivery” OR “health care delivery” OR “healthcare system” OR “health care system” OR “delivery of health care”) AND (“hospitals” [MeSH] OR hospitals OR hospital) AND (“Electronic Health Records” [Mesh] OR “Medical Records Systems, Computerized” [Mesh] OR Medical Informatics [MeSH] OR “Health Records, Personal”[MeSH] OR “Health Information Systems”[MeSH] OR “Hospital Information Systems”[MeSH] OR EHR OR EHRs OR EMR OR EMRs OR PHR OR PHRs OR “Electronic Medical Records” OR “Electronic Medical Record” OR “Computerized Medical Records”) AND (“Developing Countries” [Mesh] OR “low resource” OR “limited resource” OR “low resources”)	153
4	Global Health	TX (“delivery of health care” OR “Healthcare Delivery” OR “Health care Delivery” OR “healthcare system” OR “health care system”) AND TX (hospital*) AND TX (“Electronic Health Records” OR “Medical Records Systems” OR “Medical Informatics” OR “Personal health records” OR “Health Information Systems” OR “Hospital Information Systems” OR EHR* OR EMR* OR PHR* OR “Electronic Medical Record*” OR “Computerized Medical Records”) AND TX (“developing country” OR “Developing Countries” OR “low resource” OR “limited resource” OR “low resources”)	61

Second, to identify any other relevant peer-review publications that the electronic search of scientific databases might have missed, the author consulted international experts from the Inter-American Development

Bank in Washington, District of Columbia, and the Asian Development Bank in Manila, Philippines. Both the experts had extensive global digital health experience.

2.2.1.2 Country-focused gray literature search and review

The country-focused gray literature search included electronic health repositories of the WHO headquarter and its regional offices in Africa and Americas, the United States Agency for International Development (USAID)-MEASURE Evaluation project, and the South Africa-based non-profit organization HealthEnabled. The literature search also included communication with 17 international and country-based experts from 16 different organizations working in the digital health and health information systems domain (Table 4).

Table 4. List of experts consulted to collect gray literature

#	Organization name	Country
1	WHO Headquarter	Switzerland
2	Africa Regional Office of the WHO	Brazeville, Congo
3	Inter-American Development Bank headquarter	United States
4	Asian Development Bank	Philippines
5	United States Centers for Disease Control and Prevention	United States
6	United States Agency for International Development	United States
7	Ministry of Health, Republic of Uganda	Uganda
8	Ministry of Health, Republic of Rwanda	Rwanda
9	Health Information Systems Program	Tanzania
10	PATH Africa Region	Tanzania
11	Baobab Trust	Malawi
12	JEMBI Health Systems	South Africa
13	HealthEnabled	South Africa
14	Intellisoft, Inc.	Kenya
15	University of Lausanne	Switzerland
16	PATH	United States
17	Asian ehealth Information Network	Philippines

Table 5 provides a quantitative summary of the electronic database search results. A total of 116, 72, 153, and 61 publications were downloaded from the SCOPUS, Web of Science, PubMed, and Global Health databases, respectively. The database search resulted in a total of 402 publications, after deduplication, and a list of 14 publications was recommended by two international experts. The title and abstract screening included a total of 358 publications after removing 58 duplicates.

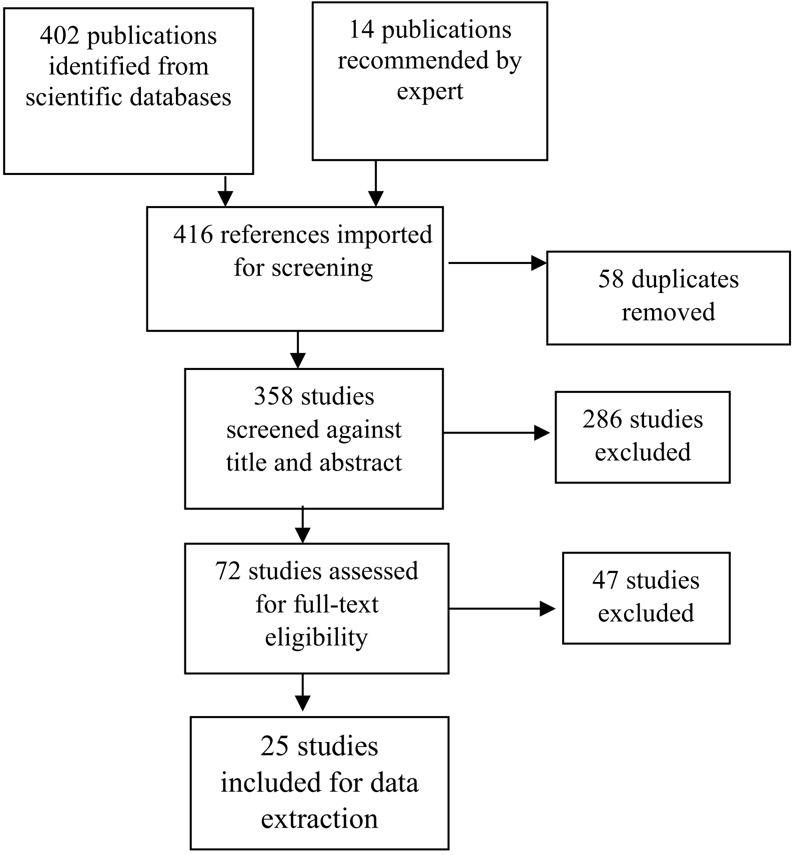
Table 5. Scientific database search results

#	Database	Result
1	SCOPUS	116
2	Web of Science Core Collection	72
3	PubMed	153
4	Global Health	61

Most of the publications were excluded, as they focused on the benefits of EHR use in different healthcare settings. Many publications described broader issues related to ehealth and health information technology in developing countries. The title and abstract review resulted in the selection of 72 publications for full-text review. Upon the full-text review, publications describing general implementation challenges were excluded, as they described post-implementation experiences without explaining the strategies used to integrate EHRs in national healthcare systems. A total of 25 publications were ultimately selected for data extraction, review, and analysis (Figure 3).

For the country-focused gray literature analysis, 49 publications focused on global ehealth, country ehealth profile, national EHR/EMR guidance, HIS policy, and digital health documents were selected. The analysis was focused on development of EHRs or EMRs and other related digital systems at the national and sub-national levels as described in the selected gray literature.

Figure 3. Publication screening and review summary



2.2.2 Inclusion and Exclusion Criteria

The peer-review publications that focused on strategies for developing national and sub-national EHRs in healthcare systems in LMICs were included for title and abstract screening. The EHR development included designing, planning, implementation, and maintenance, and use of EHRs for healthcare servicey delivery and management for clinical care, and enabling HDX for program administration, and management. All non-English-language papers and those describing the high-income country context were excluded from the review. The same screening criteria were used for the full text review. The country digital health, ehealth, and HIS strategy, policy, standards, and guidance documents describing EHRs (and/or related terms) were included in the review if available in the public domain and published in English.

2.2.3 Study Evaluation

Data analysis was primarily qualitative, and findings were organized to highlight stakeholder, health information architecture, and sustainability related results.

2.3 Results and Discussion

The findings of this literature review are presented in four subsections. The first section describes key stakeholders for development of national and sub-national EHRs. The second section presents an overview of health information architecture which describes health information needs, data flow, and health data systems used to capture and share data. The third section describes the status of country ehealth foundational elements, EHRs, and sub-systems supporting service delivery and program management decisions at national and sub-national levels. The fourth subsection presents and discusses factors affecting development of national and sub-national EHRs to enable HDX for improve healthcare service delivery and program management.

2.3.1 Key Stakeholder for the Development of National and Sub-National EHRs

Stakeholder engagement is key to development of EHRs in LMICs. In most instances, the national ministry of health offered leadership and support to the EMR/EHR implementation. However, EHR implementation was influenced by international funding agencies and implementing partners. For example, the United States (US) President's Emergency Plan for AIDS Relief (PEPFAR), the USAID, and the US Centers for Disease Control and Prevention (CDC) are among the largest donors funding the implementation of EHRs at the sub-national level with a primary focus to address HIV health care service (USAID, 2018). These government agencies have made investments in EMRs in more than 50 LMICs. A recent study showed that the patient monitoring systems are funded by multi-lateral and bi-lateral donors (Suthar et al., 2019). The national governments and in-country private and non-government organizations were also important stakeholders but with limited influence in terms of defining the requirements, technical capacity, financial resources, and access to state-of-the-art training resources for the national EHR development. Even though health care consumers were one of the key stakeholder groups, in general, their involvement in development of EHRs to deliver patient-centered health care services was negligible. Their role was limited to sharing health information with the health care providers. The health information needs of various stakeholders for decision-making varies depending on whether they are engaged in clinical care, program management or policy decision-making (Manish Kumar, Mostafa, et al., 2018). Most of the strategic decision-making, implementation and review of policies, and resource allocation across the health sectors occurs at the national level (Abouzahr et al., 2007).

2.3.2 Health Information Architecture Overview

The health information architecture, in general, involved the collection of patient-level data, mostly in paper forms, at the point of service and aggregated data was collected, shared, and used at facility, district, and national level for clinical administrative, program management, and strategic decision-making (Latifov & Sahay, 2013; Wilkins et al., 2008)(Wilkins et al., 2008). The aggregate data reporting used both paper and electronic HIS and most of the countries had electronic national HIS for collecting and using aggregate health care service data (Silvestre, E and Wood, 2019; WHO, 2016a). Analysis of the gray literature showed that many of the countries had pharmacy, logistics, and human resources information systems. However, information sharing among these systems and with the national aggregate HIS is non-existent (Nabyonga-Orem et al., 2016) or at the most in the pilot mode. These fragmented HIS aggravate challenges that are associated with multiple siloed systems.

2.3.3 Status of Country-level EHR System and Sub-Systems

The country-focused gray literature analysis showed that countries are at different stages of national and sub-national EHR development in terms of creating ehealth foundational systems, developing EHRs and other electronic systems such as their pharmacy, laboratory, and pathology information systems. Most of the LMICs have HIS strategies or policies while some had ehealth policies. As the WHO, international organizations, and donors prioritized and invested in HIS during the last 20 years, most of the countries were able to develop HIS strategies or policies, (Silvestre, E and Wood, 2019; WHO, 2016a). Ehealth and digital health efforts are still relatively new though HIS is considered as integral part of the ehealth and digital health efforts. Many countries have initiated preparing the digital health strategies with support from WHO-Africa and the International Telecommunications Union (Broadband Commission for Sustainable Development, ITU, 2017).

Many of the countries also have pharmacy, logistics, and laboratory information systems (WHO, 2016a). In recent years, global investments by PEPFAR, CDC, USAID, UNAIDS, Global Fund, United Kingdom Department for International Development (DFID), and the Bill and Melinda Gates Foundation (BMGF) drove development of these systems in the LMICs as well as the development of a number of global digital health goods such as the Open Logistics Management Information System that have become available for further investment and use in the LMICs (PATH, 2019). While these sub-systems together with EMRs have contributed to control the HIV epidemic (Matheson et al., 2012), the development of EHRs for broader health care services continues to lag behind. However, globally, there is a renewed focus on development of EHRs in the LMICs to deliver patient-level health care services and address data quality and data use challenges resulting from collection and use of aggregated data (USAID, 2018). Furthermore, HDX and data integration across different health sub-domains (services, workforce, logistics, laboratory, health finance, etc.) and other social determinants of health is hard to achieve in the absence of granular data in the EHRs (WHO, 2020b).

2.3.4 Factors Affecting Development of EHRs to Enable HDX

Health program-specific and/or disease focused EMR implementation is common in all the countries receiving funding for HIV programs from the United States government. While the development of national and sub-national EHRs in the HICs is driven by policy incentives (Payne *et al.,* 2019) and revenue generation for service delivery, the LMICs continue to rely on external funding to develop disease specific EMRs. For example, EMR implementation aimed at improving treatment and care for HIV patients is used in many countries though it is largely funded by the PEPFAR (Manish Kumar & Mostafa, 2020). In other words, the business model for development of EHRs in LMICs is largely aimed at public health care services with minimal or no service fee and is dependent on government funding and donor grants. Development of EHRs to enable HDX is intertwined with the stakeholder health information needs and the health information architecture. Stakeholders have an important role in generating system requirements, development and testing of innovations, and analysis and use of data to deliver health care services and manage population and patient health. Further, findings revealed limited application of theoretical models to guide or evaluate development of national and sub-national EHRs.

2.3.4.1 Limited healthcare service provision and geographical coverage

The analysis of peer-reviewed literature showed that terms EMR and EHR were found to be used interchangeably within the same publications. A total of eight publications had a broader focus on LMICs, developing countries, Africa, or low-resource settings. These eight papers included literature reviews (Fritz et al., 2015a; Khalifa, 2016; Tilahun & Fritz, 2015) a generic focus on ehealth benefits (Blaya et al., 2010), interface technologies (Kanter et al., 2008), and pathology and laboratory systems (Alemnji et al., 2014; Horton et al., 2018; Sayed et al., 2018). Many of the publications focused on vertical disease programs, such as HIV (4), tuberculosis (TB) (1), TB/HIV (1), and antenatal care (1). Other publications focused on rural healthcare delivery, home-based healthcare, mental health, eye care, Ebola, predicting disease patterns, mobile service trips, and pharmacies. The peer-reviewed publications spanned a wide range of geographical locations, presenting evidence from Nigeria, South Africa, Cameroon, Uganda, Ghana, Kenya, Sierra Leone, Malawi, Ethiopia, Peru, Haiti, China, Malaysia, India, Pakistan, and Sri Lanka. The findings confirmed that application of EHRs predominantly supports vertical disease programs, which are often donor funded. For example, EHR implementation in Nigeria, Uganda, Kenya, Malawi, Sierra Leone, Peru, Haiti, and Pakistan was funded by international donors. Except for the publication on Malaysia, all had a very narrow disease or health program focus and use of EHRs was described as limited to a few clinics or hospitals. This contrasts with the WHO recommendation for countries to develop national EHRs to achieve the SDGs on health and the universal health coverage (UHC).

2.3.4.2 Influence of disease programs

The full-text review of the peer-reviewed publications showed that none of the publications approached EHR development with an aim to cater to the health information needs of diverse stakeholders or to align with the national health information architecture and facilitate HDX over a period of time. Instead, the focus was primarily on vertical disease programs and HIS subsystems, such as pharmacy (Oqua et al., 2013) or pathology and laboratory medicine systems (Horton et al., 2018; Sayed et al., 2018; Wilson et al., 2018). For example, one of the publications described a study on EMR use by mobile medical service trips in remote settings (Dainton & Chu, 2017), while another described the development, implementation, and use of iSante, Haiti's national HIV care and treatment EMR system (Matheson et al., 2012). Another study focused on the development and deployment of Open Medical Record System (OpenMRS) in the context of Ebola and highlighted the challenges of developing an entire system during an emergency rather than being able to rapidly adapt an existing one (Oza et al., 2017).

2.3.4.3 Strategies for EHR implementation

Most of the LMIC countries have either HIS or ehealth policies but only few of them have developed an EHR-related guidance document. For example, Kenya has developed national guidance documents for EMR (Ministry of Health Kenya, 2014b), pharmacy (Ministry of Medical Services, 2014), and laboratory information systems (Ministry of Health Kenya, 2014a) while India has published a revised national EHR standards document in 2016 that emphasizes use of international standards such as International Classification of Diseases (ICD) (Ministry of Health & Family Welfare, 2016a). Tanzania has published guidance for development of integrated electronic facility management systems (The United Republic of Tanzania Ministry of Health and Social Welfare, 2016). These policy and guidance documents showed that each country had approached EHR development from their country perspective and are at the different stages of national EHR development. Each of these countries were using instances of OpenMRS as well as proprietary EHRs but none of these countries had developed national EHRs. With the growing emphasis on achieving UHC and the push to adopt digital health technologies, the LMICs were making efforts to develop digital health policies as evidenced by the Digital Regional East African Community Health (Digital REACH) initiative in Africa, the draft EMR implementation guidance for the Americas, and the NDHB published by Government of India (Ministry of Health and Family Welfare, 2019).

The slow uptake of EHRs is intriguing given that the WHO–Western Pacific Region published “Electronic Health Records: Manual for Developing Countries” in 2006 (WHO, 2006a). This manual provides basic definitions of EHR, EMR, and other related terms; offers guidance for developing an EHR implementation plan; describes issues and challenges associated with implementation; explains planning for EHR introduction via policies and strategies; outlines factors for consideration in the implementation plan; and treats implementation of EHRs. The manual calls for strategies to include the identification of critical factors for success, which could include patient identification, data exchange standards, education, and trainings, storing EHRs, risk management, quality assurance, and personal health records, among others. These success factors focus on functions and features of EHR, workforce training, system quality, and integrity. The manual offers guidance and information relevant to strengthening EHR implementation while assuming prior integration in the country’s healthcare system.

2.3.4.4 *Scope and focus of national EHR guidance*

Even though countries are using EHRs or other sub-systems, at least in the HIV domain, the country-focused gray literature analysis found only three countries – India (Ministry of Health & Family Welfare, 2016a), Kenya (Ministry of Health Kenya, 2014b)(Ministry of Health Kenya, 2014b)(Ministry of Health Kenya, 2014b)(Ministry of Health Kenya, 2014b)(Ministry of Health Kenya, 2014b)(Ministry of Health Kenya, 2014b)(Ministry of Health Kenya, 2014b)(Ministry of Health Kenya, 2014b)(Ministry of Health Kenya, 2014b)(Ministry of Health Kenya, 2014b)(Ministry of Health Kenya, 2014b)(Ministry of Health Kenya, 2014b)(Ministry of Health Kenya, 2014b)(Ministry of Health Kenya, 2014b)(Ministry of Health Kenya, 2014b)(Ministry of Health Kenya, 2014b)(Ministry of Health Kenya, 2014b), and Tanzania (The United Republic of Tanzania, Ministry of Health and Social Welfare, 2016) that had published standards guideline for EHRs. It is important to note that almost all the countries that had HIS or ehealth policy/strategy had a reference to patient level HIS and clearly described the importance of collecting, sharing, and using patient level data for achieving improved health outcomes. Since the global and national focus had been primarily on population health issues (emanating from the MDGs and now, SDGs of the United Nations) and regional and global health reporting, the LMICs prioritized development of national HIS for collecting, sharing, and using aggregated health services data even though most of these data were aggregated from patient-level data captured in paper-registers at the point-of-care. The LMICs have made significant progress in the development of national HIS though these countries have multiple HIS linked with vertical disease programs such as HIV, TB, and malaria. These fragmented and siloed approaches have led to duplication of financial, technological, and human resources and fragmentation of individual health care data. Development of EHR has the potential to enable HDX among diverse systems and address data quality issues associated with aggregated health care data. Further, it can reduce duplication of data collection and maximize use of limited resources through creation of shared technology infrastructure and delivery of integrated health care services through the life cycle.

2.4 Strengths and Limitations

The primary strengths of this review are the systematic search strategy used, and consultation with global and country level experts to ensure inclusion of relevant peer-reviewed and gray literature in the screening. This comprehensive review examined peer-reviewed publications written in English and indexed in scientific databases and the gray literature published by international organizations such as the WHO and the national governments. However, in general, researchers from LMICs have limited access to high-impact and/or subscription-based journals, and only a few can publish in these journals. In addition, many of the journals published in African countries are not indexed in the scientific databases included in this review; therefore, it is possible that some relevant peer-reviewed papers were not included. Despite efforts to include all published papers in this area, some may have also been missed due to publication after the electronic search was completed. Furthermore, a wide range of terms are used in LMICs to refer to EHR systems but are difficult to capture in an electronic search strategy, as their meanings vary based on the country context.

The country-focused gray literature search was conducted in the digital repositories of the WHO, the USAID-MEASURE Evaluation project, and the South Africa-based non-profit organization HealthEnabled. However, these digital repositories did not include national EHR policy and strategy document and most of the national governments did not have those documents on their public website. To overcome the limitations resulting from unavailability of policy and strategy documents in the public websites, a wide group of national and international level experts from funding organizations, governments, non-profit organizations, and technology vendors were consulted to identify relevant gray literature.

2.5 Conclusions and Future Directions

The literature review findings clearly highlight the lack of evidence for the development of EHRs that enable HDX among organizations at different health systems level for improved service delivery and program management in the context of LMICs. The review findings showed that HIS/EMRs were primarily designed to support monitoring and evaluation of health programs through vertical disease programs. Given that national governments and international donors (e.g., PEPFAR) are now paying attention to EHRs for improving patient care, there is need for further research that explains how a country can develop a national/sub-national EHR to improve efficiency and quality of patient care while supporting the monitoring and evaluation functions of the national health care programs.

The HDX is vital for facilitating population and individual healthcare service delivery, guiding resource allocation and utilization, enabling data sharing and use, and aligning health sector goals and ehealth strategies at national and sub-national levels. There is growing evidence that development of HDX is on the rise, but not in the LMICs (Oderkirk, 2017). The review findings show that most EHR/EMR adoption and implementation is limited to disease programs such as HIV and TB often in a small geographical location of a country. As a country matures the way in which they develop national/sub-national HDX, a common way to mature could be use and reuse of patient data to improve efficiency and quality of patient care and program effectiveness at national and sub-national levels. This maturity will depend on how EHRs and HDX are understood, designed, governed, and scaled. The pathway to maturity would demand in-depth research that offers an HDX model that enables patient care, population health, and program management.

CHAPTER 3: METHODOLOGY

Introduction

This chapter describes the research design and methods used to answer the research questions posed for this study. The study aims and their related research questions are discussed. Study procedures including details on the population, sample, recruitment, and study variables are included. To conclude, the data collection and analysis plans are presented.

3.1 Research Questions

The studied posed three aims and six research questions as mentioned below:

AIM 1: To identify factors that favor or hamper development of national and sub-national EHRs to enable HDX for improved maternal health service delivery (antenatal care, childbirth, and post-natal care) and program management.

R1: What are the perceived drivers of and barriers to the design, implementation, and maintenance of EHRs required for improved maternal health service delivery and program management?

AIM 2: To document and describe stakeholder, health information needs, health data systems, and workflows associated with maternal health service delivery and program management.

R2: Who are the stakeholders engaged in development of EHRs, maternal health service delivery, and program management?

R3: What are the stakeholders' health information needs?

R4: What health data systems and processes are used to collect and use data for decision-making?

AIM 3: To propose a HDX model for improved maternal health service delivery and program management at hospital, state, and national levels.

R5: What are the essential design and development requirements?

R6: How will the model enable HDX to support use and reuse of data for improved maternal health service delivery and program management at hospital, state, and national levels?

3.2 Overview of Research Design

A qualitative study design was used for this study. The study was conducted in two phases. Phase I included the development and execution of a key informant interview (KII) guide - both in English and Hindi language -

to identify factors that favor or hamper development of national and sub-national EHRs to enable HDX for improved maternal health service delivery (antenatal care, childbirth, and post-natal care) and program management, and, also, to document and describe stakeholders, stakeholder's health information needs, health data systems, and workflows associated with maternal health service delivery and program management decision-making. Phase I also included gathering essential design and development requirements for HDX through the KIIs and review of documents and artifacts. Following an iterative design process, draft process flow and HDX artifacts were discussed with the hospital administrators, state, and national health officials. The purpose was to validate initial findings and gather additional feedback before conducting a structured review of the HDX model in phase 2. Phase 2 was focused on seeking user feedback on the proposed HDX model that allowed interorganizational data exchange among organizations at national, state, and hospital levels.

The Institutional Review Board (IRB) of the University of North Carolina at Chapel Hill provided the study (IRB number: 19-3200) a notification of exemption from further review. Interview participants provided telephonic consent prior to the interviews since virtual phone interviews were substituted for in-person interviews due to the Corona virus disease (COVID) pandemic. Prior to the interviews, participants received information about the study via email or phone. Also, detailed information about the study was provided in the interview guide which was shared with the participants via email for those who asked for it. The interview guide was also shared with the Director of Medical Education, Government of Uttarakhand, India while seeking permission to conduct KIIs with study participants in a tertiary care state government hospital (TSGH). Participants completed the interviews by reviewing the interview guide and/or listening and responding to the study information over phone.

3.2.1 Study Design

A qualitative single case study design was used given that the study aimed to identify factors that favor or hamper development of national and sub-national EHRs to enable HDX for improved maternal health service delivery (antenatal care, child birth, and post-natal care) and program management at different health system levels, to document and describe stakeholder, stakeholder's health information needs, health data systems, and workflows, and to propose a HDX model for improved maternal health service delivery and program management at hospital, state, and national levels. Quantitative study designs are best suited for questions related to how much or how many and generation of parameter estimates whereas qualitative designs are indicated when the questions of interest relate to how or why something happens, and parameter estimation is not a primary goal (Creswell, 2013; Creswell & Poth, 2018).

Since this is first of its kind study, the focus was on describing and understanding the hospital context and how state and national public health, IT, and medical education organizations affected delivery and management of maternal health. The study aimed to examine and document data systems and processes within and outside the hospital and the focus was not to explore an individual event or cultural phenomenon or to develop a theory (Khan, 2014; Laws et al., 2006), the case study design was applied (Creswell, 2013; Creswell & Poth, 2018; Mfinanga et al., 2019). A single case study was adequate to collect data required to answer the research question and was feasible within the available time and funding constraints.

A detailed account of the TSGH setting, state, and national healthcare organizations, in terms of processes, people, technology, and organizational factors, as discussed in the theoretical framework, sub-section of Chapter 1, required using a qualitative study design.

3.2.2 Study Site

A TSGH in Uttarakhand, India was selected as the study site. The TSGH is one of the four tertiary care hospitals associated with a medical college in Uttarakhand. A state government hospital was selected as it is the foundational component of the expected HDX exchange envisioned at the national level in India.

The government of India had published its digital heath vision that focuses on developing HDX among local, state, and national level organizations. The study aim was aligned with the digital health vision of India and offered an opportunity to conduct research that had immediate and practical value. The national and state level health leadership (in Uttarakhand state) had offered its support for this study. Since the focus was on public health setting, the state government support for the study was critical. In hindsight, government support proved crucial for completing the data collection despite the COVID-19 pandemic. Government support allowed access to relevant documents and identification of key informants for the purpose of data collection. In hindsight, government support proved crucial for completing the data collection despite the COVID-19 pandemic.

The government support and virtual data collection techniques made it possible to overcome funding and logistical challenges. Prior to the actual KII sessions, participants received a phone call or an email to inform about the study. Participants were informed that the interview session was confidential and that anything shared in the interview would not be used outside the research study.

An overview of the healthcare system of Uttarakhand state is described in subsection 3.3 of this chapter to explain key characteristics of the study context and develop a better understanding of the research aims.

3.2.3 Data Collection

Information about health care infrastructure, services, and programs was collected from national and state program and policy documents, data collection and reporting forms and registers available on the ministry of health and family welfare (MOHFW), the ministry of electronics and information technology (MEIT), the national health agency (NHA), and state government websites, and the hospital departments.

The KII approach was used. KIIs are in-depth qualitative interviews with people who have first-hand knowledge, understanding, and are willing to share about what is happening in their setting, why, and how it can be improved. KIIs are appropriate for collecting detailed information from key informants with diverse backgrounds and opinions and they allow asking in-depth and probing questions (Creswell & Poth, 2018). Furthermore, it created a favorable environment for open conversation on sensitive topics in a one-on-one conversation setting.

KIIs were conducted to learn more about the perception, attitude, and opinion of study participants about the drivers and barriers to EHR development to enable HDX, and to document and describe stakeholders, stakeholder's health information needs, health data systems and workflows associated with maternal health service delivery and program management. In addition, KII was conducted to inform the development of HDX model envisioned in this study. See Appendix A (English) and B (Hindi) for the KII guide (including the consent form). The KII guide was developed based on the theoretical frameworks discussed in chapter 1.

Key informant selection was guided by the research questions to ensure detailed but relevant data collection. Key informants who were associated with the TSGH, government health program at the national and state levels (focusing on maternal health, EHR, and HIT), and private hospitals and clinics in a city of Uttarakhand either as an employee or as a beneficiary were eligible to participate. These key informants have roles related to clinical (obstetrics and gynecology, pediatrics), hospital administration (superintendent), maternal health policy and program, EHR standards, hospital information management system (HIMS), national health insurance, *Janani Suraksha Yojana* (JSY), and private insurance domains. Key informants were purposively selected for interviews based on their expertise, experience, and willingness to share their insights and opinions for the purpose of this study. The selection process included creating a list of national, state and hospital level stakeholders after reviewing the organizational hierarchy documents and consultation with EHR and health systems experts at the national, state, and hospital levels. These experts were not included in the study sample.

3.2.3.1 *Virtual Data Collection*

The KII sessions conducted between April-July 2020 using the (Microsoft) Skype application to call key informants over the telephone. Email, Skype calls, (Facebook) WhatsApp (messaging application), and introduction by professional colleagues to establish contact with key informants and schedule KII sessions. The Voice memos application in iPhone 6 plus was used to record the KII sessions. Audio quality was impacted by background noises on both sides though it did not affect audibility of the conversation and, hence, manual transcription and translation. The recorded sessions were stored in a secure folder accessible only through the University of North Carolina Virtual Private Network.

3.2.3.2 Virtual Data Collection – Strength and Limitations

Virtual data collection methods such as phone interviewing are commonly used in quantitative research. These methods pose unique challenges in qualitative research such as inability to observe events and participants in real-life settings (Namey et al., 2020).

An important question is related to the similarity between the data collected remotely with that collected in-person especially when qualitative research is influenced by the relationship between researcher and participants. A Patient-Centered Outcomes Research Institute funded a quasi-experimental study aimed to learn about how the mode of qualitative data collection might affect the data researchers obtain (Namey et al., 2020). The study included a total of 171 women participants in North Carolina who were in between pregnancies to understand how women perceive medical and vaccine-related risks during pregnancy, with particular attention to the Zika virus outbreak. The participants were involved in 48 individual interviews and 24 focus groups divided across four modes (in-person, online video, online chat-based and online email, or message board) of data collection. The findings showed that wherever Internet and technology infrastructure made it possible to collect data online the mode of qualitative data collection does not seem to have a great effect on the content of the findings generated.

Another challenge is associated with the lack of observing the research participants in real-life. Personal prior health sector experience and a visit to the study site in June 2019 provided necessary information about the clinical setting of a state government hospital. Further, the virtual data collection, primarily phone interviewing, allowed the study to extend the sample to geographically dispersed or mobility-limited participants during the COVID-19 pandemic with cost efficiencies resulting from obviating the need for physical travel. Also, phone interviewing offered the convenience of at-home participation in addition to removing visual social cues that might have influenced how a participant responded.

3.2.4 Sample Size

Based on an experimental study researchers (Guest et al., 2006) suggested that twelve interviews should suffice if the research aim were to understand common perceptions and experiences among participants working in a similar setting. The study also suggested to carefully conduct purposive sampling, and consider group heterogeneity, data quality, and whether the study aim was to assess variation between distinct groups or correlation among variables before deciding the sample size. The experience of most qualitative researchers conducting an interview-based study with a fairly specific research question is that little new information is generated after interviewing 20 people or so (Green and Thorogoood, 2004). Further, recent research demonstrates the greater efficiency of purposive sampling compared to random sampling in qualitative studies (van Rijnsoever, 2017). Since purposive sampling focuses on identifying ‘information-rich’ key informants a total of 20 participants were purposively selected for KIIs (Palinkas et al., 2015). Even though the study did not aim to study patient perspective or satisfaction about the service delivery, a patient was selected as a key informant. The purpose of selecting a patient was to confirm, reject, or modify information collected from other key informants about the data workflow, processes, collection, use, and sharing of patient data within the hospital setting.

3.2.5 Key Informant Interview Guide

The KII guide was developed in English and Hindi languages to collect qualitative data. The English language KII guide was pretested with a sample of three participants. The three participants were purposively selected based on their experience as a provider (clinical and research), qualitative researcher, and a patient. The pretesting aimed to assess comprehensiveness, use of relevant and appropriate questions, and terms in the KII guide. The revised English KII guide was translated to Hindi by a native speaker and pretested with the same sample of participants who were involved in pretesting the English language KII guide. The shortest KII was 30 minutes while the longest KII was 140 minutes.

The research questions and corresponding KII questions are listed in Table 6. Individual interview transcripts were cleaned, coded, analyzed, and the key findings are presented and discussed in later chapters of this dissertation.

Table 6. Research questions and corresponding key informant interview questions

Research Questions	Key-Informant Interview Questions
R1: What are the perceived drivers of and barriers to the design, implementation, and maintenance of EHRs required for improved maternal health service delivery and program management?	Q6-8, Q11-12, Q15
R2: Who are the stakeholders engaged in development of EHRs, maternal health service delivery, and program management?	Q7-8, Q11-12
R3: What are the stakeholders' health information needs?	Q1-5
R4: What health data systems and processes are used to collect and use data for decision-making?	Q1-5, Q6
R5: What are the essential design and development requirements?	Q10,14
R6: How will the model enable HDX to support use and reuse of data for improved maternal health service delivery and program management at hospital, state, and national levels?	Q13,Q15-17

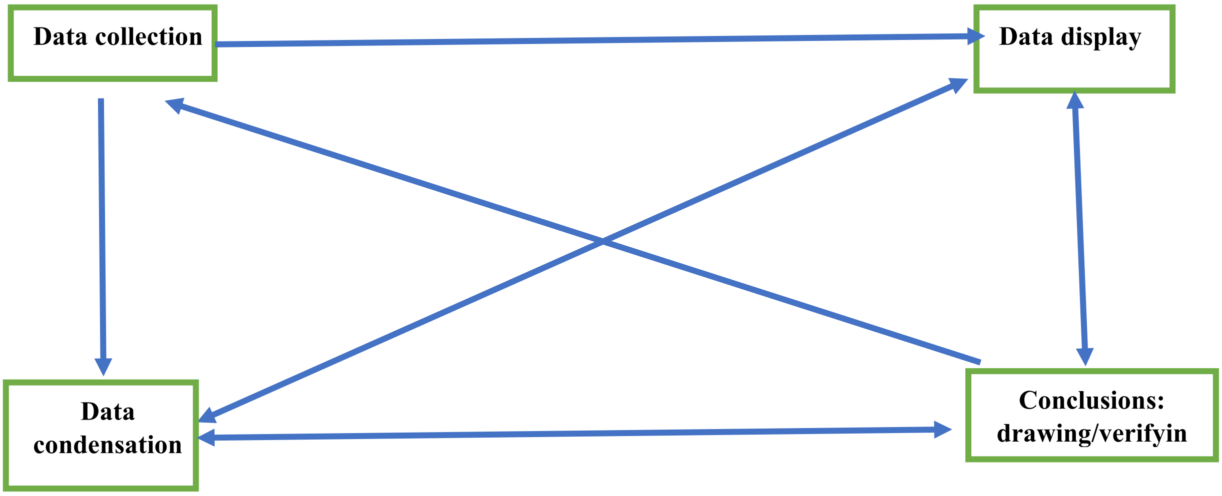
3.2.6 Measures

The KII guide included questions related to role and responsibilities of respondents, barriers, and drivers of EHR enabling HDX, stakeholder and their health information needs, health data systems, workflow, implementation, and sustainability challenges.

3.2.7 Qualitative Data Analysis

The interactive data analysis model of Miles and Huberman (1994) was adapted (Figure 4) to guide the qualitative data analysis ((Miles & Huberman, 1994). The model describes analysis as three concurrent flows of activity: data condensation, data display, and conclusion drawing/verification. The three concurrent activities underline the fact that qualitative data analysis is a continuous, iterative process. Data condensation happens throughout the research as decisions were made to select, process, and focus on specific text in the interview transcripts or program documents. Data display such as matrices, extended text, and tables were used. Throughout the data collection, data condensation, and data display activities the researcher draws conclusions which are updated/verified iteratively before finalization.

Figure 4. Components of data analysis: Interactive model



Source: Miles, M. B., & Huberman, A.M (1994). Qualitative data analysis: An expanded sourcebook (2nd ed.). Thousand Oaks, CA: Sage Publications.

The audio files (.m4a) for KII conducted in English were uploaded to otter.ai for transcription. Otter.ai, a web-based application, offers free transcription for audio files with 40 minutes of recording. However, transcription had major data quality issues due to participants English language accent. The transcription included words that participants did not use. Therefore, Microsoft Dictate, an Office add-in for Microsoft Word, speech to text conversion application was used to create the transcript from the English language audio files. For the KII sessions recorded in Hindi language, a professional translator was engaged to develop English transcripts. Each raw recording was reviewed at least twice to comprehend the conversation and identify any data quality errors associated with spellings or out-of-context translation (e.g., one of the participants mentioned use of computers for creating a staff roster which was translated as use of electronic system for staff management) or transcription. The time gap between KII session recording and final transcription was not more than 72 hours to prevent loss of contextual information from the KII sessions. All the personal or institutional identifiable information, if present, was removed from the interview transcript and the artifacts prior to analysis and inclusion in the results chapter or appendices.

The qualitative data analysis used a combination of deductive and inductive analysis though general inductive analysis was predominant. The deductive analysis was guided by key themes identified from the research questions. These included stakeholders, barriers to EHR development, health information needs, data systems, data use, and level of decision-making and HDX. Two researchers independently reviewed and coded all the 20 interview transcripts in addition to identifying appropriate themes and were not limited by the predefined themes. The first researcher was the investigator and the second researcher had experience and expertise in conducting qualitative research in the state of Uttarakhand.

A general inductive analysis was conducted since the overarching purpose of data analysis was to synthesize large and varied raw text data into a summary format, establish clear links between the research objectives and the summary findings derived from the raw data and to ensure that these links were both transparent and justifiable based on the research objectives, and to develop framework showing the underlying structure of experiences or processes that are evident in the text data (Thomas, 2006). The general inductive analysis was considered appropriate as this study did not aim to test any hypothesis.

The two researchers began with close readings of text and consideration of the multiple meanings that were inherent in the text. Each researcher read the text at least twice. The researchers identified text segments that contained meaningful units and created a code for a new category to which the text segment was assigned. Text segments were added to the relevant categories. The investigator created a hierarchy of categories to show the relationships. The two researchers held three virtual consultation to discuss and develop common understandings of initial codes and themes. Through these consultations the two researchers finalized all the codes and themes. Though the process of coding all the 20 interview transcripts by two independent researchers was time consuming, it allowed for reduction of bias and prevented decontextualization of qualitative data.

The final transcripts were imported into NVivo 12 software for conducting qualitative content analysis. "Qualitative content analysis is a dynamic form of analysis of verbal and visual data that is oriented toward summarizing the informational contents of that data" (Sandelowski, 2000). Thematic analysis was conducted on responses to questions about perceptions and opinions. For example, a key informant may have expressed concern about commenting on the effectiveness of decisions by higher authorities in his/her organization. In addition, thematic analysis, a method for identifying, analyzing, and reporting patterns (themes) within data (Braun & Clarke, 2006), was conducted on responses to the six research questions. The data were categorized by reading through each response and coding the emerging themes. Responses were assigned to multiple themes as applicable. Any personal identifiable information in the artifacts collected for this study was removed, edited, or hidden before inclusion in this dissertation.

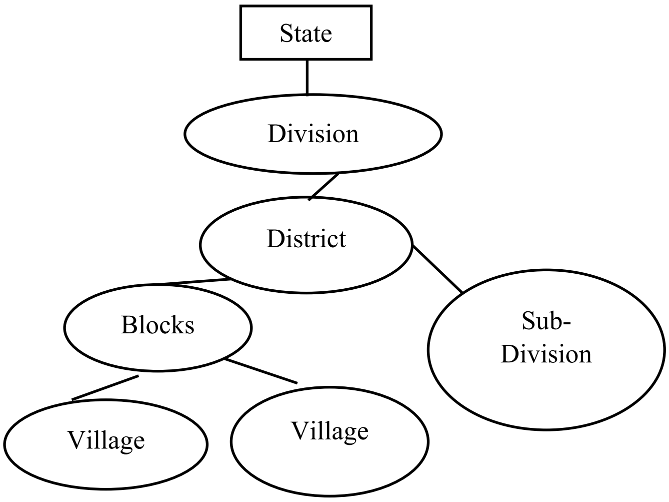
3.3 Health System of Uttarakhand-A Brief Overview

In order to understand the health system of Uttarakhand and contextualize the research study findings a brief overview of the Uttarakhand health systems is described in this section. The health system in Uttarakhand is complex in terms of multiple government departments responsible for planning, management, and implementation of clinical and public health programs besides the medical education. This section provides a brief description of public administration structure, demographic and health profile, public health agencies in relation to national programs, heath budget and expenditure, public health infrastructure and workforce, and HIS. The HIS subsection includes national HIS and digital health initiatives being implemented in the state.

3.3.1 Public Administration Structure

The public administration structure of the state is divided into two divisions, *Garhwal and Kumaon,* with seven and six districts, respectively. The 13 districts are constituted of 49 sub-divisions, 95 development blocks, 16,793 census villages out of which 15,745 villages (including forest settlements) are inhabited, and the remaining 1048 are un-inhabited. Uttarakhand is primarily a mountainous state, as the plains constitute only about 10 per cent of its total geographical area. Out of thirteen districts, only Haridwar, Udham Singh Nagar, and some parts of Dehradun and Nainital districts are located in the plains (Planning, 2018). Figure 5 shows the administrative structure and connection among different levels. This administrative structure is responsible for delivery, monitoring, and review of public services including healthcare.

Figure 5. Administrate structure of Uttarakhand



3.3.2 Demographic and Health Profile

The population of Uttarakhand is 10.08 million, out of which 70.37 percent reside in rural areas and 30.50 in urban areas (Office of the Registrar General & Census Commissioner, 2011). The state population constitutes less than 1 percent of the total population of India (1210.1 million). The state has high decadal population growth (18.81%), but lower total fertility rate (1.8) as compared to that of the national average (Table 7). The current (2012-13) MMR in Uttarakhand is 99 per 100,000 live births compared to 113 at the national level (Office of the Registrar General, 2020). In 2018, IMR (33.6) was slightly higher than the national average (32).

Table 7. Demographic and health profile of Uttarakhand and India

#	Indicator	Uttarakhand	India
1	Total population (million) (Office of the Registrar General & Census Commissioner, 2011)	10.8	1210.1
2	Decadal Growth (%) (Office of the Registrar General & Census Commissioner, 2011)	18.81	17.64
3	Infant Mortality Rate (Office Of The Registrar General and Census Comissioner, 2018)	33.6	32
4	Maternal Mortality Ratio (Office of the Registrar General, 2020)	99	113
5	Total Fertility Rate (Office Of The Registrar General and Census Comissioner, 2018)	1.8	2.2
6	Literacy (%) (Office of the Registrar General & Census Commissioner, 2011)	79.63	74.05

Table 8 shows the six most populous cities in the state of Uttarakhand. The TSGH is located in one of the most populous cities of Uttarakhand and also caters to the health care needs of the people in the neighboring state of Uttar Pradesh.

Table 8. Uttarakhand metropolitan/city population

#	City	Population	Male	Female
1	Dehradun	569,578	298,638	270,940
2	Haridwar	228,832	122,007	106,825
3	Haldwani and Kathgodam	156,078	81,955	74,123
4	Rudrapur	140,857	74,040	66,817
5	Kashipur	121,623	63,609	58,014
6	Roorkee	118,200	63,434	54,766
7	Total	1,335,168	703,683	631,485

Source: Office of the Registrar General and Census Commissioner, 2011

In Table 9, some of the key maternal health indicators are presented. According to the National Family Health Survey (2015-16) (International Institute for Population Sciences (IIPS) and ICF, 2017), the percentage of pregnant women who had at least four antenatal visits been only 30.9 % with 25.7% and 41.2% in rural and urban areas, respectively. Institutional delivery was 68.6% with 63.7% and 79.1% in rural and urban areas, respectively. The percentage of pregnant women who receive full antenatal care was very low (11.5%) . The percentage of women who received postnatal care from a trained health personnel was 54.8 %. The percentage of women in urban areas used postnatal care services from a trained health personnel relatively more (69.1%) as compared to the women in rural areas (49.1%). Only 49.4 % of mothers received financial assistance under the JSY, a Safe Motherhood Program promoting institutional delivery, with 54.2% and 41.4 % mothers in urban and rural areas, respectively. Despite the JSY, an average of $35 out of pocket expenditure per delivery was a fact even at public facilities [2].

Table 9. Maternal health indicators

Maternal Health Indicators			Rural	Urban	Total
1	Antenatal care coverage (at least four visits) (%)				
	1.1	Mothers who had at least four antenatal care visits (%) (Total)	25.7	41.2	30.9
	1.2	Mothers who had full[a] antenatal care (%)	9.4	15.6	11.5
2	Institutional delivery (%)				
	2.1	Institutional delivery (%) (Total)	63.7	79.1	68.6
3	Mothers who received financial assistance under JSY for births delivered in an institution (%)		41.4	54.2	49.4
4	Average out of pocket expenditure per delivery in public health facility		$35	$35	$35
5	Postnatal Care for mothers (%)				
	5.1	Mothers who received postnatal care from a doctor/nurse/ Lady Health Visitor/Auxiliary Nurse Mid-wife/midwife/other health personnel within two days of delivery (%)	49.1	66.1	54.8

[a] Full antenatal care is at least four antenatal visits, at least one tetanus toxoid injection and iron folic acid tablets or syrup taken for 100 or more days.
Source: Adapted from National Family Health Survey 2015-16, Uttarakhand Fact Sheet, Government of Uttarakhand, India

3.3.3 Public Health Agencies

The key public health agencies in the state falls under the jurisdiction of the state department of medical health and family welfare (DMHFW). The DMHFW is the nodal department for the design, implementation, monitoring, and management of state and nationally mandated health care programs. The DMHFW Department of medical health and family welfare is responsible for establishment, operation, management, and maintenance of public health system at all the levels of the state health care system right from the village up to the state.

Within the DMHFW, the primary responsibility for implementation of the National Health Mission (NHM) is with the Uttarakhand Health and Family Welfare Society. The society is an autonomous organization that was created under the NHM to lead the implementation, operation, and management of the NHM programs. The state program management unit of the society is responsible for collection and reporting of program data to the state and national level health information systems such as Uttarakhand *eAushadi*, *eParchi, eAttendance*, and national level systems such as the health management information system (HMIS) and the mother and child tracking system (MCTS) which is now being changed to the reproductive and child health portal of the MOHFW, Government of India.

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[2] Indian Rupee converted into dollars. 1 USD=75 Rupee.

The state health agency (SHA) is the state level organization implementing the *Pradhan Mantri Jan Arogya Yojana* (PMJAY), a national health assurance program for the economically weaker sections of the population. The medical education in the state is led and managed by the ministry of medical education. This ministry is responsible for the establishment, operation, and management of medical education and research institutions such as the medical and nursing colleges in the state including the hospitals associated with the medical colleges. Even though the tertiary care government hospital is associated with the ministry of medical education in the state, it is required to implement maternal and child health programs under the state health mission and also implement the PMJAY. The TSGH is also required to implement public welfare programs in the hospital such as low-cost prescription drugs for patients, low-cost food for patients and their attendants, and free diagnosis and treatment for the below poverty line population.

3.3.4 Health Budget and Expenditure

The NHA, an autonomous national organization, leads the implementation of the PMJAY. The SHA has support structures at the state and district levels for the successful implementation of the health insurance program. Appendix C provides an overview of the PMJAY and Appendix D shows the profile of Uttarakhand under the PMJAY. The state added an additional 10,45,932 families under the PMJAY as they were not covered as per the national criteria. The program is called *Atal Ayushman Uttarakhand* and covers the entire state population. There are 872 health benefit packages offering different health care services of which 13 are applicable only in the public hospital. The state government expenditure budget (2020-21) for medical and health welfare ministry is about $ 330,269,867 (Government of Uttarakhand, 2020). Further, the NHM has approved an annual budget of $ 3,907,600 (approximately) for HMIS, MCTS, and $2,003,87 for other information technology initiatives for strengthening healthcare service delivery in the state (Department of Medical Health and Family Welfare, 2020). The NHM budget is approved each year based on the state's program implementation plan.

According to the recent National Sample Survey 75th round (Ministry of Statistics and Program Implementation, 2019) the percentages of pregnant women receiving pre-natal care and percentages of pregnant women receiving post-natal care in India was 97% and 88% respectively. Further, the percentage of childbirths (including normal, caesarean, and other type of delivery) in public and private hospitals was 69.2% and 21.3% in rural areas whereas it was 48.3% and 47.8% in urban areas. Furthermore, the average expenditure on childbirth in public and private hospitals was approximately $ 32 and $277 in rural areas whereas it was $41 and $388 in urban areas. In the rural areas, the average expenditure was almost nine times higher in private hospitals as compared to the public hospitals where it was almost ten times higher in urban areas. Public hospitals continue to carry the burden of institutional delivery at a lower cost.

3.3.5 Public Health Infrastructure

Under the national heath mission, Uttarakhand has expanded its health infrastructure that has resulted in increased access to health care services and hence improved population health. However, given the population size, socio-economic inequality, and geographical spread, availability of functional public health infrastructure (Table 10) in many parts of the state is still a challenge. Health subcenters (HSC) are the first stop in the public health system, followed by primary health center (PHC), community health center (CHC), and district hospitals. The state also has health facilities offering services under the indigenous alternative medicine systems in India such as Ayurveda, Unani, and Homeopathy. Blood banks and T.B. clinics are also part of the health infrastructure.

Table 10. Uttarakhand state health infrastructure

#	Health Facility	Number of Institutions
1	District Hospitals	12
2	Female Hospitals	6
3	Base Hospitals	3
4	Combined Hospitals	15
5	CHC (including Identified First Referral Units)	86
6	PHC	259
7	HSC	1847
8	State Allopathic Dispensaries	317
9	Ayurvedic Hospitals & Dispensaries	543
10	Homeopathic Dispensaries	107
11	Unani Hospitals	3
12	Blood Banks	23
13	T.B. Clinic	13

Source: http://health.uk.gov.in/pages/display/65-medical-health-institutions

Table 11 shows a significant gap in availability of doctors at PHC and specialists at the CHC against the number of job positions approved (sanctioned). The CHCs, that provide basic and comprehensive emergency obstetric care and serve as a referral hospital has a gap of 91% for the specialist doctors.

Table 11. Current availability of health personnel in Uttarakhand

#	Cadre	Sanctioned	In Position	Vacant	Vacant as a Share of Sanctioned Posts (%)
1	Doctors at PHC	147	65	82	55.78
2	Surgeon at CHC	83	6	77	92.77
3	Obstetrics and Gynecology at CHC	79	7	72	91.00
4	Physician at CHC	79	5	74	93.67
5	Pediatrician at CHC	80	14	66	82.50
6	Total Specialists at CHC	321	32	289	91.00

Source: Department of Planning (2018). Uttarakhand Vision 2030. Government of Uttarakhand, India.

3.3.6 Health Information Systems

A number of national and state funded HIS initiatives are operational in Uttarakhand. The two state-wide HIS initiatives, mandated by the NHM, are the HMIS and the MCTS. Data from all the health facilities in the state are reported into the HMIS and the MCTS system.

3.3.6.1 Healthcare Level and Data Flow

The healthcare level in Uttarakhand is described based on type of healthcare facilities used to access healthcare services. These levels include government or public hospitals, charitable, trust, and non-government organization run hospitals, private hospital, private doctor and clinic, and informal healthcare providers. The government hospitals include health sub-centers which are now being upgraded to health wellness centers to offer additional screening and preventive care services. Also, it includes primary health centers, community health centers, district hospitals, and medical college hospitals. Table 12 describes each of the different health facilities in terms of their roles and responsibilities and also explains antenatal care and postnatal care.

Table 12. Type of healthcare facility

HSC: This is the most peripheral facility in the primary health care system. There is one sub-center for every 3000 population in hilly/tribal/difficult areas and 5000 population in plains. Each Sub-Centre is staffed by one or two Auxiliary Nurse/ Midwives (ANM) (female health worker) and may have a male health worker. Their main task (as perceived) is to provide immunization to children and antenatal care. Some subcenters also conduct normal delivery but they have no beds, and the Sub-Centre is not considered as an institution with in-patients. They perform some outpatient care largely in the form of treatment for basic illnesses. Any treatment taken from ANM during her visit to the village can be considered as treatment taken at sub-center.

Dispensary: This is a public institution from which medical supplies, preparations, and treatments are dispensed, but which does not have facilities for treatment of in-patients. Dispensaries are staffed by one or more doctors.

PHC: It is staffed by a Medical Officer and paramedical staff. They provide curative out-patient services and ante natal checkups and deliveries. They usually have 4-6 beds to conduct delivery. They may or may not have facilities for in-patient treatment. There is one PHC for every 30000 population in the plains and for every 20,000 populations in hilly/tribal/difficult areas.

CHC: CHC is usually located at block/division or taluk level and serves as a referral center for PHCs. It is to be staffed by medical specialists and medical officers and AYUSH doctors – but in practice there are usually only medical officers. It always has provision for in-patients and 10 to 30 beds. It usually has an Operation Theatre, X-Ray, Labor Room, and laboratory facilities.

Public Hospital: All other government hospitals, including district hospitals in the district headquarters town (which acts as referral site for all the CHCs and PHCs and sub-centers), government medical college hospitals, employees' state insurance hospitals, other government hospitals like maternity hospitals, cancer hospitals, TB or leprosy hospitals, railway hospitals, etc. run by the government covered under the category ‘public hospital’ for the purposes of this survey.

Private Hospital, private clinic: Any other hospital/ nursing home/ day care center with facilities for in-patient treatment is called a private hospital. A private clinic is one with facilities for consultation with private doctor(s) but no in-patient facility.

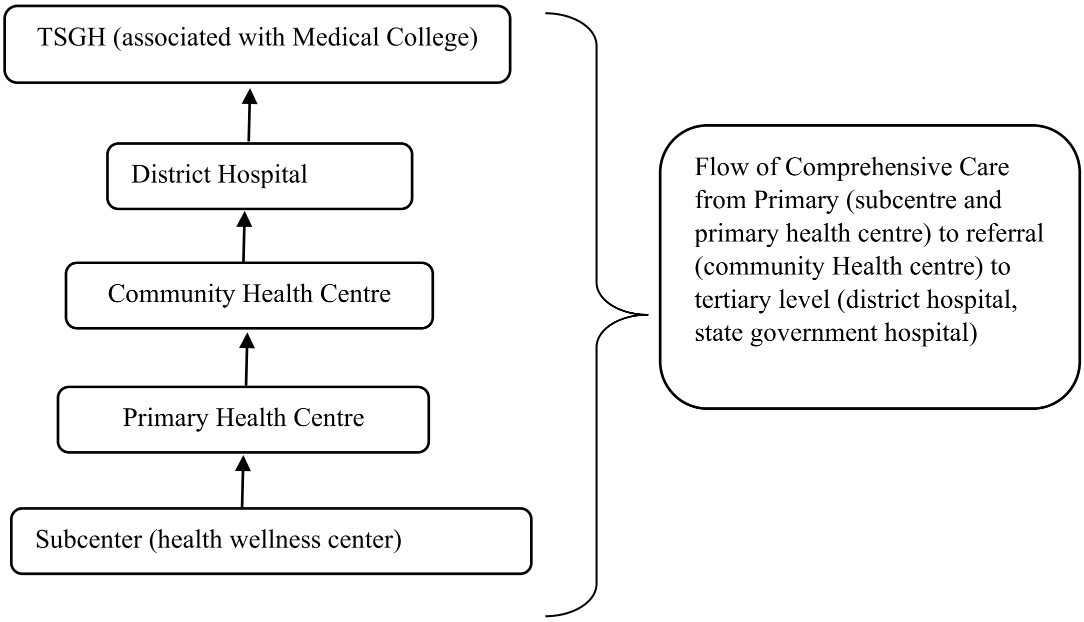
Medical institution: This includes all HSC, PHC, CHC, public dispensaries with facilities for in-patient treatment, any public hospital (district hospital/state general hospitals/ medical college hospitals etc.), and private hospital of any kind (private nursing home, day care center, private medical college and hospital, super specialty hospital, etc.).

Informal healthcare provider: This term covers a variety of health service providers who are untrained and work outside regulatory frameworks.

Source: Adapted from Key indicators of social consumption in India: Health. NSS 75th Round.

The data flow from primary, referral to tertiary level health care unit is shown in Figure 6. The subcenter is located at the village level and is at the frontline of primary care.

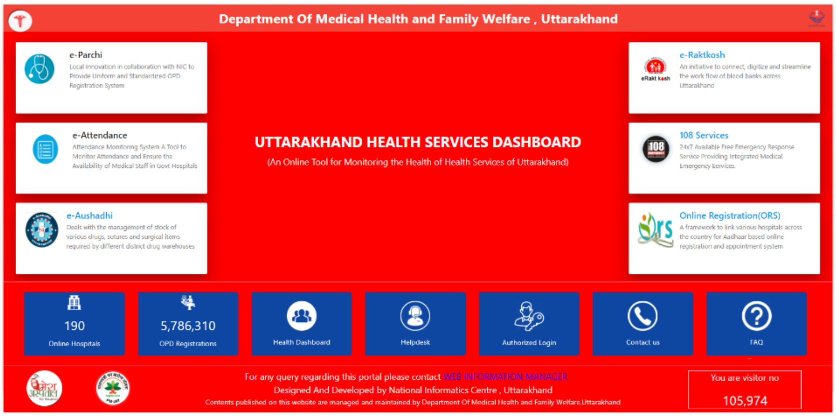
Figure 6. Flow chart of primary to tertiary level healthcare link up- Uttarakhand



3.3.6.2 *Uttarakhand Health Services Dashboard*

The DMHFW has developed a health services dashboard developed by the state national informatics center (NIC). The dashboard (Figure 7) links with electronic slip (*eparchi*), electronic attendance, electronic supply chain (e*Aushadhi*), electronic blood bank (e-*Raktkosh*), and 108 ambulance are briefly described below. Online registration, My Hospital, Electronic Blood Bank, and My Health Record are national initiatives and discussed separately.

Figure 7. Uttarakhand health services dashboard



Department Of Medical Health and Family Welfare , Uttarakhand

e-Parchi
Local Innovation in collaboration with NIC to Provide Uniform and Standardized OPD Registration System

e-Attendance
Attendance Monitoring System A Tool to Monitor Attendance and Ensure the Availability of Medical Staff in Govt Hospitals

e-Aushadhi
Deals with the management of stock of various drugs, sutures and surgical items required by different district drug warehouses

UTTARAKHAND HEALTH SERVICES DASHBOARD
(An Online Tool for Monitoring the Health of Health Services of Uttarakhand)

e-Raktkosh
An initiative to connect, digitize and streamline the work flow of blood banks across Uttarakhand

108 Services
24x7 Available Free Emergency Response Service Providing Integrated Medical Emergency Eervices.

Online Registration(ORS)
A framework to link various hospitals across the country for Aadhaar based online registration and appointment system

190 Online Hospitals

5,786,310 OPD Registrations

For any query regarding this portal please contact WEB INFORMATION MANAGER
Designed And Developed by National Informatics Centre , Uttarakhand
Contents published on this website are managed and maintained by Department Of Medical Health and Family Welfare,Uttarakhand

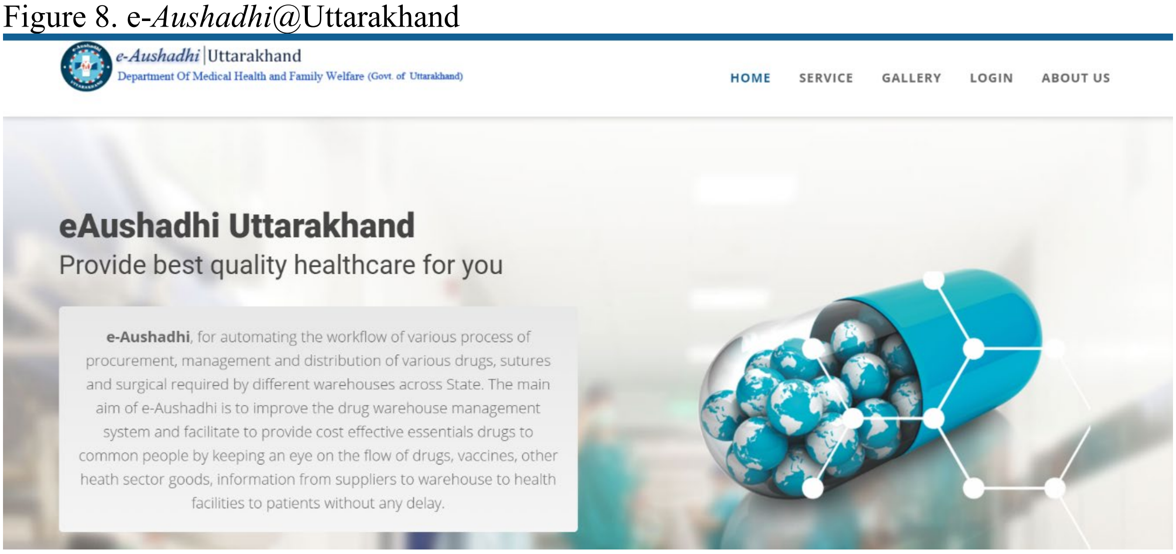
You are visitor no 105,974

Source: http://healthdashboard.uk.gov.in/ (Accessed on October 17, 2020)

e-Parchi was developed by state NIC to provide Uniform and standardized outpatient department registration system. e-Attendance monitoring system was developed to monitor attendance and ensure the availability of medical staff in government hospitals. 108 Ambulance is a 24*7 free emergency medical response mechanism providing integrated emergency medical services in the State.

e-Aushadhi@Uttarakhand is a web-based supply chain management application (Figure 8) developed to manage demand, procurement, inventory and distribution of drugs and surgical items to various district drug warehouses and their sub stores at CHC and PHC level. The software application was developed by the Center for Development of Advanced Computing (C-DAC), an agency of the MEIT, Government of India.

Figure 8. e-*Aushadhi*@Uttarakhand



eAushadhi Uttarakhand

Provide best quality healthcare for you

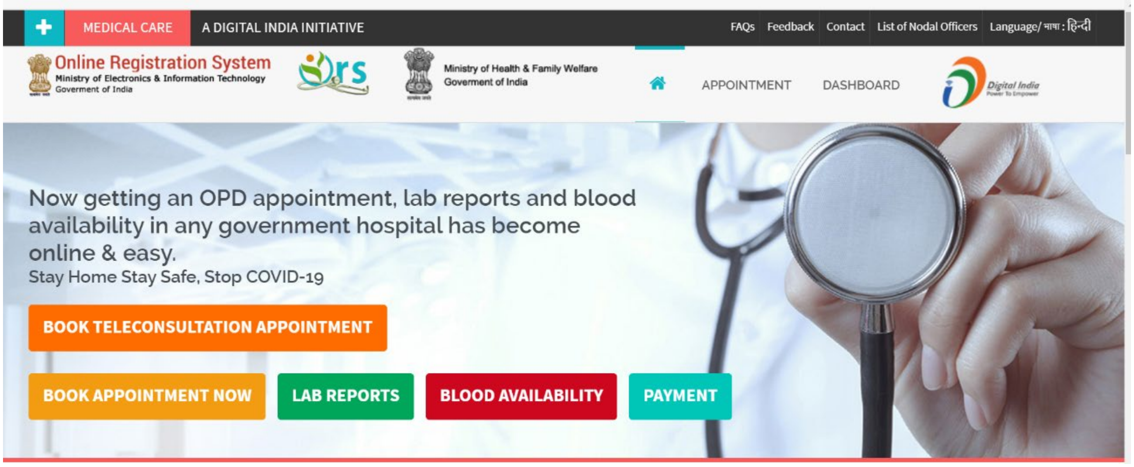
e-Aushadhi, for automating the workflow of various process of procurement, management and distribution of various drugs, sutures and surgical required by different warehouses across State. The main aim of e-Aushadhi is to improve the drug warehouse management system and facilitate to provide cost effective essentials drugs to common people by keeping an eye on the flow of drugs, vaccines, other heath sector goods, information from suppliers to warehouse to health facilities to patients without any delay.

Source: https://eaushadhiuk.dcservices.in/IMCS/hissso/loginLogin.action (Accessed on October 17, 2020)

3.3.6.3 *Online Registration System*

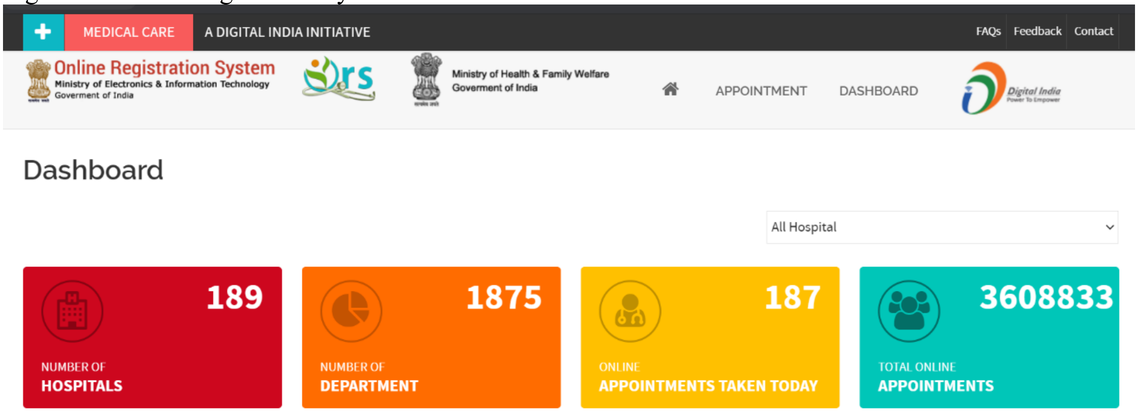
Online registration system (ORS) is a national web-based system (Figure 9) allowing patients to register and schedule appointment online rather than a desk-based out-patient registration and appointment in a hospital (Figure 10) (Ministry of Electronics and Information Technology and Ministry of Health and Family Welfare, 2020). The ORS application uses Aadhar unique identity number (a biometric-based identification system) for registration and appointment. New Patient gets appointment as well as Unique Health Identification (UHID) number. If *Aadhaar* number is already linked with UHID number, then appointment number will be given and UHID will remain same.

Figure 9. Online registration system



Now getting an OPD appointment, lab reports and blood availability in any government hospital has become online & easy.
Stay Home Stay Safe, Stop COVID-19

Figure 10. Online registration system dashboard



189 NUMBER OF HOSPITALS

1875 NUMBER OF DEPARTMENT

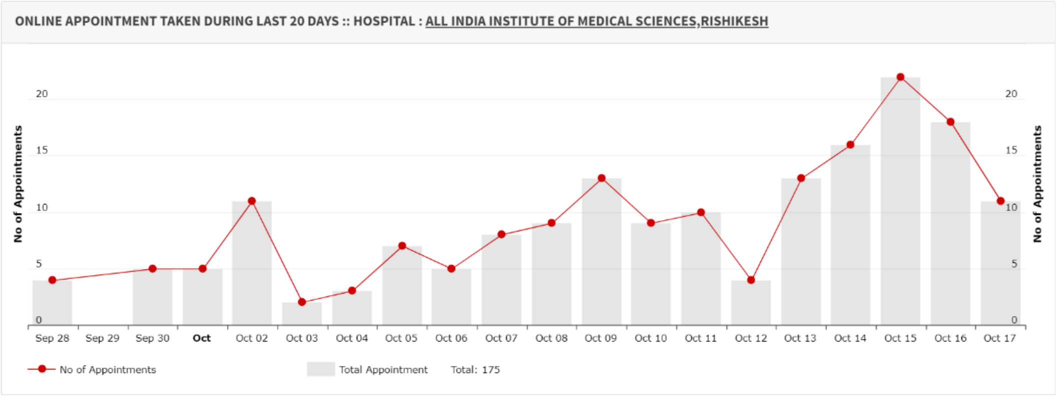
187 ONLINE APPOINTMENTS TAKEN TODAY

3608833 TOTAL ONLINE APPOINTMENTS

Source: http://www.ors.gov.in/ (Accessed on October 17, 2020)

A total of 46 Uttarakhand hospitals are using ORS. For example, the All India Institute of Medical Sciences (AIIMS), Rishikesh, Uttarakhand is reporting data as shown in the Figure 11. It is clear from the figure that there is a wide variation in the number of online appointments which can be due to uneven case load and/or data quality issues.

Figure 11. Online appointment reporting by AIIMS Rishikesh, Uttarakhand, India

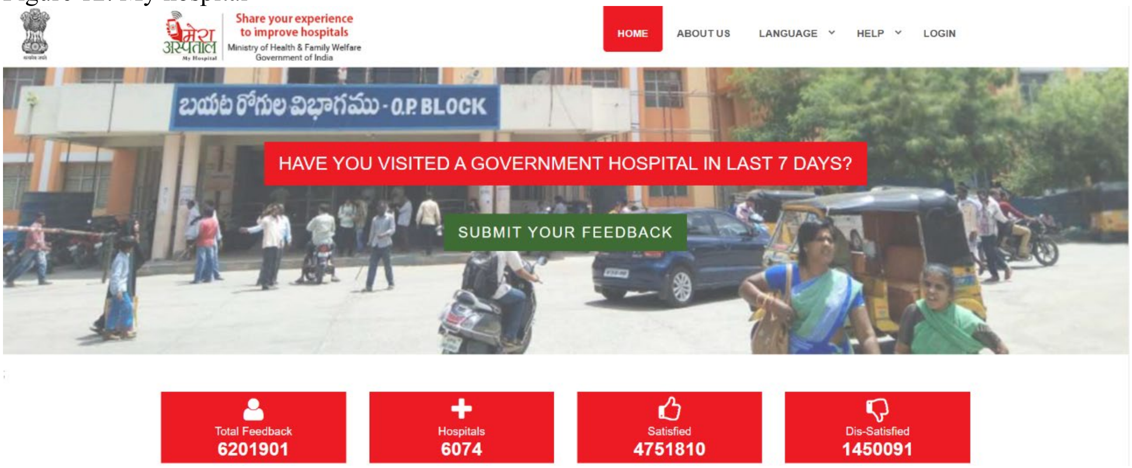


Source: http://www.ors.gov.in/ (Accessed on October 17, 2020)

3.3.6.4 *My Hospital*

My Hospital is a national initiative (Figure 12) to capture patient feedback for the services they receive at various hospitals visited in the last seven days (Ministry of Health and Family Welfare, 2020b)(Ministry of Electronics and Information Technology and Ministry of Health and Family Welfare, 2020). The data is reported from hospitals in the country through multiple channels such as Short Message Service, Outbound Dialing mobile application and web portal. The data is presented through the dashboard for use by different stakeholders at facility, district, state, and national levels. My Hospital initiative is aimed at monitoring and improving quality of healthcare delivery and increase patient engagement.

Figure 12. My hospital



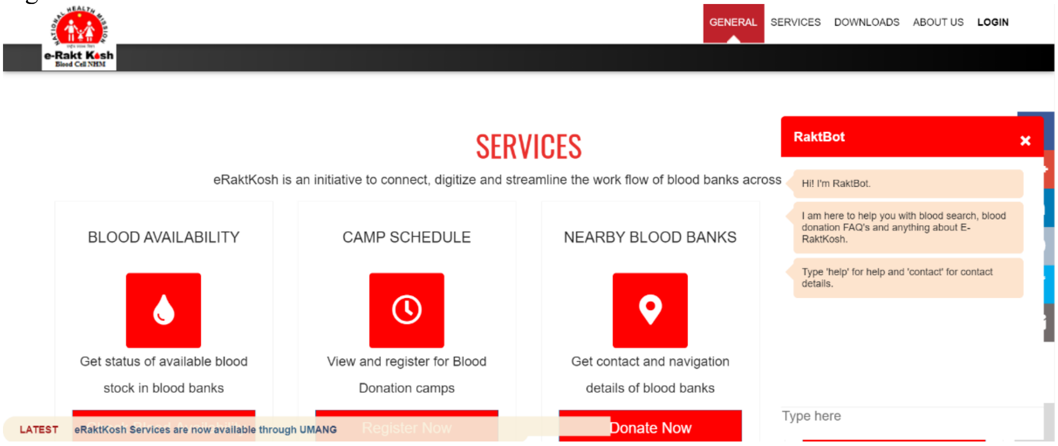
Total Feedback 6201901
Hospitals 6074
Satisfied 4751810
Dis-Satisfied 1450091

Source: https://meraaspataal.nhp.gov.in/ (accessed on October 29, 2020)

3.3.6.5 *Electronic Blood Bank*

Electronic blood bank or *e-Rakt Kosh* is a national and centralized blood bank management system (Figure 13). It is being implemented in Uttarakhand to connect, digitize, and streamline the workflow of blood banks and offers chatbot (called *Rakt*Bot) support as well. The goal is to enforce the Drug and Cosmetic Act, national blood policy standards and guidelines ensuring proper collection and donation, and effective management and monitoring of the quality and quantity of the donated blood. The web-based application was developed using a modular and scalable approach (Ministry of Health and Family Welfare, 2020a).

Figure 13. e-*Rakt Kosh*



SERVICES

eRaktKosh is an initiative to connect, digitize and streamline the work flow of blood banks across

BLOOD AVAILABILITY

Get status of available blood stock in blood banks

CAMP SCHEDULE

View and register for Blood Donation camps

NEARBY BLOOD BANKS

Get contact and navigation details of blood banks

Hi! I'm RaktBot.

I am here to help you with blood search, blood donation FAQ's and anything about E-RaktKosh.

Type 'help' for help and 'contact' for contact details.

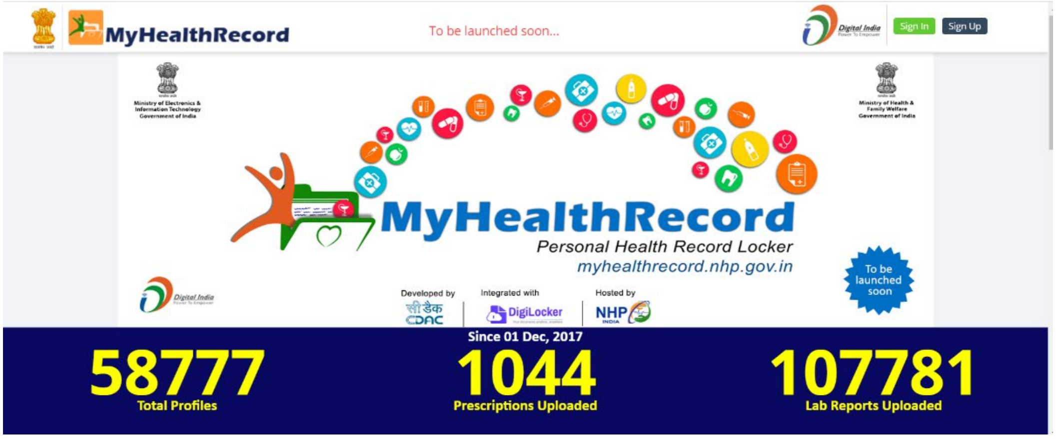
LATEST eRaktKosh Services are now available through UMANG

Source: https://www.eraktkosh.in/BLDAHIMS/bloodbank/transactions/bbpublicindex.html (Accessed on October 29, 2020)

3.3.6.6 MyHealth Record

Another national initiative likely to be implemented in the state is MyHealth Record (MHR) (Figure 14). MHR is a personal health record management system allowing patients to manage their health data online and overcome the challenges associated with paper-based record keeping. Though it is yet to be formally launched, more than 58,000 individuals have created their profiles and uploaded prescription and laboratory documents. MHR will allow individuals to synchronize data from wearable devices and offers dashboard features for monitoring of health conditions.

Figure 14. MyHealth record



Since 01 Dec, 2017

58777 Total Profiles

1044 Prescriptions Uploaded

107781 Lab Reports Uploaded

Source: https://myhealthrecord.nhp.gov.in/ (Accessed on October 29, 2020)

A person can not only maintain his/her health records like prescriptions, lab test reports, immunization details, information about your allergies, and medical images but also share it with healthcare providers (Figure 15). It was jointly developed by the MOHFW and MEIT, Government of India. MHR is hosted by the Center for Health Informatics at the National Institute of Health and Family Welfare (NIHFW), Government of India.

Figure 15. MyHealth record brochure

सत्यमेव जयते
Ministry of Electronics &
Information Technology
Government of India

Digital India
Power To Empower

सत्यमेव जयते
Ministry of Health &
Family Welfare
Government of India

MyHealthRecord*

Personal Health Record Locker

- Citizen-controlled Personal Health Record accessible over web and mobile
- Includes Allergies, Immunizations, Lab tests & Health conditions
- Provision for importing wellness (Steps, Running, Walking etc.) data from smartphones.
- Comprehensive dashboard for health monitoring
- Provision for Tele-Consultation
- Printable reports

Modelled on
**EHR Guidelines,
Ministry of Health
& Family Welfare,
Govt. of India**

Integrated with
AADHAAR DigiLocker

*To be launched soon

सी-डैक CDAC

CENTRE FOR DEVELOPMENT OF ADVANCED COMPUTING
A Scientific Society of the Ministry of Electronics & Information Technology,
Government of India,
A-34, Industrial Area, Phase-VIII, Mohali- 160 071
Phone: +91-172-6619000 Fax: +91-172-2237050-51
www.cdac.in

NHP INDIA

Source: https://www.nhp.gov.in/NHPfiles/MyHealthRecord%20Brochure(1).pdf (Accessed on October 29, 2020)

CHAPTER 4: RESULTS

Introduction

This chapter presents the qualitative data analysis and study findings. The first subsection describes characteristics of key informants. The second subsection describes barriers to development of national and sub-national EHRs to enable health data exchange (HDX). The third subsection presents findings about stakeholder type, stakeholder engagement in development of EHR, data system and workflows, health information needs, and data use at the hospital, state, and national levels. The fourth and final subsection of this chapter presents a HDX model based on the findings shared in the subsections 4.1-4.3. The proposed model aims to enable interorganizational HDX for supporting use and reuse of data for maternal health service delivery and program management decision-making at the hospital, state, and national levels. The model also illustrates how it can allow integration with clinical and research registries.

4.1 Key Informant Characteristics

A total of twenty key informants constituted the study sample. Nine (50%) of the key informants were from the public hospital whereas two were from private hospital and clinic. Four each were from the state and national levels and one of the key informants was a patient though another key informant also shared experiences as a patient (Table 13). The purpose of including a patient in the study sample was to validate the workflow, data collection, use and sharing information provided by the clinicians in the hospital setting.

Table 13. Key informant by healthcare level

Healthcare Level	# Key Informant (%)
Public Hospital	9 (45)
Private Hospital and Clinic	2 (10)
State	4 (20)
National	4 (20)
Patient	1 (5)
Total	20 (100)

The key informants represented stakeholders that were health insurance employee, health care provider, pathologist and lab technician, health information technologist, maternal child health (MCH) program expert, and patient group (Table 14).

Table 14. Key informants by stakeholder group

Stakeholder Group	# (%) Key Informant
Healthcare provider	6 (30)
Health IT	4 (20)
Health Insurance	6 (30)
Lab Technician	1 (5)
MCH Program	2(10)
Patient	1 (5)
Total	20 (100)

Most (15, 75%) of the key informants were males while five (25%) of the key informants were female (Table 15). Also, thirteen of the key informants were from the public sector and seven belonged to the private sector. The patient interviewed for the study is also categorized in the private sector (as a private citizen) though the patient availed healthcare services in the government hospital (Table 16). The key informants had a wide range of work experience (Table 17).

Table 15. Key informants by gender

Gender	# (%) Key Informant
Male	15 (75)
Female	5 (25)
Total	20 (100)

Table 16. Key informant by sector

Sector	# (%) Key Informant
Public	13 (65)
Private	7 (35)
Total	20 (100)

Table 17. Work experience

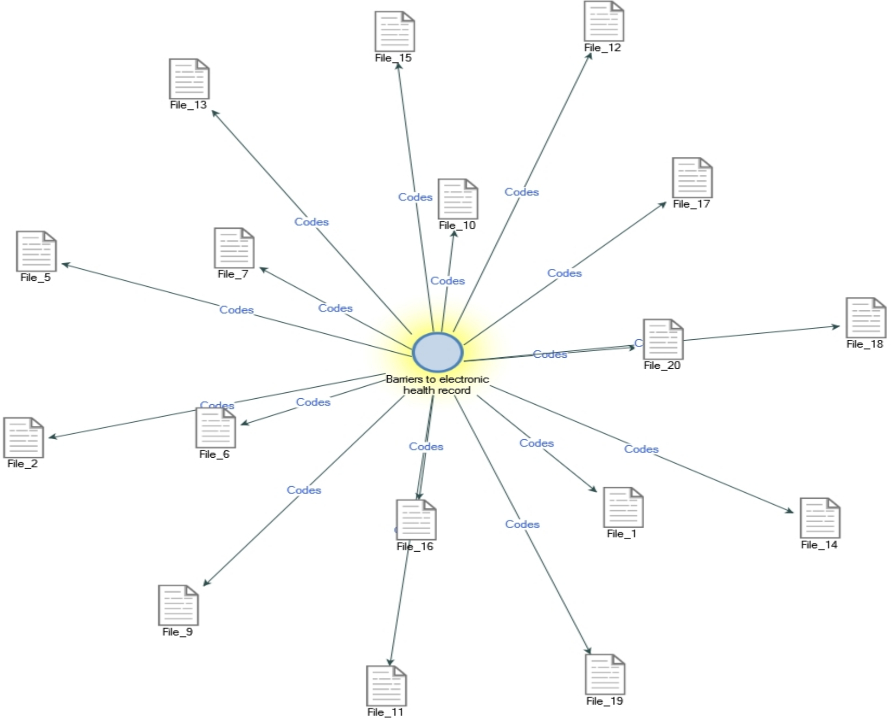
Work experience (years)	# (%) Key Informant
0 – 5	4 (20)
6 – 10	4 (20)
11 – 15	2 (10)
More than 15	9 (45)
Total*	19 (95)
* Denotes that the Patient is excluded in this summary table.	

For instance, one of the key informants was a nursing student practicing in the hospital as part of their pre-service training, whereas a majority had extensive work experience. Nine (45%) of the key informants had more than 15 years of work experience while two (10%) had work experience between 11 to 15 years. Four key informants had 6 to 10 years of work experience where the other four had one to five years of work experience. The data collected about the work experience was based on the information shared by the informant during the course of the interviews. Most of the key informants did not explicitly mention the exact number of work experience, but rather a range. The national and state level key informants (8, 40%) were the main source of information pertaining to electronic health record standards, maternal child health programming, and health informatics initiatives. These individuals represented the technical points of contact for the maternal health child health program in the country. The state health informatics point of contact was the designated expert for all the health informatics initiative in the state. Appendix E provides additional information about role of each of the key informants.

4.2 Barriers to EHR Development and HDX

Almost all the key informants talked about different barriers affecting development of EHR necessary for HDX at the TSGH, state, and national levels. Figure 16 shows that nineteen of the twenty key informant interviews had themes related to EHR and HDX. In this subsection, main barriers related to leadership support and coordination, budget and decision-making authority, data collection systems and processes, workforce capacity, health information technology education and training, and system design, are presented.

Figure 16. EHR development barrier themes in interview data



4.2.1 Lack of Leadership Support and Coordination

The findings show that inter-organizational relationships are complex and the organizational leadership and management support within the hospital as well as from the state and national government agencies is critical for the development of EHR and HDX. Figure 17 represents the complex inter-organizational linkages among national level public health, medical education, and IT agencies such as the MoHFW, the NHM, the NHA, the Department of Health and Family Welfare, other health departments, the National Medical Commission (NMC) of India, the NIHFW, the National Health Systems Resource Center (NHSRC), and the premier government IT agencies i.e., the NIC and the C-DAC. The figure also shows linkages with state level agencies such as state NIC, the SHM, the SHA, the state DME, and the DMHFW. The relationships vary from direct administrative and operational supervision, offering need-based technical assistance which includes coordination and information sharing to only need-based coordination and information sharing for the development, implementation, and review of programs.

Highlighting the challenges associated with the coordination and convergence of various health insurance programs under PMJAY, one of the key informants (KI 16) said:

> *"No, so, these kind of convergence schemes are, I mean, you know, India is a vast country, I would say are extremely affected. And, you know, there are number of things which are ongoing, and nobody knows about them, but they are ongoing, and they will give you the list of beneficiaries also. Yeah, but God knows who are those beneficiaries, who is giving money and who is taking money? So now, this is also a good platform that what we are doing is not all of us, first of all the insurance schemes which are going on in the States. And if there is some direct benefit transfer, or unconditional cash transfer scheme is ongoing. So, can we just converge this with Ayushman Bharat. So maybe by the end of this year, come up with one document, which will be showing that these are all the convergence, which has happened as policy."*

Figure 17. Interorganizational linkages between national and state level agencies

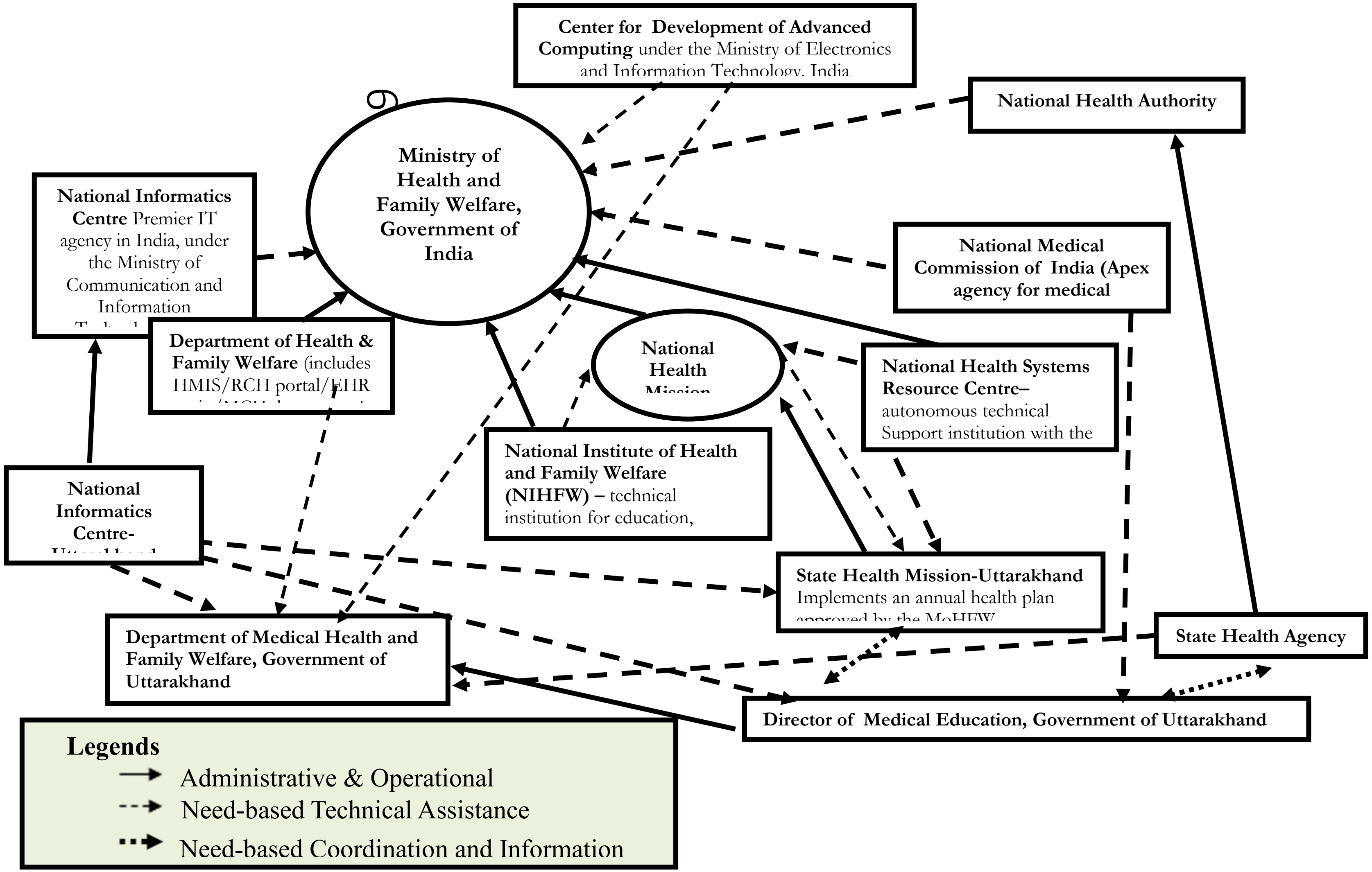
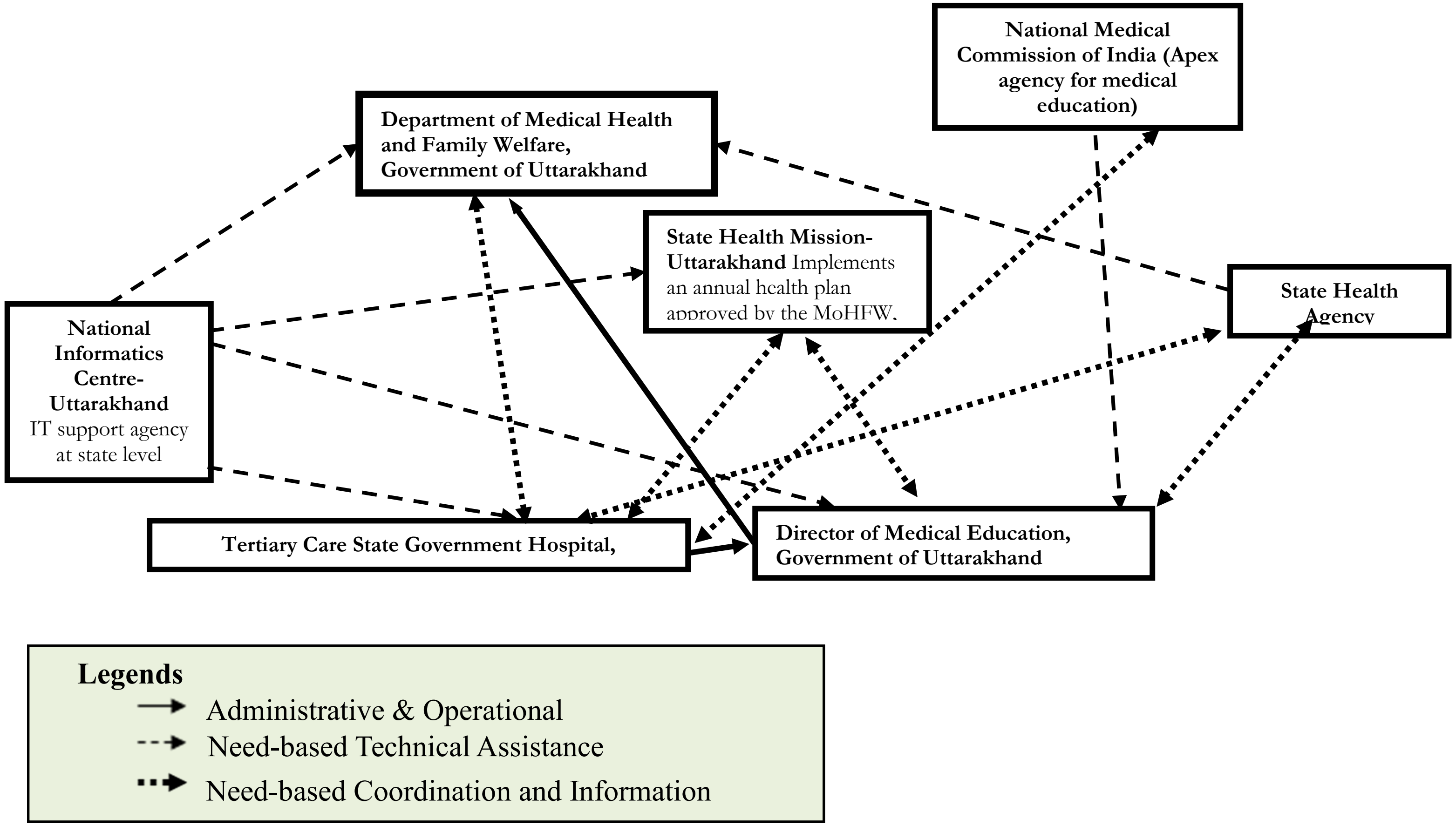


Figure 18 shows the interorganizational linkages between the TSGH and various state level agencies leading and managing public health programs, medical education, and IT efforts connected with the progress and performance of the TSGH. The relationships vary from direct supervision, offering technical assistance, to reporting and review of program performance. The senior most bureaucrat in the state ministry of medical health and family welfare represents the state government in nationally supported initiatives such as the SHM and the SHA.

Figure 18. Interorganizational linkages among TSGH, state, and national level agencies



The lack of coordination among various health care programs launched by the national and state governments compounds the limited ability of tertiary care hospitals to implement and manage various health care programs. As summarized from the key informant interviews and shown in Figure 17 and 18, the SHMs are the operational arm of the NHM and are responsible for implementing, monitoring, and managing public health programs described in the state annual program implementation plan. Similarly, the SHA is managing the PMJAY, a UHC program under the leadership of the NHA of the Government of India. As described by one of the key informants (KI 19), national and state governments have legal authority over different levels of the healthcare system such as national, state, district, subdivision (*Taluk*), and PHC:

> *"So central government does not have a lot of power when it comes to doing it directly. And therefore, in India, we have a mix setup where you have certain hospital which were created by an Act of Parliament or created by an executive order of the central government. And rest of the three-four tier health system that you see, we just start from PHC, to TALUK to district to state level specialty hospital. Those are all under the control of State Government. And then the private parties also play a big role in that."*

The findings show that the hospital is implementing two different national programs namely *PMJAY* and the *JSY* under the NHM that provides coverage for hospitalization and financial incentives for health-facility based birth in both rural and urban areas. The programs are managed by different government departments and have separate reporting requirements even though the birth occurs in the same government hospital (Figure 19). One of the key informants (KI 9) explained how the two programs avoid duplication at the hospital level:

> *"...for delivery we have a JSY program. So, it is covered under that. So, we do not take normal or caesarean delivery in Ayushman. It is already covered in the JSY where they can get the treatment and do not have to pay anything. So, we do not do it under Ayushman. It is included in Ayushman, but we do not do it. Why to increase our burden? Because you already have JSY so they can do it under NHM. We are already puzzled."*

Further, the findings show that the hospital is required to comply with accreditation requirements of the NMC of India (previously known as Medical Council of India), a national licensing and accreditation agency, since it is associated with the Government Medical College. As explained by one of the key informants (KI 19):

> *"You do not get a medical college approved unless you also have a hospital for students to practice. So, it is an integral requirement. So, anything that happens in a state medical college and hospital in terms of what like you said maternal child service guidelines are there but hospitals guidance, their infrastructure, the requirements are also somehow influenced by what comes from the Medical Council of India. They also provide guidance on what you must have before we can approve your accreditation.... Medical Council of India is fully responsible for medical college and hospital and they fully respond to MCI and not to any other body."*

The findings also reveal that the state government hospitals have the freedom and flexibility to create EHRs or new digital record system as explained by one of the key informants (KI 20):

> *"So, if the AIIMS wanted to build an electronic system no one stopped them. They had an active project. So, once they choose resource and did that and no one prevented it. We evaluated to see if it can be replicated which was not feasible. So, these institutions have liberty to do things. People are encouraged to innovate. There was an exercise in Tamil Nadu...It was a very good, low-cost model."*

For the teaching and research purposes the medical college and hospital are directly under the authority and administration of the state DME. For the implementation of national and state level maternal health programs the hospital is required to report and interact with agencies at the state and the national levels as shown in Figure 17. Apart from the multi-dimensional coordination and management requirements for the maternal health program, the hospital is also dealing with the state IT department and state unit of the NIC which is a state unit of the NIC under the MEIT. The hospital IT team is required to coordinate and seek approval from the DME before finalizing requirements, selecting EHR vendors, implementing or changing existing hospital management information systems. Implementation and use of multiple technology systems, along with the associated data collection and reporting requirements adds to the existing workload of the clinical and administrative workforce in the hospital.

As mentioned by one of the key informants (KI 3):

> *"The hospital is managing a legacy hospital information system procured by the state government 15 years ago. The IT team is also required to support clinical and administrative staff in managing or keeping hardware, software, and network functional. The hospital IT team coordinates with the state IT department to discuss and decide on the technology requirements for the hospital."*

Upgrading current hospital management information systems is complicated by the involvement of multiple government units and procurement processes. This was highlighted by one of the key informants (KI 1):

> *"So, we have the medical education department for hospital and colleges. We have approval from the government IT department, but we have not received it from the medical education department. State IT department government in automation work and worked with us to build the RFP, the tender document. We had released it once and we were expected to have minimum 5 qualified participants. So, we had five participants and we had three rounds of the selection process but only one could qualify. So, we had to cancel the tender. The secretary at that time said that let us enhance our requirement document so that we can attract some of the bigger companies like TCS. So, we upgraded it and worked with the IT department and the tender document is ready. Once we get the permission, we will float the tender and whichever vendor is selected, whoever qualifies, we will implement it."*

4.2.2 Limited Budget and Decision-Making Authority

The findings highlight that development of EHRs is a top priority under the national digital health mission of the national government but there is limited funding available within the state government budget for supporting development of EHRs. The budget is often determined by the state health department leaders who manage competing healthcare interests. Further the ability of state health department to invest in the development of EHRs depends on the financial health of the state government. As one of the key informants (KI 3) mentioned:

> *"the requirements for inviting vendors to submit proposal for the EHR is ready but medical education department approval is still pending. The department will approve the final requirements which have budgetary implications."*

Another key informant described the centralization of decision-making authority with the state and hospital administrators (KI 1):

> *"because I do not have any financial power which makes difference. To get anything done in my department, I have to talk to the principal and medical superintendent. The principal needs to be informed and has to be taken around the hospital. Then, he will decide what can be done."*

Also, the slow decision-making process and procedural requirements impact motivation of staff. As one of the key informants (KI 3) said while describing the EHR platform procurement process:

> *"I still have eight years. But you know, eight years flies in government. Sometimes it takes 10 years for approval and sometimes you can get a lot of things done in the eight years. So, people do under work but sometimes they do not get opportunity to do anything. People want to work but do not get the opportunity. I am hoping that it will not be the case with me, and I will be able to get this good work done. I will definitely be disappointed if it is not done but there is nothing that I can do. I will have to just follow whatever government asked me to do as per the rules."*

Furthermore, financial dependencies limit decision-making authority. As mentioned by one of the key informants (KI 4):

> *"Ours is a government institution, so all financial resources are provided by the government."*

Highlighting the centralized decision-making structure of the hospital, one of the key informants (KI 7) explained who the right person will be to decide about introducing EHRs in the hospital:

> *"if you come here you have to first go to the medical superintendent. So, most of the decisions are taken by the medical Superintendent."*

4.2.3 Fragmented Data Collection and Reporting System and Processes

The many different health programs being implemented by the state government, SHAs, and SHMs are is adding to poor data quality, data duplication, workforce overload, and fragmentation of processes and technology systems.

Multiple HISs has been created by the national IT agency adding to the fragmented health data landscape. As described by one of the key informants, NIC and C-DAC have created different products, each advocating for adoption of its own product at the state level.

Describing the competing software products, one of the key informants (KI 18) said:

> *"When Sanjivani was created, and Mercury was created they were two different products from two different organizations for the government, focusing two different things. Where Mercury was designed to look at, you know, doctor to doctor from perspective of, single peer-to-peer communication all the way to multi-center hospital communicating with multi-center hospital. That was the idea of Mercury. So, Mercury continues in that line and today it is cloud enable, cluster able, load balanceable, has tons of advanced features on screen sharing, you know, consultation based on, based around data. A whole consumption to autopsy based EMR system is built in. It definitely went the other way. And it was more of a think of service in one location and then let people just also multi tenancy was more of Sanjivini's thing. And the idea was low-cost devices. Whereas we looked at hospital as a corporate entity and we tried to connect it with everything out there. .... Sanjivini was more like, it is there on its own. There are a bunch of records you can create a day and then two doctors can talk."*

The premier national IT agency, the NIC, had created the MCTS which has now become the RCH portal. Describing various health IT initiatives focused on specific health program applications that included out-patient department (OPD), in-patient department (IPD) as well as enterprise resource platforms (ERPs), one of the key informants (KI 20) said:

> *"MCTS has now become RCH. It is still a software that is created, hosted by NIC. So, there were 17 programs like NISCHAY program or, you know, deal program and all of these programs NIC does for every ministry, and somewhere around that there was a requirement. Although eSushrut became an ERP of a hospital rather than HIS. Because in Sushrut... these guys can track a single bedsheet! Right from your supplies coming in and roster of doctors. It is actually a hospital wide resource system. There is also clinical module, and you know, OPD and IPD and those kinds of things. So, everything moves around patient but in reality, even rostering is done over Sushrut. So, somewhere around that and see in government something happens in two locations not only because what was being done is available and why do we use it? It is also because of capacity issue."*

Describing the data collection system and processes at the hospital level, one of the key informants (KI 3) said:

> "W*e collect data about patient admission, registration, and payment of financial incentives separately for the national health mission, the national health insurance program, and for reporting to the state health department. So, I have three people on the hardware side, and I have four people on the software side, and they are not programmers. I call them operators. We are managing both the hospital and the medical college. We have a separate application for the library. We are also conducting exam online. We are also supporting classes and exams online."*

Another key informant (KI 6) explained ad-hoc nature of creating data collection forms at the hospital:

> *"So that I saw that you were taking it is because of our officials you know whenever they want, they create register. let me give you an example so we have a lot of register in the OT. Let us see somebody did a supervisory visit and says that this task is not being done well. Based on his thinking they will say let us make a register. They said you do not take this, and you do not take that information. You do not have the right information so please make over register. This is how our written work has increased."*

Ad-hoc documentation was also reported by the team managing the PMJAY even though the program did not require storing physical copy of the *Ayushman* card, the *Aadhar* card, the diagnosis, and the pre-authorization form. One of the key informants (KI 9) said:

> *"It is not mandatory from their side. We ask it from our side because if they ask in future . If they audit, they will ask for it. Give the patient admission number and we can provide them. They just need a photograph."*

The registration, admission, billing, and discharge data is entered by a separate team. The data entry task is performed by a lower division clerk (LDC) as the hospital could not hire front desk staff with the title of receptionist. LDCs are expected to support the hospital documentation related to administrative tasks. Lab and medical record department (MRD) has its own team for data entry tasks. One of the key informants (KI 3) explained the work distribution among different teams in the hospital:

> *"There is a separate team. Whether you call them as billing or reception team, they are the same team. They are basically LDCs. We did not get approval for receptionist. So, we kept LDC on those counters. So, they take care of work related to registration, billing, and discharge. So, the requisition in the Ward is done by the nurses. The lab work is done by the lab people and this is how the work is bifurcated. MRD is doing its job and we are supporting maintenance. So, if there are some changes required in the patient record or some corrections are required or new things are coming, we do that kind of work."*

The findings show that the legacy system has unique challenges and technological advancement demands new technological platforms for EHRs:

> *"See we do not have anything for the old system. So, we cannot do much. We do not have the source code for the old system. They have given us as a gift. So, we could not do many things. They just told us that we have closed our product so we cannot support you. It is our limitation (Mazboori). It is better to get a new product because there is a big difference between the technology in 2004 and 2020. We have a lot of new ideas and we would like to implement. Building on the old system will be time taking and may not be successful. So, we would like to bring new things from the market and try to build on that and add our ideas to it."*

Fragmented data collection system and processes pose challenges for the hospital to report to the medical education directorate and department of health. One of the key informants (KI 3) in the hospital said:

> *"See we have to send it to the directorate and the department and now we have to send it for COVID. We have to collect report from different areas and then we compile it and then we send it to them. These are routine reports such as number of surgeries, number of childbirths, and we use available data to compile the report. Right now, we are the only ones working on it. We cannot generate a new report in the current HIMS."*

Another key informant (KI 13) explained how hospitals will always have a mix of paper and electronic data capture systems given the hospital workflow processes.

> *"the benefit is it will become paperless for a point but if we think it will reduce manpower that is not going to happen. We can for a moment think that hospital will become paperless, but you will have to go for your medication. So, the pharmacy receives the medication order, and someone can still carry the medication to the patient. You can make this much Hi Tech but beyond that it is not possible."*

The problem of fragmented data collection and reporting system and processes is also linked with the geographical scale and system integration requirements. Describing the challenges associated with the implementation of the PMJAY IT system, one of the key informants (KI 16) said:

> *"PMJAY is managed by the NHA in Delhi. And one more thing, just to add one more thing, because there are some of the states where this was very mature with the insurance in the north or some states in the southern part of India such as Tamil Nadu, Andhra Pradesh were very good as far as insurance schemes are concerned. These states have insurance. So, they have their own identification system in place. Based on human resources they have their own system. So then when the same device came into existence, they said that we have already invested our money and energy into infrastructure, human resources and are doing very well. So why should we merge with PMJAY? What would be the advantage Because many of the schemes they were giving has universal health coverage and they were giving a good amount. Then, the ministry said if you have your own system in place, we will not disturb it. We can just have an integration with PMJAY because there are certain things which we want at the national level. You can run your own team, let me provide you the integration. So, they have bifurcated into a greenfield scheme. Some of the states like Haryana, eastern states those who have not implemented any of their insurance scheme they do not have their platform. So, they have segregated that way. So, those who have like Kerala and Tamil Nadu, Maharashtra, Assam have their own IT system in place, they are using their own IT platforms, but they are*

> *working to integrate. API integration is going on so that they can just push up some of the data which is required from my perspective."*

Another key informant (KI 10) described the fragmented data collection and reporting system in a private hospital.

> *"So, in the lab they still write on hand, the report. So, there is a paper for the doctor, and they will just put a check mark on the paper that goes to the lab. You submit the paper, and your name is written. And then they just write the result in front of those check mark. The registration slip they give is only electronic. Otherwise, there is not much electronic as far as I have seen."*

Summarizing the challenges experienced by patients, one of the key informants (K 14) said:

> *"We need to carry the documents. We made sure that we are carrying it and in a physical form and, mostly now, with time we are careful and kept few records for electronic form also, personally, because we know you need a reference document tomorrow. So, that is one challenge because there is no electronic medium where you can store it right now. So, if I look at Lal path labs in India, which is a major Lab, for their testing requirements they have created some IDs and there is a uniform ID for a customer. So, they are actually able to record all my pathological test reports. Storage of the prescription or storage of the surgeries, there is no centralized network as of now. There are hospitals who today store it in electronic form. There is no universal portal where you can go and store it and use it. So, that is one challenge in terms of a lot of new companies or startups coming on in health sector. They are coming up with this thing where they are giving an option to store your documents via recording and storing all your information. Whatever is getting passed through them and they are giving you access to use those documents whenever you want. So, you can click it and find it out the entire history of what you have gone through in terms of the reports or in terms of any elements that you have. So, I think this is their model for digitally storage services of your records, rather than a record in a form where doctors or nurses can look at it and see your treatment history and then decide the next treatment."*

4.2.4 Lack of Workforce Capacity

Lack of an adequate skilled workforce with the right mix of skills is limiting national and state governments, and hospitals' ability to promote and increase adoption of EHRs.

As described by one of the key informants (KI 18):

> *"I think we had about 21-25 people. Maximum, I had once, it was 27 people; I think once it reduces to 14/15. So, like I said that what we did is we created separate teams. So, there is a whole, there is a bunch of people who do tooling and these guys by virtue of doing tooling become good at implementing standards because they have created a whole SDK or a whole system on top of that standard. So, these guys are also used for implementation support, and things like that. So, we got two people from clinical side. So, I have a person who has a PhD in nursing, I had a person who was PhD in pharma, I had two people earlier who were masters in physiotherapy with six years or so, experience in training and we use them to do the bridging talking to doctors and medical domain people. And also understand their requirement and translate it for us rest of the non-medical and things like that. So, there is a lot of you know, bridging work people do. It is not that there. So, even if I give you a number, say 20, it is not just that these 20 people are involve in one work, they are in all over the place."*

Another key informant (KI 1) explained how patient volume together with lack of technology and workforce capacity limits adoption of EHRs in the state hospital:

> *"We have an OPD of 100 patients in a day. So, it is not possible to do justice to 100 patients and doing it on computer, that is not possible. So, we are doing it manually. So, resources would be required. Because we have to install the computers or tablet would have to be given to all the doctors. It will have to be really quick. Also, they are not going to write a prescription as quickly as he or she will be able to write it manually. And that a computer operator has to be there who will then incorporate all that data to the computer and, so, logistics is also to be taken care of."*

Another key informant (KI 3) said that doctors and nurses were required to enter data in multiple registers related to childbirth in the hospital:

> *"So, we have admission registers, discharge register. All are maintained by staff nurse. She is the documenting what medication has been given. So, the sisters are maintaining the register. the doctors are maintaining the labor room register. So, this patient has come, and she delivered, whether it was cesarean section (C-section), or she had a normal delivery, and at what time, was there any complication. All that is entered in the labor register. Then, in the emergency OT, again we have a register to enter her address, age, this was a second baby or third visit. Is it first C-section or second C-section? Was C-section or normal delivery? All that data is also entered in emergency OT register. In these registers' entry is done by doctors. In elective OT, if some DNA procedure was done, laparoscopy was done. Again, this is entered in the elective OT register which is again maintained by the doctor."*

The workload grows exponentially given the volume of patients as explained by one of the key informants (KI 6):

"Let us say I have a JSY patient. I have to enter the discharge summary and what happens is I have 30 to 40 patients at a time and I need to enter for all of them. For JSY, we have already said that we need to enter detail and only that form can tell us whether this is a JSY patient. So, we have the written work as well as the computer work. And then we print that discharge summary and give it to the patient and say please go to the billing section, get the billing completed and then come to us again. So, you can imagine that this is the work for one patient. When people make a queue and they start altogether, it is a lot of crowd."

Another reason for an increased workload is patients insisting on interaction with the doctor irrespective of the healthcare issue. One of the key informants (KI 11) described why patients insist on meeting with the doctors:

> *"What I understand, here, people come from villages. Please understand that in this area, where I live, people come from rural areas and they will say I am not here for your advice. If I am spending so much money, I need to see the doctor. Whatever doctor will say we will do it. We are not going to listen to you."*

Apart from the workload, one of the key informants (KI 9) expressed doubt about the technical competence of the HIMS team of the hospital:

> *"It was interesting since I joined. So, for one more year basically in that phase during the implementation. Through the contract or what you call MoU or something like that was over. So, there is nothing else. Whatever there is little computer people, but they do not know really much. Two, three people are there. There is a person called computer programmer but does not know anything. Nothing is left. So much time has passed that they get used to."*

The workforce capacity is also limited by the perceived role and responsibility for data entry. One of the key informants (KI 4) mentioned:

> *"Collection and recording of data are not our work there in the department. We are concerned with our patients only . Had this interview been on something like what are the treatment protocols and all, I could have helped. But I have no idea about data collection, funding, recording, etc."*

4.2.5 Health Information Technology Education and Training Gap

The findings show that education and training are important for adoption and use of EHR training are important for adoption and use of EHR and it needs to target four groups of HIT, payors or buyers, clinicians, and patients.

As explained by one the key informants (K 18):

> *"But there was already a growing understanding and by the time from 2014 to 2016, we had already demonstrated that just working on coding part will not work because there is very little digital health everywhere. And some hospitals do not even have a necessity of having that and they do not just need it. And then there are a lot of demand saying that finally, just putting code, I mean how am I going to first make the system compliant to standard if you keep talking about the codes.*
>
> *One being the education and training, obviously. The idea was not to make experts on standards, so it was not going to be something like ISO 9001: 2000 kind of evaluators. The idea was to divide the entire landscape to three set: one being the developers, the technical people who basically sit down and code digital software or hardware. The second set which is essentially the buyers set or the payer set, or the decision maker set which is basically you have the chief executive officers and the chief technology officers, and chief information officers, the chief district medical officers, public health authorities, the insurance people, the whole regulatory framework people even ministry of health, the different wings of ministry of health are similar bodies within the states and so on and so forth. Basically, people who need to know that there is something like this and what we simply call them as executive, and policymakers. So, that will be the second group. And the third group will be the user group which need to know that something like this should be there and need to be exposed to it. So, the third group of people are basically the nurses, the doctors, the paramedics and also the patients. Something like this should be there. So, these are the three things which are missing in the whole picture, and you just cannot start putting out systems which affects everybody's life and not have these understanding across the board...So, huge tenders and buyout operations will happen within hospitals and the other centers would not even know that there was supposed to be a set of requirements that must be fulfilled by such an application. So, crores will be spent on making systems which will not be standard compliant."*

The findings also highlight implementation barriers affecting development of EHRs:

> *"So, one big aspect of education is training. The second aspect that was identified was implementation. Because having just trained will not work. Because even if we give you two-hour crash course, on a standard, still you would not know how to start. You will not know whether you are doing the right thing. And I am not talking about end user testing, I am not talking about something that you create and give to somebody who checks and certifies. I am saying, as a developer, how do you know that you are doing the right thing? How do you know that what you thought was diagnosis is supposed to be something else or is supposed to be a finding or is supposed to be a disease? or is just an observation? So, these are nuances, which basically misses out on the developer community when it comes to health. Because most of them are just engineers and they are not doctors."*

Highlighting the language barrier one of the key informants (KI 12) explained why it was difficult to expand delivery of healthcare services especially private insurance services in rural and mountain areas of the state.

> *"the main problem in the mountains is that we do not have people who can read English prepare the paper and send it to us."*

Further, findings show that learning while doing was the primary method of understanding how to use different data systems. One of the key informants (KI 7) mentioned:

> *"So, we are starting now, and we are taught about computers. So, we have knowledge of computers. In the first year we have a course about that. So, we should learn about technology and we should be in touch with the technology to provide care to the patient."*

Also, the purpose of using electronic systems in hospitals and small clinics varied widely and showed lack of proper knowledge and understanding about the potential benefits of EHRs.

One of the key informants (KI 10) said:

> *"One of the reasons might be that people want to know that how many patients came to the clinic. There is also some corruption as the person sitting at the reception desk can play with the total patient visits in the clinic."*

The findings also show that HIT training and education gap was not a barrier for the nationally funded programs such as PMJAY. One of the key informants (KI 15) explained how trained personnel used a centralized IT system to identify beneficiaries and delivery financial benefits.

> *"So, there will be a person call Prime Minister Arogya Mitra. That person will ask do you have Ayushman card ? The person may not have the card. Then the Mitra will explain to that person and will check for the name in the beneficiary identification system and will another parameter to search if they do not find the name. Then they will send it to state health agency for approval and until it is approved it is called card . Once the card is approved a printout is taken and given to the beneficiary. If the beneficiary loses the card, they can again come back with the same reference number and get a printout. If I have a card then I will say yes, I have a card . Then the Mitra search in the transaction management system using my unique ID and it linked with the beneficiary identification system through application programming interface. My entire detail will appear in the transaction management system from the beneficiary identification system. Then he will register the patient and will talk to the doctor and ask the doctor to offer the appropriate health benefit package."*

4.2.6 Poor Information System Design

The findings show that the HIT did not meet the clinical and program requirements. One of the key informants (K 18) explained that most of the systems were never designed to serve as a health record system.

> *"You know, most of those IT systems were not designed to be a record system. There was simply digitized form of what was created by the agency of the health department. Instead of filling data in to paper you basically go to a website and then fill out the Form. So, it has same sort of option, same label same text boxes are just as it is digital. So, you know, we are bringing in that concept saying that even then you need to have medical data and how to separate it out into different, you know, because EMR, EHR work on the concept of artifacts, and the artifacts are individual units rather than a composite form like yours. We even found out that some of the forms were very difficult to answer in a very definitive term and you have to be, for example, questions like, does anybody in your family has diabetes, and blood pressure? Now, if I tick, what am I ticking? Am I ticking that my father has diabetes or am I ticking my mother has BP? But the form has like that."*

Another key informant (K 11) explained how EHR platforms available in the market did not meet the data collection requirements of a private hospital:

> *"Let me tell you one more thing which is very interesting. I got a call from my marketing manager that there was a patient asking to change something in the record. So, please come and change. So, the woman who had come to the hospital had her father's name as Mr Kumar Chandra Saini in the hospital and in his Aadhar card it was Kumar Chandra Saini. I am talking about the software in my office. In the software, Mr and Mrs. are the only option. Patient's sister was saying but his name does not have Mr., why did you add it? Shri is in his Aadhar card so please write it. I was trying to explain that Mr. means Shri, but she said, no, why did you write it? It is the default option in the software. So, it will come in the print. We had the prescription printed as Mr. Shri Kumar Chandra Saini to resolve the issue. So, we have to work among those kinds of people. So, how will develop the system? User is user but who is user working for? Who is the user collecting data for and whether the user is satisfied with the output is very important?"*

Another key informant (KI 4) described how providers had limited or no role in deciding what data needs to be collected and reported through different systems.

> *"They have a set format as to what is to be collected and what not. We do not have much interference into that because that is not our field of work."*

The findings how that even the national data system was not designed for the users actually operating the system. The PMJAY centralized data system was operated by another person and not the clinical person for whom it was designed. One of the key informants (KI 15) explained why they had to user logins for the system.

> *"And there are two logins. One login is for medical coordinator which is always a clinical person. But as you know the doctor to patient ratio is very low in India. So, it is not feasible. So, to ease it down this arrangement was made."*

4.3 Stakeholder, Data System and Workflow, Information Need, and Data Use

In this subsection, the stakeholder type, and their engagement in the development of EHRs and HDX, workflow, stakeholder health information needs, and use of data for decision-making is described. The key informant profile in Appendix E includes additional information about role and responsibility of stakeholders at the different levels of the healthcare system. A visual summary of the clinical and program linkages in the hospital is presented in the health data systems and workflow subsection which describes various patient interactions in the hospital during an inpatient and an outpatient visit. It also explains different data capture points related to registration, admission, billing, lab, radiology, pharmacy, procedures, health insurance, and patient discharge. The data captured through patient interactions is also reported to the hospital administrators, state, and national level stakeholders. Detailed findings are presented under the data systems and workflow subsection.

4.3.1 Stakeholder Type

4.3.1.1 National stakeholders

This group of stakeholders include the government and private sector actors. These actors, primarily from the government, are responsible for policy, program, and health information technology-related decisions at the national level. The MCH unit of the MOHFW and the NHSRC are responsible for program guidelines. The NIC, the national EHR resource center of the MOHFW, and C-DAC are key national IT agencies. Additionally, MOHFW has its own team that manages HMIS, RCH portal, and several other health IT initiatives such as My Hospital, and Electronic Blood Bank. The national stakeholders also include the MEIT, the NHA, Indian Council of Medical Research, the professional medical associations, the NHSRC, the NIHFW. The MOHFW is organized program-wise and there is no one unit responsible for all the maternal health aspects. This was explained by one of the key informants (K 19):

> *"Medical colleges have been sanctioned some of the programs where they are involved in states like maternal health and newborn programs. They also have been sanctioned MCH wings which is as per the NHM guidelines. So, by and large, the MH departments in colleges are conducting programs according to*

> *these guidelines. They also follow the protocols decided by the NHM. . The National Health mission covers only primary and secondary care. By definition medical college is out of NHM because they offer tertiary care except for MCH wing...All the MCH guidelines are applicable to state hospitals. So, SUMAN, skill lab and others apply to them as well. If they need to establish a skill lab, they need to follow the NHM guidelines. So, since we develop the guidelines, we will be able to support them in creating this lab. So, it is through the funding and the technical guidelines and local capacity building. We do not have administrative authority. They could go outside of it. See these structures were in place even before NHM. Their work is not fully within the NHM. NHM has taken up most of their activities but there are many other things. It is program-wise division. So, it is not somebody who looks after all aspects. We will have some 20-30 programs which converge in the states."*

4.3.1.2 State level stakeholders

The state DMHFW that manages both state and federally funded health programs is one of the key stakeholder groups. The DMHFW includes policy makers, program managers, clinical, and HIT professionals. The DMHFW also oversees the SHA responsible for the PMJAY and the SHM leading implementation of federally funded health programs including maternal health programs. Another important state level stakeholder is the state DME which is the lead authority for medical colleges and associated hospitals in the state. The state department of information technology (DIT) and the state level unit of NIC are two of the key health IT stakeholders. The state level group also includes the private health insurance providers, the private hospitals and clinics, and the HIT companies.

4.3.1.3 Hospital level stakeholders

The hospital administrators, a group which includes the medical college principal, medical superintendent, and the unit lead or department heads of various health care units are one of the key stakeholder groups. Providers like clinicians, pharmacists, nurses, lab technicians, and other auxiliary health care workers are another key group of hospital-level stakeholder. The HIT, finance, operation, and maintenance comprise a third group of stakeholders at the hospital level. These stakeholders are responsible for managing financial records and technology systems that include people on the payroll of both directly and federally funded health care programs. For example, the state hospital has a team responsible for collecting, verifying, and reporting beneficiary data associated with the PMJAY. This team's mandate is to share the data with the SHA through a centralized information system. The team member is a hospital employee. Another group leads the data collection verification, and reporting associated with the beneficiaries of safe motherhood and child program, which is federally funded program implemented by the state. The team also manages the financial records for all other health care delivery programs. The hospital includes both public and private pharmacies. The hospital level stakeholders also include private laboratories, radiology, and hospitals and clinics. Patients are an important stakeholder at the hospital level as they follow or disrupt the data workflow, collection, use, and sharing processes within the hospital.

Findings show that business interests of private hospitals can hamper development of EHRs and sharing it with other provider networks. One of the key informants (KI 13) highlighted this issue.

> *"I mean if it is s a genuine person, they can send it. But many times, they think why I should give it because my patient will go to somebody else."*

4.3.2 Stakeholder Engagement

Stakeholder engagement for the development of EHRs in the tertiary care hospital is described in this subsection.

The HIT infrastructure development has happened largely due to the investments and support from the national government agencies. The NHM has played a significant role and is strengthening the physical, workforce, and technology infrastructure to implement and manage different health care programs. The NHM leads the development and implementation of policy and program guidelines associated with maternal health. Even though state government hospitals are managed by the state government and the accreditation is monitored by the NMC of India, the maternal health guidelines apply to the state government hospitals. In many states the national maternal health guidelines are the basis for developing guidelines appropriate to each state's context. As one of the key informants (K 20) mentioned:

> *"The national maternal health guidelines are applicable to the state government hospital. The state government hospital receives financial and technical support from the National Health mission to establish maternity wings in order to address infrastructure limitations hampering increased institutional delivery numbers. "*

The NIC is the primary agency that provides IT support to all the government departments at the state and district level through the state and district level informatics teams. The state units of the NIC often develop health related software applications and also provide hardware, network, and implementation support. The coordination between the state units of the NIC and it headquarters has always been challenging in terms of development, scale up, and provision of implementation support for applications developed by respective state units. As one of the key informants said (K 17):

> *"The electronic hospital information system was developed by the Tripura state unit of NIC and later on taken over by the national team to offer a centralized mechanism of promoting its implementation. However, the national team only serves as a gateway whereas the actual software development and modification work still continues with the state informatics team. The development of electronic hospital information system has limited engagement of state health departments, hospital administrators, clinical providers, or a patient."*

The ability of the state informatics teams to support multiple implementations of electronic hospital information system (eHIS) has proved to be challenging. To overcome implementation challenges the NIC has empaneled local IT companies in many states to provide necessary technology assistance to deploy and manage eHIS in hospitals. The empanelment of agencies is no longer in existence as their contracts have expired. Since eHIS was developed by a team that did not have contextual understanding of the state government hospital, the hospital IT team refused to adopt eHIS in their hospital setting. One of the key informants(K 3) described the reason this way:

> *"The eHIS application is very basic and it does not meet our requirements in the hospital which we are currently managed through both paper based and electronic information systems. Also, eHIS does not allow us to modify existing functionalities or add new functionalities To fit into the clinical and administrative workflow of the hospital. Also, we will have to be dependent on the core team based in another state to execute any changes in the current application. We told them then if you cannot modify it to fit into our context then we cannot deploy it in our hospital."*

Another national agency under the MEIT, the C-DAC, provides software development and research support to different government departments at the national and level. This agency has also implemented several applications addressing health care challenges such as *eAushadhi* for drug warehouse, *esanjivini* and *eSushrut* for patient records, HIMS and telemedicine solutions in collaboration with state level government hospitals.

Recently launched, the national digital health mission envisions the creation of foundational elements such as the health ID and doctor registry to support the HDX among national, state and facility level health care organizations. The HIT infrastructure for the PMJAY is managed by a group of public and private organizations. These organizations include the NIC, PricewaterhouseCoopers, Tata Consultancy Services, and IQVIA. It is a centralized information system. Furthermore, the NHA has invested at the state level to develop and manage IT infrastructure required for the delivery and management of the PMJAY. One of the key informants (K 9) explained the data flow of the PMJAY IT system which starts with the patient registration receipt (known as "registration slip" in the hospital).

> *"Once you login in the central web-based system, we can see the package amount for the patient. So, let us say it is a surgery. The amount for the surgical package will show and it will show how much money is left for that package. Let me tell you the procedure. The patient comes to us. We have designed a format. A patient first gets a registration slip. It visits a doctor for consultation. Doctor decides for admission. Once admitted, patient comes to us with the registration slip and with the Ayushman Bharat card. You do not get benefits with the card for OPD. But only for admission. Once the patient comes to us with the registration slip, we give a pre-authorization form. We have designed ourselves. It has patient name age, gender, and address, and it has the diagnosis. The doctor fills it with name of the package. We have distributed the list of about 1300 packages to the doctors. If the package is available, then only admission will happen under Ayushman Bharat. Let us say the patient comes with abdomen pain and if there is no package, it will be not be paid for. Sometimes government hospital admits patient just for pain. It will not work here. So, the doctor's task is to fill everything. Then patient comes to us with a signed pre-authorization form. We ask the patient to give a copy of Ayushman card, one Aadhar card of patient, one relevant investigation related to the package, let us say it is ultrasound. If it is orthopedic case, then will take an x-ray. And a bedside photo of the patient and then we upload this information. The patient come to us with all the papers and then we block into the pre-authorization software. We have to take permission from the state health agency. We upload it online in the portal and then we wait for the approval from the state health agency."*

Further the MoHFW at the national level has its own unit designing, implementing, and managing health information technology initiatives such as the HMIS, RCH portal, and several other. These centralized initiatives allow limited participation of state and lower-level health care units in terms of defining the requirements, adding functional requirements, or adapting it to the local context. The RCH portal is built on the MCTS created to track pregnant mothers and under-five children specially focusing on very specific medication records. A national support center is managed by NIHFW of the Government of India to provide technical and operational support to the RCH portal.

One of the key informants (K 20) described the evolution of MCTS and RCH portal:

> " *So, MCTS is supposed to be the future RCH portal. Actually, SUMAN should not capture it separately. It should be through RCH portal. It was given priority because of some reasons; some prominence was given to this and it is given some priority at the center. Even to understand there was some kind of rationale for pushing it forward beyond all of the programs. Separate protocols and separate mechanisms are created. Some of them some of these requirements are not very technical based.... In the ministry there is a division which covers RCH portal, HMIS, and there is also a director e-health."*

The key informant further explained how data quality issues for MCTS were addressed by the NIHFW of the MoHFW:

> *"In the campus, there is a national call center for MCTS. So, a lot of data entry issues happen and from here they call individual beneficiary and verify some of the parameters by directly calling the beneficiaries."*

These data show that health care providers have no or very limited role in informing the requirements of any EHRs platform meant to enable patient focused service provision. The involvement of hospital administrators such as the medical college principal and the medical superintendent is confined to the clinical care, hospital workforce management, and development and maintenance of physical infrastructure, and to some extent technology infrastructure. Often the providers look towards large private hospitals such as Max health care, Apollo Hospital, and national government research and teaching hospitals such as AIIMS to learn about EHR development and use. As described by one of the key informants (K 1):

> *"...in all the big corporate hospitals, have all this has been done electronically only. The discharge that are being typed electronically, even the OPD. Though not all have electronic OPD. But the discharge card, I have seen of majority of them doing it. But the treatment par, I think would be a bit difficult. I would usually take some examples from any good corporate hospitals as how they are doing it. That would be a good idea before you design it or before you can implement it. You have to take it from corporate or maybe someone like Metro City in Delhi or Bombay. You have to take it how they are doing it. How is Max doing it? How is Nanavati doing it? How is Apollo doing it? Because it is not done in our hospital so I cannot give you an idea."*

As noted, the existing HIMS was developed by a private company and implemented in the hospital with limited involvement of the providers. The findings also indicated that patients are hardly considered an important stakeholder in defining the requirements and/or the development of EHRs. Further, health literacy and digital literacy is lacking among the patients. Also, the digital literacy among hospital administrators , clinical providers, and other health care workers is very limited. One of the key informants (K 6) mentioned:

> *"I have learned to use computers for entering patient data, filling reports, and sending pharmacy or lab request in the job. Also, if I experience any problem while entering data or generating reports, I had to ask the hospital HIS team for help."*

Another key informant (K 5) explained:

> "*the patient especially from the rural areas are unable to keep their records and share with the doctor during their visit. Also, they do not understand which documentation will be required as part of their next visit. In general, such patients remember their medication by the color of the pills rather than by the drug name."*

4.3.3 Data System and Workflow

This subsection describes finding related to health data system, clinical workflow, data collection and sharing processes, available workforce, technology, and financial resources. Figure 19 provides the process overview of the linkages among various sub-systems within the hospital. As shown in the Figure a patient interacts with clinical administrative hospital staff during routine and inpatient visits. These interactions include patient registration, admission, billing, lab testing, drug prescription, physician order, labor room and surgery related encounters. The patient also interacted with the pathology laboratory, pharmacy, and the radiology laboratories for services unavailable within the hospital.

Figure 19. Current relationships among various information systems within the hospital

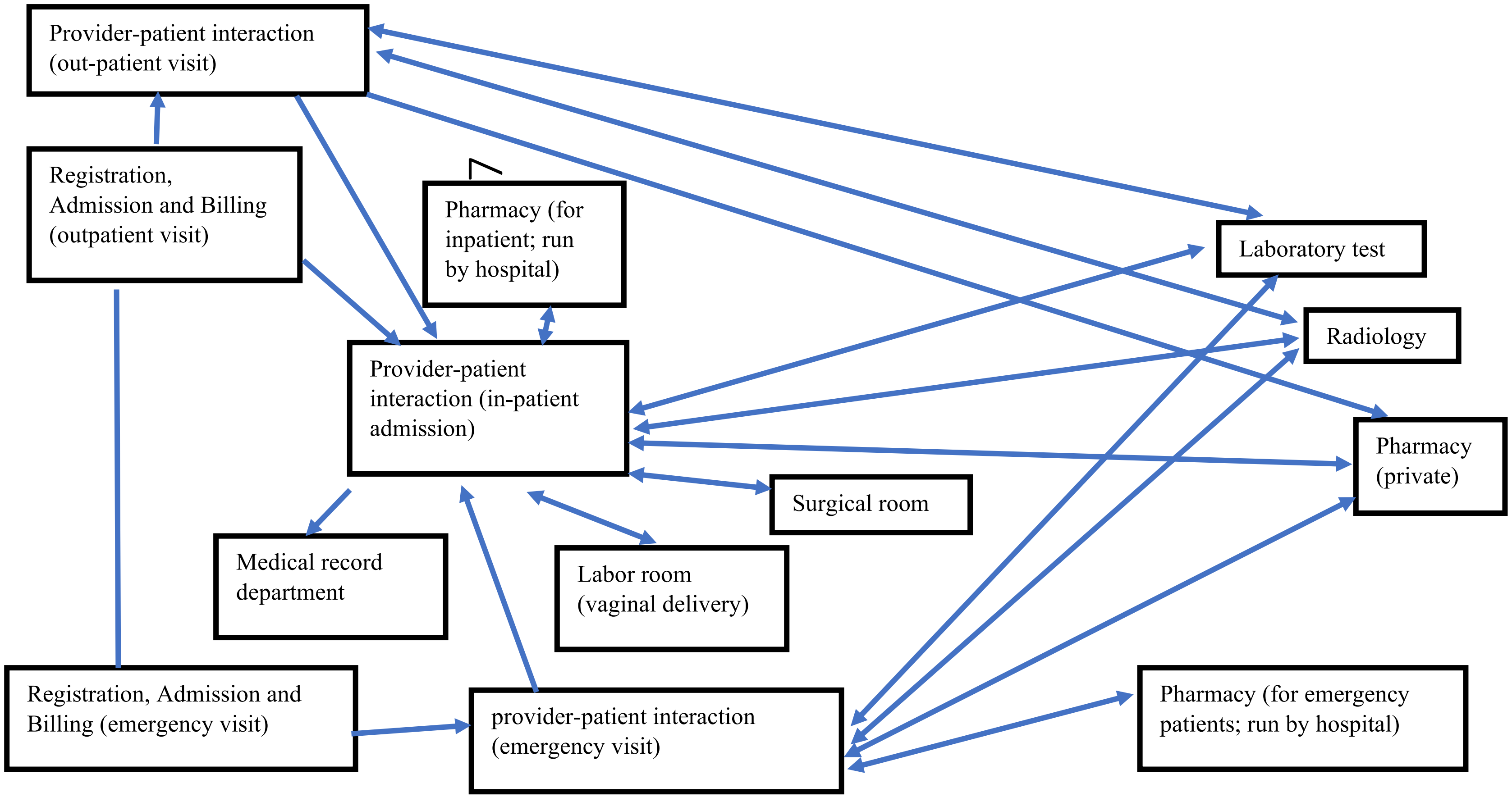
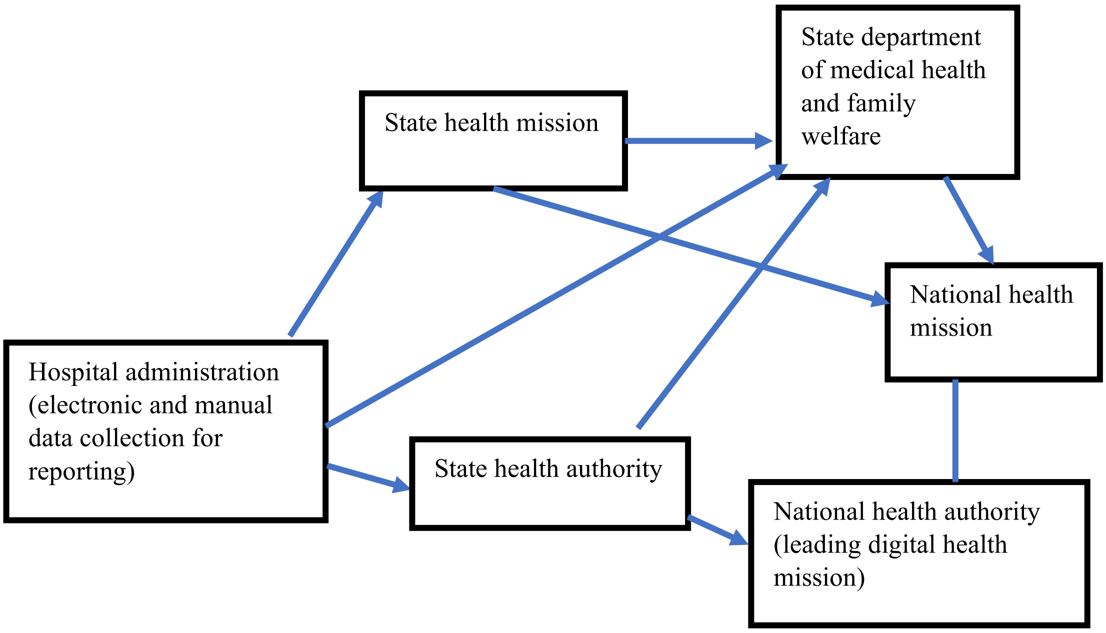


Figure 20 shows program reporting linkages involving hospital, state, and national level stakeholders. The hospital synthesizes and reports aggregate health data to hospital administrators, as well as state and national health program agencies. A more detailed process flow is presented in Appendix F.

Figure 20. Interorganizational linkages for program reporting



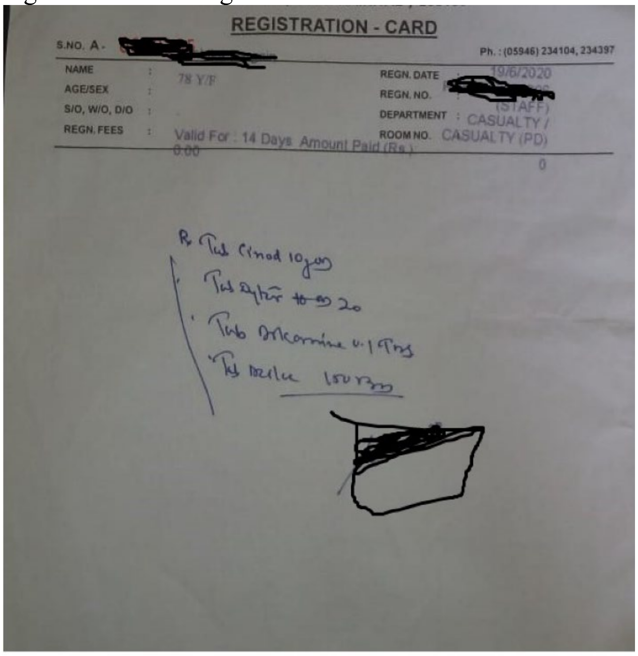
Appendices F to V show scanned copies of different data collection forms and reports (paper and electronic) used in the hospital. The forms and reports are listed in Table 18. A review of these forms and reports shows that at least 25% of the data fields are the same in each of these forms.

Table 18. Data collection forms and reports

#	Form/Report title
1	General OPD register
2	General IPD register
3	Emergency register
4	General case history form
5	Patient consent form (surgery)
6	Pathology and radiology referral form
7	Pathology OPD and IPD register
8	Hemogram and coagulation profile reporting form
9	Cardiology requisition slip
10	Referral form for CT-SCAN
11	Urine/body fluid requisition and reporting form
12	Blood requisition form
13	Blood chemistry requisition and reporting form
14	Laboratory report and discharge summary
15	Bed availability and medicine follow-up report
16	Hospital census report

The findings show that the patient data in the hospital is collected, stored, and shared through electronic and paper-based health records system. The patient registration (Figure 21) and admission (Figure 22) information are captured in an eHIS.

Figure 21. Patient registration card



REGISTRATION - CARD

S.NO. A - [redacted]

Ph. : (05946) 234104, 234397

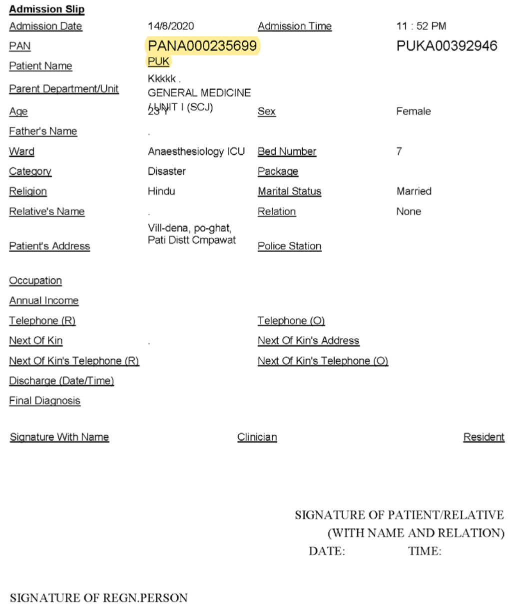
NAME : [redacted]
AGE/SEX : 78 Y/F
S/O, W/O, D/O : .
REGN. FEES : Valid For : 14 Days Amount Paid (Rs.) 0.00

REGN. DATE : 19/6/2020
REGN. NO. : [redacted]
DEPARTMENT : (STAFF) CASUALTY /
ROOM NO. CASUALTY (PD)
0

R Tab Cinod 10 mg
Tab Syltir ~~10 mg~~ 20
Tab Arkamine 0.1 mg
Tab [illegible] 150 mg

[redacted]

Figure 22. Patient admission



Admission Slip

Admission Date	14/8/2020	Admission Time	11 : 52 PM
PAN	PANA000235699		PUKA00392946
Patient Name	PUK Kkkkk .		
Parent Department/Unit	GENERAL MEDICINE / UNIT I (SCJ)		
Age	23 Y	Sex	Female
Father's Name	.		
Ward	Anaesthesiology ICU	Bed Number	7
Category	Disaster	Package	
Religion	Hindu	Marital Status	Married
Relative's Name	.	Relation	None
Patient's Address	Vill-dena, po-ghat, Pati Distt Cmpawat	Police Station	
Occupation			
Annual Income			
Telephone (R)		Telephone (O)	
Next Of Kin	.	Next Of Kin's Address	
Next Of Kin's Telephone (R)		Next Of Kin's Telephone (O)	
Discharge (Date/Time)			
Final Diagnosis			

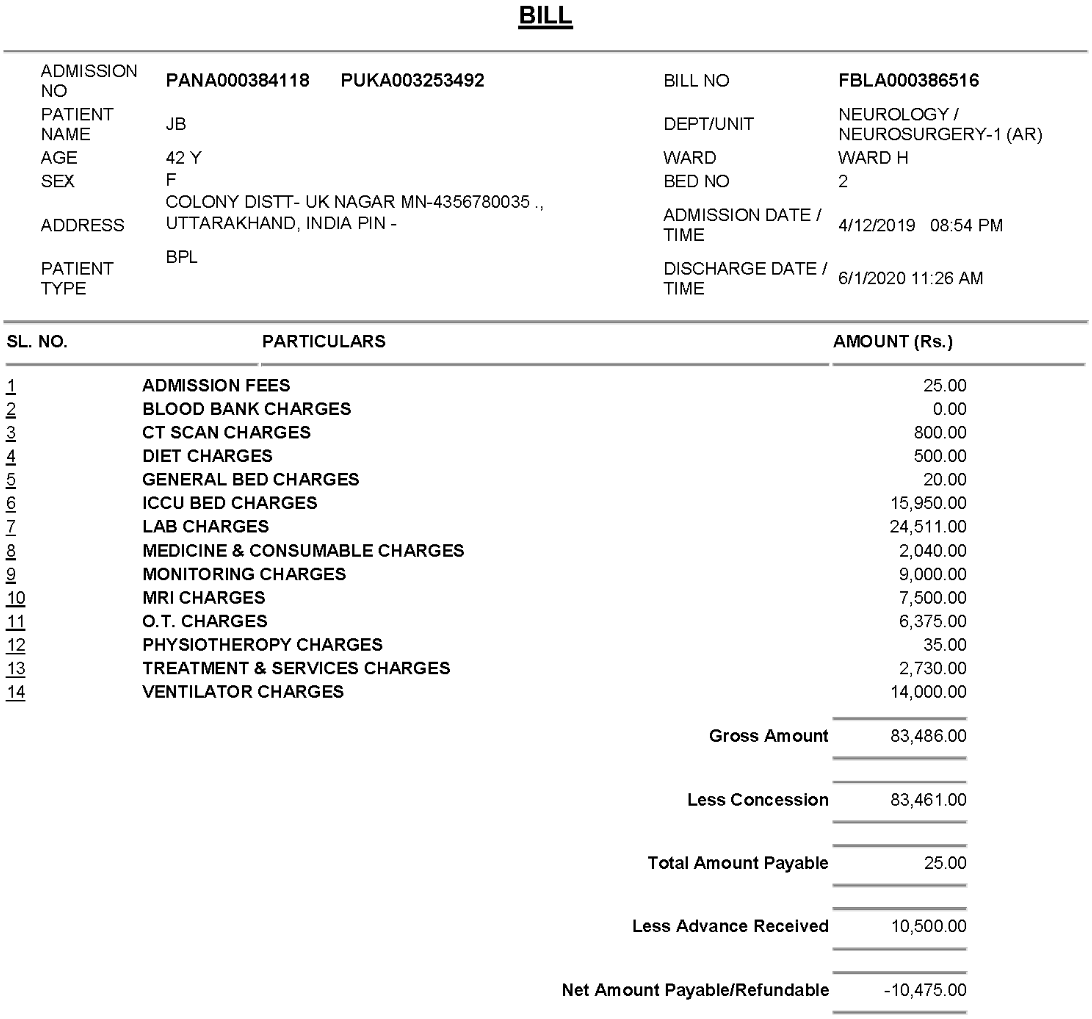
Signature With Name   Clinician   Resident

SIGNATURE OF PATIENT/RELATIVE
(WITH NAME AND RELATION)
DATE: TIME:

SIGNATURE OF REGN.PERSON

Similarly, the billing report is created through the electronic system (Figure 23).

Figure 23. Billing report



BILL

ADMISSION NO	**PANA000384118 PUKA003253492**	BILL NO	**FBLA000386516**
PATIENT NAME	JB	DEPT/UNIT	NEUROLOGY / NEUROSURGERY-1 (AR)
AGE	42 Y	WARD	WARD H
SEX	F	BED NO	2
ADDRESS	COLONY DISTT- UK NAGAR MN-4356780035 ., UTTARAKHAND, INDIA PIN -	ADMISSION DATE / TIME	4/12/2019 08:54 PM
PATIENT TYPE	BPL	DISCHARGE DATE / TIME	6/1/2020 11:26 AM

SL. NO.	PARTICULARS	AMOUNT (Rs.)
1	**ADMISSION FEES**	25.00
2	**BLOOD BANK CHARGES**	0.00
3	**CT SCAN CHARGES**	800.00
4	**DIET CHARGES**	500.00
5	**GENERAL BED CHARGES**	20.00
6	**ICCU BED CHARGES**	15,950.00
7	**LAB CHARGES**	24,511.00
8	**MEDICINE & CONSUMABLE CHARGES**	2,040.00
9	**MONITORING CHARGES**	9,000.00
10	**MRI CHARGES**	7,500.00
11	**O.T. CHARGES**	6,375.00
12	**PHYSIOTHEROPY CHARGES**	35.00
13	**TREATMENT & SERVICES CHARGES**	2,730.00
14	**VENTILATOR CHARGES**	14,000.00

Gross Amount	83,486.00
Less Concession	83,461.00
Total Amount Payable	25.00
Less Advance Received	10,500.00
Net Amount Payable/Refundable	-10,475.00

The clinical diagnosis, laboratory and imaging results, the treatment details and doctor's notes are captured in a paper form during the outpatient visit. One of the key informants (K 3) explained the current HIMS workflow:

> *"The current HIMS, we are using, the patient has to come to the OPD registration counter in the initial stage. We have two areas of OPD. One is general registration The other area is casualty OPD. If a patient comes in emergency the patient goes to casualty. He does not come in general OPD. He goes to the emergency counter. The emergency counter is 7/24. The general counter timing is 9-2. Now what part is electronic let me tell you. So, registration is electronic. Patient investigation is automated. Investigation reporting is automated. Admission referral from OPD is also automated. System generates admission slip and also the payment collection is automated. All this is through HMIS. With the hospital information system, we are looking at bed availability and then assigning it. Reception counter checks bed availability for the recommended ward. So, this is admission through general OPD.*
>
> *Once lab confirms that we have received the sample and then, it enters the process. Then, the charges are added to the patient bill for that investigation. They will do the investigation manually and manually means it is through a machine. But we have not added them to the systems from the machine because this system is old, and machines have come later. We did not integrate the machines, but we (lab staff) clean the data that comes from the lab), and after that its entry is done. So, the doctor can review and see the data in the*

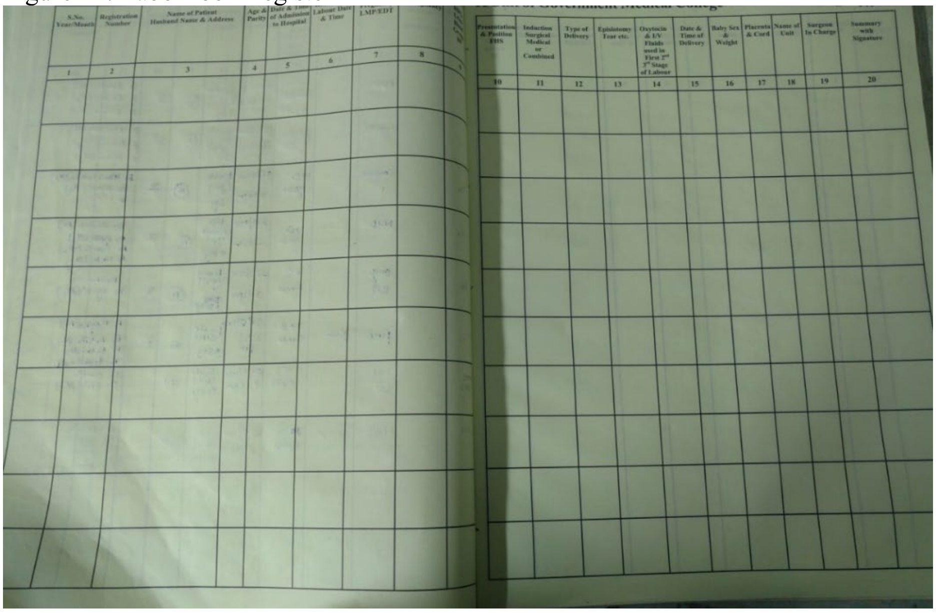
system, and they can take out the print at their end. So, this process continues even if there is a surgery and the report is generated from the system.

So, OPD reports are done manually but IPD reports are done electronically. Lab report was done manually. The billing is always electronic. A patient identifier is used for the running the process, using a PANA number, the patient admission number. So, the patient admission number is used and through that she checks whether the patient exceeded the deposit or still some money is left.

Central pharmacy is not connected. We had covered the store which included pharmacy as well. Because we have old system, so we cannot do it. But if we get a new system then we may think. Now technology has also advanced. You do not have to do a lot of manual things. You have a magnetic strip and you also have barcodes. So, there are lot of things that you can use."

If a patient is admitted into hospital, then the admission and billing information is captured in the electronic HIMS. The diagnosis and treatment details are captured in patients' paper-based health record. The lab results, prescription drugs and imaging details are also captured in the paper record. From admission until discharge, the patient data is captured in multiple registers associated with patient admission, labor room (Figure 24), operation theatre (Figure 25), childbirth, and final discharge. All the registers are paper-based records, and these register data are not entered into the computerized reports. The paper-based patient record is finally submitted to the medical record department for curation and the patient receives a discharge summary which includes diagnosis, treatment, and future actions.

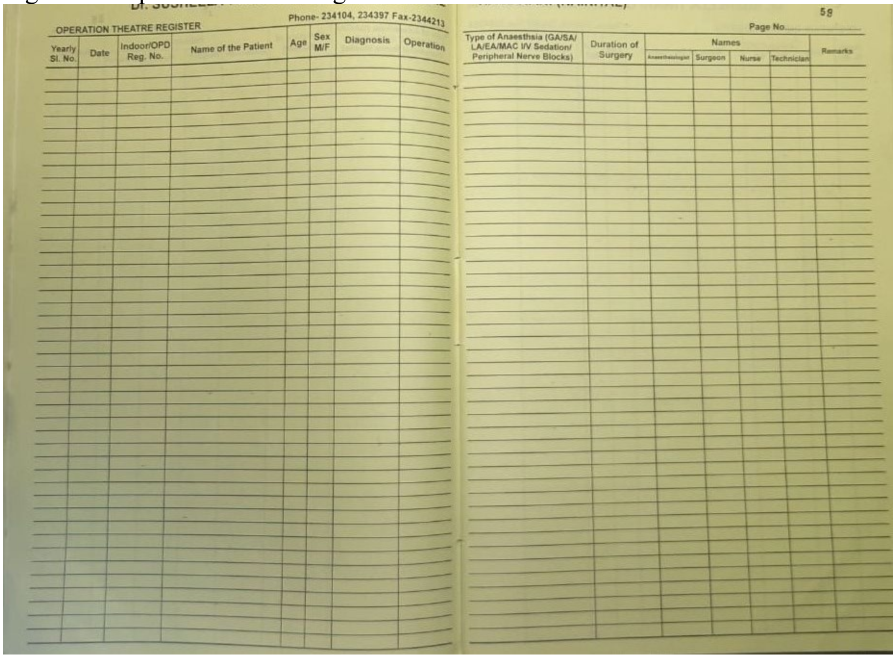
Figure 24. Labor room register



S.No. Year/Month	Registration Number	Name of Patient Husband Name & Address	Age & Parity	Date & Time of Admission to Hospital	Labour Date & Time	LMP/EDT	
1	2	3	4	5	6	7	8

Presentation & Position FHS	Induction Surgical Medical or Combined	Type of Delivery	Episiotomy Tear etc.	Oxytocin & I/V Fluids used in First 2nd 3rd Stage of Labour	Date & Time of Delivery	Baby Sex & Weight	Placenta & Cord	Name of Unit	Surgeon In Charge	Summary with Signature
10	11	12	13	14	15	16	17	18	19	20

Figure 25. Operation theatre register



Phone- 234104, 234397 Fax-2344213

58

OPERATION THEATRE REGISTER

Page No.

Yearly Sl. No.	Date	Indoor/OPD Reg. No.	Name of the Patient	Age	Sex M/F	Diagnosis	Operation	Type of Anaesthsia (GA/SA/ LA/EA/MAC I/V Sedation/ Peripheral Nerve Blocks)	Duration of Surgery	Names				Remarks
										Anaesthesiologist	Surgeon	Nurse	Technician	

Once a patient is admitted to the hospital the nurses prepare reports which capture details such as patient name, age, childbirth, and mode of childbirth. The reports are submitted through electronic HIMS. The paper file is used by the medical record department to complete national and international reporting requirements associated with maternal death using the ICD codes. The MRD uses the electronic reporting system to manage patient record in-house, but it is not connected with the electronic HIMS.

As one of the key informants (K 6) stated while explaining the record keeping for inpatients:

> *"So, once the patient is admitted, we check name, address and which doctor is treating through the computer. Once the patient is moved to labor room or operation room, those details are entered. Delivery details for normal and C-section are also entered in computer. But treatment and medication details including doctor and nurse notes are in the paper-based paper file. The paper file is submitted to the MRD section after patient is discharged from the hospital."*

The data for the PMJAY and the JSY are collected in two separate data system. The PMJAY offers a comprehensive package of health care services including childbirth. The safe motherhood program has the aim of providing financial incentives to pregnant woman to access facility-based childbirth services or a home-based childbirth facilitated by a skilled birth attendant. The financial incentive program is applicable for both public and private medical facilities. The financial amount varies for urban and rural settings and the payment is directly deposited into the bank account of the beneficiary, that is the woman giving birth to a child. One of the key informants (K 2) described the JSY process as:

> *"A patient gets the registration slip for INR 5 and then goes to the GYNAE OPD. If the doctor recommends hospitalization, then she/he fills a form and hands over to the patient who visits the registration counter. The registration counter issues a zero-fee receipt. All deliveries in the hospital are covered by JSY. The patient goes to the ward where a consultant (assistant professor, associate professor, professor, or department head) fills a form and provides the signed copy to the patient or his/her attendant. The patient*

> *or attendant goes to the reception and submits the form. They get a zero receipt and submit it to the ward. After that, all the tests and treatment for the delivery is free and managed by the ward... when the delivery is completed, there is another counter where there are two people at that counter. So, every morning, they monitor how many deliveries in the year, how many in the night. So, they go to every bed and fill a form that includes four documents. One thing is a patient discharge paper. The discharge paper is a proof that there was a delivery, and we take that on the original form so that no one can apply again. Second one is address proof whatever they have submitted for discharge. Third thing is whether the patient has TT injection or not and is proof. The fourth thing is that the money will go to the bank account. So, the copy of the bank account."*

The eHIS generates a few standardized reports for sharing with the hospital administrators. For the purpose of reporting to the state, health program managers and administrators and the HIT coordinates with different departments in the hospital to gather the data required for reporting. The team develops customized reports depending upon the request from the SHM managing programs under the NHM, the SHA, DME, DMHFW, and other national level agencies. The reporting is focused on aggregate data about the beneficiaries of financial incentive program, PMJAY, and the number of health care procedures performed. The PMJAY uses its centralized information system to capture data directly from the hospitals. It is a centralized system that has approval processes integrated for verification and accountability before depositing expenses to the hospital bank account. The PMJAY data collection, reporting, and auditing requirements are managed by a dedicated team in the hospital. While there is no requirement to keep the paper records, the team keeps a physical copy of the beneficiary documents for audit purposes. One of the key informants (K 9) said:

> *"Because I am in-charge, so it is not very hectic. I have 10-11 people under me who do the work. Sir the problem is no one takes our side. So, when the audit is done and the claims are rejected, a lot of claims affected. Here also when we get the query, there is nobody to reply for that query. Even if we do reply why we did it. They ask us we give them the information. A patient came to us they took the benefit. So, we have the paper, and we will give it to them. Sometimes audit is a trouble. But we have papers, so it is fine."*

PMJAY reporting data is also used by the state DMHFW to determine the total number of beneficiaries covered under the national and state budgets. The state had expanded the eligibility criteria of the PMJAY to include additional families into the health insurance network. The financial incentive program finds institutional reporting as aggregated data to the SHM which, in turn, shares the data with the NHM together with all other health program monitoring data.

The data collection, reporting, operation, and maintenance of health information technology infrastructure is supported by a team of seven members. The hardware, software, and network for the entire hospital and the medical college is managed by the same team of seven members. This HIT team of the hospital is supported by the staff responsible for patient registration and admission, an administrative assistant supporting data entry, the staff nurse in the inpatient ward, and the medical record department team. The data collected by the pharmacy, laboratory, and radiology teams remains in their own computer systems and the patient and/or the provider receive the information only in paper forms.

The health insurance data workflow and processes have a mix of paper and electronic systems but are relatively well defined as defined by one of the key informants (KI 12).

> *"Our cashless program is totally electronic. You get an email ID and once you get the claim you need to send it with this email ID. One thing like I told you there is a preauthorization form. So, what we have done is that once the customer goes to the hospital, they show their card to the third-party administrator who activates the process. Here the insurance agent gets an SMS, one SMS is sent to customer, another SMS is sent to the district officer, and the fourth SMS to the branch manager. So, these four people are alerted. So, the message that customer gets ask patient to contact his branch manager. The message also says that we have taken your claim and if you have any problem please contact the branch manager in case you have any difficulty."*

4.3.4 Stakeholder Health Information Needs

The national and state level policy makers and program managers require aggregated health care data to monitor progress, identify gaps, and initiate corrective actions to overcome programmatic, data systems and workflows, workforce and financial, and technology and infrastructure barriers impacting maternal health service delivery and program management. The national and state level stakeholders also need information to assess reach of maternal health care service, financial incentive programs and the PMJAY. The data is also required to ensure that all the qualifying beneficiaries of financial incentive programs are able to access those incentives. These data are also needed to monitor and enforce financial accountability.

For example, one of the key informants (K 9) mentioned:

> *"We are required to collect individual beneficiary details for the health insurance program and report through the electronic system to the state health agency. We also need to keep the individual beneficiary records for audit purposes."*

Another key informant (K 2) mentioned:

"W*e have to keep records for each childbirth in the hospital for reporting to the state health mission.*"

This requirement is associated with cash transfers for childbirth in the hospital. The data reporting allows the SHM and the NHM to determine the coverage and cost for delivering in the hospital. Aggregated data about the number of patients by type of health care services received, number of hospitalizations, drug distribution, and the number of patients receiving financial incentives is needed by the hospital administrators to monitor program progress and identify gaps in delivery of financial incentives associated healthcare services.

4.3.5 Health Data Use

The hospital administrators use service delivery, financial costs, workforce, and infrastructure data to assess operational capabilities and routine operational decision-making. The data is also used to determine future clinical, management, and operational requirements related to planning, delivery, and monitoring of maternal health care services in the hospital. As described by one of the key informants (K 1):

> *"So, college decisions are made by the principal but for things are not working, doors are broken, OT needs to be sanitized in the hospital say a patient turns out positive in COVID and those are made by the MS. Ultimate control rests with the principal only. Hospital part is with the MS and college, teaching part is with the principal. But even MS comes under the principal. But ultimately it is the principal."*

The decision to admit a patient is made by the doctor whether a patient visit is routine or for emergency reasons. This was explained by one of the key informants (K 5) for an emergency visit:

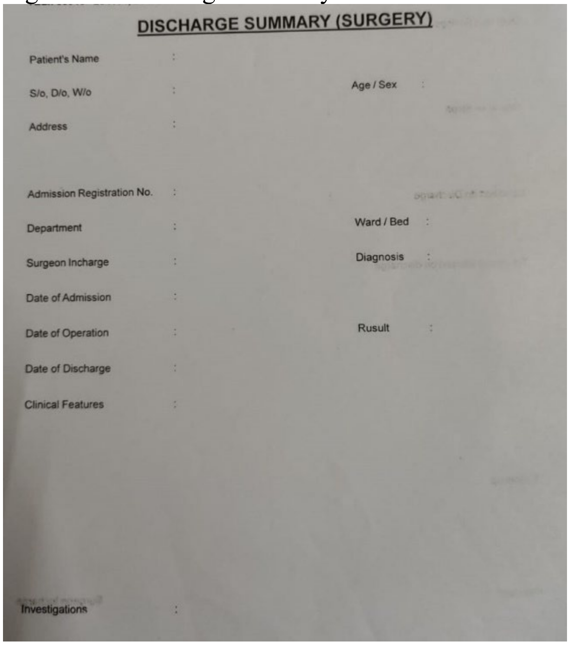
> *"The admission, billing, collection, investigation, and if they got ultra-sound or X-ray, all this is done through the emergency counter electronically. If the patient needs to be shifted to ICU or they think patient needs to be shifted to general ward, that will also happen through casualty counter based on patient condition."*

The administrators also require data about the workforce availability, their expertise, and clinical and teaching requirements to develop and implement a plan ensuring that the right people are available for the right job. One of the key informants (K 1) mentioned:

> *"I need to create a roster of all my doctors so that I can assign them clinical and teaching responsibilities on a rotation basis. The workforce data allows me to plan and I locate limited human resource for the for the fulfillment of patient care, administrative, and teaching and research responsibilities since our hospital is associated with the Medical College."*

The hospital staff responsible for the PMJAY and the JSY use beneficiary data to determine the coverage of the programs. The patients need the diagnostics, medication prescription, laboratory results, imaging, and doctors' notes for their records to help with their follow up visits with the same provider or another provider if seeking referral services. The patient receives doctors' notes, lab results, medication prescription, and imaging results in the same prescription during an outpatient visit. The OPD registration form provides a brief summary of all the diagnoses and the doctors' notes. The detailed diagnostic results, medication receipts and imaging are available separately. For an inpatient visit the patient receives a discharge summary which describes the diagnosis, result, and clinical features (Figure 26).

Figure 26. Discharge summary form



DISCHARGE SUMMARY (SURGERY)

Patient's Name :

S/o, D/o, W/o : Age / Sex :

Address :

Admission Registration No. :

Department : Ward / Bed :

Surgeon Incharge : Diagnosis :

Date of Admission :

Date of Operation : Rusult :

Date of Discharge :

Clinical Features :

Investigations :

One of the key informants (K 6) described the decision-making points by explaining how a pregnant woman was treated in the hospital:

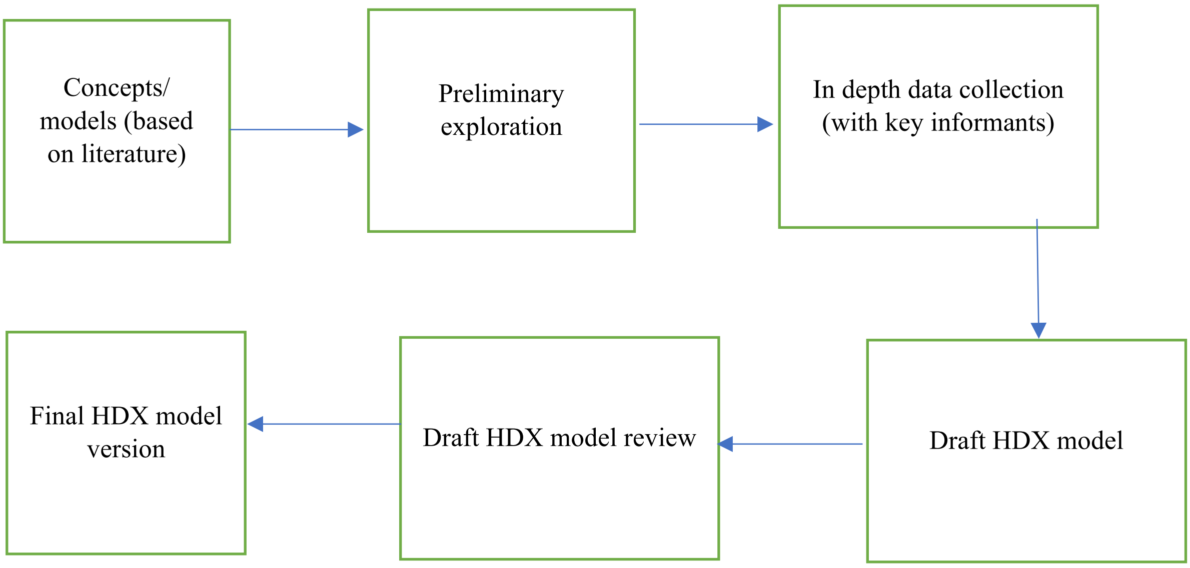
> *"Let us see a patient came in the OPD and has a nine-month pregnancy and is in labor. And the doctor decides that patient is going to be in labor. So, then they send them to the Ward. Then the doctor checks the patient in the Ward, and they admit the patient. And they will decide whether delivery will be normal or C-section. If it can be done normally, they will do it through the normal delivery procedures and will administer all the medications. But if it does feel that the fetus has any problem. They will do caesarean.... If this is the first case of the delivery, then we wait for 12 to 24 hours. Sometimes it is quicker and sometimes it takes more time. So, we keep the patient for one hour after the delivery for observation and then shift in the ward from the operation room. So, normally we have to keep the patient for 48 hours after the delivery and then only we can discharge them."*

The private health insurance providers ask for final patient diagnosis, treatment, and payment details to review eligibility and process payment reimbursement.

4.4 Health Data Exchange Model

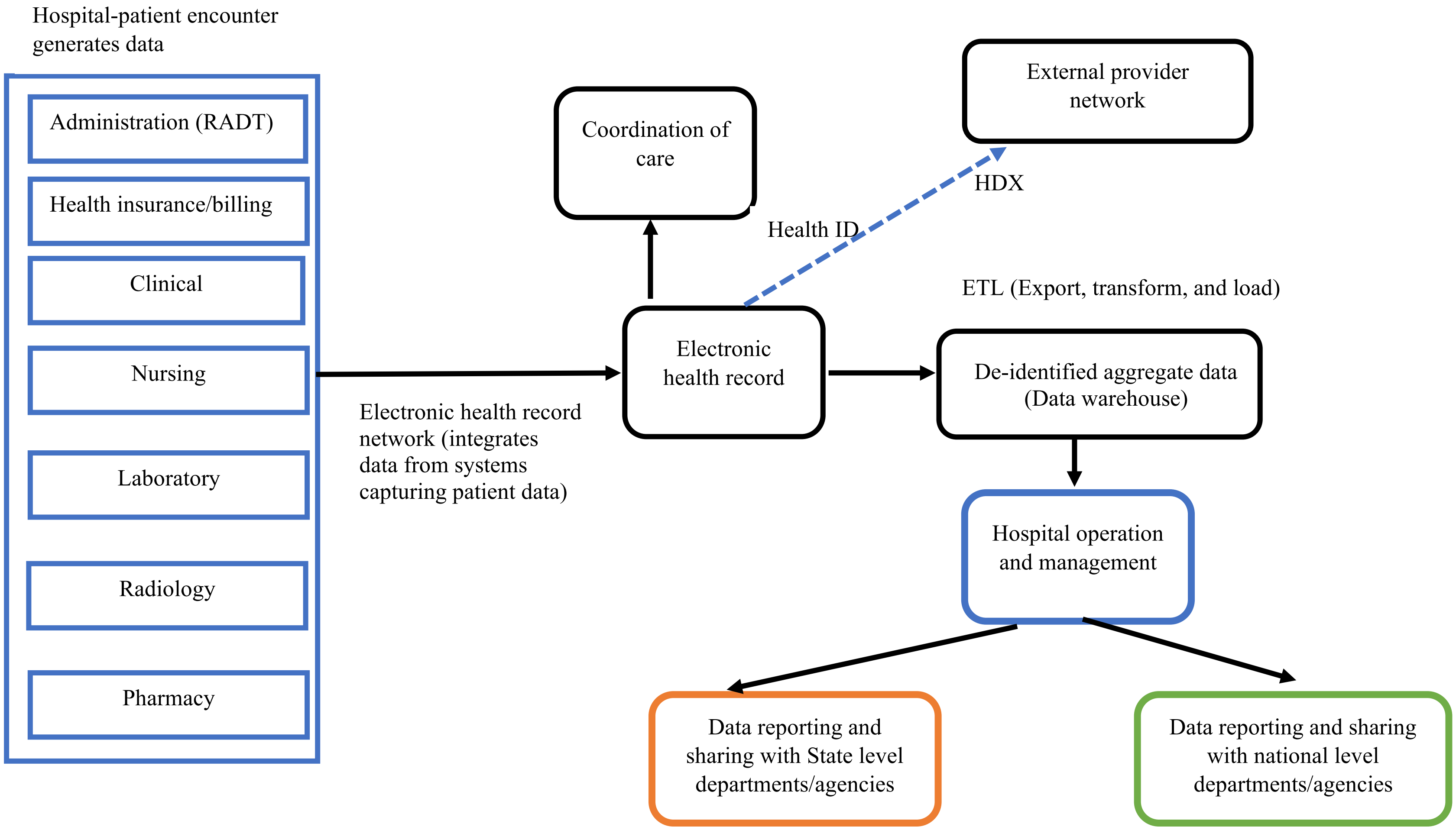
In this section, a HDX model is proposed that describes interorganizational information sharing by leveraging the hospital EHRs. The purpose of the model is to enable use and reuse of data for maternal health service delivery and program management decision-making at hospital, state, and national levels. The model development followed a systematic and iterative design process (Figure 27). The steps included review of the available literature, initial exploration with key informants, and in-depth qualitative data collection to develop and draft the HDX model. The draft model was presented to two key stakeholders in a one-to-one video conference meeting for review and feedback. One of the meetings was with a former national MCH program expert of the government. The second stakeholder was a senior hospital administrator who also had clinical responsibilities.

Figure 27. HDX model development process



Based on the combined feedback the model was revised. Final version of the model (Figure 28) is presented in this subsection.

Figure 28. Proposed HDX model



As presented in the earlier subsections, the systems, processes, and stakeholder roles and responsibilities associated with data collection, storage, reporting, and use are unclear and fragmented. A patient health record is captured in disparate systems during registration, admission, billing, transfer (RADT), inpatient care coordination and procedures, and in external interactions with providers and other health care stakeholders. To improve care coordination, use and reuse of patient and administrative data, data quality, data reporting, patients' access to their health records, and to reduce duplicate data collection and fragmentation of patient records, it is important to standardize clinical workflow, determine minimum EHR data requirements, data collection and reporting system, and data exchange mechanism. The findings showed that that current EHR system and processes add to the burden of the clinical and administrative workforce. The findings show that the patient health records are used by the clinical providers to plan and deliver health care services. The patient data is used by the administrators, insurance providers, and financial incentive programs to track delivery of services (including financial incentives) and measure health program coverage across different population groups. The aggregated patient and administrative data are used for operational, administrative, policy and program management decisions. As one of the key informants (K 1) mentioned:

> *"I use data to determine the clinical, research, and teaching workload and deploy the staff accordingly."*

Affirming the benefit of EHR for both the patients and the providers, one of the key informants (K 5) said:

> *"It will be easy for them and will be easy for us. So, patient will not have to carry health records all the time. If there is a concern from other hospital, they can easily see in what happened. If there is a complication in delivery and the patient comes to you after two years, you have the record to see what happened and how it was treated. If they do not come, they can take the record wherever they want to go."*

The findings showed that that many different types of data were collected during a patient's interactions with clinical providers and other health care professionals in the hospital. Table 19 shows that EHRs include information on patient demographics, diagnosis, problem lists, family history, allergies, immunization, medications, procedures, laboratory data, vital signs, past medical history, and radiology reports, and utilization. Social data such as income level and education, are also captured as they confirm the eligibility of a patient for the health insurance.

Table 19. EHR data types in the hospital

#	Data Type	Example
1	Demographics	age, sex/gender, race
2	Diagnoses	diagnosis, severity, medical history
3	Problem List	active diagnosis, resolved diagnosis
4	Medical History	past procedures, diagnoses, medication, lab, radiology
5	Family History	familial disorders, risk factors
6	Allergies	food and medication allergy
7	Immunization	DTaP, HepB,
8	Medications	prescriptions written, IFA
9	Procedures	inpatient, outpatient
10	Lab Orders/Values	CBC results, HbA1C levels
11	Vital Signs	BMI (weight and height), blood pressure, body temperature
12	Radiology Reports	radiology, pathology, and other reports
13	Utilization	cost, hospitalization
14	Social Data	income level, education
15	Discharge summary	inpatient summary report

BMI = body mass index; CBC = Complete Blood Count; DTaP = Diphtheria, Tetanus, & acellular Pertussis; HbA1c = Hemoglobin A1c; HepB = Hepatitis B; IFA = Iron Folic Acid

The model presented in Figure 28 shows how different workflows in the hospital can be connected through an EHR network to create an EHR for a patient. The EHR network integrates data from administrative, billing, clinical, nursing , laboratory, pharmacy, and radiology system where patient data is captured. As one of the key informants (K 8) said:

> *"So, the main thing is that the data is with us. We have all this data we can connect them. If you are patient 7273, all the labs that we have done, and CT-scan for that patient and other data is in our computers, we can connect them and the patient has the final number, we can transfer it. We can do it systematically. So, for example so we start with pathology and then we start transferring the image in one system."*

The model also shows how de-identified aggregate data can be extracted from the EHRs using export, transform, and load (ETL) processes for reporting purposes and different decision-making within the hospital and at the state and national levels. Aggregated data can be stored in a state level-data warehouse. The model also shows how EHRs can be exchanged with other health care networks through a state HDX proposed in the federated health information architecture of India. The proposed model offers a bottom-up and user-centered (providers as the primary user) HDX development model, with hospital as the main focus, which can positively impact adoption and use of EHRs. As one of the key informants (K 18) said:

> *"I mean everything in India, which has succeeded to any level, it has happened when the demand was created from bottom. And I am not referring to iPhones. I am talking about Aadhar system. Why did I get my Aadhar done? Why should I stand in line and you will get this? One of this is benefits. The other one is that once I have Aadhar no more all this JHANJAT OF YE PAPER LAAO VO PAPER LAAO (trouble of bringing this paper and that paper document). I will just give my Aadhar ID and I am done."*

The HDX model is expected to facilitate operationalization of the HDX vision proposed for the FHIA of India. Figure 29 shows how EHR will enable use of data for patient care, and reuse of data to support management and administrative decisions at hospital, state, and national levels. The interorganizational data exchange arrangements are not well defined and documented. Often, they are confounded with intra-organizational data exchange which can result into report-led data collection and sharing rather than focusing on patient care. The model presents how to balance inter- and intra-organizational data exchange needs.

Figure 29. Proposed HDX to support clinical care and program management

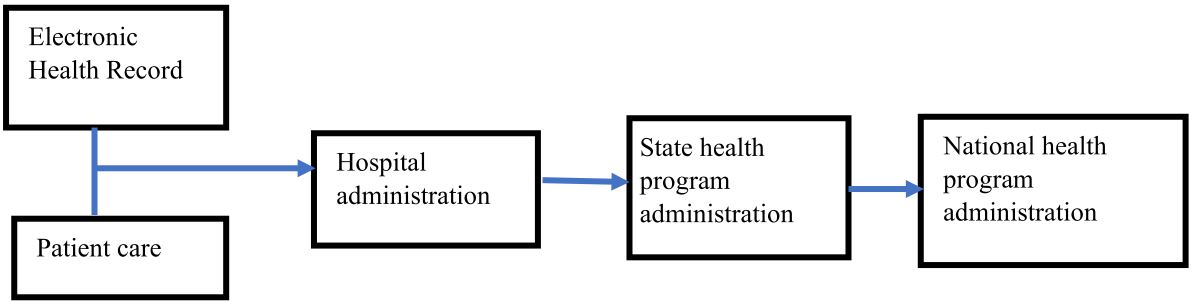
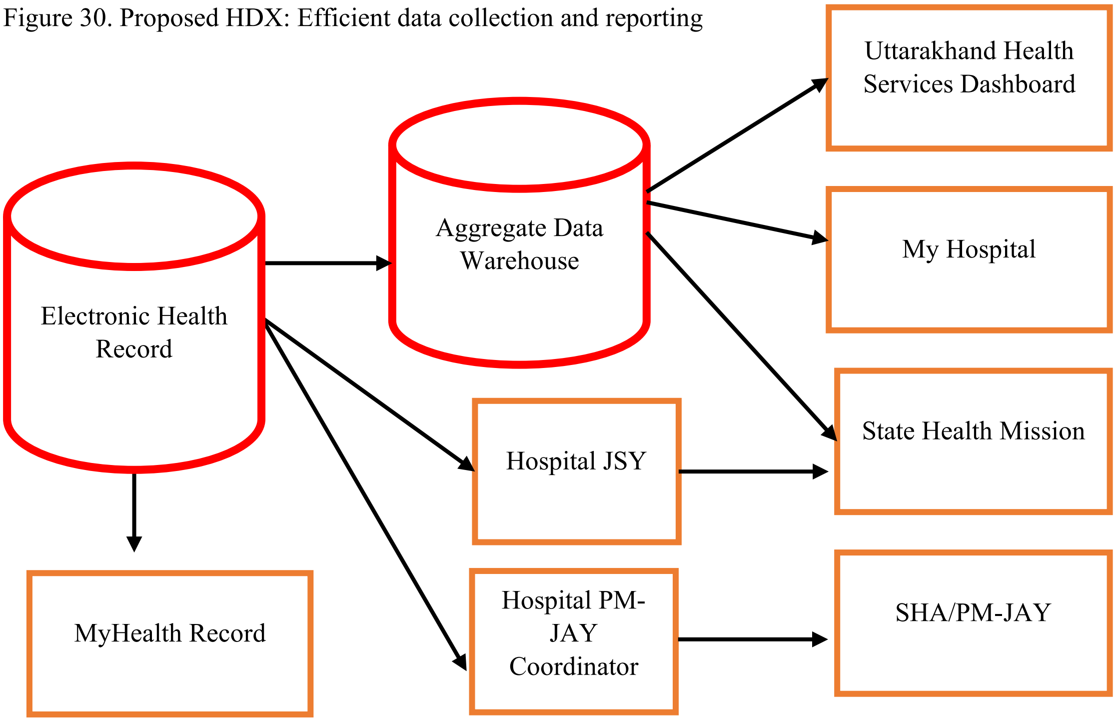


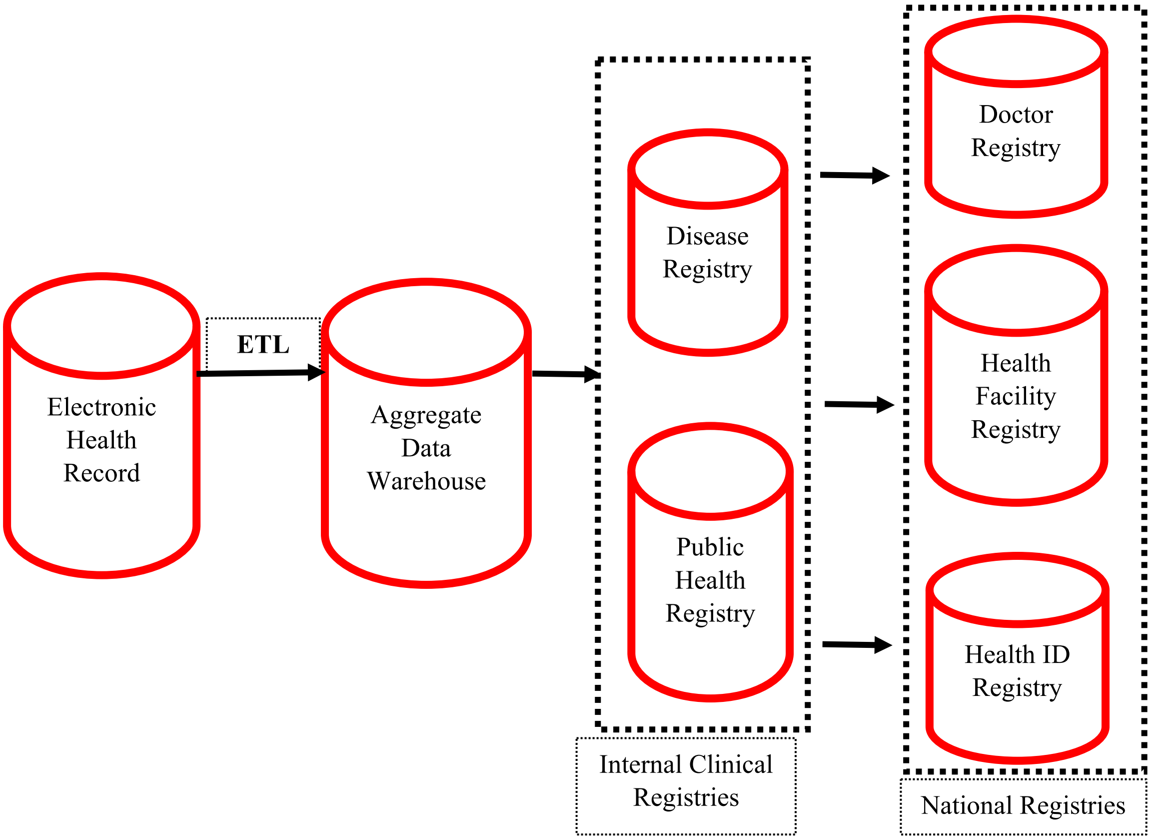
Figure 30 shows how the proposed inter-organizational HDX can improve data collection and reporting efficiency and enable patients to control and manage their health records. As presented in Chapter 3 and also described in this chapter, data collected through patient encounters is accessed and used by hospital administrators, JSY and PMJAY teams, and also feeds into the state health services dashboard besides reporting to the SHA and SHM. Further, the EHR will allow individual patients to access their health record and store it in the MyHealth portal. Lastly, the hospital can also allow patients to use My Hospital ORS for scheduling appointments in the hospital once TSGH completes onboarding process for using.

Figure 30. Proposed HDX: Efficient data collection and reporting



The findings also highlight that the national government is working to create national registries such as a doctor registry, a health facility registry, and a registry for unique health ID. The model allows linking, integration, and merging into a registry. Additionally, the personal health records proposed under the NDHM may leverage data contained in EHRs by integrating with the EHR to allow for real-time or nearly real-time data exchange or by linking with the EHR to allow for periodic transfers of data into the registry. The decision of whether and how to incorporate data from EHR is complex and should be guided by many factors, including the purpose and scope of the registry and the availability of the necessary data elements within an EHR. The TSGH may also create internal registries for diseases and public health purposes which can leverage EHRs by deploying ETL processes. Figure 31 shows the proposed approach to integrate EHR with internal and national registries to facilitate clinical care.

Figure 31. Proposed EHR integration approach with registries for clinical care



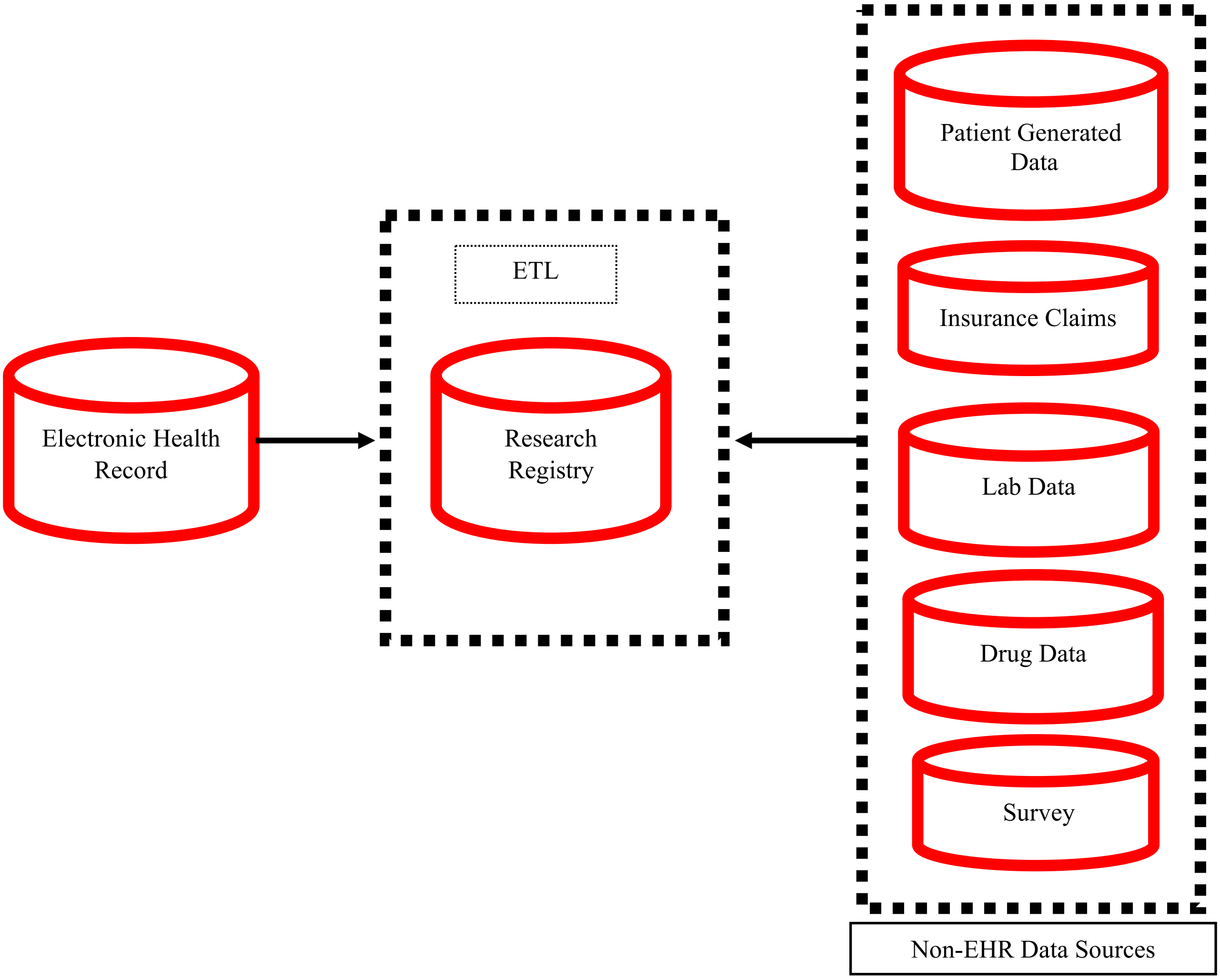
The study did not focus to explore and describe the perspective of researchers and educators. Therefore, use of EHR data for research did not emerge as an important theme. But key informant did mention about research it as it is one of the responsibilities of the clinicians who are involved in clinical research and practice given that the hospital is associated with a medical college.

Highlighting the value of EHRs for research, one of the key informants (K 8) said:

> *"It takes more than a year for a resident doctor to collect data for research work which is an important requirement of the post-graduate education. Availability of and access to electronic health data will make life easier."*

Figure 32 shows how EHR development at the TSGH can strengthen use of clinical data for research purposes by facilitating creation of a research registry. A research registry can harness available data systems for health insurance, drugs, and survey (e.g., national family and health survey) and integrate with lab and patient generated data in future.

Figure 32. Illustrative EHR linked research registry at TSGH



To support the use of data captured in EHRs for clinical, administrative, program management purposes, a health data governance framework is required.

As one of the key informants (K 20) said:

> *"What we try to do before we digitize data, we created a legal framework for data privacy. So, we have drafted something called digital information security bill. So, as per the act, the right of data resides with that person. So, if you are going to a hospital for consultation, lab test, etc., this data belongs to that patient. Which means that if the hospital decides to do anything with that data other than providing care for that patient, it requires permission from the patient."*

The development of EHR at TSGH and its potential implications for integration with research and clinical care registries will be guided by appropriate data governance regulatory frameworks such as the Digital Information Security in Health Care Act (DISHA) 2018. The purpose of the DISHA is to provide a regulatory framework for generation, collection, storage, analysis, transmission, and ownership of patient health data and personally identifiable information. Once implemented, the act would allow extraction of data from EHRs for care coordination, program management, and even research purposes in a safe and secure way.

CHAPTER 5: DISCUSSION

Introduction

The chapter begins with a discussion of the principal findings from the qualitative data analysis in relation to the research aims and questions. Further, a HDX model is presented and discussed in the context of maternal health service delivery and program management at the hospital, state, and national levels. Following the discussion of findings, a concrete set of recommendations and elaborations regarding data exchange and its relationship to EHR data standardization and adoption to support dual use of data (clinical use as primary application and decision support as secondary application). The subsection following the recommendations addresses the strengths and limitations of the research study. In conclusion, the significance of the study, its implications, and future directions are considered.

5.1 Discussion of Findings Related to Research Aims and Questions

The study findings discussed in this chapter shows how leadership capacity, management support, stakeholder coordination, financing, health workforce capacity, technology infrastructure, decision-making authority, data systems and processes, workflow, training, and education, and interorganizational relationships affect use and reuse of health data for improved healthcare service delivery and program management at the hospital, the state, and the national levels. The study did not aim to validate (Aqil et al., 2009; MEASURE Evaluation, 2018; Sittig & Singh, 2010) or propose an appropriate socio-technical model (as described in section 1.4 of Chapter 1) for HDX rather the focus was on developing a data architecture. Still, the findings reaffirm the relevance and applicability of the social-technical model and the PRISM framework reflected in the barriers, stakeholder information needs, data workflow and systems. The detail discussion is presented in the following sections.

5.1.1 Aim 1

The first research aim was focused on identifying factors that favor or hamper development of national and sub-national EHRs to enable HDX for improved maternal health service delivery (antenatal care, childbirth, and post-natal care) and program management. This research aim had one research question.

Research Question 1: What are the perceived drivers of and barriers to the design, implementation, and maintenance of EHRs required for improved maternal health service delivery and program management?

5.1.1.1 Research Question 1

5.1.1.1.1 Barriers to EHR Development and HDX

The findings showed that organizational leadership and management support within the hospital as well as from the state and national government agencies were critical for the development of EHR and HDX. The lack of coordination among various health care programs launched by the national and state governments limited the ability of the examined tertiary care hospital to implement and manage various health care programs. The programs are managed by different government departments and have separate reporting requirements even though the childbirth occurs in the same government hospital. Additionally, apart from the multi-dimensional coordination and management requirements for the maternal health program, the hospital was also dealing with multiple IT support agencies, a reality that complicated hospital-level efforts to upgrade its existing hospital management information system or procure a new technology platform to manage EHRs. The findings highlighted that limited budget was an important barrier in upgrading or procuring new EHR technology platforms. Lack of financial decision-making authority and centralized decision-making are key barriers and impact the motivation level of staff. The study findings support prior research evidence that shows organizational leadership and management capacity as one of the key categories of the success and failure factors related to EHR implementation in low resource settings (Brender et al., 2013; Feldman et al., 2014; Fritz et al., 2015a).

Furthermore, lack of adequate and right mix of trained workforce is limiting national and state governments, and hospitals' ability to promote and increase the adoption of EHRs. Increased workload is another challenge confronted by the healthcare providers. The findings showed that education and training are important for adoption and use of EHR and it needs to target technology, payors or buyers, and clinical people in an organization as well as the client population at large.

Many different health programs are implemented by the state government, the SHA, and the SHM, adding to data duplication, poor data quality, and fragmentation of processes and data systems. Multiple HIS have been created by national and state IT agencies adding to the fragmented data collection and reporting systems, and processes at the hospital, state, and national levels. The findings revealed that government HIT system did not meet the clinical and program requirements as they were not designed to serve as a health record system. The EHR platforms available in the market historically have not meet the patient health record requirements of private hospitals. The study findings are supported by previous studies highlighting adverse influence of HIS design barriers on data quality and data use in LMICs (Manish Kumar, Gotz, et al., 2018).

The findings underlined the lack of data governance mechanisms that guide collection, storage, use, and exchange of patient-level and aggregated data while ensuring data security, privacy, and confidentiality especially at the hospital level. The DISHA act is yet to be approved for implementation. Prior research shows that data governance must be integrated within the organizational strategies to define the purpose for collecting data, ownership of data, and intended use of data, as well as to ensure its implementation as part of the larger organizational effort (Fernandes & O'Connor, 2009).

5.1.2 Aim 2

The second research aim was to document and describe stakeholders, health information needs, health data systems, and workflows associated with maternal health service delivery and program management. The second research aim included three research questions.

Research Question 2: Who are the stakeholders engaged in development of EHRs, maternal health service delivery, and program management?

Research Question 3: What are the stakeholders' health information needs?

Research Question 4: What health data systems and processes are used to collect and use data for decision-making?

5.1.2.1 Research Questions 2-4

5.1.2.1.1 Stakeholder Type and Engagement

The findings describe various stakeholder groups. It was recognized that stakeholder engagement in the development of EHRs, data collection systems and workflow need to consider all stakeholder health information needs and use of data for decision-making.

The national level stakeholder group included various national government agencies and private sector IT and insurance players. The national government agencies were responsible for maternal health policy, program management and implementation, financing, training, health information and IT infrastructure development. The state level stakeholders included department of health, SHM, SHA, DME, state IT department, and state health informatics team. This group also included private health insurance providers, private hospitals, and state level health IT companies. The hospital-level stakeholder group was comprised of administrators, clinicians, pharmacist, nurses, lab technician, HIMS, JSY, PMJAY team, and private laboratories, radiology, hospitals, and clinics. Patients were an important stakeholder at the hospital level given that hospital was the point of interaction with the patient.

A diverse group of stakeholders at national, state, and hospital levels were engaged in the development of EHR. The findings showed that the development of HIT applications and platforms such as eHIS, MCTS, HMIS, *Sanjivini*, etc., were led by the national or the state units of the national agencies with limited or no engagement of the state health IT or hospital IT teams. Moreover, the recently launched NDHM was leading the development of the foundational elements such as the registry of unique health IDs for patients and the doctor registry to support the HDX involving national, state, and facility level health care organizations. Further, the state level health IT infrastructure received funding from the national health programs such as the NHM.

The findings showed that health care providers had no or very limited role in informing the requirements of any EHR platform meant to enable patient-focused service provision. The involvement of hospital administrators and clinicians was confined to the clinical care, and operational issues such as workforce management and maintenance of physical and health technology infrastructure. The findings also indicated that patients were hardly considered an important stakeholder in defining the requirements and/or the development of electronic health records. Digital literacy was lacking among hospital administrators, clinical providers, and other health care workers in the hospital.

Research (Brender et al., 2013) shows that collaboration among various stakeholders is necessary for building an effective national HIS. Such an approach is useful to facilitate discussion among various national and state level public health and IT agencies that play a role in building the health IT infrastructure and managing the maternal health programs. It is also the case that engaging private healthcare providers, insurance companies, and health IT companies in the consultation process would help to understand purpose, motive, capacity, and readiness of various stakeholders. The NDHM aims to engage diverse stakeholders (Ministry of Health and Family Welfare et al., 2020), however functional modalities of engagement remain uncertain.

The existing health IT workforce capacity, both in terms of number and competencies, of the state public health agencies and state government tertiary care hospital in Uttarakhand is very limited as evident from the number of staff managing all the national and state level systems. This finding is consistent with other research studies which describe shortage of HIT workforce as an important bottleneck for EHR development in LMICs (Mandirola Brieux et al., 2015; Munene et al., 2020).

5.1.2.1.2 Stakeholder Health Information Needs and Data Use

The findings highlight overlapping and complex data use and reporting requirements at the hospital, state, and national levels. Often, a common set of clinical and administrative data set is synthesized and reported to multiple government programs. For instance, the national and state level policy makers and program managers required aggregated health care data to monitor progress, identify gaps, and initiate corrective actions to improve program implementation. Similarly, data is required by the state and hospital administrators to review the performance of maternal health programs, JSY, PMJAY, and other welfare programs run by the state. The findings show that stakeholder health information needs are not properly documented, and data reporting processes are ad-hoc or driven by individual requirements which implies that each program or unit has its own understanding and way to determine health information needs and decision-making requirements. The centralized decision-making process further complicates the efforts focused on clarifying data needs in relation to stakeholder role and responsibilities.

The findings reveal absence of policy or guidance to inform collection, storage, and sharing of patient data within the hospital or with the organizations outside the hospital jurisdiction. The hospital administrators used service delivery, financial, workforce, and infrastructure data to assess operational capabilities and routine operational decision-making. The patients needed the diagnostics, medication prescription, laboratory results, radiology, and doctors' notes for their records to help with their follow-up visits or referral services. The private health insurance providers asked for patient diagnosis, treatment, and payment details to review eligibility and process payment reimbursement.

Despite the fact that clearly defined decision-making processes and data needs are critical to drive data demand and use (Abouzahr et al., 2007; Nutley & Reynolds, 2013), the study findings revealed lack of a data use policy and a process to continuously assess health information needs of the stakeholders. Research shows that system design barriers affect data quality and data use in the clinical settings of high-income countries (Sittig & Singh, 2010) which implies that in the low-resource settings of LMICs, the adverse impact of HIS design barriers on data integrity and health system performance might be even bigger than it is elsewhere, leading to errors in clinical care, population health management, and program management (Manish Kumar, Gotz, et al., 2018).

5.1.2.1.3 Data System and Workflow

The findings showed multiple disparate data systems were used for collection of patient information and that the clinical workflow was complex. The patient data in the hospital was collected, stored, and shared through both electronic and paper-based health records systems. The patient registration, admission, and billing information were captured in an electronic HIMS. The diagnosis, and treatment details were captured in patients' paper-based health record. The lab results, prescription drugs, and radiology details were also captured in the paper-based health records. From admission until discharge, the patient data was captured in multiple paper-based registers associated with patient admission, labor room, C-section procedure, childbirth, and final discharge. The paper-based patient record was finally submitted to the medical record department for curation and the patient received a discharge summary which included diagnosis, treatment, prescription information. Findings revealed that the financial data for national health insurance program, JSY program and hospital-based services were captured in disparate systems and reported to respective state and national agencies. For reporting to the state health agencies and state administrators, the HIMS team had to coordinate with different departments in the hospital to gather data for reporting. The reporting is focused on aggregate data about the beneficiaries of financial incentive program, health insurance, and number of health care procedures performed. While there was no requirement to keep the paper records for the beneficiary of the national health insurance program, the team in the hospital-maintained paper records for each of the beneficiaries for audit purposes. The data collected by the pharmacy, laboratory, and radiology teams remained in their own computer systems and the patient and/or the provider received the information only in paper forms.

The study findings suggest that development of EHR to enable HDX will require changes in clinical documentation, and quality management workflow process of the hospital with an aim to deliver patient-centered healthcare services while meeting the interorganizational data sharing requirements. The importance of key processes in clinical practices is well acknowledged. But implementation and sustainability of changes in clinical workflow processes is a complex, resource intensive, and slow process. In the initial phases, a communication workflow process can focus within the organization that includes patients, physicians, nurses, lab technicians, pathologists, pharmacists, and administrative staff. An effective communication workflow will enable comprehensive and accurate clinical documentation that will, in turn, strengthen delivery of quality care to patients (Sittig & Singh, 2010) and support population health reviews.

The study findings are similar to other research findings suggesting that successful HIS implementation depends on its alignment with the organizational context, perceived benefits, costs, and also organizational ability to support workflow processes (Brender et al., 2006). Studies show that information system issues are a major challenge (Feldman et al., 2014) and include information system development processes, user involvement, standards of use, system architecture, affordable and stable technologies, and technical support and maintenance services (Brender et al., 2006; Fritz et al., 2015b; Luna et al., 2014). Even though user involvement, workflow, human-computer interactions, and user experience are critical aspects of system design (Sittig & Singh, 2010), the findings suggest that these issues did not receive attention or priority. Furthermore, findings show that EHR training and education at state and hospital levels were geared toward maintenance of existing systems rather than imparting system design skills, such as requirement gathering, user-centered design, and usability evaluation to overcome system design barriers encountered by HIS users (Manish Kumar, Gotz, et al., 2018).

5.1.3 Aim 3

The third aim was to propose a HDX model for improved maternal health service delivery and program management at hospital, state, and national levels. The third research aim had two research questions.

Research Question 5: What are the essential design and development requirements?

Research Question 6: How will the model enable HDX to support use and reuse of data for improved maternal health service delivery and program management at hospital, state, and national levels?

5.1.3.1 Research Questions 5-6

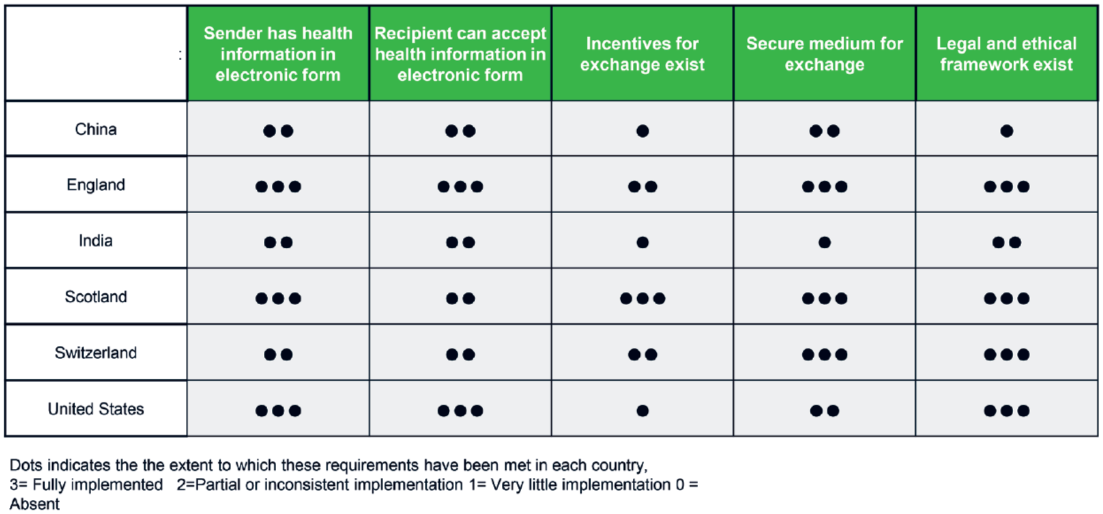
5.1.3.1.1 EHR and HDX

The recent digital health strategy and guidance documents published by international organizations aims to promote adoption of digital health technologies such as EHRs to facilitate patient-centered care delivery and data exchange for program management and policy development (African Union, 2020; WHO, 2020a). Moreover, EHRs are one of the key pillars for achieving the vision of national HDX that includes state, and facility level HDX capacity. Even though effective and efficient electronic HDX is an important health system strengthening goal for most countries, there is wide variation in what countries have been able to achieve, and particularly LMICs like India (Payne et al., 2019).

Based on the findings presented in earlier sections of this chapter, a model was proposed for the development of an EHR in a state government hospital setting to enable patient care as well as program management within the hospital and allow HDX with state and national level public health organizations. The model shows how different workflows in the hospital can be connected through the EHR network to create an EHR for a patient. The EHR network can integrate patient data from administrative, billing, clinical, nursing , laboratory, pharmacy, and radiology system. The model overcomes barriers associated with fragmented data collection systems and processes, care coordination, data quality, and access to patient health records. Further, it can reduce data entry burden on hospital staff and enable clinical providers to plan and deliver health care services. The model also shows how de-identified aggregate data can be extracted from the EHR through ETL process for reporting purposes and to aid different decision-making within the hospital and at the state and national levels. Aggregated data can be stored in a state level data warehouse. The model also shows how EHR data can be exchanged with other health care networks through a state HDX proposed in the FHIA of India. The model allows linking, integration, and merging into a registry since the NDHM has proposed to create a health ID, a doctor registry, and a facility registry. The personal health records proposed under the NDHM may leverage data contained in EHRs by integrating with the EHR to allow for real-time or nearly real-time data exchange and by linking with the EHR to allow for periodic transfers of data into the registry. The decision of whether and how to incorporate data from EHR is complex and should be guided by many factors, including the purpose and scope of the registry and the availability of the necessary data elements within an EHR. The proposed model offers a hospital focused EHR development model which can positively impact adoption and use of EHR by overcoming information system design barriers and contribute to improved data quality and data use (Manish Kumar, Gotz, et al., 2018).

The study findings and the proposed model fulfills the requirements of for an HIE outlined in a recent study (Payne et al., 2019)which compared the status of HIE in six countries including India. The study compared the HIE status across six countries using exemplar HIE scenarios focusing on transfer of care and referral and mentioned that HIE requires electronic medical record systems or other systems to gather clinical information, both at the point of capture and at the recipient organizations, incentives, and secure networks for HIE, and policy and regulatory environments. Also, the study showed that India had partial or inconsistent implementation of systems and processes capturing and sharing health information, legal and ethical frameworks, and had hardly implemented incentives and secure networks for electronic HIE (Figure 33).

Figure 33. Requirements for clinical information exchange and their state in six countries



:	Sender has health information in electronic form	Recipient can accept health information in electronic form	Incentives for exchange exist	Secure medium for exchange	Legal and ethical framework exist
China	●●	●●	●	●●	●
England	●●●	●●●	●●	●●●	●●●
India	●●	●●	●	●	●●
Scotland	●●●	●●	●●●	●●●	●●●
Switzerland	●●	●●	●●	●●●	●●●
United States	●●●	●●●	●	●●	●●●

Dots indicates the the extent to which these requirements have been met in each country,
3= Fully implemented   2=Partial or inconsistent implementation 1= Very little implementation 0 =
Absent

Source: Payne, et al., 2019. Status of health information exchange: a comparison of six countries. *Journal of Global Health*, *9*(2), 204279. https://doi.org/10.7189/jogh.09.020427

The findings of the study are aligned with research studies that underline the importance of robust processes to generate functional requirements, design, deploy, and evaluate system as functional issues are at the core of the success and failure of electronic medical record systems (Brender et al., 2013; Fritz et al., 2015a). Furthermore, the proposed model showcases how to apply the principles of federated architecture (discussed in chapter 1) which requires health data and applications at the state level, holds patient data at point of care in a system of record, state level data fiduciaries, and exchange of health information through links with facility and national levels (Ministry of Health and Family Welfare, 2019).

The NDHM has created the enabling policy and regulatory environment while the NHM, the PMJAY, and the JSY offers financial incentives to develop EHRs which are foundational for realizing the vision of federated HDX in India. For the successful implementation of a HDX, it is important to identify and address fundamental challenges.

5.2 Recommendations for HDX implementation

Based on the findings of this study and available literature, a set of recommendations are provided to support the development and implementation of interorganizational HDX.

5.2.1 Establish a HDX Governing Body

The findings highlighted lack of a governance structure as an important barrier to interorganizational HDX. It is important to establish a governing body under the leadership of the hospital administrator to define the process and roles for coordinated decision-making ((La Venture et al., 2014). The governing body needs to have representation of providers, patients, payors, health technologist, researchers, and regulators. The governance functions can include oversight and steering, project management, subject-matter expertise across domains (e.g., health system and services delivery, population health, health strategy and policy, digital health ecosystem, and other sectors like education, financing, telecommunications), and health system levels (national, state, hospital), stakeholder engagement and consultation, and communications management.

5.2.2 Create an Inventory of Available HIS

Given that TSGH is implementing and managing multiple health programs, it is important to document available HIS designed to collect, store and process data to support decision-making within and outside the hospital boundaries. An inventory of information systems and the services provided by those systems can be a starting point toward a larger needs assessment to evaluate the degree to which information systems meet the needs of clinical, administrative, and program staff (Brand et al., 2018)(WHO, 2020a). Such an inventory could include identifying or enumerating the number and types of information systems that are in use, which standards are used, the current and possible future external and internal data exchange partners/users, technical capabilities, and resource needs. Such an activity may identify opportunities to reduce duplication or address multiple uncoordinated systems while catering to the clinical, administrative, and program management data needs. Even though the initial focus could be on providers and administrators, the inventory would offer insights to understand data access and data use needs of the patients. This insight can help to design a patient-centered user interface at a later stage.

5.2.3 Incentivize Adoption, Utilization, and Sustainability of EHRs

To increase the availability of health information in electronic form suitable for HDX, there is a need to adopt EHR standards. The government has already published the national EHR standards but adoption and use of standards is not mandatory. The national and state governments can provide incentives in terms of financial, technology, and workforce support under the NDHM, NHM, PMJAY, JSY, and other national health programs to expedite the adoption, utilization, and sustainability of EHRs. Further, the hospital and state government can leverage the resources available with the National Resource Center for EHR Standards which has a mandate to provide training and education, tools and technologies, and implementation support to hospitals ready to adopt and use EHR standards. While it is important to provide financial, technology, and workforce related incentives, there is a need to establish business models, define and implement performance metrics to monitor adoption, utilization, and sustainability. Relying on voluntary adoption of EHRs without incentivization could create further fragmentation of health data systems given that there is a push under the NDHM and other national and state level health IT initiatives to increase adoption and use of digital technologies.

There is an opportunity to learn from the business models used for the PMJAY. The PMJAY allows states to operate PMJAY in the Trust or Insurance mode (or sometimes a mixture of both termed hybrid). In the Trust model, SHAs may contract implementation support agencies which are fundamentally third-party agencies, while maintaining oversight of their performance. While in the insurance model, insurance companies manage the PMJAY though the SHA is expected to maintain adequate oversight of the insurance companies (Furtado et al., 2020). Further, the PMJAY start-up grand challenge offers an opportunity to the Indian start-up community to generate cutting-edge solutions for supporting the NHA towards more effective implementation of PMJAY. The grant challenge is open to start-ups engaged in sectors such as medical devices, digital health, health communications, hospital services and hospital management, medical workforce training and capacity building, among others.

5.2.4 Develop and Implement a Central Data Strategy

There is a need to develop and implement a central data strategy to integrate data from different sources and levels to support clinical and program management decision-making. The strategy should describe a minimum data set (MDS), a process for bringing data together including standards, architectures (data, system, exchange), policies and guidelines, systems, jurisdictions, data sharing, and benefits resulting from data integration, as well as risk mitigation, and stakeholder role and responsibilities (Brand et al., 2018; La Venture et al., 2014).

Maternal health data are being collected and collated from registration and admission, care and treatment, radiology and laboratory testing, drug distribution, billing, and discharge encounters. Increasingly, these data are being centralized in databases containing individual-level data and/or aggregated data at national and subnational levels with a view to supporting data analysis and reporting as well as strengthening clinical care and population health management. epidemic control. A central data strategy will allow centralization of health data for processing, such as aggregation, analysis, reporting, visualization, deduplication, etc.

The MDS is required for clinical care, administrative, and program management decision-making for improved maternal health status at the hospital, state, and national levels. The MDS must be captured, stored, made available for retrieval, presentation, relay and sharing by an EHR system. The hospital creating a transaction must include the mandatory data elements at all times and is free to exclude optional data elements. The hospital can include additional data elements required by the administrators and program managers at the hospital, state, and national levels.

The TSGH should consider adoption of policies and frameworks necessary to support secure data exchange and data sharing within and outside the hospital. A data sharing agreement can be used to establish clear parameters for exchange between organizations or operational units within the hospital. Data sharing agreements are written agreements that may include descriptions of allowable use of data, responsibilities of the parties to the agreement, the legal authority or business reason to share data, frequency of data exchange, provisions for reporting violations of agreements, including breaches of privacy or security, privacy provisions and security provisions, and agreement of the purpose for the data exchange and agreement on specific data elements to be exchanged. The DISHA act offers an opportunity but it will have to be contextualized and harmonized in the healthcare context of each state since states have the authority to create their own policies and guidelines (Ministry of Health and Family Welfare, 2018).

5.2.5 Build Health Informatics Knowledge and Skill, and Culture of Data Use

For successful HDX, adequately trained health informatics workforce is an important requirement. A health informatics training and education plan, for both pre-service and in-service staff, is required to impart informatics knowledge and skills necessary for providers, administrators, program and HIT managers to know how to lead the creation of an health informatics vision, strategy, policies, governance, structures, and workforce for the hospital; guide the development of standard-based and cost-effective information systems; and ensure investments are monitored and evaluated to optimize appropriate, efficient, and effective utilization of resources (Laventure et al., 2017; LaVenture et al., 2015). The trained managers will be able to provide governance/oversight and clear purpose and directions for the EHR project; understand how requirements are gathered and vetted, whether end users are involved in the design, where the risks lie, and whether the system is delivering value. For the staff directly managing the EHR or HIMS, adequate training and education will help to understand the IT lifecycle, institute sound requirements gathering and change control mechanisms, and manage risks, problem solve and ensure quality information is produced to support clinical and program management decision-making. These will not only enhance individual and organizational capacity for the collection, analysis, and use of data for patient care and program management but will also strengthen belief in the value of data and promote a culture of data use.

5.3 Strengths and Limitations

The main strength of this study was its qualitative design given that the study aimed to provide a real-life and detailed account of barriers to EHR development and HDX, stakeholders and their engagement in EHR development, stakeholder health information needs and data use, data collection system and processes, and workflows at the hospital, state, and national levels. The study design allowed research of organizational, people, technology, and process related factors affecting development of EHR and HDX and provided a rich description of the study context. Of course, the qualitative design did not allow for parameter estimation, the way a quantitative design would, but a quantitative design would have been inappropriate given the aims of this study.

This study investigated the HDX with the case of a single public hospital in India. While it is hoped that the findings of this study will be of interest to others working in the context of similar health service delivery environments, in India and elsewhere, the generalizability of the study findings are limited.

Based on an experimental study researchers (Guest et al., 2006) suggested that twelve interviews should suffice if the research aim were to understand common perceptions and experiences among participants working in a similar setting. Researchers also suggested to carefully conduct purposive sampling, and consider group heterogeneity, data quality, and whether the study aim to assess variation between distinct groups or correlation among variables before deciding the sample size (Guest et al., 2006; Palinkas et al., 2015). Therefore, a total of 20 participants were purposively selected for the research study. Indeed, a strength of this study is the quality of the interviewees, which was very high, i.e., many of the study participants were the primary point of contact at the national, state, and/or hospital level for information pertinent to the study and no other study participant could have provided same level of details with authority.

However, in retrospect, if the purposive sampling plan had oversampled patients, the finding might have been more robust in terms of their information needs. Similarly, if the sampling plan had explicitly identified and over-sampled academics as a stakeholder group, the findings might have been more robust in terms implications for research and education.

The use of an inductive approach to interviewing was both a strength and a weakness in the sense that it allowed identification of themes in an organic, emergent way, without *a priori* imposition of a framework. However, as compared with a more traditional deductive approach, the inductive approach limited this study's ability to test hypotheses.

Due to the COVID-19 pandemic, the study applied phone interviewing techniques for KIIs which is another strength of this study. Virtual data collection methods such as phone interviewing are commonly used in quantitative research. While virtual data collection methods are also used in qualitative research, these methods pose unique challenges in qualitative research. An important question is related to the similarity between the data collected remotely with that collected in-person especially when qualitative research is influenced by the relationship between researcher and participants. A quasi-experimental study aimed to learn about how the mode of qualitative data collection might affect the data researchers obtain (Namey et al., 2020) showed that wherever internet and technology infrastructure made it possible to collect data online, the mode of qualitative data collection does not seem to have a great effect on the content of the findings generated.

Another limitation associated with phone interviewing was related to lack of ability to observe the research participants and the research setting in real-life. However, phone interviewing allowed the extension of the sample to geographically dispersed and mobility-limited participants during the COVID-19 pandemic with cost efficiencies resulting from not having to physically travel. Lastly, phone interviewing offered the convenience of at-home participation and removed visual social cues inadvertently given by the interviewer that might have influenced how a participant responded.

Despite the limitations, the study design produced relevant and insightful data to answer the established research questions pertaining to development of EHRs to enable HDX for improved maternal health service delivery and program management at the hospital, state, and national levels.

5.4 Significance

This qualitative study adds to the much-needed evidence base required to inform operationalization of the vision of the NDHM of India which includes an EHR as one of its foundational pillars. Since the NDHM was launched in 2020, there is a lack of evidence on how to develop inter-organizational HDX. To the best of my knowledge this is the first study aimed at development of an inter-organizational HDX to support decision-making for maternal health service delivery and program management in India. The study has proposed a model to enable interorganizational HDX among healthcare organizations at hospital, state, and national levels. Apart from these research contributions, this research study is also contributing to the practice needs of the NDHM especially at the state level. The national and state level public health leaders in India have affirmed the importance of this study and have asked to receive the final results. One of the public health leaders in Uttarakhand said:

> *"It is heartening to know that your research is related to an important determinant of maternal health as well as Health Systems in general."*

Given the global and country level focus on optimizing collection and use of patient level data at the point of care and all other levels of the health care system, the dissertation research is not only timely but will also fill an important evidence gap concerning how to enable interorganizational HDX in India and other LMICs (Manish Kumar & Mostafa, 2020). There is lack of understanding about the interactions between stakeholders, data systems and workflows, and data use decisions and as well as how such interactions impact development of EHRs and HDX even though EHRs are one of the essential components of the national digital health foundation (Liaw et al., 2020). This study will improve understanding about how stakeholders, data systems and workflows, and stakeholder health information needs and data use influence interorganizational HDX (M. Kumar & Mostafa, 2019). Both developed and LMICs are investing in the development of EHRs but only some countries are moving forward the possibility of data extraction for research, statistics and other uses that serve the public interest (Oderkirk, 2017). The study results will also enable researchers to validate and/or modify the model for developing interorganizational HDX and guide future research in this domain in India and other LMICs. Finally, this study demonstrates relevance of socio-technical theoretical frameworks to inform HIT research in LMICs.

5.5 Conclusions and Future Directions

As a country matures the way they develop interorganizational HDX, a common way to mature could be from secondary use to primary care delivery for improving efficiency and quality of patient care which will depend on how EHRs are understood, designed, governed, and scaled in the national HDX. The pathway to maturity would demand in-depth research that offers “how to guidance”, and “identifies and describes developmental stages and matrices” associated with the purpose and scope of the system (primary and secondary use of clinical data), health information architecture, leadership and governance, organizational resources (finance, workforce, information, and communication technology infrastructure), interoperability and data standards, data quality, and data use. However, national, and sub-national health systems exhibit differential capacity on important organizational, technological, cultural, social, economic, and political dimensions, which often drive or hamper the development, use, and governance of HDX. Therefore, aligning EHR development strategies around a common HDX framework, as exemplified by the national digital health blueprint of India, would be valuable as it offers policy and financial incentives to achieve the goal of interorganizational HDX at national, state, and facility levels.

Apart from sharing the studying findings with the state and national government officials in India, there are few other important directions. The findings of this study showed that further research was needed not only to validate or test the interorganizational HDX model presented in this study but also to research alternative models that can enable HDX in a federated or enterprise health information architecture. Additionally, researchers should conduct studies to measure how EHRs contribute to improved patient and population health outcomes. The future research can investigate the value proposition of health data exchange models for academician, researcher, and HIT training institutions who are working closely with the hospitals. Another important future research direction would be to study and describe what it means to have a mature HDX in LMICs. Finally, exploring whether HDX improves quality of care, reduces cost of care, and increases patient satisfaction is an important area of research not only in LMICs but also in the HICs.

APPENDIX A: KEY INFORMANT INTERVIEW GUIDE- ENGLISH

Consent Form-Key Informant Interview

Principal Investigator: Manish Kumar, Carolina Health Informatics Program (University of North Carolina at Chapel Hill)

Co-Principal Investigator/Faculty Adviser: Javed Mostafa, Director- Carolina Health Informatics Program (University of North Carolina at Chapel Hill)

Study Title: "How to develop national and sub-national electronic health records to improve maternal health service delivery and program management?"

Performance Site: India

Sponsor: This study is part of the PhD study requirement and not funded by any organization or individual.

I. Purpose of the study:

I am conducting my PhD research on the topic "How to develop national and sub-national electronic health records to improve maternal health service delivery and program management?" The research is focused on the context of lower- and middle-income countries such as India. More specifically, I am studying how stakeholders, information flow and sustainability influences the development of electronic health records. In this research, electronic health records refer to *individual health records accessible to patients and providers offering health care services to women during antenatal care, birth, and post-natal care.*

This study is not funded by any organization or individual.

I am interested in learning about a number of issues to help me better understand how maternal health service delivery and program management is currently performed, which tools and system (s) are being used to capture and use patient health records to deliver services, what can be improved, how tools and technologies were developed, and how to ensure sustainability.

The results of the study will be used to:

- Develop better understanding about how stakeholders, health information architecture and sustainability factors inform development of individual health records for maternal health service delivery and program management.
- Propose a model for developing national and sub-national individual health records to improve delivery and management of maternal health services.

ORGANIZATION IDENTIFICATION

Name of the organization:____

Location of the organization:____

ORGANIZATION NUMBER:

INFORMATION ABOUT INTERVIEW

Date:	Day: Month: Year:
Name of the Interviewer:	Interviewer Code: 01 Informant Code:

Key Informant Interview Guide- Key Stakeholders

Introductory Script

Thank you very much for meeting with me. My name is Manish Kumar, and I am a PhD researcher with the University of North Carolina at Chapel Hill in the United States.

Do you have any other questions before we start?

If you have questions during the interview, please do not hesitate to ask.

Interview Questions

First, I am going to ask you some general questions about your organization and your role in collecting, reporting, and using health data for maternal health service delivery and/or program management.

1. Can you tell me what your organization does?

   Prompts:
   - In what areas does it focus?
   - How long has it been working here?
   - What is the relationship between your organization and other government and private health care organizations?

   Follow-up: What is your role in your organization?

2. Can you talk to me about your organization's health data needs for patient care and program management?
   Prompts:
   - What kinds of data do you have to collect and report?
   - What is the frequency of data collection?
   - Who decides what data needs to be collected and reported?

- What technology infrastructure do you have?
- Who are the people involved in collecting data and maintaining the technology infrastructure?
- Who provides financial resources?
- What training (s) have you received? What is the duration and when did you receive it?

3. Can you describe how you have been collecting, reporting, and using data? Follow-up: what have been some challenges with this method?

4. Are there data quality concerns? If so, what are they and how are they being addressed?

5. How are you using the data you collect? What improvements you would like to make in data collection and use?

Okay, let us talk now about the reasons for and process of developing individual health records in your organization.

6. What type of data collection methods and systems (paper or electronic) you are familiar with and routinely use in your work?

7. Can you tell me how you have been involved with the development, implementation and/or use of individual health record systems (paper or electronic)?

   Follow-up: can you tell me if you had any prior experience working in a setting that was using an individual health record system?

8. Can you describe to me the development process for individual health record? How the idea of having an individual health record began and evolved in your organization? You can also talk about the technology aspects.

   Probes:
   - When was it first discussed?
   - What organizations (or people) were involved in the original concept?
   - What was the initial scope for the development of individual health record?
   - How resources were mobilized?

   Follow-up: What were some of the reasons this system was needed?
   - was data collection disorganized?
   - Lack of unique IDs
   - Need for a system that could be used across service points
   - Was there a champion?

9. What other options were considered besides individual health record system?

   Follow-up: Do you know why it was decided to develop the system in-house (or through a vendor)? What were some of advantages or disadvantages in your opinion?

10. From your organizational perspective, what do you need the electronic health record to do?

    Prompts: provide data in a specific format? Collect data for reporting? Use data for patient care? Aggregate data for program management? Use data for expense reimbursement and monitoring?

11. Did you or others in your organization have a role in the development of individual health record? If so, how?

    Probe about whether respondent or others in the organization were consulted about data that should be collected, who and when to use the data, how the individual health record should look and feel, including menu choices, data reporting, and so on.

Let us move on to talk about the implementation and sustainability

12. Can you describe to me the process of implementation?

    Prompts:

    - Who are the different stakeholders and what are they responsible for?
    - What are the steps to set up individual health record system in a facility?

13. What is the plan to finance and support individual health record system in the long-term?

    Prompts:

    - Governments as the primary funder
    - Private sector as the primary funder
    - Mix of government and private sector funding
    - Fee-for-service

14. What are the benefits of the individual health record systems for you and your organization? Prompts:
    - Improved ways to collect, aggregate, and check data for errors
    - Improved clinical care
    - Increased provider satisfaction
    - Reduction in patient duplication
    - Monitor insurance reimbursement
    - Improve program monitoring and evaluation
    - Enhance efficiency of resource allocation

    Follow-up: What are the benefits for your organization, specifically?

15. What do you see as potential problems and limitations of the individual health record systems?

    Prompts:

    - Hybrid system with only some facilities using the system
    - Standalone systems unable to apply ‘collect once, use multiple times’ principle
    - Sustainability
    - Not enough capacity nationwide to maintain the system
    - Concerns about data not meeting stakeholder needs
    - Privacy concerns
    - Infrastructure issues like power outages that can disrupt system use

16. How do you think success will be defined for development of individual health record in states like Uttarakhand??

17. Is there anything additional that you would like me to consider in my research? Who else do you consider as an important key informant for this study with whom I should talk to?

Closing script

That is the end of this interview. Thank you very much for taking the time to do this interview with me. Your knowledge and experience working in the health care system will be truly helpful to me to better understand the development of national and sub-national electronic health records in the lower- and middle-income countries.

Thank you again for your help with this study. I look forward to being in touch.

APPENDIX B: KEY INFORMANT INTERVIEW GUIDE- HINDI

सहमति प्रपत्र- मुख्य सूचनादाता साक्षात्कार

प्रधान अन्वेषक: मनीष कुमार, कैरोलिना स्वास्थ्य सूचना विज्ञान कार्यक्रम (चैपल हिल में उत्तरी कैरोलिना विश्वविद्यालय)
सह-प्रधान अन्वेषक / संकाय सलाहकार: जावेद मुस्तफा, निदेशक- कैरोलिना स्वास्थ्य सूचना विज्ञान कार्यक्रम (उत्तरी कैरोलिना विश्वविद्यालय, चैपल हिल)
अध्ययन का शीर्षक: "मातृ स्वास्थ्य सेवा वितरण और कार्यक्रम प्रबंधन में सुधार के लिए राष्ट्रीय और उप-राष्ट्रीय इलेक्ट्रॉनिक स्वास्थ्य रिकॉर्ड कैसे विकसित करें?"
प्रदर्शन स्थल: भारत
प्रायोजक: यह अध्ययन पीएचडी अध्ययन की आवश्यकता का हिस्सा है और किसी संगठन या व्यक्ति द्वारा वित्त पोषित नहीं है

I. अध्ययन का उद्देश्य:

मैं "मातृ स्वास्थ्य सेवा वितरण और कार्यक्रम प्रबंधन में सुधार के लिए राष्ट्रीय और उप-राष्ट्रीय इलेक्ट्रॉनिक स्वास्थ्य रिकॉर्ड कैसे विकसित करें?", इस विषय पर अपने पीएचडी अनुसंधान का आयोजन कर रहा हूं I यह अनुसंधान भारत जैसे निम्न और मध्यम आय वाले देशों के संदर्भ में केंद्रित है। मैं विशेष रूप से इस पर अध्ययन कर रहा हूं कि हितधारक, सूचना प्रवाह और स्थिरता, इलेक्ट्रॉनिक स्वास्थ्य रिकॉर्ड के विकास को कैसे प्रभावित करते हैं । इस शोध में, इलेक्ट्रॉनिक हेल्थ रिकॉर्ड्स का मतलब व्यक्तिगत स्वास्थ्य रिकॉर्ड्स से हे जो की रोगियों/महिलाओं को तथा प्रसवपूर्व, जन्म के दौरान और प्रसव के बाद महिलाओं को स्वास्थ्य एवं देखभाल सेवा प्रदान करनेवाले संस्था को उपलब्ध होता होI

यह अध्ययन किसी भी संगठन या व्यक्ति द्वारा वित्त पोषित नहीं है।

मुझे कई मुद्दों के बारे में जानने में दिलचस्पी है जो मुझे यह यह समझने में मदद करता हो कि वर्तमान में मातृ स्वास्थ्य सेवा वितरण और कार्यक्रम प्रबंधन कैसे किया जाता है, सेवाओं को वितरित करने के लिए रोगी स्वास्थ्य रिकॉर्ड को लेना और उपयोग करने के लिए कौन से उपकरण और सिस्टम का उपयोग किया जा रहा है, क्या-क्या सुधार किए कर जा सकते हैं, स्थिरता सुनिश्चित करने के लिए कैसे उपकरण और प्रौद्योगिकी विकसित किए गए थे।

अध्ययन के परिणामों का उपयोग किया जाएगा:

1) हितधारकों, स्वास्थ्य सूचना संरचना और व्यवस्था का टिकाउपन आदि कारकें मातृ स्वास्थ्य सेवा वितरण और कार्यक्रम प्रबंधन के लिए व्यक्तिगत स्वास्थ्य रिकॉर्ड के विकास को किस तरह प्रभावित करते हैं, के बारे में बेहतर समझ विकसित करना
2) मातृ स्वास्थ्य सेवाओं के वितरण और प्रबंधन में सुधार के लिए राष्ट्रीय और उप-राष्ट्रीय व्यक्तिगत स्वास्थ्य रिकॉर्ड विकसित करने के लिए एक मॉडल प्रस्तावित करने में I

II. प्रक्रिया:

यदि आप इस अध्ययन में भाग लेने को तैयार होते है, तो शोधकर्ता अध्ययन के उद्देश्य से संबंधित आपके अनुभव और राय के बारे में कई प्रश्न पूछेगा। यदि आप अंग्रेजी के अलावा किसी अन्य भाषा में खुद को सर्वश्रेष्ठ रूप से समझ और व्यक्त कर सकते हैं, तो जांचकर्ता आपसे आपकी पसंदीदा भाषा में प्रश्न पूछेगा। अमूनन साक्षात्कार एक घंटे से अधिक का नहीं होना चाहिए।

चाहे साक्षात्कार अंग्रेजी में हो या किसी अन्य भाषा में, मैं रिकॉर्ड करना चाहूंगा; हालाँकि, आपका नाम और निवास कभी नहीं बताया जाएगा। आपके साक्षात्कार को एक विशिष्ट पहचान कोड सौंपा जाएगा। आपकी प्रतिक्रियाओं को आपके किसी भी पहचान की जानकारी, जो आप स्वेच्छा से नहीं देते हैं, से अलग और गोपनीय रखा जाएगा । आपकी प्रतिक्रिया की रिकॉर्डिंग आपके

नाम और निवास के साथ एक कंप्यूटर और पासवर्ड पर सुरक्षित रखी जाएगी। आप अपने साक्षात्कार के प्रतिलेख के लिए पूछ सकते हैं। आपका नाम और निवास विवरण फ़ाइनल पांडुलिपि में शामिल नहीं किया जाएगा।

क्या आप अपने साक्षात्कार का रिकॉर्ड किए जाने के लिए सहमत हैं? कृपया अपने सहमती या असहमति की पुष्टि करने के लिए सही बॉक्स की जाँच करें।

हाँ ☐
[यदि व्यक्ति रिकॉर्ड किए जाने के लिए सहमति देता है] तो हम इस साक्षात्कार की रिकॉर्डिंग शुरू करेंगे। बाद में, मैं इस साक्षात्कार की महत्वपूर्ण बिन्दुओं को लिख कर पांडुलिपि तैयार करेंगे।]

नहीं ☐
[यदि व्यक्ति को रिकॉर्ड किए जाने की सहमति नहीं थी] तो मैं आपके साथ बात करते हुए हमारे साक्षात्कार से नोट्स लिखूंगा।

III जोखिम:

साक्षात्कार प्रक्रिया में शामिल होने से किसी भी शारीरिक या भावनात्मक परेशानी होने की संभावना नहीं है। फिर भी, अगर आपको इलेक्ट्रॉनिक उपकरणों और प्रणालियों के विकास या उपयोग में आपकी भागीदारी से जुड़ा हुआ कोई अप्रिय अनुभव रहा है, तो यह भावनात्मक तनाव का कारण हो सकता है। साक्षात्कार प्रक्रिया में आपको विराम देना और आगे बढ़ने से पहले सुनिश्चित करना की आप असहज महसूस नहीं कर रहे हैं, की व्यवस्था हे आपके द्वारा प्रदत्त जानकारी एवं आंकड़े, की सुरक्षा को सुनिश्चित करने के लिए सभी प्रयास किए जाएंगे I इन सुरक्षाओं के वावजूद गोपनीयता भंग होने की थोरी संभावना रह जाती है जो की अक्सर अनुसंधान के साथ जुडी होती है।

IV लाभ:

स्वास्थ्य रिकॉर्ड के विकास के बारे में आप अपने किसी भी अनुभव और / या राय व्यक्त करने का अवसर ही इस अध्ययन के साक्षात्कार में भाग लेने का लाभ है। अपनी प्रतिक्रिया को आपसे जोड़ कर देखने के बारे में चिंता नहीं करनी होगी।

V मुआवजा:

इस अध्ययन में भाग लेने के लिए कोई मुआवजा नहीं दिया जाएगा।

VI साक्षात्कार से विमुक्त होने की स्वतंत्रता:

इस अध्ययन में भागीदारी पूरी तरह से स्वैच्छिक है। आपको साक्षात्कार देने की बाध्यता नहीं है। यदि आप अभी भी सहमति से इनकार करते हैं, तो आपकी भागीदारी का कोई प्रमाण एवं कोई परिणाम नहीं होगा। यदि आप साक्षात्कार के दौरान किसी भी समय असहज महसूस करने लगते हैं, तो आप उसी समय साक्षात्कार रोकने का अनुरोध कर सकते हैं। रिकॉर्डिंग तुरंत खारिज कर दी जाएगी और आपकी भागीदारी का कोई अन्य दस्तावेज भी नस्ट कर दिया जाएगा । यदि साक्षात्कार का कोई एक भाग आपको असहज करता है लेकिन आप फिर भी इसको जारी रखना चाहते हैं, तो आप उस भाग के किसी भी प्रश्न का उत्तर देने से इनकार कर सकते हैं।

यदि आपके पास इस शोध के बारे में कोई प्रश्न हैं, तो कृपया इस फॉर्म के शीर्ष पर स्थित अन्वेषक से संपर्क + +919-945-4002 पर कॉल करके या manishk@unc.edu को ईमेल करके कर सकते हैं। यदि आपके पास शोध विषय के रूप में आपके अधिकारों के बारे में प्रश्न या चिंताएँ हैं, तो आप UNC संस्थागत समीक्षा बोर्ड से + 1-919-966-3113 पर या IRB_subjects@unc.edu को ईमेल द्वारा संपर्क कर सकते हैं ।

VII सहमति कथन:

अन्वेषक: "क्या आप इस अनुसंधान परियोजना के सर्वे में भाग लेने सम्बंधित जोखिमों और लाभों को समझते हैं और इस अध्ययन में भाग लेने के लिए स्वेच्छा से सहमत या असहमत हैं? यदि हां, तो मेरे बाद दोहराएं।

प्रतिभागी का समझौता:
मैंने ऊपर दी गई जानकारी पढ़ी है। इस समय मेरे मन में जो भी प्रश्न हैं मैंने सभी पूछ लिए हैं और मैं स्वेच्छा से इस शोध अध्ययन में भाग लेने के लिए सहमत हूं।

अनुसंधान प्रतिभागी का हस्ताक्षर दिनांक: ....

अनुसंधान प्रतिभागी का मुद्रित नाम: ....

सहमति प्राप्त करने वाले अनुसंधान दल के सदस्य का हस्ताक्षर दिनांक: ....

<u>सहमति प्राप्त अनुसंधान दल के सदस्य का मुद्रित नाम</u>

संगठन पहचान:

संगठन का नाम: ____

संगठन का स्थान: ____

संगठन संख्या: --

<u>साक्षात्कार के बारे में जानकारी</u>
दिनांक: ....

साक्षात्कारकर्ता दिवस का नाम: --

महीना: ....

साल: ....

साक्षात्कारकर्ता कोड: ....

साझेदार कोड: ....

साक्षात्कार मार्गदर्शिका (विस्तृत विवरण) - महत्त्वपूर्ण साझेदार
<u>परिचयात्मक लिपि</u>

मुझसे मिलने के लिए बहुत-बहुत धन्यवाद। मेरा नाम मनीष कुमार है और मैं संयुक्त राज्य अमेरिका के चैपल हिल में स्थित उत्तरी कैरोलिना विश्वविद्यालय में स्नातकोत्तर (पीएचडी) शोधकर्ता हूं।

क्या अभी भी आपके मन में इस अनुसंधान कार्य के साक्षात्कार में भाग लेने सम्बंधित कोई प्रश्न हैं?

यदि साक्षात्कार के दौरान आपके कोई प्रश्न हों, तो कृपया पूछने में संकोच न करें।

साक्षात्कार के प्रश्न
सबसे पहले, मैं आपको "मातृ स्वास्थ्य सेवा वितरण और / या कार्यक्रम प्रबंधन सम्बंधित स्वास्थ्य आंकड़े एकत्र करने, रिपोर्टिंग और उपयोग करने में आपके संगठन और आपकी भूमिका के बारे में कुछ सामान्य प्रश्न पूछने जा रहा हूं।

1. क्या आप मुझे बता सकते हैं कि आपका संगठन क्या करता है?

संकेतों:
• यह स्वस्थ्य के किन क्षेत्रों/विषयों पर मुख्य रूप से काम करता है?
• यहाँ कब से इस क्षेत्र में काम कर रहा है?
• आपके संगठन एवं अन्य सरकारी अथवा निजी स्वास्थ्य देखभाल संगठनों के बीच क्या संबंध है?
अनुवर्ती: आपके संगठन में आपकी क्या भूमिका है?

2. क्या आप अपने संगठन के रोगी देखभाल एवं कार्यक्रम प्रबंधन सम्बंधित स्वास्थ्य आंकड़े की जरूरतों के बारे में मुझसे बात कर सकते हैं?
संकेतों:
• आपको किस प्रकार का डेटा/आंकड़े एकत्र करना और रिपोर्ट करना होता है?
• डेटा संग्रह की आवृत्ति क्या है? यानी किस समय अंतराल (दैनिक, साप्ताहिक, आदि) आपको आंकड़े संग्रह करने होते हैं I
• कौन तय करता है कि किन आंकड़ों को एकत्र करने और रिपोर्ट करने की आवश्यकता है?
• आपके पास कौन सी तकनीक का बुनियादी ढांचा (basic infrastructure) है?
• स्वस्थ्य आंकड़े एकत्र करने और प्रौद्योगिकी के बुनियादी ढांचे को बनाए रखने (मेंटेनेंस) में कौन लोग शामिल हैं?
•इस काम के लिए वित्तीय संसाधन कौन प्रदान करता है?
• क्या आपको प्रशिक्षण मिला है? आपने इसे कब प्राप्त किया और यह कितनी अवधि की थी I

3. क्या आप बता सकते हैं कि आप डेटा का संग्रह, रिपोर्टिंग और उपयोग कैसे कर रहे हैं?
अनुवर्ती: इस स्वास्थ आंकड़े की पद्धति के साथ जुडी क्या कुछ चुनौतियां भी रही हैं? वो क्या थी?

4. क्या डेटा की गुणवत्ता अप्रयाप्त चिंताजनक हैं? यदि हां, तो वे कमिया क्या हैं और उसकी भरपाई कैसे की जा रही है?

5. आप अपने द्वारा एकत्र किए गए डेटा का उपयोग कैसे कर रहे हैं? डेटा संग्रह और उपयोग में आप क्या सुधार करना चाहेंगे?

ठीक है, अब आपके संगठन में व्यक्तिगत स्वास्थ्य रिकॉर्ड तैयार (विकसित) करने के कारणों और प्रक्रिया के बारे में बात करते हैं।

6. आप किस प्रकार की व्यक्तिगत स्वास्थ्य रिकॉर्ड तैयार (विकसित) करने विधियों (methods)/पद्धतियों (system) (कागज या इलेक्ट्रॉनिक) से परिचित हैं जिसका नियमित रूप से अपने काम में उपयोग करते हैं?

7. कृपया बताएं कि आप व्यक्तिगत स्वास्थ्य रिकॉर्ड/पद्धतियों (कागज या इलेक्ट्रॉनिक) के विकास, कार्यान्वयन और / या उपयोग में कैसे शामिल हैं?

संकेतों:

अनुवर्ती: क्या आप मुझे बता सकते हैं कि आपके पास ऐसी व्यवस्था में काम करने का कोई पूर्व अनुभव है जिसमे व्यक्तिगत स्वास्थ्य पद्धतियों का उपयोग होता हो? I

8. क्या आप ये वर्णन कर सकते हैं कि आपके संगठन में व्यक्तिगत स्वास्थ्य रिकॉर्ड की व्यवस्था कैसे शुरू हुई ? आपके संगठन में व्यक्तिगत स्वास्थ्य रिकॉर्ड होने और विकसित होने का विचार कैसे शुरू हुआ? आप प्रौद्योगिकी पहलुओं के बारे में भी बात कर सकते हैं।

जांच:
- पहली बार इस पर कब चर्चा की गई थी?
- मूल अवधारणा के विकास में कौन से संगठन (या लोग) शामिल थे?
- व्यक्तिगत स्वास्थ्य रिकॉर्ड तैयार (विकसित) करने की प्रारंभिक गुंजाइश क्या थी?
- इस काम के लिए संसाधन कैसे जुटाए गए?

अनुवर्ती: किन कारणों से व्यक्तिगत स्वास्थ्य रिकॉर्ड प्रणाली की आवश्यकता हुई?
- क्या इससे पूर्व डेटा संग्रह अव्यवस्थित था?
- क्या व्यक्तिगत पहचान (यूनिक आईडी) का अभाव था?
- क्या एक ऐसी प्रणाली की आवश्यकता महसूस की गई जिसका उपयोग विभिन्नसेवा केन्द्रों में किया जा सके?
- क्या किसी ख़ास व्यक्ति अथवा संगठन ने इसके लिए प्रोत्साहित किया? (क्या कोई चैंपियन था?)

- क्या इससे पूर्व डेटा संग्रह की कोई व्यवस्था थी? वह क्या थी

9. शुरुआत में व्यक्तिगत स्वास्थ्य रिकॉर्ड प्रणाली के अलावा अन्य किन विकल्पों पर विचार किया गया था ?

अनुवर्ती: क्या आप बता सकते हैं कि इस सिस्टम को संस्थान के अन्दर ही (इन हाउस)) (या किसी विक्रेता के माध्यम से) विकसित करने का निर्णय क्यों लिया गया? आपकी राय में इसके फायदे या नुकसान क्या थे?

10. आपके संगठनात्मक दृष्टिकोण से, आपको इलेक्ट्रॉनिक स्वास्थ्य रिकॉर्ड की क्या आवश्यकता है? आप इसका क्या उपयोग करते हैं/ करनेवाले हैं?

संकेत: क्या एक विशिष्ट प्रारूप में डेटा प्रदान करना ? क्या रिपोर्टिंग के लिए डेटा एकत्र करना? क्या रोगी की देखभाल के लिए डेटा का उपयोग करना? क्या कार्यक्रम प्रबंधन के लिए डेटा एकत्र करना? क्या व्यय प्रतिपूर्ति और निगरानी के लिए डेटा का उपयोग करना?

11. क्या आपकी या आपके संगठन के अन्य लोगों की व्यक्तिगत स्वास्थ्य रिकॉर्ड विकसित करने में कोई भूमिका है? यदि हां, तो क्या हे ?

इस बारे में जांच करें कि क्या उनके या उनके संगठन के अन्य लोगों सलाह ली गई थी? की एकत्र किये जानेवाले आंकड़े क्या होंगे, उसे कब और कैसे उपयोग करना है , व्यक्तिगत स्वास्थ्य रिकॉर्ड कैसा दिखाना है जिसमे मेनू विकल्प, डेटा रिपोर्टिंग, आदि शामिल हो I

आगे हम इसके कार्यान्वयन और व्यवस्था के टिकाउपन के बारे में बात करते हैं I
12. क्या आप मुझे इसके कार्यान्वयन की प्रक्रिया का वर्णन कर सकते हैं?

संकेतों:

- व्यक्तिगत स्वास्थ आंकड़े जुटाने के कार्य के विभिन्न हितधारक कौन हैं? और उनकी जिम्मेवारी क्या हैं I
- किसी स्वास्थ सुविधा केंद्र में व्यक्तिगत स्वास्थ्य रिकॉर्ड प्रणाली स्थापित करने के लिए क्या कदम उठाने पड़ते हैं?

13. व्यक्तिगत स्वास्थ्य रिकॉर्ड प्रणाली को बनाए रखने के लिए वित्त और समर्थन देने की दीर्घकालिक योजना क्या है?

संकेतों:
- सरकार द्वारा प्रमुख रूप से वित्तपोसित
- निजी क्षेत्र द्वारा प्रमुख रूप से वित्तपोसित
- सरकारी और निजी क्षेत्र द्वारा सम्मिलित रूप से वित्तपोसित
- इस काम के लिए शुल्क इकठ्ठा करना

14. आपके तथा आपके संगठन को व्यक्तिगत स्वास्थ्य रिकॉर्ड प्रणालियों के क्या लाभ हैं?

संकेतों:
बेहतर तरीके से डेटा एकत्र करने, इसके संकलन एवं त्रुटियों को जांचना
- बेहतर नैदानिक (क्लिनिकल) देखभाल
- आंकड़े प्रदाता की बेहतर संतुष्टि
- रोगी डुप्लीकेशन में कमी
- बीमा प्रतिपूर्ति की निगरानी
- कार्यक्रम की निगरानी और मूल्यांकन में सुधार
- संसाधन आवंटन की दक्षता बढ़ाना

<u>अनुवर्ती: व्यक्तिगत स्वास्थ्य रिकॉर्ड तैयार करने का आपके संगठन के लिए विशेष रूप से क्या लाभ हैं?</u>
15. आप व्यक्तिगत स्वास्थ्य रिकॉर्ड प्रणालियों से जुड़े संभावित समस्याओं और बाधाओं के रूप में क्या देखते हैं?

संकेतों:
- संगठन में केवल कुछ ही सुविधा केन्द्रों द्वारा व्यक्तिगत स्वास्थ्य रिकॉर्ड प्रणाली का का उपयोग (हाइब्रिड सिस्टम)
- एक बार आंकड़े जुटाने एवं बारम्बार उसका उपयोग के सिधांत के लिए एकाकी व्यवस्था   (स्टैंडअलोन) अप्रयाप्त हे
- इस प्रणाली का टिकाउपन स्थिरता
- इस व्यवस्था बनाए रखने के देशभर में पर्याप्त क्षमता की कमी
- व्यक्तिगत स्वास्थ्य रिकॉर्ड से विभिन्न हितधारकों की जरूरतों के पूरा नहीं होने की चिन्ताएं
- निजता की चिंता
- <u>आधारभूत संरचना</u> से जुडी कठिनाई जैसे बिजली गुल होना आदि जो सिस्टम उपयोग को बाधित कर सकते हैं

16. आपको क्या लगता है उत्तराखंड जैसे राज्य में व्यक्तिगत स्वास्थ्य रिकॉर्ड के विकास की सफलता को किस तरह परिभाषित किया जाएगा??

17. इन सब बातों के अलावा क्या कुछ अतिरिक्त है जो आप सोचते हैं/चाहते हैं कि मैं अपने शोध में विचार करूं? क्या आप अपने अलावा किसी और को इस अनुसंधान सम्बंधित जानकारी देने हेतु महत्वपूर्ण मानते हैं, जिनसे मुझे बात करनी चाहिए?
स्क्रिप्ट/आलेख बंद करना

यही इस साक्षात्कार का अंत है। मेरे साथ इस साक्षात्कार में शामिल होने हेतु समय निकालने के लिए बहुत-बहुत धन्यवाद। स्वास्थ्य देखभाल प्रणाली में काम करने का आपका ज्ञान और अनुभव वास्तव में निम्न और मध्यम आय वाले देशों में राष्ट्रीय और उप-राष्ट्रीय इलेक्ट्रॉनिक स्वास्थ्य रिकॉर्ड के विकास को बेहतर ढंग से समझने में मेरे लिए मददगार होगा।

[यदि रिकॉर्डिंग की गई है, तो प्रतिभागी से पूछें: क्या आप मुद्रित होने के पश्चात अपने साक्षात्कार की प्रतिलेख को देखना चाहते हैं?]

[यदि व्यक्ति प्रतिलेख देखना चाहता है]: मैं साक्षात्कार पूरा होने के बाद प्रतिलेखन पर काम करना शुरू कर दूंगा। यह तैयार होने के बाद मैं आपका साक्षात्कार प्रतिलेख ईमेल कर सकता हूं। आप किस ईमेल पते का उपयोग करना चाहेंगे?

इस अध्ययन में आपकी मदद के लिए फिर से धन्यवाद। मैं आपसे संपर्क में रहने के लिए उत्सुक हूं।

APPENDIX C: ABOUT PRADHAN MANTRI JAN AROGYA YOJANA

What is Pradhan Mantri Jan Arogya Yojana(PM-JAY)?

Pradhan Mantri Jan Arogya Yojana (PM-JAY) is an initiative to ensure that poor and vulnerable population is provided health cover. This initiative is part of the Government's vision to ensure that its citizens – especially the poor and vulnerable groups have universal access to good quality hospital services without anyone having to face financial hardship as a consequence of using health services.

What benefits are available under PM-JAY?

PM-JAY provides an insurance cover up to USD $6,667 per family, per year for secondary and tertiary hospitalization. All pre-existing conditions are covered from day 1 of implementation of PM-JAY.

What health services are available under PM-JAY?

The health services covered under the program include hospitalization expenses, day care surgeries, follow-up care, pre and post hospitalization expense benefits and newborn child/children services. The comprehensive list of services is available on the website.

Who is eligible to avail benefits under PM-JAY?

PM-JAY covers more than 100 million poor and vulnerable families across the country, identified as deprived rural families and occupational categories of urban workers' families as per the latest Socio-Economic Caste Census (SECC) data. There is no capping on family size and age of members, which will ensure that all family members specifically girl child and senior citizens will get coverage.

Where can beneficiaries' avail themselves of services under PM-JAY?

Services under the scheme can be availed at all public hospitals and empaneled private health care facilities.

Will beneficiaries have to pay anything to get covered under this scheme?

No. All eligible beneficiaries can avail free services for secondary and tertiary hospital care for identified packages under PM-JAY at public hospitals and empaneled private hospitals. Beneficiaries will have cashless and paperless access to health services under PM-JAY.

What is the enrolment process? Is there any time period for enrolment?

PM-JAY is an entitlement-based mission. There is no enrolment process. Families who are identified by the government on the basis of deprivation and occupational criteria using the SECC database both in rural and urban areas are entitled for PM-JAY.

Source: Adapted from Government of India, National Health Authority. *Ayushman Bharat: Pradhan Mantri Jan Arogya Yojana*. Accessed on October 17, 2020 at https://pmjay.gov.in/webfaqs

APPENDIX D: PMJAY-UTTARAKHAND PROFILE

Overview	
Name of the Scheme	*Atal Ayushman Uttarakhand Yojana*
Date of roll-out	23-09-2018
Mode of Implementation	Trust (directly implemented by the state health agency without the intermediation of the insurance company)
Number of PM-JAY eligible families	5,23,536
Number of PM-JAY additional families covered by the State	10,45,932
Number of Non-PM-JAY families covered by the State scheme	-
Financing share of national and state government	60:40
Insurance	
Name of the Third-Party Administrator (TPA)	Family Health Plan Insurance TPA Limited
Health Packages	
Number of Health Benefit Packages)	872
Number of packages reserved for government hospitals)	13
Description of the State Scheme: The objective of *Atal Ayushman* Uttarakhand is covering the families that were not covered under PM-JAY. The scheme covers an additional 10.4 lakh families with the same benefits as those under PM-JAY thereby covering the entire population of the state of Uttarakhand.	

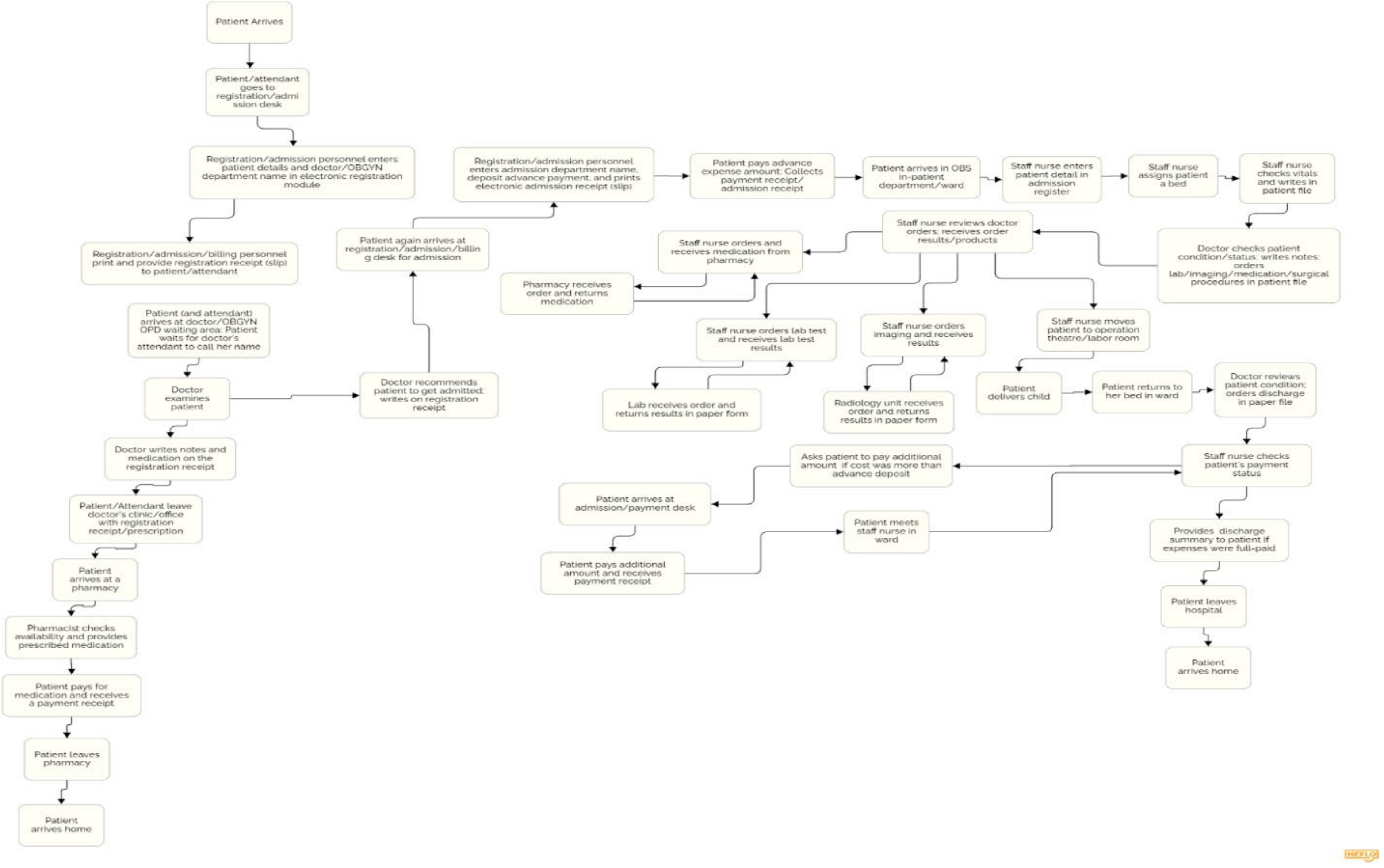
Note: Data as on 15 July 2020

Source: Adapted from National Health Authority, Government of India. 2020. Ayushman Bharat Pradhan Mantri Jan Arogya Yojana. State Profile, Uttarakhand. Accessed on October 17, 2020 from https://pmjay.gov.in/uttarakhand_profile

APPENDIX E: KEY INFORMANT PROFILE

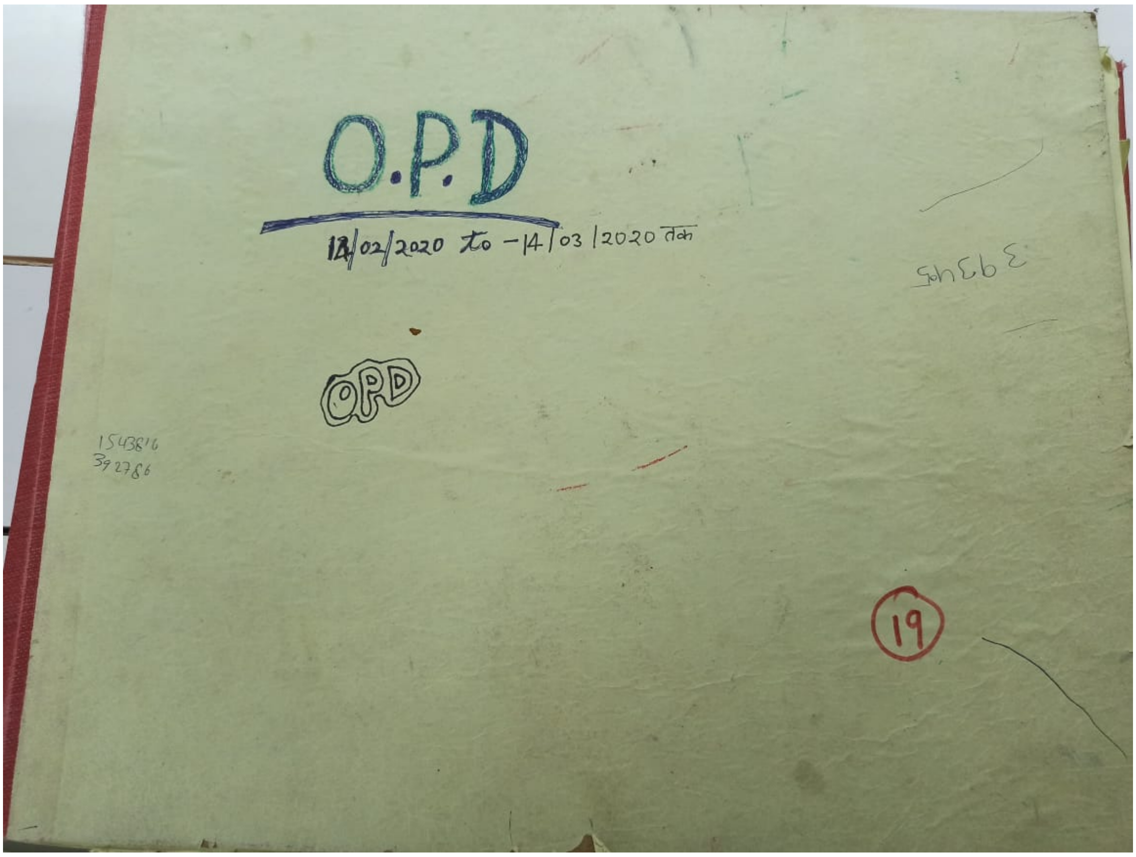
Key Informant #	Level	Type	Stakeholder Group	Years of Exp. (Approx.)	Gender	Roles
1	Hospital	Public	Healthcare provider	15	Female	Clinical (OBGYN) and administrator
2	Hospital	Public	Health Insurance	10	Male	JSY point of contact
3	Hospital	Public	Health IT	15	Male	Health IT nodal person
4	Hospital	Public	Healthcare provider	2	Female	Clinical (OBGYN)
5	Hospital	Public	Healthcare provider	2	Male	Clinical (Pediatrics)
6	Hospital	Public	Healthcare provider	8	Female	Staff nurse
7	Hospital	Public	Healthcare provider	0	Female	Nursing student
8	Hospital	Public	Healthcare provider	2	Male	Pathologist
9	Hospital	Public	Health Insurance	16	Male	Executive leading PMJAY and other financial payments
10	Clinic	Private	Lab technician	16	Male	Pathology laboratory work and patient records
11	Hospital	Private	Health IT	6	Male	Hospital administrator; IT implementer; Health Insurance
12	State	Private	Health Insurance	10	Male	State regional lead for private insurance company
13	State	Private	Health Insurance	10	Male	Marketing executive/agent for health insurance
14	Patient	Patient	Patient	NA	Male	Husband and son
15	State	Private	Health Insurance	10	Male	Coordination and management support to National Health Authority
16	National	Private	Health Insurance	15	Female	Technical and research support to National Health Authority
17	State	Public	Health IT	15	Male	State health information technology lead
18	National	Public	Health IT	15	Male	Electronic health record standards, training, and implementation
19	National	Public	MCH Program	30	Male	Technical, research and advisory to the national health mission and ministry of health and family welfare, government of India
20	National	Public	MCH Program	15	Male	Technical, research and advisory to the national health mission

APPENDIX F: TERTIARY CARE STATE GOVERNMENT HOSPITAL – PROCESS FLOW OVERVIEW

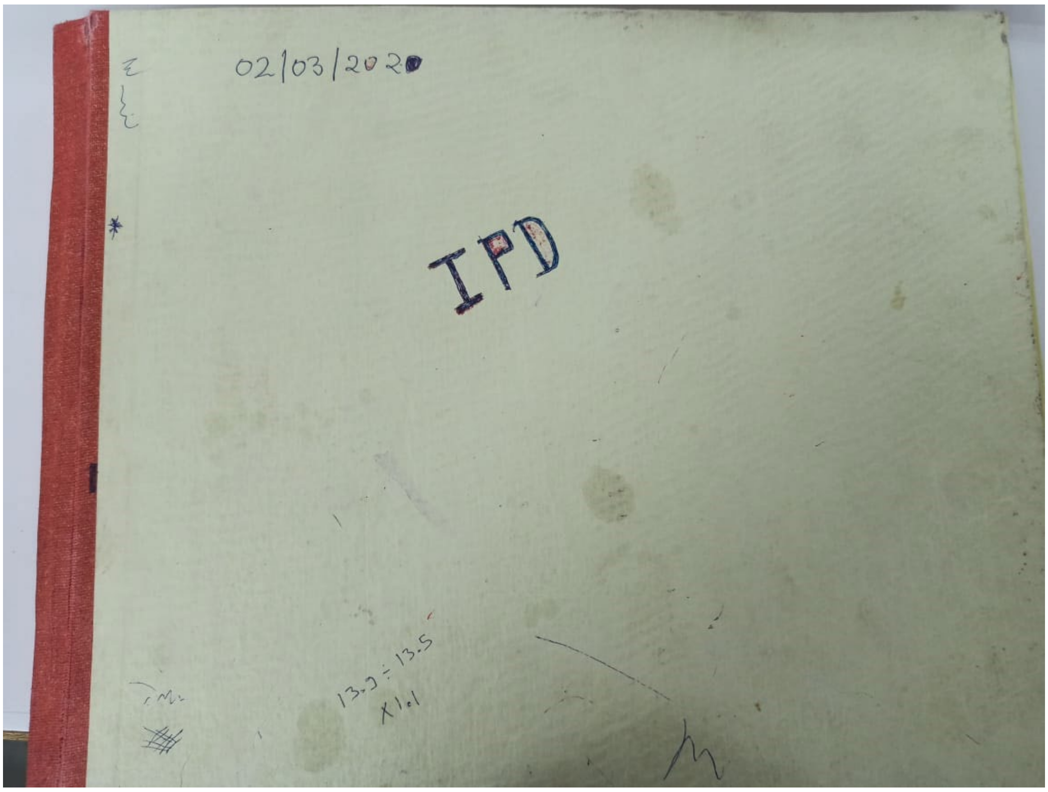


Note: *Janani Suraksha Yojana* (JSY) is a safe motherhood intervention under the National Health Mission. JSY is a centrally sponsored scheme, which integrates cash assistance with delivery and postnatal care for all pregnant women in Uttarakhand State, India. Patients need to pay only for expenses unrelated to childbirth or postnatal care.

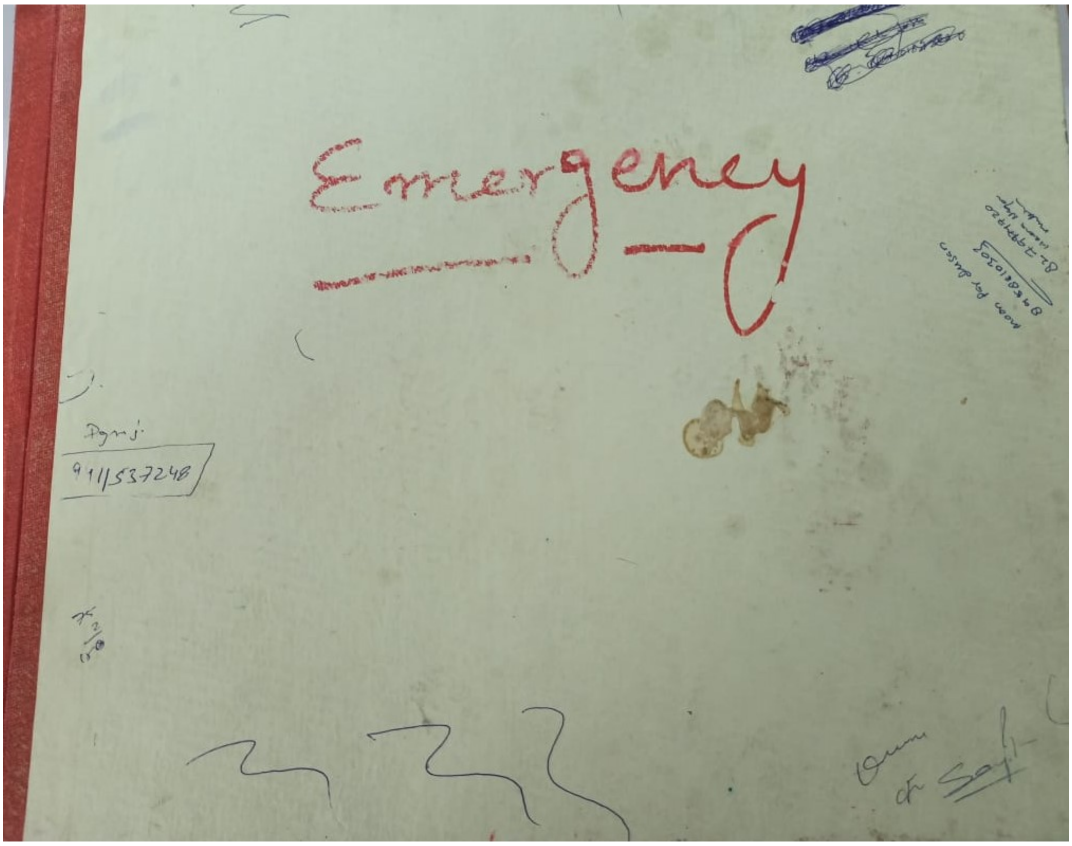
APPENDIX G: GENERAL OPD REGISTER



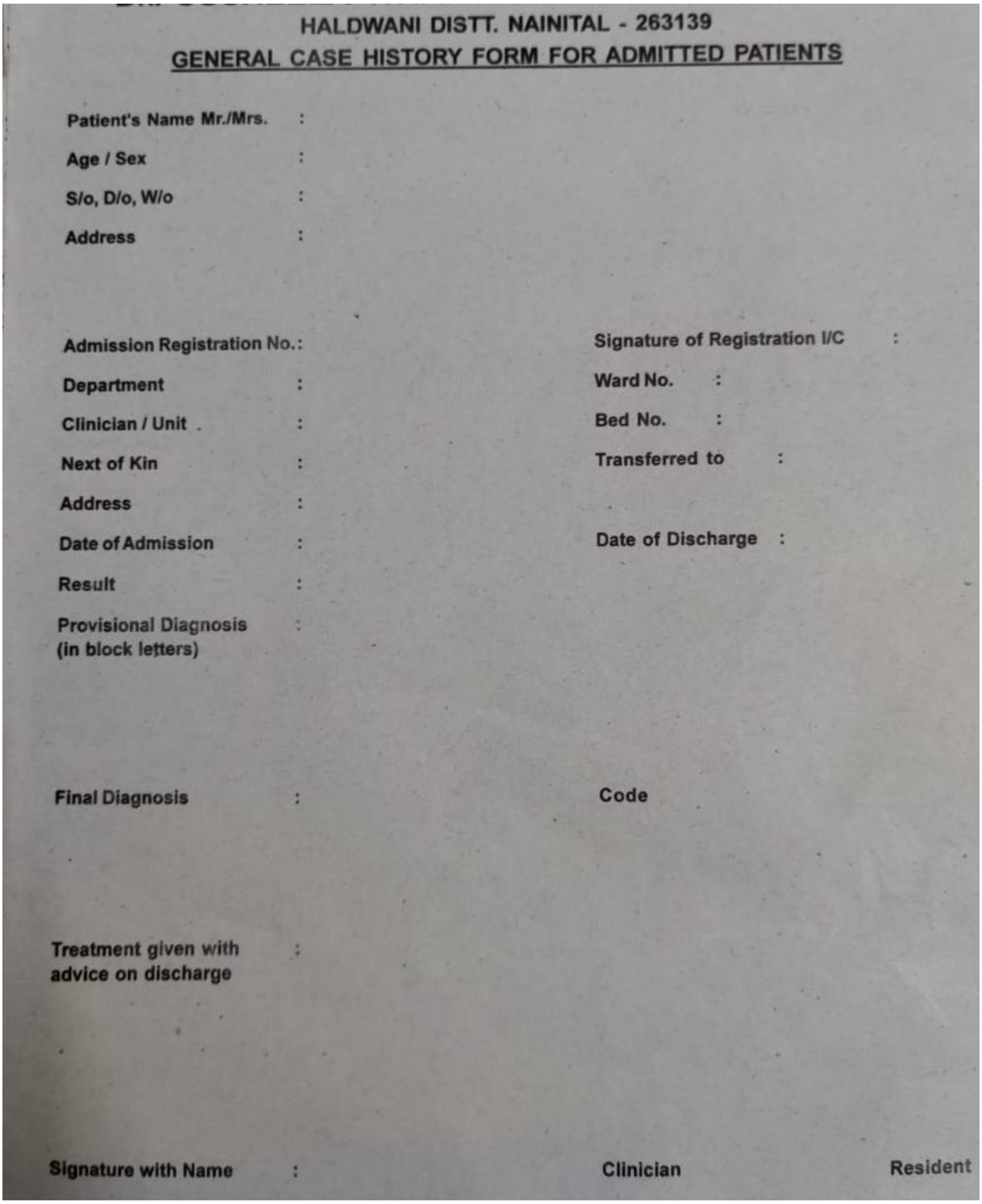
APPENDIX H: GENERAL IPD REGISTER



APPENDIX I: EMERGENCY REGISTER



APPENDIX J: GENERAL CASE HISTORY FORM



HALDWANI DISTT. NAINITAL - 263139

GENERAL CASE HISTORY FORM FOR ADMITTED PATIENTS

Patient's Name Mr./Mrs. :

Age / Sex :

S/o, D/o, W/o :

Address :

Admission Registration No.:

Signature of Registration I/C :

Department :

Ward No. :

Clinician / Unit :

Bed No. :

Next of Kin :

Transferred to :

Address :

Date of Admission :

Date of Discharge :

Result :

Provisional Diagnosis (in block letters) :

Final Diagnosis :

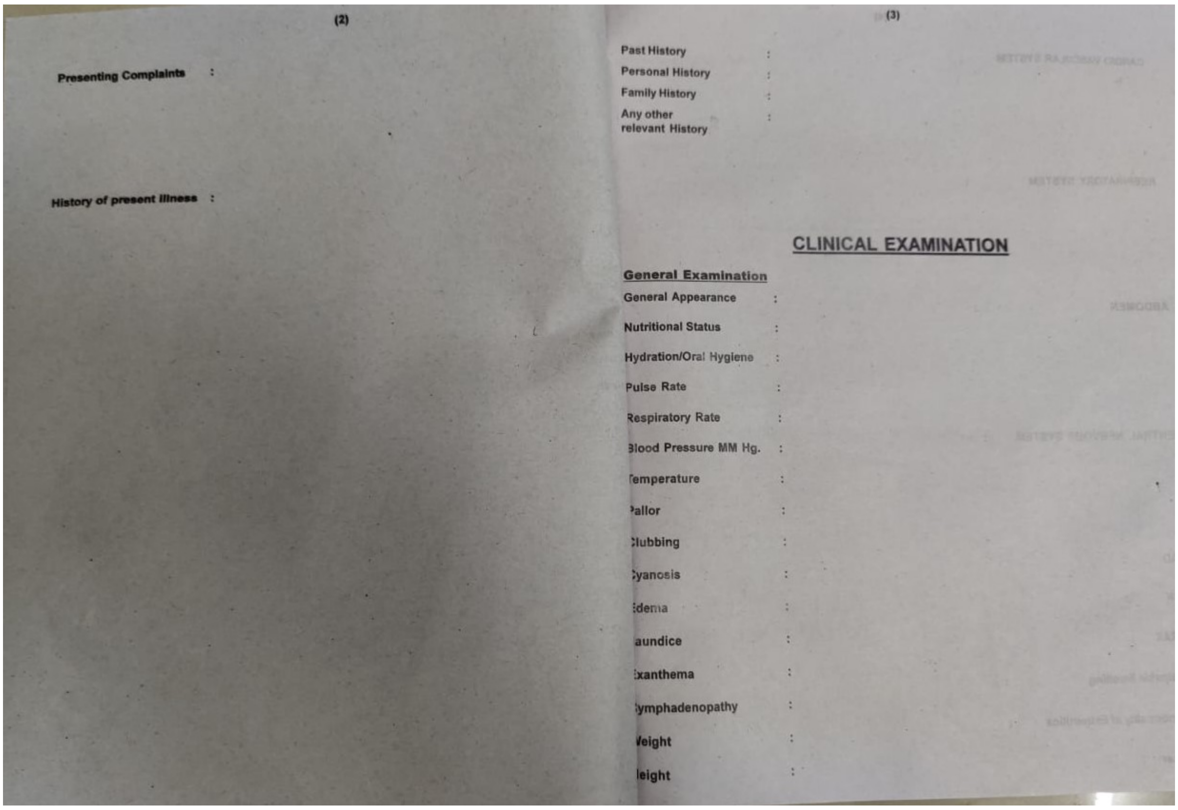
Code

Treatment given with advice on discharge :

Signature with Name :

Clinician

Resident



(2)

Presenting Complaints :

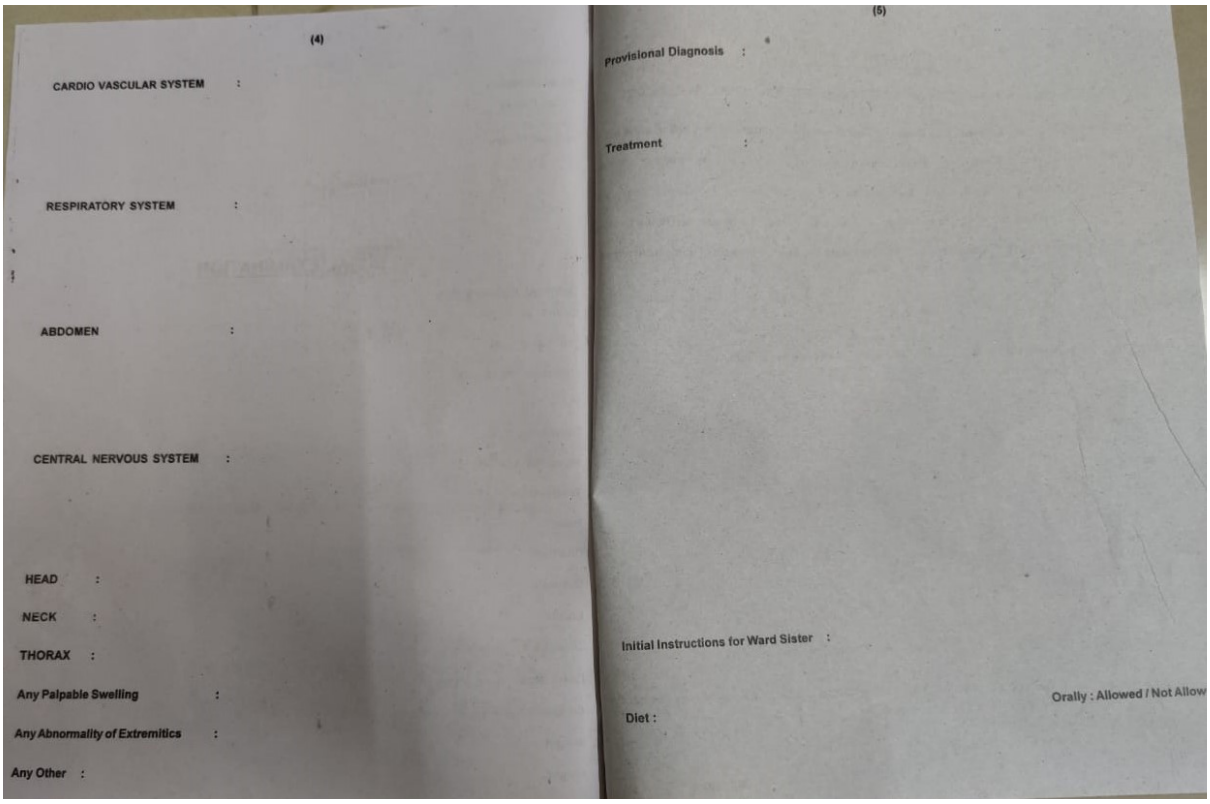
History of present illness :

(3)

Past History :
Personal History :
Family History :
Any other relevant History :

CLINICAL EXAMINATION

General Examination
General Appearance :
Nutritional Status :
Hydration/Oral Hygiene :
Pulse Rate :
Respiratory Rate :
Blood Pressure MM Hg. :
Temperature :
Pallor :
Clubbing :
Cyanosis :
Edema :
aundice :
Exanthema :
Lymphadenopathy :
Weight :
Height :



(4)

CARDIO VASCULAR SYSTEM :

RESPIRATORY SYSTEM :

ABDOMEN :

CENTRAL NERVOUS SYSTEM :

HEAD :
NECK :
THORAX :
Any Palpable Swelling :
Any Abnormality of Extremitics :
Any Other :

(5)

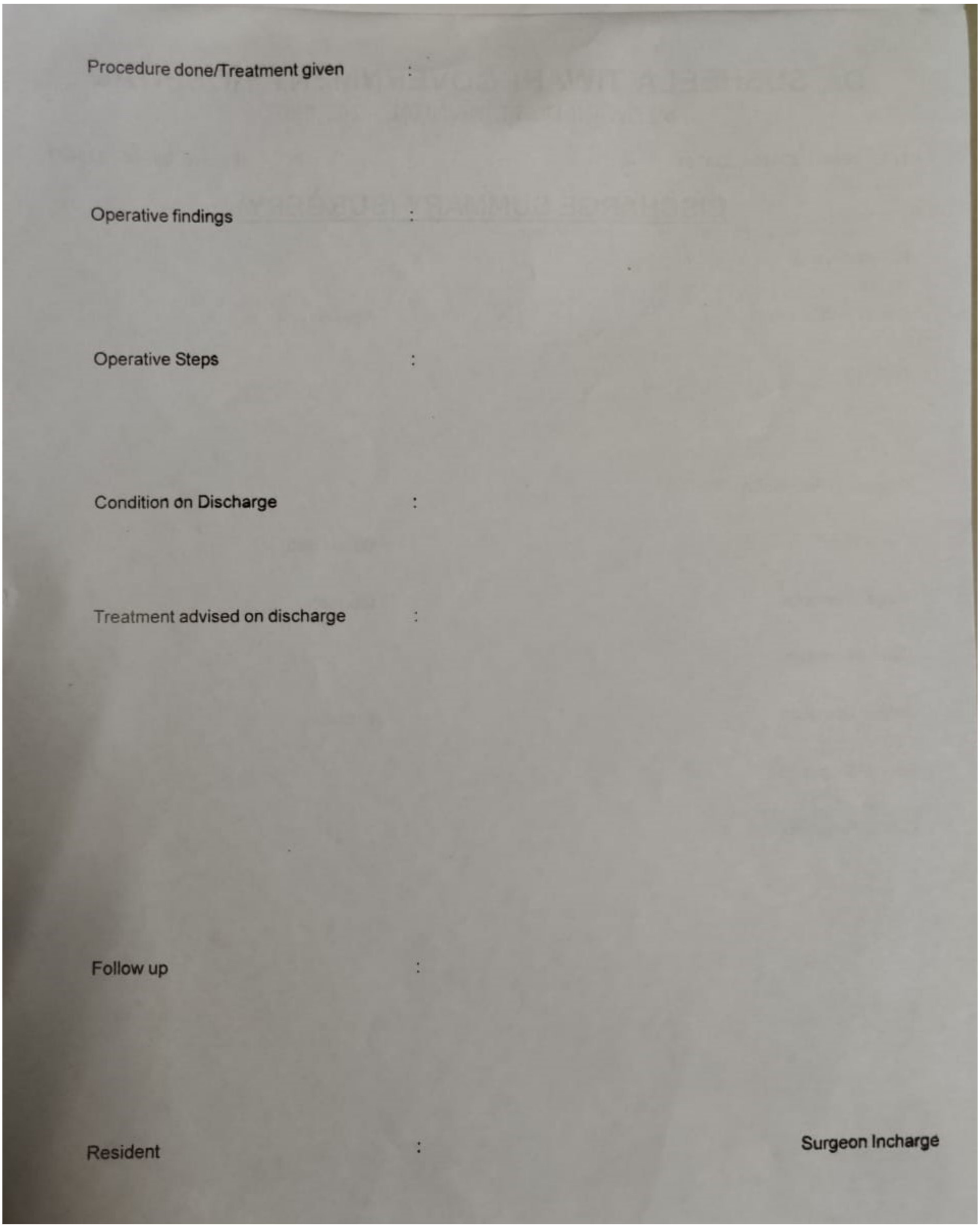
Provisional Diagnosis :

Treatment :

Initial Instructions for Ward Sister :

Diet :

Orally : Allowed / Not Allow



Procedure done/Treatment given :

Operative findings :

Operative Steps :

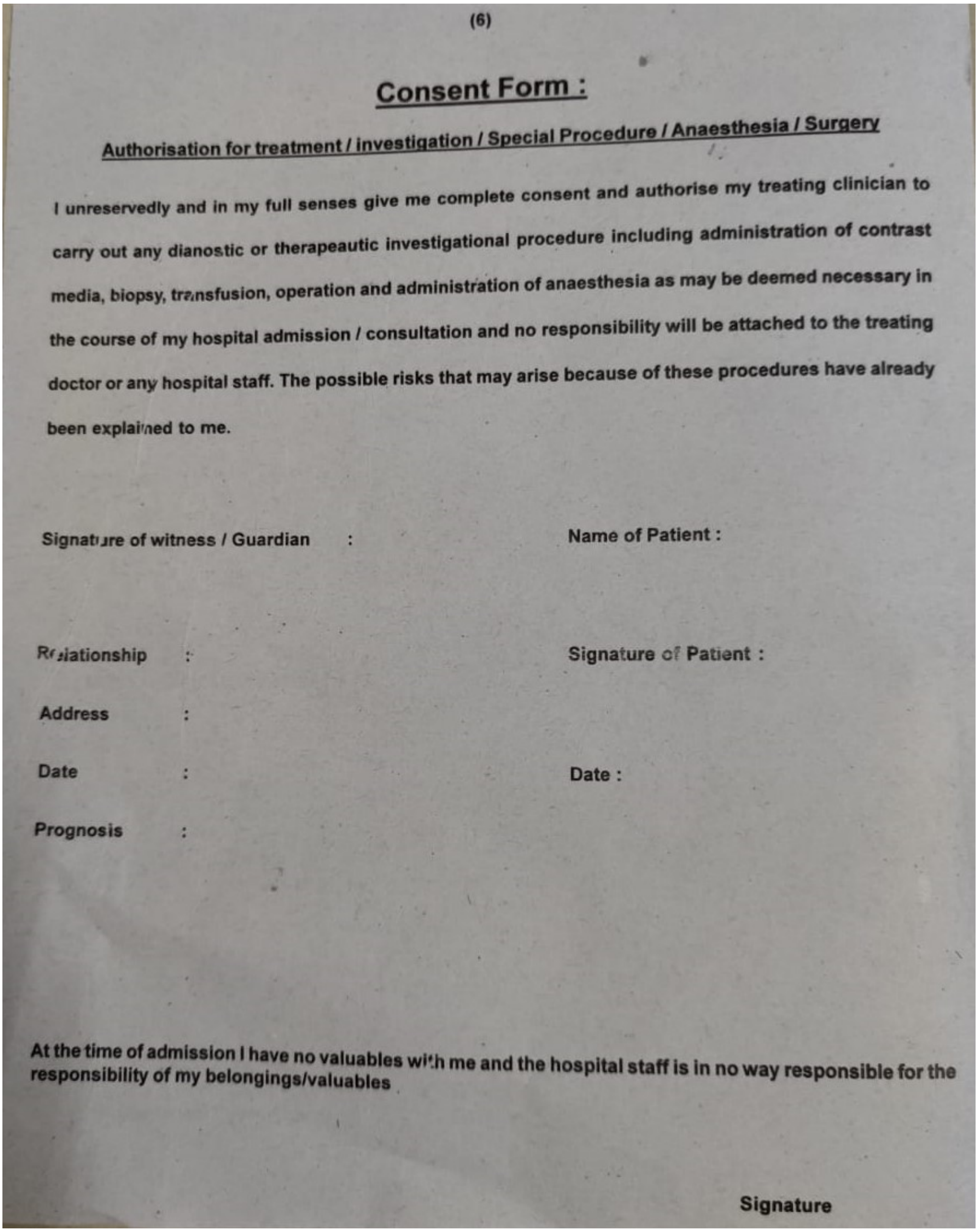
Condition on Discharge :

Treatment advised on discharge :

Follow up :

Resident : Surgeon Incharge

APPENDIX K: PATIENT CONSENT FORM (SURGERY)



(6)

Consent Form :

Authorisation for treatment / investigation / Special Procedure / Anaesthesia / Surgery

I unreservedly and in my full senses give me complete consent and authorise my treating clinician to carry out any dianostic or therapeautic investigational procedure including administration of contrast media, biopsy, transfusion, operation and administration of anaesthesia as may be deemed necessary in the course of my hospital admission / consultation and no responsibility will be attached to the treating doctor or any hospital staff. The possible risks that may arise because of these procedures have already been explained to me.

Signature of witness / Guardian :

Relationship :

Address :

Date :

Prognosis :

Name of Patient :

Signature of Patient :

Date :

At the time of admission I have no valuables with me and the hospital staff is in no way responsible for the responsibility of my belongings/valuables

Signature

APPENDIX L: PATHOLOGY AND RADIOLOGY REFERRAL FORM

Lab Request

Lab Referral Slip - PATHOLOGY

Date: 20/1/2020

Requisition	TRJA0012449104		
Patient:	AR	Patient ID:	PANA000323246
Age	30 Year	Sex	Male
Department	WARD J	Bed No	23
Referring Dept/Unit	PLASTIC SURGERY/PLASTIC SURG. (PD)		

Clinical Details

Test Name

HB
PLATELET COUNT
RETICULOCYTE COUNT

Radiology Request

Lab Referral Slip - CR X - RAY

Date: 20/1/2020

Requisition	TRJA0012449104		
Patient:	TG 22 Year	Patient ID:	PANA000323246
Age		Sex	Male
Department	TB & CHEST WARD	Bed No	4
Referring Dept/Unit	TB CHEST /UNIT I (DCP)		

Clinical Details

Test Name

CR X - RAY

Lab Referral Slip - MRI

Date: 20/8/2020

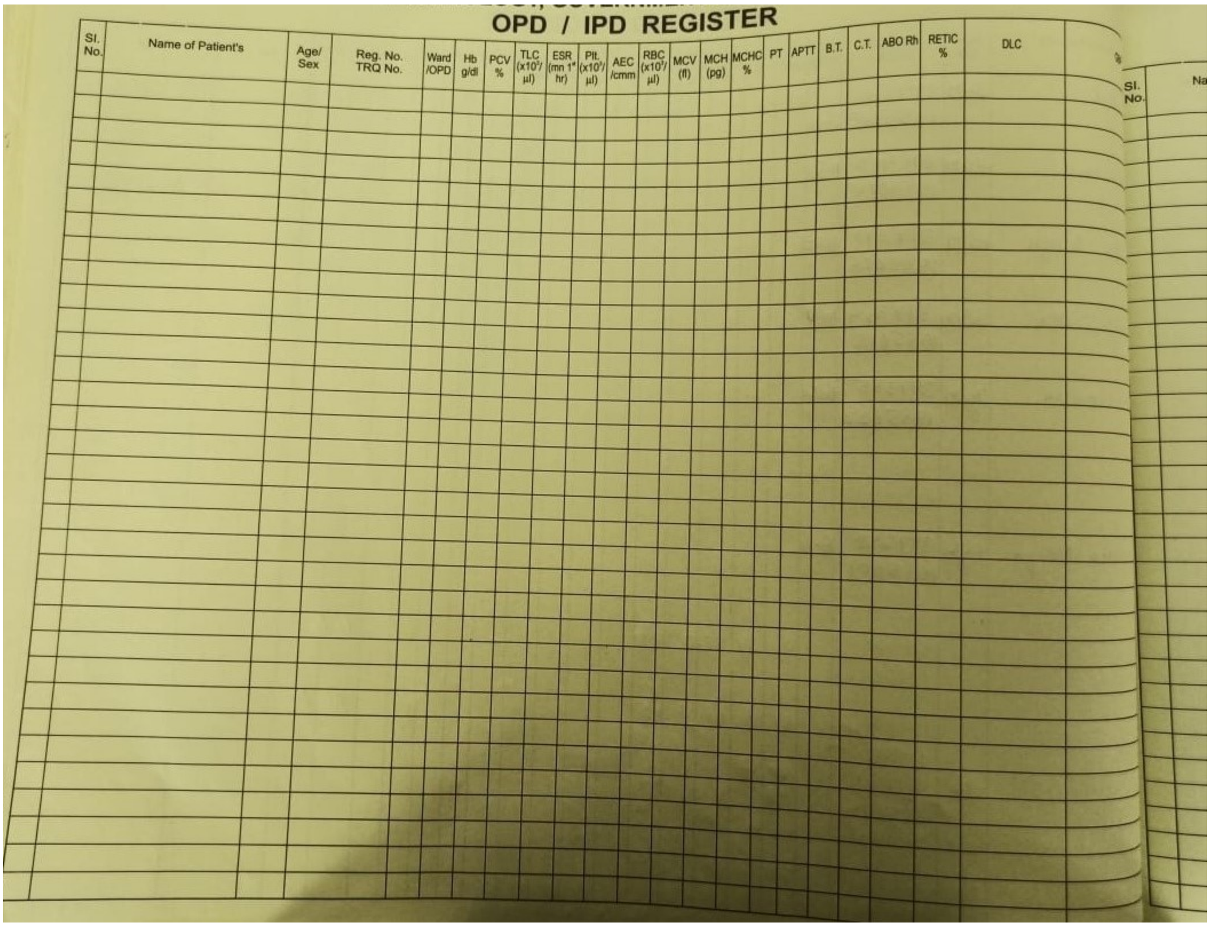
Requisition	TRJA0012449104		
Patient:	TG	Patient ID:	PANA000323246
Age	22 Year	Sex	Male
Department	TB & CHEST WARD	Bed No	4
Referring Dept/Unit	TB CHEST /UNIT I (DCP)		

Clinical Details

Test Name

MRI PLAIN SCAIN (ONE PART/ORGAN SINGLE STUDY)

APPENDIX M: PATHOLOGY OPD AND IPD REGISTER

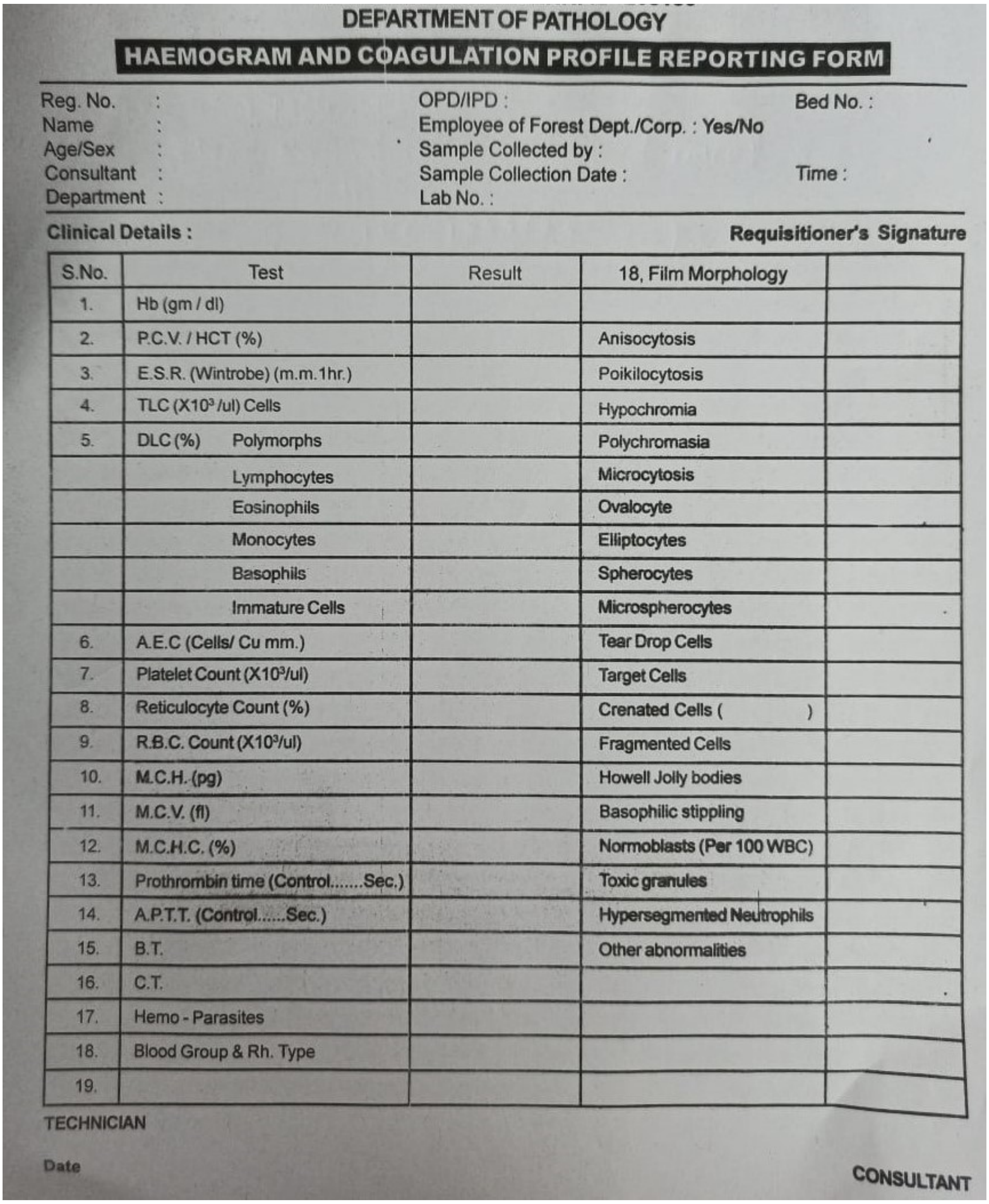


OPD / IPD REGISTER

Sl. No.	Name of Patient's	Age/ Sex	Reg. No. TRQ No.	Ward /OPD	Hb g/dl	PCV %	TLC (x10^3/ µl)	ESR (mn 1st hr)	Plt. (x10^3/ µl)	AEC /cmm	RBC (x10^6/ µl)	MCV (fl)	MCH (pg)	MCHC %	PT	APTT	B.T.	C.T.	ABO Rh	RETIC %	DLC

Sl. No.

APPENDIX N: HEMOGRAM AND COAGULATION PROFILE REPORTING FORM



DEPARTMENT OF PATHOLOGY

HAEMOGRAM AND COAGULATION PROFILE REPORTING FORM

Reg. No. :
Name :
Age/Sex :
Consultant :
Department :

OPD/IPD :
Employee of Forest Dept./Corp. : Yes/No
Sample Collected by :
Sample Collection Date :
Lab No. :

Bed No. :
Time :

Clinical Details :

Requisitioner's Signature

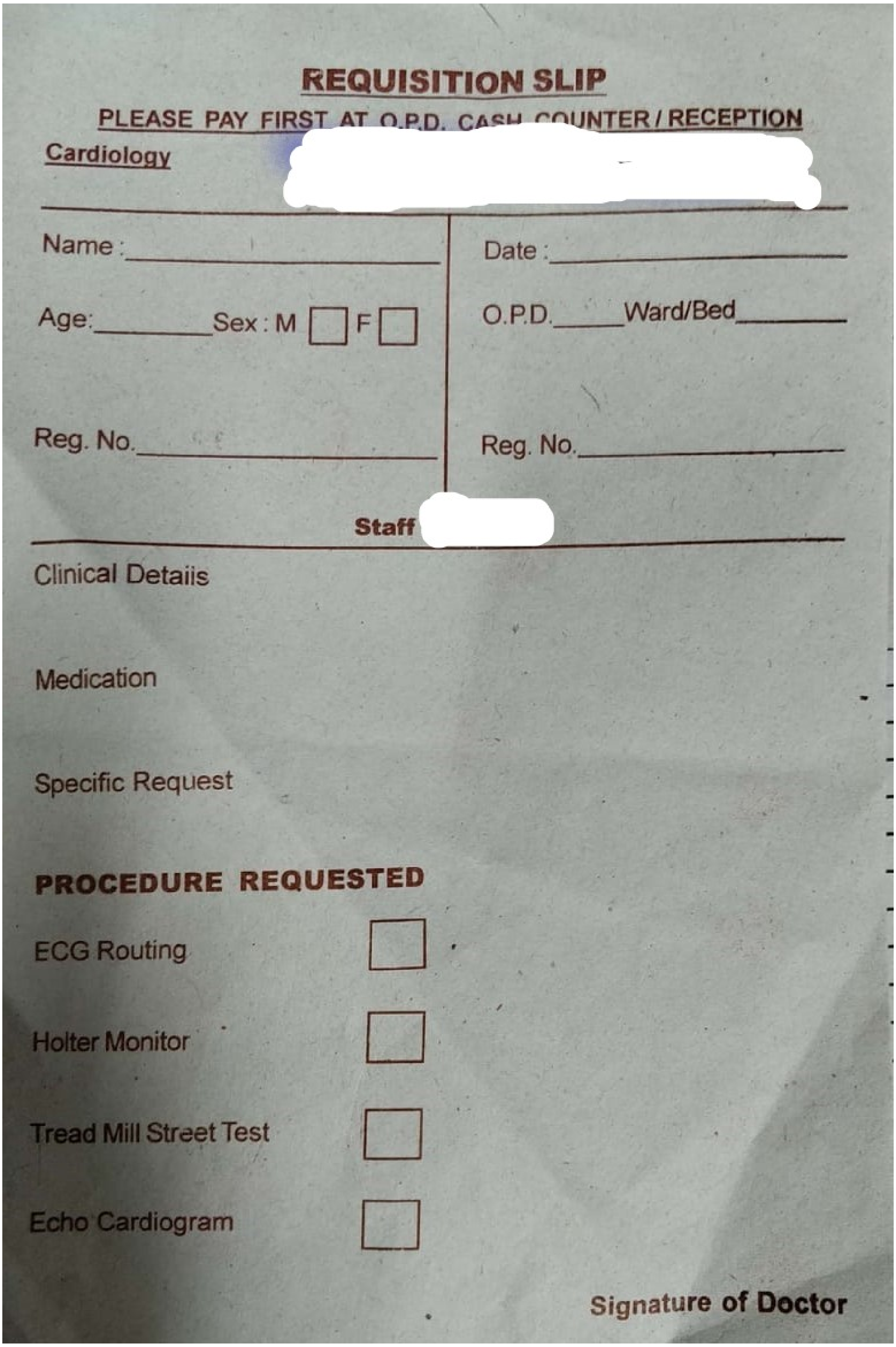
S.No.	Test	Result	18, Film Morphology	
1.	Hb (gm / dl)			
2.	P.C.V. / HCT (%)		Anisocytosis	
3.	E.S.R. (Wintrobe) (m.m.1hr.)		Poikilocytosis	
4.	TLC (X10^3 /ul) Cells		Hypochromia	
5.	DLC (%) Polymorphs		Polychromasia	
	Lymphocytes		Microcytosis	
	Eosinophils		Ovalocyte	
	Monocytes		Elliptocytes	
	Basophils		Spherocytes	
	Immature Cells		Microspherocytes	
6.	A.E.C (Cells/ Cu mm.)		Tear Drop Cells	
7.	Platelet Count (X10^3/ul)		Target Cells	
8.	Reticulocyte Count (%)		Crenated Cells ( )	
9.	R.B.C. Count (X10^3/ul)		Fragmented Cells	
10.	M.C.H. (pg)		Howell Jolly bodies	
11.	M.C.V. (fl)		Basophilic stippling	
12.	M.C.H.C. (%)		Normoblasts (Per 100 WBC)	
13.	Prothrombin time (Control.......Sec.)		Toxic granules	
14.	A.P.T.T. (Control......Sec.)		Hypersegmented Neutrophils	
15.	B.T.		Other abnormalities	
16.	C.T.			
17.	Hemo - Parasites			
18.	Blood Group & Rh. Type			
19.				

TECHNICIAN

Date

CONSULTANT

APPENDIX O: CARDIOLOGY REQUISITION SLIP



REQUISITION SLIP

PLEASE PAY FIRST AT O.P.D. CASH COUNTER / RECEPTION

Cardiology [redacted]

Name :______________ Date :______________

Age:________ Sex : M ☐ F ☐ O.P.D._____ Ward/Bed________

Reg. No.______________ Reg. No.______________

Staff [redacted]

Clinical Detaiis

Medication

Specific Request

PROCEDURE REQUESTED

ECG Routing ☐

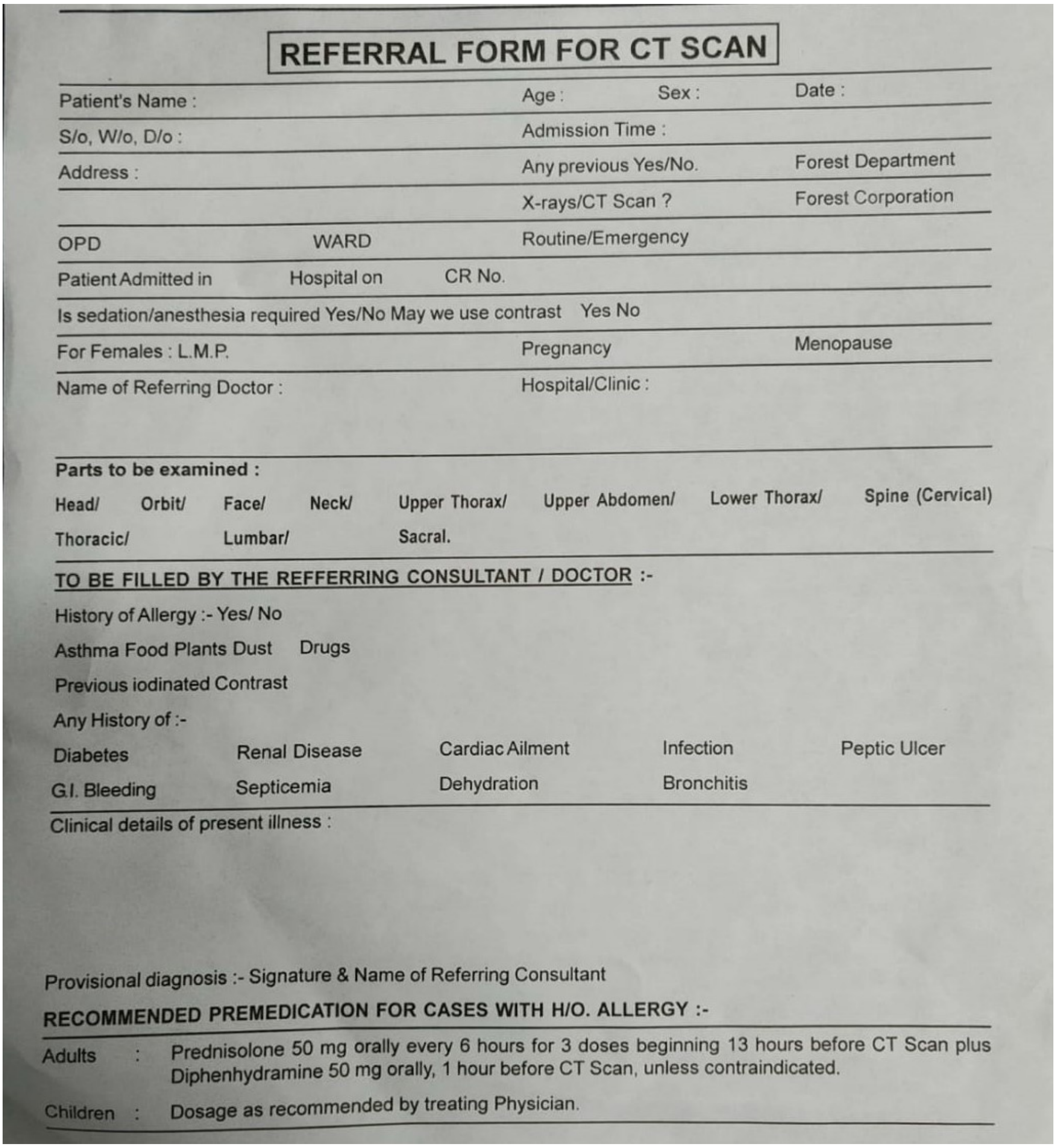
Holter Monitor ☐

Tread Mill Street Test ☐

Echo Cardiogram ☐

Signature of Doctor

APPENDIX P: REFERRAL FORM FOR CT-SCAN



REFERRAL FORM FOR CT SCAN

Patient's Name : Age : Sex : Date :

S/o, W/o, D/o : Admission Time :

Address : Any previous Yes/No. Forest Department

X-rays/CT Scan ? Forest Corporation

OPD WARD Routine/Emergency

Patient Admitted in Hospital on CR No.

Is sedation/anesthesia required Yes/No May we use contrast Yes No

For Females : L.M.P. Pregnancy Menopause

Name of Referring Doctor : Hospital/Clinic :

Parts to be examined :

Head/ Orbit/ Face/ Neck/ Upper Thorax/ Upper Abdomen/ Lower Thorax/ Spine (Cervical)

Thoracic/ Lumbar/ Sacral.

<u>TO BE FILLED BY THE REFFERRING CONSULTANT / DOCTOR</u> :-

History of Allergy :- Yes/ No

Asthma Food Plants Dust Drugs

Previous iodinated Contrast

Any History of :-

Diabetes Renal Disease Cardiac Ailment Infection Peptic Ulcer

G.I. Bleeding Septicemia Dehydration Bronchitis

Clinical details of present illness :

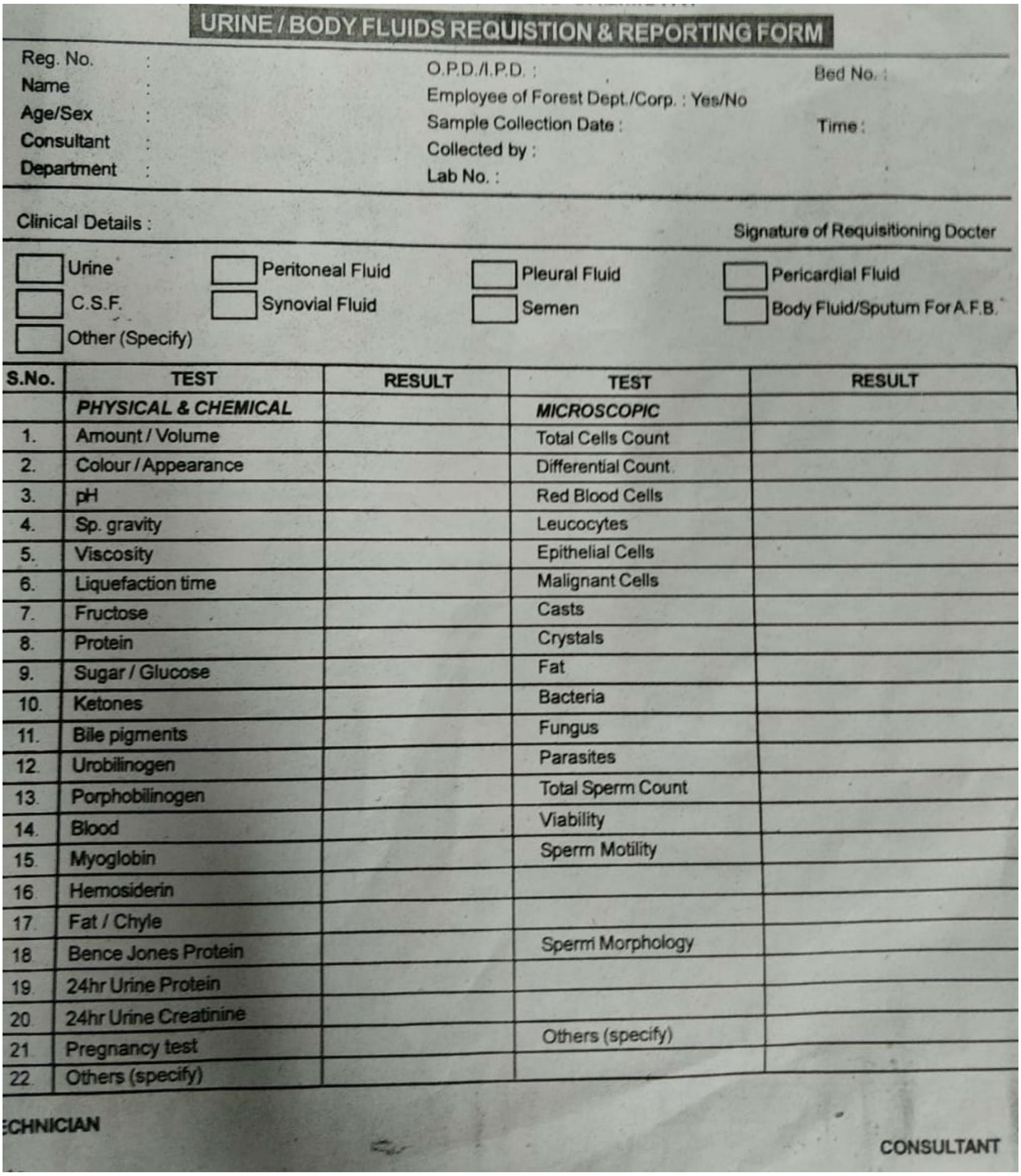
Provisional diagnosis :- Signature & Name of Referring Consultant

RECOMMENDED PREMEDICATION FOR CASES WITH H/O. ALLERGY :-

Adults : Prednisolone 50 mg orally every 6 hours for 3 doses beginning 13 hours before CT Scan plus Diphenhydramine 50 mg orally, 1 hour before CT Scan, unless contraindicated.

Children : Dosage as recommended by treating Physician.

APPENDIX Q: URINE/BODY FLUID REQUISITION AND REPORTING FORM



URINE / BODY FLUIDS REQUISTION & REPORTING FORM

Reg. No. :
Name :
Age/Sex :
Consultant :
Department :

O.P.D./I.P.D. :
Employee of Forest Dept./Corp. : Yes/No
Sample Collection Date :
Collected by :
Lab No. :

Bed No. :
Time :

Clinical Details :

Signature of Requisitioning Docter

☐ Urine
☐ C.S.F.
☐ Other (Specify)
☐ Peritoneal Fluid
☐ Synovial Fluid
☐ Pleural Fluid
☐ Semen
☐ Pericardial Fluid
☐ Body Fluid/Sputum For A.F.B.

S.No.	TEST	RESULT	TEST	RESULT
	PHYSICAL & CHEMICAL		***MICROSCOPIC***	
1.	Amount / Volume		Total Cells Count	
2.	Colour / Appearance		Differential Count	
3.	pH		Red Blood Cells	
4.	Sp. gravity		Leucocytes	
5.	Viscosity		Epithelial Cells	
6.	Liquefaction time		Malignant Cells	
7.	Fructose		Casts	
8.	Protein		Crystals	
9.	Sugar / Glucose		Fat	
10.	Ketones		Bacteria	
11.	Bile pigments		Fungus	
12.	Urobilinogen		Parasites	
13.	Porphobilinogen		Total Sperm Count	
14.	Blood		Viability	
15.	Myoglobin		Sperm Motility	
16.	Hemosiderin			
17.	Fat / Chyle			
18.	Bence Jones Protein		Sperm Morphology	
19.	24hr Urine Protein			
20.	24hr Urine Creatinine			
21.	Pregnancy test		Others (specify)	
22.	Others (specify)			

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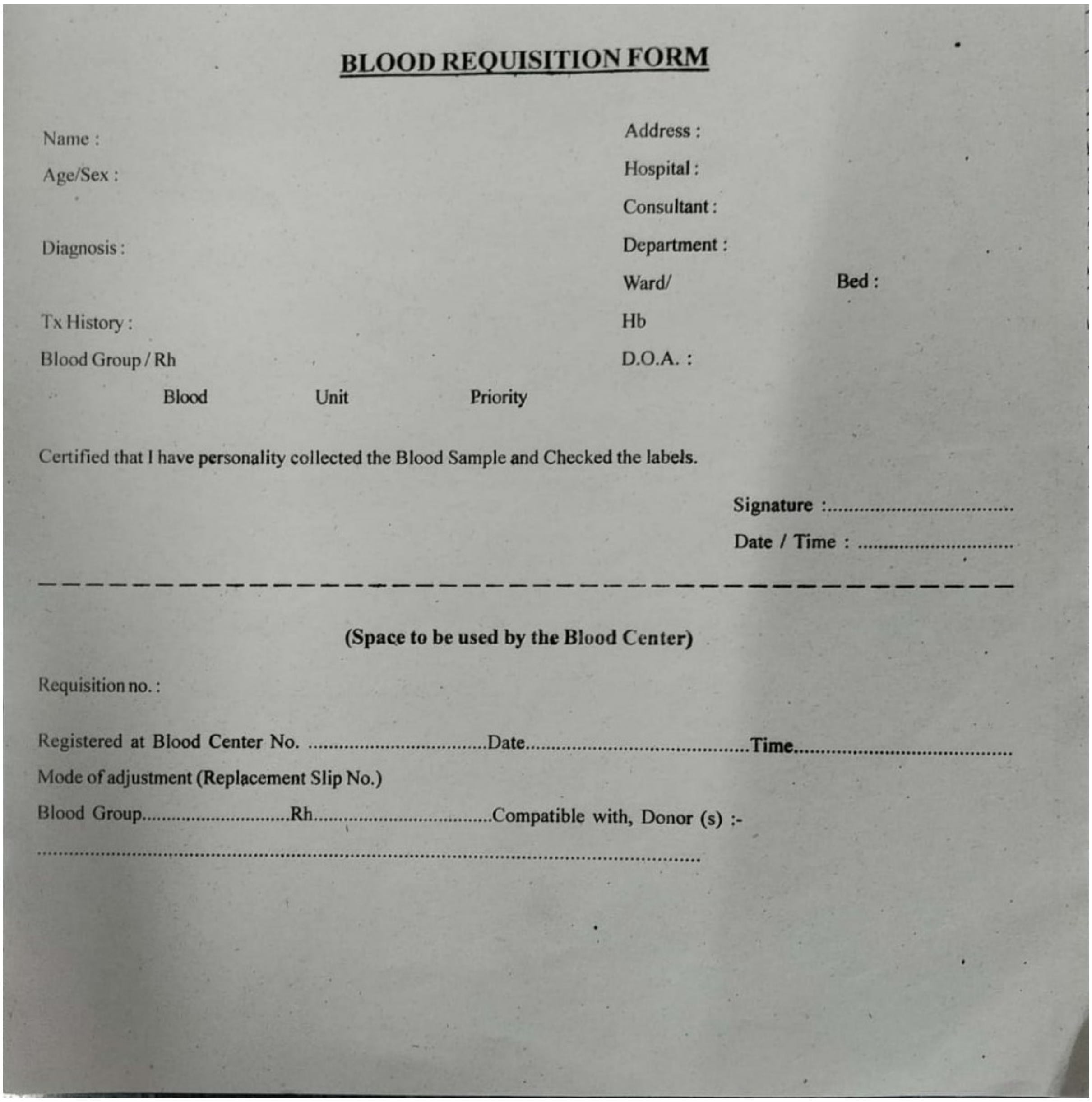
APPENDIX R: BLOOD REQUISITION FORM



BLOOD REQUISITION FORM

Name :	Address :
Age/Sex :	Hospital :
	Consultant :
Diagnosis :	Department :
	Ward/ **Bed :**
Tx History :	Hb
Blood Group / Rh	D.O.A. :

Blood Unit Priority

Certified that I have personality collected the Blood Sample and Checked the labels.

Signature :...................................

Date / Time : ....

(Space to be used by the Blood Center)

Requisition no. :

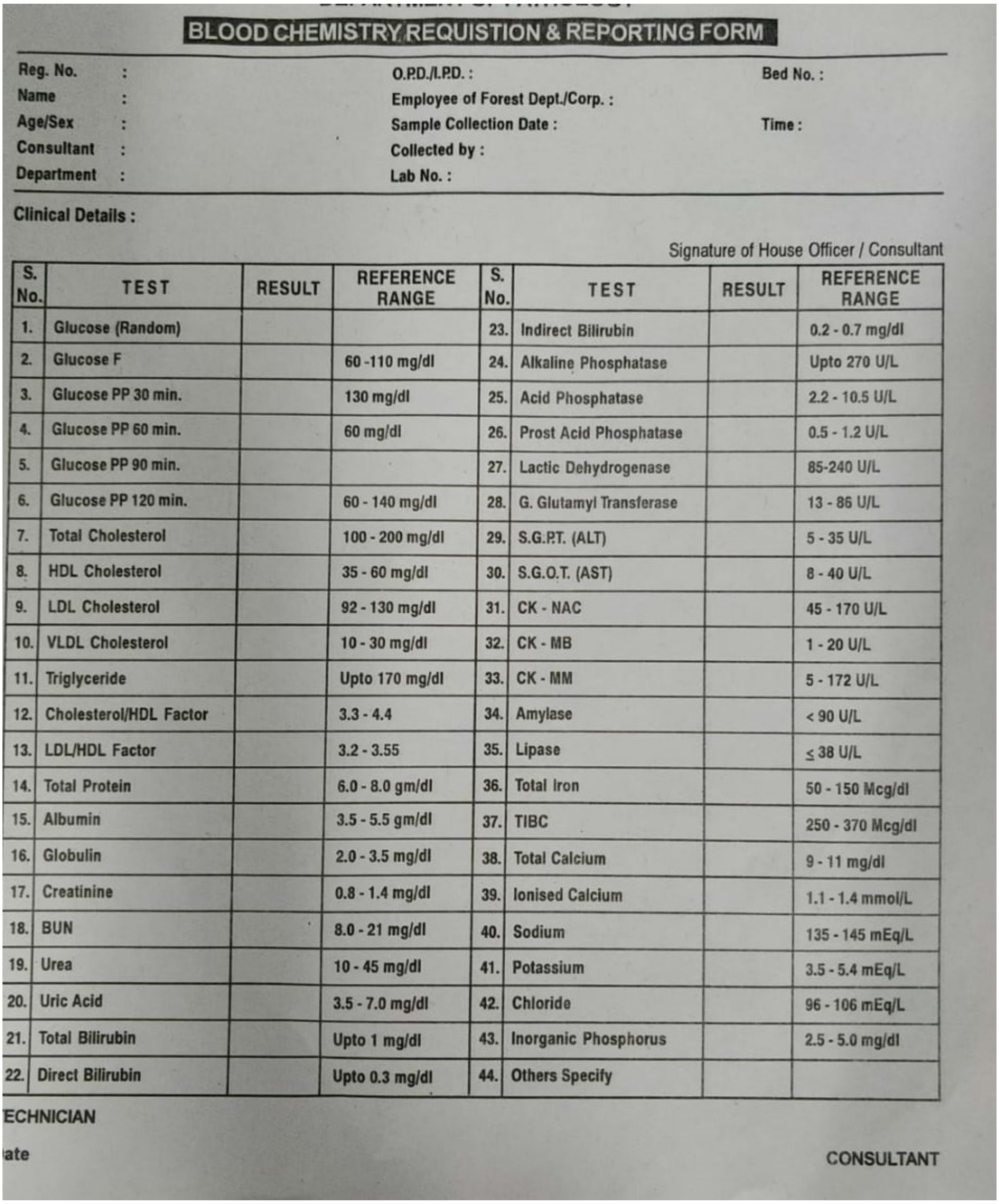
Registered at Blood Center No. ....Date...**Time**..

Mode of adjustment (Replacement Slip No.)

Blood Group.............................Rh...................................Compatible with, Donor (s) :-

....

APPENDIX S: BLOOD CHEMISTRY REQUISITION AND REPORTING FORM



BLOOD CHEMISTRY REQUISTION & REPORTING FORM

Reg. No. :
Name :
Age/Sex :
Consultant :
Department :

O.P.D./I.P.D. :
Employee of Forest Dept./Corp. :
Sample Collection Date :
Collected by :
Lab No. :

Bed No. :
Time :

Clinical Details :

Signature of House Officer / Consultant

S. No.	TEST	RESULT	REFERENCE RANGE	S. No.	TEST	RESULT	REFERENCE RANGE
1.	Glucose (Random)			23.	Indirect Bilirubin		0.2 - 0.7 mg/dl
2.	Glucose F		60 -110 mg/dl	24.	Alkaline Phosphatase		Upto 270 U/L
3.	Glucose PP 30 min.		130 mg/dl	25.	Acid Phosphatase		2.2 - 10.5 U/L
4.	Glucose PP 60 min.		60 mg/dl	26.	Prost Acid Phosphatase		0.5 - 1.2 U/L
5.	Glucose PP 90 min.			27.	Lactic Dehydrogenase		85-240 U/L
6.	Glucose PP 120 min.		60 - 140 mg/dl	28.	G. Glutamyl Transferase		13 - 86 U/L
7.	Total Cholesterol		100 - 200 mg/dl	29.	S.G.P.T. (ALT)		5 - 35 U/L
8.	HDL Cholesterol		35 - 60 mg/dl	30.	S.G.O.T. (AST)		8 - 40 U/L
9.	LDL Cholesterol		92 - 130 mg/dl	31.	CK - NAC		45 - 170 U/L
10.	VLDL Cholesterol		10 - 30 mg/dl	32.	CK - MB		1 - 20 U/L
11.	Triglyceride		Upto 170 mg/dl	33.	CK - MM		5 - 172 U/L
12.	Cholesterol/HDL Factor		3.3 - 4.4	34.	Amylase		< 90 U/L
13.	LDL/HDL Factor		3.2 - 3.55	35.	Lipase		≤ 38 U/L
14.	Total Protein		6.0 - 8.0 gm/dl	36.	Total Iron		50 - 150 Mcg/dl
15.	Albumin		3.5 - 5.5 gm/dl	37.	TIBC		250 - 370 Mcg/dl
16.	Globulin		2.0 - 3.5 mg/dl	38.	Total Calcium		9 - 11 mg/dl
17.	Creatinine		0.8 - 1.4 mg/dl	39.	Ionised Calcium		1.1 - 1.4 mmol/L
18.	BUN		8.0 - 21 mg/dl	40.	Sodium		135 - 145 mEq/L
19.	Urea		10 - 45 mg/dl	41.	Potassium		3.5 - 5.4 mEq/L
20.	Uric Acid		3.5 - 7.0 mg/dl	42.	Chloride		96 - 106 mEq/L
21.	Total Bilirubin		Upto 1 mg/dl	43.	Inorganic Phosphorus		2.5 - 5.0 mg/dl
22.	Direct Bilirubin		Upto 0.3 mg/dl	44.	Others Specify		

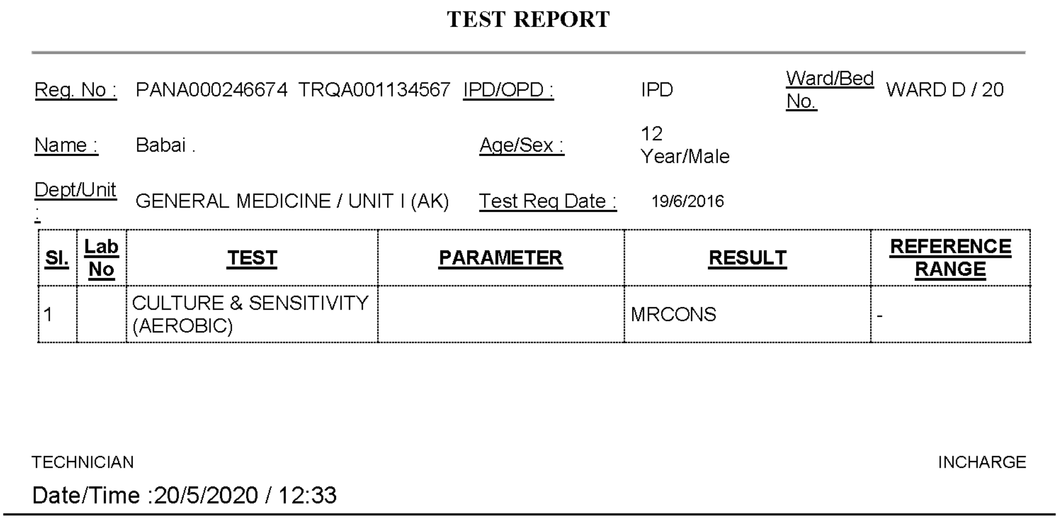
ECHNICIAN

ate

CONSULTANT

APPENDIX T: LABORATORY REPORT AND DISCHARGE SUMMARY

Lab Report



TEST REPORT

Reg. No :	PANA000246674 TRQA001134567	IPD/OPD :	IPD	Ward/Bed No.	WARD D / 20
Name :	Babai .	Age/Sex :	12 Year/Male		
Dept/Unit :	GENERAL MEDICINE / UNIT I (AK)	Test Req Date :	19/6/2016		

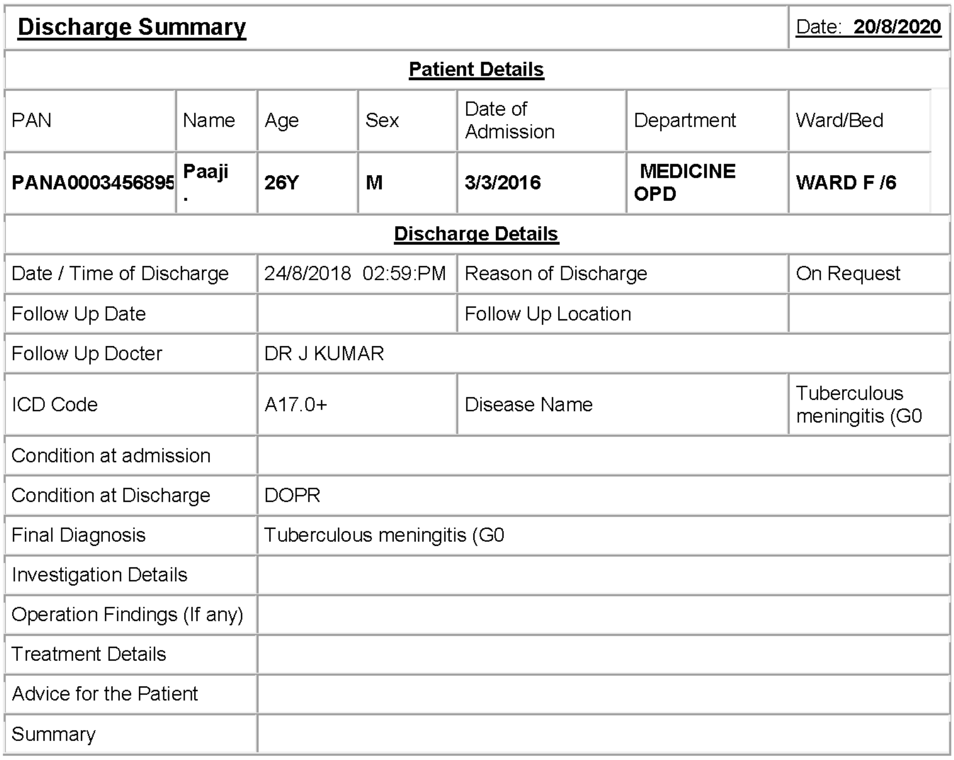
Sl.	**Lab No**	**TEST**	**PARAMETER**	**RESULT**	**REFERENCE RANGE**
1		CULTURE & SENSITIVITY (AEROBIC)		MRCONS	-

TECHNICIAN

INCHARGE

Date/Time :20/5/2020 / 12:33

ICD CODE ENTRY

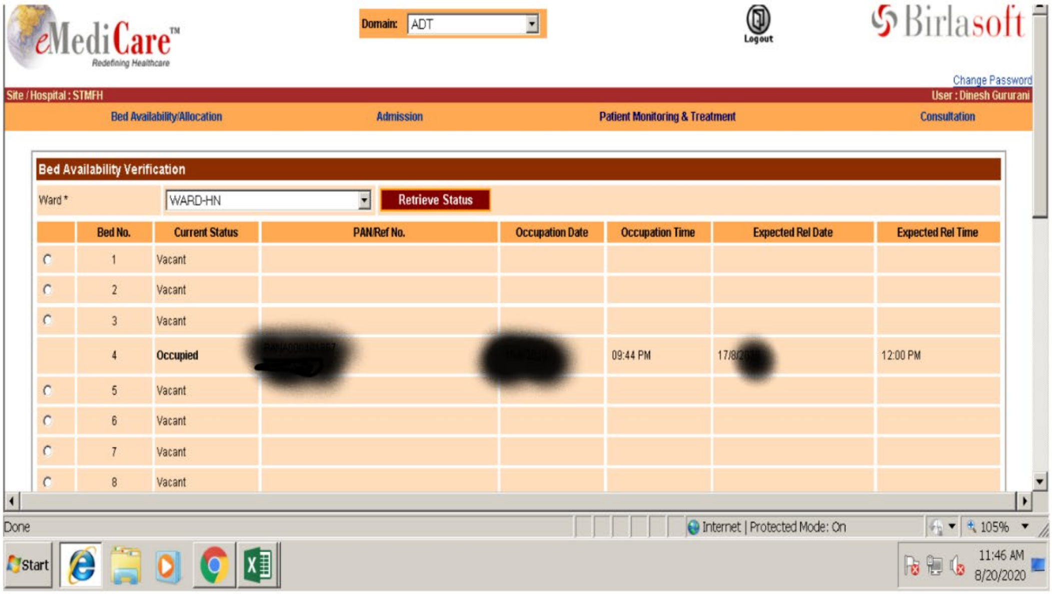


Discharge Summary						Date: **20/8/2020**
Patient Details						
PAN	Name	Age	Sex	Date of Admission	Department	Ward/Bed
PANA0003456895	**Paaji .**	**26Y**	**M**	**3/3/2016**	**MEDICINE OPD**	**WARD F /6**

Discharge Details			
Date / Time of Discharge	24/8/2018 02:59:PM	Reason of Discharge	On Request
Follow Up Date		Follow Up Location	
Follow Up Docter	DR J KUMAR		
ICD Code	A17.0+	Disease Name	Tuberculous meningitis (G0
Condition at admission			
Condition at Discharge	DOPR		
Final Diagnosis	Tuberculous meningitis (G0		
Investigation Details			
Operation Findings (If any)			
Treatment Details			
Advice for the Patient			
Summary			

APPENDIX U: BED AVAILABILITY AND MEDICINE FOLLOW-UP REPORT

Bed Availability



Site / Hospital : STMFH

User : Dinesh Gururani

Bed Availability Verification

Ward * WARD-HN

	Bed No.	Current Status	PAN/Ref No.	Occupation Date	Occupation Time	Expected Rel Date	Expected Rel Time
○	1	Vacant					
○	2	Vacant					
○	3	Vacant					
	4	Occupied	[redacted]	[redacted]	09:44 PM	17/8/[redacted]	12:00 PM
○	5	Vacant					
○	6	Vacant					
○	7	Vacant					
○	8	Vacant					

11:46 AM
8/20/2020

Medicine Follow-up.

Site / Hospital : STMFH

User : Dinesh Gururani

Medicine Follow-Up

PAN/TRN* [redacted]

Department* WARD E-PSYCHIAT [redacted]

Bed Number*

Patient Name [redacted]

Status Under Treatment

	Date & Time	Medicine	After	Dosage	Freq	Duration	Dosage Given*	Date & Time*	Doctor's Remarks	Remarks

APPENDIX V: HOSPITAL CENSUS REPORT

Date :- **02/03/2020**

Hospital Census Report Dated 28/02/2020

TEACHING BEDS						
Department	**Autho Beds**	**Ward**	**Bed Occup**	**Adm.**	**Disch/ Death**	**Rem.**
Gen Medicine	130	Mecine Ward (B+C+D)	66	17	10	
Paediatrics	64	Paedia (I)	43	4	8	
T.B. Chest	30	T B Chest	28	8	6	
Skin & STD	20	E				
Psychiatry	15	E	3		1	
Gen Surgery	140	Surgery (G + J+JB	108	14	18	
Neuro Surgery	21	Ward (HN)	14	5	2	
Ortho	60	Ortho (H)	39	5	4	
Opthalmology	30	EYE (K)	5	1	7	
ENT	40	ENT (K)	18	5		
Gynaecology	30	Gynae (F)	24	7	7	
Obstetrics	58	Obs (F)+ E (EXT.)	44	11	11	
Obs & Gyne Extra		Obs & Gyne Extra	19	2	4	
TOTAL	**638**	**TOTAL (A)**	**411**	**79**	**78**	
NON TEACHING BEDS						
Private	13	Semi Private + Delux + VIP Delux	2	1	1	Gyne-1, Neu-1
Ward E Isolation	4	Ward E Isolation				
PICU	12	PICU	11	1	2	
Oncology	31	SRMC	24	11	13	
Anaesthesiology	6	Pain & Palliative Care	5			
Casualty	22	Casualty	5			Gyne-5
TOTAL	**88**	**TOTAL (B)**	**47**	**13**	**16**	
Burn HDU	6	Burn HDU	5			
ICCU	11	ICCU	11	2	2	Med-11
SNCU	24	SNCU	24		1	
Surgery ICU	6	SICU	6	1		
Anaesthesiology	6	Anaesthesiology ICU	6	1	1	Surg-3, Neu-3
TOTAL	**53**	**TOTAL (C)**	**52**	**4**	**4**	
Number of Infant with Mother		**TOTAL (D)**	46	9	20	
G. TOTAL (A+B+C+D)	**779**		**556**	**105**	**118**	
Previous Bed Occupancy	**569**	**Today's Admission**	**105**	**Today's Discharge**	**118**	

Total Discharge Detail	
Discharge -	110
Death-	4
LAMA-	4
Abscond-	
Cancelled-	
TOTAL	**118**

Total OPD Detail	
Department	**No. of Patient**
Casualty	138
Dental	31
ENT	154
Gynae & OBS	93
G. Medicine	337
Neuro-Surgery	89
Opthalmology	125
Orthopaedic	44
PMR	91
Paediatrics	104
Psychiatry	37
G. Surgery	138
Pain & Palliative	
Plastic Surgery	
ICTC	
Skin & VD	147
TB & Chest	96
Anathesia	
Total OPD	**1624**
Now Bed Occupancy	**556**

Computer Programmer **Medical Suprintendent** **Principal**

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