

Requirements analysis for a patient-centric information system in a primary health setting: case study from India

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Abstract

Under health reforms for establishing Universal Health Coverage (UHC) in developing countries, it becomes imperative that health care should be made accessible to each and every citizen of the population at affordable costs. This requires a huge shift in building health information systems with a focus on capturing patient data rather than aggregate data which was done in the past.

Research on building a patient-centric information system is lacking in the context of a developing country like India. Even in developed countries, the concept of patient centric care is currently evolving and takes on very different forms as compared to that in a developing country. Hence the focus of my thesis is on the analysis of requirements for such a system in primary-health settings in developing countries. This has been empirically studied as part of a research project funded by the Research Council of Norway (RCN) called INTPART (International Partnership), with a focus on “Designing Information Systems for Strengthening Patient Based Care in Resource Constrained Settings”. The understanding of requirements is based on the framework of a “living lab” which was setup in the context where the implementation of the patient-centric information system was carried out. The living lab has been the primary driver of understanding the evolving requirements of the system for this case-study. The research objective of my thesis is to answer the following questions:

- What are the requirements to build a patient-centric information system in a primary-health setting?
- Analyze different technical solutions to address these requirements and to understand the efficacy of the respective solutions.

The living lab has provided important inputs for creating an integrated database covering all the health services required by the population. The requirements have evolved over various “phases” and the requirements build upon the umbrella requirements of UHC which focus on the identification of each patient and follow their care cycle from their homes to the primary care facilities then district hospitals and back.

The key requirements identified include data capture for care provided at the community level and at the facility level, generate outputs like reports, workplans and registers from the

data captured, perform data analysis at the primary health care level by building dashboards, cohort charts and GIS maps, communicate directly with the patient through SMS for follow ups and implement standards to be interoperable with other health information systems.

Keywords: patient-centric, health information systems, living lab, Universal Health Coverage (UHC), requirements, requirements-analysis, developing countries

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Acronyms

HIS	Health Information Systems
CHWs	Community Health Workers
ASHAs	Accredited Social Health Activists
ANM	Auxiliary Nurse Midwife
AWW	Anganwadi Worker
DWCD	Department of Women and Child Development
IT	Information Technology
PCIS	Patient Centric Information System
EMRs	Electronic Medical Records
INTPART	International partnership
PGIMER	Postgraduate Institute of Medical Education & Research
IFI	Institute for Informatics
UiO	University of Oslo
C3	Center for Connected Care
HISP	Health Information Systems Program
DHIS2	District Health Information Systems version 2
HMIS	Health Management Information System
OpenMRS	Open Medical Record System
LMIC	Low and Middle-Income Countries
PHC	Primary Health Center
EMR	Electronic Medical Record
MCTS	Mother and Child Tracking System
RCH	Reproductive Child Health
TB	Tuberculosis
NACO	National AIDS Control Organization
EHR	Electronic Health Record
SDLC	Software Development Life cycle
RAD	Rapid Application Development
PD	Participatory Design
CHC	Community Health Center
MPW	Multi-Purpose Worker
DFW	Directorate of Family Welfare
ANC	Ante-Natal Care
PNC	Pre-Natal Care
OPD	Out-Patient Department
CHIS	Community Health Information Systems
RHIS	Routine Health Information Systems
NPCDCS	National Programme For Prevention and Control of Cancer, Diabetes, Cardiovascular Disease and Stroke
UHC	Universal Health Coverage
UIDAI	Unique Identification Authority of India

1 Introduction

In this chapter, I introduce the concept of patient-centric systems, the context shaping the project under study and the research questions, which is the focus of my thesis. In the end, the structure of the thesis is given.

“A patient-centered care system is one where patients can move freely along a care pathway without regard to which physician, other health-care provider, institution or community resource they need at that moment in time. The system is one that considers the individual needs of patients and treats them with respect and dignity.”(Care, 2010, p. 34)

A critical challenge for health services in developing countries is to find ways to make provision of services, including their supporting Health Information Systems (HIS) more patient-centric (Rao, Peters, & Bandeen-Roche, 2006). This requires that the patient is benefited from the information generated by HIS, which will allow him/her to be able to exercise choices consistent with individual preferences, values, and beliefs. This fundamental transformative concept of patient-centricity affects how the decisions about health are made and who has the authority to make them (Robbins, Curro, & Fox, 2013). In this process, patients are expected to report increased sense of security and involvement. The concept is especially vital today, as more people require chronic health care rather than acute care.(Improvement, 2018). Globally 36 million people died in 2008 due to non-communicable diseases, which are a major contributors of chronic diseases (Gowda, Bhojani, Devadasan, & Beerenahally, 2015). Diabetes, hypertension, cardiovascular diseases and cancer are some examples of chronic diseases.

Health information systems have the potential to facilitate patient-centric care, by providing a mechanism for patients to provide their care providers with critical individual-focused information (Snyder et al., 2011). The care providers, in turn can use the HIS (like an electronic medical record), to share information with other care providers, such as in a referral case, to help provide more focused care. In addition, the patients and care providers can use information tools and resources to interact with one another in new ways, such as to improve outreach care at home.

There are different kinds of patient centric systems described in the literature from the western context. In Canada, an initiative called Telehealth Ontario which is staffed by nurses, provides health information or advice on a 24/7 basis. The nurses assess the situation and recommend a visit to a clinic, physician, hospital or other community resources as the situation demands (Care, 2010). In Denmark, patient centric care means high accessibility to health services; here clinics also see patients at nights and weekends. Weekend physicians take phone calls from patients and can readily access their medical records. At the end of the consultation, the patient's primary care physician receives an email as a record of the consultation (Care, 2010). This accessibility by telephone or email and electronic systems for prescriptions and refills makes care more patient-centric. In the United States "medical home" is in vogue where care is integrated across all levels of health care from home health agencies to specialty care to hospitals (Care, 2010). Care is facilitated by registries, information technology and information exchange(Care, 2010). Research suggests that the principles of health equity, patient-centered care and communities playing a central role in health action are becoming mainstream in modernizing societies(Agarwal, Jain, Ghosh, & Parihar, 2017).

However, in the context of developing countries, patient-centric systems in primary health are unique, being historically embedded in the legacy of paper-based flows and manual recording primarily for serving the reporting needs of higher-level bureaucrats rather than for strengthening patient level care. In recent times these systems in the primary health care, have been digitized and qualitatively redefined, because now they are performing functions of recording, reporting, tracking, referral linkages with secondary and tertiary care systems. Therefore, lot of unique challenges come in while changing the traditional work practices in primary health care to patient centric information systems, which range from design and infrastructure, implementation, governance, regulatory, privacy and security concerns.

Patient-centric care and the kind of HIS relevant in the context of developing countries, needs to be differently thought and contextually conceptualized. My thesis approaches this challenge in the context of India. My research aim is broadly, to understand the analysis of requirements to build a Patient-Centric Information System (PCIS) in India. Empirically, I seek to understand this, by an ongoing project to design, develop and implement a PCIS for primary health care in India. Digital health technologies are resource intensive and require a combination of capital, trained human resources, infrastructure upgrades, and funding for

their maintenance (Konduri, Bastos, Sawyer, & Reciolino, 2017). Meeting these resource demands is a non-trivial challenge.

1.1 The context shaping the design of patient-centric information systems in primary health care in India

According to the population census of India, in 2011, almost 68 percentage of the population lives in rural areas. Access to health facilities is limited and hence a huge army of Community Health Workers (CHWs) operate in the village level to mobilize the population for providing care. At the primary health level, the CHWs, are a powerful force around the world for promoting healthy behaviors and extending the reach of health systems (Perry, Zulliger, & Rogers, 2014). Since 2005, in India, Accredited Social Health Activists (ASHAs), who are voluntary village-level female workers, are playing this role (Sharma, Webster, & Bhattacharyya, 2014) of CHWs. Two other groups of female community-level workers who contribute to child health in India are the Auxiliary Nurse Midwife (ANM), who is with the health department as a formal paid staff, and the Anganwadi Worker (AWW), who is with the Department of Women and Child Development (DWCD)(Sharma et al., 2014).

CHWs generate lot of data in the villages; this includes data on the population they serve during their field visits. Data collected by the CHW is based on antenatal care, prenatal care, immunization and chronic diseases. They send this data to the Primary Health Center, where it is compiled in the form of monthly reports and transferred to the higher levels of the district and above. Lot of the data that the health workers collect is redundant or never utilized adequately (Krishnan, Nongkynrih, Yadav, Singh, & Gupta, 2010), since it is mainly collected on paper based formats for reporting purposes, and data analysis is not done at the primary health care level. Efficient management of data is difficult in a manual system, and often involves duplication of efforts and wastage of time. A computerized information system is one among the many ways that Information Technology (IT) can help improve the health system through better practices around data collection, storage, analysis and dissemination of information.

The existing reporting systems are primarily aggregate and facility based, while the recording systems in diaries and registers are patient/beneficiary based. Now the effort is to make this into a complete and integrated “Patient-Centric Information System” (PCIS)

In contrast to the Electronic Medical Records (EMRs) in the West, where the patient goes to the doctor for treatment, and the doctor enters all the patient information into an EMR, in the context of India we are referring to the CHWs who go on field visits and make entries in their field diaries. While traditional EMR takes place in the confines of a hospital and focuses on curative care, patient-centric care should focus on both preventive and curative care and should be able to record any care, received by the patient.

The vision of a patient centric care system could be the availability of information at all levels starting from the community, to primary health care and to secondary and tertiary health care, and their inter-linkages. It is an important step to provide continuity of care for individuals. Irrespective of the kind and place of treatment, other care providers can enter data in an electronic record, which is further accessible by all levels of health care.

Now under the ongoing health reform efforts in India, the health information systems are being revamped. Sahay, Sundararaman, and Mukherjee (2014) elaborate that:

- HIS should be able to capture both aggregate and patient-based data, which should be inter-connected.
- The data should increasingly provide real time data.
- The HIS should be more to cover populations and not just be facility based.

Patient-centric systems are seen an answer to these above requirements, which I am exploring in this thesis. In India, some of the conditions, which I identify as being relevant to understand the design of patient-centric information systems, are discussed below.

1.1.1 Bureaucracy

In the Indian context, top-down, bureaucratic , fragmented techno-centric approaches to health care have created considerable wastage of scarce resources and have failed to deliver

significant health improvements for individuals, especially those living in rural areas and who are serviced by the primary health care system (Abhiyan, 2006). In India, though the national level does the planning, health comes under the state's responsibility and many of the states do not have a clear health strategy (Ramani & Mavalankar, 2006), including related to their HIS. There is no systematic effort at the state level to plan, and monitor the delivery of health services. Health services continue to be supply pushed than demand driven (Ramani & Mavalankar, 2006). Since organization of health care delivery is around segmental lines of diseases like immunization, epidemic control, maternal health, a holistic picture of the health system is lacking. Also, the sub-ordinates at the lower levels lack the power to take decisions on plans and programs, and are always looking at the higher levels for clear orders, directions and planning (Raka & Kannan, 2006).

The implications of a bureaucratic approach are it makes the health delivery system mechanistic and very rigid, making it more bureaucracy-centric than patient-centric. Raka and Kannan (2006) state that, this kind of mechanistic approach has its merits in reaching goals like immunization, family planning, as it needs rigid work allocation and plans to be in place. However, in case of individual treatment, which varies from location to location, person to person, it is required to have certain kind of flexibility to make it more patient-centric. Patients also understand the realities of their own health conditions, and so they are well placed to inform the design of these systems.

1.1.2 Infrastructure

Primary health care in India is the first point of contact for individuals, their families and the society with the national health system. It constitutes the first element of a continuing health care process. The problems in the primary health center in rural areas range from lack of medicines, lack of facilities and doctors, underdeveloped infrastructure and lack of expert staff (Agarwal et al., 2017). In addition, patient-centric information systems are resource intensive and require good internet connectivity, uninterrupted power supply, computers, printers, servers, and trained staff. Currently, the usage of technology in primary health centers is very limited and insufficient infrastructure can prove a hindrance to patient-centric information systems.

The current working methods in primary health care in case of patient or beneficiary-based entry is limited to paper based registers, health cards and reports. To move towards patient-centric information systems, the paper-based entry should be recorded electronically. This demands skilled resources for data-entry in addition to the existing staff. Trained IT staff is required to set up the necessary servers, machines, printers and equipment. IT resources are also needed to develop, maintain and support the system. Hence, the infrastructure can prove to be resource intensive and a challenge to move towards patient centric systems.

1.1.3 Capacity and skills

CHWs go door to door to provide services to the people in the rural areas. In addition, they also collect data for the national and state administered health programs. In our study, it was observed that CHWs spent about 60 percent of their time in maintaining registers and making reports. Thus, the CHW’s are overburdened with a lot of book keeping and reporting, while their focus should be on providing continuity of care. According to WHO (World health organization) (2008), the information needs and tools at different levels of data collection vary (see Figure 1). The quantity of data collected at the community level is more comprehensive than that collected at the higher levels. Hence, the amount of data reporting and paper-based registers are varied and cumbersome and these are done by the community health workers in addition to their care services provided to the community.

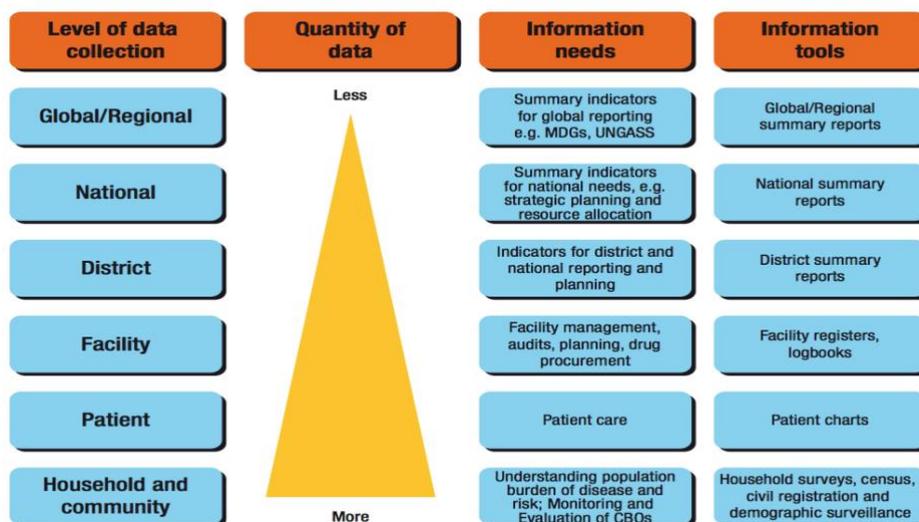


Figure 1: Information needs and tools at different levels of data collection

CHWs typically have an education up to primary level with 8 to 10 years of schooling. Thus, if information systems are introduced to the health workers, it requires upskilling and training

on how to use these systems. Getting staff engaged with new information systems involves a process to change attitudes and priorities. With the current capacity of community health workers, this is a serious implication on moving towards information systems for patient-centric care.

1.1.4 Scale

“Scaling concerns the process through which that product or process is taken from one setting and expanded in size and scope within that same setting and/or also incorporated within other settings” (Sahay & Walsham, 2006, p. 185). Sahay and Walsham (2006) discuss that scaling comes with the unique problem of “all or nothing”. This means that health information systems produce meaningful data when there is coverage of all the health centers in a particular area. Scaling can be in terms of technology, human resources, infrastructure, capacity building and training resources.

Sahay and Walsham (2006) state that scaling PHCs is a complex task due to instability and change. The implication of scaling in health information systems could offer dilemmas, of whether to treat people as statistics or as whole humans. In India, strengthening the capacity of the state to manage different providers of care is crucial to scaling-up because many patients currently use several providers, both public and private, resulting in lack of continuity of care. This will require improved governance and regulation to address variable quality (Beaglehole et al., 2008). In addition, the number of primary health centers in India is around 25,650, which makes it a giant task to cover all the facilities. Given the challenges of internet, and difficulties in using a web-based deployment, covering all the facilities requires a huge change in the current systems. These pre-requisites in scaling could have significant implications in building patient-centric information systems.

The following table summarizes the factors and its effects on the design of patient-centric information systems

Factors	Effects on design of patient-centric information systems
Bureaucracy	Makes the system rigid and lacks flexibility.
Infrastructure	Needs to move from paper-based to

	electronic formats. Hence this makes infrastructure resource intensive and needs resources skilled in information technology
Capacity and skill	Busy schedule of CHWs and the need to acquire new training require a change in attitudes and upskilling.
Scale	Scaling is complex and the challenges of internet and difficulties in using a web-based deployment, covering all the facilities requires a huge change in the current systems.

Table 1: Factors affecting the design of patient-centric information systems

Given these constraints, my research is to understand requirements of these patient-centric information systems.

1.2 Research setting

This thesis is based under the umbrella of an ongoing collaborative research project called INTPART (International partnership) which is funded by the Norwegian Research council. This is a research project between the School of Public Health, PGIMER (Postgraduate Institute of Medical Education & Research) in Chandigarh, India, Center for Connected Care (Oslo University Hospital, Norway) and Institute for informatics (IFI) in University of Oslo (UiO) along with its Indian node HISP India. The roles and responsibilities of the research partners is summarized below

Research partner	Roles and responsibilities
PGIMER (see pgimer.edu.in)	PGIMER is a center of excellence in medical education and seek to strengthen their expertise in informatics. The School of Public Health offers health services in the surrounding districts and seek to strengthen ICT support for service provision. The School

	<p>of Public Health also aims to integrate health informatics in education. A PHC under PGIMER has been taken up as the first pilot clinic to implement a patient-centric information system.</p>
<p>Center for Connected Care (C3) (see c3connectedcare.org)</p>	<p>The aim of C3 is to succeed in accelerating adoption and diffusion of patient-centric innovations, i.e. innovations that change patient pathways and delivery systems and increase growth in the healthcare industry. The themes C3 focuses on are patient-centric healthcare delivery, innovative infrastructure and interoperability and commercialization, diffusion and adoption.</p>
<p>University of Oslo (see uio.no), Department of Informatics (see uio.no/ifi)</p>	<p>The department of informatics, Information Systems group plays an active role in this research. The Health Information Systems Program (HISP) was established in 1994, under this group. HISP (see hisp.org) is a global movement to strengthen Health Information Systems in Developing countries that started in South Africa in the 1990's. HISP at UiO is one of the leading organizations in this movement and contribution includes in-country capacity building and implementation support, research, a PhD program, and hosting the core DHIS2 software development team. HISP is a global network which is comprised of 11 in-country and regional organizations, which provide direct support to ministries and local implementers of DHIS2. In the INTPART project, HISP</p>

	India is the technical partner (see hisplndia.org)
HISP India	HISP India is the technical partner in this project. HISP India strengthens the design, development, and implementation of integrated, free and open source based public health information systems. Their main role in this project was to help in the infrastructure and software development. Software development was done using OpenMRS and DHIS2.
DHIS2 software (see dhis2.org)	<p>DHIS2 is an open source Health Management Information System (HMIS) platform. The core development of DHIS2 is managed by HISP at UiO. DHIS2 supports both aggregate and case-based data.</p> <p>Various DHIS2 academies (see academy.dhis2.org) are provided for capacity building at the regional HISP organizations. In the research project, various options were explored with the DHIS2 academy and community coordinator to provide a health informatics course effectively.</p>
OpenMRS (see openmrs.org)	OpenMRS is an open source, clinical electronic medical record system. It supports integrated patient-based components within hospitals and clinical settings.

Table 2: Roles and responsibilities of the research partners

The aim of the project is to carry out collaborative research on the design, development and use of patient-centric information systems to strengthen health services delivery in primary health-care settings. It involves carrying out empirical studies for understanding existing systems and developing patient centric systems in field practice areas of PGIMER. This

project also gave opportunities to two master students from UiO and a PHD scholar from PGIMER to conduct research.

The objectives of INTPART, which was set during various workshops and review meetings, is:

- Primary objective: Develop health information systems design strategies for Patient-centric system in Low and Middle-Income Countries (LMIC)
- Secondary objective:
 - Establishing a living lab. A living lab is defined as a “User-centered, open innovation ecosystems based on systematic user co-creation approach, integrating research and innovation processes in real life communities and settings” (Eskelinen, Robles, Lindy, Marsh, & Munte-Kunigami, 2015, p. 12).
 - Conduct research into development of frugal design Strategies
 - Design a course on HIS Design Strategies for Patient based care systems for public sector in LMICs

Until date, five workshops have been held in Oslo and Chandigarh. These workshops took place between the various research partners and various stakeholders. A brief overview of the workshops is as given below:

	Place and time of workshop	Purpose of the workshop
Workshop 1- Organized by School of public health PGIMER	Chandigarh, India -April 2016	This was the kick off workshop for the INTPART project for “Designing Information Systems for Strengthening Patient Based Care in Resource Constrained Setting”. The current state of patient-centric information systems in India and the vision of the state towards patient centered care was discussed. Health care reforms towards patient centric services in Norway was discussed to know the best practices in developed

		countries. Various other stakeholders like CDAC (Center for development of advanced computing), IKP Center for Technologies in Public health and HISP India discussed health information systems built at primary health care level. The concept of a living lab was also discussed which would be the framework in which the HIS would be designed.
Workshop 2- Organized by School of public health – PGIMER	Chandigarh India, December 2016	This workshop was the first requirements gathering workshop with all stakeholders and users of the system. The participants from the School of public health (PGIMER) explained the various actors and work processes in primary health care. HISP India showed a proof of concept for building systems at the patient level. The design principles for building the system were discussed and technical analysis of requirements were done. Various registers and reports used at the primary health care were studied to find redundant data elements. Hence, rationalization of these registers and reports started with the demographic data. This workshop also included field visits to the primary health centers to study the work processes in the health center. A living lab was setup in the premises of the health center.
Workshop 3- Organized by University of Oslo with other	Oslo, Norway, May 2017	This workshop was organized in Oslo, with stakeholders from PGIMER, Norwegian research partners like Center for connected care and the Norwegian

research partners and PGIMER		institute of public health. After the second workshop systems implementation of the patient-centric information system had started and the living lab had started functioning with a developer working on premise. The progress on the system development and challenges in building the patient-centric information system was discussed. The main challenges faced were related to infrastructure (unstable internet, frequent power outages), data security and privacy, issues in interoperability and implementation of health standards.
Workshop 4- Organized by PGIMER with various stakeholders from the Ministry of health, national informatics center in India	Chandigarh, India, February 2018	Various government officials in health and information technology and research partners attended this workshop. HISP-India presented the functionality of the patient-centric information systems. The system was well received and received feedback for further improvement. Researchers from UIO and PGIMER also presented the aspects of their research. Tools to develop online health informatics course and the content of the course was presented by an expert from HISP Norway. Design for the second pilot clinic was discussed, based on the learnings and challenges from the first pilot clinic.
Workshop 5- Organized by the university of Oslo	Oslo, Norway, September 2018	Frugal innovations from the INTPART project and the functionality of the systems implemented in the second pilot clinic was presented. A PhD researcher from PGIMER presented the costing of

		<p>development and implementation of patient-centric information systems at PHC level. A fellow master student presented the challenges and standards for interoperability. A professor from UiO, presented the Norwegian context of patient centric systems involving medical homes and connected devices from UiO.</p>
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Table 3: Workshops as part of INTPART project

Other than the workshops, field visits were made to the primary health centers, interactions have been carried out with the stakeholders from the living lab both face to face and through emails and skype to discuss the evolving requirements. A detailed explanation of these empirical methods of data collection is described in chapter 4 on methodology.

My thesis is a part of the broader scope of the project described above. I started in the INTPART project with the requirement-gathering workshop in Dec 2016. In the same workshop, the living lab was setup in the Primary health care where the system was to be implemented. The living lab was set up to act as an avenue for all the stakeholders to work on generating work requirements and understand what the vision of the important features of health information system is. The requirement gathering process would inform the design and development of system mock ups and prototypes. In the framework of the living lab, the system is built incrementally, and hence the requirements are evolving all the time. The evolving requirements can provide learnings in system design and might need us to alter the technical choices made.

With the requirements gathered in the initial requirement-gathering workshop, it was required to have systems, which could:

1. Capture patient-based data for outreach programs like Mother and Childcare, Malaria, Tuberculosis and various programs carried at the state and national level.
2. Capture data for consultations, which take place in the primary health center.
3. Provide referral care
4. Integrated reporting
5. Capabilities to do data analysis at primary health care level.

6. Reduce the burden of manual reporting on the CHWs.

These were initial requirements understood, and these requirements were expanded over time as users engaged with the system and identified new requirements. Documenting these and sharing with design and development team was a primary focus of my thesis. A key step in the design of any HIS is the development and analysis of requirements (Reddy, Pratt, Dourish, & Shabot, 2003). Hence, the guiding research question for my thesis was formulated as under:

“What are the requirements to build patient-centric information systems in primary health care in India?”

Depending on the requirements gathered, technical solutions were chosen for the systems implementations process. The choice of the technical solutions was to broadly capture data for the outreach programs and to capture data at the facility. Hence a combination of OpenMRS and DHIS2 was chosen to be implemented in the pilot clinic 1. Halfway through the systems implementation, challenges were faced in trying to integrate these two systems, which led to explore the approach of using just one system.

Hence, the technical solutions chosen were

- A combination of OpenMRS and DHIS2
- Only DHIS2

The next question I address in my thesis is to

“Analyze different technical solutions to address these requirements and to understand the efficacy of the respective solutions.”

1.3 Personal Motivation

My interest in the DHIS2 platform started in my first year of Masters, where I did a course called Open source systems development. DHIS2 is an open source platform and is part of a global project called HISP, which works on implementing DHIS2 in developing countries. During this period, HISP-India was involved in the INTPART project, which had just started

with their first kickoff workshop in April 2016. The INTPART project’s focus is to build patient-centric systems at the primary health care level. Meanwhile, the second requirements gathering workshop was on its way in December 2016. Therefore, it was the right moment to start participating in the project.

India is an ideal country to study how Patient centric systems can be built at the community level. Currently, there are many systems, but all of them work in silos and there is no interoperability between them. Recently in the India rising summit, 2018, the Prime Minister of India stressed on, “Break silos, derive solutions is our mantra for growth”. The Prime Minister has emphasized how different ministries should work on breaking silos in the health sector, as depicted in the figure below:



Figure 2:From silos to solutions(Modi, 2018)

In India, there are three types of CHW’s namely: ANM, ASHA and the Aanganwadi worker. While the ANMs come under the Ministry of Health, the Aanganwadi worker is a part of the Ministry of Women and Child Development and the ASHA is a voluntary worker, who does not directly fall under the Ministry of Health like the ANM. The CHW’s come under different departments, but they collect the same data corresponding to Mother and child care. These represented silos of different ministries, which do not interact with each other. The INTPART project is a step towards combating this problem of silos and contribute to better health outcomes and it is a privilege to be a part of this change.

1.4 Expected contributions

Through this ongoing research project, the design and implementation of a patient-centric information system in a resource-constrained setting was studied, and I, as a researcher actively participated in the process of analyzing and documenting the evolving requirements of a patient-centric information system. This thesis aims to contribute to the strengthening of patient-centric information systems in India, specifically in the primary health care, the HISP project and the broader field of research on HIS strengthening and user participation in information systems design. First, concrete suggestions for improved design can feed into further strengthening the design of patient-centric information systems. Second, experiences from the participatory approach, in the framework of a living lab can strengthen local competence and foster local innovation. Third, the context defining the building of patient-centric information systems in developing countries can provide rich insight and help in local implementation in similar settings. This insight contributes to research by supporting prior literature, extending this understanding with the empirical knowledge and further provide basis for further research on this topic. On a broader perspective, under the current health reforms of Universal Health Coverage (UHC), health care should be affordable and accessible to every person in the population. Hence, the focus to build patient-centric information systems at the primary health care level can potentially contribute to the bigger agenda of UHC.

Empirically, the business requirement document, documented over the period, can serve as a master requirements document for researchers, implementation teams and business analysts to know the requirements for building a patient-centric information system in primary health settings in a developing country. Requirements analysis is an important step in software engineering as they form the building blocks of any software system.

1.5 Structure of the thesis

The thesis is structured into the following chapters:

Chapter 1: Introduction

The current chapter is an introduction to the research background, research objectives and questions, which this thesis is trying to address.

Chapter 2: Theoretical perspective

In this chapter, I have presented relevant literature to study the diversity of patient-centric systems in developed countries and LMICs, the methodologies of requirements analysis and the approaches to address the issues in building patient-centric information systems in developing countries.

Chapter 3: Project background

In this chapter, I have presented information about where the research has been conducted i.e. Chandigarh, India and the hierarchy of the health sector, infrastructure, existing landscape of health information systems in India and the problem statement at the PHC.

Chapter 4: Methodology

This chapter discusses the methodology which this thesis is based on. The various methods of data collection and how data-analysis has been carried out is also elaborated.

Chapter 5: Requirements for a patient-centric information system in primary health care

This chapter talks about the requirements of a patient-centric information system. These requirements have been captured in various “phases” and I present the various “phases” in requirements gathering.

Chapter 6: Evolving requirements post systems implementation

This chapter talks about the evolving requirements in the second pilot clinic post systems implementation of the first pilot clinic.

Chapter 7: Discussion

In this chapter, I discuss the observations and findings from the two previous chapters and answer the research questions.

Chapter 8: Conclusion and future work

In this chapter the conclusion of this thesis and the suggested future work is discussed.

1.6 Summary

I have introduced the research objectives and given a gist of the context in which patient-centric information systems will be designed in India. The next chapter discusses the theoretical perspective and the literature on patient-centered care in various countries, approaches to address the issues in building patient-centric information systems and the various methodologies of requirements analysis with focus on the living lab.

2 Theoretical perspective

This chapter discusses relevant literature and the theoretical perspective of the project. First, I present a discussion on the diversity of patient-centric systems in both developed countries and LMIC's (Low-and Middle-Income Countries). In order to carry out requirements analysis, various methodologies for requirements analysis are discussed, followed by what approaches can be taken in a LMIC to build patient centric systems.

Health information systems are dealing with processing data, information and knowledge in health care environments(Winter et al., 2011). Especially in case of chronic diseases, it is important to organize health care in a way, which is patient-centric. In this case, an integrated care is required which means it is required to provide relevant information not only within a single institution but whenever and wherever needed with a focus on the patient (Winter et al., 2011). This should include medical centers, rehabilitation centers, nursing centers and even the home of the patient.

Achieving a people/patient-centered care is an approach to strengthening health systems in all countries, irrespective of the country being low, middle or high income country (Organization, 2015). Within different countries, there are differing socioeconomic, cultural, geographical, political and health system realities that provide the context that must inform the way that patient-centered and integrated health care services are designed and adopted(Organization, 2015).

Patient-centered care is a key component of a health system that ensures that all patients have access to the kind of care that works for them. In many LMIC's, PHC (Primary Health Center) capacity is lacking, and health outcomes are poor. Across the world, these gaps are exposed by the increasing burden of non-communicable diseases and increase in care complexity. Health outbreaks like Ebola in West Africa, highlighted not only the severe shortage of healthcare infrastructure, human resources, and essential supplies in affected countries, but also poor access to and low quality of care, and a consequent lack of trust and connection between systems and the populations they serve (Bitton et al., 2017).

2.1 Diversity of patient centric systems

2.1.1 Developed countries and the context of Patient-centric information systems

In most developed countries, robust health platforms are available to provide patient-centered care. In Denmark, Norway and Sweden, the patient-oriented e-health services provided by the platforms consists of provision of health information, access to personal health data, self-care and monitoring, peer-to-peer communication, e-consultation and various administrative services (see figure 3).

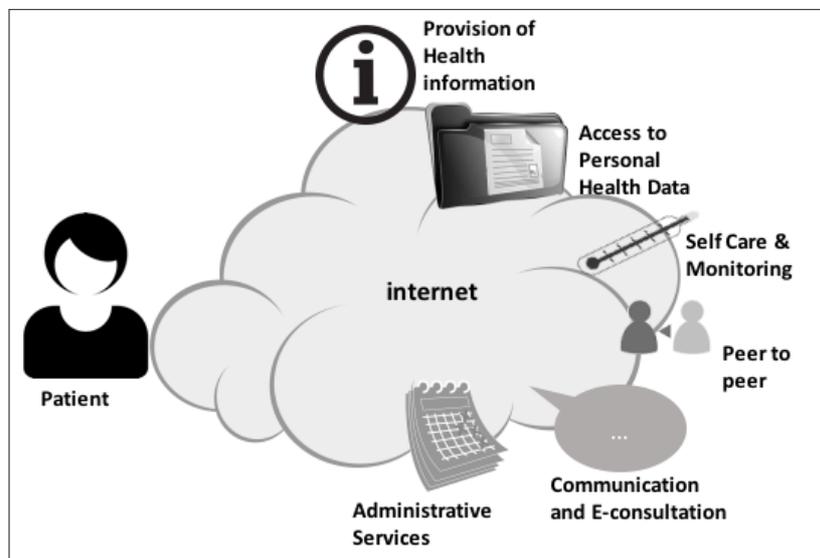


Figure 3: Patient oriented e-health services provided by the platforms (Vassilakopoulou et al., 2017)

Patient portals

One way of providing patient-centric health services is using patient portals as a platform for both the patient and the clinician. Patient portals provide access to personal health data. According to Rigby et al. (2015), patient portal offers one or more of the following functionalities

- Access to EMR data of the patient
- Access to test results.
- Printing or export of the portal data
- Medication refills
- Appointment scheduling

- Ability to obtain referrals
- Access to general medical information such as guidelines
- Secure messaging between the patient and the institution

In Denmark, the health portal is the only implementation where clinical information is shared with patients on a national scale (Rigby et al., 2015) The health portal contains information of the patient's medications, allergies, diagnosis, laboratory test results and is shared between various clinicians or specialists at public and private level nationally.

In countries like Singapore, Hong Kong and Canada, access to shared EMR data is only available to clinicians, with plans to make them available to patients in the future.

Administrative services

In England patient-centric care has reached a level where the patients have the right to choose their general practitioner , express preference for a particular general practitioner and the right to make choices about their health care and have options to support these choices (Europe, 2016). Booking appointments with the general practitioners and seeing the wait list for access to the general practitioner are some of the administrative services that the health platforms provide.

Self-care and monitoring

Medical homes are getting popular in countries like the United States, Norway. Here care is coordinated and integrated across all elements of the health –care system. This is facilitated by registries, information technology and information exchange.

The following section discusses systems existing in LMICs built for patient centric care.

2.1.2 Patient centric systems in India and Ethiopia

During the first requirement-gathering workshop in Chandigarh, India, as part of the INTPART project, a presentation of the overview of existing systems at the national and state

levels, discussed the challenges and limitation of these systems in India. “**Public health information systems in India: Need for a sustainable patient centric system for primary health care**” (Faujdar, Sahay, Singh, & Kumar, 2018) is one of the manuscripts written as part of the INTPART project. I use this paper to highlight the limitations and challenges of the existing systems used in the Indian health care.

This paper classifies the existing systems in India as Health Management Information Systems (HMIS), Surveillance and tracking systems and point of care systems as per their primary role.

National health management information systems

This portal was launched in 2008 in India to collect district level aggregate reports, but over time, it has included the primary health care facilities as well. It includes aggregate reports, and some degree of individual data comprising of information on deaths. The portal promotes centralization, as data is uploaded from all health facilities into the national database. Primary analysis of data is carried out at the national level, instead of the corresponding district or facility level staff. The system does not support the varying health information requirements, which vary from state to state. Hence, few states have adopted alternative systems to meet the particular needs of the state, incorporating various reporting formats and monitoring indicators.

Tracking and surveillance systems

There are various tracking and surveillance systems like:

1. **Mother and Child Tracking System (MCTS):** This system has features to register pregnant mothers, follow them for their ANC care visits and register children over the immunization cycle. Analysis of data was done centrally and various states were sent a SMS of the number of registrations received. There were delays in generating work plans for the ANMs, as the data entered at the sub-center, was taken by the ANM to the primary health center, for the data entry operator to make entries.

Instead of focusing on the mother and child health indicators, the system focused on monitoring health staff (Faujdar et al., 2018). This was a major setback and added a huge work burden to the health staff of entering name-based data into MCTS and to send aggregate numbers to be entered in to the HMIS portal.

In addition, the MCTS and HMIS systems did not talk to each other, which led to creating a new system called Reproductive Child Health (RCH). The features of the RCH portal include personal details of eligible couples for family planning, tracking women for ANC, delivery, and postnatal care. It also allows tracking for child immunization and the portal is also expected to support voice calls.

2. Tuberculosis (TB) case tracking and surveillance: Following a mandatory notification of TB cases in 2012, a web-based TB surveillance system called NIKSHAY was launched. It was developed for aggregated management reporting and case-based data. The system has the functionality to send SMS to district and state TB officers on patients registered in the national TB program. It also has the functionality to follow up a patient, if he/she has relocated to a new place. This seeks to ensure continuity of care to the patient. The system does not support offline application, which results that the persons diagnosed at the lowest unit of health are recorded in paper-based registers and the patient card. This data is entered into the NIKSHAY system through data entry operators at the primary health center. The system does not support data analysis and generation of indicators (Faujdar et al., 2018).

3. Strategic Information Management Systems, National AIDS Control Organization (NACO)

The system supports data entry at various levels including Reporting units, districts and state levels. The data is mostly aggregate in nature, though there is a need for case-based data to strengthen follow-up. The main limitation is it is designed for upward national reporting and provides very little feedback to users, to take action (Faujdar et al., 2018).

Point of care systems

Faujdar et al. (2018) highlight that the main use of Electronic Health Record (EHR) systems in public sector has been limited to registration, laboratory, facility, stock maintenance, and blood banks. The use of EHRs in inpatient departments has been limited to few wards where there is less workload. In Outpatient departments, the use of EHRs is almost negligible because of the high patient loads. The authors further state that to implement an EHR at the primary health care was easier, as the patient load the primary health care is lesser than that at the secondary or tertiary care. The focus of these systems then turns to just clinical care, while the other facets of preventive and promotive care are left out by the systems.

Another type of system, which exist, are a combination of electronic medical record for primary health care clinic and modules for outreach services for community worker. The limitation of this system is, the application is available online and the same can be accessible from the primary health center's computer, but in areas where there is poor connectivity, slow internet speed and electricity outages, then the function is not optimal. The system does not enable referral linkages and has poor reporting functions.

Thus, the common characteristics identified in these systems are summarized by Faujdar, Sahay, Singh, and Kumar (2018) as:

1. Focus on central reporting
2. Fragmented systems and implementation of systems in silos.
3. Limited functionalities in feedback and promotion of local use.

Health information systems have so far focused on aggregated systems and is now required to focus specifically on disaggregated systems, i.e. on patient level data. A comprehensive health information system, which has all the details of the patient, would be the need of the hour to provide focused continuity of care to the patients. Sending SMS alerts, following up on the patients based on their problems, access to the patient's health record, patients able to make choices by reading information on a health portal are some ways in which health information systems can help for providing patient-centric care.

2.1.3 Family folders in Ethiopia

In Ethiopia as well, there is a need to strengthen the HIS starting from the community level; from where the health data are mainly collected, especially in rural settings where majority of the population reside.

Abera and Moges (2013), present an idea of the kind of challenges faced while moving from multiple registers to a single paper-based family folder in Ethiopia designed to collect family health data. The family folder contains information of the entire household and is kept at the health posts. Each family will have a family folder and each family member will have an individual card in the family folder. This folder was designed as a data collection tool to collect household data at a primary health care level. The challenges identified while moving from multiple registers to a single paper-based family folder include:

- Absence of standardized data collection tools, over-reporting to the higher levels lead to poor data quality in the HMIS in many developing countries(Abera & Moges, 2013).
- The use of un-standardized registers created no coordination of the data collected and reported by the community health workers.
- Problems related to data collection tools, manual and characterized by high fragmentation and cumbersome data elements with duplication of efforts.
- Developing a standardized data collection tool with minimum data set is difficult because of the diverse interest of various health program managers and partners.
- Inconsistent and redundant reports with no feedback mechanism.

Collecting, compiling and reporting community health data, is a cumbersome task for the community health workers (Majra & Acharya, 2009). The focus of the CHWs moves from continuity of care to producing reports and data for the higher officials.

Despite these limited examples, our understanding of what are the design requirements for a patient centric system in developing countries is extremely limited. To address this gap, my

thesis focuses on understanding requirements of these systems in the Indian context. To understand the approach to build these requirements, I discuss some methodologies in use.

2.2 Methods of requirements analysis

Requirements analysis is the process of eliciting individual stakeholder requirements and needs and developing them into detailed, agreed requirements documented and specified in such a way that they can serve as the basis for all other system development activities. (Pohl, 2010). Requirements analysis is critical to the success of a development project, and must be developed in an actionable, measurable, testable manner, related to identified business needs or opportunities, and defined to a level of detail sufficient for system design. Some of the models are now discussed.

2.2.1 Software Development Life cycle (SDLC) models

The SDLC is a framework defining tasks performed at each step in the software development process. SDLC has a set of phases and depending on the SDLC model, the following phases are executed.

1. Understanding the problem (through requirements gathering)
2. Deciding the plan for a solution (Designing)
3. Coding the planned solution
4. Testing the actual program
5. Deployment and maintenance of the product

Royce proposed the waterfall model in 1970, which is a linear sequential development model. The various phases are requirements analysis, design, implementation, coding, testing, deployment and maintenance. The requirements and design risks are not discovered until late in the life cycle. Hence, it is not useful in projects where the requirements are changing dynamically.

The drawbacks of the waterfall model make it even more difficult to follow a SDLC of this nature in LMICs. Since the usage of technology in primary health care is very nascent,

requirements to build patient-centric information systems needs better understanding. In response to the weaknesses of the waterfall model, many new SDLC models were developed to add some iteration like in the case of Spiral model, V-model, incremental model and Rapid application development.

Mishra and Dubey (2013) in a comparative study have studied that most of the software development models have requirement specifications only in the beginning of the lifecycle and have limited support for evolving requirements. Except for the Spiral and Incremental models, the user involvement in the lifecycle is only at the beginning.

Features	Waterfall	V-shaped	Incremental	Spiral	RAD
Requirement specifications	Beginning	Beginning	Beginning	Beginning	Time boxed release
User involvement	Only at beginning	At the beginning	Intermediate	High	Only at the beginning
Flexibility	Rigid	Little flexible	Less flexible	Flexible	High

Table 4:User involvement in the SDLC lifecycle (Mishra & Dubey, 2013)

A key step in the design of health information systems or clinical systems is the development and analysis of requirements (Reddy et al., 2003). In software engineering, the systems developers' primary role is to be an expert in technology, tools and methods of systems analysis, design and project management. The work of a system developer is to make systems more formal and rational (Hirschheim & Klein, 1989). While clients are the ones deciding the direction, approaches based on a socio-technical perspective enables the requirements analysis staff to gather a deeper understanding of the environment surrounding the computer system, in turn highlighting awareness and coordination, embedded in the users work (Reddy et al., 2003).

The requirements phase of a large development project is the most error-prone which proves to be the most difficult to correct (Goguen, 1994). In order to build a system, which effectively meets a business need, it would be best to go and observe where the work is done

and what actually happens. The general belief in most projects is to follow the phases sequentially and that the construction of the system can be controlled in a top-down hierarchical manner. While coming specifically to the requirements phase, it is widely believed that there is a unique best model of the organization and its needs. However, it should be understood that requirements are emergent, and they do not fully pre-exist already in the minds of clients or requirement engineers. Moreover, requirements are open and they are subject to change, because the organizations and contexts are continually changing. Requirements are also local, and the requirements documents must be interpreted in the context of a particular organization at a particular time. In addition, requirements are contingent because they are an evolving outcome of an on-going process that builds on prior interactions and documents.

Hence, it is required to involve users of a system right from its inception to its implementation. Some design approaches, which involve user of a system, are discussed below:

2.2.2 Participatory design

Participatory Design (PD) emerged in 1970's to 1980's and has its roots in Scandinavia. It was pioneered in Scandinavia as a transformation of workplaces driven by the introduction of computers. PD is based on the foundation principle of democracy, which translates to people participating in the design process as co-designers. A key concern is therefore the need to understand how collaborative design processes can be steered by people affected by that design (Bergvall-Kåreborn, Howcroft, Ståhlbröst, & Wikman, 2010).

PD approaches have been described as “an old and tired” concept (Markus & Mao, 2004) , in need of some revitalization for contemporary environments. User participation is advocated within areas like innovation and product development, using concepts such as open innovation, user-driven design, crowd sourcing, and living lab, although many of these approaches take a managerial as opposed to a user perspective (Bergvall-Kåreborn et al., 2010). PD researchers draw limited attention to these concepts and hence a methodology of living lab is introduced. Living lab environments benefit from drawing on the PD principles, as a well-established field in the information systems.

2.2.3 Living lab

A living lab is defined as a “User-centered, open innovation ecosystems based on systematic user co-creation approach, integrating research and innovation processes in real life communities and settings” (Eskelinen et al., 2015, p. 12). According to Bergvall-Kareborn, Hoist, and Stahlbrost (2009), the purpose of a Living Lab is to create a shared arena in which digital services, processes, and new ways of working can be developed and tested with user representatives and researchers.

Originally, the introduction of the living lab approach was to carry out research and development in ICT more effectively by bringing all the stakeholders in the same platform. This leads to a larger mass of ideas, knowledge and sharing of experiences. The immediate benefit of this approach is the relationship created between people and technology. End users reportedly gain a greater sense of empowerment and ownership.

The advantages of a living lab include a multiple-contextual environment, meets expectations of stakeholders, provide fast feedback mechanism and integrate social and technological innovations. Living lab has its set of challenges as well, which include:

- Getting all stakeholders in the same platform, as there are varied user groups from both public and civic sector with private sector technology and service-providers. It requires a wider understanding of the process of innovation, especially in the context of the fundamentally changing society .(Eriksson, Niitamo, & Kulkki, 2005)
- It could be a challenge to function without disturbing the existing set-up. For example, the community health workers have their daily routines like immunization, Antenatal care and field visits. To get them fully involved in the building of the patient-centric information system might interfere with their daily routines.
- In resource-constrained settings, there could be technological limitations vis-a-vis the implementation, such as limitations of infrastructure.

In order to decrease risks in the product development process it is important that the customers and other stakeholders are directly integrated, and the living lab framework helps

with this (Feurstein, Hesmer, Hribernik, Thoben, & Schumacher, 2008). The following are the elements of a living lab as stated by (Feurstein et al., 2008):

Participation and contexts

The participation of all other stakeholders and not just the customers, along the whole value chain can be seen as the foremost required element for the successful operation of a Living Lab (Feurstein et al., 2008). The ability to interact with users in a multi contextual sphere is what makes living labs different from traditional user-centric design methodologies.

		Single and Controlled Contexts	Multiple and Emerging Contexts
Degree of Participation	High: Observation and Creation	Traditional Lab Experimentation	Living Lab Experimentation
	Low: Observation	Traditional Empirical Social Science Research	Ethnographical Observation

Figure 4: Participation and Context of Innovations (Feurstein et al., 2008)

Figure 4 shows that the traditional lab experimentation has high observation and the traditional empirical social science research has low observation in a single and controlled context. Living lab strives for a high level of observation in an organic and multi contextual space. This implies that the customers are observed across many aspects of their lives. The use of ICT strives to keep obtrusiveness at a minimum. Hence, this makes citizens the potential source of innovation.

Based on figure 5, Veeckman, Schuurman, Leminen, and Westerlund (2013) state that there are three pillars to the living lab: 1) the building blocks of the living lab environment; 2) building blocks of the living lab approach; and, 3) the innovation outcome.

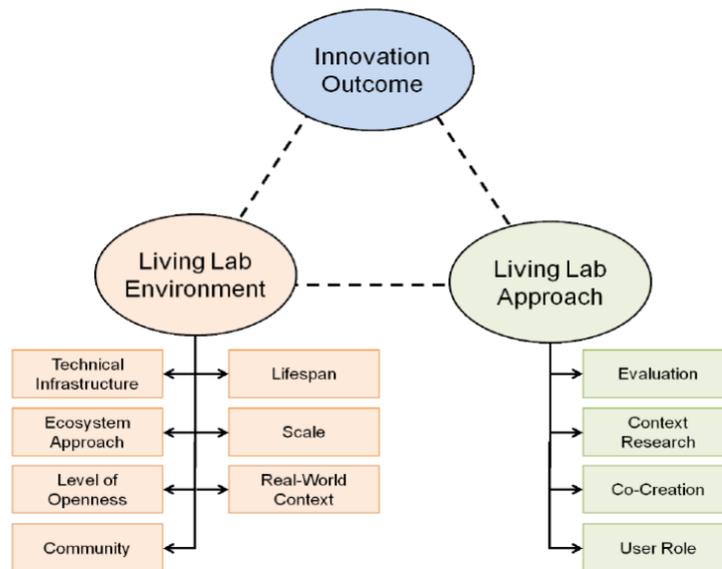


Figure 5: The Living Lab Triangle: The triangulation between environment, approach, and outcome in living labs (Veeckman et al., 2013)

Pillar 1: Building blocks of the living lab environment

Technical infrastructure: When assessing or co-creating innovations, a technical component should be available for the test users within the living lab. It should also include monitoring of the technical performance during usage and non-usage of the innovation (Veeckman et al., 2013).

Ecosystem approach: Various stakeholders from partners to users and research organizations interact to develop and evaluate a certain process, product or service within the living lab ecosystem. It is important to create value to attract and retain members and share the value within the ecosystem (Veeckman et al., 2013). In our case, we are talking about building patient-centric information systems in a primary health care setting. The various stakeholders include technological partners, public health experts, researchers, medical officers and the community health workers. A concept like building family folders is taken for patient identification. To begin with, all members in the living lab give their inputs for design, and a working model of the family folder is built into the system. This gives a strong ownership of the system for the various stakeholders.

Level of openness: One of the key principles in living labs is that the innovation process should be as open as possible, because a multitude of perspectives might speed up the development and bring more innovative ideas (Veeckman et al., 2013).

Community: Users participating in the living lab are part of a community whether or not it is geographically bound (Veeckman et al., 2013). The authors' state that it is important to know, what drives the users to participate and contribute to keep them motivated and engaged.

Lifespan refers to the duration of the living lab, in our context the lifespan is for three years.

Scale refers to the size of the number users involved in the living lab research activities.

Real-world context implies that the users studied are within a real-life context.

Pillar 2: Building blocks of the living lab approach

Evaluation, context research and co-creation

From a business perspective, it is useful to perceive Living labs as providing a set of services to the customers. Within a living lab setting, test users are involved through different phases of the innovation cycle in which they can test evaluate and co-create the innovation (Veeckman et al., 2013). Consideration to the usage of the context that influences user behavior is given. The main service of a living lab is to help co-create a product, service or application.

Public health informatics is a multidisciplinary field involving, public health, medicine, informatics and law. The living lab's co-creation stage should have a multi-disciplinary team for system design. This allows the developers of the system, an insight into the world of public health and the working practices of the community health workers. At that same time, this venue could help the community health workers and medical officers to get a strong ownership of the system, as they are part of the process of system evolution. Thus, this could help in mutually understanding the perspective of the other.

For example, during a discussion the CHWs said they wanted to generate the reports, which were sent to various levels of health care, from the system, which was being built. For this, the required formats of the reports, which were currently used was studied and the design was based on the existing data formats. The insight from the CHWs, medical officers and researchers in the living lab structured the design of the system, which when implemented provided more value and involvement to the Community health workers.

Hence it can be said that, co-creation is not only a methodology to achieve (product, service, or process) innovation, but a way to create values that are shared between participants (Puerari et al., 2018).

Pillar 3: Innovation outcome

To evaluate the success of a living lab, the innovation outcome is considered. Knowledge of the tangible outcomes enables us to assess impact and determine which approaches worked best (Veeckman et al., 2013).

Figure 4, shows that the living lab has high observation in multiple and emerging contexts. This means that we are looking at practices and processes in the real contextual world. These processes can change over time. When looked at this in a software development perspective, the system is always evolving, and they are new and evolving requirements all the time. The next section, gives a brief about user centric process within system design and evolving requirements.

User-centric process and evolving requirements

Living lab is seen in the perspective of a user-centric process. A user-centric process within system design has the following sub-processes (Rogers, Sharp, & Preece, 2011; Ståhlbröst, 2008)

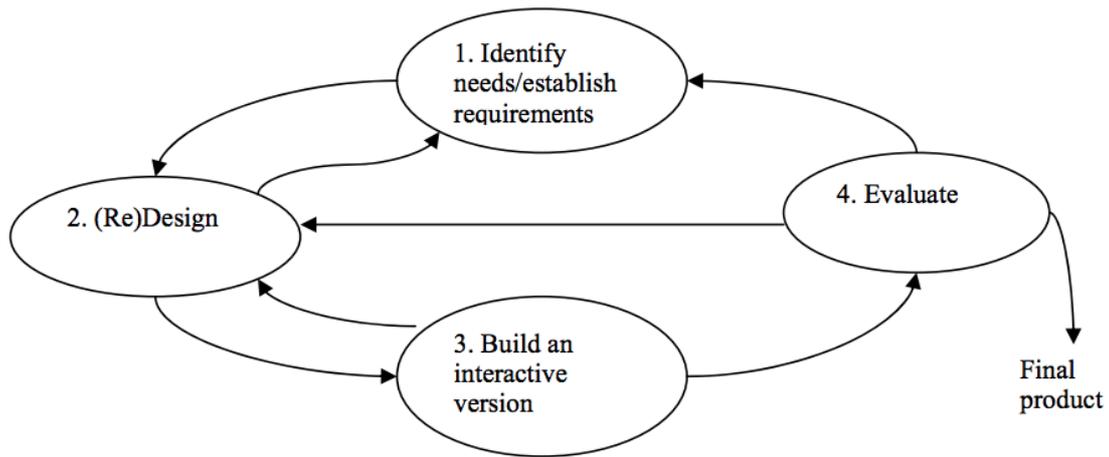


Figure 6: User centered interaction design process (Ståhlbröst, 2008, p. 24)

The user-centered interaction design process involves four basic activities which the figure above represents (Ståhlbröst, 2008):

1. Identify needs/establish requirements: To be able to design something that supports people, it is important to know who the users are and what kind of support an interactive product could, and should, provide. The identified needs then underpin the product requirements, and the design and development of the IT system.
2. Developing alternative designs. This is the core activity of designing, where different ideas, aiming to meet the established system requirements, are suggested. This activity might consist of two sub-activities: conceptual design and physical design
3. Building interactive versions of the design: Interactive design involves designing interactive products. The most rational way for users to evaluate such designs is to interact with them. This activity requires an interactive version of the system to be designed.
4. Evaluating designs: this is a process of determining the usability and acceptability of the product, or design, that can be measured in relation to a variety of criteria, including the number of errors users make using it, how appealing it is, how well it matches the requirements, and so on.

This is a continuous process and involves multiple cycle. With every cycle, the requirements are continuously evolving.

2.3 Approaches to address the issues in building patient-centric information systems in LMICs

The following approaches can aid in addressing the issues in building patient-centric information systems in LMICs.

2.3.1 Minimal dataset and the data model of a family folder.

Majra and Acharya (2009), discuss that the family is the unit of living it should also be the unit of health/illness. Majra and Acharya (2009) also mention that the family is considered as a major factor in the etiology, care and treatment of both physical and mental illness and as a basic unit of interaction and transaction of health care. Hence, the system should have the capability to have the structure of a family folder to shape patient care.

The community health workers are burdened with updating different registers to generate data and to report information to higher levels (Shivalli, Majra, Akshaya, & Qadiri, 2015). Since the data collected, is not used appropriately for future planning and prioritization, the family folder is an easy and excellent way to integrate information about different members in a family and with it strengthen the health information management system. Also, the principle of minimum data set encourages to collect only the most essential information needed by the health facilities to monitor and evaluate the health programs (Abera & Moges, 2013).

Finding an individual in a health system requires a unique identifier and does not require any other linkages to be defined, whereas in implementing a family folder model, the additional challenge of having an identifier to identify a family and a family member uniquely is required. In order to create a unit called family in the system, there should be a possibility to link family members into a family.

2.3.2 Context sensitive design

The design for a health information system at community or primary health care level should be sensitive to history and existing work practices. The systems should be simple, frugal and user friendly (Collaborative, 2017). One primary challenge in developing countries is, though the potential of ICT for developing countries and development is well established, the question of how to make ICTs relevant is still relevant. Nielsen (2017) talks that digital divide could be caused by, not taking the various contexts like information infrastructures, institutions and local practices into consideration. The other challenge is the design-actuality gaps (Heeks, 2002) ,between the developed countries where ICTs are designed and the actuality of where they are used, which are LMICs in our context. Most of the ICTs, used in the developing countries, are designed in the developed countries. The context of design and production could be hard to disentangle because of the lack of proximity – geographical and cultural. For LMICs, the design-actuality difference can be subtle, implicit and hard to identify and it can therefore be hard to think beyond the black box (Heeks, 2002).

2.3.3 Engaging user participation

A participatory approach is required to be adapted throughout the process, so as to not only passively elicit requirements of existing work from users, but also to get the users to actively engage with formulating what they would wish from the system in the future (Mukherjee, Aanestad, & Sahay, 2012). Engaging user participation through the living lab is an approach to create this engagement.

Developing countries being involved in digital innovation would significantly reduce the design-actuality gaps (Heeks, 2002). According to Msiska and Nielsen (2017), innovation should be seen in the perspective of a socio-technical generativity. This means, even if the technical attributes of the software platform play crucial roles in fostering and shaping innovation, it yields little if any innovation in the fringes of its ecosystem if not backed by strong human relationships. Generativity is about “what the future holds in store”, and is related to the transformative power of information technologies, and it goes beyond the adaptability and flexibility required for coping with everyday work contingencies. Generativity is a notion that transcends the tailorability of the technological artifact being

associated with the overall dynamics of sociotechnical configurations (Grisot & Vassilakopoulou, 2013). For example, when we look at building patient-centric information systems in a LMIC like India, the perspective of social-technical generativity has implications for both design and implementation of how these software systems should be built. Community health workers go door to door to provide health services in rural areas. Hence, the design consideration is to make it simple for the community health workers to retrieve data, such as through the structure of a family folder. Most of the software systems designed for health, support data that can be retrieved for an individual patient. Hence, the technological consideration would be to build a system designed to support a family folder. In the living lab, people work collaboratively on generating work requirements and generating a complete understanding of what is the vision of a family folder system. After this, there is development of system mock ups and prototypes, where users can give their feedback and make further improvements to the system. This leads to local innovation, which is in turn generativity.

The table below, shows the attributes of social relationships and technology capabilities which together make up socio-technical generativity.

Social Relationships	Technology Capacities
Aligned directedness	Leverage
Focus on achieving the same transformation	Increasing productivity for the users
Heterogeneity	Adaptability
Complementarity in competence, social positions and access to resources	Potential to be used for what it is not designed for
Mutual directedness	Ease of mastery
Appreciation of differences and complementarities	Limited efforts to understand and adapt
Appropriate permissions	Accessibility
Permissions to innovate	Ease to obtain access and master
Action opportunities Opportunity to change own and influence others' attributions of technology	Transferability Ease to convey from one context to another

Table 5: The dimensions of socio-technical generativity (Msiska & Nielsen, 2017)

The table represents two dimensions, out of which the social dimension represents how social relationships can be conducive for innovation and the technical dimension concerns the capacity of technology in supporting and promoting innovation (Msiska & Nielsen, 2017) . The two dimensions can mutually influence each other positively or negatively as well as mutually reinforce each other. For example, if appropriate permissions are granted to innovate, it could lead to unregulated changes being pushed in the system, making it difficult to comprehend. Hence, this calls for some regulation of permissions.

2.3.4 Incremental approaches

A system built to support community or at a primary health care level, should “Follow incremental and evolutionary principles of system design and development” (Collaborative, 2017). It focuses on adopting participatory design and prototyping processes, which are incremental and evolutionary in nature. The cycle is to build a prototype, expose it to the users and get feedback to adapt and improve the prototype. This process is iterative and has evolving user improvements and thus strengthens user ownership.(Collaborative, 2017)

2.4 Summary

The key theoretical concepts discussed in this include the issues with the current information systems in health and participatory approach in the framework of a living lab. The concepts of family folder, incremental approaches, context sensitive design and participatory approach are the key concepts that will guide the analysis of this thesis. The next chapter talks about the project background on which this thesis is based on.

3 Project background

This chapter introduces the setting in which the study was conducted, namely the Union Territory of Chandigarh in India. It presents the actors in the primary health care in India, and how the health system hierarchy is organized. This chapter will be useful to better understand the findings from data collection, as well as understand better the rationale behind decisions made during requirements gathering and the system development processes. Further, it introduces the HISP organization, which this study is part of, and its development of the District Health Information System (DHIS).

3.1 India and its union territories

Politically, India is divided into 29 states and 7 Union Territories (including the National capital Territory of Delhi). The Union Territories are Andaman and Nicobar Islands, Chandigarh; Dadar and Nagar Haveli; Daman and Diu; Lakshadweep; New Delhi and Puducherry. The president of India through his or her representative, the administrator, administers the Union Territories. The governance of these different territories is flexible and varies from territory to territory (Arnold P.Kaminsky, 2011).

3.1.1 Chandigarh

The Union Territory of Chandigarh is located about 265 km north of New Delhi. The territory is bounded by the state of Haryana on the east and by the state of Punjab on all other sides. Chandigarh city is the capital of the territory and of the states of Haryana and Punjab. The official languages in this area is Hindi, Punjabi and English, though regionally the people of Haryana speak Haryanvi.

According to the 2011 Census of India, the population of Chandigarh is approximately 1 million. As part of the INTPART project, two primary health centers were chosen to be part of the pilot. A primary health center in the semi-urban part of Chandigarh and another community health center in the rural part of Punjab. After the various actors in a community-based patient-centric health care is introduced, I describe a brief overview of the primary health center in Chandigarh where the first implementation took place.

3.2 Health Information Systems Program (HISP)

Along with various other research partners, researchers working in the HISP group, located at the University of Oslo have coordinated this project and its corresponding node in India called HISP India. The HISP group has many nodes in various developing countries and HISP India is also a node in a global network called HISP Global coordinated from University of Oslo, Norway. HISP India is comprised of professionals from the domains of informatics and public health, and draws upon the global HISP network for specific expertise as and when needed. Likewise, HISP India contributes to strengthening the global HISP network when its expertise is required. (HISP, 2018). HISP India helps in assisting health management improvements using open source tools for HMIS and hospital management systems. One such system is DHIS2, which is mainly used in developing countries, which are usually resource constrained.

3.3 District Health Information System (DHIS)

The District Health Information System 2 (DHIS Version 2) is an open source platform for health which has been developed for over two decades by adapting to changes in technology and supporting the changing needs of health systems (Braa & Sahay, 2017). Since it is open source, it is free to download and use and is very cost effective to use in developing countries.

The system is adaptive to the needs of various countries. According to Braa and Sahay (2017), DHIS2 has a flexible metadata structure, which users can manage through the user interface without the need for programming. Currently, DHIS has been used by over 60 developing countries across 4 continents (DHIS2, 2018a). It has the capability to capture data on any type of device and most of the solutions has support to work offline. It also has strong representational functionality, which makes reporting and visualization of data very easy for data analysis.

3.3.1 DHIS2 in patient-centric care

DHIS2 was initially used to send aggregated data from the primary, secondary and tertiary line of care. With the introduction of the DHIS2 Tracker, case-based data, which is granular in nature, can be tracked. The use of DHIS2 in patient-centric care is very recent and few case studies have been carried out in this field. With the INTPART project, DHIS2 tracker is used to develop a patient-centric information system at primary health care level.

3.3.2 Technical details of DHIS2

DHIS2 is written in Java and has a three-layer architecture. The system can be used on-line as well as stand alone. DHIS2 can be installed and run on a variety of platforms. DHIS2 is extensible and modular in order to allow third party and other customized applications to be build. DHIS2 can run on any database management system, is extensible and modular to address local requirements, can be run online and has a flexible data model for a variety of data capture requirements (DHIS2, 2018b).

3.4 Post-graduate institute of medical education and research (PGIMER)

PGIMER in Chandigarh, India is a center of excellence in medical education and research, which has strong partnerships with the government. The institute endeavors to produce specialists in the field of medicine and public health, and to provide the best health care, teaching and research facilities.

The Department of Community Medicine was formally founded in 1977 with the dual purpose of evolving a feasible pattern of health service delivery to the rural people and for providing community health orientation to the resident doctors of the institute. To address the emerging challenges in Public Health Education and Research, Community Medicine Department was upgraded to a School of Public Health (PGIMER, 2018), which also provides health services to the districts in Punjab and Haryana through designated facilities. The school of public health also wants to strengthen ICT support for service provision and include health informatics in their curriculum.

3.5 Key actors and work processes in the PHC sector

Given the focus of the project on patient centric systems for PHC actors, the following actors within this sector were identified, which the proposed system should support:

3.5.1 Auxiliary Nurse Midwife (ANM)

The ANM workers are a part of the Ministry of Health and Family Welfare (MoHFW) who are assigned to a sub-center and they are the first contact person between the community and health services. The implementation of all programs in the PHC are taken up by the ANM and they have predefined formats for their registers and monthly reports. The ANM workers go on field visits to provide health services. They enter the details in a fieldwork diary. After coming back to the sub center, they enter these details in various registers. They maintain around 28 registers and prepare monthly reports for various systems, which use these data.

The ANM maintains paper-based registers of the population similar to the Anganwadi worker, who is also a CHW but under a different ministry. The registers maintained by the ANM is available to the health department and has a few additional columns. The Mother and Child Tracking System (MCTS) also gives a work plan for the ANM to execute, who looks up at the various registers and marks the status in the work plan.

3.5.2 Accredited Social Health Activist (ASHA)

The ASHA is a community health worker instituted as part of the National Rural Health Mission (NRHM). They are volunteers and receive financial compensation for the services they provide. The ASHA workers support the ANMs by providing outreach services. The ASHA and Anganwadi workers work together to motivate and mobilize women to avail the health services.

The ASHA also work closely with the ANMs for taking surveys, providing antenatal and postnatal care, immunization services. The ASHA workers act as a link between the village and the ANM. The ASHA maintain a register or assist the ANM to maintain registers. On a

monthly basis, they provide data on the services they provide to the ANM, who takes this into the monthly reports.

3.5.3 Anganwadi worker

The Anganwadi worker provides basic health care in Indian villages and they work at the village level. They are part of the Integrated Child Development Services (ICDS) program and they come under the Ministry of Women and Child Development. They provide care for newborn babies and ensure that all children below the age of six are immunized. They provide antenatal care for pregnant women and post-natal care to nursing mothers. They also provide required nutrition to children, nursing and pregnant women and ensure that regular health and medical check-ups for women take place and that all women and children have access to these check-ups.

Anganwadi worker usually takes care of a population of 1000 people. A helper usually supports her. The Anganwadi worker lives in the same village where she provides health care services and maintains the most comprehensive record of the demographic information and services provided to the people in the village. They also assist the ANM and ASHA workers by sharing records of the population and other health services they provide.

The list of registers and reports maintained and generated by the ANM, ASHA and Anganwadi worker is available in the appendix section 1.

3.5.4 Medical officers in PHC

The primary health centers are the first point of contact between the Medical officer and the community. The PHCs cater to a population of 20000-30000 people. The functions of a PHC include medical Care, mother and child health, family planning, safe water supply and basic sanitation, prevention and control of local endemic disease, collection and reporting of vital statistics, education about health, national health programs, referral services, training of health guide, health worker and basic laboratory services.

The medical officer screens the patients for various chronic diseases or ailments. The patient is then diagnosed and prescribed medicines. They maintain their own set of registers for

chronic diseases like Blood pressure, Diabetes. The medical officers also refer patients to higher medical institutions (Ex: District level hospitals) for diagnosis and treatment. All these details are recorded in various paper-based registers. The medical officers send a monthly electronic summary report to PGIMER. This is based on the monthly morbidity report.

3.6 Existing interconnections and information flows

The existing interconnection and information flows show the different ministries and the community health workers. It also depicts the hierarchy of reporting in each ministry (see Figure 7)

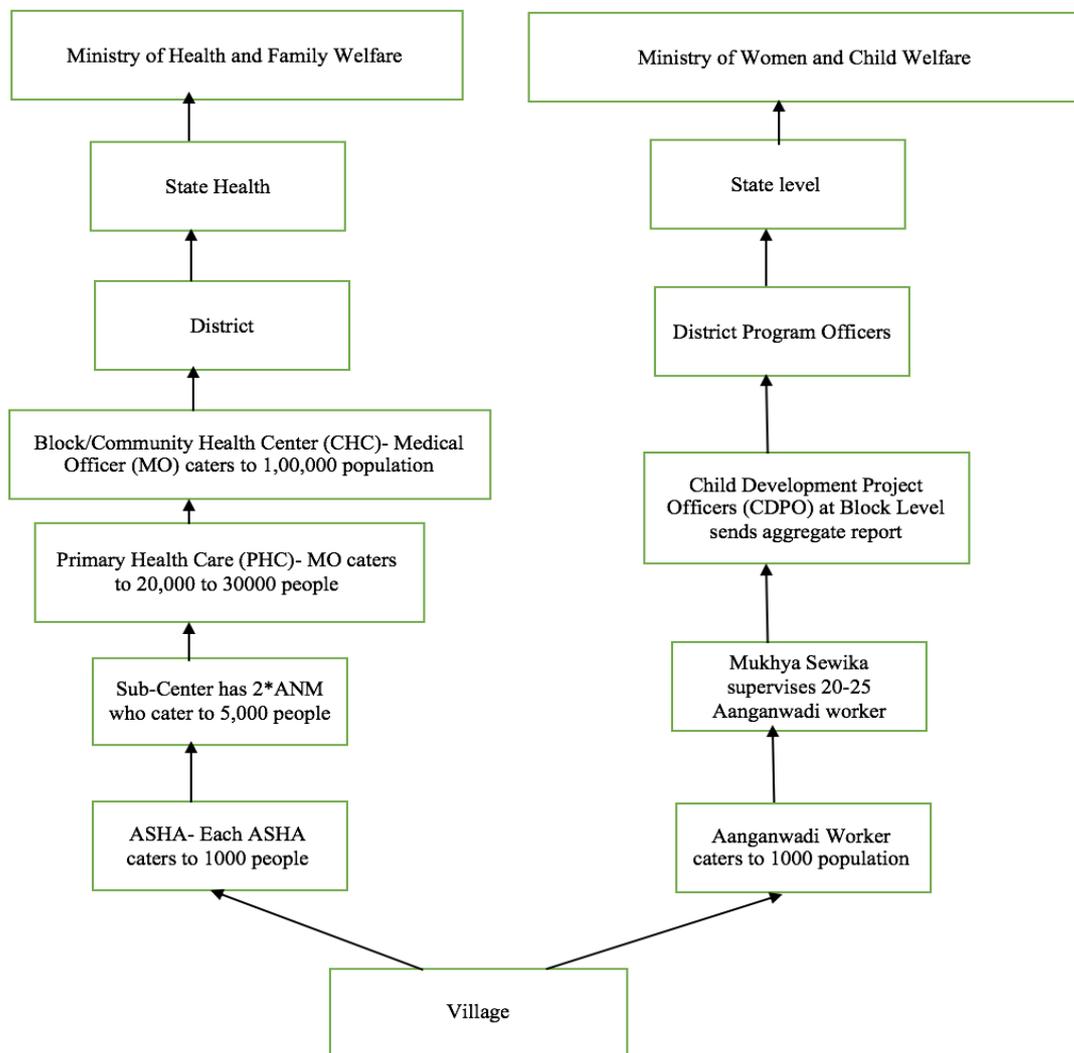


Figure 7: Hierarchy of the Public health system in rural areas

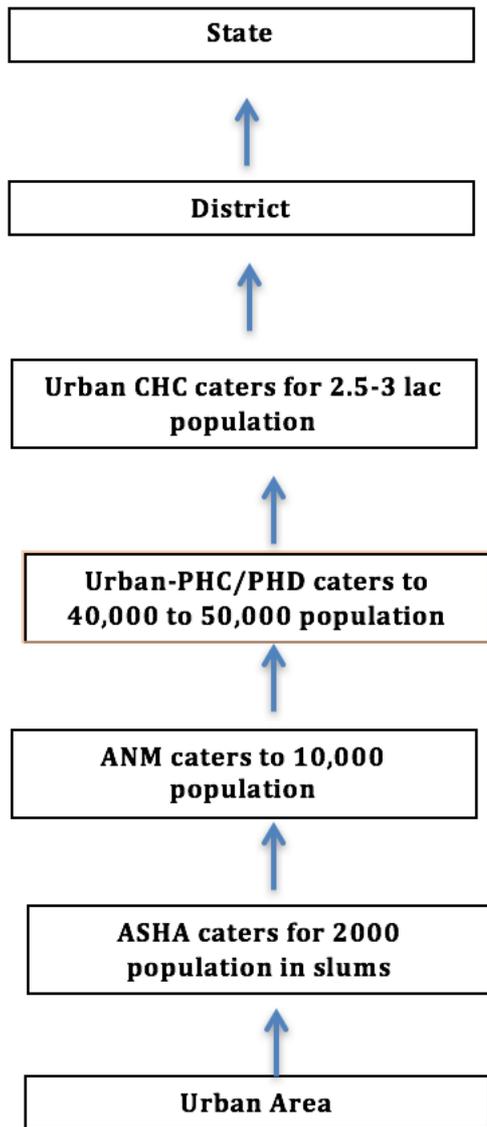


Figure 8: Hierarchy of Public health systems in urban areas

The number of people the public health system caters is more in the urban areas than the rural areas (see figure 8).

3.6.1 Primary health center in Chandigarh- Pilot clinic 1

This PHC is one of the four dispensaries falling under the ambit of the School of public health in Chandigarh. The PHC is located in a slum area, where the population is mainly underprivileged. The population is approximately 25000 and the area is densely populated. Also, the population is highly migratory and many in the population do not possess a government identification card. The facility also has a mother and child health center which

provides services which include immunization, ANC checkups, family planning and counselling to its patients.

The facility is manned by a Multi-Purpose Worker (MPW), who is also responsible for registration of patients along with drug dispensing. A register is maintained for capturing registration. The demographics captured are: Registration Number, Date, Name, Age, Sex and Address. For a revisit patient, the number of the patient is tracked from the register and a new slip bearing the same number is issued to him/her with the old registration number.

The facility receives drugs and items from the Directorate of Family Welfare (DFW) and from the medical hospital. All drugs are dispensed free of cost to patients. A Drug consumption report is shared with both agencies on a monthly basis.

There are two doctors including a Senior and Junior resident. If required, the patients are referred to the secondary health care. There are 4 ANMs and 4 ASHAs in the Public Health Dispensary. They carry out the programs which are a part of this PHC, including maintenance of registers and generating reports. The ANMs and ASHAs have the following weekly schedule as detailed in the table below:

Day	Work
Monday	Field day-Ante-Natal Care (ANC), Pre Natal-Care (PNC) and Immunization drop out Visit (Up to 10 Visits)
Tuesday	ANC Check-up and MCTS report
Wednesday	Immunization
Thursday	Field day- ANC, PNC drop out and MCTS report
Friday	Field day- ANC, PNC drop out
Saturday	Immunization

Table 6: Weekly schedule of the CHW in the PHC

3.6.2 Pilot clinic 2 in Punjab

A PHC in the rural area of Punjab was selected to implement the second pilot. The idea was to implement the system in one semi-urban clinic and in one rural clinic. This would help to know about the differences in terms of the infrastructure and the difference in implementation in both the clinics.

3.6.3 The problem

The important people at a community level are the pregnant women, new mothers and children. The CHWs encourage the pregnant women to come for four ANC visits, get their babies for vaccination to the clinic and come for follow up visits as part of PNC. When the women visit the clinic, a paper booklet is given to the women, which provides basic health information for the pregnancy and includes a schedule of the next visits.

The CHWs use registers for recording health-service delivery information. In our assessment, it was found that ANM along with the ASHA maintains around 28 registers and 28 reports. The appendix section 1 has the list of these registers and reports. Other than the daily routine of the ANM/ASHAs, the ANM and ASHA workers have to spend time maintaining the registers, which is used for various reporting purposes. One example of a register they maintain is the Reproductive Child Health (RCH) register. It has the following sections:

Section Name	No of columns
Tracking of Eligible Couples (EC) and use of Contraceptives	45
Tracking of Pregnant Woman	85
Tracking of Children	60

Table 7: RCH register sections and columns



Figure 9: Paper based registers and forms for mother and child health

The register is very bulky with a lot of data to be entered. Most of the sections mentioned above, have many redundant datasets. Depending on the needs of the government, these reports and registers change all the time, which might increase the time spent on generating these new reports and maintaining registers.

The use of these registers is also compromised in a number of ways when the CHWs go for field visits. The CHWs carry a small notebook called field diary to record information as part of their field visits. This data from the field diary is transferred to these registers when the CHWs return to the clinic. There could be problems trying to link the person in the register to that in the diary. When the governments systems change, the CHW is given a new register, but they also maintain the old register until the old systems are phased out. This increases the reporting burden on the CHWs.

The ANM is also expected to maintain a plan for the ANCs and PNCs. When the pregnant women do not turn up for the services, they have to follow-up, determine, and maintain a lapse in the schedule of care. The registers are updated by both ANMs and ASHAs depending on the services they provide. Hence, the information on a single patient could be hard to comprehend.

The health administration and planners benefit from a clear picture of the health operations and health status. Hence, the CHWs aggregate the patient-data that they have based on age, gender, disease. In our study, the CHWs estimate that they spend almost 60% of their time in

reporting and register maintenance. This data task is not part of the routine operations of the CHW and it takes away the focus on providing continuity of care.

According to MacLeod, Phillips, Stone, Walji, and Awoonor-Williams (2012), all of this combines to create information needs and bottlenecks for all the participants in the health systems: In particular,

- **Clients** seek information to guide health behavior. In our study, since the population consists of mostly daily waged workers, it is hard to get them to come to the health facility, leaving their daily jobs. At the same time, it might not be possible for the workers to be followed up by the community health workers.
- **CHWs** use paper registers to document health service delivery. However, there are systems like the MCTS to generate the work plan for tracking the patients. The data collected at the village level is sent to the block level for data entry and then a work plan for service delivery of ANM is done. The focus of this system has been on monitoring and surveillance of the health staff and it contributes little to improving maternal and child health indicators. There are only few services like monthly work plan generation. There is delay when the CHW receives the work plan to follow-up on the patients. Hence, the CHW makes her own work plan, as she knows the population she is assigned to.
- **Health administrators and planners** seek information on the health status of the population and the work of the CHWs. While the CHWs aggregate service delivery and morbidity information from the paper registers every month, this involves calculations for hundreds of data points and they are reported by age, gender, disease and type of service delivery. The quality and timeliness of the reports can be compromised.

The next chapter talks about the methodology adopted in this thesis to collect requirements and perform requirements-analysis for a patient-centric information system.

4 Methods

This chapter focuses on the methods chosen as a framework to guide the conduct of the research. The thesis comes under the qualitative research approach. I use the method of case study in my thesis. According to Alasuutari, Bickman, and Brannen (2008), a case study is a deep understanding of particular instances of a phenomenon. This overriding goal drives all practical decisions in conducting a case study like, which questions or issues might guide investigation, which data collections might be useful, which participants might be informative and so on. Alasuutari et al. (2008), mention that a deep understanding is not easily achieved and compare it to a single case of interest to each of us, the efforts to understand oneself, which is also called self-study. It takes a lifetime and is evident with the encounters with people who, despite their unlimited access to data have humble or inflated views of their capacities and importance. A case study in social sciences involves careful methodology to avoid such errors.

As patient-centric systems in primary health care are inherently socio-technical in nature, looking at just the systems implementation process will not be adequate for the purpose of this research. It is important to understand the working practices, relationships, hierarchy of health systems, reporting hierarchy, culture, political structure and other environmental factors at play. This perspective of socio-technical analysis in the framework of a living lab is particularly important to understand developing patient-centric information systems in a developing country like India. It takes the whole context into picture, rather than just looking at technical implementation of the health systems stand-alone.

This perspective has been used as a guiding concept in data collection and requirements gathering.

4.1 Action research (AR)

My thesis follows the method of case-study, but the project mainly follows the method of action research. According to Schaffers, Garcia Guzman, and Merz (2008), action research is a collaborative activity among individuals working with others in teams or communities of practice searching for solutions to everyday, real problems. A key assumption of action research is that action brings understanding and insights (new knowledge).

Schaffers et al. (2008) also state that this methodology is perfectly suited for a framework of a living lab, where there is a situation of openness and cooperation, complex social processes and the need to introduce changes into these processes and observe the effects during the process. The INTPART project follows the methodology of action research in the framework of a living lab, which fosters digital innovation.

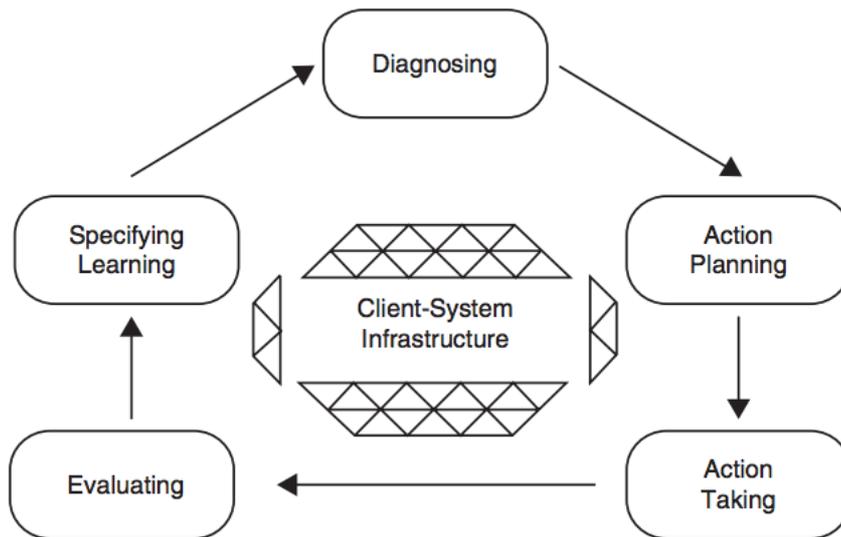


Figure 10: The AR cycle (Baskerville & Wood-Harper, 1996; Susman, 1983)

4.2 Interpretive case study

An interpretive case study focuses on providing deep understanding of specific instances. Case studies employ emergent design, which means that rather than carefully adhering to a design specified at outset, where relatively little is known about a case, a researcher is expected to improve on the original blueprint as information emerges during data collection. Interpretivist case studies tend to expand datasets as new sources are discovered and questions articulated. This expansionism allows researchers fuller access to a case's contexts, conditionality and meanings. (Alasuutari et al., 2008).

4.3 Data collection methods

This thesis employs several methods of gathering and analyzing data

4.3.1 Field trips

My research started in an exploratory fashion, to understand how patient-centric information systems were different from aggregate health information systems. Few sessions were held with the researchers and staff from the HISP project in Norway, who had already worked with the Indian case studies. After the initial understanding, a trip was scheduled to India for a requirement gathering workshop in Chandigarh, India. Before the workshop, I also visited HISP India to know their projects and their working methodologies. HISP India specializes in health information systems using free and open source technology.

4.3.2 1st Requirements gathering workshop

A requirements workshop is a facilitated group meeting. The workshop must be custom-designed for the specific group needing to deliver requirements for a specific project. The interactions in the session let the participants to discover, elaborate, clarify and discuss the project's requirements (Gottesdiener, 2002). Participants quickly and efficiently define, create, refine, prioritize and reach closure on deliverables (such as models and documents) that represent user requirements (Gottesdiener, 2002). Often held at the beginning of a project, they build positive, productive working relationships. (Gottesdiener, 2002, 2005). Requirement workshops are about information discovery and creation. They are usually intense and varied and they promote innovation and foster teamwork (Gottesdiener, 2002).

A two-day requirement-gathering workshop was organized in the School of public health in PGIMER, Chandigarh. The agenda for the workshop included the following as given below:

S.No	Agenda
1	Introduction of Participants
2	Opening Remarks
3	INTPART Project
4	Report of INPART Kick-off Workshop, April 2016
5	Assessment of Existing Information Systems
6	Health Information needs and challenges: Empowerment of health provider, consumer, and community

7	Primary Health Care System in Punjab
8	Primary Health Care Workforce Perspective (ANM, AWW & ASHA)
9	Formats & Reports generated at SC & PHC
10	Rationalizing reporting formats at PHC and SC
11	Discussing requirements for patient-centric system in Chandigarh
12	Creating a proof of concept by the members of HISP

Table 8: Agenda of the requirements gathering workshop

Following the approach of a living lab, the following were the stakeholders who participated in the workshop.

Sr.No	Role	Organization/Department
1	Professor and head of School of public health	PGIMER
2	Assistant Professor from School of public health	PGIMER
3	Researchers	University of Oslo
4	Senior Project Coordinator	HISP India
5	Masters Student- Informatics	University of Oslo
6	PhD Scholar	SPH, PGIMER
7	Senior Resident Doctor	SPH, PGIMER
8	Masters Student – Public health	SPH, PGIMER
9	Public health nursing office	SPH, PGIMER
10	MPW –Male health worker	SPH, PGIMER
11	Medical Social worker	SPH, PGIMER
12	2 ANM and 2 ASHA workers	PHD, Sector 25, Chandigarh

Table 9: Roles of participants in the requirements gathering workshop

A study of the existing Business processes

The workshop aimed at focusing on the primary health hierarchy in Chandigarh and the study of the existing business processes was important. To study the business processes, the following questions were analyzed:

- Who are the actors in a PHC?
- Where do CHWs capture data when they go on field visits?
- How is the data transferred to the corresponding registers?
- What kind of registers need to be filled periodically?
- What kind of reports need to be generated?

- Where are the patients registered in the primary health center?
- What is the unique identification to find the patients?
- What services does the clinic offer?
- Where is stock control done?
- Where do patients receive the medicines?

The participants from the school of public health, PGIMER, Chandigarh gave us an overview of the hierarchy in public health, work processes, daily routines and an overview of all the registers and reports they record data in. The ANM and ASHA workers gave inputs on the amount of time spent in registering data and how new registers and reports were time-consuming for data-entry and report generation.

The requirements gathering workshop was followed by a field visit to the primary health centers where this system would be first piloted. Two days were spent studying the daily routines in a primary health clinic. This workshop was the basis for the initial business requirement document which was used as the base for adding new requirements as and when they were discovered.

4.3.3 Workshops

The following is the list of workshops, which were held as part of the INTPART project, to build patient-centric systems

Workshop	Place and time of workshop	Purpose
Workshop 1- Organized by School of public health PGIMER	Chandigarh, India -April 2016	I was not part of this workshop, but the documents from this workshop provided valuable inputs to set the context for the project. This was the first kick-off workshop, which happened in Chandigarh. In this workshop, the participants discussed the overall landscape of patient-based systems for primary health care in India. The road map of the project was discussed, and responsibilities assigned to the different partners. These inputs set the context for the challenges, requirements for building patient-centric systems in Workshop 2. This helped to gain insights related to a patient-centric system, best practices, challenges and approaches all of which helped in shaping the system design and implementation process proposed under the INTPART project.
Workshop 2- Organized by School of public health -PGIMER	Chandigarh India, December 2016	This workshop was the requirements gathering workshop which has been described in the previous

		section.
Workshop 3- Organized by University of Oslo with other research partners and PGIMER	Oslo, Norway, May 2017	This workshop was to discuss the progress of the project until date. The systems implementation process had already started by then. The workshop was to understand the various other parameters to consider while designing and building patient-centric systems like standards, security with inputs from the Norwegian Institute of Public health (Folkehelseinstituttet) and various other research institutions. The workshop was also to critically understand the issues faced and possible approaches to address them, as well as to further review and refine the road map. A 4-person team attended the workshop from India in addition to the different research partners in Oslo.
Workshop 4- Organized by PGIMER with various stakeholders from the Ministry of health, national informatics center in India	Chandigarh, India, February 2018	This workshop was to demonstrate the work done as part of INTPART to the government officials from the national and state levels of the country, researchers and stakeholders from PGIMER and UiO, companies which had

		<p>a focus on building patient-centric information systems. A demonstration of the systems developed was shown and also a presentation on the progress of the master thesis work was given to all the stakeholders. This workshop's main agenda was to:</p> <ul style="list-style-type: none"> • Invite critical and constructive comments for improvement of systems • Plan next round of systems implementation for the next pilot primary health center. • Plan for next workshop in Oslo.
Workshop 5 -Held in University of Oslo	Oslo, Norway September 2018	This workshop focused on the progress on the implementation of the second pilot clinic in Punjab was discussed. Various research outputs as part of the INTPART project was also discussed.

Table 10: Workshops for the INTPART project

4.3.4 Field visits

In addition to the workshops, the following field visits were also conducted as part of the workshops for the INTPART project:

Field visit	Time	Description
1	December 2016	Field visit to Pilot clinic 1 in PHC sector 25, to understand the working processes of the ANM, ASHAs and the medical officers in the PHC. Field visit to PHC in Punjab.
2	February 2018	Field visit to PHC sector 25 to see how the living lab was functioning, the various working methods using the information systems.

Table 11: Field visits for the INTPART project

Field visit 1

Following the first requirement workshop, a field visit was conducted to study the working practices in a primary health center. The first field visit was conducted in PHC-Sector 25 in Chandigarh where the first pilot was planned to be implemented. Since the field visit was just after the requirements gathering workshop, a room was allocated in the premises of the primary health center, for the living lab to be setup. The existing computer equipment's and how these laptops were used by the doctors in the PHC was studied. Only the medical officers in the Out-Patient Department (OPD) had access to the computer while the subcenter, pharmacy/registration counter did not have or use any computer equipment's. The subcenter and the registration counters were mostly using paper-based registers for recording data. Access to good internet bandwidths seemed limited and there were frequent power outages.

The second day, another field visit was conducted to the second pilot PHC in Punjab where I was accompanied by the medical officers from Chandigarh. A study of the various facilities in the PHC was conducted. The medical staff were quite eager to provide inputs for such a system to be built, but they stressed that training the CHWs might be a challenge for keeping such a system alive.

Field visit 2

This field visit was conducted after a year after the initial requirements gathering. This was followed by the 4th workshop on patient centric systems in Chandigarh India. The field visit included a lot for participants from the workshop, who were mainly from health sectors in various states in India. They wanted to see if this was a system which could help in their PHC as well. They also had valuable inputs like implementation of cohort charts for seeing the trend in health parameters, and other system improvements.

Personally, for me, this field visit was a contrast from the first field visit. The PHC had changed quickly in a small period of one year. The living lab was in full action, the PHC was more organized with a queue system for the patients which the new systems were helping in turn. Paper work was innovatively tried to be reduced for the CHWs, but it was difficult to earn their trust immediately until they saw that the results from the system matched exactly with their manual results.

Requirements gathering meeting for second pilot in a PHC in Punjab.

After the 4th workshop, a requirement gathering meeting was held with PGIMER, HISP India and I joined via a Skype meeting. For the pilot clinic 2, only DHIS2 was decided to be used for the clinical module, hence the meeting focused on the gap analysis of requirements between the Pilot clinic 1 and Pilot clinic 2. The meetings main agenda was to:

1. Design a clinical module in Pilot clinic 2 using DHIS2.
2. Discuss the flow of the information between the various modules.
3. Discuss options to integrate a stock module.
4. Customizing the system developed for Pilot clinic 1 to Pilot clinic 2.

4.4 Data sources

4.4.1 Field notes

I used field notes during my field trips in Chandigarh and Punjab. I also used them extensively in the requirement gathering workshops, for meetings and discussions, which

were held. I went over these notes and reflected to fill in more details. The field notes were later used for making the Business requirements documents. This requirements document was used as the basis to start with systems design and development processes.

4.4.2 Meetings

Meetings and discussions which were held, provided valuable data for the workshop. Most of these meetings were unstructured and open discussions between the parties concerned. In India, the following meetings contributed to this thesis:

- First meeting with the stakeholders in the PHC to understand their everyday routine.
- Meeting with HISP India to understand their point of view of HIS and patient-centric information systems in India from their experience in public health.
- Second meeting with the stakeholders (Medical officers, developers in the living lab, CHWs and the data-entry operator) in the PHC, to understand how they were using the systems implemented in the PHC.

In Norway, the following meetings contributed to this thesis:

- Observing a meeting with the researchers from HISP project in Norway, where a discussion on “What are the guidelines to build Community health information systems using DHIS2?” was discussed. The purpose of the meeting was to create a guideline for data collection, data management – including integration of parallel CHIS reporting into Routine Health Information Systems (RHIS) such as DHIS2 and interoperability between CHIS and other information systems serving community-based health service providers. Case-studies were discussed from around the world, which helped me get a better understanding of the various use cases for these systems.

- A meeting to discuss rationalizing demographic information for the programs which were to be implemented in DHIS2 tracker for PHC-25. In the systems implementation process, manual register’s demographic information was rationalized in an excel sheet. This excel sheet was reviewed and later imported as data elements in the DHIS2 system.

- Meeting with HISP India team members in Norway to discuss how the issues with Integration of Open-MRS and DHIS2 in PHD25 can be addressed, using just DHIS2.

- Skype meeting for requirements gathering for the second pilot in Punjab. A skype meeting was organized to discuss what would be the requirements to create a basic clinical module in DHIS2 using the tracker module. This meeting was attended by HISP India, PGIMER team and me as a researcher on requirements. The meeting was to discuss on the current challenges at PHD25. A detailed discussion over clinical module was conducted. The discussion started with actual requirements of clinical module; what is the current scenario at the PHC in Punjab, how each and every step of clinical services is linked. This meeting set the basis for a requirement document for the PHC in Punjab.

- Other meetings which provided important inputs were to discuss the evolving requirements with the developer in the living lab.

Several other meetings were also held in Norway with HISP India, to discuss workplans and the progress of the project, but the ones listed above contributed to my progress in the thesis till date.

4.4.3 Electronic communication

During the workshops in India and Oslo, lot of action points and ideas was discussed. After the workshops, it was important to have a continuity to these discussions. The most important inputs came from the mails received from HISP India and from the members in the living lab in PGIMER, Chandigarh.

Since the requirements were continuously evolving, it was important for me to know about the developments taking place in the living lab. After the 3rd workshop in Oslo, a process was created to update the requirements documents, as and when new requirements came up. The whole idea was to maintain a master requirements document, instead of just have the information of requirements across various emails and many electronic documents.

4.4.4 Study of registers, reports and family cards at the health center

The study of the registers, reports and various other paper-based work helped to get an idea of the outputs expected out of the system. These paper registers served as the base to gather data- elements and rationalize the information from the registers.

4.4.5 Presentations from workshop

The presentations shared from all the workshops were useful to refer to, as they talked about findings and understandings from this particular problem domain.

4.4.6 Flow charts

Flow charts have been very a useful tool to understand information flows in health systems, hierarchies, reporting hierarchies and to under the processes involved in a primary health level.

4.4.7 DHIS2 Academy live videos

The DHIS2 academy which was conducted in June 2018, posted live videos on their Facebook page. They have been a valuable source of the vision of DHIS2 towards building Community health information systems. The academy sessions also had the information on the launch of the android application for Community health workers which was launched recently in September 2018.

4.5 Data analysis

The basic objective of the analysis is to derive conclusions from the data. Throughout the research process, a lot of documents were made available from the researchers in PGIMER and the various research partners from Center for Connected Care, Folkehelseinstituttet, and University of Oslo. To answer my research question, inputs from the requirements gathering workshops and other follow up workshops, led to create unstructured documents in the form of field notes. After every workshop, these field notes were studied to reflect and create and

update a master business requirement document. There were also real time inputs for the document, which came from the stakeholders in the living lab, especially the developer in the living lab and the researcher from PGIMER. The process of creating this document has been very iterative. Since the requirements have been evolving in various time frames, these requirements have been recorded in the requirements document version wise. I have attached the various versions in the appendix section 1.

In this iterative process of updating the document, the document has become more structured and it was easy to see patterns of the requirements. One distinguishing pattern which was observed was, is the requirement at the facility level or for the outreach programs in the community. Thus, this data helped me analyze the process of requirements gathering, how they evolved and this was shared with the development team for feedback and improvement.

4.6 The research processes

My research aims to study the requirements to build patient-centric information systems in the context of primary health care in a developing country like India. After studying the requirements, an analysis is done to determine which systems implementation process best addresses these requirements. This has been carried out as part of the INTPART project. This research can serve as a guideline to build patient-centric systems in community-settings for a primary health sector. The research process can be summarized into a few stages:

1. Learning about patient-centric systems, requirements gathering and DHIS2 tracker.
2. Creating a business requirement document after the requirements gathering workshop.
3. Rationalizing demographic data collected from the various registers for creating data elements in DHIS2.
4. Research on patient-centric information systems and the use of a family folder model in primary health sectors.
5. Follow-up/Information on evolving requirements in the systems implementation process and documenting the changes in the business requirements document.
6. Change in the technical solutions, for the second pilot in the PHC in Punjab, due to challenges in integrating two systems in the PHC in Chandigarh.
7. Analyze different technical solutions to address these requirements and to understand the efficacy of the respective solutions.

5 Requirements for a patient-centric information system in a primary health setting

This chapter discusses the requirements to build patient-centric information systems in a primary health setting based on the empirical work conducted in this thesis. Since the framework is that of a living lab and the systems implementation process is iterative, the requirements are consequently evolving. I present the requirements gathered in various phases to show the evolution of requirements. I use the term “phase” to reflect different parts of the process of building the requirements based on a time dimension. The different phases represent the incremental build of systems. Phase 1 is the start of the requirements gathering, whereas phase 2 builds on the requirements gathered from phase 1 and adds on new requirements identified which are to be addressed by the system. Thus, many phases have emerged with these evolving requirements. These phases were critical to make decisions about features to be added, improved or removed in the patient-centric information system. In chapter 6, the evolving requirements post systems implementation of pilot clinic 1 are discussed.

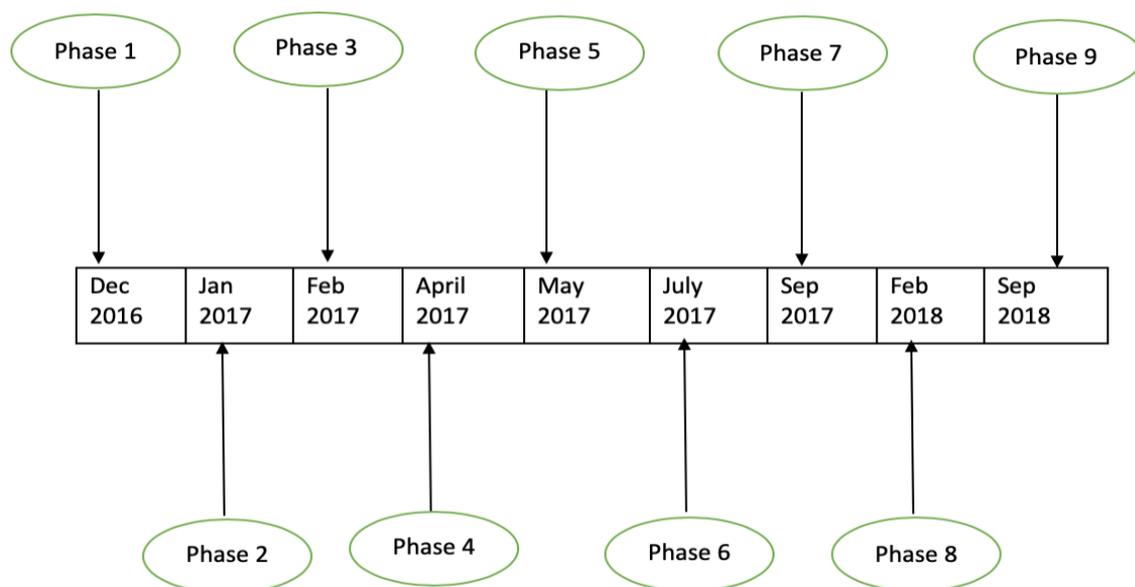


Figure 11: Timeline of phases in pilot clinic 1

The following table summarizes the phases and the requirements for pilot clinic 1

Phase	Timeline	Requirements
1-Startup and requirements workshop	Dec 2016	<ul style="list-style-type: none"> • High-level business requirements • Population database • Set up of the living lab • Technical solutions to be implemented • Infrastructure and technical installation (OpenMRS in facility and DHIS2 tracker for outreach programs)
2- Data collection and co-design of family folder and registration process	Jan 2017	<ul style="list-style-type: none"> • Rationalization of data elements • Design of family folder • Patient registration • Installation of OpenMRS and usage of EMR system in PHC (Role based access, Patient queues) • Changes in use of population database
3- Program registration co-design and EMR system requirements	Feb 2017	<ul style="list-style-type: none"> • Program registration after patient registration • Design of the NPCDCS program • EMR system (OpenMRS) requirements.
4-Integration of SMS and expand to other programs	April 2017	<ul style="list-style-type: none"> • Additions to the NPCDCS module • SMS integration • Rationalizing data elements for other programs.

5- Co-evaluation of OpenMRS and DHIS2 integration	May 2017	<ul style="list-style-type: none"> • Issues integrating OpenMRS and DHIS2 Implementation of standards.
6 -Co-design of other programs, SMS gateways	July 2017	<ul style="list-style-type: none"> • Expand to other programs like RCH, Child health, Nikshay. • SMS Gateway and usage with DHIS2 application • Mobile application requirements
7- Output generation like workplans and reports	Sep 2017	<ul style="list-style-type: none"> • Work plans for ANM • Report generation • Dashboards • Triage module in OpenMRS
8- Data analysis features	Feb 2018	<ul style="list-style-type: none"> • Design of cohort charts for data analysis • GIS maps and plans for second pilot in another PHC.
9- Mobile application support	Sep 2018	<ul style="list-style-type: none"> • Usage of mobile based application support for CHWs • Integration to other health systems

Table 12: Summary of phases and requirements for pilot clinic 1

5.1 Phase 1 of requirements gathering

In this phase, the discussion focused on high-level business requirements, population database, set up of the living lab, technical solutions to be implemented and the general design principles for designing the patient-centric information system.

With systems in India moving towards Universal Health Coverage (UHC), the aim is to make health care accessible to each and every citizen at affordable costs. As depicted in the figure

12 below, the umbrella requirements which come under the UHC agenda are referral care, first level care, periodic outreach services, community and cross-sectoral service (Organization, 2017). It should attend to people of all ages and across all communities.

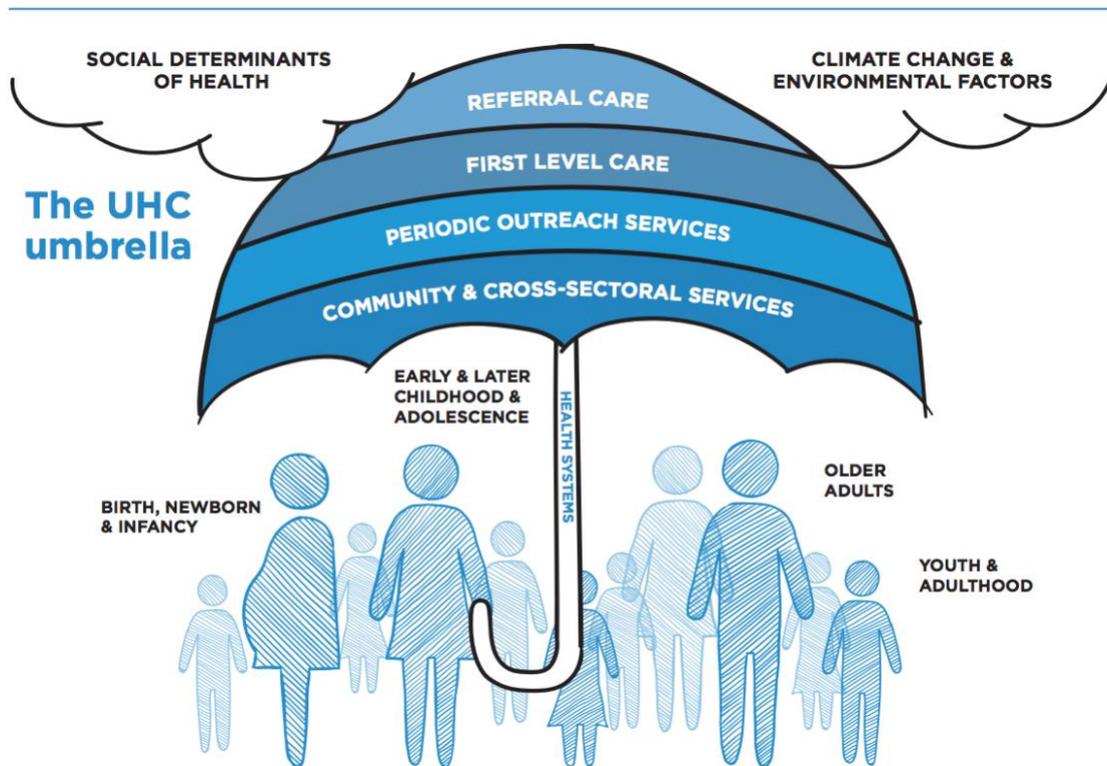


Figure 12: Universal Health Coverage (Organization, 2017)

From a UHC perspective, the two broad categories of requirements identified are:

1. **Capture patient data for the consultations at the primary health center:** This comes under the first level care and referral care requirements of the UHC. At the clinic, various patients come on a day to day basis for treatment to the PHC, hence an electronic medical record system with history of the patients visit and details of the patient is required. These patients could also be referred to district hospitals or other specialty hospitals for advanced diagnostics and specialist care.
2. **Capture patient data for the programs which they are enrolled in:** This comes under the periodic outreach services and community and cross-sectoral services of UHC. The programs run at the PHC are part of the national and state level outreach programs, to eradicate and prevent diseases. There are many programs already

running in the clinics, and new ones are being constantly added, such as the recently launched program, for chronic diseases called National Programme For Prevention and Control of Cancer, Diabetes, Cardiovascular Disease and Stroke (NPCDCS). The system needed to be designed to capture patients who would be enrolled in the NPCDCS program.

Population base data

For both the above broader requirements, the patient needs to be registered into the system. Since the primary health care, catered to the population in a particular area, the base population was relatively fixed. Various government agencies like Unique Identification Authority of India (UIDAI) (unique 12-digit number called Aadhar), national surveys collect individual data and hence, this could be loaded into the system as the base population data. So, the requirement was to explore a possibility of using the existing data sources for the population data. In case of the care provided at the PHC, it was okay to have the data patient wise, but for outreach services, the model of a family folder was a requirement. In India, the family folder system is used to record the socioeconomic and health data of each family living in the service area. It is also used to record the sociodemographic details of each family member and information on individual health, maternal health care and records of all eligible couples. Since, the CHWs go door to door to collect data for their outreach programs, it is easy to organize this information in the form of a family folder, to retrieve all the details of a family.

Infrastructure

Also, the PHC had no existing technology in place for the IT systems to be installed, hence the server administrator at HISP India had to propose a design for the hardware configuration. The hardware setup was identified by the server admin at HISP India, the mail conversation from the server admin at HISP India to the stakeholders of the project

Type	Quantity	Configuration
Desktop with normal configuration for data entry	2	CPU - intel i3 5th gen RAM - 4 GB

purposes.		HDD - 500 GB MONITOR - 19" KEY BOARD / Mouse O/S - Windows 7 Ports - USB LAN - 10/100/1000 MBPS UPS - 1 KVA Offline
Laptop for Medical officer (data entry and report generation)	1	CPU - intel i3 5th gen RAM - 4 GB HDD - 500 GB O/S - Windows 7 Screen - 14" / 15" LAN - 10/100/1000 MBPS
Offline server to be installed at the facility itself, where all the local computer will be connected through Lan connection	1	CPU - intel i3 5th gen RAM - 12 GB HDD - 1 TB GB MONITOR - 19" KEY BOARD / Mouse O/S - Windows 7 Ports - USB LAN - 10/100/1000 MBPS UPS - 3 KVA UPS Offline
Dot matrix printer at the registration counter	1	Epson / TVSE 24 pin 132 column Dot matrix printer with USB support (EPSON DOT MATRIX PRINTER MODEL: LQ-1310 24 PIN 132 COL WITH USB PORT)
Laserjet printer for medical	1	HP LaserJet Pro M202n

officer		Single Function Printer
Tablet's for ANMs	4	Lenovo Tab3 7 Essential Tablet (7 inch, 16GB, Wi-Fi+3G with Voice Calling), Ebony Black
Big power UPS from where we can supply power to all the systems	1	An offline UPS for all the devices, Desktop, Server and Network device was suggested, because it would be more cost saving option Desktops - 1 KVA Offline ups with 45 to 1-hour power backup Server - 3 KVA Offline ups 1 to 2-hour power backup
Internet connectivity for data syncing purpose		Need to explore
Lan setup		All required equipment as per discussed architecture

Table 13:Infrastructure requirements at pilot clinic 1

Living lab

A living lab was setup in the PHC in Chandigarh. The living lab was an arena to bring together all the stakeholders from technology and health to talk about the requirements of the system. For example: when the CHWs said that having the structure of a family folder could

make their field visits easier, the living lab acted as an avenue to discuss the design of the family folder. The technical team could see the feasibility of the implementation and the health workers and medical staff could provide their inputs on how the family and family members could be easily identified.

In the two- day requirement gathering and analysis workshop conducted in December 2016 in PGIMER Chandigarh; the workshop was attended by the staff from PGIMER, University of Oslo, HISP India and the CHWs from the Punjab health system. This workshop built on an earlier workshop in April 2016 where different stakeholders from the National Ministry, National Informatics center and University of Oslo and many other government and private organizations presented experiences related to building a patient-centric information system, best practices, challenges and approaches which helped to provide design inputs shaping the systems development process proposed under the INTPART project. Based on these two meetings, few design principles were agreed upon by PGIMER, UiO and HISP India at the start of the project to set a framework and goal of working. These principles include:

1. The system should aim to reduce the work burden of the Primary health center workers.
2. The system should be integrated with existing systems and work processes, seeking to rationalize, and not becoming yet another system.
3. The system should strengthen the use of information for local action.
4. The system should be user friendly and easy to use even for the level of ANMs/ASHAs.
5. The system should be scalable and present a model, which can be taken up at the state level and more.
6. The system should be primarily managed and evolved by the state, and not be reliant on external consultants.

After the first requirements gathering workshop in Chandigarh, India, the high-level business requirements, were summarized as:

1. Capable of capturing patient-based and aggregate data and recording it in various registers, which are entered manually currently. Here, patient data needed to be

gathered to incorporate requirements of UHC and aggregate data was to help with reporting data to the state and national level for planning and statistics.

2. Generate reports/registers based on the information captured since currently 28 paper-based registers and 28 reports were being generated at the PHC. This is done manually by the CHW and in our study it was found that they spent 60% of the time in data entry and report generation.
3. Help in tracking patient health, by displaying the history of their previous visits
Currently booklets are used to see the history and track pregnant women in addition to other registers

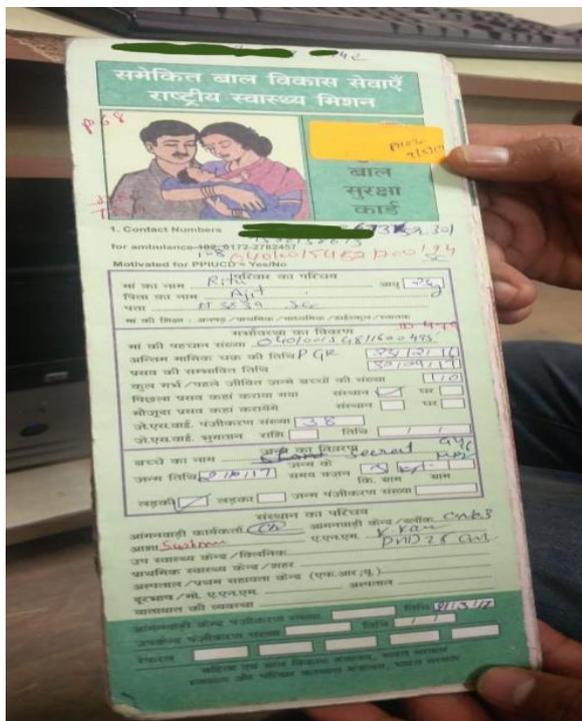


Figure 13: Booklet to track a pregnant woman

In the first workshop of INTPART, a consultant from the National Rural Health Mission shared his views on the current issues experienced with the existing systems and they can be seen as:

- Lack of integration of different systems as all have been developed in isolation.
- There is high bandwidth requirement.
- No direct communication with patients.

Hence, the following requirements were also taken up in this project

4. Interoperable and integrated with other health systems.
5. Should be available offline for the field visit of Community health workers.
6. Send SMS alerts for certain events (Ex: Reminders to pregnant women to come for their ANC).

At the end of the first requirements gathering workshop, OpenMRS was decided to be installed at the primary health care to handle registrations at the PHC for curative care by the medical officers and DHIS2 tracker was to be configured and developed to support the NPCDCS and other outreach community programs.

5.2 Phase 2 of requirements gathering

Now after phase 1, the following things were started:

- Rationalization of data elements
- Design of family folder
- Requirements for Patient registration
- Installation of OpenMRS and usage of EMR system in PHC

Rationalization of data elements and identifying a minimal dataset

An initial data set for data capture was determined. Datasets were identified by studying all important registers, health cards and reports, interviewing and observing medical officers and the CHWs who are the potential users of the system. To begin with, we started with rationalizing the demographic information across various registers and reports. The common data elements and the constant values for these data elements were also listed out. A sample of how this rationalization was done is shown in the figure below. A column against the data element shows which form and registers, this data element should be used.

Name															
Address															
Age															
Sex															
Contact No															
House number															
Area	Urban	Rural	Slum												
Eligible couple															
Total number of family member															
Relationship															
Occupation															
Marital status	Married	Unmarried													
Caste	SC	ST	General												
BPL	Yes	No													
Number of children	0-1	1-5 years	5-10 years	10-14 years	15-19 years	19-22 years									
Total Children	Male	Female													
Wife of/Husband name															
MCTS number															
Age in years	15-19 years	19-24 years	24-30 years	30-35 years	35-45 years										
DOB															
Child Name															
Child ID															
Mother Name															
Mother ID															
Place of birth															
Religion															

Figure 14: Rationalization of demographic information

Changes in the use of population data

For the population data, the anticipated Aadhar data could not be used, as the government of India had issued stricter usage guidelines of seeking consent from the individuals to use their data. The Aadhar data was individual data and not family based which was the requirement. Hence, another database provided by the Public Distribution System (PDS) was explored. This database contained only about 30% of the catchment population and was also grouped as per family. Hence, when the system was designed to import data based on the initial dataset, the base population could be imported. The rest of the data could be entered into the system by registering the patient as and when they came to the clinic to access care.

Design of the family folder

In the living lab, the design of the family folder was discussed among the technical team, researchers and CHWs. In a family folder, it should be able to identify the household members who constitute a household and the household members uniquely. When the data elements were studied in the registers, it made it even relevant to design the data capture in the form of a family folder.

This family folder was to be designed in the DHIS2 tracker module as that was used for the outreach programs. A system generated id, which was a long and an un-related number was not sufficient for this, hence a customized identification was thought of as a better idea.

In a mail received from the researcher from PGIMER, he said: “We are still trying to find a consensus for household unique id and we have discussed the same with ANMs, right now

they use house number as identifier for which we already have a separate field”. By taking inputs from ANMs, an identification scheme was designed in a manner that the CHW could identify where the patient lived and the family members of the patient. This scheme has been described by Sahay, Nielsen, Faujdar, Kumar, and Mukherjee (2018) as below:

CHD25/0345B1/HARI/H1	
CHD25	: Chandigarh Sector-25
0345	: House No.
B1	: Building with household Number 1
JA or J1	: Juggi (meaning slum dwelling) located in cluster A or Block 1
HARI	: Four initial alphabets of Head of Household Name 'HARISH'
H1	: Represents head of household

Figure 15: Family member identification design(Sahay et al., 2018)

Two modules called household member registration and household registration were planned. For the planned identification to be generated, the required data elements needed to be captured for family registration program. For example, the family registration program consisted of the following data elements.

Family Registration program data elements

Family unique id for identification of family generated by application

State: Chandigarh

Name of Village/ward/sector: Sector-25

Locality Name

Area type (Urban, Rural, Slum)

House Number

ANM Name (Drop down)

ASHA Name (Drop down)

Caste

Religion (Hindu, Muslim, Christian, Sikh, Jain, Other)

Below Poverty Line (Yes/No)

With the design of the family folder, it was decided that the system should be capable of allowing the health worker or administrator to register and search for an existing patient in the system. When a patient comes to the health facility, the health worker or administrator will search him/her in the system and if the record is found, then the health worker can add

other information to enroll them into a specific program. If the person is not available in the records, then the health worker should be able to enter all the details of a family from the family member into the system. In case of a Family folder, a family code and family member code will be available for individual members to uniquely identify them in the system.

In the household registration, there is always a head of a family, to which other household members are linked to. Different household members can be added by selecting a relationship as shown below.

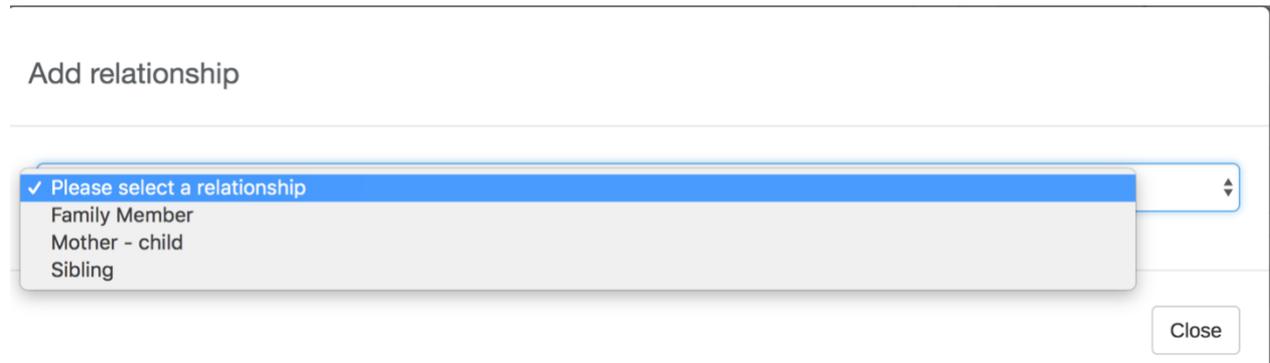


Figure 16: Selecting the relationship of a household member to the head of the family

On selecting the relationship, the household member to be linked to the family is added. The CHW (ANM and ASHA name) responsible for the family is also captured in the household and household member forms.

Installation of OpenMRS and usage of Electronic Medical Record (EMR) system in PHC

Open-MRS is an open source electronic medical record system. The main idea was that Open-MRS has the functionalities needed for doctors and nurses to track patients over time, while the aggregate data from this system is used for general health management at hospital, district, and national levels. The system is also easy to setup and can be customized with very little technical knowledge.

Open-MRS has a modular architecture and hence different modules can be either added or removed depending on the use. OpenMRS came with standard modules for Registration, Out Patient Department, Pharmacy. It was installed in the local server at the PHC and the medical officers started using it for recording the treatment given to the patients in the system.

Key business processes include:

1. Registration: Instead of a daily-visit paper-based register, patient registrations will be done in the system. The patients will be put into the system queue and called for treatment when their turn comes.
2. Triage: First the vital parameters of a patient like blood pressure, temperature, weight and height are checked before sending them for provisional diagnosis.
3. Out-patient department: The doctor provides the diagnosis and gives a prescription which can be collected from the pharmacy.
4. Pharmacy: The pharmacist can see the prescription given by the doctor and gives the medicine to the patient.

Open-MRS was first implemented in the PHC for the medical officers to make entries into the system, while the customizations for DHIS2 tracker was in progress.

Role based access

The system needed to have role-based access, i.e. limiting users to see only the data they are entitled to see. In a primary health center, there are different modules like:

- Registration (The registration and pharmacy are usually the same user in a PHC)
- OPD (can also be the admin user)
- Pharmacy (The registration and pharmacy are usually the same user in a PHC)
- Laboratory (only has access to the laboratory section)

Only the responsible person for each module can see the data, and not all the users.

Patient queues

The system should be able to display the list of persons waiting for treatment in a day, after the initial registration. The queues should be sorted according to the time of arrival of the patient.

Patient queue							
Location: GENERAL OPD ROOM NO 1							
<input type="button" value="Patient queue"/> <input type="button" value="Search patient in queue"/> <input type="button" value="Search patient in system"/>							
#	Patient id	Patient name	Age	Gender	Registration Time	Visit Type	Status
1	PHD25517513933388609-6	Ananya	~4 M	F	2017-05-13 09:34:17.0	New Patient	
2	PHD25517513950484972-5	Adam	~5 D	M	2017-05-13 09:52:05.0	New Patient	
3	PHD25517513958356508-5	Priyanka	~8 Y	F	2017-05-13 09:59:06.0	New Patient	Dr. Kanica Kaushal PROCESSING

Figure 17: Patient queues in the OpenMRS system

The OpenMRS standard functionality supported role-based access and patient queues.

5.3 Phase 3 of requirements gathering

The main requirements in this phase included: Program registration after patient registration, design of the NPCDCS program, EMR system (OpenMRS) requirements.

The following diagram shows the flow for enrolment and tracking patients, on the basis of which the systems implementation process in DHIS2 tracker was started in pilot clinic 1.

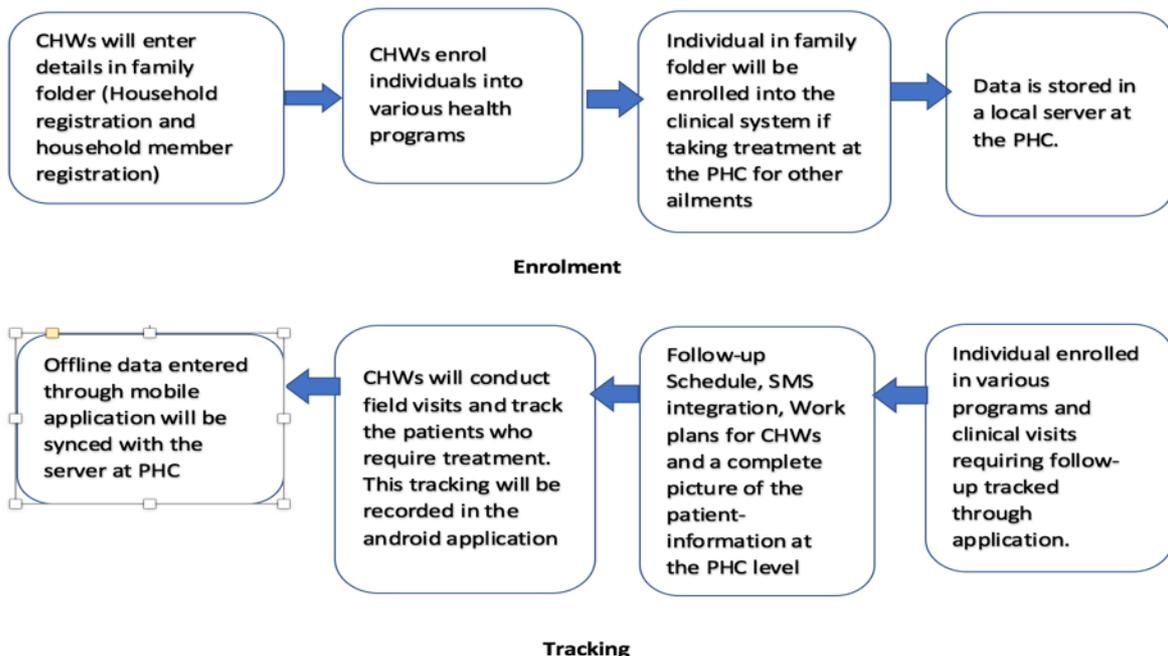


Figure 18: Enrolment and tracking flow of patients

In this phase, it was realized that the PDS data lacked good quality data and hence population data was collected by doing a short interview to collect household and household member information, when the patients came to the PHC. Once a considerable amount of data was collected through the household and household member registrations, these family members could be registered into various programs. The first program which was chosen was the national program for chronic diseases NPCDCS. Hence, the requirements which came for the technical team to handle were, the system should be able to capture the various health programs. These programs should have the capability of recording each encounter with the patient. During each encounter with the patient relevant information should be captured. At a primary health care level, a lot of outreach programs, disease specific programs and various health programs are run. The family member is registered just once in the system and this information will feed into the various programs he/she enrolls into. For each program data elements and the various sections need to be identified.

OpenMRS requirements

OpenMRS was easy to be used in the PHC with its standard modules. When the registration, pharmacy and OPD module was started to be used in the PHC. Few customizations which were identified were:

- Customization in the application for printouts and reports, which could help PGIMER in improving their services at the clinic and analyzing the data available with the application.
- Few reports which were identified to be generated were: Registration report, OPD Summary report, OPD Diagnosis report, Morbidity Report and Stock report.

5.4 Phase 4 of requirements gathering

This phase included additions to the NPCDCS module, SMS integration, rationalizing data elements for other programs.

NPCDCS requirements

When the data elements and forms were created for the NPCDCS data capture. Few other requirements which were added by the medical officer are:

Risk assessment score: A risk assessment score will be auto calculated based on a set of questions. If the score is more than 4, then it is treated as a high risk. The requirement was to add a section for a set of questions to determine the risk. If the patients were determined to be high risk, then they would need constant follow up.

It was also required to send SMS to patients to remind them of follow up visits or health promotion messages for healthy lifestyle.

SMS integration

The researcher from PGIMER contacted a government SMS gateway service called Mobile Seva and an account was created for the PHC. Hence the requirement for the technical team was to integrate this SMS gateway into the DHIS2 application.

Other programs

Once the NPCDCS program started taking shape, the other programs register like Reproductive Child Health (RCH) program, Tuberculosis program called NIKSHAY were also studied in order to rationalize the data elements.

5.5 Phase 5 of requirements gathering

In this phase it revolves around problems integrating OpenMRS and DHIS2, MDDS standards.

During the workshop in Oslo, there was a discussion on a new requirement to generate the national HMIS report. For this particular report, some of the NPCDCS data which was entered in DHIS2 tracker was also needed in addition to the data which was available in OpenMRS.

Part A	REPRODUCTIVE AND CHILD HEALTH		
M1	Ante Natal Care (ANC)		M1
1.1	Total number of pregnant women registered for ANC	35	1.1
1.1.1	Out of the total ANC registered, number registered within 1st trimester (within 12 weeks)	22	1.1.1
1.2	ANC services		1.2
1.2.1	Number of PW given TT1	32	1.2.1
1.2.2	Number of PW given TT2	13	1.2.2
1.2.3	Number of PW given TT Booster	46	1.2.3
1.2.4	Number of PW given 180 Iron Folic Acid (IFA) tablets	9	1.2.4
1.2.5	Number of PW given 360 Calcium tablets	1	1.2.5
1.2.6	Number of PW given one Albendazole tablet after 1st trimester	18	1.2.6
1.2.7	Number of PW received 4 or more ANC check ups	13	1.2.7
1.2.8	Number of PW given ANC Corticosteroids in Pre Term Labour		1.2.8
1.3	Pregnant women (PW) with Hypertension (BP>140/90)		1.3
1.3.1	New cases of PW with hypertension detected	0	1.3.1
1.3.1.a	Out of the new cases of PW with hypertension detected, cases managed at institution		1.3.1.a
1.3.2	Number of Eclampsia cases managed during delivery		1.3.2
	Pregnant women (PW) with Anaemia		1.4
1.4.1	Number of PW tested for Haemoglobin (Hb) 4 or more than 4 times for respective ANCs	21	1.4.1
1.4.2	Number of PW having Hb level<11 (tested cases)(7.1 to 10.9)	14	1.4.2
1.4.3	Number of PW having Hb level<7 (tested cases)	0	1.4.3

Figure 19: HMIS report outreach programs data sections

Part B	Health Facility Services		Part B
M14	Patient Services		M14
14.1	Out Patient Department (Outpatients) by disease/ health condition		14.1
14.1.1	Outpatient - Diabetes	61.0	14.1.1
14.1.2	Outpatient - Hypertension	60.0	14.1.2
14.1.3	Outpatient - Stroke (Paralysis)	0.0	14.1.3
14.1.4	Outpatient - Acute Heart Diseases	0.0	14.1.4
14.1.5	Outpatient - Mental illness	0.0	14.1.5
14.1.6	Outpatient - Epilepsy	0.0	14.1.6
14.1.7	Outpatient - Ophthalmic Related	4.0	14.1.7
14.1.8	Outpatient - Dental	1.0	14.1.8
14.2	Outpatients attendance (All)		14.2
14.2.1	Allopathic- Outpatient attendance	161	14.2.1
14.2.2	Ayush - Outpatient attendance		14.2.2
14.3	Inpatient		14.3
14.3.1	Male Admissions		14.3.1
14.3.1.a	Inpatient (Male)- Children<18yrs		14.3.1.a
14.3.1.b	Inpatient (Male)- Adults		14.3.1.b
14.3.2	Female Admissions		14.3.2
14.3.2.a	Inpatient (Female)- Children<18yrs		14.3.2.a
14.3.2.b	Inpatient (Female)- Adults		14.3.2.b
14.3.3	Number of Left Against Medical Advice (LAMA) cases		14.3.3
14.4	Inpatient by disease/ health condition		14.4
14.4.1	Inpatient - Malaria		14.4.1
14.4.2	Inpatient - Dengue		14.4.2
14.4.3	Inpatient - Typhoid		14.4.3

Figure 20: HMIS report facility-based data sections

Hence, it was needed to explore an approach of integrating OpenMRS and DHIS2.

At the end of the workshop, the HISP Norway team explored ways of integrating OpenMRS and DHIS2. DHIS2 tracker was based on a family folder identification system, while the OpenMRS system was based on an individual patient identification system. Hence, there was no common identifier which could identify the patient in each of the systems.

This led to a new requirement of studying the Metadata standard formats which was introduced then recently by the Government of India. Another master student, explored these standards and the feasibility of implementing standards to aid interoperability.

5.6 Phase 6 of requirements gathering

This phase talks about requirements to expand to other programs like RCH, Child health, Nikshay, SMS Gateway & updating for DHIS2 application, Integration and the mobile application

Expand to other programs like RCH, Child health, Nikshay

Once the program for chronic diseases started stabilizing, the other programs like Eligible couples, Maternal Health, Child health and Tuberculosis was started. The data elements were rationalized and the various stages of maternity and child health could be tracked using program stages and sections.

Tracker capture

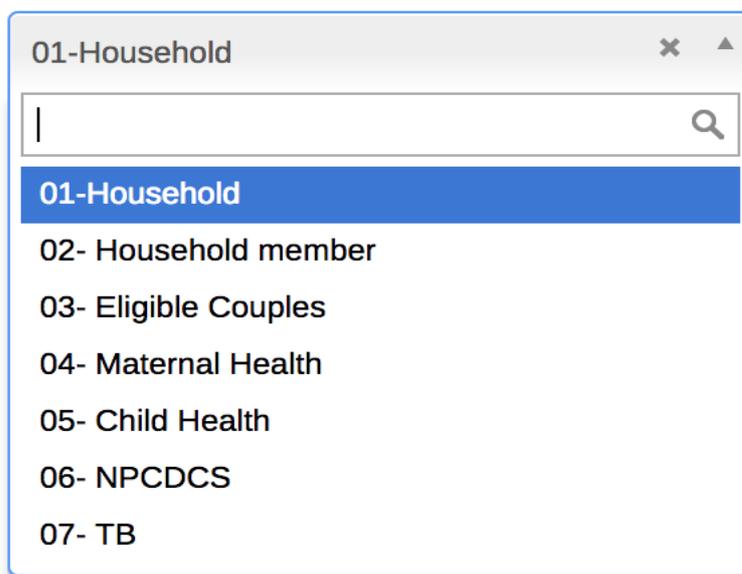


Figure 21:Programs in DHIS2 Tracker

More requirements on NPCDCS

When data started getting recorded for the NPCDCS program various reports were required to be generated based on this data like NPCDCS Cancer reports, Risk assessment report, Early detection report. These were taken as requirements by the developer to develop reports in DHIS2. The format of the reports was based on the paper-based reports currently used by the CHWs.

The medical doctors felt the need of having a history button to see the details of the last visits. Hence the requirement was that the system should be capable of displaying the medical history of visits of the patients. If a person visits the PHC for an ailment, the doctor should be able to see the history of the previous visits of the patient.

SMS Gateway and usage in DHIS2

The SMS gateway was integrated with DHIS2. The SMS gateway worked fine when sending messages in English, but to meet the needs of the population in the rural areas, it was needed to send the messages in Hindi. There were Unicode issues while sending SMS in Hindi and the text would get garbled. This requirement was sent to the global HISP Norway to fix it in the next version of DHIS2. In the meanwhile, language translators which solved the problem temporarily were used to send messages in Hindi.

Integration issues and solutions

It was concluded that the integration of OpenMRS and DHIS2 tracker was a tedious task. One reason was though both the systems had the same population registered, the underlying metadata structure was different for both systems. One followed the identification for the family folder and the other was an individual patient identifier. To solve this problem, aggregate data from OpenMRS was imported into DHIS tracker using Excel data import and the aggregate report from both the systems was generated this way. This was a learning for the next pilot in the PHC in Punjab, to try and use just one system instead of two systems.

Mobile application

A mobile application which could be used offline, was needed for the CHWs for their field visit. HISP Global team in Norway had already developed Android applications for tracker capture. DHIS2 tracker was available as an android app in offline mode and hence the requirement was to initially verify if the application was suitable for field usage.

5.7 Phase 7 of requirements gathering

In this phase, work plans for ANM, report generation, dashboards, triage module in OpenMRS are discussed.

Work plans for ANM

Once the other programs like Eligible couple, Maternal health and child health were designed in the system, these were being used to record data for the programs using a data entry operator.

When a significant amount of population was enrolled into the system, it was easy to generate work plans for the CHWs. Since every person was registered with a corresponding ANM and ASHA worker during data capture, it was easy to generate workplans for a particular CHW. The work plan had the details of the patients which the CHW had to follow up and provide care. The work plan was earlier generated by another central system called MCTS. But since it had its own drawbacks and there were delays in generating the work plan, this work plan was more accurate and more timely. This workplan could also be generated anytime it was needed.

Report generation

The rest of the reports corresponding to the programs were also taken up as requirements by the development team and the formats were designed. The base data was taken from the corresponding programs to generate the reports.

A daily reminder report was also made, which sends a bulk SMS to all patients for appointment reminders. When the reports were generated, the next requirement was to see the feasibility of generating registers from the data present in the system. The data from the family folder should flow to all the corresponding registers like survey and eligible couple register, NCD register, ANC, immunization register.



Figure 22: Family folder linkage to PHC registers

Dashboards

Since one of the main problems which was identified was, there was no analysis of data done at the PHC level; the data from the patient-centric information system should be used to generate “information for action”. The requirement was to identify a set of indicators for measuring the health parameters and these can be represented in the forms of dashboards to study how the health parameters for the population are.

The system should have dashboards to give a general idea of the populations health, with the help of charts, graphs, maps and tabular representations.

A dashboard corresponding to the Primary health center will include:

1. How many households have been enrolled into the system?
2. A chart showing the number of people diagnosed to the number of people screened

This will include the indicators:

- Tobacco users amongst total population screened
- Hypertensive among screened as above
- Diabetes among screened
- Low birth weight among total live births



Figure 23: Dashboards

Triage module in OpenMRS

In OpenMRS, a Triage module was incorporated to capture the vitals of a patient before being sent to the medical officer for diagnosis. Details like blood pressure, temperature was measured and entered before sending for further diagnosis to the medical officer.

5.8 Phase 8 of requirements gathering

The main requirements gathered in this phase are for the design of cohort charts for data analysis, GIS maps, plans for second pilot in another PHC.

In the workshop in February 2018 in Chandigarh, the systems were demonstrated to the various government and health officials. In the field visit feedback was received for systems to be improved.

In this a medical doctor from another state suggested that a cohort chart could be used to display blood pressure, diabetes over a period of time for a patient. This could give the doctor a graphical representation, instead of having to go through the numbers and analyze.

With the introduction of the Tuberculosis program, a new requirement to implement the feature of GIS maps was planned. The GIS feature could be used to geocode the location where the patients with Tuberculosis live. This could help in further analysis to see if the disease is concentrated in a particular area or does it spread. It should be possible to determine, the areas from which the patients with ailments come from. The coordinates (latitude, longitude) of the area of a patient suffering from Tuberculosis or any serious diseases should be captured.

Since the integration of OpenMRS and DHIS2 was not successful, the OpenMRS identifier was manually mapped and placed with the details of patient’s demographics in DHIS2 Tracker. Hence, this acted like a link to open OpenMRS related information from DHIS2. This made it possible to see data simultaneously, but still two systems had to be open to analyze data. Hence, in the second pilot only one system was planned to be used. The decision was to use DHIS2 tracker and implemented together with the features of the OpenMRS modules. This is discussed more in the next chapter in systems implementation.

The developer in the living lab, had also designed the registers in the DHIS2 system to generate the bulky registers which were done manually by the CHWs. At the end of the 5th workshop in Chandigarh, the required government reports and registers could all be generated from the system designed in the PHC.

National Programme for Prevention & Control															
NPCDCS Register for screening common NCDs in Government Health															
State:Chandigarh(U.T)		Type of Facility :			Name of Facility :					In-charge of Facility :					
Date :			NPCDCS Code :												
Left side of Register					Personal History					Family History					
SjNo.	Patient ID(NPCDCS CD NO.)	Name/Address	Age/Sex	Contact No.	Any Known NCD (DM/HTN/CVD/Cancer)	Smoking	Smokeless (Chewing,snuffing)	Alcohol consumption in last one month	Less Physical activity (Sedentary lifestyle)	Diabetes	high Blood Pressure	CVD	Stroke	Cancer specify if yes	
					Please mention Disease	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	
0	Hidden Personal Information				No	Yes	Yes	No	No	No	No	No	No	No	
1					No	No	No	No	No	No	No	No	No	No	
2					No	No	No	No	No	No	No	No	No	No	
3					No	No	No	No	No	No	No	No	No	No	
4					,HTN	Yes	No	No	No	No	No	No	No	No	No
5					No	Yes	No	No	No	Yes	Yes	No	No	No	No
6					No	No	No	No	No	No	No	No	No	No	No
7					No	No	No	No	No	Yes	No	No	No	No	No
8					No	No	No	No	No	No	No	No	No	No	No
9					No	No	No	No	No	No	No	No	No	No	No
10					No	No	No	No	No	No	No	No	No	No	No
11					No	No	No	No	No	No	No	No	No	No	No
12					,HTN	No	No	No	No	No	No	No	No	No	No
13					No	No	No	No	No	No	No	No	No	No	No
14					No	No	No	No	No	No	No	No	No	No	No
15					No	No	No	No	No	No	No	No	No	No	No
16					,DM	No	No	No	No	No	No	No	No	No	No
17					,DM,HTN	No	No	No	No	No	No	No	No	No	No
18					No	No	No	No	No	No	No	No	No	No	No
19					No	No	No	No	No	No	No	No	No	No	No
20					No	No	No	No	No	No	No	No	No	No	No

of Cancer , Diabetes,CVDs & Stroke (NPCDCS)														
facilities (To be filled by Sub centre,PHCS,CHC and District NCD clinics)														
Total Population														
Right side of Register														
Patient Examination									Screening Outcome			Other Comorbidities		
Height	Weight	BMI(wt in kg/ht)	Blood Pressure	Blood Sugar Fasting/Random (To mention FBS/RBS)	Oral cavity examination	Breast Examination	Visual inspection of cervix	Any other investigation/finding	Final diagnosis at NCD clinic	Date of starting treatment	Status after treatment initiation	Screened for TB symptoms & Result	On ATT	
(metre)	(kg)	(kg/m)	mm/Hg	mg/dl	Normal/abnormal	Normal/abnormal	Normal/abnormal	Normal/abnormal			1)Referred 2)on FU 3)Lost to FU 4) Died	Yes/No	Yes/No	
172cm	58kg		120/75	,RBS-88	Normal		NA		No			No	No	
150cm	57kg		113/73	,RBS-88	Normal	Normal	Not done		No			No	No	
146cm	50kg		105/77	,RBS-99	Normal	Normal	Not done		No			No	No	
151cm	68kg		118/74	,RBS-265	Normal	Normal	Not done		,DM			No	No	
149cm	66kg		172/100	,RBS-101	Normal	Normal	Not done		,HTN			No	No	
171cm	64kg		104/73	,FBS-82	Normal		NA		No			No	No	
143cm	48kg		104/68		Normal	Normal	Not done		No			No	No	
146cm	50kg		/	,RBS-118	Normal	Normal	Not done		No			No	No	
147cm	49kg		175/137	,RBS-98	Normal	Normal	Not done		,HTN			No	No	
147cm	45kg		97/72	,RBS-104	Normal	Normal	Not done		No			No	No	
155cm	55kg		131/82	,RBS-103	Normal	Normal	Not done		No			No	No	
158cm	62kg		120/79	,RBS-104	Normal	Normal	Not done		No			No	No	
145cm	75kg		151/104	,RBS-85	Normal	Normal	Not done		,HTN			No	No	
142cm	55kg		129/77	,RBS-104	Normal	Normal	Not done		No			No	No	
159cm	55kg		115/81		Normal		NA		No			No	No	
157cm	57kg		118/78	,RBS-95	Normal		NA		No			No	No	
139cm	50kg		/87	,RBS-128	Normal	Normal	Not done		,DM			No	No	
151cm	84kg		147/92	,RBS-332,FBS-155	Normal	Normal	Not done		,DM,HTN			No	No	
154cm	53kg		104/		Normal	Normal	Not done		No			No	No	
159cm	51kg		91/41	,RBS-112	Normal	Normal	Not done		No			No	No	
150cm	53kg		106/73	,RBS-90	Normal	Normal	Not done		No			No	No	
146cm	51kg		143/93	,RBS-367	Normal		NA		,HTN,DM			No	No	
163cm	54kg		103/59	,RBS-112	Normal		NA		No			No	No	

Figure 24: Registers generation from the system

5.9 Phase 9 of requirements gathering

In this phase the requirements were around the use of mobile based application support for CHWs.

Once the system started being used in the PHC, a mobile application was also needed to be used by the CHW for field visits. Hence, the requirement was to have an android app for the CHWs, who will go to door to door and collect the health information. The app should be able to support the structure of a family folder and function offline.

The collection of data in the field can be challenging and expensive. Mobile phone have the potential to address the complexity of deploying a distributive data collection system.(DHIS2, 2018c). On the field, there could be many challenges of intermittent mobile network and problems of charging the battery. Depending on the resources, a decision on how to collect and sync the field data to the server should be decided upon. For example: If network is an issue in the area, then an approach of having an offline mobile application which can be used to collect data on field, and later sync it to the server when the network is stable could be used.

HISP Norway had been working on releasing a mobile application in September 2018. It is compatible with version 2.29 and above. In the PHC, version 2.28 is being used and hence an

upgrade to the application is needed before they start using the features of the android application.

During the workshop in Oslo, the demo provided by HISP Norway seemed very relevant to the context of the PHC in Chandigarh. Currently it is yet to be tried and further customizations are required to be identified.

The Tuberculosis program had started registering patients in the system at the PHC, the next requirement was to identify how the data of the patients tested positive for Tuberculosis, could be exported and fed into the national system Nikshay, which tracks and gives care to Tuberculosis patients.

5.10 Summary

This chapter gives an overall picture of how requirements have been gathered in various phases in the framework of a living lab in the PHC. In the living lab, inputs from all the stakeholders have played an important role in how requirements have been shaped. The existing work practices of the CHWs and the medical officers have been taken into consideration. Rationalizing of data-elements from the paper-based registers before building the data entry forms has reduced duplicity of data elements. Thus, the system has been dynamic, robust and very flexible to use.

The next chapter talks about the evolving requirements in the second pilot clinic post systems implementation of the first pilot clinic.

6 Evolving requirements post systems implementation

The systems implementation in the pilot clinic lasted from December 2016 to February 2018. Halfway through the systems implementation, issues were faced trying to integrate the system used in the facility (OpenMRS) and the system used for outreach programs (DHIS2). To approach this issue, it was decided to use only one technical solution. Hence a comparison of the technical features of OpenMRS and DHIS2 was done to understand which solution solves the requirements better. Based on this decision of implementing only one technical solution, the requirements for the pilot clinic 2 are now under development and finalization for supporting deployment of revised system in pilot clinic 2.

The below figure, gives an overview of the systems implementation and the challenge in the pilot clinic 1. While both the systems had the same population data, DHIS2 had the structure of a family folder while OpenMRS identified the patient individually. Hence, there was no common identifier to link both the systems.

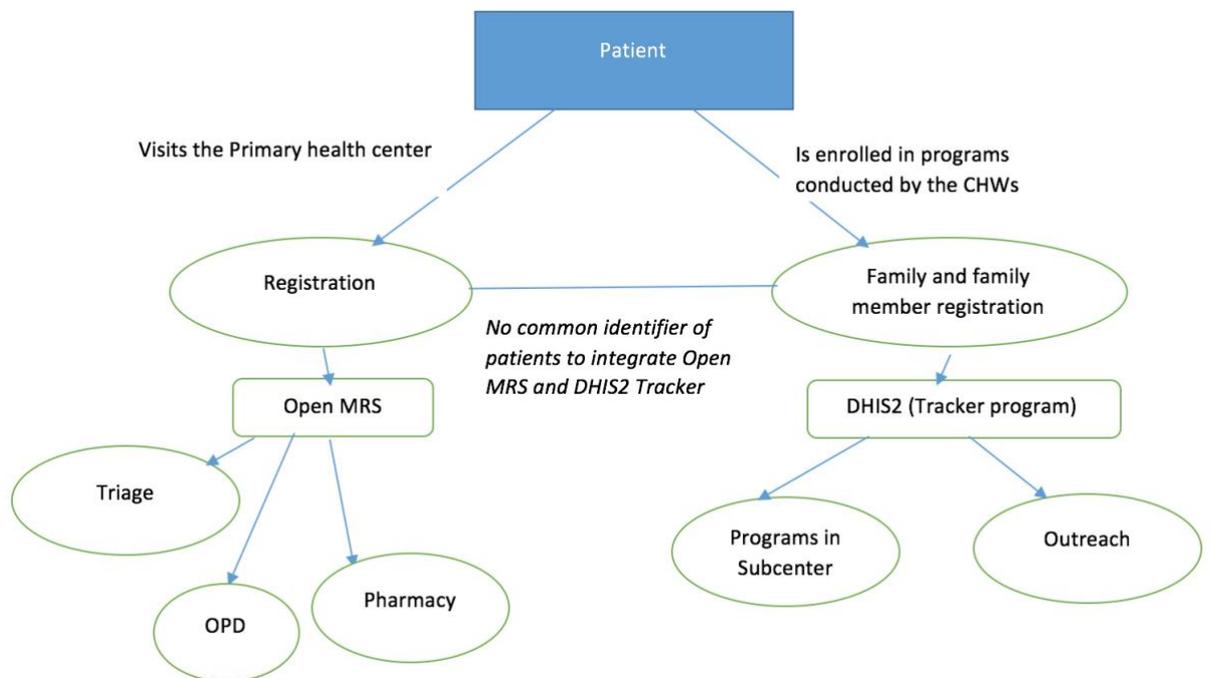


Figure 25: Issues in integrating OpenMRS and DHIS2

To approach the issue in integrating OpenMRS and DHIS2, a comparison of the features of both systems based on the main requirements was carried out

Feature	DHIS2	OpenMRS
Recording name based Data	Yes	Limited
Sending SMS alerts	Yes	Yes
Better for outreach programs	Yes	Limited
Family folder model	Yes	No
Offline support	Yes	No
Clinical and OPD Support	Limited	Yes
Data analytics and Visualization	Yes	Limited
HMIS	Yes	Limited
Role based access	Limited (needs customization for sections of data)	Yes
Patient queue systems	No	Yes
Stock module	Limited	Yes

Table 14: Feature comparison of DHIS2 and OpenMRS

Since outreach programs were better supported by DHIS2, it was decided to implement a clinical module in the DHIS2 tracker module. The evolving requirements in the pilot clinic 2, using only DHIS2 is discussed in the next section.

6.1 Evolving requirements in pilot clinic 2

Since DHIS2 was decided to be used in the second pilot, the following requirements were identified in March 2018 in a requirement gathering meeting for pilot clinic 2:

1. **Clinical module in DHIS2:** Since DHIS2 by itself is not an EMR system, the technical team from HISP India came up with the idea that, since patients could already be registered in the DHIS2 tracker using the household and household

member registration. A new program called clinical module could be created, to register the household member into this new clinical module program.

Tracker capture

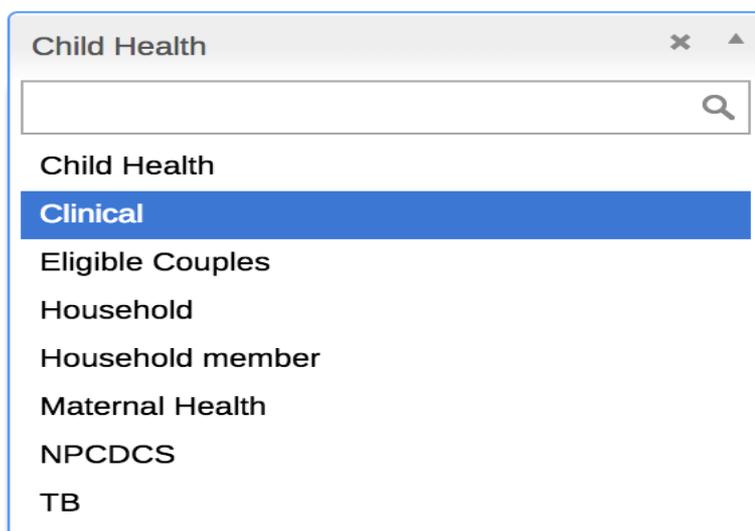


Figure 26: Clinical module in DHIS2

2. When the patient is enrolled into the clinical module, he will be placed in a patient queue. This queue will be picked, depending on the service the patient needs.
3. The clinical module should be able to capture details captured in Triage, OPD and Pharmacy every time a patient visits the clinic. For every module, the patient avails services, the patient is marked as registered to be able to be shown in the next modules queue. For example, if a patient has finished Triage, then he will be marked as registered, to be shown in the OPD modules queue.
4. The various sections of Triage, OPD and Pharmacy should be accessible only to the person handling the service. Hence, the sections should be displayed role based.
5. Since DHIS2 does not have a dynamic stock module, like that of OpenMRS, it was decided to explore the DHIS2 Stock module or the government recommended E-Aushadhi (see https://www.cdac.in/index.aspx?id=hi_dms_aushadi) system to maintain the stock of medicines and this could be integrated with the pharmacy module.

6. To study this problem of integration and interoperability, a requirement of implementing the Meta Data and Data Standards (MDDS) was taken up.

The modules which are to be implemented in the pilot clinic 2 are:

1. Registration/Pharmacy linked with the stock module
2. Triage
3. OPD
4. Outreach programs
5. Programs in subcenter

The system has been planned to be setup in the following manner at the Pilot clinic 2

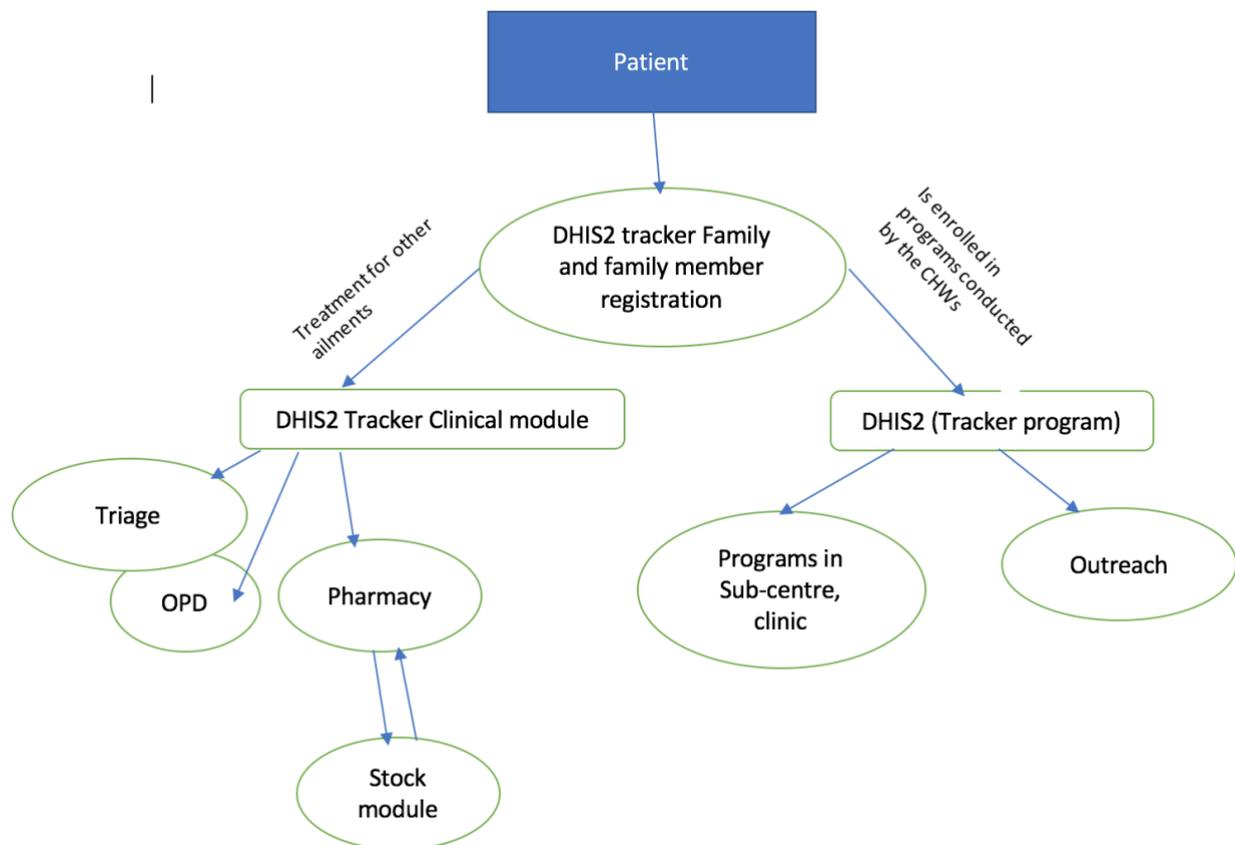


Figure 27:DHIS2 clinical module in pilot clinic 2

The idea for the clinical module has taken shape in DHIS2 and has been demonstrated in the workshop in Oslo in September 2018. It is yet to be deployed and field tested at the pilot clinic 2.

7 Discussion

This chapter discusses the answers to my research questions I have focused on.

7.1 Answering the research question

7.1.1 Question 1

My first research question is “What are the requirements to build patient-centric information systems in a developing country?”

Based on the on-going two-year research project, this thesis has discussed the requirements and their evolving nature in building patient-centric information systems for the primary care context in India. To accommodate the new health reforms towards Universal Health Coverage (UHC), health information systems need to be strengthened at the primary care level to cover populations in the rural areas. The motivation for studying the requirements was also the lack of previous studies in this particular area. Given the results of the workshops, field trips, interactions with HISP India, researchers and health officials from PGIMER I can say that the overall outcome of the thesis can be considered as successful in terms of understanding the requirements and supporting their implementation. The study is strongly linked to the methodology of requirements gathering which in my case has been the living lab. The living lab has provided an environment for context sensitive design, incremental approaches to system design and an approach to participatory design.

The living lab has provided important inputs for creating an integrated database covering all the health services required by the population. The recursive stages to identify needs/establish requirements, co-design, build an interactive version and evaluate, have led to understand the various requirements in building patient-centric information systems. Following the changes in a real time project where the requirements are changing dynamically has been very challenging, but also a deep learning experience.

The approach to design this patient-centric information system, has been very holistic and not program or disease wise. After studying the existing landscape of the existing patient-centric systems in India, the learning was to have a system which supported the activities of a CHW at the primary health care level. Most importantly, it was to reduce the reporting burden of the CHWs and with it improve their capabilities to provide care to the patients. The design started with a focus one program and later incrementally accommodated the different programs being implemented at the primary care level.

The requirements identified broadly were to help in providing health services to the entire population. Data capture is done at the facility level, where the patient goes to the primary health center for curative care and at the community level where the CHWs provide preventive care and follow up. The requirements that the study has specifically identified to build a patient-centric information system at primary health care level are:

- Support a family member and family identification, like family folders to help CHWs in their fieldwork.
- Support data capture for care provided at the community level in the form of outreach programs and at the facility level.
- Generate reports and registers from the data captured for the various programs and services offered.
- Ability to send SMS to patients for reminder of appointments and health promotional messages.
- Generate work plans for the CHWs at the PHC level. This work plan could be used to generate the list of people to follow-up and service to be provided by the CHWs.
- Perform data analysis at the PHC to improve the care provided to the population. This includes designing dashboards to study the health of the population using GIS maps and graphs. Cohort charts to see the trend of the health parameters.
- Ability to capture data both online and offline.
- Implement standards such as Meta Data and Data Standards (MDDS), to be interoperable and integrable with other health information systems.

Many countries lack the framework for creating systems and the technical capacity to design and develop the information systems needed to support UHC (WHO, 2010). Requirements are highly dependent on the context and political, technical and financial factors of each

country. Establishing common requirements and standards might speed up the design and implementation process of UHC in developing countries. This could help in moving a step closer towards the UHC objective of providing affordable and quality health care to all.

7.1.2 Question 2

My second research question is to “Analyze different technical solutions to address these requirements and to understand the efficacy of the respective solutions.”

In this case study, there have been two approaches to address the identified requirements and convert them into systems implementations.

- **DHIS2 and OpenMRS**
- **Only DHIS2**

A combination of DHIS2 and OpenMRS is implemented in the pilot clinic 1. In the pilot clinic 1, the facility also contained a subcenter which acted as a mother and child care center. DHIS2 has been mainly introduced to meet the requirements of the outreach programs, whereas OpenMRS was introduced to meet the requirements at the facility level. In DHIS2 the registration was done by capturing details of a family member and creating a structure of the family folder by linking the family members to the head of the family. The reason for the structure of the family folder was from an operational level at the PHC, outreach requires the structure of the family while at the facility level, it is required to identify the patient individually.

OpenMRS is used as an EMR system at the facility. OpenMRS comes with its inbuilt modules for a Hospital Information System and hence was easy to kick start the operations at the PHC. In OpenMRS the services provided at the facility were recorded. The modules used in OpenMRS at the PHC include OPD, Pharmacy, Triage, and Registration. The medical officers and the staff also found it easier to use OpenMRS at the facility.

DHIS2 tracker was customized to accommodate the various programs which are run at the subcenter, national and state level. These programs require constant follow-up and continuity of care by the CHWs. The first program which was run with the DHIS2 tracker, was the national program for chronic diseases which is called NPCDCS. The CHWs invite the people

in the population over 30 years and screen them for a list of chronic diseases. If they were found to have any of the chronic diseases, they were to be followed up with continuous care and sent SMS reminders for appointment and health promotion messages. Eventually the DHIS2 tracker was customized to support eligible couple, maternal health, child health and Tuberculosis programs.

When data was captured in OpenMRS and DHIS2, various reports relating to the outreach programs and the reports at the PHC could be generated from the respective systems. The challenge of using these systems was discovered when the National HMIS report was needed to be generated. The HMIS report needed data from both the systems, i.e. from both outreach programs and the facility-based services. In addition to this, the other challenges identified were, if a woman was pregnant, she was registered in the maternal health program in the DHIS2 tracker. If the same women went to the doctor for other ailments, the doctor could not see her pregnancy data in OpenMRS. This issue was also applicable when the CHWs could not see the medicines prescribed to a pregnant woman. Thus, using two systems lacked a comprehensive view of the patient. It was also a huge task for the data entry operator to register the patients in two separate systems. At a technical level, the HISP global team looked into the integration aspects of OpenMRS and DHIS2, but both the systems identified the patient in a different manner. DHIS2 identified the patient as part of the custom family identifier while OpenMRS had its own unique identifier. It was thus difficult to identify the patient uniquely in both systems. Thus, it was concluded that the integration of OpenMRS and DHIS2 tracker was a cumbersome task.

This challenge was taken as a learning from the first pilot clinic and this led to new requirements in the second pilot clinic. DHIS2 supported outreach programs better, had the features to work offline, better data analysis tools, supported the structure of family folder and had a compatible android application for outreach work. Hence, to address this challenge, it was decided to use DHIS2 tracker for the clinical module. Since the population could already be registered in the DHIS2 tracker, using the household and household member programs, a new requirement to add a new program called clinical module was designed in the DHIS2 tracker. The clinical module would consist of the various sections like OPD, Pharmacy, Registration and Triage. These sections had to be built role based and would be accessible only to the specific user responsible for the module. To handle patient load, a patient queue was also built in DHIS2 to handle the patients visiting the facility on a first

come first serve basis. The clinical module has taken shape in DHIS2 tracker and is yet to be field-tested.

Understanding the efficacy of the respective solutions

On one hand DHIS2 is used by the CHWs to perform outreach services whereas on the other hand OpenMRS is used at the facility for the clinical services provided. Since the systems are used for different purposes, it justifies using two different systems at the PHC level.

In the PHC, the patients come in mostly for Outpatient services, hence a full hospital information system is not absolutely necessary. Stock keeping of medicines is an important activity at the PHC level. While OpenMRS supports a fully integrated stock module, DHIS2 has limited features to support a stock module.

When the challenges in integrating the systems was identified, workarounds were discovered by the team in the living lab with close collaboration with the technical team in HISP India to address the issue. This included using the data import feature in DHIS2 to import the aggregated data from OpenMRS to generate the complete HMIS report. The patient identifier in OpenMRS was manually entered in DHIS2 and a hyperlink was provided to access the OpenMRS data from DHIS2 but the same was not possible from OpenMRS to DHIS2. The issue of the data entry operator performing double entries in both systems still remained.

The use of only DHIS2 solved the issue by having a single database of the entire population. In this study, the clinical module in the second pilot clinic is yet to start functioning and hence the study of using DHIS2 as a clinical module is not fully evaluated in the field setting. Another feature which is yet to be field-tested, is the use of the DHIS2 android application which could prove beneficial. Programs and health organization units the CHW has access to, can be synced with the android application which can used for field visits. This data can flow from the community to the facility level for further data analysis and follow-up. Another advantage is the offline availability of the Android application which could be a useful feature in the outreach work for the CHWs, where availability of stable internet is a common issue. The data can be synced to the DHIS2 application when internet is available.

To summarize this discussion, if the purpose of the system is to track and provide services to the patient, DHIS2 solves the requirements. But if the functioning of the facility like stock and laboratory needs to be integrated then a combination of OpenMRS and DHIS2 is needed.

8 Conclusion

The concept of patient-centric information systems is still very nascent in developing countries. Empirically this study can be seen as a redesign of health information systems in primary health care for achieving patient-centered care.

“A patient-centered care system is one where patients can move freely along a care pathway without regard to which physician, other health-care provider, institution or community resource they need at that moment in time. The system is one that considers the individual needs of patients and treats them with respect and dignity.”(Care, 2010, p. 34)

From the definition provided for a patient-centered care system, this can be seen as a vision towards the patient-centered care system. In our study, care provided to the population is captured at the community and the primary health level. Though the system captures the data for referrals, the data should further flow to the higher levels of health care and have the ability to handle referrals in the system like the ability to share the data of the patient electronically to the doctor handling the referral.

In the introduction of this study, I mention that patient-centric care should focus on both preventive and curative care and should be able to record any care, received by the patient. In our case, a first step towards moving to a patient-centered care system has been to collect patient data electronically. The focus of collecting data about the patients is to improve the health and well-being of the patients themselves.

Post implementation, the following has changed at the primary health care level:

- With almost the entire community registered in the system and also grouped as per family. The people from the community can be easily enrolled into the state and national programs and also receive facility-based care.
- The amount of time spent in manually recording data in registers and generating reports is reduced, as most of the reports and registers required by the CHWs and medical officers can be generated from the system.
- SMS is sent for appointment reminders and health promotion to provide continuity of care. Sahay et al. (2018), in their study mention that the health staff emphasize the

importance of patients taking a more active role in their own health, to comply with their timely appointments, especially in case of chronic diseases.

- Workplans for the CHWs can be generated and it is easier to track and analyze patient data. Dashboards have also used to analyze the health of the population.

Future work

The working practices of the CHW is similar across all Indian states and in most developing countries. Hence, the system can potentially be used in most contexts of primary health care. This case study can be used as a reference for developing countries who plan on building patient-centric systems at the community level.

Solutions can be explored on how to integrate OpenMRS and DHIS2. At this point, the status of the DHIS2 clinical module in pilot clinic 2, is in the testing phase. It has not yet started functioning at the Health center. A study of how DHIS2 supports the clinical module can be taken up in the future.

The biggest challenge is changing the working practice of a CHW from a paper based to a digital system. CHWs need to be trained and supervised on how to use these digital health information systems. The interface and the amount of data to collect should be kept minimal for them to get comfortable using mobile devices for data entry.

Scaling of this system could be a tremendous task and the benefits of the system can be realized when data flows from the primary health care to the tertiary health care and also when data is made available to the systems with focus on specific diseases at the national and state level.

To conclude, strengthening patient-centric care at the primary health care level can help in moving towards the goals of UHC. UHC is part of the third goal of Sustainable Development Goals which is “**Good Health and Well Being**”.

References

Abera, D. Z., & Moges, A. S. (2013). From multiple register to family folder: the transition of data collection and reporting tools for health extension workers in Ethiopia. *Journal of Health Informatics in Developing Countries*, 7(2).

Abhiyan, J. S. (2006). Health system in India: Crisis and alternatives. *Towards the National Health Assembly II, Booklet*, 2.

Agarwal, R., Jain, P., Ghosh, M. S., & Parihar, K. S. (2017). Importance of Primary Health Care in the Society. *International Journal of Health Sciences (IJHS)*, 1(1), 6-11.

Alasuutari, P., Bickman, L., & Brannen, J. (2008). *The SAGE Handbook of Social Research Methods*: SAGE Publications.

Arnold P.Kaminsky, R. D. L., Editors. (2011). *India Today, An Encyclopedia of life in the republic* Vol. 1.

Baskerville, R. L., & Wood-Harper, A. T. (1996). A critical perspective on action research as a method for information systems research. *Journal of information Technology*, 11(3), 235-246.

Beaglehole, R., Epping-Jordan, J., Patel, V., Chopra, M., Ebrahim, S., Kidd, M., & Haines, A. (2008). Improving the prevention and management of chronic disease in low-income and middle-income countries: a priority for primary health care. *The Lancet*, 372(9642), 940-949. doi:10.1016/S0140-6736(08)61404-X

Bergvall-Kareborn, B., Hoist, M., & Stahlbrost, A. (2009, 5-8 Jan. 2009). *Concept Design with a Living Lab Approach*. Paper presented at the 2009 42nd Hawaii International Conference on System Sciences.

Bergvall-Kåreborn, B., Howcroft, D., Ståhlbröst, A., & Wikman, A. M. (2010). *Participation in living lab: Designing systems with users*. Paper presented at the IFIP Working Conference on Human Benefit through the Diffusion of Information Systems Design Science Research.

Bitton, A., Ratcliffe, H. L., Veillard, J. H., Kress, D. H., Barkley, S., Kimball, M., . . . Taylor, C. (2017). Primary health care as a foundation for strengthening health systems in low- and middle-income countries. *Journal of general internal medicine*, 32(5), 566-571.

Braa, J., & Sahay, S. (2017). The DHIS2 open source software platform: evolution over time and space: Global Health Informatics. Principles of eHealth and mHealth to Improve Quality of Care. Cambridge, MA: The MIT Press.

Care, P.-C. (2010). Patient-Centered Care. *Ontario Medical review*, 34.

Collaborative, H. D. (2017). DHIS2 Community health information systems guidelines. Retrieved from

https://www.healthdatacollaborative.org/fileadmin/uploads/hdc/Documents/Working_Groups/CHISGuidelines_version_August29.pdf

DHIS2. (2018a). Retrieved from <https://www.dhis2.org/>

DHIS2. (2018b). DHIS2 Developer guide. Retrieved 25/10/2018

https://docs.dhis2.org/2.28/en/developer/html/techarch_requirements.html

DHIS2. (2018c). DHIS2 User Manual. Retrieved from

<https://docs.dhis2.org/2.24/en/user/html/ch22.html>

Eriksson, M., Niitamo, V.-P., & Kulkki, S. (2005). State-of-the-art in utilizing Living Labs approach to user-centric ICT innovation-a European approach. *Lulea: Center for Distance-spanning Technology. Lulea University of Technology Sweden: Lulea.*

Eskelinen, J., Robles, A. G., Lindy, I., Marsh, J., & Munte-Kunigami, A. (2015). *Citizen-driven innovation: World Bank Publications.*

Europe, P. I. (2016). Person-centred care in Europe: a cross-country comparison of health system performance, strategies and structures Retrieved from

<http://www.picker.org/wp-content/uploads/2016/02/12-02-16-Policy-briefing-on-patient-centred-care-in-Europe.pdf>

Faujdar, D. S., Sahay, S., Singh, T., & Kumar, R. (2018). *Public Health Information Systems in India: Need for a sustainable Patient centric*

system for Primary Health Care.

Feurstein, K., Hesmer, A., Hribernik, K. A., Thoben, K., & Schumacher, J. (2008). Living Labs: a new development strategy. *European Living Labs-a new approach for human centric regional innovation*, 1-14.

Goguen, J. A. (1994). *Requirements engineering as the reconciliation of technical and social issues*: Academic Press.

Gottesdiener, E. (2002). *Requirements by collaboration: workshops for defining needs*: Addison-Wesley Professional.

Gottesdiener, E. (2005). *The Software Requirements: Memory Jogger: a Pocket Guide to Help Software and Business Teams Develop and Manage Requirements*: GOAL/QPC.

Gowda, M. J., Bhojani, U., Devadasan, N., & Beeranahally, T. S. (2015). The rising burden of chronic conditions among urban poor: a three-year follow-up survey in Bengaluru, India. *BMC Health Services Research*, 15, 330. doi:10.1186/s12913-015-0999-5

Grisot, M., & Vassilakopoulou, P. (2013). Infrastructures in healthcare: The interplay between generativity and standardization. *International journal of medical informatics*, 82(5), e170-e179. doi:<https://doi.org/10.1016/j.ijmedinf.2012.08.010>

Heeks, R. (2002). Information Systems and Developing Countries: Failure, Success, and Local Improvisations. *The Information Society*, 18(2), 101-112. doi:10.1080/01972240290075039

Hirschheim, R., & Klein, H. K. (1989). Four paradigms of information systems development. *Communications of the ACM*, 32(10), 1199-1216.

HISP. (2018). HISP India. Retrieved from <https://hispindia.org/index.php/about-us>

Improvement, I. I. o. H. (2018). Across the Chasm: Six Aims for Changing the Health Care System. Retrieved from <http://www.ihl.org/resources/Pages/ImprovementStories/AcrossTheChasmSixAimsforChangingTheHealthCareSystem.aspx>

Konduri, N., Bastos, L. G. V., Sawyer, K., & Reciolino, L. F. A. (2017). User experience analysis of an eHealth system for tuberculosis in resource-constrained settings: A nine-country comparison. *International journal of medical informatics*, 102, 118-129.

Krishnan, A., Nongkynrih, B., Yadav, K., Singh, S., & Gupta, V. (2010). Evaluation of computerized health management information system for primary health care in rural India. *BMC Health Services Research*, 10(1), 310. doi:10.1186/1472-6963-10-310

MacLeod, B., Phillips, J., Stone, A. E., Walji, A., & Awoonor-Williams, J. K. (2012). The architecture of a software system for supporting community-based primary health care with mobile technology: the mobile technology for community health (MoTeCH) initiative in Ghana. *Online Journal of Public Health Informatics*, 4(1).

Majra, J., & Acharya, D. (2009). Impact of family folder system on the health status of the community. *The Internet Journal of Healthcare Administration*, 6(2), 1.

Markus, M. L., & Mao, J.-Y. (2004). Participation in development and implementation - updating an old, tired concept for today's IS contexts. *Journal of the Association for Information systems*, 5(11), 14.

Mishra, A., & Dubey, D. (2013). A comparative study of different software development life cycle models in different scenarios. *International Journal*, 1(5), 64-69.

Modi, N. (2018). From silos to solutions- a case of the health sector. Retrieved from <https://www.linkedin.com/pulse/from-silos-solutions-case-health-sector-narendra-modi/>

Msiska, B., & Nielsen, P. (2017). Innovation in the fringes of software ecosystems: the role of socio-technical generativity. *Information Technology for Development*, 1-24. doi:10.1080/02681102.2017.1400939

Mukherjee, A. S., Aanestad, M., & Sahay, S. (2012). Judicious design of electronic health records: Case from public health system in India. *Health Policy and Technology*, 1(1), 22-27. doi:<https://doi.org/10.1016/j.hlpt.2012.01.006>

Nielsen, P. (2017). *Digital Innovation: A Research Agenda for Information Systems Research in Developing Countries*.

Organization, W. H. (2008). Framework and standards for country health information systems.

Organization, W. H. (2015). WHO global strategy on people-centred and integrated health services: interim report.

Organization, W. H. (2017). Together on the road to universal health coverage A CALL TO ACTION. Retrieved from

<http://apps.who.int/iris/bitstream/handle/10665/258962/WHO-HIS-HGF-17.1-eng.pdf;jsessionid=2A1B59EDD90CD9FC1B263A36FA6F851D?sequence=1>

Perry, H. B., Zulliger, R., & Rogers, M. M. (2014). Community Health Workers in Low-, Middle-, and High-Income Countries: An Overview of Their History, Recent Evolution, and Current Effectiveness. *Annual Review of Public Health, 35*(1), 399-421.

doi:10.1146/annurev-publhealth-032013-182354

PGIMER. (2018). School of Public Health

. Retrieved from <http://www.healthconomics.pgisph.in/about-pgi-school-of-public-health.html>

Pohl, K. (2010). *Requirements Engineering: Fundamentals, Principles, and Techniques*: Springer Publishing Company, Incorporated.

Puerari, E., de Koning, J. I., von Wirth, T., Karré, P. M., Mulder, I. J., & Loorbach, D. A. (2018). Co-Creation Dynamics in Urban Living Labs. *Sustainability (2071-1050), 10*(6).

Raka, S., & Kannan, S. (2006). Organization of Indian Health Bureaucracy and its Delivery System.

Ramani, K., & Mavalankar, D. (2006). Health system in India: opportunities and challenges for improvements. *Journal of health organization and management, 20*(6), 560-572.

Rao, K. D., Peters, D. H., & Bandeen-Roche, K. (2006). Towards patient-centered health services in India—a scale to measure patient perceptions of quality. *International Journal for Quality in Health Care, 18*(6), 414-421. doi:10.1093/intqhc/mzl049

- Reddy, M., Pratt, W., Dourish, P., & Shabot, M. (2003). Sociotechnical requirements analysis for clinical systems. *Methods of information in medicine*, 42(4), 437-444.
- Rigby, M., Georgiou, A., Hyppönen, H., Ammenwerth, E., de Keizer, N., Magrabi, F., & Scott, P. (2015). Patient portals as a means of information and communication technology support to patient-centric care coordination—the missing evidence and the challenges of evaluation: a joint contribution of IMIA WG EVAL and EFMI WG EVAL. *Yearbook of medical informatics*, 10(1), 148.
- Robbins, D. A., Curro, F. A., & Fox, C. H. (2013). Defining Patient-Centricity: Opportunities, Challenges, and Implications for Clinical Care and Research. *Therapeutic Innovation & Regulatory Science*, 47(3), 349-355.
doi:10.1177/2168479013484159
- Rogers, Y., Sharp, H., & Preece, J. (2011). *Interaction design: beyond human-computer interaction*: John Wiley & Sons.
- Sahay, S., Nielsen, P., Faujdar, D., Kumar, R., & Mukherjee, A. (2018). *Frugal Digital Innovation and Living Labs: A Case Study of Innovation in Public Health in India*.
- Sahay, S., Sundararaman, T., & Mukherjee, A. S. (2014). Building locally relevant models for universal health coverage and its implications for health information systems: some reflections from India. *Journal of Health Informatics in Africa*, 2(2).
- Sahay, S., & Walsham, G. (2006). Scaling of health information systems in India: Challenges and approaches. *Information Technology for Development*, 12(3), 185-200.
doi:10.1002/itdj.20041
- Schaffers, H., Garcia Guzman, J., & Merz, C. (2008). An Action Research Approach to Rural Living Labs Innovation. *Proceedings of the Cunningham and M. Cunningham (Eds), Collaboration and the Knowledge Economy: Issues, Applications, Case Studies*. IOS Press.
- Sharma, R., Webster, P., & Bhattacharyya, S. (2014). Factors affecting the performance of community health workers in India: a multi-stakeholder perspective. *Global health action*, 7(1), 25352.

Shivalli, S., Majra, J. P., Akshaya, K. M., & Qadiri, G. J. (2015). Family Centered Approach in Primary Health Care: Experience from an Urban Area of Mangalore, India. *The Scientific World Journal*, 2015, 8. doi:10.1155/2015/419192

Snyder, C. F., Wu, A. W., Miller, R. S., Jensen, R. E., Bantug, E. T., & Wolff, A. C. (2011). The role of informatics in promoting patient-centered care. *Cancer Journal (Sudbury, Mass.)*, 17(4), 211.

Ståhlbröst, A. (2008). *Forming future IT : the living lab way of user involvement*. (2008:62 Doctoral thesis, comprehensive summary), Luleå tekniska universitet, Luleå. Retrieved from <http://urn.kb.se/resolve?urn=urn:nbn:se:ltu:diva-26649> DiVA database.

Susman, G. I. (1983). Action research: a sociotechnical systems perspective. *Beyond method: Strategies for social research*, 95, 113.

Vassilakopoulou, P., Grisot, M., Jensen, T. B., Sellberg, N., Eltes, J., Thorseng, A., & Aanestad, M. (2017). Building National eHealth Platforms: the Challenge of Inclusiveness.

Veeckman, C., Schuurman, D., Leminen, S., & Westerlund, M. (2013). Linking living lab characteristics and their outcomes: Towards a conceptual framework. *Technology Innovation Management Review*, 3(12 december), 6-15.

WHO. (2010). THE ROLE OF INFORMATION SYSTEMS IN ACHIEVING UNIVERSAL HEALTH

COVERAGE. Retrieved from

<https://www.who.int/healthsystems/topics/financing/healthreport/ICTTBN10.pdf>

Winter, A., Haux, R., Ammenwerth, E., Brigl, B., Hellrung, N., & Jahn, F. (2011). Health Information Systems *Health Information Systems: Architectures and Strategies* (pp. 33-42). London: Springer London.

Appendix 1- Requirements Document

An abridged version of the business requirements document is made available here. The author can be contacted for the full version of the document.



Business requirements for

Design and Development of Patient centric systems

(INPART-International Partnership)

Developed by- HISP India

Date: 19th June 2017

Revision History

Date	Version	Changes
26/12/2016	Version 1	
26/12/2016	Version 2	Section 6, updates on Equipment and networking work in the PHC 25
26/01/2017	Version 2	Requirements for OpenMRS
01/02/2017	Changes to draft copy sent by HISP India	Changes in the hierarchical system which has been updated
17/03/2017	Version 3	Section 4. Existing workflow and possible approaches Source of information has been updated. Section 7. DHIS2 Tracker customization
05/04/2017	Version 3	Update on section 7, DHIS2 tracker customization. Specification on fields like Aadhar number and mobile number. SMS alerts from tracker in section 8
29/04/2017	Version 3	Update on section 7 Open MRS requirements. Customization of reports and other problems of open MRS application. Section 9 SMS alerts update.
25/05/2017	Version 3	Update on NPCDS program in section 7 DHIS2 tracker customization
01/06/2017	Version 3	From INTPART meeting outcomes on 31/05/2017. Update on Section 7 DHIS2 Tracker customizations, development of android app for family folder and other customizations. Section 8, other open MRS customizations that needs to be done. Attached minutes of the meeting from the meeting on 31/05/2017

06/06/2017	Version 3	Reports to be generated from OpenMRS. File Name Reports to be generated from Open MRS which can be found in Section 11 1.
28/06/2017	Version 4	Based on Minutes of the meeting on 27/06/2017 at PGI. Update to the system approach in PHC Kheda.
21/08/2017	Version 5	Based on minutes of meeting on 21.08.2017 through Skype between HISP India and PGI. Update to SMS alerts (Section 9) and the Android Application (Section 8.2). Update to daily reminder dashboard (Section 8.5). Attached corresponding Minutes of the meeting in the additional documents section
29/09/2017	Version 6	Based on minutes of the meeting on 11 th September 2017 between HISP India and PGI. Requirements implemented sent by members of the living lab
26/02/2018	Version 7	New requirements, cohort chart for BP and accessing OpenMRS data from DHIS2, Triage module in OpenMRS
19/04/2018	Version 8	Generation of E-reports and E-registers
1/6/2018	Version 9	GIS functionality in DHIS2

1. Background and Scope

This document is developed in the context of the ongoing collaborative project between UiO-PGIMER-HISP India towards the design and development of a patient centric system for primary health care. Key inputs for this document come based on a 2-day requirements analysis workshop conducted in PGIMER on December 21-22 including staff from PGIMER, UiO, HISP India and community health workers from the Punjab health system. The annexure provided in this document provides details of those people who attended the workshop. This workshop builds upon an earlier workshop conducted in April where different stakeholders (National Ministry, NIC, CDAC, UiO etc.) presented experiences related to various patient centric systems. This workshop thus helped to gain experiences related to such a system, best practices, challenges, and approaches all of which help to provide design inputs shaping the system development process being proposed under this INPART project.

Certain normative design principles which we propose the system to follow include:

1. The system should be integrated with existing systems and work processes, seeking to rationalize, and not becoming yet another system.
2. The system should aim to reduce the work burden of the PHC workers.
3. The system should strengthen the use of information for local action.
4. The system should be user friendly and easy to use even for level of ANMs/ASHAs.
5. The system should be scalable, and present a model which could potentially be taken up at the state level and more.
6. The system should be such that it can be primarily managed and evolved by the state system, and not be reliant on external consultants.

2. Key actors and work processes in the PHC sector

Given the focus of the project on patient centric systems for PHC actors, we identified the following actors within this sector whose work the proposed system should support.

Anganwadi worker

The Anganwadi workers have a paper-based recording system. Some of the registers they maintain are as given below:

- Family Register
- Supplementary Food Stock (English)
- Supplementary Food Distribution (English)
- Preschool Education (English)
- Pregnancy & Delivery (English)
- Immunization & VHND (English)
- Vitamin-A Bi-Annual Rounds (English)
- Home Visits Planner (English)
- Referrals (English)
- Summaries (Monthly and Annual) (English)
- Weight Records for Children (English)

ANM and ASHA

The ANM maintains paper-based registers of the population similar to the Anganwadi worker. The register maintained by ANM is available to the health department and has a few additional columns. The MCTS systems also gives a work plan for the ANM to execute. The work plan is ANM wise. The ANM, looks up at the various registers and marks the status in the work plan. The ANM together with the ASHAs maintain the following paper-based registers:

- Survey & Eligible Couple Register
- Perinatal & Birth Register
- IUD/Still Birth Register
- ANC Register
- Death Register

- MTP Register
- Family Planning Register
- JSY Register
- Home Visit Register
- HRP Register
- PNDT Register
- RCH Register
- NPCDCS Register
- Tracking of Children
- EDD Register
- PMSMA Register
- Daily Attendance register, ANC, PNC, Child Immunization
- Nutrition & Health Education Register
- Health Talk
- Stock Register
- Register for Growth monitoring
- Register for Immunization
- Register for Malaria cases (passive surveillance)
- Register of accounts including untied funds.
- Register for water quality and sanitation
- Register for Minor ailments
- Registers for National Health Program guidelines (NLEP, RNTCP, NVBDCP, etc.)
- Register for Equipment Furniture and other accessories

The various reports generated at the sub-center include

- Monthly RCH Report
- Maternal Death Report
- NPCDCS report
- Monthly Birth Report
- Monthly report of family planning
- Monthly Vaccine report
- IUCD report
- Home Delivery reason report

- Severe anemia report
- HBNC report
- Child death review report
- LBW birth report
- MTP report
- RT/STI
- IUD/Still Birth
- HMIS report
- PTK report
- Worker wise report
- Annual survey report
- High Risk Pregnancy Report
- JSY report
- Workerwise Report
- National Immunization Programme report
- Monthly report of performance of ASHA worker
- Incentive report of ASHA under RCH and UIP
- Morbidity Report
- IDSP Weekly report
- Pradhan mantri suraksit matratav abhiyan report

Medical officers in PHC

The primary health centers are the first point of contact between the Medical officer and the community. The PHCs cater to a population of 20000-30000 people. The functions of a PHC include:

- Medical Care
- MCH and Family Planning
- Safe water supply and basic sanitation
- Prevention and control of local endemic disease
- Collection and reporting of vital statistics
- Education about health
- National health programs

- Referral services
- Training of health guide, health worker etc.
- Basic laboratory services

NPCDS Program

NPCDCS Program with auto calculation of score and giving an alert of high risk if score is more than 4. Also, Decision support system which caters to Risk assessment for NCD based on score generated from pre-defined questions.

Risk Assessment			
Question	Range	Circle any	
1. What is your age? (in complete years)	30-39 years	0	
	40-49 years	1	
	≥ 50 years	2	
2. Do you smoke or consume smokeless products such as Gutka; or Khaini ?	Never	0	
	Used to consume in the past / Sometimes now	1	
	Daily	2	
3. Do you consume Alcohol daily?	No	0	
	Yes	1	
4. Measurement of waist (in cm)	Female	Male	
	<80 cm	<90 cm	0
	80-90 cm	90-100 cm	1
	>90 cm	>100 cm	2
5. Do you undertake any physical activities for minimum of 150 minutes in a week?	Less than 150 minutes in a week	0	
	At least 150 minutes in a week	1	
6. Do you have a family history (any one of your parents or siblings) of high blood pressure, diabetes and heart disease?	No	0	
	Yes	1	
Total Score			

This can be added in the NPCDCS program for assistance of healthcare provider as ready reckoner, these questions should pop up on opening NPCDCS program

When a new schedule under NPCDCS program is made for the patient, all the fields except for field under patient examination & screening outcome head should get automatically filled up from previous visit record but they should remain modifiable.

SMS integration in NCD program

Reports

NPCDCS Cancer reports: It is an aggregate report and displays the monthly record related to cancer.

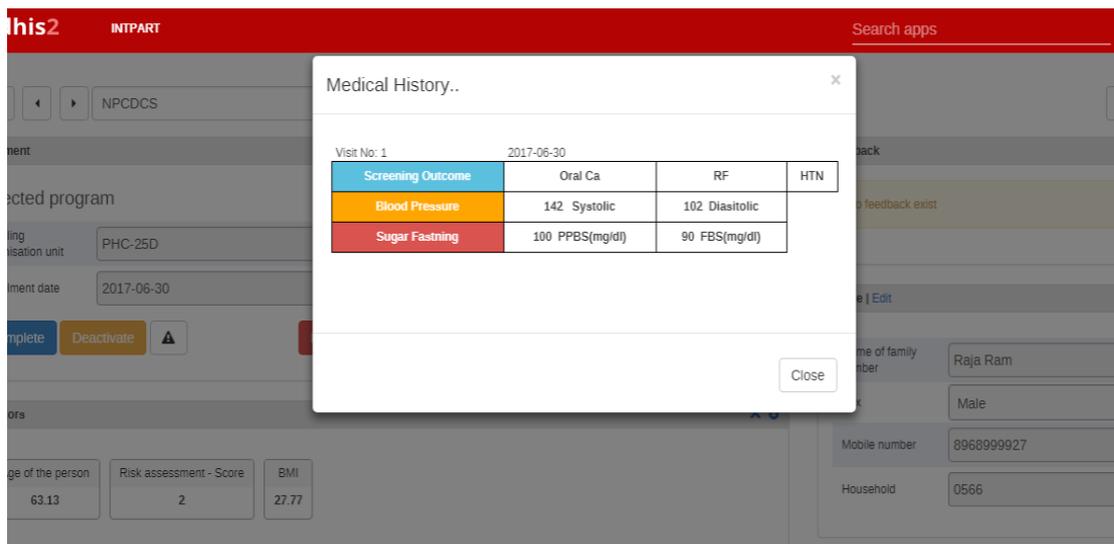
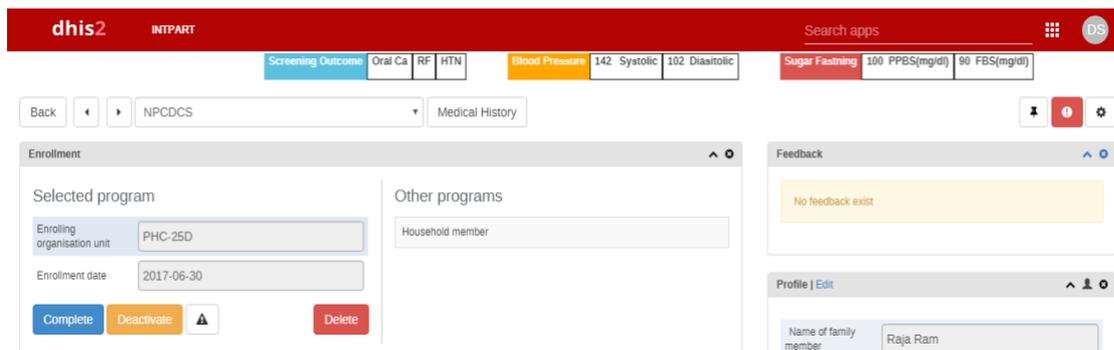
NPCDCS DM & HTN report: it's an aggregate report displays the monthly record related to DM & HTN.

Risk Assessment report: It's an individual report, it provides the risk score of all the person enrolled in that program. Example: if 70 persons are enrolled, then it displays score and its family record for all the 70 persons.

Early Detection report: It display where person is suffering from any disease. its provide the report of early detection section in NPCDCS program.

Medical history

A medical history button is available, to see the result of the previous stage. It opens the result in the form of a table. The other way to see the results is to click on the parameters, which blink on top of the screen. If we have 3 program stages, then we can see the result of last two stages. This is for NPCDCS program, and will be implemented for other programs going forward.



SMS alerts

To activate SMS feature in DHIS2, we need to activate SMS gateway which will be configured. After that in the program stage we can set-up the message which needs to be sent to health workers as well as the beneficiary. PGI has registered with Mobile seva for SMS Push service.

SMS Hindi Content: Problem of Unicode needs to be solved. The content in English content is fine, but the issue occurs in Hindi content.

Currently an adhoc measure is being adopted. The new versions of DHIS2 (version 2.8) will have the feature of supporting languages other than English and should be able to solve the problem of sending SMS in Hindi.

Two-way communication

Presently application supports only one-way communication through sending of SMS.
Explore the possibility where a patient can also raise a query through SMS or access health related general information stored in the application through his mobile.

Appendix 2- INTPART workshops

Proposed workshop agenda

Day 1: May 15: The landscape of Patient Centric Systems in Norway and India

Registration: 9 – 9.30

Overall objectives of the INPART research project - Dr. Rajesh Kumar, PGIMER 9.30 – 9.45

Landscape of patient based systems for primary health care in India - Tarundeep Singh, PGIMER, India 9.45 – 10.15

eRegistries: Electronic patient registries for women and children - Ingrid Friberg, Norwegian Institute of Public Health 10.15 – 10.45

Coffee Break 10.45 – 11.00

The C3 project: An overview - Kari Kværner, Oslo University Hospital, Oslo 11.00 – 11.30

The C3 project: Experiences from the follow up of chronic care patients - Miria Grisot/Margunn Aanestad, Department of Informatics 11.30 – 12.00

Lunch Break 12.00 – 13.00

eRegistries: Governance, data privacy, and data security considerations - Sonja Myhre, Norwegian Institute of Public Health 13.00 – 13.45

Systems and solutions for follow-up of chronic patients - Jens Espeland, Dignio 13.45 – 14.15

Online education of health personnel - Helge Høivik, HiOA 14.15 – 14.45

Coffee Break 14.45 – 15.00

Protection of health and personal data - Maryke Silalahi Nuth, Directorate of e-Health 15.00 – 15.30

The HISP research project at UiO - Petter Nielsen 15.30 – 16.00

Day 2: May 16: Operational Issues in INPART Project

Key milestones achieved till date: Dr. Rajesh Kumar, PGIMER 9.30 – 10.00

Empirical understanding of information systems requirements: Dharamjeet Singh
10.30 – 10.45

Coffee Break 10.45 – 11.00 am

The proposed approach for system design: Dr. Rajesh Kumar 11 – 11.30

Status of information system development: Dharamjeet Singh 11.30 – 12.00

Lunch Break 12.00 – 13.00 am

Masters thesis work of UiO students: Kripa and Devesh 13.00 – 13.15

DHIS2 Academy Online Platform – Mathieu Pineard 13.15 – 13.45

Plans and status of online course module development: Dr Rajesh Kumar, 13.45 – 14.00

The emerging research agenda: Sundeep Sahay 14.00– 14.30

Coffee Break 14.30 – 15.00

Discussing future road map and next steps: Dr. Rajesh Kumar, PGIMER, 15.00 – 15.30

Concluding remarks: Kristin Braa, UiO, 15.30 – 15.45

May 18: Field visit

Thanks to SIU, NRC and UiO who supports the project!



3rd Collaborative Workshop
on
“Designing Patient Centric Health Information Systems in Resource Constrained Settings”
Venue: Hotel Mount View
Date: 19th -21st February 2018

Day 1

Time	Session	Speaker
9:00- 9:30 am	Registration	
9:30 – 10:00 am	Inauguration <ul style="list-style-type: none"> • Welcome and opening remarks • Public Health and need for health information systems • Address by the chief guest • Vote of thanks 	Dr. Rajesh Kumar, Dean, PGIMER, Chandigarh Dr. Sundeep Sahay, Professor, Department of Informatics, University of Oslo, Norway Dr. Tarundeep Singh, Assistant Professor, School of Public Health, PGIMER, Chandigarh
10:00 – 10:30	Tea/coffee break	
10:30-1:00 pm	Session 1 Chair: Dr R Kumar , Dean, PGIMER, Chandigarh Co-Chair : Dr Sundeep Sahay , Prof, University of Oslo, Norway	
10:30-11:00 am	<ul style="list-style-type: none"> • Information needs for Universal Healthcare 	Dr. Nobhojit Roy, Public Health Expert, NHSRC, New Delhi
11:00 – 11:30 am	<ul style="list-style-type: none"> • Strategies for strengthening and adoption of Health Information systems in primary care 	Mr. Sunil Bhushan, Sr. Tech Director, NIC
11:30-12:00 pm	<ul style="list-style-type: none"> • Tech-enabled Primary Care: IKP-TechPrima's Story 	Mr. Sivakumar Mahalingam, Chief Technology Officer IKP Center for technologies for Primary Care, Thanjavur
12:00-12:30 am	<ul style="list-style-type: none"> • Hospital MIS system in Haryana 	Dr. Sonia Trikha Khullar, Executive Director, SHRC, Haryana
12:30 – 1:00 pm	<ul style="list-style-type: none"> • Review of Patient centric health information systems in India 	Dr. Tarundeep Singh, Assistant Professor, School of Public Health, PGIMER, Chandigarh
1:00-2:00 pm	Lunch Break	
2:00 -5:00pm	Session 2	

	Chair : Dr Supten Sarbadhikari , Dean IHMR, New Delhi, Co-Chair : Mr. Sunil Bhushan , Sr. Tech. Director, National Informatics Center.	
2:00 - 2:30 pm	<ul style="list-style-type: none"> • Challenges and Approaches in implementing Metadata and data standards in patient based system for primary health care." 	Mr. Devesh, Researcher, Department of Informatics, University of Oslo, Norway
2:30-2: 50 pm	<ul style="list-style-type: none"> • Living lab: Our design strategy 	Dr. Rajesh Kumar, , Prof & Head, School of Public Health, PGIMER, Chandigarh
2:50- 3 :10 pm	<ul style="list-style-type: none"> • Designing Patient centric health information system : Requirement gathering process 	Ms. Kripeshwari, Researcher, University of Oslo, Norway
3:10– 3:30	Tea/coffee break	
	Session 3 Chair : Dr. Sonia Trikha Khullar , Executive Director, SHRC, Haryana, Co-Chair : Dr. Biju Soman , Additional Professor, Achutha Menon Centre for Health Science Studies, SCTIMST, Trivandrum, Kerala.	
3:30-3:50 pm	<ul style="list-style-type: none"> • Building the Hospital Health Information application in OpenMRS 	Mr. Ghanshyam, Developer, HISP India
3:50-4:45 pm	<ul style="list-style-type: none"> • Demonstration of Hospital MIS application 	Mr. Dilroop, Software Developer, HISP India
4:45-5:00 pm	<ul style="list-style-type: none"> • Challenges in implementation of the Hospital MIS application 	Dr. DS Faujdar, Researcher, School of Public Health, PGIMER, Chandigarh

Day 2

	Session 1 Chair Dr SB Bhattacharya Independent Health Informatics Consultant, Co-Chair : Dr. A. Elangovan Scientist F and Divison Head, Computing and Information Science, National Institute of Epidemiology, Chennai	
9:00 – 10:30 am	<ul style="list-style-type: none"> • Demonstration of the Community Health Information application in DHIS 2 	Mr Akash Jindal, Team Lead, HISP India
10:30-11:00 am	<ul style="list-style-type: none"> • Challenges in implementation of the Community Health Information application 	Dr DS Faujdar, Researcher, School of Public Health, PGIMER, Chandigarh
11:00 – 11:15 am	Tea/coffee break	
	Session 2 : Chair : Dr Sundeep Sahay , Prof, University of Oslo, Norway Co-Chair : PVM Lakshmi , Additional Professor, School of Public Health, PGIMER, Chandigarh	
11:15-11:45 am	Online DHIS2 learning platforms: Current status and plans (with Demonstration)	Prof. D Matheiu, University of Oslo
11:45-1:00 pm	Discussion on way forward in implementation and further development of application	Prof. Sundeep Sahay
1:00 – 2:00 pm	Lunch	

	Session 3 Chair : Dr P Mathieu , Prof, University of Oslo, Norway. Co-Chair : Dr R Kumar Dean, PGIMER, Chandigarh	
2:00 –2:20 pm	Report and feedback of the course on Public Health Informatics	Dr DS Faujdar, Researcher, School of Public Health, PGIMER, Chandigarh
2:20- 2:40 pm	Discussion on course and steps to make online course	Moderator Dr. PVM Lakshmi
2:40-3 :15 pm	Research outputs from the project and timelines	Moderator Dr. Sundeep Sahay
3:15- 3:30 pm	Tea/Coffee break	

Day 3

Time	Session	Resource person
Time	Session	Resource Person (s)
09.00-10.00 am	Session-1: Field Visit to Public Health Dispensary, Sector-25	
	<ul style="list-style-type: none"> • Introduction to PHD25 Staff • Acquaintance with day to day working of PHD25 	Dr DS Faujdar, Researcher, School of Public Health, PGIMER, Chandigarh
10.00-10.30 am	Tea/Coffee Break	
10:30-1:00 pm	Session-2: Field Visit to Public Health Dispensary, Sector-25	
	<ul style="list-style-type: none"> • Set-up & Networking of IT Systems • Hospital MIS using openMRS • Health Services management using Community Health Information application 	Mr Dilroop Singh and Dr DS Faujdar
1:00 pm-2: 00 pm	Lunch Break	

Workshop Agenda

Day1 6th September 2018

- 09:00 am - 09:30 am Registration (Coffee, Tea)
- 09:30 am - 10:30 am Reiterating the background and objectives of the CCC-PGI project
Presenter: Professor Rajesh Kumar, PGIMER
Coffee /Tea
- 10:35 am - 11:15 am Living lab model for primary health care: Learning and experiences from CCC-PGI project.
Presenter Professor Sundeep Sahay
- 11:15 am - 12:00 am Design of Patient centric system for PHC: System development & functionality
Dr. DS Faujdar, Ph.D Scholar, SPH, PGIMER
Lunch
- 13:00 - 13:30 Incorporating MDDS in Patient Centric System: Process & Limitations
Mr. Devesh Sharma, Master student UiO
- 13:30 - 14:15 Digitalization agenda at the Indian Council of Medical Research ICMR:
Dr. Harpreet Singh, ICMR
Coffee/Tea
- 14.30 - 15.00 Summarizing learnings from the experience to date and planning ahead
Arunima Mukherjee, Researcher, IFI, UiO
- 15.00 - 15:45 Qualitative assessment of Patient centric System: Perception & challenges
Dr. Manmeet Kaur, Professor (Health Promotion), SPH, PGIMER

Day2 7th September 2018

- 9:30 pm-10: 30 am Development of Clinical Module in DHIS2 Tracker
Dr. Tarundeep Singh, Assistant Professor, SPH, PGIMER
- 10:30 am-11:00 am Costing of development and implementation of Patient Centric System at Primary Health Centre. *Dr. DS Faujdar, Ph.D Scholar, SPH, PGIMER*
Coffee/Tea
- 11:05 am-11:35 am "eRegistries: development and evaluation of a point-of-care tracker for antenatal care in Palestine" *Mahima Venkateswaran, Norwegian Institute of Public Health*
- 11:35 am -12:05 am Demo of new DHIS2 Android App. Marta Valla, UIO
Lunch
- 13:00 - 13:30 Development of online & face to face course on Public Health Informatics at
Dr. PVM Lakshmi, Professor (Epidemiology), SPH, PGIMER
- 13:30 - 14:15 Capacity building: Online module . *Mr. Matthieu Pinard, Software Engineer, UiO*
Coffee/Tea
- 14:30 pm - 15:15 Patient-centered solutions. (Also presented at NHS Digital Academy). *Margunn Aanested, Professor IFI, UiO*
- 15:15 - 15:45 Collaborative research; current and planned outputs . *Dr. Tarundeep Singh, Assistant Professor, SPH, PGIMER*
- 15:45 - 16:30 Building government ownership and sustainability. *Dr. Sundeep Sahay, Professor, IFI, UiO*

4th collaborative workshop on
“DESIGNING PATIENT CENTRIC INFORMATION
SYSTEMS IN RESOURCE CONSTRAINT SETTINGS”

This is to certify that

Ms Kripeshwari Sridharan

has participated at the 4th collaborative workshop about “Designing Patient
Centric Information Systems in Resource Constraint Settings” Organized by
the University of Oslo, Department of Informatics in Oslo 6-7th September
2018

Oslo, September 21st 2018



Dr. Sundeep Sahay

Professor

Department of Informatics

University of Oslo, Norway

