UNIVERSITY OF OSLO

Department of Informatics

Building Participatory Networks for HIS in a Developing Country Context
A Case Study from India

Master thesis
60 credits

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ABSTRACT

This thesis is drawn from an ongoing action research project, Health Information Systems Program (HISP) which aims at developing sustainable, computerised Health Information Systems (HIS) in developing countries in order to improve the quality of health service delivery and to create local action and analysis. The research in this thesis is conducted in Kerala in India, where the use of participatory practices is studied in a developing country perspective. Participatory Design is generally seen as a precondition of the development of successful systems. However, the PD tradition has been criticised for being outdated and incomplete. With basis in these critiques, this thesis addresses the need for a re-conceptualised PD which is more adaptable to the development of large and complex information infrastructures rather than single, locally-based systems. From this area of interest, the following research questions arose: i) How has PD been used in the HISP project in Kerala, and how has it been helpful? ii) What aspects of social, political and cultural context shapes participatory processes in a developing country context like that in Kerala, India? iii) How do participatory processes in contexts like India differ from those in Scandinavia?

I have approached the problem domain using an action research approach and draw upon the theories of PD and Information Infrastructure (II). In order to carry out the research, a thorough understanding of the HIS in Kerala had to be obtained, and hence the II theory provided a functional socio-technical perspective to study the HIS. Further I use PD theory to understand the participatory processes used in Kerala and how this theory can be further improved to suit the complex contexts of HIS in developing countries.

The main research contributions of this thesis are the building of participatory networks which involves networks of stakeholders both multi-sectoral and multi-leveled. Also the context-sensitivity of PD is emphasised and it is argued how the context of which the system is introduced highly influences the use of PD. Additionally, a need for shifting focus from PD techniques to the outputs of such processes is discussed, as well as the need to focus on structural as well as behavioural changes when conducting PD processes.
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Oslo, August 2006
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<th>Full Form</th>
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<tr>
<td>AIMS</td>
<td>Amrita Institute of Medical Sciences</td>
</tr>
<tr>
<td>AMCHSS</td>
<td>Achuta Menon Centre for Health Science Studies</td>
</tr>
<tr>
<td>B-PHC</td>
<td>Block PHC</td>
</tr>
<tr>
<td>C-DAC</td>
<td>Centre for the Development of Advanced Computing</td>
</tr>
<tr>
<td>CESS</td>
<td>Centre for Earth and Science Studies</td>
</tr>
<tr>
<td>CHC</td>
<td>Community Health Centre</td>
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<tr>
<td>DHIS</td>
<td>District Health Information System</td>
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<tr>
<td>DHS</td>
<td>Directorate of Health Services</td>
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<tr>
<td>DMO</td>
<td>District Medical Officer</td>
</tr>
<tr>
<td>EC</td>
<td>European Commission</td>
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<tr>
<td>FWC</td>
<td>Family Welfare Centre</td>
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<tr>
<td>GDP</td>
<td>Gross Domestic Product</td>
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<td>GIS</td>
<td>Geographical Information Systems</td>
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<td>HIS</td>
<td>Health Information Systems</td>
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<td>HISP</td>
<td>Health Information Systems Programme</td>
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<tr>
<td>HI</td>
<td>Health Inspector</td>
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<tr>
<td>HII</td>
<td>Health Information Infrastructure</td>
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<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<tr>
<td>HMIS</td>
<td>Health Management Information System</td>
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<tr>
<td>ICT</td>
<td>Information and Communication Technology</td>
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<tr>
<td>IEC</td>
<td>Information, Education and Communication</td>
</tr>
<tr>
<td>II</td>
<td>Information Infrastructure</td>
</tr>
<tr>
<td>IIIT</td>
<td>Indian Institute of Information Technology</td>
</tr>
<tr>
<td>IS</td>
<td>Information Systems</td>
</tr>
<tr>
<td>JHI</td>
<td>Junior Health Inspector</td>
</tr>
<tr>
<td>JPHN</td>
<td>Junior Public Health Nurse</td>
</tr>
<tr>
<td>LDF</td>
<td>Left Democratic Front</td>
</tr>
<tr>
<td>MGP</td>
<td>Modernisation of Government Program</td>
</tr>
<tr>
<td>MoU</td>
<td>Memorandum of Understanding</td>
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<tr>
<td>MPH</td>
<td>Master in Public Health</td>
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NICD - National Institute of Communicable Diseases
PD - Participatory Design
PH - Public Health
PHC - Primary Health Centre
PO - Program Officer
SC - Sub Centre
SCTIMST - Sree Chitra Tirunal Institute for Medical Sciences and Technology
UDF - United Democratic Front
UHC - Urban Health Centre
UiO - University of Oslo
UTOPIA - Utbildning, Teknik och Produkt i Arbetskvalitetsperspektiv
WHO - World Health Organisation
1 INTRODUCTION

1.1 Introduction

The mission of public health can be defined as “the fulfilment of society’s interest in assuring the conditions in which people can be healthy” (Institute of Medicine 1998). A well functioning Health Information System (HIS) plays a critical role in order to carry out this mission (Braa 2003, Lippeveld et al. 2000). Raghavendra & Sahay (2005) state that information and communication technologies (ICTs) in primary healthcare settings offer a number of opportunities to enhance the efficiency of administration and to improve delivery of healthcare services. However, HIS in developing countries have been described as being grossly inadequate due to various reasons like the gathering of irrelevant and poor quality data, duplication among parallel HIS, lack of timely reporting and feedback, and poor use of information (Raghavendra & Sahay 2005).

This thesis is part of an ongoing action research programme called Health Information Systems Programme (HISP) which aims to develop sustainable computer-based HIS in developing countries, with mechanisms for the collection, processing and analysis of data and use of information for decision-making at facility and district levels. In 1998 the first version of the District Health Information System (DHIS) software, developed by HISP, was implemented in South Africa. DHIS supports data collection and analysis at all levels of the health care system. The HISP approach has now been extended to a number of developing countries in Africa and Asia, despite the fact that replication and transfer of such systems from one country to another involves complex problems and challenges related to technological, social, cultural and political issues.
1.2 Research objective

My main research interest addressed in this thesis is the analysis of the use of Participatory Design (PD) in HIS development in a developing country context and the benefits (or disadvantages) this methodology gives. Through the HISP initiative, I had the opportunity to study these processes of participation at a close level in the state of Kerala in India. In order to have the proper foundation for this study, it was essential to understand the cultural, political and social complexities of the public health infrastructure in Kerala and the problems and challenges involved with conducting changes in such a complex infrastructure. To comprehend these issues, I wanted to study the HIS using an Information Infrastructure (II) perspective. Based on my research interests, the following research questions were addressed in this thesis:

1. How has participatory design been used in the HISP project in Kerala and what has been its impact?
2. What aspects of the social, political and cultural context shapes participatory process in a developing country context like that in Kerala, India?
3. How do participatory processes in contexts like India differ from those in Scandinavia?

1.3 Theoretical ideas drawn upon

To analyse the problems described above, I drew upon the following theoretical ideas and concepts:

1.3.1 Information Systems as social systems

Information systems often have a dominant technical orientation where human and organisational factors are not adequately considered (Byrne & Sahay 2003, Walsham et al. 1988). However, within the world of IS research, the view of information systems as social systems have been recognised and emphasised (Sahay 2005, Walsham et al 1988, Mumford 1983, Kling et al. 2000). According to Walsham et al. (1988), the interplay of human, organisational and technical factors can best be addressed by conceptualising
computer-based information systems as social systems. A socio-technical approach produces work systems which are both technically efficient and reflect social characteristics which lead to higher job satisfaction (Mumford 1983). This idea of information systems being part of the social context, something much bigger and qualitatively different from the concept of a computer, technical artefact, or a technical system, explains some of the inherent difficulties in changing information systems (Braa et al 1999).

1.3.2 Health Information Systems
A HIS is a system that integrates data collection, processing, reporting, and use of the information necessary for improving health service effectiveness and efficiency through better management at all levels of health services (WHO 2004). An HIS should support and improve health care by increasing efficiency, quality and scope of the services through more efficient planning, organisations and management functions (Heywood et al 1994). This study focuses on routine health information systems which could be defined as “information that is derived at regular intervals of year or less through mechanisms designed to meet predictable information needs” (RHINO 2002). Puri et al. (2004) state that the use of ICTs will be increasingly implicated in community development programs in the third world, for example in the health sector. Health information systems in most developing countries are inadequate in providing the needed management support (WHO 1987, Lippeveld et al. 1992). Lippeveld and Sauerborn (2000) argue that most health care providers in developing countries equate information systems with filling endless registers with names and addresses of patients, compiling information and sending out reports without adequate feedback. Hence a computerised HIS can potentially help relieve the workload and improve the quality of health services.

1.3.3 Information Infrastructure (II)
While information system design methodologies aim at developing a closed system with pre-defined start and end points for a defined customer organisation (Monteiro 2003, Chilundo and Aanestad 2003), an II perspective provides a more sophisticated social
system perspective to study heterogeneous, complex and interconnected systems (Hanseth & Monteiro 2001). IIs can be characterised as a shared, evolving, open, standardised, and heterogeneous installed base Hanseth (2002a) and the Internet can be exemplified as a typical II.

HIS are complex, highly interconnected heterogeneous systems as they tend to be deeply embedded in social, cultural, political, technical and contextual issues (Feldman & March 1981), and hence they are not closed systems with fixed start and end points. As HIS have several characteristics in common with those of an II, HIS should analytically be conceptualised as a Health Information Infrastructure (HII).

1.3.4 Participatory design (PD)

Participatory design implies that workers as users of computer products should take part in the decisions that affect the system and the way it is designed and used (Greenbaum 1993a). Over the years, user participation has become an important part in the design of effective information systems and has been considered to be an important determinant of the eventual success of the system (Puri et al. 2004). The introduction of user participation has helped refocus the previously technical orientation of system developers to also include the needs of the users, as opposed to what was common in the computer science tradition. PD assumes that the workers themselves are in the best position to determine how to improve their work and their work life. It values the users’ perceptions and feelings about technology highly and it views computers and computer-based applications in the context of a workplace – as processes rather than products (Czyzewski et al. 1990).

Research has shown that PD is a precondition for successful use of ICTs in the health care sector in developing countries (Braa 1996, Byrne & Sahay 2003, Korpela et al. 1998). Organisational complexity of the primary health care systems with multiple levels of hierarchy and various vertical programs are factors complicating the design, development and use of IS in developing countries. A step in trying to address this complexity is to enhance the use of participatory processes of various stakeholders (Byrne & Sahay 2003).
Experience suggests that systems that are designed by a team of “information experts” without adequate involvement of key stakeholders usually fails to reflect the needs and practical reality of service providers and managers, and does not encourage the ownership of the systems (RHINO 2001 p.3). Hence, the use of PD in developing countries is considered crucial.

1.4 Organisation of the thesis

The thesis is organised in seven chapters. Chapter 1 has introduced the thesis and the research objective and also the theoretical ideas which the thesis draws upon and structure of the thesis. Chapter 2 outlines the research setting with details about India and Kerala as well as their health status. It also presents HISP globally and HISP India which is the organisation in which this thesis is part of.

In chapter 3 I provide an overview of the theoretical framework where I draw upon literature related to HIS as social systems, HIS in developing countries and conceptualise HIS as HII. Then I present PD theory and its use and research in different parts of the world. I finally discuss the importance of PD in HIS development. Chapter 4 comprises of the research methods, my research approach, and data collection methods and analysis techniques. Chapter 5 comprises of the case study where my fieldwork is presented. I introduce the actors involved in the HISP project and provide a description of the content of my fieldwork in Kerala. Chapter 6 presents my analysis of the empirical findings in the case study, and chapter 7 comprises of a discussion of the analysis and concluding remarks.
2 RESEARCH SETTINGS

This chapter introduces the setting in which the study was conducted, namely the state of Kerala in India. It presents general facts, the political, educational and health related situations in both India and Kerala. Further it introduces the HISP organization which this study is part of, and its development of the District Health Information System (DHIS).

2.1 Republic of India

India (figure 2.2) is situated in the south of Asia and borders to Pakistan, China, Bhutan, Bangladesh and Burma. The area of India covers 3,287,590 square kilometres and is divided into 28 states. With a population of 1,080,264,388 people (July 2005 est.), India is the second most populated country in the world. Hinduism is the most widespread religion being followed by about 80.5% of the population, followed by Islam, Christianity, Sikh and others. Hindi is the national language and is the native tongue of 30% of the population, but there are 14 other national languages. English is the most important language for national, political and commercial communication.

India is home to one of the richest and the most ancient civilisations in the world, which existed from over 5000 years ago. This civilisation, called the Indus Valley civilisation, was the origin of many of the ideas, philosophies and movements which have shaped the destiny of mankind. In the seventeenth century, India was colonised by the British and they ruled the country for almost 300 years. When India earned their independence on the 15th of August 1947, it was freed from the British exploitation. However, many of the
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systems created by them, including that of public health, still continue to endure over time, although in a different form and shape than when it was originated.

India is the largest democracy in the world and integrates the British and US constitutional systems. The Prime Minister is the head of the administration of the country and is elected by the people, and the representative of the ruling party is appointed to this post by the president. The power of the government is divided in three branches; executive, judiciary and parliament. The central government has authority of India’s 28 self-governing states, each administered by a governor. Various portfolios like Health and Law and Order are primary responsibilities of the state government.

India is facing numerous challenges in areas like health, welfare and development. The economic growth over the recent years has not significantly benefited the average Indian. Today India accounts for close to a third of the world's software engineers and also a quarter of the world's undernourished (Thakurta 2006). Table 2.1 shows social-economic indicators in India compared to other Asian countries. Longevity, literacy and GDP per capita are considered the main indicators for human development (Pokharel et al. 2003). India ends up behind China, Russia and Sri Lanka on these three indicators. Additionally, the infant mortality rate in India is significantly higher than these countries as well (table 2.1).
Table 2.1: India compared to other countries.

Population growth has long been a concern of the government as this is seen as the greatest obstacle to economic development. Efforts to lower the birth rate were started in the mid 1970s and up to 1991 there was a slight decrease in the birth rate. However, India still has one of the most rapidly growing populations in the world. Studies showed that most couples regard family planning positively, but due to a strong preference for sons, especially in the north, rural couples keep having children until they have at least one or two sons, then they might accept sterilisation or use birth control. This preference for a son is also contributing to a decline of female versus male population ratio. Today, the population growth rate is 1.38% (2006 est.) and the birth rate is 22.01 per 1000 population.

Education is available for most of India's children and officials state that education is compulsory. In reality however, a significant percentage of children, especially girls, fail to become literate and instead carry out many other tasks in order to contribute to family income. Figure 2.3 illustrates how the literacy rate in India has increased since 1951. The rate from state to state however varies greatly.
India has the world’s largest number of poor people in a single country, most of them are in the rural areas. 25% of the population lives below the poverty line (CIA 2002) and nearly half of children under five are reported to be malnourished (World Bank 2001). India is reported to have an annual per capita income of Rs. 24,000, approximately USD 50 per month.

2.1.1 Health care in India

Although the health conditions are improving, the challenges are enormous. A high proportion of the population continues to suffer and die from preventable infections, pregnancy and childbirth-related complications, early childhood diseases and undernutrition. The infant mortality rate (IMR) is about 55 deaths per 1000 live births. Maternal deaths are similarly high due to lack of access to skilled birth attendants, antenatal and postnatal care. The major infectious diseases are bacterial diarrhoea, hepatitis A and E, and typhoid fever (food and water borne) and dengue fever, malaria, and Japanese encephalitis (vector borne). With about 5 million infected with HIV, India has the second-highest number of cases of HIV after South Africa (CFHI 2005). The disparities within the
country are large, and the poor, women and scheduled castes and tribes tend to be exposed and vulnerable (World Bank 2001). However both IMR and Birth rate are decreasing as illustrated in figure 2.4.

![Figure 2.4: The development of IMR and Birth rate](image_url)

The basic health care delivery system in India is implemented through the Primary Health Centres (PHC) system. A PHC system was conceived in India as an institutional structure to provide integrated preventive, promotional, curative and rehabilitative services for the entire rural population (Raghavendra and Sahay 2005). The public health sector includes an elaborate system of PHCs, sub-centres (SCs), community health centres (CHCs), dispensaries and hospitals (ibid.). In urban areas, the health services are offered through Urban Health Centres (UHC). Due to the poor standard in the public health centres, private spending on health in India is among the highest in the world. This puts Indians at the risk of financial ruin when they become sick as more than 40% need to borrow money or sell assets when they are hospitalised (World Bank 2001).

A challenge India is facing is to provide a universal healthcare of acceptable standards to the general population, which is the stated objective of the 2002 National Health Policy (IHEA 2005). The major constraints facing the health sector are lack of resources, lack of an integrated multi-sectoral approach, insufficient Information, Education and
Communication (IEC) support, poor involvement of NGOs, inadequate laboratory services, a manually operated health management information system (HMIS), poor disease surveillance and response systems, and the heavy investments needed in dealing with non-communicable diseases (WHO 2003). Dr. A.P.J. Abdul Kalam, the President of India, stated in his recent address to the nation (2005) that “for providing quality health care to all of our citizens, we would need at least doubling the strength of doctors and paramedical staff in the whole country”. The President sees healthcare as a priority area on the way to a developed India.

2.2 Kerala

The state of Kerala (figure 2.5), where my thesis is based, is situated in the southernmost tip of India and is one of the smallest states in the country. It has an area of 38,863 square kilometres and a population of about 31.8 million people (2001 census) which gives a density of 819.3 people per square km. Kerala consists of 14 districts and the capital is the city of Thiruvananthapuram (Trivandrum) in the south of the state.

Kerala is one of the most politically conscious states in India and the population are active participants in the political process. The first democratically elected Communist Government in India (and the world) was elected here in 1957, and has after this been elected into power on several occasions. The Left Democratic Front (LDF) lead by the Communist party and the United Democratic Front (UDF) lead by the Congress Party are dominating the political life in Kerala. The local population is participating in politics through Kerala’s 991
panchayats\textsuperscript{1} who are responsible for local public projects. In the recent elections held in 2006, the LDF were overwhelmingly voted into power over the UDF.

Kerala differs from the rest of India in terms of equality and quality of life. It has levels of health and education close to developed countries, women in Kerala have more power, the people have greater access to services and opportunities and they have a greater say in their governance. In contrast to the rest of India, there is a greater number of females than males in Kerala, and it is also one of the few states without a strict caste structure. This is suggested to be due to the mixture of the Islamic and Christian religions, the high level of education levels, or a result of the influence of the communist party in Kerala, who sought to abolish the caste system. Factors contributing to the emergence of an egalitarian society in Kerala include the implementation of land reforms, establishment of a minimum wage in agriculture and industry, stronger labour unions, and good working conditions (Vohra 1999).

\textsuperscript{1} Panchayats are a kind of village councils who take part in activities dealing with the local society. The panchayats in Kerala are quite powerful.
Table 2.2 shows some indicators in Kerala compared to the rest of India and one of the richest countries in the world, Norway.

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Kerala</th>
<th>India</th>
<th>Norway</th>
</tr>
</thead>
<tbody>
<tr>
<td>Per capita GNP</td>
<td>$324</td>
<td>$390</td>
<td>$6,300</td>
</tr>
<tr>
<td>Literacy rate</td>
<td>91%</td>
<td>65.49%</td>
<td>100%</td>
</tr>
<tr>
<td>Female</td>
<td>88%</td>
<td>54.16%</td>
<td>100%</td>
</tr>
<tr>
<td>Male</td>
<td>94%</td>
<td>75.85%</td>
<td>100%</td>
</tr>
<tr>
<td>Life expectancy (in years)</td>
<td>73</td>
<td>64.71</td>
<td>79.54</td>
</tr>
<tr>
<td>Infant mortality rate per 1000 live births</td>
<td>14</td>
<td>54.63</td>
<td>3.67</td>
</tr>
<tr>
<td>Population growth rate</td>
<td>0.91%</td>
<td>1.38%</td>
<td>0.38%</td>
</tr>
<tr>
<td>Birth rate per 1000 population</td>
<td>16.6</td>
<td>22.01</td>
<td>11.46</td>
</tr>
</tbody>
</table>

Table 2.2: Kerala comes close to developed countries in terms of welfare indicators.

From this table, it is evident that Kerala, compared to the rest of India, are approaching Western standards when it comes to the quality of life indicators. The infant mortality rate has been declining continuously since a high of 242 during 1911-1920 to the current 14 which is the lowest in India. The low infant mortality rate has contributed to the rapid increase in expectancy of life at birth. The population growth rate is also the lowest in India and according to the government this is due to the highest mean age at marriage and a very high level of acceptance and awareness of methods of family planning and fertility control. There has also been proved to be a correlation between increased levels of female literacy, and decreased fertility rates (Vohra 1999) which most likely is the situation in Kerala. Today, it is said, that the population from Kerala are primarily battling with urban diseases like in the West, such as hypertension, depression, diabetes and cardiac problems.

It may be said that it is not only economic, but also political and social factors which have led to the high level of social development in Kerala (Vohra 1999). The high quality of life, despite the low per capita income has come to be known as “the Kerala Model” which
may be taken as an early prototype of sustainable development (Parayil 1996). It can be defined as a long term strategy which enables a country, state or region to achieve a higher physical quality of life even at a low level of growth in productive sectors and a low domestic income by diverting the major share of its available resources for the creation of infrastructure for human resources development like education, medical care, housing and sanitation etc. (Wilhite 2006).

Despite Kerala’s success story when it comes to quality of life, the state suffers from economic underdevelopment and unemployment. It is argued that potential investors from outside are reluctant to engage such a highly politicised labour force (Indax 2005) and the relatively high level of minimum wages does not appear attractive for industries either. As a result, many of the investments into industries made by the rich Keralites take place in the neighbouring states of Karnataka and Tamil Nadu.

2.2.1 Health care in Kerala

From more than 5000 years ago, the ancient Hindu system of medicine; Ayurveda, was born in India. Ayurveda means “science of life/health” and is based on the belief that the body, mind and spirit are one. It aims not only at curing ailments but also preventing illness and sustaining life. Ayurveda has never received the desired attention in India, but Kerala is one of the few states where it has been kept alive in its traditional form. Here there are 108 Ayurveda hospitals, and according to the Government of Kerala, a very large selection of rural folk still depends solely upon Ayurveda. The WHO is supporting the integration of ayurveda into the national health system depending on the circumstances of its use. The WHO aims to provide technical guidance and information for the safe and effective use of such medicine, and to preserve and protect medicinal plant resources and associated knowledge with a view to makes its use sustainable (WHO 2003). However, the official system of medicine in India and also in Kerala is the Western medicine, which is practiced in the PHC structure.
Although the quality of life indicators are high, the health sector is meeting numerous challenges. The economic situation in Kerala has led to a severe decline in the quality of medical care in government hospitals. This has led to a growth of 40% in private health care in the period 1986-1996, compared to 5.5% in the government sector in the same time period (Ekbal 2000). Other than immunisation and sterilisation, most of the population's health needs are met by the private sector (Vohra 1999), causing an increase in the cost of medical care for the people, and the risk of marginalisation of the population who cannot afford private health care. Also the amount of foreign tourists coming to Kerala for health treatment is increasing. This trend is supported by several parties in Kerala as it is argued that it will promote the economy as well as tourism. However, the health tourism may further increase the prosperity of the private sector and contribute to even less use of the public health system.

As Kerala’s health indicators are approaching those of developed countries, so are the health problems common in these countries. Kerala has a suicide rate almost three times the national average – according to Maithri, a non-governmental organisation working for suicide prevention, about 26 persons die from suicide in Kerala each day. Suggested causes are social changes, mental disorders and financial debt, among other things (Maithri 2006). The morbidity rate in Kerala is higher than the rest of India. Kerala is currently facing a huge challenge in the growing incidences of diabetes and also other “western” diseases like cancer and coronary heart diseases. A rapidly changing life style and a growing geriatric population are said to be the reasons behind this growth (My-Kerala.com 2005). However, the Kerala situation is peculiar in that the infectious diseases like diarrhoea, hepatitis, tuberculosis etc are still prevalent. Epidemics that were supposed to be significantly reduced from Kerala like malaria and Japanese Encephalitis are now more apparent than before (Ekbal 2000). Additionally, like in the rest of India, instances of HIV and AIDS are continuing to increase. The government of Kerala suggests that the increasing levels of literacy and extension of medical services could cause even minor ailments to be reported as illnesses, which hence increases the reported morbidity rates. They also bring up the issue of high population density in the state and the increase in the old age population as contributing factors. Kurian (2003) claims that the high morbidity...
rates nullify Kerala’s feats in the health sector and argues that acute morbidity is significantly higher among the young and productive age groups in Kerala compared to the rest of India. He also points out that the morbidity rate is 40% higher in the rural areas than in the urban areas, a difference which is greater than in any of the major Indian states.
2.2.2 Health administrative structure of Kerala

Figure 2.6 presents the health administrative structure of Kerala. Following are the different levels of the structure described in further detail.

Figure 2.6: Health administrative structure of Kerala
Ministry of Health
The Ministry of Health is under the government of India and is the executive organisation at central level, dealing with the issues of Health and family welfare. They act as the coordinating agency between the State Health Departments, Planning Commission, Central Council of health etc. besides implementing various national programmes and items.

The main function of the Health Services Department is the delivery of Primary Health Care and the attainment of Family Welfare including Maternal and Child Health Care. The main activities of the department of health services comprises of positive, preventive and promotive health care and routine curative services.

State Department of Health and Family Welfare
The State Department of Health and Family Welfare under the Minister for Health, guides and supervises the Health and Family Welfare programme in the state. The Secretary and Additional Secretary to the Government, Health and Family Welfare Department have overall responsibility of administration and programme implementation.

Directorate of Health Services (DHS)
At the State level, various programmes on Health and Family Welfare are implemented, supervised and coordinated by the Director of Health Services. The work of the Directorate of Health Services includes the establishment and maintenance of medical institutions with necessary infrastructure, control of communicable diseases, rendering of family welfare services including maternal and child health services. They also conduct the implementation of National control/eradication programme and administration of various divisions of the Directorate.

The State Health Information Cell unit is responsible for the collection and compilation of Health Intelligence data and other vital statistics. The cell consists of two sections; Vital Statistical Section and Demographic and Evaluation Cell. The Vital Statistical Section’s main activities are the preparation of the annual administration report, collection and
compilation of health intelligence data on periodical basis, collection of data on manpower, health infrastructure, collection, their consolidation and transmission of reports on rural health statistics. The Demographic and Evaluation cell is responsible for routine health information and their main activities are collection, compilation and preparation of reports on all activities under the family welfare programme. They also compile data collected from the District Medical Office for the preparation of year book and preparation of monthly bulletin on family welfare and maternal and child health activities. The demographer is in charge of this section together with two statistical officers.

District Medical Office (DMO)
At the DMO, the District Medical Officer is in charge of all the health and family welfare activities at district level, while there are Program Officers who are responsible for the conduct of different health programmes. The DMO is the district level agency responsible for providing health service delivery, and also serves as the hub for the health information flows.

The activities of the DMO include the establishment and maintenance of medical institutions with necessary infrastructure, administration of health programmes, transfer and posting of employees, issue of medical certificates, budget allocation and monitoring. The main responsibility in terms of health care information flow is the collection of various health related data from the lower level institutions and sending the compiled reports to the Director of Health Services.

Health Service Delivery Institutions
The Health Service Delivery offered by the Department of Health Services is given through the following institutions:

- District level: Specialty hospitals
  Government hospitals
  Taluk hospitals
- Community Health Centre (CHC)/ Block Primary Health Centre (PHC)
- Mini PHC
• Sub centre/ Family Welfare Centre (FWC)

Community Health Centre (CHC) /Block PHC
There is usually one CHC for every 80,000 to 120,000 population, serving as a referral institution for a various number of mini PHCs. CHC/Block PHCs will provide clinical care with minimum in-patient service, besides providing all services as provided by mini PHCs. In-patient services include treatment for general ailments, 24 hour delivery services, normal delivery services, blood transfusion service, essential diagnostic services including ECG and ultrasound scan, paediatric case management, trauma care, first aid management of orthopaedic and other specialty cases, ambulance services and post-mortem.

Mini PHC
Theoretically, there should be one mini PHC for every 30,000 population. The services at the mini PHCs include preventive care, implementation of national programmes, prevention and the control of communicable and non-communicable diseases, school health programmes, geriatric care, disability clinic, first aid management of surgical and orthopaedic and other specialty cases, curative service limited to clinical care- out patient care only, limited laboratory investigation service.

Sub centre (FWC)
The sub centre is the community’s first level of contact with the formal health care delivery system. The sub centre is the grass root level institution to provide outreach services of primary health care to the community. The functionaries in a sub centre level are one male, JHI (Junior Health Inspector) and one female, JPHN (Junior Public Health Nurse), multipurpose health worker. Usually the sub centre is expected to cater to a population of 5000, though it may vary from 3000 to 8000 depending on the density of population, geographic terrain and other special characteristics of the region.

The services of the sub centre include out patient clinic, home visits and home care, health promotion and disease prevention programmes, IEC activities, implementation of national
programs-reproductive and child health programme, first aid, geriatric care and data collection and compilation. Sub centre staff also belongs to their parent PHC unit from where they get their resources, and also submit their monthly information reports.

2.2.3 **Health Management Information System (HMIS)**

The existing HMIS in Kerala is mostly paper based and includes a great number of forms travelling through the different administrative levels. These forms are consolidated at each level and brought manually by a health worker to the next level. According to the Centre for Development of Advanced Computing (C-DAC), a software supporting Community Needs Assessment Approach (CNAA)\(^2\) based reporting (district level onwards) was installed in all districts in Kerala in 2003. They claim that the software is operational in eight out of 14 districts and that the reports are being sent electronically through NICNET which is a satellite based nationwide computer communication network. Some district offices are also said to be using spreadsheets for consolidation and report preparation. However, in practice we saw little evidence of the use of this software by district staff.

Basically two types of reports are sent from the grass root level to the upper levels. These are monthly reports and action plans. The action plans are prepared in March each year, which is the end of the fiscal year, and indicates the services in different sectors of health and family planning required to be provided during the following year and the calculation of required service targets. The targets are calculated by using predefined formulas, and are then supposed to be approved by the health department. The monthly reports are to beanalysed at state level and the feedback is given in the form of monthly review meetings at the different levels. The reports are sent in accordance with the following schedule described in table 2.3 and 2.4.

\(^2\) CNAA is to identify the assets of a community and determine potential concerns that it faces.
Action plans:

<table>
<thead>
<tr>
<th>Action Plan</th>
<th>Form</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>State AP → Central Government</td>
<td>5</td>
<td>25th of March</td>
</tr>
<tr>
<td>District AP → Central Government</td>
<td>4</td>
<td>25th of March</td>
</tr>
<tr>
<td>CHC AP → DMO</td>
<td>3</td>
<td>20th of March</td>
</tr>
<tr>
<td>PHC AP → DMO</td>
<td>2</td>
<td>15th of March</td>
</tr>
<tr>
<td>SC AP → PHC</td>
<td>1</td>
<td>10th of March</td>
</tr>
</tbody>
</table>

Table 2.3: The schedule for sending action plans.

Monthly reports:

<table>
<thead>
<tr>
<th>Action Plan</th>
<th>Form</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>District → Central Government</td>
<td>9</td>
<td>25th every month</td>
</tr>
<tr>
<td>CHC → DMO</td>
<td>8</td>
<td>20th every month</td>
</tr>
<tr>
<td>PHC → DMO</td>
<td>7</td>
<td>20th every month</td>
</tr>
<tr>
<td>SC → PHC</td>
<td>6</td>
<td>15th every month</td>
</tr>
</tbody>
</table>

Table 2.4: The schedule for sending monthly reports.

With the present system, manual consolidation and entry of data is required for the preparation of consolidated reports. As forms regarding national health programmes also are required, the workload of the staff has increased at all levels, resulting in a deterioration of the reliability of the reported information. Additionally, the service delivery will also get affected when the workload is increased.

The state of Kerala has ambitions about setting up an IT-based health information system to improve the quality of healthcare services offered by the DHS, but the process till date has not been very effective and very slow. HISP India is an organisation aiming at improving the HMIS in developing countries. This study is part of the HISP initiative which has been started in Kerala in 2004. I now provide a brief overview of this initiative.
2.3 Health Information Systems Programme (HISP)

HISP is a collaborative action research project started in 1995 by two universities (Western Cape in Cape Town, and the University of Oslo), health departments at various levels and non-government organisations. It is a development project that has designed and implemented mechanisms for the collection, processing and analysis of data and the use of information for decision-making at facility and district level (Williamson et al 2000). HISP is operating as a global network within the health care sector across a number of developing countries like South Africa, Ethiopia, Mozambique, Tanzania, Malawi, India, Vietnam, Mongolia and China. The official vision of HISP is described as follows:

“To support the development of an excellent and sustainable health information system that enables all health care workers to use their own information to improve the coverage and quality of health care within our communities.”

(HISP 2006)

This action-led approach is aimed at creating a nucleus of health workers who are competent to manage information at facility and district levels and support decisions based on accurate information.

HISP started in South Africa in 1994, where one of the least equitable health care systems in the world was inherited due to the legacy of apartheid (Braa 2002). In the first pilot phase from 1996 to 1998, the focus was on identifying information needs and development and implementation of essential data sets. In 1998, the first version of the District based Health Information System (DHIS) was implemented and used to capture and analyse monthly data at district, regional and provincial levels in Western Cape. In 1999, the Department of Health in South Africa adopted the strategies, processes and software as the national standard and in the second phase (1999-2001) these were rolled out to all the districts (Braa 2002). Despite generally being perceived as a success, no funding was secured in South Africa for the following year. Braa (2002) states how this illustrates a basic ambivalence in the HISP process: HISP has never been fully accepted by official structures, but never also fully dismissed. Being a bottom-up, grass-roots
movement, this is probably inevitable and indicates both the strength and the weakness of a movement like HISP: independence and vulnerability.

After South Africa, the HISP project was initiated in Mozambique in 1999 and India in 2000. Despite obvious problems occurring when conducting such large changes to respond to the different health infrastructures, HISP is still running in all the countries taking part in the project, except Cuba. In Cuba the centralised political control combined with a volatile political situation internationally led to severe problems. But despite not being a success, the project gave useful experience from the Latin-American world as HISP is might expanding there in the future.

2.3.1 DHIS

DHIS is a routine District Health Information System designed in South Africa by using participatory prototyping and it is initiated and managed by HISP. The DHIS allows health services to enter, validate, and analyse routine data, semi-permanent data and survey data. Primarily it aims at enabling the use of information at all levels including the grass root levels, hence being a potential bottom up empowerment tool.

The DHIS has come in several versions. The original version implemented in South Africa, the DHIS 1.3 and the next version, the DHIS 1.4 were both programmed in Visual Basic and based on a Microsoft Access relational database with Microsoft Excel used for data analysis. The code is open and free, but the Microsoft software requires relatively expensive licences for both Windows operating system and the Office pack. Due to the desire of DHIS being completely free and open source, the work started on a new version of the software, the DHIS 2.0. This version is java-based with a MySQL database and is able to run on Linux, which is a free operating system. The piloting of DHIS 2.0 started in Kerala, India in the spring of 2006 and the idea is that this version will be implemented in all the HISP countries eventually. Since its inception in Kerala, HISP India has expanded the project to other Indian states including Jharkand and Gujarat. Figure 2.7 shows the data entry screen of DHIS 2.0.
HISP India is one of the nodes in HISP Global and was initiated in the state of Andhra Pradesh in India in December 2000. The HISP India Team comprises of a multidisciplinary group with backgrounds in informatics, medicine, public health, computer science, anthropology and development studies. The team has slowly evolved over time through grass root activities. The team is supported and guided by faculty members and has funding from the University of Oslo, Norway, and also from some of the health departments in the states where they are operational.

The state of Andhra Pradesh, in the south east of India, was chosen for the pilot project since the state had been demonstrably keen to introduce e-governance based reforms (Puri et al. 2004). The health related information processing in this state was mainly paper-based and carried the legacy and inefficiencies of a bureaucratised set up, with massive duplication of data and a variety of data formats (ibid.).
After gaining the necessary approvals, the customisation process of DHIS started with a situation analysis in the selected pilot district, Chittoor. The situation analysis helped the HISP team members to develop an understanding of the working of the PHC structure, its information flows and contributed to the process of defining a minimum data set. Through an intensive participatory process the data items were reduced from 1000 to 350 and the 20 existing forms reduced to two main forms (Nhampossa & Sahay 2005). The participatory prototyping for the minimum data set was carried out for over a year, and involved multiple discussions on data elements and forms used as well as through several workshops (Puri et al. 2004). After presenting the progress to the then State Chief Minister, he gave permission to pilot the system in nine PHCs included in his electoral constituency.

During the development of DHIS “version 0” in Andhra Pradesh, the minimum data set was implemented into DHIS. To be compatible with the state standards, the Community Needs Assessment data was entered exactly in the same order as it appeared on the paper form, making it easier for data entry (Nhampossa & Sahay 2005). The strategy was to try to develop local capacity and commitment through having the health workers entering the data themselves. By identifying the routine reports that needed automation, the health workers would see some usefulness of the system in alleviating the burdens of their everyday work.

Three categories of reports were identified; 20-30 routine reports, health related monitoring reports and analysis reports for the evaluation of facility performance and calculation of health indicators (Nhampossa & Sahay 2005). In the continuous customisation of DHIS, a district database was created to give the district authorities a picture of the state with a district focus and additional monitoring and analysis reports were included.

In January 2004, a Memorandum of Understanding was signed between HISP and the State Government, and the HISP approach was extended to over 1300 PHCs based on the software being installed in the district headquarters, covering the entire state of Andhra
Building participatory networks for HIS in a developing country context – a case study from India

Pradesh (Puri et al. 2004). HISP were contracted to create a state level database and the district database piloted in Chittoor was modified and implemented in each district, and populated with data (Nhampossa & Sahay 2005).

In 2004, the HISP approach was expanded to the state of Kerala. The present study focuses on the situation in Kerala.

2.4 Summary
This chapter have introduced the contextual settings in which this research is conducted. It presents the state and challenges of both India and the state of Kerala. It has been pointed out how the quality of life indicators of Kerala is reaching the levels of the developed world, but that Kerala still faces challenges concerning health care delivery. Additionally, this chapter has introduced the HISP organization which this study is part of. In the next chapter, I discuss the theoretical underpinnings of my research.
3 THEORY

This chapter comprises the theoretical framework relevant to the thesis. Firstly I argue why information systems (HIS) should be viewed as social systems. Secondly I present the theory on HIS, its role in developing countries and argue how it can be conceptualised as a health information infrastructure (HII). I follow this by presenting the theory of participatory design (PD) and outlining the importance of user participation in HIS and the history and research on participatory design in Scandinavia, UK, US and developing countries. This overview helps me to analyse the inherent challenges in trying to move approaches and methodologies developed in the West to other settings where the context is quite different.

3.1 Information systems as social systems

Information systems research often has a dominant technical orientation where human and organisational factors are not adequately considered (Byrne & Sahay 2003, Walsham et al. 1988). However, within the world of IS research, the view of information systems as social systems have been recognised and emphasised (Sahay 2005, Walsham et al 1988, Mumford 1983, Kling et al. 2000). According to Walsham et al. (1988), the interplay of human, organisational and technical factors can best be addressed by conceptualising computer-based information systems as social systems. ICTs do not exist in social or technological isolation. Their “cultural and institutional contexts” influences the ways in which they are developed, the kinds of workable configurations that are proposed, how they are implemented and used, and the range of consequences that occur for organisations and other social groupings (Kling et al 2000). A socio-technical approach produces work systems which are both technically efficient and have social characteristics which lead to high job satisfaction (Mumford 1983). This idea of information systems being part of the
social context, something much bigger and qualitatively different from the concept of a computer, technical artefact, or a technical system, explains some of the inherent difficulties in changing information systems (Braa et al 1999). Walsham et al. (1988) mentions that the problems of information systems development in developing countries are often more severe in terms of factors such as the current state of knowledge, availability of suitable equipment and infrastructure, lack of financial resources, shortages of technically competent personnel and constraints imposed by the social and political context, including the role of international donor agencies. They argue that as the social systems paradigm implies that all work in a particular country and organisational context must involve a good understanding of such factors, the country, its culture and the organisation in which the information system is to be implemented or used. This paradigm thus provides a useful lens to understand the issues around ICT based systems implementation in the context of developing countries.

3.2 Health Information Systems (HIS)

A HIS seeks to integrate data collection, processing, reporting, and use of the information necessary for improving health service effectiveness and efficiency through better management at all levels of health services (WHO 2004). In particular, it is essential for the monitoring the health situation, the performance of promotive, preventive and curative health services and activities.

The information obtainable through an HIS may be categorised into the following (interrelated and possibly overlapping) subsystems (WHO 2000):

- Epidemiological surveillance (e.g. disease case and outbreak notifications).
- Service records and reporting (from community health workers and health care delivery facilities).
- Programme monitoring and evaluation (e.g. TB, maternal and child health, family planning and epidemiology).
- Administration and resource management information systems (e.g. budget, personnel, supplies etc.).
• Vital registrations (e.g. births and deaths).

Heywood et al. (1994) argue that it is important to look at the HIS as a tool for improving health care, and not as a solution in itself. An HIS should support and improve health care by increasing efficiency, quality and scope of the services through more efficient planning, organisations and management functions (ibid.).

Health information systems are mainly classified into two groups; clinical and routine. Clinical HIS are typically large and complex hospital information systems that focus on patient specific data. It has proven to be difficult to develop such systems in both developed and developing countries due to various reasons including failure to take social and professional culture into account, dissonance between the expectations of the involved parties, and underestimation of the complexity of routine clinical and managerial processes (Littlejohns et al. 2003, Heeks and Bhatnagar 2001).

Routine health information systems could be defined as “information that is derived at regular intervals of a year or less through mechanisms designed to meet predictable information needs” (RHINO 2002). For example, information gathered from data collected by health workers/staff at different intervals on various health programs like Maternal and Child Health, HIV/AIDS, Communicable diseases, Tuberculosis etc. An important strength of routine HIS is that decision makers and managers at all levels of the health system potentially have direct access to data (Quraishy 2004). This study focuses on the implementation of systems to support routine health information systems.

A HIS cannot exist by itself, but is a functional entity within the framework of a comprehensive health system oriented to improve the health of individuals and the population. As such it is a management information system (MIS) (Lippeveld 2001). WHO (1993) defines a HMIS as an information system specially designed to assist in the management and planning of health programmes, as opposed to the delivery of care.
The Information Cycle (figure 3.1) is a diagrammatic way of looking at information and shows the links between the six phases of collecting, processing, analysing, presenting, interpreting and using information (Heywood et al. 1994). A HIS deals with all the parts of the information cycle.

![The Information Cycle](image)

**Figure 3.1: The Information Cycle**

**Collection:**
The purpose of data collection is to calculate indicators to measure how well the various programs are performing (Heywood et al. 1994). The main data collectors in a routine health unit-based system are the care providers themselves (Lippeveld 2001).

There are three main types of data collected:

- **Routine data:** Data collected at regular intervals (weekly, monthly, quarterly), for example data for national programmes (TB, malaria, immunisation etc).
• **Semi-permanent data:** Data that changes over a long term duration, for example population and logistics data which can be updated on an annual basis.

• **Organisation data:** includes information about health facilities, its infrastructure, type of services offered, staff position etc.

**Processing data:**
Before it can be turned into information, raw data needs to be processed to ensure quality, consistency, and accuracy. The data should be controlled for errors and aggregated before being sent to the next level in the reporting chain (Heywood et al. 1994).

**Analysing data:**
The data should be analysed, typically including the computation of indicators, which is a tool for enabling comparison between different facilities and districts.

**Presenting data:**
Data needs to be analysed and displayed to be functional. The indicators are nice to have, but to make them really useful, they need to be displayed in the form of tables or graphs that can be readily seen and understood and discussed at all health service gatherings and community meetings (Heywood et al. 1994).

**Interpretation:**
Interpretation of the information is one of the most important and most difficult aspects of using the information system. Interpretation should bring together routine information from other sources and needs to be supplemented with good, old-fashioned “common sense” (Heywood 1994).

**Use:**
Just having information does not mean that managers will use it. Information use is made easier if it is ritualised and routines are set up as part of the “information culture”. In other words, everything done at a facility must be on the basis of information. Every decision made, every action taken, and every change made should be guided by information
coming from within the facility and influenced by outside policies, norms and regulations (Heywood et al. 1994).

### 3.2.1 Health information systems in developing countries

The use of ICTs has been expanding during the last decade or so in the developing world as well as in the developed world (Puri et al. 2004). In poor countries ICTs are expected to play a key developmental role, but there are multiple problems regarding achieving these developmental benefits. Many organisations have difficulties in nurturing and cultivating complex technology projects over long periods of time. The resulting ICT-based systems often have little impact on the organisational weakness they were intended to alleviate (Sahay & Avgerou 2002). Puri et al. (2004) state however that the use of ICTs will be increasingly implicated in community development programs in the third world, for example in the health sector. Thus there is a need to upgrade our approaches and strategies of implementation.

Raghavendra and Sahay (2005) draw attention to how contextual influences create challenges in introducing ICTs in the healthcare sector. These are influences like inadequacies in both computer-based and physical infrastructure, the persistent presence of legacy systems embroiled with different institutional interests, weak human resource capacities both in numbers and skills, heavy workload of health staff and a culture of information use which sees periodic reports as primarily fulfilling the needs of the bureaucracy rather than of using the information to support action. They state that introducing computers does not itself lead to better handling and use of information and the challenge is to initiate a culture where information is seen as a resource for action rather than one for only fulfilling the needs of the bureaucracy.

Health information systems in most developing countries are inadequate in providing the needed management support (WHO 1987, Lippeveld et al. 1992). Lippeveld and Sauerborn (2000) argue that most health care providers in developing countries equate information systems with filling endless registers with names and addresses of patients,
compiling information and sending out reports without adequate feedback. The data received by the management are often incomplete, inaccurate, untimely, obsolete and unrelated to the priority tasks and functions of local health personnel – and hence not helpful for management decision making. Additionally, a large part of the data collected passes to the national level without being analysed and used. Consequently, HIS tend to be “data-driven” instead of “action-driven” (Sandiford et al. 1992), which typically see data as an end in itself, rather than as a basis for planning, making and evaluating interventions (Raghavendra and Sahay 2005).

Another source of problem is the existence of parallel and fragmented systems caused by donor assistance focusing on particular disease specific programs rather than a unified HIS (Lewis 2005). HIS initiatives often rely on foreign experts who regard the user organisation only as consumers of the technology, and not as active participants in the design and development process which in turn leads to the creation of unsustainable HIS (Kimaroa & Nhampossa 2005). There is a common comprehension that information systems for the developed world are not directly transferable to the developing world with expectations of similar results. Such a “technology transfer” from one site to another, relies on the transfer of the entire context of the technology, including work routines and organisation, in order to be successful (Braa 1996).

Many countries in the third world are in the midst of a process of decentralising their health sectors based on computer based information systems support (Braa et al. 2001). In 1978, WHO and UNICEF called a meeting where primary health care (PHC) were declared as a strategy to be adopted by all countries (Grace 2004). Principles of decentralisation, local control of information and empowerment are embedded in the concept of primary health care. The challenge is to analyse and use the information immediately and at the same level where it is collected, thus generating local information to support local action (Braa et al. 2001). As early as 1981, the WHO emphasised the importance of HIS and related skills training as a part of the primary health care approach (Williamson, Stoops & Heywood 2001).
There is generic evidence that a significant majority of information systems initiatives are failures in both the private and public sector (Heeks et al. 1999). Raghavendra and Sahay (2005) state that there is an urgent need to shift the focus from computerisation itself to the question of “what is it that we want to achieve through computerisation?” Lippeveld and Sapirie (2000) have identified four preconditions for a successful HIS. These include (i) high level direction and coordination in the restructuring of a health information system, (ii) broad agreement with the principle of “information for action” at all levels, (iii) HIS development to be strongly linked to the overall health system development and reform process, and (iv) the availability of a core multidisciplinary HIS development team. Heeks et al. (1999) argue that a health care information system’s success or failure depends on the degree of mismatch between the conceptions in that system’s design and the realities into which it is introduced. They propose the ‘ITPOSMO’ model which measures the gap between current reality and the design proposal for a new HIS based on seven different dimensions given below:

**Information:** How the information provided by the system covers the information needs of its users.

**Technology:** How the technology of the system differs from the technology in the environment of which it is introduced.

**Processes:** How the system supports the process reality in the organisation where it is introduced.

**Objectives and values:** How the system’s design match with the objectives and values of the users.

**Staffing and skills:** The gap between conceived and actual human capacity requirements.

**Management and structures:** How the system is designed to fit within the existing health structures.

**Other resources:** Other factors influencing the gap between the system’s qualities and the environment where it is introduced.
According to Heeks et al., the risk of failure of a HIS can be minimised by considering these seven dimensions.

As mentioned, contextual influences often provide challenges in introducing ICTs in the health care sector. Taking these contextual influences into account before developing an HIS will benefit the implementation and minimise the risk of failure. Concepts drawn from information infrastructure (II) theory provide an approach to develop such a broad framed analysis.

3.2.2 **HIS conceptualised as HII**

II theory provides and extends upon a social system perspective to study systems. After giving the general theory on information infrastructures, I will argue why HIS should be conceptualised as HII.

3.2.2.1 **Information Infrastructure**

IIs are more than pure technology; they are rather better conceptualised as socio-technical networks (Hanseth & Monteiro 1998). While information system design methodologies aim at developing a closed system with pre-defined start and end points for a closed customer organisation (Monteiro 2003, Chilundo and Aanestad 2003), an II perspective provides a more sophisticated social system perspective to study heterogeneous, complex and interconnected systems (Hanseth & Monteiro 2001). The kind of IT solutions we are developing today and will increasingly do so in the future, will necessarily involve the integration of multiple systems across organisational and geographical borders. As a result, these networked, technical and institutional, systems, are in many respects significantly different from traditional information systems, and are arguably better conceptualised as information infrastructures, not systems (Hanseth 2002a).

A number of keywords are mentioned when characterising an II (Hanseth 2002a), including II as a shared, evolving, open, standardised, and heterogeneous installed base.
McGarty (1992) defines an II with the following keywords: shareable, common, enabling, physical embodiment of an architecture, enduring, scale and economically sustainable.

One of the fundamentals when it comes to infrastructures is that it is not developed from scratch - they are designed as extensions and improvements of existing infrastructures. (Hanseth 2002a) describes an installed base which as it evolves, its development and further growth becomes self-reinforcing. A success factor in developing infrastructures is to create this self-reinforcing process and then to manage its direction (ibid). Hanseth (2002a) calls the strategies for creating and managing this process as one of cultivation, as contrasted to that of construction, which refers to something being constructed from scratch. A key characteristic of an infrastructure is that it evolves continuously, and over time includes more users and use areas. This is similar to that of a road infrastructure – any new road is an improvement of the existing infrastructure, and with its evolution it necessarily gets interlinked with other forms of infrastructures.

Hanseth and Monteiro (1998) have identified three core aspects of infrastructures – of them being enabling, shared and open. Being enabling implies that an infrastructure is designed to support a wide range of activities, and is not especially tailored to one predefined use. It is enabling in the sense that it is a technology intended to open up a field of new activities, not just improving or automating something existing (ibid). An infrastructure is shared in the sense that it is a single object shared between a number of users or user groups although they might perceive the infrastructure differently. This is opposed to the traditional view where IS are being seen as individual tools, developed for very specific and predefined purposes (Hanseth 2002a). The infrastructure can evolve continuously because it is open. An infrastructure has no borders regarding the number of elements it might include, how many users it has or the number of use areas it may support (Hanseth 2002). It is also open in the sense that there is no limit to who may contribute to the development of the infrastructure, and there is no finite beginning or ending in the development of the infrastructure (ibid.).
Infrastructures are heterogeneous in the sense that it includes elements of different qualities, technological as well as non-technological (human, social, organisational etc.). It is also heterogeneous in the sense that larger components or infrastructures are built based on existing smaller, independent components which when brought together will become interdependent. When one of the components is changed, the others will often need to be changed as well. Consequently the II is irreducible and cannot be studied as a separate individual component. In such a large network, standards are essential in order for the various components to communicate. In case of two networks without the same standard, gateways can be created, for example as a link between different elements. They are considered being the cheaper and easier means to integrate two already existing large networks as compared to building a new network which executes both of the already existing networks (Hanseth 2002b). An example of a gateway is the “Nordunet plug” which was developed as a gateway between different networks utilised by the users and was an instrumental factor to how the Nordic countries (except Denmark) became the leading ones in the adoption and use of the Internet (Hanseth 2001).

The Internet is one of the classic examples of an II. It has evolved over time from being a small network of few users to being the largest existing network in the world, consisting of millions of files shared by even more users. The Internet is continuously growing and elements are added continuously. There are no limits to what can be included or to who can contribute and there is no beginning or end to its evolution. The Internet is a network consisting of a vast variety of elements ranging from servers and users to a huge number of different types of files communicating with each other. Consequently the Internet is a shared, evolving, open, standardised, and heterogeneous installed base.

Another concept associated with infrastructures is bootstrapping. This term is used in conjunction with getting an infrastructure “up and going” – bootstrapping the installed base. To do this, one must attract users even though not being able to offer the benefits of a large network. According to Hanseth (2002a), this may be achieved by making the first version of a new infrastructure tailored to specific needs of the first users so that they get some other benefits from using it than those created by network externalities. Being a first
adopter of an infrastructure involves higher costs and risks than being a later one, and accordingly, the version adopted by the first users must be as cheap as possible in order to make the investments profitable within a reasonable time span (Hanseth 2002a).

For example, the attraction of the instant messaging service, MSN Messenger, is the network itself. It had to be bootstrapped in order to get some people to start using it without the benefit of the network. When it had attracted some users, the network would cultivate and become self-reinforcing.

As HIS are complex networks reflecting the characterisations of an II, I argue that HIS should be conceptualised as HII. These arguments are presented in the section below.

3.2.2.2  

HIS conceptualised as HII

As mentioned previously, IS design methodologies typically aim at developing a closed system with start and end points for a closed customer organisation (Monteiro 2003, Chilundo and Aanestad 2003). However, HIS are complex, highly interconnected heterogeneous systems as they tend to be deeply embedded in social, cultural, political, technical and contextual issues, and hence they cannot be treated as closed systems with start and end points. As HIS have several characteristics in common with those of an II, I argue for the need to conceptualise a HIS as a health information infrastructure (HII). Braa et al. (1999) state that conceptualising HIS as IIs imply that they develop and grow over a long time with layers upon and within one another. New features tend to get added as extensions of or changes of something already there, the installed base. For example through the HISP project in Mozambique, the legacy information system (LIS - installed base) was cultivated through a replacement-integration-add-on strategy which implies that functionality was added to DHIS without modifying the LIS, and to connect the old and the new through gateways. In this way, the installed base was cultivated in a sensitive manner by gradually adding layers to it (Nhampossa 2005).

One of the fundamental concepts of II is the installed base and how an II can not be made from scratch. When changing and improving an HIS, it is essential to take the existing
system, both technical and institutional, into consideration and understand its complexity and the challenges it poses to making rapid and vast organisational changes. As HIS are highly interdependent where all the components depend on each other, they are irreducible. As an II, as opposed to a traditional IS, applied methodologies need also to see the systems as irreducible, in a holistic manner which emphasises the need for sensitivity to developing and sustaining the interconnections.

When HIS are conceptualised as HIIs, the associated methodologies need also to be re-conceptualised so as to account for the networked, heterogeneous and evolving nature of infrastructures. A key concept or methodology that needs to be re-conceptualised concerns approaches to Participatory Design (PD), which is the focus of this thesis. In the next section, I provide some of the traditional ways in which PD has been treated in IS research, which then provides the foundation to how PD should be re-conceptualised.

### 3.3 Participatory design (PD)

Historically, PD has proved to be an important success factor in systems development. In this section, I will argue for the importance of using PD in the development of HIS after giving an introduction to the general theory of PD. Furthermore, I will argue that existing approaches to PD need a radical re-conceptualisation in line with the turn of looking at HIS as HIIs.

#### 3.3.1 Participatory design theory

There are several definitions of PD. Greenbaum (1993a) says that PD implies that workers as users of computer products should take part in the decisions that affect the system and the way it is designed and used. CPSR (2005) sees PD as an approach to the assessment, design, and development of technological and organisational systems that places a premium on the active involvement of workplace practitioners (usually potential or current users of the system) in design and decision-making processes.
Over the years, user participation has become an important part in the design of effective information systems and has been considered to be an important determinant of the eventual success of the system (Puri et al. 2004). The introduction of user participation has helped to refocus the previously technical orientation of system developers to also include the needs of the users, as opposed to what was common in the computer science tradition. While user centred design helps paving the way towards PD, it is not necessarily participatory in itself. Participatory design of computer systems needs also to include work organisation, job content and the way technology is used to support these activities (Greenbaum 1993a).

Participatory design differs from traditional design in several ways. It sees computerisation as an attempt to give workers better tools for doing their jobs rather than automating the existing skills of human workers. It assumes that the workers themselves are in the best position to determine how to improve their work and their work life. It values the users’ perceptions and feelings about technology highly and it views computers and computer-based applications in the context of a workplace – as processes rather than products (Czyzewski, Johnson and Roberts 1990). PD has focused on what goes on before the system is decided on, arguing that an understanding of the use context may result in different systems (Bratteteig 2003). This is part of mutual learning which means that users and designers learn from each other during the design process, and both qualify themselves with respect to the systems development process they are involved in. Bratteteig emphasises mutual learning as an important aspect of PD.

Greenbaum (1993b) has identified three different perspectives that argue for the need of participatory approaches:

- **A pragmatic perspective:** A strategy to build systems that work better and to increase product and service quality.
- **A theoretical perspective:** A strategy to overcome the problem of lack of shared understanding between developers and users.
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- A political perspective: A democratic strategy to give people the means to influence their own workplace.

These perspectives are rooted in Scandinavian experiences, but according to Greenbaum, they are adaptable cross-culturally. Braa (1996) proposes one more perspective in addition to the ones above for striving for democracy and technological influence in third world computing:

- A community perspective: A strategy to enhance both the community as well as prepare technical development that goes beyond mimicking the first world.

This perspective is derived from a political orientation, but is extended to encompass both the workplace and the community.

In order for the users to learn about the possibilities given by technology and for the designers to learn about the users’ needs, there needs to be interaction between these two parts. The designs that emerge from consensus decision-making contain the knowledge and experience not only of the individuals but also of their respective roles and tasks, so that the final design meets all aspects of the users' needs (Wilson et al. 1992).

There is a general agreement amongst researchers that PD is useful and necessary in IS development. However, Markus and Mao (2004) criticise the traditional IS participation theory for being outdated and propose a new theoretical framework with a redefinition of traditional participation. They point out three explanations for how and why participation leads to system success as presented by PD literature: the creation of psychological buy-in; the improvement of system quality; and, the emergence of relationships among developers and users. How Markus and Mao argue that these three explanations leave important issues in PD unaddressed is explained below.
Creation of psychological buy-in refers to participation being experienced as personally relevant and important, leading participants to feel committed to the system they help develop and hence induce them to adopt and use it. Markus and Mao argue that this can only be the reason of system success as long as the entire user group of the intended system is participating. When there are intended users who have not participated, other causal processes (such as committed participants who act as persuasive advocates) must be present to explain system success.

In traditional participation literature, participation is seen to improve the system quality by giving developers the information they need to produce a high-quality design. Markus and Mao argue that just because participation activities provide developers with information they need to build a system that meets users’ requirements, does not mean that the system developed will actually incorporate those requirements. Developers might have other objectives in addition to meeting user requirements. For the quality explanation to explain system success, additional causal processes such as the technical design process are required.

A third explanation often used for analysing participation effects on system success focuses on emergent interactions between developers and users. This view focuses on the relationship evolving between developers and user participants, and how these contribute to the incorporation of user requirements in system design. Markus and Mao argue that this can lead to a system satisfying the participant’s desires, but not meeting organisational needs, and hence it can not completely explain system success.

Markus and Mao propose a new question for IS participation research: “How can change agents employ participation practices to increase the chances of success in varied IS development contexts?” They argue that this question will lead us to be explicit about 1) the success outcomes, 2) actors, including change agents and others, 3) activities devised by change agents for others’ participation, and, 4) hypothesised links between activities and outcomes.
The critique presented by Markus and Mao includes the important point for improving the use of PD to achieve system success. Particularly important is the shift from the PD presented in the traditional research, which tends to support the development of a separate system, to PD for use in large and complex development projects such as Enterprise Resource Planning systems (ERPs). However, they have less focus on external factors influencing participative processes, and more on who is participating, how these have been selected to participate and how the behaviour of the participants and the relations between these shape the system outcome. I will take these inferences introduced by Markus and Mao and extend it for use in an II perspective given my conceptualisation of HIS as HII.

Another source for the need for extending PD thinking is that traditional approaches to PD were applied in Western contexts, while what I am arguing for is its use in developing country settings. A number of issues arise in the transfer of such methodologies across countries. There is considerable diversity in participatory approaches to IS development depending on the countries where the traditions are developed (Nhampossa 2005). I will provide an overview of the history and research from four areas; Scandinavia, UK and Europe, US and the developing world. This provides the basis for presenting my perspective on PD which accounts for both the infrastructural nature of health systems, and the fact that it involves a cross-country circulation of methodologies.

3.3.1.1 Scandinavia

The concept of user participation in system development has been present in Scandinavia for more than four decades. It started with the discussion about the relationship between work and democratic values in around 1960. In order to increase productivity and efficiency, it was agreed to try and create opportunities of increased individual engagement and the industry’s levelling of the general democratic principles in society (Bjerknes & Bratteteig 1995). Around the same time, The Norwegian Federation of Trade Unions (LO) designed and conducted a large action programme in cooperation with The Norwegian Employer’s Federation (NAF). This programme was an industrial democracy programme for improving the working life in Scandinavia. One of the results of the
Cooperation Projects was a revised *Worker Protection and Working Environment Act* which states that workers and their representatives shall be kept informed about systems used for planning and performing work and about planned changes in such systems. The main idea is that the workers themselves shall control and be responsible for performing work (Bjerknes & Bratteteig 1995).

The first political project was initiated by the Norwegian Iron and Metal Workers' Union (NJMF) in a resolution made at the national congress in 1970 (Nygaard 1979). The resolution stated that the trade unions had to start up research of their own, as the employers had been doing for a long time. Money was appropriated and the “Iron and Metal Project” started in 1971 and was completed in 1973. The objective was to apply a workers’ perspective on the development and introduction of new technology in order to produce an action plan that would represent and strengthen the workers’ position with respect to the introduction and use of computer technology. The NJMF project emphasised that locally gained knowledge should be the basis for the trade unions to act on a central level (Bjerknes & Bratteteig 1995).

Other Scandinavian projects included the Swedish DEMOS projects (DEMOkratiske Styringssystemer) and the Danish DUE project (Demokrati, Udvikling og Edb). The first lasted from 1975 – 1979 and was a project on “trade unions, industrial democracy, and computers”. The aim was to identify possibilities for the unions to influence the design and use of computer-based systems at the local level in the companies (Ehn 1993). The Danish project took place from 1977 – 1980 and the primary objective was to contribute to the efforts of the unions to gain influence on the use of computer systems, in accordance with their interests (The DUE Project Group 1979).

As stated by Bjerknes and Bratteteig (1995), these projects have some characteristics in common as they aimed at strengthening the labour side in relation to the contradiction between workers and management. They were also striving for creating a democratic research and development process claiming that researchers have the duty to support those with less power and resources. The researchers of the projects believed that working life
democracy could be reached through trade unions as institutions representing a workers’ collective.

The trade union projects showed that strong unions could increase the workers influence on technology, but not sufficiently. It appeared to be necessary to create alternative technologies as well, to fight vendors’ monopoly (ibid.). From a union perspective, important aspects such as opportunities to develop skills and to increase influence on work organisation were limited (Ehn 1993). As a result, the focus shifted to production and working conditions, and the next ‘generation’ of projects concentrated on the development of technological alternatives (Bjerknes and Bratteteig 1995).

The UTOPIA (Utbildning, Teknik och Produkt i Arbetskvalitetsperspektiv) project lasted from 1981 to 1984, and was a cooperation between the Nordic Graphic Workers’ Union and researchers in Sweden and Denmark with experience from the first generation of work-oriented design projects. IT was a research project on the trade-union-based design of, and training in, computer technology and work organisation (Ehn 1993). The UTOPIA project specifically addressed the need for alternative systems in the newspaper industry for page make-up and image processing. Mutual learning was used in the project, while the graphic workers learned about the technical possibilities and constraints of computer technology, the designers learned about the craft and profession of the graphic workers. The communication between the designers and graphic workers using traditional approaches like data or information flow was problematic, so they shifted to a “design-by-doing” approach. This approach included the use of mock-ups and other prototyping design artefacts and the workers could actively participate in the design process. The UTOPIA project was seen as a success as it showed that the latest technology may be designed and put into use to improve, not decrease, the skills of graphic workers. However, due to the limited resources in the Scandinavian countries, the system, called TIPS, was sold before its final development as a market product (Ehn 1993). Bjerknes and Bratteteig (1995) states that UTOPIA was considered a continuation of the history of guilds and trade unions and consequently not a contribution to the workplace democracy.
where all the stakeholders have a voice in the design of a new computer system. Participatory design was arguably academically invented in this project.

Later, two research projects in the Systems Development Group at the University of Oslo aimed to add to the systems development discipline by concepts and techniques (Bratteteig 2003). The Florence project (1983-1987) aimed to develop and try out techniques for user participation in systems development, and the FIRE project (1991-1994) studied systems development practices aiming to re-conceptualise systems development as a continuous redesign of computer-based information systems, emphasising the need to present the systems (to the users) as a whole rather than a collection of different systems (ibid.).

Bratteteig (2003) identifies two approaches within the Scandinavian tradition. A socio-technical approach stresses that employers and employees have a common interest in developing useful computer systems, and provides techniques for stakeholder participation. The organisation as a whole is addressed, and the emphasis is on balancing different interests. The critical tradition, however, emphasises the fact that there is an inherent conflict between employers and employees, and that it is the researchers’ duty to support the weaker party, i.e. the employees. What seems to be common in Scandinavia is the democratic work life that characterises and is part of society, and the deeply felt respect for users’ expertise on equal terms. The fact that the socio-cultural context encourages democratic dialogue makes possible real participation in all parts of systems development (ibid).

Beck (2001) argues that PD in Scandinavia is in danger of becoming a “repetition exercise” lacking what once was innovative and world-changing. She states that the renewal of PD happens outside of Scandinavia and expresses her concern on how little debate or interest there is in renewing key aspects of PD within Scandinavia. Further she argues that the realising of PD’s potential requires a renewed conceptualisation of areas and means of impact of politically motivated systems design research.
Spinuzzi (2002) argues that later Scandinavian work tends to focus on functional rather than democratic empowerment. He states that “…the most important response to the Scandinavian challenge has been the Scandinavians’: methodologically, they have crept ever closer to their compatriots in the US” (ibid. p.213).

Researchers seem to agree that the Scandinavian tradition is in need of refreshment. The political context from where it evolved is changing, and the Scandinavian PD approach has not been able to follow this change. Although participation is highly used in development projects in Scandinavia, there is no framework for this use. Rather, anything regarding user involvement is alleged to be participatory design. The research on PD in Scandinavia has mainly been with a focus on the workplace environment where the employee’s power is relatively high. It pays less attention to how PD works in different contexts that might not have the same prerequisites for PD. Consequently PD needs to be re-conceptualised to suit other environments where the context is different. Also, this redefinition needs to reflect the technological changes that are taking place in various sectors, including in health.

3.3.1.2 The United Kingdom and Europe

While the Scandinavian tradition is characterised by emphasising that users are co-designers and that systems development involves organisational, technical, and human change process, PD seems to be conceived differently in other places. In other parts of Europe, PD design was carried out through a variety of methods based on systems thinking (Bratteteig 2003).

In the UK, the researchers focused on autonomy in work-group organisation through “socio-technical systems design.”(Asaro 2000). They saw a union-centred approach as only being viable in the political environment of Scandinavia and as failing to theorise the organisation of labour on a fundamental level. The Scandinavians on the other hand, saw group dynamics as being ineffectual because it failed to consider the predominant power struggles of class and capital. Both approaches, however, were motivated by a shared
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corn for workplace democracy and the humanisation of work and both contributed to the broader Quality of Working Life movement beginning to take shape (ibid.). The underlying assumptions of the socio-technical approach were to emphasise what humans consider important in their work, and seek consensus amongst management and workers over a specific project’s aims and implementation (Nhampossa 2005). Floyd et al. (1989) termed the socio-technical approach as being premised on a harmony perspective. The project-based orientation of the socio-technical approach is confined to individual organisations, “rather than building up a general strategy for democratisation,” (ibid. p.268), and therefore has attracted criticism from trade unions.

The socio-technical approach led to research in Britain focusing on autonomy in work group organisations through power sharing, joint responsibility and multiple leadership. This was exemplified through the ETHICS (Effective Technical and Human Implementation of Computer-based Systems) method developed based on research done by the British Professor Enid Mumford. This methodology was developed to assist the introduction of organisational systems incorporating new technology, and its principal objective was the successful integration of company objectives with the needs of employees and customers (Mumford 1983).

3.3.1.3 The United States

In the 1990s, participatory approaches to design increased in popularity in the United States. Here, the PD approach was adopted on a different scale governed by the socio-political conditions that are different from those obtaining in the Scandinavian countries (Puri et al. 2004) While the high degree of unionisation in the Scandinavian countries and legislation-regulated participation in most European countries has helped build a base for participatory ideas, some of the participatory design advocates worried about how the lack of unions would prevent the development of PD in the United States (Greenbaum 1993a). It is however argued that strong opinions about the value of democracy could form a base for building participatory projects in the United States (ibid.).
After the UTOPIA project, the US took up on this “Scandinavian Challenge”, but it lost some things in the translation (Spinuzzi 2002). While unionisation had been considered a key ingredient for PD in Scandinavia, the unionisation in the US was only about 15%. Consequently, the academics and researchers modified the techniques and goals of the Scandinavian approach, and added their own. Two results of this were PICTIVE (Plastic Interface for Collaborative Technology Initiatives through Video Exploration) and CARD (Collaborative Analysis of Requirements and Design) developed by Michael Muller. He found that, in sidestepping the unions, his focus broadened to workers other than end users whose work lives would be affected, such as technical writers. Together, PICTIVE and CARD provided a “bifocal” approach that allowed designers and workers to partner on both “microscopic” and “macroscopic” levels (ibid.)

In 1998, Beyer and Holzblatt published a book describing their design approach called contextual design (Spinuzzi 2002). The book describes contextual design as a “customer-centred” design approach that revolves around observing aspects of employees’ work, developing work models based on these observations, and basing new system designs on the work models. The workers, although they are termed “co-designers”, are emphatically not designing the system using the prototypes: “It’s their job to do their job, not design systems” (ibid, p.208). Contextual design emphasized the prototyping component, and was designed to disrupt work as little as possible and to relieve workers of the additional work of design. This encourages them to make minor changes and suggestions – but explicitly not to become designers themselves or to disrupt the division of labour established by the design team. While UTOPIAn mock-ups reflected a desire for democratic empowerment, in which workers made decisions along with management; contextual design strives for functional empowerment, in which workers are better able to perform their jobs (ibid.).

In main, participatory approaches to system design in the US were adopted by way of “engineering co-development” (Puri et al. 2004). This approach was a customer-centred prototyping methodology which placed a great deal of emphasis on obtaining customer reactions to working prototypes placed in the customers' workplace. The idea was thus to "tune" the artefact to the work environment in which it was to serve. Nhampossa (2005)
summarises the features of participation in the US as follows: the right to participate in design by users is limited; most design decisions are driven by the managerial domain; in most cases the user participation takes place mainly for instrumental reasons; and there is a limited concept of workplace democracy.

The key idea of PD – namely to increase the workers or end-users’ influence on their daily work, was not the key emphasis in the US. The use of PD was rather economically driven than for creating workplace democracy.

To summarise, PD evolved in Scandinavia, with users as co-designers in systems development with the aim of achieving workplace democracy. The focus was on enriching system design with domain knowledge for lowering the resistance of workers to new technology. In Europe there was mainly a socio-technical approach with research on autonomy in work group organisations through power sharing, joint responsibility and multiple leadership. This was exemplified with the ETHICS methodology. In the US, PD was used merely for instrumental reasons. Design decisions were mainly taken by managers, and the emphasis on workplace democracy was very limited.

The difficulties experienced when trying to “export” the concept of participation from Scandinavia to other parts of the world show that the use of PD is highly influenced by the context in which it is introduced. Information systems development has changed since PD was introduced in Scandinavia. That is when the systems usually were single, internal and locally based. Today, the system development industry is dominated by large networks of interconnected systems. Consequently the concept of PD needs to be re-conceptualised to suit the development of large information infrastructures with various interest holders with a consideration for the context in which it is introduced. Hence it needs to take into account the social, cultural and political issues affecting the infrastructure.
3.3.1.4 PD in the context of HIS in developing countries

Research has shown that PD is a precondition for successful use of ICTs in the health care sector in developing countries (Braa 1996, Byrne & Sahay 2003, Korpela et al. 1998). The potential of ICTs in this area is being increasingly recognised and various developing countries are in the process of implementing various health reform initiatives involving technology. However, despite the potential of ICTs in this relation, many systems have failed to provide the promised potential (Byrne & Sahay 2003). The reasons for this are diverse, but the organisational complexity of the primary health care systems with multiple levels of hierarchy and various vertical programs are suggested to be contributing factors (ibid). Other factors of history, geography, culture, infrastructure, inadequate skill levels and pressures of everyday work heighten the complexity. These complexities shape the design, development and use of IS. A step in trying to address this complexity is to enhance the use of participatory processes of various stakeholders (ibid.). Experience suggests that systems that are designed by a team of “information experts” without adequate involvement of key stakeholders usually fail to reflect the needs and practical reality of service providers and managers, and does not encourage the ownership of the systems (RHINO 2001 p.3). Research has emphasised the contribution of participatory processes in IS development, however these have particularly been articulated in western settings where the conditions are quite different from the developing country primary health care situation (Byrne & Sahay 2003).

The information handled in the health care environment includes, amongst others, patient data, scientific knowledge and professional communication. Consequently technical systems used in health care need to meet a variety of goals, adhere to multiple work routines, and serve different users (Sjöberg & Timpka 1998). Being complex, interconnected heterogeneous systems that are deeply embedded in social, cultural, political, technical and contextual issues, HIS needs to be designed not only with a technical orientation, but with considerations for an enormous number of components both technical and non-technical. These components are for example, health staff at different levels, government officials, technical infrastructure, work routines and organisational health structure.
PD has proved to be important in HIS development in both developed and developing countries. In Norway, the success of the Florence project, which included nurses in the development of a computer system for nurses (Bratteteig 2003), proved the benefits of user participation in the development of health care systems in a developed setting. However, the importance of PD in developing countries is particularly emphasized. Braa et al. 2004 state that local participation and commitment in the development and running of locally based HIS is seen as key issues in the delivery and management of health services in developing countries. They also argue that the non-working of HIS in developing countries arises from the organisational and social issues being inadequately addressed in implementation. Nhampossa (2005) states that the participation of the potential users of a HIS is of crucial concern and that the user’s sense of ownership is significant for the sustainability of a system.

Through research on a project regarding health care for children under five in South Africa, Byrne & Sahay (2003) contribute to the re-conceptualisation of participation in HIS design from a human rights perspective. They emphasise that the need for community participation cannot be ignored, and for taking the community into account, a multi-levelled, multi-sectoral approach is required. They found that community health outreach workers are central in developing IS that are culturally sensitive, flexible and used. They also point out that the ability to claim a right or fulfil duties requires the individual to have the capacity and information to recognise the rights and what needs to be done to achieve it.

It has proven to be difficult to adapt systems from a western context into a developing country context. Nhampossa (2005) discusses how the role of participation influences this “technology transfer” from north to south. He states that with the objective of building sustainable networks, user participation is crucial both for exercising control of the system and its institutionalisation, and also to develop user capacity so that they are able to evolve the systems in the future. The extent and quality of user participation thus fundamentally influences the process of technology translation. However, he emphasises that user
participation is a context sensitive process requiring both the mechanisms of participation and its content to reflect the local conditions, rather than being unproblematically “transferred” from the West.

Through discussion on different case studies using participatory design, Puri et al. (2004) supports the proposition of participatory approaches in developing countries tending to be behavioural. They emphasise that what is important in participation is who decides what data to collect, who collects it, who interprets the information and uses the finding, and how participation can make decision-making a more democratic process. Participation in ISD should be a process of bringing people together to understand different views and share decision-making so a sustainable IS is designed that is culturally and locally specific (ibid., Byrne & Sahay 2003). They also state that an interpretive approach to participatory IS design is needed to understand the socio-economics, cultural and political context that shapes the behaviour and actions of the users of the system.

Korpela et.al (1998 p.339) ask “if participation is so strongly conditioned by the national political climate, is cooperative design of information systems possible at all in developing countries where few “indigenous opportunity factors” seem to be available to ordinary workers?” He states however that the dismal experiences of many top-down international development projects pushed non-governmental and inter-governmental organisations to develop various participatory approaches. If this approach works in such projects, then it should also be valuable for IS development in developing countries as well.
In their article on community participation in health informatics in Africa, Korpela et al. (1998) conclude that for PHC information systems design, a tripartite participation is required – a partnership between designers (computer personnel), users/providers (health care personnel) and community representatives (figure 3.2). When these three parts is represented in a project, it encourages capacity building in the sense of empowerment of local or indigenous communities with information and skills needed to carry out specific activities. It also gives a sense of ownership and sustainability of the project when the donors leave.

Lessons from Korpela et al.’s research show how full participation in such projects is dependent on how three basic steps or activities are managed: (i) entry into community, (ii) capacity building, and, (iii) project implementation. The correct entry points into the communities need to be found. To do this one need to be aware of community needs, sensitivities and practical matters (Georgetown University 2005). The entry points can for instance be through government authorities and religious leaders depending on where the project is to be executed. There is a need for capacity building for all the arms of the partnership. Different levels of participation will exist and should be spelled out from the beginning of the project. Different groups have varying backgrounds and it is essential that each group have a good understanding of the other groups. Potential difficulties should be identified in the beginning of the project (Korpela et al. 1998). The positions of the team members should be understood to allow for effective and sustainable implementation. It is essential to have mechanisms for feedback which will facilitate community empowerment and sustainability and help keep the project on course and in focus.

According to Braa (1996), community participation means that the information systems must give the community the possibility to both survey the health system and the health status of the population and to set and assess targets. He identifies community
involvement as a central issue for community empowerment - as well as striving for influence, which is a pre-condition for community empowerment.

Braa (1996) describes two cases of system development taken place in South Africa; one with situations and problems relatively well known from the first world and one with new solutions addressing third world problems. In both cases, participatory design was seen as a pre-condition to success and progress. Korpela (1998) states that his workshop experience suggests that participation and cooperation are not only possible in a deprived African country, but a must. A computer based system will not survive the harsh socio-economic conditions without the dedication of its users, which requires users to be genuinely involved (ibid.).

Braa et al. (2004) address the issues of user participation in the centralised context of the Ministry of Health in Cuba. Their research confirms the suggestion that participative methods may be less feasible in centralised and politically controlled organisational environments such as in Cuba. Here, the centralised organisational and political setting has made it very difficult to mobilise support that is contradicting the official political structures, thus confirming that centralised organisations provide serious obstacles to participatory approaches (ibid.). However, the conditions for participation were good with a view on the people, as they were willing and allowed to participate, but the problems were rather related to the implementation of design decisions coming out of the process of participation. The need of support from the political structure was needed, but not easily obtained. However, if top level decisions have been taken, they will be executed. Hence this support was crucial, but not reachable in this case. This research further emphasises how participatory design is sensitive to the context in which it is introduced, and needs to be re-conceptualised to support different contexts.

As seen, participation is considered to be a crucial factor in IS development in developing countries. Multi-levelled and multi-sectoral community participation is essential for capacity building, a feeling of ownership and for sustainability. People need to be brought together to share views and participate in decision-making to enhance democracy, as well
as to build a culturally and locally specific system. User participation is seen as a context sensitive approach which is needed in order to achieve community empowerment. However, there is potential for improvement of the use of PD in developing countries. Puri et al. (2004) state a need for more debate that moves beyond the theoretical and ethical arguments, and discusses in detail the process of participation undertaken in IS development. Korpela et al. (1998) and Byrne & Sahay (2003) argue that PD must be expanded from designers and workers to the communities which are served by the workers and the system. Byrne & Sahay (2003) also argue for the need to move away from the workers for improved design towards participation as a right, involving a more multi-layered and multi-sectoral approach, and from skill enhancement in system design to capacity development which facilitates participation and that addresses the challenges faced within systems and structures of health and related sectors.

3.4 Proposed theoretical approach

Based on the theory and criticisms in the above chapter, as well as my experiences in developing countries, I have tried to re-conceptualise the concept of participation to suit the HII context. The main implications of this re-conceptualisation results in four principles; creating participatory networks, context sensitivity, focus on outputs, not just on techniques and focus on structural and behavioural changes. What these principles involve is explained below.

3.4.1 Building participatory networks

The creation of participatory networks implies shifting the focus from PD for designing single systems, to PD for designing large networks of interconnected systems. This involves identifying key stakeholders, not only from the user group, but from a number of interest groups which are necessary involved in the development of a large infrastructure. These stakeholders should be identified during the situation analysis and initial phase, and can only be identified on the condition of a thorough context analysis.
For example in the development of a HII, stakeholders range from end users, health staff, the community, government officials, educational institutions, funding agencies, NGOs, private organisations and change agents (developers). All these groups have different interests and they should not only communicate with the developers in specifying a systems description, but they should communicate with each other as well in order to share decision making and ideas. In this way a participatory network is formed, rather than a end-user focused participatory group which is commonly focused on in traditional PD literature.

3.4.2 Context sensitivity

Through the discussion of PD research, it has been shown that the transfer of participatory practices from one context to another is difficult and complicated. The political and cultural circumstances in one country may provide a fruitful use of PD, while other circumstances in another country makes similar use of these techniques problematic. For example, the use of PD in the democratic and worker-empowered Scandinavia is not transferable as it is to the centralised and politically controlled Cuba. Hence PD is highly context-sensitive and this should be taken into account when planning participatory approaches in IS development.

In order to address this issue in a development process, a context analysis needs to be conducted prior to initiation of the development and implementation process. This way, contextual factors such as political, social and cultural issues can be addressed and taken into account when planning participatory practices and contribute to successful use of PD.

3.4.3 Focus on outputs, not just on techniques

When planning a participatory approach, it is important not to blindly focus only on the participatory techniques addressed in theory, but also the results achieved from it. Participatory activities will give the most rewarding outcome when adapted to the environment where it is used. For example, if the participators are children then the participatory activities should be children-friendly, like low-tech prototyping, “sticky
note” brainstorming and drawings. Perhaps in some situations PD is not even necessary for the desired achievement. Hence, the output from use of PD should be considered just as much as what techniques to use.

3.4.4 **Focus on structural and behavioural changes**

When using PD in the development of an II, it is important to consider behavioural constraints and opportunities between the participants. This implies how the behaviour of the participants and the relations between these shape the system outcome. As the number of stakeholders and the complexity of the needs the system has to cater for increases in the development of large interconnected networks, it is important to take the behavioural factors into account when planning participatory practices.

However, it is also important to focus on structural changes, which often are a result when making changes in an II. For example in an HIS, the development could involve changes in the work routines or reporting practices. Structural changes highly influence the life of those affected by them and hence these should be included in the development through participatory processes, to make these changes as gentle as possible. Failure to do so may lead to opposition and resistance to the changes.

3.5 **Summary**

This chapter has explained why information systems should be viewed as social systems and presented the theory of II and how an HIS can be viewed as an HII. Further, research and use of PD in different contexts have been discussed and particularly the use of PD in HIS development in developing countries. Finally it is argued that PD theory is not sufficient for use in HIS development in development countries and an approach for re-conceptualisation of PD is outlined. The following chapter outlines the research methods used in this study, which builds a basis for the re-conceptualisation of PD.
4 RESEARCH METHODS

This chapter presents the research approach and the different qualitative research methods used in this study. My empirical focus was on the development the HIS in Kerala, particularly on the participatory methods used in this development. The chapter is arranged as follows: section 4.1 gives an introduction to my research interest and context, section 4.2 presents the research approaches; action research and case study. Section 4.3 explains the methods used for data collection, including interviews, observation and document analysis. Section 4.5 explains how the data is analysed, and finally section 4.6 gives a summary of the chapter.

4.1 Introduction

This research is a part of an ongoing action research programme called HISP, which works with introducing and improving HIS in various developing countries including India. My study deals with the initial development of HIS in Kerala and the methods used for successfully introducing the approach with a focus in particular on participatory design and the analysis and development of the associated information infrastructure. In order for such a project to be successful, it is crucial to gain knowledge about the existing system, organisational structure and work routines through extensive study and participatory practices.

Throughout my research, I aimed at gaining an understanding of how the existing HIS worked with data collection routines, reporting systems and the social and political environment in Kerala. In order to do this, I conducted interviews, participated in meetings and events arranged by HISP and others, and made observations. I participated in events arranged by HISP and others, and spent time studying the large amount of reports and other documents being sent within the health care system. I also contributed by making a
web-based training manual covering relevant topics as a resource for the health staff and other interested.

4.2 My personal background

Prior to my master’s degree, I had mainly a computer science background, and was introduced to health information systems through various courses at the University of Oslo (UiO). It was particularly in the course “Health Information Systems” (INF5760) that my interest for the topic arose. Additionally, I caught an interest for the topic of user participation which also was introduced to me at UiO. I have always been intrigued with India, and while meeting a senior professor from UiO and HISP India, I learned about Kerala where the HISP project was in the initial phase. Given the unique political and social situation of Kerala, we felt that this would provide a good research arena for studying the use of PD.

Before arriving in Kerala, I tried to read as much as possible about Kerala, its culture and society as well as the work conducted by HISP in India and participatory design. On arrival in Kerala I was welcomed by members of the HISP India team and introduced to their work and to the Kerala society. As the HISP India team had made contacts with government officials and health staff in Kerala, I used these to introduce my work, learn about the HII and to gain access to the research field. An important part of my fieldwork was also to study the work done by HISP India. As I was accommodated next to the HISP India office, I had the chance to be really immersed in their everyday work and work routines.

4.3 Research approach

Research methods are usually categorised into quantitative and qualitative research methods. Quantitative research methods were originally developed in the natural sciences to study natural phenomena. This method is now also accepted in the social sciences and includes methods like surveys, laboratory experiments and numerical methods. This study however is based on qualitative research methods which were developed in the social
sciences to study social and cultural phenomena. Qualitative research methods includes observation, interviews and questionnaires, documents and text and the researcher’s impressions and reactions. Qualitative research methods are designed to help researchers understand people and the social and cultural contexts within which they live (Myers 1997). This method is increasingly being employed in IS research due to a general shift away from technological issues towards managerial and organisational issues.

My aim is to re-conceptualise the concept of user participation through studying the use of it in Kerala, India. In order to do so, I have to understand the HII and the social and cultural context in which it is situated. Also, in studying the user participation used in the HISP project in Kerala, social and cultural issues need to be considered. As I am interested in people’s views, thoughts and feelings to be able to study in these areas, qualitative research methods provided me with the best methodology to do so, hence I adopted this approach. During my research, I used several qualitative research methods which I will now explain in greater detail.

4.3.1 Action Research

Action Research can be defined as “...social research carried out by a team encompassing a professional action researcher and members of an organisation or community seeking to improve their situation. Action research promotes broad participation in research process and supports action leading to a more just or satisfying situation for the stakeholders (Greenwood & Levin, 1998 p.4).”

Action research is an established qualitative research method in use in the social and medical sciences since the mid-twentieth century, and has increased in importance for information systems towards the end of the 1990s. The method combines theory and practice (and researchers and practitioners) through change and reflection in an immediate problematic situation within a mutually acceptable ethical framework (Avison et al. 1999) and therefore produces highly relevant research (Baskerville 1999). Action research
encourages researchers to experiment through intervention and to reflect on the effects of their intervention and the implication of their theories.

HISP India works to improve the HIS in Kerala, which implies making changes in a large interconnected network. These changes will influence organisational structure, work routines and cultural, social and political issues. My aim is to re-conceptualise user participation framed within an II perspective. To do this, I needed to research on the HIS in Kerala to understand its way of working and social and cultural implications. Action research has an agenda of social change. Greenwood and Levin (1998) describe the action research process to be built upon the conjunction of three elements of research, action and participation. As I wanted do research, as well as trying to bring new knowledge on the issue of user participation in developing countries by participating in the HISP project, I adopted the action research approach.

In action research, it is agreed that complex social systems can only be understood as whole entities with human and technological components. Baskerville (1999) argues that the fundamental contention of the action researcher is that complex social processes can best be studied by introducing changes into these processes and observing the effects of these changes. These changes are what have shaped the action research approach profoundly. Braa et al. (2002) emphasise the importance of situating the action within networks rather than on singular units. The emphasis on networks was a response to an increase in complexity and an underestimation of the effort to make change sustainable. A source of variation in action research is pointed out by Brown (1993), namely the distinction between the “Northern” and “Southern” traditions in participatory action research. While the “Northern” tradition is concerned with reforming organisations through problem solving, the “Southern” tradition is primarily committed to community transformation through empowering disenfranchised groups (ibid.). With the ambition to empower health workers at the local level, HISP India is mainly following the “Southern” tradition, however as the organisation is growing, elements of the “Northern” tradition might also be beneficial.
Action research is an iterative process involving researchers and practitioners acting together on a particular cycle of activities, including diagnosis, action planning, action taking, intervention, evaluating and specifying learning (Avison et al. 1999, Baskerville 1999), as shown in figure 4.1. Each iteration of the action research process adds to the theory.

![Figure 4.1: The Action Research Cycle (Baskerville 1999)](image)

**Client-System Infrastructure**

The Client-System Infrastructure is the specification and agreement that constitutes the research environment. It provides the authority, or sanctions, under which the researchers and host practitioners may specify actions. The researchers work closely with practitioners who are located within the client-system. These individuals provide the subject system knowledge and insights necessary to understand the anomalies being studied (Baskerville 1999). In my study, the Client-System Infrastructure was the health sector in Kerala, with the government officials who provided the permissions for the types of actions that could be performed and how. HISP worked closely with these instances to provide the details of the project progress. The client-system infrastructure also comprise of representatives.
from the health staff, the community and educational institutions who provide knowledge and insights in the change process.

**Diagnosing**

Diagnosing corresponds to the identification of the primary problems that are the underlying causes of the organisation’s desire for change (Baskerville 1999). In Kerala, representatives from HISP India conducted a thorough situation analysis, including mapping of the hierarchical structure of the HIS, its infrastructure, the reporting system and the work routines. The HIS was then assessed (diagnosed) and areas of improvements were identified. Issues identified were the time consuming reporting system with very limited use of computers, the lack of feedback and analysis provided to the institutions at the lower levels and the lack of local action. The situation analysis resulted in a proposal for implementation, which was provided to the health government. When I came to Kerala, the preliminary situation analysis had already been conducted, however the work continued with gaining more knowledge and details of the reports in the reporting system, identifying data elements and identifying partners and building alliances, in which I took part.

**Action planning**

Action planning implies the planning of actions to solve the problems identified in the diagnosing phase. This plan establishes the target for change and the approach to change. In Kerala, this phase included planning the actions based on the situation analysis and identifying the needs with regards to developing the functionality of the DHIS to support the needs of the actors at different levels. A number of interconnected activities were planned:

- Conducting user needs analysis.
- Developing software prototype and its testing and continuous refinement.
- Conducting training of health staff and trainers.
- Institutionalisation of technical systems and associated practices to enable their effective use.
- Creating mechanisms for sustainability and scaling.
Action Taking

In the action taking phase, the above mentioned activities were conducted. The DHIS was customised to suit the user’s needs by identifying the reports that were needed to be computerised as well as the corresponding data elements. Training of the newly hired trainers was conducted, and two training seminars were arranged. These seminars contributed to the further refinement of user needs as well as provide inputs on the DHIS 2.0. Additionally, demonstrations of DHIS were conducted in the CHCs and Block PCHs of Trivandrum District. After this, computers were placed in the clinics, and training of the staff at the clinics was initiated. Mechanisms for sustainability and scaling were sought to be provided by building a network of partners who could contribute with knowledge and resources.

Evaluating

After the actions are completed, the researchers and practitioners together evaluate the outcomes. Evaluation includes determining whether the theoretical effects of the action were realised, and whether these effects relieved the problems. If the change was unsuccessful, some framework for the next iteration of the action research cycle should be established (Baskerville 1999). The HISP project in Kerala had not yet completely reached this phase during the time of my fieldwork, however interim evaluations were being conducted continuously. A great deal of valuable and useful knowledge were gained from the activities specified above, the seminars provided the forum for hearing the doctors’ views and opinions on the HIS. Although slightly belated, the computers were successfully placed in the institutions, so training and data entry could commence. Hence the project can be categorised as being successful so far.

Specifying learning

This phase is usually an ongoing process where the knowledge gained in the action research (whether the action was successful or unsuccessful) can be directed to three audiences: i) The restructuring of organisational norms to reflect the new knowledge gained by the organisation during the research. ii) Where the change was unsuccessful, additional knowledge may provide the foundations for diagnosing in preparation for
further action research interventions. iii) The success or failure of the theoretical framework provides important knowledge to the scientific community for dealing with future research settings.

Restructuring of organisational norms can be exemplified through the changes made in the reporting procedures of the JPHNs and JHIs, which will minimise their work on reporting. Based on the knowledge of junior health staff spending a great amount of time on reporting, actions were taken to reduce the time spent on reporting and thus enhance the time on health service delivery. So far, the HISP project can be said to be successful in the sense that most of the users see value and advantages with the new system and expresses enthusiasm to get it up and running. However, it is hard to see any outcomes to learn from at such an early stage in the project. The iterations of the action research cycle will continue, and with time, further areas of learning will be identified and used.

Figure 4.1 shows a timeline for the different phases of the action research cycle conducted while I was in India. The times for the phases are approximate, as some of the phases overlap, it is difficult to be exact.

<table>
<thead>
<tr>
<th>2004</th>
<th>2005</th>
<th>2006</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nov</td>
<td>Dec</td>
<td>Jan</td>
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<tr>
<td>Diagnosing</td>
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<td>Action planning</td>
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<td>Action taking</td>
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<td>Evaluating</td>
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<td>Specifying learning</td>
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Table 4.1: Timeline of the phases of the action research cycle in the HISP India project

4.3.2 Case study

Case study research is the most common qualitative method used in information systems research (Orlikowski & Baroudi 1991, Alavi & Carlson 1992) and implies that the researcher explores in depth a program, an event, an activity, a process, or one or more

3 Junior Public Health Nurse (JPHN) and Junior Health Inspector (JHI) are the junior health staff in Kerala. Their work will be elaborated in chapter 5.
individuals. The case(s) are bounded by time and activity, and researchers collect detailed information using a variety of data collection procedures over a sustained period of time (Stake 1995). The essential characteristic of case studies is that they strive towards a holistic understanding of cultural systems of action (Feagin et al. 1991). Cultural systems of action refer to sets of interrelated activities engaged in by the actors in a social situation. The case studies must always have boundaries (Stake 1995). Case studies serve to develop multi-perspective analyses. This means that the researcher considers not just the voice and perspective of the actors, but also of the relevant groups of actors and the interaction between them (Tellis 1997).

A *positivist* approach to case studies generally treat the social world as a hard, external, objective reality like in natural sciences (Burrell and Morgan 1979), independent of the observer (researcher) and his or her instruments (Myers 1997). While positivist studies generally attempt to test theory, and increase the predictive understanding of a phenomenon, *interpretive* studies usually attempt to understand phenomena through the meanings that people assign to them (ibid). Walsham (1993 p. 4-5) says that interpretive methods of research in IS are "aimed at producing an understanding of the context of the information system, and the process whereby the information system influences and is influenced by the context". Due to my interest in developing an in-depth understanding of the context of the HIS and its cultural, social and political influences, I adopted an interpretive case study method. Also, the multi-perspective analyses which case studies involve, particularly suited my research as I wanted to see the case through many sides and aspects. A case study would provide me a good way to gain in-depth and foundational knowledge for use in re-conceptualising user participation.

Although the main direction of the research was predetermined prior to commencement, the research questions took shape during and after the fieldwork. Consequently, it is an exploratory case study where fieldwork and data collection may be undertaken prior to the definition of the research questions and hypotheses. However the framework of the study must be created ahead of time (Tellis 1997). The time frame of my fieldwork was four months divided in two parts, and a number of data collection methods were used during
the period. The case study dealt with a study of the introduction of the HISP approach in the state of Kerala and the participatory processes used. Although this subject includes a wide area of study, I drew the boundaries to what I found relevant to the research. I also drew a time limit at the time of finalisation of the fieldwork and have not included details on the progress after this time.

4.4 Data collection methods

There are several techniques available for collecting empirical data. In this section, I will in greater detail explain the data collection methods which I have used.

4.4.1 Interviews

Interviewing provides a way of generating empirical data about the social world by asking people to talk about the issues involved (Holstein & Gubrium 1997). An interview can be viewed as a special kind of conversation which may vary from highly structured, standardised, quantitatively oriented survey interviews, to semi–formal guided conversations and free-flowing informational exchanges. However, all interviews are interactional (ibid).

During my fieldwork, interviews were conducted in order to gain a thorough knowledge about the health care and reporting system in Kerala. To get a true reflection of the HIS, the interviewees were representatives from different levels of the infrastructure. Most of the interviews had a generally informal, conversation-like nature and were conducted face-to-face. Some of the interviews were conducted together with HISP India team members. The selection of who were chosen for interview was influenced by the network made by HISP India and also the availability of people, like the program officers who often were busy with various duties, including serving as election officers. Table 4.2 provides an overview of the conducted interviews and topics of discussion.
<table>
<thead>
<tr>
<th>Interviewee</th>
<th>Topic of Interview</th>
<th>Location</th>
<th>Recording</th>
</tr>
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</table>
| Technical Secretary      | - His role in the DHS  
- The Kerala government’s improvement plans for the HIS  
- The C-DAC project  
- Meeting the Program Officers                                                                                                                                 | DHS              | Written   |
| Addl. DHS PH              | - His area of responsibility  
- The reporting procedures on communicable diseases                                                                                                                                                               | DHS              | Written   |
| Addl. DHS Planning        | - His area of responsibility  
- The reporting procedures  
- Areas of improvement                                                                                                                                                                                            | DHS              | Written   |
| Demographer              | - Her area of responsibility  
- The reporting procedures  
- Calculation of indicators  
- Consolidation of reports                                                                                                                                                                                          | DHS              | Written   |
| Health Inspector and     | - Work routines  
- Reporting procedures  
- Hierarchical structure of the clinic  
- The facilities at the clinic                                                                                                                                                                                       | Vizhinjam CHC    | Written   |
| Health Supervisor        |                                                                                                                                                                                                                  |                  |           |
| Medical doctors           | - Their view on DHIS  
- Their views on the existing reporting system  
- How they think a computerised system will work in their clinic                                                                                                                                                 | At SCTIMST during training seminar | Written   |
Table 4.2: Interviews conducted

The language presented a challenge for me as I sometimes had difficulties grasping the “Indian-English” language which, in my ears, was spoken very quickly. Many of the JPHNs and JHIs only spoke Malayalam (the local language in Kerala), and also the Health Supervisors and Health Inspectors spoke little English. So in those cases, I had someone interpreting the interview for me. This was complicated at times as I was a bit uncertain whether the questions and answers were comprehended properly, both by myself and the others involved.

4.4.2 Observations

The purpose of observations is to collect data on the behaviour and activities of individuals at the research site. The role of the observer may vary from non-participant to a complete participant. A participant observer will participate in the research setting opposed to observing people at a distance (Silverman 2001).
During my fieldwork, I was a participant observer in the HISP organisation, studying their work practices and methods, interactions between staff and their ways of building alliances. I participated in two training seminars arranged by HISP and Sree Chitra Tirunal Institute of Medical Sciences and Technology, where the Medical Doctors had an opportunity to express their opinions about the improvement of the HIS and to test the DHIS software. Observations were also used as a means to derive an understanding of the health infrastructure and the ways of running of the clinics at local level. I observed the work routines at different clinics at the local level, particularly in the pilot site, Vizhinjam CHC, as well as the demonstrations of DHIS which were being held for the health staff at a number of CHCs/BPHCs

I also observed the HISP India team in regards to how they worked and how they were organised, and particularly how they used participatory design in the development of the HIS. Due to the location of my accommodation, I was provided with an excellent basis for observations of the work conducted by HISP India.

4.4.3 Document analysis

Texts and documents can be used to identify data which have been recorded without the intervention of a researcher. Texts are sometimes only important as “background material” for the “real” analysis, but in literate societies, they are an important feature of many settings (Silverman 2001). In my research, I used document analysis to understand the health infrastructure of Kerala and the work of the HISP organisation. The many reports, including action plans, monthly reports, reports on communicable diseases and consolidated reports, were studied in order to gain an understanding of the reporting system and the work performed by the health staff. I studied the master plan made by C-DAC as it provided an overview of the health structure and current situation of the HIS in Kerala, as well as the solution for an improved HIS suggested by C-DAC. Additionally, HISP documents such as letters for gaining permissions, MoU drafts and proposals were studied as well as the design and configuration of DHIS.

4.4.4 Other forms of data collection

In addition to the above data collection methods, photos were taken frequently to provide evidence from the fieldwork, for example the different forms, and for presenting the fieldwork. Additionally, e-mail communication was used for data collection, particularly in between and after the two fieldwork phases, when I did not have access to the field.

4.5 Data analysis

Data collection and analysis processes tend to be concurrent, with new analytic steps informing the process of additional data collection and new data informing the analytic processes (Thorne 2000). The theoretical lens from which the researcher approaches the phenomenon, the strategies that the researcher uses to collect or construct data, and the understandings that the researcher has about what might count as relevant or important data in answering the research questions, are all analytic processes that influence the data collection and interpretation processes. Analysis also occurs as an explicit step in conceptually interpreting the data set as a whole, using specific analytic strategies to transform the raw data into a new and coherent depiction of the thing being studied (ibid.). Morse (1994) believes that all qualitative analysis involves the following points:

- **Comprehending** the phenomenon under study
- **Synthesising** a portrait of the phenomenon that accounts for relations and linkages between multiple sources.
- **Theorising** about how and why these relations appear as they do.
- **Re-contextualising**, or putting the new knowledge about phenomena and relations back into the context of how others have articulated the evolving knowledge.

I have used ethnographic research methods which derive from anthropology’s tradition of interpreting the processes and products of cultural behaviour (Thorne 2000). These methods include coming to know a culture or a group through immersion and engagement in fieldwork, participant observation and also through texts, all of which also reflect methods used by me in this research.
Consequently I also used ethnographic analysis which uses an iterative process in which cultural ideas that arise during active involvement "in the field" are transformed, translated, or represented in a written document. In the process, I have sorted through the data which I collected in order to find inconsistencies and contradictions which can be used for re-conceptualising participatory design.

The analysis and data collection was at times concurrent, as the analysis often led to the identification of more data needed to be collected. An example of this is after learning that the reporting system was time-consuming and inefficient, more data needed to be collected to find why this was the case. After collecting data, I tried to interpret it and relate it to other data collected, for example how my understanding of the HII obtained through various interviews correlated with the analysis made by C-DAC in their master plan. Sometimes I discussed my findings with members of the HISP India team to get an objective view of the data. After gaining an understanding of the HII, I used the data to reflect on how PD best could be used in the context of Kerala and to contribute in the arrangements of participatory activities (like the conduct of collaboration meetings and seminars). Observations from these activities were further analysed to determine how PD best can be used in a context such as in Kerala and build the basis for re-conceptualising the concept.

4.6 Summary

In this chapter, I have presented the strategy and methodologies for this research. I have given an introduction to qualitative research methods and detailed explanation of the different methods used; interviews, observation and document analysis. I have also presented the work I have done under each of these categories, followed by the approach for data analysis. In the next chapter, I present my case study.
Building participatory networks for HIS in a developing country context – a case study from India
5

CASE STUDY

The work described in this thesis is a part of the ongoing action research project called Health Information Systems Programme (HISP) as described in the research settings. This chapter describes the situation of the HIS in Kerala since the initiation of the HISP approach and until the end of the fieldwork period. It portrays the initiatives carried out by HISP during the introduction of the program in Kerala, and observations and experiences gained throughout the fieldwork.

5.1 The Actors

Changing something as large and complex as HII is a process requiring the involvement of a great number of actors and elements. In addition to the HISP India team and government health authorities described in the research settings, the involvement of various other actors are also described in this section.

5.1.1 Sree Chitra Tirunal Institute for Medical Sciences and Technology (SCTIMST)

The Sree Chitra Tirunal Institute for Medical Sciences and Technology (SCTIMST) is an autonomous Institute under the administrative control of the Department of Science and Technology, Government of India, and is situated in Trivandrum. Its mission is to enable the indigenous growth of biomedical technology, besides providing highly standard patient care in medical specialties and evolving postgraduate training programs in advanced medical specialties, biomedical engineering and technology, as well as in public health.

The health sciences wing of the SCTIMST is called the Achuta Menon Centre for Health Science Studies (AMCHSS) and its main objective is to train health professionals in health research and in the formulation and implementation of health policies. The AMCHSS
became interested in the HISP project because they had realised the benefits of information and communication technology (ICT) in the health care sector. They were also involved in a project on Geographical Information Systems (GIS); which interested them into becoming partners in the development of the HIS.

5.1.2 Centre for Earth Science and Studies (CESS)

The Centre for Earth Science and Studies (CESS) is a centre of excellence in earth sciences. CESS is an autonomous research centre working to promote and establish modern scientific and technological research and development studies in the domain of earth sciences. They pursue a multidisciplinary approach to problems related to land, sea and atmosphere and are engaged in the development of GIS, satellite maps and geo-referencing. GIS provides an excellent method to analyse health data through visualisations in maps. CESS conducted a project in collaboration with SCTIMST in Kerala on mapping health data which was connected to locations in maps for later analysis using GIS tools. CESS was a relevant actor in the network as the use of GIS tools was planned to be integrated in the HII of Kerala.

5.1.3 Centre for Development of Advanced Computing (C-DAC)

Centre for Development of Advanced Computing (C-DAC) is a Scientific Society of the Department of Information Technology under the Ministry of Communications and Information Technology in India. Their vision is to emerge as the premier research and development (R&D) Institution for the design, development and deployment of world class IT solutions for economic and human advancement. The European Commission is sponsoring the government in Kerala with funding for the development an HMIS, and the government appointed C-DAC to develop various health related information systems for them. Potentially, HISP and C-DAC have areas of overlap with respect to the HMIS development.
5.1.4 **Amrita Institute of Medical Sciences (AIMS)**

The Amrita Institute of Medical Sciences (AIMS) is a 1000 bed specialty tertiary care health centre, in conjunction with a medical college hospital. AIMS is a not-for-profit organisation dedicated to establishing a centre of health care excellence and improving the well being of the community through quality programs of preventive medicine, medical education, and research. AIMS was included in the HISP project to assist in getting hospital data into the stream of HIS, since HISP is currently only taking care of PHCs and Government Hospitals.

5.1.5 **The pilot site – Vizhinjam CHC**

The Vizhinjam CHC (see figure 1.1) was chosen to be the pilot site of the HISP project as suggested by the Director of Health Services. The CHC covers a population of 123,315 people and comprises three mini-PHCs; Venganoor, Thiruvallam and Mukkula. Vizhinjam CHC also acts as the Venganoor PHC, which includes eight Family Welfare Centres (FWC).

Figure 5.1: Location of Vizhinjam

5.2 **Background**

The HISP project was initiated in Kerala in November 2004 when staff from HISP India and the University of Oslo (UiO) approached the Health Department in Kerala including the Principal Secretary and the Additional Secretary of Health for permission to initiate the HISP implementation. After obtaining permission, a preliminary situation analysis of the HIS in Kerala State was conducted, in which various PHCs, Sub Centres, district and state level officers were visited. As part of the analysis, meetings were conducted with different functionaries in order to understand the information requirements, data collection and
reporting, and the nature of the information flows. Through the situation analysis, the absence of any computerised system was apparent.

The health structure differed from Andhra Pradesh where the hierarchy consists of Sub Centre → PHC → District. In Kerala the structure is slightly more complex with one more element in the hierarchy; Sub Centre → Mini PHC → Block PHC/CHC → District. Additionally, in some cases like curable diseases, malaria and TB, the Mini PHC will report directly to the District and not to the Block PHC/CHC.

A requirement stipulated by the State Government was the sole use of free and open source software. In April 2004, a full-time office was opened in Trivandrum and two full-time M.Sc. Graduates in Computer Applications were hired to develop the software for Kerala. Additionally, two M.Sc. students from the Indian Institute of Information Technology were taken on as summer interns for development work related to the database maintenance module. The work was supervised by HISP India team members, and support was given by Ph.D. students, M.Sc. students, and a senior faculty member from the University of Oslo.

In order to have permission to test the software at a pilot site in the field, a formal application was sent to the Additional Secretary and Director Health Services (DHS). After consent was given, Vizhinjam CHC, 16 km from Trivandrum, was chosen as a pilot site as suggested by the DHS.

5.3 Fieldwork

My fieldwork was conducted in two periods, each lasting two months. The first period lasted from September to November 2005 and the second from January to March 2006. This section provides details about activities performed during the fieldwork, both by HISP India and myself, with particular emphasis on gaining an understanding of the HII and of the participatory activities conducted.
5.3.1 Building alliances

A crucial task for HISP was to make alliances within the Health Department and other relevant agencies. This was a necessary step in getting different stakeholders involved in the development work to build alliances, both in multiple sectors and at different levels.

In the beginning of the first period of fieldwork, I went along with one of the HISP India team members to meet with the Director of Health Services. The aim of the meeting was to update her on the progress of HISP and to inquire about the Memorandum of Understanding (MoU) between HISP India and the state government of Kerala which was reportedly in the State Law Department for clearance. We also asked for permission to conduct research on user participation in the development of the HMIS system and requested to meet with the program officers to gain an understanding of their work and reporting procedures. Due to the busy election season in September, she did not grant permission to meet the program officers (POs) as many of them were on election duty. This meeting was my first encounter with the government in Kerala and the Indian hierarchical nature was quite apparent. The director harbours considerable respect and her authority was visible through how people around her acted. Her office is large with numerous chairs in front of the desk where people sit and wait for a quick word with her. The body language of people approaching her was very submissive, which emphasised the authority she radiates. During my fieldwork, there were quite a number of visits to the DHS to seek various permissions, which helped me to gain a more subtle understanding of the dynamics around the hierarchical structure of the Indian health care organisation in particular, and within the broader Indian society in general.

The Additional Secretary works with the Principal Secretary and is responsible for the overall health issues for the whole state. He had previously showed great support of HISP and we met with him to provide an update on the project and to introduce myself and my research objectives. As he is above the DHS in the hierarchy, we also asked him about meeting the program officers, and in spite of the election season, he thought it was a possibility to meet them. He arranged contact with the Technical Secretary, European Commission, who is working under the Addl. DHS Planning to organize these meetings.
The Technical Secretary knew the people and the structure of the government’s health authorities well, and was able to arrange meetings with two of the program officers, the Addl. DHS Public Health and Addl. DHS Planning, and also with the demographer. The HISP project was introduced to the Technical Secretary and he explained, in general terms, how the reporting system worked and he also provided information about an HMIS project under development which the C-DAC was responsible for.

The Addl. DHS Public Health (PH) is in charge of the Epidemiology section along with malaria and communicable diseases. Every district has a separate Epidemiology cell, which receives all the reports related to epidemiology from the district. This is unlike the other programs where the reports are received from the demographer/statistical office. There are two sets of reports on malaria, one weekly (sent every Monday) and one monthly (sent at end of the month). For communicable diseases, reports are sent daily in case of an outbreak, usually in the monsoon season. Otherwise they are sent weekly to the state level DHS, National Institute of Communicable Diseases (NICD), government secretaries and even to the private secretary of the chief minister (head of state). Both the daily and the weekly communicable disease reports are sent by fax. WHO is sponsoring an online project in all the districts so that the reports of communicable diseases can be sent more effectively (over the internet). According to the Addl. DHS, the online system would be introduced very soon – maybe in a couple of months (from Sept. 2005). The system was however still not introduced when I left India in March 2006.

The Additional DHS Planning receives the requirements from all the District Medical Officers (DMO) in the state regarding different programmes in the district, and he is also responsible for budgeting and allocating funds to the districts. At the end of every month, he attends a meeting with the DHS and the DMOs to inform them about the allocation of funds. Every month, he receives Form 9 from the DMO (consolidated monthly report of district achievement), and sends it to the Central Government. He said that the transfer of the data is very slow, as it is all transferred manually. Due to this, when the meeting takes place, it is not the previous month’s requirements that are discussed, but those of the month before that. The information cycle (data collection, reporting, analysing, local
action and feedback) is not always completed due to this slow data transfer. He seemed to be aware of, and frustrated over, the challenges of the reporting system and stated that “a computer system would make transfer of the reports faster and then the analyses could be conducted on time.”

The demographer explained her work routines which included consolidating the reports from the districts and sending them to the program officers and Central Government. At this time, they did not use computers for data collection or generating reports. We were allowed to see reports from April to July 2004 which was a consolidation of all the reports from the districts. There were a few indicators present in the consolidated material, but these were calculated for three months, using the target for the whole year as basis, which resulted in significantly lower indicator frequency than actually achieved in this period. Whether this was a mistake, or intentional, it is not known, but the demographer emphasised, however, that she “…is not a medical person and doesn’t have much knowledge of the data elements”.

The Technical Secretary informed us that the HMIS project in progress in the state was initiated by the DHS and is sponsored by the European Commission (EC). In 2003, the C-DAC was engaged by the DHS to prepare a master plan for setting up the HMIS for Kerala. The objective of this was “to improve the quality of healthcare services by providing a state-of-the art reporting system using e-connectivity” (C-DAC 2003). The master plan is the result of a one-year study of the information requirements and the existing reporting system. The recommendations in the plan included the development of software, which will be hosted centrally in one server to be accessed by the 14 DMOs. It is stated that if a computer or internet is not available in the PHCs, they will send the reports to the DMO which will enter the data on their behalf.

The software developed by the C-DAC, as seen in figure 5.2, was being piloted in Malappuram district, but was not yet up and running. It has three main modules; health program, employee details and budgeting. The health program module is mainly about data entry and has limited reporting and analytical capabilities as well as indicators. The
employee details module contains information about all the employees of hospitals and clinics, their attendance, salary and vacancies.

**Figure 5.2: The software developed by C-DAC: Data entry module**

HISP India arranged a meeting with the joint director of the C-DAC in an attempt to explore how integration between their and C-DAC’s efforts could take place. The work of HISP was introduced and the benefits of integration with DHIS, which captures data from the peripheral levels, and the C-DAC software which works at district level, was discussed. The C-DAC agreed that it was a good idea to try to integrate the two applications. It was suggested that this could be done using a bridge which is capable of aggregating the routine health data from DHIS 2 into a convertible format which can be imported into their district-based software. The connection of these two applications will potentially contribute to the increased complexity of the HII.

During a visit to the Vizhinjam CHC to examine the pilot site, the staff at the CHC informed us of another project underway there, organised by the Achuta Menon Centre at the SCTIMST in collaboration with CESS. It is a GIS research project carried out in conjunction with the Master of Public Health (MPH) program run at Achuta Menon. Outputs from the GIS can be categorised into low and high end use. Low end use consists
of mapping the diseases and socio demographics features while high end use involves disease forecasting over the period and area. The goal of the CESS project is to show how maps can be used in public health as a model for the whole state of Kerala.

This project is also a model for how local participation can be executed. About 30 locally based, female volunteers had been engaged to work in pairs covering in total 15 wards of the Vizhinjam CHC area. In each pair, one is trained to use measuring tape and other technologies to make marks in a map of their section, while the other person is responsible for making household surveys covering who lives there, income, education, domestic animals and medical history etc. All the houses and roads are marked on the map (see Figure 5.3) and given an ID number which later is used to link the houses up with the survey information. Eventually these data will be available in a GIS tool where analysis of the information can be performed, which, like the C-DAC software, will contribute to increase the complexity of the HII.

The volunteers were given two week’s training before they were given a sample map for trial mark plotting. After successfully completing the sample map, they were given real maps and started gathering data. Since the volunteers are originally from the area they are covering, they are quite familiar with the surroundings which helps make the mapping more accurate. Despite limited technical education amongst the volunteers, they quickly adapted to the job and performed it successfully.
Later, we attended a workshop which took place at the Vizhinjam CHC regarding the GIS project. Representatives from CESS and SCTIMST as well as the volunteers were present at the workshop. The purpose of the workshop was to evaluate the study and discuss the maps containing the markings made by the volunteers (figure 5.4). The volunteers seemed to be very engaged and dedicated to the work. The main attraction of the workshop was that the geomatic scientists and public health researchers were working along with local inhabitants for developing spatial (maps, roads, etc) and non-spatial (socio-demographic) data. For HISP India, this was a valuable interaction, as it provided the opportunity to connect with additional stakeholders.

On October 28th 2005, a meeting was arranged at the SCTIMST as the first initiative to bring different stakeholders together to share views and ideas for an improved HIS in Kerala (see Figure 5.5). The representatives at the meeting were SCTIMST, CESS, CDAC, HISP, the Centre for Digital Health, and Amrita Institute of Medical Sciences. Among the delegation from HISP were also some professors from the University of Oslo who were doing research on the HISP project in India. The purpose of this meeting was to make a plan on how to improve the health service delivery by integrating different projects rather than having individual and redundant projects. The stakeholders introduced themselves and their work before the discussion primarily focussing on how best to cooperate.

Figure 5.4: Representatives from CESS, SCTMSIT and the volunteers are discussing the maps.
Figure 5.5: The collaboration meeting at SCTIMST

The potential areas of collaboration discussed were:

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<th>Software:</th>
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<tr>
<td>1</td>
<td>Spatial linking of health data to maps.</td>
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<td>Field testing – for both health science and community.</td>
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<td>2</td>
<td>Education and training:</td>
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<td>Public awareness – community level.</td>
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<td>Health staff – different levels.</td>
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<td>Masters and doctoral studies.</td>
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<td>3</td>
<td>Spatial data:</td>
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<td>Integrated databases.</td>
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<td>Customisation of GIS applications.</td>
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<td>Hospitals – ERP:</td>
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<td>5</td>
<td>Methodology:</td>
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<td>Community focus.</td>
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<td>Public health inputs.</td>
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<td>6</td>
<td>Analysis of health data:</td>
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<td>Disease patterns.</td>
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Table 5.1: Areas of collaboration discussed in collaboration meeting
Some concrete actions were identified, and responsibilities were assigned between the present members:

1. Comparative analysis of community data collected by Sree Chitra and HISP.
2. Telecast to community level doctors and onsite training.
3. Disease-specific surveillance courses.
4. Consolidating user requirements.
5. Proposal to DHS for creating state wide spatial database.

5.3.2 The pilot site – Vizhinjam CHC

The Vizhinjam CHC (figure 5.6) has 26 Junior Public Health Nurses (JPHN) and 13 Junior Health Inspectors (JHI) divided amongst the different mini PHCs. Each of the family welfare centres (FWC) is run by one JPHN. The area of Vizhinjam CHC is divided in 13 sections, with the JHIs being responsible for one section each. The JPHN is mostly responsible for mother and child health and family planning, while the JHI is responsible for the collection of blood smears. They also share many common tasks like making home visits and checking for communicable diseases and doing field surveys. Any incidents of communicable diseases are brought in to the CHC.

Figure 5.6: Vizhinjam CHC: HISP India team member and health supervisor
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The JPHN and JHI are out in the field every day. They each have a diary (figure 5.7) where they take notes of the home visits; who they have visited, what was done and if there were any diseases, etc.

**Figure 5.7: A JPHN/JHI field diary**

The collected blood smears are documented on a form as shown in figure 5.7. The house numbers and names identify the patients, and a unique serial number is given for each blood smear. The blood smear sample is marked with this serial number so it can be identified with the patient.

**Figure 5.8: Form for the reporting of blood smears**

When visiting a pregnant woman, the JPHN fills out a form called a Mother and Child Care record (Figures 5.9 and 5.10) which includes the name of the mother and details about her health. When a child is born, an additional line on the next page of the book is filled out with details about the child. These details include general information such as the date of birth and gender, and what kinds of vaccines were administered.
The Health Inspector is the supervisor of the JHI but since there is no Lady Health Inspector at Vizhinjam, the Lady Health Supervisor is responsible for the JPHN. The Lady Health Supervisor was on leave during the time of my research, so the Health Supervisor was looking after the JPHN in addition to serving as the supervisor of the HI. The HI evaluates the work of the JHIs, receives the different reports containing information gathered, and consolidates this data. Figure 5.11 shows the structure of Vizhinjam CHC.

Figure 5.11: The structure of Vizhinjam CHC
The Health Supervisor and Health Supervisor (figure 5.12) receive the consolidated data from the Health Inspector. They also transfer requests received from higher administrative levels to the lower levels. Their tasks include field inspection and supervision, supervision of the Health Inspector and assisting the Medical officer when needed. They will also serve as the program officers of any current program.

Figure 5.12: Health Inspector and Health Supervisor at Vizhinjam CHC

The Medical officer is the institutional head and administers both preventive and curing treatments to patients. She leads the health education classes together with the Health Inspector and Health Supervisor.

In October 2005, a computer was placed in the administrative office of Vizhinjam CHC (figure 5.13). As none of the staff members had any computer experience, there was a period of general computer training before the DHIS software was introduced. The staff seemed pleased, although not too enthusiastic about the computer. While the administrative staff

Figure 5.13: Computer placed by HISP India in use by staff
started computer training, it proved difficult to involve the junior health workers who always claimed to be too busy. However, there could be other reasons as one of the administrative staff stated; “it is not practical that the junior staff learn the computer”. Hence a change of attitude may be required in order to create an inclusive environment in which all the staff could be encouraged to learn the computer.

The Panchayat of Vizhinjam was also contacted, and a partner at the SCTIMST introduced the HISP project to the panchayat members and explained the benefits of the system. Their responses were positive and they even offered to contribute with funds to support training processes. Some panchayats also have computers which could be used for data entry by JHI/JPHN/mini PHC so they would not have to go to the CHC or Block PHC to enter the data.

5.3.3 Training seminar I

On the 27th and 28th of January 2006, a training seminar was arranged for all the 19 medical doctors in Trivandrum district and a group of Master of Public Health (MPH) students. The arrangement was a co-operation between the SCTIMST and HISP India, with permission from the government of Kerala. HISP India asked the DMO to issue letters of invitations to the clinics. The DMO said, however, that HISP India could issue the letters, but respecting the DMO authority, HISP India preferred that the letter was sent from him otherwise attendance may be low. His presence at the seminar was also requested, as this would probably make the participants more committed to the project. However, the DMO could not attend the seminar.

As the letter was sent from the DMO somewhat late, and also due to time conflicts with various other ongoing training programmes, only nine of the 19 medical doctors attended the seminar. The theoretical topics covered were basic concepts of HMIS, use of HMIS software, data quality, use of indicators and the use of GIS and maps for public health planning. Another important aspect of the seminar was to get views and opinions from the participants, especially the medical doctors, on issues concerning the transition from
paper-based to computer-based HMIS. The participation of the MPH students was important as they represent the next generation of medical doctors, and hopefully some of them would be working with HMIS.

The participants appeared to be positive towards computerisation in the clinics and showed great enthusiasm. Especially the male doctors took part in the discussions; the female doctors seemed to be a bit more reserved. Some of the doctors already had reflected on the need for computers and presented their ideas and thoughts. However, a few of the medical doctors also expressed some doubts due to the lack of computer skills and the changes it would bring about in their daily work.

The participants emphasised the need for computers at the Block PHC/CHC level and for the field level staff to analyse data. While some of them contended that the existing system worked fine, others said it was not good that the peripheral level workers are overloaded with work due to all the reporting demands. Many of them were also very involved in the local panchayats which was said to affect their work, so a dialogue with the panchayats was considered necessary. A problem raised was about incidences of data manipulation which occurs due to fear of reprimands from higher levels when targets are not met. One of the participants stated that “if we have a result of 98% immunisation coverage, they (the government) will inquire why it was not 100% rather than acknowledging the result.” Hence a dialogue may be needed with higher levels to replace reprimands with constructive feedback and strategies for improvement, as well as for lowering unreasonably high targets.

Figure 5.14: Training seminar I
The participants were concerned with the sustainability of the system and the importance of training, which is also an important area of focus for HISP India. There was general agreement about the need for close, follow-up training for the project to succeed. There were different opinions about who should be responsible for data entry. Some suggested hiring of new staff, while others felt that whoever showed the most interest should have the responsibility. Still others felt that the health supervisor and lady health supervisor should be responsible, since information management was already part of their job. The topic was discussed, but no consensus was reached, and the matter was left open for each of the clinics to decide individually.

The medical doctors found that there was a need for conformity in reporting requirements applied from the higher levels since many current forms are made in undefined formats, with significant variance between the institutions. A checklist for the JPHN and JHI to use during house visits was also considered necessary, since currently there was no standard format, and they made notes in their individual diaries or notebooks when out in the field. A unanimous opinion among the doctors was that they wanted to have all the reports computerised, not only the routine reports. They also wanted formats for daily reports during outbreaks of communicable diseases, involving additional reports and data elements. It was suggested that the same format used in the GIS project fieldwork could be used by the peripheral health workers when collecting their data.

There was a discussion about who should access the computers once placed in the institutions. Suggestions to prevent misuse included having a system password or a system password and a user password, or that the medical doctor alone should be in charge of computer access. Here, the hierarchical structure reflected the manner in which the top person was expected to control, and the lower person was assumed to misuse the computer. It was argued, however, that the more restrictions placed on the computer, the more people will try to break them. An important aspect is really to encourage the staff to use the computer and with strict control they might be discouraged. One suggestion was to develop a system where a book was to be kept next to the computer so the staff could write down if they, for instance, took a printout, so they could pay for it. It was argued that
if the staff feels they are trusted then they will also act in a trustworthy manner. However, some of the participants thought this system would not work, as they feared the staff could not be trusted in writing down when they had taken a printout.

In the hands-on session, the participants were given the chance to try the software and give feedback (figure 5.15). The feedback was mainly positive. They seemed to like the software and felt that it would be a useful tool in the institutions. Again, what they emphasised was the need of training in order for the system to work. A number of points for improvement of DHIS were given by the participants, and these were noted by HISP India members. However, since DHIS version 1.4 was used in the session, and DHIS 2.0 is the version which will be installed in the clinics, all the comments regarding functionality might not be relevant.

**5.3.4 Training in the Block PHCs/CHCs**

In the first week of February, I went with the HISP India trainers to the institutions to train the health staff. The plan was to install the computers at the same time, but due to the problems in buying the computers, only one institution received a computer at this time. The training sessions were scheduled to coincide with the monthly meetings, so that the JHIs, JPHNs and mini PHC staff would be present. All the demonstrations and training sessions were held in Malayalam.
The sessions were started by giving a brief introduction to the work of HISP followed by a demonstration of the DHIS software. The DHIS 1.4 web version was demonstrated using a laptop brought by the trainers. In some of the institutions where there were many people, and some had some trouble seeing the screen, but otherwise the demonstrations proceeded smoothly. When demonstrating the software, actual data provided by the participants were entered into the software. This way they could better relate to how the software functioned.

Generally the health workers were positive towards the introduction of the computer. The doctors were also very helpful during the presentations, and it seemed as they had briefed the staff in advance. In one institution, the health workers feared that the computer would be a substitute for their jobs. The trainer explained, however, that the aim of the software was to reduce the time of reporting, not to reduce the number of staff. This made them more positive about the project.
5.3.5 Training seminar II

On the 15th of February, a one day seminar was held for the remaining ten medical doctors who did not come for the previous seminar. Eight of the ten doctors attended this time. The day started with some general information and a lecture on the HMIS development in Kerala before they were given an introduction to DHIS 2.0. Then they were allowed to try the software themselves in the computer lab, perform data entry and the generation of reports.

There was a bit of confusion in the hands-on session, as the DHIS 2.0 was newly released, not all of the HISP representatives were comfortable with the software yet. They still tried to help the participants, however, and many areas for improvements were found. As the datasets used in the session not were defined, they had to be defined in the session, which made the software seem more difficult to use than it really was. These datasets will be predefined before use in the clinics so the health staff does not have to worry about that during the field implementation.
5.3.6 Actions conducted by HISP following the training seminars and demonstrations

A lot of input was given throughout the sessions of training seminars and demonstrations. As the staff was keen on having as many reports as possible computerised as soon as possible, the most important reports were given priority. To ease the work load of the JHIs and JPHNs, an idea was to create a single form for each of them, containing all the data elements they have to collect. This way, they wouldn’t have to fill out the same data several times, and redundant elements were eliminated. As the areas and work of the JHIs and JPHNs overlapped at times, there would sometimes be a different result of the same data element collected by both. For example, if the JHI had registered three cases of measles and the JPHN had registered two, it would be hard to say how many cases there really were because they could have reported the same incident twice. HISP India aimed to solve this problem through making different forms for the JHIs and JPHNs so that their work would not overlap and they would have a checklist to follow when out in the field as suggested in the seminar. This would decrease their reporting burden as only one form would need to be filled out and all the necessary reports could be generated from the data elements in that form. This idea was discussed between the stakeholders, but some thought it not a good idea, as it would increase the workload initially when both paper-based and computerised systems needed to be maintained. Hence it might cause resistance to the new, computer-based system. However, with proper information it was argued that this issue could be coped with, and it was therefore decided to try this solution. When confronted with the idea, the junior health staff seemed to be positive towards the solution of only having a single form to fill out. They usually spend between two and four hours each day doing reporting, so hopefully this initiative will free some of their time.

5.3.7 Software development strategy

As previously mentioned, the Government of Kerala wanted to have a web-based, centralised, free and open source HMIS software, as their prior experience with distributed database software was not so good. At the time of the fieldwork, the version of DHIS used in India was DHIS 1.3 which is a stand alone version based on Microsoft Access. As
Microsoft Access is license based, the platform had to be changed, and the development of a new version, DHIS 2.0, was planned.

5.3.7.1 The development of DHIS 2.0

The first steps towards the new version of DHIS started in the spring of 2004. Some representatives from the University of Oslo started discussing the need of platform-independent, web-based, open source software. The main characteristics of the new version were for it to be web-based and to eliminate the need of Microsoft. At this time, none of the Block PHCs or CHCs has internet connection, so the software will not work centrally, but the possible will be there in the future when connectivity is present. After some discussion about what framework to use, Java was chosen quite quickly. It was also decided to make the software modular to simplify local updates and to share the development globally. SPRING was used for modularity and worked well although it was a difficult technology to learn. Other technologies were WebWork, Hibernate and Maven.

In the fall of 2004, some students from UiO started working on the development of DHIS 2.0 and in the following year, the course “open source software development” was held at UiO. In this course, the students learned the framework and tools used in the development of DHIS 2.0. The idea was to get some of the students to do their master’s theses in conjunction with HISP, thus also contributing to the project aims.

In the late spring 2005 it was decided to try to make an Indian team of developers. People from the University of Oslo visited India to put together the team. Two software developers were appointed to develop DHIS 2.0 and two master’s students from IIIT helped to develop the organisational maintenance module. Soon after, one of the two hired developers resigned, and the master’s students returned to IIIT. Due to of lack of skilled developers and confusion about what technology to use, no progress was made on the development. Later, a developer from a professional software company in Norway came on voluntary basis for one week to finish some of the modules of DHIS 2.0. On his advice, the programming was done in Perl which he said was faster than doing it in Java.
However, the knowledge about Perl was limited in the HISP India team. It proved difficult to find qualified Perl programmers to continue the development work from this stage and it was decided to develop DHIS 2.0 in Java and MySql as the access to qualified labour was relatively better. At this time, a Java Developer with supposedly three years of experience was hired full time. After one month he left the position without any work of note having been done. At this time, the development of DHIS 2.0 stagnated completely in India and the development was continued in Oslo. Since it seemed that the development of DHIS 2.0 would take significantly longer time than previously thought, the DHIS 1.4 stand alone version was installed at Vizhinjam CHC to start data entry and training.

Due to the delay in developing DHIS 2.0, which was assumed will take another two years, and the eagerness of the Kerala Government to get the computerised system up and running, it was decided to make a web version of DHIS 1.4 in Java Server Pages (JSP) so that the installation could start in more of the PHCs. Finding qualified computer professionals in Kerala was not an easy task. The wages were higher in Kerala than Andhra Pradesh and HISP India was not so well established here. Therefore, developers from Andhra Pradesh were hired for the development of the web-based 1.4 version.

However, during the fall of 2005, progress was made on the development of DHIS 2.0 in Oslo, and by Christmas 2005, the portal for connecting the different modules was finished. Early 2006, some of the developers from Oslo came to Kerala to implement the new version, and to teach the HISP India developers about the new technology. Due to the need of DHIS in training seminars, there were strict deadlines for the developers, causing a great pressure without proper time to learn the technologies. On February 15th, the first version was released. This version was not fault-free, but was used in the second training seminar so the participants could report errors and suggest areas for improvement.

5.3.8 Hardware procurement strategy

The state of Kerala did not provide computers to the institutions, so the computers were initially provided by HISP. All in all, there were 14 districts in Kerala with 113 Block
PHCs and 115 CHCs which would potentially need computers. HISP agreed to provide computers for the district of Trivandrum and would try to find other sources for funding computers for the rest of the state. 138 of the institutions were included in a program called the Modernisation of Government Program (MGP). They worked to raise operational efficiency levels in the government and some of the institutions participating had submitted proposals for computers. Most of the DMOs already had computers and additionally, the EC was planning to provide about five computers to each DMO in 2006.

A number of companies and organisations have been contacted in order to get funding for computers, but without a finalised MoU it proved problematic. After finalising the MoU, funding can potentially be sought from sources like the EU, World Malayalee Association and NORAD, in addition to different companies.

So far, funding had been arranged from HISP Global for the purchase of 17 computers. This was sufficient for the district of Trivandrum, as two of the 19 CHCs/Block PHCs already had computers. A demand from the Kerala Government was that only new computers be placed in the CHCs/Block PHCs. First, an arrangement was made with a computer store in the neighbouring state of Tamil Nadu as it could provide computers with Pentium IV processors at a reasonable price. Pentium IV was preferred as this processor is supposed to work best with Linux, the free operating system to be installed on the computers. Problems occurred, however, when the PCs were to be delivered, because a tax would be applied at the border to Kerala, making the price considerably higher. This purchase was then cancelled, and a deal was made with a local computer supplier who also could provide maintenance of the computers, which was essential. This time the computers, at about Rs.18 000 each, were fitted with Celeron processors as the Pentium IV processor was more expensive.

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5 A Global Malayalee community network focusing on bringing Malayalam-speaking people across the planet together.
At the time of installing the first nine computers, the formal letter from the Government granting permission to do so was not yet ready. But due to the enthusiasm shown by the medical doctors at the training seminar held on the 27th and 28th of January as well as the support from the District Medical Officer, the computers were installed in the home institutions of the nine medical doctors present at the seminar.

5.3.9 **How is HISP India managing?**

Since HISP was initiated in Andhra Pradesh in January 2000 it has evolved continuously, not only within the state of Andhra Pradesh but also in Kerala and gradually in the state of Jharkand in the north of India. The project has also proved to be sustainable, which is one of the most important issues regarding such projects. The greatest challenge for HISP India at present is the lack of resources. The project is funded by the University of Oslo until other sources of funding are located. Compared to other countries where the HISP project is running, funding received by HISP India is very limited. Lack of economic resources causes inability to offer attractive wages which makes it difficult to find competent labour. In Kerala, there have been several problems regarding human resources. There has been a high rate of resignations, and hiring of staff has not given the desired results. As HISP India is a small organisation with relatively few employees, they do not have adequate experience and resources in hiring and training new employees. Hiring has therefore been a learning-by-doing process. Another issue relates to the lack of communication which has been an issue with the development of DHIS 2.0, causing great delays.

5.4 **Training Manual development**

To contribute to the HISP project, I made a framework for a comprehensive training manual to use for the staff at the clinics as well as for others interested (Figure 5.20). The manual is web-based and will be installed locally at the clinics since they have no internet connection. It is also available from the HISP India website.
The training manual is adapted to the average health worker who, in general, has limited computer skills and can benefit from the covered topics in his or her daily work. It covers several topics listed below.

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<td>Basic computer awareness</td>
<td>Generation and interpretation of reports</td>
<td>Strategies for integration of HMIS</td>
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<td>E-mail</td>
<td>Issues of data quality management</td>
<td>Using information for action</td>
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<td>Basic concepts of HMIS</td>
<td>Development and use of health indicators</td>
<td>Using GIS for health planning</td>
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<tr>
<td>Use of HMIS software</td>
<td>Development and implementation of data standards</td>
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**Figure 5.19: Topics covered by the training manual**

There are five subsections under each topic. The training material covers basic theory and/or gives tutorials on the various topics. Additionally, there are sections for presentations, case studies, assignments and relevant links where information can be added to become a comprehensive source of knowledge.
5.5 Summary

This chapter has described the fieldwork I have conducted throughout my stay in India. Through various data collection methods, I have obtained knowledge about the nature of the HII in Kerala with particular emphasis on the context and related processes, with a focus on those related to participation. In the next chapter, I present the analysis of my findings drawing upon the theoretical framework described in chapter 3.
In this chapter, I provide an analysis of the empirical material developed through this research. The chapter is divided into two sections. The first section comprises of an analysis of the HIS in Kerala. It includes a section on why the HIS should be viewed as an HII followed by an analysis of the installed base and the cultivation of it. The second section deals with the use of PD in the HISP approach in Kerala and findings implying that PD needs to be re-conceptualised. Finally a summary of the chapter is provided.

6.1 Analysis of HIS in Kerala

In this section, I will provide an analysis of the HIS in Kerala. Firstly I explain the theoretical benefits of viewing the HIS as an HII including an analysis of the existing installed base, and the cultivation process after HISP was initiated. I then analyse how PD was used in the cultivation process of the HII.

6.1.1 The HIS in Kerala as an HII

I have previously mentioned the various characteristics of an II and how and why an HIS should be conceptualised as an HII. Seeing the HIS in Kerala as an HII provides a way of understanding the HIS as a complex interconnected unit with a number of heterogeneous factors influencing it. The HII in Kerala can be seen to have no starting or ending points, as it has evolved over time continuously adding elements into the infrastructure like new clinics, national programmes, new or changed data elements and improved reporting strategies (i.e. computerisation). The HIS can not be seen as one individual component as it is influenced by a large number of factors. Political decisions influences the way of what is reported and to whom, the organisation of the society determines to what extent the HIS can be changed and roads and transportation influences how the reports are being
transmitted, for example the delays in reporting. Traditional IS development does not consider factors such as these and hence II theory provides a better and more holistic way of viewing large interconnected networks.

The existing HIS in Kerala can be treated as a complex and heterogeneous installed base. It consists of a five-level, mostly paper-based reporting system, where the reports are prepared and then sent manually to the next level. Through the research carried out by the HISP team as well as myself, it was evident that the reporting system comprises of several problems. The reports often have poor data quality and are often incomplete. For example, I saw reports which had been sent, where more than half of it was empty. During visits to the clinics it appeared that there are no standards in the filling out of forms - in cases where the data is zero, some of the health staff leave it as blank and others as a “0”, causing the forms to look more incomplete than they really are. A large number of forms are to be filled out every month, due to various program specific reports, contributing to an increased amount of work to the health staff at the peripheral level. Several of these reports contain the same data elements which causes redundancies in data collection and registration. As the reports are transported manually, the consolidated reports reach the highest level often not before a month after it was sent from the lowest level causing delays in giving (alleged) feedback. The manual transportation also sometimes causes reports to be misplaced, making consolidated reports to be even more incomplete. Due to high pressure from higher levels on achieving good results and targets, it is not uncommon that data may be “manipulated” to fulfil these demands. In case of what higher levels regard as unsatisfying results, the feedback typically is in the form of reprimands rather than guidance and constructive problem solving support. The health staff spends significant time filling out the forms often without fully understanding the usefulness of it for supporting their everyday work. There is very limited constructive feedback from higher levels and the data is not analysed and used at local levels.

These problems with the existing HIS, emphasises even more why the HIS should be viewed as an HII. Several political, contextual and social influences affect the HIS. Societal elements such as the quality of roads and the accessibility of public transportation
affect how and when the reports reach their destination, lack of standardisation in filling out forms and often the need for manipulation reflects some of institutional constraints and influences. Redundant data due to the compartmentalised styled functioning of the various national programs are contributed to by political influences arising due to vertical donor support. For example, the HIV/AIDS program is a nationally administered vertical program which does not “speak” to the PHC system dealing with antenatal care. It is important to understand such influences and to consider them when attempting to make changes in such a large and complex network. Hence, I argue for the need for the HIS to be seen as an HII.

Despite being a complex infrastructure, the HII does offer flexibility and the potential to change. The reporting system does have the potential to be completely automated, provided that the conditions around the system are improved and adjusted, such as electricity, computers and internet connection at all clinics. Furthermore, training and education is required to develop capacity amongst the health staff to deal with the automated system and shift from the existing manual ways of working. This however requires a significant investment of resources and according of a high priority to the HMIS, treating it as a core process for the health department. However, providing Block PHCs and CHCs with computers and sufficient training would contribute significantly to develop a foundation for a more effective HMIS.

Historically, Kerala has a relatively high degree of decentralisation, visible through the robust panchayat system. As decentralisation tends to involve more power at peripheral levels, it is an important factor in contributing to strengthening processes of local action and empowerment. Research has shown that local action is crucial for improving health care services, and in Kerala this factor helps to introduce improvements in the health care sector through local action. For example, in some of the PHCs we were told by the doctors that they can give a proposal to the panchayat to obtain a computer. If changes and automation in the reporting system is supported by the local panchayat, it can potentially help provide sustainability of the system, as the network for the use of the system is more robust and extended.
6.1.2 Cultivation of the HII

The aim of HISP is to release work from the health staff by automating the reporting system as well as providing a system with analysis capabilities for supporting local analysis and action. Altogether this will increase the quality of the health care services in Kerala. I have previously mentioned the benefits of viewing the HIS in Kerala as an HII. The HII consists of a large number of components and after the initiation of HISP in Kerala in 2004, HISP has become one of these components, seeking to cultivate the HII with computerisation, capacity building efforts, and attempts to change the work routines relating to how data is collected, analysed and transmitted.

Taking the installed base as the point of departure, HISP has tried to bootstrap the project with the aim to become a state wide HIS. Through extensive work, HISP has achieved to map the health infrastructure of Kerala through a situation analysis, and to customise the DHIS to suit the Kerala context. The installed base has been taken into great consideration throughout the implementation phase. Changes are made to one part at a time making it “inter-operable” with the existing elements of the old system. For example, the reports have been developed so as to have the exact same appearance as the paper-based reports, making the introduced changes (through computerisation) to be relevant and seen as incremental extensions and not radical changes with the rest of the installed base. As not all the clinics in the infrastructure can be computerised at the same time, some clinics will be entering data on computers and some by hand, and these would be consolidated at an appropriate level (the Block CHCs where the computers are located) to be sent to the higher levels. This shows how one part of the system has been changed and improved, but still works together with the installed base, helping to develop the foundation for further incremental changes.

Performing changes in the HII will often cause organisational changes in terms of work routines and division of labour. The change of the data entry system, where the JPHNs and JHIs will have only one form to fill out, and have all the reports (which they currently develop manually) to be automated, will potentially help to create a pool of interested users, and with it develop network externalities such that other users will see the benefits
and be motivated to also join the network. There will be a relatively radical change in the work routines of the field staff, potentially seen positively, which will serve as mechanisms for motivation, and hopefully freeing up their time which can then be used to strengthen delivery of health services. Using a checklist rather than, or in addition to the field diaries, can also help to change their work out in the field, such as the division of work between the JPHNs and JHIs.

In order to bootstrap such a project, it was essential to create value in the system at an early stage and so as to contribute to its sustainability. In the initial transition period, it would be necessary to maintain reporting in both paper- and computer formats in order not to lose any data and to slowly institutionalise the new work routines. Initially this dual reporting structure would create more work for the health staff, and further education and training is required to assure the health staff that this is a transition phase which will be followed by longer term benefits. PD processes, which are now described, could potentially be used to meet these training and education needs.

### 6.2 The use of PD in Kerala

Within the HISP structure more specifically, and HIS research more broadly, PD is seen as a foundational method in reaching the goal of empowering the peripheral levels in health care systems and to create local action (Braa 1996, Byrne & Sahay 2003, Puri et al. 2004).

Subsequent to successfully using participatory methods through the rollout of the HISP approach in the state of Andhra Pradesh in India, the HISP approach in Kerala also involved the use of such methods. In order to utilise PD, the HISP team had to firstly understand the context in which the system will work. Researchers have argued that many HIS fail due to mismatch between the conceptions in the system’s design and the realities into which it is introduced (Heeks et al. 1999). PD can be used to minimise this gap and help and contribute to system success. In Kerala, the project implementation profited by using the knowledge and learning gained from the experience in Andhra Pradesh. However, the context in Kerala is significantly different from that in Andhra Pradesh, for
example the strong panchayat system, requiring a change in the approaches and mechanisms used to enable participation. Through a thorough situation analysis, the HISP India team gained knowledge about the structure and functioning of the health care system as well as about the cultural and political context. Due to Kerala being a politically conscious state with people actively involved in politics and aware of their rights, it has an environment potentially conducive to adopting PD techniques. However, being a state with a strong left tradition, there are also challenges in doing so, as health staff are often sceptical about new initiatives, especially those introduced by foreign agencies.

The point of entry into the community was made through the Health Department in Kerala. In order for successful continuance of the programme, finding the correct point of entry is crucial. As the Indian society is characterised as a relatively strict top-down hierarchy, it was essential to gain permissions at the top in order to get acceptance of the programme at lower levels. HISP India had continuous contact with officials at the district, state, and sub district levels throughout the initiation phase of the project. The DHS and Principal Secretary were continuously informed about the progress of the project, and all permissions for various activities went through them. For instance, when arranging the training seminars in Kerala, the letter inviting to the seminar had to be sent from the DHS to the DMO and then to the Medical Officers in the clinics to gain entry. If HISP India had mailed the letters themselves, it may have led to the participants not showing up. Consequently, the HISP strategy involved a combination of bottom-up and top-down approaches, where the top level enabled and opened the space for initiating activities at the bottom level.

With the permission and support from the government in Kerala in hand, attempts were made to build capacity and networks. Researchers have argued that a tripartite design, consisting of computer professionals, users (health care providers) and local community, is required in HIS design and implementation. While HISP represented the computer professionals in this tripartite cooperation, networks were built with the public health institution through SCTIMST, the health workers, firstly at the pilot site, Vizhinjam CHC, and later with the medical doctors as well as other staff at the CHCs and Block PHCs in
Trivandrum District. Additionally, the panchayat at Vizhinjam CHC were contacted through SCTIMST and introduced to the HISP project and explained how they could support it and be provided monthly reports in turn. Being a kind of village council, Panchayats are the elected representatives of the community, allowing HISP to try and fulfil the tripartite involvement, and consequently create a broad based sense of involvement and ownership of various stakeholders. Such a sense of broad based involvement potentially lays the foundation of a sustainable system.

A number of participatory actions were taken by HISP in the initiation phase of the project. The most apparent was the two initial training seminars, which provided participants with the opportunity to express their opinions on the customisation of the software and to try the demo version. Simultaneously, through these seminars the HISP team had the opportunity to introduce to the participants the aims and objectives of the project. Through giving ideas and suggestions, and a sense that these were being listened to and taken into consideration, the participants could get the feeling of taking part and actively shaping the dynamics of the system design and implementation trajectory. Such a sense of active participation could support the successful implementation of the system, and enable the introduction of gradual changes into their work routines and procedures. It was important to have the support of the medical doctors who attended the seminars, as they represent the points of authority within the clinic, and whose approval is needed to enrol the health staff in the clinics.

By visiting the clinics and demonstrating the system to the JPHNs and the JHIs, the software was demonstrated, and the staff had the opportunity to ask questions and give ideas and recommendations. Through these participatory processes, the staff was positive and welcoming of the computer and software installation, making the initiation of the implementation process relatively unproblematic. Four Malayalam-speaking trainers were employed by HISP India to conduct trainings in the clinics. They were each assigned four clinics, which allowed them to have training sessions in each clinic at least one time per week based on predefined schedules. Thus there was an attempt to establish a direct one to one contact with the staff in order to give the best training possible. However, due to
training being a time-consuming process, the large number of people at the clinic and the fact that there was only one computer, training needs to be conducted even more than once a week in the future to give the desired outcomes.

PD involves valuing the needs of the users before technical orientation. While a good technical solution can not be underestimated, it has no value unless adapted and accepted by its users. Through participation, HISP were able to design the reports in formats accepted by the users as they represented the manual formats which they were expected to complete every month. The standardised forms (i.e. Forms 6-8) were made exactly the same as the paper reports, making the transition from paper-based to computer based reporting system as gentle and incremental as possible. The non-standardised forms were designed into standard formats through close cooperation with peripheral health staff. This standardisation also helped to reduce the work load, for example by reducing their time in manually making out the multiple and often redundant formats.

Apart from the tripartite collaboration explained earlier, HISP India also made alliances with private organisations, such as software firms, and NGOs such as the Free Software Foundation. At the collaboration meeting arranged by HISP India, different stakeholders from private organisations, government and educational institutions, as well as HISP India, were brought together to share ideas and to enable a forum for participatory decision making. While the seminars, demonstrations in the clinics and the meetings with government officials provided multi-levelled participation, such collaboration meetings contributed to developing multi-sectoral participation.

In the development of a system such as HII, it is practically impossible to involve all the users, given their large number and diversity. In the Kerala case, taking Trivandrum district, all the clinics that received computers were visited periodically, theoretically giving all of the users a chance to learn about the system, give inputs and ask questions. It can’t be assumed though, that all of the staff was present at the demonstration, that they understood what was going on and that they felt they were involved in the development. However, that was not the assumed outcome either, because as stated initially, with such a
large user group, the achievement of full involvement is very unlikely. However, the potential was opened up for a larger base of participation, and in the future, regular training and education is required to ensure that this potential is meaningfully realised.

It is argued that although the developers are provided with inputs from users, it is not for certain that they can all be meaningfully incorporated, as some of these would require changes in the core development that was primarily taking place in Oslo. Since the Oslo group has its own priorities given the development needs of HISP global, the Kerala requirements could often get a lower priority. Furthermore, there are other external factors such as development constraints and technological limitations, which could further slow down the meeting of local needs.

Through the analysis of the various processes, it is evident how the complex nature of the HII complicates the use of PD. In an II, the number of stakeholders is vast, the systems are large interconnected networks rather than single, stand-alone systems and additional considerations such as cultural, political, social and infrastructural issues needs to be taken into account. Given these conditions, I argue that PD needs to be re-conceptualised, which I do in the next chapter based on the theoretical principles outlined earlier in chapter 3.

6.3 Summary
This chapter has provided an analysis of the empirical findings in chapter 5. It is argued that the HIS in Kerala should be seen as an HII as it shares the characteristics as that of an II. Making improvements to this II, and with it arguably to health services delivery, is undoubtedly a complex, long term, and incremental process. The initiation processes carried out by HISP, undoubtedly has laid the foundation for achieving these positive results in the future.
DISCUSSION AND CONCLUSIONS

This chapter offers a discussion of the analysis in the previous chapter, and tries to support the claim of the need of re-conceptualisation of PD. I also attempt to answer the research questions posed in the introduction of this thesis, which for purposes of emphasis are re-presented below:

1. How has participatory design been used in the HISP project in Kerala and what has been its impact?
2. What aspects of the social, political and cultural context shapes participatory process in a developing country context like that in Kerala, India?
3. How do participatory processes in contexts like India differ from those in Scandinavia?

Answers to these three questions are addressed in the three sub-sections following respectively.

7.1 PD in the HISP project in Kerala

As emerged from the analysis, PD has been used to a great extent through the HISP project in Kerala. The HISP India team thoroughly mapped the context in which the project was introduced, the health staff gave inputs on how the reports should be computerised, how the work could be reduced at the sub centre level, thus providing important inputs to the DHIS2 customisation and adaptation processes. However, till date, the participation used in the HISP project has been more focused on data elements and design of the reports rather than in the development of the analytical functionalities of the DHIS 2.0. The core developers (from Oslo) did not have much interaction with users, and
these requirements have been relayed through the local team over the internet, which no doubt will lead to issues of “being lost in translation”. Also, since the local developers were from Andhra Pradesh and could not understand the local language of Malayalam, a further loss in translation would have occurred.

A great deal of the participatory processes done by HISP in Kerala can be described as a kind of “reverse participation” in the sense that the HISP India team immersed themselves in the everyday life of the health staff, and spent a lot of time interacting with government officials and other community members. In this way, they were able to understand the context in which the system would be used and gain knowledge of how to adapt the system to the users’ needs. The opposite of “reverse participation” would be the users being immersed into the work of the developers, which also was used to some degree. For example in the training seminar, the participants had the opportunity to give feedback and ideas directly to the developers.

In the case of Kerala, the reverse participation has arguably provided benefits to the HISP project. In addition to providing them with a much needed understanding of the cultural and political issues in the context in which the system was introduced, it also helped to build a participatory network of actors. As the HII in Kerala consists of a large number of interest partners and stakeholders, it was important to try and bring them together and consider their opinions and ideas in the system development and implementation process to help assure the sustainability of the system. Thus the use of reverse participation helped them in gaining knowledge about the context as well as building participatory networks, which highly benefited the project.

Throughout the process of applying the HISP approach in Kerala, it was apparent that the situation analysis and development of contextual understanding was essential for carrying out participatory practices. Through those activities, vital information like where and how to get permissions, the conditions and challenges in the health structure, and the working of the reporting system was obtained. Contextual understanding was arguably enhanced through these processes of “reverse participation.”
As mentioned, it is impossible to involve all the prospective users of a system at one time. Perhaps the odds for obtaining system success are higher if more users are involved. However, the needs of a CHC in one district in Kerala are likely to a great extent be somewhat the same as the reporting needs of a CHC in another district. Although there are slight differences within Kerala, they are by and large fighting the same diseases, reporting the same data-elements and drawing up on similar standardised (although not always) formats. My argument is that health staff generally shares the same frustrations and needs in their work in spite of being in the north or south of Kerala. Hence if a system is adapted to and used successfully by Vizhinjam CHC in Trivandrum district in the south, it has a high probability of being useful for Neeleswaram CHC in Kasaragod district in the north, provided that proper information and training is provided. Hence, I argue that involving one core group of users and drawing upon their experience and circulating to support others will potentially help meeting the needs of the entire user group.

Users usually come from different backgrounds and have experienced varying degrees of training which can both enable and constrain participatory processes. The users need to be capable of participation in order for successful participation to take place. A user who doesn’t know anything about computers is not the most effective contributor to the technical development or design of the system. Hence the users’ understanding of the issues needs to be enhanced to support the participatory processes. HISP India thus conducted various training seminars to increase the users’ knowledge on HIS, and also through this enhance their own knowledge of the local context.

The participatory processes conducted by HISP India were necessary, but also time-consuming and resource intensive. The multiplicity of stakeholders, the complexity of the work practices and reporting requirements, and the paucity of resources all contributed to make this a very challenging endeavour. Also, since there were some competing interests, for example C-DAC was also developing a HMIS, there was the need to also be sensitive to the varying political interests and agendas. All this required PD processes to be developed and implemented in non-traditional ways opposed to what is typically
associated with the creation of stand alone and independent information systems. For example, while traditional PD often only involved end users due to the low complexity of individual systems, in Kerala, several stakeholders and interest groups needed to be involved, as the HII is large and interconnected and affects more people than just the end users.

7.2 Aspects shaping the participatory process

The participatory processes conducted in Kerala were highly influenced by social, political and cultural factors. The development required participation between several groups, like government officials, health staff at different levels, panchayat and external organisations. The PD aimed not only at supporting technical considerations, but also political, social and cultural aspects. This need for such a broad understanding heightens the complexity in managing participatory processes, and in aligning the multiplicity of interests and agendas.

As the government in Kerala had already started planning a computerised HIS, they did not need much convincing in the needs and benefits of such a system. Given the largely hierarchical and formal style of functioning of the health structure, the involvement of the senior administrators was crucial for carrying out any participatory practices. Permissions to conduct any actions related to the project had to be granted from state government before they could take place.

As the people of Kerala typically are politically conscious, it creates a positive environment for PD. Traditionally, people in Kerala are involved in political processes and demanding of their local rights through organisations like the trade unions. In this way, political factors can potentially influence participatory processes in a positive manner. The respect of authorities has been described by various researchers to be one of the defining characteristics of Indian society (Sahay & Walsham 1996, Puri 2003). This became apparent to me during my conversations with the JPHNs and JHIs. At some times, it felt that they rather than giving their own opinion, gave answers which they thought we wanted to hear and did not contradict with the official views. Another social factor
influencing participatory processes was the existing hierarchy in the clinics. For example, there were instances we felt that the senior staff did not want to participate with junior staff in joint activities such as training, and simultaneously the junior health staff might have been inhibited in expressing their opinions in similar joint settings.

India is a country of many languages. Malayalam is the official language in Kerala, but the interactions throughout the project took place primarily in English. Some in the HISP India team did not speak Malayalam, and also some participants, like the MPH students at SCTIMST were non-Malayalam speaking. Generally this was not a problem, as a majority of Indians are comfortable in English. However, it can be said that lack of fluency in Malayalam would lead to challenges in understand the subtleties of the issues, and the tacit ways in which work was done. Additionally, the feeling of not mastering English sufficiently may have caused reservation from the health staff speaking their own opinion, especially in front of many people, like in the training seminars where some of the participants were from abroad. In the peripheral areas, the health staff had less knowledge of English, and the training had to be done in Malayalam, requiring the use of the newly appointed Malayalam speaking local staff, who came with their own constraints of not understanding very well the HISP related processes because of their lack of experience.

Clearly there are issues of political, social and cultural character affecting participatory practices, and it is important that the change agents, in this case the HISP India team, try to address these factors and take them into consideration while conducting participatory practices. Understanding an HIS as an HII emphasises the need to take into account these political, social and cultural issues, and how these shape PD processes.

7.3 Participatory processes in developing countries drawn from Scandinavia

When PD techniques drawn from one context (Scandinavia in our case) is transferred to another setting (Kerala in our case), there are inherent challenges to be addressed. There are several contextual differences between the setting arising from issues of culture, infrastructure, resources, society, and priorities. In Scandinavia, PD is primarily connected
with workplace democracy and the employee’s right to influence his or her work conditions. Through the years, legislations and unions have helped the worker to have more influence on changes in their workplace, and today, involving users in development projects in Scandinavia is seen as a common practice.

In developing countries, workplace democracy is not as widespread or as important a priority as in the Western world. Rather, a lot of research is focused on the use of IT to develop and empower deprived communities in the third world (Braa 1996) and how PD can give important inputs on improved systems development, and with it seek to empower peripheral level health workers and lead to local action and improved health conditions.

Opposed to the developed world where the lower levels are relatively empowered through legislation and other forms of formal rights, using only a bottom-up approach in developing countries may prove not to be very feasible. For example in Cuba where the society is strictly politically controlled, a bottom-up approach will not provide the required support of the system to assure sustainability (Braa et al 2004). Given the strong hierarchical structures existing in Kerala, merely using a bottom up process may be insufficient as it could lead to processes where the lower levels do no have the space to function. Through involving the top level, a space for PD can be opened up, thus I emphasise the need for a combination of top-down and bottom-up approaches.

7.4 Re-conceptualisation of PD

After discussing the use and complexities of PD in the above sections, I will in the following section discuss the re-conceptualisation of PD through the theoretical principles mentioned in chapter 3.

7.4.1 Building participatory networks

Traditional PD theory has generally been focused on single, stand-alone and independent systems, where participation has implied the involvement of end users. From the experiences with the HII development in Kerala, it is evident that this use of PD is not
sufficient. While literature, the Scandinavian in particular, mostly focus on the participation of users of the system, I argue for the need of a shift from user participation to broad stakeholder participation. An HII is a large and interconnected network with a great amount of stakeholders, representing a vast number of interests. In Kerala for example, these stakeholders ranged from health staff, community members, government officials, educational institutions, non-governmental and private organisations and systems developers. Initiating the development of this HII with the traditional PD approach would most likely result in a system failure. Merely considering end-users in such a large and complex interconnected system, would lead to a number of unfulfilled interests and resistance with stakeholders whose support is crucial. The aim should be to create both multi-sectoral and multi-levelled participatory networks of stakeholders. Multi-sectoral as this ensures consideration of interests in all parts of the infrastructure and contributes to a sustainable system and multi-levelled because it is crucial to include top levels in order to sustain local level participation and action.

7.4.2 Context sensitivity

Traditional PD research has mostly focused on workplace democracy where the aim is for the worker to have more influence on his or her daily work. This research is mainly based on western settings where the worker is seen to be relatively empowered. Transfer of this use of PD to other contexts, like from Scandinavia to the US, has proved to be difficult, which supports the statement of PD being highly context sensitive. Research has not focused on the difficulties of adapting PD practices from one context to another, consequently I attempt to add focus of context sensitivity into the concept of PD.

In developing countries in general, the context differs greatly from a Western setting. Participation at local levels is usually not common practice and many developing country societies are characterised by a distinct top-down hierarchical structure. While literature rather focuses on the individuals who participate in development projects, I argue that prior to commencing PD activities in HIS development, the context should be thoroughly analysed in order to reveal contextual issues which may influence these activities.
Contextual issues may be of political, social, cultural, geographical or infrastructural in nature and needs to be thoroughly addressed in order for successful carrying out of PD processes. For example, HISP India conducted situation analysis in order to map contextual issues in Kerala prior to initialisation of the project. Through this analysis, important issues were revealed such as the hierarchical structure, political conditions and the state of infrastructure. Without knowledge about and consideration of these issues, participatory processes would most likely not have succeeded to the extent it did so far in the project. Hence I argue that the context of which it introduced needs to be included into the concept of PD as an important factor for the success of participatory processes for example through “reverse participation” as previously described.

7.4.3 Focus on outputs, not just on techniques

Researchers have characterised PD as an important success factor in IS development. However, it has gotten to this point that PD sometimes is used only because it is stated to be important, without considerations for what outcome such practices may produce. A number of different PD techniques have been developed over the years, for example PICTIVE which produces a mock up of the system, intended to be modified by the users. However, the focus should be on how such techniques work in the context they are introduced and what will be the output, rather than merely being used slavishly. If necessary, the techniques should be modified to suit the situation in which they will be used. I argue that a re-conceptualised PD should focus on the outputs and results of using such methods, rather than just on the use of the techniques in itself.

7.4.4 Focus on structural and behavioural changes

The development of single stand-alone systems rarely considers behavioural and structural changes in conjunction. However, when changes are conducted in large interconnected networks such as HIIs, the chance is that such changes will occur. For example, in Kerala, the introduction of a computerised system, potentially will imply behavioural changes, for example that the peripheral levels can speak more freely towards higher levels, and that higher levels will treat lower levels with more respect and consideration. Markus and Mao
(2004) stated the need to emphasise on behavioural issues, however, HII development will also imply structural changes, for example in Kerala, the changed and improved reporting procedures for JPHN and JHIs. I have taken their emphasis on behaviour and addressed the need to focus on structural changes as well. In situations were behavioural and structural changes will occur, it is particularly important to use PD, as it is important to ensure that such changes occur on the level with the participant’s interests. If this is not done, they might end up with changes they didn’t want, which often will lead to resistance to the system.

The main issues in the re-conceptualisation of PD are summarised in table 7.1 below.

<table>
<thead>
<tr>
<th>Traditional PD</th>
<th>Re-conceptualised PD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Involvement of end-users.</td>
<td>Creation of multi-sectoral and multi-levelled participatory networks with not only end-users, but representatives from all groups of stakeholders.</td>
</tr>
<tr>
<td>PD used as in its original context of workplace democracy.</td>
<td>Adaptation of use of PD into the context it is introduced, with focus on political, social and cultural issues influencing the processes.</td>
</tr>
<tr>
<td>PD techniques being used merely because it is considered important, without focus on the outcome of such techniques.</td>
<td>Focus on results and outputs of PD processes. Adaptation of PD techniques to suit the situation where it is to be used, rather than techniques being followed slavishly.</td>
</tr>
<tr>
<td>No focus on changes beyond automation.</td>
<td>Focus on behavioural and structural changes which are being controlled using PD processes.</td>
</tr>
</tbody>
</table>

Table 7.1: Main issues of the re-conceptualisation of PD.
My re-conceptualisation of PD will potentially be useful for future HIS development projects, particularly in developing countries, and also in India, for example in other states of Gujarat and Jharkand where HISP is now operating.

7.5 Research contributions

Traditional PD research has long focused on the development of individual stand-alone systems. However, modern IS development trends are leading towards the development of large heterogeneous, highly interconnected networks of systems, rather than single systems. Hence traditional PD theory is outdated and needs to be adapted to this shift in IS development. Through this thesis, I have attempted to re-conceptualise PD to suit the development and cultivation of information infrastructures, through a developing country perspective.

My key contribution to theory is the need to focus on building of participatory networks, rather than only focusing on end-users as in traditional PD theory. Infrastructures consist of a large number of stakeholders and interest groups, who need to be considered when making changes, in order to obtain stakeholder satisfaction and to ensure the sustainability of the changes being made. Transfer of PD practices between different parts of the world has been proven to be complicated. With the increase of globalisation of software, I argue that knowledge of the context in which the system is introduced is highly required, as PD processes are highly sensitive to political, social and cultural issues. I also argue for an increased focus on outputs from PD practices and the incorporation of both behavioural and structural changes.

7.6 Conclusions

In the contemporary IS development context, the cultivation of large and interconnected networks of systems is becoming more and more common as opposed to single locally-based systems. These systems can be best understood by using an II perspective, however, traditional PD remains rather stagnant, still mainly focusing on single systems.
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Through the Kerala experience, it is evident that “reverse participation” as described, lays an important foundation for the involvement of users as conceptualised as socio-technical and heterogeneous networks, as this facilitates the development of a contextual-understanding which is highly important when developing HIIs. Without a clear understanding of the context in which the system will be introduced, the chances of success are severely limited. Participatory practices are influenced by issues of political, social and cultural issues which need to be addressed at all stages if systems design, configuration and implementation. Failure to do so, may lead to unsuccessful accomplishment of participatory practices and an antagonism of the users to the system due to a lack of contextual adaptations.

Participation in a developing country context requires extra considerations compared to initiating similar process in settings of the developed world. It is important to approach such environments with considerations of the users’ position, customs and ways of thinking, and varying institutional considerations. In order to empower the lower levels, the top has to be included in the process, especially in its initiation. In complex networks such as HIIs there is a vast number of interests and stakeholders. I argue for the building of participatory networks in order to bring these stakeholders together to share interests and decision making. Such participatory networks should be both multi-sectoral and multi-levelled in order to assure system sustainability and success.

Based on the above experiences, I argue for the need of re-conceptualisation of PD towards their use in an II context. My main areas of re-conceptualisation are: i) The building of participatory networks, ii) Context sensitivity, iii) Focus on outputs in addition to techniques used, and, iv) Focus on behavioural and structural changes. While highly relevant for use of PD in developing countries, this re-conceptualisation is also applicable to the developed world where there also are differences in culture and contexts between countries, and systems are becoming larger, more interconnected and complex, like for example Enterprise Resource Planning systems (ERPs).
This thesis has addressed the need of a re-conceptualisation of PD for use in HIS development based on research conducted in Kerala, India. Four areas of improvement has been identified which can contribute to make the concept of PD more usable in developing country contexts. This re-conceptualisation can provide a basis for future research which should continue focusing on the further adjustment of PD practices for successful use in the contexts of developing countries.
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