

Co-operation for health data quality: health informatics in Nepal and the developing world

by

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Abstract

The need for reliable global health data and the advancement of information and computer technology has led to developing countries struggling to implement electronic health information systems. Due to limited financial and human resources, a lack of infrastructure, and fragile national health systems, many systems have failed to be sustainable in the long run. In this paper I investigate the importance of health informatics for generating reliable health data, the barriers to implementing health informatics in developing countries and extending them to rural areas, and the importance of collaboration between local and global actors for a long-term success, using Nepal as a case study. The main barriers to health informatics in Nepal are the lack of electricity infrastructure, road access and human resources. Access to health care in the country is also limited, leading to unreliable data. To overcome these problems Nepal needs to work closely with its development partners to strengthen the health system, and allow for time to extend the system in stages with research and preparation at every stage.

Preface

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List of abbreviations and acronyms

ANC: Ante-Natal Care
AusAID: Australian Agency for International Development
DAM: Department of Ayurvedic Medicine
DFID: Department for International Development
DHO: Distric Health Office
DHOS: Department of Health Services
DHS: Department of Health Services
DIN: Drugs Information Network
EHIS: Electronic Health Information System
EMRS: Electronic Medical Records System
FCHV: Female Community Heath Volunteer
GIS: Geographical Information Systems
GoN: Government of Nepal
GTZ: Deutsche Gesellschaft für Technische Zusammenarbeit GmbH
HFOMC: Health Facility Operation and Management Committees
HIS: Health Information System
HMIS: Healt Management Information System
HMN: Health Metrics Network
HP: Health Post
HuRIS: Human Resources Information System
ICT: Information and Communication Technology
IHP+: International Health Partnership
ILO: International Labour Organization
INGO: International Non-Government Organisation
IT: Information Technology
JICA: Japan International Cooperation Agency
KfW: Kreditanstalt Für Wiederaufbau
LMIS: Logistcs Management Information System
MDGs: Millennium Development Goals
MoHP: Ministry of Health and Population
NGOs: Non-Governmental Organisations

NHDP: Nepal Health Development Partnership
PHC: Primary Health Centre
PHO: Primary Health Office
SDC: Swiss Agency for Development and Cooperation
SDIP: Safe Delivery Incentives Programme
SHP: Sub-Health Post
SWAp: Sector Wide Approach
TB: Tuberculosis
UNDP: United Nations Development Programme
UNFPA: United Nations Population Fund
UNICEF: United Nations Children's Fund
USAID: United States Agency for International Development
WHO: World Health Organization

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1 Introduction

People have been struggling to control the spread of infectious diseases for thousands of years. The fact that diseases have no respect for national borders has forced countries to work together to contain them, resulting in the first International Sanitary Conference in Paris in 1851, the establishment of Office international d'Hygiène publique in 1907, the Health Organisation of the League of Nations after World War I and eventually the World Health Organisation (WHO) in 1946 (WHO, 2012a). Cooperation between countries for the sake of international health originally related to infectious diseases, and they are still a high priority today. In September 2000, a gathering of the representatives of 147 countries met and agreed upon a number of issues that should be prioritised in international development, and eight *Millennium Development Goals* (MDGs) were chosen which are to be met by all the countries of the world by 2015 (Attaran, 2005). Three of the eight MDGs are health related, and every year vast amounts of money flow into health interventions aimed at tackling HIV/AIDS (and other infectious diseases), and child and maternal mortality rates (UNDP, 2010).

These focus areas emphasised by the MDGs, are consistent with the global health priorities generally presented by the world's biggest donors of development aid (the United States government, the World Bank, the Bill and Melinda Gates Foundation, and the Global Fund). The majority of the money that goes to health related development aid is aimed at communicable diseases such as malaria and tuberculosis (TB); maternal health; child health; HIV/AIDS; and nutrition (Sridhar and Batniji, 2008). These priorities have been criticised for being too narrow and too focused on the needs of the very poorest countries, rather than actual global need. In fact, while they do represent the situation in Sub-Saharan Africa, Ollila (2005, p. 3) claims that they are not representative of health in any other region of the world. Where these priorities come from is debated, but funding is directed in certain directions (such as towards HIV/AIDS prevention) while many low and middle income countries are facing increasing rates of cardiovascular disease and other non-communicable diseases (WHO, 2011).

Saith (2006) and Attaran (2005) also question the reliability of the data used to justify these particular focus areas and points out that for most developing countries there is limited (if any) access to reliable health data. In the last few decades the call for better quality health data has been on the rise as it is needed to track progress on the many programmes and interventions that have been established to improve global health (Chan et al, 2010), as well as to support evidence-based decision-making both nationally and globally (Pappaioanou et al, 2003). Without functional health information systems (HIS) much of development aid aimed at health care is likely to be misused,

ineffective, or simply wasted. In order to move forward it is essential to improve health systems (Zwi and Yach, 2002) and improved technology (such as in the field of IT) is key to that (Williams and Boren, 2008).

The use of computer science in healthcare in the developed world has become widespread, and so-called 'health informatics' have been a part of the curriculum for the last 20-25 years (Kimball et al, 2009). The electronic medical record (EMRS) is one of the tools that falls under the health informatics umbrella, and according to Williams and Boren (2008, p. 503) it "serves as a catalyst and gold standard for development." Using EMRS instead of paper-based medical records is believed to improve the quality, reliability and timeliness of health data, which in turn helps build up and support health care (Williams and Boren, 2008; Azubuike and Ehiri, 1999). However, in the developing world the introduction of electronic health information systems (EHIS) has been a very slow process, marred with repeated failures (Heeks, 2002).

Nepal is one of the world's poorest countries, it ranks number 157 on the Human Development Index and in 2006 a decade long civil war ended, leaving the country fragile and politically unstable (World Bank, 2012). Despite improvements in health in Nepal since the end of the war, health indicators remain below the regional average (WHO, 2012b). Access to primary health care is very limited in parts of the country, and differences between rural and urban populations are substantial (Central Bureau of Statistics, 2011). Nepal is one of the world's most rural countries, with only 19% living in urban areas (Dahal et al, 2012), and with its rugged, mountainous terrain large portions of the population are hard to reach. Furthermore, infrastructure is highly lacking, with 61% living without electricity (Mainali and Silveira, 2011), and only 43% having access to all weather roads (Dahal et al, 2010). There is a national health information system being run by the Department of Health Services (DHS) which receives information from all public health facilities in the country (Vaillancourt and Pokhrel, 2011), but lack of access to health care in remote areas and limited integration of information collected by alternative health providers has implications for the quality of the data (Schmidt, 2009).

In this paper I investigate the need for increased use of health informatics in Nepal and the developing world. I discuss the barriers to their implementation, particularly in rural areas, as well as how collaboration between national and global actors can help overcome them.

In chapter two I discuss health informatics in general and their role for national and global health. In chapter three I look at the barriers to the implementation of health informatics in Nepal and other developing countries and finally in chapter 4 I will discuss possible solutions to these barriers.

1.1 Research questions

1. How can health informatics be used in mapping the spatial, temporal, and social patterns of health?
2. How can the use of health informatics potentially improve primary health care and health data collection, and what barriers are there to their implementation, particularly in relation to rurality and remoteness?
3. How can health informatics be used to improve health interventions and evidence based local health policy in rural Nepal?
4. What role does collaboration between NGOs, national governments and international donors play in overcoming the barriers to health informatics implementation in Nepal and other developing countries?

2 Health informatics and reliable health data

2.1 Health information for better health in developing countries

One of the main issues that the MDGs are criticised for, is that there is very little mention of general national health system strengthening, but fragile national health systems are the main barrier to meeting the goals. Government run health systems in developing countries often suffer from limited financial resources, a shortage of trained personnel, and weak information systems. Additionally, in many developing countries a large proportion of health care funding comes from international donors, whose priorities are poorly coordinated.

In the Declaration of Alma Ata from 1978, health system strengthening was put on the agenda, as emphasis was put on primary health care as the most important part of the health system:

It urges governments, WHO and UNICEF, and other international organizations, as well as multilateral and bilateral agencies, nongovernmental organizations, funding agencies, all health workers and the whole world community to support national and international commitment to primary health care and to channel increased technical and financial support to it, particularly in developing countries. The Conference calls on all the aforementioned to collaborate in introducing, developing and maintaining primary health care in accordance with the spirit and content of this Declaration (WHO, 1978).

However, Travis et al (2004) claim that despite the declaration many donors rejected the idea that general support of primary health care should be emphasised because they believed that a more direct focus on a number of particular health issues would have more impact. This has led to most developing countries having multiple parallel health projects running at once, each one with a disease specific focus.

The health related MDGs are in large part based on priorities some claim have less to do with the reality of global health and more to do with the interests of the donors (Saith, 2006; Ollila, 2004). Saith (2006) also claims that the baseline data used to justify these priorities is largely unreliable and in some cases completely absent. He points out that in countries where the help is most needed, the data is least likely to exist and the health systems have the least capacity to meet the goals. This indicates that information about global health is sorely lacking. If the MDGs are to be met, then efforts need to be made to properly assess which strategies and interventions are working. Travis et al (2004, p. 900) identify weak information systems as a “major shortfall” in achieving the MDGs and emphasise the importance of knowledge.

Much global health information is generated every year through research, but according to McMichael, Waters and Volmink (2005, p. 217), most of this research takes place in developed countries. Less than 10% is spent on research into health problems that afflict 90% of the global population. Interventions and trials that take place in high income countries do not necessarily apply to low income contexts. In randomised trials, for instance, the participants in developing countries are very different from those in developed countries. They have more underlying health problems that can skew the results, such as malaria, and undernourishment. Culture, lack of resources, and inefficient facilities may also affect comparability with trials run in high income areas.

Most of the information currently available from developing countries comes from household surveys, birth and death registration, census data, and surveillance systems such as health facility reporting systems (Chan et al, 2010). These are not perfect sources, birth and death registration is often incomplete (Saith, 2006), household surveys and censuses are periodic rather than continuous, and data from health facilities and surveillance systems often does not include the very poorest as they are more likely to turn to traditional health providers, whose work is rarely included in national health information systems (Kanjo, 2011).

Considering the relative shortage of reliable information coming from research and other sources, supporting the implementation and extension of national health information systems is crucial to generate the data needed to support evidence-based decision making. Health informatics can further strengthen such systems, by improving their efficiency and reliability. Additionally, reliable health information can draw the interest of researchers, as well as create the kind of baseline data needed to assess the effectiveness of interventions and public health strategies.

2.2 Health information systems and health informatics

The modern concept of health informatics is relatively new, as the term itself only came into use around 1973 (Coiera, 2003). The study of health informatics is concerned with the way that health knowledge is created, stored and used and can be defined as “the systematic application of information and computer science technology to public health practice, research, and learning” (Kimball et al, 2009, p. 2). The health sector itself is very large and the need for information technology (IT) to manage all the data that is generated on a daily basis, means that the development of new health related IT is continuous (Tomasi et al., 2004).

The concept of health informatics applies to a large set of information technologies that are used to support health care. Health informatics can provide access to important information about the latest developments in medications and treatments. Such systems can support health

practitioners' decisions on treatment by warning of drug interactions, for instance. Telemedicine is another branch of health informatics; doctors and nurses in remote areas or smaller health facilities, can get advice from specialists in larger hospitals by phone or the internet. Patients who cannot travel from home can also be monitored from a distance using technology which regularly sends information about blood pressure, heart rate, etc (Coiera, 2003). Decision-support systems, medical imaging and telemedicine, in addition to EMRS have been a priority for health informatics implementation in developing countries (Kouematchoua and Rienhoff, 2007), although the technical infrastructure to support these systems is largely lacking outside of urban areas (see discussion in chapter 3). Health information systems in rural areas are mainly paper based and while such methods are better than no data collection at all, their usefulness is highly limited. Compiling data from paper based records in order to file reports is time consuming and difficult (McMichael, Waters and Volmink, 2005), and it takes away valuable time from health workers that would be better used taking care of patients (Rotich et al., 2003).

Replacing paper based medical records with electronic ones can improve health care in a multitude of ways and on a number of scales. The most immediate is in local health care. Paper based records are difficult to manage, they take up storage space, and do not allow for much flexibility. They can also easily be destroyed by adverse weather events, accidents, or neglect (Coiera, 2003). Electronic records enable health workers to improve their service to patients. With a well designed system a health worker can easily register and access information about a patient's medical history without having to search through a pile of notebooks. Such a system stores information that can be used to monitor trends in an individual's health, their medications, and treatments (Tomasi et al., 2004; Coiera, 2003).

In their evaluation of the Mosoriot Medical Records System (MMRS) which was installed in a rural hospital in Kenya, Rotich et al (2004) found that replacing logbooks, in which information about every patient visit was logged, with electronic records made the work easier for the staff. Less time was spent on writing down information, staff had more free time, consultations were shorter, and the time it took to compile monthly reports shortened from 2 weeks to a few minutes. Easy access to medical data made it easier to analyse them and evaluate the overall health outcomes in the area the hospital served. The staff were able to notice a high prevalence of sexually transmitted diseases in one village, and low vaccine coverage in another. As a result they were able to take better care of their patients. A surveillance component for injuries was later added to the MMRS. The system enabled researchers to use Geographical Information Systems (GIS) to explore patterns of injuries in the area (Odero et al, 2006).

Medical records are also a tool used to monitor and compile health information on a regional and national scale. With a powerful national system, different areas can be compared, and their needs assessed. A state's health landscape can be made visible in a way that encourages evidence based resource allocation (Braa, Monteiro and Sahay., 2004). While many health related aid programmes emphasise the importance of compiling data of their work, this data is often used to satisfy a donor's need to see where funds are headed and to evaluate the effectiveness of health interventions. This data is often of limited use outside of these particular programmes, and is rarely linked to larger networks of health data collections (Haines and Cassels, 2004). Criticism of the MDGs is often based on these facts, as their focus on particular areas of health leads to a narrow focus on collecting data related to these health issues, while other issues are neglected (Murray et al., 2004). In many countries even births and deaths are not registered or reported (Attaran, 2005), which in many cases means that whatever reliable information is available is relevant only to parts of the country or to specific health issues focused on by NGOs or large donors, with the rest of the country remaining blank. The health interventions and services based on such limited information is therefore skewed and does not reflect actual national need. Effective health planning needs to be based on reliable information and evidence, without it waste of valuable resources can be expected. In most developing countries medical resources are limited and and costly, allocating them based on estimates and guesswork can lead to much of it being wasted where it is not needed, while other areas go without (Braa, Monteiro and Sahay, 2004). For NGOs working in impoverished areas who rely on funding and aid from independent donors, as well as national or international organisations, reliable information about the needs of the people they serve is invaluable. The ability to compile and analyse medical data quickly makes putting together requests for funding an easier job, and the information is likelier to convince donors that the funding is needed.

However, while NGOs and other organisations can and do take care of much of the information gathering that takes place in developing countries, it is important to put pressure on governments to implement their own information systems. There is often much external demand for information on particular diseases and health problems, such as from large international organisations providing funding and resources for these problems. This can lead to health systems that are already vulnerable and struggling being forced to spend too much time, effort and money on compiling information which ultimately does not serve or support their health system as a whole (Haines and Cassels, 2004). There has been increased awareness of the need for general strengthening of national health systems in developing countries, as their fragility can serve as a "bottleneck" that prevents aid and health interventions from being as effective as they could be (Travis et al., 2004).

The lack of reliable health information systems in the developing world has global implications as well. Global health priorities, in theory, are based on global health data, but as previously discussed this data is largely unreliable and patchy, particularly data from the global south. In an effort to tackle this problem, the World Health Organisation (WHO) established the Health Metric Network (HMN) in 2005, whose aim is to “improve global health by improving the availability and use of health information to advance evidence-based decision-making” (Stansfield et al., 2008). This is a positive step forward, as there is a need for a global health information system architecture to ensure cooperation and comparability of the data collected (Murray et al., 2004; Chan et al., 2010). The HMNs existence also provides an opportunity for the global community to reach a consensus on what kind of data needs to be collected and how it should be used.

In the last two decades a number of international organisations and partnerships have been established to support developing countries in developing and implementing information systems. The Health Information Systems Programme (HISP) created the District Health Information Software (DHIS) as a result of a project in South Africa in 1994 (HISP, 2012). Since then the programme has been extended to other countries in Africa and Asia (such as India, Tanzania, Mozambique, Ethiopia and more). The DHIS has been developed as an open-source software for developing countries.

There are however a number of barriers to the implementation and maintenance of health information systems in the developing world. According to Rotich et al (2003), the key to the success of such a system is sustainability. They claim that in order to cross the digital divide it is necessary to allow room for flexibility and compromise, as only the continued use of the system is likely to result in the financial cost of its installation being offset by the benefits it provides. According to WHO’s (2006) guidelines for electronic medical records, issues to consider include accuracy of data and environmental problems. Disease classification and coding as well as staff’s knowledge of them affect the quality of the data that is entered into the system, and awareness and preparedness to deal with issues such as power outages are important. Williams and Boren (2008) also point out that in designing and evaluating an EMRS the views of its users is essential. The system is not likely to be successful in the long run if the health workers themselves are unhappy with the way it works. In addition problems which are already present in the paper-based records can be transferred over to the electronic records during the change, therefore such issues need to be addressed before the EMRS is installed. Privacy and confidentiality issues also need to be settled beforehand, because electronic records are easier to access and they are likely to be used for purposes other than simply providing a service to the patient (WHO, 2006).

2.3 The Nepalese health sector and health information systems

The DHS and the Department of Ayurvedic Medicine (DAM) provide all primary health care in the Nepalese public sector. The system is run centrally by the DHS from the capital city, Kathmandu, but since the decentralisation of Nepal's health sector, the management of each of the 75 districts lies in the hands of district health authorities (the decentralisation of the health sector is examined in more detail in chapter 4). At the lowest level of the system are the sub-health posts (SHB), of which there were 3,129 as of 2007, as can be seen in table 2.1. The government runs 94 hospitals, in addition to two teaching hospitals. There are also nine teaching hospitals run by the private sector, three community-run hospitals, 12 hospitals runs by NGOs, 16 eye hospitals, and 74 hospitals and nursing homes run by the private sector.

Aside from health facilities there are also Female Community Health Volunteers (FCHVs) (close to 50 thousand), Traditional Birth Attendants (over 12 thousand), Outreach Clinics (15,000+), and Immunisation Centres (15,000+) (WHO Country Office for Nepal, no date, p. 10). Nepal also has a network of ayurvedic health facilities, including two hospitals and hundreds of dispensaries around the country (WHO Country Office for Nepal, no date, p. 12).

Table 2.1 – Health facilities in Nepal by type and service level

Service level	Facility	Number
Specialised	Hospital	3
Capital	Hospital	5
Region	Hospital	2
Sub region	Hospital	1
District	PHOs/DHOs/Hospital	14/61/67
Electoral constituency	PHCs/HPs	193/701
Village Development Committee	SHBs	3,129

Source, WHO Country Office for Nepal, no date, p. 10.

PHO: Primary Health Office, DHO: Distric Health Office, PHC: Public Health Centre, HP: Health Post

The Nepalese national health policy was adopted by the Ministry of Health and Population (MoHP) in 1991. It emphasises:

the Preventive, Promotive and Curative health services, basic primary health services, ayurvedic (alternatives medicine) and other traditional health services, community participation in health services, development of human resources for health, resource mobilization in health services, private, non governmental health services and intersectoral coordination and health research and decentralization (Ministry of Health and Population, 2011).

With the Second Long-Term Plan (1997-2017)¹ the Ministry of Health and Population (MoHP) increased its focus on improving the overall health of the nation, with an emphasis on extending health services to the poor and marginalised populations (WHO Country Office for Nepal, 2007). This focus on equality in access to health has remained on Nepal's agenda, as improving the health of the entire population was main focus of the Tenth Plan (2002-2007) (Ministry of Health and Population, 2011). The GoN went even further and cemented the idea of health as a human right in its interim constitution, and its forthcoming constitution (Vaillancourt and Pokhrel, 2012).

The Government of Nepal (GoN) runs a set of information systems, listed in table 2.1. The HMIS is the main system for health data, while the others serve the financial, human resources and logistics aspect of the health system. HMIS, HuRIS and LMIS have been running since 1994, while the DIN was established in 1991 (Ministry of Health and Population, 2006). The HMIS is run on computers at the district level, and reports are generated by the MoHP on a monthly basis. There are a number of parallel information systems, mainly for TB and HIV/AIDS. Birth and death registration is handled by the MoH, in accordance with law, but the coverage is low. Despite the HMIS data being generally consistent with that of population surveys, it is hard to assess the quality of the data (International Health Partnership, 2011).

Table 2.1 – Health information systems and sources of health information in Nepal

Information system/source	Data
Health Management Information System (HMIS)	Information from all health services from government health facilities.
Human Resource Management Information System (HuRIS)	Information on all human resources for all government health facilities.
Logistics Management Information System (LMIS)	Receives quarterly information on supply, consumption and stock from all government facilities.
Financial Management Information System (FMIS)	Budget and expenditure reports every 4 months to district centres.
Drug Information Network (DIN)	Manages and disseminates information about drugs (adverse reactions, contraindications, toxicity, proper handling, etc.)
Ayurveda Reporting System (ARS)	Monthly reports to the Department of Agriculture from all Ayurveda facilities on services, infrastructure, herbs and quality control.
Army and police hospitals	Maintain own HIS, police hospital service data is incorporated into the HMIS.
Institute of Medicine (IOM) and other teaching hospitals	Maintain own HIS, not fully integrated with HMIS.

¹ The First Long-Term Health Plan was for the years 1975-1990 and will not be discussed here.

Private clinics

Maintain own HIS, some hospitals/nursing homes send service data to HMIS, most do not.

Source: Ministry of Health and Population, 2006

The Ministry of Health and Population (2006) identifies a number of problems with the system such as missing information (on health status as well as quality of services); the data is not being used or analysed in some areas; it is unreliable and inconsistent; coordination between different data collectors; delays; different systems do not work together; lack of personnel, equipment and financial resources; and they do not always meet donor requirements.

Despite the HMIS generally being considered good, or “well-functioning [and] fairly reliable” (Vaillancourt and Pokhrel, 2012, p. 17), the fact that access to health care in the country is very unequal, despite efforts to extend health services to all according to the national health policy, indicates that there might be large portions of the population that cannot be reached and are therefore not represented in the data. I will discuss this further in chapter 3.5.

3 Barriers to the implementation of health informatics in developing countries

While it is clear that the implementation of health informatics – particularly in the form of EMRS – is an important part of improving the effectiveness of rural healthcare in developing countries, there are a number of barriers that need to be overcome. Each location and context for which an EMRS must be adapted is different (Heeks, 2002; Chilundo and Aanestad, 2004; Kimaro, 2006), however the barriers faced in each case are generally variations of a number of issues relating to remoteness, lack of infrastructure, human resources, cost, and politics (Williams and Boren, 2008; Oak, 2007). In this chapter I examine these barriers first in a general way before discussing the situation in Nepal specifically.

3.1 Remoteness and access to health care

Remoteness is an important factor when it comes to health care provision in general, particularly in developing countries. Despite the increasing global urbanisation, a large proportion of the population of the global south lives in rural areas, many of which are hard to access. 51% of the world now lives in urban areas, but the development has been uneven as 82% of the population of Northern America and 73% in Europe lives in urban areas, compared with 39% of Africa, and 44% of Asia, for instance (United Nations Department for Economic and Social Affairs, 2012). In Nepal, only 18% of the country's 30 million live in urban areas (World Bank, 2012).

The differences between urban and rural populations can be substantial, as rural populations tend to be poorer, less educated, and less healthy (Wilson et al, 2009). Remoteness serves as a barrier to the access rural populations have to even the most basic services, such as education and health care. Additionally, where poverty and poor health is the norm, people can be unaware of the fact that they are ill, so they do not seek health care when they need it (O'Donnell, 2007). The factors that influence whether or not people seek health care that is available to them is an important consideration when it comes to evaluating and improving public health. Pokhrel and Sauerborn (2004) claim that the decision to utilise health services is not a simple choice of yes or no, but rather a process by which an individual or household has to make a series of choices. After an illness has been perceived, they must choose whether or not health care is needed, then they must choose which provider to turn to, and eventually choose how much money they are willing to spend. Each step is influenced by socio-economic status, cultural beliefs, available facilities, and even the sex of the patient. In South-Asia it is not uncommon for households to be willing to spend more money on treatment for boys than girls, as boys are seen as more valuable (Pokhrel et al, 2005).

Rural road access is an issue that has received more attention in the last 20 years as restructuring of the concept of poverty has brought to light the impact isolation can have on the lives of rural populations (Plessis-Fraissard, 2010). Travel distance can have a large impact on whether or not people seek health care, and this impact can be compounded by terrain and weather conditions. In elevated areas with rugged terrain and unpredictable weather patterns, a relatively short distance can become next to impossible to traverse under the right conditions (Perry and Gesler, 2000).

This can not only affect demand for health care, but also present a barrier to provision of health services. An isolated population to which health services can not easily be extended, is therefore likely to be underrepresented in any health data, even if EMRS are available for use. Therefore, the most obvious barrier to implementing effective health information systems (whether they are digital or paper-based) is simple *access*. If health care does not reach everyone, then the information is incomplete and less reliable (Braa, 2001). This is true for most of the rural population of the developing world.

Improving road access can have a significant impact on rural communities in general. Khandker, Bakht and Koolwal (2009) claim that despite the high cost of road construction and maintenance, the long-term benefits are worth it. Their evaluation of two road improvement projects in Bangladesh showed that better access to all-weather roads led to 36-38% lower transport costs for households, 5% lower fertilizer prices, 27% higher agricultural wages for men, 4-5% higher crops prices, 14-20% higher school participation, and 5% poverty reduction.

While the goal is to extend transport networks to the entire population, in many cases the cost of constructing all-weather roads cannot be justified (Devkota, Dudycha and Andrey, 2012). 31% of the world's rural population lives more than 2 km away from an all-weather road (Plessis-Fraissard, 2010) and it will take time before the isolation of all these people can be alleviated with paved roads. In the mean time many transportation and access problems can be solved with smaller scale, needs-based solutions such as trail-bridges (Devkota, Dudycha and Andrey, 2012), bicycle ambulances (Forster, 2010), and improvements to existing trails to increase mobility (e.g. steps on hills, cutting of vegetation, lights, and bridges) (Vijayakumar, 2010).

Clearly remoteness and access are important factors in health care provision, and as a result, also a factor when it comes to the implementation of EMRS and other health information systems, as well as the completeness of the data collected through these systems. Remoteness and poor rural development has made extending infrastructure such as electric grids and phone networks to the poorest populations of developing countries difficult, yet both of these are critical elements for the use of information technology in rural health care (Williams and Boren, 2008; Oak, 2007).

3.2 Infrastructure and technology

While the advancement of technology, ICTs in particular, has been growing exponentially in the developed world, the developing world has for the most part been lagging behind. As a result the digital divide between North and the South has been and continues to grow. Access to improved energy sources, for instance, in developing countries is very limited, as 50% and 75% of the people of South Asia and Africa respectively, currently live without electricity (World Bank, 2011a), and access to ICTs is even more incomplete.

Attempts to tackle the issue of electricity, computer technology and internet infrastructure in developing countries have met with varying success. In Africa, less than 3% of the population has access to the internet, despite the continent constituting over 14% of the world's population (Fuchs and Horak, 2008). The long term sustainability of an EMRS system hinges on the availability of a reliable source of energy, and for such a system to reach its full potential, access to a larger scale information network is also necessary (Chilundo and Aanestad, 2004).

Sheikh and Braa (2011) have pointed out that while in most donor funded health informatics projects the necessary technology has been paid for and installed, the longer term maintenance of this technology is too rarely assured. Computer based HIS systems too often fail because they are being installed in areas that lack the kind of technological culture required to maintain them. For instance, there are often no people available who have the technical know-how to deal with malfunctions, regardless of whether the malfunction has to do with hardware or software. In cases where the project included training opportunities, there is rarely a system left in place to ensure continued training when it is needed. These problems stem from two potential issues. Either the donor organisation's project did not include enough consideration of sustainability, or the technology is not appropriate for the situation (Kimaro and Nhampossa, 2007; Braa 2011).

Kouematchoua and Rienhoff (2007) warn that the technology is merely a tool, and for it to do its job, there must be people who are adequately equipped to use it.

3.3 Human resources

Any introduction of new technology to an organisation requires a period of adjustment, particularly when the change is radical. Its users need to be trained, work flow and routines adjusted, and a positive, enabling learning environment must be assured (Kimaro, 2006). In the case of developing countries, especially in remote areas, this is easier said than done. Education and training for the use of ICT and HIS in developing countries is hard to come by. Even providing primary education and raising basic literacy rates is a challenge (Kimaro, 2006). Enrolment in primary school in developing countries has improved considerably in the last 20 years, with access going up from 82% in 1999 to 90% in 2010. Sub-Saharan Africa has seen great improvements (58% in 1999 and

76% in 2010), as has Southern Asia (77% in 1999 and 93% in 2010). In fact, Sub-Saharan Africa is now the only region where enrolment is below 90%. This process, while worthy of celebration, has not been entirely even. The children who are most likely to be out of school generally come from poor and/or rural households (United Nations, 2012a).

The development and implementation of HIS is generally aimed at educated people, such as health workers. Therefore, low literacy rates in the area is not much of an issue. However, literacy on its own does not necessarily enable a person to use a computer, and despite their often advanced education, many health workers lack so called “digital literacy” (Oak, 2007; Kimaro, 2006; Chandrasekhar and Ghosh, 2001). The long-term sustainability of an HIS requires extensive training for health workers, to ensure that they are capable of using the system effectively.

The purpose of EMRS in rural areas, as I have established, is first and foremost to improve health care and collect data. Reliable data is essential to evidence-based health policy and the use of HIS (digital and paper-based) has been emphasised in the strengthening of health systems in developing countries (Stansfield et al., 2008). It is important to note that health information is not only an important tool for health systems on a larger scale, it is also significant for the local provision of quality health care. That means that the data should not be collected solely for the purpose of generating reports for authorities higher up in the health system hierarchy, it should also be available to local health workers so they can themselves evaluate the quality of their work. This adds another dimension to the education issue, because not only do health workers need to be able to use the system, they also need at least a basic understanding of medical statistics and some training in outreach and planning, so they can make use of the data they have collected (Braa 2001; Chandrasekhar and Ghosh, 2001; Kimaro and Nhampossa, 2007). Education is needed not just to ensure human capacity, but also to encourage an interest in the system and an understanding of its importance (Littlejohns et al, 2003). Without this its use runs the risk of becoming, in the minds of the health workers, a part of the job description which serves only the needs of distant bureaucrats, and will therefore become a chore, left for quieter moments (and thus likely to build up or be less reliable), rather than an important part of the health service itself (Braa, 2011).

3.4 Politics and international development

Due to the international pressure on developing countries to meet the MDGs, efforts to build and maintain efficient information systems in the health sector have been on the rise. Many of these systems have met with substantial barriers and even failure, mostly due to insufficient funds, a lacking “data-use culture” (Pappaioanou et al, 2003), inadequate training of staff at all levels, and a

clash between the needs of the national HIS and a multitude of systems implemented to serve the needs of donor funded projects (Chilundo and Aanestad, 2004; Nyella and Mndeme, 2010).

The health sectors in most developing countries are often very centralised, urban based systems that were originally established by colonial powers. Efforts to decentralise the systems in the hope of improved national coverage have been somewhat successful. Unfortunately, in some cases, this has also led to an unequal developments between districts and regions, as some have more stable economies or less corrupted officials (Green, 1999). Different parts of the countries can therefore not only have very different health outcomes, but also less reliable data with which to work. In addition to this, it is clear that while the goal is to improve over all health outcomes, the decision makers are products of their environments. Priorities are therefore not always according to need, but rather based on cultural values (Oliver, 2006). Health outcomes in developing countries (as well as in many developed countries) reflect strongly on social determinants such as gender, ethnicity, religion and other cultural factors (Marmot, 2005). Distribution of resources and funds have a strong tendency to be pro-rich, and to leave the poor and other marginalised populations without (Oak, 2007). This can have a profound effect on the implementation of health information systems in remote areas, particularly as public health care is more likely to be available in rural areas and it is more often than not underfunded.

Governments of developing countries are often forced to rely on financial support from various international organisations and donors to run their health systems. Understandably this puts much of the decision making power in the hands of the donors, most of which demand information that assures them that their money is being well spent (Nyella and Mndeme, 2010). There is unfortunately limited consensus between these organisations and the governments of the world as to what kind of health information needs to be collected (Azubuike and Ehiri, 1999). Developing countries receive money from many different donors at the same time, each of them often focused on particular health issues or diseases (Chilundo and Aanestad, 2004). The resulting health information systems are fragmented, overlapping and inefficient. The people in charge of gathering and compiling the data are overrun trying to please the donors. Meanwhile the national HIS has limited room to grow. This kind of top down decision making does not take into account the very different needs of the many districts and regions of the countries (Alvarez, 2004). The end users of the systems (the health workers) are rarely consulted and their work can be negatively affected by the increased workload (Sheikh and Braa, 2011). Disorganisation of this sort makes building an ICT based HIS a challenge, as it would require integration and cooperation between all these different actors, as well as the valuable input of the system's users at all levels.

Kanjo (2011) also warns that even in cases where an HIS is in place, top down health policy can create barriers to its effective use, due to the often absent consideration of local context. As an example he mentions that for the purpose of encouraging expectant mothers to go to official health facilities when giving birth, traditional birth attendants (TBAs) were forbidden from delivering babies in Malawi. In rural areas, access to official health care is limited and factors such as distance to facilities and cultural views of giving birth² can lead to many women choosing to give birth at home. Before the policy change many TBAs had been trained to register information about the children they delivered, but they stopped doing so after the ban. As a result, information that had previously been collected was no longer available.

The implementation of computer-based HISs is about more than hardware and money. An environment needs to be created and maintained where the collection of health data is seen as a crucial part of the work on all levels of the hierarchy, and health policy is based on the needs of the health system itself and its staff, rather than pressure to conform to external demands of donors and international development goals such as the MDGs. Where this is lacking, no amount of money or hardware is going to create a sustainable system.

3.5 Barriers to implementing electronic health information systems in Nepal

Despite the Nepalese government's expressed commitment to implementing a widespread, decentralised health information system across the country (WHO Country Office for Nepal, 2007a), there are a number of substantial barriers that must be overcome, particularly if computer based systems are to be used. For example, in 1977 the Nepali started registering births, deaths, marriage, divorce and migration in their Vital Registration System. Although the system has been in place ever since, even now the information it collects is incomplete. In 2005 only 16.27% to 37.45% (depending on region) of all deaths were registered in the system. Thus any real data on cause of the death in the country is going to be unreliable and largely based on estimates (WHO Country Office for Nepal, 2007a). The data is also unlikely to properly represent the real population because the people reached by the system are generally the richer people, or at least those who have access to and utilise health services. The country's true health landscape is therefore obscured.

Out of the close to 30 million people who live in the country, 81% live in rural areas (WHO, 2012a). Around half of the population in 2001 lived in the so-called Terai area, which is the part of the country that lies beneath 610 metres above sea level; it comprises about 23% of the land. The other half of the country lived in the hills (610-4876 m) and the mountains (over 4876 m), with

² For example, many women are pressured by family members to give birth at home because it is believed that the point at which the pain of delivery becomes hard to bear, they are likely to be

approximately 7% living in the mountains. Due to the difficult terrain and variable climate (90% of the yearly precipitation falls during the 3 month long monsoon period), only 43% of the population has access to all-weather roads³ (Dahal et al, 2010) and 60% of the existing road network is concentrated in the Terai region (World Bank, 2011b). Road construction in the parts of the country where the roads are most needed (hills and mountains) is in many cases prohibitively expensive (Dahal et al, 2010), which has serious implications for rural development and access to essential services (Dahal et al, 2010; Devkota, Dudycha and Andrey, 2012). Table 3.1 illustrates the difference in access to health services between rural and urban areas. The difference in access to health posts and sub-health posts is less serious than that of access to public hospitals and clinics and private hospitals. It is clear from these numbers that there is significant regional disparity in health care coverage. In the mountains up to 50% of the population must walk for more than 3 hours to get to a public hospital and and less than half of them live within 30 minutes walk from a health post. Meanwhile in the central development region 88% live within an hour from a health post, and 44.8% less than 30 minutes away from a public hospital. It is important to point out that in areas where people live 3 or more hours away from services, in some cases the distances measure in days rather than hours (Acharya and Cleland, 2000).

Table 3.1 – Difference in access to health facilities in Nepal between rural, urban and poorest populations

	Less than 30 minutes			More than 3 hours		
	Urban	Rural	Poorest	Urban	Rural	Poorest
Health post/sub-health post	85.9	59.0	51.4	0.1	1.9	3.3
Public hospital	82.6	20.6	15.2	0.1	21.5	30.5
Clinic/Private hospital	92.0	43.2	33.2	0.1	17.3	23.6

Source: Central Bureau of Statistics, 2011

Poverty is a strong indicator of access to and usage of health care in Nepal. Despite the proportion of people living in poverty having fallen from 42% in 1990-1995 to 31% in 2003-2004, the change has been uneven and large parts of the population have fallen behind, as 35% of the rural population is still poor, compared with 10% of those who live in urban areas (WHO Country Office for Nepal, 2007b). In Nepal, as elsewhere, causes of poverty are complicated and varied. The population is very diverse with over 90 spoken languages (Nepali is the mother tongue of just under 50%), and between 60 and 65 different caste and ethnic groups. Religious diversity is also a factor, with about 80% of the population being Hindu, 10% Buddhists, and 4% Muslims. Poverty and

more truthful about who the father really is.

³ Less than 30 minutes on foot.

social exclusion based on religion and caste/ethnicity is a recognised problem in the country. The main groups that are identified as being excluded or politically isolated are women, indigenous nationalities (Janajatis), the Madhesi people,⁴ the Dalits⁵ (Ministry of Health and Population, 2011), and people who are discriminated against due to their sexual orientation or gender identity (such as third sex) (Keeling, 2007). Poverty levels amongs the different castes and ethnicities of Nepal are indicative of their importance in determining the level of political and economic inclusion. Compared with 11.7% of the Brahmin (upper caste Terai) living under the poverty line, 47.6 and 45.7 per cent of the Hill and Terai Dalit respectively are defined as poor. Other marginalised groups include the Hill and Terai Janajati (42.8% and 33.0%) and Muslims (41.4%) (Ministry of Health and Population, 2011). The exclusion of these groups and their lower standing in society is likely to have an impact on their access and utilisation of health care, which in turn would make them underrepresented in any health data.

Women's (mainly reproductive) health has become an important issue in recent years due to Millennium Development Goal number 5, which calls for improved maternal health. Health care demand and utilisation in Nepal, particularly when it comes to maternal and child health, has proven to be greatly affected by women's education and ability to take part in household decision making (Furuta and Salway, 2006; Shrestha and Shrestha, 2011; Hotchkiss, 2001). The number of antenatal care (ANC) visits a woman receives is greatly affected by education, but according to Shrestha and Shrestha (2011) only 15% of women who had no education had more than 4 ANC visits, compared with 60% of those with secondary education or higher, and the richest women were 5 times more likely to get more than 4 ANC visits than the poorest. In fact, 50% of the poorest women get no ANC visits. Furuta and Salway (2006) also point out that fewer than 10% of women have jobs and have influence on how their earnings are spent. Table 3.2 shows that while education and literacy is relatively low for the population (56% in Nepal compared with 61% for South Asia, 62% for Sub-Saharan Africa and 58% for the Least Developed Countries (United Nations, 2012b), the difference between men and women is significant. Fortunately, the National Free Delivery Policy was adopted in 2009, with support from DFID. The aim of this policy is to encourage women to deliver their children in health facilities, rather than at home. In 2007 user fees for deliveries were abolished in all health posts and primary health care centres. In 2009, with the introduction of the policy, the programme was extended to all district hospitals. As of 2011, the policy is being extended to community, mission and NGO hospitals and the private sector will be

⁴ The Madhesi are Terai based underprivileged people who cover a number of different castes from Dalit to high Terai castes. They are marginalised by other traditional ruling castes (Keeling, 2007).

⁵ Untouchables, constitute about 14% of the population (Aasland and Haug, 2011).

included in the future (Witter et al, 2011). The Safe Delivery Incentives Programme (SDIP) was implemented at around the same time. The programme is intended to provide women with further incentive to seek health facilities for giving birth, by providing them with payment to cover travel expenses (Safe Motherhood in Nepal, 2009).

Inefficiencies in the health sector need to be overcome to ensure these programmes are successful. Witter et al (2011) claim that it is not always clear what services are being offered for free, and that payments to health centres to cover the cost are often delayed, particularly in the beginning of the year, due to delays in national budget approvals. They also warn that there is a risk of health facilities “cutting corners”, which means that improvements in quality monitoring are needed (Witter et al, 2011, p. ii90).

Table 3.2 – Literacy and education in Nepal 2011-2012

Literacy	Population	Men	Women
6 years and older	61%	72%	51%
15 years and older	56%	72%	44%
Education	Adult population (15+)	Men	Women
Never been to school	34%	23%	44%
Been to school in the past	28%	36%	22%
Currently going to school	38%	41%	34%

Source: Central Bureau of Statistics, 2011

Gender disparity also has an impact on child health. In Nepal, much as in the rest of South Asia, boys are valued more than girls. While the decision to seek health care once a child’s illness has been noted, households are more likely to spend money on more expensive private health care for boys. Pokhrel et al (2005) claim that this is due to culture, not money, as the same pattern of health expenditure for children can be found in all income groups.

Table 3.3 – Comparison of mobile-cellular and fixed-telephone subscriptions for Nepal and regions of the world 2011

Subscriptions	Developed world	Developing world	Asia and Pacific	Nepal
Mobile-cellular subscriptions (per 100 people)	122.3	77.8	76.7	43.81
Fixed-telephone subscriptions (per 100 people)	43.6	12.0	13.3	2.77

Source: International Telecommunication Union, 2012

With large parts of the country's population being as physically isolated as it is, it is no surprise that when it comes to access to telecommunication and information technology, Nepal's rural people are also socially and politically isolated from not only their own society, but also the global one. Table 3.3 shows mobile-cellular and fixed-telephone subscriptions in Nepal compared with the region, the rest of the developing world and the developed world. Nepal is lagging behind in both.

Efforts have been made to improve telecommunication in rural Nepal in a joint project between the Government of Nepal and UNDP where the goal was to build telecentres and improve rural people's access to information on agriculture, economics, health, and more. The hope was that this might empower the people to take an active part in their own development (Harris, 2003). A number of national councils and committees whose job it is to evaluate the country's needs and find ways to meet them. There is for instance the National Information Technology Development Council, the National Information Technology Co-operation Committee, and the National Information Technology Centre and Information Technology Park Development. All these and more, in addition to introduction of the Information Technology Policy in 2000 (Pradhan, 2002).

In order to improve access to information technology, both for the people and the rural health posts, access to electricity needs to be widespread and reliable. This is not the case however as 61% of the population lacks access to electricity (Mainali and Silveira, 2011). The coverage is very uneven, but only 34% of the rural population has electricity, compared to 90% of the urban population (Mainali and Silveira, 2012). About 85% of the country's energy consumption is fuel wood, agricultural residue or animal waste. Electricity only accounts for 1.5% of the energy use. Lack of electricity and the overuse of traditional, unsustainable energy sources is not only a hindrance to rural development, it also has a negative impact on health (Shrestha, 2005). Due to how expensive rural electrification is, the financing of extending the electric grid to remote areas has been difficult to accomplish. The people who most need it, are also those least likely to be able to afford paying for it (Mainali and Silveira, 2011). Consequently there are large areas of the

country where there is no electricity with which to run computers or other electrical devices which could be used for gathering health data.

Considering the already poor state of education in the country, as discussed above, it is not surprising that human resources are lacking, just as much as infrastructure and financial resources. The largest group of health workers in Nepal are female community health volunteers (FCHVs) (Keeling, 2007), which number in the tens of thousands, as can be seen in table 3.4. For a population of 28 million, 62 thousand FCHVs amount to around 470 people per volunteer. The FCHVs receive no pay for their work and limited support from the health system (Keeling, 2007; World Health Organization: Country Office for Nepal, 2007a). Meanwhile there are much fewer doctors and trained nurses, less than 4,000 doctors (over 7,000 patients for each one) and not many more nurses.

Well educated and trained medical professionals mainly come from the richer social groups who are able to pay for their education, and they are not commonly interested in working in remote, resource poor areas. Most choose to work in the larger cities, or abroad (Karki, Courney and Woollard, 2009). Consequently, there are few health workers in rural areas who are likely to have the kind of education needed to use health information systems effectively, or the digital literacy required to incorporate computer technology in their work.

Table 3.4 – Number of skilled health workers in Nepal

Description	1996-1997	1999-2000	2001-2002
Doctors	894	1259	3944
Nurses/Auxiliary Nurse Midwives	4706	4655	4315
Ayurvedic Physicians	290	211	387
Baidhya	219	210	354
Paramedics/Health Assistants	5152	5295	5295
Village Health Workers	-	4015	3985
Maternal and Child Health Workers	3187	3190	3190
Female Health Community Volunteers	42427	46737	62546
Traditional Birth Attendants	12682	14951	-

Source: World Health Organization: Country Office for Nepal, no date.

As the discussion here above illustrate, there are a number of issues which need to be addressed in order to improve the collection of health information in Nepal, and even more if it is to be done using IT. The country's ruling body is willing and has demonstrated their commitment to reach these goals. Nepal is a very poor country however, and these changes will take time and a great deal of money. According to the Second Long-Term Health Plan the goal for the period of

1997-2017 is to raise the total health expenditure to 10% of total government expenditure (WHO Country Office for Nepal, 2007b). In 2000 it was 6.5%, and as of 2009 it was 7.7%, which is good compared with 4.9% of the region, but there is still a ways to go to reach that of Europe or the Americas, with 14.6% and 16.9% respectively (WHO, 2012b). The financing of health information systems is therefore not quite straightforward.

4 Collaboration for a sustainable future for health informatics

The preceding chapter may make it seem as if making electronic health information systems in developing countries work is next to impossible. There are many physical, technical, political and social barriers that need to be overcome, and some of them are considerable and complicated. In spite of that, there is no reason to believe that solutions to these problems cannot be found. The issue has, in fact, been accepted as an important factor for global health and evidence-based health policy on a national as well as global level. Reliable health data is vital to an effective health system, but a strong health system is also needed to encourage the collection of reliable data. In this chapter I examine the ways that recent efforts to strengthen health systems with decentralisation and coordination between donors and governments are paving the way for improved health informatics in developing countries, and how these efforts can be complemented with long-term strategies for introducing health informatics to remote areas.

With the emergence of the MDGs increasing attention has been brought to the importance of general health system support, as well as the empowerment of local government leadership. In the 1990s the problems caused by the way development aid was being done came under scrutiny for being highly fragmented, overlapping and ineffective. They were considered to be too focused on donor priorities rather than that of the local governments, or actual need. As a result a new approach emerged, the Sector Wide Approach (SWAp). According to Peters and Chao (1998, p. 177) the SWAp “is based on a new type of partnership, led by government, and involving a number of donor agencies and other groups in civil society.” Instead of organisations starting their own programmes independently, they work with the governments to support and strengthen the health system itself by funnelling the money into one ‘basket’ which can then be used to create a large scale budget with input from all of the actors involved. The aim is to give the government a larger stake in the decision making, and thus alleviate some of the power imbalance caused by the donors being in charge of the money, while at the same time making the work more efficient, by encouraging discussion, co-operation and integration of different priorities (Cassels and Janovsky, 1998; Peters and Chao, 1998; Martínez, 2006; Chansa et al, 2008). This focus on government ownership and the collaboration of development partners was further emphasised by the Paris declaration on aid effectiveness in 2005 (OECD, 2008).

While clearly a step in the right direction, the SWAp has unfortunately not always lived up to its promise. In Zambia, despite 16 years of following the approach, there is a substantial amount of money coming into the country which is earmarked for disease specific programmes and not run

through the SWAp basket, and there are still numerous agencies in the country working outside the SWAp (Chansa et al, 2008). Martínez (2006) also points out that the SWAp has not entirely fixed the problem with coordinating vertical projects in Mozambique. Chansa et al (2008) emphasise that despite efforts to improve communication and shared decision making, the number of agencies and organisations involved have the potential of drowning out government voices, regardless of one of the SWAp's objectives being the empowerment of government leadership.

The GoN adopted the SWAp in 2004 with the signing of the Nepal Health Development Partnership I (NHDP I), the Statement of Intent to Guide the Partnership for Health Sector Development in Nepal, along with 12 development partners.⁶ In 2009 the GoN officially joined the International Health Partnership (IHP+) with the signing of the NHDP II, the IHP Global Compact, with eight development partners⁷ (Vaillancourt and Pokhrel, 2012). Despite these commitments to the SWAp, there are still many vertical projects running outside the SWAp, and two of the largest donors (India and China) refuse to participate in it. Furthermore, aid accounts for 50% of the health sector budget, making it hard to establish government leadership (Schmidt, 2009). Nevertheless, approaches such as the SWAp are necessary if developing countries are to have hope of incorporating effective data collection into their health systems. While many development donors may resist these efforts (Moon et al, 2010), large organisations such as WHO and the World Bank must continue to insist on development aid being more coordinated and supportive of national ownership.

Decentralisation of public health care has become increasingly common in developing countries in the last few decades, as many believe it may serve to improve access to health care for marginalised groups (Bossert and Mitchell, 2011; Madon, Krishna and Michael, 2010; Regmi et al, 2009). Decentralisation refers to "...a political reform, designed to reduce the extent of central influence and promote local autonomy" (World Bank, 2011c). During the decentralisation of health care, the management of health services is moved from the MoHP into the hands of district authorities, in order to bring public health policy and decision making closer to the citizens of the country (Regmi et al, 2009). The government of Nepal has been working on decentralising its governance for decades, with efforts being pushed even harder with the Local Self Governance Act (LSGA) of 1999 (Gurung, 2011). The government's commitment to a decentralised and locally empowered health care system was further emphasised in the second long-term plan for 1997-2017, where the focus on equal access to health care for all was made clear. "Self-dependence, gender

⁶ AusAID, DFID, GTZ, KfW, ILO, JICA, SDC, World Bank, UNICEF, UNFPA, USAID and WHO.

⁷ AusAID, DFID, GTZ, UNAIDS, UNFPA, UNICEF, WHO, and the World Bank.

awareness, decentralisation, effective and efficient organization and management, full people's participation, partnership among government, NGOs and private sectors, are the policies adopted by this long term plan" (Paudel, 2008, p. 7). As part of the decentralisation framework local health facilities should be run by Health Facility Operation and Management Committees (HFOMCs) in which there must be representatives of underprivileged groups such as women, dalits, and the poor (Gurung, 2011; Regmi et al, 2009). Nevertheless, despite the effort the results have been less than satisfactory. The system is still highly centralised, particularly in terms of budgeting and resource allocation (Schmidt, 2009). The needs of local populations have not been reflected in the budget (Regmi et al, 2009), and despite the guidelines requiring HFOMCs to include members of vulnerable groups, the requirement has not always been met. Vaillancourt and Pokhrel (2012) point out that while some districts are doing well, they are still often understaffed, and capacity building is lacking. Bossert and Mitchell (2011) claim that successful decentralisation must be paired with local capacity building if district authorities and management committees are to be able to fully realise their potential.

A strong health system relies on the availability of many, well educated health workers. Building up the country's human resources and capacity requires the collaboration of the MoHP with not only donors and NGOs, but also other parts of the government. The education of health workers must include training of at least basic skills in using health statistics. Additionally, building up the country's telecommunication network must be accompanied with more IT based education. Chandrasekhar and Ghosh (2001) point out that the issue of education causes something of a dilemma. Scaling up education in IT may draw necessary funds from primary education, which may potentially undermine the development progress. However, providing health workers with better IT skills extends the benefits to more people, as the patients themselves are the final beneficiaries. Thus education and "knowledge capital" (Kimaro, 2006, p. 2) building must be included in any SWAp generated health policy.

One aspect of a decentralised health system is its potential for integration of vertical programmes on the ground as local authorities can mediate between the realities and needs of the citizens on the one hand, and the government and large donors on the other (Madon, Krishna and Michael, 2010). Encouraging this element of the health system is crucial for health information quality. Klugman (2000) emphasises the important role NGOs play in not only providing important services where the government cannot reach, but also in influencing policy, on a national and global level. Policy making is a highly political process and led more by the influence of powerful stakeholders than actual evidence (Oliver, 2006). NGOs that work on the ground are important sources of information about global public health and the needs of the marginalised parts of society.

When they work together for a common goal, they can influence national and global policy making by drawing attention to issues that would otherwise be overlooked, such as by empowering the marginalised and powerless to make themselves heard.

There are thousands of national NGOs at work in Nepal. In 2008 they were approximately 37,000 (Paudel, 2008) in addition to about 300 international NGOs (INGOs) (Schmidt, 2009). About a third of the INGOs belong to the Association of International NGOs in Nepal (AIN) and the association claims to be supportive of the SWAp and in favour of coordination and cooperation with the government and aid donors (AIN, 2011). However, it is not known how many NGOs specialise in health (Paudel, 2008), and according to Schmidt (2009) Nepal's civil society has not been included in SWAp meetings. Additionally, all INGOs work under the Ministry of Social Welfare, regardless of their focus, which means that ones that provide health services are not accountable to the MoHP (Vaillancourt and Pokhrel, 2012). Nevertheless, NGOs are very important providers of health care in the remote areas of the country where public health services are unavailable.

Clearly there is a willingness to move forward and the country's health policy reflects the acknowledgement that the knowledge generated at the local level is necessary for a robust health system. While the ultimate goal clearly is to ensure that health care reaches the whole population, the fact that this will take years to accomplish must be taken into account for the design of an HIS, as it has implications for the completeness of the data collected. The implementation of an HIS in urban areas and where health care provision coverage is good, will take place in a shorter period of time than in rural, hard to access areas. If a future in which access to reliable health data from developing countries is to be realised, it is therefore imperative that the process take place in stages, with long term goals taking precedence over short-term benefits (Kanjo, 2011). Extending the system in stages is in its essence a highly top-down approach, and thus has the potential of failing to reflect the needs and practices of all of its users, particularly those furthest away from the centre (Kimaro and Nhampossa, 2007). It follows that every stage must be preceded by research and analysis of the context into which the system is to be extended, as each community is different (Harris, 2003; Heeks, 2002).

The process of implementing a system which fails to meet expectations due to its inappropriateness for the situation, can lead to the users being skeptical of further efforts, which in turn undermines the potential of subsequent efforts. Including evaluation and context analysis in the design/implementation process can prevent this from happening. According to Heeks (2002) many of the HISs used in developing countries have been designed and developed in more technically advanced countries, leading to a large gap between the context within which the system was

designed and the context in which it will be used. For this reason Sheikh and Braa (2011) emphasise the importance of making sure the end users (e.g. health workers at local clinics) are consulted and their needs taken into account. A system that is adapted for the situation and that allows for local improvisation has a greater chance of being sustainable.

At this point, it is important to discuss the fact that in some cases the use of IT may not be feasible (Chilundo and Aanestad, 2004). In Nepal there are large areas of the country where access to roads and electricity may be years in the future, but providing health care and including the people who live there in the data should not have to wait. Until the digital divide that separates these communities from the rest of the country can be overcome, a less advanced paper-based system should be used.

Considering that only 59% of the rural population of Nepal lives less than 30 minutes away from a health post (CBS, 2011), many of them are likely to seek alternative health providers (such as TBAs). The exact number of traditional health providers is hard to determine and people use their services for a variety of reasons; they are easier to access, where there are health posts available absenteeism is a problem, they can pay for the service with goods rather than cash, and their services can include religious or spiritual elements (O'Donnell, 2007; Ensor and Cooper, 2004). This results in illnesses, deaths and births going unreported and even portions of the country's population being largely invisible to the health system. Reaching out to traditional health providers and counting their contribution to Nepal's public health might fill in some of the gaps. In cases where the educational level of the available health workforce is low, less technologically advanced tools are more appropriate.

Finally, building up an information system that generates reliable information, must include a mechanism for local use of the information itself (Braa, 2001; Kanjo, 2011; Mengiste, 2010). The decentralisation of the health system creates opportunities for this, as in such a system a hierarchy exists where at every step the information collected can be used to further improve health care provision. If an IT based HIS is rolled out in stages, this means that different parts of the country will be in different stages of HIS development, for instance in areas where paper records are used (Mengiste, 2010). One possible solution to this is to hire people to travel to such areas on a regular basis to collect the information. The people could be trained to educate these remote populations on the importance of the information that is being collected, and thus preparing them for future evolution of the system. In order to do so the information must be analysed at a higher level and the results brought back. Making the information available at lower levels can encourage an interest in and understanding of public health interventions, and mobilise marginalised social groups to make demands. The information therefore must not only be collected for the sake of evaluating the cost-

effectiveness of decisions made at the top, the system must be designed with information analysis and use at every level in mind, and the flow of information should extend from the top to the bottom, as well as bottom to top. As Braa (2001) points out, information collected in facilities is sent on to district managers which then aggregate the data and pass it on further. District managers need to be able to analyse the data they receive for each facility and provide them with feedback to better guide their work.

As this discussion shows, there is still a long way to go towards a strong health system with a large scale IT-based HIS that reaches every corner of the country of Nepal. Collaboration between donors, NGOs and the government is essential to strengthening the country's health system, which in turn is vital to the implementation of the HIS. Health data quality relies on the system's ability to reach everyone, therefore it's development must be tied in with general health system strengthening and the extension of health care provision to the whole community. This will take time, and the implementation of HIS must therefore be built on a long-term commitment by all relevant actors.

5 Conclusion

In this paper I have explored the importance of good quality health information for local and global public health, and the the potential health informatics have for supporting the development of functional national health information systems in developing countries. Reliable health data is crucial to effective health policy and decision making on all scales, from the smallest village to large multinational organizations, and collaboration between all actors on all levels is critical if the digital divide is to be crossed.

Health informatics have a great deal of potential for health care in developing countries. They are more reliable than paper-based information systems, the data they are used to collect is more easily available, and accurate information can more easily be passed on from the patient to national and even global decision makers. The barriers to their implementation, however, are substantial though not necessarily insurmountable.

Nepal, like most of the poorest countries in the world, has a very large rural population. The people are physically, socially and politically isolated and their access to basic services are very limited. Information about the true state of the the health of the population is therefore hard to come by and decisions on research allocation and health policy not likely to be as evidence based as it they should be.

The implementation of health informatics is not merely dependent on a strong health system. Road access in rural Nepal is limited, the landscape rugged and not easily traversed. The national electrical grid does not cover large portions of the country, making the introduction of computer technology impossible at this point in time. Furthermore, there is a pronounced shortage of people who have the education required to work with computers, particularly in the more remote areas of the country. Not only must they have IT experience, they must also be trained to use and understand statistical data.

Things are looking up, though. With the introduction of the SWAp and the Paris declaration for Aid Effectiveness, the government of Nepal and its development partners, have incredibly been coordinating their work in order to strengthen the government's health system and offset some of the power imbalance that is so often inherent in development aid. The decentralisation of the health system has also provided districts with more room to evaluate their priorities and allocate resources according to need. However, the government is fragile and unstable, and the districts are not equally equipped to tackle the health issues they are faced with.

The MoHP is currently running a fairly good information system, HMIS, along with a number of other information systems which monitor the health of the people as well as human resources, drugs, finances, logistics and more. However, these systems are not linked, and there are still a number of parallel information systems managed by the private sector, donors who refuse to collaborate, and large programmes for HIV/AIDS and TB. The lack of access to health care in the country also has implications for the accuracy and reliability of the HMIS.

The development of an entirely computerised HIS in Nepal is going to take a long time and the cooperation of the MoHP, the country's development partners, as well as other ministries of the country is critical. The project will have to be built on a long-term sustainable strategy where parts of the country are incorporated into the system in stages. Before the system is implemented in each stage, it must be preceded by research of the context into which it is to be introduced, and education and training of local personnel to ensure that it is welcome, the staff understand why they are supposed to use it, and how they can use it to improve their own work. The education of staff at all levels of the health system is important as well to ensure that the data is being used to improve health services everywhere, and not simply being collected for aggregation into a large national report.

The implementation of health informatics in developing countries tends to be either for national information systems, or in particular locations for the support of vertical programmes. The situation is further complicated by the multitude of systems already in place, which form a tangled web of similar kinds of information being collected for different reasons, for different goals, and none of them meant to fill in the gaps in the big picture. I believe that there is a need for a more global effort to deal with this problem. While the SWAp has led many of the larger donors to collaborate more closely with aid recipients to coordinate their work and integrate their information streams, there is still very little international consensus on what kind of information should be collected. Braa, Monteiro and Sahay's (2004) network theory is important here, except that I believe it should be more of a global network.

What I believe is needed, is a global leadership for health information and a framework for health informatics that guides the development of computerised health information systems, but is flexible and adaptable enough to incorporate the different needs of health services on a national and well as a global scale.

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