Facilitating Health Information Exchange in Low- and Middle-Income Countries: Conceptual Considerations, Stakeholders Perspectives and Deployment Strategies Illustrated Through an In-Depth Case Study of Pakistan

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Declaration

I hereby declare that this thesis was composed by me and is entirely my own work. It has not been submitted for any other degree or professional qualification.

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Abstract

Background
Health information exchange (HIE) may help healthcare professionals and policymakers make informed decisions to improve patient and population health outcomes. There is, however, limited uptake of HIE in many low- and middle-income countries (LMICs). While resource constraints are an obvious barrier to implementation of HIE, it is important to explore what other political, structural, technical, environmental, legal and cultural factors may be involved. In particular, it is necessary to understand associated barriers in relation to context-specific HIE processes and deployment strategies in LMICs with a view to discovering how these can be overcome. My home country Pakistan is currently struggling to implement HIE at scale and so I undertook a detailed investigation of these issues in the context of Pakistan to generate insights on how best to promote uptake of HIE in Pakistan and in LMICs more generally.

Aims
The concept of HIE is evolving both over time and by context. To gain a clearer understanding of this terrain, I began by identifying different definitions of HIE in the literature to understand how these had evolved and the underlying conceptual basis for these changes. Second, I sought to understand the barriers and facilitators to the implementation and adoption of HIE in LMICs. Building on this foundational work, I then sought to explore and understand in-depth stakeholders perspectives on the context of and deployment strategies for HIE in Pakistan with a view to also identifying potentially transferable lessons for LMICs.

Methods
I undertook a phased programme of work. Phase 1 was a scoping review of definitions, which involved systematically searching the published literature in five academic databases and grey literature using Google to identify published definitions of HIE and related terms. The searches covered the period from January 1900 to February 2014. The included definitions were thematically analysed. In Phase 2, to identify barriers and facilitators to HIE in LMICs, I conducted a systematic review and searched for published and on-going (conference papers and abstracts) qualitative, quantitative and mixed-method studies in 11 academic databases and looked for unpublished work through Google interface from January 1990 to July 2014. Eligible studies were critically appraised and then thematically analysed. Finally, in Phase 3 I conducted a case study of HIE in Pakistan. Data collection comprised of interviews of different healthcare stakeholders across Pakistan to explore attitudes to HIE, and barriers and facilitators to its deployment. I also collected evidence through observational field notes and by analysing key international, national and regional policy documents. I used a combination of deductive thematic analysis informed by the theory of Diffusion of Innovations in Health Service Organisations that highlighted attributes of the innovation, the behaviour of adopters, and the organisational and environmental influences necessary for the success of implementation; and a more inductive iterative thematic analysis approach that allowed new themes to evolve from the data. The findings from these three phases of work were then integrated to identify potentially transferable lessons for Pakistan and other LMICs.

Results
In Phase 1, a total of 268 unique definitions of HIE were identified and extracted: 103 from scientific databases and 165 from Google. Eleven attributes emerged from the analysis that characterised HIE into two over-riding concepts. One was the ‘process’ of electronic information transfer among various healthcare stakeholders and the other was the HIE ‘organisation’ responsible to oversee the legal and business issues of information transfer.

The results of Phase 1 informed the eligibility criteria to conduct Phase 2, in which a total of 63 studies met the inclusion criteria. Low importance given to data informed decision making, corruption and insecurity, lack of training, lack of equipment and supplies, and lack of feedback were considered to be major challenges to implementing HIE in LMICs, but strong leadership and clear policy direction coupled with the financial support to acquire essential technology, provide training for staff, assessing the needs of individuals and data standardisation all promoted implementation.

The results of Phases 1 and 2 informed the design and content of Phase 3, the Pakistan case study. The complete dataset comprised of 39 interviews from 43 participants (including two group interviews), field observations, and a range of local and national documents. Findings showed that HIE existed mainly in/among some hospitals in Pakistan, but in a patchy and fragmented form. The district health information system was responsible for electronically transferring statistical data of public health facilities from districts to national offices via provincial intermediaries. Many issues were attributed to the absence of effective HIE, from ‘delays in retrieving records’ to ‘the increase in antibiotic resistance’. Barriers and facilitators to HIE were similar to the findings in Phase 2, but new findings included problems perceived to be the result of devolution of health matters from the federal to provincial governments, the politicised behaviour of international organisations, healthcare providers’ resistance to recording consultations to avoid liability and poor documentation skills. Public pressure to adopt mobile technology frameworks was found to be a novel facilitator whereas sharing regional health information with international organisations was perceived by some participants as disadvantageous as there were concerns that it may have enhanced espionage activities in the region.

Conclusions

HIE needs to be considered in both organisational and process terms. Effective HIE is essential to the provision of high quality care and the efficient running of health systems. Structural, political and financial considerations are important barriers to promoting HIE in LMICs, however, strong leadership, vision and policy direction along with financial support can help to promote the implementation of HIE in LMICs. Similarly, the federal and provincial governments could play an important role in implementing HIE in Pakistan along with the support of international organisations by facilitating HIE processes at federal and provincial levels across Pakistan. This however seems unlikely for the foreseeable future. At a meso- and micro-level, HIE in Pakistan and other LMICs could be achieved through using leapfrog mobile technologies to facilitate care processes for local organisations and patients. Specifically, the study on Pakistan has highlighted that LMICs may achieve modest successes in HIE through use of patient held records and use of now ubiquitous mobile phone technology with some patient and organisational benefits, but scaling these benefits is dependent on the creation of national structures and strategies which are more difficult to achieve in the low advanced informatics skill and resource settings that characterise many LMICs.

Lay Summary

Effective health information exchange (HIE) can help healthcare stakeholders to make informed decisions in order to improve individual and population health outcomes. HIE is required for various purposes such as diagnosis and treatment, billing and reimbursement, population health surveillance and medical research. Due to its many uses, the term HIE has been used in different ways by various stakeholders such that there is considerable ambiguity in how it is used in different contexts. Moreover, despite its many uses, the uptake of HIE in low- middle-income countries (LMICs) is limited due to many barriers to its implementation and adoption. Apart from financial constraint, there are other factors; social, political, organisational and infrastructural that hinder the diffusion of HIE in LMICs. Similarly, my country Pakistan, is currently facing many challenges in implementing HIE at scale.

For these reasons, first of all, I undertook a detailed review of HIE definitions to identify the underpinning constructs of the term HIE and to see how it has evolved over time in various contexts. Building on the concepts of HIE, I undertook another detailed review of the factors responsible for impeding and facilitating the implementation of HIE in LMICs. Finally, building on both these reviews, I specifically explored attitudes to HIE and its deployment issues in the context of Pakistan by conducting interviews of healthcare stakeholders including citizens.

The review characterised HIE into two over-riding concepts. One was the ‘process’ of electronic exchange of health information between various stakeholders and the other was an ‘organisation’ responsible to manage the business and legal issue pertaining to information transfer. Major barriers to the development of HIE were the low importance given to data in decision making, corruption and insecurity, lack of training, lack of equipment and supplies, and lack of feedback, but strong leadership and clear policy direction coupled with the financial support to acquire essential technology, train staff, assess the needs of individuals and data standardisation were major facilitators to implement HIE in LMICs. Similar barriers were found in the context of Pakistan, but the novel ones were the devolution of health matters from the federal to provincial governments, the politicised behaviour of donor organisations, healthcare providers’ resistance to recording consultations to avoid liability and poor documentation skills. Public pressure was found to facilitate the implementation of HIE in Pakistan due to ubiquitous usage of mobile technology. Overall, findings showed that HIE existed mainly in/among some hospitals in Pakistan, but in a patchy and fragmented form.

The thesis concludes that leapfrog mobile technologies could facilitate HIE implementation in Pakistan and other LMICs at meso- and micro-level useful for some patients and organisations, but more substantial and sustained success is dependent on the creation of national strategies and bodies in order to align and supervise HIE processes which are difficult to achieve due to poor governance and lack of resources in most of the LMICs.

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Dedication

This thesis is dedicated to my elder and only brother, Ahmer Akhlaq (late), who had supported me in every aspect and was martyred (robbed and shot) at a young age of 38 years when he was out to perform a few banking tasks required for my travel to Edinburgh. May Allah bless his soul.

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Abbreviations

ACO	Accountable Care Organizations
A&E	Accident and emergency
BHUs	Basic Health Units
CHW	Community health workers
CIE	Clinical information exchange
CIIMS	Childhood immunisation information management system
CO	Charity organisation
CZ	Citizens
DEWS	Diseases Early Warning System
DHIS	District health information system
DHMIS	District health management information system
DHP	District Health Profile
DHQs	District Headquarters Hospitals
EBM	Evidence based medicine
ECS	Emergency Care Service
EDI	Electronic Data Interchange
eH	eHealth
EHR	Electronic health record
EMR	Electronic medical record
EPR	Electronic patient record
FA	Facility administrators
FATA	Federally Administered Tribal Areas
FD	Facility directors
FFC	Family Folder Collection
FLCF	First level care facilities
FM	Facility managers
FP/RH	Family planning / reproductive health
GDP	Gross Domestic Product
GIS	Geographical information system
GO	Government officials
GP	General practitioner
HCIE	Healthcare information exchange
HEPC	Health expenditure per capita
HICs	High-Income Countries
HIE	Health information exchange
HIEI	HIE and interoperability
HIPAA	Health Insurance Portability and Accountability Act
HIS	Health information system
HIT	Health information technology
HITECH	Health Information Technology for Economic & Clinical Health
HIV/AIDS	Human immunodeficiency virus infection and acquired immune deficiency syndrome
HMIS	Health management information system
HMN	Health Metrics Network
HP	Healthcare professional
IDSP	Integrated Disease Surveillance Project
IDSR	Integrated Disease Surveillance and Response
IHIE	Indiana HIE
IO	International organisations
IT	Information technology

JICA	Japan International Co-operation Agency
KPK	Khyber Pakhtunkhwa (city)
LHIO	Local health information organisations
LMICs	Low- and Middle- Income Countries
MCT	Mobile Computing Technology
MDGs	Millennium Development Goals
MEEDS	Malaria Epidemic Early Detection System
MMAT	Mixed Method Appraisal Tool
MR	Medical record
NeHII	Nebraska Health Information Initiative
NGOs	Non-governmental organisations
NHIS	National health information system
NHS	National Health Service
NPT	Normalization Process Theory
PC	Primary care
PEOU	Perceived ease of use
PMTCT	Prevention of mother-to-child transmission
PO	Private officials
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PSIS	Patient Safety Information System
PU	Perceived usefulness
RA	Rural areas
RHCs	Rural Health Centres
RHIO	Regional health information organisations
RTI	Road traffic injury
SC	Secondary care
SCR	Summary Care Records
SDGs	Sustainable Development Goals
SNO	Sub-network organisations
TA	Thematic analysis
TAM	Technology Acceptance Model
TB	Tuberculosis
TC	Tertiary care
TH	Telehealth
THQs	Tehsil Headquarter Hospitals
UA	Urban areas
UK	United Kingdom
UN	United Nations
UNICEF	United Nations Children's Emergency Fund
US	United States
USAID	United States Agency for International Development
VCT	Voluntary Counselling and Testing
VHF	Very high frequency
WHO	World Health Organization
ZEPRS	Zambia Electronic Perinatal Record System

Chapter 1 Introduction and rationale for research

1.1 Background

The availability of health data – whether patient, management or administrative – is essential to efforts that aim to support better decision making, improve quality of care and enhance health outcomes. Patient-related data, such as demographic information, symptoms and signs, diagnoses and treatments are routinely gathered by health professionals and administrators in the course of health care delivery, along with other relevant data such as insurance coverage (1). There are various purposes for which it is necessary to exchange this information between, for example, departments within organisations, and across organisations or wider health systems in order to inform decision making and trigger action. These include diagnosis and treatment, coordination of interdisciplinary care, billing and reimbursement, strategic planning, audit and quality improvement, medical research and integration of population health surveillance, amongst others (2, 3).

A major barrier to knowledge-based healthcare is lack of access to information as health systems within hospitals, pharmacies, urgent care centres, clinical laboratories, or physicians' clinics are usually isolated geographically (4). A common challenge for many economically-developed, -transition and -developing countries is to make valid and up-to date information available to health workers at the right time to support their patients (5).

Dr. Najeeb Al-Shorbaji, former Director of Knowledge Management and Sharing at the World Health Organization (WHO), has noted:

> *"People are dying because of a lack of knowledge. A lack of healthcare information leads to poor and uninformed decisions, poor planning and evaluation, poor research process and results and the formation of hasty and baseless opinions."*(6)

Policymakers, healthcare professionals, industry groups, and researchers recognise health information exchange (HIE) as a vital component of the solution to the current problems posed by disparate and fragmented health systems and non-interoperable technologies (3, 7, 8). According to the European Commission report, 'Benchmarking deployment of eHealth among general practitioners', *"HIE is the process of electronically transferring / sharing / enabling access to patient health information and data"* (9). It may be the path to an interoperable health information infrastructure that enhances the efficiency and quality of care (10). HIE allows, for instance, physicians, nurses, pharmacists, healthcare providers and patients, to access patients' medical information which makes the process of patient care more cost-efficient (11) (such as reduction of repeat investigations) and effective by enhancing quality of care (11), its promptness and patient safety by reducing medical errors and medications (11). Previously inaccessible data can become available through HIE to stakeholders and policy makers, resulting in more complete clinical information and promoting potential improvements in healthcare coordination which can improve individual and population health outcomes (12, 13), thereby potentially reducing healthcare delivery costs (14). Other benefits of HIE include:

- Reducing unnecessary paperwork (increasing efficiency) (15),
- Enhanced effective care and diagnosis using clinical decision support tools (15),
- Provision of vital history on past medical examinations and treatments (15),
- Protecting health data (16),
- Provision of real time data on epidemics (such as Zika virus) and in times of emergency and disasters (such as earthquakes) (17), and
- Automatic appointment reminders (15).

Many initiatives on electronic HIE have been undertaken in various countries. For example, the Health Information Technology for Economic & Clinical Health (HITECH) Act is the most recent example of support for HIE in the United States (US). Under HITECH 'Meaningful Use' Stages 2 and 3, electronic health records (EHRs) need to be connected in a manner that can provide electronic exchange of health information between providers thereby supporting efforts to improve the quality of healthcare and achieve improved patient health outcomes.

Other examples of successful HIE implementations in high-income countries (HICs) include:

- The Emergency Care Summary (ECS), part of the National Health Service (NHS) Scotland eHealth strategy was built in 2011 (18). The ECS provides a summary of the demographics, medications and allergies for Scottish patients which can be securely accessed by the healthcare professionals treating patients outside the general practitioner (GP) practice such as emergency out-of-hours clinicians, Accidents and Emergency (A&E) Departments, Acute Receiving Units and to paramedics in Emergency Ambulances (18).

- In Denmark, the national healthcare system and a high level implementation of information technology (IT) have facilitated robust exchange of patient data through the national network (19).

However, many barriers and facilitators have been identified in implementing and using HIE in HICs. Cost was found to be a major and consistent barrier in the US (20). The HITECH Act provided funds and the US federal government asked the states to contribute to the establishment of HIE throughout the US but it was suggested that HIEs will either come up with practical business plans or shut their activities in future soon after the federal funding has been consumed (20). Second, several barriers were responsible for the incomplete patient information – these included patients reluctance to participate because of privacy concerns and/or they received care in the area where HIE was unavailable, and hospitals reluctant to exchange information with competitors because of concerns about losing patients and business (21). Third, organisational and workflow barriers in Austria, Finland, Denmark and the US included separate logins and too many clicks to retrieve information, and it was difficult for providers to get privileges to access shared data (20, 21). Fourth, technical barriers in Europe and the US included too much or irrelevant information for providers, lack of contextual information in patient notes, lack of data standards, and concerns about timeliness of information (better to go directly to the hospital information portals than to rely on HIE) (21). Finally, lack of awareness, value difficult to measure (the cost of participating in the HIE may certainly be greater than the cost of repeating tests), and hampered competition (inequity between providers of information/those who pay to participate in HIE and those who benefit from the availability of information such as disparate organisations and patients) also impeded HIE process (20).

To facilitate financial barriers, Kruse et al. (20) concluded that the US may need to facilitate providers with additional incentives or that more health plans were required to contribute HIE process (20). Second, in order to increase the availability and use of health information, it was considered essential to construct transparent policies and promote awareness of data sharing and privacy among all healthcare stakeholders (such as patients and providers) (21). Third, single login, sufficient technical assistance and training to support the new workflow, availability of champion users, a focus on required culture change (for example physicians expressed a view that they just wanted to see patients and found HIE habitually difficult) and use of non-physician proxies (such as of admitting staff and nurses) allowed greater use of HIE addressing organisation and workflow barriers (21). Fourth, to address technical and user needs, it was essential to acquire the ability to send brief reports before full access, share contextual notes, automate integration with existing provider systems, and pay attention to the needs of providers and proxy users when designing an interface (20, 21). Further, the HITECH Act with the establishment of Regional Extension Centers provided technical assistance to the organisations interested in participating in HIE or transitioning to EHRs. Finally, Kruse et al. (20) concluded that efforts from senior leadership (once they realise the value of HIE) to help curb the competitive environment might enable nations to participate more and increase inter-organisational trust towards HIE (20).

Countries with national health system such as the United Kingdom (UK) do not face barriers related to competition. HIE in the UK has been achieved through robust infrastructure and policies (such as privacy protection) which in turn built strong financial and clinical incentives that nurtured an ecosystem of applications (such as SCR and repositories) essential for HIE (22). Despite these advances, complete health records could not be transferred between different cities of the UK at the time of an emergency (22). However, the GP2GP service has allowed electronic transfer of health records directly and securely between GP practices in England (23).

The ‘2015 World Health Organization (WHO) Global Survey on eHealth’ in the WHO European Region revealed that around 30-31 Member States (70% of the total surveyed) had a national eHealth policy and financial resources earmarked for implementation (24). Moreover, technical colleges and universities provided students and professionals necessary training on eHealth (transfer of healthcare and health resources electronically) and health information technology (HIT). Funding was found to be the main barrier to implement national EHR systems in 22 Member States. Political commitment, dedicated eHealth strategies and adoption of standards were the key recommendations among others (such as guidance on telehealth and regulations in mHealth) to implement eHealth in the European region (24).

Unfortunately, health systems responsible to facilitate the health related challenges in low- and middle-income countries (LMICs) are typically confronted with scarce resources and limited capability (25). According to the WHO report on country health information systems (HIS’), countries faced with the greatest health challenges generally have the weakest systems for gathering, managing, analysing and using health information (25). Lack of knowledge and information obstructs the delivery of healthcare that results in many preventable deaths in LMICs (26). For example, information is required to determine whether patients with malaria or human immunodeficiency virus infection and acquired immune deficiency syndrome (HIV/AIDS) are getting essential treatments and services. Many LMICs are incapable of producing complete, timely and reliable patient health information and this lack of information prevents adequate planning of services and targeting in areas of greatest need and also affects the ability to attract funding because it is not clear if key indicators such as Millennium Development Goals (MDGs) have been met and /or Sustainable Development Goals (SDGs) will be met (27, 28). Countries now need to work harder for the aid they depend to provide evidence of success of healthcare programmes (25) because increasingly national and international funders demand data to monitor programme implementation, evaluate progress and performance and ensure accountability, a major driver for substantial investment in health information collection and exchange (29). This is underlined by the findings from the Rio+20 United Nations (UN) conference on sustainable development where the importance of measuring health for the development of the three pillars of sustainability – social, environmental and economic was highlighted (30).

Scarce and inaccessible health information makes it difficult for LMICs to be able to realise the objectives of a truly informed healthcare system (31). Countries in a number of high-income groups have in general made more progress in eHealth than LMICs (25). Although data reporting and recording systems in most of the LMICs produce poor quality data (25, 32-40) inappropriate for transferring, processing and making analysis, there has been increasing evidence from regional and local studies that careful system design and innovation through eHealth can provide feasible solutions to data related problems and thereby enhance the process of HIE (25).

A process of health system reforms has been initiated in several LMICs – for example, Belize, China, Ethiopia, India, Pakistan and Thailand, that includes streamlining of data collection and the introduction of eHealth and open source technologies to promote recording, reporting, quality control and analysis of data at various levels of the health system (25). HIE at the provincial or national level can only be useful if connectivity and exchange of health information exist at the individual, community or district level in the first instance.

There are numerous regional studies from LMICs (41-43) that have identified a range of issues associated with the use and management of health information. For example, many health programmes (e.g. HIV/AIDS, maternal child health, malaria, polio) running in various LMICs require information at every single point with the aim of organising and managing their resources in a better way than was done previously. However, past experience shows that programmes that run without the mechanism of data collection and use are destined to fail because it was hard to set realistic targets or learn lessons from failures with no information available to asses performance (44).

Despite strong initiatives by national and international organisations such as the Global Observatory on eHealth (to inform eHealth policy and practice) and Health Metrics Network (HMN) by WHO (which provided HMN framework and standards to develop HIE interventions such as HIS' for LMICs to enhance sharing of information for evidenced-based decisions) (45), implementation and adoption of HIE interventions have been very slow, usually fragmented and uncoordinated, providing low quality and incomplete healthcare data unsuitable for health policy making and planning (25, 32-40, 46). This then begs the questions of what are the reasons behind the slow diffusion of HIE in LMICs and what factors impede and/or support the implementation of HIE in LMICs?

1.2 Rationale for research

Apart from scarce resources such as limited funds and poor infrastructure in LMICs, there may be other barriers to HIE such as political, structural, cultural, environmental, organisational and technical at national, provincial and community levels that need to be identified and addressed. Therefore, it is an essential need to identify factors that hamper or enable the HIE process and its deployment in LMICs.

However, before moving on to identifying barriers and facilitators to HIE in LMICs, it was important for me to understand the concept of HIE and its underpinning constructs because when I was planning my PhD project, I had come across literature that appeared to characterise HIE as a process, a vision for change, a type of software, or an information centre. This drew attention to the potential for ambiguous or inconsistent definitions which might hinder meaningful dialogue around health informatics policy, research and practice. Also, I did not find the term HIE in my initial literature searches on LMICs, but found HIE processes running through technologies and interventions, such as HIS, Health Management Information System (HMIS) and District Health Information System (DHIS). So, first I decided to undertake a review of HIE definitions in order to analyse the ways in which the term has been evolved and interpreted in the literature and how these varied across different organisations and contexts. It was also important to identify the underpinning attributes of HIE in the first instance in order to inform and develop a search strategy to identify barriers and facilitators to HIE in LMICs (as discussed above).

Furthermore, it was also important to explore context-specific HIE processes and deployment strategies in individual LMICs. This was important because LMICs vary widely in resources, capability and in their social determinants of health such as conditions people were born in, live, grow, work and the health systems responsible for their well-being. Being acutely aware of the Pakistan context (me a Pakistani national), I hardly found any HIE mechanism in Pakistan when I had a gun-shot spinal injury (that made me paraplegic) 12 years ago. Although many things had changed a lot since then, I still did not see any proper patient referral or health data sharing system in Pakistan. Moreover, the dual burden of diseases, low life expectancy, high maternal and child mortality and frequent natural and man-made disasters (such as the war on terror and the resulting high frequency of internally-displaced people) in Pakistan and other LMICs during the last three decades have triggered exponential growth of fragmented and time-bound healthcare programmes, projects, facilities and interventions supported by different levels of government and private partners (47). Lack of effective HIE among these facilities/programmes and poor coordination between supporting stakeholders resulted in ineffective policies which in turn led to wastage of resources and programme failures (47). Few regional studies on Pakistan were based on HIS' (37, 48, 49) and very few studies have been conducted to explore HIE processes for effective decision making essentially helpful for policymakers and healthcare facilities. I am aware that Pakistan and almost all LMICs have limited resources and capability to implement HIE, but the objectives of HIE were hardly met even with the financial, infrastructural and technical support from international organisations such as United States Agency for International Development (USAID) (50) and Japan International Co-operation Agency (JICA) (51). Most of the foreign supported programmes usually run for a limited time period and were only for specific health problems.

Therefore, in order to inform strategies for the effective implementation and development of HIE infrastructure in Pakistan, it was essential to understand the current process and issues of HIE in Pakistan from the perspectives of different healthcare stakeholders. It was also valuable to look at the various technical, strategic and cultural barriers to HIE that existed in different contexts of the health system to understand the opportunities and measures required to implement HIE in individual facilities across care settings.

I decided to undertake three phases of research in my PhD (see Figure 1-1). The first phase examined the underpinning constructs of the term HIE. The second phase focused on the barriers and facilitators to HIE in LMICs. Informed by the first two phases, the third phase explored the current processes and deployment strategies for HIE in various healthcare settings in the context of Pakistan (e.g. public, private, primary, secondary, tertiary) through the perceptions of key healthcare stakeholders and citizens. All these phases are discussed in detail in the following chapters.

Figure 1-1 Phases of research

1.3 Conclusions

In this first chapter, I have explained the importance and need of HIE to improve the safety, quality and efficiency of healthcare. I have discussed about the importance of evidenced-based decision making in healthcare and gave examples of the uptake of HIE in many HICs. Efforts have also been made to implement and diffuse HIE in LMICs using many eHealth technologies but still its uptake has been slow in many LMICs. Weak data collection processes and analytic capability impedes HIE among healthcare stakeholders in LMICs resulting in ineffective decision making and uninformed health policies.

This PhD comprises of three research phases. First of all, I sought to understand the underpinning concepts of HIE, how the term has evolved with the passage of time and in what contexts it has been used by various organisations, researchers and policymakers, as it has been used extensively in the literature. Second, I aimed to identify and classify the barriers and facilitators to HIE in LMICs from the literature to know the challenges faced by healthcare stakeholders in implementing and adopting HIE and what enablers such as technologies and/or interventions can be used to make their HIS' capable for HIE. Finally, I sought to understand the current processes of HIE and the various types of barriers that existed in different context of the health system of Pakistan to generate insights on how best to promote uptake of HIE in Pakistan and in LMICs more generally.

I will now move on to the second chapter to outline the aims and objectives of my PhD project.

Chapter 2 Aims and objectives

2.1 Introduction

Having described the three research phases in Chapter 1, I will now detail the aim and objectives of each phase. The first two phases are based on literature reviews to explore how HIE has been defined and evolved over the years and to identify and document barriers and facilitators to HIE in LMICs. The third phase is a qualitative study to understand how healthcare providers in Pakistan and other stakeholders within public and private organisations and non-governmental organisations (NGOs), perceive the current status of HIE in Pakistan, see its potential benefits, and understand the factors which are likely to encourage or hinder its effective implementation in the Pakistan healthcare context.

2.2 Overall aim

The overall aim of the research was to understand how HIE can be effectively deployed in Pakistan and extract some potentially transferable lessons for other LMICs.

2.3 Detailed objectives

The detailed objectives of my study were to:

- **Explore** the different facets of HIE in Phase 1 to understand how these had evolved and the underlying conceptual basis for these changes.

- **Identify** the barriers and facilitators to HIE in LMICs in Phase 2 at socio-political, infrastructural, organisational, technical and individual levels, for example.

- **Explore** and understand the in-depth stakeholders perspectives in Phase 3 on the context of and deployment strategies for HIE in Pakistan with a view to also identifying potentially transferable lessons for LMICs.

2.4 Conclusions

Having described the aims and objectives of the three research phases, I will now move onto the next chapter to describe methods and theoretical frameworks in answering my research questions. Next, I will draw on a range of selected approaches and will justify their appropriateness to find my research answers.

Chapter 3 Overview of methods and theoretical underpinnings

3.1 Introduction

Having delineated the aims and objectives and research phases in Chapters 1 and 2, I will now give an overview of different methods and theoretical considerations required to achieve my study aim and objectives. I undertook a theoretically driven mixed-methods phased programme of work that built progressively on previous phases. In the first two phases, I reviewed the literature. I used scoping review and systematic review methodology to search and thematically analyse the published definitions of HIE and the barriers and facilitators to HIE in LMICs. The third phase was a case study on Pakistan based on interviewing healthcare stakeholders and citizens to investigate and explore the factors obstructing and/or facilitating the deployment of HIE in various healthcare contexts across Pakistan. In this chapter, I will discuss the philosophical underpinnings of my PhD work, describe the mixed-methods approach, sampling framework, data analysis methods, and finally attempt to theoretically ground my study.

3.2 Philosophical underpinnings of my PhD thesis

Methods for obtaining knowledge (methodology) are influenced by assumptions about nature of physical and social reality (ontology) along with assumptions that how we can learn about reality and what form the basis of our knowledge (epistemology) (52).

In a positivist research philosophy, physical and social reality exist independently of individuals' knowledge of it. Positivists try to understand a priori fixed relationships within a phenomena examined typically by structured instrumentations to obtain responses, rated by subjects usually on a Likert-type scale (53, 54). Theories are empirically tested in order to explore general principles or laws that explain the constructs of physical and social world (53). A positivist research philosophy perceives organisation as having a structure and reality but remains neutral and objective from action of its members (52, 55).

In spite of its universal acceptance, positivism has been criticised because of a 'naive realism' where reality and knowledge can be easily apprehended and generalised without taking account of the context or prevailing circumstances (56). In response to this critique, many post-positivism paradigms have arisen to support the ontological and epistemological issues of positivism. One of the most prominent among these is ‘critical realism’ in which reality is assumed to exist independently of human knowledge but to be only apprehendable imperfectly due to fallibility of human knowledge and the underlying intractable nature of reality or event/phenomenon (56-58). In other words, proponents claim that reality must be examined as critically as possible in order to capture reality as closely as possible (but never faultless) (56). Furthermore, based on the principles of realism, Pawson and Tilley (59) developed a realist evaluation approach that focused not only on what results are yielded from interventions but also how they are produced and in what circumstances. The realist evaluation model provides a ‘context mechanism, outcome pattern configurations’ (CMOCs) approach that allows an investigator to understand what works (or not) for whom and in what conditions (60). Realist evaluation use the lessons learnt from one evaluation and apply them across a range of different contexts, particularly allowing the investigator to understand the effective and ineffective aspects of intervention and the factors required to replicate the interventions into other settings.

The interpretivist paradigm aims to understand the phenomena from the perspectives of participants directly involved with the phenomenon being investigated (61). In this approach, the reality is more subjective where humans as social actors construct and interpret the social product according to their beliefs and social system (55).

Case studies (discussed in Section 3.6 below) can be carried out within both the positivist and interpretivist philosophical paradigms (52, 61). In positivism, case studies are evaluated according to natural science model of research which employs four major assessment criteria: controlled observations, controlled deductions, replicability and generalisability (62). However, in a case study research, it is not possible to manipulate variables in order to control observations as done in experiments, therefore, naturally occurring controls can be identified to conduct case study as a form of natural experiment (62). Moreover, case study with qualitative analysis (verbal propositions) can make use of the rules of formal logic to make controlled deductions using words and sentences (62). Furthermore, findings can be replicated using either a logical replication, that is applying tested theories in similar setting to find similar results, or theoretical replication that is applying the same theories to a different set of initial conditions to find different predictions (61, 62). Finally, case study theory can claim theoretical generalisability only when it is tested by additional case studies against the empirical circumstances of other settings (62). In contrast to positivism, interpretivist studies are evaluated through the evaluation of researcher's interpretation where the interpretation should be logically consistent, subjective and adequate (61).

Consequently, throughout my three research phases, I attempted to be as explicit as possible about my assumptions and methodology (see Chapters 3, 4, 5 and 6). On the basis of ontology, I perceived participants as knowledgeable whose knowledge could be attained with the methodology chosen, and interpreted by me using an interpretivist approach (see Chapter 6). I chose interpretivist approach because methods used in the natural sciences are not suitable for investigating the social world because the social world is not regulated by natural laws (human actions according to virtue e.g. ethics), rather, mediated through meaning and human knowledge (63). By exploring meanings and interpretations from the participants' responses, I tried to gain a vision of their subjective realities, but also acknowledged my own subjectivity as a part of the process.

Overall, the interpretive approach is well-suited for my reviews and especially the case study with the qualitative exploration of stakeholder perceptions in implementing and adopting technology (64, 65).

3.3 Mixed methods approach

Two or more different methods are employed in mixed methods research to meet the aims and objectives of a research study to provide superior research findings and results (66). Mixed methods should not be limited to different quantitative and qualitative methods, but can also include different methods within a same tradition such as observation and interviewing (67). Mixed methods provide researchers with additional research tools and provide additional perspectives and insights through synthesis of research traditions not possible through single research method (68). Mixed methods studies are common in health service research because of the comprehensiveness of the approach to explore issues in complex healthcare environments (69).

I intended to use a mixed methods research approach because the objectives of my research phases (see Chapter 2) can only be achieved by using different methods. I used mixed methods phased programmes of work that built progressively on previous steps involving scoping review, systematic review and case study methodology using qualitative interviews and documentary analysis. Mixed methods approach collated and synthesised data from multiple phases of research to provide overarching findings (see Chapter 7). Review methods, case study methodology and triangulation are discussed in the subsequent sections and chapters.

3.4 Scoping review

A scoping review is a technique used to map the current literature in a field of interest, the key concepts underpinning a research area and the main sources and kinds of evidence available (70, 71). It was first defined by Mays et al. that the scoping review *“aims to map rapidly the key concepts underpinning a research area and the main sources and types of evidence available”* (71). It has become an increasingly popular method for synthesising research evidence (72, 73) which can be of particular use when the topic is of complex and heterogeneous nature or has not been studied comprehensively (71).

There are different ways of conceptualising scoping reviews (74). For example, according to Arksey and O'Malley (70), a scoping study seeks to provide the broad coverage of the existing literature with varying degrees of depth to investigate the extent, range and nature of research activity; determine the value and potential cost of undertaking a full systematic review; summarise and disseminate research findings to the interested readers; and identify research gaps in the existing literature (70). Another purpose is ‘literature mapping’ to map the literature, and to synthesise findings from different types of studies; or ‘conceptual mapping’ to establish how a particular term is used by whom, for what purpose and in what literature; or ‘policy mapping’ to identify the relevant documents from government and professional agencies (75). According to the National Institute for Health Research Service Delivery and Organisation Research and Development Programme (NIHR SDO), it is also useful for the elucidation of working definitions and conceptual boundaries of a particular topic area, conducted systematically but explicitly excluding the systematic review – the need for quality appraisal, to establish a frame of reference (74).

It can be used as a preliminary step to a systematic review as it provides a rigorous and transparent approach for mapping areas of research (70).

3.4.1 Rationale for scoping review

For my scoping review, I used the NIHR SDO and the ‘conceptual mapping’ approaches suitable for reviewing the HIE definitions and finding out how the term HIE was used in the literature by whom and in what contexts (see Chapter 2). This systematic scoping review of definitions enabled me to understand the different aspects of HIE used in the existing literature in various contexts and provided a foundation from which to conduct more focused research through a systematic review on barriers and facilitators to HIE in LMICs in the next phase of this research.

3.5 Systematic review

A systematic review is a *"review of the literature according to an explicit, rigorous, and transparent methodology"* (76). Systematic review address a specific research question by collating all evidence that fits the specified eligibility criteria and seeks to minimise bias by using systematic, explicit methods (77). Although scoping and systematic review methods both use rigorous and transparent methods in order to comprehensively identify and analyse the literature to answer a specific research question (78), these review methods have different aims and purposes (79). First, systematic reviews are summaries of the best available evidence for clearly defined clinical, policy and simple research questions (70, 80, 81). Second, systematic reviews aim to accumulate empirical evidence to answer a focused research question from comparatively smaller number of studies (70). Third, systematic reviews used to specifically address the effectiveness of interventions often through randomised controlled trials (70) but they are now used for all sorts of studies (such as systematic review of barriers and facilitators to HIE in Phase 2). Fourth, systematic reviews aim to critically appraise the quality of studies that are used to provide synthesis of evidence (77).

Healthcare providers, researchers and policymakers need systematic reviews to efficiently integrate the existing body of evidence in order to support rational decision making (81). The use of systematic explicit methods limits bias and reduces chance effects, thus improving the reliability and accuracy of recommendations (77, 81).

3.5.1 Rationale for systematic review

Systematic reviews can be helpful for informing evidenced-based strategies to address the problems faced by LMICs (82). After mapping and understanding the concept of HIE by analysing its different dimensions through a scoping review, I found it helpful to conduct a systematic review rather than another scoping review to answer a more focused research question: 'What are the barriers and facilitators to HIE in LMICs?' (see Chapters 2 and 5) that attempted to capture, critically appraise and synthesise the existing empirical evidence systematically identifying and documenting barriers and facilitators to HIE in LMICs.

3.5.2 Critical appraisal tool

The critical appraisal is a systematic process of examining research articles to evaluate their validity and relevance in a given context (83). Critical appraisal tools are used to assess the methodological quality of research articles (83, 84) and usually use the quality assessment to undertake sensitivity analyses (84). However, some reviews include/exclude studies on the quality of evidence because methodologically flawed research could lead to a significant bias (systematic error or deviation from the truth) in the findings of a systematic review (85). Thus, appraising articles critically is indispensable for the development of a methodologically strong review (86).

3.5.2.1 Rationale for selecting critical appraisal tool for the systematic review

I intended to include qualitative, quantitative and mixed methods studies in the systematic review (see full eligibility criteria in Chapter 5). Many critical appraisal tools are specifically developed to evaluate primary qualitative and quantitative studies but critical appraisal tools designed to evaluate mixed methods research are hardly found in scientific literature (86) (see the list of critical appraisal tools on the webpage of International Centre of Allied Health Evidence, University of South Australia (87)). The methodological quality of primary mixed methods studies including two or more research designs cannot be sufficiently appraised by applying the combination of qualitative and quantitative critical appraisal tools (86, 88). Therefore, I looked specifically for a critical appraisal tool useful for appraising primary qualitative, quantitative and mixed methods studies for a mixed studies systematic review.

Crowe and Sheppard (88) reviewed 44 critical appraisal tools and found only one, the Mixed Methods Appraisal Tool (MMAT) (89), designed for the mixed methods systematic review. MMAT was found to be among the top five critical appraisal tools with respect to the explanation given on how it was developed and the available tutorial for using it (88).

The MMAT includes components to appraise the quality of qualitative, quantitative and mixed methods studies separately. Furthermore, the tool has been pilot tested for reliability, has undertaken content validation using evaluation from experts and workshops, and has been used in more than 50 systematic review. It also allows using summary score which is useful to rank the articles. The availability of psychometric properties, user manual, tool optimised through pilot testing and a clear user-friendly scoring system makes a good critical appraisal tool (86), therefore, I found the MMAT as the most suitable critical appraisal tool for my mixed methods systematic review. How the MMAT has been used and its limitations will be discussed in detail in Chapter 5.

3.5.3 Narrative synthesis

Narrative synthesis methods can be used to analyse both qualitative and quantitative data and have been used when included studies in a systematic review are not sufficiently appropriate for a meta-analysis (90). In addition, narrative synthesis can systematically look and organise data need to be integrated and described in the text of a review even in a meta-analysis (91). Popay et al. (92) provided guidance to conduct a narrative synthesis from the Economic and Social Research Council Methods Programme. Four main elements to a narrative synthesis have been identified in the guidance document along with particular tools and techniques suggested for an appropriate narrative synthesis (see Table 3-1).

Elements of a narrative synthesis	Tools and techniques
How the interventions work, why and for whom – developing a theory	No particular tools and techniques suggested. However, those suggested for other elements can also be applied for development theory.
Developing an initial description of the findings of included studies.	Textual description, clusters and groupings, tabulation, vote counting as a descriptive tool, transforming data by constructing common rubric across quantitative studies, content or thematic analysis for translating data.
Exploring relationships between and within studies/data	Graphs, funnel plots, frequency distributions, L'Abbe plots and forest plots; idea webbing and conceptual mapping; moderator variables and sub-group analyses; reciprocal and refutational translation; investigator/moderator triangulation; conceptual triangulation. qualitative case descriptions;
Examining the robustness of synthesis	Checking the synthesis with authors of primary studies; critically reflecting on the synthesis process; use of validity assessment.

Table 3-1 Elements of a narrative synthesis with given tools and techniques

3.5.3.1 Rationale for narrative synthesis

Narrative synthesis may be undertaken where the study designs and data extracts are heterogeneous or too diverse (e.g different technologies, interventions, methods). As discussed in the previous sections, I intended to conduct a systematic review of mixed methods studies and expected diverse methodologies, healthcare and regional contexts, data (such as barriers and facilitators), wide range of HIT and study populations (see Chapter 5 for more details), therefore, I found narrative synthesis useful to report results of the systematic review in Phase 2 of my research.

3.6 Case study

Case study, as a research strategy, is an empirical investigation of a *"contemporary phenomenon in-depth within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident"* (93). It is the research approach that aims to yield an in-depth appreciation of a complex event, issue or phenomenon of interest in its real life context (94). Case studies may utilise qualitative, quantitative or mixed methods (93) and rely on multiple source of evidence (93). The evidence may come from archival records, interviews, ethnography, surveys, reports or any combination of these.

Yin (93) identified case studies as exploratory (at times referred as an introduction to social research such as an intervention evaluated has no definite, single set of results), explanatory (for causal investigations) and descriptive (to describe a phenomenon or an intervention in the given context). Stake (95) categorises case study as intrinsic (to study a unique phenomenon that distinguishes it from all others), instrumental (to use a particular case to gain a broader understanding of an issue or a phenomenon) and collective (involves studying multiple cases sequentially or simultaneously).

Case studies can involve either single-case or multiple-case designs. A single case study may be chosen to critically test a well-formulated theory in order to confirm, challenge or extend the theory; to illustrate an extreme/unique case (e.g. a specific injury or a technology bug such as 'year 2000' (Y2K) bug); where it is a representative or typical case (e.g. to capture circumstances of everyday situation); where it is a revelatory case (e.g. to uncover a previously inaccessible social science enquiry); or where it is a longitudinal case studying the same single case at two or more different points of time (93). Multiple case studies, on the other hand, allow examination of a particular phenomenon through a replication design (in a manner similar to multiple experiments either with exact or altered experimental conditions). Yin (93) differentiates between 'literal replication' (where the multiple cases are selected to corroborate each other,) and 'theoretical replication' (where the multiple cases are selected to anticipate contrasting results but for predictable reasons) (see Peter Szanton' book, *Not Well Advised*, for an excellent example of a multiple case replication design (96)).

It is important to define the unit of analysis (or the case itself) when designing and conducting a case study (93) to ensure that the case is suitable to the issues and questions of interest. Moreover, a single-case design study may be either holistic (one unit of analysis) or embedded (multiple unit of analysis). Within a single case, subunits can provide opportunities to enhance the insights into the single case through extensive analysis (e.g. a single case might be a health programme that covers many funded projects – which would then be the subunits). Similarly, multiple cases within a multiple case design study may be either holistic or embedded (93) (e.g. multiple cases might be multiple health programmes such as HIV/AIDS and Tuberculosis (TB) that involved many sources of funding within each health programme – which would be the embedded units). When using an embedded design, each individual case may in fact include the use of quantitative analysis (e.g. surveys) within each case (93).

Case study research can be used to achieve various research aims: to provide descriptions of phenomenon, generate theory, and test theory (55). It is mainly suitable when theoretical knowledge of a phenomenon is limited or when the requirement for capturing context is essential (61). Other research approaches, such as grounded theory, may be used to develop theory in which patterns and concepts emerge as the researcher gathers data and examines phenomenon (97).

Testing theory through case study requires specification of theoretical propositions derived from an existing theory. The case study findings are used to compare with the predicted propositions by which the theory is either validated, or may be further refined on the basis of case study results (55)

Case study research can result in the production of very large amounts of data in order to strengthen the depth and breadth of a case study. The major strength of a case study research is to use triangulation, that is, to use multiple sources of evidence to overcome and counterbalance the deficiencies and biases that result by using single source and/or method of data collection. Types of triangulation include data type triangulation (98), data source triangulation (98), investigator triangulation (99), theory triangulation (99), methodological triangulation (99) and analysis triangulation (100).

3.6.1 Rationale for using case study

Case study research is valuable research strategy where broad, complex questions have to be answered in complex circumstances (101). Case study can be an appropriate research strategy for information systems (a set of integrated components, for example, software and hardware, to collect, transfer, store, fetch, utilise, or display information, in order to support people, organisations, or other computer systems (102)) because the capturing of context is always significant when discussing people–related and organisational phenomena (61). The field of information systems has seen a swing from technological to managerial and organisational questions, hence there is more interest in how context and innovations interact (65).There are three reasons why a case study approach is appropriate for information system research (65). First, an investigator can study information system in natural environments and generate theories from practice; second, it lets the investigator answer ‘how’ and ‘why’ questions; and finally, it allows the investigator to research an area which has not been studied in-depth previously.

In this study, I have chosen to explore Pakistan’s health system which is a complex structure comprised of public and private sector and NGOs (see Chapter 6 for details). The phenomenon of HIE deployment is studied through the lens of healthcare stakeholders in the context of Pakistan (see Chapter 6 for full country background and health system) where I had no control over events (e.g. environmental and political factors). The context of Pakistan was developed using national and regional documents and reports prepared by NGOs. The case study was based on a theoretical model that is identified in the subsequent sections. The study was taken as a single case because it was based on an in-depth investigation of a single country, Pakistan. Moreover, the case study was exploratory rather than explanatory or descriptive because this case study explored the factors responsible for the deployment of HIE in Pakistan through the perceptions of participants (93). The research questions mainly focused on ‘what’ (such as ‘What are the barriers and facilitators to HIE?’) and ‘how’ questions (such as ‘How information is exchanged between providers?’), justifiable for conducting an exploratory study and helpful in developing related hypothesis and propositions for future research (93).

3.7 Data collection methods

Case studies employing qualitative methods are most valuable where research questions address the in-depth investigation of a natural phenomenon within its contexts (103), in this case, deployment of HIE in Pakistan. There are various methods of data collection in qualitative research such as interviews, focus groups, archival records, videos and observational methods. However, the most common methods used are interviews and focus groups (104, 105)

3.7.1 Overview of interviews

Interviews are the most common qualitative method used in healthcare research. Their purpose is to discover the views, experiences, beliefs of individuals on particular matters. They are most suitable where detailed insights are required from a recruited participant or when little is known about the study phenomena (106). Moreover, they are particularly appropriate for exploring sensitive issues that participants may be reluctant to talk about in group discussions.

Advantages of interviews (107, 108) include:

- It ensures direct feedback from the participant.
- Researcher has the opportunity to probe participants for in-depth responses.
- Helps in developing rapport with the participant through personal interaction.
- Allows researcher to observe settings that provides additional information.
- Can be conducted at flexible times and in flexible venues.
- Gives the opportunity to clarify questions and answers that increases data accuracy.
- Provides rich data and details in participant's own words that can be quoted when presenting results.

Disadvantage of interviews (107, 108) include:

- Consumes a lot of time in scheduling, conducting, transcribing and analysing interviews.
- Perceptions which may or may not correspond with beliefs, practices etc.
- Requires preparation such as pilot testing of the topic guide.
- Costly in terms of scheduling, conducting and transcribing interviews.
- Produces lots of data which are difficult to analyse.
- Disturbing environment can have inconsistences during the interview.

There are three main types of interviews (106):

3.7.1.1 Structured

Structured interviews have a fixed choice of responses, in which a list of predetermined questions is asked that do not require further elaboration (106). These are verbally administered questionnaires and are of little use if 'depth' is required (106).

3.7.1.2 Semi-structured

Semi-structured interviews consists of several open-ended key questions that help to define the area to be explored, but also allows the interviewer and interviewee to deviate from the structured set of questions in order to seek more detailed idea or response (105).

3.7.1.3 Unstructured

There are generally no preconceived theories or ideas reflected in unstructured interviews (109). Their format is unorganised and they are usually considered where significant ‘depth’ is required or when very less is known about the subject area (106).

3.7.2 Rationale for choosing semi-structured interviews rather than structured or unstructured interviews, focus groups or questionnaire

Interviews were employed as the primary data collection method as the focus of my research was on exploring processes and perceptions of individuals (see Chapter 6). Semi-structured interviews were selected because a list of questions was required to be covered in an interview and it was unlikely to get another chance to interview any particular participant. Moreover, the topic guide enabled me to focus on my research questions as most of the busy interviewees had limited spare time to give interview.

Furthermore, it was difficult to gather busy people (such as senior bureaucrats, policy makers and facility directors) from various urban and rural regions for a PhD project focus group. Moreover, it was possible that participants may not openly discuss their views in front of other participants, just as to present themselves as socially acceptable to other participants of the groups. I did not use observational approach due to limited time and accessibility for data collection, however, I made field notes after every interview to remember and record behaviours, events and activities of the settings where I conducted my interviews. Finally, I planned to generate theory by doing both inductive and deductive analysis, therefore using questionnaire would not have been helpful.

3.7.3 Documentary data and field notes

Documents can provide a valuable, effective and rich source of data in variety of forms (such as news, manuals, and reports) (110). Documentary research can be useful for historians, librarians and information science specialist, but it can also be particularly useful for researchers in policy implementations (111, 112).

Two type of documents, primary and secondary, are typically used in analysis. The primary documents are the eye witness accounts collected by individuals who experienced the events (such as me writing down field notes), whilst the secondary documents are produced by outsiders not present at the event but those who have read eye witness accounts (such as crime reports and policy documents). The quality control criteria for handling documents are ‘authenticity’ (genuine evidence from impeccable sources), ‘credibility’ (error and distortion free evidence), ‘representativeness’ (typical evidence and to what extent it is untypical), and ‘meaning’ (clear and understandable) (110).

3.7.4 Rationale for using documentary data and field notes

It is essential to use documents for a variety of purposes in this study. First, analysing documents can be particularly suitable to qualitative case studies that helps to produce rich description of the context, phenomenon, event or organisation (93). Documents can provide data to develop and understand the context in which the research participants operate (112). I was therefore interested in obtaining a range of national and regional documents that were about the economics of Pakistan and its health system (see Chapter 6, Sections 6.1.1 ‘Pakistan context’ and 6.1.2 ‘Health systems of Pakistan’). I was also interested in technical reports of NGOs (such as JICA and WHO that aided and supported the government of Pakistan in developing DHIS) (see Chapter 6). Second, the document analysis is frequently used in combination (mixed methods) with qualitative methods (such as interviews) as a means of triangulation (112) (triangulation is discussed more in Chapter 6). Third, information in documents may suggest questions that need to be asked or verified as part of the research (112), for example, the DHIS process in Pakistan (see ‘results’ section in Chapter 6). Fourth, documents can be used to verify findings from other sources (112) (in this case findings from the interviews that may resonate with findings from the documents, see Chapter 6). Finally, I recorded descriptive details of the participants’ settings and things and reflected on the data and the process of research (see ‘field work’ in Chapter 6) which helped me to enrich the research context, document my biases, problems, mistakes, and responses to interviewees and field work (113) (see for example sections on ‘reflexivity’ and ‘quality in my research’ in Chapter 6).

3.8 Sampling

Purposive sampling technique, also known as judgement sampling, is the intentional choice of a respondent due to the qualities possessed by the respondent (114). The aim of the purposive sampling is to recruit ‘information-rich’ participants for study in-depth (115). Through ‘information-rich’ participants, a researcher can acquire great knowledge on the issues central to the purpose of research (115). It is a non-random sampling method that does not require underlying theories or a set number of respondents (114). Putting it simply, the researcher decides the key questions based on the topic of interest and sets out to find people who can participate to provide the information based on their knowledge and experiences and provide a range of views (116, 117).

Extreme or deviant case sampling, maximum variation sampling and snowball sampling are some of the different strategies for purposefully choosing ‘information-rich’ participants (115). Extreme case purposive sampling focuses on unusual or special participants (such as individuals from rural or urban area; outstanding successes or unexpected failures) to learn lessons about unusual circumstances or extreme outcomes pertinent to research aims (115). Maximum variation sampling aims to achieve heterogeneity to understand how the phenomenon of interest is understood by different people in different settings (such as healthcare professionals, bureaucrats and citizens in this study). In snowball sampling, a researcher requests selected respondents to suggest other suitable respondents valuable for research (118).

There is no limit to the number of respondents for purposive sample as they are continuously recruited as long as the needed information is obtained (116). That is, respondents are recruited to the point of data ‘saturation’ at which no new information or themes are emerging from the data (119). In health science research, data saturation has become the gold standard to determine the sample size for purposive sampling (119).

Purposive sampling is not free from bias, unlike random sampling, but it can nonetheless provide reliable and robust data as the aim in qualitative research is more for depth of analysis than representativeness (114). To put it simply, the goal of purposive sampling is not to randomly sample individuals from a population but to focus on specific characteristics of a population that may provide in-depth knowledge in the area of interest.

3.8.1 Rationale for using purposive sampling

I constructed a sampling matrix and use this for maximum variation sampling. One of the major benefit of purposive sampling is the use of wide range of sampling techniques to recruit ‘information-rich’ participants (as discussed above) such as deviant case sampling, maximum variation sampling, and homogenous sampling (units or people with similar characteristics). When used properly, purposive sampling is more efficient than random sampling in practical field environments (116), for example the randomly selected respondent may not be as knowledgeable and experienced as an expert respondent (120).

Respondents were recruited based on their experiences, gender, location, and positions in the healthcare sector, including citizens, from different urban and rural regions (cities and towns) of Pakistan in order to achieve heterogeneity and deviant cases. After every interview, respondents were requested to suggest references or provide contact details of potential candidates useful for this research.

Heterogeneity can be a problem because of respondents having varying attributes pertinent to their positions, settings and experiences, however, common patterns emerging from the data having great variations provide core findings by capturing the core experiences of respondents which are of particular interest and value (115).

3.8.2 Thematic analysis

Thematic analysis (TA) is one of the most common qualitative data analysis methods used in the social, behavioural and health sciences. *“It is a method for identifying, analysing and reporting patterns (themes) within the data”* (121).

There are different ways TA can be approached (121) (see Box 3-1):

- An inductive approach – code and theme development are data-driven;
- A deductive approach – code and theme development are based on an a priori constructed template of codes;
- A semantic approach – coding and theme development are identified within the surface meaning or explicit content of the data;
- A latent approach – coding and theme development identify underpinning data, ideas, assumptions and conceptualisations;
- A realist or essentialist approach – focuses on theorising reality (experiences, motivations and meanings) evident in the data;

- A constructionist approach – focuses on how certain reality (experiences and motivations) is produced and reproduced by the data.

Box 3-1 Approaches of TA.

Advantages of TA (121)

- Flexibility – independent of theory and epistemeology;
- Provide detailed and complex account of data;
- Relatively quick and easy to study and perform;
- Accessible to novice qualitative researchers;
- Can offer a 'thick description' (detailed account of a phenomenon) of the data set;
- Can provide useful summary of the main features of a large data set;
- Can provide insights into differences and similarities through the data set.
- Can be useful to perform analysis for policy development.

Box 3-2 Advantages of TA

3.8.3 Framework analysis

Framework method of data analysis was developed by the National Centre for Social Research (Nat Cen), the largest, independent not-for-profit research organisation in the UK (122). *"Framework appoach involves a systematic process of sifting , charting and sorting material according to key issues and themes"* (63). Framework analysis manages and organises data systematically into rows and columns in the form of a matrix, providing researchers with highly structured outputs of summarised data (63). The matrix structure can facilitate researchers to recognise patterns emerging with in the data set.

Framework analysis is gaining popularity in health services research (63) and shares many of the common features of TA. It was explicitly developed for applied research that aims to meet specific information needs and deliver outcomes within a short duration. It is useful when multiple researchers are engaged in a project, particularly in multi-disciplinary research groups. Training is usually essential to use this method successfully and it is also important that the project should be headed by an experienced qualitative researcher (122). Finally, the framework method is not suitable to analyse highly heterogeneous data (122).

3.8.4 Content analysis

Another qualitative analysis method, content analysis can be used to identify patterns across qualitative data and occasionally treated as similar to thematic approaches (123). *"It is a systematic coding and categorising approach used for exploring large amounts of textual information unobtrusively to determine trends and patterns of words used, their frequency, their relationships, and the structures and discourses of communication"* (124). Content analysis often provide counts or frequency at micro level of the data including texts, expressions, and images (123) and initially allows quantitative analysis for qualitative data (125). In contrast to content analysis, the themes in TA tend not to be quantified.

3.8.5 Rationale for using thematic analysis

TA was chosen because it allows discovering patterns and themes. In TA, themes can be identified inductively and deductively. TA is a flexible method in a number of ways, for example, it involves analytic processes common to most of qualitative research, such as thematic coding in grounded theory (125), it is used across a range of epistemologies (121), it works with a broad span of research questions ranging from those about people's experiences or understanding to those about the representation and development of specific phenomenon in specific contexts, and it can be applied to construct theory-driven or data-driven analyses (121, 126)

Framework analysis cannot facilitate highly heterogeneous data as individual interviews in this study may have varying views or experiences in relation to each question (122). In content analysis, results that are generated rely exclusively on frequency outcomes and researchers utilising this method sometimes are criticised for removing meaning from its context (127).

Preferably TA is able to achieve the 'systematic element characteristics' of content analysis, but also allows the investigator to perform analysis of the frequency of codes keeping their meaning in context (127).

3.9 Theoretical frameworks

I searched the literature for theoretical models relevant to my research study such as, Greenhalgh's et al. Diffusion of Innovations in Health Service Organisations (76, 128), Davis' Technology Acceptance Model (TAM) (129), and May's et al. Normalisation Process Theory (NPT) (130). A very brief over view of each theoretical model is given below.

3.9.1 Diffusion of Innovation in Health Service Organisations

Greenhalgh et al developed a model of Diffusion of Innovations in Health Service Organisations through a systematic literature review (128). Most of the attribute and factors in Greenhalgh et al.'s model were adopted from Roger's model of Innovation Diffusion Theory (131).

Roger defines **Diffusion** as the process by which *"an innovation is communicated through certain channels over time among the members of a social system"* (131). Greenhalgh defines **Innovation** in service delivery and organisation as a "*novel set of behaviours, routines, and ways of working that are directed at improving health outcomes, administrative efficiency, cost effectiveness, or users' experience and that are implemented by planned and coordinated actions"* (76).

A summary of the components of the Greenhalgh's model are given in Box 3-3 (Source: '*Introduction of shared electronic records: multi-site case study using diffusion of innovation theory in health services'* (76, 132)).

1. Material properties of the technology

To be successfully and widely adopted, a technology must include key functionality and work smoothly and efficiently under real conditions of use

2. Attributes of the technology as an innovation

To be successfully and widely adopted, a technology must be seen by potential adopters as having

- Relative advantage (that is, clear benefits over existing technologies)
- Simplicity
- Compatibility with existing values and ways of working
- Trialability (can be tried out on a limited basis "without obligation")
- Observability (benefits can be seen directly)
- Potential for reinvention (capacity for users to customise and adapt it)

3. Concerns of potential adopters

Adoption is a process, not a one-off event, and is influenced by concerns, including

- Before adoption—what are its properties and potential benefits?; what will it cost me?
- During early use—how do I make it work?; when and how should I use it?
- During established use—how can I alter or improve it?

4. Communication and influence

A person's decision to adopt an innovation is influenced by

- Mass media (press, mail shots), which can raise awareness
- Interpersonal influence (by champions, opinion leaders, for example),which can change people’s attitudes towards adoption

5. Organisational antecedents for innovation
Organisations may be more or less innovative. Differences are explained by several factors:

- Absorptive capacity for new knowledge
- Leadership and management
- Risk taking climate
- Effective data capture systems
- Slack resources

6. Organisational readiness for innovation
An organisation must be “ready” for a specific innovation. Readiness includes

- Innovation-system fit
- Tension for change
- Balance between supporters and opponents
- Specific preparedness

7. The implementation and routinisation process
Implementing a complex innovation, and making sure it becomes business as usual, is a highly non-linear process, typically characterised by shocks and setbacks. Critical success factors include

- Appropriate change model (balance between “make it happen” and “let it emerge”)
- Good project management
- Autonomy of frontline teams
- Human resource factors, especially the selection, retention, continuity, and training of staff
- Alignment between new and old routines

8. Linkage
Innovation is more likely when there is

- Early and ongoing dialogue between the developers of the innovation, the change agents charged with promoting its adoption, and the end users
- Communication within the organisation and between similar organisations

9. The wider environment
Innovation in organisations is more likely when a “following policy wind,” a conducive socio-political climate, and specific incentives and mandates at national level are present

Source (132)

Box 3-3 Components of the diffusion of innovation model for complex innovation. (Reproduced with permission)

3.9.2 Technology Acceptance Model

TAM is the modified version of Theory of Reasoned Action specifically tailored for modelling user acceptance of information system (133). The model suggests that when a user is offered a new technology, a number of external factors influence internal beliefs, attitudes and intentions. Two particular beliefs, perceived usefulness (PU) and perceived ease of use (PEOU) are of primary significance for acceptance of information system.

- PU: *"the degree to which a person believes that using a particular system would enhance his or her job performance"*.
- PEOU: *"the degree to which a person believes that using a particular system would be free from effort"*.

These two beliefs are the antecedents of a factor, **Attitude**, which determines the use of a system. TAM postulates that the use of information system is determined by the behavioural intention which in turn determined by the person's attitude towards the use of the system.

3.9.3 Normalisation Process Theory

NPT focuses on implementation (social organisation of work), embedding (turning practices into routine elements in day to day life) and integration (preserving embedded practices among social settings) of an innovation. It is an action theory, which explains what people do rather than their attitudes or intentions (134). It focuses on factors that inhibits or facilitates routine embedding of complex interventions in healthcare settings. NPT has four constructs: coherence, cognitive participation, collective action and reflexive monitoring.

Here I will only define 'collective action' as this explains the operational wok that people do to enact a new technology or a complex healthcare intervention, e.g. HIE. This construct also includes four components:

- Interactional workability – how people interact with each other and operationalise practices in everyday settings.
- Relational integration – how people in a network understand a practise that affects not only their knowledge but also the ways they understand the actions of people around them.

- Skill-set workability – the effect of the innovation on the present division of labour and the way skills are defined.
- Contextual integration – the way the innovation is incorporated collectively which affect the existing set of practices and resources.

3.9.4 Rationale for using constructs from Diffusion of Innovation in Health Service Organisations

Here I present the rationale for using Greenhalgh's model for my third phase of research (see Chapters 2 and 6).

TAM emphasises attitudes and behaviours of individuals and focuses on factors and decision processes that affect individuals to adopt and use the technology or an innovation (135). The two key factors (i.e. PU, PEOU as discussed above) influence the intention of an individual to either adopt or reject the technology. TAM has been criticised for several limitations including the use of an inherent construct 'subjective norm' based on the Theory of Reasoned Action (136), that it is difficult to differentiate whether the technology acceptance behaviour is caused by the influence of external factors or by an individual's attitude (137). Further, the model also not considers non-organisational settings (138). My research was not only about the adoption of HIE by individuals, but had a wider scope in that I was interested in factors responsible for the implementation of HIE in different organisational and non-organisational settings (such as in field and socio-political settings) of the healthcare in Pakistan. Furthermore, the research also had to study the current manual processes of information exchange and look for the benefits and harms associated with HIE.

NPT is a theory of action that explains the embedding of a complex intervention and how it is operationalised by users using it (134). NPT helps to understand the dynamic processes that are confronted while implementing complex healthcare interventions and organisational or technological innovations (139). It has been widely used to understand implementation, embedding and integration of innovations in healthcare contexts (139). My research did not involve implementing and implanting HIE in healthcare practices across Pakistan nor did it involve evaluating factors that promote or inhibit the routine incorporation of HIE in practice; rather, I explored and sought to understand in-depth stakeholders perspectives on the context of and deployment strategies for HIE in Pakistan with associated barriers and facilitators which may be responsible for its implementation and adoption.

Diffusion of Innovation theory (131) explains the process of cultural transmission of an innovation (*an idea, practise or object; in this case, HIE*) that seek to describe how innovation spreads. As defined by Rogers, *"an innovation is an idea, practice, or object that is perceived as new by an individual or other unit of adoption"*(131). This definition gives more importance to individual behaviour but give less consideration to organisational level (140). Moreover, the theory including the adopters' categories lacked evidence from public health domain and was not explicitly developed to apply for health innovations (141).

Diffusion of Innovation in Health Service Organisations was tested on four case studies of complex healthcare innovations (telemedicine, EHRs, GP fundholding in the UK and integrated care pathways) (128). The theory resonates well with my research objectives and provided a theoretical framework to explore the perceptions of healthcare stakeholders on to how HIE will spread among healthcare organisations of Pakistan; what are the attributes of innovation (HIE) that facilitates its adoption such as relative advantage (whether the individuals perceive HIE advantageous), trialability (experiencing of limited availability of HIE by individuals in few healthcare organisations), compatibility (HIE consistent with the needs, values and past experiences of potential users), observability (positive results of HIE communicated to others make it easier to adopt e.g. through vertical healthcare programmes or private providers) and less complexity (perceived and actual barriers). Moreover, HIE (innovation) is more likely to spread by key opinion leaders (in this case experts, policy makers, politicians and bureaucrats for example) and involving similar groups of people sharing related traits, professional and cultural background (such as healthcare professionals and citizens) (76).

Further research is suggested by policymakers using the constructs of this model to find and understand the determinants of success of an innovation in a particular context and its failure in a comparable programme in a different context because programme settings are a rich data source about mechanisms of success and failures (76). Therefore, in Phase 3 of my research, I report on a case study (see Chapter 6) to understand the deployment strategies of HIE (an innovation) in the context of Pakistan focusing on the perceived failures (barriers) and success (facilitators) of HIE. The study further explored the attributes of innovation (advantages, trialabilty and compatibility of HIE) in the context of Pakistan as perceived by different types of adopters (such as innovators, early adopters and early majority) (see sampling matrix in Chapter 6 for types of healthcare stakeholders).

Finally, I conclude this chapter here and start with my first phase of research in the next chapter to conduct the scoping review of HIE definitions.

3.9.5 Applicability of Diffusion of Innovation in Health Service Organisations in LMIC settings

Roger's work of Diffusion of Innovations (131) included many case examples from LMIC settings, for example, persuading housewives in a Peruvian village to boil drinking water ('Water Boiling in a Peruvian village: Diffusion that failed'), which failed due to local traditions that associated hot food with illness; the diffusion of ultrasound technology in India and China ('Preference for sons in India and China') which resulted in uneven sex ratios of the population; the continuous use of polluted canal water by Egyptian villagers ('Pure drinking water in Egyptian villages') because users' needs were not taken into account by the engineers who planned the pure water system; and 'Diffusion of farm innovations in a Colombian village in the Andes' which became the successful diffusion case that encouraged more research on diffusion in LMICs. Also, Roger gave examples of cases from the rural settings of HICs such as 'Hard tomatoes in California' and Diffusion of hybrid corn in Iowa that played main roles in building up the classical diffusion paradigm.

Following Roger's findings, Greenhalgh conducted a systematic review of healthcare literature (76, 140) that also included studies from LMICs such as of Gladwin (142) and Bourdenave (143). Greenhalgh used Gladwin's study to support a construct 'context-specific psychological antecedents' of the proposed model (Diffusion of Innovations in Health Service Organisations) according to which an intended adopter is more likely to adopt a particular innovation when the adopter is motivated by values, goals and skills. Moreover, Greenhalgh also mentioned about diffusion of development studies in LMICs which were succeeded by using the Bourdenave framework (an innovation that narrows socioeconomic gaps and benefits people) (140). Greenhalgh also gave reference of 'rural sociology' which is one of the four research strategies of 'early diffusion research'. The other three are 'medical sociology', 'communication studies' and 'marketing'. The 'rural sociology' encompassed the social difficulties of a rural life and has produced the largest number of diffusion studies in rural settings such as on agriculture and farmers (131). Additionally, Greenhalgh tested the model on four case studies (see the previous section) of complex healthcare innovation, one of which was on telemedicine that served remote and possible low-income areas to narrow the inequality gap.

Greenhalgh’s model and/or its constructs has been used in studies on LMICs such as ‘Diffusion of complex innovations – implementation of primary care reforms in Bosnia and Herzegovina’ (144); and ‘Do we have the right models for scaling up health services to achieve the Millennium Development Goals?’ (145). Other articles that present findings from LMICs and interpreted on the basis of Greenhalgh’s model included, ‘Why do some hospitals achieve better care of severely malnourished children than others? Five-year follow-up of rural hospitals in Eastern Cape, South Africa’ (146).

On the basis of this discussion, I found Greenhalgh’s model reasonable to apply in LMIC settings, therefore, I used the model for the Phase 3 of my research in Pakistan (see Chapter 6).

3.10 Conclusions

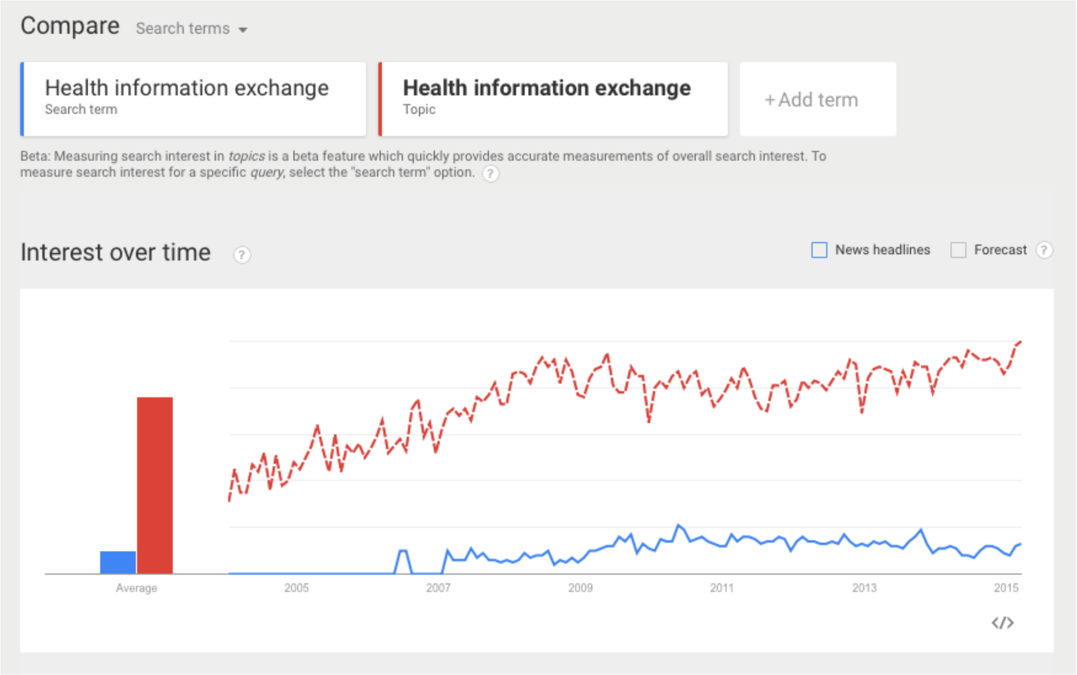
I began by discussing philosophical underpinnings of my PhD thesis and the importance of mixed methods approach for my research phases. Then I described scoping and systematic review methods followed by an overview of case study methodology. I then discussed data collection methods and found semi-structured interviews the most useful way to collect data. Also, I outlined a range of data analysis methods and explained my choice of TA for my data analysis. Finally, I explored different lenses of theoretical frameworks and found Diffusion of Innovation in Health Service Organisations (76) appropriate to inform my qualitative work. Having explained my methodological rationale for my research, I will now begin with the first phase of my research in the upcoming chapter.

Chapter 4 What is health information exchange? A scoping review of published definitions

4.1 Introduction

This chapter covers the first phase of research exploring the underpinning constructs of HIE and how it has evolved gradually with the passage of time (see Chapter 2 for aims and objectives). A scoping review (see Chapter 3) of published definitions has been reported on in this chapter.

Healthcare has tended to lag behind other sectors in the adoption of IT, such as banking and tourism (147, 148), and varies between health systems internationally. Recently, there has been substantial investment by the US federal government in an attempt to catalyse the move from paper-based to EHRs and similar developments are afoot in many other countries (149). The 'Meaningful Use' criteria required by the US HITECH Act, includes an imperative to improve health disparities through better information sharing between relevant stakeholders (150, 151), so as to enhance the quality, safety and equity of care. While these developments have drawn particular attention to the concept of HIE in the US, the term is also used elsewhere. For illustration purposes, the screenshot below (Figure 4-1) shows the number of global Google searches, since 2004, for the term 'health information exchange' (lower line) and the topic more generally, which is computed from several indicators (upper line).



Beta: Measuring search interest in *topics* is a beta feature which quickly provides accurate measurements of overall search interest. To measure search interest for a specific *query*, select the "search term" option.

Figure 4-1 Google searches for health information exchange as search string and a topic, since 2005

Source: Google Trends. Computed March 22nd, 2015

Although the term HIE is widely used by policy makers, academics, professional organisations, funding bodies and other stakeholders, it varies widely and interpreted in different contexts such as **occupational HIE** (152), HIE as the **national EHR** (153) and HIE as the **corporate network of data warehouses** of the health department (154). I therefore set out to answer the question ‘What is HIE?’ with reference to the ways in which it has been defined and the constructs underpinning these definitions (see Chapter 2). The approach was inspired by earlier scoping reviews of the term ‘eHealth’ (155, 156) and aimed to clarify the different uses of the term to in order aid the sharing of information about HIE across stakeholders and inform emerging taxonomies in health informatics (157, 158).

4.2 Methods

4.2.1 Design

I undertook a systematic ‘scoping’ review of the published and grey literature (159).

4.2.2 Inclusion criteria

Definitions appearing in print or digital format were searched which focused on HIE or its synonyms such as Clinical Information Exchange and Healthcare Information Exchange and related concepts such as electronic data interchange (EDI). Searches were not limited by any language, data or publication status or by use of the word ‘electronic’. In order to merit inclusion, documents either had to explicitly define the concept (e.g. *“HIE is the movement of patient information across nodes of a health system using health information technologies and standards for data exchange”*) or do so via a concrete description of the underpinning constructs (e.g. *“Organisations exchange health information using middleware systems and interoperability standards such as HL7”*.)

4.2.3 Exclusion criteria

Reports that did not explicitly define or describe the concept of HIE were excluded.

4.2.4 Sources and queries

Searches were not limited by language. The searches covered the period from 1900 to February 2014.

Google: I and Claudia Pagliari first conducted a Google web search using the narrative terms shown in Table 4-1.

Scientific databases: The structured search queries shown in Table 4-2 were used to interrogate Medline; Web of Science; Library Information Science and Technology Abstracts; EMBASE; and CINAHL Plus. There was no MeSH (Medical Subject Headings) term available for HIE, Clinical Information Exchange or Healthcare Information Exchange, hence the reliance on key words.

Search String	**Hits**	**Total Results Viewed**	**Unique Definitions**
What is health information exchange definition	33,000,000	1000 (100 pages)	61
Health information exchange definition	32,200,000	1000 (100 pages)	13
What is HIE	38,900,000	997 (100 pages)	35
What is HIE health information exchange	2,160,000	991 (100 pages)	42
Clinical information exchange	20,300,000	993 (100 pages)	10
Healthcare information exchange	111,000,000	1000 (100 pages)	13

Table 4-1 Summary of Google searches

Database	**Search String**	**Keyword / Topic**	**Hits**	**Results after duplication removed**	**Unique Definitions**
Medline	‘health information exchange’ OR ‘clinical information exchange’ OR ‘ healthcare information exchange’	Keyword	400	23	14
Web of Science	‘health information exchange’ OR ‘clinical information exchange’ OR ‘ healthcare information exchange’	Topic	408	50	30
Library Information Science and Technology Abstracts	‘health information exchange’ OR ‘clinical information exchange’ OR ‘ healthcare information exchange’	Keyword	81	70	2
EMBASE	‘health information exchange’ OR ‘clinical information exchange’ OR ‘ healthcare information exchange’	Keyword	460	293	69
CINAHL Plus	‘health information exchange’ OR ‘clinical information exchange’ OR ‘ healthcare information exchange’	Keyword	230	167	9

Table 4-2 Summary of searches of academic databases

4.2.5 Search strategy

Query strings were adapted as necessary for each academic database and for the purposes of searching Google. Titles, abstracts and text of the citations identified in the academic databases were independently reviewed by two reviewers (Claudia Pagliari and I) before articles were retrieved for further analysis. Any disagreements between the investigators were resolved by a third reviewer (Aziz Sheikh).

Reference lists of the included articles were also scrutinised for any relevant sources and cited work. Websites included reports, encyclopaedias, dictionaries, blogs, hospitals, vendors, letters, presentations, documents, white papers, articles and references. Duplicate citations and definitions were excluded from the results.

4.2.6 Data extraction

Data extraction tables were prepared to accommodate definition, author, source, year, and country of origin. Duplicates appearing in more than one database were excluded prior to further analysis.

4.2.7 Analysis

As this was a scoping review of definitions (see Chapters 2 and 3), rather than a systematic evidence review, there was no requirement for critical appraisal of study quality (156, 160-162).

Initially all the extracted data were analysed in order to determine whether they contained an explicit definition of the term or formal description of the concept. After cleaning the data set, definitions were descriptively analysed according to publication date, geographical origin, provenance, and terminology used. I undertook a high level pass through the data to create a draft coding framework, which was refined in consultation with Claudia Pagliari before beginning the coding process (156, 160). Definitions were thematically analysed and each definition was coded according to its various qualitative attributes; the codes were continually adapted or supplemented as necessary until the point of saturation when no new codes were required to describe the data.

4.3 Results

Google: The searches yielded 5981 web pages referring to the term HIE.

Scientific databases: The searches revealed 603 articles referring to the term HIE (see Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram in Figure 4-2).

From the above results, 298 statements were extracted resembling a definition or description of HIE: 174 from Google and 124 from scientific databases. Out of these, nine from Google and 21 from scientific databases were excluded from the data for not falling under the eligible criteria. The remaining dataset consisted of 268 explicit definitions, 165 from Google and 103 from scientific databases (Appendix 1 includes exact definitions extracted) .

Definitions dated back to the year 1957 (163). The shortest definition included 11 words (164) whereas the longest one comprised of 146 words (165). Three definitions of EDI, a technology developed in the 1990’s for communicating and exchanging documents between different facilities, were found, highlighting the exchange of health information between different stakeholders (166-168). Moreover, many definitions were using terms synonymous with, or closely equivalent to HIE, such as six definitions of ‘Clinical Information Exchange’ (22, 169-173), another six definitions described ‘Healthcare Information Exchange’ (174-179), two definitions of ‘Clinical Health Information Exchange’ (180, 181), one definition focusing on ‘Clinical Document Exchange’ (182), another relating to ‘Medical Data Exchange’ (183) and a definition concerned with ‘Information Exchange’ (184). The key concept uniting these terms and definitions was to facilitate the exchange of health information among different systems or stakeholders.

Most of the definitions (n=239) were from the US. Other contributing countries were the UK (n=5) (18, 22, 185-187), Australia (n=3) (168, 188, 189), the Netherlands (n=3) (153, 167, 190), Canada (n=2) (191, 192), Germany (n=1) (178), Denmark (n=1) (193), New Zealand (n=1) (194), Sweden/Finland (n=1) (195), Israel (n=1) (196), Switzerland (n=1) (197), Portugal (n=1) (198) and the European Union (n=1) (9). The origins of eight definitions were unclear.

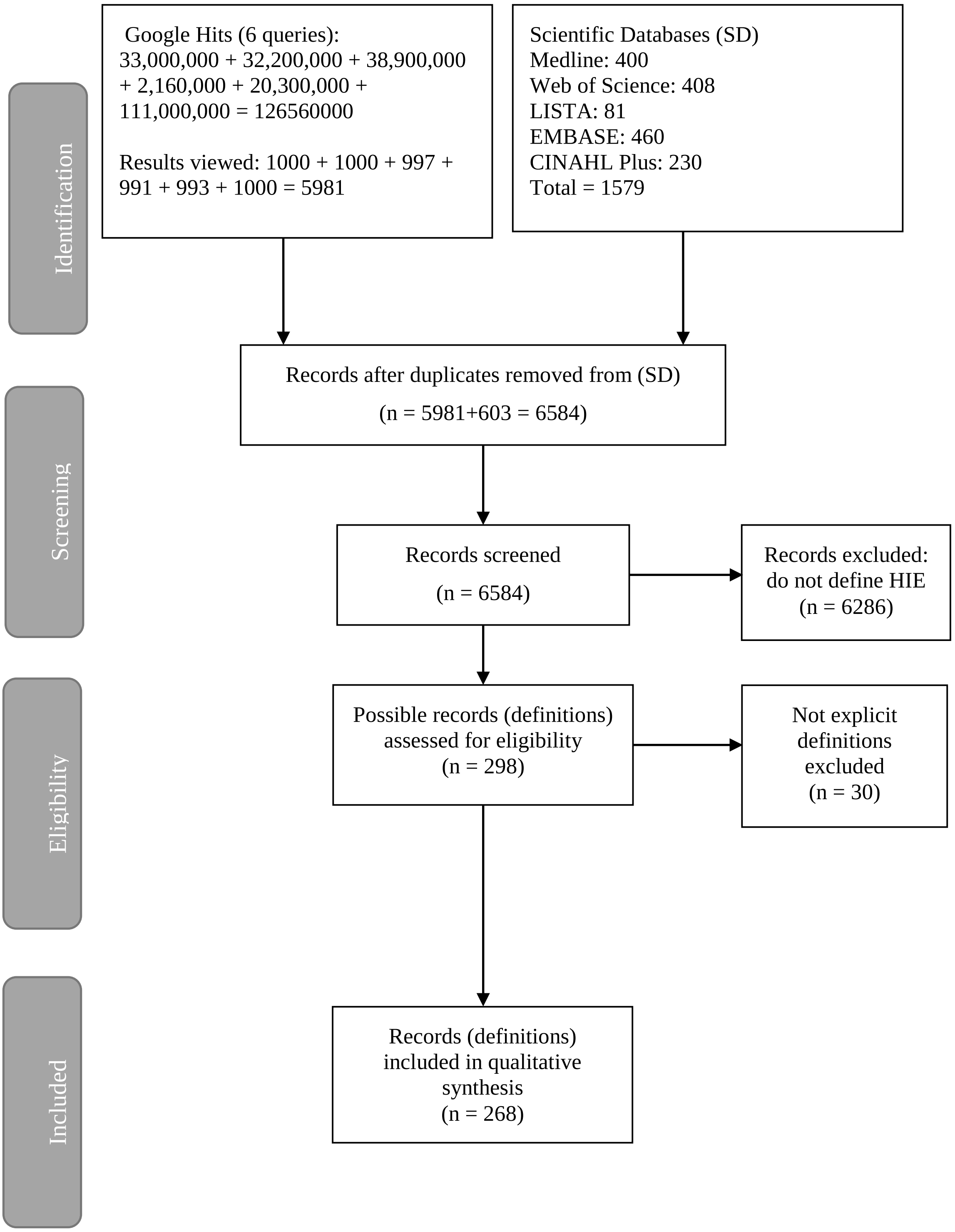


Figure 4-2 PRISMA diagram of HIE scoping review

4.3.1 Key themes identified

Analysis of these definitions revealed 11 core ‘themes’ (see Figure 4-3) arranged in a descending order according to the frequency of constructs occurred in total definitions (given as a percentage rounded off to the nearest whole number) (see Table 4-3 and Appendix 2). The concepts represented within each higher order theme are described below.

Themes	**Frequency of occurrence in %**
Usage of ‘data and information’	91%
‘Information transfer as a function’	89%
‘Stakeholders’ involved in HIE	75%
‘Outcomes’ of HIE	69%
‘Information technology’	40%
‘Focus’/ ‘Context of use’	34%
‘Data standards’	30%
Connectivity between different ‘locations’	26%
‘Public health’	12.6%
‘Business’ solutions/objectives of HIE	8%
‘Sectoral or regional scope’	3%

Table 4-3 Themes evolved and the frequency of their occurrence

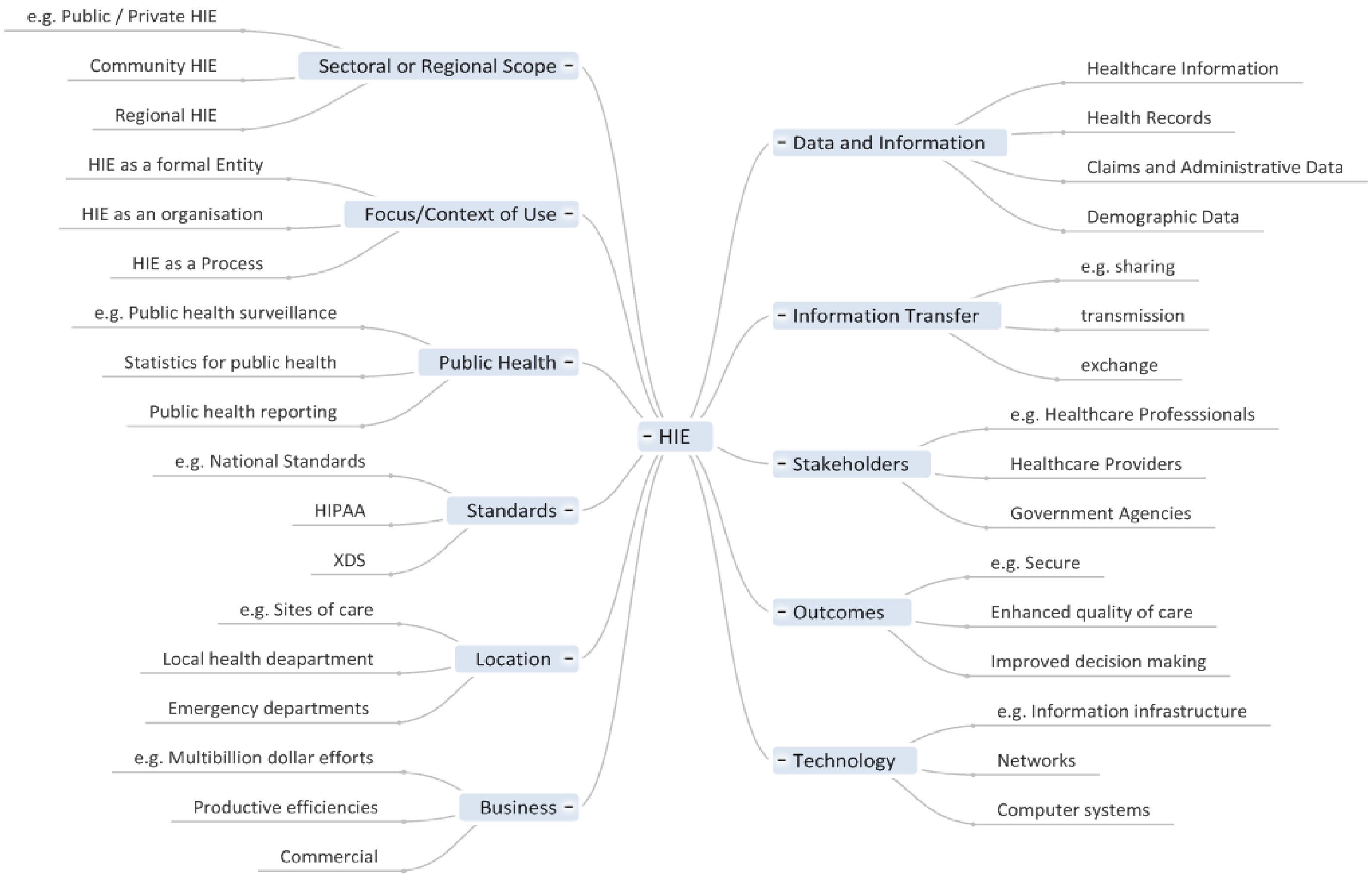


Figure 4-3 HIE themes

The concepts represented within each higher order theme are described below.

4.3.1.1 Usage of data and information

The theme ‘data and information’ was further divided into categories that included ‘healthcare information’, ‘health records’, ‘claims and administrative’ and ‘demographic data’.

4.3.1.1.1 Healthcare information

The definitions referred to the types of information given which could be shared, accessed or exchanged are given in Box 4-1.

‘Health information’(10, 153, 191, 194, 199-243), ‘clinical information’(169, 177, 184, 192, 206, 216, 233, 242, 244-265), ‘clinical data’ (149, 170, 174, 177, 232, 255, 256, 266-275), ‘health data’ (165, 171, 189, 214, 215, 221, 245, 276-284), ‘ ‘patient data’ (175, 177, 200, 252, 285-289), ‘healthcare information’ (179, 217, 229, 255, 260, 270, 290-292), ‘clinical patient data’ (1, 293), ‘patient clinical data’ (294), ‘patient health information’(295-302), ‘patient information’ (164, 173, 181, 186, 187, 193, 210, 242, 261, 303-309), ‘medical information’ (15, 169, 178, 180, 242, 252, 273, 310-314), ‘health-related information’ (164, 226, 227, 266, 307, 315-325), ‘patient-medical information’(326, 327), ‘personal health information’(328), ‘clinical and demographic data’ (329, 330), ‘healthcare-related data’ (331-333), ‘health surveillance data’ (334), ‘clinical and other patient data’ (289), ‘surgical procedures’ (188), ‘International Classification of Diseases’(188), and ‘diagnostic codes and record episodes’(188).

Box 4-1 Terms used to represent healthcare information

4.3.1.1.2 Health records

Healthcare information was categorised into various types of health records as given in Box 4-2.

‘Paper records’ (305), ‘provider health records’ and ‘state registries’ (224), ‘digital medical records’ (335), ‘electronic medical record’ (EMR) (258, 309, 334, 336-341), ‘EHR' (153, 202, 212, 226, 252, 280, 306, 312, 322, 342-352), ‘health information records’(274), ‘care records’ (353), ‘personal health record’ (PHR) (259, 337), ‘patient health records’ (354), ‘electronic patient records’ (EPR) (355), ‘patient clinical records’ (198).

Box 4-2 Terms used to represent types of health records

Further, the contents of healthcare information and health records included are given Box 4-3.

‘Problem lists’ (187, 250), ‘illness’ (241, 328), ‘injuries’(241), ‘procedures’ (188, 250, 270, 302, 327), ‘test results’ (233, 241, 250, 328, 356, 357), ‘radiology reports’ (233, 350, 358, 359), ‘allergies’ (233, 241, 250, 275, 328), ‘images’ and prescriptions (187, 327), ‘medicines’ (241, 328), ‘medications’ lists (187, 233, 250, 270, 275), ‘hospitalization summaries’ (233) and ‘discharge summaries’ (239, 250, 338).

Box 4-3 Terms used to represent ‘contents’ of healthcare information and health records

4.3.1.1.3 Claims and administrative data

Other health information involved claims and administrative data (see Box 4-4).

Claims related to ‘health insurance and payments’(168), ‘claims information’(360) and ‘health encounter claims’(224) whereas administrative data were labelled as ‘administrative health data’(214), administrative data(311), ‘administrative information’ (262, 341) and ‘orders’ (309).

Box 4-4 Terms used to represent claims and administrative data

4.3.1.1.4 Demographic data

Demographic items such as name, date of birth, address and insurance of the patients were exchanged along with the clinical information (182, 188, 233, 329, 330).

4.3.1.2 Information transfer as a function

It was evident from nearly all the definitions that information was being exchanged electronically through HIE. Words and expressions used for the transmission of information are given in Box 4-5.

‘Exchange’ e.g. (200-202, 285), ‘access’ e.g. (214, 227, 282, 350, 361-363), ‘movement’ (298, 307, 315, 316, 318-320, 364), ‘sharing’ e.g. (204, 211, 244, 343, 365), ‘multi-directional transfer’ (366), ‘moving’ (271, 367, 368), ‘bi-directional’ (193, 334, 337), ‘mobilizes’ (369), ‘connectivity’ (199), ‘data flow’ (267), ‘transferring’ (200, 206) , ‘transfer’ (203, 215, 254, 257, 260, 277, 304, 359), ‘feed data repositories’ (254), ‘transmission’(221, 225, 329, 331, 332, 360, 370, 371), ‘transport’ (194, 245, 327), ‘moves’ (306), ‘access to and retrieval’(232, 255, 256, 260, 266, 274, 304), and ‘link’ / ‘linking’ (334, 372-374).

Box 4-5 Terms used to represent information transfer

Further, health information was being exchanged and transferred through different mediums and methods such as ‘e-transfer’ (200), ‘application-level communication’(194), ‘email’ (338, 353), and ‘secure messaging’ (339) .

4.3.1.3 Stakeholders involved in HIE

The third theme related to the range of stakeholders engaged in HIE. These stakeholders included (see Box 4-6):

‘Doctors’ (15, 212, 214, 230, 241, 286, 300, 322, 327, 328, 375-377) or ‘physicians’ e.g. (149, 169, 222-224, 288, 306, 378-380), ‘clinicians’(1, 201, 232, 242, 244, 254, 275, 279, 305, 356, 361, 381-383), ‘nurses’ (15, 230, 327, 377, 384, 385), ‘patients’ e.g. (153, 185, 235, 254, 277, 282, 349), ‘pharmacists’ (15, 210, 327), ‘health educators’ (210), public health officials’ (277), ‘healthcare professionals’(177, 181, 183), ‘medical professionals’ (235), ‘insurers’ (286), ‘payers’ (214, 222, 318, 360, 386), ‘policy makers’ (376), ‘social workers’ (210), ‘ healthcare providers’ (172, 203, 235, 250, 270, 285, 296, 298, 313, 339, 340, 348, 351, 365, 373, 387), ‘customers’ (190), ‘hospitals’ e.g. (149, 167, 170, 244, 246, 265, 365, 388), ‘health plans’ (169, 212, 223, 224, 314), ‘laboratories’ e.g. (212, 222, 230, 389), ‘ radiology centres’(233), ‘pharmacies’ (177, 212, 230, 275, 286, 306, 307, 326, 378, 389, 390), ‘hospitals’ e.g. (169, 176, 268, 327, 338, 358, 365, 380), ‘organizations’ e.g. (278, 366, 369, 391, 392), ‘institutions’ (178, 183, 190, 244, 285, 393-395), ‘emergency departments’ (172, 272, 286, 356), ‘nursing homes’ (149, 246), ‘clinics’ (ambulatory / community) (176, 224, 259, 265, 268, 359), ‘quality assurance groups’ (259), ‘government agencies’ (166, 331-333), ‘state agencies’ (224), ‘public health agencies’ (229, 246, 317, 318, 380, 386), ‘public health facilities’ (224), ‘public health entities’ (259), ‘health information organizations’ (331-333), ‘insurance companies’ (166, 177), ‘research groups’ (259), ‘public health departments’ (149) and ‘federal reporting entities’ (396).

Box 4-6 Terms used to represent different types of stakeholders involved in HIE

Other terms were less specific with regard to stakeholders. They included (see Box 4-7):

‘Stakeholders’ (195, 213, 219, 229, 251, 262, 270, 271, 324, 397), “multi-stakeholders” (214, 237, 338, 384), ‘public-private stakeholders’ (236),’ public health stakeholders’ (397), “other or third parties” (165, 287) and “other healthcare providers” (172, 298).

Box 4-7 Other terms for stakeholders

4.3.1.4 Outcomes of HIE

Many definitions emphasised the ‘benefits’ and potential benefits of using HIE, most importantly, the ability to transfer information in a secure way (see Box 4-8).

Information security e.g. (172, 174, 189, 205, 215, 234, 240, 243, 245, 271, 297, 301, 308, 316, 325, 334, 341, 370, 377, 381, 398), ‘coded’(187, 338), improved capacity for informed ‘decisions’ (165, 182, 185, 193, 209, 214, 228, 254, 261, 296, 372, 388, 390, 396), ‘effective’ e.g. (169, 216, 248, 260, 266, 273, 304, 377, 395), ‘efficient’ e.g. (177, 229, 240, 266, 292, 304, 376-378), ‘safer’ (184, 216, 232, 255, 256, 266, 376), ‘coordinated’ (226, 377), ‘equitable’ (184, 216, 255, 256, 260, 266, 273, 274), ‘timelier’(248, 266), patient-centred healthcare (184, 216, 229, 255, 256, 260, 266, 273, 274), ‘real-time’ information transfer (182, 244, 283, 308, 341, 399), enhance ‘quality’ of healthcare e.g. (197, 204, 251, 276, 285, 356, 400); reduce costs e.g. (211, 290, 320, 359, 393, 401), deliver ‘accurate’ (242, 252, 356, 390), ‘seamless’ (193, 244, 284, 398), ‘empowerment’ (238) and ‘complete’ (13, 182, 242, 263, 288, 294, 305, 355, 365, 383) health information.

Box 4-8 Terms used to represent potential benefits of HIE

4.3.1.5 Information technology

Inevitably, technology was an important theme. Almost all of the definitions referred to ‘electronic’ or ‘digital’ data exchange. Other related terms included (see Box 4-9):

‘Technology platform’ (189, 193, 309, 368, 402), ‘network infrastructure’ e.g. (7, 188, 247, 254, 270, 275, 362, 370, 392, 402-410), ‘health information technology’ (298, 315, 332), ‘computer-based systems’ (369), ‘technology model’ (270), ‘information technology’ (13, 195, 209, 226, 291, 391, 411), ‘HIE systems’ (346, 412), ‘document exchange system’ (173, 182, 396), use of ‘online metadata registry’ (385), ‘powerful technology’ (382), ‘web-based delivery systems’ (358), ‘technical infrastructure’ (7, 277), ‘information infrastructure’ (413), ‘electronic networks’ (251), ‘electronic system’ (296), ‘portal’ (187), ‘computer network’ (330), ‘interoperable technologies’ (414), ‘central information systems’ (303), ‘collection of activities and technologies’ (249, 415), ‘component of innovative’ (416), ‘friendly user interfaces’ (417), ‘secured website’ (261, 313), ‘communication based on web services’ (198), ‘health care technology’ (241), ‘health information systems’ (407), ‘mobile computing technology’ (264), ‘hubs’ (280), ‘open source’ (374) and ‘data formats’ (392).

Box 4-9 Terms used to represent information technology

4.3.1.6 Focus / context of use

Different definitions also considered HIE with reference to different contexts of use. For instance, ‘nursing interventions’ (418), ‘registered nurses’ working in home healthcare improving the quality of care through HIE (384), contributing to ‘emergency departments’ (171, 264, 268, 286, 305, 356, 382) and focusing on preventive and outcome-based medicines (302). HIE was also used for occupational health (163), mental health (419), HIV (210, 373) cancer care (175) and cardiac surgery (264).

It is also referred as a ‘set of activities’ to transfer information from one place to another (344, 420), as a component of eHealth (189, 389), as a method of utilising EHR (226, 288, 312, 347, 352) or EPR (355) and as an important requirement of Stage 1 ‘Meaningful Use’ for hospitals (220, 250, 346, 352, 421).

HIE was seen as a technical infrastructure as well as an entity, organisation or process as described below.

4.3.1.6.1 HIE as an entity or organisation

In many definitions, HIE was labelled as an 'entity' (205, 215, 218, 219, 222, 228, 287, 370, 422) that was established to exchange health information in a secure manner. It has also been prefixed as 'legal entity' (205), and 'person or governmental entity' (370).

In some definitions HIEs were conceived as 'organisations' (329, 423) or sets of organisational 'services' and infrastructures to support or streamline the exchange of health information (217, 293, 309, 340, 349, 424). (7, 220, 405) (274). Here HIE was used as a 'noun', to describe an entity responsible for the exchange of health information (329, 360, 423). The term HIE was synonymously interchanged with Local Health Information Organisations (LHIO) (324), Regional Health Information Organisations (RHIO) (10, 170, 191, 196, 217, 247, 324, 350, 425) and Sub-Network Organisations (SNO) (324), though different names, but serving the same purpose. Others perceived that HIEs were run and controlled by RHIO (10), and were funded by healthcare delivery organisations (262). HIEs were occasionally recognised as multi-stakeholder organisations responsible for managing business and legal matters involved in the exchange of information (214). Moreover, HIEs were even regarded as the foundational part of Accountable Care Organizations (ACO) (258) because they allowed EMRs to exchange information between various types of medical records. The other way around, HIEs were important for organisations that were transitioning into ACO (239).

4.3.1.6.2 HIE as a process

Here HIE was considered as the **process of** transferring electronic or digital health data in a protected environment among multi-stakeholders (213, 226, 289, 321, 323, 343, 366, 367, 378, 403, 422, 423). Moreover, it was the process of utilising technology and systems to capture, store, share and retrieve the data electronically (9, 179). In a few definitions, HIE was also reflected on as a 'verb', an action, a process responsible for transmitting health information (165, 329, 360, 423) and collaboration among providers (169, 176, 239, 262, 314)

4.3.1.7 Data standards

Incompatibility between systems and software has presented a barrier to HIE and for this reason the importance of interoperability standards is emphasised in the majority of definitions. Keywords and phrases related to this are given in Box 4-10.

‘Standards’ (323, 344), ‘nationally recognized standards’ (245, 266, 281, 298, 316, 318-320, 371, 422), ‘nationally recognized vocabularies’(338), ‘policies and standards’ (277), ‘standardise’ (293, 296, 351, 397), ‘standardized content’ (194), ‘standard procedures’ (273), ‘nationwide standards’ (422), ‘national standards’ (297, 331-333), standards-based infrastructure’ (174),’ standard based exchange/solution’(183, 381), ‘XDS’ (329) to ‘Health Insurance Portability and Accountability Act (HIPAA) standards’(234).

Box 4-10 Terms used to represent use of standards

4.3.1.8 Connectivity between different ‘locations’

Definitions falling within this theme emphasised the exchange of information among facilities or organisations located in different areas (see Box 4-11).

Such as within a ‘region’ (169, 195, 211, 214, 217, 221, 232, 255, 260, 289, 291, 306, 307, 314, 374, 376, 400), or at a ‘regional level’ (153, 186, 190, 200, 220, 227, 228, 412, 422), ‘community’ e.g. (175, 211, 214, 227, 247, 254, 268, 309, 390, 426), ‘non-clinical settings’ (210), ‘metropolitan regions’ (268), ‘sites of care’ (294), ‘delivery settings’ (199, 204), ‘city’ (376), ‘state/state-wide’ e.g. (169, 186, 227, 275, 300, 308, 311, 334, 346, 348, 376), ‘member sites’ (7), ‘geographic area’ (198, 213, 217, 219, 282, 289), ‘provincial’ (186), ‘local level/ local health departments’ (176, 220, 283, 412), ‘national level’ (186, 190, 220, 412), ‘across countries’ (221), ‘neighbourhood / neighbouring states’ (311, 422), ‘multi-state’ (228) and ‘nationwide’ (202, 399, 422).

Box 4-11 Terms used to represent different locations

4.3.1.9 Public health

The uses of HIE in population health were stressed in a number of definitions (242, 271, 309, 398, 427). Relevant concepts covered the uses of HIE for supporting public and community health practices, population health monitoring and research (see Box 4-12).

Concepts included connecting ‘public health departments’(267, 283), supporting ‘public health practices’ (397), undertaking ‘public heath activities’ (294), linking ‘public health surveillance data’ (334), ‘public health reporting’ (292, 396), evaluation and planning of ‘public health services’ (292), ‘public health event-monitoring capability’ (399), ‘public health situational awareness’ (399), analysing the ‘health of the population’ (255), ‘countrywide population health’(260), ‘statistics for public health’ (217), assist ‘public well-being' (422), protecting 'public interest' (236), 'public health organizations' (176), promote 'population health' (209, 254, 285, 292, 386), health data on a 'population level' (283), 'track population health'(396), refine 'US health care system' (201, 219), HIE for a '16 county region'(314) and 'community betterment'(232, 311).

Box 4-12 Terms used to represent public health functions of HIE

4.3.1.10 Business solutions/objectives of HIE

A number of definitions conceived of HIE as either a business, or in terms of its business objectives (428). For example, one vendor represented itself as a national HIE 'company' (429), while other definitions emphasised issues like scalability and efficiency [258]. Siemens offered a four dimensional HIE 'solution', organised according to 'economics', 'care', 'service' and 'technology' (341). Transactions between providers, or between services or suppliers often involve secure data exchange (165, 245) . This may be conceived in terms of 'data supplier and data receiver' (165) but also 'competitors' (189) and 'customers'(190). HIE has been spoken about in terms of exchanging health information across traditional business boundaries (207) and also characterised as 'large multi-billion dollar efforts' (395). HIE has also been characterised as an infrastructure which includes business models, technology model and the legal model to facilitate the exchange of information among various organisations (236, 270). The 'primary business focus' of networks involved in building HIEs was to create value for the provider community by forming 'productive efficiencies' (247). One author described HIE as entities built on 'bilateral legal agreements' between proprietary information systems to be able to share different kinds of data (320). HIE can thus be seen as an administrative as well as a clinical tool (182, 262, 311), and as a tool for exchanging insurance information (430).

4.3.1.11 Sectoral or regional scope of HIE

Many definitions conceived HIE in terms of sectoral, geographic or occupational scope (see Box 4-13)

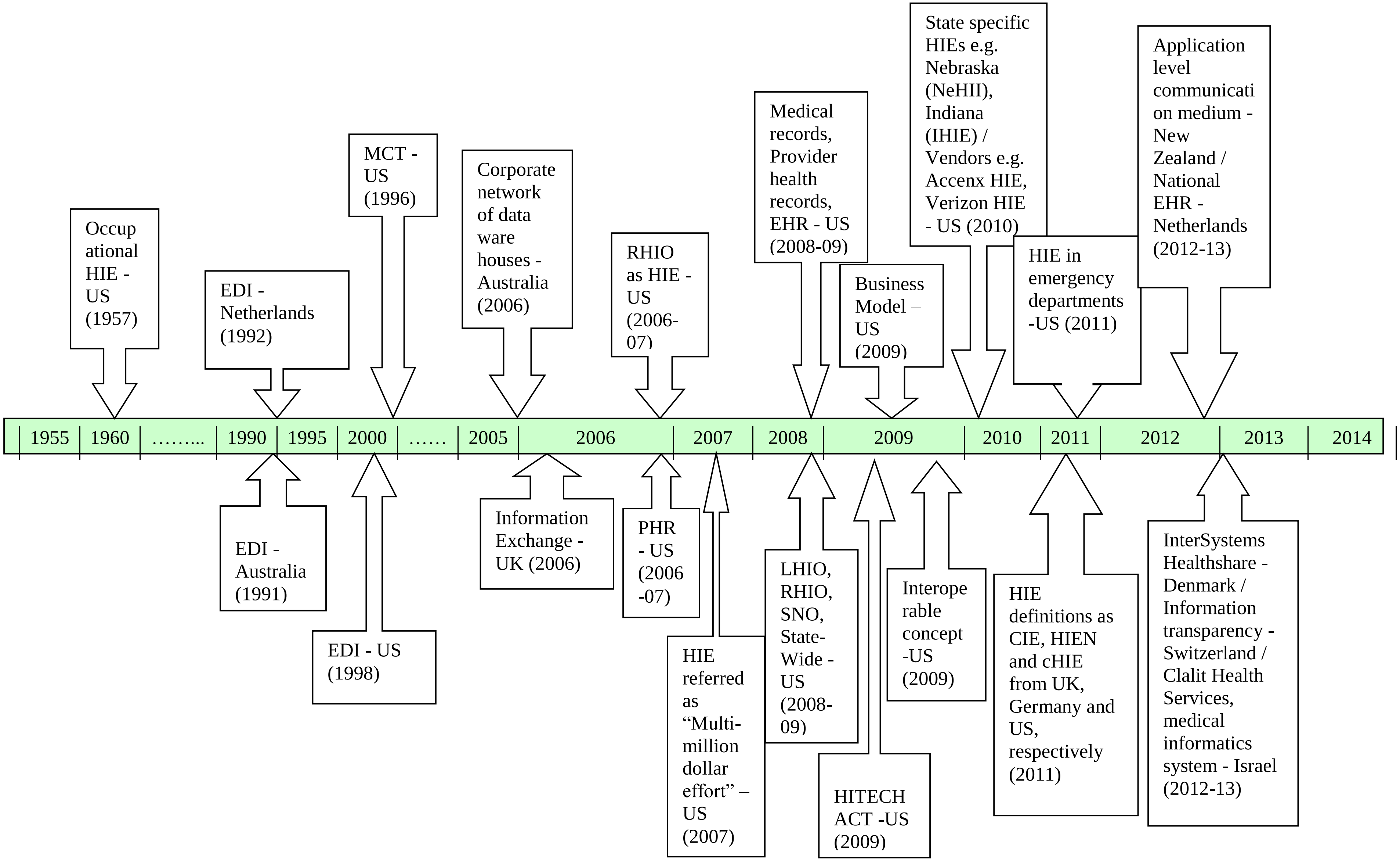
Such as 'public' HIE (309), 'private' HIE (309), 'local' HIE (277, 294), 'regional' HIE (277, 358), 'national' HIE (429), 'nationally-accessible electronic record' (18), and 'community' HIE (357).

Box 4-13 Terms used to represent sectoral or regional scope of HIE

4.4 Changing definitions over time and different national perspectives

Figure 4-4 illustrates a timeline of the included definitions. The concept of HIE evolved with the rise in occupational health problems in the US when Byers in 1957 recognised the need for a central coordinating organisation. Early ‘occupational HIE’ aimed to collect, collate and disseminate all types of information related to occupational health problems (152). In the early 1990s, references to EDI systems for transferring data between GPs, hospitals and various other stakeholders to enhance quality of care, appeared in the literature from Australia (1991) (168), Netherlands (1992) (167) and the US (1998) (166). In 1996, the term Mobile Computing Technology (MCT) was used in the US to describe clinical information exchange between older cardiac surgery patients at home and healthcare providers to give additional information of patients’ recovery to providers after surgery (264).

Figure 4-4 Changing definitions over time and different national perspectives



In 2006, a report from Australia defined HIE as the corporate network of data warehouses of the health department that contains data on surgical procedures, international classification of diseases, diagnostic codes, record episodes, information and diagnoses and some demographic items (188). Again in 2006, the first definition from the UK defined HIE in terms of ‘information exchange’ between patients and health professional to achieve shared decision making (185).

Between 2006-2007, the terms HIEs and RHIOs were used interchangeably in the US to facilitate the flow of clinical information (247, 431). Around this time, the concept of linking patients’ health records across organisations emerged in the US (354), which included medical records (179), provider health records (224) and EHRs (342). Between 2008-2009, HIE organisations were also referred to in the US using location-specific names such as LHIO, RHIO, SNO and ‘state-wide’, all serving the purpose of overseeing and governing the exchange of health information among different healthcare stakeholders (324).

The funding environment for enabling and sustaining HIE is emphasised in a number of definitions. In 2007, a US definition described HIE as a ‘multimillion dollar effort’ and insisted on establishing a reason to sustain the effort (HIE) (432). In the same year, the business case for investment in HIE was argued in terms of its potential to create productive efficiencies for the provider community (247). Another US definition from 2009 defined it as ‘a business offering services to generate revenue that must exceed its expenses and should provide services according to the expectations of stakeholders’ (428).

References to the term ‘interoperability’ became more common in 2009 (419) in a US definition HIE along with the term ‘standardised electronic exchange’, recognising the need to manage incompatibilities between systems and software (351) .

48 definitions appeared during the period 2009 and 2010, all from the US, with the exception of two from Canada, illustrating the increasing importance of HIE in North America in the immediate aftermath of the enactment of the HITECH Act in 2009 and the associated attention from researchers, providers, payers and vendors in the US. Along with the general definitions of HIE, a number of HIE definitions are specifically associated with certain states’ and vendors’ names, for example, Nebraska Health Information Initiative (NeHII) (311), Indiana HIE (IHIE) (433), South Carolina HIE (434), and New York Clinical Information Exchange (171), whereas vendors involved were Accenx Exchange (309), Centricty HIE (275) and Verizon HIE (293).

By 2011, the concept of HIE dispersed to the other parts of the world and the literature included definitions from Germany, UK, and Finland / Sweden. There were slight modifications of the term HIE such as Healthcare Information Exchange Network in a definition from Germany (178), Clinical Information Exchange in definitions from the UK (22) and US (171), and Clinical Health Information Exchange in a definition from the US (181). A definition from the UK stressed the accomplishment of HIE through policy, infrastructure and systems of care. Moreover, it further emphasised the need to acquire and build computing applications and make use of financial and clinical incentives to sustain Clinical Information Exchange. Several definitions dating from 2011 focused on the use of HIE in emergency departments, for supporting access to patient records for the purposes of out-of-hours medical care.

As the topic of HIE gained momentum, more countries, states and vendors came out with definitions in 2012-2013. New Zealand referred to it an ‘application level communication medium’ to exchange health information (194). Denmark, a global leader in software for connected care, has aligned the concept of HIE very much with the vendor system procured for national use InterSystems HealthShare™ (193). A definition from the Netherlands referred to HIE as national EHR (153) while a definition from UK referred to it as “nationally-accessible electronic records” (18). A definition from Switzerland aligned the concept of HIE with the benefits and challenges it generates, such as greater care coordination through transparency, balanced by risks of greater disclosure and the need to change the habits and practices of patients and health professionals (197). Finally, a definition from Israel identified ‘Clalit Health Services’ as an HIE entity, which uses a single medical informatics system to exchange health information between a national network of hospitals and community care (196).

4.5 Discussion

The analysis has revealed considerable variability amongst existing definitions of HIE and how many different concepts are embedded within these. To an extent, this reflects the emerging nature of the field and the changing relevance of HIE to different stakeholders and contexts.

The majority of the definitions originated in the US, no doubt reflecting the considerable investments in HIE through the federal government’s HITECH Act (150, 151), which aimed to accelerate the adoption of interoperable health information systems and integrate the healthcare delivery systems for the benefit of patients. This has fuelled a growth in interest in HIE amongst healthcare professionals, providers, payers, technology companies, policy makers and researchers.

With respect to international variations, the related terms, HIE, Clinical Information Exchange, Healthcare Information Exchange, EDI and Clinical Health Information Exchange were used mostly in the US whereas in the UK only HIE and Clinical Information Exchange terms were typically used when referring to the exchange of health information. HIE and EDI were preferred in publications emanating from the Netherlands and found one definition on Healthcare Information Exchange Network from Germany (178).

Although the term EDI was used more in the contexts of exchanging business information using a standard format, our review found two definitions of EDI dating back to 1992 (167) and 1998 (166), that fit our inclusion criteria as describing HIE.

Most of the definitions identified from the search of online grey literature were derived from vendors' webpages; for example Cisco (183), Siemens (339, 341) and Xerox (302); books, theses, news portals, dictionaries, government websites, government and corporate reports, glossaries, electronic articles, web posts, presentations, acts, workshop documents, blogs, magazines, security guide, white papers and bills.

Many definitions included not only the exchange of patient information, but also other types of information such as demographics, claims and administrative data. Concepts originally used in the healthcare setting therefore appear to be developing into solutions for other kinds of data sharing. Definitions also described health information sharing and connectivity at the level of organisations, states or regions and nations, possibly reflecting the different ways in which care is organised in different national contexts. Organisations exchanging health information were also known by different names such as LHIO, RHIO and SNO (324). In some cases, the terms HIE and RHIO were used interchangeably (172, 191, 213, 217, 247) although RHIO typically referred to an infrastructure that enabled HIE within the healthcare administrative regions (196, 350).

While the US government has provided incentives for the adoption of HIE securing long-term funding has been a major challenge for sustainability (435). Many of the definitions referred to HIE as a business to provide required data exchange services (236, 247, 262, 428). For example, one described the creation of value for healthcare providers through 'productive efficiencies' which generate modest revenues (247), whereas another characterised HIE as ‘a business’ that offered services to the market at a bearable price in such a way that revenue exceeds expenses (428). Implementing HIE represents an investment and not simply a cost and this is accompanied by a realisation that policy makers must find approaches to assure that all stakeholders who benefit from HIE pay to support it (435) and specifically, that efforts should be made to engage private payers (435).

A wide variety of stakeholders are engaged in HIE, not only including healthcare professionals and patients, but also policy makers, researchers, and insurance companies, for example. Although infrastructural, economic, technical and cultural barriers have impeded the participation of some stakeholder groups in HIE efforts, it remains the core of the vision for a connected, coordinated and learning health system (436).

Not surprisingly, the majority of definitions highlighted the importance of secure information exchange and many pointed to the requirement for common data standards to allow accurate transmission of data across participating institutions. Standards are necessary for the quality of data content, clinical documentation, data mapping and most importantly, interoperability between disparate systems. (344). Common standards will also contribute to data protection, confidentiality, interoperability and privacy (181, 273, 332, 371).

The value of HIE for supporting public health is referred to in many of the definitions, with the ability to meaningfully move clinical data across disparate systems being seen as vital for effective health surveillance and management of care delivered outside health facilities (437). For instance, IBM’s prototype Nationwide Health Information Network was described to the US Department of Health and Human Service (HHS) as a means of improving bi-directional communication with public health agencies and enabling early disease detection and prevention (438).

The origins of the various definitions lie in a range of contexts, reflecting the importance of HIE for various purposes across the health industry, for e.g., occupational health HIE, community HIE, HIE for public health. Most of the definitions prioritise regional or national perspectives, although a few make reference to the value of HIE on a global level (232, 262, 311). At the macro level, natural disasters and viral outbreaks present requirements for global monitoring or coordinated international responses, for which effective HIE is essential. For example, this was demonstrated in the aftermath of Hurricane Katrina in the US, where healthcare organisations throughout the region and nationwide exchanged health information in order to take care of inhabitants displaced by the storm (8). The value of HIE in managing the recent Ebola crisis has also been described (439).

4.5.1 Strengths and limitations

This review aimed to identify and classify definitions of HIE and was not intended as an in-depth analysis of the challenges and opportunities presented by HIE, although such issues were inevitably to an extent reflected in many of the definitions. The search terms used to identify definitions of HIE were limited to those which I considered most relevant and it is possible that extending them to include other pertinent concepts in health informatics might have revealed further descriptions of HIE and HIE-like concepts. However, I have followed previous authors in prioritising the search for explicit definitions, as a means of generating insights into how the concepts has evolved and how it is being discussed (156, 160). Using both research databases and a general web search gave me greater scope to reach both academic and non-academic literature. As this was not a systematic review, it was not appropriate to attempt critical appraisal of study quality.(160) Internet searches were restricted to Google and whilst it is possible that additional definitions may have been found using other search engines, the very large number of hits produced by my queries suggest that it was an effective means of identifying the majority of relevant content in the online grey literature.

The included definitions reflect the dominance of the US literature pertaining to HIE and, to some extent, the language used to describe information sharing concepts in that national context. I acknowledge this limitation, but interpret the results as a consequence of the major investment in HIE in the US over recent years, with its inevitable knock-on effects to the volume of literature emerging from that part of the world. As the term gains wider international currency and other countries prioritise investments in HIE this national balance may change. As national health systems vary widely in their structure, funding and reimbursement models, concepts such as ‘insurance’ will feature less in discussions about HIE than in others, again reflecting the fact the relevance of culture for characterising and interpreting terms in health informatics.

A post-hoc analysis excluding the US definitions revealed similar weightage of themes such as ‘usage of data and information’ and ‘information transfer as a function’ having 90% of occurrence but ‘public health outcomes’ with the lowest weight of 4.7% (see Table 4-4). This resonates well with the analysis of 268 definitions and infers that the concept and function of HIE is almost same in the US and other parts of the world.

Themes	Frequency of occurrence in %
Usage of ‘data and information’	90%
‘Information transfer as a function’	90%
‘Stakeholders’ involved in HIE	71.4%
‘Technology’ required for HIE	57%
‘Potential benefits’ of HIE	47.6%
‘Data standards’	28.5%
Connectivity between different ‘locations’	23.8%
‘Focus’/ ‘Context of Use’	23.8%
‘Business’ objectives of HIE	9.5%
‘Public health’ outcomes	4.7%

Table 4-4 Weightage of themes excluding US definitions

Finally, I recognise the considerable progress that many countries across Europe, New Zealand, Australia, Israel and elsewhere have made in implementing national and regional health information infrastructures to support HIE, which are not fully reflected in the corpus of HIE definitions. Extending the search to related terms such as ‘national health information infrastructure’ would no doubt uncover additional definitions and future authors may wish to extend the review to capture broader aspects of health informatics.

4.5.2 Implications for practice, policy and the next phase of my research

The definitions of HIE appearing in the literature vary on a number of philosophical and conceptual attributes, and many are context specific. The ways in which different authors choose to describe concepts is inevitably influenced by their backgrounds and vested interests and it is therefore not surprising to observe the differences in emphasis. However, I was struck by the clear alignment of the HIE concept with specific technologies or business opportunities in some definitions, where HIE is used as a noun; describing a service, an organisation or a technology, rather than a process or concept. Such uses often came from businesses promoting their products, or in the context of state information systems, where ‘the exchange’ is pictured as an operational entity. This creates important obstacles to communication about HIE, particularly for policymakers involved in making decisions about strategy and procurements.

While I have not found a single definition which encompasses all of the key attributes of HIE identified by the TA, the one offered by Finn is an example that is comprehensive and differentiates ‘Health Information Exchange’ as a concept related to the *processes* of data transfer and sharing, and ‘Health Information Exchanges’ as *entities* responsible for overseeing effective HIE, whilst also recognising the benefits, scope and stakeholders involved (214). The broad concept of HIE also describes a set of *enabling technologies* that support these processes and for this reason I have adapted Finn's definition to make it succinct and to add themes of *Data standards* and *Public health.* I recognise that the concept of HIEs as organisational entities is largely a US construct, which may not be applicable in all contexts, and I therefore have therefore separated the two concepts.

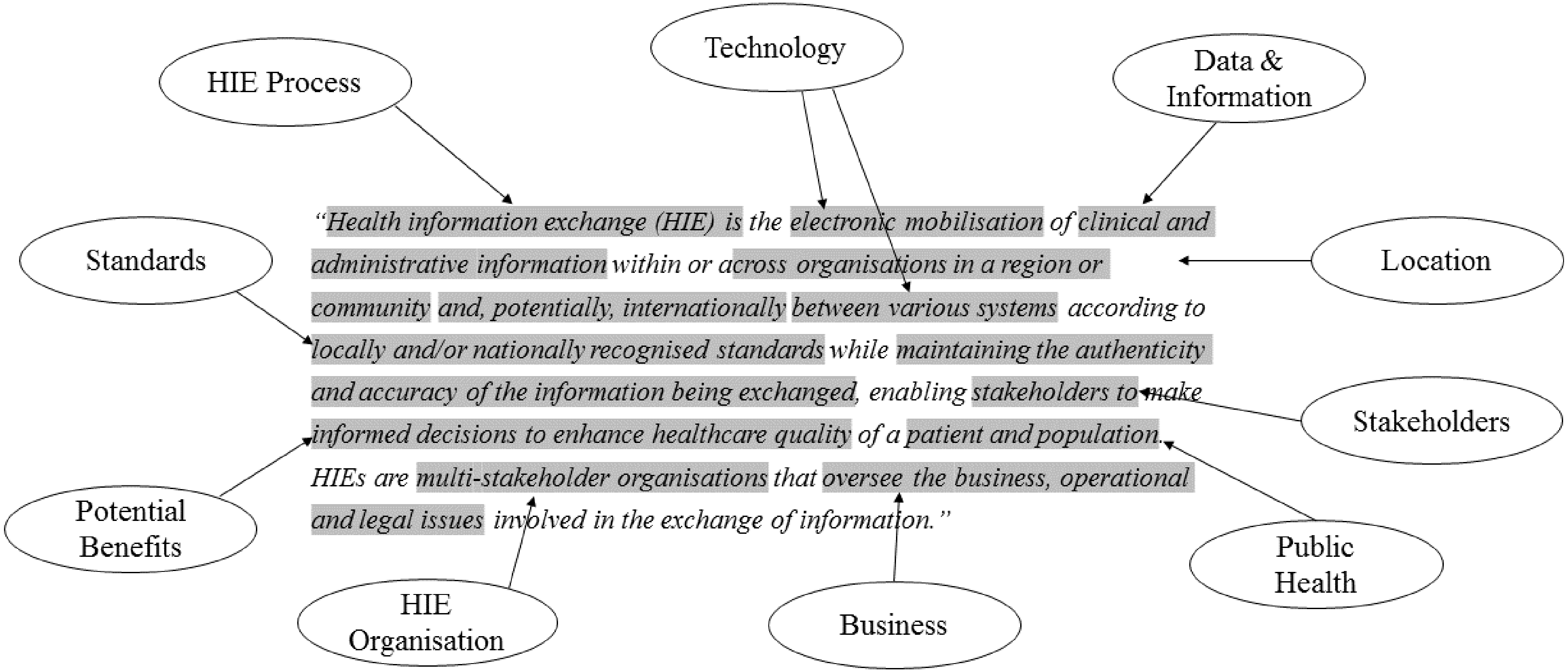
"Health information exchange (HIE) is the electronic mobilisation of clinical and administrative information within or across organisations in a region or community and, potentially, internationally between various systems according to locally and/or nationally recognised standards while maintaining the authenticity and accuracy of the information being exchanged, enabling stakeholders to make informed decisions to enhance healthcare quality of a patient and population. HIEs are multi-stakeholder organisations that oversee the business, operational and legal issues involved in the exchange of information." (Adapted from Finn (214))

While this definition may not suit all users (such as HIE for specific diseases), I believe it provides a good fit with almost all the themes identified in the heterogeneous corpus of definitions revealed by this review, mindful of the nuances that may be required for different contexts (see Figure 4-5, to generalise the definition, I omitted the theme 'Sectoral or regional scope', though the definition includes terms such as 'regional' and 'community').

This review has provided the underpinning concepts of HIE that will assist me in conducting more focused research in Phase 2 (Chapter 5), a systematic review of barriers and facilitators to HIE in LMICs (see Chapters 2 and 3 for aims and methods).

This review helped me in understanding and differentiating HIE as a process and as an organisation which will assist me in finding relevant literature for my second review. I will look in the literature for interventions and technologies facilitating exchange, sharing and usage of patients' health data and information in LMICs, and on the other hand, will look for HIE organisations that manage the business and legal issues involved in the HIE process. Also, the detailed constructs of HIE definitions will help me to develop eligibility criteria for the systematic review (for example, stakeholders and technologies involved in HIE) (see Chapter 5). I decided to use the constructs of HIE as given in the proposed definition to search for the literature on LMICs because although the majority of the definitions were from the US, the healthcare system of the US is similar to many healthcare systems of LMICs in as much as they are lacking in centralised governance and consist of a complex mix of public and private healthcare stakeholders and grapples with fragmentation (440). Moreover, there are organisations in LMICs such as health ministries, NGOs and hospitals which are running HIE processes nationwide or in silos. For example, ministries of health in many LMICs are using technologies such as DHIS to collect statistical healthcare data from their primary and secondary healthcare facilities and transferring it to higher authorities (stakeholders) to analyse and respond back effectively for necessary action. Similarly, health ministries together with NGOs are running HIE processes as vertical healthcare programmes using surveillance and global positioning systems to track immunisation coverage and accelerate vaccine-preventable diseases, for example. Surveillance reports are then passed to the responsible decision makers (such as donors) through the HIE process. Also, hospitals in LMIC settings using EHRs also make use of HIE but in silos usually within their organisations.

Many fruitful examples of knowledge transfer from richer to poorer countries or the other way around exist in the literature (441). For example, the use of mobile phone technology is more effective in LMICs than in HICs. Also, lenses developed for the poor population in India are used in cataract operations globally. Similarly, although, the constructs of HIE were evolved from the literature of HICs, HIE will never make sense without any of its constructs in whatever settings it is applied. Therefore, this proposed definition may work well for both HICs and LMICs.



"Health information exchange (HIE) is the electronic mobilisation of clinical and administrative information within or across organisations in a region or community and, potentially, internationally between various systems according to locally and/or nationally recognised standards while maintaining the authenticity and accuracy of the information being exchanged, enabling stakeholders to make informed decisions to enhance healthcare quality of a patient and population. HIEs are multi-stakeholder organisations that oversee the business, operational and legal issues involved in the exchange of information."

Figure 4-5 Proposed HIE definition composed of themes identified.

The definition also informed the diverse healthcare stakeholders involved in HIE. The healthcare stakeholders included healthcare facilities, providers, citizens, public health managers, bureaucrats, government and business sector. This domain of healthcare stakeholders will be useful to conduct a sampling matrix in order to recruit interview participants for my third phase of research from various healthcare settings in rural and urban regions of Pakistan, including public/private officials and providers, citizens and NGOs (see Chapter 6). Moreover, this review also informed my topic guide for the case study by using HIE constructs such as 'benefits' (perceived advantages and disadvantages), 'information transfer' (the information exchange process between various healthcare stakeholders) and 'information technology' (potential technologies that can be used for HIE).

4.6 Conclusions

This review has shed light on the different facets of HIE by analysing a pool of 268 definitions. Analysis of these definitions gave a rich understanding of HIE's attributes by revealing 11 main themes characterising descriptions of HIE. Not surprisingly, the 'exchange' of health related 'data and information' amongst different clinical stakeholders and parts of the healthcare system were core themes. These are underpinned by the 'technologies', needed to support health information infrastructures and the 'standards' to enable effective 'information transfer' which will bring 'benefits' to the various 'stakeholders' and to support 'business' processes and efficiencies in the through timely and accurate HIE. The definitions recognised different 'locations' across which data must be exchanged and the differences between organisational, regional or national level ('public health') HIE, as well as the HIE 'entities' that 'focus' on particular healthcare settings. Without any of these attributes, the concept of HIE seems to be incomplete.

HIE remains an evolving concept which, due to its complexity, presents challenges for developing fixed, agreed definitions. In the spirit of promoting further scholarly discussion and debate, I have proposed a definition that encompasses the key underpinning constructs. I recommend that future authors consider the findings of this review before developing new definitions of HIE, in order to avoid adding further heterogeneity. I also hope the review has value for policymakers involved in planning, procurement and evaluation of HIE.

Based on the concepts of HIE revealed through this scoping review, I will conduct a systematic review in Phase 2 of my research, which is reported on in the next chapter (Chapter 5).

Chapter 5 Barriers and facilitators to health information exchange in low- and middle-income country settings: A systematic review

5.1 Introduction

Having understood the concept of HIE by analysing definitions in various contexts (see Chapter 4), I used the constructs of HIE to inform my plans to undertake a systematic review of the barriers and facilitators to HIE in LMICs.

Reliable health information presents the health status of patients and provides evidence to help clinicians and policymakers with their decisions and actions through feedback and exchange of health information (442, 443). Stakeholders need to exchange health information regularly through available HIS' and other technological interventions, such as EHR, mobile phones and Geographical Information Systems (GIS), to respond effectively to, amongst other things, the rapidly changing epidemiological environment.

The availability and quality of health data in LMICs is often insufficient to inform health policies and resource allocation (444). In this review, I sought to capture, appraise and synthesise the existing evidence around barriers and facilitators to HIE in LMICs in the hope that this would help inform national healthcare stakeholders as well as international donor agencies and thereby enable them to plan effective strategies to implement HIE in LMICs.

5.1.1 Past similar reviews / systematic reviews / studies: identifying gaps

Related similar systematic and academic reviews had been conducted, but these have major limitations.

A systematic review of barriers to data sharing in public health by van Panhuis et al. (445) discovered 20 potential and real barriers to data sharing in public health and placed them under six themes namely 'technical', 'motivational', 'economic', 'political', 'legal' and 'ethical'. The review had a weak search strategy using only Medline database to search the literature. The review did not mention any timeframe or language to conduct searches for selected studies. It did not mention whether the studies were selected form HICs and/or LMICs. However, findings included references from LIMCs. Moreover, it did not make use of any quality appraisal tool to appraise the selected studies. Finally, the review did not provide or discuss facilitators to data sharing in public health.

Williams and Boren (446) studied the benefits of electronic medical records (EMR) with respect to patients, physicians and other care providers and its contribution to the development of healthcare delivery in developing countries. It involved searches of only four academic databases (i.e. Medline, CINAHL, COMPENDEX, Academic Search Premier) and had a sub-optimal search strategy. Articles not published in the English language were excluded. Another important limitation was that no quality assessment tool was used to appraise the methodologies of the included studies. The first eligible study found was from the year 1995. The study found that most of the developing countries lack the experts, funds, infrastructure and sustainable energy necessary to implement the healthcare technology. In contrast, support from developed countries in designing and implementing the computer-based health records in developing regions and availability of open source software were found as facilitators.

Another systematic review by Ndabarora (447) focused primarily on problems with health data quality and health information management, and evidences of best practices and use at community and district level in LMIC to improve these. It involved searches of five academic databases (PubMed, Medline, LISTA, CINAHL, Cochrane) and a Google search engine to search for citations, conference proceedings and disease surveillance reports from 2000-2011. The quality of the included studies was assessed in term of study outcomes, but it was unclear which if any quality assessment tool was used. Only English language articles were included in the review.

A comparative study by Mutale (448) focused on improving health information systems (HIS) for decision making in five sub-Saharan African countries, namely Ghana, Mozambique, Rwanda, Tanzania and Zambia connected with each other through the Population Health Implementation and Training (PHIT) Partnerships to enhance district health systems. The study described, compared and contrasted the PHIT approaches from these five countries to strengthen HIS and encourage the use of data in decision making focusing on the implementation strategies from the African Health Initiative.

Generally, an academic review on health systems in LMIC (449) revealed that the strengthening of the health systems in LMIC is a long-term evolutionary process. There is no single blueprint for a perfect healthcare system (449) as healthcare systems are complex social systems (450). A stronger evidence base is required to strengthen the healthcare systems in LMIC that contributes to cross-country learning (449).

While some of the above reviews have considered issues relevant to electronic health information exchange none was specifically focused on barriers and facilitators to HIE. Keeping in view the research gaps, limitations and future directions mentioned in the previous reviews, a new systematic review is required on a broader scale that encompasses all the relevant domains of barriers and facilitators to HIE in LMIC. Therefore, this systematic review answered the research question ‘what are the barriers and facilitators to the implementation and adoption of HIE in LMIC settings?’

5.2 Methods

5.2.1 Study registration and protocol publication

This review was registered with PROSPERO, the International Prospective Register of Systematic Reviews (CRD42014009826) (451). I provide below an overview of the methods employed. Also, see the published protocol attached after appendices (452).

5.2.2 Eligibility criteria

The eligibility criteria were informed by the scoping review of definitions (see Chapter 4). For example, the scoping review helped me to know the types of health information (such as health, demographics and administrative) shared and exchanged. It also informed me what technologies (such as EHR, computer networks) I needed to include for eligible interventions. Finally, from the scoping review I came to know the types of healthcare stakeholders involved in HIE that allowed me to include eligible participants for the systematic review.

5.2.2.1 Eligible Participants and Care Settings

Eligible participants included were healthcare and medical professionals, patients, carers, facility managers and national authorities responsible for exchange of health information. All healthcare settings were considered, but only in LMICs, as defined by the World Bank which categorises countries on the basis of Gross National Income (453).

5.2.2.2 Eligible Interventions

A study was eligible for inclusion if it was related to health information that was transmitted, shared or needed to be exchanged electronically within and across organisations (e.g. hospitals and clinics), located within the same or different regions (e.g. within city or intercity transfer) or at a national level. Relevant health information included patients' clinical information and data, demographics, health records, claims and administrative data.

The eligible studies included components of HIE responsible for sharing and exchanging data, for example, EHR, HIS, hospital information systems, hospital information management systems, synonyms of HIE (clinical information exchange, healthcare information exchange, electronic document exchange, medical data exchange), health information infrastructure, and e-mail. It also included short message service (SMS), telephone and fax used for exchanging health information.

5.2.2.3 Outcome Measures

I sought to identify and understand the financial, cultural, organisational or technical barriers and facilitators to HIE in LMICs irrespective of whether these were operating at the individual, organisational, community, regional or national levels.

5.2.2.4 Eligible Studies

I considered published, unpublished or on-going qualitative, quantitative and mixed method studies designed with the purpose of examining barriers and/or facilitators to the development, adoption or use of electronic systems for exchanging patient or administrative data within or across parts of a healthcare delivery system.

5.2.3 Search methods

The searches were not restricted by language, data or publication status. Where relevant, papers were translated into English. I searched the literature from January 1990 to July 2014 for research investigating problems and challenges in exchanging health information. This start date was chosen because it was the time when policymakers and researchers first became interested in problems associated to HIS, a system that collects, saves, process and shares/transmits information related to health of individuals and organisational activities (a potential component of HIE), in LMICs (454-456). Experts were contacted for unpublished / in progress research by sharing the list of eligible studies. See Appendix 3 for details.

5.2.4 *Electronic searches*

I and Khalid Bin Muhammad (KBM) searched for published, unpublished and on-going studies in the following electronic databases. The scoping review (Chapter 4) included five major academic databases, but this review also involved regional academic databases along with the other major international databases for more robust searches.

- MEDLINE
- EMBASE
- ISI Web of Science: Science Citation Index Expanded (SCI-EXPANDED)
- CINHAL Plus
- PakMediNet
- IndMED
- Global Health
- Global Health Library (Regional Indexes and WHOLIS)
- African Index Medics
- KoreaMed
- Google Scholar

Relevant reports were searched through Google search engine (first 200 results). See Appendix 4 for search strategy

5.2.5 *Quality assessment tool*

The MMAT version 2011, a quality assessment tool (Appendix 5), (89), was used to appraise the quality of qualitative, quantitative and mixed methods studies. This instrument has previously been used in many other mixed methods systematic reviews (457-459) and has proven to be effective and practical to assess the quality of the mixed method review (460, 461) (see Chapter 3). I and KBM independently assessed the quality of included studies. Any disagreements with respect to the quality of studies were resolved through discussion or arbitration by a third reviewer, if necessary.

For each retained study, an overall quality score was calculated using MMAT. The overall score was represented using the following descriptors: *, **, ***, ****. For qualitative and quantitative studies, all four criteria needed to be met to get the highest score. The score can also be expressed as the number of criteria met divided by 4 to obtain a percentage score (scores varying from 25% (*) i.e. one criterion met to 100% (****) indicating that all criteria were met). For mixed method studies, the overall quality score is the lowest score of the study components – qualitative and quantitative, i.e. it cannot surpass the quality of its weakest component.

5.2.6 Data extraction

I and KBM independently abstracted the data onto customised data extraction sheets (see Appendices 6 and 7). The variables extracted were: author and year of publication; country of origin; language; healthcare setting; participants and sample size; technology used; intervention; methodology and design of study; data collection tool(s); barriers; and facilitators.

5.3 Data analysis

The results were first narratively synthesised (see Chapter 3) descriptively due to heterogeneity of study designs, systems, types of barriers and facilitators and study population and context. Important chracteristics of the selected studies were tabulated (see tables below in the section ‘Results’) in order to to get familiar with the findings of the included studies (125, 462). Barriers and facilitators were thematically analysed and placed under different emerging themes as represented in the included studies (91, 462) No study was excluded from the analysis on the basis of its quality, keeping in view the exploratory nature of this systematic review.

5.4 Results

5.4.1 Study selection and study characteristics

The searches yielded a total of 6091 citations. De-duplication resulted in 5461 citations. After screening the titles and abstracts, a total of 326 articles were scrutinised in detail. Of these, 56 articles, 3 conference abstracts and 4 reports met the inclusion criteria. The study selection process is summarised in the PRISMA flow diagram (Figure 5-1).

The included studies were from the year 1997 to 2014. The selected studies were in English, except for one in Chinese (463). The included research papers and abstracts were from 27 LMICs (Table 5-1). One research report was based on case studies of three countries: Brazil, India and Zambia (38). The report also briefly discussed HIS' of 19 LMICs from Asia, the Caribbean, Latin America and Sub-Saharan Africa (38). Another report discussed HIS and the critical factors responsible for the success and failure of HIT in the Pacific region (including countries such as Fiji, Papa New Guinea and Vanuatu) (464) (see Appendix 6).

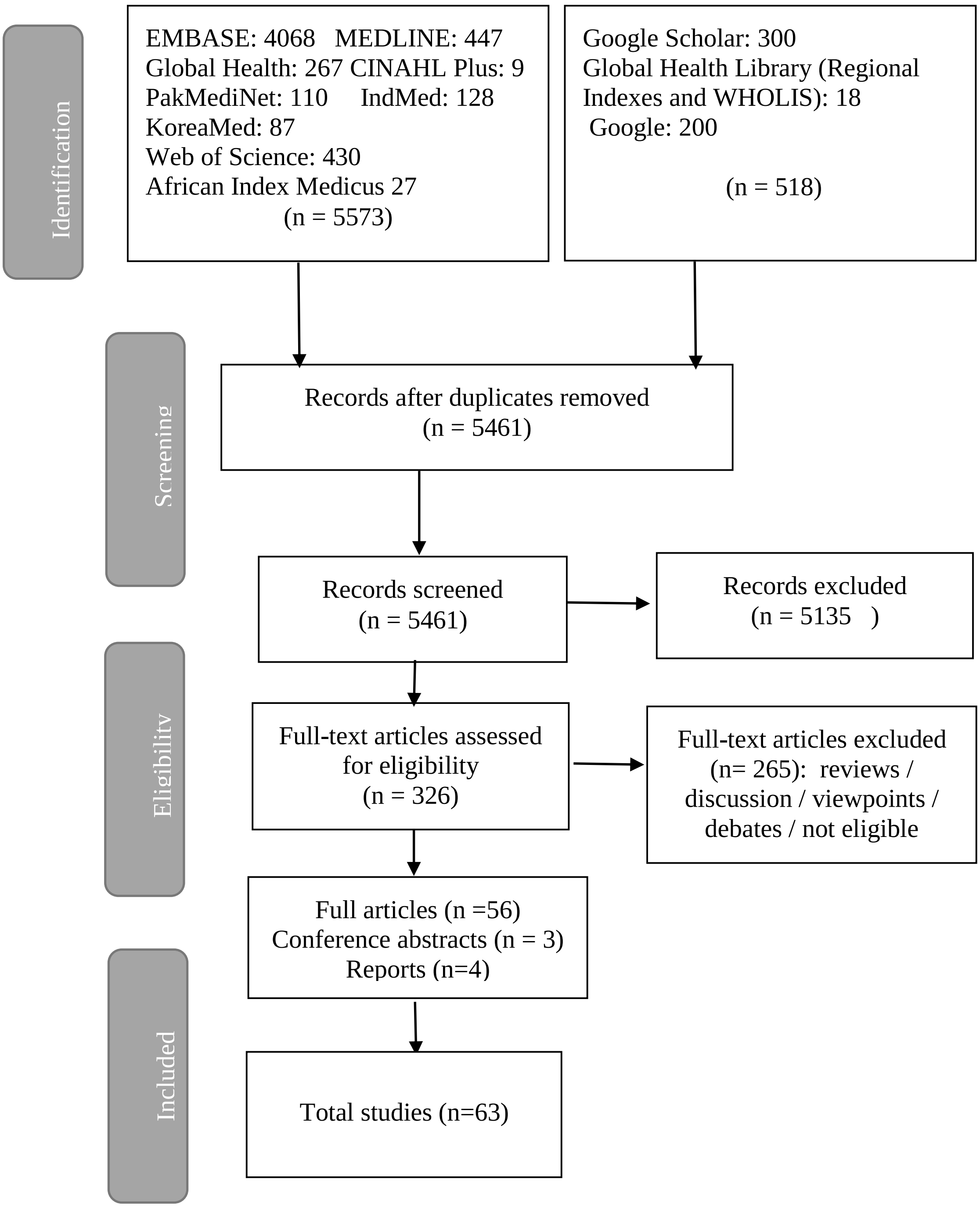


Figure 5-1 PRISMA diagram of barriers and facilitators to HIE in LMIC

Name of Countries	Number of studies from each country (total)
Botswana, Cameroon , Colombia, Malawi, Mexico, Nepal, Nigeria, Senegal, Somalia and Turkey	1 (10)
Brazil, China, Peru/Nicaragua, Sri Lanka and Thailand/ Cambodian	2 (10)
Ethiopia, Ghana, Iran and Rwanda	3 (12)
Tanzania and Uganda	4 (8)
India, Pakistan and South Africa	5 (15)
Kenya	6 (6)

Table 5-1 Number of studies from specific LMICs

The studies encompassed various healthcare settings where HIE was used to manage different types of patients and diseases (Table 5-2). The care of HIV/AIDS patients was however a particularly strong driving force to the development of HIE.

A wide spectrum of participants was found in the retained studies including patients with malaria, HIV, and trauma; midwives and clinical staff (doctors, nurses and laboratory personnel); medical students; health managers; secretaries and managers; administrators; medical directors; information officers, computer operators and other IT personnel; state, provincial, district and community-level officials; parliamentarians; government agencies; non-governmental agencies; system and tool users; and citizens.

Health Care Settings	Number of studies from each setting (total)
Emergency medicine, Hansen’s disease (leprosy), family planning, infectious disease, midwifery, Paediatric, pandemic influenza A H1N1, reproductive and child care, maternal mortality, reproductive tract infections, road traffic injuries, T.B.	1 (13)
Cancer, mother and child health	2 (4)
Hospitals, malaria	3 (6)
HIV/AIDS	9 (9)
No health settings given	31 (31)

Table 5-2 Number of studies according to healthcare settings.

The types of HIT covered in selected studies are represented in Table 5-3. Three studies which were based on the information needs of stakeholders did not mention any specific technology (5, 465, 466).

Type of IT	Number of studies
Geographical Information System	3
Hospital Information System, DHIS, DHIS2, National Health Information System (NHIS)	5
Surveillance systems	5
Electronic medical/health/patient records	4
Others: e.g. Telephone, web-based, internet and computers, database, District Health Profile (DHP) tool	8
Telehealth and Telemedicine	10
mHealth	9
HIS, HMIS, IS, Patient Safety Information System (PSIS)	16

Table 5-3 Types of IT in selected studies

A quantitative approach (mainly surveys and secondary sources) was employed in 17 published studies and two conference abstracts, whereas a qualitative approach was employed in 19 published studies and 1 conference abstract. Mixed methods were employed in 24 published studies (see Table 5-4).

Study Design	Number of studies and methods used to collect data	
Quantitative	19	Questionnaire or surveys, medical records, reports, databases, registers, pharmacy files and systems' data
Qualitative	20	Interviews, document analysis, programme auditing, focus groups, direct observation, group discussion, workshops, trainings, evaluating implementations and case study
Mixed Methods	24	Case studies, interviews, discussions, meetings, focus groups, registers, documentary review, call data, observations, summary reports, databases, text queries, usability testing and close-ended/ structured questionnaire surveys.

Table 5-4 Study designs and methods used in data collection

Most of the selected studies described interventions in the context of assessment or evaluation of current or newly implemented technologies and processes, for example to: assess infectious disease surveillance systems (467); evaluate the existing information system at the district level (468); and to assess the strengths and weaknesses of the data management and reporting system (469). Other interventions described were on the basis of implementation and introduction of a specific IT, for instance, implementation of EHR in a health organisation (470); use of telephone/mobile to connect mid-level healthcare workers with general practitioners (471); and adoption of telemedicine (472). See Table 5-5 for full details.

S. No.	Reference	Methodology	Objective
1.	(33)	Qualitative	To do a situational analysis of HMIS in Pakistan observing strengths and weakness. To review the present role of GIS in the health information system in Pakistan.
2.	(473)	Qualitative	To document the process of identifying areas within the EMR programme requiring and implementing interventions using multiple strategies to improve EMR data quality and use of the data to improve patient care.
3.	(474)	Qualitative	To describe the operation of a mobile-based community data collection system designed and implemented to provide quality fro the national HMIS software, DHIS2.
4.	(475)	Qualitative	To evaluate the DHIS in rural settings.
5.	(476)	Qualitative	Evaluating the design and implementation of an EHR in the public health system of Colima, its perceived benefit and limitations and recommendations for improving the implementation process.
6.	(465)	Qualitative	A need assessment to better understand health information needs and barriers across all levels of healthcare system.
7.	(34)	Qualitative	To investigate the barriers to the use of information and communication technology for improving healthcare delivery system.
8.	(35)	Qualitative	To determine the process of recording and reporting of health information.
9.	(477)	Qualitative	The study aimed to identify priority health information needs among managers and providers working in HIV/AIDS and family planning / reproductive health (FP/RH). To explore the opportunities and challenges for improving information flows. To design an intervention to improve access health information in Malawi.
10.	(470)	Qualitative	A case study at a healthcare organisation to test its applicability and assess the preparedness for eHealth system.
11.	(478)	Qualitative	The study discovers the challenges of introducing computer-based HIS in the Ethiopian public healthcare systems.
12.	(479)	Qualitative	To assess the implementation of the NHIS by knowing the experiences of stakeholders.
13.	(36)	Qualitative	The study provides an example of the development and application of a decision-support tool, DHP and its effect on data-informed decision making at the district level.
14.	(468)	Qualitative	To evaluate the existing district health management information systems (DHMIS) that have supported the operational management of health services at the district level.
15.	(37)	Qualitative	The study explores the perceptions of health managers of HMIS within their organisations in the context of decentralisation process in Pakistan.

S. No.	Reference	Methodology	Objective
16.	(480)	Qualitative	The study developed a framework of a PSIS.
17.	(466)	Qualitative	A study of health information needs, flow and use.
18.	(481)	Qualitative	The paper describes a mobile phone-based health information system, K-Shree Health Information Dashboard that is developed to facilitate the reporting of reproductive health issues among the women.
19.	(482)	Qualitative	To allow health care workers to use a tablet PC to access patients' health records through an application, Family Folder Collection (FFC).
20.	(483)	Qualitative	To explore and examine the role of mobile phones in emergency medical services in rural Uganda.
21.	(484)	Quantitative	To optimise the malaria data recording system in malaria endemic region.
22.	(463)	Quantitative	To evaluate the coverage of childhood immunisation information management system (CIIMS)
23.	(485)	Quantitative	To assess the infrastructure for telemedicine and barriers to healthcare providers in applying telemedicine.
24.	(486)	Quantitative	To estimate the benefits of telemedicine in healthcare system in rural India.
25.	(487)	Quantitative	To evaluate the acceptability and impact of a telephone consultation service, Uliza! clinicians' HIV hotline.
26.	(49)	Quantitative	The study examines the role of HMIS in disease reporting.
27.	(488)	Quantitative	To assess the effects of the Enlace Hispano Americano de Salud (EHAS; Hispanic American Health Link) system on the working environments of rural healthcare workers.
28.	(489)	Quantitative	To assess the completeness and accuracy of prevention of mother-to-child transmission (PMTCT) of HIV data elements collected and reported routinely through DHIS of all clinics and hospitals.
29.	(32)	Quantitative	To assesses the effectiveness of integrating the use of cell phones into a routine malaria prevention and control programme, and to improve the management of malaria cases in under-served population.
30.	(490)	Quantitative	The paper describes a national electronic cell-phone based and web-based monitoring and evaluation system, Treatment and Research AIDS Center (TRACnet), for both pre antiretroviral therapy (ART) HIV care and ART services.
31.	(491)	Quantitative	To investigate the availability of information support for public sector healthcare management by knowing the perceptions of health managers.
32.	(492)	Quantitative	To determine the ability of HIS to establish evidence based medicine (EBM).
33.	(48)	Quantitative	The paper describes a setting up an urban Road Traffic Injury (RTI) surveillance programme in the emergency departments of five major hospital in Karachi.

S. No.	Reference	Methodology	Objective
34.	(493)	Quantitative	The study evaluates the potential of GIS in the creation of a HIS for cancer. It also illustrates the shortage of data in developing country.
35.	(494)	Quantitative	To evaluate the performance of newly implemented surveillance system, Integrated Disease Surveillance Project (IDSP), in terms of completeness and timeliness of information reporting weekly.
36.	(495)	Quantitative	To evaluate the impact of an inexpensive business process re-engineering on the accessibility and completeness of patient information by implementing a hospital-wide patient registration and medical records.
37.	(496)	Quantitative	Introducing telemedicine and perceptions of local clinicians.
38.	(497)	Quantitative	To analyse malaria epidemic early detection system (MEEDS) data and to see trends related to outbreak detection in numerous MEEDS attributes.
39.	(498)	Quantitative	A pilot study at a public HIV clinic to support clinical decision making by providing mobile telephone system to community health workers.
40.	(499)	Mixed	To examine the readiness of University of Ghana hospital towards the implementation of the Electronic Patient Record (EPR).
41.	(500)	Mixed	To improve patient access to specialised healthcare through implementing and maintaining Telehealth.
42.	(501)	Mixed	1. To assess the acceptability and feasibility of mobile phone application (Mobilize) to record and submit adverse events forms weekly during multidrug-resistant tuberculosis therapy. 2. To evaluate mobile healthcare workers perceptions throughout the pilot study period.
43.	(502)	Mixed	To evaluate the impact of mHealth (mobile phone) on AIDS care in rural Uganda.
44.	(503)	Mixed	A formative study to guide the development and implementation of task-shifting mHealth HIV/ AIDS care interventions to be used by community health workers (CHW).
45.	(41)	Mixed	The aim of this paper to evaluate the national notifiable disease information system (SINAN), quality of data input, the exchange of data from the municipality to state levels, human resources and other aspects related with HIS infrastructure.
46.	(469)	Mixed	The study assesses strengths and weaknesses of the data management and reporting systems form the point of generation to the point of incorporation.
47.	(504)	Mixed	The empirical analysis of the consultation, information and training needs of health staff in rural areas that can be approved by accessible communication networks.
48.	(467)	Mixed	To assess the infectious disease surveillance system in relation data management tools and identify barriers and facilitators in its implementation.

S. No.	Reference	Methodology	Objective
49.	(471)	Mixed	A pilot study to increase referral and connectivity between district centre and peripheral health facilities.
50.	(472)	Mixed	A case study on the adoption of telemedicine in Rwanda.
51.	(505)	Mixed	1. To assess and compare the electronic eHMIS with the paper based HMIS for accuracy, availability and timeliness of routine health reports 2. To assess the staff satisfaction with the new eHMIS.
52.	(506)	Mixed	The study inspects how HITs are used to facilitate communication and information sharing among stakeholders in terminal cancer cases for the purpose of managing patients.
53.	(507)	Mixed	An exercise was created out to determine the barriers to the flow data in voluntary counselling and testing (VCT) centres.
54.	(39)	Mixed	To assess the Integrated Disease Surveillance and Response (IDSR) in selected districts.
55.	(508)	Mixed	The paper investigates the information and communication system of Iranian health organizations for emergency management in response to disasters.
56.	(509)	Mixed	The paper provides an overview of an Ethiopian telemedicine case study, highlighting its challenge, success and failures.
57.	(510)	Mixed	To assess the practice of Diseases Early Warning System (DEWS) in Azad Kashmir and suggest ways to improve it.
58.	(511)	Mixed	A case study on web-based asynchronous teleconsulting service in Spanish, Doctor Chat, for consumers.
59.	(512)	Mixed	A usability study presents midwives working in rural Ghana with a mHealth application, mClinic.
60.	(38)	Mixed	To review health care systems facing threats and challenges in developing countries, To survey efforts for creating successful HIS at national levels, and To examine three in-depth case studies to review the significant challenges and opportunities in building up effective HIS.
61.	(25)	Mixed	To assess country HIS' of LMICs.
62.	(40)	Mixed	To examine the role of mobile technology and HIT to improve access to quality health information, To examine health information flows from patients to healthcare organisations and to identify information gaps technology can address, and To identify barriers and recommendation for using HITs to provide efficient information flows.
63.	(464)	Mixed	To categorise and discuss HIS in developing countries, To summarise the potential benefits and opportunities presented by the use of HIT, and To discuss barriers and facilitators of HIT.

Table 5-5 Objectives of selected studies

5.4.2 Quality appraisal

Overall, the included studies were judged to be of high quality. Out of 56 full research papers appraised, 34 had a quality score equal to or greater than 75%. The quality score of quantitative studies was the highest among all types of methods, followed by mixed methods studies and qualitative studies (see Table 5-6)

	Number of studies and methodological appraisal scores			
Study Design	25% (*)	50% (**)	75% (***)	100% (****)
Quantitative	-	-	2	15
Mixed Methods	3	5	7	5
Qualitative	6	8	5	-

Table 5-6 Study designs and methodological scores (excludes conference abstracts and reports)

5.5 Synthesis of results

The seven themes which arose were: ‘socio-political’, ‘financial’, ‘infrastructure’, ‘organisational’, ‘technical’, ‘individual’ and ‘data management’. Barriers and facilitators identified under each theme were presented in Table 5-7. In addition, barriers and facilitators were also grouped according to the types of HIT in Table 5-8.

General themes	Barriers	Facilitators
Socio-political	Not using available information (34-36, 475) Officers do not routinely review data (36, 38, 489) Low importance and priority given to work (49, 469) Oral passing of information (477) HIS is not used by those responsible for managing health services at local levels (38) Staff may not give importance to the quality of data collection (489) Female patients resist using camera during teleconsultation (496) Gender inequality in owning technology (phones) (483) Detrimental to human interactions e.g. snatching/ stealing of equipment (gadgets, phone, etc.) (464, 474, 503) Difficult to coordinate between federal, provincial, city and many hospitals (25, 48, 498, 508) Corruption (37, 49) Lack of political will (25, 476) Unpredictable and uncertain environment of public healthcare system (new policies, strategies and regulations) (478)	Creation of culture of using information (39) Need to perceive data as intrinsically valuable in the management of patients and performance (489) Evidence-based decision making culture and practice is required (491) Political commitment (25, 37, 466, 476) Reform efforts, polices to share information (40, 491, 497) Innovative partnerships required (48) Establish role model (37) Active participation of stakeholders (509) National practices, experiences and guidelines (509) Heath information strategies (25, 478) Enabling policy environment (509)
Financial	Financial constraints (25, 34, 37-39, 48, 463, 464, 472, 476, 478, 485, 486, 499, 504) Management cost (37, 463, 464, 505) Maintenance cost (37, 464, 476, 502, 504) High air time cost (466, 477) Use of expensive systems (504)	Funds /investment (48, 463, 469, 476) Hotline/ toll numbers to reduce call costs (502) Establish alliance with other sectors to raise capital and investment (485) Use cost effective technology (38, 464, 474, 483, 487, 488, 495, 500, 501) Develop business models (509) Grants from international NGOs (25)

General themes	Barriers	Facilitators
Infrastructural	Electricity shortage (40, 464, 466, 471, 477, 495, 499, 504, 505) Lack of infrastructure (office space, equipment, supplies, computers, printers) (34, 38, 40, 41, 48, 49, 463, 466, 468, 478, 484, 505, 513) No/limited internet connectivity (38, 463, 464, 466, 470, 472, 499) Poor telecommunication network coverage (464, 474, 477, 487, 504, 505) Fragmented healthcare delivery (36, 485, 498) Lack of healthcare systems (40, 48, 480, 508) Limited phone access (464, 502, 503) Lack of alternate power generating equipment (486) No maintenance of the system (486) Slow and unreliable dial up connections (477) No national system or central repository (477) Network load (471) Limited bandwidth (472, 486, 499)	Use of Very High Frequency (VHF) radio (477, 488, 504) Use of mobile phones to report, share or exchange data (466, 477, 490, 502, 506) Alternate source of electricity (464, 474, 499, 505) Internet connectivity and availability of phone lines (464)
Organisational	Lack of training (25, 33, 36, 37, 464, 466, 472, 474, 476, 486, 494, 503, 510) Lack of human resource (25, 34, 38, 40, 41, 49, 464, 466, 475, 477, 504, 505, 507) Lack of skills (34, 37, 38, 467, 474, 475, 478, 503) Overburdened staff (35, 38, 39, 467, 469, 471) Absence of effective coordination, management and supervision (34, 37, 41, 49, 467, 503) Lack of managerial commitment and strategy (472, 474, 505) Professional hierarchies create communication gaps (477) Lack of information on management issues (33) High turnover of staff in public sector due to low salaries (25)	Training (25, 33, 35, 37-39, 49, 467, 469, 474, 475, 485, 487, 492, 499, 501, 504, 505, 508-510) Motivate staff (incentives) (25, 37, 39, 468, 471, 505, 514) Hire more staff (25, 33, 38, 505) Involve key health personals for new policies (39, 485) Define organisational and career structures (37, 49) Specify and roles and responsibilities (37, 49) Climate-controlled and dust fee environments required for equipment (464)

General themes	Barriers	Facilitators
	Tropical climate of the Pacific region is damaging to the equipment (464)	
Technical	Fragmented systems (37, 468) System design flaws/ incapable systems (464, 468, 492) Faulty data recordings and compiling systems (484) Limited functionality of locally developed programs (463) Overuse of technical language (466, 477) Electronic submission errors (40, 501) Memory limitations (41) Lack of user-friendly interface (486) Rigidity of the system (476) Lack of IT personnel (472) No data tracking system to identify delays (507) Product development is difficult due to unclear needs (38) Lack of unique health identifiers (40) Downtime of mobile devices (474) Limited software have been developed in languages other than English (464)	Use of computerised systems (465, 468, 504, 506) Use simple technology (500, 501, 509) Automated and user friendly tools (473, 474, 505, 509) Availability of internet / internet based reporting (465, 466, 490) Use of email (466, 504) Use of open technologies (32, 504) Government to support ICT in healthcare (48, 472) Enhance ICT skills of medical practitioners (506) Fax (466) ICT must be locally relevant (use local language software) (464)
Individual	Unaware of technology/application/knowledge (48, 49, 467, 485, 487, 492) Privacy concerns of individuals of their health information (468, 486, 502, 503) Resistance to new work process (474, 476, 495, 500) Slow response time of users (487, 495) English language / software (not easily understood by officers and staff) (37, 465) Users' dissatisfaction with the technology (470, 491) Lack of motivation (33) Job insecurity due to new technology (503) Improper use of technology (phone selling, personal use) (503)	Perceived usefulness to use and exchange health information (36, 501, 505, 511, 512) Improve attitude towards HIE (36, 471, 495, 496) Need assessment of users (37, 465, 500, 501) Educate users (37, 49, 470, 503) Improve human-computer interactional design (470, 474, 497, 512) Tailor the information according to the need of users (465) English language should be simple at higher levels (465) Local language should be simple at lower levels (465) Awareness of technology (40)

General themes	Barriers	Facilitators
	Information requirements of the users neglected (468)	
Data Management	Lack of timely reporting and feedback (32-34, 36, 37, 39, 41, 465-467, 475, 490, 504, 507) Too much /irrelevant information/redundant (25, 35, 36, 38, 465, 466, 477, 490, 504, 507) Data duplication due to vertical programs (25, 38, 475) Data quality issues (25, 32-38, 40) Lack of analysis tools (25, 34, 467, 468, 470, 477, 510) Inadequate usage of information (33, 48, 475) Incomplete patient information (32, 470, 493) Lack of standards (25, 39, 40) Limited access to information (465) No data from the private sector (38, 484) Inadequate data collection tools (467)	Regular feedback (37, 38, 41, 480, 507) Supportive supervision (41, 467, 489) Integration of vertical systems (37) Reviews to monitor the systems (41, 467, 494, 505) Automatic synthesis of data (480, 505) Standardised data sets and forms for reporting (25, 38, 475, 480, 510) Create protocols and standards (25, 40, 508) Develop a single source of information to guide data management (469) Technical working group can facilitate communication (477) Decentralise usage of information (41) Data streamlining and validation efforts (38)

Table 5-7 Barriers and facilitators to HIE in LMIC settings under given themes

5.5.1 Socio-political

This theme comprised of cultural, environmental and political factors.

5.5.1.1 Cultural

Research from India, Kenya, South Africa and Tanzania on managing and using different types of HIS', found that the healthcare stakeholders gave low importance and priority to data and therefore did not use available health information when making clinical decisions (34-36, 475, 489). A quantitative study in Sri Lanka (491) emphasised the need to promote evidenced-based decision making among health managers by enabling HIS to transform information into valid evidence. Healthcare stakeholders needed to perceive data as intrinsically valuable in the management of patients and their own performance by simplifying data collection and reporting process (489).

In a qualitative study on HIV and family planning conducted in Malawi, it was found that healthcare workers preferred face-to-face interactions, such as meetings, to seek immediate feedback on health issues, but due to the high cost required to regularly gather large number of healthcare workers, took up mobile phones for information sharing (477). In a study involving interviews and focus groups in rural Uganda on the usage of mobile phones in delivering emergency medical services for maternal and child health, it was found that gender inequality in the possession of phones was the biggest challenge in adopting mHealth (483). Another example of cultural influence was that discussions on sex-related topics with healthcare workers and professionals were considered taboo by the local population of Colombia, but a teleconsultation service facilitated the discussion and encouraged individuals to ask open questions from healthcare professionals (511).

5.5.1.2 Environmental

Insecurity to healthcare workers and professionals was a major drawback for HIE in a few LMICs (464, 474, 496, 503). For example, in war-torn Somalia, where doctors worked in one of the most insecure environments in the world, a teleconsultation service gave professionals a feeling of proximity and unity with senior associates (496). In a study to improve HIV care, researchers in Uganda conducted interviews and focus groups with a variety of healthcare stakeholders, and found that community healthcare workers felt insecure in field work carrying a smartphone for fear of theft of the phones (503).

5.5.1.3 Political

Lack of leadership and coordination to ensure collection and exchange of information between community and national levels make decision-making difficult, especially in times of disasters and emergency (48, 498, 508). Corruption and unpredictable change in policies and regulations were other important barriers here. For example, a questionnaire study from Pakistan revealed that some employees failed to comply with HMIS reporting as they knew that no action could be taken against them due to their associations with corrupt politicians (49). Similarly, in a qualitative study from Pakistan, health managers raised concerns about the corruption of HMIS staff and management citing the misuse of HMIS office resources, such as typing of unofficial letters, the appropriation of computers by senior management and data manipulation to hide the causes of epidemic diseases (37). A perceived lack of interest of the ruling elite of Mexico (476) and the unpredictable uncertain environment of the public healthcare system (new policies, strategies and regulations) in Ethiopia (478) were considered to have deterred development of HIS' and HIE.

Authors from Ethiopia, Mexico, Nigeria, Pakistan, Senegal and Sri Lanka, concluded that political and administrative will, which led to reformed and flexible policies, the establishment of innovative partnerships and role models, and the documenting of practices and guidelines may help to facilitate the implementation and adoption of HIE in their countries (25, 37, 40, 48, 466, 472, 474, 476, 478, 491, 509).

5.5.2 Financial

Financial constraint or lack of funds was identified as the main barrier to HIE implementation and adoption in LMICs under this theme (25, 34, 37-39, 48, 463, 464, 472, 476, 478, 485, 486, 499, 504). Maintenance costs (37, 464, 476, 502, 504), management costs (37, 463, 464, 505) and high air time costs (mobile minutes) (466, 477) were additional cost-related barriers of post implementation of HIE.

Researchers from Botswana, China, Mexico and Pakistan gave high importance to invest more in building electronic medical systems and training of personnel (25, 48, 463, 469, 476). Studies from Ethiopia and Ghana on implementing telemedicine emphasised the need to establish alliances with other sectors to raise capital and investment and to develop a business model for telemedicine (485, 509). Cost-effective technologies for HIE included the use of email and voice communication, for example, in telehealth/telemedicine and DHIS2 (464, 474, 488, 500), usage of hotline/toll numbers to reduce communication costs between healthcare workers and clinical staff (487, 502), and the use of freely available open source software, for example, OpenMRS and DHIS (38, 473, 474).

5.5.3 Infrastructure

Lack of infrastructure (e.g. office space, supplies, equipment, computers, printers, alternate power) (34, 38, 40, 41, 48, 49, 463, 466, 468, 478, 484, 486, 505) and shortage of electricity (40, 464, 466, 471, 477, 495, 499, 504, 505) were the two most prominent infrastructure barriers in LMICs. Communications challenges were due to limited internet services (463, 464, 466, 470, 472, 486, 499), poor telecommunication network (464, 471, 474, 477, 487, 504, 505) and limited access to phones (502, 503). In several studies, it was demonstrated that lack of working HIS' in facilities contributed to the fragmented healthcare delivery (40, 48, 480, 508).

Usage of mobile phones (464, 466, 477, 490, 502, 506) and Very High Frequency (VHF) radios (477, 488, 504) were found to facilitate rapid communication among healthcare workers and providers. Alternate sources of electricity (such as generators) were suggested to overcome power shortages to meet the requirements of electronic systems (464, 474, 499, 505).

5.5.4 Organisational

Lack of training (25, 33, 34, 36, 37, 466, 467, 472, 474-476, 478, 486, 494, 503, 510) was cited as the main barrier under this theme followed by lack of human resource (25, 34, 38, 40, 41, 49, 464, 466, 475, 477, 504, 505, 507). For these reasons, staff felt overburdened and unable to fulfil their tasks efficiently (35, 39, 467, 469, 471). Absence of effective coordination, management and supervision among organisational departments and professional hierarchies created communication gaps and management issues (33, 34, 37, 41, 49, 467, 472, 474, 477, 503, 505).

Training of staff and healthcare professionals was found to be the most essential facilitator (25, 33, 35, 37-39, 49, 467, 469, 470, 474, 475, 485, 487, 492, 499, 501, 503-506, 508-510) under this theme. The second most important facilitator was to motivate staff by offering incentives for using information in decision making. (25, 37, 39, 468, 471, 505, 514). Hiring more staff (33, 38, 505), involving key health personnel for new policies (39, 485), and defining new roles and careers structures for managing HMIS (37, 49) were suggested to facilitate health information management and sharing.

5.5.5 Technical

Incomplete, faulty, rigid, fragmented and limited functionality of electronic health systems (37, 40, 41, 463, 468, 469, 476, 484-486, 492, 499, 501) were the main technical barriers in LMICs. Additionally, overuse of technical language (466, 477) and HIS' not meeting the expectations of health managers (470, 491) may be due to neglecting users' requirements when designing systems (468), which in had negative consequences on HIE. Another key technical challenge was that individual patients were often not uniquely identified within the national HIS because data were usually statistical and lacked patient identification (40). Moreover, limited software have been developed in languages other than English which has been a barrier for low-populated countries, especially in the Pacific regions, where locals speak a number of different dialects (464).

The most notable technical facilitators found were usage of simple and user friendly technology e.g. use of pocket digital camera and desktop for telemedicine, fax, internet and email (465, 466, 473, 490, 500, 501, 504, 509), computerise the existing manual systems for data collection and sharing e.g. DHIS (465, 468, 474, 504, 506) and use of open source technologies e.g. OpenMRS (32, 473, 504). Finally, software must be developed in local languages to make the technology more meaningful to the users (464).

5.5.6 Individual

Unawareness of technology, applications or processes (48, 49, 467, 485, 487, 492) were the most frequent individual barrier to adopt HIE. Privacy concerns of individuals for their health information being revealed (468, 486, 502, 503) and resistance to new work processes (33, 474, 476, 495, 500) were found to other important challenges for HIE under this theme. Furthermore, inadequate English language skills (37, 465) deterred the HIE process because it was difficult to understand and process information in English.

It was seen to be important to assess the needs of users when adopting or improving technology or intervention (37, 465, 470, 474, 497, 500, 501, 512). In particular, perceived usefulness was found to be the important facilitator for individuals to adopt HIE (36, 501, 505, 511, 512). Willingness and cooperation of staff to support HIIE was another important facilitator (36, 471, 495).

5.5.7 Data management

Lack of timely reporting of health data and lack of feedback from supervisors were found to be important barriers to health data management in LMICs (32-34, 36, 37, 39, 41, 48, 465-467, 475, 490, 504, 507). The delivery of too much / irrelevant / incomplete / redundant information (25, 32, 35, 36, 38, 465, 466, 470, 475, 477, 490, 493, 504, 507) was another barrier which in turn may have exacerbated perceived data quality issues (25, 32-40). Other significant issues were the lack of data analysis tools (25, 34, 467, 468, 470, 477, 510), no data capture or exchange from the private sector (38, 484) and lack of data standards for reporting data and interoperability (25, 39, 40).

Availability of standardised data sets and forms for reporting (25, 38, 40, 475, 480, 508, 510), regular feedbacks (37, 38, 41, 480, 507), supportive supervision (41, 467, 469, 477, 489), and regularly evaluating and monitoring systems at health facilities (41, 467, 494, 505) were the most promising facilitators to HIE under this theme.

Technology	**Barriers**	**Facilitators**
Surveillance System	Lack of training (510)	Introduction to a recording system of a code for the area of residence of a patient (484) Uniform units for geographic measurement (484) Computer-based system could improve surveillance systems (504) Proper training (491, 510) Presence of public health specialist to develop action oriented surveillance system (494)
EPR / EMR / EHR	Users not given importance when designing EPR (499) Resistance by physicians to use the ICD-10 to code diagnoses that was not included in their medical education (476) Physicians perceived EHR to monitor medical stuff (Trust issues) (476) State level officers have paternalistic view of EHR and dubious about its quality (476)	Provision of EPR (499) OpenMRS Program (473) Investment in EMR system (469) EHR facilitates sharing and protects privacy (470) Introduction of EHR (505)
GIS		Introduction of GIS in to HMIS to integrate all vertical health programs (33) GIS has significant potential to add value to HIS for cancer in developing counties (493)
DHMIS / DHIS / DHIS2 / HIS	Fragmented DHMIS (468) Low key perceptions of DHS managers on information activities (468) Dissatisfaction of health managers on routine HIS (491) Incapability of HIS (492)	Identify the most productive actions and approaches for information users (467)
Telehealth / Telemedicine	Unfamiliarity with the telemedicine application (485) Limited number of trained doctors in telemedicine (472) Unavailability of ‘tele-ready’ medical equipment (472) Still immature technology (509) Negate the use of camera (496)	Telehealth requires a collaborative network of educational and research institutions, government, technology providers and funders (500) Training in Telemedicine (472, 485, 509) Involve key health personals for new policies in telemedicine (485) Provision of video conferencing facilities (472)

Technology	Barriers	Facilitators
		Integrate telemedicine and eHealth (509) Telemedicine needs a business model (509) Teleconsultation service encouraged open questioning and facilitated discussion (511)
Information management systems / Voluntary Counselling and Testing (VCT) database / Road Traffic Injury (RTI) system / Emergency Management (EM)	Poor understanding of the RTI systems (48) Lack of EM systems (508)	Promote extensive implementation of information systems (463) Motivate DHS mangers financially and morally (468) Link VCT database to other monitoring national and evaluation systems (507) Government support of RTI (48)
mHealth / web-based / eHealth	Screen freezes, electronic submission errors (Mobilize application) (501) Limited phone access to patients (502) Phone maintenance (battery charging) (502) Phone security (theft, traveling at night) (503) Improper use of technology (phone selling, personal use) (503) Job insecurity due to new technology (mobile use) (503) Poor cellular network (487) Gender inequality in the ownership of phones is the biggest risk to mHealth (483)	Low-cost, perceived usefulness (Mobilize application) (501) Mobile phone (rapid communication between health workers and clinical staff) (483, 502, 506) Easy accessibility to service (487) Easier to collect data (32) eHealth policy (509) Encourage use of mobile phones (494) Easy to use hand held mHealth tool (498)

Table 5-8 Barriers and facilitators according to the type of IT

5.6 Discussion

From the scoping review (see Chapter 4), I found two over-riding concepts of HIE – a process that mobilises healthcare information electronically within or across organisations, and a multi stakeholders organisation that manages the business and legal issues involved in the exchange of information. In this systematic review, many technologies and intervention were found to achieve the purpose of HIE processes in various healthcare settings in LMICs but I hardly found any HIE organisation facilitating the HIE process in LMICs. Moreover, the healthcare stakeholders involved in HIE processes in LMICs (see Appendix 6) resonates well with the ones found in the scoping review on HIE definitions.

Below I discuss the findings of this systematic review.

5.6.1 Statement of principal findings

Socio-political factors such as a stable and honest political system, promotion of an evidence-based decision making culture and a secure environment are very important factors to facilitate the implementation and adoption of HIE in LMICs. Although finance, too, is an important factor to develop infrastructure, buy technology and to provide training and human resource, it can only be used efficiently and effectively when there is a strong political will and the system is free of corruption. In particular, mHealth, telehealth/telemedicine and other open source technologies have been facilitating HIE in LMICs because of their cost-effectiveness, user-friendliness and easy availability, replacing faulty, rigid and power-dependent systems. Other issues comprised unawareness of technology, resistance to new processes, lack of timely reporting and feedback, and poor data quality. In order to address these issues, it is essential to assess users' needs when implementing HIE, provide timely feedback and data standards to improve data quality and interoperability. Figure 5-2 represents the primary and secondary drivers to implement and adopt HIE in LMICs.

Despite these challenges, some LMICs have managed to implement HIE interventions such as the introduction of disease and treatment of malaria module using mHealth in Thai-Cambodian region (32), use of mHealth application for treating TB in South Africa (501), a telephone consultation service for HIV care in Kenya (487), implementation of road traffic injury surveillance in Pakistan (48) and use of telehealth in connecting clinics with hospitals in Brazil (500). The concern here is that all these interventions were pilot-based that have never been scaled up because they often require a high amount of financial resources, therefore, LMICs should plan HIE interventions with a view to a large scale that can also be sustained in the long term.

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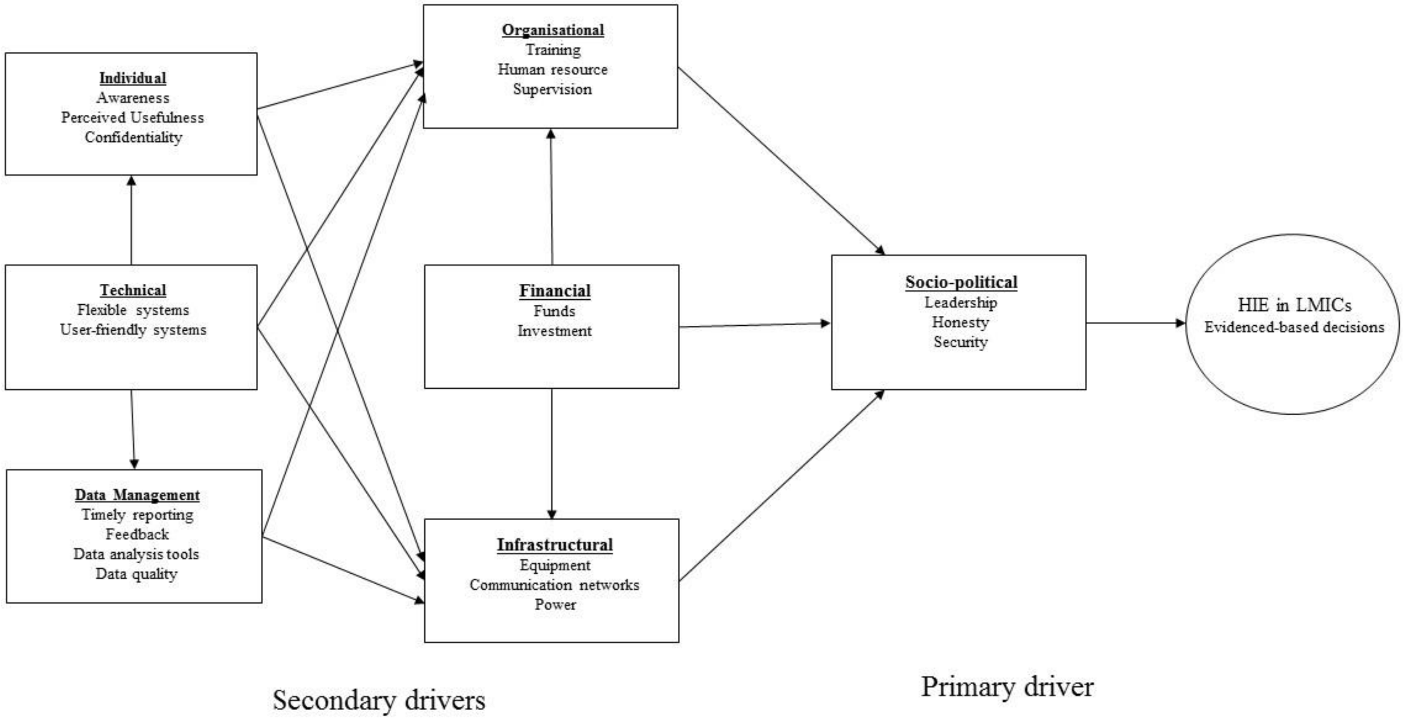

Figure 5-2 Relationship between the main themes in achieving HIE in LMIC settings

5.6.2 Strengths and limitations

This review made use of an exhaustive search strategy including 11 national and international databases for search queries; applied no language restrictions; included all types of IT and interventions; a wide spectrum of stakeholders ranging from healthcare professionals to health managers, bureaucrats and patients; and included all types of study designs. I applied methodological appraisal scores to assess the quality of individual studies.

Studies merely detailing software and/or system development (515-517), were discarded. The MMAT is an efficient quality appraisal tool, however, its reliability requires further improvements particularly for the two items in the qualitative section including the sentences 'appropriate consideration' (See Appendix 5, Sections 1.3 and 1.4) (items 1.3 'Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?' and 1.4 'Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?') (460). Generally, few qualitative papers correspond to the detailed features of these items, whereas, in some qualitative research either these features do not exist or only provide very less details (460). Similarly in this review, the appraisal scores of qualitative studies were lower than quantitative and mixed methods studies because details corresponding to these two items were rarely present. I did not exclude any study on the basis of low quality scores as the purpose of the review was exploratory. I may have found other relevant literature by including other international academic databases and search engines but I restricted the searches due to time constraints. It is also possible that some key developments may not have been written up and some findings might be dated. Finally, I have found HIE processes in different contexts (such as HIV/AIDS, family planning, malaria) using different technologies (such as mHealth, telehealth, DHIS, GIS), it was difficult to make inferences from one context to another.

5.6.3 Interpreting the findings in the context of wider published literature

5.6.3.1 Socio-political system

The structure of a social system can impede or facilitate the diffusion of innovations, HIE (131). Unfortunately, political, environmental and cultural barriers pose major challenges despite the availability of adequate finance. Efforts to promote data exchange are most likely to prove successful when a perceived need is addressed and the social context is taken into account (518). For example, the difficulty of coordination between federal, provincial and district levels can throw up barriers to HIE at macro and lower levels of public health system. Similarly, lower and higher ranking officers in organisations may give low importance to use available health information (36, 475), possibly because there is no internal or external political pressure to make decisions based on available evidence. Also, the unstable public healthcare system with ongoing modification of policies (478) and insecure environment compromising lives of healthcare professionals created complexities for HIE. For example, targeted killings of polio vaccinators in Pakistan and Nigeria during polio vaccine campaigns that halted the immunisation process, crippled the collection of health information of children that led to polio virus spreading in these countries (519). Socio-political barriers to HIE can be addressed through strong political commitment and effective policies that may promote mandatory evidenced-based decision making and health planning (37, 39, 466, 476). Therefore, governments should deliberately guide diffusion of HIE through leadership and stewardship and provide funds to purchase or implement health technologies (520).

5.6.3.2 Role of investment

Technology diffusion in LMICs has been found to be positively correlated with national per capita spending (521). According to WHO, national and international goals such as MDGs and SDGs were and remain impossible to accomplish unless and until there is greater and effective investment in health systems and services. For example, availability of funds is necessary to train individuals in order to make them adopt certain skills; implement technology and provide equipment; capacity building of organisations, hire more human resource to facilitate overburdened staff; and to improve infrastructure. Financing, therefore, underpins the health system building blocks among service delivery, workforce, information, commodities and governance, of the WHO Health System Framework (522). However, while LMICs may lack financial resources, their health budgets have sometimes increased from national and international donors such as The Global Funds to fight HIV/AIDS, TB and Malaria to provide funding into vertical programmes; and USAID that provide funds and technical support for building infrastructure. The increase in international funding for health has however also accelerated the demand for more reliable health data and information that are required to track performance and ensure accountability (523). This is again only possible through strong administration and supervision. Donors that particularly contribute to strengthening health information systems include; the WHO, the JICA (such as the DHIS project for Pakistan), the USAID (such as the MEASURE evaluation project), the UK

Department for International Development and Global Alliance for Vaccines and Immunization. Increasingly, donors are mainly disbursing funds to countries that provide reliable and updated information on how the funds are utilised and outcomes achieved (524). This then begs the question as to why so many countries are ill-equipped to provide health information data in spite of available funds from national and international organisations. Again, the evidence suggests, it is because of weak political systems (38, 49).

5.6.3.3 Infrastructure and technology

Infrastructure and technical limitations in LMICs need not completely prevent the diffusion of HIE. One example of a successful leapfrog approach is the diffusion of mobile phones in LMICs leapfrogging some of the intermediate phases of development – in particular, wired phone systems – found in HICs (525). The opportunities for HIE and improvement in healthcare delivery offered through mobile phones has generated considerable enthusiasm for mHealth projects in LMICs. Likewise, alternate power resources such as generators and uninterruptible power supply may enable HIE implementation and adoption (466, 499) by providing necessary electricity required for electronic medical systems. It is also important to use simple and user friendly technology because simple to use innovations are more likely to be adopted by individuals and organisations (131).

5.6.3.4 Human aspects

It is essential to give importance to the needs of individuals when developing and implementing electronic health systems because perceived usefulness and advantages offered by the innovation are important facilitators to HIE. This resonates well with the Innovation Diffusion Theory (131) and TAM (129) (see Chapter 3). For instance, instead of perceiving the usefulness of EHRs such as enhanced availability and sharing of data (526), physicians in Mexico resisted adopting it because they perceived it to be monitoring their work and challenging their trustworthiness (476) . The perceived complexity of the innovation can be reduced by demonstration and practical experience whereas perceived risk can be minimised by trying to counter-balance the benefits and risks of HIE (76) in the management of patients and improving performance (489). Similarly, training of individuals (staff and healthcare professionals) may facilitate using data analysis skills and tools in order to manage, analyse and improve quality of data for decision making. Moreover, team-based training is more effective than individual training when learning complex technology or innovation provided with high-quality training material, essential for the successful and sustainable implementation of an innovation (76).

5.6.4 Implications for policy, practice and the next phase of my research

Identifying and classifying barriers to HIE has provided a landscape of data-exchange challenges in LMICs that must be addressed to ensure successful implementation comprehensively utilising the range of recognised facilitators. Governments need to take a leadership role and emphasise the need for accurate information on which to base decisions that in turn will be attractive to external funders. Governments must also provide the groundwork to address infrastructure, organisational, technical, individual, and data management barriers to HIE with the support of international organisations.

However, although the available resources to tackle barriers (e.g. infrastructure organisational, technical, data management) vary in each of the LMICs there is benefit in LMICs sharing their resources (experts, workforce, technology, interventions) and learning to develop HIE. Collaborative governance and technical partnerships, for example, Population Health Implementation and Training (PHIT) partnerships to enhance district health systems in five sub-Saharan African countries, namely Ghana, Mozambique, Rwanda, Tanzania and Zambia (527), may facilitate successful implementation and adoption of HIE.

Those LMICs that still haven’t taken the HIE initiative and are planning to do so, may learn from these examples and avoid unnecessary mistakes and failures. Similarly, international organisations that support LMICs financially, technically and providing infrastructure may make use of these classified facilitators to improve outcomes. A summarised conceptual map of barriers and facilitators is given in Figure 5-3.

This review provided a useful evidential underpinning to plan and conduct a case study for the third phase of my research (see Chapters 2 and 6). Through this review, I have learned about the technologies and interventions essential to run HIE processes in LMICs which has allowed me to understand different modalities of HIE such as patient data exchange through telehealth, statistical data transfer through DHIS and facilitating maternal data exchange through mHealth. These findings allowed me to focus my research to explore various potential modalities of HIE in Pakistan such as HMIS, DHIS and EHRs. In this review, I also found HIE processes running in different healthcare settings and contexts such as those involved in the management of malaria, T.B. and maternal/child health that further allowed me to recruit participants from various healthcare programmes running in Pakistan. Moreover, sampling of participants (stakeholders) found in the selected studies of the systematic review allowed me to develop a sampling matrix for my potential interviewees (see Chapter 3 for methodology and Chapter 6 for sampling matrix), which also resonated well with the one of the attributes (‘Stakeholders’) of the HIE definition proposed in Chapter 4. Finally, both the literature reviews have helped me in developing a topic guide for conducting interviews (see Chapter 6) focusing mainly on health information needs of the government, providers and citizens; barriers and facilitators; and perceived advantages and disadvantages of HIE (see Chapters 2, 4 and 6).

5.6.5 Similarities and differences between the barriers and facilitators to HIE in LMICs and HICs

In Chapter 1, I discussed barriers and facilitators to HIE in HICs. The main and perhaps the most important barrier to HIE in both LMICs and HICs was the finance. Although, HICs have the finance to implement HIE, they were still debating for the sustainability of HIE projects especially in the US and the European region. The stakeholders in HICs who have implemented and have been using HIE have concerns about how HIE will be supported after the government funding has been used. On the contrary, LMICs have less financial resources but get donors’ support which was underutilised by corrupt leadership. The mind-set of leadership in LMICs was the biggest barrier giving no importance to the potential benefits of HIE. Another similar barrier to HIE in both LMICs and HICs was the incomplete patient information which is mainly because of hospitals not exchanging health information with each other due to competition and concerns over losing patients and business. Furthermore, too much or irrelevant information, lack of data standards, unawareness and timeliness of information were similar issues for HIE in both LMICs and HICs.

In contrast to HICs, LMICs have poor infrastructure and weak organisational capacity to run HIE processes and establish HIE organisations. The major barriers under these themes were lack of equipment, poor communication networks and lack of technical human resource. On the other hand, HICs have organisational and workflow barriers to HIE that included too many separate logins and privileges to access shared data. Both HICs and LMICs have privacy concerns about sharing and exchanging of confidential data. Similarly, healthcare professionals and workers in both HICs and LMICs resisted using HIT for HIE.

Funding was required in forms of aid and/or health plans to establish HIE in HICs and LMICs. Further, both HICs and LMICs needed to train their human resource to adopt HIT skills essential for HIE. Other facilitators to HIE in both HICs and LMICs were to use data analysis tools to achieve good quality data for making instant and effective decisions.

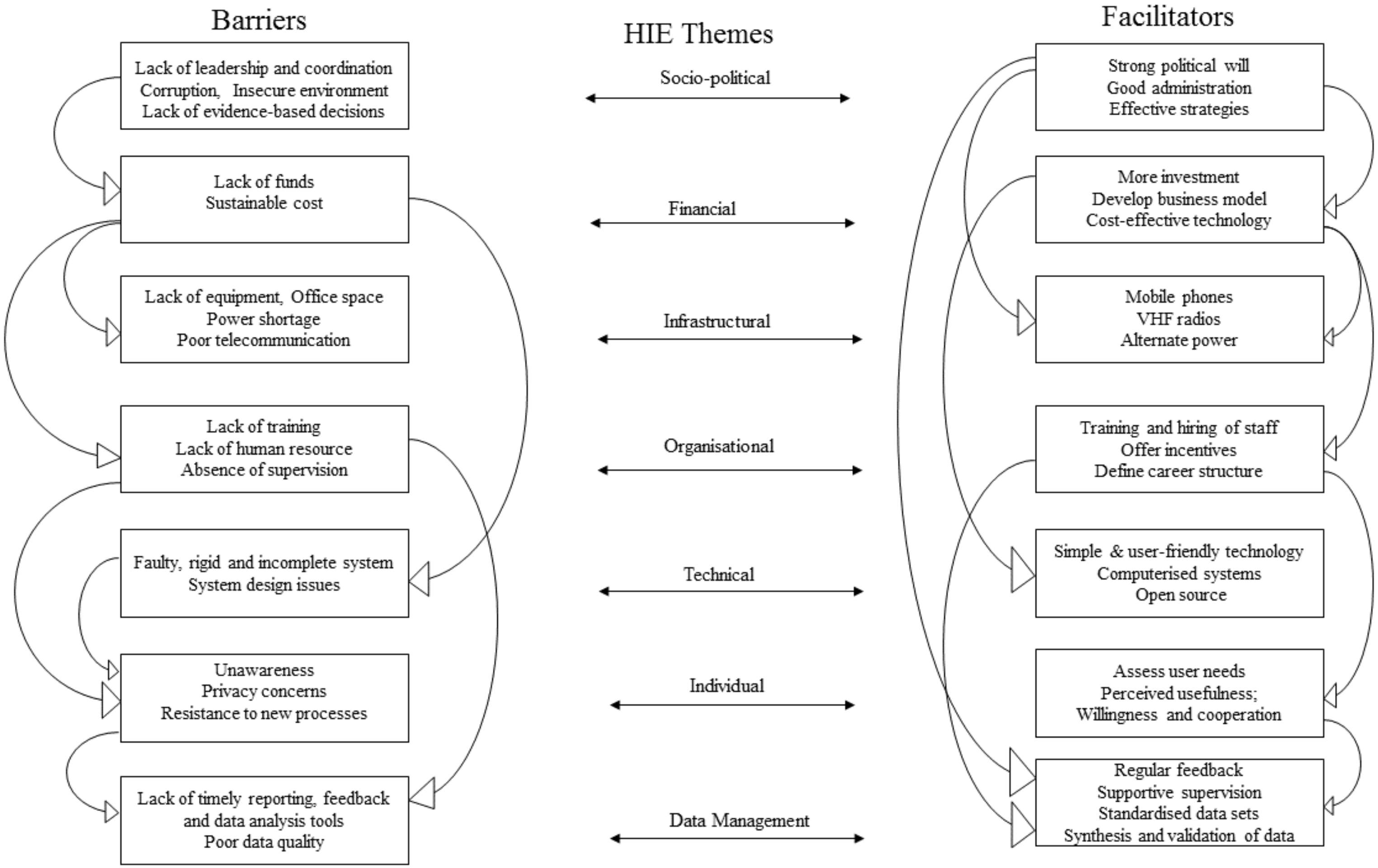

Figure 5-3 Conceptual map of barriers and facilitators to HIE in LMIC settings

5.7 Conclusions

While finance is essential to build infrastructure, organisational capacity and provide training and technology, implementations will fail unless government and administrators in LMICs promote an evidence-based decision-making culture through effective policies and demonstrate strong political will to push these forward to make effective and efficient use of investment from international and national channels. It is important that any implementation of HIE clearly meets national priorities for the countries and the needs of key stakeholders. I have identified several examples of successful HIE processes in LMICs, these being achieved through leapfrog technologies (such as mobile phones and GIS) that can help, at least partially, to overcome the problems resulting from poor infrastructures and weak organisational capacities.

In the following chapter, I will present a case study focusing on the deployment strategies of HIE in Pakistan which primarily involved interviewing a range of healthcare stakeholders and citizens from various regions and healthcare domains. This will allow me to know the needs of key stakeholders and the national priorities important to deploy HIE in Pakistan

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Chapter 6 Deployment of health information exchange: An in-depth case study of Pakistan

6.1 Introduction

Conducting the systematic review (see Chapter 5) helped me to identify many technologies, for example health surveillance systems (484), EHRs (470), HIS' (41), telehealth (500), GIS (493) and mHealth (503, 511) in several LMICs to enable reporting, sharing and exchanging of health information. Moreover, it allowed me to understand the various research methods applied in previous studies on HIE that assisted me to explore the most appropriate methods for my personal research of Pakistan.

This chapter will cover the third and last phase of my research, which explored in-depth the perspectives of healthcare stakeholders for the deployment of HIE in Pakistan (see Chapters 1 and 2).

6.1.1 Pakistan context

Pakistan's population is 191.7 million about 2.5% of the world's population. It is the sixth largest population in the world (528). It has four provinces, namely Baluchistan, Khyber Pakhtunkhwa (KPK), Punjab and Sindh; and four federal territories known as Federally Administered Tribal Areas (FATA), Azad Kashmir, Gilgit-Baltistan (formerly known as Northern Areas) and Islamabad Capital Territory (529) (see Figure 6-1 (530)). Karachi is the most populated city whereas Punjab is the most populated province of Pakistan. Though Baluchistan is the province that covers the largest area (44.0%), it has the least population (8.5 million; 4.6%). With a population growth rate of 2.0% in 2012-2013, it is expected that Pakistan will have the fifth largest population in the world by 2050 after China, India, Indonesia and Nigeria (528, 531). The Gross Domestic Product (GDP) growth rate is 4.2% for the fiscal year of 2014-15, compared with other countries in the South Asian region such as India, 7.5% and Bangladesh, 6.1% (528). Pakistan comes under the category of lower-middle-income country with the current (2014) Gross National Income per capita in US$ 1,410 (532). About a quarter of the population, 22.3%, lives below the poverty line (532) on less than US$ 1.25 per day (533).

Figure 6-1 Map of Pakistan showing provinces and federally administered areas
Source (530)

In 2015, the literacy rate was 58% compared to 60% in 2012-2013 (528). Pakistan ranks 147 among 187 countries in the world as assessed by the Human Development Index (534), which is a composite statistic developed by a Pakistani economist Mahbub ul Haq in 1990, and used by UN to measure key dimensions of human development – life expectancy, education and standard of living. Most of the population, about 62%, resides in rural areas (532). In the transparency international perceived corruption index, Pakistan ranks 117 out of 168 (535).

Pakistan was under military rule for 33 of 68 years after its independence. It has been in dispute with India over Kashmir since its independence and has fought four wars with India in 1948, 1965, 1971 and 1999. In the era of Cold War and after 9/11, the country's growth, development and social structure have been affected due its geostrategic position (536). Moreover, unprecedented increase in terrorism by the infiltration of militants groups such as Tehreek-Taliban and Al-Qaida (537) and terrorist funding and involvement of foreign agencies such as Research and Analysis Wing (RAW) from India (538) have challenged state capacity and have weakened the economy of Pakistan (537). These challenges have led to a constant increase in defence and national security budget which is approximately 3.5% of GDP in 2015, 19.0% of the country's total budget (539).

The next section gives a short overview of the culture of Pakistan. Culture influences actions, values and beliefs of people, therefore it is essential to understand the cultural context because it helps to interpret the behaviour of individuals.

6.1.2 A short introduction to the culture of Pakistan

Pakistan, ideologically, is an Islamic state and around 97% of the population in Pakistan are Muslims (540). Urdu is the national language and is spoken and understood in all parts of the country and is the national language of communication among all regions, but other languages such as Baluchi, Punjabi, Pushto and Sindhi are also spoken in different regions of Pakistan along with Urdu (540). English is mainly used in government setups, private and multinational organisations and academic establishments.

Pakistan’s culture is greatly influenced by British, Indian, Central Asian and Middle Eastern cultures. It varies widely among provinces, from Sindh and Punjab to Baluchistan and Khyber, but all cultural aspects are mainly based on the Islamic principles (541). Literature is an important aspect and most of the poets reflect Islamic code of life and deliver the message of love and brotherhood (such as Poet of the East, Dr. Allama Muhammad Iqbal) (542).

The national dress of Pakistan is Shalwar Kameez and the majority of the population in all the provinces wear it. There are some additional accessories that are worn with the national dress in different provinces/regions and for different purposes (such as Turban in Punjab and Baluchistan; Ajrak (a block printed shawl) and Sindhi cap in Sindh) that depicts regional affiliation. Also, additional clothing is worn for different purposes and occasions such as Sherwani (a long coat-like garment) are usually worn by high profile government male officials in national ceremonies (543) and by grooms on weddings (544).

Pakistan craftsmen are popular in foreign countries and are known for their high quality work they produce that includes carpet making, wood work, glazed pottery, leather products and hand embroidery (540).

Pakistan is a male dominant society where male members enjoy the key position in family. In most of the families, male members at key positions are the only source of income (540). It is a hierarchical society where people are given importance due to age and position (545). Pakistan women are usually homemakers and the largest percentage of women working are teachers and nurses.

6.1.3 Health system in Pakistan

Pakistan’s current expenditure (2014-15) on health is 0.4% of GDP (546) (health expenditure per capita (HEPC) US$ 37.8 in 2013) (547), whereas other countries spend more for example India, another LMIC, spends about 4.0% (548) (HEPC US$ 61.4) (547) and the UK, a HIC, around 8.8% (549) (HEPC US$ 3597.9)(547). Health is, under the constitution of Pakistan, the principal responsibility of the provincial government except in the federally administered areas (529). However, national government is responsible to formulate health policies and it is the responsibility of the provincial governments to implement these policies (529). The Ministry of Health was devolved to the provinces under the 18th amendment by the Federal Government on 30 June, 2011 (550) in order achieve the goal of an equitable health system by making effective and friendly policies keeping in view the needs of communities and the local population (551). The provincial governments are now responsible to make health policies, approve healthcare laws, control drugs, recruit the workforce, and plan and implement healthcare programs in their provinces (551). However, the central Ministry was re-installed as Ministry of National Health Services, Regulation and Coordination in April 2013 (552) and is involved in regulatory and monitoring functions, managing federally administrated hospitals, offices and procurement throughout the country, inviting donors to support healthcare processes, and gathering healthcare related data (551, 552).

Pakistan has a mixed health system comprised of public and private sectors (536) (see Tables 6-1 to Table 6-4). The government provides a three-tiered healthcare system and a range of public health interventions (553). The primary healthcare structure comprises of Basic Health Units (BHUs), Rural Health Centres (RHCs), lady healthcare workers and other first-level care facilities. Secondary care providing acute, ambulatory and inpatient care includes first and second referral facilities, namely Tehsil Headquarter Hospitals (THQs) and District Headquarters Hospitals (DHQs), which are backed by tertiary care from Teaching Hospitals. Maternal and Child Health Centres are also a part of BHUs and RHUs that provide basic obstetric care with local community outreach programmes through lady health workers to address the needs of deprived rural population and slum dwellers. District Health Systems under the District Government are now responsible for planning, development, implementation and management of healthcare from DHQs down to the local community programmes (553).

Hospitals		Hospital Beds		Total	Hospital beds per 10,000 population
Public	Private	Public	Private		
972	692	108 137	20 000	128 137	6

Table 6-1 Distribution of public/private hospitals/beds in Pakistan
(Data from WHO report (554))

Primary healthcare clinics and centres		Pharmacies		Diagnostic facilities	
Public	Private	Public	Private	Public	Private
5941	73 650 (92%)	15 000	40 000 (73%)	1600	2400 (60%)

Table 6-2 Public and private: primary health care clinics centres, pharmacies and diagnostic facilities of Pakistan
(Data from WHO report (554))

Workforce per 10 000 population			
Public sector		Private sector	
Physicians	Nurses	Physicians	Nurses
7.8	2.9	19	1.9

Table 6-3 Health workforce in Pakistan: public-private disaggregated data
(Data from WHO report (554))

Medical Schools		Schools of pharmacy	
Public	Private	Public	Private
32	39	-	-

Table 6-4 Medical universities in Pakistan
(Data from WHO report (554))

In contrast to the to the public health sector, the private health sector is composed of various groups of healthcare stakeholders such as doctors, nurses, pharmacists, traditional healers (such as hakims), homeopaths, shopkeepers, laboratory technicians, drug vendors and unqualified practitioners (553). Apart from private secondary and tertiary healthcare, the not-for-profit NGOs and philanthropic organisations such as Indus Hospital Karachi (555) and Imran Khan’s Shaukat Khanam Cancer Hospitals in Lahore and Peshawar are also considered as part of the private sector (553). Standalone private clinics are the major providers of outpatient care all across Pakistan (553). The majority of private sector hospitals and standalone clinics have sole proprietorship or partnership model (553). Seventy-eight percent of the population pay for their health services at the point of care (556). With very low governmental budgets, the private sector provides two-thirds of health services (556) using a fee for service system (see Figure 6-2).

Lack of private sector regulation, poor public spending and overall mismanaged governance have led to poor access and utilisation of services, equity and quality problems (556). Poor dietary habits, environmental hazards such as pollution, rapid urbanisation, food insecurity, lack of access to safe drinking water, corruption, and illiteracy are major factors that contribute to the ill health of this growing population (528).

The government developed the HMIS in 1992 with the technical and financial support of USAID (51) and later on supported by the World Bank, Asian Development Bank, United Nations International Children's Emergency Fund (UNICEF) and WHO (557). HMIS remained limited to first level care facilities (FLCF) – BHUs, RHUs, Maternal and Child and Health Centres – and out-patient departments of some secondary hospitals only (557). The HMIS – FLCF data were moved directly from peripheral health facilities to districts, provinces and to federal levels (553, 557). After introducing devolution of health from provincial governments to district governments in 2001 (558), the JICA on request of the Pakistan government conducted a study in 2004-2007 on improving routine HIS that replaced HMIS-FLCF into more efficient DHIS that collects data only from primary and secondary public healthcare facilities including BHUs, RHUs, THQs and DHQs, and then the data are processed and analysed in district health offices and provincial health departments (557, 559) to support evidenced-informed routine operation and budget planning at district levels throughout the country (560).

The DHIS also incorporates selected data from vertical programmes information systems and HIS sub systems namely financial, human resource, logistics, capita assets HIS' for performance and self-regulation at facility, district and provincial levels (557) (see Figure 6-3).

Unfortunately, Pakistan has no apex organisation for health information (556). Many barriers to HIE in Pakistan have been reported though a systematic review (see Chapter 5) that included corruption, lack of training and motivation among healthcare service personnel, political affiliation of employees, poor infrastructure, lack of funds, and poor coordination among federal and provincial public bodies (see Chapter 5 and Appendix 7 for more details). The earthquakes in 2005 and 2015, annual floods, outbreaks of dengue and influenza and reported cases of polio virus have drawn attention to the need for integrated disease surveillance systems (556). Information systems for infectious diseases are available in the country but are incomplete and donor dependent (561). Hospital e-solutions are limited to large standalone public hospitals and in high-end private facilities; they are not the part of the national DHIS (556). Effectively managing this complex health structure requires efficient information systems to fulfil information needs of several decision makers and stakeholders of the healthcare delivery systems (562).

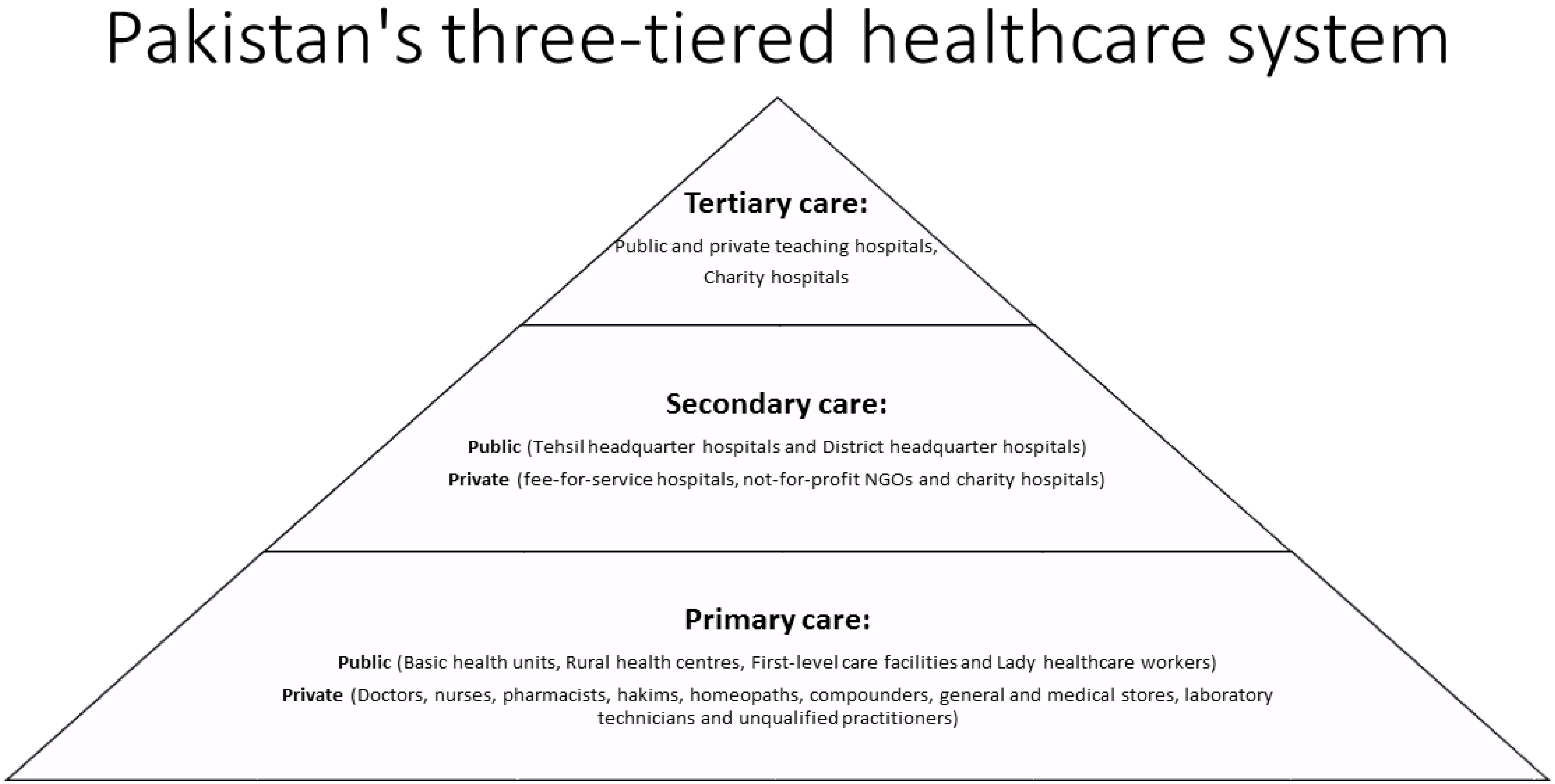

Figure 6-2 Three-tiered healthcare system of Pakistan

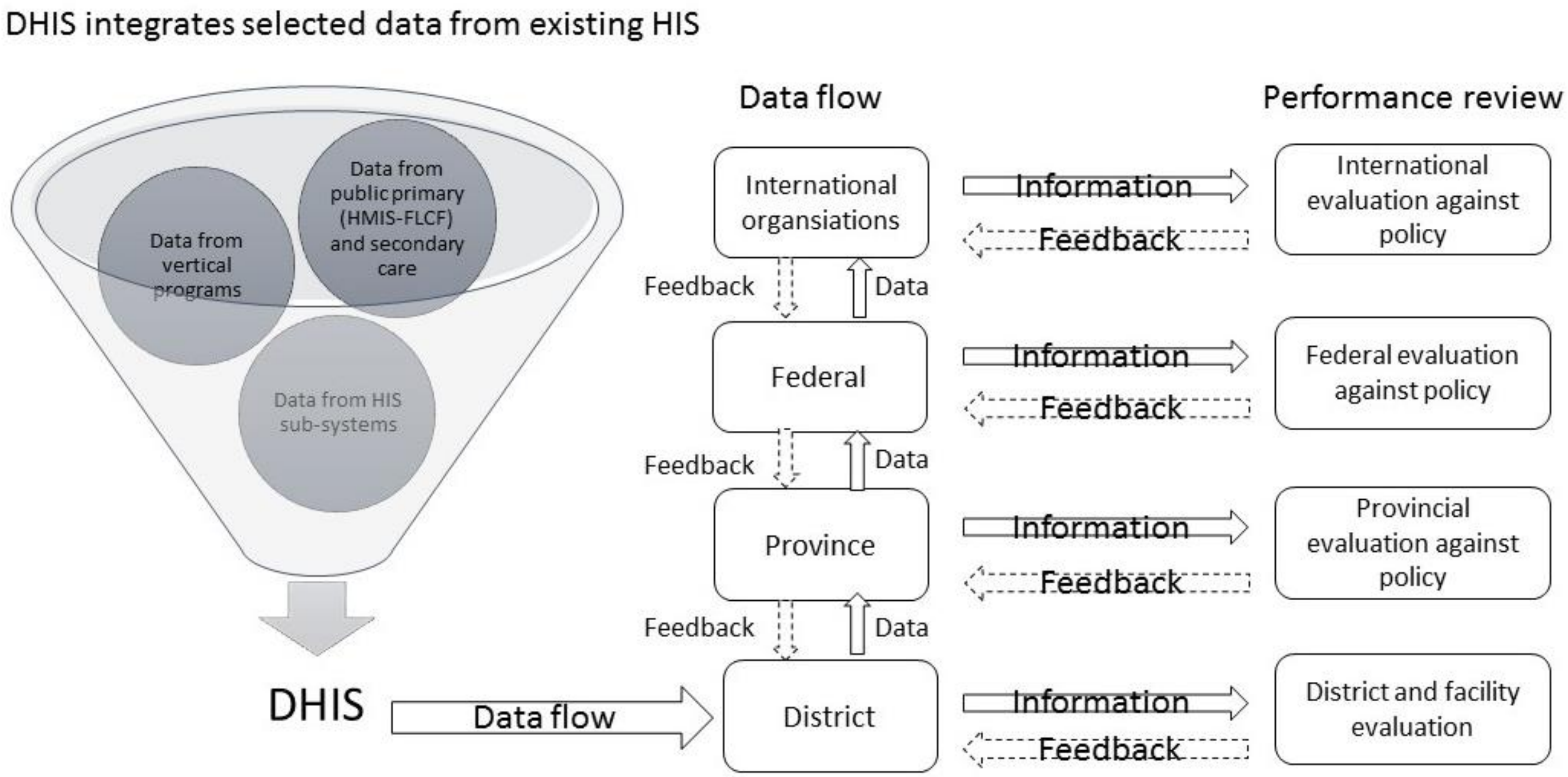

Figure 6-3 DHIS data flow and activity

6.2 Materials and methods

6.2.1 *Design*

In this case study, I used constructs from Greenhalgh's model 'Diffusion of Innovations in Health Service Organisations (128) (see Chapter 3). It involved interviewing key healthcare stakeholders from across Pakistan from a range of organisational, professional and disciplinary contexts to explore factors responsible for the deployment of HIE (see Chapter 3). I undertook semi-structured interviews with participants using a topic guide. Interviews were conducted face-to-face in my home city of Karachi and by Skype, fixed-line and mobile telephone from other regions of Pakistan. Relevant international and national documents were also analysed.

The case study approach was intrinsic (studying HIE phenomenon in the Pakistan context) but it was also instrumental as findings will identify potential transferrable lessons for other LMICs (94, 95) (see Chapter 3).

6.2.2 *Sampling and recruitment*

Participants were selected through purposive and snowball sampling techniques (see Chapter 3). I created a sampling matrix of healthcare stakeholders informed by the analysis of HIE definitions (see Chapter 4 and Appendix 1) and my systematic review (see Chapter 5 and Appendix 6). The construct 'Stakeholders' of the HIE definitions informed the types of stakeholders involved in HIE. Also, the wide spectrum of participants found in the studies included in the systematic review further informed the sampling matrix. The matrix included healthcare providers (public/private), policymakers, organisational/facility heads, managers and staff; and citizens (with no background of major disease or injury). In an attempt to ensure that there was an opportunity for deviant cases to be uncovered, this also involved sampling of deviant cases (115, 563, 564) (see Chapter 3). For example, the deviant cases included conflicting viewpoints of public and private professionals/providers and participants from rural and urban areas with a huge digital divide (according to the World Bank report, Pakistan ranks fourth in the list of least connected nations with India at the first position, followed by China and Indonesia) (565). Table 6-5 shows details of the sampling framework. No patients were consulted and no patient information was accessed.

Sampling Framework consists of the following domains:
Charity organisations (CO)
Citizens (CZ)
eHealth (eH) / HMIS / Telehealth (TH)
Facility directors (FD) / Facility administrators (FA) / Facility managers (FM)
Government officials (GO) /Private officials (PO)
Healthcare professional (HP)
International organisations (IO)
NGOs
Primary care (PC)
Rural areas (RA) / Urban areas (UA)
Secondary care (SC)
Tertiary care (TC)

Table 6-5 Sampling framework

The sampling framework was reviewed constantly throughout the data collection process and was adapted, where necessary, to ensure breadth and depth of coverage. I continued recruiting and interviewing until data saturation had been attained (see Chapter 3).

Participants were recruited based on the information available on organisational websites and LinkedIn, a social-networking website. It was convenient to recruit participants through LinkedIn because I had the opportunity to view limited profiles of individuals and that usually included contact details such as email addresses and mobile numbers helpful to make contact. Moreover, access to other linked connections with an individual’s profile helped recruiting more participants in diverse healthcare settings. Participants were selected from across Pakistan including the four provinces and federally administered areas (see Section 6.1.1 above). In order to seek their agreement to be interviewed and a suitable time, participants were contacted by email or through LinkedIn messages, and individuals who did not respond were contacted via telephone and/or mobile approximately one week later. Participants without email address and LinkedIn profiles (especially citizens and healthcare workers) were contacted through given mobile/telephone numbers. Citizens were recruited through personal contacts and snowball sampling. Non-responders were sent a maximum of three reminders. Figure 6-4 shows the interview flow diagram. It shows the number of participants contacted through various media, the number who declined and did not respond and the number who responded and subsequently interviewed.

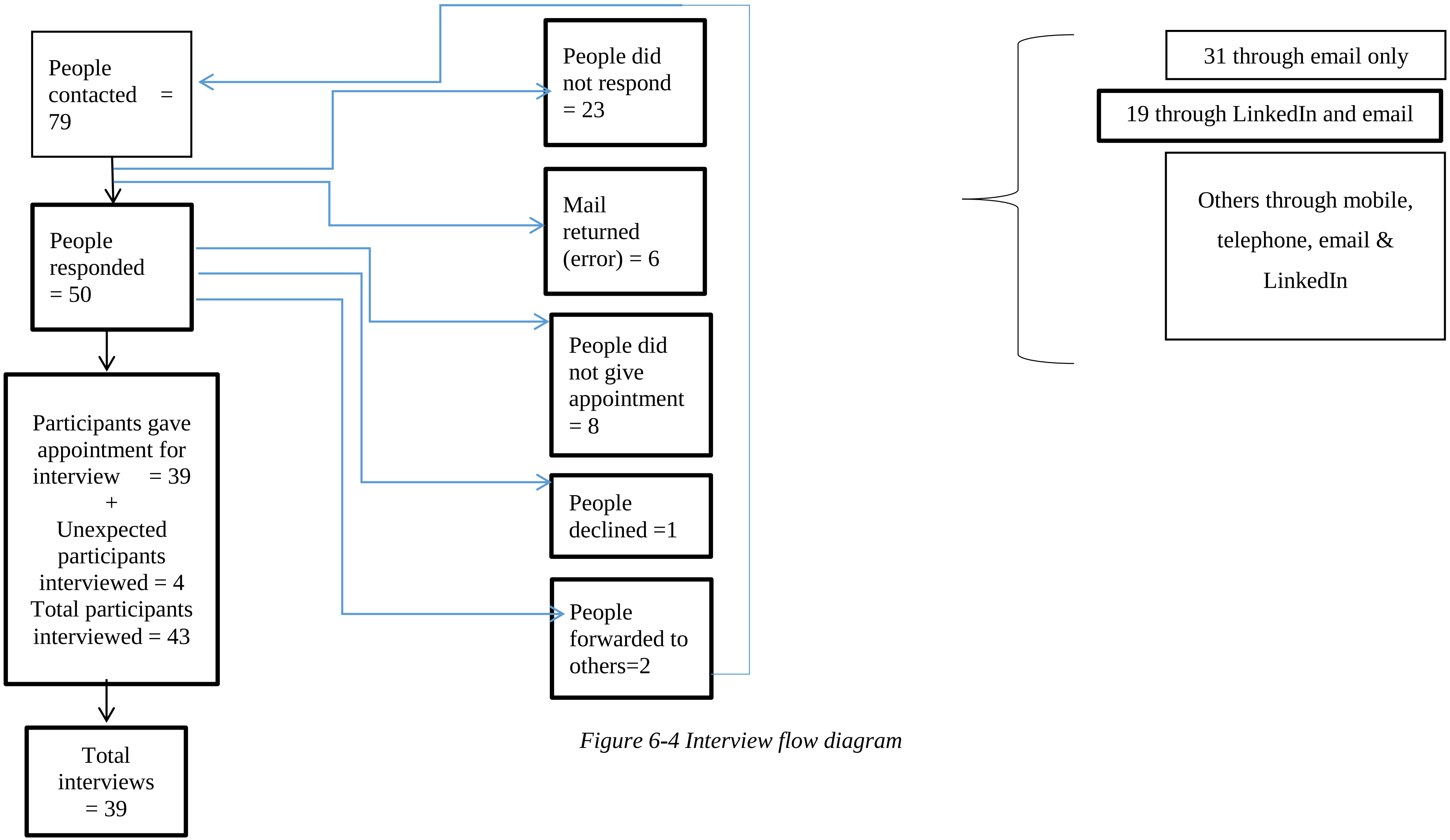

Figure 6-4 Interview flow diagram

6.2.3 Ethical considerations

I abided with the principles associated with the ethical conduct of my research that involved human participants (566). Making an application for ethical approval further prepared me to understand arising ethical issues that I subsequently confronted during research activities.

Ethics approval was obtained from the Ethics Committee of Centre for Population Health Sciences, The University of Edinburgh (Appendix 8). I informed Higher Education Commission (HEC) Pakistan before I went to conduct interviews but HEC did not require me to obtain additional ethics approval in Pakistan.

I needed to safeguard the information given in confidence irrespective of whether there was sensitive information or not. I realised that participants had potentially disclosed sensitive information (such as criticism of government by public officials) by putting a great deal of trust in me, therefore it was my ethical obligation not to harm them by misusing or losing their information (see the following section on confidentiality and anonymity).

An informal chat was started by me to break the ice and make them comfortable (such as "How are things today?"; "There are no wrong and right answers…your views are important for this study"). I also repeated the aims of my study and reiterated that interviews were recorded. I also took written notes during the interview in case there was any problem with the recording. I obtained written consent from all the interviewees interviewed in-person. Many of them did not sign the form in the first instance as they had no concern of confidentiality and anonymity. Even after signing the form, some of them wanted their names to be quoted in reports. A few participants, recruited from an international organisation, seemed to be hesitant giving the required information, as according to them, it was not allowed to give out the information of the organisational processes due to policies and security reasons in Pakistan. However, after reassuring them of data confidentiality and participants' anonymity they agreed to answer my questions. There were no instances during any interview where participants indicated that they did not wish to continue.

6.2.3.1 Consent

It was my responsibility to inform the participants of the nature of my study before they chose whether or not to participate. Selected participants were sent an information leaflet (Appendix 9) and a consent form (Appendix 10) in English that explained about the research topic and confidentiality of the data. I did not find it necessary to make and send these documents in Urdu because majority of the individuals I recruited were well educated such as directors, providers and bureaucrats (see section above on sampling and recruitment). For participants not well- versed in English such as majority of citizens and healthcare workers for example the vaccinator, I explained these documents to them in Urdu on mobile/telephone before undertaking the interviews. I could not send these documents to them beforehand as they did not have email addresses. Moreover, citizens (especially females) and healthcare workers were reluctant to share their mailing addresses probably for security reasons. I also read these documents in English to those participants who were good in English but I contacted them through mobile/telephone with no email or mailing addresses provided. The information leaflet explained the rationale of my study, outlined the participation criteria and strictly emphasised on handling the data and its confidentiality. Written or recorded verbal consent were sought from the participants before each interview. In group interview, consent was sought individually from every participant in the group. Interviews began with a greeting and thanking the participants for giving their time.

6.2.3.2 Confidentiality and anonymity

It was my ethical responsibility to keep the participants' data confidential and anonymised. In doing so, I removed identifying information from transcribed data as well as from notes and assigned alpha-numeric coded identity to each participant. I transcribed all the interviews myself and no recorded data were sent to any transcribing agency. Recorded and transcribed data were kept in a password-protected computer in a locked office at The University of Edinburgh and on my personal notebook.

6.2.4 Triangulation

A case study makes use of multiple methods and sources of evidence to establish construct validity and to strengthen researchers' belief in the validity of their findings (101). In order to avoid results of weak validity from any one source or method, this case study uses triangulation strategies (564, 567).

First, 'data source' triangulation is applied by selecting different types of healthcare stakeholders from different domains (98) (see Table 6-5). This allowed me to take views of variety of participants in different social situations (567). Each social group may have valid but different views of events which were captured by using interviews (101).

Second, utilising different methods of data collection resulted in ‘methodological’ and ‘data type’ triangulation (98, 99). Besides semi-structured interviews, rich field notes were written immediately after every interview that recorded behaviour of the participants and the events of the settings. The notes also included examination of official paper file health records, and forms to capture health data offered by two participants during the interview. Further, I got the chance to visit and see a few departments and how they operate (e.g. using satellite systems to locate ambulances for emergency patients; server room of provincial disaster management). In addition, a range of national documents and other material available online (e.g. health budgets, economic surveys and NGOs’ websites) were also scrutinised for relevant data (see Chapter 3 and subsequent sections).

6.2.5 Finding and analysing documents

6.2.5.1 Finding documents

I used Google search engine to search for relevant reports, news articles, and surveys. Examples of the key terms I used to search documents were: *Pakistan health system; HMIS/HIS/DHIS Pakistan; primary secondary tertiary care Pakistan; Pakistan economic/health surveys; WHO Pakistan data; World Bank Pakistan data; and USAID Pakistan.* Interviewees also provided with some important links to reading material available online. Finally, I also looked reference lists of articles and relevant hyperlinks given on the retrieved websites. (See Table 6-6 below for the list of documents used).

6.2.5.2 Documentary analysis

Documentary analysis comprises reading (examine thoroughly), skimming (examine superficially) and interpretation (112). This iterative process combines elements of TA (see Chapter 3) and involves a focused review and careful re-reading of data (112). The codes developed and used in interview transcripts may be used on the text of documents (112). I integrated codes and themes generated through document analysis with the codes and themes generated by interview analysis (see subsequent Section 6.2.9). I also used documents to build case study context (see sections above, 6.1.1 Pakistan context and 6.1.2 Health system in Pakistan)

Reference	Title	Type of document
(51)	The District Health Information System (DHIS) Project for Evidence-Based Decision Making and Management	Webpage
(546)	Pakistan Economic Survey 2014-15	Survey
(531)	World Population Prospects: The 2015 Revision, Key Findings and Advance Tables.	Report
(532)	Pakistan data	Webpage
(533)	National Literacy Programme	Webpage
(534)	Human Development Indicators	Webpage
(537)	Charting Pakistan's Internal Security Policy	Report
(549)	Expenditure on Healthcare in the UK, 2013	Report
(548)	Health expenditure, total (% of GDP)	Webpage
(550)	Health and the 18th Amendment: constructive tensions?	Report
(553)	Health System Profile - Pakistan	Report
(568)	Brief National DHIS Report-2013 Pakistan	Report
(561)	Public health surveillance system: a call for action Ministry of Health, World Bank, Centres for Disease Control, World Health Organization, Islamabad	Report
(562)	Pakistan desperately needs IT-based health management system	Newspaper article
(569)	Health and Social Work Private Sector Hospitals	Report
(570)	PM health programme: National health insurance to be launched by year-end	Newspaper article
(571)	National Health Insurance Schemes	Webpage
(557)	The study of improvement of management information systems in the health sector in in the Islamic Republic of Pakistan.	Report
(547)	Health expenditure per capita (current US$)	Webpage
(555)	The Indus hospital: delivering free health care in Pakistan	Case study
(572)	Electronic DEWS A National Electronic Disease Surveillance System	Report
(573)	Health Systems Governance Challenges and Opportunities after Devolution	Report
(574)	Post Devolution Challenges and Opportunities in Health Governance in Pakistan	Report
(575)	Electronic Recording and Reporting at Indus Hospital, Karachi, Pakistan	Report

Table 6-6 List of documents analysed to build case study context and for triangulation

6.2.6 Topic guide

A summary topic guide of the areas to be explored during the interview was sent to the participants who agreed to participate. The topic guide was based on my scoping review (see Chapter 4), systematic review (see Chapter 5) and theoretical underpinnings (see Chapter 3). For example, I included questions such as 'What are the benefits/advantages of HIE?' and 'How is health information is exchanged?' between various healthcare stakeholders, which were based on the HIE constructs found through the scoping review. Similarly, based on the findings from the systematic review, I included questions like ‘What are the barriers and facilitators to HIE?’ and ‘What role government (stakeholders) and technology can play in the promotion of HIE in Pakistan?’ The topic guide helped the participants to understand the types of questions that would be asked and to make any necessary preparations they may have required (see Box 6-1).

The main areas explored in interviews were:

- Collecting and saving of health information manually and electronically.
- The extent to which HIE achieved through electronic means
- Problems associated when processing manual data.
- Advantages and disadvantages of HIE
- Barriers and facilitators to HIE
- Path to HIE/interoperability and NHIS
- Room for improvement for health data management and HIE

Box 6-1 Areas covered in interviews

I did a pilot test of the topic guide by conducting mock interviews both in English and Urdu with students and staff available in the University. This enabled me to determine flaws within the interview design prior to conducting my field work (576). The pilot tests helped me to refine the wording of few questions that seemed unclear to the mock interviewees (576).

Initially the topic guide included eight questions (see Appendix 11.1). After the first few interviews, the guide was refined and two more questions were added after identifying other important aspects which needed to be explored further (See Appendix 11.2). The number of questions asked varied between participants as some were not relevant to certain professional groups. Apart from the topic guide, probing questions were asked to obtain more specific or in-depth information or when I did not fully understand the response or when answers were vague or ambiguous. Furthermore, at the start of the data collection I was inclined to ask more questions surrounding context, which reduced over time as I was getting more familiar with the respective contexts.

The topic guide allowed me to structure the conversation. Both negative and positive views were actively sought from all the key stakeholders. I preferred a non-directive style, that is, ‘to start the conversation from any point the respondent like to’, of asking questions that allowed the interviewee to set the parameters of the interview, and used active listening to bring out respondent's feelings and attitude in order to obtain private, honest and reflective accounts (577). Due to the long prevailing political instability in the country, most of the participants discussed issues openly and wanted these to be raised somewhere such as in a policy or a research paper. I prepared and kept rich field notes during and after every interview in order to make the research process as transparent and reflexive as possible (see Appendix 12). The last question in every interview was to encourage participants to add anything on the topic that might had been missed by me and was important.

6.2.7 Fieldwork

In research, fieldwork refers to primary research that is carried out in the field outside the controlled variables of a laboratory experiment (578). My fieldwork, data collection, started from the day after I landed in Pakistan (30 September 2014). I conducted interviews face-to-face and through Skype and/or mobile/telephone calls. All the interviews conducted in Karachi were face-to-face except for one female participant because she only had time in evenings and was more comfortable to give interview on telephone than face-to-face. Interviews from other regions of Pakistan were taken via Skype and/or mobile/telephone. Several female participants, around 11, replied to the research invitation recruited through both purposive and snowball sampling, but only nine agreed to an interview. It was also difficult to get female contacts from the recruited participants because female contacts are not usually passed to anyone without consent in Pakistani society.

I am a paraplegic and used a wheelchair to move around. I couldn't visit some participants' workplaces in Karachi as a few of the buildings, especially public buildings, were not wheelchair accessible. After getting the respondent's affirmation to conduct an interview, I usually asked the respondent about the accessibility of their workplace (unless they worked in a hospital). I allowed the participants to select a venue for the interview. On one occasion I had to be lifted on a wheelchair by security guards to cross the stairway to a participant's office. One of the interviews was conducted in a hotel, one in a restaurant and three at my home, after office hours.

Karachi is a politically disturbed city and there were certain areas in which people normally don't go because of risks of robbery, assault and abduction etc. I had a group interview in that area to include a charity healthcare organisation well-equipped with electronic health systems and facilitating a slum of population living in Karachi. I conducted that interview in morning because usually these areas can be accessible before sunset. Upon discussing with my supervisors, I was advised not to conduct more interviews in these danger zones.

Skype and/or mobile/telephone interviews were occasionally problematic in that some participants didn't take my call on the given time which had to be rescheduled. Furthermore, calls during the interview occasionally got disconnected due to technical problems. Sometimes the call was re-connected immediately, but at times it took a few minutes. Because of this disengagement and delay, the participants sometimes appeared to lose some interest. Participants' voices were also sometimes unclear and I had to request themselves which also disturbed the pace of interviews. All the issues were individually recorded in my field notes (see Appendix 12).

6.2.8 Data generation

Interviews were planned for a maximum of 60 minutes and the majority of sessions were within this length (median 28.0 minutes; inter-quartile range (IQR) 22.0-40.5 minutes). The shorter interviews were mainly those that were conducted with citizens and busy healthcare professionals. Interviews were undertaken by me from 01 October 2014 to 06 March 2015. Interviewees were asked to give their preference of interviewing either in Urdu, the national language of Pakistan, or in English. 18 interviews were in Urdu, 11 were in English and 10 were in a mixture of both these languages.

6.2.9 Data handling and analysis

Interviews were digitally recorded and then transcribed. Transcribing and analysing interviews on an ongoing basis allowed me to inform successive interviews, going back and refining questions and looking for deviant or negative cases to ensure the robustness of the study (98, 579). Emerging ideas were discussed with my supervisors in fortnightly Skype meetings.

Transcripts were stripped of identifiers and checked. Field notes were also converted subsequently after every interview into Microsoft Word format. Transcripts, documents and field notes were uploaded into QSR Nvivo (v10) for analysis. The analysis was interpretative and informed by TA (see Chapter 3). I used a combination of deductive and inductive TA (579). Deductive analysis was informed by the literature on the Diffusion of Innovations in Health Service Organisations (see Chapter 3) (76) while a more inductive iterative approach allowed new themes to emerge from the data.

6.2.9.1 Analytical steps

The TA was informed by the approach of Clarke and Braun (121). TA offers an accessible form of analysis because it does not require the detailed theoretical and technological knowledge of approaches, such as discourse analysis and grounded theory (121).

Clarke and Braun provided an outline guide that involved six stages of analysis, which are applied to this research in the following sections below:

- Familiarising yourself with your data
- Generating initial codes
- Searching for themes
- Reviewing themes
- Defining and naming themes
- Producing the report

It is important to note here that the qualitative analysis guidelines are not rules and the stages outlined above can be applied flexibly to fit the research data and questions (115). Additionally, analysis is a recursive process rather than a linear process, the researcher needs to move back and forth throughout the stages as required and should give ample time to data analysis.

6.2.9.1.1 Stage 1: Familiarising myself with the data

I collected all the data myself in the forms of interviews and field notes. This allowed me to have some prior knowledge of the data, some initial trends and thoughts. All the interviews were transcribed by me that took nine months, from October 2014 to June 2015. I used the notation [xxx] as untranscribable when I found the speech difficult to understand. Initially, it seemed time-consuming and frustrating, but this was the best way I familiarised myself with the data. Throughout this stage of transcribing and active reading of the transcripts, meaning and patterns were created that helped me generating codes both inductively and deductively.

6.2.9.1.2 Stage 2: Generating initial codes

I started generating initial codes as soon as I transcribed the first interview. I coded the first 15 interviews in MS Word software and discussed emerging codes with my supervisors in fortnightly meetings. I made a list of codes as they arose to develop a coding framework.

Later, I recoded all the MS Word coded transcripts in to NVivo version 10 which also enabled me to refine the coding framework. The codes were both data-driven and theory-driven.

Overall, I coded for as many likely categories/themes as possible because no one knows what might be interesting later (121). I coded the data by keeping up the surrounding data to preserve the context. Individual extracts of data were also coded into more than one codes if they fit into different categories.

6.2.9.1.3 Stage 3: Searching for themes

Before searching for themes in the long list of the different codes, I sorted the codes into potential categories. Codes were collated and combined to form overarching categories. In turn, the categories were collated and combined to form overarching sub-themes and themes.

At this stage, I had a set of codes that did not seem to belong anywhere. Instead of discarding these, I kept them for further analysis as they might be useful later when reviewing themes in the next stage.

In this stage of analysis, I sensed the significance of individual themes emerging from the coded dataset (121).

6.2.9.1.4 Stage 4: Reviewing themes

In this stage, I refined the themes that emerged in the previous stage. It involved two levels of reviewing and refining themes – internal homogeneity and external heterogeneity (115).

To achieve internal homogeneity, I read all the collated categories for each theme and tried to find whether the themes appeared to form a coherent pattern of overarching categories. This also involved going back to Stage 2 and rearranging codes in collated categories to make the categories more coherent. In some cases, I also had to go back to Stage 1 to read the coded data extracts where I hardly found any difference between categories. This recursive examination helped me to rework my categories, either merging them together or creating new ones. In some instances, categories that did not fit into themes were set aside because there were not enough data to support them.

This exercise also enabled the formation of new themes. Further, I reviewed themes to decide whether they need to be merged with other evolved themes. Clarke and Braun called this stage a ‘thematic map’ where the researcher is satisfied that the themes adequately forms the outline of the coded data. From here, I moved on to achieve external heterogeneity.

I was assured that there was clear and recognisable distinctions between themes. Validity of individual themes is confirmed when the thematic map reflects data set as whole. As coding is an ongoing organic process (121), the dataset was re-read to code any additional data within themes that has been overlooked in previous coding steps. However, it is important not to get excessively excited with endless re-coding (121). I stopped coding my dataset when I found no other substantial information useful for my research.

6.2.9.1.5 Stage 5: Defining and naming themes

It is essential not to try to get a theme to do everything, or be too varied and complex (121). At this stage, it is necessary to recognise the essence of what each theme is about and to decide what data each theme captures. Here, I looked for sub-themes and amalgamated them to form large, complex, coherent and internally consistent themes which provided useful structure and exhibited hierarchy of meanings within the data.

It is useful to define a theme by the end of this stage because, if a researcher cannot define a theme in a couple of sentences, this is indicative that the theme requires further refinement. Moreover, names of themes should be brief and vivid that straightaway tells the reader what each theme is about.

6.2.9.1.6 Stage 6: Producing the report

The objective of the write-up of a TA is to write a story in a way that the reader is convinced of the merit and validity of the analysis (121). It should provide short, coherent, rational, and valid account of the story within and across themes (121).

I provided sufficient evidence of enough data extracts to show the pervasiveness of themes. The extracts were rich examples that captured the core point I wanted to demonstrate. The write-up was not only to provide and describe data, but to go beyond description of the data, so my analysis was based on how participants interpreted the circumstances and making claims in relation to the existing literature. I also integrated my findings with field notes in order to lay out the context to the case study and support the respondents’ data with facts and figures by using information from the documentary evidence (references to documents were given in Section 6.4 ‘Results’ below).

Throughout my work, from data collection processes until producing report and making interpretations, I tried to make my position as clear as possible which is why I will now move on to discuss reflexivity in the next section.

6.2.10 My role as a researcher

Reflexivity is to recognise the influence of the researcher on the phases of research process (580). This involves the ways the researcher and the research procedures have shaped the collected data including researcher's prior experience and prior assumptions (564). Moreover, it also recognises the effects of personal characteristics such as age, gender, profession (doctor, student, nurse etc.), social class on the choices made within the study and the 'distance' (stranger or acquaintance) between the researcher and the research participants (564, 580).

I was a 35 year old (when I did field work) male PhD student with a background in business and computer sciences. I was working in academia as a lecturer before I started my PhD. I openly referred to this background in interviews whenever participants mainly asked questions such as, whether I was a medical doctor or lived entirely in the UK or Pakistan. I felt that this information might have given the participants the notion that I knew the culture and political conditions of Pakistan and therefore it would be easier to discuss research with me in the native context. I think it helped in building and maintaining good rapport with the respondents. Furthermore, I think the brand, *'The University of Edinburgh'*, also helped me in accessing some top level participants as they were themselves Edinburgh's alumni or had visited Edinburgh for short courses. I felt that they were motivated to meet with someone from the same university in which they had studied because, before the interviews, they sometimes shared memories of their stay in Edinburgh, which also helped in developing a good rapport.

I had a gun-shot spinal injury 12 years ago that made me paraplegic. I used a wheelchair to visit participants whose buildings were accessible. Further, there were areas in the outskirts of Karachi that normally people did not go due to security problems (such as robbery and killings). I experienced fear when I went to take an interview in politically disturbed areas (see section on fieldwork above) but I felt relieved when my supervisors told not to take more interviews in these unsafe areas. Apart from face-to-face interviews, I conducted interviews through Skype and mobile/telephone with people living outside my hometown, Karachi. However, sometimes telephone interviews were not effective as face-to-face interviews due to technical problems and the inability to read body language but lack of face-to-face interaction and the promise of confidentiality possibly allowed participants to give private accounts (581).

I had no prior experience of interviewing and doing qualitative analysis except for the courses I took during my PhD (e.g. qualitative research in health and NVivo). This most likely affected both the conduct and analysis of the data. However, I was in constant touch with my supervisors via Skype discussing issues during the data collection process. Moreover, I had detailed discussions on data analysis with the members of my Centre in The University of Edinburgh who were experts in qualitative research. These discussions and the available literature on data analysis were very helpful in managing and analysing my data set and helped curbed the inconsistencies of data analysis faced by a novice qualitative researcher.

Many authors have discussed the significance of reflecting on researchers' emotions as data collection is not an emotion-free experience and emotions are important in the production of knowledge and need to be drawn into analysis and interpretation (582, 583). I was nervous in my first few interactions as this was my first experience to conduct interviews. I experienced anxiety when meetings with high profile participants, but that concern attenuated away as I continued. I was also uneasy to disclose about my disability and to confirm about the accessible venue when the participant agreed to participate. I was afraid that the participants might not have accessible buildings and may say no to the interview.

Further, interviews and excerpts in Urdu were translated and transcribed into English. Researchers are required to maintain translational quality, using a certain amount of flexibility and willingness to change the source language in interviews (584). I placed high importance on the meanings of study items rather than literal translation to minimise data contamination (584). I also used bilingual online dictionaries (585) and web tools (such as Google Translate) to clear my doubts on particular words, proverbs or idioms during translation.

6.2.11 Quality in my research

It has sometimes been argued and criticised that qualitative research lacks scientific rigour such as the validity and reliability found in quantitative research. The most common criticisms are, firstly, that qualitative research is a narrative sketch of personal impressions strongly subject to researcher bias, secondly, it lacks reproducibility – a different researcher may come to a different conclusion and, finally, it lacks generalisability (586). However, several ways to ensure quality in a qualitative research have been discussed in the literature, for example, by Lincoln and Guba (587) and Mays and Pope (564). The four criteria proposed by Lincoln and Guba are credibility (confidence in the value of results), transferability (results applicable in other contexts), dependability (results are consistent and can be repeated) and confirmability (to what extent the researcher has shaped the results or a degree of neutrality) (587). In the subsequent paragraphs, I gave account of the methods employed to ensure rigour and quality in my study.

To ensure credibility, I used different kinds of triangulation methods as discussed in detail in Section 6.2.4 above. I validated my findings by collecting data from different ‘data sources’ (healthcare stakeholders from different domains of the health system) and employing different ‘methods’ (interviews, field notes and documents) to approach the same issue from variety of respondents and to address weaknesses of each individual collection method. Moreover, I attained ‘referential adequacy’ (587) by analysing data at the early stage of my field work to develop preliminary findings. Data collected and analysed at later stages of my field work was later tested to validate my preliminary findings.

Purposive sampling enhances sample coverage and comparability that helps to signify the rigour of the qualitative study (586, 588). Purposive sampling used in this research selected respondents who either hold characteristics or were aware of settings relevant to the social phenomenon under investigation (586). It also addressed selection bias inherent in convenience sampling and deliberately looked for outliers such as including respondents both from the rural and urban population (586, 588). I focused on outliers as ‘deviant cases’ in which the elements of the theoretical proposition (such as HIE is required to enhance decision making process) were weak or did not resonate with the majority of respondents (586, 588, 589).

Transparency is also recognised as essential for guaranteeing quality in qualitative research (564, 586, 590). Since the methods employed in research inevitably affect the objects under investigation, qualitative researchers ensure the reliability of their analyses by providing clear, explicit and open account of the methods and procedures used for data collection and the ways interpretations and conclusions were reached. Lincoln and Guba refer to this context as ‘thick description’ which give a detailed account of field work describing how the research was conducted in a given context and how the researcher and the research process shaped the collected data (see section above on reflexivity) (587). Therefore, transparency and reflexivity go side-by-side, since reflexivity makes less sense in a superficial account (without transparency), but in return, reflexivity effectively supports transparency (591). I made every effort to address these issues in detail by being rational in selecting and employing methods of data collection and analysis, while critically reflecting on my own role as a researcher (as discussed in my field notes and in previous sections).

Finally, in order to optimise the validity and credibility of my research findings, I used the ‘member checking’ or ‘respondent validation’ procedure (587, 588). I shared summarised findings of my research with the participants (results emailed to individual participants) that allowed them to check results in accordance to what they have conveyed during the interviews (592). Participants were requested to critically reflect on the research findings in order to reduce any incorrect interpretation of data and to make findings more original and authentic (593). Around 25% of the respondents replied and thanked me for sharing research findings. From these, three participants also appreciated the results and found them interesting. This positive feedback increased the validity of my findings and thus improved quality of my research.

6.3 Transferability

Transferability in qualitative research is akin to generalisation in quantitative research. Transferability can be achieved through external validity, when the researcher provides a thick description of a phenomena, allowing the reader to determine if the conclusions drawn are transferable to their contexts, situations and people (588, 594). Transferability could also be attained through purposive sampling, since the participants most consistent with the research design are selected, keeping in view the limitations and delimitations (characteristics that can be controlled to define the scope of the study, e.g. research questions or population) of the study, which in turn enables readers to evaluate the degree of transferability to their own settings (594). The use of purposive sampling and detailed outlines of methods and data analysis throughout this case study have increased its degree of transferability.

Critics have argued that it is difficult to generalise and apply findings to other contexts from single case study research probably due to lack of statistical techniques applied in these studies (595). However, Flyvberjg (596) addressed this misunderstanding and outlines that in order to generalise, it is important to make extreme clever choices when sampling for case study (e.g. Galileo chose metal and feather for acceleration in free fall by eliminating weights of the objects. The point to note here was Galileo's clever choice of the extremes of feather and metal instead of using large range of materials for his experiment (596)). In my case, I have chosen respondents from several domains from various regions to maximise the transferability of this study. It follows that although multiple cases enable analysis of data across cases, it may not enable the same rich description of a rare phenomenon as studies of single cases contribute to knowledge (61, 93), thus increasing transferability.

6.4 Results

The response rate was 63% (50/79). Out of those 50 invited, 39 participants agreed for the interviews. Four unexpected participants were included in two of the interviews which were then conducted as group interviews. This was because the two respondents with whom the interviews were originally scheduled called their colleagues and subordinates to join the interview sessions to answer some job-specific questions (such as IT related and hospital administration). In the end, I conducted 39 interviews with 43 participants (see Figure 6-4 above). This also included nine solo interviews with the female participants.

The key characteristics of the participants were given in Table 6-7.

Interviews	Domains	Gender	Location	Interview method
RJ_20_1	FD/HP/IO/NGO/SC	Male	Karachi, Sindh	in person
AT_38_2	FD/GO/HP/TC	Female	Karachi, Sindh	in person
JR_16_3	GO/PO/SC	Male	Karachi, Sindh / Federal Islamabad	in person
QSAA_72_4 (Group Interview)	HA/ HP/GO/SC	Male	Karachi, Sindh	in person
KK_74_5	eH/GO/RA/SC/TH	Male	Karachi/ interior / rural Sindh	in person
FR_86_6	CZ/FD	Male	Karachi, Sindh, /Pakistan	in person
JR_28_7	FA/HP/SC	Female	Karachi /Pakistan	in person
JJ_52_8	FA/IO/PC/RA	Male	Hyderabad, Interior / rural Sindh	Skype
ASWMBTAR_82_9.1/9.2 (Group Interview)	CO/FD/FC/HP/NGO/SC	Male	Karachi / Rural Area	in person
KAM_54_10	GO	Male	Sindh	in person
MAM_88_11	eH/FM/PC/PO/RA / SC/TH	Male	Karachi / Gilgit / Baltistan /	Skype
SS_90_12	CO/FM//HMIS/SC	Male	Karachi	in person
AF_92_13	FM/HMIS/RA/SC/ semi-GO	Male	Raiwand, Punjab	Mobile
AF_25_14	GO/HP/PC/RA	Male	Rahim Yar Khan, Punjab	Mobile

Interviews	Domains	Gender	Location	Interview method
AA_94_15	GO/PC/RA/ Vaccinator	Male	Rahim Yar Khan, Punjab	Mobile
NM_44_16	FM/GO/HMIS	Male	Sindh	in person
MR_96_17	FD/GO/HP/PC/RA	Male	Sindh	in person
PS_66_18	FM/HMIS/semi-PO	Male	Karachi	in person
SS_106_19	HP/IO/PC/RA	Female	Sindh	Mobile/ Telephone
KAM_118_20.1/20.2	GO/HP/Quality	Male	Peshawar, Khyber Pakhtunkhwa	Skype
FA_124_21	eH/ HP/semi-PO NGO/RA/TH	Female	Federal, Islamabad / Zhob, Baluchistan / Skardu, KPK	Mobile / Telephone
SN_110_22	GO/PC/RA	Male	Gwadar, Baluchistan	Mobile
TS_120_23.1/23.2	GO/HP/SC	Male	Quetta, Baluchistan	Mobile
MM_60_24	FD/GO	Male	Federal, Islamabad	Mobile
AS_98_25	CO/FM/HMIS /RA / UA	Male	Lahore, Punjab	Mobile
KA_130_26	HP/IO/PO	Female	Federal, Islamabad	Mobile/ Telephone
LAS_112_27	FM/GO/HP/RA	Male	Mastang, Baluchistan	Mobile
BH_136_28	CZ	Female	Karachi, Sindh	in person
MA_116_29	FA/GO/ HP/RA	Male	Azad & Jammu Kashmir	Mobile/ Telephone
BO_160_30	CZ	Female	Lahore, Punjab	Mobile
YS_140_31	CZ	Female	Karachi, Sindh	in person
AJ_142_32	GO/HP/TC	Male	Lahore, Punjab	Mobile
FJ_150_33.1/33.2/33.3/33.4	HP	Male	Karachi, Sindh	Mobile
AZ_152_34	GO/ PC/PO	Male	Karachi, Sindh	in person
BR_154_35	CZ	Male	Sukker, Sindh	Mobile
ZH_146_36.1/36.2	CO/FM/HMIS/SC	Male	Rawalpindi, Punjab	Mobile/ Telephone
SA_148_37.1/37.2	CO/HP	Male	Peshawar, Khyber Pakhtunkhwa	Mobile/Telephone
MS_144_38.1/38.2/38.3	eH/GO/IO	Male	Federal, Islamabad	Mobile/Telephone
RA_178_39	CZ	Male	Karachi, Sindh	in person

Table 6-7 Characteristics of interviewees

The following key themes emerged from the analysis of interviews, documents and field notes and the findings are ordered accordingly: i). Advantages and disadvantages of HIE; ii). Issues attributed to the absence of effective HIE; iii). Existing forms of fragmented HIE interventions and recommendation for HIE implementation; and iv). Barriers and facilitators to HIE.

These themes partially resonate with the findings of the scoping (see Chapter 4) and systematic (see Chapter 5) review. The theme barriers and facilitators to HIE evolved with similar subthemes as were found in the systematic review. Also, it was found that fragmented and patchy HIE existed in Pakistan as well as in other LMICs with both paper and electronic information systems running in parallel. Finally, potential advantages of HIE and how information was transferred across regions, organisations or stakeholders were similar to the findings of the scoping review (see HIE constructs 'benefits' and 'stakeholders' in Chapter 4).

6.4.1 Advantages and disadvantages of HIE

6.4.1.1 Perceived advantages

Most importantly, HIE was perceived to enhance quality of care of an individual patient and as well as for the whole population by improving decision making (such as better diagnosis) and health policy planning (such as evidence-based health budgets).

"...it really, really improves coordination…it really improves cooperation..." KAM_118

"...and the benefit to the government is that they will know about the population health ... right now they are not aware that how many of our people have this" FJ_150

Other advantages stated by stakeholders included:

- Easier to enter, retrieve, analyse and share electronic information than paper-based information,

"Electronic data which is coming...is easy because everything is already there...they just need to enter data...input data and send it …" SN_110

- Effective and efficient work processes (quick response time in times of disasters and outbreaks, decreased workload of users, eliminated paper, storage and travelling costs, and time saving)

"…it facilitates, enhance clinicians' expertise" TS_120

"…time, money and personnel…it saves all the three…" ASWMBTAR_82 (group interview)

"In fact in floods and earthquakes there are many patients who go injured or other problems, diseases...so in this case electronic system can be very useful as you can keep the record of all..." BR_154

- Reliable and safe data, and

"…reliability will increase…availability will increase…" NM_44

- Monitor and track resources (such as stocks, equipment and activities of employees could be trailed).

"…misuses of things are tracked ...inventory is being controlled..." ZH_146

6.4.1.2 Perceived disadvantages

Disadvantages of HIE reported were:

- Malfunctioning of systems causing them to get slow, crash and lose data,
- Insecurity of data such as hacking and data tampering, thus compromising data confidentiality,

*"…that because of a problem the systems shuts down completely…"*AF_92

"…if any fault comes and all the data is lost...then it will be a problem" AJ_142

- Unavailability of health data safety laws, and

"…again there is no role of HIPAA here…nobody even understands HIPAA here…" PS_66

- Sharing and exchanging health information with international NGOs could enhance terrorism/espionage activities in the region (such as happened in the case of Dr. Shakeel Afridi, who provided information to the US Central Intelligence Agency (CIA) of Osama bin Laden's location in Pakistan (597))

"We are having much problems in FATA [Federally Administrated Tribal Areas], *Baluchistan and KPK* [Khyber Pakhtunkhwa] *…when we take sample of someone we have to take his whole history...home address, father's name etc.…so people get very reluctant just because of the Afridi case that had happened…"* MM_60

"so this is very critical information and specially giving it to WHO...then passing it to UN...this is a total security breach...it is just like axing your own feet...we don't trust US per se ...we don't trust India per se...we don't trust WHO per se ...many of the diseases that are spreading because of them or not...we don't know…this a fact...the war that has been forced upon us..." ZH_146

6.4.2 Issues attributed to the absence of effective HIE

Providers and public officials both from urban and rural regions reported many problems attributed to the absence of HIE which included:

- Difficulty in taking preventive and curative measures in times of outbreaks due to delays in recording, retrieving and transferring data manually,

> *"...initially it was like that BHUs basic health units or sole dispensaries ...data that was coming from them was manual ...and it took 2 to 3 months for the data to reach DHQ...then from district it was send to provincial...the timeliness was very long…"* SN_110

- Manipulation of data, errors and incomplete information,

"…when we enter data manually again and again, errors do come mistakenly…" MM_60

"…we get validation issues this way …that 3 months data came just after 1 day of request …then there will be something…problem with the data…" MM_60

- Loss of paper records,

"…it's quite possible that he [patient] may have lost half of the records…" QSAA_72

- Wastage of resources (stationery, time and space),

"…they don't care about long term that if they are on computer...they will save that much on daily basis...stationery will be saved ..." SA_147

- No proper patient referral system existed in between public and private setups

The private healthcare sector has increased its role enormously to cater for the growing healthcare demands due to rising population pressure on public healthcare facilities (528). It was stated by one of the high-designated public officer that the referral system from public to private care hardly existed due to lack of money because poor patients could not bear the high costs of private care. I personally observed patients concerned about being referred to private laboratories and hospitals for some medical tests unavailable in charity hospitals (see field notes).

"... but this system is not here...they go direct to tertiary level hospital without any proper referral form from primary, secondary ..." MA_116

"…not really…I mean it's always best to be able to exchange information with each other…like you said ...in the …referral … there… there is no system of formal… for instance how could I refer a patient to Aga Khan [large private hospital]*… my patient is poor … I am*

paying for every of his …even paying his fare to go home …so how can I refer this patient to Aga Khan even if I want wanted to …" AT_38

One of the healthcare professionals from the rural region perceived that the increased antibiotic resistance among the population was due to lack of referring patients' previous history because of high patient inflows with respect to less number of medical professionals ((one doctor for 1073 persons, one dentist for 12, 447 persons (528)).

"…whenever he comes his complaint would be different so you will think that probably this is his problem … if you are looking 300 patients a day …you cannot see what complaint he had if he comes after a month … so the resistant…so the medical resistance is booming because we are changing the regime of antibiotics very often…" AF_25

6.4.3 Existing forms of fragmented HIE interventions and recommendations for HIE implementation

Stakeholders reported that HIE existed mainly in/among the hospitals of Pakistan in a patchy and fragmented form.

6.4.3.1 Public, private and charity hospitals

Both electronic- and paper-based systems were running in parallel in most of the public and private secondary and tertiary care hospitals. The lab data (such as computed tomography (CT) scans, X-rays) of both public and private hospitals in big cities were usually electronic and accessible within the organisation.

"…so this hospital is completely networked…and you know every station has a…computer…all the computers are networked…and there…there is wireless…and VPN [virtual private network]*…so all those things are there…"* JR_18

"…the health information is divided into those which are exchanged electronically and that which is exchanged non-electronically…specially paper-based and verbal…so the paper based…the electronic exchange of information is primarily the lab data…because that is…I think…most of the time it's coming directly to the…directly through the…machines and easier to enter…everything else is pretty much…paper-based." RJ_20

Generally, charity hospitals (such as Shaukat Khanam Cancer Hospital (tertiary care) and Indus Hospital (secondary care) (555, 575)) were better equipped than government funded hospitals as it was reported by the IT head of a charity hospital that their hospital system was fully automated and all data related tasks were performed electronically (I personally observed the well-equipped data centre in the IT department of the hospital where the interview took place). Two stakeholders also confirmed that some different not-for profit (semi-private) hospital organisations had the ability to transfer data electronically to other not-for profit hospital organisations.

"It is electronically available right from the registration, after that, to the dispensing of medicine as well as lab investigation…" AF_92

"We can share our information electronically with Shaukat Khanam Hospital only…rest…we have a hospital in Muzaffargarh [city]*…we can also transfer information there…because we have tower connectivity with both the hospitals…"* AF_92

6.4.3.2 Public DHIS

According to public officials, statistical data (classification of diseases and number of cases) were fed into the DHIS from BHUs and RHCs (568), processed at district health offices and were sent electronically to federal level via provincial intermediaries and finally to the international organisations (557) (see Figure 6-3). No data from the public tertiary hospitals and private healthcare care were captured by the DHIS though the design and implementation of Public Tertiary Hospital Information System and Private Health Sector Information System had been planned along with the DHIS in 2006 (557).

"The report made at the national level is shared with the all the provinces…it shows the disease trends of every provinces…" MM_60

6.4.3.3 Recommendations

Almost all the respondents believed that electronic health systems (such as EHRs) were better than paper-based health record setups. They felt it was best to implement HIE in Pakistan, but that paper structures would always exist in parallel with the electronic system.

"This health information system is not good...it is very poor ...it is necessary to make it better ... and the best option is to make it an electronic system...this is my suggestion..." MA_116

"I think it will never be paperless in our setup…because we will have to have some kind of you know backup ...paperwork…" AT_38

"I think as far as Pakistan is concerned…this mixed system is the best…because I cannot ignore the importance of collection of digital data because this is the call of the day…you cannot handle this much data manually…that's why I think mix is a wonderful idea..." MR_96

Some stakeholders were of the view that it would be indispensable to start implementing HIE from primary care and then moving forward to secondary and tertiary care step by step which would be easy and tractable. However, others suggested that it would be better to start implementing from tertiary level due to availability of finance and equipment. In addition, it was also recommended to implement HIE on targeted urban regions where adoptability rate would be higher than in rural regions.

"Definitely it shall start from primary because the primary person gives you a general idea that you might have this disease...according to him...after meeting with the secondary person will let him know that he has this disease not this disease...because tertiary will never know about it directly...he needs guidance from the root that what information has been given overall... so I think it should be from primary..." BR_154

"...it will be more beneficial if we start from primary ...because if we'll start from the middle then we will not know what we have in front and what we have at the back ..." FJ_150

"…as far as finances are concerned...tertiary centres are the best option for this...because there will be less hindrance…" SA_147

"…for a particular population you can do it…if you are doing for targeted areas, targeted audiences ...you can do it.." KA_130

Finally, to start with HIE in Pakistan, one of the IT head of a chain of semi-private secondary hospitals suggested that they may start HIE processes among their hospitals and may invite other hospitals to join and use HIE services.

"We are that chain (of hospitals), we have 11 hospitals so we probably may start this...may be ...and we become a central authority and say to others that we have made it together and other small and big hospitals and clinics are joining with us…" ZH_146

6.4.4 Barriers and facilitators to HIE

Many barriers and facilitators to HIE were identified as reported below.

6.4.4.1 Socio-political

The major barriers reported under this subtheme were the mindsets of policymakers, corruption of healthcare professionals, politicised activities of international organisations, devolution of the health system from federal to provinces, and insecurity/terrorism activities in the region. Political commitment and clear policy direction were found essential to overcome these socio-political challenges.

The biggest barrier stated by almost all the stakeholders was the mind set of policymakers and the people running the health sector as priorities were given to the basic requirements and direct services (such as buying X-ray machines) rather than to IT or interventions beneficial for public health. It was further reported by an eHealth public official that policymakers and healthcare professionals did not emphasise the importance of an evidence-based decision making culture. One of the senior public officials felt that HIE was not essentially required in a LMIC such as Pakistan and the present public DHIS system fulfilled the needs of decision making.

"The biggest barrier is mind-set of the policy makers…ministers…bureaucrats …they don't...they would see it as waste of resources..." RJ_20

"…but as a decision maker people don't use it...the big bosses say...do the way I am saying it...rather than taking inference form what is there in the ground..." MS_144

"…you can do it but for a country where per capita income is…you can call it just $5, $3…$2…so…I don't think it's financially feasible…but you know as far as the health strategy is concerned we get a sufficient evidenced based…data…on the basis of we can make our evidenced based decisions…" MR_96

Two of the citizen interviewees labelled 'doctors' as the most corrupt profession in Pakistan because doctors preferred patients to go for new tests and diagnoses instead of consulting current/previous medical information in order to make more money for themselves and for their counterpart organisations.

"…but in this profession you'll rarely find faithfulness (honesty)…it is the most corrupt profession in Pakistan…the way it is going..." FR_86

"…and the instant you go to the doctor he asks to go to that lab or this lab ...they have commission everywhere...there is so much corruption in this field…" RA_178

Additionally, IT managers and bureaucrats perceived that even international organisations had unclear and politicised criteria to make appointments for their key offices in Pakistan and they did not consider the needs of the community when implementing systems.

"WHO has its own political ...you know, solidarity ...and they give…they appoint... people who doesn't have knowledge…know the work…" KAM_54

"...when they [international organisations] *come and implement a project in an organisation…they hardly give importance to the needs of the local organisation…"* NM_44

Moreover, according to the views of healthcare providers, devolution of the health system from the federal to provinces and districts through the 18th Amendment of the Constitution of Pakistan (546, 550) was another barrier to HIE because it developed lack of inter-provincial coordination between provinces and the federal government (574). In contrast to these views, a rural district healthcare manager appreciated the devolution of the health system because it involved local communities in the decision making process which was beneficial for the local population.

"…the way health was structured in this country…fragmented, inter-provisional, federal, and district health authority and so…it's not going to work…there isn't one force leading…health in this country…and so health information" JR_18

"…unless and until we don't take community along... it is impossible to implement anything …" LAS_112

Another important barrier reported under this theme raised by healthcare mangers/workers was the prevailing political instability in Pakistan that had given rise to insecurity and terrorism. It was difficult for healthcare workers and professionals to carry gadgets (such as laptops and smartphones, usually used to send health data to the regional office) or use company's car during their fieldwork in rural areas due to the risk of being burgled or killed.

"…going there means endangering our lives…if you move into UN's car means you are being specially focused…going there needs a security clearance and to take police squad with us…" JJ_52

To overcome the above challenges, almost all the stakeholders were of the view that government and political commitment could play the leading role in implementing HIE across Pakistan by making it mandatory and directing good policies that may also include regulating the private sector.

"First of all…most important is the political commitment…" AF_92

"There should be a…centralised…database…where all the hospitals should share their information ASWMBTAR_82

"…if we regulate them and made a regulatory authority for private hospitals...and bound them that with in this regulation you have to work and share data ... SN_110

6.4.4.2 Finance

Almost every stakeholder was of the view that funds were essential to develop infrastructure, buy technology, conduct training and pay for maintenance costs. Project managers specified that usually projects implemented by NGOs or donors agencies did not survive in the long run because of the discontinuation of funds as they may not see any return on investment in implementing HIE interventions.

"It needs much investment which is not done right now...." ZH_146

"…we asked them to continue but they didn't…for two years [only] *they did.."* KK_74

"People don't really see the value of making investment in this area…this is the problem…" JR_18

IT managers suggested the use of open source technology, such as, Android platform and Linux operating system to facilitate costs of technology and interventions.

"…so we have used open source…open source technologies…and make our own…" MAM_88

In public hospitals, electronic health systems and computerised labs were mostly funded by NGOs (569) whereas charity hospitals were mainly dependent on grants and donations including Zakat (a religious duty for all Muslims who meet the required criteria of wealth to give away their 2.5% of savings every year to/for the poor and needy) (569). Apart from these government initiatives, stakeholders were of the opinion that international NGOs could also help to implement HIE as they have been doing in the past, for example, JICA introduced the DHIS in Pakistan in the year 2004-2007 (51, 557) and WHO established electronic DEWS that recorded and transferred data using mHealth intervention (572).

"… there was JICA, it was very popular…they brought the health project for a decade approximately… TS_120

6.4.4.3 Infrastructure

The main infrastructure issues highlighted by almost all the respondents were poor connectivity, power shortages (especially in rural regions) (569), and lack of equipment and software.

"There in villages is no electricity from 18 to 24 hours…" MM_60

"...you don't have internet access…access and availability are issues…" KA_130

"…but hardware is not available in the lab…buy hardware then you don't get software…" FR_86

Some healthcare providers were of the view that it was more important to provide medical necessities, and develop infrastructure in the first instance than to implement HIE.

"...first of all fulfil the basic needs ...where there is no normal saline, dextrose and other things at primary level ..." SA_147

Healthcare and IT managers suggested that providing equipment and electricity backups (generators) would help to implement HIE. They had a positive view about the use of mHealth technology that could leapfrog the poor telecommunication networks in rural regions. Moreover, it was further stated that public pressure could facilitate the diffusion of HIE across Pakistan because of the adoption of media and mobile technologies among younger generations (such as use of internet, gadgets and mobile apps) that had created pressure on businesses to adopt new technology frameworks.

"...these devices should be on alternate power ...where there is power issue..." LAS_112

"Telephone well we...we don't have the regular telephone lines over there...something known as a wireless PTCL [Pakistan Telecommunication Limited]*...yeah a Vfone...yeah a Vfone... you know...Kohat and Luck Marwat and Bannu...mobiles usually work out there...mostly...definitely above 70% ..."* KAM_118

"All software are moving into app world...may it be your mobile devices or tablets ..." ZH_146

*"...public pressure is coming...people ask for quick and easy ways... like if I don't give online reports and my neighbour does...people will go to him..."*ASWMBTAR_82

6.4.4.4 Organisational

Lack of technical staff, unawareness of healthcare technologies, providers lacking computer and documentation skills, and unavailability and disparity of data standards between organisations were reported as major organisational barriers. Also, data duplication problem was reported due to the running of individual vertical information systems of many healthcare programmes (such as malaria and TB).

"We don't have the system we don't have the trained manpower...trained manpower could be one issue" MA_116

"The expertise to fix complicated electronic equipment is not available with in the hospital ..." AT_38

"There is no standard...data capturing methodology ...or system...even paper-based in the emergency departments..." RJ_20

"Our information system is dispersed...means the information system is in many parts...it is not coordinated or one...information is being doubled..." LAS_112

"I don't know what a tablet [iPad equivalent] *is..."* AA_94

"I think I must say that 70-80% of district managers may not have the idea of district health information system..." MS_144

To address these issues, administrators, providers and IT managers suggested trainings of staff and providers, hiring technical resource, introducing health informatics curriculum in teaching hospitals, standardising data collection among healthcare organisations and integrating vertical programmes to improve data quality.

"Whatever new thing you bring...there should be training base for it ...." FJ_150

"Make health information technology as part of the curriculum…absolutely mandatory…in nursing curriculum, doctors' curriculum... PS_66

"All the hospitals need to come on the…a single protocol…which is HL7…it's being internationally accredited …" SS_90

"…if there is one integrated system...information will go into only one" LAS_112

6.4.4.5 Patients and providers

Respondents had the perception that patients were not usually interested in healthcare technology, instead, they were more interested in service quality because they hardly get any quality service in public healthcare facilities due to the very low government spending of < US $ 40 per capita (548) which was further underutilised due to poor planning and mismanagement of funds (573).

"Patient himself is a barrier…because patient is not educated, they are not computer savvy…they are not technology…oriented…yes they use mobiles…they use communication but they are not into internet, they don't… will not go for appointments online, they will not check their reports online…" PS_66

"…he will complain that your doctor was not on time…I repeatedly called the nurse but she didn't respond…pillow was not clean...your food was like that…we didn't get the medicine on time…he will not be bothered that you are giving me my information electronically…" ASWMBTAR_82

Healthcare providers reported that majority of the healthcare professionals were seen as resisting recording records electronically because of the old writing habits (comfortable using pen and paper), to save oneself from any liability for any negligence or malpractice in treating patients and to avoid sharing information due to limitations in English language.

"…they have a habit of writing with pen …they don't want to leave it…" AF_92

"No record no liability…that's the principal everybody follows…if I don't have a record I am not liable…so…so that's what people hide behind…" ASWMBTAR_82

*"We are not very willing to share any documentation that is done in English because we may feel it may not be up to par…so we feel very ashamed…"*ASWMBTAR_82

Finally, one senior healthcare director emphasised the use of the national language (Urdu) for adopting HIE processes, especially for patients, as it was easier to understand and communicate in Urdu than in a foreign language (English).

"There is a huge need for improvement on eHealth through local languages... what patients sees and understand feels comfortable with largely local language" RJ_20

6.5 Discussion

6.5.1 *Overview of findings*

Many issues were attributed to the absence of effective HIE such as ‘big time-lags in transferring information’ and ‘increased antibiotics resistance’ among population. HIE mainly existed in public and private hospitals of Pakistan but even then in fragmented and patchy form, especially in lab settings of secondary and tertiary care. A few private and charity hospitals had better HIE processes than the public hospitals. In addition, inter-organisational HIE also existed between hospitals of the same organisations as well as between different hospital institutions.

The significant barriers to HIE that respondents identified were the mindset of policymakers, corruption, and lack of evidenced-based decision making followed by financial constraints, poor infrastructure, and lack of skills and data standards. In addition to these barriers, respondents reported that healthcare providers usually resisted writing health records to save themselves of any accountability and because of the lack of documentations skills. The majority of stakeholders believed that these barriers could be overcome if the government stimulated supportive policies to promote evidence-based decision making. Furthermore, respondents identified the use of open source and mHealth technologies, and data standardisation as potentially important facilitators of particular salience in LMICs such as Pakistan. It was also stated that the younger generation were more inclined to adopt new technologies and more efforts were required to test eHealth solutions using the national language of Pakistan.

There were many perceived advantages – most of which are in keeping with those known about from other countries – but also some pretty uniquely identified risks (such as espionage activities), which are like to be peculiar to the region/countries with unstable governments

6.5.2 *Differences in attitudes depending on the stakeholders – outliers*

Majority of the stakeholders appreciated the use of HIE in the near future due to its many potential benefits but a few stakeholders had some dissenting views of using HIE in the context of Pakistan and LMICs. For example, as mentioned in the results section above, a public officer thought of HIE as a luxury in Pakistan and LMICs where per capita income is low. According to him, the current DHIS system of Pakistan is sufficient enough to make healthcare policies and informed decisions. More dissenting views from other stakeholders were to give importance to service provision that is, spending on medicines that are hardly available, buying beds and diagnosing equipment such as X-ray machines, rather than implementing HIE.

Also, most of the stakeholders perceived the devolution of health system from federal to provinces as a barrier to HIE but one of the district managers from the rural area found the devolution of health favourable to address health issues at regional and community level.

Another difference of opinion came from an eHealth manager of a large organisation and a federal public officer that HIE could be used for espionage and terrorist activities due to the geo-strategic position of Pakistan as happened in the past (Osama bin Laden case as discussed above).

Finally, citizens regarded doctors as the most corrupt profession because according to them doctors make money through repetitive laboratory tests. The reason might be the rising healthcare costs in Pakistan where around 70% of the population receive free healthcare.

6.5.3 Strengths and limitations

Building upon literature reviews (see Chapter 4 and 5), the study included the maximum variation sampling strategy exercised (resulting in a wide range of respondents including some very high-designated public and private officials), conducted interviews in participants’ preferred language, achieved triangulation by conducting documentary analysis and keeping of contemporaneous field notes, iterative approach to data analysis which involved both inductive and deductive analysis, interviewing until saturation was achieved (see Chapter 3), response rate of 63% (50 participants responded out of 79; 39 interviews from 43 participants) and respondent checking. Finally, participants were given the opportunity to raise their own issues for discussion if they had not been raised in the interview.

However, there are limitations that need to be acknowledged. First of all, whilst the response rate was high not all the participants agreed to participate. I kept recruiting participants until I achieved data saturation. It was my first experience to conduct a qualitative study but the continuous guidance from my supervisors helped me a lot in attaining good quality data.

Also, it was not possible to travel to other parts of Pakistan for face-to-face conversations therefore, more than half of the interviews were conducted through Skype or mobile/landline which did not allow me to record observations and any interesting events that may have occurred during the interviews. It was difficult to get female contacts from other participants without the consent of females, however, I managed to recruit nine female interviewees. Due to inaccessible premises, some of the interviews were undertaken in noisy/busy public places (hotel and restaurant) which were intermittently paused due to the noisy environment. This may have disturbed the rhythm of the interviewees. Some of the high-designated participants, especially public officials, were cautious to agree for up to one hour interview, however, they agreed to spend no more than half an hour. It may be therefore possible that they did not completely uncover the issues on some perspectives. Finally, as with all qualitative work, there are concerns to transfer findings to other LMICs but I believe that a number of findings are likely to be most applicable to low-income country contexts because many of the middle-income countries (such as Brazil and South Africa) seemed to be more advanced than low-income countries.

6.5.4 Considering findings in the light of the existing literature and Greenhalgh's model

The findings of this study are broadly in keeping with the existing literature demonstrating that diffusion of health innovations (in this case, HIE) not only depend on the motivation of health managers and physicians, but also on other factors such as finance, infrastructure, decision-making culture of the organisations responsible, technology, workforce trainings, and people (patients) education, requirements and preferences (520, 598, 599).

6.5.4.1 Socio-political system

An innovation must be guided through the health system and this guidance should be provided by government and stewardship (520). Stewardship is the essence of good governance and provides strategic guidelines to all the stakeholders responsible for the health system (600). Stewardship, one of the core four functions of the health system, has a profound influence on the other three, service provision, resource generation and financing (600). Leadership should come up with effective policies and regulations keeping in view the needs of the population. Governments need to implement effective financing mechanisms for HIE, build infrastructure and acquire technology, provide skills to its human resource, (520), set standards for interoperability (601) and monitor the diffusion pathways in order to track progress and/or failures. Similarly, Greenhalgh found that support of top management and a ‘policy’ push for implementing an innovation in the early phases can enhance innovation’s probability of success and increase motivation among organisations, possibly by providing dedicated funds (76).

The governments of some HICs, such as Canada, the UK and USA, have spent billions of dollars on HIE and interoperability in order to exchange health data to improve patient care (601). Similarly, the governments of some LMICs have realised the need for HIS’ to manage health information. Dr. Gonzalo Vecina Neto, the head of the Brazilian National Health Regulatory Agency, supported this perspective by saying, *“there is no health without management, and there is no management without information”* (602) and countries such as Brazil (500), Kenya (468), Rwanda (490), South Africa (501) and Uganda (503) have begun implementing and adopting healthcare technologies to provide interoperability for evidenced-based decision making. For example, the use of OpenMRS, an open source, non-proprietary medical record system being used in LMICs such as in Pakistan for managing TB patients by the support of many international and national governments and aids, NGOs, and non-profit and profit organisations (575). However, overall in LMICs, very few EHR systems were installed primarily in hospitals, but even these existing ones were unable to share data due to lack of data standards (601). Priority was given to national statistics by policymakers and healthcare planners in these LMICs to build national databases on the endemic of diseases and its consequences, but regrettably lack of standards impedes generation of statistical data because different data terminologies are used by different organisations that create inconsistencies in recording, synthesising and analysing data (601).

Technology diffusion in LMICs is slower when compared with overall penetration level in HICs because its diffusion is dependent on to the condition of the healthcare system, which is why strengthening the health system has been a priority of policy makers and leadership in international development (520). Therefore, it is reasonable to infer that because the health system is a public responsibility, the government of Pakistan and LMICs have to develop capacity in stewardship and management to generate resources, finance, and provide services by itself or with international support such as WHO (520). Otherwise, without effective stewardship as available in HICs, diffusion of HIE technology will not be possible in LMICs or Pakistan (520).

6.5.4.2 Role of investment

According to the Greenhalgh's model, a political directive at the initial stages of implementation of an innovation can enhance its chances of adoption, probably most significantly when simultaneously a dedicated finance channel is provided (76). Ongoing and dedicated funding is more likely to implement and routinise the innovation than a short term funding (76). Diffusion of innovation has been found to be positively correlated with the government per capita expenditure and negatively associated with the cost of the technology (521). Lack of finance is also an important barrier for the diffusion of innovation in LMICs. The governments of almost all LMICs have low financial capacity to purchase new technologies (603). For this reason, aid agencies and donors are active funders to implement health technologies in LMICs but failed to develop business models to expand or sustain these projects. Business innovations are required in LMICs to deliver healthcare solutions. For example, micro-franchising, a business innovation, integrates superlative public goals with small-scale entrepreneurship (604). BroadReach, a company in South Africa, aimed to bring public health good intentions into reality with the involvement of the private sector (605). They used IT to deliver advice of medical professionals to the population in rural areas through call centres, trained workforce to recognise, educate, and support people in times of urgent need and set out to develop a large-scale model that provided individual monitoring (605). Thus, only a long-term investment prospect that allows the iterative improvement of technologies and business models will stimulate and deliver innovations for eHealth and mHealth (606).

6.5.4.3 Effective partnerships

These investments for health innovations are possible through effective, active and long-standing partnerships. Several examples of academic/interdisciplinary and public/private partnerships exist in the real world. For example, Partners in Health, a multidisciplinary academic partnership, and an organisation that provides enhanced healthcare to the poorest nations worldwide through electronic information management (607). Partners in Health has, for example, developed and implemented EHR systems in many countries such as in Haiti, Peru, Philippines, and Rwanda, particularly aimed to improve clinicians' capacity to access and use health information such as laboratory results (608).

Likewise, Greenhalgh found that cosmopolitan organisations (that is, those that are externally well-connected with others), inter-organisational networks and integrative organisational forms (such as national healthcare, health insurance and networks of private healthcare providers) can help promote innovation among member organisations (76).

6.5.4.4 Training and education

According to the Greenhalgh's model, an innovation that integrates well with the organisation's supporting technologies is likely to be assimilated easily (76). Similarly, if a technology is supplied with customisation, training and support, it will be adopted more easily (76). To improve clinicians' awareness and skills for HIE, it is essential to develop project-centric training approaches in LMICs. During my fieldwork I observed that it is better to understand the needs of the workforce in various settings because the workforce in urban regions have different knowledge and capacity parameters than the rural workforce. Greenhalgh found that innovation is readily adopted by 'homophilous' individuals having similar educational, socioeconomic, cultural and professional backgrounds (76). Being responsive to local needs will be the key to success in effective training and education of the workforce because innovations that are compatible with the intended users' norms, values and perceived needs are adopted more easily and readily (76). For example, mobile phones are common to the population both in rural and urban areas but even to implement mHealth for HIE, it is necessary to acquire training and local technical capacity (599) through practical experience and demonstration in order to reduce adopters' perceived complexity of the innovation (76).

6.5.4.5 mHeallth technology

Many mHealth innovations have sprouted from the areas collectively referred to as global South (nations of Africa, Central and Latin America, and most of Asia) (609). Countries from the global South are tapping mobile technologies to harness their health systems. LMICs provide big opportunities for mobile technology care because they are composed of large, rural and unconnected communities with low access to healthcare professionals and limited health budgets (610). mHealth has the potential to reduce costs of hospital visits that positively affects the health seeking behaviour in LMICs. Long queues and waiting periods, a major reason patients and elderly people hesitant to seek medical advice can be avoided by connecting patients at remote locations with consultants at healthcare centres through tele-services of mHealth. Moreover, mHealth leapfrogged the land-line stage of telecommunication and seemed to be a reasonable alternative to fixed-line physical infrastructure which would otherwise require long construction time, and high implementation and maintenance costs. Low mobile call tariffs in LMICs such as India and Pakistan has opened the doors for implementing mobile interventions. This resonates well with Greenhalgh’s model that cost-effective innovations are more easily implemented and adopted (76). This increasing penetration and ownership of mobile phones means that a LMIC which has a weak health infrastructure has a lot to gain from technology enabled care (610). For example, diffusion of mobile phones in Africa has reached 82% of the population (610). According to PricewaterhouseCooper, China will reach up to US$ 2.5 billion market growth for mHealth with 37% market share in Asia Pacific followed by India with market growth up to US$ 0.6 billion and 8% market share by 2017 (611) . In addition, mobile apps have been playing a significant role in providing digital healthcare solutions by supporting several ways of communication which include data collection, data retrieval, voice calling, video calling, texts messaging, emails, multimedia messaging, conference and connecting clinicians with health facilities (612). Due to these observed benefits (76) of mobile apps, mHealth is more likely to be adopted by healthcare stakeholders in LMICs. The ability of LMICs to leap ahead than HICs in using healthcare mobile technologies is due to the lack of healthcare in LMICs. Therefore, people in LMICs adopt mHealth due to greater demand for change to provide quality healthcare (613).

6.5.4.6 Advantages of HIE

Lastly, HIE solutions for specific healthcare programmes have been implemented and adopted by LMICs because of its many advantages over paper-based records. Innovations that have clear and unambiguous advantages are more easily implemented and adopted (76). HIE in HICs has improved data quality (36) by reducing medication and medical errors essential for decision making and patient safety stands out as one of the most potential advantages (13)among others. Other potential advantages include fast retrieval of health information at any time, safety of information, reducing paperwork and increases efficiency, provide interoperability among EHRs at various facilities, save resources (time, stationery, space) and reduce costs.

6.5.5 Implications for policy, practice and research

The role of government is important to diffuse HIE in the unorganised health market of Pakistan because diffusion is a complex process which depends on socio-political, financial, and structural components, and any lapse or absence in any of the these fundamental components may adversely impact on diffusion (implementation and adoption) process (520). Implementation of HIE needs to be done step by step by the efforts wisely orchestrated among federal, provincial and local governments. These tiers of government need to develop a business model for HIE and convince the key stakeholders such as sponsoring organisations, investors, ministries of finance, national and community leaders, providers, vendors, professionals, citizens about the value of HIE and the difference it can bring to the healthcare quality of the population (607). When implementing HIE in Pakistan or in other LMICs, it is essential to consider the needs of people, their culture and the environment in which they will work.

Moreover, partnerships between national and international organisations that may include NGOs, private providers and academic institutions such as teaching hospitals, could facilitate technical and financial resources to implement HIE in Pakistan and other LMICs.

It is essential now to build on this research and address the main challenges in implementing HIE identified, these including the need of clear policy directive on evidence-based decision making, make substantial investments on power, mobile communication networks, and trainings and standardise health data for interoperability. It is also useful to continue with the development of the Public Tertiary Hospital Information System and Private Health Sector Information System as were proposed in the National Action Plan (which also included DHIS) for the development of HIS in Pakistan to improve information needs of the health sector (557). However, it looks challenging in the foreseeable future due to a huge disparity in the healthcare provision in the private sector (from hi-tech hospitals and homeopaths to hakims and general stores). Though, this has not been an easy task, even for the economically-developed world, Pakistan and LMICs have to be patient as this will take time and try accommodating small failures with continuous exertions focusing on the long-term predefined goals.

"We choose to go to the moon in this decade and do the other things, not because they are easy, but because they are hard ..." President John F. Kennedy (1962) (614)

6.6 Conclusions

Collecting, managing and exchanging health information is essential to provide high quality, efficient healthcare to individual patients and to the whole population. Due to many problems in using paper-based information systems in Pakistan, effective interoperable HIE systems were required to access and exchange timely information from all various sources in order to use it for decision making and health planning.

This phase of work revealed that HIE existed mainly in the hospitals of Pakistan in a patchy and fragmented form. HIE processes in private and charity based organisations were better than in public organisations where it has been present mainly in laboratories. High quality private hospitals have a ‘fee for service’ business model and usually invest in technology infrastructure to gain returns on investment and to raise their healthcare quality. Charity hospitals provide a free healthcare service and usually receive donations (obligatory Zakat, and voluntary alms-giving) that helped them provide free healthcare and invest in HIE technology making their processes effective and efficient in order to curb unnecessary costs. In public organisations, NGOs usually provided funds to invest in HIE interventions as the government preferred to spend more on direct services such as to provide medicines, beds and X-ray machines. The government sector used electronic DHIS to gather statistical health data from all districts and transfer it to national level through provincial offices for health policy and planning.

Many barriers and facilitators to deploy HIE in Pakistan have been identified through this in-depth work. Most importantly, strong political leadership and policy direction were identified as the main promoters to deploy HIE across Pakistan by prioritising the usage of information and regarding it essential for decision making. Government and NGOs should come up together by providing funds to build infrastructure, provide skilled workforce through education and trainings, standardise data collection and management for interoperability and make use of cost-effective technologies such as mHealth to address poor infrastructure and power shortages. The influence of media and technology on the population was also asserted to enhance public pressure on health organisations to adopt technological frameworks such as mobile apps for HIE. Moreover, a fear of audit that stopped healthcare providers to write and maintain health records would need a clear exhortation of keeping good records which would be audited. Although there are existing ethical guidelines provided by the Pakistan Medical and Dental Council on the confidentiality of patient information and the fair use of health records they do not provide any rules around properly writing and updating health records (615). However, things are improving and the latest example of collecting, preserving and processing patients’ data into meaningful information in the form of monthly and annual reports is shown by a 1054 bed-hospital, the Pakistan Institute of Medical Sciences (616). Regulations were also required to involve private sector in the HIE processes. Partnering and/or offering incentives may encourage private sector to share and exchange data.

The majority of the stakeholders found HIE to be potentially advantageous over accessing and exchanging health information manually using paper-based systems (617). HIE was perceived to provide safe and sound health information to stakeholders for decision making and planning (617). The process was thought as easy to use and found to be effective and efficient. HIE was potentially useful to track and monitor resources, eliminate corruption and loss of resources. Potential disadvantages identified includes loss of data and confidentiality issues that may give rise to espionage acts in the region.

In the next and final chapter, I will mainly discuss the overarching findings of the three phases of research and finally conclude my thesis.

Chapter 7 Overarching findings of scoping review, systematic review and case study

7.1 Introduction

In this last chapter, I will integrate findings of the three phases of research, namely the scoping review, systematic review and the case study. The scoping review analysed the published definitions of HIE defined in various contexts with several conceptual attributes (see Chapter 4). The scoping review provided a platform of knowledge that comprised the underpinning constructs of HIE and showed that how the term has evolved over time. This foundational work enabled me to clarify the concepts of HIE that further helped me to characterise HIE into two over-riding concepts – a ‘process’ for information interoperability and an ‘organisation’ to oversee the HIE business and legal issues involved in information transfer. Equipped with this understanding, I conducted the second phase of my research to systematically search and critically appraise the literature on HIE in order to identify barriers and facilitators to HIE in LMICs and to explore the modalities of HIE such as telehealth, DHIS, and mHealth (see Chapter 5). Finally, findings from the scoping and systematic reviews informed the topic guide (benefits and barriers of HIE; stakeholders involved in HIE, and how information transferred in HIE), and the sampling matrix (stakeholders involved in the management of the HIE process; understand the types of stakeholders involved in previous studies) for the case study (the third phase of research) that primarily involved conducting interviews with healthcare stakeholders to know their perceptions on the deployment strategies for HIE in Pakistan (see Chapter 6). The systematic review also provided an overview of the range of research methods used in previous studies that also helped me to start exploring appropriate methods for my primary research (see Chapter 3 and Appendix 6).

In the subsequent sections, I will start the discussion with the HIE definition that has been adapted and presented in the scoping review (see Chapter 4). I will discuss the components (process and organisation) of the HIE definition aligning them with the overarching themes of the systematic review (see Chapter 5) and the case study (see Chapter 6).

7.2 Overarching findings in the context of widespread literature

7.2.1 HIE: a process or/and an organisation

The adapted HIE definition as given in Chapter 4 is as follows:

"Health information exchange (HIE) is the electronic mobilisation of clinical and administrative information within or across organisations in a region or community and, potentially, internationally between various systems according to locally and/or nationally recognised standards while maintaining the authenticity and accuracy of the information being exchanged, enabling stakeholders to make informed decisions to enhance healthcare quality of a patient and population. HIEs are multi-stakeholder organisations that oversee the business, operational and legal issues involved in the exchange of information."
(Adapted from Finn (214))

The definition here presents HIE both as a process and an organisation. The **process segment of HIE** given in the definition is, "*Health information exchange (HIE) is the electronic mobilisation of clinical and administrative information within or across organisations in a region or community and, potentially, internationally between various systems according to locally and/or nationally recognised standards while maintaining the authenticity and accuracy of the information being exchanged, enabling stakeholders to make informed decisions to enhance healthcare quality of a patient and population.* Whereas, the **organisation section of HIE** is given as, "*HIEs are multi-stakeholder organisations that oversee the business, operational and legal issues involved in the exchange of information."*

All interventions and technologies such as mHealth, telehealth and DHIS found in the systematic review and case study were facilitating the *process* of HIE (as per the definition) in LMICs. Whereas the concept of HIE as an organisation usually comes in the context of a state entity overseeing and enabling the process of HIE, such as for example I found the DHIS in Pakistan and the DHIS2 in Ghana running under the health ministries. However, in the US, many state HIEs (see Chapter 4), for example Florida HIE, have been established to provide network services connecting healthcare providers to enable exchange of health information across a state wide information highway. In Pakistan and LMICs, almost all the processes of HIE were in silos or routed through several unintegrated vertical programmes.

7.2.2 HIE: individual and population

Moving forward with the HIE process, the definition states that HIE is beneficial for the individual patient as well as for the whole population. It improves individual healthcare quality by establishing coordination among diverse providers and systems, decrease medical errors and lower healthcare costs. Benefits to the population include early detection of infectious disease in an outbreak and enhanced tracking of chronic disease management such as TB thorough electronic data surveillance reporting and facilitating investigation (3, 617). An encouraging example from LMICs is the INDEPTH network that provides best available evidence in the form of demographic and health data to establish health priorities and policies and to effectively set resources in order to ensure and supervise progress towards national objectives (2, 618).

The health information of an individual is both indispensable and valuable because health information of individuals can be aggregated to provide a ‘health information trail’ for population in communities, districts, provinces and states, thus, helping policy makers in shaping healthy health policies (619). Many HIS’ in LMICs, like the DHIS in Pakistan, do not maintain data in the form of an individual patient record. Instead, statistical data comprised of classification of diseases and number of cases, are aggregated with no obvious link to the individual patient, making it challenging to keep track of patients over time. Moreover, data of NHIS or DHIS in LMICs are driven vertically and these systems do not share data horizontally causing problems to uniquely identify individuals due to lack of unique health identifiers of individuals (40). Particularly, it is difficult for LMICs to implement such systems that collect, manage, exchange and use patient data with unique identifiers due to strained health budgets and other challenges. However, many countries such as India, have initiated good attempts to assign unique identification to individual citizens (40).

7.2.3 Mixed health systems in LMICs

Health systems in many LMICs such as Pakistan are usually mixed with a blend of private and public providers, influenced by many socioeconomic and political challenges (440). Mixed health systems in LMICs vary widely, however, they share a number of challenging common characteristics such as limited funding and financing mechanisms that result in patients bearing most of the health expenditure themselves, lack of capacity building and variable healthcare quality across providers. Further, governments in LMICs usually give priority to direct provision of care, which resonates with my findings on Pakistan, rather than to uptake innovation, leverage with private providers, and accomplish high quality care for its people (440).

The US can serve as a valuable example for LMICs with mixed health systems as the US health system also consist of mix of public and private stakeholders responsible to finance, deliver and regulate healthcare (440). However, it is also encompassed by number of grave healthcare dilemmas including high healthcare costs, variable healthcare quality, and irregular access to healthcare (440), but healthcare in the US has advanced in many areas, including innovations (HIE exists in both forms – HIE process and HIE state organisations), involving stakeholders in policy making and collaboration between public and private sector. Unfortunately in LMICs, governments direct their resources and concentration only to public healthcare delivery, not paying attention to their role of stewardship for a whole healthcare system, restricting their capabilities to evaluate, monitor, and correct their healthcare system, thus losing opportunities to promote and deliver key healthcare innovations (440).

Therefore, LMICs have to strive hard to strengthen the stewardship of mixed health systems to improve fragmented healthcare infrastructure, enhance quality of care, support regulations and enact policies.

7.2.4 HIE barriers and facilitators

Even in HICs, such as the US, technical limitations and financial constraints were the major impediments to HIE. Finding a suitable sustainable business model for HIE and interoperability and the question that who will pay for HIE after the federal funding expends is still a debate in the US (620). Similarly, financial constraint, no doubt, is the apparent barrier to HIE in LMICs but findings from the systematic review and the case study on Pakistan showed that many other factors also served as major obstacles in the way of progress.

The most significant impediment for the diffusion of HIE in Pakistan (see Chapter 6) and in other LMICs (see Chapter 5) was the socio-political factors that comprised lack of leadership, mindset of policy makers, corruption, insecure environment for healthcare workers and lack of evidence-based decision making culture. Almost all the LMICs have financial constraints and infrastructural issues such as shortage of equipment, office space and power, and poor communication networks (see Chapter 5 and 6). Moreover, staff usually lacked essential trainings and are overburdened due to shortage of staff and high patient inflows (see Chapter 5 and 6). Unavailability or disparity of data standards for interoperability are major technical issues which possibly leads to faulty, rigid and incomplete systems (see Chapter 5 and 6). Individuals lacked awareness of health technology, and professionals resist to new process of writing records possibly due to old writing habits or to save oneself from any liability (see Chapter 6). Finally, lack of timely reporting of data by healthcare workers and facilities, late feedback from supervisors, and loads of irrelevant information from various vertical programmes leads to poor data quality and compromise the efficiency of the DHIS (see Chapter 5 and 6).

On the other hand, similar facilitators were found from the systematic review (see Chapter 5) and the case study (see Chapter 6) to counteract these barriers. Strong political will, effective strategies and administration, and the support of international organisations would be the key driver to implement and diffuse HIE in LMICs (see Chapter 5 and 6). This resonates with the WHO Health Systems Framework in which leadership/governance is one of the system building blocks among the other five, financing, workforce, products and technologies, information and research, and service delivery (522). Moreover, this also echoes with one of the core functions of the individual country health systems, ‘stewardship’ that stimulates the other three, service provision, resource generation and financing (600). This finding also resonates with the diffusion of innovation theory that social system influence the diffusion of innovation (131). Lack of funding has been addressed by investments through national and international donors, developing business models through partnerships between academic and service sectors and using cost-effective and free (open source) technologies. Infrastructural issues were resolved through the availability of alternate power by providing generators and/or uninterruptible power supplies, and communication through mobile networks and VHF radios especially in rural regions with poor wired telephone infrastructure. Furthermore, it is essential to hire other staff to relieve work pressure from the overburdened workforce, provide them with necessary trainings and skills, and motivate them through financial incentives and boost in career. Providing user-friendly computerised systems, giving importance to the needs and perceived usefulness of users, use of data standards to achieve interoperability of information, and regular feedback and supportive supervision can further facilitate the HIE process in LMICs.

7.2.4.1 Poor data quality

DHIS systems used in Pakistan, Rwanda (621) and South Africa (475) are examples of community information systems used to collect routine health data from primary facilities. DHIS in these settings has limited impact on outcomes due to poor quality of data captured and shared by these systems. Lack of staff training and data analysis tools lead to poor data quality in LMICs. Moreover, data is collected manually from the primary facilities and is sent either on paper or through text messages to district offices where it is fed into computer systems and then aggregated electronically. This manual collection and entry of data by apathetic and inexperienced staff is prone to number of errors and data loss, which, in turn lead to poor data quality.

7.2.5 HIE mainly exists in large organisations in LMICs

In LMICs, electronic medical record systems such as OpenMRS (622), Dream software (623), Baobab Health (Malawi) (624), Zambia Electronic Perinatal Record System (ZEPRS) (625) are usually available in larger hospitals and support HIE processes within these hospitals but are rarely found in smaller facilities such as primary care (626). Similarly, I found HIE processes only in few secondary and tertiary care hospitals in Pakistan rather than in any primary care facility. There were also few hospitals where HIE existed only in radiology departments and laboratories. However, the use of picture archiving and communication systems (PACS) is growing rapidly in LMICs because it may lead to enhance clinical efficiency and lessen in-patient stays (626).

7.2.6 Impact of HIE on healthcare

However, many examples are available in the literature that showed the potential impact of these electronic health systems to improve access to healthcare. For instance, following the implementation of SIGA Saúde HIS in Brazil, preliminary outcomes from Sao Paulo showed that patient flows and optimisation of resource usage has enhanced outpatient services productivity by 35% (38). Health officials from another Brazilian city, Campinas, indicated that after the implementation of the same system, patients’ visits increased by 30% without adding additional healthcare workers or healthcare units (38). Moreover, increase in patient satisfaction from 32% to 50% was reported from Campinas city (38). Similarly, availability of real time data through ZEPRS in Zambia increased HIV testing rate by 10% for new antenatal patients (627). Furthermore, DHIS of Pakistan frequently provides regular information on many priority health problems while saving costs. Before the DHIS, health departments in Pakistan relied on estimations or carried costly community based surveys to determine disease prevalence (568).

7.2.7 Information from the private providers

Regrettably, the DHIS of Pakistan or other LMICs usually do not contain data from the private sector. DHIS only comprised data from the public health facilities and underrepresent findings, for example disease burden, of the whole population in a region. Private providers, often, are weakly interconnected with national HIS (628). Data on private spending and utilisation of private providers suggested that large private health business markets prevail in LMICs due to great demand of private sector care for many reasons, such as, private providers are geographically more accessible than public providers, adhere to patient privacy, provide fast service and offer good quality healthcare (628). Generally, private providers in LMICs' mixed health systems are poorly organised, therefore, governments find it extremely difficult and costly to interact and collect key information from private providers, to regulate quality and involve them in policy making because of lack of resources (such as finance), provider fragmentation and lack of systematic process for collecting data (440). On the contrary, there were some cases in which private providers resist sharing health information with the government, for example, findings from a survey of private actors in Ghana revealed that they hardly share data because no incentives were offered, and when they shared data, they received little feedback (629). Furthermore, donors have often been more active than governments in collecting information about private care (440). For example, the private sector partnerships – One Project by USAID funded several private sector assessments in many LMICs and built a searchable database of the private sector projects of family planning, reproductive health and HIV/AIDS (630)

Moving ahead, governments should come forward to prioritise and drive data collection activities from private providers in order to make policies and decisions based on the data that represent the whole population.

7.2.7.1 Information from the private providers: Example of the US for LMICs

Also, the US mixed health system encompassed with achievements and challenges can be a good example for LMICs that shows how to involve private providers in data collection and HIE. In the US, private companies help in data collection because data is valuable to them in improving their own services, securing their market share, and achieving business targets through better marketing (440). In the same way, there are some private companies in LMICs such as pharmaceutical companies, medical product vendors and NGOs with good reputation, interested in knowing about private providers and the extent and type of care provided, in order to market their products and distribute their health interventions. It will be helpful for the governments of LMICs to consider making partnerships with these types of organisations to collect information because they may also provide some or all the resources such as funds, technology and capacity to collect information (440), although caution is required as the drivers and ultimate goals for commercial companies are sometimes not the same as those of governments. Further, data are also be provided by large provider groups in the US, for example Kaiser Permanente Medical Group, to manage and improve clinical effectiveness and healthcare marketing (631). LMICs too could collect information by establishing partnerships with larger provider hospital systems (440), for example the Fortis group in India that have an induced motivation to collect data to know about the potential referral providers.

The strong financial incentives to participate in Medicare and Medicaid promote coordinated care among providers to improve care and deliver data to the government (632, 633). Almost all the providers in the US participate in Medicare and receive payments from the government against the claims data reported. Similarly, the providers in LMICs will be more likely to register and share information if LMICs start to pay for care through national insurance system. Few of the examples of LMICs that provide care to its people through national insurance system are Ghana (634) and India (571), whereas Pakistan plans to introduce national health insurance scheme by the end of 2015 (570).

7.2.8 Investment needed for HIE

Generally health is a local matter first rather than a global one. No global model exists of a health system that may fit into any country. Challenges faced by LMICs are aggravated by three main factors (635). First, cost to develop their health systems in the same way as in HICs is unaffordable. Second, LMICs have double the disease burden of HICs. While they prioritise providing basic health service delivery and reducing cases of communicable diseases, they also have to confront the rise of non-communicable diseases due to an ageing population and unhealthy living such as smoking and misuse of alcohol. Third, the factors of demand and supply of healthcare delivery in LMICs are not balanced and are more complex than HICs. For example, violence, insecure environments, poverty and poor basic health delivery issues in Somalia aggregate to magnify demand for healthcare but poor infrastructure and lack of healthcare professionals weaken healthcare supply that could not balance increased healthcare demand.

Fortunately, HIE can both improve quality of services and reduce costs (636). All countries need to examine and measure three important domains of health – determinants of health, health system and health status – for planning, monitoring and evaluation of national programmes (45). Therefore, it is essential to invest in health information to restrain cost for three reasons (636, 637). First, making right investments on the basis of reliable epidemiological information and health system performance indicators can lead to cost savings. Second, the latest information on the delivery and operation of health services can increase efficiency and information based quality improvement techniques are well adopted in HICs. These are also gaining popularity in LMICs. Last of all, substantial cost cuttings in the health sector are due to use of HIT as found in HICs, for example, bringing timeliness, efficiency and cost-effectiveness of care through growing adherence to disease-burden guidelines and reducing the rate of medication errors, for example (638).

The importance of investing in health information is also supported by the post-2015 development agenda and the SDGs for the quality and availability of statistics essential to manage, design and monitor performance (29). Statistical systems in LMICs such as DHIS in Pakistan are vital elements for good governance. A total of US$1 billion per annum needs to be invested to develop and implement statistical systems in all 77 lower income countries across the world to support and measure SDGs (29). In addition, donors must carry on the contributions, around US$300 million per annum, to statistics, and further supporting country efforts by extra US$100-200 million (29). This investment is necessary to mobilise the data revolution in order to monitor improvement, hold governments liable and promote sustainable development across the world. But investing only in statistical systems will not be enough for the desired outcomes. Other areas that may help the data revolution may require new funding streams for capacity and resources, innovations, partnerships and leaderships, and data literacy and use (639).

A report, ‘Global Health 2035: A world converging within a generation’, published by the Lancet Commission on Investing in Health, states that to achieve ‘grand convergence’ in health in LMICs, investments must be increased for scaling up new and current health interventions, and also for the system that deliver these intervention (637). Strengthening systems is necessary to achieve “grand convergence” and should certainly require developing HIS and HIE (636).

7.2.9 Technology for HIE

To eliminate financial barriers, policy makers, donors and project implementers are seeking innovative approaches. The use of mobile phones and wireless technologies as well as improvements in their innovative applications can help address the challenges of availability, quality and financing of healthcare in LMICs (640, 641). The increase of mobile phone use and internet services coupled with low prices of services and devices in LMICs, allowed them to ‘leapfrog’ many stages of development, jumping directly from little or no landline services to the same or better mobile technologies used in HICs (635, 641). The diffusion of cellular networks in LMICs has surpassed the infrastructure of roads, transportation, water and electricity shortages (641).

From the systematic review it was found that mHealth HIE interventions have been used by many LMICs for various healthcare programmes. For example South Africa used it for the TB therapy to record and submit adverse events forms weekly (501), Uganda for HIV/AIDS care, calls and texts from peer health workers to higher level providers with patient-specific clinical information (502), India for reporting reproductive tract infections among women living in outlier communities (481), Ghana for midwives to access eHealth platform that captures data for managing patient care (512), Pakistan for pneumonia surveillance (641) and Tanzania for weekly reporting of confirmed malaria cases (497) (see Appendix 6). According to the WHO mHealth survey across member states, health call centres/ health care telephone helplines (59%), emergency toll-free telephone services (55%), emergencies (54%), and mobile telemedicine (49%) were the mHealth initiatives used most frequently universally (641).

Findings from my case study also emphasised the use and adoption of mHealth for HIE due to public pressure. The population of Pakistan, like other LMICs, is also influenced by media and mobile technology and majority of the population use smart phones for data and voice communication. The high number of mobile users exerts public pressure on health organisations to introduce HIE interventions using mobile phones. China and India are among the top LMICs with mobile connections increasing at a rapid rate and this outburst of mobile usage in LMICs provoked UNICEF to strengthen health programmes, such as accumulating feedback information form communities on access to emergency medication and water sanitation, based on mobile apps in around 190 countries (642).

Another opportunity is to provide affordability to the users with mobile apps. There is very large pool of free, cheap but useful apps available on Android, iTunes, Windows and other platforms. These mobile apps, for example ‘iBlueButton’ (643); ‘Medical and Health Records Caddy’ (644) and ‘Patient Access’(645), will provide affordable solutions for HIE especially in LMICs where out of pocket cost is high in healthcare expenditure (646).

Organisations in LMICs are adopting mHealth because it provides greater access to healthcare workers, improves capacity for health systems (through education and training of healthcare workers/staff on mHealth solutions to enhance end-user expertise; and promoting implementation, customisation and troubleshooting of mHealth platform to minimise costs and encourage ownership of the project), as well as delivering cost-effective technology solutions to many challenges such as lack of skilled healthcare workers, lack of timely and actionable disease surveillance, slow rates of information flow and reporting delays and poor drug inventory and supply chain management (647).

Therefore, mHealth HIE solutions have potential in both LMICs and HICs, however, they must be designed keeping in view the local context and requirements. It is important to highlight the potential of mHealth among decision makers in Pakistan and other LMICs.

7.3 Implications for future research and efforts required to promote HIE in Pakistan and other LMICs

7.3.1 Transferability of findings in other LMICs

Most essentially, outcomes of my research in Pakistan need to be verified in other LMICs to assess the transferability of my findings. This is most likely to take the shape of qualitative research because the focus of my research was to investigate HIE process and its deployment issues. However, the inclusion of quantitative methods (such as surveys and use of secondary data (statistical) from documents and HIS') will be useful to asses and evaluate the running HIE interventions such as surveillance systems or telemedicine in LMICs. There is also a need to conduct longitudinal studies investigating HIE initiatives following their implementation in LMICs to observe their benefits in extended timeframes and to analyse wide range of variables affecting these initiatives.

Although, the systematic review identified barriers and facilitators to HIE in LMICs, more research would be beneficial to explore the untapped impediments and enablers of HIE in other LMICs. For example an unexpected finding in my study of Pakistan was healthcare professionals' resistance to write medical records in order to save themselves from any liability or accident based on possible erroneous treatment and/or diagnosis. In addition, bad documentation skills of healthcare professionals also deterred the process of HIE. Another novel finding was the precarious national security of Pakistan (having borders with Afghanistan and India) with some providers/workers concerned that the health information of any of its regions leaked or was stolen by banned terrorist organisations or foreign intelligence agencies while exchanging it with international organisations, may give boost to terrorism or espionage activities (see Chapter 6) as happened when the location of Osama bin Laden was shared with the US Central Intelligence Agency (CIA) by running a vaccination drive in northern areas of Pakistan (597). It is likely that, such unexpected findings may be uncovered with further research based on different contexts, varying cultures, problems and fluctuating strategies in LMICs.

7.3.2 How to promote HIE in Pakistan and other LMICs

Policy makers in Pakistan or in other LMICs first of all want to know the anticipated costs for the implementation of HIE and the practical and tangible returns on its investment in order to buy HIE interventions. They will hardly give importance to the theory of HIE alone. HIE is a broad term encompassed by many modalities such as EHRs in hospitals and mHealth for field work and surveillance, it will may be easier to sell the modalities of HIE (such as health surveillance, health surveys, national health account analysis, hospital health records, civil registration and vital statistics (recording birth and deaths)) rather than the broad concept of HIE to policy makers. Next, it will be important to know and decide in which healthcare level – primary, secondary or tertiary care HIE should be implemented in Pakistan or in other LMICs. Secondary and tertiary care is better in terms of infrastructure and equipment than primary care and is capable of implementing and adopting HIE (see 'results' section in Chapter 6).

Champions of HIE need to convince policy makers and managers at the hospital or institutional levels and promote HIE by demonstrating its efficiency, effectiveness and the quality of healthcare it brings. Champions also have to provide software, hardware, trainings and technical resource to establish pilot projects of HIE in order to promote HIE in Pakistan and other LMICs as these projects will be the best advertisements of HIE. It will also be essential to decide which health sector – private or public to focus on. The challenges in the public sector are that it is difficult to work with public officials because they believe in status quo, they don't want change, they are happy as it is, improvement is not their priority, they are more interested in procedures than its products and outcomes (648, 649), however, government also includes sensible and good people who may welcome the idea of HIE. The size of the public health sector is bigger than the private health sector in Pakistan (see Chapter 6), therefore implementing HIE in the public sector will bring a dramatic change in the health sector in terms of quality and efficiencies which may induce private sector to adopt HIE and participate in the healthy competition. In contrast to the public health sector, it has been observed in LMICs such as Pakistan, Egypt and Iran, for example, that the private sector usually resists to adopt HIE or come under any regulation due to accountability and the tax-net (554).

After exploring the perceptions of stakeholders on the processes of HIE, next it will be important to know the types of HIE, such as EHRs or health surveillance, that will work most effectively in LMICs in the first instance. The successful implementation of any particular modality of HIE will enable the deployment of other HIE modalities on a larger scale. Therefore, further research is required to know the viable modalities of HIE.

7.3.3 Further research on interoperability and standards

More research is required on HIE and interoperability because it is required to ensure the social and economic benefits that can be availed by the adoption of widespread EHRs (650).

Organisations have started implanting and adopting EHRs but use different vendor specific-standards which cause issues to communicate between these systems. Without HIE and interoperability, health information will strengthen itself in propriety information silos, through which healthcare organisations hopes to reap more profits by inflicting high charges on patients switchover (650). From my findings on Pakistan, interoperability was the issue within or among the same hospital organisations (see Chapter 6). In addition, inter-organisational HIE rarely occurs between different hospital organisations in LMICs. To overcome communication issues between different systems, more research is also required on the development and adoption of data standards essential for HIE and interoperability because if standards are not built and consolidated in the near future, then all the efforts, for example, a generation of investment for the implementation and adoption of HIE will be useless (650).

7.3.4 Further research on key opinion leaders and similar groups (cohort)

But even after agreeing common standards, it is not really possible to force health organisations to adopt HIE and interoperability. As found in the study by Miller, larger hospitals in HICs are most likely to share patient information internally rather than sharing it externally with other hospitals (651). The research (651) suggested that the adoption of EHRs and the capacity of data sharing may not be adequate to realise the full potential of HIT in terms of enhanced health outcomes and lower healthcare costs. This gives a strong reason for government policies aiming to support electronic exchange of health information between boundaries of healthcare organisations. As my research included interviewing various healthcare stakeholders including citizens to explore the deployment strategies of

HIE, in future, it will be essential to explore the opinions of public leaders, politicians and bureaucrats in other LMICs to know their strategies, plans and policies for the adoption of HIE. Political leadership is the primary driver to promote HIE in LMICs as found through the systematic review (see Chapter 5) and case study (see Chapter 6).

Moreover, it will also be important to do more research exclusively on the perceptions of citizens or patients because the future of connected healthcare also include healthy patients, who are not ill, but though always connected through email, video chat, social media, or even email, for some routine check-ups or health maintenance (652). The future HIE has to adopt this culture to involve citizens in the process in order to save healthcare costs and improve health outcomes (652). From the case study (see Chapter 6), it was evident that public pressure will be the main facilitator of HIE, therefore, this area needs to be studied further as people have different beliefs on innovations in different regions. Finally, a study on donor agencies will also be useful because pressure from them to support evaluations will be an important additional source of HIE movement.

7.3.5 Further research to evaluate benefits and weaknesses of mHealth for HIE interventions in LMICs

Finally, I have found that mobile technology provided many mHealth solutions for HIE based on local needs and contexts, that undoubtedly provided numerous benefits in enhancing health outcomes for both the urban and rural populations in LMICs. Further research is required to evaluate the benefits and drawbacks of HIE interventions through mHealth in LMICs due to increasing use of this technology perceived to be cost-effective and efficient in areas with poor infrastructure and resources.

7.3.6 Recommendations to guide implementation of HIE to facilitate main challenges in Pakistan's health system

HIE implementation in Pakistan on a national scale is impossible in the foreseeable future due to many barriers as stated in Chapter 6. Moreover, HIE implementation has not yet been deployed on a national scale even in many HICs such as the failure of SCR in England which confronted numerous social and technical challenges such as the low adoption and usage by clinicians, implementation workload, very low public awareness and interest, and uneven geographical implementation of the programme (the SCR was implemented at some practices but not to adjacent ones) (132, 653-655).

However, many examples from Chapter 4 and Chapter 5 showed successful implementation of HIE in vertical healthcare programmes in both HICs and LMICs. Therefore, here I will recommend implementation of HIE for a few vertical programmes in Pakistan that need utmost attention such as polio, malaria/dengue and internally displaced persons (IDPs)

Pakistan along with Afghanistan and Nigeria are still endemic with polio virus (656) . Diffusion of polio virus from Pakistan pose a high risk to other countries. Pakistan has been facing international travel bans and require mandatory polio vaccination for all international travellers. Eradication of polio has been continued as a national emergency in Pakistan.

Similarly, monsoon floods every year present a high risk of malaria and dengue outbreaks to thousands of families surrounded by stagnant water. Around 177 million (98%) of the population are at risk of malaria/dengue with 3.5 million confirmed cases annually (657).

Also, since the commencement of military operation ‘Zarb – e – Azab’ against Taliban militants in 2014 and other related violence, more than 1.8 million people from the northern areas of Pakistan were forced to leave their homes and territories (658). IDPs, mostly women and children, face severe health hazards due to lack of sanitation facilities, hot weather, water-borne diseases and lack of reproductive health services.

7.3.6.1 BelowI discuss on these problems and their HIE solutions. Polio

7.3.6.1.1 Background and problems

The main reason that Pakistan could not eradicate the polio virus is the lack of coverage and information of vaccinated and non-vaccinated children (659). Pakistan lacks data on which citizens were vaccinated and which needed to be vaccinated (659). Information about health workers reaching underserved areas is not centralised which makes it difficult to realise what part of the population has been vaccinated and which areas need more attention. As a result , some children were immunised various times and some were never immunised because of isolated hard-to-reach areas and political instability (659).

Other factors responsible for low immunisation coverage in Pakistan is lack of security, lack of electronic records and population-based registries, low demand of polio vaccination among population, overestimated vaccine coverage, human errors, and lack of education about immunisation among guardians and parents (660).

7.3.6.1.2 Solutions

The main thing that is required to eradicate polio is to know about areas where polio is occurring and then vaccinating children in these areas. For this purpose, a centralised database should be developed to facilitate polio-related HIE. The database may contain data about polio cases, the size of the outbreak and the people affected. It may also contain information about the vaccination programmes. Data on reported polio cases and immunisations should also be collected form private healthcare stakeholders along with public healthcare facilities. This will enable wider polio coverage in Pakistan than the current coverage (which only covers public healthcare facilities) and will provide massive and complete data for analyses. The information may be used to build up new interventions for polio and provide better population estimates than the current parameters such as knowing the amount of vaccines needed for the affected areas.

Mobile phone texts, interactive voice response technology, and voice and video messages in national and local languages could be used as HIE modalities to educate parents and guardians about polio vaccination and surveillance. Stakeholders including religious and community leaders should also be involved in polio eradication activities because of the misconception people have about the polio vaccines (such as inclusion of ‘haram’ ingredients in vaccines). These measures could increase awareness of polio and may also increase demand of polio vaccines.

Geographic information system can be used to locate affected people in underserved and unmapped areas where there are hardly any roads and signage (660). Partnerships between mobile providers are essential to track health workers / vaccinators, volunteers and patients who have received vaccinations. The tracking may help stakeholders know in real time which areas have been visited by healthcare workers, how many children have been vaccinated, how many areas require to be visited, number of particular healthcare workers involved in immunisation in particular areas, and how many households refused to take vaccines which may further require contact to religious and community leaders to convince those families and counteract their refusal (661). Finally, mobile text messaging can be used to record polio cases along with position coordinates in a regional and/or national databases to keep track of the vaccinated population.

7.3.6.2 Malaria and Dengue

7.3.6.2.1 Problems

Pakistan is an endemic for malaria but the dengue endemic in 2011-12 in Lahore was a calamity which affected thousands (around 21000) of people. The provincial government of Punjab took assistance from Punjab Technolgy Information Board (PITB) to fight dengue. PITB developed a smartphone app that allowed dengue fighting teams to record their activities with geo-tagged pictures which were then displayed on a map for analysis with a spatial algorithm (662). Data analysis of spatial data showed emerging cases of dengue in regions that required immediate attention to take preventive measures (662). The intervention drastically helped to reduce number of patients to only 258 in the consecutive year (662).

Health departments responsible for tackling malaria and dengue throughout the country face many problems. A discussion with a federal officer looking after the malaria/dengue healthcare programme, raised many issues (apart from funding, supervision etc.) regarding eradicating these mosquito-borne viruses, which are given as follows.

First of all, the data is collected manually from BHUs and then entered into computer systems at district levels. The patients are registered on paper registers and there is no unique identification number for patients. The computer system existed as Malaria Information System but the users are uncomfortable using it mainly due to lack of training. Main transmission of malaria is from Novemebr to December (3 months) but due to late reporting and submission of data, decisions could not be made timely and effectively. Lack of inter-coordination among other ministries such as Ministry of livestock, Ministry of agriculture, Ministry of meteorological and irrigation department, is the biggest barrier in fighting malaria and dengue. For example, it is necessary to know from the agriculture department about the kinds and amount of pescticide used and cropping patterns of rice because rice fields are the breeding grounds for malaria and dengue. Similarly, rain forecasts are required from the meteorological department to take necessary measures against breeding of mosquitoes in standing waters.

7.3.6.2.2 Solutions

First of all, the HIE process should start from data collection by electronic means in order to avoid delays and data entry errors. Secondly, malaria/dengue patients should be given a unique identification patient number to record patient history including demographics.

EMR/EHR can be used in the primary care health facilities either through computers or mobile phones to record patients' demographics and history. Thirdly, inter-organisational sharing of data between other ministries will be helpful in making quicker and effective decisions in order to take preventive measures. All concerned ministries could be linked through a central database and the necessary information could be pulled up by the required stakeholders for their analyses and decision making. Finally, malaria/dengue data could also be linked with other vertical health programmes such as AIDS and TB. This is because people who have low immunity, such as an AIDS patient, will act as a reservoir to these parasites and will help mosquitoes to spread the disease to other humans.

7.3.6.3 Internally-displaced persons (floods and war on terror)

7.3.6.3.1 Problems

IDPs require additional support in reproductive health interventions that include female doctors and nurses, reproductive health kits, lady health workers and laboratory personnel (663). Also, healthcare centres are required to treat malnutrition complications (663). Healthcare facilities face a shortage of medical supplies, trained human resources and lack of capacity building of clinical staff (663). The following issues were raised after discussing IDPs' problems with the public officer in the Provincial Disaster Management Authority (PDMA) who also had work experience of the National Disaster Management Authority (NDMA).

- Information exchange is usually paper-based from primary healthcare facilities to Distict Disaster Management Authority (DDMA). Information exchange through emails started three years ago.
- Emails do not have a legal cover, therefore paper documents are necessary to fulfil the formality.
- NGOs, local institutions, government organisations and local communities all contribute in the disaster management but there is no central database or dedicated network that connects these stakeholders for decision making and taking actions.
- Lack of awareness of communication technologies.
- Lack of training of staff.
- Time bounded (no 24 hour service).
- No legal routes dedicated for communication between departments of district, provincial and national government.

7.3.6.3.2 *Solutions*

Reliable data collection of IDPs is the utmost step to facilitate HIE to make necessary analysis. Demographic data, socio-economic data, and protection data are required to implement feasible solutions for IDPs (664). For example, demographic data is essential to know gender and age brackets; to identify vulnerable populations such as disabled, separated children, and female-headed families; and to evaluate the needs and priorities of the community. Similarly, socio-economic data facilitates to understand the health, job, education and infrastructure requirements. Protection data identify, for example, legal status, right to return, access to social services and property rights of the IDPs. Moreover, institutional data is also required to evaluate the capacity of local and national authorities in order to provide reasonable solutions for the IDPs (664).

Telehealth and telemedicine interventions of HIE shall be used to cater the over-burdened healthcare facilities, shortage of clinical staff and healthcare professionals. Training should be provided to the local community to assist clinical staff and professionals. Surveillance and monitoring of medical equipment/supplies and staff may ensure the effective use of resources and may help in reducing mismanagement and corruption.

For the DDMA, PDMA and NDMA, an e-government framework should be implemented to facilitate the legal communication barriers between them. Moreover, electronic information should be given the same legal status as the paper-based information. Development of a dedicated network between all the stakeholders (NGOs, local communities, organisations, for example) may be essential to enhance decision making abilities. Finally awareness of technologies should be raised among users and adopters through training in order to make proper and effective use of HIT and communication technologies to address the needs of IDPs.

7.4 Conclusion to thesis

The progression of HIE definitions showed that it is an evolving concept and furthermore that uses of the term vary across settings, presenting challenges for communication. Developing a generic term is difficult, given the importance of context, but I have suggested an adapted definition that encompasses almost all the 11 key underpinning themes. Using constructs from a large pool of definitions and characterising HIE into two over-riding concepts, a process of information transfer and exchange (works both in HICs and LMICs) and an organisation that oversees the business and legal issues pertaining to HIE process (usually found in the US and other HICs; and health ministries of LMICs running DHIS or using HIE for vertical healthcare programmes, for example), makes the proposed definition operational worldwide for both HICs and LMICs. This is because the HIE trend is expected to spread in the near future due to efforts of international organisations such as UN to achieve SDGs that may provoke the establishment of HIE organisation especially in LMICs to measure individual country performances. Moreover, I believe that donors such as WHO should enforce countries receiving funds to instigate HIE processes and launch organisations that may provide donors with some information on the effectiveness of their efforts. In order to encourage the use of this definition, I intend to use and publish it in my papers from this research.

Understanding the underpinning constructs of HIE, helped in reviewing the literature systematically to identify barriers and facilitators to HIE in LMICs. Despite of scarce resources and poor capacity, I found many successful models of HIE interventions running for specific health programmes only (such as HIV/AIDS, TB, malaria and RTI) in LMICs such as Brazil, Kenya, Pakistan and South Africa, making use of cost-effective and open source technologies, namely, telemedicine/telehealth, HIS’, and mHealth. This suggests that if individual vertical healthcare programmes can be managed by different modalities of HIE in individual LMICs then serious efforts by key stakeholders would help implement HIE across the whole health systems of LMICs.

Governments of LMICs should realise the potentials of HIE and the benefits it can bring to the people and state through process and cost efficiencies. They should come forward to minimise corruption and insecurity through accountability, effective policies and show strong leadership in order to promote evidence-based decision making culture and making efficient use of investments from national and international funding streams. Undoubtedly, investment is required to build up the poor infrastructure, increase organisational capacities such as providing equipment and trainings to staff and professionals keeping in view their needs and working environments. Along with supervision and feedback from the programme supervisors, abiding with data standards and using analysis tools, may help to improve quality of health information that in turn enhance healthcare quality and healthcare outcomes of individuals and population.

Based on the first two phases, I developed research questions, the sampling matrix and the topic guide to study the deployment strategies of HIE in Pakistan. HIE existed mainly in/among the hospitals of Pakistan in fragmented and patchy forms with both electronic and paper-based systems running in parallel in public and private hospitals but with better HIE processes in private and charity-based hospitals than in the public sector. Inter-organisational HIE existed between a few hospitals of the same and/or different hospital organisations. Public facilities usually exchange statistical health data from districts to national bodies through DHIS and get feedback reports through emails, mobile communication and websites. Barriers and facilitators to HIE in Pakistan were similar to the ones found in other LMICs. In addition to the efforts of government to build infrastructure and increasing organisational capacity, international organisations such as USAID are helping Pakistan and other LMICs in various fields such as energy, infrastructure (such as dams and roads), economic growth (harnessing private sector), agriculture (improving quality and productivity), and education (such as trainings to unskilled workforce and scholarships) (50). Hospital organisations such as teaching hospitals may conduct seminars and add informatics courses in their curriculum to equip healthcare providers with knowledge on informatics. Integration of vertical programmes running in the country may help discard repetitive and redundant information. Public pressure would also help to induce HIE in Pakistan due to the rising influence of media, mobile technologies and apps. Other findings revealed that the exchange and use of information without HIE caused many issues in terms of cost and health outcomes, therefore, stakeholders perceived HIE to have many advantages over other methods of exchanging and using health data.

I hope the analysis of HIE definitions may be of value to policymakers involved in planning, procurement and evaluation of HIE. In order to avoid further heterogeneity, I recommend that future researchers should study the results of HIE definitions review before coming up with any new definitions of HIE. In addition, the barriers and facilitators to HIE identified may help national and international healthcare stakeholders to plan effective strategies to implement HIE interventions in LMICs making the right choices and using appropriate resources. To end with, I believe more of the similar research will be beneficial in other LMICs to explore other unknown factors responsible for the success and failure of HIE because all LMICs vary in resources, culture, and contexts. It would be favourable to promote HIE interventions through collaborative governance and technical partnerships among LMICs and HICs.

“Without data, you’re just another person with an opinion.” -W. Edwards Deming, Data Scientist.

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Appendices

Appendix 1. Extracted definitions

S.No.	Author	Source	Year of Publication	Country	Definition
1.	1st PC (321)	Web page: 1st Providers Choice, Solution Provider	Unknown	US	Health Information Exchange (HIE) refers to the process of reliable and interoperable electronic health-related information sharing conducted in a manner that protects the confidentiality, privacy, and security of the information.
2.	4Med (331)	Web page: Educational Resource for Healthcare Information Technology	Unknown	US	Health Information Exchange (HIE) represents the transmission of healthcare-related data among facilities, health information organizations (HIO) and government agencies according to national standards. HIE is an integral component of the health information technology (HIT) infrastructure under development in the United States and the associated National Health Information Network (NHIN).
3.	Abhyankar et al (358)	Scientific	2010	US	Some regional health information exchanges (HIEs) provide web-based delivery systems that accept lab results messages from many sources (e.g. hospital laboratory, stand-alone radiology services) and deliver them in a uniform format to physician offices.
4.	Accenx (309)	Web page: Healthcare information technology & IT strategy news	2009	US	The Accenx Exchange is a health information exchange (HIE) services platform that brings the medical records in any given community much closer together by actually extending the reach out to the physician practices, hospitals and other healthcare organizations. It allows public or private HIEs to immediately establish a technology and service platform for sharing clinical results, orders and other patient information among providers using virtually any EMR system - or no EMR at all.
5.	Adler-Milstein et al (267)	Scientific	2011	US	Central goal of the legislation was to promote broad-based electronic HIE, in which key clinical data flow among providers and between providers and other stakeholders, such as public health departments.
6.	Adler-Milstein et al (199)	Scientific	2011	US	Health information exchange enables patients’ health information to follow them between delivery settings in order to support care coordination and avoid duplication of services. There is broad consensus that such connectivity is critical to improving care and reducing healthcare costs.

S.No.	Author	Source	Year of Publication	Country	Definition
7.	Adler-Milstein and Jha (149)	Scientific	2012	US	Health information exchange (HIE) is the act of sharing clinical data among health care practitioners and practice settings (physicians, hospitals, nursing homes, etc.) who are not part of the same organizational entity.
8.	Adler-Milstein et al (200)	Scientific	2013	US	Health information exchange (HIE) refers to the process of electronically transferring, or aggregating and enabling access to, patient health information and data across provider organizations. Exchange may take place between different types of entities, for example, e-transfer of patient data between ambulatory care providers or e-transfer of data at the regional level.
9.	AeHN (164)	Web page: Alaska eHealth Network	Unknown	US	Health information exchange (HIE) is the electronic sharing of health-related information.
10.	Afzal (216)	Conference: Maryland's Health Information Exchange. SOA in Healthcare Conference. The Role of Health Information Exchange in Driving Toward Interoperability	2011	US	Health Information Exchange, or HIE, allows clinical information to move electronically among disparate health information systems. The goal of HIE is to deliver the right health information to the right place at the right time—providing safer, more timely, efficient, effective, equitable, patient-centered care.
11.	AHA (388)	Report: Health Information Exchange Projects What Hospitals and Health Systems Need to Know by American Health Association	Unknown	US	Health information exchange enables hospitals to bring better information to the point-of-care and enhances opportunities for clinical decision support.
12.	AHIMA (319)	Web Page: American Health Information Management Association	Unknown	US	An HIE is the electronic movement of health-related information among organizations according to nationally recognized standards. HIE is also sometimes referred to as a health information network (HIN)

S.No.	Author	Source	Year of Publication	Country	Definition
13.	Alert (198)	Web page: Alert HIE, Provider		Portugal (Head Office)	ALERT® HIE is an integration infrastructure that provides the ability to access patient clinical records from different healthcare facilities located in different geographical areas.
14.	Altman et al (244)	Scientific	2012	US	HIE enables digital, clinical information sharing among disparate institutions, which allows for a more seamless transition of care between providers. With HIE, patients can have their existing clinical information viewed by providers across different healthcare organisations, keeping all of their providers informed. Using HIE, community clinicians can also follow their patients' interactions with participating hospitals in real time.
15.	AMA (219)	Web page: American Medical Association	Unknown	US	Health Information Exchanges (HIEs) are entities that bring together health care stakeholders within a defined geographic area and govern the electronic sharing of health information among them for the purpose of improving health and care in that community. The fundamental concept behind creating HIEs is that the ability to exchange health information electronically is critical to the efforts to improve the US health care system.
16.	Amatayakul (324)	Web page: Healthcare Financial Management business journal	2008	US	HIE organizations go by different names-local health information organizations (LHIO), regional health information organizations (RHIO), sub-network organizations (SNO)--they serve the same purpose: to oversee and govern the exchange of health-related information among disparate stakeholders for the purpose of improving health and health care.
17.	Ancker et al (285)	Scientific	2012	US	Health information exchange (HIE), the exchange of electronic patient data among healthcare providers and institutions, is being promoted by national policy because of its potential to improve healthcare quality and efficiency, engage consumers, and promote population health.
18.	ArkansasOHIT (308)	Web page: Arkansas Office of Health Information Technology	Unknown	US	The Arkansas State Health Alliance for Records Exchange (SHARE) is a statewide health information exchange (HIE) that solves this problem. SHARE allows primary health care providers, related health services professionals, and public health authorities to access and exchange with each other real-time, electronic patient information that is secure and protected by current federal and state privacy and security laws. Through its implementation and use, SHARE will reduce medical errors and duplicate testing, promote improved management of chronic diseases, and improve patient care coordination among unaffiliated health care providers.

S.No.	Author	Source	Year of Publication	Country	Definition
19.	Aspelin (220)	Web page / Post: Mark Aspelin, Health IT Manager / Writer	Unknown	US	Health Information Exchange (HIE) is a term that is used to describe the sharing of health information electronically among two or more entities. The term is also used to describe an organization that provides services that enable the electronic sharing of health information. The concept of a health information exchange is a critical element of Meaningful Use, and the future of healthcare reform at the local, regional, and national level.
20.	Axolotl Corp. (311)	Web page: Axolotol Corporation provider for browsing based-products	2009	US	NeHII is a statewide Health Information Exchange designed to share clinical and administrative data among providers in Nebraska and neighboring states. NeHII's purpose is to achieve health care transformation through community betterment collaboration while protecting the security and privacy of medical information.
21.	Barton et al (188)	Scientific	2006	Australia	The HIE is the department's corporate network of data warehouses. It contains data on surgical procedures on inpatients and international classifications of diseases, 10th edition (ICD-10) diagnostic codes, and records episodes of care and contains information on diagnosis, procedures and some demographic items
22.	Birkle et al (178)	Scientific	2011	Germany	Healthcare Information Exchange Networks (HIEN) enables the exchange of medical information between different institutions.
23.	Bostick et al. (318)	Report: Sustaining Health Information Exchange: A State Toolkit by National Governors Association Center for Best Practices State Alliance for eHealth	2011	US	The term "health information exchange" (HIE) refers to the electronic movement of health-related information among organizations such as health care providers, public health agencies, and payers, according to nationally recognized standards.
24.	Bouhaddou et al (245)	Scientific	2012	US	Health information exchange (HIE) refers to the activity of secure health data exchange between two authorized and consenting trading partners. It is a secure data service that utilizes nationally recognized standards to enable electronic transport of clinical information among separate health care organizations that are motivated by common interests and governed by rules that ensure the rights of patients and participants are protected.

S.No.	Author	Source	Year of Publication	Country	Definition
25.	Boyle (186)	White paper: Privacy Lessons Learned from an Operational Health Information Exchange by FairWarning	2011	UK	Health Information Exchanges (HIEs) which facilitate the electronic exchange of patient information between care providers at a provincial, state, regional or national level.
26.	Braithwaite (166)	Scientific	1998	US	Workgroup Electronic Data Interchange (WEDI), a coalition of representatives from various components of the health care industry, including insurance companies, managed care organizations, health care provider organizations, government agencies, and health care clearinghouses.
27.	Bredfeldt (359)	Scientific	2013	US	Electronic health information exchange (eHIE) facilitates coordination of care by enabling information transfer across providers and medical clinics. By increasing care coordination, eHIE is expected to reduce healthcare costs resulting from redundant lab tests and radiology studies.
28.	Bresnick (355)	Web page: ehrintelligence.com for latest technology news and white papers / Article	2013	Unknown	Health information exchange (HIE) makes many promises: a complete, structured, electronic patient record, available to any provider at the push of a button, instantly updated and always reliable.
29.	Bugge et al (185)	Scientific	2006	UK	Information exchange between patients and health professionals is fundamental to achieving patient participation in decision-making and shared decision-making is said to require the exchange of “all information relevant to decision-making”.
30.	Byers (163)	Scientific	1957	US	The Occupational Health Information Exchange will serve as a central agency for the collection, collation, and dissemination of all types of information pertinent to occupational health problems.
31.	Cannoy (179)	PhD Thesis: The Implications of HIE on Healthcare Consumers: The Case of Consumer Empowerment.	2008	US	The capability to use technology to electronically exchange medical records is called Healthcare Information Exchange (HIE). HIE is the process of utilizing information systems and technology for electronic storage, retrieval, and sharing of healthcare information among participants in the healthcare system so that information is accessible at the point of care.

S.No.	Author	Source	Year of Publication	Country	Definition
		Business Education Department, North Carolina A&T State University			
32.	Care Accord (327)	Web page: Oregon HIE	Unknown	US	Health information exchange (HIE) allows doctors, nurses, pharmacists and other health care providers to securely share a patient's medical information electronically — reducing the need for patients to transport or relay their medical history, lab results, images or prescriptions between health professionals. Instead, this information is shared between health care professionals before the patient arrives for an appointment or goes to the pharmacy. HIE can also reduce orders for duplicate procedures or tests because information is available where and when it is needed, as well as enabling smoother transitions of care because providers, hospitals and long term care facilities can more easily share information.
33.	Carter (426)	Scientific	2006	US	There are a multitude of terms currently used to describe a networked community of healthcare entities using interoperable electronic health record systems to exchange health information. These include regional health information organization (RHIO), health information exchange (HIE), the nationwide health information network, and at one time, community health information network.
34.	CDC (256)	Presentation: Department of Health and Human Services, USA / Centre for Disease Control and Prevention	Unknown	US	HIE provides the capability to electronically move clinical information between disparate health care information systems while maintaining the meaning of the information being exchanged. The goal of HIE is to facilitate access to and retrieval of clinical data to provide safer, more timely, efficient, effective and equitable, patient-centered care."
35.	Centricity (275)	Web page: eHealthserver News, GE Healthcare, a division of General Electric Company and global eHealth specialist	2009	US	Centricity® Health Information Exchange services connects, stores and shares clinical data from hospitals, physician offices, pharmacies, labs and other sources to help improve communication flow between care providers and patients and clinicians. The resulting network enables state, government or healthcare delivery organizations to create a secure exchange to share patient conditions, allergies, medication history and other appropriate clinical data across the continuum of care.

S.No.	Author	Source	Year of Publication	Country	Definition
		InterComponentWare, Inc. (ICW) joint HIE			
36.	Cerner (381)	Web page: Cerner, Solution Provider	Unknown	US	Clinical Exchange Platform is a major Cerner Network offering that focuses on the secure exchange of critical patient summaries within the clinician’s workflow. Clinical Exchange Platform leverages a suite of open source solutions brought together by proprietary intellectual properties creating a low cost IHE Standards based exchange.
37.	Chaudhary (343)	Scientific	2012	US	Health Information Exchange (HIE) is the process of reliable and interoperable electronic health record (EHR) sharing, conducted in a manner that protects the confidentiality, privacy, and security of the information.
38.	Cisco (183)	Webpage: Cisco, Solution Provider	Unknown	US	The Cisco Medical Data Exchange Solution (MDES) is an integrated end-to-end, standards-based solution that facilitates patient-centric access to medical records. It gives healthcare professionals from multiple institutions access to patient data from previously disconnected systems with incompatible formats and disparate medical terminology. Now providers can quickly and easily access and review a patient's medical data gathered by different applications and stored in separate locations.
39.	Citius Tech (396)	Web page: Technology and Solution Provider	Unknown	US	Health Information Exchanges (HIEs) offer significant opportunity for cross enterprise document sharing in healthcare – positively impacting both quality and cost of healthcare delivery. HIEs provide flexible data sharing capabilities with hospitals, public health and federal reporting entities. HIEs can also offer strong analytics and reporting capabilities to track population health and support a wide range of clinical decision support capabilities.
40.	C. Kibbe (282)	Web page / Post: The Society for Participatory Medicine, e-patients.net	2009	US	Health information exchange between and among providers, especially when these providers are independent entities or exist in separate geographical locations, helps create continuity of patients’ experience by providing continuity of information flow and access where once there were only isolated silos of health data. There is widespread belief that health data sharing could improve care, safety, and decrease waste and duplication.
41.	C. Livingood et al. (393)	Report: Public Health & Electronic Health Information Exchange: A Guide To Local	Unknown	US	The focus on electronic health information exchange (EHIE) emphasizes how data can best be shared and utilized across healthcare institutions and among providers to improve patients’ health, improve the quality of care, increase efficiency, and reduce costs.

S.No.	Author	Source	Year of Publication	Country	Definition
		Agency Leadership by The Institute for Public Health Informatics and Research Duval County Health Department			
42.	Clemens (303)	Scientific	2012	US	Health information exchanges, in which all individual patient information is routinely and entirely managed through a central information system
43.	Clinical Connect (400)	Web page: Clinical Connect is a western Pennsylvania's first HIE	Unknown	US	ClinicalConnect is western Pennsylvania's first Health Information Exchange (HIE). A partnership of leading regional health care providers, ClinicalConnect will help to improve the safety, quality, and efficiency of care for patients throughout the region by securely connecting clinicians with patients' vital electronic medical records
44.	Codagnone (9)	A study prepared for the European Commission	2013	European Union	Health Information Exchange (HIE): is the process of electronically transferring / sharing / enabling access to patient health information and data.
45.	CORHIO (305)	Report: HIPAA and HIE by Colorado Regional Health Information Organization	Unknown	US	CORHIO's HIE makes it possible for providers to access and exchange patient information electronically, improving patient safety and reducing delays in care that can be caused when paper records are illegible, get lost, are accidentally destroyed by fire, flood or natural disaster, or are sent to the wrong fax machine or address. It also helps providers access more complete and up-to-date patient medical records, which is especially helpful in emergency situations or for patients who have a chronic medical condition for which they see many providers over the course of a year.
46.	CSC (189)	Web page: Healthcare Group / Service Provider	Unknown	Australia	CSC is taking a Health Information Exchange approach to enabling secure health data sharing between hospitals and other care providers. CSC's approach to Health Information Exchange (HIE) provides not only a solution to enable the many and diverse CSC applications for the eHealth agenda but also an agnostic design that will allow our partners and competitors to leverage this platform.
47.	Daurio et al (246)	Scientific	2009	US	An exchange of clinical information between Brooklyn hospitals, nursing homes, and home health agencies that aids in the transition of care for its shared patients.

S.No.	Author	Source	Year of Publication	Country	Definition
48.	Deas Jr and Solomon (405)	Scientific	2012	US	The term HIE is also used to describe formal organizations that provide the infrastructure for electronic exchange.
49.	De Brantes et al. (247)	Scientific	2007	US	Health information exchanges or regional health information organizations (HIEs or RHIOs) have emerged as vehicles to facilitate the flow of clinical information between providers in the community; they are building on the foundation laid by the pioneers in the field, the Indiana Health Information Exchange, the Inland Northwest Health System, HealthBridge and a few others. The primary business focus of these networks has sought to create value for the provider community by creating productive efficiencies. In doing so, they have been able to generate modest revenue, and therefore have achieved a modest but sustainable business model.
50.	Delfan (153)	Master Thesis: Computer Science Delft University of Technology	2013	Netherlands	Health Information Exchange (HIE) is a term used to describe the sharing of health information electronically among two or more entities. These entities are mostly organizations, which provide health services to their clients (the patients) and also enable the sharing of electronic health information. The exchange of medical data takes place primarily between different medical departments within the same health organization. This happens most of the time through an Electronic Health Records (EHR) system within the organization, but also across the organizational borders on the regional level (through Regional Health Information Systems, RHIS) or across the country (National EHR).
51.	Dimitropoulos and Rizk (419)	Scientific	2009	US	An interoperable system of HIE—that is, one in which various parties can share and exchange data among them.
52.	Dobbs et al (665)	Scientific	2010	US	HIEs would provide a unified view of a patient across health care providers and would serve as data collection points for clinical and resource utilization data.
53.	Downing et al (666)	Scientific	2010	US	Collaborative relationships among primary care and specialty providers and their patients and families can be enhanced through electronic HIE.
54.	Dullabh and Hovey (204)	Scientific	2012	US	There is widespread consensus that Health Information Exchange, the electronic sharing of patients' health information between delivery settings, is critical to improving the quality and efficiency of patient care.

S.No.	Author	Source	Year of Publication	Country	Definition
55.	eHealth Initiative (420)	Report: Health Information Exchange: From Start Up to Sustainability by Foundation for eHealth Initiative	2007	US	"Health information exchange" describes a commonly understood activity: the sharing of patient care data between non-aligned health care organizations for the purposes of enhancing quality and efficiency.
56.	eHEalth Initiative (206)	2011 Report on Health Information Exchange: The Changing Landscape	2011	US	The act of transferring health information electronically between two or more entities.
57.	eHealth Privacy 360 (212)	Web page: California Government	2011	US	The electronic exchange of health information allows your health care information to be shared between health care providers. This exchange is done through the EHR system. Your health information may be exchanged between doctors, laboratories, hospitals, pharmacies, and other providers you have visited. Health information from your health plan may also be exchanged and used for your care.
58.	Emdeon (378)	Web page: Vendor / Solution Provider	Unknown	US	Emdeon connects physicians, hospitals, pharmacies and labs to securely exchange information when it can save the most money and provide the most benefit - right at the point-of-care. Emdeon, currently performing more than 6.4 billion health information exchanges per year, makes the process of sharing information easy, efficient and affordable.
59.	Excelicare (187)	Web page: Axsys Health, Excelicare Solution Provider	Unknown	UK	Excelicare™ Clinical Portal allows users to explore information relevant to the care of every patient, regardless of where it was first recorded. As a care-giver, the portal offers you a composite view of patient information, in a clinically relevant format, with hyperlinks that let you drill to underlying details. Laboratory results and outstanding orders, recent medications and prescriptions, x-ray images and reports from radiology, coded problem list, clinical notes from any specialty – all these are presented in an easy-to-access, relevant way. But it doesn't have to stop there. Referral and discharge letters, GP notes, appointments, assessments, clinical alters, and information from community health can be included.
60.	Finn (214)	Scientific	2011	US	Health information exchange (HIE) is defined as the mobilization of health care information electronically across organizations within a region or

S.No.	Author	Source	Year of Publication	Country	Definition
					community. It provides the capability to electronically move health information between various systems, while maintaining the authenticity and accuracy of the information being exchanged. This sharing of critical and administrative health data electronically enables a care team to make more informed decisions. HIEs are multi-stakeholder organizations that oversee the business and legal issues involved in the exchange of information. The stakeholders are diverse and generally include large doctor groups, solo practices, competing hospitals, and payers. Patients have been visibly absent from the discussions, interactions, and agreements that form and run these HIE organizations. Patient access to their own information from an HIE has also been limited, but that promises to change over time.
61.	Florida HIE (297)	Web page: Florida HIE	Unknown	US	The Florida Health Information Exchange (HIE) provides entities with timely, secure, and authorized exchange of patient health information. The services we offer are based on national standards for secure exchange of health information.
62.	Florida HIN (240)	Web page: Florida Health Information Network	Unknown	US	The Florida Health Information Exchange (Florida HIE) enables the secure exchange of health information. It allows authorized medical providers to quickly and efficiently review their patients' medical records to facilitate diagnosis and treatment.
63.	Forcare (190)	Web page: Dutch software company providing software products and service for healthcare	Unknown	Netherlands	A Health Information Exchange is a network, allowing our customers to exchange medical data to support key clinical processes. Examples include imaging networks, referral networks and communication to GPs. An HIE can be built around a single hospital, or can cover a regional or national group of healthcare institutions.
64.	Frankel et al (196)	Scientific	2013	Israel	The vertically integrated Clalit Health Services seeks to completely open information exchange between hospital and community care by providing a single medical informatics system across the spectrum of care.
65.	Frisse (205)	Scientific	2010	US	This model — often called a health information exchange — differs from others in that the collection of health information exchange services commonly is managed through a designated legal entity, and data may be accessed from a highly secure set of services that provides the performance and simplicity of a centralized database.

S.No.	Author	Source	Year of Publication	Country	Definition
66.	Frisse et al (424)	Scientific	2012	US	HIE is a set of services that supports access among parties who are motivated by common interest and governed to ensure that the rights of patients and participants are protected.
67.	Furukawa et al (365)	Scientific	2013	US	Electronic health information exchange can improve care coordination for patients by enabling more timely and complete sharing of clinical information among providers and hospitals.
68.	GAO (218)	Report: Health Care Entities' Reported Disclosure Practices and Effects on Quality of Care by United States Government Accountability Office Washington, DC 20548	2010	US	Health information exchanges–entities that were formed to facilitate the electronic sharing of patients' health information among providers.
69.	Gadd et al. (268)	Scientific	2011	US	Its goal was to create an HIE that meets the basic needs of an underserved metropolitan region through exchange of clinical data among hospital emergency departments and community-based ambulatory clinics.
70.	Gaebel (304)	Web page / Post : HIMSS HIE Wiki	Unknown	US	A Health Information Exchange (HIE) assists with the transfer and sharing of health related information that is typically stored in multiple organizations, while maintaining the context and integrity of the information being exchanged. An HIE provides access and retrieval of patient information to authorized users in order to provide safe, efficient, effective, and timely patient care.
71.	Gartner (262)	IT Glossary: Gartner, Inc. Research and Advisory Company	Unknown	US	A health information exchange (HIE) is a regional collaboration among independent healthcare organizations for sharing clinical information. Often, administrative information is shared as well. HIEs may be categorized in terms of their approach to governance. In some countries, they may be run by a governmental agency. Other HIEs may be run by nonprofit corporations with a board of governors that represent community stakeholders. Still others are lines of business of for-profit vendors. A final form of HIE is funded and controlled by healthcare delivery organizations (HDOs) to meet

S.No.	Author	Source	Year of Publication	Country	Definition
					their own business concerns, rather than being neutral to all community stakeholders.
72.	Gassert (264)	Scientific	1996	US	Mobile computing technology (MTC) could provide older cardiac surgery patients with a portable computer system to be used at home for accessing, collecting and transmitting clinical information related to their recovery.
73.	Geissbuhler (197)	Scientific	2013	Switzerland	The transparency resulting from a streamlined exchange of information may improve the continuity, quality and efficiency of care, while, at the same time, reveal and challenge habits and practices of care professionals and of citizens.
74.	Genes et al (286)	Scientific	2011	US	Health Information Exchange (HIE) has the potential to improve patient care by bringing relevant patient data to the point of care. HIE seems particularly promising in emergency departments (EDs), where patients frequently present outside their usual medical home and outside the normal hours during which primary care doctors, pharmacies or insurers can typically be reached
75.	Georgia HIV HIE (373)	Web page: HIV HIE, Georgia Department of Public Health	Unknown	US	HIE proposes to develop and implement a system to alert healthcare providers of a patient's "out-of-care" care status so that they can re-engage them in HIV care. By improving linkage to and retention in care, and encouraging adherence to antiretroviral therapies, HIE will support clinical efforts to reduce viral loads and achieve an "undetectable viral load" or viral suppression.
76.	Grannis et al. (397)	Scientific	2010	US	HIEs standardize, aggregate and streamline information sharing among data partners, including public health stakeholders, and HIE has supported public health practice in Indiana for more than 10 years.
77.	Greenhalgh et al. (18)	Scientific	2013	UK	A nationally-accessible electronic record (known in the USA as health information exchange).
78.	Grinspan et al.(170)	Scientific	2013	US	NYCLIX (New York Clinical Information Exchange), a regional health information organization (RHIO) that draws clinical data from several New York City hospitals.
79.	Grossman et al. (294)	Scientific	2008	US	Local health information exchanges (HIEs) hold the promise of collecting patient clinical data across sites of care to provide more complete and timely information for treatment, as well as supporting quality improvement and reporting, public health activities, and clinical research

S.No.	Author	Source	Year of Publication	Country	Definition
80.	Gulf Coast(387)	Web page: Gulf Coast HIE / Company	Unknown	US	Health Information Exchange (HIE) is the term used to describe large-scale electronic communication of patient information between unaffiliated healthcare providers.
81.	Haggstrom and Doebbeling (394)	Scientific	2011	US	Information exchange offers the potential to pool a single patient's data across multiple institutions; conversely, information exchange allows institutions to aggregate their own data across multiple patients. Patient-level aggregation offers the promise of improving clinical care across a fragmented health care delivery system, while institution level aggregation has the potential of serving as a data infrastructure for quality measurement.
82.	Halamka (356)	Scientific	2013	US	Intuitively, health information exchange should improve safety, quality, and efficiency by providing emergency department (ED) clinicians with accurate lifetime medical histories, up-to-date test results, and evidence of previous problematic therapies. However, studies demonstrating these benefits are few.
83.	Hall (290)	Electronic Article: Diagnostic Intelligence and Health IT Initiatives College of American Pathologists	2009	US	Broadly defined, a Health Information Exchange (HIE) exists whenever two or more organizations share healthcare related information electronically. Exchanging healthcare information between organizations improves patient care and reduces costs by fostering collaborative care and reducing administrative burden.
84.	Harris (239)	Web page: Harris Healthcare Solutions	Unknown	US	Harris enables IDNs, physician practices, medical groups and other care providers to exchange health information as never before, empowering provider collaboration - send and receive results and discharge summaries, exchange information on orders, engage in clinical messaging and share documents. Such data exchange is increasingly important as organizations respond to delivery-system reform by transitioning to new models such becoming an Accountable Care Organization (ACO).
85.	Hasman et al. (167)	Scientific	1992	Netherlands	Electronic Data Interchange (EDI) is a reasonable substitute of the traditional mail for the communication between hospital and GP. It will lead to higher quality of data and to new applications that will enhance the quality of care.
86.	Hazamy et al. (173)	Scientific	2013	US	HEALTHeLINK, a clinical data exchange system to share patient information as a way to improve patient care.

S.No.	Author	Source	Year of Publication	Country	Definition
87.	HC (306)	Web page: Greater Houston Health Connect, Greater Houston Health Information Exchange (GHHIE)	Unknown	US	A health information exchange is a network of electronic health records designed to link all providers in a specific region. With this network, patient information moves electronically between physicians, hospitals, labs and pharmacies.
88.	(332)Healthcare IT (332)	Web page: Healthcare IT News	Unknown	US	Health information exchange is the transmission of healthcare-related data among facilities, health information organizations and government agencies, according to national standards for interoperability, security and confidentiality. It is an important part of the health information technology (HIT) infrastructure under development in the U.S., and the associated National Health Information Network (NHIN).
89.	HealtheLink (169)	Web page: HealtheLink is a non-governmental, multi-stakeholder RHIO	Unknown	US	HEALTHeLINK, the Western New York Clinical Information Exchange, is collaboration among the region's hospitals, physicians, health plans and other health care providers to serve the eight counties of western New York State. HEALTHeLINK was created to enable the exchange of clinical information in secure and meaningful ways to improve both efficiency and quality, while also helping to control health care costs. Patients who provide consent allow physicians and providers directly involved in their treatment to securely access relevant medical information via HEALTHeLINK, resulting in more timely and effective treatment at the point of care.
90.	Health Insights (348)	Report: Public Perception and Utah's Clinical Health Information Exchange, based on consumer focus groups conducted by Health Insights	2011-2012	US	One of the first state-run Health Information Exchanges (HIEs), cHIE allows healthcare providers to share their electronic health records (EHRs) to better coordinate patient care
91.	Health IT(15)	Web page: HealthIT.gov	Unknown	US	Health Information Exchange allows health care professionals and patients to appropriately access and securely shares a patient's vital medical information electronically. There are many health care delivery scenarios driving the technology behind the different forms of health information exchange available today.

S.No.	Author	Source	Year of Publication	Country	Definition
92.	Health IT(15)	Web page: HealthIT.gov	Unknown	US	Electronic health information exchange (HIE) allows doctors, nurses, pharmacists, other health care providers and patients to appropriately access and securely share a patient’s vital medical information electronically—improving the speed, quality, safety and cost of patient care.
93.	Health Leaders (335)	Web page: Health Leaders is a multi-platform media company to meet the information needs of health professionals	2009	US	The Exchange is an electronic health information system that will allow for the exchange of digital medical records between healthcare facilities, doctors' offices, and the Kentucky Department.
94.	Health Unity (398)	Web page: Vendor / solution Provider	Unknown	US	The HealthUnity HIE solution provides a one-stop solution for enabling seamless bidirectional communication between a wide array of entities including various types of providers, patients as well as public health. Services we provide include secure messaging, record location service, analytics service, results delivery service etc.
95.	Hersh (207)	Scientific	2009	US	Health information exchange (HIE), which is the exchange of health information for patient care across traditional business boundaries in health care
96.	Herwehe et al (334)	Scientific	2012	US	The Louisiana Public Health Information Exchange (LaPHIE) is a novel, secure bi-directional public health information exchange, linking state-wide public health surveillance data with electronic medical record data.
97.	HHS (281)	Report: National Biosurveillance Strategy for Human Health V2.0 by Centers for Disease Control and Prevention, US Dept. of Health and Human Services	2010	US	Electronic health information exchange is defined as the sharing of digitized human health data and information according to nationally recognized standards among organizations that can utilize the information to improve individual and community health security.
98.	HIE Answers (295)	Web page: HIE Answers, Advancing Health Information / Online knowledge resource	Unknown	US	Health Information Exchanges are typically categorized by how a patient’s health information is stored and how the legitimate members or participants can access patient health information.

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99.	HIE Bridge (261)	Web page: A Minnesota certified HIE by a certified HIO	Unknown	US	HIE-Bridge™ is a Minnesota state certified health information exchange (HIE) allowing providers to locate and access key clinical information that is vital when making medical decisions. Through HIE-Bridge health providers have access to authorized patient information through a secure web-based information exchange platform.
100.	HIECC (224)	Meeting: Meaningful Health Information Exchange by Health Information Exchange Coordinating Committee (HIECC) and State Electronic Prescribing Advisory Panel (SEPAP)	2009	US	“Meaningful health information exchange” refers to achieving a high level of participation in electronic health information exchange among hospitals, clinics, physicians, public health facilities, other health care providers, health plans and state agencies including data from health encounter claims, provider health records and state registries that has a measureable effect on community health care including improved efficiency of care (224)management processes, enhanced patient safety, increased effectiveness of care, and a measureable effect on population health including reduced disease incidence and prevalence.
101.	HIE Nevada (390)	Web page: Health HIE Nevada, state-wide community HIE	Unknown	US	HealtHIE Neveda is the new state-wide community-based Health Information Exchange (HIE) that lets doctors’ offices, hospitals, clinic, labs, pharmacies and other healthcare profesionals easily access and share patient medical records quickly, securely and accurately at the point of care. The HIE helps Neveda health care providers improve the coordination and quality of patient care. Decisions can be made more quickly and with a greater understanding of patient history than ever before.
102.	HIE Ohio (370)	Summary of Ohio Revised Code Chapter 3798	2012	US	Health Information Exchange is defined as “any person or governmental entity that provides in this state a technical infrastructure to connect computer systems or other electronic devices used by covered entities to facilitate the secure transmission of health information.”
103.	HIMSS (316)	Report: Putting the HIE into Practice by HIMSS	Unknown	US	The electronic movement of health-related information among disparate organizations according to nationally recognized standards in an authorized and secure manner.
104.	HIMSS HIE Committee (165)	Report: HIE Implications in Meaningful Use Stage 1 Requirements, by HIMSS	2010	US	In its most conservative definition, HIE (the verb) is the activity of secure health data exchange between two authorized and consenting trading partners. Data exchange occurs between any two trading parties—a data supplier and a data receiver. It can also be facilitated by one, two or more third parties who operate between the data supplier and the data receiver. To

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					add complexity, a third party could also be storing data from and on behalf of the data supplier and be transmitting data on behalf of the data supplier (in such case, the third party would be considered to be the data supplier). Further, a third party could be receiving data on behalf of a data receiver. While this may be complex, HIE activity can enhance virtually any clinical function by virtue of providing a broader set of data upon which clinical decisions can be based.
105.	HINAz (379)	Web page: Health Information Network of Arizona	Unknown	US	A Health Information Exchange, such as HINAz, is a secure network that takes health care information from multiple health care organizations and sources and provides it to a patient's physician at the point of care when it is needed.
106.	HINAz (322)	Web page: Health Information Network of Arizona	Unknown	US	A Health Information Exchange provides a network and universal format that connects hospitals, doctors and other providers. When needed, HIEs allow electronic health records, containing health-related information about a patient, to be securely shared among health care organizations.
107.	Hincapie et al (248)	Scientific	2011	US	Health information exchange (HIE) is a potential solution to providing timely and effective clinical information at the point of care
108.	HIS (288)	Web page: Indian Health Service for American Indians and Alaska Natives	Unknown	US	The goal of a Health Information Exchange (HIE) is to drive towards efficient exchange of patient data, so that a unified and holistic view of patient data is obtained. This, in turn, will enable physicians to offer better care for patients because providers of care will have a complete picture including all available medical records.
109.	HISO (194)	Report: Health Information Exchange Architecture Building Blocks by National Health IT Board	2012	New Zealand	Application-level communication medium with standardised content and transport, across which participants exchange health information.
110.	HITECH (342)	HITECH ACT	2009	US	A critical step toward realizing the full potential of electronic health records (EHRs) to improve the coordination, efficiency, and quality of care.
111.	Hixny (314)	Webpage: Healthcaer Information Xchange of New York, an InterSystems partner	Unknown	US	HIXNY (“hix-knee”), the Healthcare Information Xchange of New York, is a not-for-profit collaborative of health plans, hospitals, physician practices, and other healthcare entities working together to enable secure access and

S.No.	Author	Source	Year of Publication	Country	Definition
					electronic exchange of medical information to coordinate quality care, improve patient safety and reduce healthcare costs.
112.	HRSA (266)	Web page: US Department of Health and Human Service, Health Resource and Service Administration	Unknown	US	Health information exchange (HIE) is the electronic of health-related information among organizations according to nationally recognized standards. The goal of health information exchange is to facilitate access to and retrieval of clinical data to provide safer, timelier, efficient, effective, equitable, patient-centered care.
113.	Hripcsak et al (10)	Scientific	2007	US	Health information exchange (HIE) projects—which are often run by regional health information organizations—may be a stepping stone to a fully interoperable health information infrastructure that improves the quality and efficiency of health care in the United States
114.	HT (231)	White papar Health Texas Provide Network	Unknown	US	HIE stands for Health Information Exchange and is a term used to describe the sharing of health information through a secure electronic network that allows participating health care systems and providers to electronically share health information about their patients with each other, with other providers who have a treatment relationship with the patient, and for other healthcare operations related activities.
115.	Iatric (667)	Web page: Solution Provider	Unknown	US	Iatric Systems Clinical Document Exchange allows your healthcare organization to send and receive the pertinent clinical, demographic, and administrative data in real time for a single patient in industry-standard documents, such as those listed in Consolidated Clinical Document Architecture (C-CDA) for Meaningful Use. This document exchange provides caregivers a more complete picture of patient health, leading to more informed treatment decisions and better coordination of care.
116.	ICA (429)	Web page: Informatics Corporation of America, provides platforms and services	2012	US	AlliedHIE is a patient-centric, purpose-driven, point-of-care focused national health information exchange company with a mission to include allied health organizations in order to priority connect our most vulnerable and at-risk patients.
117.	IHIE (428)	Report: Nationwide Health Information Network (NHIN) Trial Implementations presented to Office of	2009	US	HIE is a business and as with all businesses, creating a sustainable HIE requires offering services that the market wants at a price the market will bear and doing so in such a way that revenue exceeds expenses. It also means that the services delivered by the HIE must be at a level that healthcare organizations have come to expect from their suppliers.

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		the National Coordinator for Health Information Technology US HHS by Indiana Health Information Exchange			
118.	IGI Global (323)	Dictionary: IGI Global, publisher	Unknown	Unknown	Health information exchange (HIE) refers to the process of reliable and interoperable electronic health-related information sharing conducted in a manner that protects the confidentiality, privacy, and security of the information. Essential to this process is the capability to employ recognized standards as they are established incrementally, further enabling interoperability, security and confidentiality of the information as well as authorization of those who access the information.
119.	ILHIE (346)	Report: Illinois HIE Strategic & Operational Plan by the Illinois Office of Health Information Technology	2010	US	The creation of a State-level health information exchange system will allow, among other benefits, the widespread utilization of electronic health records by health care providers and patients in order to ensure that Illinois health care providers can achieve the Meaningful Use of electronic records, as defined by federal law, and participate fully in the health information technology incentives available from the federal government under the Medicare and Medicaid programs.”
120.	Illinois General Assembly (215)	Webpage: Illinois Health Information Exchange and Technology Act	Unknown	US	The Illinois Health Information Exchange ("ILHIE"), to promote and facilitate the sharing of health information among health care providers within Illinois and in other states. ILHIE shall be an entity operated by the Authority to serve as a State-level electronic medical records exchange providing for the transfer of health information, medical records, and other health data in a secure environment for the benefit of patient care, patient safety, reduction of duplicate medical tests, reduction of administrative costs, and any other benefits deemed appropriate by the Authority.
121.	Infor (223)	Web page: Infor Company / Solution provider (IBM Enterprise Master Person Index (EMPI))	Unknown	US	Health information exchange (HIE) initiatives that focus on facilitating the exchange of health information electronically among physicians, hospitals, health plans, and patients.

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122.	Infor Cloverleaf (174)	Web page: : Infor Company / Solution provider / Products	Unknown	US	Infor Cloverleaf Hosted Healthcare Information Exchange is a secure, standards-based infrastructure that integrates clinical data from across disparate systems and manages the wide variety of clinical records, document types, and content pervasive in today's healthcare community.
123.	iNexx (229)	Web page: Solution provider	Unknown	US	Health information exchange (HIE) is the secure, electronic exchange of health information among authorized stakeholders in the healthcare community – such as care providers, patients, and public health agencies – to drive timely, efficient, high-quality, preventive, and patient-centered care. This exchange of healthcare information improves patient care and reduces costs by fostering care collaboration and lowering administrative encumbrances.
124.	Inspira (233)	Web page: Inspira Health Network / service provider	Unknown	US	Health information exchange (HIE) allows the sharing of your health information among participating doctors' offices, hospitals, labs, radiology centers, and other health care providers through secure, electronic means. The purpose is to provide participating caregivers the most recent health information available. This health information may include lab test results, radiology reports, medications, hospitalization summaries, allergies, and other clinical information vital to your care. Certain demographic information used to identify the individual such as name, date of birth, address, insurance may also be shared.
125.	Inteli Chart (368)	Web page: Inteli Chart / Solution Provider	Unknown	US	Health Information Exchange is much more than just moving data from one spot to another – it's about making the data meaningful, useful and relevant. InteliChart's approach to HIE solutions focus on the acquisition of data and then aggregating the data into a standardized and structured format.
126.	InterSystem (193)	Webpage: ehealthnews.eu / Denmark Selects InterSystems HealthShare for Countrywide Health Information Exchange	2012	Denmark	InterSystems HealthShare is a strategic healthcare informatics platform that enables the sharing of patient information via seamless, bi-directional integration, using active analytics to drive decision-making, and unlocking the unstructured data that is found in patient records

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127.	IOM (201)	Report: Institute of Medicine , Crossing the quality Chasm	2001	US	Health information exchange (HIE), the exchange of electronic health information across health care clinicians and organizations, has the potential to improve health care quality delivered by the US health care system
128.	J. (249)	Scientific	2011	US	Health information exchange—the collection of activities and technologies for sharing data generated from separate sources of clinical information— to manage both individual patients and groupings of people with similar clinical conditions
129.	Joshi (310)	Scientific	2010	US	Health Information Exchanges (HIE) are rapidly advancing as the next step in improving patient care using technological applications. HIE affect the fundamental patient care system by transforming how medical information is delivered and disseminate
130.	Johnson and Gadd (395)	Scientific	2007	US	Health information exchange (HIE) systems are large, multimillion dollar efforts that are implemented despite initial institutional apprehension, with largely unanticipated effects on the clinical workflow, and with a primary goal of establishing a reason to sustain the effort.
131.	Jones et al (250)	Scientific	2011	US	Health information exchange (HIE), i.e., electronically exchanging key clinical information such as discharge summaries, procedures, problem lists, medication lists, medication allergies, and diagnostic test results with other external healthcare providers is a core requirement of Stage 1 “meaningful use” for hospitals.
132.	Kaelber and Bate (13)	Scientific	2007	US	Better patient safety through enhanced, technology enabled, HIE will directly improve patient safety because it will provide a more complete clinical picture of a patient.
133.	Karl (423)	Scientific	2012	US	The term "HIE," acronym for health information exchange, is being used interchangeably to define both the organization that is responsible for managing the exchange of the data (the noun) and the process by which the data can be exchanged (the verb).
134.	KC (283)	Web page: Kane County Health Department	Unknown	US	The Health Information Exchange (HIE) will allow local public health departments to be able to evaluate real-time health data on a population level, in order to monitor the health of our community, as well as to assure that we provide the highest quality service to our residents. In addition, we will be better able to respond to health issues in our community.

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135.	Kern and Kaushal (208)	Scientific	2007	US	HIE involves the sharing of health information electronically across health care settings.
136.	Kern et al (269)	Scientific	2009	US	Health information exchange involves the electronic sharing of clinical data, including sharing of clinical data across health care providers caring for the same patient.
137.	Key Stone (347)	Web page: Key Stone HIE, Provider	Unknown	US	Keystone Health Information Exchange (KeyHIE) streamlines treatment decisions and care coordination with quick access to both in and out-of-network electronic health records (EHRs)-when and where you need them.
138.	Kijsanayotin et al.(372)	Scientific	2007	US	In a health information exchange (HIE) project, linking patients' health records across organizations while maintaining appropriate patients anonymity is essential.
139.	KLAS (287)	Web page: Research company	2014	US	Health information exchanges (HIEs) are defined as non-owned hospitals, health systems, ambulatory entities, and/or other third parties that share/exchange patient data and other information.
140.	Kongstvedt (222)	Book: Essentials of Managed Health Care, Sixth Edition	2012	US	An entity to facilitate the electronic exchange of health information between physicians, hospitals, laboratories payers and so on, that is sponsored by a state or a federal government.
141.	Kralewski et al (380)	Scientific	2012	US	Electronic health information exchange (HIE) among physicians, hospitals, and public health agencies is a fundamental dimension of most proposals for health care reform. It is argued that enabling providers in different settings easy access to a patient’s health record would reduce duplication of services and improve treatment decisions.
142.	Kuperman (276)	Scientific	2011	US	Health-information exchange, that is, enabling the interoperability of automated health data, can facilitate important improvements in healthcare quality and efficiency.
143.	L. Block (668)	Web page: Health Information Technology Knowledge Base	Unknown	US	Health information exchange supports the sharing of health-related information to facilitate coordinated care through the utilization of EHRs. EHRs draw information from many sources through health information exchange. Thus, the process of health information exchange is another piece of the health information technology infrastructure and informatics
144.	Lee et al (270)	Scientific	2010	US	The South Carolina Health Information Exchange (SCHIEx) provides a state-level information infrastructure for connecting local healthcare

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					providers and other stakeholders. The network enables providers to view clinical data that include medications, diagnoses, and procedures. HIEs provide the infrastructure for information exchange, including the business model, governance structure, operating principles, legal model, and technology model for the exchange of healthcare information among various organizations.
145.	Liu (265)	Scientific	2007	US	To provide patient care across the continuum of healthcare delivery sites, care delivery organizations need to consolidate the clinical information from hospitals, clinics, physicians' offices, labs, specialty facilities, and even home healthcare into a single patient record to support the delivery of healthcare services. .The ability to exchange and aggregate information from these various systems is essential to improve health, quality, and safety within the US healthcare system.
146.	Lloyd-Puryear and Brower (412)	Scientific	2010	US	While several elements are in place to realize a systems approach, the authors think that the key is an integrated, multidirectional health information exchange system that functions locally, regionally and nationally, and enables information exchange between private and public health sectors.
147.	LMO (234)	Web page: Liquid Medical Office, Inc. Solution Provider	Unknown	US	Health information exchange (HIE) is a secure electronic exchange of health information among authorized healthcare networks to improve safety, efficiency, and continuity of care. Data exchanged through the HIE is shared safely and securely, meeting or exceeding HIPAA standards.
148.	Lobach et al (209)	Scientific	2007	US	Information technology, and in particular a health information exchange (HIE), has the capacity to enhance the management of the health of populations by promoting the sharing of health information across independent healthcare organizations. The information available through HIEs can be used by clinical decision support (CDS) systems to identify sentinel health events and patient-specific care needs, and then to promote proactive interventions.
149.	Loonsk (338)	Web page: CGI, Initiative for Collaborative Government	2010	US	HIE" is used to describe: hospitals sharing lab reports and discharge summaries with affiliated providers; multi-stakeholder Regional or State Health Information Organizations (RHIOs, HIEs, HIOs); the exchange of information among the products of a single EMR vendor; the secure

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					emailing of documents; and, perhaps most simply and broadly, the ability of any piece of software to exchange information. HIE can include information being browsed, “pulled” and/or “pushed,” and information that is fully coded with nationally recognized vocabularies or information that is in barely processable document formats.
150.	Lori (364)	White paper: What is HIE? A Federal and State Perspective bu Object Health, LLC. Women Consulting Group	Unknown	US	The movement of data between health information systems for the purposes of: Patient communication Provider Communication State Communication Health information exchange describes an action: Provider orders a lab test Lab result is delivered to Provider Provider tells the patient the results.
151.	Louisiana (325)	Webpage: Louisiana Health Information Exchange	Unknown	US	Known as LaHIE, the exchange allows authorized providers and organizations to electronically access and share health-related information through a secure and confidential network for the purpose of improving patient safety, quality of care and health outcomes.
152.	Luo (336)	Scientific	2006	US	Exchange of information is one of the key elements to making EMRs beneficial to patients across the healthcare spectrum, whether at the physician's office, hospital, or pharmacy.
153.	Mäenpää et al. (195)	Scientific	2011	Finland / Sweden	The implementation of a technology such as health information exchange (HIE) through an (regional health information systems) RHIS should improve the mobilization of health care information electronically across organizations within a region, by coordinating care and bringing together local stakeholders.
154.	Maine (301)	Web page: Maine State HIE	Unknown	US	CMS defines HIE as the secure and interoperable sharing of health information in a manner that protects the confidentiality, privacy, and security of an individual’s information.
155.	marchcarson100 (422)	Blog: mandmhitech	2011	Unknown	HIE is a group of entities with the capability to move info digitally using nationwide standards. HIE is a Process

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					Health Info Exchange (HIE) refers back to the strategy of enabling the dependable sharing of digital patient care-associated data amongst health care associated entities and networks. This sharing is done in a way that protects the confidentiality, privacy and safety of the information. Central to this concept is the usage of nationally recognized standards currently in place and future ones as they are published. HIEs can even provide key information to people to promote improved health and wellness, and can be used to assist research, public well-being, emergency response, and high quality improvement. Additionally, an HIE allows the sharing of health-related data amongst healthcare organizations and with individuals on a neighborhood, regional, and nationwide basis.
156.	Marchibroda (389)	Book: Health Literacy, eHealth, and Communication	2009	US	Health information exchange is another major component of eHealth. This refers to the electronic exchange of data across organizations and disparate information systems, including data from laboratories, pharmacies, plans, physicians, or hospitals
157.	Matthews et al. (243)	White Paper: Indiana and Ohio Health Information Exchanges Connect for Nation's First Live, Multi-Region Clinical Information Exchange	2009	US	Live exchange will allow secure electronic exchange of health information, reduce duplication, improve efficiency, improve patient care and further the nation's goal to interconnect healthcare
158.	McIlwain and Lassetter (337)	Scientific	2009	US	A well-designed HIE should enable bi-directional integration between practice and hospital EMRs, as well as interoperability with other physicians' EMRs or outside systems, such as reference labs. Patients should also be able to integrate their medical histories with a personal health record (PHR), such as Google Health or Microsoft's HealthVault.
159.	Mearian (293)	Webpage: Computer World, News. Verizon creates medical information exchange cloud	2010	US	Verizon Health Information Exchange, consolidates clinical patient data from various providers and translates it into a standardized format that can then be accessed via a secure Web portal.

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160.	Merrill (175)	Web page: Molly Merrill is the Associate Editor of Healthcare IT News. She covers physician practice IT issues and national breaking news.	2009	US	The Georgia Cancer Coalition, an independent, not-for-profit organization based in Atlanta, will use a state-wide healthcare information exchange to share evidence-based medicine with community cancer care centers. The exchange will serve as a trusted third party in the state to acquire, analyse and report de-identified patient data around quality measures from providers and hospitals that deliver cancer care.
161.	Merrill et al (292)	Scientific	2013	US	Electronic HIE for public health reporting (HIE for PH) is a powerful strategy for shaping both short and long term policies to promote the health of populations through: rapid and efficient identification, monitoring, investigation, and treatment of communicable and emerging diseases; early identification of food borne outbreaks and environmental exposures; identification of health risk factors; and planning and evaluation of public health services.
162.	Mental Health (203)	Mental Health Information and Primary Care Integration Act of 2011	2011	US	Health information exchange: an electronic system that receives maintains and facilitates the transfer of protected health and mental health information by and between mental health and healthcare providers.
163.	MHIE (669)	Web page: Memorial Hermann Information Exchange for authorized exchange members	Unknown	US	MHiE’s (Memorial Hermann Information Exchange) suite of solutions facilitates access to important clinical information to provide safer, efficient and equitable patient-centered care.
164.	Michigan (273)	Report: 2007-2008 Report to the Michigan Legislature by the Michigan Health Information Technology Commission	2008	US	Health Information Exchange is a way to electronically move personal health and medical information securely between various health care organizations and providers under current medical privacy and confidentiality standard procedures. The goal of HIE is to facilitate delivery and retrieval of clinical data to provide safe, timely, efficient, effective, and equitable patient-centered care. In short, the goal of HIE is to ensure that providers have the right information about their patient at the right time to provide the best possible care.
165.	Minnesota (371)	Web page: Minnesota Department of Health	Unknown	US	Health information exchange, or HIE, in Minnesota means the electronic transmission of health related information between organizations according

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					to nationally recognized standards .This means each time information is sent electronically to another provider it is done in a uniformly accepted way that meets specific standards to ensure protection of the data and privacy of the patient. It also means the information will be received in a way that is usable for the recipient.
166.	Minnesota health (670)	Web page: A Practical Guide to Understanding HIE, Assessing Your Readiness and Selecting HIE Options in Minnesota by Minnesota Department of Health	Unknown	US	HIE refers to the secure electronic sending and receiving of clinical health information in ways that the information can be understood by both the sender and the receiver of the information.
167.	Mobile MD (339)	Web page: Siemens HIE Solution	2011	US	MobileMD® is a vendor-neutral, fully outsourced health information exchange (HIE) for health systems, hospitals, physicians, labs and ancillary healthcare providers. It offers secure messaging, analytic solutions, an EMR to physician practices, and connects healthcare providers and patients through secure clinical and patient portals. Together, the HIE enriches care teams with information as patients move through the healthcare system.
168.	Mobile MD (341)	Web page: Siemens HIE Solution	Unknown	US	MobileMD®, a Siemens solution, is a four-dimensional health information exchange – care, service, economics, and technology – providing physicians with near real-time, secure, clinical and administrative information regardless of location, affiliation, EMR technology, or vendor.
169.	Moore (251)	Blog / Report	2011	US	A Health Information Exchange (HIE) is a technology network infrastructure whose primary purpose is to insure the secure, digital exchange of clinical information among all stakeholders that are engaged in the care of a patient to promote collaborative care models that improve the quality and value of care provided.
170.	Moore et al. (671)	Scientific	2012	US	A health information exchange (HIE) can provide automatic notifications to its members by building services on top of their existing infrastructure.
171.	Morgan Hunter (259)	Blog: Company, Morgan Hunter Healthcare Inc.	Unknown	Unknown	HIE refers to any ongoing exchange of electronic clinical information between organizations such as hospitals, physician offices, clinics, clinical research groups, public health entities and quality assurance groups. It also

S.No.	Author	Source	Year of Publication	Country	Definition
					includes the ongoing exchange between care provider organizations and consumers’ personal health records (PHRs).
172.	Morrissey (344)	Magazine	2013	US	Health information exchange — that set of activities concerned with getting clinical documentation from the places where it was created to other places that could really use the information — lacked some basic components: a critical mass of computer systems to create discrete data; standards allowing data from one electronic health record to be taken in by another; and routine methods to transmit the data anywhere it needed to go.
173.	Mosbys (418)	Mosbys Medical Dictionary	2009	US	A nursing intervention from the Nursing Interventions Classification (NIC) defined as providing patient care information to other health professionals
174.	Mount Sinai (672)	Web page: Mount Sinai HIE, Mount Sinai Hospital	Unknown	US	Health Information Exchange is the sharing of health information electronically between providers. This exchange can be done directly between two providers that care for the same patient or can be enabled through a technology that provides the electronic information to a provider. Information can only be shared between providers if a relationship exists with a patient or the patient explicitly gives their approval to access their information.
175.	MSV (227)	We page: Medical Society of Virginia	Unknown	US	Virginia's health information exchange (HIE) aims to help connect providers and patients. A HIE provides authorized users with access to patients' health-related information that is typically stored in multiple organizations, while maintaining the integrity of the information being exchanged. It may be a community-based, regional, statewide or larger exchange that facilitates the electronic exchange of information between providers. These resources will help you understand the state's framework for health information exchange and how it will facilitate improvements in care coordination and information sharing.
176.	MTBC (274)	White Paper: What is Health Information Exchange (HIE) by MTBC, healthcare IT company	Unknown	US	Health Information Exchanges (HIE) are organizations that synergize and effectively streamline health information records. Many state governments provide funding for HIE implementation with the goal of facilitating access to and retrieval of clinical data to provide more timely, focused, and equitable patient-centered care.

S.No.	Author	Source	Year of Publication	Country	Definition
177.	Munoz et al. (362)	Scientific	2013	US	HIEs are electronic networks into which health providers can connect to have access to all medical records for an individual within a particular community
178.	Murphy a (375)	Web page: ehrintelligence.com for latest technology news and white papers / Article	2012	US	Exchange of electronic information between providers and across platforms that is secure and safeguards patient privacy. HIE is closely aligned with interoperability so that information can flow back and forth between doctors, patients, and health networks.
179.	Murphy b (427)	Web page: ehrintelligence.com for latest technology news and white papers / Article	2012	Unknown	An HIE bridges the knowledge gap between providers, allowing them to trace the treatment of patients by various providers and act upon this information in a meaningful way. But on a higher level, an HIE could prove invaluable for an entire population.
180.	Myers et al.(210)	Scientific	2012	US	Health information exchanges (HIE) that facilitate the exchange of health information across clinical and non-clinical settings can support teams of providers – physicians, health educators, social workers, and pharmacists – caring for patients with HIV (673) by expanding access to patient information.
181.	NAHIT (315)	Report to the Office of the National Coordinator for Health Information Technology on defining key health information technology terms	2008	US	Health information exchange is another form of HIT, which enables electronic movement of health-related information among organizations.
182.	NAHP (352)	Report: EHR by National Association for Health Professionals	2011	US	Health information exchange (HIE) has emerged as a core capability for hospitals and physicians to achieve "meaningful use" and receive stimulus funding. Healthcare vendors are pushing HIE as a way to allow EHR systems to pull disparate data and function on a more interoperable level.
183.	Nakamura et al (674)	Scientific	2010	US	Hospitals' involvement in HIE, defined as active exchange of electronic data by a hospital outside its system.
184.	NaviNet (430)	Blog: The Medical Quak, post: NaviNet HealthCare	Unknown	Unknown	NaviNet helps doctors' offices instantly access patients' insurance information, such as their benefits eligibility and claims status, over the Web.

S.No.	Author	Source	Year of Publication	Country	Definition
		Communication Network – Transactional Portal Information Exchange			
185.	NCHICA (351)	Report: Prepared by the NCHICA Consumer Advisory Council on Health Information (CACHI) for The North Carolina Health Information Technology Strategic Planning Task Force	2009	US	The standardized electronic exchange of health records (typically EHRs) between healthcare providers to enable continuity of care.
186.	NC HIE (296)	Web page: North Carolina Health Information Exchange	Unknown	US	NC HIE operates North Carolina's statewide health information exchange, a secure, standardized electronic system in which providers can share important patient health information. The use of this system promotes the access, exchange, and analysis of health information. NC HIE enables participating organizations to: Save time and reduce paperwork Facilitate more informed treatment decision-making Leads to improved care coordination, higher quality of care, and better health outcomes.
187.	NDHIN (225)	Web page: North Dakota Health Information Network	Unknown	US	Health information exchange that utilizes information infrastructure and systems in a secure and cost-effective manner to facilitate the collection, storage, and transmission of health information.
188.	NRC (263)	Book: Networking Health: Prescriptions for the Internet	2000	US	Health information exchange (HIE) makes previously inaccessible data available, resulting in the availability of more complete clinical information, which could improve the quality of care.
189.	NV HIE (236)	Web page: Nevada HIE	Unknown	US	The chief purpose of the NV-HIE is to provide oversight and governance of the statewide system for the authorized and secure electronic exchange of

S.No.	Author	Source	Year of Publication	Country	Definition
					health information and to establish and maintain a sustainable governance and business structure which achieves broad-based public-private stakeholder collaboration with transparency and accountability while protecting the public interest
190.	OCI (317)	Report: Building a Health Information Exchange for the State of Missouri by Object Computing, Inc.	2009	US	A Health Information Exchange (HIE) enables sharing of electronic health-related information among health care providers, patients, and public health agencies.
191.	One Partner HIE (232)	Web page: One Partner HIE	Unknown	US	A health information exchange (HIE) is the electronic mobilization of health information across healthcare organizations within a region, across the nation, and globally. Basically, it’s the "one-to-many" or the "many-to-many" delivery of health information to improve care, making care more patient-centric. The foremost goal of an HIE is to make possible the access and retrieval of clinical data so care may be delivered in a safer and more timely manner. Fostering improved patient care by encouraging involvement of multiple clinicians from across the patient care spectrum, continuity of care is greatly improved.
192.	Onyile et al. (171)	Scientific	2011	US	The New York Clinical Information Exchange (NYCLIX), a functioning health information exchange, is used by emergency department (ED) personnel to obtain prior health data.
193.	Onyile et al.(172)	Scientific	2013	US	The New York Clinical Information Exchange (NYCLIX) was a Manhattan-based RHIO, which built an operational, secure HIE available to authorized hospitals and other healthcare providers in the NYC metropolitan area. NYCLIX was a collaboration among ambulatory physician groups, long-term care facilities, a Medicaid managed care plan, the nation's largest home healthcare provider and academic medical centers.
194.	Open Source (374)	Web page: Hartford Hospital: Open Source HIE. Open Source		US	Health Information Exchange (HIE) that will link the acute care hospitals with the ambulatory and tertiary care facilities along with the labs and diagnostic centres in the region.

S.No.	Author	Source	Year of Publication	Country	Definition
		Community for Healthcare.			
195.	OPTUM (258)	Web page: Company / Solution Provider	Unknown	US	HIE provides the capability to electronically move clinical information among disparate health care information systems while maintaining the meaning of the information being exchanged. An HIE is a foundational piece of the Accountable Care Organizations (ACO) because it provides a way for EMRs to exchange information across different types of medical records.
196.	Oracle (284)	White paper Oracle Health Information Exchange: Secure, Seamless Data Sharing	2012	US	Health information exchange (HIE)—the seamless, secure, electronic sharing of health data across networks.
197.	Orion HIE (242)	Web page: Orion Health, Solution Provider	Unknown	US	Orion Health™ Health Information Exchange (HIE) is a powerful health information backbone that enables organizations and clinical communities to exchange medical information and share complete patient records. Whether a hospital or health system, a public or regional HIE, Orion Health gets your organization connected. Orion Health HIE enables the exchange of any clinical information between organizations, ensuring that all clinical staff have access to relevant, up-to-date and accurate patient information regardless of where care is provided or the clinician is located.
198.	Overhage et al (211)	Scientific	2005	US	Health information exchange, defined as the electronic sharing of health information across health care organizations within a region, community, or hospital system, is advocated as essential to improving health care quality and reducing costs
199.	Overhage et al (407)	Scientific	2007	US	The country has identified health information exchange (HIE) as an essential strategy to address our crisis of cost, quality, and safety in health care. (HIE) networks that are, in turn, a collection of interconnected, interoperable health information systems (HIS).
200.	Ozkaynak and Brennan (675)	Scientific	2013	US	Health information exchange (HIE) allows clinicians to access patient level health care information.
201.	PAeHealth (230)	Electronic Article: What is the Difference between HIX and HIE?	Unknown	US	HIE stands for health information exchange. HIE plays an important role in giving the healthcare system a 21st century upgrade. It gives providers—doctors, nurses, hospitals, pharmacies, laboratories and others—the ability to

S.No.	Author	Source	Year of Publication	Country	Definition
		By PA eHealth Partnership Authority			exchange health information electronically with other providers in a secure environment
202.	Palmetto (340)	Web page: Palmetto Health: Healthcare, non-profit healthcare resource	Unknown	US	A Health Information Exchange (HIE) is a convenient electronic service that allows healthcare providers at multiple sites to have access to a patient's EMR. Palmetto Health recently launched Provider HIE, which includes Palmetto Health hospitals and physician practices. There is no cost to you to allow your EMR to be accessible through the HIE.
203.	Payne et al. (22)	Scientific	2011	UK	Clinical information exchange in the UK was accomplished by establishing a foundation of policy, infrastructure, and systems of care, by creating and acquiring clinical computing applications, and with strong use of financial and clinical incentives.
204.	PCMAG (217)	Web page: pcmag.com for tech news, buying guides, reviews etc.	Unknown	US	Health Information Exchange, a service that enables exchange of healthcare information between hospitals and regions. The information is not only used to provide medical data for people who move to a different geographic area, but also to provide statistics for public health in general. There are many regional health information organizations (RHIOs) throughout the U.S. that are involved in health information exchange (HIE), and the terms RHIO and HIE are used synonymously.
205.	PDN (252)	Web page: Professional Dynamics Network Inc.	2011/12	US	HIE (Health Information Exchange) refers to the technological network infrastructure, that has the chief purpose of assuring accurate medical information exchange. This patient data and electronic health records (EHR), which is digital information and secure, is clinical information used in between medical organizations who are responsible for providing healthcare to the patients. A Health Information Exchange provides a technology platform that promotes collaborative care models that are crucial to improve the value and quality of the healthcare provided.
206.	PDN (260)	Web page: Professional Development Network, Inc.	Unknown	US	Health information exchange system is responsible for mobilizing the healthcare information electronically throughout the associated organizations that are bordered by community, hospital system and region. Health information exchange can endow us the ability to transfer clinical information electronically in between the network of health care (260)information systems and at the same time maintaining and securing the true meaning of the information being exchanged. It is the job of health

S.No.	Author	Source	Year of Publication	Country	Definition
					information exchange system to provide the access to and retrieval of the medical data in order to facilitate effective, patient-centered, timely, safe, secured and equitable health care. The health information exchange system is also fruitful in terms of providing assistance to the Public Health authorities in the analyses of the countrywide population health.
207.	Pennsylvania (320)	Report: Pennsylvania eHealth Collaborative Strategic Plan for Health Information Exchange 2012	2012	US	Health Information Exchanges (HIEs) are entities often built on a series of often bilateral legal agreements between different, often proprietary information systems to be able to share certain kinds of data. The electronic movement of health-related information among unaffiliated organizations according to nationally recognized standards. HIE provides the opportunity to improve quality and safety of care, improve efficiency, reduce costs and make care more convenient for
208.	Princeton (241)	Web page: Princeton Healthcare System	Unknown	US	Princeton HealthCare System's Health Information Exchange (HIE) called Princeton HealthConnect® uses health care technology allows hospitals, doctors and other health care providers to electronically share health information with each other in a secure, timely manner. This health information could include reports about your illnesses, injuries, allergies, medicines and test results.
209.	Privacy Rights (363)	Web page: California Medical Privacy Fact Sheet C2: How Is Your Medical Information Used and Disclosed - With and Without by Privacy Rights Clearing House	2012	US	HIE will make your records electronically accessible to all permissible health care personnel, wherever those records may be.
210.	Prism (386)	Web page: Prism Health Services, Consulting Company	Unknown	US	An HIE enables the exchange of health-related data among health providers, public health agencies, payers, and patients. Again, the core purpose is for improving the quality and efficiency of healthcare delivery and, ultimately, the improvement of population health. Building trust and consensus among stakeholders is key to ensuring the success of an HIE.
211.	RCHN (213)	Web page: RCHN Community Health	Unknown	US	Sometimes the term HIE is used as part of the name of a Regional Health Information Organization, or RHIO, defined in the same report as, “a health

S.No.	Author	Source	Year of Publication	Country	Definition
		Foundation (RCHN CHF) is a not-for-profit operating foundation			information organization that brings together health care stakeholders within a defined geographic area and governs health information exchange among them for the purpose of improving health care in that community." Here "HIE" mean the process of sharing information and "RHIO" mean the organization that facilitates the sharing.
212.	Rebryna (191)	Scientific	2009	Canada	Regional health information organizations (RHIOs) or health information exchanges (HIEs) vary in definition, but the overall concept rests on the exchange of health information across organizations.
213.	Recogniti (312)	Web page: Recogniti, Solution provider	Unknown	US	Health Information Exchange allows health care professionals and patients to appropriately access and securely shares a patient's vital medical information electronically. There are many health care delivery scenarios driving the technology behind the different forms of health information exchange available today. Health Information Exchange (HIE) is one of the most common forms of utilizing an EHR solution.
214.	Reeder (353)	Web page / Post: Vendor, EHRDoctors	2011-2012	US	When asked for a definition of HIE, the answers we get back range from: paperless, email, provider portals, and electronic summary of care records.
215.	Reeder et al (271)	Scientific	2012	US	A Health Information Exchange (HIE) provides a secure, interoperable infrastructure for electronically moving clinical data between heterogeneous health information systems and its stakeholders, including public health.
216.	Regan (168)	Scientific	1991	Australia	Electronic Data Interchange (EDI) promises to speed the transfer of medical data, insurance information and payments.
217.	Revere and Stevens (399)	Scientific	2010	US	HIEs have developed real-time, nationwide public health event-monitoring capability to assist with and improve early event detection, public health situational awareness, outbreak management, and countermeasure and response administration.
218.	Rhode Island (235)	Web page: State of Rhode Island, Department of Health	Unknown	US	Rhode Island's health information exchange system is an electronic network that gives medical professionals access to their patient's health information. It will help healthcare providers give their patients the best possible care by giving healthcare providers access to their patient's health information, including information that comes from other providers. Health care consumers can choose to participate in current care and can control who can access their health information.

S.No.	Author	Source	Year of Publication	Country	Definition
219.	RIQI (300)	Web page: Current Care Rhode Island HIE, Rhode Island Quality Institute	Unknown	US	CurrentCare, Rhode Island’s the Statewide Health Information Exchange (HIE), is a secure electronic system which will allow doctors and other care givers immediate access to a patient’s up-to-date health information in order to provide the best possible and most comprehensive care.
220.	Ross et al.(357)	Scientific	2010	US	COMMUNITY-HIE: Currently engaged in community-wide HIE, defined as a system that consolidates and provides more than one category of information (e.g., laboratory test results, radiographic results, clinical notes) from more than one independent organization. COMMUNITY-HIE practices could use either paper or electronic medical records.
221.	Rouztan (313)	Web page / Blog: Central Illinois Health Information Exchange Blog	2013	US	What an HIE does is allow a healthcare provider to log into a secured website and pull up all of the medical information about you from all of your medical caregivers (as long as they are participating in sharing data with the HIE) in one place. This is similar to searching a site like Expedia for travel options. It goes out and pulls all the information into one screen for you.
222.	Rowley (280)	Post: Healthcare Technology Consultant	2013	US	Health Information Exchanges (HIEs) are defined in HITECH, and are envisioned as hubs where different systems can exchange health data (assuming they have cracked the patient-identity nut) and break down the silos of EHR data.
223.	RSA Index (228)	Web page: New Hampshire Revised Statutes Annotated (RSA) Index	1989	US	“Health information exchange” means an entity established for the primary purpose of enabling and overseeing the exchange of protected health information for clinical decision-making purposes. The entity may operate on a regional, statewide, or multi-state basis. The entity may be developed by multiple stakeholders, including, but not limited to, the department of health and human services, a non-profit entity, or a for-profit entity.
224.	SafeNet (177)	Security Guide: What You Need to Know About Securing Healthcare Information Exchanges by , SafeNet, a global leader in information security	2010	US	Healthcare Information Exchanges (HIE) provide the capability to electronically move clinical information among different healthcare organization like hospitals, physician offices, pharmacies, and health insurance companies. HIEs are quickly emerging since they facilitate access to clinical data allowing healthcare professionals a more efficient and simple way to access patient data
225.	San Diego (176)	Web page: San Diego Regional HIE	Unknown	US	The San Diego Regional Healthcare Information Exchange (San Diego Beacon) is a collaborative of local hospital systems, community clinics,

S.No.	Author	Source	Year of Publication	Country	Definition
					emergency medical services and public health organizations whose goal is to deliver the highest quality health care to all San Diegans.
226.	SCA (257)	White Paper: Healthcare Identity Management: The Foundation for a Secure and Trusted National Health Information Network. Smart Card Alliance Position Paper for Government Policy Makers and Healthcare Stakeholders	2009	US	An HIE provides the capability to securely and confidentially enable electronic transfer of clinical information among separate healthcare information systems, while maintaining the meaning of the information being exchanged.
227.	Schulte (289)	Book: Healthcare Delivery in the U.S.A.: An Introduction	2012	US	HIE refers to the technology and process infrastructure that supports the sharing of clinical and other patient data within a geographic region and among the organizationally unrelated providers of care in that region.
228.	SEMHIE (237)	Web page: Southeast Michigan Health Information Exchange (SEMHIE)	Unknown	US	The Southeast Michigan Health Information Exchange (SEMHIE) is a multi-stakeholder initiative dedicated to delivering the promise of integrated health information exchange throughout Southeast Michigan. When successfully deployed, SEMHIE will: Enhance patient care, quality and safety Increase effectiveness and efficiency of healthcare delivery Reduce healthcare costs.
229.	Shade et al (366)	Scientific	2012	US	Health information exchange (HIE) is the process of electronic multi-directional transfer of identifiable, patient-level information between different organizations.
230.	Shapiro et al.(382)	Scientific	2007	US	Health information exchange (HIE) is a potentially powerful technology that can improve the quality of care delivered in emergency departments,
231.	Shapiro (272)	Scientific	2007	US	They (HIE) aim to bring previously unavailable clinical data from patients' disparate health records, which may be spread over multiple provider and payer networks, to the point of care where clinicians and their patients need it most.

S.No.	Author	Source	Year of Publication	Country	Definition
232.	Shapiro et al (345)	Scientific	2010	US	Health information exchange, which enables the flow of electronic data among disparate providers and electronic health records
233.	Shapiro et al (7)	Scientific	2013	US	The NYCLIX HIE provided the technical, organizational, and policy infrastructure to support electronic data exchange across member sites.
234.	Sicotte and Paré (391)	Scientific	2010	Canada	Interest in health information exchange (HIE), defined as the use of information technology to support the electronic transfer of clinical information across health care organizations, and continues to grow among those pursuing greater patient safety and health care accessibility and efficiency.
235.	Sittig and Joe (277)	Scientific	2010	US	The local and regional Health Information Exchanges (HIEs) should provide the technical, financial, privacy oversight and governance of all aspects of an electronic portal through which individual patients' health data can be transferred between and among authorized users, in accordance with agreed-upon information exchange policies and standards, and subject to strict privacy and security protections. Users of an HIE can include patients, providers, public health officials, payers, and researchers.
236.	Smith (360)	Web page / Post	2012	US	Health Information Exchange (HIE) is both a verb and a noun; it is the transmission of clinical or claims information from one party to another, and may occur without the presence of a data warehouse or centralized registry, typically known as a HIE.
237.	Steward et al (392)	Scientific	2012	US	Health information exchanges (HIEs) require a synthesis of goals, protocols, data formats, and infrastructure within and across organizations.
238.	STHL (291)	Web page: Southern Tier HealthLink (STHL), a non-profit RHIO	Unknown	US	A health information exchange (HIE) is technology that allows healthcare information to pass electronically across organizations within a particular region or community. Clear and strict state and federal guidelines govern how the information can be exchanged, viewed, and used. The goal of the HIE is to make the information available when and where it is needed.
239.	Stoten (350)	Scientific	2009	US	The Indiana Health Information Exchange (IHIE), known throughout the United States as being in the forefront of the Regional Health Information Organizations (RHIO) initiative, allows physicians to access information directly from their website or through a hospital portal. IHIE provides results such as dictation, lab, and radiology results and information is delivered to the physicians through direct connections with an EHR

S.No.	Author	Source	Year of Publication	Country	Definition
240.	SuccessEHS (329)	Web page: SuccessEHS Solution Provider	Unknown	US	HIE is both a verb and a noun. HIE as a noun: A health information exchange (HIE) refers to an exchange network or an organization that operates a network that connects the electronic health information systems of different health care providers. HIEs enable those providers to share clinical and demographic data of patients they have in common. For instance, a primary care physician may share a patient's data with that patient's cardiologist. HIE as a verb: Health information exchange is the actual transmission of health information. There are multiple types of HIE, including Direct, XDS, Exchange and custom HL7.
241.	Suenaga (326)	Web page: About the State HIE , Hawaii Health Information Exchange	2012	US	The State Health Information Exchange is a secure electronic network that enables Hawaii health care providers – such as physicians, pharmacies, labs and other medical providers – to exchange select patient medical information.
242.	Tang and Lee (403)	Scientific	2009	US	Health information exchange (HIE), a process that has been referred to as 'tethering' or 'interconnecting'
243.	Texas HIE (298)	Web page: Texas HIE		US	Electronic health information exchange, or HIE, is the secure electronic movement of health information among treating physicians and other healthcare providers and related organizations according to national and state laws and nationally recognized standards.
244.	THHSC (238)	Web page: Texas Health and Human Service Commission	Unknown	US	The creation of a statewide health information exchange will allow health information to be securely exchanged between providers within Texas. This will increase the coordination and quality of care while improving efficiency in the health care system and increasing consumer empowerment and control.
245.	Thomas (221)	Web page / Post: Open HIE Wiki	2013	Unknown	A Health Information Exchange (HIE) makes the sharing of health data across information systems possible. Like a universal translator, an HIE normalizes data and secures the transmission of health information throughout databases, between facilities, and across regions or countries
246.	Tripathi et al (676)	Scientific	2009	US	Health information technology (IT) and health information exchange (HIE) are increasingly viewed as key steps in improving the quality, safety, and efficiency problems that plague U.S. health care delivery

S.No.	Author	Source	Year of Publication	Country	Definition
247.	Unertl et al.(278)	Scientific	2012	US	Health information exchanges (HIE) support automated sharing of health data across organizational boundaries.
248.	Utah (180)	Report: Utah Statewide Clinical Health Information Exchange 2011, Annual Legislative Report by The Utah Legislative Health and Human Services Interim Committee	2011	US	The goal of the Utah cHIE initiative is to create a secure electronic clinical health information exchange (cHIE) network whereby a Utah health care provider can, with patient permission, access basic medical information about their patients no matter where the patient receives are in Utah. Health care providers are not required to participate but may choose the option to participate in the cHIE.
249.	Utah State (181)	Report: Utah Clinical Health Information Exchange, Government to Business, State of Utah	2011	US	The Clinical Health Information Exchange (cHIE) provides physicians a way to share and view patient information in a secure electronic manner. This information is accessible, with patient consent, to authorized users while maintaining the highest standards of patient privacy. The goal of the cHIE is to improve the quality of care you receive by increasing efficiency and maintaining patient safety. This is accomplished by enabling healthcare professionals to be better informed, and by reducing time and expense associated with missing information and ordering of duplicate tests.
250.	UW Health (349)	White paper: The University of Wisconsin-Madison, school of medicine and public health	Unknown	US	Electronic health information exchange is a service for patients who may receive care at more than one health care organization using electronic health record software.
251.	Vaidya et al. (384)	Scientific	2012	US	HIE, which enables the exchange of clinical information among multiple stakeholders, offers hope for improving the quality of care delivered by registered nurses (RN)s working in home healthcare.
252.	Vanguard Systems (333)	Webpage: Vanguard Systems, Solution Provider	Unknown	US	Convergent's OmniMD health information exchange (HIE) is meant to transmit healthcare-related data among facilities, health information

S.No.	Author	Source	Year of Publication	Country	Definition
					organizations (HIO) and government agencies according to national standards
253.	Vest (383)	Scientific	2009	US	Health information exchange (HIE) makes previously inaccessible data available to clinicians, resulting in more complete information.
254.	Vest and Jasperson (421)	Scientific	2012	US	Health information exchange (HIE) is an avenue to improving patient care and an important priority under the Meaningful Use requirements.
255.	Vest (367)	Scientific	2012	US	Health information exchange (HIE), the process of electronically moving patient-level information between different organizations, is viewed as a solution to the fragmentation of data in health care.
256.	Vest et al. (401)	Scientific	2013	US	Health information exchange (HIE) is a promising approach to improving the cost and quality of healthcare
257.	Virginia (677)	Web page: ConnectVirginia HIE, Inc. is the Statewide Health Information Exchange (HIE) for the Commonwealth of Virginia	Unknown	US	ConnectVirginia provides a secure, confidential electronic system to support the exchange of patient medical records among participating health care providers in Virginia and beyond.
258.	VITL (330)	Web page: VITL Solution Provider	Unknown	US	A health information exchange (HIE) is a secure computer network that connects the electronic health information systems of different health care providers, enabling those providers to share clinical and demographic data of patients they have in common.
259.	Voigt and Torzewski (254)	Scientific	2011	US	Health information exchange (HIE) has long been touted as a silver bullet, streamlining patient transfers, reducing duplication, enlightening population health, and generally improving health outcomes. It promises to connect clinicians, empower patients, feed data repositories, and trigger decision support alerts from a community-wide set of patient records, among other things. Critical to these solutions is an HIE network that is broadly adopted within a patient community and a rich flow of discrete clinical information.
260.	Vreeman (279)	Scientific	2007	US	A comprehensive health information exchange must coalesce all of the various sources that produce health data in order to provide clinicians with information when and where they need it.

S.No.	Author	Source	Year of Publication	Country	Definition
261.	Walker et al.(376)	Scientific	2005	US	Many providers and policy makers now recognize that the sharing of data among hospitals, doctors, and other health care organizations in a given city, state, or region often referred to as health information exchange (HIE) can make health care safer, more efficient, and more effective.
262.	Warholak et al (369)	Scientific	2011	US	HIE was defined as a computer-based system that mobilizes health care information electronically across organizations within a region.
263.	Whittenburg (385)	Scientific	2008	US	Health information exchange using an online metadata registry allows nurses, health professionals, hospital administrators, and diverse information systems to make significant strides towards improving health outcomes and human quality of care
264.	Wikipedia (255)	Webpage: article on HIE	Unknown	Unknown	Health information exchange (HIE) is the mobilization of healthcare information electronically across organizations within a region, community or hospital system. HIE provides the capability to electronically move clinical information among disparate health care information systems while maintaining the meaning of the information being exchanged. The goal of HIE is to facilitate access to and retrieval of clinical data to provide safer and more timely, efficient, effective, and equitable patient-centered care. HIE is also useful to public health authorities to assist in analyses of the health of the population.
265.	Williams et al. (377)	Scientific	2012	US	The goal of health information exchange is for information to follow patients, wherever and whenever they seek care, in a private and secure manner so that teams of doctors, nurses, and care managers can provide coordinated, effective, and efficient care.
266.	WPF (307)	Web page: HIE in California. World Privacy Forum, public interest research group.	Unknown	US	A Health Information Exchange, or HIE, is technology that enables the electronic movement of health-related information among health care providers and others. HIEs are an increasingly popular way for hospitals, pharmacies, labs, and emergency room physicians to share patient information. Some HIEs just share information within one hospital network, some share information across many hospitals or physicians in a region, and some HIEs share information across the state.
267.	Wright et al (1)	Scientific	2010	US	HIE is the ability for clinicians to share a core set of clinical patient data across practices and entities

S.No.	Author	Source	Year of Publication	Country	Definition
268.	Xerox HIE (678)	Web page: Xerox healthcare IT solution	Unknown	US	Focusing on preventive and outcomes-based medicine, the HIE solution makes comprehensive patient health information available, even at the point of care. This exchange of information helps reduce medical errors and redundant medical procedures as well as improves patient safety and well-being.

Appendix 2. Recurrent topics in definitions

Author	Data and Information	Information Transfer	Stakeholders	Potential Benefits	Technology	Location	Business	Standards	Public Health	Sectoral or Regional Scope	Focus / Context
1st PC (321)	*	*		*							* process
4Med (331)	*	*	*			*		*			
Abhyankar et al (358)	*	*	*	*	*						
Accenx (309)	*	*	*	*					*	*	* Service
Adler-Milstein et al (267)	*	*	*						*		
Adler-Milstein et al (199)	*	*	*	*							
Adler-Milstein and Jha (149)	*	*	*								
Adler-Milstein et al (200)	*	*	*			*					* Process
AeHN (164)	*	*			*						
Afzal (216)	*	*		*	*	*					

Author	Data and Information	Information Transfer	Stakeholders	Potential Benefits	Technology	Location	Business	Standards	Public Health	Sectoral or Regional Scope	Focus / Context
AHA (388)	*	*	*	*							
AHIMA (319)	*	*	*					*			
Alert (198)	*	*	*		*	*					
Altman et al (244)	*	*	*	*							
AMA (219)	*	*	*	*		*		*			* Entity
Amatayakul (324)	*	*	*	*							
Ancker et al (285)	*	*	*	*				*	*		
Arkansas OHIT (308)	*	*	*	*	*			*	*		
Aspelin (220)	*	*	*			*		*			* Organization / meaningful use
Axolotl Corp. (311)	*	*		*		*	*	*	*		

Author	Data and Information	Information Transfer	Stakeholders	Potential Benefits	Technology	Location	Business	Standards	Public Health	Sectoral or Regional Scope	Focus / Context
Barton et al (188)	*	*			*			*			
Birkle et al (178)	*	*	*								
Bostick et al. (318)	*	*	*					*	*		
Bouhaddou et al (245)	*	*	*	*			*	*			
Boyle (186)	*	*	*			*		*			
Braithwaite (166)	*	*	*	*				*			* EDI
Bredfeldt (359)	*	*	*	*							
Bresnick (355)	*	*	*	*							* Complete EPR
Bugge et al (185)	*	*	*	*							
Byers (163)	*	*		*				*		*	* Occupational
Cannoy (179)	*	*	*	*	*						* Process
Care Accord (327)	*	*	*	*	*						

Author	Data and Information	Information Transfer	Stakeholders	Potential Benefits	Technology	Location	Business	Standards	Public Health	Sectoral or Regional Scope	Focus / Context
Carter (426)	*	*	*								
CDC (256)	*	*		*	*	*					
Centricity (275)	*	*	*		*	*		*			
Cerner (381)	*	*		*	*						open source
Chaudhary (343)	*	*		*							* process
Cisco (183)	*	*	*	*	*	*					* Vendor solution
Citius Tech (396)	*	*	*	*		*		*	*		* Document sharing
C. Kibbe (282)	*	*	*	*		*					
C. Livingood et al. (393)	*	*	*	*							
Clemens (303)	*	*	*		*			*			

Author	Data and Information	Information Transfer	Stakeholders	Potential Benefits	Technology	Location	Business	Standards	Public Health	Sectoral or Regional Scope	Focus / Context
Clinical Connect (400)	*	*		*	*	*		*			
Codagnone (9)	*	*									* Process
CORHIO (305)	*	*		*							* Emergency / chronic conditions
CSC (189)	*	*	*	*	*		*				* eHealth Solution
Daurio et al (246)	*	*	*	*							
Deas Jr and Solomon (405)		*									* organization
De Brantes et al. (247)	*	*	*	*		*	*				* organization
Delfan (153)	*	*	*			*		*			

Author	Data and Information	Information Transfer	Stakeholders	Potential Benefits	Technology	Location	Business	Standards	Public Health	Sectoral or Regional Scope	Focus / Context
Dimitropoulos and Rizk (419)		*	*								
Dobbs et al (665)		*	*	*	*						
Downing et al (666)			*	*							
Dullabh and Hovey (204)	*	*	*	*		*					
eHealth Initiative (420)	*	*	*	*							* activity
eHEalth Initiative (206)	*	*	*								
eHealth Privacy 360 (212)	*	*	*	*							
Emdeon (378)	*	*	*	*							* Process
Excelicare (187)	*	*	*	*	*						
Finn (214)	*	*	*	*	*	*	*				* Organization

Author	Data and Information	Information Transfer	Stakeholders	Potential Benefits	Technology	Location	Business	Standards	Public Health	Sectoral or Regional Scope	Focus / Context
Florida HIE (297)	*	*	*	*	*			*			
Florida HIN (240)	*	*	*	*							
Forcare (190)	*	*		*		*	*	*			
Frankel et al (196)	*	*	*		*				*		
Frisse (205)				*	*			*			* Entity
Frisse et al (424)			*	*							* services
Furukawa et al (365)			*	*							
GAO (218)	*	*	*								* Entity
Gadd et al. (268)	*	*	*			*					* ED
Gaebel (304)	*	*	*	*							
Gartner (262)	*	*	*			*	*	*			* Regional Collaboration

Author	Data and Information	Information Transfer	Stakeholders	Potential Benefits	Technology	Location	Business	Standards	Public Health	Sectoral or Regional Scope	Focus / Context
Gassert (264)	*	*	*	*	*						* cardiac surgery
Geissbuhler (197)		*	*	*							
Genes et al (286)	*	*	*	*							* ED
Georgia HIV HIE (373)	*	*	*	*							* HIV care system
Grannis et al. (397)		*	*	*				*	*		
Greenhalgh et al. (18)					*			*		*	
Grinspan et al.(170)	*	*				*					
Grossman et al. (294)	*	*	*	*				*	*	*	
Gulf Coast(387)	*	*	*								
Haggstrom and Doebbeling (394)	*	*	*	*		*					
Halamka (356)	*		*	*							*

Author	Data and Information	Information Transfer	Stakeholders	Potential Benefits	Technology	Location	Business	Standards	Public Health	Sectoral or Regional Scope	Focus / Context
											ED
Hall (290)	*	*	*	*							
Harris (239)	*	*	*	*							* collaboration
Hasman et al. (167)	*	*	*	*							* EDI
Hazamy et al. (173)	*	*		*							* Data exchange system
HC (306)	*	*	*		*	*					
(332)Health CareIT (332)	*	*	*	*	*	*		*			
HealtheLink (169)	*	*	*	*		*		*			* Collaboration
Health Insights (348)	*	*		*				*			
Health IT(15)	*	*	*	*	*						
Health IT(15)	*	*	*	*							

Author	Data and Information	Information Transfer	Stakeholders	Potential Benefits	Technology	Location	Business	Standards	Public Health	Sectoral or Regional Scope	Focus / Context
Health Leaders (335)	*	*	*		*	*		*			
Health Unity (398)	*	*	*	*					*		
Hersh (207)	*	*					*				
Herwehe et al (334)	*	*		*				*	*		
HHS (281)	*	*	*	*		*		*			
HIE Answers (295)	*	*	*								
HIE Bridge (261)	*	*	*	*	*			*			
HIECC (224)	*	*	*	*	*				*		* Meaningful HIE
HIE Nevada (390)	*	*	*	*		*					
HIE Ohio (370)	*	*	*		*			*			* Entity
HIMSS (316)	*	*	*	*				*			
HIMSS HIE Committee (165)	*	*	*	*			*				* process

Author	**Data and Information**	**Information Transfer**	**Stakeholders**	**Potential Benefits**	**Technology**	**Location**	**Business**	**Standards**	**Public Health**	**Sectoral or Regional Scope**	**Focus / Context**
HINAz (379)	*	*	*	*							
HINAz (322)	*	*	*								
Hincapie et al (248)	*	*	*	*							
HIS (288)	*	*	*	*							* Holistic view of records
HISO (194)	*	*	*		*						
HITECH (342)	*	*		*	*						
Hixny (314)	*	*	*	*	*	*					* Collaboration
HRSA (266)	*	*		*	*			*			
Hripcsak et al (10)	*			*	*			*			* organization
HT (231)	*	*	*	*	*						
Iatric (667)	*	*		*			*				*

Author	Data and Information	Information Transfer	Stakeholders	Potential Benefits	Technology	Location	Business	Standards	Public Health	Sectoral or Regional Scope	Focus / Context
											Document exchange
ICA (429)	*		*		*		*	*		*	
IHIE (428)	*		*				*				
IGI Global (323)	*	*	*	*	*						* Process
ILHIE (346)	*	*	*	*	*			*			* Meaningful use
Illinois General Assembly (215)	*	*	*	*				*			* Entity
Infor (223)	*	*	*								
Infor Cloverleaf (174)	*	*		*	*	*					
iNexx (229)	*	*	*	*			*		*		
Inspira (233)	*	*	*	*		*					
Inteli Chart (368)	*	*		*	*						*

Author	Data and Information	Information Transfer	Stakeholders	Potential Benefits	Technology	Location	Business	Standards	Public Health	Sectoral or Regional Scope	Focus / Context
											meaningful data
InterSystem (193)	*	*		*	*						
IOM (201)	*	*	*	*				*			
J. (249)	*		*	*	*						
Joshi (310)	*	*		*	*						
Johnson and Gadd (395)				*			*				
Jones et al (250)	*	*	*								* Satge1 “meaningful use”
Kaelber and Bate (13)			*	*	*						
Karl (423)	*	*									* Both organization and process
KC (283)	*		*	*					*		
Kern and Kaushal (208)	*	*	*			*					

Author	Data and Information	Information Transfer	Stakeholders	Potential Benefits	Technology	Location	Business	Standards	Public Health	Sectoral or Regional Scope	Focus / Context
Kern et al (269)	*	*	*								
Key Stone (347)	*	*		*	*						* EHR
Kijsanayotin et al.(372)	*	*	*	*							
KLAS (287)	*	*	*								* Non-owned hospitals, health systems, ambulatory entities
Kongstvedt (222)	*	*	*					*			* entity
Kralewski et al (380)	*	*	*	*		*			*		
Kuperman (276)	*	*		*							
L. Block (668)	*	*	*	*	*						* EHR / process

Author	Data and Information	Information Transfer	Stakeholders	Potential Benefits	Technology	Location	Business	Standards	Public Health	Sectoral or Regional Scope	Focus / Context
Lee et al (270)	*	*	*		*		*	*			
Liu (265)	*	*	*	*		*		*			
Lloyd-Puryear and Brower (412)	*	*	*						*		
LMO (234)	*	*		*	*						
Lobach et al (209)	*	*	*	*	*				*		
Loonsk (338)	*	*	*	*	*			*			
Lori (364)	*	*	*								
Louisiana (325)	*	*	*	*	*						
Luo (336)	*	*	*	*	*	*					
Mäenpää et al. (195)	*	*	*	*	*	*					
Maine (301)	*	*		*							

Author	Data and Information	Information Transfer	Stakeholders	Potential Benefits	Technology	Location	Business	Standards	Public Health	Sectoral or Regional Scope	Focus / Context
marchcarson 100 (422)	*	*	*	*	*	*		*	*		* Entity / process
Marchibroda (389)	*	*				*					* eHealth
Matthews et al. (243)	*	*		*				*			
McIlwain and Lassetter (337)	*	*	*								
(293)	*	*	*	*	*						* Service
Merrill (175)	*	*		*				*			* cancer care / third party
Merrill et al (292)	*			*				*	*		
Mental Health (203)	*	*	*	*	*						* Mental health
MHIE (669)											

Author	**Data and Information**	**Information Transfer**	**Stakeholders**	**Potential Benefits**	**Technology**	**Location**	**Business**	**Standards**	**Public Health**	**Sectoral or Regional Scope**	**Focus / Context**
	*	*		*							
Michigan (273)	*	*	*	*	*			*			
Minnesota (371)	*	*	*	*				*			
Minnesota health (670)	*	*	*	*							
Mobile MD (339)	*	*	*	*	*						
Mobile MD (341)	*	*	*	*			*				* Vendor’s Solution
Moore (251)	*	*	*	*	*						
Moore et al. (671)	*	*	*	*							
Morgan Hunter (259)	*	*	*					*	*		
Morrissey (344)	*	*		*	*	*					* Set of activities
Mosbys (418)	*	*	*								*

Author	**Data and Information**	**Information Transfer**	**Stakeholders**	**Potential Benefits**	**Technology**	**Location**	**Business**	**Standards**	**Public Health**	**Sectoral or Regional Scope**	**Focus / Context**
											Nursing Intervention
Mount Sinai (672)	*	*	*		*						
MSV (227)	*	*	*	*				*			
MTBC (274)	*	*		*				*			* organization
Munoz et al. (362)	*	*			*	*					
Murphy a (375)	*	*	*	*							
Murphy b (427)		*	*	*					*		* Knowledge provider
Myers et al.(210)	*	*	*	*		*					* HIV patients
NAHIT (315)	*	*	*		*			*			
NAHP (352)	*	*	*		*		*				*

Author	Data and Information	Information Transfer	Stakeholders	Potential Benefits	Technology	Location	Business	Standards	Public Health	Sectoral or Regional Scope	Focus / Context
											Meaningful use / EHR
Nakamura et al (674)	*	*	*			*					
NaviNet (430)		*	*	*			*				* Insurance information
NCHICA (351)	*	*	*	*	*						
NC HIE (296)	*	*		*	*			*			
NDHIN (225)	*	*		*							
NRC (263)	*	*		*							
NV HIE (236)	*	*	*	*	*		*	*	*		
OCI (317)	*	*	*					*	*		
One Partner HIE (232)	*	*	*	*	*	*		*			
Onyile et al. (171)	*	*									* ED
Onyile et al.(172)			*	*		*		*			

Author	Data and Information	Information Transfer	Stakeholders	Potential Benefits	Technology	Location	Business	Standards	Public Health	Sectoral or Regional Scope	Focus / Context
Open Source (374)	*				*	*					
OPTUM (258)	*	*		*							* Part of an organization
Oracle (284)	*	*		*	*						
Orion HIE (242)	*	*	*	*		*			*		
Overhage et al (211)	*	*	*	*		*					
Overhage et al (407)				*	*						
Ozkaynak and Brennan (675)	*	*	*								
PAeHealth (230)	*	*	*	*	*						
Palmetto (340)	*	*	*		*	*					* service
Payne et al. (22)	*			*	*			*			

Author	**Data and Information**	**Information Transfer**	**Stakeholders**	**Potential Benefits**	**Technology**	**Location**	**Business**	**Standards**	**Public Health**	**Sectoral or Regional Scope**	**Focus / Context**
PCMAG (217)	*	*	*			*		*	*		* Service / organization
PDN (252)	*	*	*	*	*						
PDN (260)	*	*		*	*	*		*	*		
Pennsylvania (320)	*	*	*	*	*		*	*			* entities
Princeton (241)	*	*	*	*	*						
Privacy Rights (363)	*	*	*		*	*					
Prism (386)	*	*	*	*				*	*		
RCHN (213)	*	*	*	*		*					* process
Rebryna (191)	*	*	*								* organization
Recogniti (312)	*	*	*		*						* EHR solution

Author	Data and Information	Information Transfer	Stakeholders	Potential Benefits	Technology	Location	Business	Standards	Public Health	Sectoral or Regional Scope	Focus / Context
Reeder (353)	*	*			*						
Reeder et al (271)	*	*	*	*	*			*	*		
Regan (168)	*	*	*		*						* EDI
Revere and Stevens (399)				*				*	*		* Event monitoring
Rhode Island (235)	*	*	*	*							
RIQI (300)	*	*	*	*	*			*			
Ross et al.(357)	*	*	*			*				*	
Rouztan (313)	*	*	*	*	*						
Rowley (280)	*	*			*						
RSA Index (228)	*	*	*	*		*					* entity
SafeNet (177)	*	*	*	*	*						

Author	Data and Information	Information Transfer	Stakeholders	Potential Benefits	Technology	Location	Business	Standards	Public Health	Sectoral or Regional Scope	Focus / Context
San Diego (176)	*		*	*		*		*	*		* Collaboration
SCA (257)	*	*		*	*						
Schulte (289)	*	*			*	*					* process infrastructure
SEMHIE (237)	*	*	*	*				*			
Shade et al (366)	*	*	*								* process
Shapiro et al.(382)				*	*						* ED
Shapiro (272)	*	*	*	*		*					
Shapiro et al (345)	*	*	*			*					
Shapiro et al (7)		*	*		*	*					* Organization, policy infrastructure

Author	Data and Information	Information Transfer	Stakeholders	Potential Benefits	Technology	Location	Business	Standards	Public Health	Sectoral or Regional Scope	Focus / Context
Sicotte and Paré (391)	*	*	*	*	*						
Sittig and Joe (277)	*	*	*	*	*		*	*	*	*	
Smith (360)	*	*	*								* Organization / process
Steward et al (392)			*		*	*					
STHL (291)	*	*	*	*	*	*		*			
Stoten (350)	*	*	*	*	*						* organization
SuccessEHS (329)	*	*	*								* Organization / process
Suenaga (326)	*	*	*								
Tang and Lee (403)					*						* process

Author	Data and Information	Information Transfer	Stakeholders	Potential Benefits	Technology	Location	Business	Standards	Public Health	Sectoral or Regional Scope	Focus / Context
Texas HIE (298)	*	*	*	*	*			*			
THHSC (238)	*	*	*	*				*			
Thomas (221)	*	*		*	*	*					
Tripathi et al (676)				*				*			
Unertl et al.(278)	*	*	*	*		*					
Utah (180)	*	*	*		*			*			
Utah State (181)	*	*	*	*							
UW Health (349)	*		*	*	*						* Service
Vaidya et al. (384)	*	*	*	*							* RN
Vanguard Systems (333)	*	*				*		*			
Vest (383)		*	*	*							
Vest and Jasperson (421)	*			*							*

Author	Data and Information	Information Transfer	Stakeholders	Potential Benefits	Technology	Location	Business	Standards	Public Health	Sectoral or Regional Scope	Focus / Context
											Meaning ful use
Vest (367)	*	*	*								* process
Vest et al. (401)	*			*							
Virginia (677)	*	*	*	*				*			
VITL (330)	*	*	*		*						
Voigt and Torzewski (254)	*	*	*	*	*	*		*	*		
Vreeman (279)	*		*	*							
Walker et al.(376)	*	*	*	*		*		*			
Warholak et al (369)	*	*	*		*	*					
Whittenburg (385)			*	*	*						
Wikipedia (255)	*	*	*	*		*		*	*		
Williams et al. (377)	*	*	*	*							
WPF (307)	*	*	*		*	*		*			
Wright et al (1)	*	*	*			*					

Author	Data and Information	Information Transfer	Stakeholders	Potential Benefits	Technology	Location	Business	Standards	Public Health	Sectoral or Regional Scope	Focus / Context
Xerox HIE (678)	*	*		*							* preventive and outcomes-based medicine

Appendix 3: List of experts contacted

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Appendix 4. Search Strategy

MEDLINE/ EMBASE / Global Health

1. algeria/ or egypt/ or libya/ or morocco/ or tunisia/ or cameroon/ or central african republic/ or chad/ or congo/ or "democratic republic of the congo"/ or comoros/ or gabon/ or burundi/ or djibouti/ or eritrea/ or ethiopia/ or kenya/ or rwanda/ or somalia/ or sudan/ or tanzania/ or uganda/ or angola/ or botswana/ or lesotho/ or malawi/ or mozambique/ or namibia/ or south africa/ or swaziland/ or zambia/ or zimbabwe/ or benin/ or burkina faso/ or cape verde/ or cote d'ivoire/ or gambia/ or ghana/ or guinea/ or guinea-bissau/ or liberia/ or mali/ or mauritania/ or niger/ or nigeria/ or senegal/ or sierra leone/ or togo/ or "antigua and barbuda"/ or cuba/ or dominica/ or dominican republic/ or grenada/ or haiti/ or jamaica/ or fiji/ or "american samao"/ or saint lucia/ or "saint vincent and the grenadines"/ or belize/ or costa rica/ or el salvador/ or guatemala/ or honduras/ or nicaragua/ or panama/ or "gulf of mexico"/ or maldives/ or mexico/ or argentina/ or bolivia/ or brazil/ or chile/ or colombia/ or ecuador/ or marshall islands/ or guyana/ or paraguay/ or peru/ or suriname/ or uruguay/ or venezuela/ or kazakhstan/ or kyrgyzstan/ or tajikistan/ or turkmenistan/ or uzbekistan/ or russia/ or micronesia/ or cambodia/ or papua new guinea/ or indonesia/ or laos/ or malaysia/ or samao/ or myanmar/ or philippines/ or thailand/ or vietnam/ or bangladesh/ or bhutan/ or india/ or afghanistan/ or iran/ or iraq/ or jordan/ or lebanon/ or syria/ or turkey/ or yemen/ or nepal/ or pakistan/ or sri lanka/ or china/ or "democratic people's republic of korea"/ or mongolia/ or albania/ or latvia/ or lithuania/ or bosnia-herzegovina/ or bulgaria/ or kosovo/ or "macedonia (republic)"/ or moldova/ or montenegro/ or "republic of belarus"/ or romania/ or serbia/ or ukraine/ or armenia/ or azerbaijan/ or "georgia (republic)"/ or "sao tome and principe"/ or seychelles/ or timor-leste/ or tongo/ or tuvalu/ or vanuatu/ or "west bank and gaza".mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]

2. Hospital Information Systems/ or Medical Records Systems, Computerized/ or Medical Record Linkage/ or Information Systems/ or Electronic Health Records/

3. (health information exchange* or healthcare information exchange* or clinical data exchange* or regional health information organization* or local health information organization* or personally controlled health record* or personally-controlled health record* or regional health information or regional health information exchange* or regional health information infrastructure* or regional health information network* or regional health information organization* or rhio or regional health information system* or local health information or local health information exchanges or local health information infrastructure or local health information system or local health infrastructure or local health initiatives or local health institutions or healthcare information organization* or healthcare information exchange or medical information exchange or medical document exchange or personal health record* or electronic medical record*).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]

4. (health information system* or hospital information management system* or hospital management information system* or health infrastructure* or health network* or district health information system* or District Health Management Information System* or healthcare information system* or personal health record* or electronic medical record*).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]

5. ((patient record or medical record or electronic health record or health information) adj3 (exchange* or shar* or access)).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]

6. ((third world or emerging or low or middle or resource-poor) adj3 (countr* or nation* or setting*)).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]

7. Developing Countries/

8. (Barrier$ or Hurdle or barricade* or Promot$ or Obstruct$ or Facilitat$ or Support$ or Cause$ or Encourag$ or challeng* or problem* or threat*).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]

9. (exchange* or shar* or access* or transfer* or transmission or mov*).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]

10. 1 or 6 or 7

11. 2 or 4

12. 9 and 11

13. 3 or 5 or 12

14. 8 and 10 and 13

15. limit 14 to yr="1990 -Current"

Web of Science / PakMediNet / IndMED / KoreaMed/ African Index Meidcs

Free-Field Format

1. ("third world" or "emerging" or "low-income" or "middle-income" or "resource-poor" or "developing") AND (countr* or "nation" or setting*)

AND

2. (Barrier$ or Hurdle or barricade* or Promot$ or Obstruct$ or Facilitat$ or Support$ or Cause$ or Encourag$ or challeng* or problem* or threat*)

AND

3. ("health information exchange*" or "healthcare information exchange*" or "clinical data exchange*" or "regional health information organization*" or "local health information organization*" or "personally controlled health record*" or "personally-controlled health record*" or "regional health information" or "regional health information exchange*" or "regional health information infrastructure*" or "regional health information network*" or "regional health information organization*" or "rhio" or "regional health information system*" or "local health information" or "local health information exchanges" or "local health information infrastructure" or "local health information system" or "local health infrastructure" or "local health initiatives" or "local health institutions" or "healthcare information organization*" or "healthcare information exchange" or "medical information exchange" or "medical document exchange" or "health information system*" or "hospital information management system*" or "hospital management information system*" or "health infrastructure*" or "health network*" or "district health information system*" or "District Health Management Information System*" or "healthcare information system*" or "personal health record*" or "electronic medical record*" or "patient record" or "medical record" or "electronic health record" or "health information")

AND

4. (exchange* or shar* or access* or transfer* or transmission or mov*)

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health information exchange or barriers or facilitators or low-income or developing countries

Appendix 5. Mixed Method Appraisal Tool (version 11)

Types of mixed methods study components or primary studies	**Methodological quality criteria**	**Responses**			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)?				
	Do the collected data allow address the research question (objective)? E.g., consider whether the follow-up period is long enough for the outcome to occur (for longitudinal studies or study components).				
Further appraisal may be not feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.					
1. Qualitative	1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?				
	1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)?				
	1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?				
	1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?				
2. Quantitative randomized controlled (trials)	2.1. Is there a clear description of the randomization (or an appropriate sequence generation)?				
	2.2. Is there a clear description of the allocation concealment (or blinding when applicable)?				
	2.3. Are there complete outcome data (80% or above)?				
	2.4. Is there low withdrawal/drop-out (below 20%)?				
3. Quantitative nonrandomized	3.1. Are participants (organizations) recruited in a way that minimizes selection bias?				
	3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?				
	3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?				
	3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?				
	4.2. Is the sample representative of the population understudy?				
	4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)?				
	4.4. Is there an acceptable response rate (60% or above)?				
5. Mixed methods	5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?				
	5.2. Is the integration of qualitative and quantitative data (or results*) relevant to address the research question (objective)?				
	5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative				

	data (or results*) in a triangulation design?				
	Criteria for the qualitative component (1.1 to 1.4), and appropriate criteria for the quantitative component (2.1 to 2.4, or 3.1 to 3.4, or 4.1 to 4.4), must be also applied				

Appendix 6. Study characteristics of systematic review

S. No.	Author (Year)	Country of Study	Language	Healthcare Setting	Participants / Sample Size	Technology	Intervention	Methodology / Design	Data Collection Tool	Quality Score
1.	Abeysekera, Wickremasinghe (484)	Sri Lanka	English	Public / Private health care facilities (19) for malaria (Rural)	Patients / 321	Surveillance System / Area maps digitised with ARCINFO Software	Patients' residential address were digitised and distances were calculated to the health care centres	Quantitative	Questionnaire	****
2.	Adjorlolo and Ellingsen (499)	Ghana	English	University hospital	Health workers (nurses, doctors, laboratory technicians, pharmacist) and hospital administrators (record workers, medical director, administrator) / 30	EPR	n/a	Mixed	Case study Semi-structured interviews , observation, document analysis and closed-ended questionnaires	**
3.	Ali and Horikoshi (2002) (33)	Pakistan	English	General	Government, donor agencies, and private sector specialists	HMIS and GIS	Introduce GIS into HMIS and GIS integrate vertical health	Qualitative	Interviews, document analysis	*

S. No.	Author (Year)	Country of Study	Language	Healthcare Setting	Participants / Sample Size	Technology	Intervention	Methodology / Design	Data Collection Tool	Quality Score
							programmes information systems into one integrated system			
4.	Alkmim et al. (2012) (500)	Brazil	English	State university hospitals / municipal health departments	Users / 1284, electrocardiograms / 905, municipalities / 86, clinical staff and municipal healthcare practitioners	Telehealth	Connect State university hospitals with remote municipal health departments to provide tele-assistance, tele-electrocardiography and teleconsultations	Mixed	Discussions, Meetings, auditing, survey	***
5.	Amoroso et al. (2010) (473)	Rwanda	English	Rural health centres / HIV patients	16 Health centres / HIV patients	EMR	Introducing data error types for data quality / a new module for detection of HIV patients to get CD4 results / auditing module developed to	Qualitative	Programme auditing	***

S. No.	Author (Year)	Country of Study	Language	Healthcare Setting	Participants / Sample Size	Technology	Intervention	Methodology / Design	Data Collection Tool	Quality Score
							see the usage of EMR / Targeting children of adults having HIV positives			
6.	Asangansi et al. (2013) (474)	Nigeria	English	Maternal mortality, etc.	Data entry staff, HMIS officers, supervisors, managers, field workers, administrators / 49	HMIS, mHealth	Android application OpenDataKit (ODK) System, DHIS2	Qualitative	Observations, discussions, meetings	*
7.	Cao et al. (2009) (463)	China	Chinese	General	Children (patients) / 4370603136 (file records)	Information management system	CIIMS	Quantitative	Immunisation cases and user's file records archives in CIIMS	****
8.	Chaiyachati et al. (2013) (501)	South Africa	English	TB	Healthcare workers / 5	mHealth (CommCare / Nokia 2700 and 2730 models)	Mobilze trial	Mixed	Questionnaire, focus group interviews,	***
9.	Chang et al. (2011) (502)	Uganda	English	HIV / AIDS	peer-health workers (PHW) /29, clinical staff / 38, patients / 970	mHealth (mobile phone)	Mobile phone used by PHW on AIDS care	Mixed	Survey, in-depth interviews, focus groups	****

S. No.	Author (Year)	Country of Study	Language	Healthcare Setting	Participants / Sample Size	Technology	Intervention	Methodology / Design	Data Collection Tool	Quality Score
10.	Chang et al. (2013) (503)	Uganda	English	HIV / AIDS	CHW, clinical staff / (survey (27, interviews 10), patients / (interviews 10) 6 focus groups	mHealth	mHealth HIV/ AIDS care intervention to be used by CHW	Mixed	In-depth interviews, focus groups, survey	****
11.	Darkwa (2000) Darkwa (485)	Ghana	English	Hospitals (1 urban and 1 rural)	Doctors and administrators / 30	Telemedicine	Use of telemedicine	Quantitative / descriptive	Survey	****
12.	Galvao et al. (2008) (41)	Brazil	English	Hansen's diseases (HD	Notification forms / 4671; health professional / 14; coordinators / 27; secretaries and health managers / 14.	Health Information System (HIS)	SINAN	Mixed, cross sectional	SINAN forms and flow, Semi-structured interviews, questionnaires	***
13.	Garrib et al. (2008) (475)	South Africa	English	General	Clinic supervisors, district information officers, management staff / sample size not given	DHIS	Use of DHIS	Qualitative	Interviews, raw data from DHIS software	*
14.	Ghia et al. (2013) (486)	India	English	General	Doctors / 223	Telemedicine	Web enabled telemedicine	Quantitative	E-survey	****

S. No.	Author (Year)	Country of Study	Language	Healthcare Setting	Participants / Sample Size	Technology	Intervention	Methodology / Design	Data Collection Tool	Quality Score
15.	Hernandez-Avila et al. (2013) (476)	Mexico	English	General	Federal officers, State level officers, hospital and healthcare managers, IT staff (interviews) / 27; physicians (4 focus groups) / 35	EHR (MS-SQL, Visual Basic)	Use of EHR (SAECCOL) by stakeholders	Qualitative	Interviews, focus groups	**
16.	Kapadia-Kundu et al. (2012) (465)	India	English	General	State-level officials, district and block officials, auxiliary nurse-midwives (ANM), accredited social health activists (ASHAs), USAID officers, staff of non-governmental organisations and other professionals / 46	n/a	n/a	Qualitative	Interviews, focus groups	**

S. No.	Author (Year)	Country of Study	Language	Healthcare Setting	Participants / Sample Size	Technology	Intervention	Methodology / Design	Data Collection Tool	Quality Score
					(interviews); 9 (focus groups)					
17.	Karari et al. (2011) (487)	Kenya	English	HIV/ AIDS	Consultants / Healthcare providers (medical officers, clinical officers, nurse / 79	mHealth/ Telephone	Telephone consultation provided to healthcare providers using cellular phones	Quantitative	Surveys, forms, charts, medical records	****
18.	Kimaro and Twaakyondo (2006) (34)	Tanzania	English	General	Health workers, health information compilers, secretaries and managers / (sample size not given)	HMIS	Managing health information through HMIS	Qualitative	Interviews, observation, group discussions, workshops and trainings	**
19.	Kumar et al. (2012) (49)	Pakistan	English	General	Data reporting personnel, district HMIS coordinator and computer operator / HMIS data	HMIS	Managing and using health information effectively through HMIS	Quantitative	Questionnaire	****
20.	Lal et al. (2002) (35)	India	English	Reproductive and child health (RCH)	Female health workers / 35	HIS	HIS use in RCH	Qualitative	Case study ,Observation, interviewing	*
21.	Ledikwe et al. (2014) (469)	Botswana	English	HIV / AIDS	Public servants,	Data management	Monitoring and	Mixed	In-depth interviews,	****

S. No.	Author (Year)	Country of Study	Language	Healthcare Setting	Participants / Sample Size	Technology	Intervention	Methodology / Design	Data Collection Tool	Quality Score
					individuals working at healthcare facilities, individuals working at nongovernmental, community-based and faith based organisations / 129	and reporting system	evaluation of health services through data management and reporting system		reference material (registers, tools, electronic system)	
22.	LeMay and Bocock (2012) (477)	Malawi	English	HIV / AIDS, FP/RH	Central, district and community level officers / 25 (interviews), 10 (focus groups)	n/a	Knowledge management	Qualitative	Interviews, focus groups	***
23.	Li et al. (2013) (470)	China	English	Pandemic influenza A H1N1	3 group interviews / (2; 12; 12) ; physicians, IT manager, administrative officers directors / 23	Surveillance system / EHR	Surveillance system for the influenza A outbreak / implementation of EHR	Qualitative, case study	Group interviews, individual in-depth interviews	***
24.	Martinez et al. (2004) (488)	Peru	English	General	Medical facility in charge / 27	Telemedicine / voice and email	Connecting health centres with health	Quantitative	Interview surveys	****

S. No.	Author (Year)	Country of Study	Language	Healthcare Setting	Participants / Sample Size	Technology	Intervention	Methodology / Design	Data Collection Tool	Quality Score
						communication	posts through telemedicine			
25.	Martinez et al. (2005) (504)	Peru / Nicaragua	English	General	Programme, regional, provincial directors; health workers, technicians, managers and administrators / 16 (interviews); 4 (focus groups)	Computer-based systems	Epidemiological surveillance system, emergency management, doubt consultation, distance training	Mixed	Interviews, focus groups, questionnaire	***
26.	Mate et al. (2009) (489)	South Africa	English	PMTCT HIV	Clinics and hospitals / 316	DHIS	PMTCT data elements collected and reported through DHIS	Quantitative	DHIS monthly reports	****
27.	Meankaew et al. (2010) (32)	Thai-Cambodian border	English	Malaria	Malaria patients / 534	Web-based and mobile technologies	Disease and treatment monitoring of malaria (DTMM) module	Quantitative	Data extracted from DTMM databases	****
28.	Mengiste (2010) (478)	Ethiopia	English	General	Mangers (regional, zonal, district levels), health workers, HMIS	HIS	Transition from paper-based to computer-based HIS	Qualitative, case study	Interviews, observations, document analysis	**

S. No.	Author (Year)	Country of Study	Language	Healthcare Setting	Participants / Sample Size	Technology	Intervention	Methodology / Design	Data Collection Tool	Quality Score
					officers, and Health Information System Program (HISP) Ethiopia team members / not given					
29.	Mghamba et al. (2008) (467)	Tanzania	English	Infectious diseases	Health staff / 21 health facilities	HMIS	IDSR strategy	Mixed	Interviews, documentary review	**
30.	Morrison et al. (2013) (471)	Nepal	English	General	Health workers / 24; GPs / 3	Any phone	Mobile / tele phone intervention – *celemedicine* – connects mid-level health workers with GPs	Mixed	Call data / telephone survey	*
31.	Nchise et al. (2012) (472)	Rwanda	English	General	Medical doctors, medical students, IT technicians / 15	Telemedicine	Interaction between medical personnel and patients through telemedicine	Mixed, case study	Open interviews, documentary sources, observations	**
32.	Ndira et al. (2008) (505)	Uganda	English	Mother and child health (MCH)	Nurses and midwives / 15; mothers (pre-implementati	eHMIS	Use of eHMIS for improvement in accuracy, availability	Mixed, comparative intervention study	Interviews, summary reports, hospital database	***

S. No.	Author (Year)	Country of Study	Language	Healthcare Setting	Participants / Sample Size	Technology	Intervention	Methodology / Design	Data Collection Tool	Quality Score
					on) / 222; mothers (post-implementation) / 341		and timeliness of health reports			
33.	Ngwakongnwi et al. (2014) (479)	Cameroon	English	General	Stakeholders / 4	NHIS	Implementation and use of NHIS	Qualitative	Interviews, documentary evidence	**
34.	Nsanzimana et al. (2012) (490)	Rwanda	English	HIV / AIDS	Patients on ART / 160 to 1354	Cell-phone and internet-based (mHealth)	TRACnet	Quantitative, cohort study	Standardised pre-ART and ART registers, medical records and pharmacy files	****
35.	Nutley et al. (2013) (36)	Kenya	English	General	Tool users / 10; non-users / 3	DHP	Use of DHP tool for improvements in decision making	Qualitative	In-depth interviews	***
36.	Nwagwu et al. (2013) (506)	Turkey	English	Terminal Cancer	Doctors / 50 ; senior medical staff / 6	ITs: Mobile, internet, computers	Use of ITs by doctors to manage patients	Mixed	Survey questionnaire, interviews	***
37.	Odhiambo-Otieno et al. (2005) (468)	Kenya	English	General	DHMIS operators, health workers / 30	HMIS	DHMIS	Qualitative	Interviews, document analysis, observation	*
38.	Otwombe et al. (2007) (507)	Kenya	English	HIV / AIDS	VCT sites / 332; key informants / sample not given	VCT database	VCT	Mixed	Survey, semi-structured questionnaire	*

S. No.	Author (Year)	Country of Study	Language	Healthcare Setting	Participants / Sample Size	Technology	Intervention	Methodology / Design	Data Collection Tool	Quality Score
39.	Qazi and Ali (2009) (37)	Pakistan	English	General	Health managers / 30	HMIS	Use of HMIS in decision making and effective planning	Qualitative	In-depth interviews	**
40.	Ranasinghe et al. (2012) (491)	Sri Lanka	English	General	HM /33	HIS	Use of HIS by health managers for information support	Quantitative	Questionnaire survey	***
41.	Rangraz Jeddi et al. (2013) (492)	Iran	English	General	soft ware / 30	Hospital Information System	Use of HIS to establish EBM	Quantitative	Two-part check list (background information of the hospitals and observing HIS')	****
42.	Razzak et al. (2012) (48)	Pakistan	English	Road Traffic Injury	Victims / not given	GIS, RTI system	Implementation of RTI surveillance system in emergency departments	Quantitative	Pro-forma	****
43.	Rumisha et al. (2007) (39)	Tanzania	English	General	Health facilities / 109; staff groups	Surveillance system	IDSP	Mixed	Record review, group discussion	**
44.	Scott et al. (2002) (493)	South Africa	English	Cancer	Data records / 3384	GIS, HIS	Use of GIS in the creation of HIS for cancer patients	Quantitative, case study	Data records of cancer patients	****
45.	Seyedin and Jamali (2011) (508)	Iran	English	Emergency Medicine	Public health and therapeutic	Information and	Information and communicati	Mixed	Semi-structured interviews,	***

S. No.	Author (Year)	Country of Study	Language	Healthcare Setting	Participants / Sample Size	Technology	Intervention	Methodology / Design	Data Collection Tool	Quality Score
					affairs mangers / 65; health managers / 230	communication systems	on systems for EM in disasters		questionnaires survey	
46.	Sheikhtaheri et al. (2013) (480)	Iran	English	General	Informants (medical directors)	PSIS	Developing PSIS framework	Qualitative / Comprehensive review	Interviews / scientific databases	**
47.	Shiferaw and Zolfo (2012) (509)	Ethiopia	English	General	Physicians / 10	Telemedicine	Teledermatology, teleradiology and telepathology	Mixed	Interviews, questionnaires, project documents, reports	**
48.	Srivastava et al. (2009) (494)	India	English	General	Staff: data entry operators, medical officers, laboratory personnel, health workers / not given	Surveillance system	IDSP	Quantitative	Interview questionnaire	***
49.	Sylla et al. (2012) (466)	Senegal	English	Family Planning /Reproductive Health	Ministries and other governmental agencies in health, NGOs, parliamentarians, public/ private health providers,	n/a	Analyse the use of FP/RH information	Qualitative	Interviews, focus groups	***

S. No.	Author (Year)	Country of Study	Language	Healthcare Setting	Participants / Sample Size	Technology	Intervention	Methodology / Design	Data Collection Tool	Quality Score
					community health workers, civil servants, news media, local officials, communicators, professional network /75; 2 focus groups					
50.	Thomas et al. (2012) (481)	India	English	Reproductive Tract Infections (RTI)	Targeted Women / 45 (interviews); focus groups / 7	mHealth	Mobile technology-based IT solution to enable communication and engagement between the women and health workers	Qualitative / design and implementation	Semi-structured and unstructured interviews	*
51.	Usmani (2006)(510)	Pakistan	English	General	Medical officers, dispensers, rural medical assistants, lab technicians / 20	Surveillance system	DEWS	Mixed	Questionnaire, interviews	*

S. No.	Author (Year)	Country of Study	Language	Healthcare Setting	Participants / Sample Size	Technology	Intervention	Methodology / Design	Data Collection Tool	Quality Score
52.	Valenzuela et al. (2007) (511)	Colombia	English	General	Men / 102, women 168	Telemedicine	Doctor Chat	Mixed	Free-text queries generated by consumers	****
53.	Vanessa et al. (2012) (482)	Thailand	English	General	CHW / 24; volunteers / 3; project managers 6; community members / 8	Teleconsultation	FFC	Qualitative	Interviews	**
54.	Velez et al. (2014) (512)	Ghana	English	Midwifery	Midwives / 7	mHealth	mClinic	Mixed	Software testing, usability questionnaire, interviews	****
55.	Wong and Bradley (2009) (495)	Ethiopia	English	General	Physicians / 9; pre study medical records 31; post study medical records 35	Medical records	Pre-post intervention study / Implementation and evaluating of medical record	Quantitative	Audit of medical records, survey	****
56.	Zachariah et al. (2012) (496)	Somalia	English	Paediatric	Clinicians / 7; programme data (346 cases of telemedicine)	Telemedicine	A real time audio-visual information exchange	Quantitative	Programmed data, semi-structured survey	****

Conference Abstracts

S. No.	Author (Year)	Country	Language	Health Setting	Participants / Sample Size	Technology	Intervention	Methodology/ Design	Data Collection
57.	Al-mafazy et al. (2012) (497)	Tanzania	English	Malaria	Malaria cases	Mobile phone (mHealth)	MEEDS	Quantitative	System data
58.	Cohn and Xiong (2012) (498)	Kenya	English	AIDS	Community health workers (CHW) /17	Telemedicine	Mobile telephone system, ClinipakMobile, used by CHW	Quantitative	Survey
59.	Williams (2013) (483)	Uganda	English	Maternal and Child health	29 interviews, 8 focus groups	mHealth	Use of mobile phones in emergency medical services (EMS)	Qualitative	In-depth interviews, focus groups

Reports

S. No.	Report Title – *Author (Year)	Country	Language	Health Setting	Participants / Sample size	Technology	Intervention	Methodology / Design	Data Collection
60.	Health Information Systems in developing countries - by Vital Wave Consulting (2009) (38)	Primary research – Brazil, India, Zambia Secondary research – 19 countries including	English	General	System vendors and implementers, IT officials and academic subject-matter experts. Sample size not given	HIS	Use of HIS at district and national levels	Literature review / qualitative, case study	Interviews, site visits

S. No.	Report Title – *Author (Year)	Country	Language	Health Setting	Participants / Sample size	Technology	Intervention	Methodology / Design	Data Collection
		1. Asia, Bangladesh, China, India, Indonesia, and Vietnam; 2. Sub-Saharan Africa , including Ethiopia, Ghana, Kenya, Mozambique, Rwanda, Sierra Leone, South Africa, Uganda, and Zambia; and 3. Latin America and the Caribbean , including Belize, Brazil, Haiti, Mexico, and Peru							
61.	Country health information systems: A review of the current situations and trends – WHO (2011) (25)	Low- and middle income countries	English	General	n/a	HIS	Use of HIS for collecting, managing and analysing health information	Review	Survey
62.	Health information as health care. The roles of mobiles in	Low- and middle income countries	English	General	n/a	HIT and mobile technology	Data flows in surveillance systems	Discussion paper	Survey

S. No.	Report Title – *Author (Year)	Country	Language	Health Setting	Participants / Sample size	Technology	Intervention	Methodology / Design	Data Collection
	unlocking health data and wellness – Ranck (2011) (40)								
63.	Understanding the role of technology in health information systems – (464)	Pacific region	English	General	n/a	HIT and mobile technology / HIS	Extended HIS	Consultative meetings and review	Discussion and literature review

Appendix 7. Barriers and facilitators extracted from selected individual studies

S. No.	Author (Year)	Barriers	Facilitators
1.	Abeysekera, Wickremasinghe (484)	1. Malaria data from the private sector is not recorded 2. Malaria cases where microscopy is not available are not recorded. 3. Faulty data recording and compiling system leads to distortion of the data, numerically as well as spatially	1. Introduction of a recording system of a code for the area of residence of a patient. 2. Uniform units of geographic measurement to be used by all sectors in a country.
2.	Adjorlolo and Ellingsen (499)	1.Finanacial constraints 2. Users not given importance when designing EPR 3. Weak IT department 4. Unreliable internet connectivity and limited bandwidth 5. Electricity shortage	1. Training of staff in computing 2. Alternate source of electricity 3. Provision of internet infrastructure 3. Provision of EPR
3.	Ali and Horikoshi (2002) (33)	1. Lack of information on management issues 2. Poor quality of data (lack of training to health workers in data collection methods / lack of motivation among health services personnel) 3. Lack of timely reporting and feedback 4. Inadequate information usage	1. Launch of National HMIS 2. Refresher trainings and hire more staff.
4.	Alkmim et al. (2012) (500)	1. User resistance to new work process	1. Telehealth requires a collaborative network of educational and research institutions, government, technology providers and funders 2. Meet the real needs of local health professionals 3. Use simple, low-cost technology
5.	Amoroso et al. (2010) (473)	Not given	1. Partners in Health (PIH) OpenMRS program in Rwanda 2. Automated and user friendly tools
6.	(474)	1. Paper-based systems 2. Resistance to change and practices. 3. Data lost if the mobile device is lost or stolen. 4. Poor network coverage. 5. Mobile device downtime. 6. Policy gap for data security and privacy. 7. Weak organisational capacity.	1. Low cost. 2. Easy to retrieve data through mobile device. 3. Portable solar systems and portable recharging devices. 4. Newer models of mobile devices that are cost-efficient and their battery lasts longer. 5. Automated messaging system to tracks and forward important instructions to field workers.

S. No.	Author (Year)	Barriers	Facilitators
			6. Dashboard to manage filed operations. 7. Develop a context-specific policy. 8. Trainings. 9. Improving usability design and continuous testing of mobile applications.
7.	Cao et al. (2009) (463)	1. Slow internet 2. Lack of funds 3. Locally developed client-side programmes have limited functionality 4. Lack of computers and printers 5. Data collected locally cannot be shared 6. Too many locally managed programme increased the cost of management	1. Extensive implementation must be promoted 2. Funding for system-building should be increased 3. Must accelerate the issue of data exchange with the local information systems
8.	Chaiyachati et al. (2013) (501)	1. Technical issues (screen freezes, electronic submission errors)	1. low-cost application 2. In-depth training 3. Perceived usefulness by the healthcare workers (sense of team, better communication) 4. Stronger consideration of end-user perspectives
9.	Chang et al. (2011) (502)	1.Limited phone access to patients 2. Privacy concerns 3. Cost (patient access) 4. Phone maintenance (battery charging due to electricity shortage, phone theft)	1. Mobile phone (rapid communication between PHW and clinical staff, text messaging improved quality of work) 2. Hotline / Toll-free numbers to reduce call costs 3. programme policies to replace stolen phones by PHWs themselves
10.	Chang et al. (2013) (503)	**Other care challenges** **1.** Communication difficulties among CHW and clinical staff due to limited access to phones 2. Lack of CHW training and skill 3. CHW supervision and quality assurance **mHealth challenges** 1. Job security 2. Confidentiality (patient's data) 3. Security (theft, insecure feeling travelling at night times) 4. Detrimental to human interactions	1. mHealth intervention 2. Sensitise users

S. No.	Author (Year)	Barriers	Facilitators
		5. Improper use of the phone (personal use, selling)	
11.	Darkwa (2000) Darkwa (485)	1. Financial constraints 2. lack of basic information technology 3. Unfamiliarity with the telemedicine application 4. Fragmented nature of healthcare delivery	1. Training in telemedicine 2. Involve key health personnel to amend and explore new policies on telemedicine 3. Address the infrastructural imbalance through a national policy 4. Establish strategic alliance with other sectors to raise capital and investment
12.	Galvao et al. (2008) (41)	1. Lack of human resources (limited staff and development) 2. Lack of infrastructure (office space, computers, supplies, etc.) 3. Absence of effective coordination, management and supervision 4. Memory limitations of the computer at municipal level returns the data 5. Lack of feedback from municipal authorities and other officials	1. Regular feedback 2. Supportive supervision visits 3. Annual reviews to monitor the system 4. Make sure the information is decentralised to be used by the primary health services and coordinators
13.	Garrib et al. (2008) (475)	1. Culture of information use is weak 2. Severe shortage of health information skills 3. Lack of human resources in the sub-district level 4. Duplication of data collection for vertical programmes adds burden and negatively affects data quality 5. No feedback to clinic staff on data submissions	1. Staff should be encouraged to monitor their performance towards achieving targets related to health indicators 2. Clinic supervisors should be trained in the interpretation and use of clinic data 3. Use the data set concept to avoid duplication of data
14.	Ghia et al. (2013) (486)	1. Huge investment in equipment 2. Technical issues 3. confidentiality of the patients' information 4. negative attitude of the patients 5. Lack of user-friendly interface 6. Lack of staff training in IT 7. Concern about legal responsibility 8. Provision of bandwidth 9. Power equipment and maintenance	Not given

S. No.	Author (Year)	Barriers	Facilitators
15.	Hernandez-Avila et al. (2013) (476)	1. Resistance by physicians to use the ICD-10 to code diagnoses that was not included in their medical education 2. Physicians perceived EHR to monitor medical stuff (Trust issues) 3. Insufficient attention to recurrent resources needed to maintain the system 4. Pressure from federal programmes to establish parallel IS 5. Sustainability (funds / political will) 6. State level officers have paternalistic view of EHR and dubious about its quality 7. Insufficient training for data entry 8. Rigidity of the system 9. Resistance to change 10. Lack of information policy and normative framework	1. Operating funds 2. Political commitment 3. IT department build up a list of most common diagnoses with their respective ICD-10 codes
16.	Kapadia-Kundu et al. (2012) (465)	1. Language (English is not easily understood at state, district, and village level) 2. Too much information 3. Time and timeliness of information 4. non-simplification of information 5. Access to information	1. English should be simple at higher levels 2. Hindi should be simple at lower levels 3. Actionable information (cut down the unnecessary information) 4. Tailor the information according to the need of users 5. Availability of computers and internet at all levels to access information
17.	Karari et al. (2011) (487)	1. Poor cellular phone network coverage at few sites 2. Non users of the service were unaware of Uliza!	1. Providers needed additional clinical mentorship and training 2. Easy accessibility of the service 3. Reliable and convenient to use 4. Cost effective
18.	Kimaro and Twaakyondo (2006) (34)	HMIS 1. Lack of timeliness (lack of resources (human financial, material), skills and motivations, overburdened) 2. poor quality data due to lack of supervision 3. lack of data analyses due to lack of skilled personnel, analysis tools, not using information 4. Culture that emphasised on collecting and reporting but not making use of it to make power decisions	

S. No.	Author (Year)	Barriers	Facilitators
		5. Lack of motivation due to low salaries, heavy work load and poor working conditions 6. Software design limitations (unmodifiable data fields, absence of source code, unavailable user support) 7. Inadequate technical knowledge and resources (short term trainings) 8. lack of infrastructural support (hardware maintenance, data management utility, anti-virus updates and other IT security)	
19.	Kumar et al. (2012) (49)	HMIS reporting: 1. Low level staffing at various health facilities 2. Political affiliation of the employees leading to non-compliance in HMIS reporting as no administrative action can be taken against such elements Outpatient registers maintenance: 3. Lack of infrastructure and tools (stationery, calculators, telephone, computer system, printer and fax machine 4. Corruption 5. lack of supervision on accountability 6. Scarce resources 7. Lack of knowledge of staff and carelessness 8. Lack of interest and cooperation by staff 9. Low importance and priority given to work	1. Capacity development of district health managers Initiate organisational development and institutional strengthening: 2. Defining organisational and career structures, 3. Specifying roles and responsibilities 4. Managing resources 5. Training personnel 6. Creating sense of responsibility 7. Motivate staff (incentives)
20.	Lal et al. (2002) (35)	1. Workers were overburdened with 13 different registers to generate data and to report information to higher levels 2. Supervisors never used the information as management tool to monitor and evaluate the services and development of health teams at sub centre level. 3. Much of the information tends to be irrelevant, of poor quality and redundant	1. Training, continuing education of health workers and managers
21.	Ledikwe et al. (2014) (469)	1. Incomplete electronic systems 2. Systems lack integration 3. Unreliable systems	1. Investment in electronic medical record system and tertiary training programmes 2. To guide data management, develop a single source of information

S. No.	Author (Year)	Barriers	Facilitators
		4. Double reporting burden (data captured in both paper-based and electronic systems) 5. Data-related activities are sacrificed due to competing priorities and high time commitments	
22.	LeMay and Bocock (2012) (477)	1. No national system for knowledge sharing and no central repository to find complete, up-to-date information on HIV/ AIDS and FP/ RH 2. Unreliable mobile phone network and costly air time 4. Majority of district health officers have limited access to computer and internet whereas community-level officers have no access 5. Understaffing prevents seeking or sharing information 6. Professional hierarchies create communication gaps 7. Health information too dense 8. Overuse of technical jargon (language) 9. Funds 10. Slow and unreliable dial up connections 11. Shortage of electricity 12. Oral culture of passing information	1. Use various communication channels 2. Existing technical working groups can facilitate communication between governmental and nongovernmental organisations 3. District learning centre for the staff 4. The use of radio to meet the needs of an oral culture and to address language issues 5. Use of mobile phones to improve sharing information between district and community workers
23.	Li et al. (2013) (470)	1. Patient information were incomplete and inaccurate 2. Clinicians' dissatisfaction with the software in use 3. Clinician's concern about IT reliability and high investment and low reimbursement of the system implementation 4. No internet access to physicians and unavailable software tools to answer patients' queries	1. EHR system would enable sharing of patient health records with patient privacy protected 2. Automatic check of contradiction when electronic information is updated to reduce prescription errors 3. Education and awareness plans to improve clinicians understanding of how EHR can benefit their performance 4. Exploring ways to improve human-computer interactional design
24.	Martinez et al. (2004) (488)	Not given	1. Voice and email communication via VHF radio is economical and sustainable 2. Training sessions of no more than 10 days to the nursing technicians with no university education 3. active participation of users for sustainable services

S. No.	Author (Year)	Barriers	Facilitators
25.	Martinez et al. (2005) (504)	1.Weak telecommunication infrastructure a. No electricity b. Rural establishments have limited funds c. High maintenance costs d. Few well-trained people for management, maintenance and repair of IT 2. Expensive surveillance systems 3. Frequent data errors due to redundancy, impossible to make corrections and lack of feedback	1. Computer-based systems could improve epidemiological surveillance system, emergency management, doubt consultation, distance training 2. Low-speed systems such as email could be use 3. Radio-based system could be used 4. Remote maintenance should be installed wherever possible 5. Use open technologies 6. Training
26.	Mate et al. (2009) (489)	1. District Information Offices did not routinely review data completeness so as to improve data systems 2. Staff at clinics may not give importance to the quality of data collection	1. Clinic staff need to perceive data as intrinsically valuable in the management of their patients and their own performance 2. Clinic staff need to be supported and supervised in the execution of data management responsibilities
27.	Meankaew et al. (2010) (32)	1. Sustainability issues 2. Data quality, data integrity, completeness and timeliness issues.	1. Easier to collect data through DTMM at local clinic 2. Additional data collected through mobile phones during home visits 3. Open Source 4. Financial assistance for sustainability 5. Dedicated staff 6. Well-trained staff in geographical-information and mobile-technology applications
28.	Mengiste (2010) (478)	1. Uncertain and unpredictable environment of public healthcare system (new policies, strategies and regulations on public health and HIS initiated by WHO-HMN, government (national, regional, district), NGOs) 2. Lack of infrastructure 3. Lack of finance 4. Lack of skilled human resource	1. Flexible strategies to deal to deal with context-sensitive challenges
29.	Mghamba et al. (2008) (467)	1. inadequate data analysis 2. Poor supervision and feedback 3. Overburdened staff to compile and submit reports 4. Lack of computer knowledge and skills of health personnel	1. Review data at both facility and district level 2. Training and supervision of staff at both facility and district level 3.Monitoring and evaluation at both facility and district level 4. New IDSR strategy to identify the most productive actions and approaches for information users

S. No.	Author (Year)	Barriers	Facilitators
30.	Morrison et al. (2013) (471)	1. Workload of GPs will increase 2. Technical issues (power cuts and network overload)	1. Success depends on the motivation of mid-level health workers, willingness of the doctors and willingness and ability of patients to follow advice.
31.	Nchise et al. (2012) (472)	Technology 1. Unreliable and limited internet connections to transfer data in real time 2. Limited number of IT personnel 3. Limited number of trained doctors in telemedicine 4. Unavailability of high bandwidth Organisational 5. Financial capital 6. Managerial commitment and strategy Government 7. Inability to provide the requisite ‘tele-ready’ medical equipment	1. Video conferencing facilities 2. Training of doctors in the basics of telemedicine, legal and ethical issues, video conferencing, practical digital photography and tele-education 3. Government’s initiative to promote ITs in health care
32.	Ndira et al. (2008) (505)	1. Power shortages 2. Lack of technical infrastructure 3. Lack of country wide network backbone 4. High cost 5. Managements’ commitment (organisational, managerial and social challenges) 6. Parallel use of paper based system 7. Human resource constraints	1. Continuous monitoring and evaluation of the quality and consistency of usage of the system 2.Power backup 3. Value addition of the electronic system evident to users 4. Capacity building, adaptability and extensibility
33.	Ngwakongnwi et al. (2014) (479)	1. Inefficient system 2. Lack of personnel to check the data quality 3. Labour-intensive process of data entry 4. Delays in getting reports from health centres and field workers 5. Lack of incentives to field workers 6. Infrastructural problems (power, poorly organised health system, personnel lacking computer skills)	1. Financial motivation for field workers 2. Automatic synthesis of data 3. Introduction of electronic health records (EHR)

S. No.	Author (Year)	Barriers	Facilitators
34.	Nsanzimana et al. (2012) (490)	1. Late reports 2. Incomplete data 3. lack of feedback from central levels to peripheral levels	1. Cell-phone and internet-based reporting of key HIV care and treatment indicators facilitated rapid reporting of national ART
35.	Nutley et al. (2013) (36)	1. Fragmentation of data reporting 2. Proliferation of indicators 3.Poor data quality 4. Insufficient data feedback, 5. Data feedback in formats that are difficult to understand 6. Insufficient review and interpretation of data 7. Insufficient use of data to monitor and improve programmes DHP tool 8. Insufficient training 9. Lack of support from supervisors to use the tool 10. Users had conflicting priorities (undefined users roles) 11. Lack of infrastructure (printers, computers)	1. Need for greater value placed on data 2. Improve attitudes towards data and data use
36.	Nwagwu et al. (2013) (506)	Not given.	1. Mobile phones was the tool used most for linking either with patients or with their relatives and colleagues 2. The expansion of ITs skills of medical practitioners 3. Capacity building of the medical practitioners 4. Promote clinical uses of the technology such as point of care, electronic health records, clinical decision support tools and order entry systems
37.	Odhiambo-Otieno et al. (2005) (468)	1. Design flaws in DHMIS 2. Fragmented DHMIS 3. Information requirements of the users were neglected 4.Variation in data collection tools did not allow comparison in terms of performance among DHSs 5. Staff complained about inadequate supplies of basic resources required for effective operation 6. Low-key perception of DHS managers on information activities	1. Urgent needs to computerise the existing manual system 2. Secure the support of DHS managers both financially and morally

S. No.	Author (Year)	Barriers	Facilitators
38.	Otwombe et al. (2007) (507)	1. Complicated presentation of the data due to different data collection tools. 2. Data delays from sites that were remote and rural 3. Staff shortages due to the time given to urgent medical needs and could not devote time for VCT 4. No data tracking system to identify locations of delay	1. Feedback mechanism should be developed on the performance of VCTs that should increase submission of reports 2. Link VCT data to other national monitoring and evaluation systems
39.	Qazi and Ali (2009) (37)	1. Lack of skilled personnel 2. Lack of financial resources affected: a. training of health staff b. Computer repairs, internet and software purchase c. travelling allowance to health staff 3. Misuse of resources 4. Data quality issues (incomplete data, little knowledge of English) 5. Delays in publishing reports due to outdated methods used for saving and sending data (floppy disks) 6. Lack of coordination among various vertical information systems 7. lack of inter- and intra-departmental coordination	1. Political will and feeling of ownership 2. Defining the structure of organisations: a. specifying the roles, responsibilities and defining a career structure 3. Managing resources: a. Training personnel b. Need assessment c. Creating sense of responsibility d. Motivate staff e. Encourage staff by giving incentives on good work 4. Introduce and make staff and managers act on work ethics 5. Integration of vertical systems 6. regular feedback from centres to auxiliary levels 7. Establish role models districts
40.	Ranasinghe et al. (2012) (491)	1. Routine HIS does not meet expectation of HMs and failed in providing the required information support for health planning and management	1. Evidence-based decision making culture and practice is required 2. Capacity building and reform efforts are needed
41.	Rangraz Jeddi et al. (2013) (492)	1. HIS' lack the ability to establish EBM in providing access to CDSS and getting information via reference database and internet 2. Physicians and healthcare providers do not have sufficient knowledge of the CDSS and to use it efficiently	1. Training physicians to increase the quality care and fast access to the treatment methods
42.	Razzak et al. (2012) (48)	1. Lack of support, limited health budgets, competing priorities and poor understanding of the RTI system	1. Government's ownership on direct financial support of the RTI system is needed 2. Innovative partnerships are required

S. No.	Author (Year)	Barriers	Facilitators
		2. Poorer utilisation of available information due to lack of ownership of the problem by the lead agency for road safety 3. Lack of pre-hospital and hospital based trauma care system led to challenges in finding users of the medical information 4. Coordination between federal, provincial and city government and many private hospitals is difficult and reluctant to exchange patient information	3. A stable funding is required for the system
43.	Rumisha et al. (2007) (39)	1. Overburdened health facility staff 2. Poor communication (feedback and supervision, weak reporting)) 3. Lack of uniformity in recording due to lack of case definitions 4. Poor incentives 5. Poor organisational capacity (lack of adequate information exchange facilities and systems) 6. Insufficient financial resources	1. Health workers to be involved in a participatory manner to improve their timely reporting 2. Creation of culture of using information and motivation of health workers 3. Strengthen capacities of health workers for the sustainability of IDSP
44.	Scott et al. (2002) (493)	1. Incomplete details in hospital records that hampered spatial reference for each cancer case	1. GIS has significant potential to add value to HIS for cancer in developing counties for understanding the disease more comprehensively, providing improved methods for disease reporting and to promote the location of appropriate healthcare facilities
45.	Seyedin and Jamali (2011) (508)	1. Lack of information strategy at both national and local levels with regard to disaster management 2. Lack of EM information system	1. Creating a national networked database for emergency related information 2. Creating protocols and standards for communication 3. Training the staff on how to communicate with media and how to acquire appropriate information from different places
46.	Sheikhtaheri et al. (2013) (480)	1. Lack of formal PSIS for collecting, analysing, disseminating and sharing patient safety information in many Iranian hospitals	1. Iranian hospitals and health authorities should develop standardised data sets, standard forms for reporting, mechanism for data analysis and feedback modes

S. No.	Author (Year)	Barriers	Facilitators
47.	Shiferaw and Zolfo (2012) (509)	1. Telemedicine is still premature in Ethiopia	1. For success of telemedicine, an eHealth policy and 'enabling-policy environment' are required 2. Use of simple, local and user friendly technology according to the local context 3. Telemedicine and eHealth should also be encouraged in private health organisations for public private partnerships 4. For sustainability telemedicine need a business model 5. Referring national practice and experiences, guidelines and IT security protocols are needed. 6. Training of paramedics and nurses in using telemedicine tools 7. Active participation from policy makers, technology providers, IT experts, researchers and health professionals, under the umbrella of a coordinating body
48.	Srivastava et al. (2009) (494)	1. No personnel trained to report epidemiological and etiological diseases	1. Presence of public health specialist to develop action oriented surveillance system 2. Usage of mobile phones / IT must be encouraged for timely reporting 3. Need to review laboratory services and infrastructures in rural surveillance settings
49.	Sylla et al. (2012) (466)	1. Barriers to accessing, sharing, and using health information exist at all levels of the health system 2. Lack of units and personnel trained and responsible for information management 3. Delays in receipt of information 4. Low relevancy of information 5. Illiterate communicators 6. Lack of internet access 7. Electricity shortage 8. Poor access to training in use of IT 9. High costs of mobile minutes 10. Problems in understanding technical language 4. Lack of infrastructure (computer and photocopy machines)	1. Use of mobile phones and SMS text messaging 2. Political support 3.Intrenet and email, and fax

S. No.	Author (Year)	Barriers	Facilitators
50.	Thomas et al. (2012) (481)	1. Incapable systems to collect data. 2. No functionality exist to consolidate data for later analysis	1. Trained workers to use the system. 2. Educated population to report symptoms through mobile phones.
51.	Usmani (2006)(510)	1. Lack of proper training for DEWS 2. Deficient tools of DEWS in most of the health units	1. Proper training of DEWS 2. Tools of DEWS such as case definition document, reporting forms, and weekly charts should be provided 3. Incentives and rewards 4. Necessary administrative and disciplinary action
52.	Valenzuela et al. (2007) (511)	1. Cultural (sex related topics are considered taboo), 2. Infrastructural and, 3. Connectivity barriers	1. Teleconsultaion service encouraged open questioning and facilitated discussion 2. Users and specialists are positive about the service
53.	Vanessa et al. (2012) (482)	1. Wireless connectivity issues 2. Weak mobile technology infrastructure 3. Maximising the use of mobile device	1. Training to address the needs of CHWs to use Skype during critical emergencies
54.	Velez et al. (2014) (512)	1. Usability problems with the system	1. For successful implementation, scalability and long term sustainability, careful and thoughtful design is essential 2. Perceived usefulness of mClinic is higher than perceived ease of use
55.	Wong and Bradley (2009) (495)	2. Resistance from the staff to use the new system 3. Power shortages	1. Cooperation from the hospital staff is essential to success 2. Inexpensive intervention
56.	Zachariah et al. (2012) (496)	1. Deprived and insecure environments (war-torn)	1. Teleconsultation service
57.	Al-mafazy et al. (2012) (497)	1. Technical problems prevented data transmission from many clinics	1. Efforts and resources are required to increase the timeliness 2. Improved representativeness of the system
58.	Cohn and Xiong (2012) (498)	1. Weak integration of information gathered at the community level with the national health information system 2. Poor linkages to the formal health sector 3. Busy clinicians may not note clinical ‘red flags’ that were recorded by CHW during home visits	1. ClinipakMobile is easy to use hand held mhealth tool to improve CHW functioning to care patents

S. No.	Author (Year)	Barriers	Facilitators
59.	Williams (2013) (483)	1. Gender inequality in the ownership of phones is the biggest risk to mHealth	1. Mobile phones strengthen health systems through flow and sharing of information and coordination of the limited health workforce. 2. Increasing affordability of healthcare
60.	Health Information Systems in developing countries - by Vital Wave Consulting (2009) (38)	1. HIS only collects data from the public sector. 2. Data duplication and fragmentation. 3. HIS is not used by those responsible for managing health services at local levels. 3. Data collection is a burden on staff. 4. Various systems were seldom integrated. 5. Poor quality data 6. Shortage of qualified personnel 7. Lack of respect for data in government. 8. Limited budgets. 8. Lack of technical resource and support 9. Difficulty in teaching clinicians how to use health record to improve care. 10. Lack of infrastructure. 11. Product development is difficult due to unclear needs. 12. Limited network connectivity.	1. Data streamlining and validation efforts 2. Involve community in health plans to increase data demands. 3. Feedback mechanism for workers and community members. 4. Addition of data staff. 5. Establish standard data formats and electronic submission guidelines. 6. Make easy and inexpensive for regions to integrate with national systems. 7. A common code base and support team. 8. Additional trainings to understand the system and its features
61.	Country health information systems: A review of the current situations and trends – WHO (2011) (25)	1. Inadequate leadership and coordination for collection and use of data. 2. Lack of health information policies and comprehensive plans 3. Limited funds 4. Shortage of staff 5. Lack of skills 5. High turnover of staff in public sector due to low salaries 6. Huge volume of reporting 7. Standards unavailable for collecting and analysing data 8. Not implementing data management protocols 9. Fragmented and parallel systems 10. Poor data quality 11. Poor analytical capacity	1. High level leadership and coordination to ensure efficient collection and use of data. 2. Health information strategic plans. 3. Grants from international NGOs 4. Improve staffing capacity 5. Trainings 6. Motivation 7. Diverse reporting formats and periodicities 8. EHR facilitate accessing individual records maintain confidentiality and protection of data 9. Standards for data collection

S. No.	Author (Year)	Barriers	Facilitators
62.	Health information as health care. The roles of mobiles in unlocking health data and wellness – Ranck (2011) (40)	1. Fragmentation of health system 2. Lack of unique health identifiers 3. Poor data quality 4. Lack of standards and interoperability 5. Limited human resources 6. Inadequate IT infrastructure (IT communication and network errors; interruptions in electrical supply; and IT devices infected with malware or viruses) 7. Jurisdictional barriers to sharing information 8. Lack of data standards	1. Standards to enable interoperability 2. Policy agreements to share data across boundaries 3. Awareness of technology
63.	Lewis (2012) (464)	1. Poor telecommunication infrastructure. 2. High cost of equipment and accessing services. 3. Insufficient bandwidth. 4. Limited and unequal access. 5. Low investment in infrastructure networks. 6. Intermittent power supply. 7. Low quality of phone lines. 8. Lack of trained human resource. 9. Lack of organisational capacity. 10. Reliance on external capacity drives HIT costs upwards. 11. Hidden costs such as license fee, technical support, upgrades and ongoing trainings. 12. Limited software have been developed in languages other than English. 13. Tropical climate of the Pacific region is damaging to equipment. 14. Detrimental human actions (stealing of phones). 15. Lack of human resource.	1. Electricity systems 2. Internet connectivity. 3. Availability of phone lines. 4. International consultants must understand the local conditions and know about the local resources. 5. Affordable technology. 6. Improve the economic situation for long tern sustainability of projects. 7. HIT must be locally relevant (use local language software). 8. Climate-controlled and dust fee environments required for equipment.

Appendix 8: Ethics approval

THE UNIVERSITY of EDINBURGH

CENTRE FOR POPULATION HEALTH SCIENCES
Ethics Review Group
Medical School
Teviot Place
Edinburgh EH8 9AG

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email: cphs.ethics@ed.ac.uk

07 July 2014

Dear Mr Akhlaq

Re: Electronic Health Information Exchange (eHIE) in Low-Income Countries: Perceptions of Healthcare Stakeholders in Pakistan

Thank you for resubmitting your documentation with the amendments that were requested by the CPHS ethics committee. The amendments have been judged satisfactory. I am therefore pleased to be able to inform you that the above study have been granted ethical approval.

The committee has asked that you give the documents a good proof read for typos. Please send a copy of any documents changed to the committee (via me), so that we have an up-to-date version.

Please be aware that this ethical approval is in respect of the protocol and methods as described in the documents submitted to the committee (with amended documents superseding predecessors). If there is in the future *a change* to the study design/protocol/methods, you should check whether this means your level 2 application form needs to be revised, and submit to the committee (via me), any documents that have been revised (study materials/protocol/level 2 form), using tracked changes. You should make clear in your covering email whether:

(i) you are requesting ethical review of a study amendment; or

(ii) you are not sure whether such is needed and, in the first instance, would like the committee's opinion on whether a formal approval is needed of the amended design/methods.

Yours sincerely

LMcgoohan

Lesley McGoohan

Ethics Review Group Administrator

Appendix 9: Information leaflet

Health Information Exchange in Low- and Middle-Income Countries: Perceptions of Healthcare Stakeholders in Pakistan

"Participant Information Sheet"

Name of Principal Investigator	Ather Akhlaq
Name of Organization	The University of Edinburgh

Introduction

I am Ather Akhlaq, PhD student, working in the eHealth Research Group, Centre of Population Health Sciences, University of Edinburgh, UK. I am doing research to understand the ways in which patient information can be exchanged and used between healthcare providers using electronic information and communications systems and how this is being realised in Pakistan. Electronic Health Information Exchange (HIE) has potential to improve clinical decision-making and patient outcomes but can be challenging to implement. The aim of this research is to understand how healthcare providers in Pakistan and other stakeholders within public and private organizations, perceive the current status of HIE in Pakistan, see its potential benefits, and understand the factors which are likely to encourage or hinder its effective implementation in the Pakistan healthcare context

Before you decide to take part, I would like to let you know about the study and what it involves. This leaflet provides the required information for you. Once you have read this, please feel free to contact me with any questions you may have.

Background

Pakistan is a low- and middle-income country with various economic, social and political problems, in addition to a lack of basic infrastructure for supporting the health of the population. The earthquake in 2005 / 2013, floods in 2010, maternal and children health problems, outbreaks of dengue and influenza; polio virus, terrorism acts such as target killings, bombs blasts, political violence have drawn attention to the need for stronger health systems. The health system is now quite fractured and uncontrolled, which makes coordination of services and access to integrated patient information across institutions difficult. The recent rise in the population is also creating new challenges for the capture, retrieval and processing of health data.

According to WHO, Pakistan would benefit from a national information system that can collect data from multiple data sources in order to strengthen the health care system and help to achieve the Millennium Development Goals (MDG) and address the other health related issues mentioned above. Decision makers have to take effective steps to integrate all disparate health facilities, institutions and health information systems into one national system to allow the exchange of health information for better and coordinated healthcare delivery. While this is a major undertaking it begins with individual facilities taking the decision to adopt appropriate technologies such as electronic health records (EHR) to underpin HIE.

Purpose of the Study

Coordinating and communication between different healthcare stakeholders requires a robust network infrastructure that can support the exchange and use of health information for better healthcare outcomes. In order to inform strategies for the effective implementation of HIE infrastructure in Pakistan, it is essential to understand the current process of HIE in Pakistan and the various technical, strategic and cultural barriers to HIE that exist in different contexts of the health system. In order to inform strategies for the development of HIE, it is valuable to look at the issue from the perspective of different stakeholders, so as to understand the opportunities and measures required to implement HIE in individual facilities across care settings. We believe that you can help us by telling us what you know about the current relationship between health and eHealth infrastructure of Pakistan, and challenges associated with it. We also need to know about the information needs of different healthcare stakeholders, how patient information is exchanged at present and the role that eHealth that can play in fulfilling the needs of a regional and national health system.

Why have I been invited to take part?

You are being invited to take part in this research because we feel that your experience can contribute much to our understanding and knowledge of health information needs of healthcare professionals and how HIE can be useful in satisfying their information needs for enhanced health outcomes.

Voluntary Participation

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. The choice that you make will have no bearing on your job or on any work-related evaluations or reports. You may change your mind later and stop participating even if you agreed earlier.

Reimbursement

You will not be provided any incentive or payment to take part in the research.

How much time and effort is required?

The interview/discussion is anticipated to take at most 1 hour.

Benefit

There will be no direct benefit to you, but your participation is likely to help us find out more about the health information infrastructure of Pakistan.

Risks

No risks are involved except using your time for the interview.

Confidentiality

Your name will not be shared with the other participants in the study and your data will be protected by removing names and identifiers from the transcripts and ensuring that only the researcher has access to your data. As one of the methods we will be using to identify participants is personal recommendation, and because there may be more than one person from your organisation being interviewed, there is a possibility that some participants may know about one other’s involvement in this research. However the interview recordings will not be heard by anyone other than the researcher and will be kept secure. Any information about you will have a number on it instead of your name.

Only the researcher will know what your number is and your data will be stored in a locked filing cabinet or in password protected computer. In our reports, I may quote you, writing down what you said in your own words but I will not use any information which could identify you (like your name, where you work etc.). The recordings and data will be destroyed after 3 years of this research.

Who to Contact

If you have any questions, please ask now or later. You may contact any of the following:

Researcher

Ather Akhlaq (email: ather.akhlaq@ed.ac.uk) , Mobile: 0092 333 2355161 / 0044 7831 550424)

Supervisors

Aziz Sheikh (email: aziz.sheikh@ed.ac.uk) ,
Brian McKinstry (email: Brian.McKinstry@ed.ac.uk)

Appendix 10: Consent form

Room 112
eHealth Research Group
Centre of Population Health Sciences
Medical School, Teviot Place
Edinburgh EH8 9AG,
Scotland, UK

Health Information Exchange (HIE) in Low- and Middle-Income Countries: Perceptions of Key Healthcare Stakeholders in Pakistan

“Participant Consent Form”

Please read and complete this form carefully. Please initial the following statements if you are happy with them and leave blank any that you are not happy with. If you do not understand anything and would like more information, please ask.

	Initials
The research has been explained to me in a way I can easily understand (written or verbal)	
I have had the opportunity to ask questions about the study and understand what is involved.	
I understand that my interview will last no more than one hour and will be recorded by using digital equipment.	
I understand that it will not be possible to identify me when using direct quotations from me in future publications.	
I understand that I may withdraw from this study at any time without having to give an explanation. This will not affect me in any way.	
I am willing for my anonymised data to be archived and used for this research project and I understand that all data will be destroyed at the end of the project.	

I freely give my consent to participate in this research study and have been given a copy of this form for my own information.

Participant Name:	Date:
Signature:	
Name of the Person taking Consent:	Date:
Signature	

Appendix 11.1: Topic guide

1. Please can you explain how health information is exchanged and used between:

   a) healthcare providers;

   b) healthcare professionals;

   c) between providers and patients and

   d) between providers/professionals and government agencies?

   e) between public and private providers

2. What works well in these processes?
3. Where is there room for improvement?
4. To what extent is this health information exchange achieved through electronic means?
5. Are there any particular advantages/disadvantages to electronic HIE?
6. How might such electronic HIE be enhanced? Are there any particular barriers or facilitators that come to mind?
7. In your opinion, how practical would it be to develop national health management information system? Why or why not?
8. Anything the interviewee would like to add.

Appendix 11.2: Topic guide version 2

1. How patients' information / data are being collected?
2. Please can you explain how health information is exchanged and used between:

   a) healthcare providers;

   b) healthcare professionals;

   c) between providers and patients and

   d) between providers/professionals and government agencies?

   e) between public and private providers

3. What works well in these processes?
4. Where is there room for improvement?
5. To what extent is this health information exchange achieved through electronic means?
6. Are there any particular advantages/disadvantages to electronic HIE?
7. How might such electronic HIE be enhanced? Are there any particular barriers or facilitators that come to mind?
8. What is the path to interoperability in the healthcare?
9. In your opinion, how practical would it be to develop national health management information system? Why or why not?
10. Anything the interviewee would like to add.

Appendix 12: Field notes

RJ_20_1
Meeting time: 2 pm October 1 2014
Approx. interview duration: 23 min
Start: 2 pm / End: 3 pm

I was received by the worker outside the elevator on the ground floor. I was taken to the second floor and was guided to the interviewee (IV)'s office. The office was straight inside the corner. The IV was present on his chair and greeted me. He asked me for the tea or coffee but I did not take it. The IV asked me to remind the objective of the study. I was given the glass of water. The room was big and quite.
The interview began. The door was open so it was slightly noisy (staff talking).
After the interview, he offered me to visit the telemedicine department and the Emergency Medical Service (EMS) department. In the telemedicine department he and the in-charge told me how they handle calls, call charges, service cost, and business model (charity-based). Similarly in the EMS department, they showed me the ambulance tracking system and briefed me about its mechanism.
We thanked each other warmly and I left the room.

AT_83_2
Meeting Time: 9 am October 3, 2014
Approx. interview duration: 53 min
Started: 9:05 End: 10:00

I called the personal secretary of the IV when I reached outside the office. While going to her office I saw patients being moved on stretchers to different departments in the scorching sunlight. Paper medical reports were used by their attendants to cover the faces of patients from direct sunlight.
I was given a protocol to park my car and was directed to the IV's office. The office was a big room but the IV was not present. I was told to wait for few minutes. The IV came to the room after 5 minutes. We exchanged greetings with each other. I was asked for tea to which I said yes. IV read the consent form and told me that she has to rush in another meeting and could not give me an hour. I told her not to worry for that.
The interview begun and in between IV called her assistant to bring the sample files and documents to show and explain me. In the end she also gave me yearly booklet of the symposium for my information.
The interview ended and she wished me good luck. She also asked me to share the results of this research on which I told her that it will take at least two years to get it published. We warmly thanked each other and again I was taken to my car.

JR_18_3
Meeting Time: 3 pm October 9, 2014
Approx. interview duration: 19 min
Start time: 2: 50 pm / End: 3:10 pm

I reached the IV's office 15 min before the meeting time. I was guided to the IV's office by his assistant. The IV was busy in his computer and had his back towards me when I entered the room. His assistant informed him about my arrival. He greeted me and asked me about my project. I gave him the project introduction and gave him the consent form to start something with. He asked me that why I have chosen him for the interview. I explained him a little about the sampling framework. The room was fine and many badges were hung on

the front wall. We started the interview. Soon the IV had a mobile call and he got busy talking with someone and looking for some papers. I paused the recorder. The interview was resumed again after few minutes. Again after few minutes he got another call and got busy with pen and paper for another few minutes. This time I didn't pause the recorder. Again the interview was resumed again but I was getting very short answers of my questions. After the last question the IV told me that he has to go and see his patient in critical condition. He also gave me the reference of his assistance who looked after the telehealth project in rural Sindh.
I thanked him and we left the room together and went into opposite directions.

QSAA_72_4
Meeting Time: 11:30 pm October 11 2014
Approx. interview time: 22 min
Meeting Start: 11:30 am / End: 12: 45 pm

I reached the main gate of the venue at 11 am. I was not allowed to enter the hospital gate to park my car because no information of my arrival was given to the security gates. The traffic police was not allowing me to park car outside due to busy road and they asked me to move my car from the gate. I requested them to give me few minutes as I am on wheelchair. I called the IV from my mobile while in the car and requested him to please allow me to park the car inside. He sent his assistant to the main gate after ten minutes and I was taken inside the building.
I was taken through the lift to the first floor then to the IV's office. The IV's room was good and big. He was busy with his files. I greeted him as soon as I entered. I reminded him about the project on his request. He called someone on the telephone and asked to join us as because I cannot go to that person's office on the wheelchair. The interview started after the consent form was signed. After few minutes somebody came inside with the bunch of files on which the IV signaled to keep quiet, and put the file on the table and go away. After few minutes another person came and greeted us but again the IV signaled to keep quiet as the recording was on. That person was the IT manager and he also joined the conversation and answered many questions related to his field. After the recording, I made the IT manager signed the consent form as well.
After the interview, I was offered tea and we all discussed the prevailing conditions of Pakistan, especially Karachi. The IT manager was talking about the IT professionals' job role and demand in the market. The IT manager left the room early. I also asked for other reference and was given two.
I thanked the IV and he got up and opened the room for me.

KK_74_5
Meeting Time: 3 pm October 11 2014
Approx. interview Duration: 47 min
Meeting start time: 3pm / End 4pm

I called the IV when I reached outside the building to know the office directions. He himself came downstairs to guide me to his office at second floor. He took me and my helper to his room. There were other people (2) in the room using their PCs. It was a joint room and every other person can listen to our conversation. I gave him the consent form and started the interview. Sometimes IV was looking to his neighbor during the conversation and his neighbor nodded in yes to confirm what the IV was saying. The room was quite except of the typing noise made by other staff in the room. After a while the other person left the room and only IV and his neighbour were left.

In the end of the interview, there were couple of mobile calls for the IV but the IV did not respond. After the interview IV's neighbour gave couple of other references. Then we all chat of the current affairs and politics of the organisation and the country.

FR_86_6

Meeting Time: 11 am October 17 2014
Approx. interview Duration: 25 min 39 sec
Meeting start time: 11am / End 12 noon

I reached the location before time. There were few steps to the building so the guards there lifted me on the wheelchair to get me in the building. Again when I was taken in, there were few steps to the office. Peons were called to lift me on the wheel chair to take me in the office premises. There was the reception and huge glass rooms. I was greeted by the participant and was taken in to one of the room. The room was walled with glass so you can see the garden and the caged birds outside. I was asked for tea for which I said yes.
I introduced the project to the IV. I asked the question in English but I got response in Urdu so I continued asking other questions in Urdu. The environment was peaceful and the IV looked relaxed. There were few calls the IV attended during the interview. He also made me talk on his mobile to the one of the reference.
It was good and the IV was very courteous and helpful.

JR_28_7

Meeting Time: 1030 am October 20 2014
Interview Duration: 27 min 49 sec
Meeting start time: 1040 am / End 1145 am

I was looking for the participant's office so two ladies, probably staff, guided me to the IV's office. The participant was standing outside her office. She welcomed me and probably going somewhere. I was lead in the room and was told that the IV would be coming in a while as she had some meeting to attend. I was there 5-10 mins before the appointment. I was offered tea by her assistant. The IV came after 10 mins and the interview started. Her room was neither big nor small. There was not any disturbance except of few ringing emails. The interview started in English but in the mid she started giving answers in Urdu. Her secretary brought tea for her in the mid of the interview. She introduced her to me and we exchanged greetings with each other. The interview continued again. She answered informally to every question. The interview ended and with good wishes given to me.

JJ_52_8

Meeting Time: 0300 pm October 20 2014
Interview Duration: 24 min 59 sec
Meeting start time: 0300 pm / End 0325 pm

The meeting was on Skype. I read the consent form on which the participant said yes to all the clauses. First he was looking reluctant to give the interview as he said that he was not allowed to give any information related to his job. I convinced him by telling him that his name will not be recognised by any means.
First we had a video call for a minute but due to distortion I called him again switching off the video. The call was fine then. In the last answer to the question I asked, the call got disconnected. I tried again but could not connect. Then after 2 or 3 min I got a call on my mobile from the IV apologising that there was no electricity. The interview was almost done.

ASWMBTAR_82_9.1/9.2

Meeting Time: pm October 21 2014
Interview Duration: Part 1 22 min 36 sec, Part 2 23 min 27sec
Meeting start time: 1100 am / End 1230 pm

The medical facility was in the NO GO AREA of Karachi. It was in the rural area of Karachi which was not safe to move around. I was afraid to go to that place but I went there for my field work. The facility was newly built and was unexpectedly clean and good. I waited at the reception and saw a women (looked poor) sitting on the floor. She came to me and showed me a prescription. She asked me whether I knew any laboratory or hospital where she can go for the test for free or subsidised. I told her that you were in the charity hospital and you can go here for free but she informed that this hospital had no facility for this particular test. I went to the IV's room after making the enquiry from the reception. The IV was not in the room. I waited there for few minutes. There were 2 other staff members having meeting in the room. They left the room after few minutes. I was given a cup of tea. Then the IV arrived with two other gentlemen. They were IV's colleagues. They also joined the IV session. After listening to my project, the IV called another colleague to join with us. The colleague came but did not participate due to his other meeting. The interview started. After 10 15 min, the CEO came to the room and joined with the other participants. Few minutes later another gentleman, a foreigner from Rome came into the room with his luggage, probably came directly from the airport. The interview was paused. The foreigner sat there for 10 min and realised that there was a meeting going before his arrival. He was accommodated to the dining area. The participants were in a hurry to finish the interview. The interview started and ended well in another 20 min. I asked all of the participants to give me their email addresses.

KAM_54_10
Meeting Time: 7 pm October 22 2014
Interview Duration: 32 min 54 sec
Meeting start time: 0700 pm / End 0800 pm

The IV's place was not accessible so we met in a Hotel's lobby. The IV was there on time. We introduced ourselves to each other. I asked the permission to start the interview and started it after the formalities. Our location was near the lift so we can see people passing us. Sometimes, there were children shouting and yelling while passing by. The IV was speaking in a low tone so I came closer to the IV. The interview went well. I offered IV a drink to which IV refused.

MAM_88_11
Meeting Time: 10 am October 23 2014
Interview Duration: 38 min 51 sec
Meeting start time: 10 am / End 1040 am

The IV's place was not accessible for me so the IV requested for a Skype call. The interview started exactly on time and there was no distortion throughout. The interview went well and all questions were answered.

SS_90_12
Meeting Time: 12 noon October 23 2014
Interview Duration: 27 min 54 sec
Meeting start time: 1210 pm / End 1250 pm

The IV was in his room having meeting with a colleague when I reached there. He looked very busy with papers and computers. He requested me to wait for a while. After the meeting the IV called me closer to his desk. The room was walled with glass and any happening can be seen from inside or outside. I requested the IV to close the door to curb the noise. The IV closed the door. The interview started. In the middle someone was willing to enter the room but was stopped by the IV's signal. Un the end there was a mobile call that was ignored by the IV. The IV behaved very friendly and in a peaceful way.

AF_92_13
Meeting Time: 04:30 pm November 05 2014
Interview Duration: 22 min 22 sec
Meeting start time: 0430pm / End 0500 pm

The meeting was through a mobile. There was no disturbance throughout. The participant was relaxed.

AF_50_14
Meeting Time: 07:30 pm November 06 2014
Interview Duration: 43 min 44 sec
Meeting start time: 0730 pm / End 0815 pm

The meeting was through a mobile call. The participant was happy to give the information.

A?_94_15
Meeting Time: 02:15 pm November 08 2014
Interview Duration: 26 min 42 sec
Meeting start time: 0215 pm / End 0245 pm

The meeting was through a mobile call. The participant requested to call him back after 20 minutes as he was on the way to his home. I called him back and then took the interview.

NM_44_16.1/16.2
Meeting Time: 02:15 pm November 11 2014
Interview Duration: 45 min 10 sec
Meeting start time: 0230 pm / End 0340 pm

The meeting was at the participant's office. As I was not aware of the location it was difficult to get to the exact address. When I reached IV's office he was not there and was gone for the prayers. I was taken to the IV's room and waited there. After 10-15 minutes, the IV came and apoligised for the delay. The meeting started and went well. I was being asked for tea on which yes as I was feeling hungry at that time. After 17 minutes, the IV was called by the boss. IV left the meeting and went to attend the meeting. I waited in the IV's room for 15 minutes. Then the IV came and the interview was started again. In the end the IV wanted to show me few related websites but could not because of the internet problem. The IV went into the server section within the IV's room. He worked for around 10 minutes and asked me that if I am in hurry? I told him yes because I need to meet some other person in 5 minutes. The IV came back to the desktop and showed me few related websites that can be helpful for new contacts/ participants. Then after few minutes we end the meeting.

MR_96_17
Meeting Time: 12:00 pm November 11 2014
Interview Duration: 29 min 55 sec
Meeting start time: 0430 pm / End 0500 pm

The participant's office was at the location I was not aware of. I roamed for an hour in my car searching for the IV's office but could not reach on time. I called the IV and asked for the address again. The IV guided to the right address but rescheduled the meeting from 12 noon to any time after 0330 pm.
I called the participant **NM_44_16.1/16.2** and informed that I will be coming to meet the IV.

After meeting **NM_44_16.1/16.2.** I went to meet **MR_96_17** at 4 pm. I was taken to the conference room and waited there. There were few steps on the entrance. The people there assisted me and pulled up my wheel chair. The conference room was vacant and I waited there for 10 minutes as the IV was having lunch in his office. I could not go to his office on the first floor as there were no elevators. I was offered tea and water. The IV came with his colleague or worker and talked to him in Sindhi language for 5 minutes that I did not understand. The interview started and the IV said that the IV could only give 15 minutes as there was another meeting. During the interview, another person came into the room, hopefully, whom I think the IV need to meet after our meeting. The meeting continued and ended well. The IV said that the IV had given me around 30 minutes on which I thanked the IV.

PS_66_18
Meeting Time: 07:00 pm November 18 2014
Interview Duration: 28 min 02 sec
Meeting start time: 0715 pm / End 0750 pm

The IV asked me to arrange the meeting at a restaurant or a coffee shop after office hours. I arranged the meeting in a coffee shop and informed the IV a day before. I reached the venue before 10 minutes of the scheduled time. The IV called me and informed that the IV will be late. The IV came after 10 minutes of the scheduled time. We settled and ordered coffee. The interview started fine but the environment was very noisy. People talking very loudly and the noise of coffee making was too much. I could not change the venue at that time and continued. I requested the waiter to low down the music volume but it did not make anything better.
The IV was cooperative and spoke loudly for a better recording. The meeting went well.

SS_106_19
Meeting Time: 02:00 pm November 20 2014
Interview Duration: 14 min 08 sec
Meeting start time: 0215 pm / End 0230 pm

The meeting was through mobile. After 2- 3 minutes I realised that the sound had distortions so I requested the IV to provide me the landline number. Instead of giving me the number the participant called me back. The sound was much better from the landline call.

KAM_118_20.1/20.2
Meeting Time: 10:00 am November 21 2014
Interview Duration: 44 min 58 sec
Meeting start time: 11: am / End 1200 noon

The meeting started an hour later. I was online on time and waited for the participant to come on Skype. I also called when the IV was online but IV's assistant picked up the call

and asked me to wait for a while and disconnected the call. I text the IV and got his reply that the IV will be online in few minutes.
The meeting started and went well. After approximately 26 minutes the call got disconnected. I tried to call back few times but could not connect. Then after few minutes the IV called me back and the interview continued. The meeting ended well and good.
After the interview I checked the recording. Unfortunately the Skype recorder did not record the first 26 minutes of the conversation till the line call got disconnected. The last 18 minutes were recorded only (the second call).
I emailed the IV to share interview notes with me if possible so the IV sent me the scanned one page notes the IV prepared for the interview. This helped me to compensate the data lost.

FA_124_21
Meeting Time: 03:00pm November 21 2014
Interview Duration: 36 min 53 sec
Meeting start time: 03 pm / End 3:45 pm

I called the interview on telephone from my mobile. It went well

SN_110_22
Meeting Time: Unscheduled
Interview Duration: 30 min 40 sec
Meeting start time: 2: 10 pm November 23 2014 End 2: 42 pm

I have left my contact details and requested the IV to let me know when the IV would be free. The IV called me on my cell that the IV was ready for the interview. I requested IV to give me 5 minutes to call the IV back. It went well.

TS_120_23.1/23.2
Meeting Time: 10:00pm November 23 2014
Interview Duration: 46 min 36 sec
Meeting start time: 10 pm / End 10: 47 pm

I received the IV’s email to call at 2 pm. I called the IV twice but the IV didn’t take the call. Then I received the call of SN_110_22 and I got busy the IV.
During the interview I got a text on my mobile to call this IV back as he was busy in lunch. I replied the IV that I was on another call and will call the IV as soon as I get free. I called the IV back after taking the interview of SN_110_22 but the IV didn’t respond. I also text the IV but got no response. I felt the IV did not like me taking any other interview when the IV asked me to call.
In the evening, I made an apology through email on which I got a response to call the IV at 10 pm. I called the IV from my mobile to the IV’s mobile. I had to disconnect the call with the permission of the IV as there was distortion coming along. Then I made another call but again there was distortion coming intermittently. Overall it was good.

MM_60_24
Meeting Time: 10:00 pm November 25 2014
Interview Duration: 41 min
Meeting start time: 10: 10 pm / End 11 pm

I was ready on Skype at the given time but the IV was not online. I waited for 5 minutes and then text on the IV’s mobile asking IV to come on Skype. I got a call at the same instant from the IV that there was some internet problem at the IV’s end so we could talk on mobile.

I requested the IV to please disconnect and let me make a call. Then I made a call and it went good.

AS_98_25
Meeting Time: 11:00 am November 26 2014
Interview Duration: 34 min 18 sec
Meeting start time: 11: am / End 11: 35 am

I called on the IV's telephone PABX and asked the operator to connect me with the IV. IV picked up the phone and the interview started. Throughout the interview, the IV was speaking very softly and sometimes it was inaudible. I requested the IV twice to please speak a bit louder on which the IV did speak loudly but only for few minutes. I didn't ask the IV again to speak louder just not to interfere with the IV. Moreover it also felt awkward to ask the same thing again and again and remained patient.

KA_130_26
Meeting Time: 12:00 noon November 28 2014
Interview Duration: 24 min 21 sec
Meeting start time: 12:07 pm / End 12: 32 pm

I called the IV 7 minutes late due to some problem with the charger. The IV warned me that the IV needed to go for another meeting at 1230 so I need to be very quick. The IV was very much concerned about the clauses of the consent form. I explained every clause to the IV as the IV had confusion about them. This took around 3 to 4 minutes. The IV was talking like as if I was not aware of many things and felt that I was interpreting the IV's answers wrongly. The IV said when I do the analysis I should show the IV of my interpretations made of the IV's quote. The IV also warned not to keep the IV's designation's record with me. The IV wanted me to email the IV by saying that I will not record the IV's current designation and the IV will be recognised as what the IV wanted to. So I did email the IV as soon as the interview ended.

LAS_112_27
Meeting Time: 12:00 noon or 1230 November 30 2014
Interview Duration: 27 min 08 sec
Meeting start time: 12:15 pm / End 12: 45 pm

The interview was on mobile. The IV looked very relaxed and peaceful. The IV's attitude was very kind and helpful. The interview went well.

BH_136_28
Meeting Time: 07:00 pm November 30 2014 (Unexpected)
Interview Duration: 14 min 11 sec
Meeting start time: 07:00 pm / End 07: 15 pm

The interview was at the IV's place in the drawing room. I came to know about IV through my relative and requested the IV for the interview. I sent the IV all the project details through email. The room was quiet and big. The interview went well.

MA_116_29
Meeting Time: 06:00 pm December 02 2014
Interview Duration: 18 min 56 sec
Meeting start time: 06:15 pm / End 06: 35 pm

I called the IV on the landline number. The voice was clear and audible. In the middle some guests came to meet the IV. He made me hold for a minute. Then the IV continued again and the interview ended well.

B_160_30
Meeting Time: 03:15 pm December 11 2014
Interview (call) Duration: 18 min 31 sec
Meeting start time: 04:00 pm / End 04: 20 pm

The interview was on mobile. The IV was comfortable throughout.

YS_140_31
Meeting Time: 03:15 pm December 23 2014
Interview Duration: 29 min 10 sec
Meeting start time: 01:00 pm / End 01: 30 pm

The IV took me into IV's office. I explained the project to the IV. First of all IV asked few questions about the project then signed the consent form. The interview started and ended peacefully.

AJ_142_32
Meeting Time: 03:15 pm December 23 2014
Interview Duration: 21 min 05 sec
Meeting start time: 09:00 pm / End 09: 25 pm

The interview was through mobile. Sometimes there was distortion during the call.

FJ_150_33.1/33.2/33.3/33.4
Meeting Time: 03:15 pm December 29 2014
Interview (call) Duration: 34 min 59 sec
Meeting start time: 03:30 pm / End 04: 05 pm

The interview was conducted through a mobile call. Unfortunately, the IV's mobile had a technical problem so the line got disconnected three times. IV then finally gave me the landline number to call on.

AZ_154_34
Meeting Time: 03:15 pm January 03 2015
Interview (call) Duration: 23 min 34 sec
Meeting start time: 02:30 pm / End 03: 30 pm

I requested IV to please visit my home to meet for the interview because the IV's clinic was not accessible for me. Thankfully, IV came at my place and we sat in the drawing room. The interview started and after 5 minutes coffee was served. It was a bit noisy in the beginning due to kids playing outside the room but I think someone moved them away from the drawing room. The interview went well.

BR_154_35
Meeting Time: 09:00 pm January 03 2015
Interview (call) Duration: 19 min 36 sec
Meeting start time: 09:00 pm / End 09: 20 pm

The interview was through a mobile call. The IV seemed to be relaxed and calm. The IV was at the IV’s home.

ZH_146_36.1/36.2
Meeting Time: 03:15 pm January 07 2015
Interview (call) Duration: 20 min 46 sec
Meeting start time: 12:33 pm / End 12: 55 pm

I got the message from IV to call as the IV was free for only half an hour. I called on the IV’s mobile. I found the IV’s voice unclear so I requested IV to share any landline number to call on. The IV said that the IV will call back on my mobile. The IV called back on my mobile and the sound was better then. Due to time constraints, IV answered questions briefly.

MS_144_38.1/38.2/38.3
Meeting Time: 12:45 pm January 31 2015
Interview (call) Duration: 45 min 44 sec
Meeting start time: 12:50 pm / End 01: 35 pm

I called the IV on the landline number. IV picked the phone and then I start the interview after taking the IV’s verbal consent. After 35 minutes call got disconnected. I called again on the landline but no one responded. Then I called on IV’s mobile and got connected. The interview restarted and after 1 minute IV requested me to spare him 5 minutes as IV’s guest had arrived. I disconnected the call and waited for 5 minutes and then made another call on his landline. IV attended and we continued the interview. IV seemed to be relaxed.

RA_178_39
Meeting Time: 0830 pm March 06 2015
Interview Duration: 16 min 22 sec
Meeting start time: 09:00 pm / End 09: 17 pm

I invited the IV at my place. IV came on time and we settled in the drawing room. We started the discussion on hospitals and doctors. In the meantime tea was served. After having tea we started the interview in peaceful environment. The IV was happy to speak on the topic given as he had many experiences with healthcare provider and health professionals while looking after his family.

Appendix 13: Contributions to science

Research papers published:

1. Akhlaq, Ather; Sheikh, Aziz; Pagliari, Claudia (2015) Barriers and facilitators to health information exchange in low-and middleincome country settings: a systematic review protocol *Journal of Innovation in Health Informatics* 22 (2), 284-292
2. Akhlaq, Ather; McKinstry, Brian, Muhammad, Khalid B; Sheikh, Aziz (2016) Barriers and facilitators to health information exchange in low-and middleincome country settings: a systematic review *Health Policy and Planning* fist published online May 16, 2016 doi:10.1093/heapol/czw056

Research papers accepted:

1. Defining helath information exchange? Scoping review of published definitions (Journal of Innovation in Health Informatics). Defining health information exchange: Scoping review of published definitions (Journal of Innovation in Health Informatics)
2. Health information exchange as a complex and adaptive construct: Scoping review (Journal of Innovation in Health Informatics)

Papers submitted:

1. Akhlaq, Ather; Sheikh, Aziz; Pagliari, Claudia, Stakeholders persepectives and deployment strategies of helth information exchange illustrated through an in-depth case study of Pakistan, International Journal of Medical Informatics

Conference abstracts:

1. Akhlaq, Ather; McKinstry, Brian and Sheikh, Aziz, Health information exchange and its barriers and facilitators in low- and middle-income countries: key healthcare stakeholders' perceptions from Pakistan. British Computer Society, Health Informatics Scotland 2015

Poster presentation:

1. , Health information exchange and its barriers and facilitators in low- and middle-income countries: key healthcare stakeholders' perceptions from Pakistan. Health Informatics Scotland 2015

Appendix 14: Glossary

Accountable Care Organizations (ACO)	*"Accountable Care Organizations are groups of doctors, hospitals, and other health care providers, who come together voluntarily to give coordinated high quality care to their Medicare patients."* (www.cms.gov)
DHIS2	*"DHIS2 is the flexible, web-based open-source information system used as national health information systems for data management and analysis purposes, for health program monitoring and evaluation. "* (www.dhis2.org)
eHealth	*"E-health is the transfer of health resources and health care by electronic means."* (WHO)
Health Insurance Portability and Accountability Act (HIPAA)	*"The Health Insurance Portability and Accountability Act Privacy Rule establishes national standards to protect individuals' medical records and other personal health information and applies to health plans, health care clearinghouses, and those health care providers that conduct certain health care transactions electronically."* (The U.S. Department of Health & Human Services (HHS))
Health information technology (HIT)	*"Health information technology is a broad concept that encompasses an array of technologies to store, share, and analyze health information."* (www.healthit.gov)
Health Level Seven International (HL7)	*"Health Level Seven International (HL7) is a not-for-profit, ANSI-accredited standards developing organisation dedicated to providing a comprehensive framework and related standards for the exchange, integration, sharing, and retrieval of electronic health information that supports clinical practice and the management, delivery and evaluation of health services."* (www.hl7.org)
Information Technology (IT)	*"Information technology (IT) is the use of any computers, storage, networking and other physical devices, infrastructure and processes to create, process, store, secure and exchange all forms of electronic data."* (www.techtarget.com)
Interoperability	*"Interoperability describes the extent to which systems and devices can exchange*

	data, and interpret that shared data. For two systems to be interoperable, they must be able to exchange data and subsequently present that data such that it can be understood by a user." (HIMSS)
mHealth	*"Mobile Health (mHealth) is an area of electronic health (eHealth) and it is the provision of health services and information via mobile technologies such as mobile phones and Personal Digital Assistants (PDAs)."* (WHO)
Open source	*"The term 'open source' refers to something that can be modified and shared because its design is publicly accessible. Open source software is software whose source code is available for modification or enhancement by anyone."* (www.opensource.com)
Telehealth	*"Telehealth uses computer-assisted telecommunications to support management, surveillance, literature and access to medical knowledge."* (WHO)
Telemedicine	*"Telemedicine is the use of telecommunications to diagnose and treat disease and ill-health."* (WHO)