An Analysis of Approaches for Developing National Health Information Systems: A Case Study of Two Sub-Saharan African Countries

by

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PREFACE

The research contained in this dissertation was completed by the candidate while based in the Discipline of Computer Science, School of Mathematics, Statistics and Computer Sciences of the College of Agriculture, Engineering and Science, University of KwaZulu-Natal, Westville Campus, South Africa.

The contents of this work have not been submitted in any form to another university and, except where the work of others is acknowledged in the text, the results reported are due to investigations by the candidate.

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Signed: Mr A. Pillay

Date:

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Signed: Dr D. Moodley

Date:

DECLARATION 1: PLAGIARISM

I, Thinasagree Mudaly, declare that:

(i) the research reported in this dissertation, except where otherwise indicated or acknowledged, is my original work;

(ii) this dissertation has not been submitted in full or in part for any degree or examination to any other university;

(iii) this dissertation does not contain other persons' data, pictures, graphs or other information, unless specifically acknowledged as being sourced from other persons;

(iv) this dissertation does not contain other persons' writing, unless specifically acknowledged as being sourced from other researchers. Where other written sources have been quoted, then:

a) their words have been re-written but the general information attributed to them has been referenced;

b) where their exact words have been used, their writing has been placed inside quotation marks, and referenced;

(v) where I have used material for which publications followed, I have indicated in detail my role in the work;

(vi) this dissertation is primarily a collection of material, prepared by myself, published as journal articles or presented as a poster and oral presentations at conferences. In some cases, additional material has been included;

(vii) this dissertation does not contain text, graphics or tables copied and pasted from the Internet, unless specifically acknowledged, and the source being detailed in the dissertation and in the References sections.

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Signed: Thinasagree Mudaly

Date:

LIST OF PUBLICATIONS

1. T Mudaly, D Moodley, A Pillay, CJ Seebregts; *Architectural Frameworks for Developing National Health Information Systems in Low and Middle Income Countries*; Enterprise Systems Conference (ES), 2013, Cape Town, 2013, pp. 1-9. 978-1-4673-6412-6, IEEE

ABSTRACT

Health information systems in sub-Saharan African countries are currently characterized by significant fragmentation, duplication and limited interoperability. Incorporating these disparate systems into a coherent national health information system has the potential to improve operational efficiencies, decision-making and planning across the health sector. In a recent study, Coiera analysed several mature national health information systems in high income countries and categorised a topology of the approaches for building them as: top-down, bottom-up or middle-out. Coeria gave compelling arguments for countries to adopt a middle-out approach. Building national health information systems in sub-Saharan African countries pose unique and complex challenges due to the substantial difference between the socio-economic, political and health landscapes of these countries and high income countries. Coiera's analysis did not consider the unique challenges faced by sub-Saharan African countries in building their systems. Furthermore, there is currently no framework for analysing high-level approaches for building NHIS. This makes it difficult to establish the benefits and applicability of Coiera's analysis for building NHIS in sub-Saharan African countries.

The aim of this research was to develop and apply such a framework to determine which approach in Coiera's topology, if any, showed signs of being the most sustainable approach for building effective national health information systems in sub-Saharan African countries. The framework was developed through a literature analysis and validated by applying it in case studies of the development of national health information systems in South Africa and Rwanda. The result of applying the framework to the case studies was a synthesis of the current evolution of these systems, and an assessment of how well each approach in Coiera's topology supports key considerations for building them in typical sub-Saharan African countries.

The study highlights the value of the framework for analysing sub-Saharan African countries in terms of Coiera's topology, and concludes that, given the peculiar nature and evolution of national health information systems in sub-Saharan African countries, a middle-out approach can contribute significantly to building effective and sustainable systems in these countries, but its application in sub-Saharan African countries will differ significantly from its application in high income countries.

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LIST OF ACRONYMS

Acronym	Meaning
ACM	Association for Computing Machinery
AIDS	Acquired Immune Deficiency Syndrome
CSRQ	Case Study Research Question
DHIS	District Health Information System
EA	Enterprise Architecture
EHR	Electronic Health Record(s)
EMR	Electronic Medical Record(s)
EU	European Union
GDP	Gross Domestic Product
HIE	Health Information Exchange(s)
HIS	Health Information System(s)
HIV	Human Immunodeficiency Virus
HMIS	Health Management Information System
HMN	Health Metrics Network
ICT	Information and Communication Technology
IEC	International Electrotechnical Commission
IEEE	Institute of Electrical and Electronics Engineers
ISO	International Organization for Standardization
ISO/TC	ISO Technical Committee
IT	Information Technology
LMIC	Low and Medium Income Country(/ies)
MOH	Minister of Health
NDOH	National Department of Health
NGO	Non-Government Organisation(s)
NHIS	National Health Information System(s)
NHS	National Health Service
OpenMRS	Open Medical Record System
RQ	Research Question
SCR	Summary Care Record(s)
SEHR	Shared Electronic Health Record(s)
SSA	sub-Saharan African

SSAC	sub-Saharan African Country(/ies)
TB	Tuberculosis
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

Acronym	Meaning in the Context of Rwanda
RHEA	Rwanda Health Enterprise Architecture

Acronym	Meaning in the Context of South Africa
DHMIS	District Health Management Information System
HNSF	Health Normative Standards Framework
LOGIS	Logistical Information System
NHC/MIS	National Healthcare Management Information System
NHI	National Health Insurance
NHIRD	National Health Information Repository and Data Warehouse
PHC	Primary Healthcare

CHAPTER 1: INTRODUCTION

Health information systems (HIS) manage and provide the information required for improving the effectiveness and efficiency of health systems [1]. However, many HIS in sub-Saharan African Countries (SSAC) are frequently characterized by significant fragmentation, duplication and limited interoperability, making them ineffective in meeting the requirements of the health system. Incorporating these disparate systems into coherent National Health Information Systems (NHIS) has the potential to improve operational efficiencies, decision-making and planning across the health sector. Many SSAC are, therefore, attempting to build their NHIS, but are struggling to overcome specific challenges with its development. Health information systems remain predominantly paper-based in SSAC. In contrast to SSAC, HIC have made substantial progress in developing their NHIS [2]. Patient-based HIS, dealing with detailed, granular records such as the patient's profile and health encounters, are now ubiquitous at facility level in HIC. In addition, HIC with mature NHIS have already started implementing advanced, national patient-based systems such as electronic health record (EHR) systems and self-service portals [3].

One of the key reasons for SSAC struggling with their NHIS is the lack of a sustainable, high-level approach for building an NHIS that effectively meets the requirements of the health system it serves. Building and successfully establishing socio-technical systems, as complex as an NHIS, requires an overarching national approach that includes more than just guidelines for software design and engineering, but also addresses the complex mix of social, economic and political concerns. In a recent analysis of mature NHIS in HIC, Coiera [4] highlighted the importance of the high-level approaches used for building NHIS, and proposed a topology that distinguishes between three types of approaches, viz. top-down, bottom-up and middle-out. He also gives compelling arguments for countries to take a middle-out approach.

Coiera's analysis, however, did not consider the unique challenges faced by SSAC in building their NHIS. Most SSAC [5] share, though in varying degrees, common problems [6] such as: widespread and chronic absolute poverty, increasing disparities in income and between urban and rural standards of living and economic opportunities, and increasing dependence on foreign resources and often inappropriate systems [7]. Health systems are weak and inequitable. A

larger percentage of the population is dependent on the public and rural systems. However, doctors and nurses are concentrated in urban areas, and private and urban health services are often far superior to public and rural health services. Mortality, communicable disease and chronic non-communicable disease levels are high - some at pandemic level [8]. In contrast, in high income countries (HIC), mortality [9] and infectious diseases levels have declined, and health threats now come from chronic and degenerative diseases such as cancer, and stroke [8]. So, while SSAC still struggle with public health issues, many HIC have progressed to focusing on providing patient-centric health care [10].

Heavily overburdened by disease [11], most SSAC have so far focused mainly on implementing population-based HIS that combine public health data from multiple sources [10]. Some SSAC are now trying to implement patient-based HIS for use at point of care for the management of diseases such as HIV. However, given the lack of resources and increasing burden and urgency of public health issues, developing patient-based HIS is of a lower priority to population-based HIS in SSAC.

The selection of an approach for building NHIS in SSAC must take into account the specific socio-economic and political conditions of SSAC and their health landscapes. It must also give due priority to the development of population-based systems and more widespread implementation of patient-based systems.

1.1 Problem Statement

Given the substantial differences between the health landscapes of HIC and SSAC, there is a need to assess the applicability and benefits of Coiera's analysis for building electronic NHIS in SSAC. However, no theoretical framework currently exists for analysing high-level approaches for building NHIS, which makes it difficult to establish the benefits and applicability of Coiera's approaches in SSAC.

1.2 Research Aim and Objectives

The research aimed to develop and apply a framework for (1) characterising the high level approach taken by an SSAC in developing its NHIS, (2) determining which approach from

Coiera's topology is followed by an SSAC, and (3) assessing the consequences of an SSAC taking such an approach..

The following main objective of the study covered the four general types of purposes for research viz. descriptive, exploratory, explanatory and improving [12]:

- Develop an analytical framework for characterising the high-level approach taken by an SSAC in developing its NHIS, and use it to describe the evolution of NHIS in SSAC
- Use the framework to determine whether an SSAC is taking an approach from Coiera's topology and explain the differences between the NHIS development landscapes of HIC and SSAC
- Use the framework to assess the consequences of an SSAC taking an approach from Coiera's topology and explore the consequences of taking a top-down, bottom-up and middle-out approach, respectively, for building NHIS in SSAC
- By evaluating these consequences determine which approach, if any, showed signs of being the most sustainable approach for building NHIS that effectively meet the requirements of health systems in SSAC.

1.3 Research Questions

An analysis of these complex and abstract objectives resulted in the following sub-questions that guided the research:

(RQ1) What is the nature of the approaches in Coiera's topology?

RQ1.1.Which aspects of the systems and software engineering practice are influenced by the approaches?

RQ1.2.Which aspects of the NHIS are influenced by the approaches?

(RQ2) Are there fundamental differences between the development of NHIS in HIC and SSAC?

RQ2.1.What are the distinguishing characteristics of SSAC and HIC in the context of this study?

RQ2.2.What is the perspective/scope/interpretation of the NHIS and its development in SSAC and HIC?

RQ2.3.What aspects of the development of NHIS are common to both HIC and SSAC?

RQ2.4.What are the fundamental differences between HIC and SSAC, in terms of (a) health system objectives and strengthening initiatives, (b) the current state and evolution of NHIS, and (c) the development of NHIS?

(RQ3) What are the consequences of applying Coiera's framework for building NHIS in SSAC?
RQ3.1.What are the key characteristics of each approach?
RQ3.2.Are SSAC naturally evolving towards any of these approaches?
RQ3.3.Should NHIS in SSAC be developed using any of these approaches?
RQ3.4.What interventions are necessary to implement such an approach in SSAC?

1.4 Methodology

An analysis of the literature was undertaken and used to develop a theoretical framework for analysing high level approached to building NHIS in SSAC. The approach was validated on two case studies.

Given the relative immaturity and inherent complexity of NHIS in SSAC, the scarcity of studies that analyse approaches for building NHIS in SSAC and the lack of a framework for such analyses, a case study approach was adopted. South Africa and Rwanda were selected as the cases to study because each has made great strides towards building their NHIS. Through an analysis of the literature, a theoretical framework was developed for the analysis of the case studies. It comprises of (1) the key characteristics distinguishing the approaches in Coiera's topology from each other, and (2) the key considerations for building NHIS in SSAC, in comparison to HIC. The development of NHIS in each case was analysed in terms of this framework. The framework was then also used to analyse how well each approach in Coiera's topology supports the key considerations for building NHIS in SSAC. The results of this analysis were then assessed with the aim of determining which approach showed signs of being the most sustainable for building NHIS in SSAC.

Paper based systems still play an important role in existing health information systems in SSAC. This study, however, concentrates mainly on electronic HIS due to their increasing importance in developing NHIS in SSAC. In general, throughout the dissertation, unless specifically qualified to be paper-based, references to HIS are assumed to be referring to electronic HIS.

1.5 Contributions

The key contribution made by the study was the development of a theoretical framework based on Coiera's topology of approaches, for (1) characterising the high-level approach taken by an SSAC in developing its NHIS, (2) determining whether an SSAC is taking an approach from Coiera's topology, and (3) assessing the consequences of an SSAC taking an approach from Coiera's topology.

The framework comprises of (1) the key characteristics for distinguishing the approaches in Coiera's topology from each other, and (2) the key considerations (or development strategies) for building NHIS in SSAC, in comparison to HIC.

The development of the framework was guided by studying the key challenges faced by SSAC when building NHIS. While much literature exists, the generally accepted set of key challenges with developing NHIS in SSAC has not been consolidated. Proposed solutions for building NHIS in SSAC cannot be properly evaluated without first understanding these challenges.

The validity of the framework was established by applying the framework to two case studies. The application of the framework established the consequences of applying Coiera's topology of approaches for building NHIS in SSAC, a previously established theory based only on an analysis of implementations in HIC. While it was found that a middle-out approach can contribute significantly to building effective NHIS in a sustainable manner, given the nature and evolution of NHIS in SSAC, its application in SSAC will be significantly different to its application in HIC.

The study provided an in-depth analysis of NHIS development in South Africa and Rwanda. It also established that NHIS in SSAC generally evolve through three stages. Understanding this evolution may give a SSAC some indication of how its NHIS may evolve in the future. The theoretical framework developed as part of this study can be used to study other SSAC and be extended for application to low and middle income countries (LMIC). The analysis that emerged from the study may assist a SSAC in developing its own NHIS, and aid in the development of frameworks for building NHIS in SSAC. Global health organisations such as the WHO, Ministries of Health in SSAC, donors and research organisations interested in building NHIS in SSAC, may be guided by this study to advise SSAC on how to practically implement their NHIS.

1.6 Structure of the thesis

The dissertation is structured as follows:

Chapter 2 describes the research design and methods used.

The analysis of the literature is covered in chapters 3 and 4.
Chapter 3 describes the nature of NHIS, Coiera's topology of approaches for building NHIS in HIC, and the key characteristics distinguishing the approaches from each other *(addressing RQ1)*.

Chapter 4 describes the nature of NHIS in SSAC, as well as the key challenges with, and the key considerations for developing NHIS in SSAC *(addressing RQ2)*.

Chapter 5 and 6, describe the current state of NHIS and its development in South Africa and Rwanda, respectively *(addressing RQ2)*.

Chapter 7 presents and discusses the research findings, including the current evolution of NHIS in SSAC, and the consequences of adopting an approach from Coiera's topology for developing NHIS in SSAC *(addressing RQ3)*.

Chapter 8 concludes the study *(addressing RQ3)*.

CHAPTER 2: MATERIALS AND METHODS

The aim of this research was to analyse the possible consequences of adopting an approach from Coiera's topology for building NHIS in SSAC. The methodology was designed to first answer the research questions. Then, analysing the answers to these questions determine which approach, if any, showed signs of being the most sustainable approach for building NHIS that effectively meet the requirements of health systems in SSAC.

NHIS are inherently complex, multi-dimensional, socio-politico-technical systems that are relatively immature in SSAC. The significance and contemporaneousness of the field of NHIS development is evident in the current, and high activity in the field – in the way of research, 'industrial' projects and discussion. However, there is a scarcity of studies that analyse approaches for building NHIS [6], specifically in SSAC, and a lack of mature research tools for their study. Thus, a case study approach was deemed most appropriate to achieve the research objectives.

A theoretical framework for the analysis of the case studies was required. However, since theories in the field of NHIS development are underdeveloped at present, an analysis framework was developed for the study by an extensive analysis of the literature. This framework, comprises of (1) the key characteristics for distinguishing the approaches in Coiera's topology from each other, and (2) the key considerations for building NHIS in SSAC, in comparison to HIC. The validity of the framework was established by applying it to two case studies. The framework was used (1) to develop the case study research questions which were used to analyse NHIS development in the two cases studied i.e. South Africa and Rwanda, and (2) to analyse how well each approach in Coiera's topology supports the key considerations for building NHIS in SSAC.

This chapter is structured as follows:

- Analysis Framework Design, describes the development of the analytical framework used in the study

2.1 Analysis Framework Design

A general framework for the analysis of high-level approaches for the development of NHIS is lacking. An analysis framework had to be developed to objectively analyse the cases.

The key characteristics distinguishing the approaches in Coiera's topology from each other formed the first part of the framework. A foundational understanding of the state of the art of the NHIS development landscape was developed through a literature search. (Search term used: "nation health information systems". Generally, when searching for information related to the NHIS the search was also extended to include the following terms: "health information system", "eHealth", "electronic health records".) A study of the middle-out approach, more generally, in software engineering highlighted the key specialisations of the approaches in Coiera's topology, *answering RQ1.1.Which aspects of the systems and software engineering practice are influenced by the approach.* (Search terms: "middle-out software engineering", "middle-out architecture", "emergent enterprise software systems".) The key differentiating characteristics of each approach were then identified and formalised [13, 14], mainly from an analysis of [4], and papers documenting further insights from NHIS implementations in the UK, Australia, USA, New Zealand, and Greece, *answering RQ1.2.Which aspects of the NHIS are influenced by the approaches.*

Given that Coiera abstracted the middle-out approach from his analysis of NHIS development in HIC only, it was important to understand the fundamental differences between the NHIS and development of NHIS in HIC and SSAC. A Google search provided definitions for "sub-Saharan African countries" and "high income countries". The nature of the NHIS development landscape in HIC, in which the approaches in Coiera's topology have actually been implemented, and the practical implications of implementing these approaches was studied first. (Search terms: "health systems in developed countries", "national health information systems in developed countries"). Then the landscape of NHIS development in SSAC (a specialised case of developing countries) was studied. (Search terms: "national health information systems in" + "developing countries"). This analysis served to scope-out and clarify the nature of the problem areas that need to be addressed by the study, *answering RQ2.2.What is the perspective/scope/interpretation of the NHIS and its development in SSAC and HIC.*

The key considerations for building NHIS in SSAC, formed the second part of the analysis framework. The key challenges that SSAC face were identified. (Search terms: “challenges with national health information systems in” + “developing countries”/“sub-Saharan Africa”/“Rwanda”/”South Africa”). From the same set of papers, the key considerations for building NHIS in SSAC, in particular in mitigating the identified key challenges were also elicited. The data was evaluated by showing how large numbers of different previously observed challenges could be uniformly explained, and addressed [12, 13]. The data was also analysed for common patterns in NHIS development landscapes in HIC and SSAC. This provided a motivation for considering the approaches tested in HIC for application in SSAC. *This analysis provided answers to RQ2.3.What aspects of the development of NHIS are common to both HIC and SSA, and RQ2.4.What are the fundamental differences between HIC and* SSAC.

- Case Study Design, describes the design of the case studies, the results of which are presented in chapters 5 and 6 of the dissertation.
- Literature Review and Data Collection, describes the techniques used to collect and analyse the data, the results of which are presented in chapter 7 of the dissertation.
- The chapter concludes with a summary and discussion of the validity of the results of the study.

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2.3 Case Study Design

The aim of the case studies [12], was to gain an in-depth understanding of the NHIS development landscape in SSAC, giving due consideration to the contextual factors that influence it and to validate the analysis framework developed by the study. NHIS are complex systems with many, functionally as well as structurally, interconnected human and non-human components, which may interact unpredictably [15]. The development of NHIS in SSAC is also heavily influenced by social, political, policy, as well as technical issues, making them difficult to study [16].

Case studies have been criticized for being of little value and not generalizable [12]. However, the development landscape of NHIS in SSAC is complex, non-deterministic and emerging – one that cannot be carefully controlled for, say, a statistical evaluation. Lucas [17] found that initial small-scale success in HIS development, from artificially controlled research, does not guarantee sustainable large-scale benefits [18-20]. The growing number of failed pilot projects in SSAC confirm that the issues are themselves complex, and cannot be feasibly controlled or replicated [21]. Furthermore, this study is not focused on the static design of the NHIS for or at a particular point in time. Its concerns include the manner and method in which the NHIS changes over time. For example, the study allows for knowledge of how and why the NHIS in SSAC have changed in the past, to inform the way in which they will evolve in the future [22-24]. The case study approach [12] was therefore appropriate for understanding and explaining the contemporary complexities involved in building NHIS in SSAC, and their impact on the resulting NHIS [19].

Researcher bias [12] is also an important factor that may impact negatively on the reliability of case study research. The researcher's bias was generally mitigated by triangulation throughout the study:

- Multiple research methods, viz. literature analysis and case studies, were used to research the emerging phenomena associated with complex ICT initiatives such as building NHIS in SSAC.
- More than one data source was used for critical data. This is evident in the multiple references supporting key statements.
- More than one method of data collection was used. Data was collected from documented text, as well as formal and informal interviews and discussions with experts in the field.

- Different viewpoints and rival theories were taken into account and investigated. For example, some sources claimed that an NHIS could hugely benefit SSAC despite their low resources, while others were sceptical about the value that NHIS could offer SSAC. Rivals theories were evaluated in answers to each of the research questions e.g. in comparing the consequences of implementing alternative approaches for developing NHIS in SSAC.

2.3.1 Case Selection

Rwanda and South Africa were the cases chosen to be studied because they provide a good cross-section of contrasting features which help to generalise the common findings to other SSAC. The following distinguishing features of each country influenced their choice:

- In terms of availability of resources, Rwanda is a low income country, while South Africa is a middle-income country. This characteristic also makes them critical cases, as, in terms of resource availability, most other SSAC would fall in the range between them.
- Rwanda and South Africa generally exhibit varying levels of maturity with respect to their NHIS and their development. Each case also offered valuable data not available in the other. For example, Rwanda has already adopted an EMR system for country-wide rollout, and moving towards connecting them through its national health information exchange. On the other hand, South Africa has moved ahead in linking its aggregated-data systems across the country.
- Both countries generally share the challenges with building NHIS, as well as the key considerations for mitigating these challenges, identified in the literature review.

The lack of clear boundaries between the phenomenon (e.g. the approach for building the NHIS) and context (the NHIS) of the study was evident, from the lack of clear, accepted definitions, specifications and frameworks in the fields of eHealth and ICT. The case studies helped to clearly and explicitly define for SSAC, the key characteristics of the NHIS environment, the NHIS, the evolution of NHIS, and the approach for developing NHIS. This ability to make explicit the boundary of the cases proved the case studies to be exemplary in the context of SSAC [25].

2.3.2 Interviews

Interviews were conducted to help corroborate some of the findings of the case study research questions, with the experience of experts in the field, who generally know what's actually happening in practice. The goal of the interviews was to 'see' the interviewee's perspective on the NHIS, its evolution and its future. The field experts provided insights from their first-hand experience in planning for and building national-level HIS in the cases studied. They were able to explain how and why they came to have particular perspectives, comment on the generalizability of previously obtained qualitative findings [26], help to correct some researcher bias, and verified to some degree the quality of the documents studied i.e. to what extent interviewees agree with the contents [12]. The interviews also allowed for specific conflicting or ambiguous topics related to the case study to be explored in order to make explicit the boundary of the cases [26]. For example, it was found that experts differ in their interpretation of the terms NHIS and eHealth.

Skype-interviews were done because a postal survey would likely have had no response [26]. While the aim of the interviews was to focus on eliciting information on specific situations in the world of the interviewee, given the limited information available on the research topic, abstractions and general opinions were also allowed [26]. Since the nature and range of participants' opinions about the research topic could not easily be quantified in a structured open-response interview, the interviewee was encouraged to actively shape the course of the interview rather than passively respond to the interviewer's questions [26]. This semi-structured approach was taken because the interview itself was not testing any formal hypothesis, and the researcher did not know in advance the amount and type of factual information the participants would be able to provide.

The interviews were guided by the following questions:

1. What has been your involvement in eHealth related projects in <Rwanda/South Africa>

*(CSRQ3) What is the nature and state of the NHIS IT architecture**?***

2. Does < Rwanda/South Africa > have an NHIS? If so, what are the main information systems comprising the NHIS?
3. How widespread are electronic medical record (EMR) systems deployed across the country -<30% or >90%?
4. Do these systems exchange EMR across facilities?

(CSRQ2) How is the NHIS organised and controlled

5. What are the key roles and responsibilities of these entities in terms of the NHIS

5.1. each level of the health sector - the states/provinces, local government and individual facility level – and

5.2. the private and non-government organisations,

6. How much autonomy do these entities have in the procurement, designing and implementing HIS that manage data critical to an NHIS?

*(CSRQ4) How is the NHIS evolving**?***

7. What were the significant milestones in the evolution of the NHIS?
8. Does < Rwanda/South Africa > have a vision for its NHIS? If so,

8.1. What are the main components of this vision?

8.2. What will national EMR systems look like in 5 years' time?

8.3. Is a shared health record desirable? How much of a priority is it?

9. What are the 5 main challenges with NHIS development?

9.1. Is a shared health record achievable?

10. What are my best sources of information related to < Rwanda/South Africa >'s NHIS and its development – documents and/or people?

The following people, with key knowledge of the Rwandan and South African NHIS, were interviewed:

- Mr Emmanuel Rugomboka, Jembi[1] country coordinator in Rwanda, for his knowledge of HIS development in Rwanda , on 13/05/2015
- Mr Gaurang Tanna, Director of HIS, NDOH, for his knowledge of HIS development in SA, on 25/06/2015

The transcripts of interviews were sent to the respective interviewees for review, to confirm that their responses were not misunderstood and still stand.

[1] Jembi Health Systems NPC, is a nonprofit organisation that works in developing countries in Africa and focuses on the development of eHealth and HIS.

2.3.3 Case Study Research Questions

The main objective of the case studies was to gain the knowledge required to answer the research questions (search terms: “health systems in” / “national health information systems in” + “Rwanda”/”South Africa”). In particular, the case studies provided evidence to support *answers to RQ2.3.What aspects of the development of NHIS are common to both HIC and SSA, and RQ2.4.What are the fundamental differences between HIC and* SSAC.

The analysis framework was used to translate the research questions into the following case study research questions:

- (CSRQ1) How is the health sector organised and controlled?
    - What is the country’s regional breakdown?
    - Do patients move between care centres?
    - What resource constraints does the health sector experience?
    - What are the key problems faced by the health sector?
    - What are the objectives of the health system
    - What are the key roles and responsibilities in managing the health sector – both official and operational?
    - What is the role of the non-government and private organisations in the health sector?
- (CSRQ2) How is the NHIS organised and controlled?
    - Is the control of the NHIS centralised or decentralised?
    - Who controls the budget for HIS?
    - Is the NHIS implemented by the execution of a plan?
        - If a plan exists, (a) does the plan involve large scale rollouts or smaller incremental changes, (b) is the plan controlled and executed by the centralised organisation, (c) how much autonomy does each level of the health sector have in the execution of the plan, (d) which of the following are in place or planned: an eHealth strategy, an interoperability framework, an enterprise architecture, HIS standards and policies?
    - How are HIS standards and policies enforced? (Not just the planned enforcement, but what is actually happening on the ground)
        - Who decides which systems are deployed?

        - How much autonomy does (1) each level of the health sector - the states/provinces, local government and individual facility level – and (2) the private and non-government organisations, have in the procurement, designing and implementing HIS?
        - Are private and non-government organisations at liberty to implement their own systems or do they need to implement a government or government-endorsed system?
- (CSRQ3) What is the nature and state of the NHIS IT architecture?
    - What HIS are in place?
    - What is the nature of these HIS?
        - Are they regional or disease specific?
        - Are they based on a uniform IT architecture?
        - Are NHIS architecturally centralised or decentralised?
    - What are the drivers for exchanging information between systems within the NHIS?
    - What is the health sector's requirements for the integration and interoperability of systems within the NHIS?
    - Is there a health information exchange? What is the level of integration between these systems with respect to the exchange of EMR?
- (CSRQ4) How is the NHIS evolving?
    - How did the NHIS evolve to its current state?
    - What are the key challenges with developing NHIS?
    - What is the future of the NHIS?

2.3.4 Analysis

The study of each case, based on the case study research questions, was reported on using the following linear-analytic report structure:

1. Introduction
2. The Organization and Governance of the Health Sector *(addressing CSRQ1)*
3. The Organization and Governance of the NHIS *(addressing CSRQ2)*
4. The Key Information Systems within the NHIS *(addressing CSRQ3)*
5. Challenges with developing the NHIS *(addressing CSRQ4.2)*
6. The Evolution of the NHIS (addressing CSRQ4)

7. Conclusion

Abstractions and inferences were then drawn from the cases studies to critically analyse the current NHIS development practices in SSAC, with an aim of improving them [12], *(addressing (RQ3) What are the consequences of applying Coiera's framework for building NHIS in SSAC)*. By analysing events related to HIS development in SSAC over time [12], a model of the evolution of NHIS in SSAC was formulated. The model highlights the introduction of different types of HIS at each stage in the evolution of NHIS in SSAC. The various previously observed implementations of the different types of HIS, could now be uniformly explained [13] by this model. *This analysis answered RQ3.2.Are SSAC naturally evolving towards any of these approaches.*

The key characteristics distinguishing the approaches from each other, were analysed against the development of NHIS in SSAC, based on the South Africa and Rwanda case studies. The top-down, bottom-up and middle-out approaches were then critically evaluated in terms of how well each supports the key considerations for building NHIS in SSAC. Conclusions were then drawn from this analysis on the approach that showed signs of being the most sustainable for developing NHIS in SSAC, and the interventions necessary to implement this approach in SSAC. *This addressed RQ3.3.Should NHIS in SSAC be developed using any of these approaches and RQ3.4.What interventions are necessary to implement such an approach in SSA.*

2.4 Literature Review and Data Collection

Qualitative secondary data was mainly collected using an independent, third-degree method [12] from focused internet searches and experts in the field of HIS development in SSAC. The following repositories were searched, with preference given to data from the last ten years: Google & Google Scholar, Science Direct, IEEE Xplore, ACM Digital Library, Pubmed, amongst others on a more ad-hoc basis. A potential limitation is the bias in collecting data (the limited number databases searched, and the exclusion of non-English data) and the inclusion of grey literature (documents and web pages).

An unstructured, appreciative, mode of inquiry was adopted in reviewing data, focusing on the nature of a problem, without quantifying it. Analysis was carried out in parallel with the data

collection, to allow the analysis to guide the collection of additional data [12, 27]. An objective, open coding scheme was applied to the data, with the aim of identify patterns, sequences and relationships [12, 28]. The data and annotations were clustered around their relevant codes in a word document. The initial codes (short phrases depicting themes or concepts [29]) were based on the search terms defined in the analysis framework design. The less formal, more intuitive initial approach evolved to a more systematic and objective discovery during subsequent content analyses, as the themes developed [29]. The key themes eventually became the headings within the dissertation [12].

The iterative analysis of the literature allowed for the inclusion of observations that were not anticipated. To ensure that the analysis did not only include material supporting the hypotheses [29], a negative case analysis technique was used to find alternate explanations and theories. Cases were sought that did not fit an observation, and discarded with a documented reason for its exclusion or the observation reformulated to account for it, until "practical certainty" of the observation was attained [29].

No audit trail was maintained. No ethical issues needed consideration.

2.5 Validity

Since this study relied primarily on qualitative data and only theoretical research [30], a key weakness of the study is the possible influence of the opinions of the researcher, supervisors and those of the field experts on the outcome of the study. Using data already interpreted means that the data may also have been coloured by the bias of the writers.

External validity was addressed by the description of the context in the introduction, including the relevance of the study for SSAC. Construct validity was addressed by the detailed documentation of the study's research methodology in this chapter. Internal validity and reliability were addressed by using triangulation to increase the precision of the empirical research, reduce bias by individuals and increase the innovation in the analysis.

2.6 Summary

A case study approach was used to achieve the research objectives. An extended literature review was conducted to (1) develop the framework for analysing the cases, (2) highlight the specialised and complex nature of the NHIS development landscape, (3) support answers to the research questions, as well as (4) acknowledge the large body of existing knowledge upon which this research was based and developed. The analysis framework comprises of (1) the key characteristics for distinguishing the approaches in Coiera's topology from each other, and (2) the key considerations for building NHIS in SSAC, in comparison to HIC. The framework was used (1) to analyse NHIS development in the two cases studied i.e. South Africa and Rwanda, and (2) to analyse how well each approach in Coiera's topology supports the key considerations for building NHIS in SSAC.

CHAPTER 3: Coiera's Topology of Approaches for Building NHIS

An NHIS is described as

> "*the nationwide organized and integrated network of resources and processes that contribute to the overall production and communication of health-related information, composed by multiple specific information systems (maintained by various programs, offices and institutions) functionally interacting at different levels of a country. This network is coordinated by the national health authority, with the primary goal to support evidence based decision and action in the health sector*" [31].

This chapter describes the state of the art of NHIS and their development in high income countries. It starts with descriptions of the role of eHealth, the nature of NHIS, NHIS in HIC and the challenges with developing NHIS. This is followed by a description of Coiera's topology of approaches for building NHIS. The chapter concludes with the key characteristics differentiating these approaches, which will be used later in the analysis of the approaches in SSAC.

3.1 The Role of eHealth

Access to comprehensive clinical and operational health information is more critical than ever, given the challenges faced in delivering high-quality and accessible care under increasing fiscal pressures [32, 33]. Given the drive to reform health systems, one of the most important uses of HIS today is to track trends in health systems performance and certain diseases. Patients, health professionals and policy-makers rely on good quality information to make resource, policy and planning decisions [34-36],[37]. Events such as bioterrorism [33], SARS and Avian flu are driving the need for information from the grass-roots [8]. Driven by the millennium development goals there is a need to share health knowledge globally. The rapid growth of the private sector is also driving the need for information to monitor policy, regulatory and operational guidelines [38]. The general public have also become consumers of health information, in ensuring their well-being through access to more reliable, accredited health information [33, 39]. There is also a growing need for patient-based systems to improve the delivery and continuity of care, of patients who are more often, now, visiting multiple centres of care.

eHealth is defined as

> "*the cost-effective and secure use of information and communications technologies in support of health and health-related fields, including health-care services, health surveillance, health literature, and health education, knowledge and research*" [40].

It is widely recognised for its potential to improve health systems safety, quality and efficiency [40, 41]. It is an all-encompassing term which includes all electronic HIS, including, but not limited to (1) population-based HIS (2) patient-based HIS, and (3) the national HIS. The advancement of technology has made possible some innovative solutions to improve the quality of health services provided [42], especially evidence-based practices [36]. It has also reduced the number and skill level of human resources required in managing health information [43], medical errors and costs in delivering care [44]. Information amassed over time can also provide valuable know-how for process improvements [45], which will in turn improve the quality, availability and use of health information [46, 47]. The better the quality of the information (right, accurate, appropriate, meaningful, timely and fast), the more effectively can HIS support the health system [32, 48].

3.2 The nature of an NHIS

The broad goal of an NHIS is to deliver information to users when and where they need it [33]. It must ease access to the diverse national-relevant health-related information coming from multiple sources, as well as drive the generation of new knowledge of health and the health sector [4, 15, 31, 49]. An NHIS can be viewed as a system of heterogeneous sub-systems, that encompasses different HIS and applications, that span across: public and private healthcare [4], formal and informal organizations, different geographical levels (district to national), different health delivery services (primary, public, personal, research), different health domains (workforce, financing, governance, medical products, vaccines and technologies), different diseases, different health specialties, as well as different sectors in government (e.g. armed forces' health services, environmental services) [31].

An NHIS must satisfy the requirements of the various types of information users across the health sector, including: patients/citizens/consumers, health system managers, policymakers,

payer institutions, and researchers [50, 51]. The functional coverage reached by the NHIS also extends beyond the boundaries and functions of the health sector of a country [31]. An NHIS supports sharing of information across national boundaries to facilitate cross-border learning, and to enable global public health surveillance and medical research to combat global issues like HIV [33]. The health organisational hierarchy spans from global through national, region, district, facility/community, to the patient level. Doctors require detailed patient information, districts require aggregated community-level information, while the national authority requires indicators to prepare budgets and take strategic decisions [52]. Typically, the granularity of the information required decreases as one moves up the hierarchy [52].

An NHIS encompasses a number of electronic HIS for collecting and sharing health information. An NHIS architecture will comprise mechanisms by which various HIS communicate with each other to facilitate information sharing, generation, and use. NHIS are complex systems with many, functionally as well as structurally, interconnected human and non-human components [53]. Interoperability is the ability for heterogeneous, autonomous, systems to function jointly, and to share their resources - information and services - in a reciprocal way [52]. An NHIS is a conceptual system that facilitates a single "source of the truth" through nationwide interoperability [54, 55].

3.2.1 Electronic Health Records

An NHIS can connect different silos of data by sharing health records [16, 56]. The key types of health records are described in the following paragraphs.

An electronic medical record (EMR) is an electronic record of an episode of medical care within and owned by a single institution e.g. a general practitioner practice or a single hospital [57]. They ease the access to historical data, over trying to wade through a paper-based patient folder. They are used to manage chronic patient care, to exchange information between the patient's healthcare providers, for research, legal purposes, quality-assurance, and the management of healthcare facilities and services[58].

Continuity of care is greatly enabled by access to distributed patient health records [59]. While EMR are described as provider-centric, electronic health records (EHR) are described as person-centric [57]. An EHR has been described as

> "*a longitudinal electronic record of patient health information generated by one or more encounters in any care delivery setting. Included in this information are patient demographics, progress notes, problems, medications, vital signs, past medical history, immunizations, laboratory data, and radiology reports*" [57, 58, 60, 61].

A personal health record (PHR) is a specialisation of an EHR under the custodianship of a person(s) e.g. a patient or family member [57]. A shared-EHR (SEHR) is an implementation of an EHR, in which a single instance of each EHR is stored centrally and shared nationally. The type and extent of EHR varies from one implementation to another, and unfortunately, is sometimes also referred to inter-changeably as EMR in the literature [59, 61].

3.3 NHIS in High Income Countries

By 2005 [62] many HIC had already initiated plans to address the lack of flexibility, scalability and reusability of the complex and heterogeneous HIS that resulted from siloed development programmes [22, 63]. They started to leverage the advances in health architectures and frameworks to enable the delivery of affordable, scalable health services, as well as better personalized care.

The lead responsibility of many NHIS sits with the MOH. To address challenges posed by political and legal systems, advisory bodies involving e.g. health provider and patient representatives have been established as part of the eHealth governance [64], and supporting organisations like Canada Health Infoway and Australia's National eHealth Transition Authority (NEHTA) have been funded by the government to lead the eHealth initiatives at a national level [65, 66].

Many HIC eHealth strategies generally include policies, legislation and governance to support the NHIS. HIC, such as Australia, Canada, Spain, Sweden and Denmark, developed health enterprise architecture frameworks that focus on standards and guidelines for improving the interoperability of their HIS in an incremental and progressive manner [63, 66]. The frameworks are used to create a common understanding of a country's NHIS design [64] and to provide guidance to business and IT experts delivering eHealth systems to the country [65, 67]. Some countries, like the UK, have made substantial investment in developing central

infrastructures. Others, like Canada and Australia, promote the use of a service-oriented architecture (SOA) approach [66, 68, 69], allowing the development of individual IT systems at the local level [70]. Some countries have detailed architecture blueprints e.g. Canada's EHRS Blueprint [69] and Australia's NEHTA Blueprint [65, 66].

In developing their national health architecture frameworks, HIC have leveraged existing architecture frameworks. For example, Canada's EHRS Blueprint has been created by adapting and using the Zachman Framework [69]. Australia's processes and principles are aligned with the Open Group Architectural Framework (TOGAF) [65, 66, 71] and its interoperability framework is based on ISO/IEC RM-ODP [65, 72]. The Health Informatics Service Architecture (HISA) (a European standard), Generic Component Model (GCM) and Reference Model of Open Distributed Processing (RMODP) standards have been implemented in many European countries [73].

To drive eHealth reform across its region, the EU agreed on an eHealth Action Plan with the objective of addressing common challenges through pilot projects and disseminating best practices [3]. This common action by the Member States did not materialise largely due to the differences among the Member States and regions in the Union [3]. The EU has since adopted a less formal, more flexible approach to cater for its federated 'organisation' and complex policy development [10]. The EU countries are now independently evolving to a set of common targets [10]. This centralised action led by the EU has had considerable success [3]. All states have strategies for eHealth, many are working on legal frameworks [15], standards for EHR have been developed, and the EU public health and best practice portals offers reliable and timely information for a variety of users.

3.4 The Challenges with Developing NHIS

While the scope and implementation of an NHIS generally differs per country [74], building an NHIS involves connecting the EMR systems [33] through a combination of technology, standards and agreed upon rules and processes [75]. NHIS have, generally, proven difficult to realize on a nation-wide scale, usually as a result of high costs, complexity, uncontrollability, and unintended consequences [15, 33, 53]. Despite funding and resources, implementing EHR remains a stumbling block for many HIC [69, 76, 77] due to the continuous change of system characteristics, the politically driven relationships among healthcare providers [2] and the fact

that local organisations have different starting points, goals and resources [61, 78]. Some, like Coiera [78], question the value of share EHR and summary care records (SCRs) vs distributed but nationally shareable records, in the early phases of the NHIS [2, 4, 78, 79]. They advocate for an NHIS to be driven by country needs and policies, and be justified by feasibility, readiness and cost benefit [31], rather than by pressure from technology producers [80].

3.5 Coiera's Topology of Approaches for Building NHIS

NHIS architectures in HIC range from unified centralized systems like the National Health Service (NHS) in the United Kingdom (UK) to decentralized systems like that of the United States (US) [4]. Coiera [4] suggests that the issues to consider when comparing development approaches are: the role and control of government, a strategy for system architecture, common functions, standards compliance, and procurement. Coiera also distinguishes three approaches for building NHIS: top-down, bottom-up and middle-out [4].

In a top down approach, central government builds and controls an NHIS, including its system architecture, standards compliance, procurement process and implementation strategy [4]. The NHIS is made up of standardised IT systems, and centrally stored and shared EHR [22]. It is often implemented through a "rip and replace" strategy, where HIS compliant with national standards replace existing non-compliant systems. The UK initially adopted this approach for building its National Health Service (NHS) [4].

In a bottom-up approach, there is no nation-wide implementation plan for the NHIS. It develops as more local health organizations share more locally stored EMR with each other. There is also no national governance of the resulting NHIS nor its implementation. The development of the NHIS is in complete control of de-centralised local authorities. The USA initially adopted this approach [4]. Systems at regional level connect through regional HIE, but there is no national plan for connecting these systems. Instead of a shared EHR, the system enables the aggregation of information from regional systems.

In a middle-out approach, in collaboration with local organisations, the government drives the development of a national set of goals, policies and standards. Local organisations are encouraged with incentives to meet national goals, and for their health systems to comply with the national policies and standards [78]. To cater for its complex and heterogeneous HIS,

Australia adopted a middle-out approach. They started by developing architecture frameworks that focus on standards [66] and interoperability [63, 65, 69]. They have now progressed on to developing its Person Controlled EHR system [4].

3.6 An Analysis of the Differences between the Approaches

In architecting a system, it is important to first understand the principles governing its design and evolution [81]. Conceptualisation of a system's architecture and adherence to architectural precepts assists the understanding of the system's behaviour, composition and evolution [81]. This, in turn, provides insights into its feasibility, utility and maintainability [81]. Being able to constantly and smoothly re-engineer an NHIS is a complex IT, strategic and organizational challenge [54].

The literature describes Coiera's topology, the characteristics of each approach in the topology, the characteristics of the exemplars of each approach [4], lessons learnt from the exemplars [2], the possible reasons the examplars took their respective approaches [22], and what is being achieved by the countries taking such approaches [82]. However, it does not provide a consolidated framework for (1) characterising the high level approach taken by an SSAC in developing its NHIS, (2) determining whether an SSAC is taking an approach from Coiera's topology, and (3) assessing the consequences of an SSAC taking an approach from Coiera's topology. This section aims to formalise such a framework, by a detailed analysis of the existing literature on the characteristics of each approach in Coiera's topology.

Building on the differentiating components Coiera identified, this study identified the following key perspectives from which the approaches in Coiera's topology may be differentiated:

- Technical Architecture: This relates to the technical architecture of the NHIS, with specific focus on the location, access and exchange of EMR.
- Organisation: This relates to the (non-technical) organisational structures that influence and control the NHIS, and the standards and policy frameworks that support its governance. The role of government is of central concern here.
- Implementation Strategy: This relates to the strategies by which the NHIS is implemented, including strategies for setting and enforcing goals, standards and policies.

The differentiating characteristics of the approaches were then abstracted from an analysis of their technical architecture, organisation and implementation strategy.

3.6.1 Technical Architecture

The connectivity of HIS is a key aspect of an approach for building NHIS [83]. Of particular importance is the electronic exchange of health information among organizations, usually facilitated by a technical infrastructure referred to as a health information exchange (HIE). An HIE may be implemented as part of an NHIS to facilitate the exchange of health related data between HIS, including EMR and other HIS dealing with patient-level data, according to recognized standards [84]. It links data across systems using unique patient identifiers, and authorises access to the data using unique provider and facility identifiers [64]. The HIE is likely to consist of many, often geographically-dispersed, networks that are capable of communicating and exchanging information with each other [85].

Privacy and security are key in fostering trust in an NHIS [64]. An HIE's long-term success depends on the level of trust within the networked community and the strategic advantage offered by the network to its users [86]. The choice of HIE must therefore balance privacy and security against the ability share information [86]. Overall, an HIE architecture may be categorised as having one of the following governance/operational models [86, 87]: centralized, decentralized (peer-to-peer, federated) and hybrid.

Information exchange in a top-down approach is facilitated by a centralised system, in which all data is stored in a single central repository [86, 87]. Any patient medical data captured in local sources is collected and stored in the central repository, for sharing across points of care in the network connected by the HIE. All information exchanges are routed through the central repository [86, 87]. To facilitate information exchange, systems within the NHIS are standardised in terms of data and technology, and some processes in which the EHR play a role may also be integrated and standardised nationally.

In a bottom-up approach, through voluntary collaboration, some local authorities share data between their heterogeneous systems, via proprietary interfaces - resulting in a de-centralised HIE with an inter-dependent subset of systems with shared services. Individual organizations have control of the patient medical data [86, 87]. There is no central repository [86, 87]. The

individual systems are linked through record locator services that enable them to exchange information [86, 87].

In a middle-out approach, local authorities may share data between their, respective, heterogeneous systems, via nationally-standardised interfaces, connected through a hybrid HIE. The patient medical data is usually stored and managed at organizational or regional levels. The information-exchange is enabled through a central hub and supporting central repositories [78] that store a minimal set of specific data that is shared across the network [86, 87]. The central repositories include vital registration and unique identifier look-up systems. The concrete technical implementation of the central hub or service bus is sometimes also referred to as an HIE. Systems that comply with the national standards and policies may seamlessly access and share data through the HIE. Some systems will be capable of conforming to the technical standards imposed by an NHIS; those not able to can be connected through "middleware" technologies [85].

3.6.2 Organisation

In HIC, NHIS architecture and the approach to its development has largely been influenced by the structure and nature of its health system, especially its policy and economic nature [22]. The culture of the NHIS formed by its people and leadership - including the culture of ICT use, government stewardship and organisational systems - can have a significant impact on its achieving its goals [16, 83, 88]. The approach for building an NHIS influences key decisions such as the level of local autonomy allowed, governance to be enforced, and level of involvement of key stakeholders in the NHIS development process [4, 78].

In a top-down approach, complete accountability, control and leadership for the NHIS, including the local systems of which it comprises and connects, is centralised at national-level, limiting local autonomy and collaboration.

In contrast, in a bottom-up approach there is no accountability for the NHIS at national-level. Local authorities have complete autonomy over their respective local systems. Collaboration is voluntary and generally only occurs at the local level, and is made possible only by the high level of trust between collaborating entities. The limited governance at national level is mainly to protect privacy and equality of access.

A middle-out approach aims to balance local and national interests and in order to improve connectivity across the NHIS [22]. The middle-out approach is not a completely new approach. Rather, it is a 'hybrid' of the top-down and bottom-up approaches, embracing and extending the activities, processes and structures that is good in each.

The term 'middle' in 'middle-out' does not refer to a position in the organisational hierarchy, as the terms 'top' and 'bottom' do. Rather it refers to a negotiated, operational stance or 'middle-ground' between the top and the bottom of the hierarchy, generally facilitated by an organisation delegated with the responsibility for the NHIS. The term 'out' in 'middle-out' indicates that guidance is provided from this negotiated middle-ground to both the top and bottom of the hierarchy. This guidance is the stance resulting from the negotiation of requirements coming from the top and bottom of the hierarchy. The rules governing this negotiation are highlighted below.

In a middle-out approach, overall accountability and leadership for the NHIS is centralised at national-level. [4] advises that government should not be embedded in the IT process, and instead, must outsource this activity to experts in the field, through a single joint well-resourced entity [4]. This responsibility is generally delegated to a single public-private collaborative - a government function, an independent public/private partnership, or a private organization [85]. Governments' role is to (1) define the policy framework to converge public and private, as well as local and central systems, into a functional national system, (2) fund public sector and provide incentives for private sector initiatives to join the NHIS, (3) develop the platform including standards frameworks, ICT infrastructure, health informatics workforce, progress monitoring and evaluation mechanisms, (4) institute legislation to protect the interests of citizens [4, 78]. Local authorities have complete autonomy over their respective local systems. They are, however, accountable to the national authority for sharing, at national-level, critical data generated by their local systems, in accordance with the national goals, policies and standards [2].

3.6.3 Implementation Strategy

The capacity to sustainably build and maintain an effective NHIS is another key aspect of an approach for developing NHIS [83].

In a top-down approach, the NHIS is developed typically through national-scale projects with planned fixed timelines and deliverables, driven by national goals, such as public health [4]. With an emphasis on technical implementation and change management [89], and policy, procedural, and technical standardisation [90], a detailed strategy, detailed enterprise architecture specification, and detailed projects plans direct the development of the NHIS. National-scale rollouts replace non-compliant with compliant systems [4]. These rollouts are few and far between to minimise the impact of changes, especially on core business functionality, and to maximise returns on existing investments [4].

In a bottom-up approach the NHIS evolves organically and indirectly through the plans of local authorities to enhance local systems, driven by the goals of the respective local health systems. The NHIS develops in an ad-hoc manner, through voluntary, locally-initiated projects to enable interoperability between specific local systems. While interoperability across the health sector may be a national desire, the national authority has no formal plan or framework for developing its NHIS, and local authorities consider it of secondary importance in comparison to their patient care services.

In a middle-out approach, through facilitated stakeholder collaboration, the national authority develops a set of common technical goals, policies and standards within a strategy framework, which guides the development of the NHIS as a whole. This approach ensures quality control and protects the interests of the nation and patient. The government may be required to drive the development of some central systems, such as its national ICT infrastructure, health registries and the HIE infrastructure. But, the development of the local systems and their connection to the NHIS, are driven by local authorities who have a vested interest in meeting the common national goals, which may be associated with high-level timelines. Interoperability across the health sector is a common goal, enabled by the national authority, achieved incrementally over time by the local authority. The NHIS evolves incrementally through voluntary, locally-initiated projects to make local systems compliant with national standards and driven by the goals of the respective local health systems, but balanced by common national goals. Various parts of the NHIS may develop independently, at different rates, without affecting core business functionality. Government does not dictate (rather encourages) compliance to the common standards and goals [4]. Local organisations will gradually bring existing systems up to national, as their resources permit, through an “embrace and extend”

strategy [2]. Typically, solutions to a focused subset of NHIS requirements are developed by participants drawn from across the sector [91].

3.7 Summary

The literature review highlighted the absence of a detailed framework for establishing the benefits and applicability of Coiera's analysis of approaches for building NHIS in SSAC. This chapter formalised such a framework. Coiera's topology of approaches for building NHIS, differ along the following perspectives: technical architecture, organisation, implementation strategy. The table below summarises the key differences between the approaches, along these perspectives.

Table 1 Key Characteristics Distinguishing the Approaches in Coiera's Topology of Approaches for Building NHIS

Perspective Approach	Technical Architecture	Organisation	Implementation Strategy
Top-Down	Centralised HIE, and standardised systems. System interoperability is inherent in the architecture of an NHIS.	Centralised leadership and governance. Limited, if any, local autonomy.	Detailed strategy, architecture and project plans drawn up by the national authority, upfront. Planned national-scale rollouts, few and far between, replace non-compliant with compliant ones.
Bottom-up	De-centralised systems, with no enforced national standards. System interoperability is achieved as a side-effect of uncoordinated, ad-hoc, local integrations.	De-centralised. Local authorities have complete autonomy.	No overall, upfront, implementation plan.
Middle-out	Hybrid HIE, with some centralised systems and some not-necessarily-	Centralised leadership.	Common goals, policy and standards, evolve over time, driven by the national

standard, de-centralised systems. System interoperability is achieved through local collaboration facilitated by the national authority through common goals, policy and standards (particularly data and interface standards).	Centralised governance of common goals, policies and standards. Local authorities have autonomy over local systems, but must strive towards goals and adherence to national policies, and standards	authority, in collaboration with local authorities. Incremental evolution towards this common, evolving, target state, mainly through local projects, encouraged and supported by the national authority.

Despite the lack of empirical evidence of successful NHIS implementations developed through a middle-out approach, its flexibility often makes the middle-out approach the best initial strategy for a country [4, 22]. It is also possible for a country to evolve from a bottom-up or top-down to a middle-out approach over time [4]. Hence, [2] recommends a middle-out approach for Greece, [3] for all EU countries, and the UK and USA are also now migrating towards a middle-out approach [22, 92]. The US's change in approach was motivated by the realisation that direction and support from the national-level was essential to achieve national connectivity [22]. In the UK, the central control of the NHS migrated, over time, to complex, devolved governance and funding structures consisting of multiple, diverse and partially autonomous organisations with varying resources and IT capabilities. It became far less uniform and amenable to the top-down approach initially taken [22]. The UK, therefore, have now decided to allow NHS organizations some level of autonomy in the development of their local systems [93].

CHAPTER 4: NHIS Development in SSAC

Despite the declaration of Alma Ata in 1978 to protect and promote the health of all people, SSAC, and within countries poor people, tend to have worse health outcomes than higher-income countries, and people, respectively [94, 95]. Furthermore, it is predicted that, globally, the health system in 2020 will have to treat proportionately more patients and illnesses, with less funds and workers [78]. Consolidating the currently fragmented, domain-specific health information systems in SSAC, into a coherent NHIS, can improve the quality of information available to improve patient care, enable policy-making and increase operational efficiencies throughout the health sector [33, 38, 96]. This will, in turn, lead to better health outcomes for the population.

This chapter describes the development landscape of NHIS in SSAC, highlighting in particular the key differences between NHIS development in HIC and SSAC. It concludes with the key challenges with- and considerations for developing NHIS in SSAC.

4.1 NHIS in Sub-Saharan African Countries

The promise of a more co-ordinated, well-architected, interoperable NHIS may benefit SSAC [5], where (1) systems are distributed over remote, geographically-dispersed environments and (2) government often do not have sufficient funding for public HIS and (3) donor driven projects implement HIS for the purposes of monitoring and evaluating only their specific programs, e.g. an HIV system used to monitor and evaluate an HIV treatment program at a few clinics. While NHIS planning and implementation in many SSAC is still largely absent, some SSAC have initiated programmes to develop their NHIS, including artefacts such as standards and interoperability frameworks [97]. SSAC must simultaneously try to introduce more patient-centric technologies, and connect existing systems, while still focusing on public health issues [10].

Despite resource limitations, success stories towards the development of NHIS include the deployment of aggregated-data systems such as the District Health Information System (DHIS) [98, 99] and patient-based systems such Open Medical Record System (OpenMRS) [100-103], both of which are implemented widely in several SSAC. The DHIS is a free and

open source application for sharing aggregated data collected from facilities with higher levels in the public health sector. It derives a combination of health statistics on health service delivery in sub-districts, districts, provinces and nationally [104-106]. OpenMRS [101, 102, 107] is a multi-institution, non-profit collaborative with a growing global network focused on creating EMR systems, and enabling local HIS development and self-reliance within resource-constrained environments [108].

However, the quality, timeliness and relevance of health information needs much improvement [21, 34, 48]. High-quality health information is currently not available when and where it is needed due to a number of critical challenges that make its collection, access and application problematic. Even the most basic administrative tasks in the health sector are more complex than their non-health equivalents [109]. Managing the exponential growth of complex health information, and implementing the ever-changing rules from the various sources that govern the information, has become an increasingly resource-intensive activity [33]. Lost information, poor documentation, and lack of access to available information, impede the delivery of high quality health services in SSAC [38].

There is still a predominance of paper-based systems. In the absence of ICT infrastructure such as computers, electricity and mobile phone coverage, paper-based systems are often the most feasible and cost-efficient solution [110]. However, limitations of paper-based systems include illegibility, ambiguity, incomplete data, poor availability and data fragmentation [110, 111]. Hence, a variety of program-specific electronic HIS are being used e.g. for the care of HIV patients [112]. This siloed and ad hoc development of HIS, result in a complex, fragmented NHIS made up of a number of pilot HIS that do not scale, are not interoperable and overlap in function [100, 113] [21].

There is currently insufficient information on the users of health services. Health plans are, therefore, often based on expressed sentiments, estimations and guess work. This situation directly contributes to inefficiency, inequity, and waste in the provision of health care services [21, 34]. As a result, SSAC are often caught unprepared by fairly predictable epidemics, which place an even heavier burden on health systems that could have been prevented if there was adequate planning and monitoring of trends [34]. Health information available to citizens also varies in quality and is often conflicting [33].

Despite the various initiatives and effort invested in strengthening HIS in SSAC, progress is slow and unsustainable [114]. SSAC developing NHIS generally have some leadership and sponsorship for their NHIS, and many are working towards a defined strategy [112]. Many SSACs claim that their HIS are inadequate or non-existent, because they do not have the financial, human, and infrastructure resources, and policies in place to implement and manage an NHIS. These SSACs also agree that they need help with developing strategic plans for their NHIS [47]. Other high-level issues with current approaches for developing NHIS include: inconsistent planning methods, "techno-centric" rather than "health system-centric" focus, insufficient collaboration & cooperation, regulation and security complexities [115], and over-ambitious goals [31].

4.2 The Benefits of Developing NHIS in SSAC

Many commentators have raised concerns that ICT has yet to deliver on its promises, and that the rapid adoption of ICT is a risk [78]. Furthermore, not everyone is convinced that ICT development will advantage SSAC. Most eHealth solutions have been developed in high income countries (HIC) contexts to improve diagnosis and reduce costs [41]. While public HIS are a priority for SSAC, current HIC architecture frameworks have a greater focus on developing patient-based HIS. Developing and maintaining the architecture frameworks used by HIC generally depends on a high level of financial, human and infrastructure resources.

[41] suggests that ICT offers no immediate benefit to SSACs struggling with inadequate service provision, as opposed to just high costs. In particular, some question the ethics of advocating for large-scale EHR implementation in SSAC, especially against the proven alternative healthcare interventions, such as safe water and immunizations, that compete for the same resources [116]. The evidence of the benefits, risks, costs and social value of EHR in developing countries and how these change over time is scant [116].

Even a well-built NHIS IT solution cannot guarantee that it will be used effectively [31]. There is limited capacity, institutional culture and political will for using information to support policy- and decision-making [31, 75]. Decision-making continues to be carried out on the basis of tradition, ignoring available information and evidence [31]. In particular in SSAC, the transition from paper-based records to EMR represents a paradigm shift for the health sector

[59]. Many health workers still document information on paper during patient encounters, re-capturing them later in electronic format [59].

Despite its complexity and the challenges with its development and use, many other experts believe that the benefits to be gained by implementing an NHIS far outweighs the initial difficulties encountered [59]. [96] motivates the need for an integrated NHIS in SSAC to support management, planning, and policy development. Since patient care, today, involves several different types of healthcare providers, it is increasingly necessary for the various providers to exchange patient records to accurately diagnose and treat complex conditions [58, 117]. There is also a need for the simultaneous access to patient records by multiple users to inform decision making at various levels and areas across the health sector [118].

SSAC, donors and other stakeholders involved in health have agreed that strengthening NHIS is essential to achieve and sustain improvements in the health sector [21, 36, 96].

4.3 Adopting an Approach from HIC

SSAC and HIC share some common characteristics. For example, some of the key goals of the health systems in HIC and SSAC are to achieve Universal Health Coverage, facilitate more evidence-based decision making, offer patient-based solutions and reduce non-communicable diseases. SSAC also have complex organisations with multiple, distributed authorities, and their patients also move between care centres. Health system connectivity is important, for continuity of care of patients moving between facilities and for the country-wide collection of data to monitor and control epidemics. HIC have also had to address the existence and interoperability of heterogeneous systems giving due consideration to (1) security and privacy, (2) the inherent complexities of the health domain, such as the high rate of change, non-standard clinical terminology, and (3) the lack of globally accepted standards. Given the common challenges they face, SSAC may benefit from adopting an approach for developing NHIS tested in HIC.

SSAC, however, have further challenges, not relevant to HIC, which influence the approach they take in developing their NHIS. For example, SSAC are struggling to reduce communicable disease and poverty related health issues. They are struggling to meet the Millennium Development Goals, a pre-requisite to achieving Universal Health Coverage. NHIS in SSAC are weak and fragmented, while HIC have advanced infrastructure, advanced data-aggregating

systems and large coverage of patient-based HIS. The main focus of HIC is on facilitating widespread interoperability between their already ubiquitous EMR systems, through the implementation of EHR systems. In contrast, SSACS, while promoting interoperability between its EMR systems, are still struggling with the deployment of EMR systems, especially in rural areas.

4.4 The Challenges with Developing NHIS in SSAC

Developing a national information system of the scale, complexity and heterogeneity of an NHIS, poses complex, unique challenges in SSAC. In this section, the key challenges faced by SSAC, over and above the common challenges faced by all countries with developing NHIS, are described.

4.4.1 Resource Constraints

Inadequate resources hinder the development of the NHIS in SSAC [36, 47].

Huge investments and national budgets in excess of US$36 billion have enabled the great advancement of NHIS in HIC [44, 119-121]. In contrast, less than US$2 billion a year, almost half sponsored by donors, is spent on different eHealth initiatives in SSAC [21]. Even this investment is becoming more difficult to raise in a struggling economy [122, 123]. Furthermore, much of the investment is used in a manner that is uncoordinated duplicative and fragmented [21], mostly due to the lack of HIS policy [47], planning [124], local ownership and leadership [125, 126]. Long-term national government funding and political support [52] for HIS fluctuates, as HIS initiatives compete with political and social goals such as the reduction of poverty and health service delivery [38, 127] [109, 128].

Many health workers in rural areas, do not understand English, are not computer literate or skilled [44], and have limited access to training [35, 129]. Acquiring specialised [34, 125] resources locally is expensive [34, 38] and difficult [35, 47, 48, 75, 129]. As a result, there is a strong dependence on external resources to implement HIS [17, 114, 125].

The limited, unstable resource availability [129] will often inhibit the distribution and development of infrastructure [36], especially if state-owned. The limited infrastructure, even access to power

[129], [96] is mostly deployed in urban areas [130]. The disconnected remote areas, supporting the majority of the population [44], are a particular challenge [131] when developing HIS for country-wide deployment [103], and can account for why many 'pilot projects' [41] are not implemented nationally [17]. While mobile phone access is prolific [132], bandwidth, where available, is expensive, and network speed is low, and therefore, impractical for use in most rural areas [44, 132].

4.4.2 Socio-political Environment with Distributed Autonomy

NHIS development is influenced by the politics of diseases and sponsorships, national and local authorities, vendors and users, and the public [128]. The lack of policies and strong leadership often results in a misalignment of their priorities [114]. This manifests in complicated and unclear governance processes [125], too many diverse and sometimes conflicting requirements for the NHIS [75], overlaps and gaps in the NHIS architecture, a general lack of focus and a waste of already limited resources [31, 124].

The complex processes and relationships of the NHIS spans multiple government departments [38]. On recommendation from the WHO and the World Bank [133], many SSAC have implemented a variety of decentralisation mechanisms to transfer responsibility for health service delivery from the MOH to local authorities [134, 135]. Health care delivery is also highly dependent on the private sector which generally shares only a limited amount of its data and not involved in driving NHIS development [75]. Health systems influence, and are also influenced by the departments of agriculture, labour, education, water and sanitation [21, 48].

Many development programmes run in parallel silos, each developing their own HIS [52, 96, 124, 136]. Since half the HIS budget originates from multiple donor organisations [21], the driving force behind many of these programmes are individuals or groups with diverse political interests, the money they bring in, and the particular diseases in which they are interested [128]. When donors withdraw, they typically do not leave in place a sustainability strategy to ensure that the benefits, if any, are sustained and can be further strengthened over time [35, 114, 128].

HIS development is also greatly influenced by the social and professional cultures of healthcare organisations [36, 109, 131]. Employees often resist new systems, with a fear of being replaced

or restricted by them [131]. The adoption of eHealth is also constrained by a concern for privacy, security and confidentiality of personal health data [39, 85].

As a result of the multiple units of autonomy, local implementation often contends with national HIS policy, goals and control, and. Available resources, especially those already burdened with data collection, are stretched beyond their limits as a result of sometimes duplicative and conflicting administrative, economic, legal, vendor or donor pressures [16, 38] [34, 46].

4.4.3 Dynamic, Heterogeneous Systems

NHIS in SSAC comprise of HIS that are heterogeneous technically (in terms of application, platform, protocols, language), in relation to funding mechanisms (from government, donor agencies, the World Bank), and with respect to institutional grounding (central ministries, district administration, local health clinics, vertical programs) [128].

Supporting the varied information needs from district to national level [135], and keeping pace with new developments and technologies [52] is a challenge when an NHIS comprises such varying levels of maturity [137]. Infrastructure range from no electricity to mobile networks and the Internet [11]. HIS are, therefore, also characterised by various, evolving levels of maturity, driven also by changing health priorities [53, 109]. Different systems within the health sector are, at the same time, maturing: 1) from paper-based to electronic records, 2) from stand-alone computers to networked systems, 3) from local to global (mobile and internet-based) HIS architectures [138], 4) from EMR to EHR systems [103] and to supporting 5) new technologies e.g. monitoring centres and wearable devices and 6) new types of data e.g. DNA or protein data [138].

Replacing the heterogeneous HIS that are currently providing value, with homogeneous alternate solutions is not viable in SSAC, as it can result in either marginalising the low resource settings, or retarding the advancement of high-resource settings. Due to ease of use and legal constraints, even the paper-based forms will not be eliminated in the foreseeable future.

4.4.4 Inadequate Systems Design

In a recent survey, most SSAC requested help with developing strategic plans for their NHIS [47]. Many do not have a systematic, high-level, national approach to design an NHIS. [21]. The lack of cohesive planning, an eHealth policy [47, 139, 140], thorough costing analysis, research and requirements gathering, limit the opportunity, for example, to develop common architectural solutions [125].

HIS are often implemented on an ad hoc basis, by foreign software developers, to meet the specific needs of disease-specific programs [48]. There is limited consideration for interoperability at a national level [11, 38, 96], and reusability across systems [11, 31, 44]. Too often, ineffective systems are developed as a result of the lack of understanding, and underestimation of the complexity of health processes and the environment in which the HIS are to be deployed [31, 109, 124]. Many electronic HIS are a direct computerisation of the paper-based systems, perpetuating existing problems [52] [48].

Few implementations from one setting are reused at another [78]. 'Pilot' projects are necessary to enable innovation, but scarce resources have been wasted on too many pilot projects that cannot be effectively scaled-up [17]. Too many artificially controlled research projects do not go further than the 'pilot project' phase [141], because their long term success, typically, depends on implementing environments not characteristic of SSAC [17, 128]. The substantial investment in such heterogeneous legacy systems have made health organisations now reluctant to spend more money on proposed solutions [39].

Existing frameworks for developing NHIS, mainly implemented only in HIC, tend to be voluminous, focused on only a subset of the requirements for an NHIS, difficult to apply and require a great amount of configuration for the health sector in SSAC. For example, the Health Metrics Network framework prescribes resources that are not widely available in SSAC [103].

4.5 Key Considerations for Developing NHIS in SSAC

For an effective NHIS to be sustainable [142], it must

> *"(1) meet its' present needs, without compromising its' ability to meet its future needs, (2) be able to identify and manage risks threatening its long-term viability and*

(3) not be dependent on outside support to continue its existence" [114].

The following section describes the key considerations for developing effective NHIS in SSAC in a sustainable manner. These considerations or development strategies are focused specifically on mitigating the key challenges just described.

4.5.1 Capacity Maximisation and Building – dealing with unstable, constrained funding

SSAC must take ownership of, and lead their NHIS development efforts. Capacity must be continuously built. At the same time, economic and political feasibility, and the capacity of national management to implement the NHIS [31, 36] must be balanced with a realisation of benefits [33, 35, 51, 78]. For example, development could focus first on simplifying current processes, and use the gains in the efficiency for further improvements e.g. (1) reducing the overhead of data capture procedures allows users to capture additional data and (2) instead of a replacing entire systems with seemingly superior systems, retaining existing systems with which users are familiar, and gradually introducing enhancements, may reduce training costs and resistance to changes [36]. SSAC must also encourage locally developed and maintained IT solutions [137, 139]. Fortunately, many international donors are making greater efforts to involve country partners in their projects [21, 52].

4.5.2 A systems thinking approach – dealing with system complexity

SSAC must adopt a systems thinking approach to developing its NHIS [143-145]. The relationship between the NHIS and its environment is a key component in the design of an NHIS [146]. The interconnected human and non-human components of an NHIS may interact unpredictably, with change in one components having an impact on others [15]. Ineffective systems can have a disruptive effect on an already overburdened health sector [11]. Solutions must be grounded in the realities of practice – both socially and technically. ICT plans must be accompanied by parallel plans to optimise performance in other areas of the health sector such as the redesign of processes, and reimbursement incentives that influence behaviours, and skills development [33, 96]. The work already done must be embraced and extended by applying the lessons learned from one case to the next [11, 18, 40].

4.5.3 Interoperability – dealing with heterogeneity

Some of the factors that influence an NHIS, including the decentralised nature of its health care system and its heterogeneous HIS, are entrenched and not likely to change [16, 85]. Policies, standards and technical goals must serve to improve the interoperability of heterogeneous systems and organisations [2]. They must guide the long-term convergence of the existing and new, public and private, local and central systems into a functional NHIS [2, 33, 47, 78, 147]. Most existing standards have been developed for HIC, largely without influence from SSAC. Standards more relevant to SSAC must be developed and adopted [39]. Due to the high cost involved in the generation of Patient Unique Identifiers (PUI) [44], SSAC can use citizen unique identifiers to distinguish the patient and its records from all others [44, 148].

4.5.4 Collaboration and Coordination – dealing with organisational complexity and autonomy

SSAC need a comprehensive and collaborative national strategy for developing an NHIS, responsive to the needs of stakeholders at all levels of the health sector [38, 40, 128, 149]. Implementing NHIS involves a complex set of relationships among individuals and organizations with competing goals and priorities. The politics of negotiating changes among the actors at various levels in government between private, public and non-profit organisations, donors and development partners is key to ensuring the nation-wide use and development of the NHIS [16, 31, 40, 51, 52, 64, 75, 114, 150]. NHIS plans must generally also be aligned with the country's strategies for eHealth, non-health national information systems, as well as global information systems. Country plans to improve an NHIS can help bring together international donors, and health and ICT resources in a shared mission to strengthen the NHIS [38].

The NHIS must engender trust at all levels [59, 82, 151], in order for the introduced processes and systems to establish and embed themselves [82]. With support from the NHIS leadership, protagonists can spearhead and coach their counterparts to improve NHIS implementations across a greater scope of the health sector [20, 47]. Collaboration, coordination and alignment will enable the development of holistic solutions, policies and standards, reduce the duplication of effort, avoid gaps in requirements and disparity in solutions, and make possible access to the skills and capabilities lacking in government [38, 52, 68, 131].

Such coordination requires strong, committed, local and national, health sector and IT, ownership and leadership. Coiera [78] advises government to delegate this responsibility to a senior IT capability that can drive and vet the development of the NHIS, while outsourcing the development of the system to experts in the IT industry. The leadership of the NHIS must strive to take away constraints, and establish a network of stakeholders, empowering them to innovate [152], increase the reuse of software components and address interoperability issues. Its high-level governance mechanisms ensure that projects achieve both local and health-sector-wide objectives [153].

4.5.5 Incremental and Iterative Progress – dealing with resource constraints

It is difficult and risky to implement systems requiring rapid adoption of ICT or substantial change to existing operations and workflows [11, 78]. Problems cannot be completely and sufficiently solved in a single cycle. Iterations enable the systematic identification of problems and evaluation of solutions to address them [52, 148]. An iterative and adaptive development approach, in which benefits and challenges are continuously assessed [22, 53, 64], allows for better risk management. An incremental approach to NHIS development [128] allows countries to optimise their use of scarce resources by starting with simple solutions, and increasing in sophistication as resources become available [36, 114]. Initially, the level of detail of the architecture will be very low - giving the designers much flexibility in their designs. Over time the level of detail will increase, as standards are adopted and enforced, and the design evolves to address the changing needs of the increasing numbers of users [85]. The continuous improvement process must embrace and extend existing systems and knowledge [38]. Standards will also evolve through ongoing negotiations between actors [52, 136].

4.5.6 Flexible, Agile and Adaptable Systems - dealing with dynamism

The nature of diseases and health sector operations is changing at a high rate. Connecting the silos is the initial focus of development in SSAC. Over time an NHIS must become agile enough to adapt to the changes in its environment. Solutions must be flexible enough to be enhanced and adapted as more resources become available and more mature/complex techniques are adopted. Solutions must be able to scale to national level, in an incremental manner, without fundamental changes to its design [11]. Systems developed for SSAC must cater for the users' limited, but improving, skill level. For example, it may be pragmatic to initially provide simple,

non-feature-rich systems that can be used by people with limited skill and experience with computers, with plans to enhance features as the users become more skilled in the use of those systems [36]. To support the changing health environment, an NHIS must support customization and re-configuration [152]. It may be necessary for the NHIS to support different solutions for the varying environments, yet fostering re-use across those systems where possible. [103]. For example, solutions must be able to cater for electronic and paper-based systems as well as connected and disconnected environments [11]. Systems, their architectures and the approach to their architecture must therefore be flexible, agile and adaptable.

4.6 Summary

Building an NHIS poses unique and complex challenges in SSAC. NHIS development is usually associated with high costs, complexity, uncontrollability, and unintended consequences. In addition, power outages and broken equipment, as well as the human factors associated with working in technologically, cognitively, and socially complex environments are common-place in SSAC [78]. Despite the inadequate systems design, and limited availability of resources that challenge the development of systems [11], NHIS need to become stronger, in order to achieved and sustained improvements in the health sector gains. Given the challenges they share, SSAC may benefit from adopting a high level approach for developing NHIS that has shown to be effective in HIC. The approach, however, must support the following key considerations for developing NHIS in SSAC: (1) maximising and building capacity to deal with unstable, constrained funding (2) taking a systems thinking approach to deal with system complexity (3) improving interoperability with the NHIS to deal with heterogeneity (4) facilitating collaboration and coordination to deal with organisational complexity and autonomy (5) making progress incrementally and iteratively to deal with resource constraints, and (6) developing flexible, agile and adaptable systems to deal with dynamism.

CHAPTER 5: Case Study - South Africa

South Africa is a middle-income country, with one of the strongest economies in Africa [154]. Despite this, the South African health system is weaker than other SSAC that spend a smaller percentage of their GDP on health care [83].

5.1 The Organisation and Governance of the Health Sector

South Africa has a health profile of communicable and non-communicable diseases, and incidences of injuries and trauma [154]. Over 85% of its 52.98 million people have access to health care [154] mainly through public health facilities – with 400 of the over 4000 facilities being hospitals [155]. However, delivery of high quality health services is constrained, mainly due to the shortage of financial resources (particularly staff, infrastructure and supplies) [156], and to the residence of a large majority of its population in rural areas [157].

While primary healthcare is provided free at public primary care clinics, a major inequality in healthcare funding exists [158]. 60% of the total health spend in South Africa is consumed by the 15-18% of the population who have medical insurance and can access the private medical sector [154, 157]. Furthermore, urban health services are far superior to rural services. It is common place for patients to move between care centres [117], due in some part to doctors in rural areas using urban public or private facilities as referral centres [159]. The costs associated with clinic and hospital visits (specifically transport and opportunity costs) are a serious deterrent to health system utilisation [158].

Public health services in South Africa are coordinated by the National Department of Health (NDOH), funded mainly through the National Treasury [106, 160], and is organized as four main areas: facility-based, outreach, community, and emergency preparedness and response [154, 161]. Government provides resources, develops policies and coordinates health strengthening initiatives [154]. The MOH and the Members of the Executive Council (MEC) of the nine provinces are committed, by the negotiated service delivery agreement (NSDA) with the President, to deliver [162] on its current priorities [163], consistent with the health-related millennium development goals [164]:

- The National Health Insurance (NHI), a financing system for the provision of essential healthcare for all citizens of South Africa and legal long-term residents. It is an initiative towards achieving universal health coverage.
- To address HIV, AIDS and TB in an integrated manner, and to combat Malaria (as they each contribute significantly to the burden of disease faced by South Africans, particularly by the poor and vulnerable groups).
- To strengthen the Primary Health Care system.
- To reduce the high maternal and child mortality rates in the country.

While the MOH sets the strategy and policies for the country, the Provincial Departments of Health are responsible for the delivery of healthcare, including the HIS, processes and procedures, in their province [135, 157, 160].

South Africa is composed of 9 provinces, which are further divided into 52 districts [165]. In 1997 South Africa committed to a district health system based on the Primary Health Care approach. Decentralization is achieved through the delegation of authority to health districts. The responsibility for managing health service delivery is delegated to districts [154], in-keeping with the district-based model recommended by the WHO, which promotes empowering districts to manage health. In general, national and local governance, while crucial, is poor [159, 166].

The NDOH also has over 25 development partners directly involved in the funding, implementation and rollout of mainly HIV and AIDS programmes to districts [154]. The siloed programmes has resulted in fragmentation and low health outcomes [154]. To avoid duplication and overlap in effort and resources, all partners have pledged their commitment to the 2005 Paris Declaration and the Joint Assistance Framework aimed at promoting consistency and alignment in sustainable support [154]. However, a recent evaluation of the Paris Declaration shows that there is still an increasing misalignment between vertical partner programmes with that of the NDOH, in terms of, but not limited to, accountability, roles and responsibilities [154].

5.2 The Organisation and Governance of the NHIS

The NDOH is required in terms of the National Health Act, 2003 (Act 61 of 2003) to facilitate and coordinate the establishment, implementation and maintenance of an NHIS, which will be operational at all levels of the health sector; including the private sector [160]. Although there is no specific allocation, funding for the NHIS must come from provincial and municipal budgets [160]. Individual health departments are responsible for improving their effectiveness through eHealth [160]. For example, in the selection of patient-based HIS at facility level, it is understood that the NDOH has taken the approach of evaluating all systems available in South Africa and creating a short-list from which provinces may select a particular system. The results of the evaluation are yet to be announced. The individual facilities have very little if any ability to make autonomous decisions around HIS - it may need to be approved at the provincial level at least [167].

Various other organisations support the NDOH in establishment, implementation and maintenance of the NHIS [157, 168]. The Technical Advisory Committee of the National Health Council (TAC-NHC) functions as the technical implementation forum of the NHC which is responsible for the implementation of strategic health priorities [169]. The National Health Information System (NHISSA) Directorate in the NDOH, consisting of senior managers for HIS and ICT in the 9 provinces [160], is responsible for policy, regulation and coordination of eHealth [157]. The Health Data Advisory and Coordination Committee (HDACC) is tasked with establishing a monitoring and evaluation system for the negotiated service delivery agreement (NSDA) [170]. The State Information Technology Agency (SITA) is mandated to "consolidate and coordinate the State's information technology resources" [160]. Local eHealth research and development by government bodies and universities is often funded by government [157, 168]. In the private sector, in accordance with the Medical Schemes Act, the Council for Medical Schemes (CMS) is responsible for disseminating private health information [171].

5.2.1 Policies

Polices and legislation are not fully implemented or enforced [157, 168], due to problems with the interpretation of legislation. Enforcement is especially problematic in the private sector [168]. [166] highlights the contrasting understanding of policy implementation between the top and bottom of the health hierarchy.

5.2.2 Standards

As with policies, there is a lack of advocacy, adoption and governance of standards [160]. South Africa, with its observer ("O") membership in ISO/TC 215 Health Informatics [157], is unable to vote on the development of international eHealth standards [160]. However, [160] recognises that technical standards are essential for the successful implementation of an eHealth strategy. Several standards have been adopted to promote interoperability[157]. The NDOH Data Dictionary, developed to support the District Health Management Information System (DHMIS) policy, provides a reference point for selected health information standards such as data set specifications (data elements, indicators, and data validation rules) and the organisational unit hierarchies. The role of the strategy outlined in the Health Normative Standards Framework (HNSF) is to enable the desired network effect of an NHIS [57]. The HNSF provides guidance in navigating through the multitude of eHealth standards, and assists in the assessment of the applicability of international eHealth standards to healthcare information systems deployed in South African healthcare institutions [57]. The MOH has also approved the establishment of an eHealth Standards Board for South Africa to support governance and regulation [169].

The Private Healthcare Information Standards Committee (PHISC) also monitors health information standards in the private sector, and facilitates cooperation related to eHealth standards across the country [160, 171].

5.3 The Key Information Systems within the NHIS

Some of the key strengths in South Africa's development of HIS include: its capacity to report on notifiable diseases; the use of health information for strategic planning; and the work being undertaken on EMR systems [168]. In terms of the five stages of HIS maturity identified in [113], South Africa is placed at Stage 3, with various regions within the country ranging from Stages 1 to 4.

[57] provides a comprehensive report on patient-based systems; [168] lists documented reviews by a number of HIS stakeholders of (a) various aspects of the South African HIS and (b) policies, strategies and legislations that support the development of the NHIS. The following

sections briefly describe the country's public and private sector systems as they relate to the development of the NHIS.

5.3.1 Population-based HIS

The Department of Health routinely disseminates statistics on notifiable medical conditions, health status and operational aspects of national and provincial health [209]. Health data is usually generated from censuses, civil registration and surveys, as well as individual, service and resource records [168] [171]. Donors and research projects, and other government departments also continually generate valuable health information [183]

All this information, however, is scattered in many different, geographically-dispersed vertical data collection systems, and managed by various different organisations – not always under the control of the NDOH [104]. For example, though often related, the data generated directly from populations is stored in systems stored and managed separately from vital (birth and death) registrations [168]. The numerous disease-specific registers and surveillance systems are also managed by different organisations in various parts of the country [168]: the National Electronic TB Register used by all provinces, the Department of Health's Clinical Trials Register, National Health Laboratory Service's National Cancer Registry, UNISA and the Medical Research Council's Injuries surveillance system. The multiple (often donor-driven) health monitoring and evaluation systems has resulted in a lack of information ownership, variable data quality, often confusing data variations, lags between collection and analysis, and the lack of granular demographic, social status and locality data [154, 157, 168, 172].

On a positive note, South Africa has done some good work in establishing a data flow through the health system hierarchy [173]. It has adopted the District Health Information Software (DHIS), implemented by each of the provincial Departments of Health [135, 157, 160] and now synonymous with the District Health Management Information System (DHMIS), for managing routine data in support of the NHIS [174]. Well-established [157, 173], it provides a large proportion of the information used for decision-making at all levels of the health sector. [104] provides an official regulatory framework for the DHMIS.

The National Electronic TB Register, the National Electronic HIV Register, the Supply Chain Management System and the National Health Laboratory Service are also operating country

wide (albeit with gaps in certain areas) and delivering data to the national level. A National Health Information Repository and Data Warehouse (NHIRD) was developed to integrate data from various specialist information systems [183]. To procure, control and regulate optimal stock levels of supplies national and provincial departments use Logistical Information System (LOGIS); district and local municipalities may use various financial and procurement systems such as excel, Pastel or even SAP depending on the resources available to at the facility [175].

5.3.2 Patient-based HIS

While electronic HIS in most hospitals generally support patient-centric administrative processes such as registration of visits and client statistical surveys (many even making use of recognised standards), fewer than half meet typical patient administration requirements and fewer than a third meet typical patient care requirements [57]. In the private and public sector, the financial management and laboratory modules incorporated in EMR systems have increased the rate of acquisition of EMR systems [59]. Large hospital systems include Meditech, Medicom and Clinicom [157]. Several smaller applications exist, such as PAAB. Unfortunately, no system has reached 100% coverage in any one province [61]. Despite the use of electronic records for administration, and the benefits associated with EMR, patient records remain mostly paper-based [57, 58], due to several factors including illiteracy, electricity, broadband coverage [61] and the high cost of EMR systems.

Some vertical national level patient-based HIS do exist, though not exactly EMR systems. For example, the National Health Laboratory Service (NHLS) supports over 80% of the population through a national network of laboratories [176]. It is inherently a patient-based HIS by its management of individual patient specimens. The Western Cape has implemented the patient-based Primary Health Care Information System (PHCIS) for its primary health care facilities and Patient Record and Health Management Information System (PREHMIS) for the City of Cape Town Metropolitan Municipality [177]. MomConnect [178] is an example of a new era of systems that are truly at a national level; even though it is still being rolled out nationally to all sites, because of the fact that it is a solution leveraging mobile technologies and is one of the first applications based on the HNSF, it is actually accessible country-wide [179]. The government-owned patient administration and billing system (PABS) is used in three provinces [169].

Patients moving between public or private hospitals have no means by which their health records can be transferred between these hospitals, due in some part to patient's health records not being stored electronically in most public hospitals, while private hospitals store patient health records in electronic format [180].

5.3.3 Health Information Exchange

The NHIS is fragmented, unsustainable, unwieldy and inoperable [57]. A national data dictionary is available [181], but, data is generally confined to the private or public HIS that generated the data and cannot be accessed by any other HIS [180]. In many health care facilities data collection and management are computerised [105, 157], but, the various HIS are often not standardized nor interoperable [57, 157, 173]. Of those systems that do share data, few abide by international health data-exchange standards [57]. An exception is the health information exchange technology on which the MomConnect and National Pregnancy Registry is based, which fully implements the requirements of information exchange laid out in the South African National Department of Health's Normative Standards for Interoperability Framework [182]. The system (including the OpenHIM on which the Rwandan HIE is based) delivers accurate data, securely throughout South Africa [182].

5.3.4 Private Sector Systems

In general, HIS in the private sector support mainly administrative functions [160]. There is no nationally connected network of HIS that supports patient care across the private healthcare sector [171]. Some networks of health specialists such as pathologist groups have their own HIS, with varying capabilities, as there is currently no standard to which they must comply [171].

The White Paper on Healthcare Reform: 1997 [183] proposes the integration of private health sector HIS into the NHIS [168]. However, there is limited, if any, interoperability between HIS in the private and public sectors [58, 171], due in part to the absence of a strategy for assessing the quality of information in the private sector [160, 168, 171]. Fortunately, the requirements for medical scheme claims have prompted significant consultation and joint decision-making by the NDOH, the Council for Medical Schemes and relevant stakeholder groups, laying the foundation for further collaboration on HIS issues [160].

5.4 Challenges with Developing the NHIS

South Africa has faced many challenges in implementing its eHealth strategy. The NDOH's uncoordinated eHealth investments have yielded local benefits but not the interoperability required between the heterogeneous systems of the NHIS [57, 173]. The increased demand for accurate and relevant routine information has revealed [104, 168] a range of problems [157]. Without high-level strategic and policy support from government challenges include: (1) a misalignment of goals across the health sector, (2) inadequate involvement of authorities at various levels of the sector in the management and use of information, (3) inefficient and effective HIS, and (4) inadequate governance, management and accountability [83], [104, 160].

Another key challenge is the inequity in resources and services between rural and urban districts [157]. South Africa's HIS landscape includes both high and low resource settings [11], with a marked variance in eHealth maturity across the country [160]. While the larger cities have advanced HIS technologies, rural settings have little or no electronic HIS [11]. Compounding this, the lack of resources makes even the paper-based systems ineffective [168].

Many doctors and nurses in state hospitals also have limited or no access to Internet, either because there are insufficient computers or because hospital management views internet access as a potential source of distraction which will reduce productivity [157]. Furthermore, while the South African telecommunications market is the largest in Africa (mobile phone penetration is estimated at 75% with approximately 90% of the country covered by mobile telephony), bandwidth is still very expensive and broadband penetration is low [157].

Inadequate ICT infrastructure development and management makes a shift to the use of web-based systems difficult [104], and, coupled with a lack of health resources in may facilities, also hinders clinical data being captured at the point of care directly by healthcare professionals [57]. The shortage of computer literate health workers and medical informatics skills, especially in rural areas, has also created a huge dependence on foreign experts [104, 157, 168]. [59] assessed the technology challenges with EHR system implementation as less complex than the people and cultural issues, such as privacy and security of patient information, and the reluctance of practitioners to adopt new systems that interfere with their workflow [59].

5.5 The Evolution of the NHIS

This section describes South Africa's approach to building its NHIS in terms of Coiera's topology of approaches, by understanding (1) how the NHIS evolved to its current state and (2) the possible future of the NHIS.

5.5.1 The Past

During the apartheid era, superior services were provided for whites than blacks, especially in comparison to those living in rural areas [133]. In fierce opposition to apartheid's racial fragmentation of health services, and deregulation of the health sector, a range of organisations (mainly Churches and NGO) and individuals were organised, in the 1980s, to develop and promote a national primary healthcare (PHC) strategy for South Africa, based on a system where services in a 'health ward' are integrated with the district hospital at its core [158]. The National Health Plan, the few years prior to 1994, sought to (1) make comprehensive, community-based health care accessible to all South Africans, by decentralising the organisation and management of health services and establishing PHC centres as the foundation of the national health system, and (2) eliminate the fragmentation and duplication of services by integrating all health services under a single Ministry of Health [158]. Post 1994 the public HIS were re-developed to support the new PHC approach. The core modules of the National Healthcare Management Information System (NHC/MIS) were originally envisaged to be: patient registration, a basic summary care record, patient billing, appointment scheduling, clinical pharmacy, a patient master Index (PMI) [160].

In 1996 the NHC/MIS was decentralised to provincial level [160]. The DHIS was also developed in 1996. In 1999 the first national minimum data set for PHC was rolled out to all public primary level facilities [104]. The DHIS has since been implemented by most provinces. Instead of a government mandate, its adoption was enabled by the supporting processes that government developed around the DHIS product which made it attractive for provincial authorities [155]. In the absence of a national eHealth strategy with policy related to eHealth procurement from the government, and enabled by the decentralised management of the health system, in an uncoordinated bottom-up fashion, local authorities acquired different EMR systems for of their choice. Because of varying degrees of capabilities and maturities within and across the provinces, several disparate systems - neither compatible nor interoperable with

each other - have been implemented in the provinces [57, 160] Also as a result of the decentralisation, many of the envisaged components of NHC/MIS were not implemented [57].

Unfortunately the under-performance of PHC-based health system increased the reliance of the South African population on the complementary use of public and private (including traditional healers, herbalists, inyangas, faith healers and prophets) services [158]. This further fragmented the NHIS, as patient records, if captured at all, was now also being stored in private systems with no interoperability with public systems.

The government, showing political will, have since moved to more centralised control. It has assigned the responsibility for eHealth policy, regulation and programme coordination to the Policy Co-ordination and Integrated Planning Cluster within the NDOH [157]. In response to the uncontrolled growth of EMR systems, it has placed a moratorium on EMR systems [57] and attempted to link the various, provincial DHIS [157, 173, 184]. It also undertook a national HIS assessment based on the Health Metrics Network framework [168], the results of which suggested: (a) the development and implementation of strategic plans for an NHIS; (b) the enforcement of the legal framework; and (c) the active promotion of standards in health information production [168].

5.5.2 The National eHealth Strategy

Strengthening the NHIS, will enable the use of information to improve planning, management, and the quality of care provided across the health system, both public and private [154]. The NDOH recognises that for such eHealth benefits to exceed the costs over time, requires an approach that includes (1) the adoption of appropriate architecture, standards and policies that will ensure long-term interoperability and quality, (2) the identification of opportunities and setting of priorities, and (3) the development of feasible plans [160]. The national eHealth Strategy provides a roadmap for NHIS development [163]. It identifies ten strategic priorities: Strategy and Leadership, Stakeholder Engagement, Standards and Interoperability, Governance and Regulation, Investment, Affordability and Sustainability, Benefits Realisation, Capacity and Workforce, Applications and Tools to support Healthcare Delivery, Monitoring and Evaluation of the eHealth Strategy, and eHealth Foundations (infrastructure, connectivity, registration of patients, facilities and providers, and a basic national EHR) [160]. The new strategy is for the NHIS to evolve incrementally, building on what exists, with a focus on

standards, interoperability and collaboration [160]. The strategy defines common goals and mentions the development of an enterprise architecture, but only elaborates implementation plans for common infrastructure components [160]. The private sector has not been involved in the development of this strategy [157, 168]; it is proposed that the private sector be included as key stakeholders when strong policies (especially around governance, procurement and standards) are in place and practised [160]. South Africa's strategy also includes plans for developing an enterprise architecture. The country acknowledges that the development of the NHIS must be a partnership between the NDOH and Universities, private sector, NGO and civil society [155]. The NDOH will guide the development with the expertise that they have around social development, and the tools that they have been using and developing over the years [155].

The current strategy also gives provincial authorities autonomy over their systems, but with the requirement that they adhere to policies, comply with standards and strive towards common country goals in order to connect to the NHIS. South Africa aims to encourage (rather than mandate) compliance to their goals and frameworks. Incremental evolution towards common goals, mainly through local projects, is being encouraged and supported by the national authority. The common goals, policy and standards, are also intended to evolve over time, driven by the national authority, in collaboration with provincial authorities.

5.5.3 The Future

South Africa's national HIS has many facets that can now be managed in a more integrated manner [174], through the co-ordination and synergy offered by its national eHealth strategy [185]. However, considerable efforts are required to address the country's NHIS requirements [185].

5.5.3.1 Population-based Systems

There is a need to improve South Africa's capacity to monitor and rapidly respond to public health emergencies [160]. A new civil registration system is being developed [185]. National indicators and targets have now been agreed for priority areas [185]. The NHI will require a 'National Health Data Dictionary' for the various coding systems that are to be developed [185]. Information generated through vertical disease-specific systems should be made available to facility and district users, perhaps through the DHIS [106]. Similarly, the information required

by the NHI that resides in the NHIRD must also be made available to facility and district users [183]. In addition, health care providers at clinic level should be encouraged to influence the development of the systems that they use [106].

5.5.3.2 Patient-based HIS

The envisaged National Health Insurance (NHI) is expected to increase the need for improved continuity of care information [58]. Functionally, it requires the details of individual encounters - what treatment was received, what payment methods were used [185]. Technically, it requires an effective, national, automated, transaction-based, standards-based, patient-based HIS, that supports interoperability across the public and private sectors [160, 170, 185]. Given that many SSAC (including Kenya, Rwanda) have adopted OpenMRS for all their primary care facilities [148], including HIV, TB and Malaria, it may be worthwhile for South Africa to consider its adoption.

5.5.3.3 EHR and HIE

More boldly, [57] recommends a "*person-centric healthcare*", "*cloud-based shared national eHealth infrastructure*" be established, with an enterprise architecture that "*will define how eHealth solutions, across all levels of healthcare, in both the public and private health systems, will interoperate with each other to support person-centric continuity of healthcare*". While researchers, such as [61], suggest that the current lack of eHealth capability cannot justify a national initiative of the magnitude of a national EHR implementation, driven by the NHI [59, 160] includes plans for a basic National EHR and information exchange. Integrating patient health records across the health sector will involve great effort and must leverage innovative solutions from across the country [185]; for example, the Western Cape's Primary Healthcare Information System (PHCIS) and Patient Master Index (PMI) module, which maintains a unique reference number across all its primary health care facilities for every individual patient [177]. The National EHR will be interoperable with legacy provincial electronic health repositories, and allow patient tracking wherever patients present themselves [157, 160, 184].

Architecting a SEHR at this stage is very much in its infancy [186]. The Patient Register and the Master Patient Index (MPI), identified as the main repositories of the core patient records to which all patient related systems and applications should be linked, do not currently exist [160]. For this purpose the NHIS/SA adopted the national ID number as the unique identifier

in health [169]. All systems must use the ID number in building databases making it possible for the sharing of data between hospitals in the province as well as between provinces. A Health Population Registry System (HPRS) is being developed to be deployed at all national health insurance pilot sites [179]. Smart cards are expected to cater for mobile/offline access to the EHR from facilities or providers that will not always be connected to the online EHR services [157, 184].

To increase the feasibility of EHR systems, [58] promotes a phased adoption of standards-based EMR across South Africa. In most cases, the current EMR systems in hospitals can be scaled up to interoperate with a shared national infrastructure [57]. The further adoption of standards-based EMR systems by primary healthcare providers, however, continuously increases the feasibility of an EHR system [58]. The country-wide TIER.Net EMR rollout is another example of such an approach [160], using a configurable middle tier to support the migration towards EMR systems [187]. Paper-based and electronic systems are combined in a unified system to produce common nationally required indicators [187]. For example, in the Western Cape, HIV reports are based on a combination of reports from paper-based antiretroviral registers, TIER.Net (the offline tier-2 software) and EKAPA (the tier-3 networked EMR) [187]. As resources and infrastructure improve, facilities can transition to the more technologically sophisticated tiers [187].

Taking a similar evolutionary approach in the private sector, the effective administrative HIS, that already support a large proportion of private sector, could provide patient records in the future [171]. [180] further recommended that the services of the PAAB system in public hospitals be extended to incorporate patient health records, and be integrated with the EMR systems found in private hospitals through the use of a service hub [180].

5.5.3.4 Standards

Compliance with nationally adopted standards may reduce HIS implementations costs [160]. At the highest level, the planned eHealth enterprise architecture will need to be aligned with the Government Wide Enterprise Architecture (GWEA), Minimum Interoperability Standards (MIOS) and Government IT Architecture (GITA) frameworks, which guide the development of public and private national information systems in South Africa [57, 115, 188]. The NHIS/SA sub-committee on Architecture and Standards is working on a national guideline for

uniquely identifying patients of public facilities. As a prerequisite to integrating private and public data, the role of private health sector in the NHIS must be clarified, as well as the rules governing the interoperability of the public and private HIS [168]. The actual development of standards will be an ongoing process. Since data interchange standards alone are insufficient for a national-scale information infrastructure [189], the CSIR [57] makes the following recommendations: (1) the localisation of the document content standards , (2) make the HNSF applicable to facility-based EMR systems, (3) the establishment of a data dictionary for eHealth in South Africa, (4) set up a mechanism to conduct interoperability conformance testing of vendor/supplier products and existing HIS against the HNSF [57].

5.6 Summary

In this chapter, South Africa was studied using the analysis framework defined in the methodology section. South Africa's NHIS has historically been implemented in an uncoordinated manner, leaving the NHIS fragmented and unsustainable. South Africa first introduced aggregated-data public health surveillance systems (most notably the DHIS), vital registration systems and management systems (PAAB). They then started introducing EMR systems at provincial level, but like other HIS across the country, these systems are heterogeneous in nature, and generally not interoperable.

CHAPTER 6: Case Study – Rwanda

Rwanda is a low-income, small, landlocked East African country with few natural resources and the highest density of people in mainland Africa.

6.1 The Organisation and Governance of the Health Sector

Rwanda has a population health profile that includes communicable diseases – notably acute respiratory infections and tuberculosis, a generalized HIV/AIDS epidemic and periodic outbreaks of malaria, cholera, meningitis, measles and bacillary dysentery [190]. 75% of the population lives within 5 km of a health facility. However, 87% of Rwanda's 11.78 million people live in rural areas [94, 191]. Mainly due to their extreme poverty and sheer difficulty in reaching care centres, less than a third of citizens requiring treatment are able to see a healthcare professional [94, 192]. Still developing its health care infrastructure, access to health is further threatened by the shortage of experienced healthcare professionals, poor facility infrastructure and inefficiencies of the healthcare system [193]. Since Primary Health Centres (PHC) only address basic health problems and Secondary Health Care Centres (SHC) only certain diseases [194], patients must generally access care from different health care centres for a full range of care [195].

The Ministry of Health (MOH) is responsible for supervising healthcare delivery - whether public, private or not-for-profit [190, 193]; and through its programs and institutions, guides and oversees technical, and policy and standards decisions throughout the health sector [196]. With the goal of providing universal health care [193], the MOH has the following priorities [196]:

- Achieve millennium development goals 1 (nutrition), 4 (child mortality), 5 (maternal health) and 6 (disease control) by 2015.
- Improve accessibility to health services, quality of service provision, and quantity and quality of human resources for health
- Reinforce institutional strengthening

Rwanda is divided into 4 provinces, which are subdivided into districts (the basic politico-administrative unit), then into sectors, and again into units and finally into villages [190].

Rwanda's health sector is decentralized and operates within a 3-tier pyramid of responsibility [190]:

- The central level, comprising the central departments of the Ministry of Health and national reference hospitals, have overall responsibility for the health system at national level, including health policies, strategic planning, high-level technical supervision, and resource coordination.
- The intermediate level, comprising the administrative district health departments, is responsible for developing and providing administrative, logistical, technical and political supervision to the operational level.
- The operational level, comprising the district hospitals, health centres, dispensaries and health posts, have a limited role in deciding how health finances are allocated, but their allocated funds go directly to them [193].

Community health workers, elected by their community, deliver basic health care and promote lifestyles [197]. They also need to provide monthly health indicator and service delivery reports to district-level using a CHW web-based HIS hosted on the national PBF server [197]. Traditional healers and faith-based organisations are recognised and being incorporated in the health policies and strategies [190, 197]. The health sector is also supported by other government ministries, non-governmental organizations (NGO), professional associations, and regulatory bodies [196].

The government has implemented a "top-down and bottom-up" planning, budgeting and monitoring process [196]. Performance standards for the district are set from the top, delinking the accountability of district officials to their citizens; so, while having some degree of autonomy, districts are weak in comparison to central government [198]. Within the district, however, the community participates in joint planning, execution and monitoring of primary health care [193].

Development partners, including international organisations, are included in local and national planning and implementation [197]. Although all activities are controlled centrally, through the health hierarchy, decentralisation has allowed partners to interact directly with local authorities, eliciting their requirements and spreading ideas and good practice [197]. More than half of the health budget comes from external sources and about a third private health schemes, with the

governments contribution including loans and grants [197]. Instead of the vertical and disease-specific funding mechanisms characteristic of SSAC, pooled funds finance the integration of primary health care services [193], minimising overlap and duplication, and ensuring support for rural areas as well [197]. However, while some donor partners are fully aligned to the sector structures, others still maintain parallel vertical systems for budget execution and accounting [196]. Despite its heavy dependence on aid being a risk to sustained progress, the effective use of resources has had a widespread benefit to Rwanda's health sector [197]. The poorly organised private sector, with a greater presence in urban areas, is inadequately regulated by- or aligned with the public health sector [190, 197, 199, 200].

The MOH's creation of the Rwanda Biomedical Centre (RBC) and the closely linked reorganization of the pharmaceutical supply and management system will fundamentally change the landscape of Rwanda's health sector [198, 201]. The RBC is a central autonomous body, with the responsibility for drug procurement and supply chain management for the public sector [201]. It is responsible for addressing issues of quality, cost and sustainability of health care services, through innovation and development of evidence-based practices [201].

6.2 The Organisation and Governance of the NHIS

Rwanda's eHealth industry is growing. Stakeholders, including the government, non-government, and private sector partners are jointly developing and implementing Rwanda's eHealth strategy [202]. High-level management and governance is centralised at national level under the leadership of the Ministry of Health (MOH), with support from the Ministry of Science, Technology, and Scientific Research, and the Rwanda Information Technology Authority (RITA); but local authorities have autonomy over their local systems [203]. The RITA is responsible for facilitating the private sector in the development of ICT in Rwanda [112, 202]. The government facilitates fundraising, and the design and implementation of all major systems [202]. As a result, Rwanda was nominated as the eHealth centre of excellence for the East Africa community, and was the beneficiary of a 5 year grant from the USA government to continue building national eHealth systems for HIV/AIDS [186]. The government and its partners, control the incentives for eHealth innovation and implementation, and have hence been the main driver of health ICT [202].

A single government sponsored entity (the eHealth Steering Committee) has been tasked with standards and policy, regulation and enforcement of eHealth in Rwanda [195, 203]. The eHealth Department, comprising of a skilled team of people, spearheads the planning and implementation of eHealth initiatives [112, 195, 202]. However, collaboration is encouraged on a national scale, at all levels of the NHIS. Discussions and plans for NHIS implementation are developed through collaborations between government, academic institutions and NGO [202] e.g. the Rwanda Health Enterprise Architecture (RHEA) and Rwanda Health Information Exchange projects.

6.1.1 Policies

Rwanda has a progressive and expansive eHealth policy. 2008 introduced a National Policy for Quality Health Care, which focuses on strengthening the supervisory system at facility and community levels [197]. The Health Sector Data Sharing Policy is aimed at enhancing access to quality data [204].

Decision-making power in Rwanda is highly centralized [198]. Health facilities belonging to the government cannot procure any HIS without authorisation from the central level [205].

According to [198],

> *"there is a tendency at all levels for government to sidestep effective participation by giving citizens and their organizations a minimal role in the policy-making and planning processes. Although some policy and programmatic decisions are appropriately made by the central government structures (e.g., national health priorities, regulation, and technical standards), the system runs the risk of missing feedback on health needs and on uptake of health programs from the district and its citizens."*

However, in contradiction, [197] claims that

> *"supported by development partners, the MOH has developed and applied a regulatory framework at all levels to ensure that rules and regulations are followed and objectives are accomplished. The system in place to operationalise accountability ensures that there is constant feedback from the bottom to the central level and vice versa. To formulate policies that match the needs of the population, Rwandan policymakers apply a participatory approach, involving communities in identifying their own problems. Policies and strategies implemented in Rwanda often start as pilot initiatives, usually under NGO supervision. If they show results, the government scales*

them up at national level. For instance, good results from pilots spurred rollout of the Mutuelle and Performance-Based Financing, tailored to the national context. Effective governance, strong accountability mechanisms and zero tolerance of corruption are essential to the successful implementation of strategies and policies. "

6.1.2 Standards

A standardized data quality assessment methodology at national and district levels has addressed issues of data quality [204]. Rwanda promotes the adoption of international standards to enable interoperability between systems in its NHIS without significant re-engineering of existing systems [195].

6.3 The Key Information Systems within the NHIS

Rwanda has made significant progress in developing its NHIS [203]. In terms of the five stages of HIS maturity identified in [113], the various regions or districts in Rwanda are generally at Stages 1, 2 and 3; with evidence of a move towards stage 4 in the Rwamagana district [203]. The following sections briefly describe the country's public and private sector systems as they relate to the development of the NHIS.

6.1.3 Population-based HIS

Rwanda has made Health information is publicly accessible [193]. This has enabled the prioritization of evidence-based policies and strategies [193] for more effective decision-making across the health sector [193]. Monitoring and evaluation systems are key enablers of this strategy. The information reported on, however, is scattered in many databases [202]. The HSSP III document [196] outlines Rwanda's health sector performance indicators and the sources of data for the monitoring and evaluation of the sector. The various data are entered separately in siloed systems [202]: nurses fill out different, mutually exclusive forms [202], community health workers fill out daily paper-based reports, and community supervisors enter the data from the paper-based reports into the Community Health Information System (SISCom), where it is aggregated at the health centre, district, and national levels [94].

The Rwanda Health Management Information System (R-HMIS), based on DHIS-2, provides access to information consolidated from over 700 different public health facilities [206]. Nearly 70 private clinics and dispensaries have also started to share their information through the R-HMIS [206]. An indicator for Mutuelle has now been built into the system and SISCom is in transition to be included in the R-HMIS platform [201]. SISCom is a text message system that allows maternal health workers to send patient records via text messages and identification numbers of pregnant mothers as well as any incidents during the pregnancy to the district hospitals [201].

Mutuelle is the national public health insurance scheme, subscriptions to which are subsidized by the government in accordance with the Ubudehe categorisation [201]. The Ubudehe classification of citizens into socio-economic categories is a key tool for the implementation of social protection programs and the targeting of beneficiaries [207]. A common national Ubudehe database is used to stratify the contribution of the population to Mutuelle according to their capacity to pay [207].The Ubudehe categorization database can be used in villages without internet or computers [201].

The web-based District Health System Strengthening Tool (DHSST), managed by the Decentralization & Integration unit of the MOH, consolidates data from a various sources to cater for the evidence-based performance evaluation for health facilities [208] [196]. A national data warehouse and dashboard portal consolidates data from the HMIS, SISCom, Demographic and Health Survey, and other sources, to provide indicator data [196, 209]. It is managed by the HMIS Department, which controls the access to data across all HIS based on a Data Sharing and Confidentiality Policy [196].

TRACnet, managed by the central government, enables clinics to report aggregated HIV data [202]. It uses fast and cost effective interactive voice response technology to gather information through the web and mobile phones [201]. The data is then recorded and reported by CHWs, and later aggregated and analysed on a national level [201]. The ability to send data through SMS is significant as many centres do not have internet connections or electricity; especially as it allows critical tests to be sent to and analysed by the national laboratory [201]. TRACplus adds TB and malaria indicators as well [201].

The MOH, together with NGO, with financial and strategic support from the government, developed a cloud-based medical supplies distribution system and has plans to monitor its blood bank online [202, 210].. The Logistics Management Information System (LMIS), together with Electronic Medical Records System (e-MRS), is used to maintain and control adequate drug stocks [201]. Other primary routine data collection systems include the HRIS (Human Resource Information System), and the Resource Tracking Tool (RTT) which provides data related to financial resources committed to and disbursed to districts by donors and the government [196]. Telemedicine is also currently used to connect three major hospitals in Rwanda [201].

6.1.4 Patient-based HIS

There is no standard format for medical records across hospitals, though [194] Rwanda has endorsed a rollout of OpenMRS, effectively standardising on the OpenMRS patient management system as the application to support the patient care needs of primary health sites [112]. OpenClinic GA, an integrated hospital information management system, that provides support for EHR, and administration has also been implemented in Rwanda [211]. To date EMR systems have mainly been used to manage HIV patients under chronic care with anti-retroviral treatments [202]. Facility-level information management, which, at this stage, mainly includes a basic link to the DHIS to generate report indicators, is being enhanced to service facilities better [94]. RapidSMS is an SMS-based alert system used by Community health workers to track pregnant women, and improve communication with other health and district level facilities [201, 212].

6.1.5 Health Information Exchange

Interoperability between the various heterogeneous HIS in Rwanda is limited [202]. The MOH and its partners developed a pilot health information exchange (HIE), through which existing point of care systems interoperate, to share patient demographic and clinical information between different health facilities in the Rwamagana district [182].

6.1.6 Private Sector Systems

There is no policy governing the procurement of HIS in private facilities. These facilities are, however, expected by law to send certain data in specific formats to the ministry [205].

6.4 Challenges with Developing the NHIS

Developing an NHIS in such a complex and harsh environment is constrained by the costs and risks involved [213]. The sheer remoteness of facilities, lack of electricity, and significant staff turnover in remote areas are major hurdles [190, 193, 201].

The structural and functional weakness of the HIS [190, 193] is due in large part to (1) too many eHealth interventions being implemented [201] and (2) different software platforms established with partners support [204]. Many government systems work independently of one another, which creates duplication and inefficient resource management [213]. There is thus a need to harmonize the systems in order to avoid duplication and additional costs and to strengthen the capacity to support the roll-out of the eHealth system in order to make it sustainable [196, 201, 204, 214].

Rwanda does not have an affordable national data centre [204] and in comparison to other SSAC, has fewer users of technology [202]. The insufficient technical capacities of health facilities is due the limited access and high costs of energy, ICT and skills, and insufficient international bandwidth [213]. The need for further investments has unfortunately also delayed the establishment of a nationwide fibre-optic network in Rwanda, which will pave way to more web-based applications that will in turn enable fast and effective data exchange in Rwanda [201].

6.5 The Evolution of the NHIS

This section describes Rwanda's approach to building its NHIS in terms of Coiera's topology of approaches, by understanding (1) how the NHIS evolved to its current state and (2) the possible future of the NHIS.

6.1.7 The Past

From the 1960s, health care was provided for free in Rwanda, with public subsidies through infrastructure, equipment, personnel, drugs and other supplies [215]. The economic problems of the 1980s and 1990s led to a dilapidated system, with poor quality of care [215]. So in 1992,

the government introduced community participation to ease the financing and management of health care [215]. Between 1994 and 1999 assistance with emergency humanitarian situations and rehabilitation where channelled mainly through non-governmental organizations from the donor countries [190]. Since 1999, when Rwanda began to stabilise politically and economically, donor assistance is channelled directly through the government [190]. Post 2006 of the number of donors increased [190]. In an effort to control how the donor funds was being spent, the government began, in a top-down manner to channel all eHealth investment through the MOH. The government is considered as one of the most "effective" in sub-Saharan Africa, with Rwanda ranking on "Control of Corruption" behind only Botswana and South Africa [202].

To bring first-line medical care closer to every Rwandan, in 2005 the Ministry of Health initiated an ambitious plan to train three individuals as CHWs in each of the country's 15,000 villages [94]. Though CHWs generally have little formal education, through training and support from facility-based supervisors, Rwanda's voluntary workers provide an effective first line of health care and referral [94]. As Rwanda's CHW program matured, demand for quality facility-based services grew, but many could not afford it [94]. In 2006, Rwanda decentralized its health sector, granting managerial autonomy to facilities [208], and launched a national community-based health insurance (CBHI) scheme [94].

The decentralisation increased the demand for quality data at the facility level [208]. To monitor the performance of community healthcare and reduce the high turnover of CHWs, the MOH developed the community HIS (SISCom), and a community performance-based financing (PBF) systems [94]. However, a great portion of Rwanda's information systems were developed, from the bottom-up, by NGO from donor countries, developing systems for their specific vertical programmes. The health ministry had multiple systems to gather data from the country's health services, but the systems used to aggregate and analyse the information were weak and not interoperable [94]. Each month, to aggregate data, each of the country's 450 health centres entered their information in local databases and sent a flash drive to one of the 40 district hospitals, which consolidated and sent district data to the central level on a flash drive [94]. Multiple systems existed to gather data on the country's 45,000 community health workers, HIV services, human resources, and other special programs—but these systems could not interact[94]. Despite spending considerable time and money in collecting immense amounts

of data, the MOH was unable to effectively use that information for strategic planning or immediate action [94].

The eHealth initiatives to strengthen and coordinate its NHIS in large measure began in 2007 [94]. The Rwandan government took a top-down approach in developing a full Health Management Information System (HMIS) to address the lack of interoperability between various existing systems [202]. In recent years the reporting indicators were simplified and standardized, and the R-HMIS, in 2012, replaced the HMIS [94]. The R-HMIS allows health centres at all levels to enter interact directly with the national database to capture data and use data [94]. They also moved all of the performance-based financing databases and the national disease surveillance and response system to the DHIS-2 platform [94]. The Rwandan Data Warehouse now also provides the ministry with a clear overview of the health care situation [94]. According to the [94], the Rwandan health system "has the information it needs to adapt and quickly react to changes or stressors in its environment".

The eHealth Steering Committee has more recently become responsible for regulation and enforcement of standards and policy, to accelerate and coordinate the development and implementation of NHIS projects and programmes for the country. Rwanda has also involved the key health stakeholders in the development of its eHealth strategies.

6.1.1 The National eHealth Strategy

Rwanda has developed a National eHealth Strategic Plan, which aims to

> "*provide and maintain highly effective, reliable, secure, and innovative information systems to support clinical decision making, patient management, education and research functions of the health sector in Rwanda in a bid to improve healthcare service delivery*",

with the common goal of having

> *"an integrated, interoperable eHealth system that spans and supports the entire continuum of care across all of the many settings and locations where healthcare is provided and accessed"* [195].

The national eHealth coordination unit is strengthening the NHIS with the phased implementation of independent projects [112, 182, 202] such as the Rwanda Health Enterprise Architecture (RHEA) project, which developed an enterprise architecture specification that includes the following components [112]:

- The National Registry Service caters for access to the common resources.
- The Client Registry caters for the management of identity and demographic information for persons who receive healthcare services within Rwanda.
- The Facility Registry caters for the management of identity and related information (e.g. location, capabilities, etc.) of the health care facilities. This registry serves 2 purposes. The first is to identify the various significant locations, e.g., health care provider, warehouse, village, and to provide geographic coordinates so that spatial relationships can be managed. The second is to identify regions, and to locate places within regions to support creation of maps and to allow summary reporting based on geographic entities.
- The Provider/Practitioner Registry caters for the management of identity and related information of health care providers (practitioners), including their specialties and associated capabilities and facilities.
- A Data Extraction Layer on the National Data Warehouse makes available information through reporting and ad hoc queries.
- The Shared Health Record caters for the management of clinical data that has been recorded for patients within the health care system.
- The Terminology Server caters for the management of different code systems and value sets (vocabulary) that are needed to support processing by the HIS components.
- The RapidSMS application provides a single point of contact for receiving care and managing information that is provided by community health workers. Communication between the individual community health worker and the RapidSMS system takes place via cell phone.
- A hybrid HIE, with nationally-standardised interfaces, facilitates interoperability between its existing and future heterogeneous HIS, allowing its NHIS to evolve incrementally [203].

The architecture developed by the RHEA project [203] may be seen as the eHealth Strategy Framework. The rules governing the integration with the HIE could effectively become Rwanda's Integration Framework.

6.1.8 The Future

A strong NHIS could reduce the paperwork burdening health workers and allow the government to more effectively evaluate health service performance, to identify health service challenges, and to improve quality of service across the health sector [202]. The government continues to provide strong leadership in developing the NHIS which will [195]:

- support country-wide access to health insurance information
- enable the delivery of medication and other health supplies through the national drug procurement and tracking information system
- share human resource information through the Human Resource Management Information System

Ideally, government would like existing and future systems to be interoperable with the R-HMIS [202]. The HIE will facilitate information sharing between the connected systems [182], especially of continuity of care records that will enable access to a patient's clinical information from different health facilities and levels in the health system [182]. A National HIE will enable interoperability between the systems making up the NHIS by encouraging compliance to its goals and frameworks – but not mandating this compliance, yet. The intention is to develop the NHIS in an incremental manner, giving provincial and district authorities complete autonomy over their HIS.

6.6 Summary

In this chapter, Rwanda was studied using the analysis framework defined in the methodology section. Rwanda's NHIS has historically been implemented through isolated projects, leaving the NHIS fragmented and unsustainable. Its NHIS now comprises aggregated-data and patient-based HIS which are heterogeneous in nature, and generally not interoperable. Despite the challenges, Rwanda still has some of the most advanced HIS in Africa.

CHAPTER 7: RESULTS AND DISCUSSION

The aim of this study was to develop and apply a framework for (1) characterising the high level approach taken by an SSAC in developing its NHIS, (2) determining whether an SSAC is taking an approach from Coiera's topology, and (3) assessing the consequences of an SSAC taking an approach from Coiera's topology.. The framework, based on the analysis of Coiera's topology, comprises three perspectives viz. technical architecture, organisation and implementation strategy. The framework was validated by applying it in case studies of national health information systems development in South Africa and Rwanda. The results of the case studies were compared and analysed, with the aim of identifying their key similarities and differences that could affect the selection of an approach for building NHIS. A formalisation of the evolution of NHIS in these countries emerged from this analysis. It highlighted specifically the influence of the health systems requirements for public health information and patient-based records on the development of its NHIS. By applying the framework, it was possible to then also assess how each approach in Coiera's topology supports the key considerations for building NHIS in SSAC. This chapter is a discussion of this analysis. It concludes by suggesting which approach shows signs of being the most sustainable for building NHIS in SSAC, highlighting the value of the framework developed for analysing the high-level approaches for developing NHIS in SSAC.

7.1 A Technical Architecture Perspective

The technical architecture perspective, explained in more detail in section 3.6.1, deals with the location and movement of health-related electronic information across the health sector.

An analysis of the technical architectures and the history of HIS implementation in South Africa and Rwanda revealed the development of two key distinct types of HIS in SSAC: population-based and patient-based HIS. It also revealed the need to exchange information between the various heterogeneous HIS to effectively support health systems in SSAC. The analysis suggests that NHIS in SSAC generally evolve through three different stages of maturity, with each stage (a) addressing a different management requirement, (b) characterised by different types of systems, and (c) often demanding different strategic approaches. A description of these stages in the next section is followed by an evaluation of how each approach in Coiera's

topology supports the inherent characteristics of the technical architecture emerging in NHIS in SSAC.

7.1.1.1 Evolution of the NHIS in South Africa and Rwanda

A combination of planning and events have influenced SSAC evolution to their current state, for example: (1) the increased demand to manage data related diseases like HIV, and (2) plans to take advantage of opportunities that could be gained from the very rapid improvement in information and communication technology, and the adoption of health information standards. An analysis of the evolution of the NHIS in South Africa and Rwanda provides valuable insights on a tried and tested transition path from which lessons can be learnt for other SSAC that are developing NHIS.

Stage 1 – Population-based HIS

Both South Africa and Rwanda initially embarked on population-based HIS aimed at supporting public health management and policy-making. These systems include birth and death registration systems, disease surveillance systems (including aggregated indicators), health management information systems (monitoring for example bed counts in hospitals), and logistics systems.

The case studies reveal that both Rwanda and South Africa first deployed national birth and death registration systems as part of their civil registration systems. The threat of diseases such as TB and HIV on public health in South Africa and Rwanda then led to the implementation of disease surveillance systems. Rwanda implemented TRACnet for HIV reporting, and South Africa implemented its National Electronic TB Register.

Both countries also implemented health management information systems. Rwanda implemented its HMIS and South Africa its provincial district HIS, both based on the DHIS software. The 'official' national public HIS are usually initiated by the government, with implementing partners from the private sector. Systems, such as those based on DHIS and the national data warehouses in South Africa and Rwanda, were implemented to support planning and policy-making across the health sector by reporting on essential country wide health indicators. Patient-based records still largely remain paper-based. To minimise the burden of routine data collection, the national minimum core indicators in Rwanda and South Africa

exclude some determinants of health private sector indicators. Starting with only the essential indicators on national and district data repositories, helped to improve quality of data collection and use. Aggregated data is manually captured at facilities and sent via districts to national levels where they are imported into systems that use them to produce the country wide indicators.

As its medical supply-chains grew in complexity, logistics systems become essential to effectively manage health logistics. The Logistics Management Information System (LMIS) in Rwanda controls drug stocks. Similarly, in SA, various different supply chain management systems such as excel, Pastel or SAP were implemented at district level and LOGIS was implemented for use by the provincial and national levels.

Rwanda and South Africa both show that population-based HIS are typically the first sub-systems of NHIS implemented in SSAC. The study characterised this phase as Stage 1 in the evolution of NHIS in SSAC. A typical stage 1 NHIS will include birth and death registration systems, disease surveillance systems, health management information systems, and logistics systems.

Stage 2 –Patient-Based HIS

In both South Africa and Rwanda, the next phase includes the proliferation of public, private and donor sponsored patient-based HIS aimed at using information at the point of collection to directly support health care delivery. Patient-based HIS provide access to historic episodes of medical care with the primary purpose of managing patients, with for example HIV, who are managed over a long period of time. Patient-based HIS are also used for sharing patient information between healthcare providers, research, legal and quality-assurance activities, and management of healthcare facilities and services.

Both South Africa and Rwanda have implemented a variety of different patient-based HIS to support local authorities, the private sector, donors and NGO's for their specific programs. Rwanda has implemented systems based on OpenMRS. In South Africa provincial authorities have implemented various different types of patient administration systems including the Western Cape's Primary Health Care Information System and Primary Health Care Management Information System. In both countries the private sector have also implemented a variety of proprietary patient-based HIS mainly for billing and administration, used in

conjunction with paper-based medical records. Due to resource constraints, though, only less than half of the public facilities in South Africa and Rwanda are able to implement these patient-based HIS.

There is also little or no interoperability across facilities between the patient-based HIS, as they each maintain their EMR in their own formats, usually specific to a disease or health service. There is, however, some aggregated data export from the patient-based HIS for import into the aggregated-data systems. Patient-based HIS such as OpenMRS in Rwanda and Meditech in South Africa allow for some aggregated data to be exported. This data is then sent from facilities to district and national levels, where it is imported into the aggregated-data systems described in stage 1. Both South Africa and Rwanda have, for example, national data warehouses that are fed from various information systems. Rwanda's data warehouse forms part of its HMIS.

Rwanda and South Africa both show that patient-based HIS are typically the second sub-systems of NHIS implemented in SSAC. This study characterised this phase as Stage 2 in the evolution of NHIS in SSAC.

Stage 3 – Interoperable Systems

South Africa and Rwanda are currently taking steps to improve the interoperability between the heterogeneous systems in stage 2, driven by the need for (1) more optimal use of resources allocated to the development of sub-systems of the NHIS (2) greater data usage, especially local authorities' use of patient-based records, (3) greater access to patient records, especially across facilities, and (4) improved quality of data. Both countries are currently working on national eHealth strategies, and adopting policies and standards to improve interoperability between the sub-systems of their NHIS. They are also in the process of designing and developing foundational health information exchange architectures to facilitate the exchange of patient-based records across patient-based HIS, with automatic feeds into population-based HIS.

Despite having greater resource constraints, Rwanda has made more progress towards interoperability within its NHIS than South Africa. Rwanda is working with its donor, NGO and private sector partners to improve the interoperability between the existing as well as new systems within its NHIS. The Rwanda Health Information Exchange is being piloted to improve interoperability between maternal and child HIS in a single district, with plans for other domains and districts. In the maternal health sector in South Africa the MomConnect health

information exchange has been implemented nationwide. To improve the interoperability between the some of its HIV systems within their NHIS, South Africa implemented TIER.Net, a system that caters for the export of HIV data from patient-based HIS to support eKapa, the national HIV/AIDS HIS, and iteratively enable further interoperability between these systems.

South Africa and Rwanda have both also developed national eHealth strategies and promoted the adoption of many international standards such as HL7 for their NHIS. South Africa has also defined the Health Normative Standards Framework, which provides guidance in navigating through the multitude of eHealth standards, and assists in assessing the applicability of international eHealth standards to HIS deployed in South Africa. Future system interoperability in both countries is planned to be achieved through local collaboration facilitated by the national authority, in a phased manner.

Rwanda and South Africa both show that HIE architectures typically follow the implementation of patient-based HIS in SSAC. The study characterised this phase as Stage 3 in the evolution of NHIS in SSAC. A typical stage 3 NHIS will include technical architectures to share patient-based records, and supporting policies and standards.

7.1.1.2 Dealing with an Evolving and Heterogeneous NHIS

In stage 1 of the evolution of NHIS in SSAC, development of the aggregated-data systems are driven by requirements for less detail by users higher up the organisational hierarchy. Their requirements can typically be achieved with integrated systems such as the HMIS in Rwanda, exhibiting characteristics of the centralised technical architecture described in 3.6.1, or homogeneous HIS such as the provincial DHIS in SA, as the data being captured is usually (in most cases, de-identified) aggregated data, standardised across the country. A top-down approach can generally support the development of these aggregated-data systems.

In stage 2, South Africa's implementation of patient-based HIS and Rwanda's donor system implementations shows local authorities and organisations driving the development of the patient-based systems. Managing the various types of data (e.g. across disease types and health services), with varying levels of granularity, with homogeneous HIS is extremely difficult. Hence the proliferation of various heterogeneous patient-based HIS by local authorities and organisations. A key characteristic of a top-down approach is its centrally architected and

standardised systems. Taking a top-down approach can limit the incidence of heterogeneous systems, conflicting with the manner in which patient-based HIS are usually implemented in typical SSAC. A bottom-up approach, void of any rules governing the implementation of systems and any requirements for systems to be homogeneous, can support the heterogeneous patient-based systems implemented in typical SSAC. Preserving such systems that are already entrenched and adding value in existing processes, automatically gets the buy-in of "owners and supporters" of these systems, who already understand their value proposition.

The model of the evolution of NHIS in South Africa and Rwanda highlights an increase in granularity of the data in focus from stage 1 (mostly population-based aggregated data) to stage 2 (granular patient-based records). Left uncontrolled, the 'unofficial' patient-based HIS can divert resources from coherent plans for the NHIS aimed at making more optimal use of scarce resources for the greater good of the health system as a whole. They also often create confusion with inconsistent data. Storing data in different locations, in different formats and in different datasets adds complexity to the processes providing the single view of the health status of the country sought in stage 1. Also, any interoperability between the patient-based HIS in stage 2 is implemented by donors and local authorities, exhibiting characteristics of the de-centralised technical architecture described in 3.6.1. Allowing this ad hoc implementation of proprietary interfaces, without national standards, can make the system even more complex with each integration project.

Many SSAC, including SA, Rwanda and Ghana, have now prioritised interoperability between components of their NHIS as a key element of future development. By stage 3, in both South Africa and Rwanda, the complexity of systems increases exponentially, as the focus moves to connecting the systems in a manner that caters for more effective use of the various types of available data for the benefit of both the individual patient and public health. Designs for introducing interoperability between the existing systems can get convoluted. Incompatible data models increases the complexity of interoperability and data reconciliation across HIS, making it difficult to align these systems with national priorities and goals. In addition, the geographical and administrative regions within SSAC may evolve at different rates depending on their access to resources. South Africa encountered such a problem with the implementation of its various provincial and donor-driven patient-based HIS. To prevent further fragmentation of its NHIS South Africa has placed a moratorium on the introduction of 'unofficial' new patient-based HIS. This type of moratoria has been implemented in other SSAC as well e.g. Uganda.

A health information exchange (HIE), one approach to interoperability, is an important technical infrastructure of an NHIS that facilitates the electronic exchange of health-related information among the organizations that need access to it. It is implemented to facilitate the exchange of health related data between HIS, including EMR and other systems dealing with patient-level data, according to recognized standards. Each approach in Coiera's topology is associated with a different technical architecture depending on their respective governance and operational models: (a) centralized in the top-down approach, (b) decentralized in the bottom-up approach, and (c) hybrid in a middle-out approach.

Specialised expertise, which is not easily available in SSAC, is required to manage the technical complexities of NHIS in stage 3. The implementation of the Rwanda HIE pilot required the expert assistance of foreign organisations and donors to enable interoperability between the patient-based HIS it connects. Even SA, one of the more technologically advanced countries in SSA, is currently struggling with the development of its NHIS.

Through common goals, standards and policies, the middle-out approach can cater for the existence and interoperability of heterogeneous systems with different transition strategies, addressing the varying ICT capability and maturity across the health sector in SSAC. Architectures such as the Rwandan HIE and South Africa's TIER.Net will facilitate interoperability between the new and existing heterogeneous systems of the NHIS. Preserving existing systems makes optimal use of resources allocated to the development of systems. Standards and policies allow for the re-use of data and systems which also improve resource usage. Being able to automatically share and exchange records reduces the duplication in capturing information allowing the saved resources to be used to capture other information which increases the access to information. Capturing more information of value to the local authorities can improve their usage of information. The automatic sharing and exchange of data can also reduce the errors associated with the capture and storage of the same data in multiple systems by multiple people, greatly improving quality of data.

The analysis of the evolution of NHIS in South Africa and Rwanda highlighted the heterogeneous nature of NHIS in SSAC. It confirmed the importance of improving interoperability between the sub-systems of these NHIS in order to effectively evolve into an

NHIS which serves the country equitably at all levels of the hierarchy through a well-functioning health information exchange.

From a technical perspective, Coiera's top-down approach will not inherently support the heterogeneous systems of NHIS in SSACS, and the bottom-up approach will not facilitate interoperability between these systems. The middle out approach will most likely enable interoperability between these heterogeneous systems.

7.2 An Organisational Perspective

The organisational perspective, explained in more detail in section 3.6.2, deals with the non-technical organisational structures that influence and control the NHIS, especially the role of government. Each approach in Coiera's topology is associated with a different organisational structure: (a) in the top-down approach leadership and governance is centralised at national level, with minimal local influence, (b) in the bottom-up approach local authorities have complete autonomy, and (c) in the middle-out approach centralised leadership and governance is coupled with local autonomy.

South Africa and Rwanda show that the health systems in SSAC comprise of a mix of public and private services. Furthermore, South Africa and Rwanda, like many SSAC, have decentralised their health systems. In South Africa provinces are run autonomously under the leadership of the MOH, while in Rwanda, complete control remains under the MOH. However, in Rwanda in particular, the local authorities have also in the past left donors of vertical programmes in control of various health data.

Transformational projects of the scope of an NHIS require holistic planning and design. The NHIS strategy must, therefore, be aligned with the agendas and concerns of all levels of the decentralised health sector. Effective collaboration and coordination will be needed for developing holistic solutions, negotiating interoperability, policies and standards, reducing duplication of effort, avoiding gaps in requirements and disparity in solutions, and enabling access to the skills and capabilities lacking in government. Each approach is analysed below for its ability to deal with the level of organisational complexity and local autonomy characteristic of NHIS development in SSAC.

7.2.1 Dealing with Organisational Complexity and Autonomy

The centralised management of the top-down approach attempts to control all aspects of the NHIS from the top of the health system hierarchy, leaving little room for influence from the local authority. Central control is useful when starting the architecting process for political and policy negotiations, but, localised decision-making is equally important to sustain the change process. Even in Rwanda where control is centralised under the MOH, the MOH is heavily influenced by donors and encourages high levels of local autonomy. Developing systems without the co-operation of donors and local authorities can lead to local disaffection. While the standardised systems and processes of a top-down approach seem to imply a reduction in complexity, in the top-down approach users are rarely able to effectively adopt systems implemented for them without their involvement.

While the health systems in many SSAC are decentralised, national public health issues are driving the demand for population-based HIS at national level. Unfortunately, however, their highly political environments make access to data a challenge. The bottom-up approach pays little attention to support relationships between the various systems that support the health system. Any relationship forged is voluntary and ad-hoc. Nation-wide change can be hampered by lengthy joint decision-making involving the autonomous local authorities. This could account for the lack of interoperability between the provincial EMR systems implemented in South Africa.

While the top-down and bottom up approaches fail to acknowledge the impact of influential actors and their relationships, the middle-out approach acknowledges and supports these relationships within the NHIS. In a middle-out approach, the government, with policies and incentives, is better able to create a collaborative environment where a network of communities, including donors and the private sector, behave in a manner that benefits public good and their own agendas. South Africa and Rwanda show that in an effort to curb the proliferation of disparate systems in stage 3, a government sponsored entity can assume control of the sector, and create various approaches to national coordination and interoperability to improve resource utilisation and the quality and use of information. South Africa has delegated the responsibility of developing its NHIS to the Technical Advisory Committee of the National Health Council, and Rwanda to its eHealth Steering Committee. Their national departments of health have been tasked with the responsibility of developing policy and regulation of eHealth. By government driving the development of the common infrastructure, it is also better able to protect privacy,

security and equality of access for all, enabling trust. A decentralized and federated technical architecture, governed by standards and policies, while allowing accurate and timely access to information, greatly reduces the risk of data misuse.

From an organizational perspective, the top-down approach will not generally cater for the requirements of the local authority. And, the bottom-up approach will not cater well for aggregating data across systems for public health reporting at national level. However, in the middle-out approach, central management facilitates coordination and collaboration across the health system in order to (1) cater for, and balance, the requirements of the local and national, and public and private users, and (2) enable private partners and donors to invest resources to develop the NHIS.

7.3 An Implementation Strategy Perspective

The implementation strategy perspective, explained in more detail in section 3.6.3, deals with the strategies for setting and enforcing the goals, standards and policies required for developing the NHIS. Each approach in Coiera's topology is associated with a different implementation strategy. In the bottom-up approach there is no overall, nationally driven, high-level strategy. In the top-down approach a detailed strategy, including architecture and project plans for national-scale rollouts, is drawn up by the national authority. In the middle-out approach the national authority develops common goals, policy and standards in collaboration with local authorities to incrementally evolve the NHIS, mainly through local projects encouraged and supported by the national authority.

Each approach is analysed below for its ability to sustain the development of an NHIS despite unstable, constrained resources, dynamism and the level of complexity characteristic of NHIS development in SSAC.

7.3.1 Dealing with Unstable Funding and Resource Constraints

Governments in SSAC do not generally have the funds or technical expertise to drive the development of an NHIS without external assistance, hence their high dependence on donor sponsored foreign experts as seen in Rwanda. Maximising and building capacity is critical in developing NHIS in SSAC.

While a top-down approach seems to offer economies of scale, massive top-down projects are associated with greater upfront costs, time and skills for planning, implementation and maintenance in comparison to bottom-up projects. In contrast to the huge budget (almost US$20 billion) available in the UK for its NHIS implementation, South Africa's entire health sector received US$9 billion from the 2013 National Budget. A nationwide design and rollout of new systems, apart from being extremely expensive and wasteful, is a complex task. The limited IT infrastructure in SSAC does not support the development of a central technical architecture that can immediately offer national interoperability. The top-down approach with its high initial upfront investment and the promise of a long term, risky return on investment is often not a compelling motivation to leverage funding from an already constrained health budget in SSAC.

The bottom-up approach requires no upfront resource commitments and is, thus, more easily implementable in a resource-constrained environment. Retaining existing systems that satisfy local requirements, instead of procuring new systems that will also require additional staff training can be cost-effective. The NHIS may be developed incrementally, through the implementation of smaller projects as resources become available. The primary focus of the local authority remains on primary health, with a secondary focus on public health. Local systems can evolve independently, without central coordination. However, at national level, this approach leads to unpredictable costs and adhoc use of limited resources, which in the long term may have a negative overall impact in resource-constrained environments. For example, predicting the cost of interoperability between systems that were implemented independently, or how much information can feasibly be shared with other providers is an enormous task. In South Africa, prior to the development of the national eHealth strategy and the moratorium placed by the national authority on EMR acquisitions, limited resources were being spent on various standalone patient-based HIS. In Rwanda, which is heavily dependent on donor funding, predicting and justifying a return on donor investment can become a major hurdle. Furthermore, in an environment where public health issues add a huge burden on the health system, SSAC may be better served giving greater priority to national goals that make better use of existing capacity. South Africa having come to this realisation, placed a moratorium on the acquisition of EMR systems at provincial level.

In a middle-out approach both local and national stakeholders agree on common goals and standards. This allows both national strategic goals and local practical conditions to be

balanced. This helps to mitigate over-ambitious expectations by national stakeholders, a common problem with the top-down approach. The middle-out approach may bear similar costs to the bottom-up approach, but the common goals and central co-ordination offer enough predictability and potential optimisation in the use and acquisition of resources. This makes it easier to convince donors on the returns on their investments and enables SSAC, like Rwanda, to take advantage of economies of scale. In a top-down approach there is also a high risk of vendor lock-in. In a middle-out approach, competitive markets are encouraged. Rwanda's NHIS funding initiatives show that a competitive market can make available private sector resources to the national authority. South Africa's NHSF provides a basis for a policy and standards framework, to regulate competition.

7.3.2 Dealing with Dynamism

The nature of diseases and health sector operations is changing at a high rate. An NHIS must be agile enough to adapt to the changes in its environment.

The bottom-up approach, free of any central management, is adaptable to local requirements, since new technology and system design decisions are made locally. Local systems only need to take into account local conditions which eases the risk and cost of design and implementation. Moreover, systems can be changed more rapidly to deal with changes in conditions at local sites. This characteristic allows local authorities and donors to implement systems which may not have been possible if their implementation was controlled from national level. System requirements driven from national level would be broader and complex in nature, in order to take into account the different conditions and requirements of multiple facilities across different regions. The focus on locally-driven requirements is probably the driving factor behind the implementation of effective systems like OpenMRS and DHIS in many facilities in SSAC. However, scaling to national level from the bottom-up is difficult, as local systems often do not cater for requirements outside of the environment in which they are deployed.

The large, long-term, top-down projects are able to execute nation-wide implementations. However, the high rate of change in the health system and unavailability of funding in the short term may make initial upfront designs obsolete. By the time the systems get to implementation stage, requirements for those systems, and health systems priorities may have changed and lead to a waste of scarce resources. Even small changes have a ripple effect across the health sector.

Transitioning from existing IT systems to new ones, as well as upgrades to the new systems, is especially challenging. The dependence on costly outsourced resources at the central level to implement changes, makes system updates in a top-down approach more costly than a bottom-up approach and also hampers innovation and agility.

The middle-out approach enables innovative local change from the bottom up, and caters for nation-wide change through its centralised leadership. This makes the middle-out approach less dynamic than the bottom-up, but enables it to support nation-wide change that is not supported by a bottom-up approach. Innovation increases as a result of the variety of ideas surfacing through collaboration within the NHIS. Central leadership can align the various initiatives started at different times in different places for the progression of the NHIS as a whole. Standards and policy frameworks, such as the NHSF in SA, allow for systems to evolve independently to attain national standards, giving priority to local use over national interoperability, without unnecessarily increasing the overall complexity of the NHIS.

7.3.3 Dealing with System Complexity

SSAC need help with developing their eHealth strategies. Many do not have a systematic, high-level, national approach to design an NHIS. Complex systems theory and documented field experience suggests that NHIS in SSAC need evolutionary development strategies. An evolutionary approach enables large, complex problems to be solved in more predictable, incremental iterations.

The evolutionary management style of the middle-out approach allows for patterns of problematic behaviour to be observed, and possible solutions to such problems to be tested, iteratively, over time. The feedback loop, which is a key component of an evolutionary development strategy, is lengthy in a top-down approach and may be biased in only supporting feedback from the national authority. No structure exists to facilitate this feedback loop in a bottom-up approach, hence the implementation of various disparate patient-based HIS by various local authorities in South Africa.

In a middle-out approach, policies, goals and standards are not all developed up-front. They are refined over time through collaborations with experts across the health system to meet current requirements, and to accommodate health and technology changes, guiding the incremental

convergence of local systems into an evolving NHIS. Also unlike the top-down approach, the absence of solutions to complex problems, such as the development of systems for the limited infrastructure in SSAC, does not hinder the delivery of achievable solutions that are immediately useful. The NHIS becomes more useful over time and more reactive to change. By starting small, early successes can incrementally build confidence and buy-in from all stakeholders.

From an implementation strategy perspective, the middle-out approach is (1) more predicable than the bottom-up, but less predictable than the top-down, in terms of resource usage for planning, implementation and maintenance and the resulting architecture, and (2) associated with lower and more manageable costs than the top-down approach. The middle-out approach's evolutionary strategy enables (1) national change not catered for by the bottom-up, in a more sustainable manner than the top-down approach, (2) dynamic change at local level, unlike the top-down approach, and (3) better prioritisation of resource usage to cater for the needs of national-level and local authorities.

7.4 A middle-out approach for building NHIS in SSAC

The middle-out approach seems better able to address the key challenges with developing NHIS in SSAC. Comparing how well each approach supports the key considerations for building NHIS in South Africa and Rwanda, it was found that the middle-out approach combines the best attributes of the top-down and bottom up approaches. The population-based HIS generally require the predictability of a top-down approach. The productivity and economies of scale of a top-down approach are necessary in situations where timing is crucial to the success of implementing change, and the national health authority needs a greater guarantee that specific instructions will be executed. On the other hand, the health care delivery information systems benefit from the flexibility and support for local autonomy of a bottom-up approach. Furthermore, SSAC with stage 3 NHIS are already characterised by centralised organisation, high-level of local autonomy, some centralised and some non-standard de-centralised systems. They may be able to migrate to a middle-out approach without completely overhauling their NHIS and thus reduce resistance from key stakeholders.

7.4.1 Implementing a middle-out approach in SSAC

Many HIC with mature NHIS are adopting a middle-out approach. However, their implementation of a middle-out approach will differ starkly to a SSAC implementation. Some considerations for adopting a middle-out approach in SSAC, especially in managing the risks associated with the unpredictable nature of a middle-out approach, are discussed below.

A clear, well-articulated strategic framework that builds on existing efforts and allows the goals, policies and standards to evolve over time, is an important starting point, as it will accelerate the development of the NHIS. Although a detailed strategic framework is impractical in the early stages, it may help guard against an unnecessary increase in complexity that results from dealing with heterogeneity, autonomy and dynamism. Initial high-level, long-term strategies will develop and evolve and increase in detail over time.

Strategic frameworks like the Health Metrics Network framework, ISO eHealth architecture maturity model and the WHO eHealth strategy toolkit can guide the common goals set for the NHIS as it evolves. They also provide a common collaboration point across to leverage resources available across the world. The system evolves to some level through trial and error through goal setting and feedback, so regular appraisal of the goals, standards and policies is necessary to keep the NHIS current and effective. [15] and [38], amongst others, have developed frameworks for evaluating the progress and effectiveness of an NHIS.

Instead of developing the NHIS from first principles alone, it is proposed that the NHIS be developed additionally through the adoption of specific methods and models from existing frameworks and implemented solutions, where they are found to be suitable in addressing the SSAC requirements. Strong leadership will be required to balance and co-ordinate the requirements from all levels of the health system. Since attainment of common goals must often be incentivised, novel approaches to encourage a convergence towards common goals will be required in the resource-constrained environment of SSAC.

7.5 Summary

In this chapter, the framework developed in the study was used to analyse how well Coiera's approaches for building NHIS support the key consideration for developing NHIS in SSAC. Results were drawn from an analysis of the case studies, and substantiated by the literature

review. Even though South Africa and Rwanda are in stage 3 of the evolution of NHIS development in SSAC, and already developing health information exchanges, the analysis is not dependent on the existence of an exchange in these countries. Furthermore, since the analysis was based on the key challenges faced by South Africa and Rwanda, the findings of the study have relevance to other SSAC that share similar challenges.

From a technical perspective, it was found that the top-down approach would not inherently support the heterogeneous systems of SSAC, and the bottom-up approach would not facilitate interoperability between these systems. The middle-out approach seemed most likely to enable interoperability between these systems.

From an organizational perspective, it was found that the top-down approach would not generally cater for the requirements of the local authority, and the bottom-up approach would not cater well for aggregating data across systems for public health reporting at national level. The middle-out approach seemed most likely to (1) cater for, and balance, the requirements of the local and national, and public and private users, and (2) enable private partners and donors to invest resources to develop the NHIS.

From an implementation strategy perspective, the middle-out approach seems more predicable than the bottom-up, but less predictable than the top-down, in terms of resource usage for planning, implementation and maintenance. It also appears to be associated with lower and more manageable costs than the top-down approach. Furthermore, its evolutionary strategy enables (1) national change not catered for by the bottom-up, in a more sustainable manner than the top-down approach, (2) dynamic change at local level, unlike the top-down approach, and (3) better prioritisation of resource usage to cater for the needs of national-level and local authorities.

The results show that both South Africa and Rwanda are migrating towards a middle-out approach. The middle out approach appears to be more effective in dealing with the key challenges faced by SSAC, than the top-down and bottom-up approaches. Fortunately, SSAC may be able to naturally migrate towards a middle-out approach when expanding their NHIS. A middle out approach can allow SSAC to improve the effectiveness and quality of information provided by their NHIS and optimise the use of limited resources available for NHIS

development. However, specific customisation for each SSAC, to account for individual conditions, is required for practical implementation of the middle-out.

The results of this analysis confirms the value of the framework developed for analysing the high-level approaches for developing national health information systems in SSAC.

CHAPTER 8: CONCLUSION

8.1 Summary of findings

An effective NHIS can help strengthen a weak and overburdened health system in a SSAC. SSAC are, however, complex environments for building NHIS, and hence, are currently characterized by disparate and fragmented HIS. In a recent analysis of mature NHIS in HIC, Coiera [4] highlighted the importance of the high-level approaches used for building NHIS, and gives compelling arguments for countries to take a middle-out approach. While the overall long terms benefits of taking a middle out approach in high income countries have been analysed and explored [22, 91], it is not apparent that this approach is also applicable for SSAC. However, given the substantial structural differences between NHIS in HIC and SSAC Coeira's approach cannot be directly applied to analyse NHIS in SSAC. Based on an analysis of Coiera's topology of approaches, a framework to perform such an analysis in sub-Saharan Africa, was developed, for (1) characterising the high level approach taken by an SSAC in developing its NHIS, (2) determining whether an SSAC is taking an approach from Coiera's topology, and (3) assessing the consequences of an SSAC taking an approach from Coiera's topology. The framework was validated by applying it inan in-depth analysis of NHIS development in South Africa and Rwanda, supported through interviews with experts in the HIS development in these countries.

Through the application of the framework, it was established that NHIS in SSAC generally evolve through 3 stages. The key considerations or development strategies necessary for building NHIS in SSAC were also elicited from an analysis of the cases and the literature, and were focused specifically on mitigating the key challenges highlighted by the study. Coiera's topology of approaches for building NHIS were then evaluated for their support of these key considerations. The scope of this evaluation spanned not only the development of national patient-based HIS – but also national aggregated-data systems. It was found that the top-down approach works well when applied to projects with a single, clearly-defined national purpose. The inefficient and often fragile bottom-up approach works well when no future-proof planning is required, but dynamic local change is important. However, the middle-out approach showed signs of being the most sustainable approach for building complex systems, like the NHIS, with rapidly changing national and local requirements that do not behave and evolve in a predictable way.

While lessons may be learnt from NHIS development in HIC, their approaches, in their entirety, may not be appropriate for SSAC, due to differences in the socio-political and economic landscapes. The timeline and path for building NHIS in SSAC may not be as direct as the path taken by well-financed HIC. It can be concluded that while a middle-out approach can contribute significantly to building effective NHIS in a sustainable manner, given the nature and evolution of NHIS in SSAC, its application in SSAC will be significantly different to its application in HIC. It is recommended that SSAC review their current approaches for building NHIS in terms of Coiera's topology of approaches and consider a move towards a middle-out approach.

Given the resource constraints in SSAC, it is unlikely that their NHIS will reach the technological sophistication and maturity of those in HIC. For example, in SSAC the minimum infrastructure may not include nationwide real-time access; as and where necessary, real-time access may be prioritised for monitoring public health risks. However, with a competitive market, SSAC have the opportunity to develop innovative and effective NHIS; for example, new, possibly simpler, more streamlined technical paradigms, such as systems supporting mobile technologies, which can then be fed back into the global networks, to benefit other countries, including HIC.

8.2 Limitations and Future Work

The problem addressed by the study is an on-going one. The health sector will change over time, and new challenges may appear in SSAC over and above those that were identified in the study. As such the main limitation of the study is that the predicted success of a middle-out approach has not been practically confirmed – neither in HIC nor SSAC. The results of the research were validated only analytically, with only a very limited number of interviews with experts in the field. The results should be validated by practical, field implementations. By observing formal implementations of a middle-out approach in SSAC, the limitations and shortcomings of this study may be highlighted, and further research can address the problem more completely. The time and resources available for this study did not make this feasible. Since the NHIS in SSAC are still far from mature, the case studies should be repeated periodically as the NHIS in SSAC develop. By studying the research questions over time, analysis can be based on a richer data set that more accurately represents the evolution of NHIS

in SSAC. Only multiple, successful national implementations of the middle-out approach in SSAC will eventually validate the results of this study.

The research is biased by the cases selected. For example, South Africa and Rwanda are both in stage 3 of NHIS evolution and both are developing health information exchanges, while most SSAC are still between stages 1 and 2. More cases should be studied in order to further extend the context and increase validity of findings to SSAC in general. The sampling strategy must give consideration to SSAC (1) at different stages in the evolution of NHIS in SSAC (described in 7.1.1.1) (2) in which innovative new NHIS solutions are tested, (3) that face unique challenges, and (4) that could possibly overturn current hypotheses. Also, while South Africa and Rwanda are low and middle income countries (LMIC), the results of the study may also apply to other LMIC. However, the study did not deal with the broader scope of LMIC. The methodology designed for this study may be extended in a further research initiative to increase the scope of its applicability to LMIC in general.

The study did not deal with any detailed analysis of NHIS such as its engineering, procurement, nor concrete technical architectures. For example, an analysis of the challenges with developing NHIS in SSACS, as well as a framework to address them is still to emerge. An evidence-base of the benefits of NHIS implementations must be developed to justify public expenditure. Given their predominance in SSAC, the influence of paper-based health information systems is also acknowledged by the study. While this was not explicitly excluded from the results, the focus of the study was on the development of electronic HIS.

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