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Analysing the National Notifiable Diseases Surveillance System in South Africa

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in fulfilment of the requirements for the degree of

Doctor of Philosophy

Johannesburg

15 June 2018

DECLARATION

I, Frew Gerald Benson, declare that this thesis is my original work. It is being submitted for the degree of Doctor of Philosophy at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University. I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong. I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.

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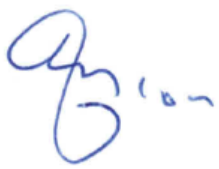
Signature: 

Frew Gerald Benson 15 June 2018

DEDICATION

In dedication to my wonderful wife

Josephine Henrietta Benson

For all your love and support over the last 36 years

PRESENTATIONS ARISING FROM THIS STUDY

1. **Benson FG**. Poster presentation: "Is the South African Notifiable Diseases Surveillance System effective in preventing outbreaks? Perceptions of key stakeholders" at 17th International Congress of Infectious Diseases 2- 5 April 2016, Hyderabad, India.

2. **Benson FG**. Oral presentation: Comparing laboratory surveillance with the notifiable diseases surveillance system in South Africa" International Meeting on Emerging Diseases, 2 -7 November 2016, Vienna, Austria.

PUBLICATIONS ARISING FROM THIS STUDY

1, **Benson FG**, Musekiwa A, Blumberg L, Rispel LC. Survey of the perceptions of key stakeholders on the attributes of the South African Notifiable Diseases Surveillance System. BMC Public Health. 2016;16(1):1120. doi: 10.1186/s12889-016-3781-7.

2. **Benson FG,** Musekiwa A, Blumberg L, Rispel LC. Comparing laboratory surveillance with the notifiable diseases surveillance system in South Africa. International Journal of Infectious Diseases. 2017;59:141-7. doi: 10.1016/j.ijid.2017.03.007.

3. **Benson FG**, Levin J, Rispel LC. Health Care Providers' compliance with the Notifiable Diseases Surveillance System in South Africa. *PLoS One* 2018, **13**(4):e0195194.

ABSTRACT

Background

Outbreaks of infectious diseases contribute to premature mortality and underscore the importance of effective disease surveillance and response systems. There is limited knowledge on the performance of the South African notifiable disease surveillance system (NDSS).

Objective

The aim of this PhD study was to analyse the NDSS of South Africa. The specific objectives were to: analyse key informants' perspectives on system attributes of the National NDSS; analyse the NDSS attributes through comparing notifications with laboratory surveillance; determine the factors influencing provider compliance with the NDSS; and make policy recommendations to improve the effectiveness of the NDSS.

Methods

This thesis combined a novel comparative analysis of laboratory and notification records for three tracer conditions of measles, meningococcal meningitis, and typhoid with two cross-sectional, analytical studies among NDSS key stakeholders (n=169) and health care providers (n=1050) respectively. STATA® 14 was used to conduct quantitative, statistical analyses.

Results

The key stakeholders' survey had an 84% response rate: 25% perceived the system to be acceptable; 51%, flexible; 45%, timely; 61%, useful; and 74%, simple. Stakeholders with more experience were less likely to perceive the NDSS as acceptable (OR 0.91, 95 % CI: 0.84–1.00, p = 0.041); those in disease detection were less likely to perceive it as timely (OR 0.10, 95 % CI: 0.01–0.96, p = 0.046) and those participating in National Outbreak Response Team were less likely to perceive it as useful (OR 0.38, 95 % CI: 0.16–0.93, p = 0.034).

For all three diseases, fewer cases were notified than laboratory confirmed. Completeness for the laboratory system was higher for measles (63% vs. 47%, p<0.001) and meningococcal meningitis (63% vs. 57%, p<0.001), but not for typhoid (60% vs. 63%, p=0.082). Stability was higher for the laboratory (all 100%) compared to notified measles (24%, p<0.001), meningococcal meningitis (74%, p<0.001), and typhoid (36%, p<0.001). Representativeness was also higher for the laboratory (all 100%) than for notified measles (67%, p=0.058), meningococcal meningitis (56%, p=0.023), and typhoid (44%, p=0.009). The sensitivity of the NDSS was 50%, 98%, and 93%, and the PPV was 20%, 57%, and 81% for measles, meningococcal meningitis, and typhoid, respectively.

The response rate for the health care provider (HCP) survey was 90%. In the year preceding the survey, 58% diagnosed a notifiable disease; 92% of these HCPs reported the disease, but only 51% notified correctly to the Department of Health. Factors influencing notification were HCPs perceptions of workload (OR 0.84, 95% CI 0.70 - 0.99, p=0.043) and that notification data are not useful (OR 0.84, 95% CI 0.71 - 0.99, p=0.040).

Conclusion

The NDSS in South Africa performed poorly on most of the system attributes. In addition, HCP compliance with the NDSS was suboptimal. The study generated new knowledge on the performance of the NDSS in South Africa, which should inform the revitalisation and reforms of the system.

Keywords

Notifiable diseases; surveillance system; acceptability; flexibility; simplicity; timeliness; usefulness; completeness; stability, representativeness, sensitivity; positive predictive value; health care providers; compliance and South Africa.

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NOMENCLATURE/LIST OF ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immuno Deficiency Syndrome
CDC	Centres for Disease Control and Prevention
CFR	Case Fatality Rate
CHCs	Community Health Centres
CI	Confidence Interval
DOH	Department of Health
EPI	Expanded Program on Immunisation
EVD	Ebola Virus Disease
GHSA	Global Health Security Agenda
GP	General Practitioner
HCP	Health Care Provider
HIC	High Income Country
HIV	Human Immuno-Deficiency Virus
HREC	Human Research Ethics Committee
IDSR	Integrated Disease Surveillance And Response
IHR	International Health Regulations
ILI	influenza-like illness
IPC	Infection Prevention and Control
IQR	Inter-quartile Range
JEE	Joint External Evaluation
LMIC	Low and Middle Income Countries
NaPHISA	National Public Health Institute for South Africa
NDOH	National Department of Health
NDSS	Notifiable Diseases Surveillance System
NGO	Non-Governmental Organisation
NHI	National Health Insurance
NHLS	National Health Laboratory Service
NICD	National Institute for Communicable Diseases
NMC	Notifiable Medical Condition

NORT	National Outbreak Response Team
OR	Odds Ratio
PHC	Primary Health Care
PhD	Doctor of Philosophy
PHEIC	Public Health Emergency of International Concern
PORT	Provincial Outbreak Response Team
SADC	Southern African Development Community
SARI	Severe Acute Respiratory Illness
SARS	Severe Acute Respiratory Syndrome
TB	Tuberculosis
UN	United Nations
UNMEER	United Nations Mission for Ebola Emergency Response
WHA	World Health Assembly
WHO-Afro	World Health Organization - African Region
WHO	World Health Organization

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CHAPTER 1. INTRODUCTION

1.1 Background

Communicable diseases constitute a major proportion of the global burden of disease; four of the top six causes of the global burden of disease in 2016 were caused by communicable diseases [1, 2]. In the last decade pandemics have underscored the need for strong global and national notifiable disease surveillance systems (NDSS) to ensure appropriate public health preparedness and response. Notable examples include: the influenza pandemic (H1N1) of 2009 which caused 18,449 known deaths in 214 countries and territories [3]; the 2012 outbreak of Middle East Respiratory Syndrome Coronavirus with 1,952 cases and 693 deaths confirmed up to 20 April 2017 [4]; the 2014 - 2016 Ebola Virus Disease (EVD) outbreak with 28,616 cases and 11,310 deaths [5]; the Zikavirus outbreak of 2016 with more than one million cases globally [6]; and the 2016 yellow fever outbreaks [7]. These epidemics caused public health emergencies of international concern (PHEICs) that could have been prevented through effective surveillance systems that enable early detection, management at source and prevention of their spread.

The World Health Organization (WHO) defines surveillance as "the continuous, systematic collection, analysis and interpretation of health-related data needed for the planning, implementation, and evaluation of public health practice" [WHO, 2017:webpage][8]. It is essential for any country to have a surveillance system to ensure its effective response to communicable diseases [9]. In the health system, surveillance of communicable diseases is used to: provide an early warning of a potential outbreak and facilitate early public health response interventions; track the impact of public health response interventions; monitor trends in the epidemiology of the communicable diseases in order to inform policy development and policy changes [8].

In this PhD study, I use a systems approach to analyse the notifiable disease surveillance system (NDSS) in South Africa in order to contribute to health policy changes during a critical stage of the country's health sector reforms.

This introductory chapter provides the background to and context of this PhD study. In section 1.2, I outline the evolution of the NDSS globally with particular focus on Africa. Section 1.3 summarises the development of the NDSS in South Africa, and health system reforms relevant to the NDSS. Section 1.4 underscores the importance of regular NDSS evaluations. In section 1.5 I describe the rationale for this PhD research, while section 1.6 summarizes the development of a conceptual framework for the analysis; 1.7 presents the conceptual framework used; section 1.8 summarises the aims and objectives of the study; while section 1.9, provides an overview of the structure of the PhD thesis.

1.2 The evolution of Notifiable Diseases Surveillance Systems

Public health surveillance has its origins in the "great pestilence" that occurred in 3180 B.C. in Egypt [10]. Since this epidemic and throughout recorded human history, communicable disease surveillance systems have been developed and shaped by the occurrence of major outbreaks or pandemics [10]. In the last century in the USA, the fight against a malaria epidemic and the establishment of malaria surveillance systems in 1941, led to the establishment of the Communicable Disease Center, the precursor of the present Centers for Disease Control and Prevention (CDC) in the late 1940s [11]. In response to global health challenges accentuated by the second world war, the WHO was founded in 1948, after the establishment of the United Nations in 1945 [12]. In 1951, member states adopted the International Sanitary Regulations, which were aimed at the

surveillance and control of six epidemic-prone diseases; that were later reduced to three diseases, namely cholera, smallpox and yellow fever [13].

The use of the surveillance systems in public health came to further prominence with the control of malaria in the USA by 1955, the global polio vaccination programme in 1955, the Asian influenza pandemic of 1957 and the global smallpox eradication programme between 1967 and 1977 [11]. The International Sanitary Regulations were revised in 1969 and named the International Health Regulations (IHR) [13, 14]. Notwithstanding two amendments of the IHR in 1973 and 1981, these regulations were insufficient to provide for global public health security during the period 1970 to 1995, when globalisation increased the threat of the spread of diseases, [15, 16]. The process to revise the IHR was started in 1995, and completed in 2005 with the adoption of IHR (2005) that came into effect in 2007 [17].

Communicable diseases are associated with underdevelopment and poverty – they occur amongst the nations with the most inefficient health systems and the lack of resources to deal with them effectively [18-20]. Consequently low and middle income countries (LMIC), particularly African countries, have been disproportionately affected by a high burden of infectious diseases, while their core capacities are the weakest to combat these diseases [18, 19, 21]. Africa has the world's highest burden of communicable diseases such as malaria, tuberculosis and HIV/AIDS [22-25]. In 1998 members of the African region of the WHO adopted the integrated disease surveillance and response (IDSR), thus committing themselves to increased surveillance for public health action [24, 25]. Since its adoption, a review in 2015 found that 43 African countries have implemented the IDSR [26]. Despite adoption of the IDSR, South Africa as a member state of the region has never implemented the IDSR.

1.3 Development of the Notifiable Diseases Surveillance System in South Africa

Early colonial health services in South Africa were established to deal with scurvy and imported infectious diseases of the immigrants at the time of the establishment of a Dutch colony in the Cape, in the 17th century [27-29].

The public health system had its origins in several quarantine ordinances and the Cape Public Health Act of 1883 which were aimed at controlling communicable diseases [27-29]. The devastation caused by the Spanish flu of 1918 underscored the need for a national public health system and led to the enactment of the Public Health Act of 1919 and the establishment of a national Department of Health (DOH) [27-29]. The national DOH played a major co-ordinating role and retained the power to intervene in provinces, but local authorities were responsible for the control and reporting of communicable diseases [27-29].

The Public Health Act of 1919 was amended 21 times between the period 1920 to 1975 but remained the main public health legislation in the country until 1977 when a new Health Act was adopted [29]. This Act laid the foundation for the present NDSS in South Africa. However, in 1998, Klugman, a distinguished infectious diseases expert in South Africa, described the NDSS as still "in its infancy" with a strong laboratory network but weak clinical and laboratory-based surveillance in place [30].

The advent of democracy in South Africa in 1994 brought about the establishment of a unitary health system from the fragmented apartheid system of the past. This was accompanied by the adoption of enabling policies, such as the National Health Plan of 1994, through which free primary health care (PHC) services and free hospital services to children under five and pregnant women were introduced [31]. The 1997 White

Paper for the transformation of the health system in South Africa, provided for a major overhaul and restructuring of the health system focused on disease prevention health promotion and comprehensive management and treatment [32]. The South African Constitution was adopted in 1996; which provided for health as a concurrent responsibility of the national and provincial levels of government [33]. The Health Act of 1977 was reviewed and a new National Health Act was promulgated in 2005, which provides for communicable diseases and notifiable medical conditions regulations [34]. However, NDSS regulations to give effect to the provisions of the National Health Act have not yet been promulgated.

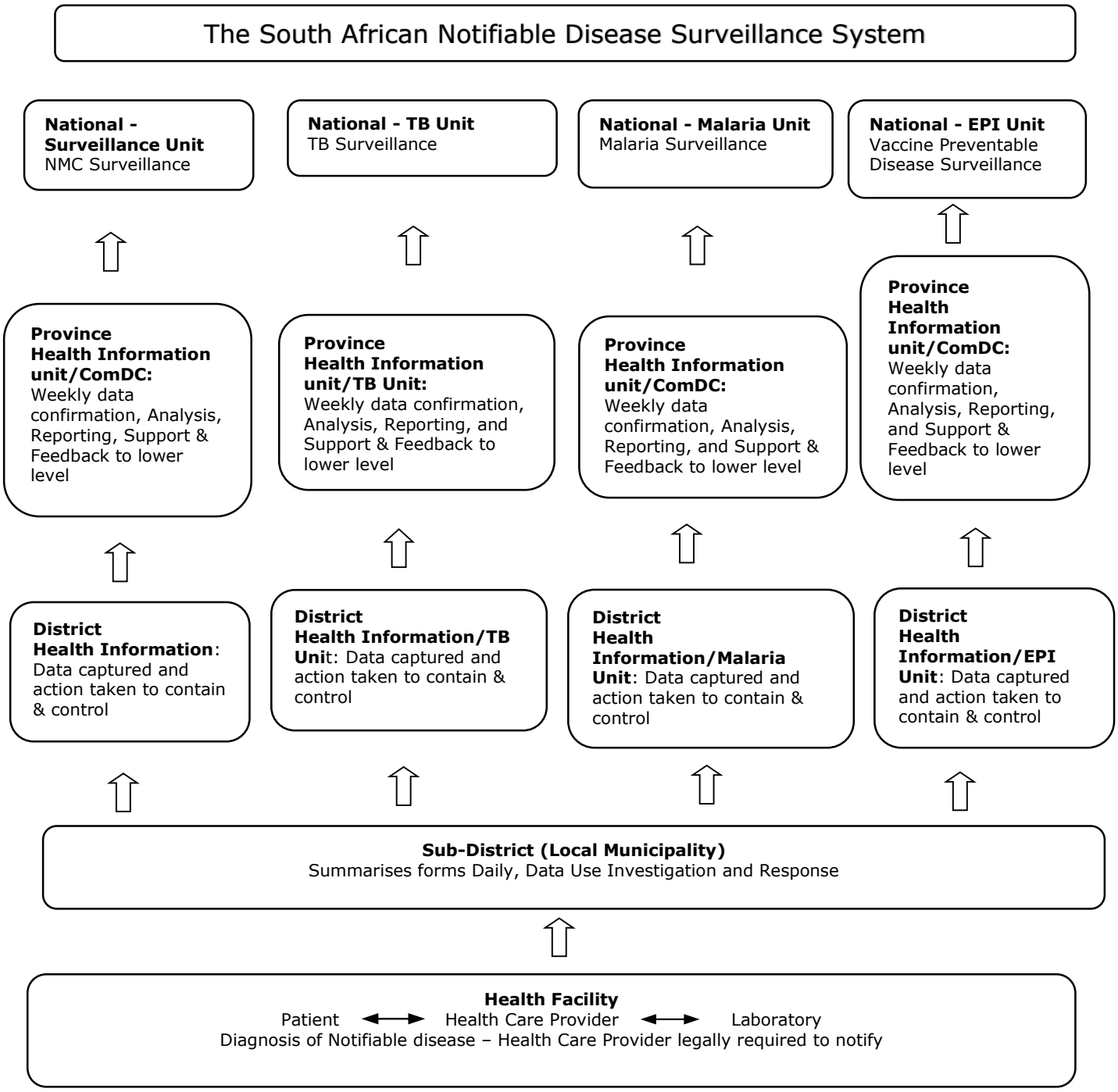
Despite the transformation of the South African health system and the adoption of new policies and legislation, there is evidence that the performance of the health system is sub-optimal [35-39]. At the same time there is an increased need for health care services to manage South Africa's quadruple burden of disease (tuberculosis and HIV/AIDS; maternal and child mortality, non-communicable diseases; and injury and violence) [35, 38-43]. Population health indicators are poor relative to the country's economic development indicators and health care expenditure. Contributing factors include: sub-optimal leadership and stewardship at various levels of the health system; resource constraints; major gaps in the quality of services; inequities between urban and rural areas, and between the public and private health sectors; and the sub-optimal monitoring, information and surveillance systems [35, 38-43].

In 2009, the Minister of Health, Dr Aaron Motsoaledi, adopted a strong evidence-based approach to tackle these challenges [43, 44] and introduced several policy initiatives. These included: leadership to implement the country's HIV and AIDS strategic plan that ushered in the largest antiretroviral treatment programme in the world [45]; initiatives to strengthen the South African health system through the re-engineering and revitalisation of PHC [46, 47]; introducing strategies to improve human

resources for health [48]; and introducing an office of Health Standards Compliance with the mandate of implementing compulsory accreditation of all health facilities, in an effort to improve the quality of health care within public health institutions [49, 50]. More recently South Africa is in the process of reforming its health system to introduce universal health coverage through the phased implementation of a National Health Insurance (NHI) system [51, 52]. The department also announced its intention to establish a CDC-like organisation that will be responsible for disease surveillance, a National Public Health Institute for South Africa (NaPHISA) [53] and published an IHR bill with the intention of making the 2005 IHR applicable in the country [54].

In light of the impending health reforms, a well-functioning surveillance system is vital to an effective and responsive health system. Research to provide scientific evidence that will inform policy reforms to the present NDSS is therefore opportune.

South Africa presently has a NDSS that is non-electronic and tracks 33 medical conditions [55]. Health care providers are legally obliged to notify these conditions to their local authority, which in turn reports it to the district, district to province, and province to the NDOH (Figure 1.1) [55]. Parallel systems have been developed since 1996 for the surveillance of tuberculosis (TB), malaria and Expanded Programme on Immunisation (EPI) diseases. The NDSS relies on the clinical skills of health care providers to diagnose the list of communicable diseases based on clinical suspicion and to request laboratory confirmation. Case definitions are only used during outbreaks and for active surveillance [55]. There are no legal provisions for laboratories to notify communicable diseases [56, 57].



NMC = Notifiable Medical Condition, EPI = Expanded Programme on Immunisation, TB = Tuberculosis, ComDC = Communicable Diseases Control

Source: National Department of Health [55] Surveillance Unit, TB Unit, Malaria Unit and EPI Unit

Figure 1.1: Schematic presentation of the South African Notifiable Disease Surveillance System

1.4 The case for regular NDSS assessments

Regular evaluations of the NDSS are needed to ensure that the system is capable of the timely identification and response to the emergence of epidemic-prone diseases that may cause local, national, regional or global outbreaks. Shortly after the adoption of the 2005 IHR, in May 2006 the global community called for regular evaluations of the NDSS to ensure epidemic preparedness and response [58]. The legally binding 2005 IHR obligations took effect in June 2007 and compelled countries to report annually to the World Health Assembly (WHA), on the status of their surveillance system, amongst 12 other IHR core competencies [9]. Since 2008, a standard format has been used for the report. Self-reporting by countries does not require the provision of objective scientific evidence. Annual reports are published by the WHO on a regional basis in their web-based data repository, Global Health Observatory [59].

Since the implementation of the 2005 IHR, there has been a major cholera outbreak in 2008-2009 that affected nine of the 15 countries in the Southern African Development Community (SADC) region [60-63]. This outbreak tested the ability of the NDSS to detect and assist in containing these outbreaks. The outbreak started in a urban district in Harare, Zimbabwe, where it was detected early and brought under control [62]. However, it reoccurred in the same urban district and spread rapidly to other districts and cities in Zimbabwe before it was recognised as a potential PHEIC [62, 63]. It soon spread beyond Zimbabwe's border to nine countries in the region, including South Africa [62, 63]. In South Africa the outbreak was not detected through the NDDS, but through parallel systems in the national laboratory system [60, 61]. The regional outbreak was only brought under control in August 2009, after more than 4300 deaths [62, 63], 69 of which were in South Africa [60]. This regional outbreak demonstrated the need for assessment and strengthening of the NDSS to

deal with an outbreak effectively before it spreads beyond a country's borders.

At a global level, the H1N1-Pandemic of 2009 provided the first worldwide test to the strength of countries' NDSS, after the adoption of the 2005 IHR. The hysteria around the outbreak of Severe Acute Respiratory Syndrome (SARS) in 2003 [64], and the high case fatality rate associated with the Avian Influenza A/H5N1 outbreak [65], underscored the need for a global focus on strong pandemic preparedness plans, with surveillance playing a central role. Mexico had a preparedness plan and routine surveillance system which enabled the country to detect and respond to the novel influenza cases that occurred there in April 2009 [66, 67]. However, the virulence of the influenza virus and the extensive nature of global travel contributed to the spread of the virus to more than 214 countries and territories around the world by mid-2010 [3]. In South Africa the first imported case was detected in July 2009 through enhanced laboratory surveillance and by October 2009, 12 331 cases and 91 deaths were laboratory confirmed [68, 69].

In 2011 a WHO appointed independent Review Committee on the functioning of the 2005 IHR in relation to the 2009 H1N1 Pandemic, reported that although the IHR increased pandemic preparedness and helped the global community to deal with the pandemic, "the world is ill-prepared to respond to a severe influenza pandemic or to any similarly global, sustained and threatening public-health emergency" [WHO, 2011:12][70]. The pandemic therefore demonstrated the need for evidence-based improvements of the NDSS as part of strengthening national and global epidemic preparedness [71].

The Ebola outbreak of 2014-2016 underscored the finding of the WHO's Review Committee that the world was ill-prepared for major public health emergencies. The index case of the outbreak was a two-year old patient

who died in December 2013 in Gueckedou, Guinea [72], and was not detected and identified as Ebola until March 2014, when the disease had spread to two other countries in West Africa [72]. EVD was only recognized as a PHEIC in August 2014 and dealt with as a global public health emergency [73, 74]; but by that time 1,711 cases had occurred and 932 deaths resulting in a Case Fatality Rate (CFR) of 54% in four countries [75]. The PHEIC was declared over by March 2016 following 28,616 cases and 11,310 deaths (CFR 40%) [5, 76]. In an effort to assess the global response to the EVD outbreak, the WHO appointed an independent panel in 2015 which found that countries failed to develop IHR surveillance core capacities [77]. The panel questioned the reliability and validity of the annual mandatory IHR self-assessments and stressed the need for regular objective evaluations [77]. A United Nations High-level Panel on the Global Response to Health Crises concurred with the findings of the WHO independent panel, regarding inadequacy of health surveillance systems and recommended the need for objective evaluations [78]. On the strength of these findings the WHO adopted a new IHR monitoring and evaluation framework which included the concept of voluntary joint external evaluations (JEE) for the assessment of countries' compliance to the IHR [79, 80].

Although the value of the JEE in strengthening surveillance still needs to be determined, it has introduced some objectivity in IHR assessments. By June 2017, 44 countries had undergone a JEE [80, 81], but South Africa is not one of these countries.

Hence the need for objective scientific evaluations of the NDSS has been established at a global level.

There is a dearth of studies on the NDSS in South Africa. A 2009 study focused on the completeness and reliability of the electronic TB surveillance system in three provinces in the country [82], and a 2005 - 2009 study

assessing national WHO acute flaccid paralysis indicators used secondary data [83]. Both these studies are focused on parallel, vertical systems that have developed because of perceived weaknesses in the NDSS and do not represent the national NDSS. There have also been an evaluation of the NDSS in Gauteng province [84] and three studies on tuberculosis (TB) surveillance in two Western Cape districts [85-87]. These few studies were limited in scope and scale and cannot be generalised to the entire country. Furthermore, these studies predate the global policy initiatives, notably the JEE and the new IHR framework. The need for a systematic and objective evaluation of the NDSS at the national level in South Africa is critical.

1.5 Study Rationale

Since 1977, there has been no systematic and objective evaluation of the national NDSS in South Africa. More importantly, there has been no critical evaluation of the NDSS since the adoption of the WHO strategies on IDSR and the IHR. Consequently, the NDSS remains untransformed.

This PhD study was conceived as addressing the knowledge gap on the South African national NDSS, thus contributing to proposed health sector reforms enunciated in the NHI White Paper [52]. The rationale for the PhD research study was premised on the following:

1. The study was the first systematic, objective analytical study of the South African national NDSS.
2. Generation of new knowledge on the:
    a. performance of the national NDSS against key system attributes;
    b. extent to which health care providers comply with the NDSS and the determinants of such compliance.

3. Contribute to health policy and health care system interventions that will lead to improvements in the functioning and effectiveness of the NDSS.

1.6 Developing a framework for the assessment of the NDSS

Over the last 20 years there have three frameworks used globally for the objective assessment of countries surveillance systems, these are the CDC's "*Updated guidelines for evaluating surveillance systems*" [88], the WHO's "*Protocol for the assessment of national communicable disease surveillance and response systems: guidelines for assessment teams*" [89], and the IHR JEE-tool referred to above.

The CDC's framework is the result of a review of the guidelines developed for evaluating surveillance systems in 1988 [90]. The 1988 guidelines were developed to ensure efficient health resource utilisation through effective surveillance systems [90]. The updated guidelines were developed in 2001 at the time of the adoption of the IDSR by WHO Afro [88], with the CDC playing a leading role. The main purpose of the update was to accommodate the need to respond to emerging public health threats [88]. The 2001 guidelines used the approach of the "*Framework for Program Evaluation in Public Health*" [91] to update the 1988 guidelines and added the engagement of the stakeholders involved in the system to the assessment.

The WHO's "*Protocol for the assessment of national communicable disease surveillance and response systems: guidelines for assessment teams*" was developed at the time of the implementation of the IDSR in the WHO Afro region, to promote an integrated approach to the surveillance and control of communicable diseases [89]. The protocol proposes an assessment of core and support functions of the surveillance system and focused on the

structure, organisation, processes and output of surveillance and response systems at different levels of the health care system [89].

The JEE assessment tool is based on the Global Health Security Agenda (GHSA) external evaluation assessment tool developed by the CDC and piloted in five countries in 2015 [92, 93]. The GHSA is an initiative driven by the USA in 2014 [94-96] to "accelerate progress towards a world safe and secure from infectious disease threats" [CDC, 2017:Webpage][92]. With the call for more objective IHR reporting after the Ebola outbreak, the JEE tool was developed as an adaptation of the GHSA tool in 2016 [80, 97].

The IHR JEE-tool was not used in the conceptual framework for this PhD study for several reasons. It was developed after the conceptualisation of this study in 2014; it is broad-based and not specific for the assessment of surveillance systems [97]; and there are only a few countries that have published their experiences of undergoing a JEE [98-100].

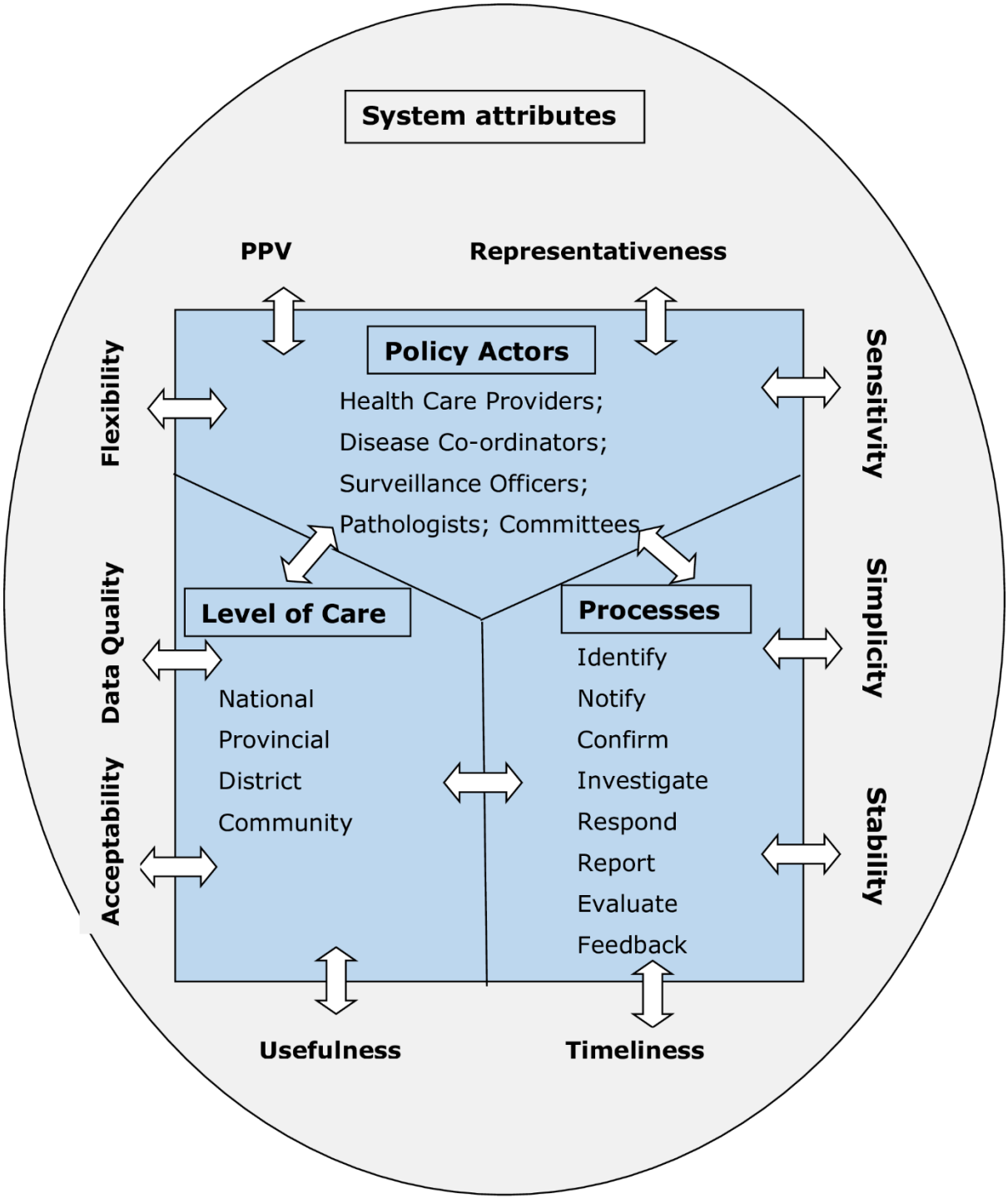
1.7 Conceptual Framework for the PhD

In this PhD study, I have used an adapted analytical framework that draws on the 2007 WHO systems approach [101, 102] and the internationally accepted principles and concepts of the WHO's IDSR [24, 25], and the CDC guidelines [88].

Elements of the framework used in this PhD study are shown in Figure 1.2 below. The NDSS functions as a subsystem of the broader health system. The NDSS consists of three interlinked elements, namely: (a) **the level of care** where patients present for services or where individuals with infectious diseases present for the first time; (b) the **policy actors** or key stakeholders who interact with the NDSS or with patients at the different levels of the health system; and (c) the appropriate public health **processes** that are essential to the NDSS functioning. The **attributes** of

this interlinked system (shown in the surrounding circle) need to be evaluated to ensure effective performance.

The NDSS is initiated when an individual person presents with a listed notifiable communicable disease at the appropriate level of care. A health care provider (HCP) at that level, whether in the public or private health sector, needs to identify the disease, notify on clinical grounds and then send specimens to the laboratory where pathologists confirm the diagnosis. The notification initiates an appropriate public health response by surveillance officers and communicable disease co-ordinators at the level of the local DOH after an analysis of the data. The local DOH reports on the occurrence of the communicable diseases to the higher level in the system, that in turn respond if needed. The compliance of the HCP with the NDSS is a key aspect to its successful functioning.



Source: Modification of WHO Health Systems, IDSR and CDC Framework

PPV=Positive Predictive value

Figure 1.2: Conceptual framework for the analysis of the NDSS

1.8 Study Aim and Objectives

1.8.1 Aim

The aim of the study was to conduct a systematic, objective analysis of the NDSS of South Africa, thereby informing health policy and health system interventions to improve the NDSS functioning and effectiveness.

1.8.2 Objectives

The specific objectives of the study were to:

1. Analyse key informants or policy actors' perspectives on the system attributes of usefulness, timeliness, simplicity, flexibility and acceptability of the National NDSS.
2. Analyse the NDSS attributes of representativeness, stability, data quality, sensitivity and positive predictive value.
3. Determine the factors influencing provider compliance with the NDSS.
4. Make policy recommendations to improve the effectiveness and efficiency of the national NDSS in the country.

1.9 Structure of the PhD thesis

Chapter 1: An appraisal of the need for and importance of a NDSS, followed by an outline of NDSS evolution both globally and in South Africa. The chapter concludes with the study justification, conceptual framework used, and study aims and objectives.

Chapter 2: A description and critique of the relevant literature on the evaluation of the NDSS are presented.

Chapter 3: A detailed description of the methods used in the PhD study is presented.

Chapters 4, 5, 6 and 7:

The study findings as reflected in the relevant papers are presented under the following headings:

Chapter 4: Survey of the perceptions of key stakeholders on the attributes of the South African notifiable diseases surveillance system.

Chapter 5: Comparing laboratory surveillance with the notifiable diseases surveillance system in South Africa.

Chapter 6: Health Care Providers' compliance with the notifiable diseases surveillance system in South Africa.

Chapter 7: Perspectives of health policy actors on reforming the notifiable diseases surveillance system in South Africa.

Chapter 8: This concluding chapter provides an integrated narrative for all the studies that form part of the PhD thesis. It presents the policy impact and scholarly contribution of the PhD; as well as recommendations for further study.

CHAPTER 2. LITERATURE REVIEW

2.1 Introduction

In this chapter, I use the conceptual framework described in Chapter 1 to review the relevant literature and to identify the knowledge gaps, especially those that this PhD thesis focused on. Section, 2.2 contains the definition of terms used in the thesis. In section 2.3, I review and critique the literature on the opinions of policy actors or key stakeholders on the attributes of the NDSS; in section 2.4, I review the literature on laboratory surveillance in comparison to notifications. In section 2.5, I review the literature on the compliance of health care providers (HCPs) with the NDSS and the factors that influence their compliance. In the last section, 2.6, I summarize the gaps in the literature and the knowledge contribution of my thesis.

2.2 Definition of terms

This thesis used the following definitions:

Acceptability	Indicates the willingness of providers to participate in the surveillance system [88].
Correct notification /Compliance	Compliance or "correct notification" is HCP notification to the local, provincial or national department of health.
Data quality	The completeness and validity of the data recorded in the surveillance system [88].
Flexibility	Adaptability of the NDSS to changing circumstances and needs with little additional resource implications [88].

Health care provider	A medical doctor or professional nurse with at least four years of training.
Notifiable diseases surveillance system (NDSS)	Surveillance based on the notification of communicable diseases that is used to provide an early warning, and facilitate early public health response to an outbreak [8].
Positive predictive value	The proportion of reported cases diagnosed with the communicable disease under surveillance [88].
Representativeness	The ability of the system to describe accurately the occurrence of a health-related event over time [88].
Sensitivity	The proportion of cases of a communicable disease detected by the surveillance system [88].
Simplicity	The ease of understanding the processes and procedures of the NDSS [88].
Stability	The reliability of the data recorded in the surveillance system [88].
Stakeholder	These are individuals actively involved in the NDSS, or in structures and committees set up to deal with any aspect of the NDSS in South Africa, including individuals involved in disease control and response; disease detection; and health management.
Surveillance	"The continuous, systematic collection, analysis and interpretation of health-related data needed for the planning, implementation, and evaluation of public health practice" [WHO, 2017:webpage][8].
Systems approach	An approach that "applies scientific insights to understand the elements that influence health outcomes; models the relationships between those elements; and alters design, processes, or policies

	based on the resultant knowledge in order to produce better health" [Kaplan, 2013:4][102].
Timeliness	The speed with which the provider takes the appropriate steps after an event came to her/his attention [88].
Tracer	A specifically selected communicable disease that makes it possible to assess the attributes of the surveillance system in order to determine its performance [103].
Usefulness	Whether the data contributes to an outbreak response, or the prevention and control of communicable diseases or improved public health knowledge of communicable diseases [88].

2.3 Policy actors and the attributes of the NDSS

The involvement of stakeholders, also called policy actors, in health policy development or analysis is critical, both to obtain their inputs and to build mutual understanding and trust [104-108]. Furthermore, studies have highlighted the importance of the roles, power, interests, and values of stakeholders in developing and implementing health policies or reforms [109-111].

The CDC framework for the evaluation of surveillance systems advocates the involvement of key stakeholders in assessments [88], and the WHO's 2020 strategic policy framework [112] emphasises the importance of including all stakeholders in decision-making and health system reform initiatives [113]. In South Africa, several studies have pointed to sub-optimal policy implementation or policy failures because of the lack of involvement of policy actors, particularly those responsible for the implementation of these policies [110, 114-117]. Hence, it is critical to

obtain the perspectives of key health policy actors on the attributes of the NDSS and the reforms that are needed.

The 2001 framework developed by the CDC [88] and that of the WHO, have been widely used to evaluate surveillance systems. A 2009 literature review by Sahal et al, reported on 20 NDSS evaluations in high-income countries (HICs) and 12 in low- and middle-income countries (LMIC) that used either the CDC or WHO framework [118]. In HICs in Europe [119] and Australasia [120, 121], evaluations of the NDSS used the CDC framework and focused on data quality, usefulness, acceptability, timeliness, as well as the simplicity of the system. Studies in LMIC in the Americas [122, 123], Europe [124], Asia [125], and Africa [126-129], focused mainly on core and support surveillance functions, such as provision of laboratory services, supervision, monitoring, organisational capacity, staffing and resources. These LMIC studies found that challenges with laboratories, supervision, monitoring, organisational capacity, staffing and resources impede NDSS functioning [126-129].

In recognition of the importance of stakeholders, several countries have conducted surveys among NDSS stakeholders' to ascertain their perceptions of system attributes. A 2003 German assessment of the NDSS scored the system 90% on acceptability [130]; a Canadian study published in 2018, rated the usefulness of their surveillance system between 74-97% [131]; in Australia, a NDSS study on the attribute of usefulness found that 94% of participants reported reading NDSS reports and 85% reported utilisation of the data [120]. In Thailand, a 2016 study on the malaria surveillance system measured timeliness at three to four days [132], while in the Maldives, timeliness for dengue fever was two days and acceptability levels were only 2% amongst doctors [133]. In Africa, a 2017 study on influenza in Madagascar showed acceptability levels that ranged from 84%-98%, timeliness of reporting of 70% within 48 hours, 94% of stakeholders found the system simple and the system was reportedly flexible in that it

was used for four diseases and able to pick up 14 respiratory viruses [134]. A 2010 Ugandan study found that stakeholders scored the timeliness of the NDSS at 68%-73% [126]; and a 2016 study on measles in a Nigerian state found the timeliness of the system to be 65% [135].

Some studies among stakeholders have used a qualitative approach. In a 2004 study on the Australian NDSS, stakeholders rated their operations and processes as complex [120]. In China, stakeholders reported the surveillance system as flexible, useful and acceptable [136], and in Taiwan stakeholders reported the NDSS as acceptable [137] and useful [138].

Despite the literature on stakeholder perceptions on NDSS attributes, these findings are not generalisable to South Africa due differences in context, the burden and profile of infectious diseases, structure of the health care system, and in the availability of resources [24, 88, 139]. Furthermore, there is a dearth of studies on stakeholder perceptions of the attributes of the NDSS and that focus on the entire country [84, 86, 87]. Hence, generating new information on stakeholders' perceptions of the NDSS attributes in South Africa can assist policy-makers with efforts to improve the performance of the system, and contribute to the successful implementation of health sector reforms.

2.4 NDSS attributes, laboratory surveillance and notifications

Laboratories play an essential and important role in the management of communicable diseases, and are often the first to identify or confirm the organism involved, except when point of care diagnostic equipment is used. They serve to confirm the clinical diagnosis made by the HCPs. For these reasons many countries have introduced measures to make it compulsory for laboratories to notify communicable diseases and have dual reporting

systems in order to overcome the problem of under-reporting and timeliness of reporting [137, 140-147].

In many HICs, the strong laboratory networks have made the mandatory reporting by laboratories an effective step in improving the functioning of the NDSS [140-144, 148]. However, many of these countries also introduced further steps, such as the introduction of electronic laboratory reporting, to improve compliance and the timeliness of reporting. In the USA, many states introduced laboratory reporting at the onset of mandatory reporting by clinicians [149] and after the terror attacks of 11 September 2001, funds were provided through CDC for the implementation of electronic laboratory reporting in states and local territories [150-152]. By 2013, 62% of approximately 20 million laboratory reports were received electronically [152], and by July 2014, this had increased to 67%, with the aim of reaching 80% by 2016 [153]. Comparisons of electronic and paper-based laboratory reporting in the USA showed that electronic reporting identified 4.4 times more cases and 7.9 days earlier than paper-based reporting [144].

The majority of studies that compare electronic laboratory reporting systems with paper-based notifications have been done in HICs [144, 148, 154-156]. Some of these comparative studies in HICs have examined the attributes of surveillance systems [142, 144, 154, 155, 157-159], while some have compared different electronic systems with each other [157, 158], or active surveillance with passive surveillance systems [159, 160]. However, there is a dearth of studies that compared national notification systems with laboratory surveillance. I could only find one 2005 Swedish study that compared the parallel systems of clinical and laboratory notifications [142]. This study on the sensitivity of the Swedish NDSS used four tracer diseases and found that dual reporting was beneficial and that the sensitivity of clinical and laboratory notification was higher than 91% for all the tracers [142].

Some LMIC in the Far East, such as China and Taiwan, have stronger laboratory systems and have been able to emulate practices in HICs, through the introduction of electronic laboratory reporting [137, 145-147]. In many LMIC, particularly in Africa, laboratory networks are relatively weak and the reliance on HCPs to notify diseases is therefore stronger. In Africa evaluation studies have focused on the implementation of the integrated disease surveillance and response (IDSR), and have emphasised weak laboratory networks that impede the effective functioning of the NDSS [118, 127-129]. Hence, the evidence on the extent of the improvement in timeliness and compliance in LMIC, brought about by the introduction of laboratory reporting is scant. There is also a dearth of comparative studies that focus on notification and laboratory surveillance systems in LMIC.

In South Africa, despite a relatively strong laboratory network, these laboratories are not required by law to report communicable diseases [55-57]. Since the 2000s, several laboratory-based sentinel surveillance initiatives have been implemented, such as influenza-like illness (ILI) and severe acute respiratory illness (SARI) surveillance [161], as well as the group for enteric, respiratory and meningeal disease surveillance (GERMS) [162]. However, these sentinel surveillance systems were developed by researchers independently of the NDSS in South Africa. Although the knowledge generated has contributed to health policy development such as the introduction of rotavirus and pneumococcal vaccination programmes [163-165], the overall NDSS in South Africa has not changed fundamentally.

Importantly, there is a knowledge gap on how the paper-based notification system compares with the laboratory surveillance system. Although a South African study compared notifications and laboratory surveillance for hepatitis B for the period 1985 – 1988 [166], this was more than 28 years ago, and the South African health system has undergone major changes

since the 1980s. This PhD is novel as it was one of the first studies to use three tracer conditions to compare laboratory surveillance with the notifications of these tracer conditions to the department of health.

2.5 Health care providers' compliance with the NDSS

Notifiable communicable diseases need to be reported to the relevant health care authorities to ensure appropriate investigation and implementation of disease prevention and control measures. HCPs are at the coalface of service delivery, responsible for the diagnosis and treatment of infectious diseases; they are critical to an effective NDSS and resilient health systems [167]. The optimal performance of the NDSS is dependent on HCPs who in addition to the management of patients with infectious diseases, are also aware of measures to prevent the spread of the infection, the importance of notification to enable an appropriate public health response.

Around the world, many countries have made it mandatory for HCPs to report notifiable diseases upon clinical suspicion and/or laboratory confirmation [55, 141-144, 149, 159, 160, 168-187]. The timely compliance of HCPs is essential to the effective functioning of any NDSS. Information on HCP compliance is important for shaping NDSS reforms, ensuring effective disease response and compliance with the IHR, and monitoring trends and/or benchmarking the performance of HCPs [167].

In the USA, individual states are responsible for the monitoring of communicable diseases. Mandatory reporting by HCPs in some states dates back a time prior to the establishment of the CDC. In Michigan, which was the first state to take action to make reporting by HCPs mandatory, mandatory reporting dates back to 1883 [149]. By 1925, all states in the USA were taking part in a national reporting system, resulting in a system of reporting morbidity and mortality data on 49 infectious diseases to the CDC [149]. However, despite the legal obligation, as early as 1999 an

analytical review of studies in the USA has shown that underreporting affected all states and all notifiable diseases and was as low as 9% for some diseases [141]. This review has shown that the reporting was higher for tuberculosis, AIDS, and sexually transmitted diseases (mean 79 %) than for all other diseases (mean 49 %) [141]. In 2004, the median timeliness of national reporting in the USA ranged from 12 days for meningococcal disease to 40 days for pertussis [188].

Some European countries [142, 143, 169-175] and Australia [159, 176-178] have documented the problems of under-reporting in the NDSS, despite compulsory notification by HCPs. These countries have taken steps to identify and address the factors which cause non-compliance or under-reporting. Factors found to influence compliance were: willingness to notify, workload, training on the NDSS, understanding of the purpose of the NDSS, knowledge on what to notify, possession of notification forms and feedback given [141, 176, 177]. Many of these countries have introduced parallel laboratory reporting and electronic systems in order to address HCPs' non-compliance. Studies in LMIC in Latin America, the Middle East and Asia have found that the factors influencing HCP compliance with the NDSS were similar to those in HICs, and included lack of knowledge, understanding of the purpose of notifications or lack of logistics needed to notify [160, 179-184]. Timeliness studies in these countries showed delays of up 20 days median time from disease onset to notification in China and Korea [145, 146]; in Thailand reporting was considered timely in 45% of cases [147]. These countries have also introduced laboratory and electronic reporting to increase compliance and timeliness [137, 145-147].

There is a dearth of studies on the compliance of HCPs with the NDSS in Africa. I could only find three studies in Nigeria [185-187] and a study in a district in Zimbabwe [189]. A study in one of provinces of Nigeria showed that 38% of HCPs surveyed were aware of the NDSS [185] and two national Nigerian studies showed that the most common reasons for not reporting

were lack of knowledge amongst HCPs and lack of infrastructure or logistics for reporting [186, 187]. The study in the Zimbabwean district showed that only 20% of HCPs surveyed knew about their legal requirement to notify infectious diseases [189]. Both Nigeria and Zimbabwe lack the necessary infrastructure and resources to introduce electronic systems to improve the compliance and/or timeliness of reporting [186, 187, 189].

In South Africa, there have only been a few evaluations of HCPs compliance with the NDSS since its inception in the 1970s [84, 166, 190, 191]. These included a study on reporting of hepatitis B for the period 1985 to 1988 [166]; a 1996 study at one institution on reasons for under-reporting [191]; a study on rheumatic fever for the period 1990-2004 [190]; and one on notifications amongst private general practitioners (GPs) in Gauteng province in 2006 [84]. These studies precede the implementation of the 2005 IHR and are focused on limited geographical settings or diseases. Furthermore, the South African health system has undergone with the revitalisation of primary health care [46, 47], the introduction of universal health coverage through the NHI [51, 52], and the establishment of a public health institute [53]. There is a dearth of information on factors associated with HCPs compliance with the NDSS, with only one study found that is more than 20 years old and was done at one institution [191]. Given this knowledge gap, this PhD was one of the first studies to examine HCPs' compliance with the NDSS in South Africa and the factors associated with their compliance. The information so generated could inform NDSS reforms and/or continuing education programmes.

2.6 Summary

Table 2.1 summarises the identified gaps in the literature, and the contribution of the PhD in addressing some of the gaps.

Table 2.1: Summary of the Literature Review

Study Objectives	What is known	Knowledge Gaps	Scholarly contribution of the PhD
Policy actors and the attributes of the NDSS	Policy actors or stakeholders are critical to NDSS performance Majority of surveys on stakeholder perceptions of NDSS attributes done in high income countries	Dearth of studies assessing the NDSS attributes from perspectives of key stakeholders in South Africa and in Africa	This PhD contributes to new knowledge on the NDSS attributes of acceptability, flexibility, simplicity, timeliness and usefulness. in South Africa
Comparing laboratory surveillance with the NDSS	Laboratories are critical in the NDSS for diagnosis or confirmation of the infectious agent In high-income countries, it is mandatory for laboratories to notify infectious diseases In LMIC, laboratory networks are weak In South Africa, despite a strong network of laboratories, they are not required to notify infectious diseases	There is a dearth of studies: • assessing the NDSS attributes of data quality, representativeness sensitivity stability and positive predictive value • comparing notifications with laboratory surveillance • Knowledge gaps are more pronounced in LMIC, especially in Africa • In South Africa, no comprehensive study that compares laboratory surveillance with notifications • No NDSS evaluation since the 2005 IHR	The PhD is the first comparative study between the NDSS and laboratory surveillance It has generated new knowledge on the attributes of the NDSS of data quality, representativeness, sensitivity stability and positive predictive value
Health care providers' compliance with the NDSS and the determinants of their compliance	The notification of communicable diseases must lead to an appropriate public health response HCPs are critical to the optimal performance of the NDSS Extensive literature on HCP compliance and factors influencing compliance in HICs and LMIC in Asian countries of China, Thailand and Taiwan Knowledge on measures introduced to overcome non-compliance and under-reporting	Dearth of HCP compliance studies in Africa Lack of HCPs compliance is unknown in South Africa	One of the first studies on the compliance of HCPs with the NDSS in South Africa and determinants of their compliance Add to the body of knowledge on determinants of HCP compliance in an African and middle-income country setting

CHAPTER 3. METHODS

3.1 Introduction

In this chapter I describe the methods used in the PhD to achieve the study objectives. In section 3.2, I outline the overall methodological approach, including the timeframes within which the PhD was completed. In section 3.3 the ethical considerations are discussed. In sections 3.4 to 3.8, I summarise the study setting, the study population, sampling methods, development of data collection tools, data collection, data management and data analysis. In section 3.9, I outline the triangulation methods, and in Section 3.10, I discuss the study limitations and the steps taken to prevent or overcome these. In the concluding section 3.11, I highlight the strengths of my PhD study.

3.2 Overall methodological approach

This PhD thesis consisted of three inter-related components, based on the objectives of the doctoral study described in Chapter 1. The three distinct, but inter-linked studies were derived from the conceptual framework to answer the research questions and meet the study objectives. The three studies were:

I. A survey of the opinions of key informants (or policy actors) in the NDSS on system attributes of usefulness, timeliness simplicity, flexibility and acceptability;
II. An analysis of NDSS system attributes of representativeness, stability, data quality, sensitivity and positive predictive value; and
III. An analysis of health care provider compliance with the NDSS and the factors that influences compliance.

A fourth objective focuses on NDSS reforms needed and was addressed by a combination of studies I, and III. Table 3.1 provides an overview of the objectives, methods used, data collection instruments used in the studies and the publication outputs; while Table 3.2 shows the overall study components of the PhD. Each of the studies is described individually.

Table 3.3 shows the timeframes within which the PhD study was completed. The development of the study protocol started in February 2014 and its approval from the Faculty of Health Sciences Graduate Studies Committee was obtained in June 2014. Approval from the University Ethics Committee was obtained in August 2014 (Appendix 1) and that from the relevant health authorities, such as the Director-General of Health (Appendix 2) and provincial Heads of Departments (Appendix 3), as well Chief Executive Officers of the national laboratory and private hospital groups (Appendices 4 and 5) were obtained over a six month period until February 2015. Data collection for all three studies started in March 2015 – I personally collected the data for studies I and II and trained 12 fieldworkers in May 2015 to assist with data collection for study III. This was because 77 health facilities and 70 general practitioners' (GPs) practices were involved and it was not possible for me to do all the data collections in three provinces. I provided leadership, on-site supervision and ensured the overall quality assurance for the study.

Data for study I was captured electronically by participants at the time of completion of the questionnaires into the secure, web-based Research Electronic Data Capture (REDCap) programme hosted at the University of Witwatersrand [26]; data for study II was captured by me in Microsoft Excel over a three month period starting from May 2015. Two data capturers were trained in June 2015 to double capture the study III data on REDCap over a two month period. The data analysis and report writing was staggered one after the other from June 2015; each manuscript took about

one year from data analysis to final publication (paper 4 has not yet been published at the time of submitting my thesis).

Table 3.1: Methodological Approach

Objective	**Methods**	**Data collection Instrument(s)**	**Research Output**
1. Determine key informants' opinions on the NDSS attributes of simplicity, timeliness, acceptability, usefulness and flexibility	• A survey of communicable diseases co-ordinators, surveillance officers at national, provincial and district level, as well as role-players in NDSS stakeholder forums.	• Semi-structured questionnaire specifically designed for the survey	• Survey of key stakeholders on the Notifiable Diseases Surveillance System in South Africa **Chapter 4**
2. Analyse the system attributes of data quality, stability, representativeness, sensitivity and positive predictive value of the National NDSS	• Retrospective record review and comparison of the data on 3 tracer notifiable diseases for 2013, using both the Central Data Warehouse of the National Health Laboratory Service (NHLS) and the records of notifications at the Department of Health.	• Specifically designed record review form	• Comparing laboratory surveillance with the Notifiable Diseases Surveillance System in South Africa **Chapter 5**
3. Determine the factors influencing provider compliance with the NDSS (knowledge, attitudes and practices)	• A survey of health care providers (doctors and nurses) at provincial and district levels	• Semi-structured questionnaire specifically designed for the survey	• Health care providers' compliance with the Notifiable Diseases Surveillance System in South Africa **Chapter 6**

Objective	Methods	Data collection Instrument(s)	Research Output
4. Make policy recommendations for interventions to improve the effectiveness and efficiency of the National NDSS in the country	• Draw conclusions from questions raised in the surveys in studies one and three and make relevant policy recommendations	• Self-administered questionnaires used in studies one and three	• Perspectives of health policy actors on reforming the notifiable diseases surveillance system in *South Africa* **Chapter 7**

Table 3.2: Overall PhD study components

Components	Study 1	Study 2	Study 3
Study Setting	9 Provinces	9 Provinces	3 Provinces – urban, rural, mix
Study Population	Key stakeholders involved with analysing, interpreting, responding, reporting and providing feedback; as well as monitoring and evaluation	All data for three tracer notifiable diseases (measles, meningococcal meningitis and typhoid) in the laboratory records and records of notifications for 2013	Health care providers, doctors and professional nurses, involved with the identification and notification of communicable diseases
Sampling approach	Entire population of key stakeholders	All data for the selected notifiable diseases for 2013	A multistage stratification by province and type of facility
Sample size	n = 169	measles = 8,228 meningococcal meningitis = 8,714 and typhoid = 24,264	n = 1050
Data collection	Electronic REDCap self-administered questionnaire	Record review data collected from the NHLS and NDOH	Field worker assisted data collection using self-administered questionnaires
Data Analysis	Quantitative analysis with STATA® 14	Quantitative analyses with Microsoft Excel and STATA® 14	Quantitative analysis with STATA® 14
Integrating narrative	Triangulation and integration of the findings of the various studies		

REDCap = Research Electronic Data Capture, programme hosted at the University of Witwatersrand [26]

NHLS = National Health Laboratory Services

NDOH = National Department of Health

Table 3.3: Time-frames of the various studies

<table>
<tr><th>Studies</th><th colspan="2">2014</th><th colspan="2">2015</th><th colspan="2">2016</th><th colspan="2">2017</th></tr>
<tr><th></th><th>Semes 1</th><th>Semes 2</th><th>Semes 1</th><th>Semes 2</th><th>Semes 1</th><th>Semes 2</th><th>Semes 1</th><th>Semes 2</th></tr>
<tr><td>Study 1</td><td rowspan="3">Protocol develop -ment</td><td rowspan="3">Obtaining approvals</td><td rowspan="3">Data Collection and Data Capturing</td><td>Data Analysis</td><td>Report Writing P1</td><td></td><td></td><td rowspan="3">Thesis Writing and Report writing P4</td></tr>
<tr><td>Study 2</td><td>Data capturing</td><td>Data Analysis</td><td>Report Writing P2</td><td></td></tr>
<tr><td>Study 3</td><td>Data capturing</td><td></td><td>Data Analysis</td><td>Report Writing P3/P4</td></tr>
</table>

Semes = Semester P = Paper

3.3 Ethics

I obtained ethical approval from the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, in August 2014 (Clearance certificate M140624, attached as Appendix 1). Approval for the research was also obtained from the Director- General of the DOH, the heads of the relevant provincial DOHs (Gauteng, KwaZulu-Natal and Limpopo), the Chief Executive Officers of the NHLS and each of the private hospital groups. (Appendices 2 -5)

The PhD research study also complied with all the ethical guides of the Singapore Statement on Research Integrity in that it adhered to the principles of honesty, accountability, professionalism, and stewardship [192]. The ethical matters considered and how they were addressed, are outlined below:

a. Compliance of fieldworkers with principles of honesty, accountability, professionalism and good stewardship of the research

I developed a procedure manual (Appendix 6) and trained all skilled fieldworkers who were professional nurses for one day on all aspects of the study and data collection. The training focused on their professionalism and courtesy in providing information to potential participants, the importance of informed consent, maintaining confidentiality and good stewardship of

the data. I accompanied each provincial group on the first day of data collection to ensure that they performed as trained and required. All fieldworkers were given the contact details of the researcher to ensure that urgent queries that arose were addressed immediately.

b. Potential of my position as Chief Director: Communicable Diseases to influence participation in the survey

At the time of my PhD, I was the Chief Director: Communicable Diseases at the NDOH. Hence I was in a senior position to many of the study participants. To ensure that this did not have an influence on their participation, I drew a clear distinction between the research undertaken by me as a PhD student of the University of Witwatersrand, and emphasised that it was not part of my official work. The information sheet (Appendix 7) only referred to my status as a university student and did not refer to my official position. I further took steps not to involve any of my subordinates as fieldworkers or promoters of the research. Invitations to participants were sent from my private e-mail address and all were given the option to refuse participation, with the guarantee that there would be no negative consequences should they decline participation.

c. Informed and voluntary participation

All participants received an information sheet (Appendix 7) and voluntary, informed consent was obtained prior to their participation in the research. It was emphasized that participation was voluntary and of their own free will – there were no consequences for refusal to participate and no direct benefits of participation (besides the indirect benefits that may arise from policy recommendations for improvements to the NDSS at the conclusion of the study). All participants received the contact details of the researcher, the research supervisors and the Chair of the Human Research Ethics committee of the University of the Witwatersrand on the information sheet.

d. Privacy and confidentiality for the participants of surveys

The survey questionnaires were completed anonymously. Questionnaires were coded and no personal identifiers were obtained to ensure confidentiality.

e. Privacy and confidentiality for the patients whose records were reviewed

The researcher is registered with the Health Professions Council of South Africa as a medical practitioner, and understands the importance of confidentiality. Only the researcher had access to the personal identifiers, obtained from patient laboratory and notification records. This information was stored in a password protected computer that only the researcher had access to.

f. Securing the information after data collection and maintaining confidentiality of records

Responses from the two questionnaires (studies I and III) and the record review (study II) were stored on a secure computer. These responses were password protected and only the researcher had access to this password.

3.4 Study setting

The study setting for studies I and II covered all nine South African provinces and 52 health districts. The nine provinces consists of two urban ones, Gauteng and Western Cape; four rural provinces, Limpopo, Mpumalanga, Northwest, and Northern Cape; and three mixed urban-rural provinces, Eastern Cape, Free State and Kwazulu-Natal [193].

In study III, three provinces were randomly selected, namely Gauteng, Kwazulu-Natal, and Limpopo. They represent the urban, rural and mixed urban-rural groups of provinces. Gauteng is geographically the smallest province with the biggest population and the economic capital of South Africa; Limpopo is the country's northern most province that borders on three countries, and has a high influx of migrant populations en route to

Gauteng province; and Kwazulu-Natal is the second most populous province with the country's biggest seaport [193].

3.5 Study I

The methods used in this study are summarized below with further details provided in Chapter 4.

3.5.1 Study population

The study population for this study consisted of all stakeholders involved with analysing, interpreting, responding, reporting and providing feedback on data collected; as well as those involved with monitoring and evaluation of the system at a national and provincial level. These stakeholders were: all surveillance officers at national and provincial levels; all communicable disease co-ordinators at national and provincial levels; and participants of the National Surveillance Forum, the South African Malaria Elimination Committee, the National Outbreak Response Team (NORT), the South African Expanded Programme on Immunisations Committee and the Provincial Outbreak Response Teams (PORTs).

3.5.2 Sampling

The sample size included the entire population of key stakeholders. As experience is an important determinant of the perspectives of the stakeholders, those with less than one year experience of the NDSS and those not working in a health-related field were excluded from the study.

3.5.3 Development of data collection tool

I could not find a standardised tool to measure key stakeholders perceptions on the attributes of the national NDSS. I therefore designed an information sheet (Appendix 7) and a self-administered questionnaire in

English (Appendix 8) for use in the survey. English is one of the 11 official languages of South Africa and is the main language used to conduct official business in. It was assumed that all of the key stakeholders had a good working knowledge of this language and no translations were made of the questionnaire. The different components of the questionnaire are shown in figure 3.1.

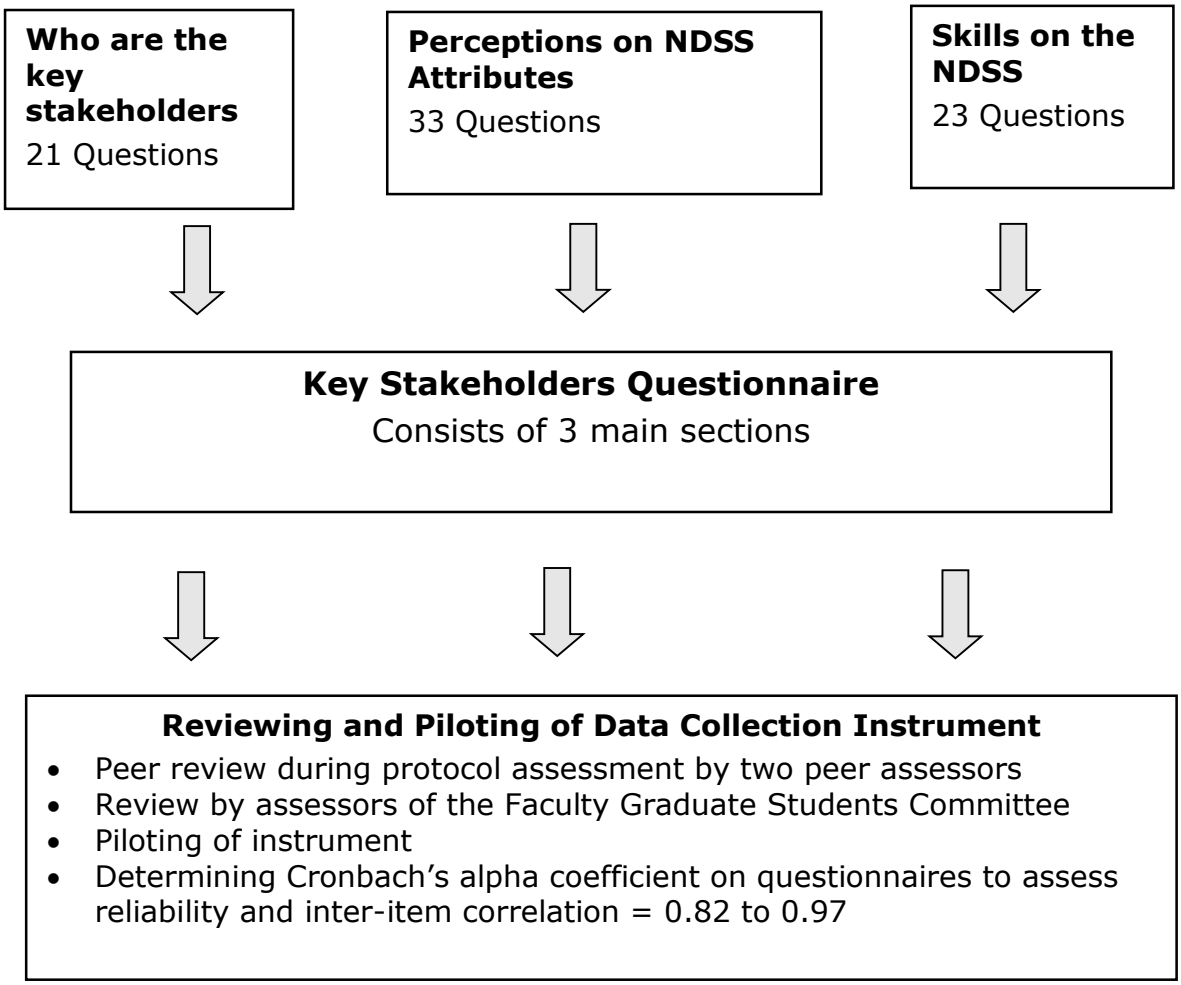


Figure 3.1: Development of Key Stakeholder data collection instrument

3.5.4 Piloting of data collection instruments

The questionnaire was piloted with three key stakeholders similar to the study population, prior to data collection, to determine the clarity of questions and time taken for completion. The questionnaire took an average of 20 minutes to complete and no changes were deemed necessary after the pilot study. These questionnaires completed in the pilot study were excluded from the main study.

3.5.5 Determining reliability and inter-item correlation

Cronbach's alpha coefficients were calculated on the key stakeholders' questionnaire to determine reliability and coherence between items. They were found to be ranging from 0.82 to 0.97, which indicated a high reliability and inter-item correlation.

3.5.6 Data collection

The e-mail addresses of all key stakeholders were obtained through the secretaries of all the national committees and my address book of provincial coordinators, that I had as part of my portfolio as Chief Director: Communicable Diseases at the NDOH. Steps were taken to ensure that my position did not interfere with the study, as described under ethics above. I used the secure, web-based Research Electronic Data Capture, REDCap, programme hosted at the University of Witwatersrand [26], to send invitations to key stakeholders to participate in the electronic survey and sent weekly reminders to non-responders (see Chapter 4). The data were recorded directly into REDCap upon their completion of the questionnaire.

3.5.7 Data capturing and management

The participants completed an electronic survey on REDCap. Upon the completion of the questionnaire, it was checked for quality, cleaned, coded

and stored on a secure computer. The data were password protected and only the researcher had access to this password. Data were labelled and exported into STATA® 14 for analysis (see section 3.8).

3.6 Study II

Chapter 5 describes the methods used in study II in detail. Here, I summarize the methods briefly.

3.6.1 Study population

For purposes of the study, three tracer notifiable communicable diseases were selected for inclusion into the study based on the following: each condition is discrete and easily identified or diagnosed; the condition is a good indicator to measure the attributes of the NDSS; and the condition result in considerable morbidity and mortality that require an urgent public health response (see Chapter 5 and paper 2 for more details [57]). All records of the three tracer conditions: measles, meningococcal meningitis and typhoid, in the data of the National Health Laboratory Services (NHLS), the national public sector laboratory service provider, and the records of notifications held at the national Department of Health (DOH), for the selected study period, 1 January 2013 to 31 December 2013, were included in the study.

3.6.2 Selection of tracers

In this study, I selected three tracer diseases for the comparative study: measles, meningococcal meningitis, and typhoid. Measles and meningococcal meningitis were selected as they are endemic in all provinces [194, 195], highly contagious, distinct and easily identifiable diseases for which early notification on clinical grounds [55] and a public health response is needed. Measles is also a re-emerging, vaccine-

preventable disease, aimed at elimination [196, 197], that had two recent major outbreaks that affected all provinces in 2003-5 [198] and 2009-11 [199-201]. Typhoid is less clinically distinct, but is also endemic in South Africa and has caused considerable morbidity and mortality, which are largely preventable through public health measures [202, 203]. These factors make the tracers good indicators to measure the attributes of the NDSS.

3.6.3 Sampling

The study sample included all data (both from NHLS and the DOH) for the selected notifiable diseases for 2013, which was the study period. All records with inconclusive diagnostic information were excluded from the laboratory records.

3.6.4 Record review form and study pilot

I developed a record review form (Appendix 9) to extract socio-demographic, travel history and clinical information from the laboratory and notification records.

The record review form was piloted for both the laboratory and notification systems, using three records for each of the tracers for the year 2012. During the pilot study, I found that due to the high level of incomplete information in the records, case-matching between the two systems was difficult without including names, hence, the record review form was revised to include the names of individuals with the tracer conditions.

3.6.5 Data collection, capturing and data management

I reviewed and extracted all the laboratory data at the NHLS and the national records of notifications at the DOH for the period, 1 January 2013 to 31 December 2013, on the three tracer diseases, captured them into

Microsoft Excel spreadsheets. I cleaned and coded the data in Microsoft Excel. The data were password protected on a computer that only the researcher had access to in order to ensure confidentiality. Microsoft Excel was used to determine some of the system attributes (as discussed below) and the data were exported into STATA® 14 for further analysis. Figure 3.2 shows the development of the record review form, data capturing and data management of study II.

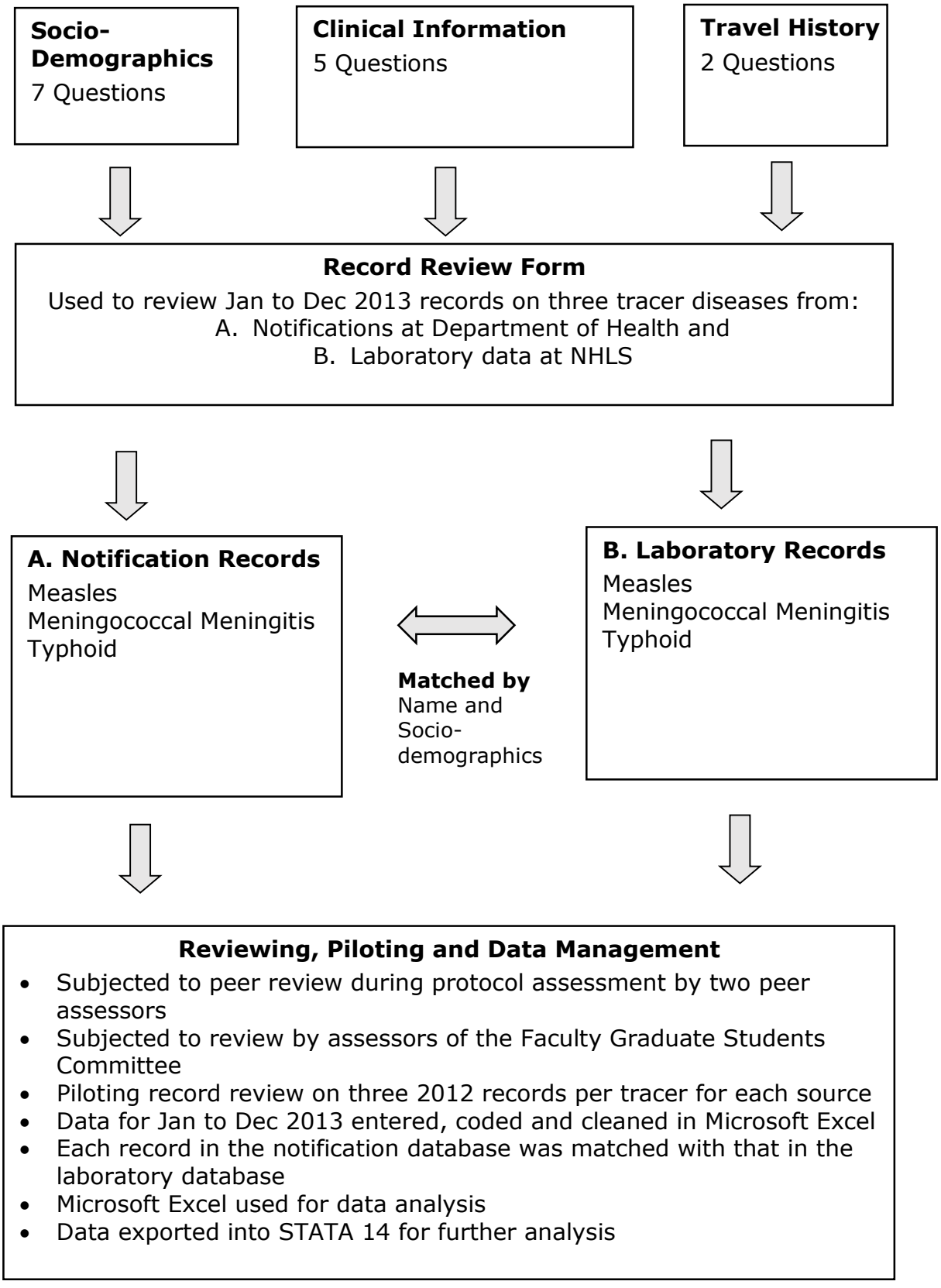


Figure 3.2: Development of record review form, data capturing and data management of Study II

3.7 Study III

The methods used in study III are summarized below and discussed further in Chapter 6.

3.7.1 Study population

The study population consisted of all health care providers (HCPs), specifically doctors and professional nurses (with four years of training), involved with the identification and notification of communicable diseases at institutional level in both the public and private health sectors. These providers include: primary health care (PHC) clinicians; frontline hospital clinicians (in medical casualty, medical and paediatric out-patients' departments, internal medicine and paediatrics); infection prevention and control nurses at hospitals; and GPs.

Enrolled and student nurses were excluded from the study, because they are not involved in the notification of infectious diseases.

3.7.2 Sampling

The sample size was estimated using Epi Info statistical software, version 7.2, for population surveys, assuming: a) the acceptable margin of error as $\pm$ 5%; b) approximately 40% would notify correctly (estimated from a previous Gauteng study [84]); and c) design effect of 2.5 to account for clustering effects (this is conservative). This required an overall sample size of 936 HCPs. To allow for a non-response of 10% I targeted 1,050 HCPs. Figure 3.3 shows the sampling approach used in study III.

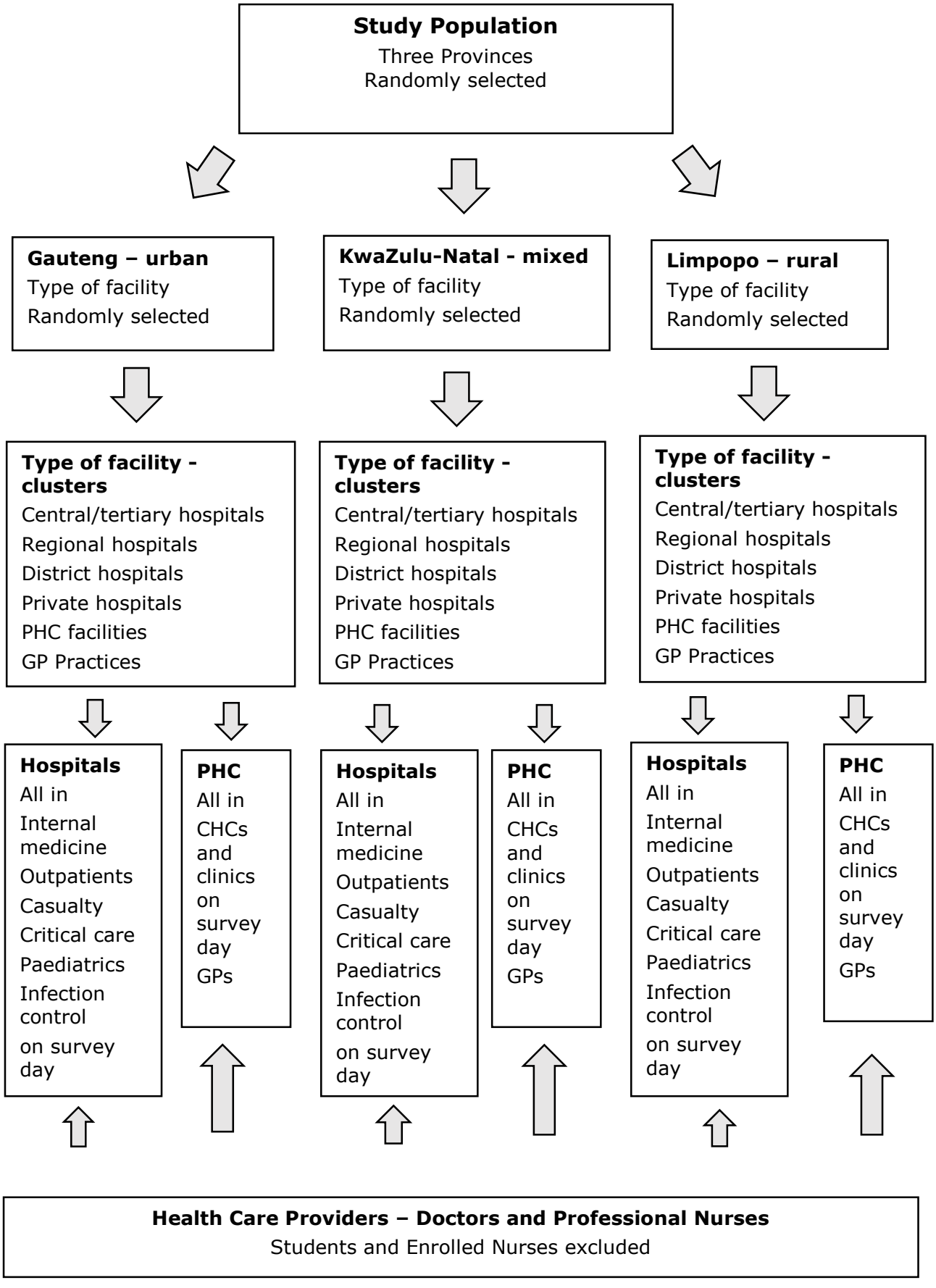


Figure 3.3: Sampling approach used in Study III

Three of the nine provinces were selected randomly, and the final sample consisted of the provinces of Gauteng (urban), KwaZulu-Natal (mixed urban-rural) and Limpopo (rural). I then stratified by type of health facilities, namely central /tertiary hospitals, regional hospitals, district hospitals, primary health care facility (which included community health centres (CHCs) and clinics), private hospitals and private general practitioners (GPs). Satellite and mobile clinics (as they operate only for a few hours per week and therefore see a very limited number of patients), as well as private hospitals with fewer than 100 beds (which have limited scope and practices, and do not have the targeted health disciplines that deal with the NDSS) were excluded from the study.

The target sample size for each province was chosen proportional to the number of HCPs in that province. In order to select the number of facilities of each type to be sampled in each province, I assumed an average number of HCPs for that facility (e.g. I assumed that at each clinic around seven HCPs would be present on the day of the survey); a pre-specified number was chosen to lead to an overall sample of 1050 HCPs. This allowed us to select a sample of facilities randomly in each province.

In each sampled facility, all nurses and doctors who worked in the divisions of internal medicine, out-patients, medical casualty, critical care, paediatrics and infection control units were targeted on the survey day. In PHC facilities all nurses and doctors were requested to participate in the study. I also randomly selected 70 general practitioners (GPs) in private practice as part of the private sector facilities: 20 in Gauteng province, 20 in Limpopo and 30 in KwaZulu-Natal, using an electronic database of private GPs. Sampling weights were calculated based on the total number of HCPs in each stratum.

3.7.3 Development of data collection tool

I could not find a standardised tool to measure HCP compliance and perceptions on national NDSS. I therefore designed an information sheet (Appendix 7) and adapted the questionnaire developed for key stakeholders (section 3.6.3) for use by HCPs (Appendix 10). The questionnaire was developed in English, the official business language of South Africa, to measure compliance with the NDSS as well as factors associated with compliance, as reported in the literature. Figure 3.4 outlines the development of the questionnaire.

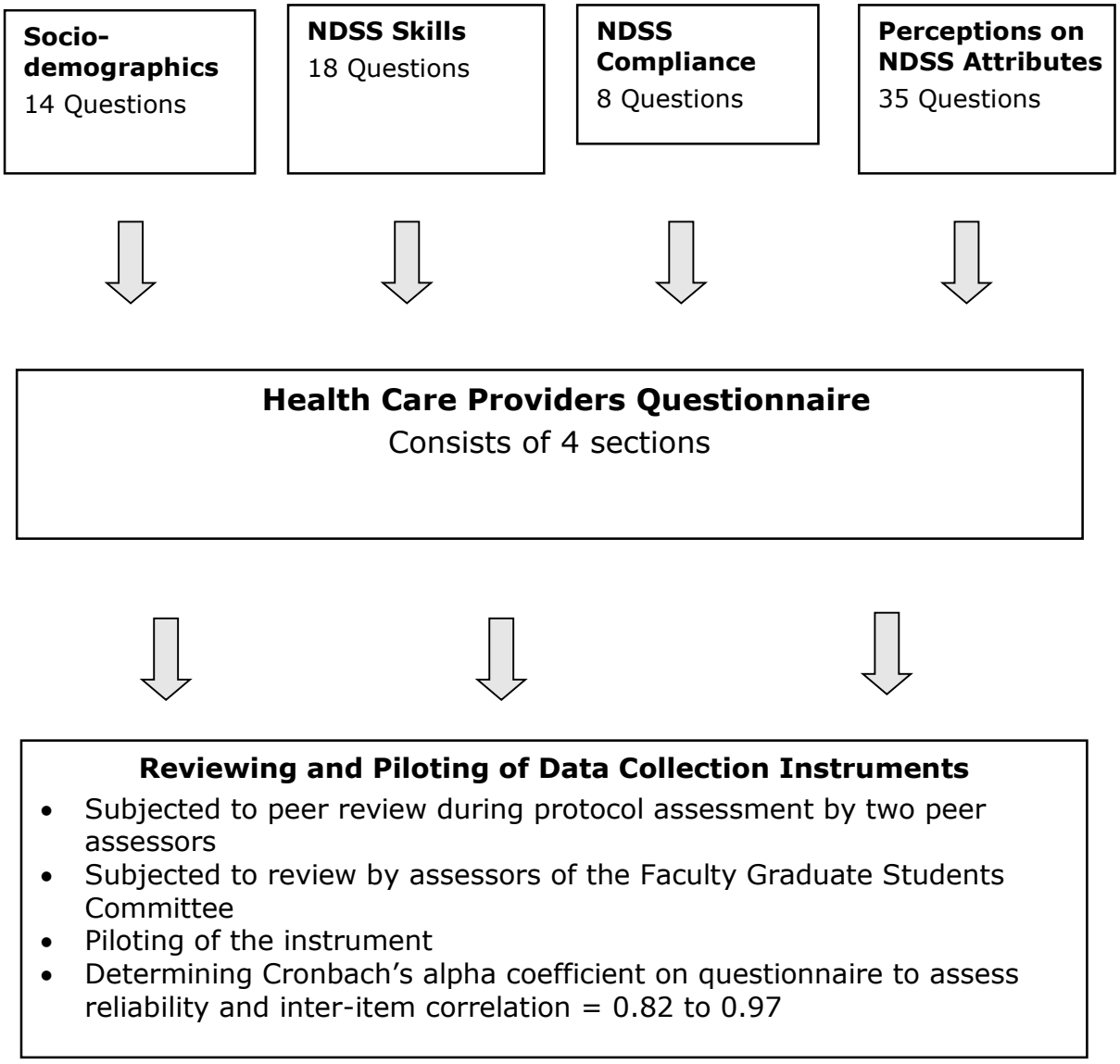


Figure 3.4: Development of the HCP data collection instrument

3.7.4 Piloting of data collection instruments

The questionnaire was piloted amongst three HCPs, similar to the study population, prior to data collection, to determine clarity of questions and time taken for administration. It took an average of 20 minutes to complete and no changes were deemed necessary upon completion of the pilot study. The questionnaires completed in the pilot studies were excluded from the main study.

3.7.5 Determining reliability and inter-item correlation

Cronbach's alpha coefficients were calculated on the HCP questionnaire to determine reliability and coherence between items. The results were similar to the key stakeholders' questionnaire and ranged from 0.82 to 0.97, indicating high reliability and inter-item correlation.

3.7.6 Data collection

I identified and recruited 12 professional nurses as fieldworkers, five each in Gauteng and KwaZulu-Natal provinces, and two in Limpopo province, through Health Systems Trust, a non-governmental organisation in South Africa. I developed a procedure manual (Appendix 6) and trained each group of fieldworkers over one day on all aspects of the study and data collection. I accompanied each provincial group to two institutions where they needed to collect data, to ensure that they performed as trained and required. The fieldworkers collected data at two central, three tertiary, seven regional and eight district hospitals, as well as 11 CHCs and 38 clinics in the public sector. In the private sector, they collected data from 18 hospitals. I took responsibility for ensuring procedures were adhered to and overall quality assurance. I provided my contact details to all fieldworkers and participants and remained in contact for consultation and questions as they arose (further information is provided in Chapter 6).

3.7.7 Data management and capturing

Responses from the HCPs questionnaire of Study III were checked for quality and completeness by a trained senior fieldworker per province, sealed in an envelope and hand delivered (in the case of Gauteng province), or couriered (in the case of the other two provinces) to the researcher. Two data capturers were recruited and trained to double capture the data into REDCap. This data were checked again for quality, cleaned and coded. The data were password protected and only the researcher had access to this password – data capturers had limited access to REDCap to ensure the double capturing of data.

3.8 Data analysis

Data were exported into STATA® 14 for further cleaning and analysis. Data analysis is outlined in Table 3.4 and is described further in Chapters 4, 5 and 6.

Table 3.4: Outline of Data Analysis

Sections	Study 1	Study 2	Study 3
Data Cleaning	Imported, coded and cleaned in STATA® 14	Coded and Cleaned in Microsoft Excel	Imported, coded and cleaned in STATA® 14
Socio-Demographic Tables	Descriptive statistics - Frequencies and percentages of categorical data Medians and Interquartile ranges of continuous data	Descriptive statistics - Frequencies and percentages of categorical data Medians and Interquartile ranges of continuous data	Descriptive statistics - Frequencies and percentages of categorical data Medians and Interquartile ranges of continuous data
Perceptions/ System Attributes	Descriptive statistics – Percentages of who agreed/ disagreed with an attribute. Performed sensitivity analysis	Descriptive statistics – Calculated three system attributes as percentages in Microsoft Excel. Determined two attributes as percentages in STATA® 14 Inferential statistics – Chi-square test on two attributes; non-parametric Wilcoxon test on one attribute Sensitivity analysis performed	Not Done
Practices	Not applicable	Not applicable	Descriptive statistics - frequencies and weighted percentages of diagnosis and notification Inferential statistics - the

Sections	Study 1	Study 2	Study 3
			Rao-Scott correction to the Chi-square test to compare public and private systems
Factors associated with attributes / practices	Unconditional multiple logistic regression model at significance level of 0.05	Not applicable	Robust survey logistic regression at a significance level of 0.05

I computed frequency and summary tables to describe participants' age, gender, location, professional category, experience and training on the NDSS. I summarized categorical variables in tables showing frequency and percentages and numerical variables using medians (inter-quartile ranges).

I used the Chi-square test (the Rao-Scott correction to the Chi-square test [204] in study III) to compare groups with each other. I determined whether participants' age, gender, experience, training, professional category, sector and place of employment, workload, possession of notification forms, knowledge of the NDSS were associated with each of the NDSS attributes (study I) or correctly notifying (study III) using the unconditional multiple logistic regression model and robust survey logistic regression respectively. The outcome variables were whether the participant agreed with the attribute or not (study I) or correct notification of relevant disease/s (study III). I calculated odds ratios (OR), 95% confidence intervals (95% CI) and p-values. P-values of less than 0.05 were considered to be statistically significant.

3.9 Integration of the key findings from studies I, II and III

I summarised and integrated the key results of studies I, II and III, as well as the results of the analysis described above, using the conceptual framework of the PhD. I used three of the four triangulation strategies, namely: methodological, data, and theoretical triangulation [205-207]. Methodological triangulation was done through conducting two cross-sectional surveys, one among key stakeholders/policy actors and the other among health care providers, as well as a review of 2013 notifications and laboratory records for three tracer diseases. Data triangulation was done through collecting and comparing data from two sources in the record review, as well as contrasting this to the data collected in the surveys. I used theoretical triangulation in deriving a conceptual framework that draws on the WHO health systems model [101], the IDSR [24] and the CDC frameworks [88] for the assessment of surveillance systems

3.10 Study Limitations and prevention/amelioration

3.10.1 Cross-sectional nature of the surveys

The main limitation of the cross-sectional nature of the two surveys, which were done over the period April to June 2015, is that it gives a picture of what the perceptions of key stakeholders and HCPs were at the time of the study. These views may have changed since the surveys have been conducted. However, they were balanced by the more longitudinal nature of the record review. Furthermore, they provide important information on the views of key policy actors on the NDSS.

3.10.2 Social desirability bias

The two surveys were reliant on the perceptions and reporting of key informants and HCPs which were subject to social desirability bias and may have resulted in over- or under-reporting [208]. However, the questions were phrased in such a manner as to get truthful responses. These were again balanced by the comparative analysis of three tracer conditions that examined attributes of the system between the actual notification system and the laboratory records.

3.10.3 Selection bias

The study setting for studies I and II represents the entire country and is therefore generalisable. However, the setting for study III represents three of the nine provinces and the inclusion of the urban, rural and mixed urban-rural provinces. This study may be affected by a selection bias. However, clusters of HCPs were randomly selected per type of health facility in proportion to their number in each province. The novel nature of the study, the high number of 1,050 HCPs recruited, and the high response rate of 90%, present an objective evaluation of HCPs compliance with the NDSS

3.10.4 Data limitations

There were limitations arising from the data collected, which were addressed in the analysis of data through sensitivity analyses, as described in the relevant papers and in Chapters 4 and 5. The first issue that arose was in study I, with the number of key stakeholders that answered neither agreed nor disagreed to a statement on the attributes of the NDSS. Three scenarios were assumed in sensitivity analysis: in Scenario I the total number of stakeholders that gave this answer was excluded from the analysis; in Scenario II the total number of stakeholders that gave this answer was assumed to have agreed to the statement and added to this figure in the analysis; and in Scenario III these stakeholders were assumed

to have disagreed and added to those in the analysis as described in Chapter 4.

The second issue was with the percentage of cases in the notification records that could not be matched to the cases in the laboratory records due to insufficient information in Study II. Similarly were three scenarios assumed in sensitivity analysis to address this problem: these records were first excluded from the analysis in Scenario I; in Scenario II the records were regarded as positive in the data analysis; and in Scenario III the records were regarded as negative in the analysis, as described in Chapter 5.

Hence the analysis dealt adequately with the data limitations.

3.11 Strengths of the PhD study

3.11.1 Scholarly contribution

This study is the first systematic and objective evaluation of the national NDSS in South Africa since its inception in 1977, and since the adoption of the WHO strategies on IDSR and the 2005 IHR. The study has generated new knowledge on the present status of the NDSS in South Africa at a time when the Ebola outbreak underscored the importance of these surveillance systems to national and global health security [209].

Studies I and II had a national coverage and are therefore representative of the entire country. Study III covered 77 randomly selected institutions, both in the public and private sectors, as well as 70 randomly selected GP practices in three provinces. Each of these provinces represented the urban, rural and urban-rural mix of the provinces in the country.

Both of the surveys had high response rates; study I, 84%; and study III, 90%. The survey conducted as part of study I involved all key stakeholders involved with the NDSS at a national and provincial level, while the survey conducted with the 1,050 HCPs as part of study III was the first such broad study done on the compliance of HCPs in South Africa.

Study III was the first comparative study between the NDSS and laboratory surveillance that employed methodology was new and described by Girdler-Brown as "the first of its kind for South Africa" [210]. It provides the basis for future research in the country and the broader scientific community; it was further described as "important, both for the southern African region as well as more widely" [Girdler-Brown, 2017:140][210].

3.11.2 Policy relevance

A well-functioning NDSS is not only important in the fight against the emergence and re-emergence of infectious disease epidemics. It is also vital to the monitoring and evaluation of public health interventions, and can assist with resource allocation decisions [210]. An effective and efficient system has major public health policy relevance. This current research study into the status of the NDSS is aimed at informing policy interventions to ensure a well-functioning surveillance system in South Africa.

CHAPTER 4. SURVEY OF THE PERCEPTIONS OF KEY STAKEHOLDERS ON THE ATTRIBUTES OF THE SOUTH AFRICAN NOTIFIABLE DISEASES SURVEILLANCE SYSTEM

4.1 Background

Notifiable disease surveillance systems (NDSS) in the 21st century should be capable of rapid identification of priority diseases that cause national, regional or public health emergencies of international concern (PHEIC). An effective and efficient NDSS could enhance the ability of a country to respond rapidly to outbreaks before they become PHEICs. Regular evaluations of the surveillance system are needed to ensure this capability, as well as relevance and usage by the key stakeholders. Furthermore, the PHEICs caused by the Ebola Virus Disease (EVD) outbreak from 2014 to 2016 [73] and the 2016 Zika virus outbreak [211] demonstrated that the status of the NDSS in each country could impact on global health security. Hence the outcome of NDSS evaluations is of relevance to the global community.

At a global level, an independent panel appointed by the World Health Organization (WHO) in response to the EVD outbreak found that countries failed to develop International Health Regulations (IHR) surveillance core capacities [77]. The panel also questioned the reliability of the annual mandatory self-administered IHR assessment questionnaires that are required by WHO of all member states [77]. These findings underscore the need for objective evaluations of the NDSS at country level. Many countries have begun to use to framework developed by the Centers for Disease Control and Prevention (CDC) to evaluate their surveillance systems [88].

In high-income countries in Europe [119] and Australasia [120, 121], evaluations of the NDSS have focused on data quality, usefulness, acceptability, timeliness, as well as the simplicity of the system. Studies in low- and middle-income countries in the Americas [122, 123], Europe [124], Asia [125], and Africa [126-128], have found that challenges with laboratories, supervision, monitoring, organisational capacity, staffing and resources impede NDSS functioning. These findings might not be relevant to South Africa as a comparative study of the NDSS in China and the USA found that differences in context, background and resource availability among countries make it difficult to generalize findings from one country to the other [212].

The NDSS in South Africa has been in existence since the late 1970s. The NDSS in South Africa is a paper-based system that tracks 33 medical conditions. In terms of existing legislation, all health care providers are obliged to notify these 33 conditions to their local authority, which in turn reports it to the district, district to province, and province to the NDOH (Chapter 1) [55]. In the preceding 15 years, parallel surveillance systems have been developed for tuberculosis (TB), malaria and vaccine-preventable notifiable diseases. We could only find three evaluations of specific diseases at provincial level in South Africa [84-86]. However, there has been no systematic and objective evaluation of the NDSS at the national level or an evaluation of the NDSS since the adoption of the IHR in 2007. The need for such an evaluation is critical, in light of health sector reforms in South Africa, which include the implementation of a National Health Insurance System [51] and the establishment of a National Public Health Institute [53].

The involvement of key NDSS stakeholders in evaluations and policy development is critical to obtain their inputs and to build mutual understanding and trust [106-108]. In this paper, the term stakeholder is used to describe individuals actively involved in the NDSS, or in structures

and committees set up to deal with any aspect of the NDSS in South Africa. The stakeholders include individuals involved in disease control and response; disease detection; and health management.

As part of a broader evaluation of the NDSS in South Africa, a survey was conducted among key stakeholders in South Africa on their perceptions of the NDSS attributes of acceptability, flexibility, simplicity, timeliness and usefulness.

4.2 Methods

During April and May 2015, we invited all communicable diseases coordinators, epidemiologists and surveillance officers at the National Department of Health (NDOH) and all nine provincial health departments, as well as members of the National Surveillance Forum, the South African Malaria Elimination Committee, the South African Expanded Programme on Immunisations Committee and the National and Provincial Outbreak Response Teams (NORT and PORT respectively), to participate in a cross-sectional survey. Exclusions were as stated in the previous chapter.

4.2.1 Measurement and data collection

We used an electronic questionnaire in REDCap to elicit information on participants' perceptions of the NDSS attributes of acceptability, flexibility, simplicity, timeliness and usefulness [88], in addition to socio-demographic information.

The questionnaire consisted of one to four questions per attribute for each of the five system attributes. The questions were designed on a 7-point Likert-scale ranging from 1 (strongly disagree) to 7 (strongly agree). The questions were phrased in a manner that attempted to minimise an unreflective response by participants, for instance questions requiring a positive response were alternated with questions requiring negative

responses so that respondents would not be tempted to continue answering all the questions using the same response. Cronbach's alpha coefficients were calculated to determine reliability and coherence between items and ranged from 0.82 to 0.97, indicating high reliability and inter-item correlation.

On 7 April 2015, we sent electronic invitations for participation in the survey to all identified key stakeholders. The information sheet was the first page of the questionnaire, as well as a consent or opt out option. We sent four reminders to participants who did not respond after two weeks and we closed the survey on 31 May 2015, after 54 days from the enrolment date.

4.2.2 Data Analysis

We captured data entered by participants in REDCap and exported the data into STATA® 14 for cleaning and analysis.

We analysed responses from 7-point Likert scale attribute questions by describing the frequency distribution for each point on the scale. In order to simplify the interpretation of the results, we then categorized the responses to each question on NDSS attributes as agree or disagree. We excluded the 'neither agree nor disagree' response in the analysis. We then computed the percentage of respondents who agreed with a particular attribute. We conducted a sensitivity analysis using two additional scenarios: in 'scenario 2', we combined the responses of participants who indicated 'neither agree nor disagree' with the responses of those participants who indicated 'agree' to the questions; in 'scenario 3', we combined the responses of participants who indicated 'neither agree nor disagree' with the responses of those participants who indicated 'disagree' to the questions. In the final stage of the analysis, we determined whether participants' age, experience, training and roles with regards to the NDSS were associated with each of the attributes using the unconditional logistic regression model.

4.3 Results

4.3.1 Key stakeholders' socio-demographic information

We enrolled a total of 141 participants and obtained a response rate of 84%. After excluding those who did not give consent (n=11), worked in a non-health related field (n=9), and with less than one year's experience with the NDSS (n=7), the final sample size was 114. The median age of key stakeholders was 49 years, ranging from 26 to 69 years. The median number of years of experience in the NDSS was 11 years (inter-quartile range (IQR): 5 to 20 years). The median duration of NDSS training was 2 weeks. Most of the key stakeholders who participated in NDSS committees, participated in the NORT (43%).

Key stakeholders' areas of work responsibilities were regrouped into disease control and response (communicable disease co-ordinators and public health officials); disease detection (epidemiologists, surveillance officers and pathologists); health management (general health managers); and others (undetermined responsibility in the NDSS). Most key stakeholders were involved in disease control and response (53%), and these stakeholders were younger, with a median age of 41 years, compared to 55 years in the health management group (Table 4.1).

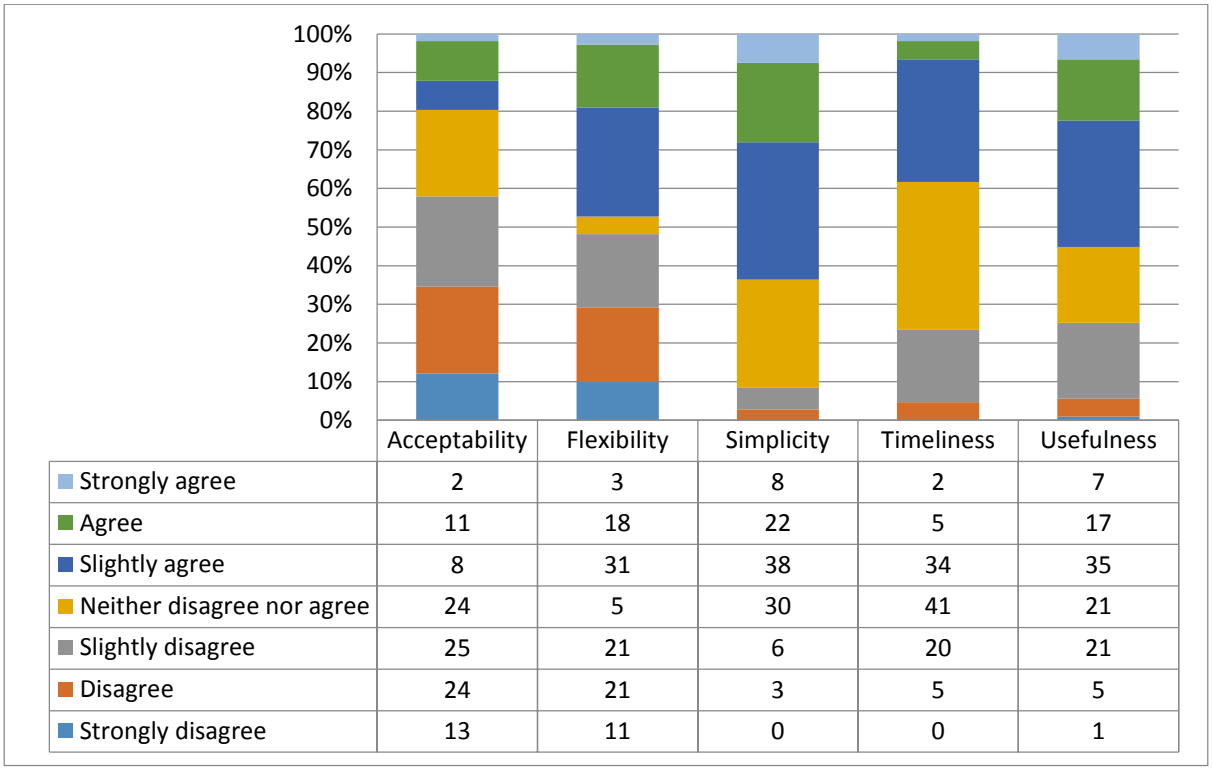
Table 4.1: Socio-demographic characteristics of the sample of key stakeholders of the South African Notifiable Diseases Surveillance System, April - May in 2015

Socio- demographic Characteristics (N= 114)	**N (%)**
Age (years)	
25-34	14 (13%)
35-44	30 (27%)
45-54	31 (28%)
55-64	33 (30%)
65-69	3 (3%)
Experience in NDSS (years)	
1-5	31 (27%)
6-10	24 (21%)
11-15	19 (17%)
16-20	13 (11%)
21-25	9 (8%)
>25	18 (16%)
Training in the NDSS	70 (61%)
Duration of Training in NDSS	
<= 1 week	31 (46%)
2 to 4 weeks	21 (31%)
5 to 12 weeks	7 (10%)
13 to 26 weeks	3 (4%)
27 to 56 weeks	5 (7%)
57 to 104 weeks	1 1%)
Participation on NDSS Committees	
National Outbreak Response Team	46 (43%)
Provincial Outbreak Response Team	26 (25%)
Malaria Elimination Committee	21 (21%)
Surveillance Forum	22 (22%)
EPI Committee	19 (19%)
Area of Responsibility	
Health Management	10 (9%)
Disease Detection	38 (33%)
Disease Control and Response	60 (53%)
Other	6 (5%)

NDSS = Notifiable disease Surveillance System
*Not all participants answered all questions, and some participated in more than one committee

4.3.2 Perceptions on the NDSS attributes

The proportion of participants who strongly agreed with any of the attributes was small, with the highest value of 7.5% for simplicity. The proportion of participants who agreed was slightly higher at around 10% except for timeliness. An even higher proportion slightly agreed, at around 30%, with the exception of acceptability. The proportion of participants who neither agreed nor disagreed was also around 30% for all attributes with the exception of flexibility. The proportion of those who slightly disagree were higher in all attributes with the exception of simplicity. The proportion of those who either disagreed or strongly disagreed was higher for acceptability and flexibility, but negligible for the other attributes. The perceptions of participants for each attribute are shown in Figure 4.1.



	Acceptability	Flexibility	Simplicity	Timeliness	Usefulness
Strongly agree	2	3	8	2	7
Agree	11	18	22	5	17
Slightly agree	8	31	38	34	35
Neither disagree nor agree	24	5	30	41	21
Slightly disagree	25	21	6	20	21
Disagree	24	21	3	5	5
Strongly disagree	13	11	0	0	1

Figure 4.1: Perceptions of a sample of South African Notifiable Diseases Surveillance System stakeholders on the system attributes, April 2015

After categorising the responses into agree/disagree and excluding those that neither agreed or disagreed, we found that 25% of the stakeholders perceived the NDSS to be acceptable, 51% to be flexible, 74% to be simple, 45% to be timely, , and 61% to be useful . A higher percentage of participants in Health Management perceived the system to be simple, useful and timely. Participants from the 'Other' category that includes those with an undetermined responsibility in the NDSS, perceived the system to be more flexible. Similarly, stakeholders participating in PORT perceived the system to be more simple and useful, compared to those in other NDSS committees. (Table 4.2)

Table 4.2: Key stakeholders' perceptions on the attributes of the South African Notifiable Diseases Surveillance System by role, training and participation on committees in 2015,

(%)	Acceptability	Flexibility	Simplicity	Timeliness	Usefulness
Overall sample (N=107*)	25	51	74	45	61
Area of Responsibility					
Health Management	14	50	100	86	100
Disease Detection	30	44	75	38	56
Disease Control and Response	27	50	72	46	58
Other	0	100	50	0	60
Training in the NDSS	29	61	77	41	68
Participation on NDSS Committees					
National Outbreak Response Team	29	49	70	45	50
Provincial Outbreak Response Team	23	53	100	52	79
Malaria Elimination Committee	13	64	71	33	67
Surveillance Forum	30	50	74	47	57
EPI Committee	31	57	73	35	61

NDSS = Notifiable disease Surveillance System
* = 7 participants did not record their perceptions on the NDSS
EPI = Expanded Programme on Immunisations

The results of the sensitivity analysis showed that the scores on simplicity and timeliness were higher in Scenario 2, when "neither agreed nor disagreed" were added to "agreed". (Table 4.3)

Table 4.3: Sensitivity Analysis of Key stakeholders' perceptions on the attributes of the South African Notifiable Diseases Surveillance System in 2015.

(%) N=107	Acceptability	Flexibility	Simplicity	Timeliness	Usefulness
Scenario 1: used in the study – "Neither agree nor disagree" excluded	25	51	74	45	61
Scenario 2 : "Neither agreed nor disagreed" included as part of "agree"	42	65	92	77	75
Scenario 3 : "Neither agree nor disagree" included as "disagree"	20	36	64	38	55

Scenario 1 was used to determine the factors influencing key stakeholders' perceptions on specific attributes of the NDSS. The logistic regression analysis revealed that the stakeholders with more years of experience were significantly less likely to perceive the NDSS system as acceptable (OR 0.91, 95% CI: 0.84 - 1.00, p=0.041). Participants working in disease detection were less likely to perceive the NDSS as timely (OR 0.10, 95% CI: 0.01 - 0.96, p=0.046), while those participating in NORT were less likely to perceive the NDSS as useful (OR 0.38, 95% CI: 0.16 - 0.93, p=0.034). However, there was no association between years of experience or respondents' place of employment and the stakeholder perceptions on the NDSS attributes of flexibility and simplicity (Table 4.4).

Table 4.4: Factors associated with the key stakeholders' perceptions on the attributes of acceptability, simplicity, usefulness, flexibility and timeliness of the South African National Diseases Surveillance System in 2015

System Attribute	Factor	Logistic Regression Analysis			Multivariate Analysis		
		Odds Ratio	95% CI	p-value	Odds Ratio	95% C I	p-value
Acceptability	Years of Experience	0.91	0.84 - 1.00	0.041*	0.91	0.84 - 1.00	0.041*
	Participation in NORT	1.21	0.44 - 3.32	0.708			
	Participation in PORT	0.76	0.24 - 2.44	0.651			
	Training in the NDSS	1.36	0.43 - 4.31	0.601			
Flexibility	Training in the NDSS	2.18	0.80 - 5.95	0.129			
Simplicity	Training in the NDSS	1.85	0.67 - 5.09	0.234			
	Participation in NORT	0.75	0.29 - 1.95	0.550			
Timeliness	Participation in NORT	1.17	0.50 - 2.76	0.714			
	Disease Detection	0.10	0.01 - 0.96	0.046*	0.10	0.01 - 0.96	0.046*
Usefulness	Training in the NDSS	2.47	1.00 - 6.07	0.049*	1.98	0.75 - 5.21	0.168
	Participation in NORT	0.41	0.17 - 0.98	0.045*	0.38	0.16 - 0.93	0.034*
	Participation in PORT	2.5	0.83 - 7.56	0.105			

*p values significant at 5% level 95% CI = 95% Confidence Interval;
PORT = Provincial Outbreak Response Team;
NORT = National Outbreak Response Team
NDSS = Notifiable Diseases Surveillance System

In Scenario 2, participants younger than 35 years were more likely to perceive the NDSS as acceptable (OR 0.96, 95% CI 0.92 - 0.99, p-value 0.044) and those trained in the NDSS perceived the system to be simpler (OR 4.74, 95% CI 1.17 - 19.33 p-value 0.030).

4.4 Discussion

Our findings indicate that 25% of key stakeholders perceived the NDSS to be acceptable, 51% to be flexible, 74% to be simple, 45% to be timely, and 61% to be useful. Overall, these findings contrast with the 2014 self-administered questionnaire that South Africa submitted to the WHO on the implementation of the IHR core competencies in which it scored 100% in surveillance core capacity [59]. The variation in scores could be explained by the different methodologies used, the differences in study periods, and because the 2014/16 EVD outbreak in West Africa could have influenced the perceptions of key stakeholders in this study.

The NDSS perceptions of key stakeholders in this study differed from the experience of the successful containment of several high profile outbreaks in South Africa since 2008, which included a novel arena virus, Lujovirus [213]; a major cholera outbreak [60, 62]; influenza pandemic [68]; a Rift Valley Fever outbreak [214]; and a measles outbreak [215]. However, the high media attention during these events could have increased the index of suspicion and sensitivity of the surveillance system, which might not be a true reflection of the South African NDSS. Laboratories, which are not obliged by current legislation to notify diseases, may also provide information during high profile outbreaks which contribute to enhanced surveillance during these periods. Nonetheless the difference in the findings of this study and the 2014 IHR report indicates the need for more objective IHR core capacity assessments.

The study found that only 25% of the stakeholders perceived the system to be acceptable, which implies that the stakeholders may be unwilling to participate in the system. This score of less than 50% is similar to the finding of the 2007 study in one South African province, which found that 37% of general practitioners indicated that they complied with the NDSS (reflection of acceptability) [84]. Comparing acceptability against the German NDSS [130] score of 90%, the South African NDSS score was

significantly lower. The participation of the health care providers is essential to ensure an effective and efficient system. Hence, this attribute needs to be addressed in the reform of the South African NDSS.

Only 51% of key stakeholders perceived the system to be flexible, implying that there are problems with the adaptability of the NDSS to changing circumstances and needs. This finding is similar to that of a qualitative evaluation study on TB surveillance in one district in the Western Cape Province of South Africa that found that although the software used was adaptable, the system did not adjust according to the changing needs [86]. It should be noted that TB has an electronic surveillance system, whereas the surveillance system for all other notifiable diseases is paper-based. Although a comparison with TB surveillance should be made with caution due to these technological differences, the adaptability of the NDSS to the development of new technology appears to lag behind. This suggests the future use of an electronic NDSS system that is responsive to the needs of various stakeholders.

In this study, simplicity obtained the highest score of 74% compared to the other NDSS attributes. This finding is comparable to a study on the Australian NDSS system in 2004 [120] which rated their operations and processes as complex. The introduction of a simple electronic NDSS system in South Africa could potentially address the perceived complexities of the NDSS [216] and also increase efficiency. The timeliness score of 45% is also lower compared to the findings of a 2010 Ugandan study that found a score of 68%-73% [126]. Although the different methodologies of the two studies may account for the differences, the lower score in our study may imply that many health care providers and public health officials do not take prompt appropriate steps when an increase in specific diseases come to their attention through the NDSS. As prompt action is essential to contain any outbreak, timeliness must be addressed in the future reforms of the South African NDSS.

The usefulness score of 61% was also lower than the one obtained in the Australian study that found that 94% of participants reported reading NDSS reports and 85% reported using the data [55]. This may indicate that there are gaps in South Africa in the utilisation of the NDSS data for outbreak response, or for prevention and control of communicable diseases. This attribute must therefore be addressed in the reform of the South African NDSS.

When considering perceptions in terms of responsibility in the system, those stakeholders involved at an operational level (disease detection and response) scored the usefulness, simplicity and timeliness of the NDSS lower than those in health management. The perceptions of health management may be an overestimation because they may have regarded the NDSS evaluation as a reflection of their own performance. Hence the scores may reflect social desirability bias. In terms of participation in NDSS committees, those participating in the provincial committees, PORT, scored the simplicity and usefulness of the NDSS higher than those in national committees. As is the case with health management, social desirability bias may again have played a role here as provinces are mainly responsible for the NDSS implementation.

Results from the logistic regression analysis showed that the stakeholders in disease detection and national committees, NORT, involved with oversight of the system, as well as those with more years of experience with the system were less likely to perceive the NDSS as acceptable, timely or useful. This may represent a true reflection of the level of functioning of the system as the surveillance officers, epidemiologists, pathologists, communicable disease coordinators and public health officials are involved with the NDSS on a daily basis in an operational and monitoring capacity – the acceptability, timeliness and usefulness of the NDSS have direct application to their daily work. On the other hand, the perceptions of oversight structures may be a reflection of their distance from the operational functioning of the NDSS.

Although the result of the sensitivity analysis in Scenario 2 showed an increase in timeliness to 77%, this would not alter our conclusion as it still fall below a level that could be regarded as satisfactory for the effective function of the NDSS. However, in Scenario 2, a score of 92% for simplicity is very good, and implies that no intervention is needed to improve the simplicity of the NDSS.

With regard to factors found to be associated with the perceptions in Scenario 2, the finding that training was associated with simplicity imply that addressing training needs would increase the understanding of the processes and forms used in the system. The finding that participants younger than 35 years found the system more acceptable, should inform additional training and feedback that should be used to revitalise the NDSS. Training and feedback influence the value that stakeholders at the coalface attach to the system and affect their willingness to participate in it. Without the participation of stakeholders at all levels the NDSS cannot fulfil its purpose.

4.5 Limitations of the study

The main limitation of this study was that it was based on the perceptions of individuals and not on the actual records of notifications, which is the focus of another study. Perceptions are influenced by social desirability bias among stakeholders surveyed. Although every attempt was made to include all the relevant key stakeholders at national and provincial levels, some stakeholders may not have been identified. The findings of this study will be validated through further studies on the actual records of notifications. Another limitation was the dearth of national or provincial studies on the South African NDSS to compare the research findings with.

4.6 Conclusions

The study findings suggest the need for reforms of the South African NDSS, with particular focus on the attributes of acceptability, flexibility, timeliness and usefulness. We recommend the phased introduction of an electronic system that includes the use of mobile telephone technology to address the current perceived weaknesses in the NDSS attributes. This is because the latter has a high penetration in the South African population. In 2015 there have been some encouraging developments with regard to malaria surveillance [217] that could be built upon. The 2014-2016 EVD outbreak and the current Zika virus outbreak provide a window of opportunity that should be used to strengthen the NDSS system. We further recommend additional training and feedback to all stakeholders in the system.

At a global level, the findings of this study indicate a need for objective evaluations in support of annual IHR country submissions to the WHO. We recommend that objective assessments, using the baseline data provided in this study, be conducted every three to five years. This should be complemented with comparative studies of notification versus laboratory surveillance to provide a comprehensive evaluation of the NDSS in South Africa.

Authors' contributions

Conceived and designed the research concept: FGB, AM, LB and LCR. Analysed data: FGB and AM with input from LCR. Contributed to the writing of the manuscript: FGB, AM, LB and LCR. All authors read and approved the final manuscript.

CHAPTER 5. COMPARING LABORATORY SURVEILLANCE WITH THE NOTIFIABLE DISEASES SURVEILLANCE SYSTEM IN SOUTH AFRICA

5.1 Introduction

An effective notifiable diseases surveillance system (NDSS) is essential for any country to respond to communicable disease outbreaks [218]. Outbreaks of emerging and re-emerging communicable diseases threaten the health and wellbeing of communities and when uncontrolled can lead to a global threat. National and global disease vulnerabilities were demonstrated by the 2014 to 2016 Ebola Virus Disease outbreak [219], the 2016 Zika virus [220] and the 2016 yellow fever outbreaks [7]. When a country deals effectively with an outbreak at source, it prevents the spread of the disease beyond its borders, thus preventing spill-overs into neighbouring countries and beyond.

All countries need to evaluate their surveillance system regularly to ensure an effective NDSS. Several countries have done so using the 2001 framework developed by the United States Centers for Disease Control and Prevention [88]. A 2009 review of NDSS evaluations in 20 high-income countries (HICs) and 12 low- and middle-income countries (LMIC) found weaknesses in data quality in HICs, resource constraints, health infrastructure challenges and sub-optimal NDSS functioning in LMIC [118]. Several comparative studies have examined the attributes of surveillance systems [142, 144, 154, 155, 157-160], including comparisons of electronic reporting versus traditional reporting systems [144, 154, 155], different electronic systems with each other [157, 158], and active surveillance with passive surveillance systems [159, 160]. In Africa, evaluation studies have focused on the implementation of the integrated disease surveillance and response (IDSR) [127-129]. These studies support

the findings of the 2009 NDSS review that health system challenges impede the effective functioning of the NDSS [118].

South Africa is a member state of the World Health Organization (WHO) that adopted the IDSR in 1998, but is one of the few African countries that has never implemented the IDSR. The NDSS in South Africa is a paper-based system that tracks 33 medical conditions. In terms of existing legislation, all health care providers are obliged to notify these conditions to their local authority, who in turn reports it to the district, district to province, and province to national [55]. The NDSS relies on the clinical skills of health care providers to diagnose the list of communicable diseases based on clinical suspicion and to request laboratory confirmation. Case definitions are only used during outbreaks and for active surveillance [55]. There are no legal provisions for laboratories to notify communicable diseases [56].

There has been no systematic and objective evaluation of the NDSS in South Africa since its inception in the 1970s. There have only been a few evaluations of the surveillance systems at provincial level in South Africa [84-86], one on the NDSS in one South African province and two evaluation studies on tuberculosis (TB) surveillance in two Western Cape districts. These studies were focused on limited settings and hence cannot be generalised to the entire country. Although a South African study compared notifications and laboratory surveillance for hepatitis B for the period 1985 – 1988 [166], this was more than 28 years ago, and the South African health system has undergone major changes since the 1980s. South Africa is in the process of reforming its health system through the phased introduction of a National Health Insurance system [51], and the establishment a National Public Health Institute that will be responsible for disease surveillance [53]. An evaluation of the current status of the NDSS is timely and will feed into the reform processes.

There is a dearth of studies, especially in low-and middle-income countries that compare national notification systems with laboratory surveillance because many countries require and rely on laboratories to report notifiable diseases. We could only find one 2005 Swedish study that compared the parallel systems of clinical and laboratory notifications [142].

The purpose of this study was to describe and compare the South African NDSS and laboratory system attributes of data quality, stability, representativeness, sensitivity and positive predictive value (PPV) for the tracer diseases of measles, meningococcal meningitis and typhoid, as part of a larger doctoral study aimed at generating new information on the performance of the NDSS.

5.2 Methods

5.2.1 Study design

This was a retrospective record review of the national public sector laboratory data and the national records of notifications for the study period, 1 January 2013 to 31 December 2013, on the three tracer diseases.

5.2.2 Selection of tracer conditions

The three tracer diseases for the study were measles, meningococcal meningitis, and typhoid. Measles and meningococcal meningitis were selected as they are endemic in all provinces [194, 195], highly contagious, distinct and easily identifiable diseases for which early notification on clinical grounds [55] and a public health response is needed. Measles is also a re-emerging, vaccine-preventable disease, aimed at elimination [196, 197], that had two recent major outbreaks that affected all provinces in 2003-5 [198] and 2009-11 [199-201]. Typhoid is less clinically distinct, but is also endemic in South Africa and has caused considerable morbidity

and mortality, which are largely preventable through public health measures [202, 203]. These factors make the tracers good indicators to measure the attributes of the NDSS.

5.2.3 Measurement and data collection

We included all available data for the study period on the tracer diseases from the two data sources into the study sample. All records with inconclusive diagnostic information were excluded from the laboratory records.

5.2.4 Data Analysis

After data cleaning, we measured data quality (measured by the percentage of completeness of all data on the record review form), as well as stability (reliability of the system in providing a diagnosis – percentage of cases with a diagnostic result) and representativeness (percentage of provinces represented in the system) in Microsoft Excel. We exported the data into STATA® 14 for further analysis. We used the non-parametric Wilcoxon test to compare the completeness of the two systems. We determined reliability and representativeness as indicated above and used the Chi-square test to compare the two systems. All tests were conducted at 5% significance level.

We name-searched and matched (names, age, sex, date and place of occurrence) each positive, negative and case without laboratory result in the NDSS database with the NHLS database to determine sensitivity (the proportion of cases detected by the surveillance system) and PPV (the proportion of reported cases that actually have the communicable disease under surveillance). The NHLS database was used as the gold standard to compare with the NDSS. Table 5.1 shows the calculation of sensitivity and positive predictive value.

Table 5.1: Calculation of Sensitivity and Positive Predictive Value

NDSS	Laboratory Surveillance		TOTAL
	Positive	Negative	
Positive	True Positive (A)	False Positive (B)	A + B
Negative	False Negative (C)	True Negative (D)	C + D
TOTAL	A + C	B + D	

Sensitivity = A/(A +C); Positive Predictive Value = A/(A + B)
NDSS = Notifiable Diseases Surveillance System

We defined true positives as either (1) both positive NDSS and laboratory cases or (2) no result in NDSS and positive laboratory case. We defined true negatives as either (1) negative NDSS cases (suspected cases are notified) and negative laboratory cases or (2) no result in NDSS and negative laboratory case. We defined false positive as positive NDSS cases that were not positive laboratory cases and false negative as NDSS negative cases that were not negative laboratory cases. For unmatched NDSS cases with no results in the laboratory database, we did a sensitivity analysis using the following three scenarios: Scenario I excluded cases without laboratory results from the analysis (this was the selected scenario); Scenario II assumed that these cases were laboratory positive (therefore true positive); Scenario III assumed that these cases were laboratory negative (therefore true negative).

5.3 Results

5.3.1 Socio-demographic information on the tracer diseases

For the study period from 1 January until 31 December 2013, the NHLS recorded 8,310 measles, 8,862 meningococcal and 24,516 typhoid patients

tested. Following exclusion of records with inconclusive diagnoses, the final sample size was 8,228 for measles; 8,714 for meningococcal meningitis and 24,264 for typhoid.

The socio-demographic information of the measles IgM positive cases, *Neisseria meningitides* and *Salmonella typhi* culture positive cases, in comparison to the cases that were notified during the same period are shown in Table 5.2. The number of notified cases is fewer than laboratory cases for all three tracer diseases - measles and meningococcal meningitis were less than 1.5% of the patients tested. Three provinces, Mpumalanga, Northern Cape and North West, provided no notification data on all three diseases; Limpopo province, on meningitis and typhoid ; and Free State province, on typhoid. For meningococcal meningitis and typhoid, most cases fell in the same age-group for both notifications and the laboratory, whereas for measles, most cases fell into different age-groups for the two systems.

Table 5.2: **Socio-demographic factors of laboratory diagnosed versus notified cases with Measles, Meningococcal Meningitis and Typhoid, South Africa, 1 January to 31 December 2013**

Variable	Measles N (%)		Meningococcal Meningitis N (%)		Typhoid N (%)	
	Laboratory	NDSS	Laboratory	NDSS	Laboratory	NDSS
Province						
Eastern Cape	3 (2)	2 (2)	46 (20)	1 (1)	1 (2)	2 (7)
Free State	2 (1)	4 (4)	13 (6)	5 (4)	2 (3)	No data
Gauteng	159 (92)	21 (19)	68 (30)	62 (48)	24 (38)	7 (25)
KwaZulu-Natal	3 (2)	52 (46)	39 (17)	11 (9)	11 (17)	8 (29)
Limpopo	0 (0)	7 (6)	1 (0.4)	No data	0 (0)	No data
Mpumalanga	0 (0)	No data	4 (2)	No data	11 (17)	No data
Northern Cape	1 (1)	No data	2 (1)	No data	0 (0)	No data
North West	1 (1)	No data	7 (3)	No data	1 (2)	No data
Western Cape	4 (2)	27 (24)	50 (22)	49 (38)	14 (22)	11 (39)
Total	173 (100)	113 (100)	230 (100)	128 (100)	64 (100)	28 (100)
Age (years)						
<1	38 (29)	2 (2)	51 (23)	3 (5)	2 (3)	3 (15)
1-4	25 (19)	23 (25)	54 (24)	24 (36)	9 (16)	2 (10)
5-14	13 (10)	57 (63)	44 (19)	17 (26)	16 (28)	5 (25)
15-24	25 (19)	3 (3)	27 (12)	8 (12)	8 (14)	4 (20)
25-34	23 (17)	2 (2)	29 (13)	6 (9)	14 (24)	4 (20)
>=35	9 (7)	4 (4)	22 (10)	8 (12)	8 (14)	2 (10)
Total	133 (100)	91 (100)	227 (100)	66 (100)	57 (100)	20 (100)
Gender						
Female	74 (53)	46 (51)	102 (46)	28 (43)	32 (52)	14 (67)
Male	65 (47)	45 (49)	118 (54)	37 (57)	30 (48)	7 (33)
Total	139 (100)	91 (100)	220 (100)	65 (100)	62 (100)	21 (100)

NDSS = Notifiable diseases surveillance system
Not all cases had socio-demographic information

Of the laboratory cases, 190 meningococcal sero-groups (not shown) were typed, with W135 the most common type 51% (97); no meningococcal sero-groups were recorded in the notification records.

5.3.2 Results on system attributes

The comparative result on the system attributes is shown in Table 5.3. It shows that the completeness for the laboratory was higher than the notified cases for both measles and meningococcal meningitis. The attribute of stability was significantly higher for the laboratory cases for all three tracer diseases, as well as for representativeness of meningitis and typhoid. The

sensitivity of the NDSS ranged from 50% to 98% and the PPV ranged from 20% to 81 % for the three diseases.

Table 5.3: **Comparison of system attributes of notified versus laboratory diagnosed cases of measles, meningococcal meningitis and typhoid for South Africa, 1 January to 31 December 2013**

(1) Attributes	Measles			Meningococcal Meningitis			Typhoid		
	NDSS	Lab	p-value	NDSS	Lab	p-value	NDSS	Lab	p-value
Completeness %									
Median	47	63	<0.001[a]	57	63	<0.001[a]	63	60	0.0818[a]
Range	20-67	37-69		40-80	50–69		40–80	54-67	
Stability %	24	100	<0.001[b]	74	100	<0.001[b]	36	100	<0.001[b]
Representativeness %	67	100	0.058[b]	56	100	0.023[b]	44	100	0.009[b]

(2) Attributes	Measles	Meningococcal Meningitis	Typhoid
Sensitivity %	50	98	93
95% CI	15.7-84.3	90.9-100	66.1-99.8
PPV %	20	57	81
95% CI	5.7-43.7	46.7-66.6	54.4-96.0

(1) Attributes were determined using the full dataset of notified and laboratory diagnosed cases
(2) Attributes were determined by excluding NDSS data that were not matched in the laboratory dataset
To determine Sensitivity and PPV the laboratory surveillance was used as the gold standard
NDSS = Notifiable diseases surveillance system
Lab = Laboratory
PPV = Positive Predictive Value
CI = Confidence Interval
a. Determined through the nonparametric Wilcoxon test
b. Determined through the Chi-square test

In the sensitivity analysis (Table 5.4), Scenario III showed similar results to Scenario I, adopted in this study. In scenario II the sensitivity and PPV for all the three tracer diseases were higher, the sensitivity ranged from 94% to 99% and PPV ranged from 65% to 88%.

Table 5.4: Sensitivity Analysis of Sensitivity and Positive Predictive Value of the NDSS for measles, meningococcal meningitis and typhoid for South Africa, 1 January to 31 December 2013

	Measles			Meningococcal Meningitis			Typhoid		
Number of NDSS cases	113			128			28		
Number of unmatched NDSS cases with no results,	59			23			10		
Sensitivity Analysis Scenarios	I	II	III	I	II	III	I	II	III
Number True Positive (A)	4	63	4	58	81	58	13	23	13
Number False Positive (B)	16	16	16	44	44	44	3	3	3
Number False Negative (C)	4	4	4	1	1	1	1	1	1
Number True Negative (D)	30	30	89	2	2	25	1	1	11
A + B	20	79	20	102	125	102	16	26	16
A+ C	8	67	8	59	82	59	14	24	14
Sensitivity (A/(A+C))	50%	94%	50%	98%	99%	98%	93%	96%	93%
Positive Predictive Value (A/(A+B)	20%	80%	20%	57%	65%	57%	81%	88%	81%

NDSS = Notifiable diseases surveillance system. Laboratory surveillance was used as the gold standard
Scenario I: Unmatched NDSS cases with no results excluded from the analysis
Scenario II: Unmatched NDSS cases with no results, assumed as laboratory positive (therefore true positive)
Scenario III: Unmatched NDSS cases with no results, assumed as laboratory negative (therefore true negative)
True positive cases = either (1) positive NDSS cases and positive laboratory cases or (2) no result in NDSS and positive laboratory case
True negative = either (1) negative NDSS cases (suspected cases are notified) and negative laboratory cases (2) no result in NDSS and negative laboratory case
False positive = positive NDSS that were not positive laboratory cases
False negative = NDSS negative cases that were not negative laboratory cases

5.4 Discussion

This is one of the first studies in South Africa to compare laboratory surveillance with the NDSS. The study found that for most attributes, notifications for all three tracer diseases were significantly lower than cases that were laboratory diagnosed. These findings give credence to the survey among key NDSS stakeholders that scored the NDSS low on the attributes of acceptability, flexibility, simplicity, timeliness and usefulness [56].

The finding of around 64% completeness for both the laboratory and NDSS is low compared to a 2013 study on tuberculosis (TB) and HIV surveillance systems in a Western Cape district of South Africa, which showed completeness levels of above 98% for socio-demographic variables and above 75% for most clinical variables [85]. Some of the differences in our findings may be due to the existence of a TB electronic surveillance system for reporting, whereas the NDSS is paper-based. However, a 2013 study, evaluating the quality of mortality reporting in South Africa, describes completeness of less than 90% as unsatisfactory [221]. Although it can be argued that these systems do not necessarily require the same standard as mortality reporting to be used effectively, the findings indicate that both the laboratory system and the NDSS require substantive improvement.

The low NDSS scores on stability imply that the reliability of the NDSS in providing a diagnostic result on the tracer diseases is low – it is expected that all cases notified on clinical suspicion to have these diseases, would be followed through to obtain a diagnostic result. A 2013 study on the 2009-2011 measles outbreak in South Africa[199] recommended that all suspected measles cases should be managed and followed up to confirm the diagnosis. Studies on meningococcal meningitis [222-224] also demonstrated the importance of diagnosis and sero-grouping in the effective surveillance and epidemiology of this disease; as did studies on typhoid [202, 203, 225, 226]. Our finding that in a large percentage of

NDSS cases a diagnostic result was not obtained is a cause for concern that should be addressed in the reform of the South African NDSS.

Our finding on the low (44-67%) representative coverage of all the provinces in the country demonstrates a further NDSS weakness that needs to be addressed. For the NDSS to be effective and efficient, a representative coverage of all the provinces of the country is essential. A 2013 mortality study similarly described coverage of less than the total population as unsatisfactory [221]. The fact that the tracer diseases should be notified on clinical suspicion [55] and that thousands of laboratory tests were requested in 2013 on all three diseases in all provinces, demonstrates that the NDSS is underperforming in this specific area. The high number of laboratory tests conducted is a reflection of the quadruple burden of disease in South Africa, including a large burden of communicable diseases such as HIV &AIDS and TB [35]. The number of laboratory positive cases of the tracer diseases is in line with the level of endemicity of the diseases - the number of positive bacterial meningitis and typhoid cases correspond to the number of cases as stated in the National Institute of Communicable Diseases (NICD) Bulletin of April 2014 [227]. Measles is the only disease with different numbers from the NICD bulletin because of a parallel surveillance system for the Expanded Programme on Immunisation diseases that has been developed over the years in the country - differences in measles surveillance is therefore a subject of a further paper in our broader study on the South African NDSS. A recently published South African paper on meningitis [228] indicated different numbers to our study, mainly because they cover a different study period and only one province. Our findings have shown that measles and meningococcal meningitis notifications were less than 1.5% of the suspected cases (patients tested). The provinces of Free State, Limpopo, Mpumalanga, Northern Cape, and North West did not report some notification data for 2013 and our findings have further shown that few cases (only one each in the provinces of Limpopo, Northern Cape and North West) were laboratory confirmed as

positive. The finding of fewer laboratory confirmed cases in rural provinces with a lower number and concentration of laboratories [195] reflects the financial and human resource inequities between urban and rural provinces that need to be addressed. It is likely that the few diagnosed cases in these provinces were not detected by the NDSS as illustrated by the general low rate of notifications versus laboratory cases.

The finding on the low sensitivity of 50% for measles is similar to the finding of a study in Gauteng, South Africa in 2006 [84] which showed a sensitivity of 26% for malaria. The findings of sensitivities of above 90% for typhoid and meningococcal meningitis are similar to a 2005 Swedish study that found sensitivities for salmonellosis of 99.9%, and meningococcal infection of 98.7% [142]. Notwithstanding the lack of international standards, as reported by a 2010 systematic review of surveillance systems [229], and the difficulties of comparing international surveillance systems because of differences in context, disease profiles and resources [139], the study findings suggest low sensitivity for measles, but high for the other two tracer diseases. However, when Scenario II is used which assumes that unmatched NDSS cases with no results are laboratory positive the sensitivity for all three tracer diseases was high.

We found that the PPV levels were 20%, 57% and 81% for measles, meningococcal meningitis and typhoid, highlighting the variation in the proportion of reported cases that actually have the communicable diseases across the three tracer conditions. However, the PPV is influenced by differences in disease prevalence and disease management programmes [230]. The low PPV for measles, which is targeted for elimination and notified on clinical suspicion, is acceptable as it translates into a low number of notified cases that actually had measles. This is similar for meningococcal meningitis, which clinicians are strongly encouraged to notify on clinical suspicion, although it is not targeted for elimination. The PPV for typhoid is similar to a 2011 North Carolina study which considered PPV levels of above

80% as high [231] and a 2014 South African study, that compared verbal autopsies and death certification records, which considered a PPV level of 78% as relatively high [232]. When Scenario II was used that assumed unmatched NDSS cases with no results as laboratory positive, the PPV for the three diseases were 80%, 65% and 88% respectively. The variation in the sensitivity and PPV due to the large number of NDSS cases without results underscores the need to address this shortcoming in the NDSS.

We found under-reporting for the three tracer diseases in the NDSS. This is a common finding for passive surveillance systems [84, 141, 160, 190, 191]. The reasons why clinicians do not report notifiable cases include insufficient knowledge and understanding of the public health reasons to notify, their perceptions of the seriousness of the condition that they are dealing with, and perceived or real impediments to the process of notification such as workload, unavailability of forms and/or means of communication [84, 141, 160, 190, 191]. As control for this we selected tracer diseases that can be identified on clinical suspicion and for which prompt public health interventions are indicated; one of which (measles) caused a major national outbreak the year preceding the study and for which we assumed that a high index of suspicion existed among clinicians. The fact that thousands of laboratory tests for these diseases were performed countrywide during the study period, means that the number of notified, clinically suspected cases should have exceeded laboratory confirmed cases.

5.5 Limitations

A limitation of the study is that the numbers used in the calculation for sensitivity and PPV were low as a result of the low number of notification cases that cross-matched with laboratory cases, due to incomplete information. Low numbers have resulted in less precise estimates for the sensitivity and PPV, as shown by the wide 95% confidence intervals in some

instances. However, this limitation is a confirmation of the poor quality of the NDSS records and indicates the need to recalculate sensitivity and PPV once data quality is addressed. A further limitation is the exclusion of data from private laboratories. This may account for some of the cases that did not match between the two systems, because the notified NDSS cases include those cases seen in the private sector. Although a much lower percentage of patients with infectious diseases are seen in the private sector [35], it is necessary to include them in national surveillance systems and our recommendations are therefore also applicable to private laboratories.

Another limitation of this study is that three to five provinces did not report notifications of the tracer diseases during the study period. The non-reporting is in itself an illustration of the underperformance of the NDSS.

5.6 Conclusion

Despite the above limitations, the comparison of laboratory surveillance with the NDSS provides empirical evidence of the under-performance of the NDSS, which need to be addressed as part of the South African health sector reforms. A system that would make it easy for clinicians to complete and submit the minimum information needed to trigger further public health investigation should be introduced. We also recommend a revision in the legislative requirements to compel all laboratories in South Africa to notify the 33 conditions as this would help to address gaps in the NDSS. The problem with the completeness of laboratory records may relate to the same reasons why clinicians fail to comply with the completion of notification forms and should also be addressed.

Authors' contributions

Conceived and designed the research concept: FGB, AM, LB and LCR. Analysed data: FGB and AM with input from LCR. Contributed to the writing of the manuscript: FGB, AM, LB and LCR. All authors read and approved the final manuscript.

CHAPTER 6. HEALTH CARE PROVIDERS' COMPLIANCE WITH THE NOTIFIABLE DISEASES SURVEILLANCE SYSTEM IN SOUTH AFRICA

6.1 Introduction

The 2014 to 2016 Ebola Virus Disease outbreak [219], the 2016 Zika virus [220] and yellow fever outbreaks [7] underscore the need for effective country-based notifiable diseases surveillance systems (NDSS). An effective NDSS enables a country to deal with outbreaks of emerging and re-emerging communicable diseases at source and to prevent their spread within and beyond its borders.

Health care providers (HCPs), defined as medical doctors and professional nurses, are critical to strong, resilient health systems, [167] and are at the coalface of service delivery, responsible for the diagnosis and effective management of infectious diseases. The optimal performance of the NDSS is dependent on HCP compliance with communicable disease notification. Their compliance ensures appropriate investigation and control measures by relevant health care authorities. Furthermore, compliance with the NDSS facilitates uniformity in morbidity and mortality reporting that allows for comparisons within and among countries. However, differences in context, background, healthcare systems and resource availability complicate comparisons among countries. Nonetheless, many countries around the world have made it mandatory for HCPs to notify certain notifiable diseases upon clinical suspicion and/or laboratory confirmation [55, 149, 168].

Despite this legal obligation, underreporting of notifiable diseases is a common problem for passive surveillance systems in all countries, regardless of income [141-144, 159, 160, 169-187]. Many high-income countries (HICs) [140-143] have introduced measures to make it

compulsory for laboratories to notify communicable diseases and have dual reporting systems in order to overcome the problem of under-reporting. However, the strong laboratory networks in these HICs proved effective in improving the functioning of the NDSS. In contrast, in low- and middle-income countries (LMIC), a 2009 review of NDSS evaluations found that resource constraints and health infrastructure challenges contributed to sub-optimal NDSS functioning [118]. In these countries, particularly in Africa, laboratory networks are relatively weak and the reliance on HCPs to notify diseases is therefore stronger. Hence, there is a need in these countries to assess the level of compliance amongst HCPs periodically and to take steps to identify and address the factors which cause non-compliance or under-reporting.

In South Africa, the NDSS is a paper-based system that tracks 33 medical conditions. Existing legislation obliges all HCPs to notify these conditions to their local authority, which in turn reports it to the district, district to province, and province to the national department of health (DOH) [55, 56]. There are no legal provisions for laboratories to notify any communicable disease in the country.

In South Africa, there have only been a few evaluations of HCPs compliance since the inception of the NDSS in the 1970s [84, 166, 190]. These include studies on reporting of hepatitis B for the period 1985 to 1988 [191], rheumatic fever for the period 1990-2004, and notifications amongst private general practitioners (GPs) in Gauteng province in 2006. A limitation of these previous studies is that they precede the implementation of the International Health Regulation (IHR) and are focused on limited geographical settings or diseases and hence cannot be extrapolated to the entire NDSS. There is a dearth of information on factors associated with HCPs compliance with the NDSS. Furthermore, the South African health system has undergone and continues to undergo major changes, and is inter-connected with a global world. Information on HCP compliance is

important for shaping NDSS reforms, ensuring effective disease response and compliance with the IHR, and monitoring trends and/or benchmarking the performance of HCPs [167]. In light of this, and the dearth of empirical information, the objectives of this study were to determine HCPs' compliance with the NDSS in South Africa; and to determine the factors associated with their compliance. The study is part of broader doctoral study to evaluate the performance of the NDSS in South Africa.

6.2 Methods

6.2.1 Study setting

The study was conducted in three of the nine South African provinces, one of each representing the urban, rural and the mixed urban-rural groups of provinces.

6.2.2 Study population

The study population consisted of all HCPs, specifically doctors and professional nurses (with four years of training) involved with communicable diseases, working in the public and private health care sectors at primary health care (PHC) and hospital levels.

Enrolled and student nurses were excluded from the study. There were 49,260 eligible HCPs working in the selected facilities (see sampling design).

6.2.3 Sample size

The sample size was estimated using Epi Info statistical software, version 7.2, for population surveys, assuming: a) the acceptable margin of error as $\pm$ 5%; b) approximately 40% would notify correctly (estimated from a previous Gauteng study [84]); and c) design effect of at most 2.5 to

account for clustering effects (this is conservative). This required an overall sample size of 936 HCPs. To allow for a non-response of 10% we targeted 1050 HCPs. This number was 2.1% of the total eligible HCPs in the study population.

6.2.4 Sampling design

Three of the nine provinces were selected randomly, and the final sample consisted of the three provinces of Gauteng (urban), KwaZulu-Natal (mixed urban-rural) and Limpopo (rural). We then stratified by type of health facilities, namely central /tertiary hospitals, regional hospitals, district hospitals, primary health care facility (which included community health centres (CHCs) and clinics), private hospitals and private general practitioners (GPs). Satellite and mobile clinics (as they operate only for a few hours per week and therefore see a very limited number of patients), as well as private hospitals with fewer than 100 beds (which have limited scope and practices, and do not have the targeted health disciplines that deal with the NDSS) were excluded from the study.

The target sample size for each province was chosen proportional to the number of HCPs in that province. In order to select the number of facilities of each type to be sampled in each province, we assumed an average number of HCPs for that facility (e.g. we assumed that each clinic would contain 7 HCPs on the day of the survey); a pre-specified number was chosen to lead to an overall sample of 1050 HCPs. This allowed us to select a sample of facilities randomly in each province.

In each sampled facility, all nurses and doctors who worked in specific divisions (internal medicine, out-patients, medical casualty, critical care, paediatrics and infection control units) were targeted on the survey day. In PHC, all nurses and doctors were requested to participate in the study. We also randomly selected 70 general practitioners (GPs) in private practice as

part of the "private sector facilities" (20 in Gauteng province, 20 in Limpopo and 30 in KwaZulu-Natal) using an electronic database of private GPs. Sampling weights were calculated based on the total number of HCPs in each stratum.

6.2.5 Measurement and data collection

We could not find a standardised tool to measure HCP compliance with the national NDSS. We designed a self-administered questionnaire in English, the official business language of South Africa (Supplementary file 1). The questions focussed on socio-demographics, participant knowledge, attitudes and practices to disease notification and factors influencing compliance with notification reported in the literature. We defined "correct notification" as notification to the local, provincial or national DOH. An assessment of the quality of the information they provided to the DOH did not form part of this study and is therefore not included in the definition of "correct notification". We calculated Cronbach's alpha coefficients to determine reliability and coherence between items - they ranged from 0.82 to 0.97, indicating high reliability and inter-item correlation. We piloted the questionnaire among 12 HCPs similar to the study population prior to data collection to determine clarity of questions and time taken for administration, and no changes were deemed necessary.

The survey was conducted from 22 May to 19 June 2015. Twelve professional nurses were recruited as field workers and trained to assist with data collection in the selected facilities.

On the day of the survey, all eligible study participants were given an information sheet and requested to participate in the study on a voluntary basis.

We double captured data into the web-based Research Electronic Data Capture (REDCap), programme hosted at the University of Witwatersrand in Johannesburg [233].

6.2.6 Data Analysis

We exported the data into STATA® 14 for cleaning and analysis. To specify the survey design, we used the stratum (combination of province and type of facility), the cluster (i.e. facility) and calculated sampling weights based on the number of doctors and nurses in each stratum. All analyses were appropriate for survey data using the identifiers for stratum and cluster as well as the calculated sampling weights.

We computed frequency and summary tables to describe participants' age, gender, location, professional category, experience and training on the NDSS. We summarised categorical variables in tables showing frequency and weighted percentages of each category. We summarised numerical variables using medians (inter-quartile ranges).

We analysed the number and weighted percentage of HCPs who diagnosed and notified notifiable diseases in the preceding year. We used the Rao-Scott correction to the Chi-square test [204] to compare the practices of public and private HCPs. The outcome variable was correct notification of relevant disease/s. We determined whether participants' age, gender, experience, training, professional category, ownership (public or private) and place of employment, workload, possession of notification forms, knowledge of the NDSS were associated with correct notification (to the DOH) using robust survey logistic regression. We calculated odds ratios (OR), 95% confidence intervals (95% CI) and p-values. P-values of less than 0.05 were considered to be statistically significant.

6.2.7 Ethics approval and consent to participate

The Human Research Ethics Committee (Medical) of the University of the Witwatersrand in Johannesburg provided approval for the study (Clearance certificate M140624). All participants provided written informed consent, no personal identifiers were collected and data are reported in aggregate.

6.3 Results

6.3.1 Socio-demographic factors of health care providers

Of the total of 1,050 HCPs that were targeted, we enrolled a total of 942 participants (response rate 90%). After excluding those who did not give consent (n=5), were enrolled nurses (n=10), or did not state their professional category (n=8), the final sample size was 919. The majority of participants (81%) were in the public health sector and professional nurses (76%).

The median age of the HCPs was 41 years, inter-quartile range (IQR) 33 to 50 years. In the public sector, the median age of doctors was 37 years (IQR 30 - 44). The majority of all participants were female (81%). In the private sector, the majority of doctors were male (72%), compared to the public sector in which the majority of doctors were female (55%). In the public health sector, 39% of doctors were from regional hospitals, and 41% of nurses from PHC facilities. In the private sector, 59% of nurses reported that they were trained in the NDSS, while 41% of public sector nurses reported NDSS training. The median number of years of experience in the NDSS was 4 years (IQR 0 - 10). The experience of private sector doctors, 10 years (IQR 3 - 25), was higher than public sector doctors, 6 years (IQR 0 - 15) (Table 6.1).

Table 6.1: Socio-demographic factors of health care providers 2015

Variable	Public Sector N (%)		Private Sector N (%)		Total
	Medical Doctors	Professional Nurses	Medical Doctors	Professional Nurses	n=919
Province					
Gauteng	91 (46)	178 (43)	14 (40)	91 (42)	374 (43)
KwaZulu-Natal	68 (30)	188 (35)	17 (48)	98 (45)	371 (36)
Limpopo	41 (24)	96 (21)	8 (11)	29 (13)	174 (20)
Total	200 (100)	462 (100)	39 (100)	218 (100)	919 (100)
Type of facility					
Central/Tertiary	76 (7)	52 (1)			128 (3)
Regional Hospital	68 (39)	78 (13)			146 (19)
District Hospital	34 (36)	68 (23)			102 (26)
PHC	22 (11)	264 (41)			286 (34)
Private Hospitals			11 (4)	218 (23)	229 (18)
Private GP practice			28 (3)	0 (0)	28 (1)
Total	200 (94)	462 (77)	39 (6)	218 (23)	919 (100)
Age Median (IQR)	37 (30 – 44)	43 (34 – 52)	41 (36 - 52)	41 (34 - 49)	41 (33 - 50)
Age (years)					
20-30	55 (30)	71 (15)	1 (2)	28 (14)	155 (18)
31-40	64 (33)	103 (27)	17 (46)	61 (33)	245 (30)
41-50	38 (24)	121 (30)	8 (22)	66 (35)	233 (29)
51-60	12 (6)	90 (23)	7 (25)	27 (14)	136 (18)
61-70	11 (7)	15 (4)	3 (5)	5 (3)	34 (5)
Total	180 (100)	400 (100)	36 (100)	187 (100)	803 (100)
Gender					
Female	104 (55)	415 (89)	8 (28)	196 (90)	723 (81)
Male	96 (45)	43 (11)	31 (72)	21 (10)	191 (19)
Total	200 (100)	458 (100)	39 (100)	217 (100)	914 (100)
Nurse Category					
PHC Trained		153 (31)		19 (9)	172 (26)
General Nurse		217 (46)		102 (47)	319 (46)
Trauma and Casualty		2 (1)		17 (8)	19 (2)
ICU and High Care		11 (2)		27 (12)	38 (4)
Midwifery		14 (5)		7 (3)	21 (4)
Theatre		1 (0)		8 (4)	9 (1)
Infection Prevention		29 (7)		22 (10)	51 (8)
Paediatric		35 (9)		16 (7)	51 (8)
Total		462 (100)		218 (100)	680 (100)
Doctor Category					
Intern	17 (7)		0 (0)		17 (6)
Medical Officer	92 (63)		2 (7)		94 (60)
Private GP	13 (7)		27 (43)		40 (9)
Registrar	23 (4)		0 (0)		23 (4)
Specialist Physician	19 (4)		6 (29)		25 (5)
Paediatrician	29 (14)		2 (11)		31 (14)
Other Specialists	7 (2)		2 (11)		9 (3)
Total	200 (100)		39 (100)		239 (100)
Training in NDSS	66 (35)	180 (41)	16 (44)	126 (59)	388 (43)
Formal training in Epidemiology	52 (27)	78 (16)	11 (24)	51 (24)	192 (20)
Experience in the NDSS – years					
Median (IQR)	6 (0 - 15)	4 (0 - 10)	10 (3 - 25)	4 (0 - 10)	4 (0 - 10)

Weighted percentages are presented
NDSS = Notifiable Diseases Surveillance System
GP = General Practitioner
ICU = Intensive Care Unit
PHC = Primary Health Care
IQR = Inter quartile range

6.3.2 Diagnosis of notifiable diseases

More than half of the HCPs (58%), reported that they have diagnosed a notifiable disease in the year preceding the survey, with a significantly higher percentage in the public sector (62%), compared to 43% in the private sector (p=0.001). A significantly higher percentage of public sector nurses in KwaZulu-Natal province (57%) reported diagnosis of a notifiable disease, compared to private sector nurses (41%, p=0.019). In the public sector, 94% of doctors, reported diagnosis of a notifiable disease, compared to 89% in the private sector.

In both the public and private sectors, 92% of all study participants who have diagnosed a notifiable disease(s) indicated that they reported the notifiable disease(s). Public sector doctors in KwaZulu-Natal and private sector doctors in Limpopo notified lower percentages of cases (80% and 75% respectively) compared to other HCPs (Table 6.2). Two thirds (67%) of HCPs who indicated that they notified in the preceding year, reported that they did so within 24 hours of diagnosis; only 1% reported that they did so after more than 1 week (Figure 6.1).

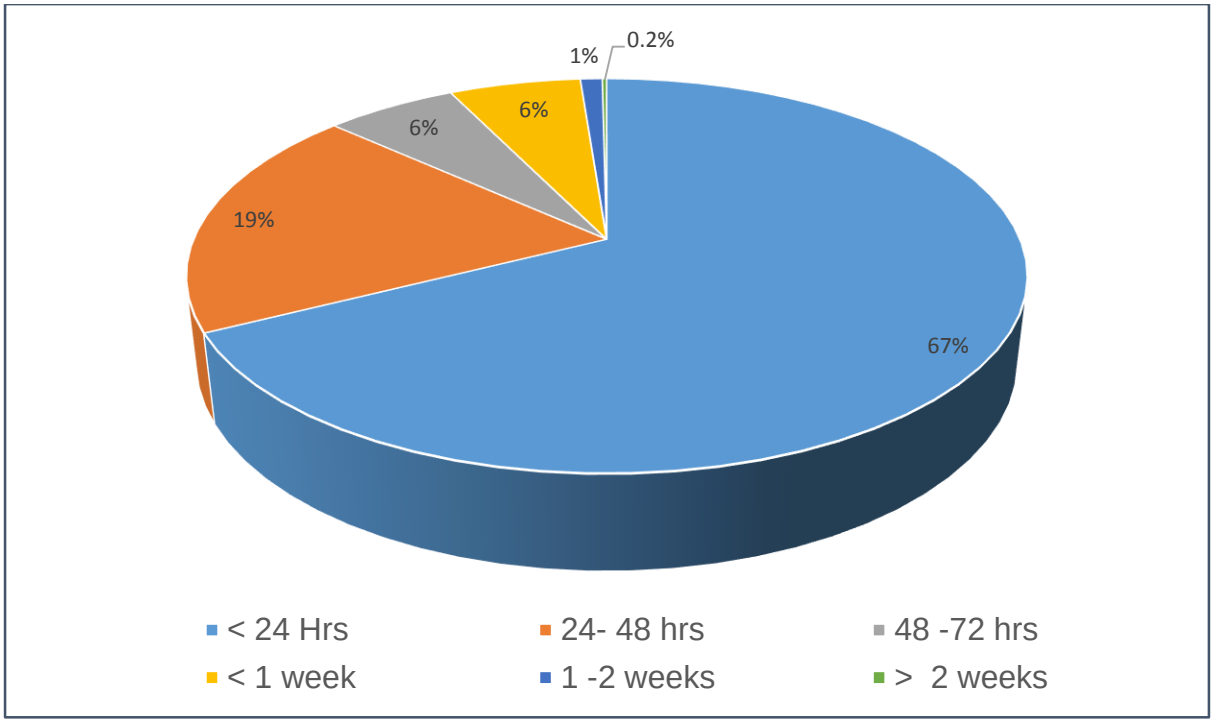
Table 6.2: Health care providers who: (a) have diagnosed, and (b) notified a notifiable communicable disease in the preceding year, South Africa, by sector, professional category and province, 2015.

a) Health Care Providers who have diagnosed a notifiable disease in the preceding year									
i) By Sector									
Sector	**No**	**Yes**	**Unsure**	**Total**					**P-value[c]**
Public	231 (37)	397 (62)	11 (1)	639 (100)					
Private	128 (56)	113 (43)	3 (1)	244 (100)					0.001*
Total	359 (41)	510 (58)	14 (1)	883 (100)					
ii) Doctors by Province									
Province	**Public Sector**				**Private Sector**				
	No	**Yes**	**Unsure**	**Total**	**No**	**Yes**	**Unsure**	**Total**	
Gauteng	9 (8)	81 (92)	0 (0)	90 (46)	2 (17)	12 (83)	0 (0)	14 (40)	0.094
KwaZulu-Natal	6 (6)	61 (93)	1 (1)	68 (30)	3 (9)	14 (91)	0 (0)	17 (48)	0.715
Limpopo	2 (1)	38 (98)	1 (2)	40 (24)	0 (0)	8 (100)	0 (0)	8 (11)	0.902
Total	17 (6)	180 (94)	2 (1)	197 (100)	5 (11)	34 (89)	0 (0)	39 (100)	0.199
iii) Professional Nurses by Province									
Gauteng	97 (59)	59 (40)	3 (1)	159 (43)	53 (65)	28 (34)	1 (1)	82 (42)	0.512
KwaZulu-Natal	84 (42)	96 (57)	5 (2)	185 (35)	57 (59)	39 (41)	0 (0)	96 (45)	0.019*
Limpopo	33 (43)	62 (54)	1 (1)	96 (21)	13 (48)	12 (44)	2 (7)	27 (13)	0.502
Total	214 (49)	217 (49)	9 (2)	440 (100)	123 (60)	79 (39)	3 (1)	205 (100)	0.073
b) Health Care Providers who have notified the diagnosed disease(s) in the preceding year									
i) By Sector									
Sector	**No**	**Yes**	**Unsure**	**Total**					
Public	26 (5)	358 (92)	11 (3)	395 (100)					
Private	11 (6)	100 (92)	2 (1)	113 (100)					0.602
Total	37 (6)	458 (92)	13 (3)	508 (100)					
ii) Doctors by Province									
Province	**Public Sector**				**Private Sector**				
	No	**Yes**	**Unsure**	**Total**	**No**	**Yes**	**Unsure**	**Total**	
Gauteng	7 (7)	73 (93)	1 (0.1)	81 (46)	1 (4)	11 (96)	0 (0)	12 (40)	0.720
KwaZulu-Natal	8 (11)	48 (80)	5 (9)	61 (30)	3 (10)	10 (87)	1 (3)	14 (48)	0.906
Limpopo	2 (3)	35 (94)	1 (2)	38 (24)	2 (25)	6 (75)	0 (0)	8 (11)	0.115
Total	17 (7)	156 (89)	7 (4)	180 (100)	6 (10)	27 (89)	1 (2)	34 (100)	0.736
iii) Professional Nurses by Province									
Gauteng	4 (6)	53 (91)	1 (3)	58 (43)	3 (11)	25 (89)	0 (0)	28 (42)	0.189
KwaZulu-Natal	3 (2)	91 (97)	1 (1)	95 (35)	2 (5)	36 (92)	1 (3)	39 (45)	0.368
Limpopo	2 (4)	58 (93)	2 (4)	62 (21)	0 (0)	12 (100)	0 (0)	12 (13)	0.688
Total	9 (4)	202 (94)	4 (2)	215 (100)	5 (6)	73 (92)	1 (1)	79 (100)	0.333

Weighted %

* Significant P-value

c) Test specific P-values are from the Rao-Scott correction to the Chi-square Test [204]
"Unsure" was regarded as missing data in the calculation of P-values



(**Weighted %**)

Figure 6.1: Timeframe after diagnosis of a notifiable communicable disease in the preceding year that health care providers reported they notified the disease, South Africa, 2015

6.3.3 Correct notification of diseases

Only 217 (51%) of the HCPs who reported diseases, indicated that they notified the case(s) to the DOH, while 34% of HCPs reported notifiable disease(s) to institutional infection control nurses; these categories where mutually exclusive – the few who indicated they reported to the department and others, were taken as reporting to the department (Table 6.3). Fewer HCPs in the private sector notified cases correctly, but this was not statistically significant (p=0.091). Professional nurses in the public sector (58%) were more likely than those in the private sector (37%) to report, correct notification, compared to 58% in the public (p= 0.042). In Limpopo province, private sector HCPs reported significantly lower correct notifications (Figure 6.2).

Table 6.3: Reporting authority of notifiable communicable diseases by sector, province and professional category, South Africa

a) Who reported to by sector and province							
Who reported to	**Public Sector N (%)**			**Private Sector N (%)**			**Total**
	Gauteng	**KwaZulu-Natal**	**Limpopo**	**Gauteng**	**KwaZulu-Natal**	**Limpopo**	
Department	63 (49)	70 (55)	47 (57)	13 (35)	21 (49)	3 (18)	217 (51)
Infection control	41 (39)	48 (30)	26 (28)	14 (45)	14 (34)	8 (58)	151 (34)
Local clinic or hospital	6 (3)	7 (5)	1 (1)	4 (3)	4 (3)	2 (16)	24 (4)
Nurse in charge or Doctor	10 (8)	11 (6)	13 (13)	4 (13)	3 (7)	3 (6)	44 (9)
Patient and other	1 (0.1)	2 (4)	1 (1)	1 (3)	3 (7)	1 (2)	9 (2)
Total	123 (100)	138 (100)	87 (100)	36 (100)	45 (100)	17 (100)	445 (100)
b) Who reported to by sector and professional category							
Who reported to	**Public Sector N (%)**			**Private Sector N (%)**			**Total**
	Medical Doctors	**Professional Nurses**	**Public Total**	**Medical Doctors**	**Professional Nurses**	**Private Total**	
Department	70 (46)	110 (58)	180 (53)	11 (50)	26 (37)	37 (39)	217 (51)
Infection control	58 (37)	57 (30)	115 (33)	5 (29)	31 (44)	36 (42)	151 (34)
Local clinic or hospital	6 (2)	8 (5)	14 (4)	8 (14)	2 (3)	10 (5)	24 (4)
Nurse in charge or Doctor	21 (15)	13 (4)	34 (9)	3 (5)	7 (10)	10 (9)	44 (9)
Patient and other	1 (0.1)	3 (3)	4 ((2)	1 (2)	4 (6)	5 (5)	9 (2)
Total	156 (100)	191(100)	347 (100)	28 (100)	70 (100)	98 (100)	445 (100)

Weighted percentages are presented

All categories where mutually exclusive – the few who indicated they reported to the department and others, were taken as reporting to the department

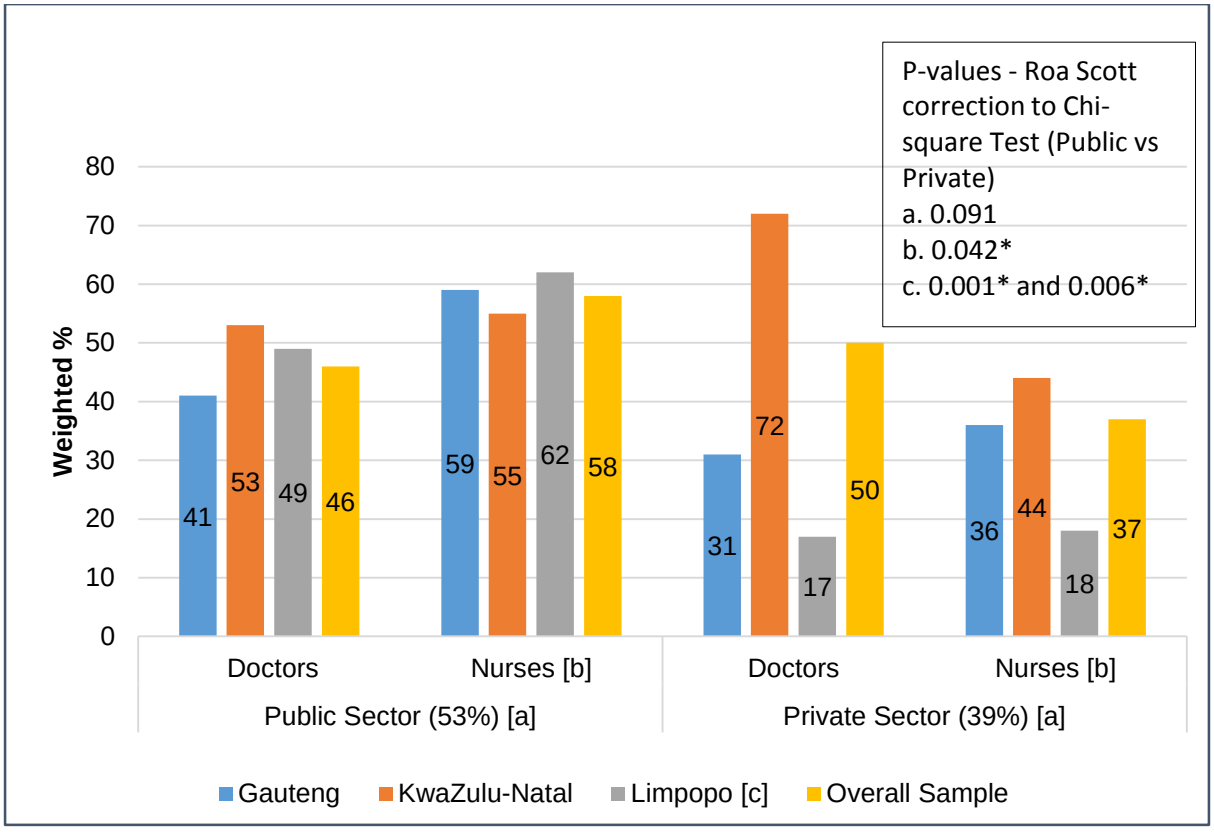


Figure 6.2: Reported correct notification by health care providers in South Africa, 2015

6.3.4 Factors associated with correct notification

Unadjusted logistic regression analysis showed that general and critical care nurses were significantly less likely to notify correctly and that HCPs in PHC facilities were more likely to report correct notification. Other factors significant in unadjusted analysis were the possession of notification forms, knowledge of the notification process and the perception of ease of the notification process. All of the aforementioned factors were not significant in multivariable analysis.

Only 15% of paediatricians notified correctly, with multivariable analysis showing that paediatricians were less likely to notify a notifiable disease correctly (OR 0.01, 95% CI 0.00 - 0.12, p=0.001) (Table 6.4). It also showed that HCPs perceptions of their workload (OR 0.84, 95% CI 0.70 - 0.99, p=0.043) and their belief that notification data are not used for

outbreak response (OR 0.84, 95% CI 0.71 - 0.99, p=0.040), had a significant impact on them notifying diseases. The number of HCP patient consultations per day had no significant association with correct notification (OR 1.00, 95% CI 1.00 - 1.01, p=0.578).

Table 6.4: Factors associated with Health care providers notifying a notifiable communicable disease correctly in the preceding year, South Africa, 2015

Factor	Unadjusted Logistic regression			Multiple Logistic regression		
	Odds Ratio	95% CI	P-value	Odds Ratio	95% C I	P-value
Age	1.02	1.00 - 1.04	0.063			
Gender	0.97	0.51 - 1.82	0.912			
Years' experience	1.02	0.99 - 1.05	0.261			
Professional Category	1.36	0.71 - 2.59	0.345			
Paediatrician	0.07	0.01 - 0.59	0.017*	0.01	0.00 - 0.12	0.001*
General nurse	0.44	0.24 - 0.89	0.012*	1.29	0.57 - 2.91	0.522
Critical Care Nurse	0.01	0.00 - 0.12 .	0.001*	0.08	0.01 - 1.03	0.053
Infection Prevention Nurse	1.68	0.41 - 6.90	0.457			
Type of facility	1.3788	1.14 - 1.67	0.002*	1.38	0.41 - 4.59	0.583
Primary health facility	3.54	1.62 - 7.76	0.002*	3.80	0.01 - 1233.74	0.637
Sector Employed	0.57	0.30 - 1.11	0.094			
Knowledge of notification process	1.07	1.00 - 1.14	0.037*	0.99	0.85 - 1.14	0.843
Willingness to notify	1.00	0.90 - 1.12	0.963			
Not easy to comply	0 .85	0.74 - 0.98	0.025 *	0.94	0.80 - 1.11	0.473
Training on NDSS	1.16	0.83 - 1.61	0.383			
Formal training Epidemiology	1.45	0.84 - 2.50	0.176			
Understanding the purpose of NDSS	0.97	0.88 - 1.14	0.736			
Knowledge on what to notify Immediately	1.07	0.97 - 1.18	0.153			
Knowledge on what to notify	1.05	0.98 - 1.13	0.142			

in 24hrs						
Have notification forms	0.46	0.22 - 0.95	0.037*	0.30	0.03 - 2.96	0.285
Number of patients seen per day	1.00	1.00 - 1.01	0.578			
Workload prevents notification	0.83	0.76 -0.91	<0.001*	0.84	0.70 - 0.99	0.043*
Feedback given	0.92	0.82 - 1.03	0.151			
Data not used for response	0.88	0.78 - 0.99	0.029*	0.84	0.71 - 0.99	0.040*

*P-value significant at 5% level. 95% CI = 95% Confidence Interval
ICU = Intensive Care Unit NDSS = Notifiable Diseases Surveillance System

HCPs' willingness to notify, experience, training on the NDSS, understanding of the purpose of NDSS, knowledge of what to notify, and perception of feedback given, had no association with correct notification. Working as infection control nurses was also not associated with the correct notification of communicable diseases.

6.4 Discussion

This is one of the first studies in democratic South Africa to determine HCPs' compliance with the NDSS at a national level and to determine the factors associated with compliance. The study found that 58% of HCPs indicated that they diagnosed a notifiable disease in the year preceding the survey and that 92% of these indicated that they have reported the disease. However, only 51% of those notified the disease/s correctly to the DOH.

A 2015 empirical study that compared South African notifications and laboratory surveillance, found that only 1.5% of suspected measles and meningococcal meningitis cases were notified [57]. This in sharp contrast to the HCP self-reports of 92% notification. The latter is also in contrast to the finding of a 1985-88 SA study that found that only one in seven hepatitis B cases were notified in South Africa [166]. The variations could

be due to differences in the denominator (the record reviews measured reporting per case while our survey does this per HCP), and the social desirability bias of self-reported information. The self-reported timeliness of the notifications (67% within 24 hours) was also high. This was in contrast to the poor perceptions of timeliness among key stakeholders, where 45% of national and provincial stakeholders considered the NDSS as timely [56]. Nonetheless, the high proportion of participants that reported notification, albeit incorrectly, is a reflection of HCP willingness to comply with the NDSS.

In this study, one in two (51%) of HCPs reported correct notification of diseases. A 2002 American review, that measured HCP compliance with TB, HIV and sexually transmitted diseases (STIs) reporting, found it to be 79%, and compliance of 49% when dealing with other diseases [141]. Our study excluded HIV, which is not notifiable in South Africa, and is based on HCPs reporting their compliance. We found a similar level of reported compliance as for other diseases in the American review and a lower level than for TB and STIs. Despite the difficulty of cross-country comparisons, and the methodological difference between this study and the American study, our study finding suggests low compliance, particularly in light of South Africa's high TB disease burden and the fact that TB is the most common notifiable disease [35]. The reported compliance in our study is also lower than a 2014 Irish study which found 98% compliance, when hospital data were compared to notifications [140], and a Taiwan study which found 83.5% compliance amongst HCPs [180]. In Africa, a Nigerian state study found that only 38.2% of HCPs were aware of notifications and 71% reported disease notification [185]. A 2008 Nigerian study in six cities found that 66.5% of doctors reported disease notification, with 65% of those that did not notify indicating that they never diagnosed a notifiable disease [187]. Differences with our study could be because we only focused on notification practices in the preceding year. However, a NDSS cannot function

effectively when only half of HCPs notify diseases correctly, particularly when it is not mandatory for laboratories to notify diseases.

We found that significantly fewer HCPs in the private sector diagnosed notifiable diseases. This could be because the private sector serves people with private health insurance, and communities who are dependent on the public sector have a higher incidence of communicable diseases [40]. The study found that a significantly higher number of public sector nurses diagnose and report a notifiable disease. This is because PHC facilities in the public sector are staffed primarily by nurses, who play a greater role in the diagnosis and management of diseases [40]. . This study also found that private sector nurses were less likely than those in the public sector nurses to notify correctly, even though they reported the highest level of training in the NDSS. Hence, they should be a focus group for NDSS intervention programmes. Our study found that similar proportions of public and private sector doctors diagnosed or notified diseases. These findings differ from the findings of other studies that reported differences between the two groups. An Indian study [182] and a study in Portugal [172] showed higher levels of compliance amongst public sector doctors, while a Maltese study showed earlier reporting amongst private doctors [174]. The implication of our finding is that similar interventions could be applied amongst doctors in both sectors to improve compliance with the NDSS. The finding that private HCPs in the peripheral and rural province of Limpopo notified fewer diseases correctly indicates the need for interventions to target rural areas. The 50% of private sector doctors (who were mostly GPs) who reported correct notification was comparable to the findings of a 2007 study which showed notification compliance of 37% amongst GPs in Gauteng province [84].

Although there was a statistical association between HCPs perceptions of workload and their reported compliance, there was no statistically significant association between compliance and the reported number of

patient consultations per day. This could be because workload is influenced by disease burden, patient management, the number of patients and time spent per patient. However, these factors were not assessed in our study. Our study further showed that HCPs opinions on the usefulness of notification were associated with correct notification to the DOH. This implies that the DOH should communicate to HCPs that notifications influence outbreak management and response. Our study found willingness to notify, training on the NDSS, understanding of the purpose of the NDSS, knowledge on what to notify, possession of notification forms and feedback did not influence HCP compliance with the NDSS. Other studies have found these factors to be important [84, 141, 160, 176, 177, 183, 184, 190, 191]. The differences in our findings and these studies may relate to differences in methodology, and do not mean that these are not important factors that require ongoing attention in ensuring an effective NDSS. Our finding that a high percentage of HCPs did not notify correctly indicates that clear guidelines are needed to ensure optimal functioning of the South African NDSS.

Most HCPs indicated that they reported the diagnosed notifiable disease to other HCPs, probably with the expectation that those individuals would report the disease to the DOH. Infection control nurses were the group most diseases were reported to. However, the study found that being an infection control nurse was not associated with correct notification.

A limitation of the study is the self-reported information that may have been influenced by social desirability bias. Another limitation is its cross-sectional nature - it provides a picture of practices at the time of the study. With the high clinical staff turn-over in South Africa [48], practices are unlikely to remain static and ongoing evaluations are needed. The survey also did not allow HCPs who diagnosed more than one notifiable disease in the preceding year, to differentiate their notification practices for these diseases. This might lead to an over-estimation of compliance among HCPs.

Despite the above limitations, the study has provided valuable insights into reported compliance with the NDSS in SA and showed that 51% of study participants reported correct notification, which we have used as proxy for compliance with the NDSS. HCPs demonstrated a willingness to participate with the NDSS when the percentage who reported diseases incorrectly to other HCPs is also taken into consideration. This level of willingness is encouraging and provides a foundation for the introduction of NDSS reforms. These include the introduction of a simplified notification system that makes it easy for clinicians to notify diseases to the correct authority, thus enabling the implementation of appropriate public health measures. Given the high penetration of mobile technology in the country and successful pilot studies on malaria surveillance with mobile technology [217], this is an area that should be explored in addressing the performance of the NDSS as part of the South African health sector reforms. Changes in the NDSS should be accompanied with clearly communicated guidelines and support programmes, both for the public and private health sectors. In other countries, infection control nurses played a critical role in improving communicable disease reporting [234, 235]. In our study, a high percentage of HCPs reported notifiable diseases to them, hence infection control nurses should be used more effectively as a channel of communication between the DOH and HCPs. Paediatricians should also be a specific focus group for training on NDSS and other appropriate interventions, considering their lower compliance with the NDSS and their work with children, who are prone to childhood infections.

6.5 Conclusion

Although a high percentage of HCPs reported compliance with notification of diseases, this compliance was not according to prescribed standards. Hence, the compliance of HCPs in South Africa with the NDSS is suboptimal. The study found that HCPs perceptions of workload and usefulness of notifications were associated with their compliance with the NDSS. In light

of the important role of HCPs in the effective functioning of the NDSS, regular feedback to HCPs on the usefulness of notifications, training of paediatricians and rural private sector doctors, as well as guidelines on correct notification procedures are needed to increase their compliance in South Africa.

Authors' contributions

Conceived and designed the research concept: FGB, and LCR. Analysed data: FGB and JL with input from LCR. Contributed to the writing of the manuscript: FGB, JL and LCR. All authors read and approved the final manuscript.

CHAPTER 7. PERSPECTIVES OF HEALTH POLICY ACTORS ON REFORMING THE NOTIFIABLE DISEASES SURVEILLANCE SYSTEM IN SOUTH AFRICA

7.1 Introduction

There is global consensus that the threat from infectious diseases is growing [236]. The 2014 Ebola epidemic in West Africa and 2016 Zika virus outbreak in Brazil underscored the importance of effective surveillance and response systems, and the impact of weak national health systems on countries' economic and social security [88, 118, 188, 219, 236-240]. The World Bank has estimated that the economic impact of a pandemic similar to the 1918-19 influenza pandemic is around 5 percent of global gross domestic product or US$3 trillion [236]. These enormous costs of pandemics can be prevented with strategic investments in research, surveillance systems, universal health coverage reforms, capacity building, and financing [241].

There is a substantial body of literature on the evaluation of national notifiable disease surveillance systems (NDSS), particularly in high income countries [118-121]. Although these surveillance systems perform reasonably well, studies have found weaknesses of data quality, variations in completeness of data for different infectious diseases, and for electronic versus paper-based systems, lack of timeliness, and complexity and inflexibility of some surveillance systems [118-121]. An emerging body of literature in low and middle-income countries (LMIC) have pointed to weak health systems, human resource constraints, under-reporting, and lack of feedback mechanisms [122-125]. In sub-Saharan Africa, studies have found that surveillance systems are hampered by numerous health system deficiencies, including inadequate or absent laboratory capacity, staffing

and resource constraints, inadequate supervision, poor monitoring, and weak organisational capacity [126-129].

In South Africa, my PhD study was one of the first objective assessments of the NDSS. My first study among key stakeholders involved in infectious disease control and response (Chapter 4) found that 25% perceived the system to be acceptable, 51% to be flexible, 45% to be timely, 61% to be useful, and 74% to be simple [56]. My second study (Chapter 5) used data on three tracer notifiable diseases – measles, meningococcal meningitis, and typhoid, to compare the NDSS with laboratory surveillance for the system attributes of data quality, stability, representativeness, sensitivity and positive predictive value (PPV). The study found that the NDSS performed poorly on most system attributes for the tracer conditions [57]. My third study (Chapter 6) examined notification compliance among health care providers and found that of those HCPs that diagnosed a notifiable disease in the year preceding the survey, only 51% notified the disease/s correctly to the Department of Health [242]. Hence, my PhD study findings present scientific evidence on the need for the revitalization of the NDSS in South Africa. This concurs with one of the key recommendations of the Commission on a Global Health Risk Framework for the Future, established in response to the threat and risks of infectious diseases, that national public health capabilities and infrastructure should be revitalized [236].

Notwithstanding the scientific evidence generated by my PhD, the WHO's 2020 strategic policy framework [112] emphasises the importance of including all stakeholders in decision-making and health system reform initiatives [113]. The Commission on a Global Health Risk Framework for the Future also underscores the importance of leadership and coordination for infectious disease preparedness and response [236]. In South Africa, several studies have pointed to sub-optimal policy implementation or policy failures because of the lack of involvement of policy actors, particularly those responsible for the implementation of these policies [110, 114-117].

Hence, it is critical to obtain the perspectives of key health policy actors on the NDSS reforms that are needed.

This chapter draws on Bressers' Contextual Interaction Theory [243] to explore the perspectives of health policy actors on NDSS reforms needed in South Africa. The health policy actors are the key stakeholders involved in disease control and response, and the health care providers (HCPs) responsible for disease notification.

7.2 Methods

In this chapter, I have combined the findings of two surveys, one among key stakeholders (Chapter 4), and the other among HCPs (Chapter 6). The detailed methods on each survey are described in Chapters 4 and 6, and summarised in Chapter 3.

7.2.1 Conceptual framework

Bressers' Contextual Interaction Theory proposes that policy implementation occurs within specific, structural and wide context [243]. The specific context refers to the stakeholder or policy actor's previous experience; structural context refers to the actor's position and responsibilities for implementation, while wider context refers to political, economic and cultural issues that influence the actor's activities or responses [243]. Stakeholders or policy actors interact with the context, and these interactions are influenced by their knowledge, motives, and power, all which shape policy implementation [243].

7.2.2 Study setting

Survey 1 focused on key stakeholders involved in the NDSS at national and provincial levels, while the survey among health care providers was done in the provinces of Gauteng, KwaZulu-Natal and Limpopo.

7.2.3 Research design and methods

As described in Chapters 3, 4 and 6, cross-sectional surveys were conducted among key stakeholders and HCPs. Both surveys were based on structured, self-administered questionnaires (Appendices 8 and 10 respectively for the two groups). In a section of the questionnaires, participants were asked to score the organisational capacity for the NDSS (facility, district, province or national), human, and financial resource investments, using a five point Likert-scale scale that ranged from very poor to very good. Another section asked these two groups of NDSS policy actors to rate the impact of certain interventions in the NDSS, using a ten point Likert-scale, from '1' for 'no benefit to '10' for 'maximum benefit'. The interventions that they were asked to rate were: addressing staffing, funding, and organisational needs, as well as introducing an electronic or mobile system.

7.2.4 Data analysis

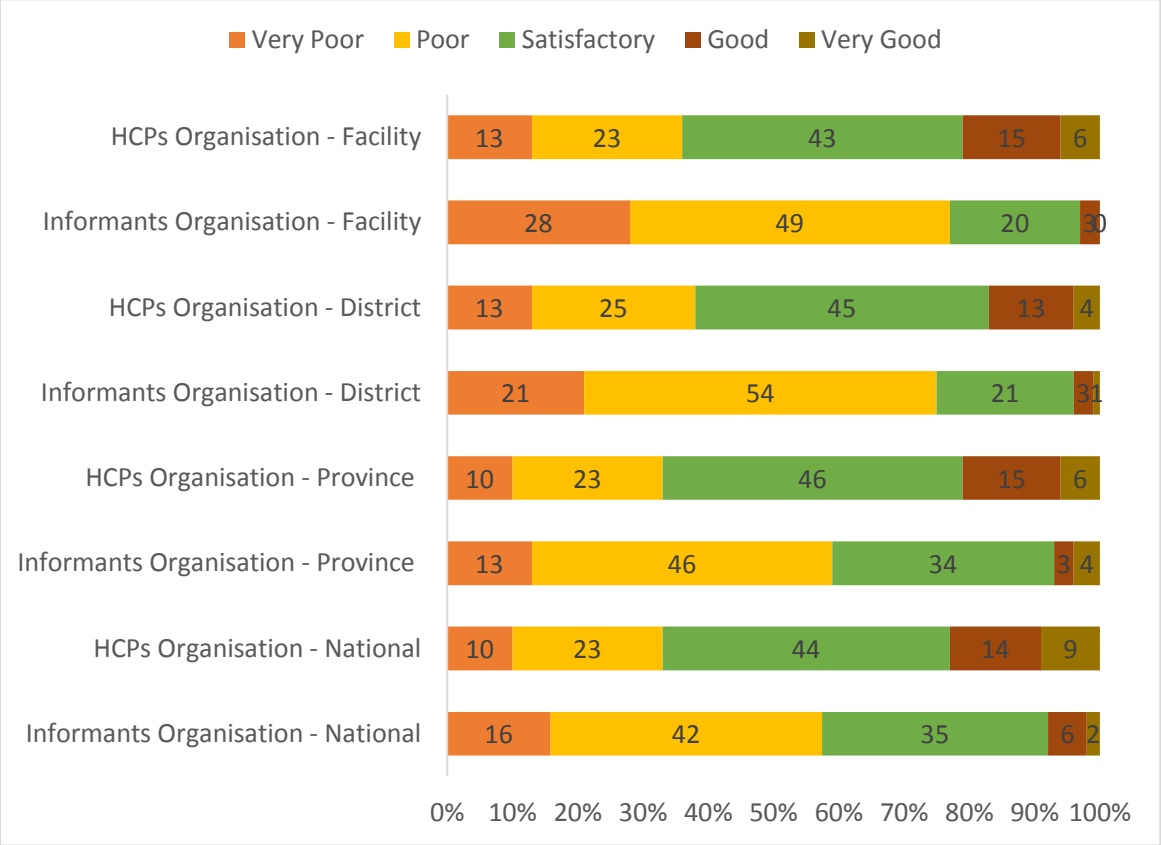
STATA® 14 was used to analyse the data from the two surveys. The data were weighted to take account of the sampling strategy in the HCP survey. For each of the categories of NDSS organisation, human and financial resource investments, I determined the proportion of participants in each survey that selected a particular score (very poor to very good). I also determined the mean scores for each of the two groups of policy actors on how they rated the different interventions on the NDSS. I performed linear regression analysis on the mean intervention scores at a significance level of 5%.

7.3 Results

7.3.1 Organisational capacity for the NDSS

The majority of key stakeholders who scored the organisational capacity for the NDSS as poor to very poor, varied from 58% to 87%; while the

proportion of HCPs who scored the organisational capacity as poor to very poor varied from 33% to 38% (Figure 7.1). Few key stakeholders scored the organisational capacity for the NDSS as very good, with the highest percentage of 4% for provincial organisation. The proportion of HCPs who regarded organisational capacity as very good varied from 4% (district) to 9% (national). The proportion of key stakeholders who scored organisational capacity as satisfactory varied from 20% (facility level) to 35% (national level). HCPs provided similar satisfactory scores for all NDSS levels (Figure 7.1).



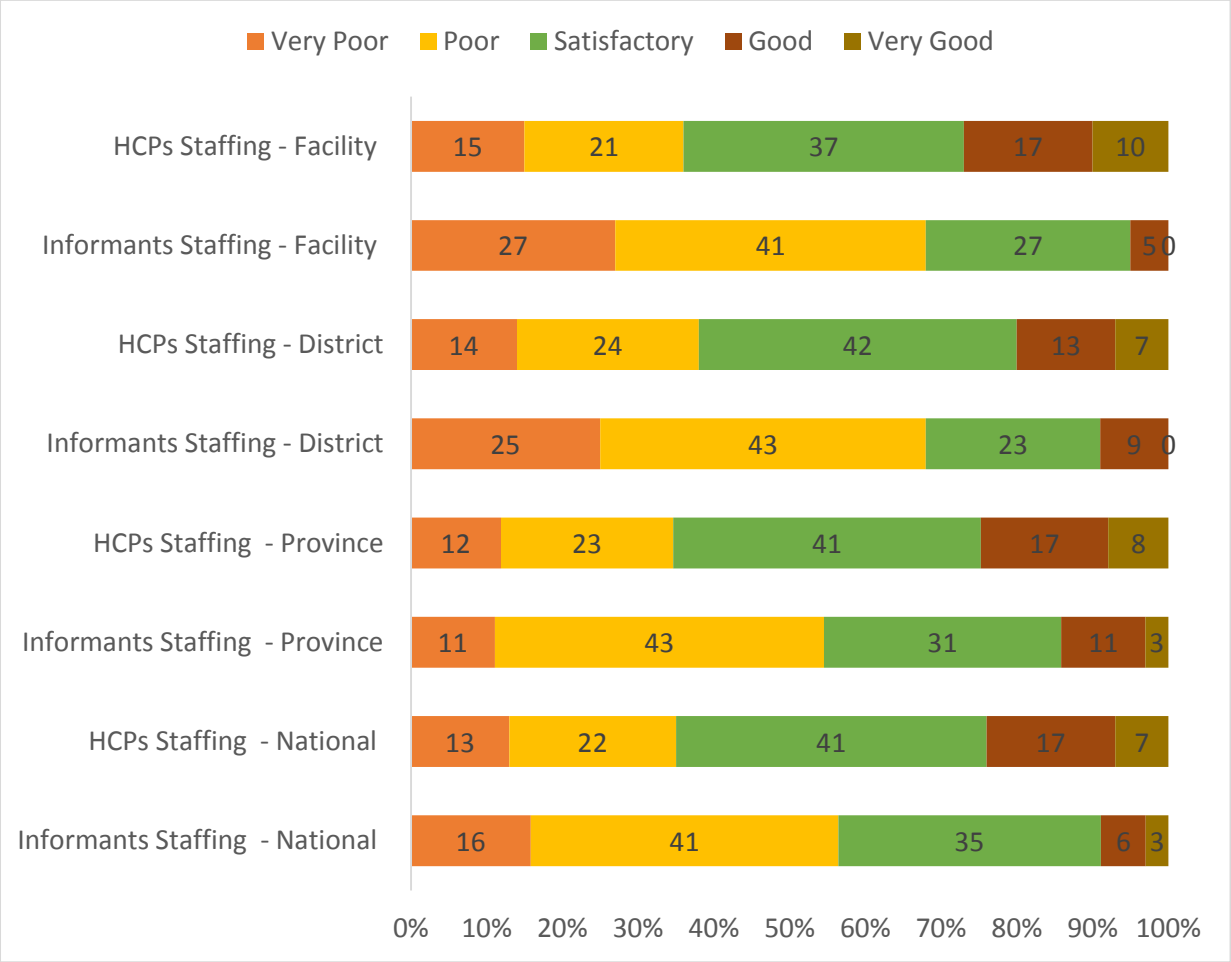
HCPs = Health Care Providers Informants = Key Stakeholders

Figure 7.1: Policy actors' perspectives on organisational capacity for the NDSS, 2015

7.3.2 Resources for the NDSS

Most key stakeholders scored the human resources within the NDSS, as poor or very poor (Figure 7.2). In contrast, the proportions of HCPs who scored human resources as poor or very poor were lower (Figure 7.2).

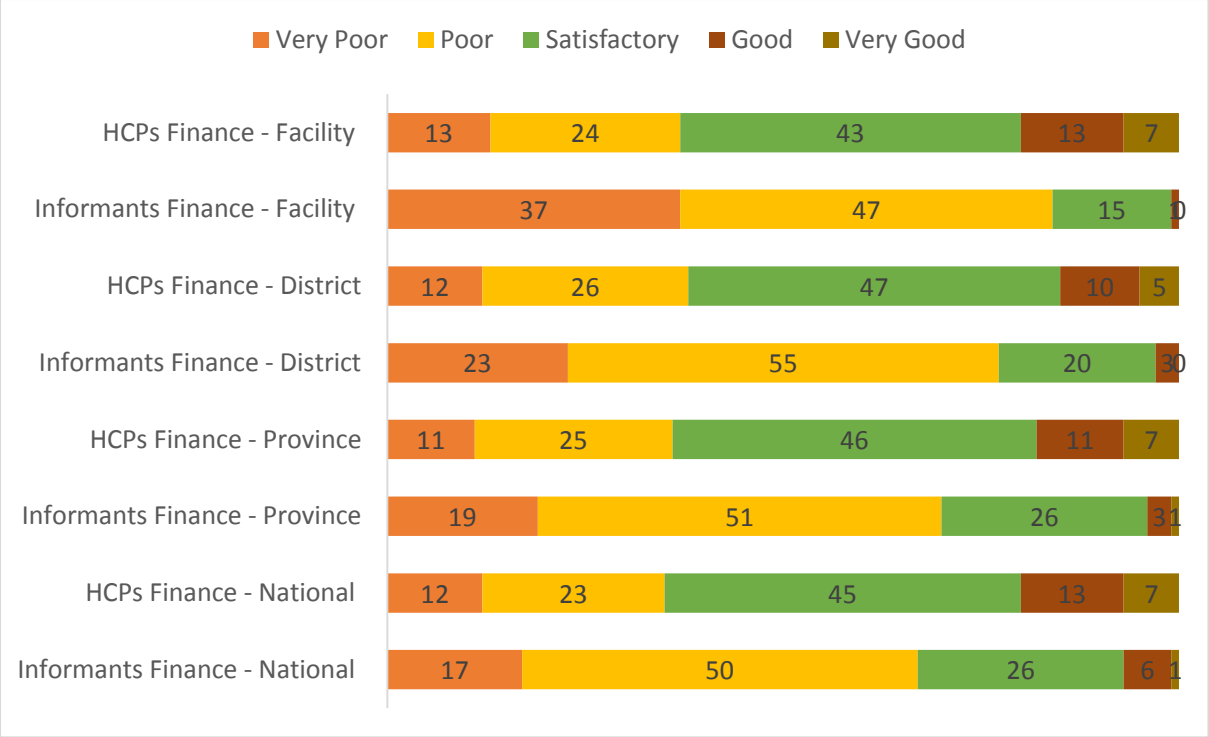
Fewer key stakeholders scored human resources as good or very good, compared to HCPs (Figure 7.2).



HCPs = Health Care Providers Informants = Key Stakeholders

Figure 7.2: Policy actors' perspectives on human resources for the NDSS in South Africa, 2015

Similar to human resources, most key stakeholders scored financial resources for the NDSS as poor or very poor, (Figure 7.3). As was the case with human resources, fewer HCPs' than key stakeholders scored financial resources as poor or very poor. Only 1% of key stakeholders scored financial resources at national level as very good, whereas 7% of HCPs scored financial resources as very good.



HCPs = Health Care Providers Informants = Key Stakeholders

Figure 7.3: Policy actors' perspectives on financial resources for the NDSS in South Africa, 2015

7.3.3 Policy actors' opinions of the effect of interventions

Key stakeholders rated the introduction of an electronic system as the intervention that would have the highest impact on the NDSS. They gave the intervention a mean score of 90%, while the HCPs scored it 80%, which was their second highest score. HCPs rated the use of mobile technology as the intervention with the highest score (81%; and scored investing more staff, more finances and addressing the level of organisation equally at 76%. Key stakeholders scored all interventions, except for investing more staff, significantly higher than HCPs in bivariate linear regression. In multivariate linear regression, introducing an electronic system (Coefficient - 0.010 $p<0.001$), investing more staff (Coefficient 0.002 $p=0.029$), and addressing the level of organisation (Coefficient -0.006 $p=0.049$) are scored significantly higher for key stakeholders (Table 7.1).

Table 7.1 Key-stakeholders (KSHs) and Health care providers (HCPs) ratings of the effect of interventions on the NDSS South Africa 2015

Interventions	KSHs	HCPs	Bivariate Regression		Multiple Regression	
	Mean	Mean	Coefficient	p-value	Coefficient	p-value
Investment of staffing	81%	76%	- 0.002	0.146	0.002	0.029*
Investment of funding	79%	76%	- 0.002	0.021*	0.005	0.151
Addressing level of organisation	84%	76%	- 0.004	0.022*	- 0.006	0.049*
Introducing an electronic system	90%	80%	- 0.007	<0.001*	- 0.010	<0.001*
Using mobile technology	88%	81%	- 0.005	0.021*	0.003	0.337

* Significant p-value

7.4 Discussion

This was one of the first studies to ascertain the opinions of policy actors (key stakeholders and HCPs) on NDSS reforms in South Africa. The study found that key stakeholders, i.e., those at policy planning, monitoring and evaluation levels, regarded organisation and investments as poor, whereas HCPs, i.e. those at the coalface of service delivery level regarded organisation and investments as satisfactory. As Bressers' contextual theory proposes, differences in these groups' specific, structural and wide context may account for their differences in perspectives [243-245]. Key stakeholders were older than HCPs, with more experience in the NDSS, and more training in the NDSS (Chapters 4 and 6), which may have shaped their opinions of the system.

The finding that most key stakeholders regarded the current level of organisation and resource investment in the NDSS as poor, is in line with their low perceptions on the attributes of acceptability, flexibility, timeliness and usefulness of the NDSS (Chapter 4) [56], and the poor performance of the NDSS on the attributes of completeness, stability and

representativeness when compared against laboratory surveillance (Chapter 5) [57]. Poor human resources for health is a global problem [167, 246, 247] and in most LMICs, especially in Africa [248-252]. African countries have also been affected negatively by the out-migration of HCPs [253]. Although South Africa has more human resources than most other African countries, a 2015 study found that South Africa had fewer doctors per population compared to India, China and Brazil [254]. The National Department of Health highlighted a critical shortage of nurses at all levels, in its national nursing strategy [255]. Hence the perceptions of key stakeholders on human resource shortages are supported by evidence.

The finding that almost one in two of HCPs scored the resources and organisational level for the NDSS as satisfactory is in sharp contrast to the opinions of the key stakeholders. This is surprising as HCPs are at the coalface of service delivery, where the impact of resource shortages, such as human resources, would be more evident. The comparative study on notifications and laboratory surveillance (Chapter 5) found that there were fewer laboratory confirmed cases in rural provinces, illustrating that financial and human resource inequities affected the NDSS [57, 195]. The surprising finding may be that the key stakeholders and HCPs interpreted the notion of "satisfactory" differently, as alluded to by Bressers' Contextual Interaction Model [243]. The differences in context [243] with the longer NDSS training and experience that the key stakeholders had, may have contributed to better insights into the needs of the NDSS and translated into differences in their opinions. Both the key stakeholders and HCPs surveys could have been affected by social desirability bias [208]. Key stakeholders scored an intervention regarding NDSS organisation significantly higher than HCPs in multivariate linear regression (Coefficient -0.006 p=0.049). The IDSR emphasizes the need for strong organisation at all levels in establishing an effective NDSS [24]. Several studies in Africa have demonstrated the relationship between health system structure and organisational issues, such as over-centralization and weak laboratories on

the functioning of NDSS [128, 129, 256-258]. South Africa has a strong laboratory surveillance system [57], but a relatively weak primary health care system [259]. Although PHC reforms are underway in South Africa [51], policy analysts have proposed that concomitant NDSS reforms need to be introduced [260].

A limitation of this study was that it did not include an empirical study of the resources within the NDSS. However, there is evidence of human and financial resource constraints at all levels of the health system, which are more acute at the district health system level. The reform of the NDSS should include an assessment of resources, and benchmarking of the resource investments needed against other countries with similar levels of income and similar burden of infectious diseases. The assessment of current resources, and investments needed should be accompanied by a clear plan on addressing constraints in a phased manner.

The finding that key stakeholders regarded the introduction of an electronic system as the best intervention for the NDSS is in line with global studies which have shown that electronic systems improved the functioning of the NDSS [261-264]. In South Africa, studies on the surveillance of TB have shown that the introduction of an electronic system can make a difference to the usefulness and other attributes of the system [85, 87]. The successful introduction of an electronic system for TB is a precedent that can be followed for the rest of the system. The fact that both the key stakeholders and the HCPs rated this intervention highly can be regarded as an indicator of their willingness to cooperate with the introduction of such a system.

The finding that HCPs rated the use of mobile technology as the intervention with the highest score, is in keeping with the high penetration of mobile technology in the South African market – the country is ranked 27th in the world on the number of mobile phones and has 117 phones per

100 people [265]. Given the high penetration of mobile technology in the country and successful pilot studies on malaria surveillance with mobile technology [217], this is an area that should be explored in reforming the NDSS. NDSS reforms should be accompanied with clearly communicated guidelines and support programmes. Mobile technology has been effectively used in communicable diseases surveillance globally [266-269] and in Africa [270-273]. In South Africa, there have been initiatives to use mobile technology in malaria surveillance [217] and in the care and management of pregnant woman [274]. HCPs are at the first level of interaction between patients and the health care system; the introduction of the use of mobile phones in the NDSS could lead to them effectively notifying diseases and to a better response to outbreaks.

A limitation of the study is that it was based on a quantitative analysis of role-players' opinions on the possible effect of a list of five interventions on the NDSS; a qualitative analysis with open questions would have allowed an assessment of a broader scope of issues to take into account, and additional interventions. Nonetheless, we focused on a list of interventions that have shown to be effective in other countries that are implementing NDSS reforms.

7.5 Conclusion

This study provided new knowledge on the perspectives of health policy actors on reforming the notifiable diseases surveillance system in South Africa. The policy actors at different levels of the NDSS in South Africa had different opinions on the level of organisation and resource investment in the NDSS, as well as the interventions needed to reform the surveillance system. Those at service delivery level regarded human and financial resource investments as satisfactory and regarded the introduction of mobile technology as the best intervention to improve the NDSS; while those at the monitoring and evaluation level regarded human and financial

resource investments as poor with the introduction of an electronic system as the best intervention. In light of the important role of both groups of policy actors in the effective functioning of the NDSS, their opinions should be used to inform the reforms of the NDSS in South Africa. An electronic system with a mobile interface for HCPs should be introduced and both resource shortages and organisational weaknesses at institutional, district, provincial and national level must be addressed as part of the NDSS reforms.

CHAPTER 8. DISCUSSION AND RECOMMENDATIONS

8.1 Introduction

The 2017/18 listeriosis outbreak in South Africa has highlighted the criticality of an effective NDSS to the health and well-being of communities, and the prevention of premature mortality [275].

This PhD study was based on: two cross-sectional surveys conducted in 2015, one among key stakeholders involved with analysing, interpreting, responding, reporting, monitoring and evaluation of the NDSS at a national and provincial level (Chapter 4); the other among HCPs involved with the identification and notification of communicable diseases at institutional level in both the public and private health sectors (Chapter 6); and a comparative study of notifications and laboratory surveillance (Chapter 5). The cross-sectional surveys also elicited the perspectives of policy actors (key stakeholders and HCPs) on organisational and resource reforms of the NDSS (Chapter 7).

In this concluding chapter I integrate the key findings of this thesis (Chapters 4 to 7), to propose recommendations for reforming the NDSS in South Africa. In Section 8.2 I summarise the key findings and recommendations of the PhD study. In Sections 8.3 and 8.4 I highlight the scholarly contribution and policy impact of the PhD respectively. Section 8.5 contains recommendations for further research.

8.2 Key Findings and Recommendations

8.2.1 Summary of key findings

The key findings of all the studies the PhD are summarised in Table 8.1, and discussed below

Table 8.1: Summary of the key findings of the PhD

• 25 % of key NDSS stakeholders perceived the system to be acceptable, 51 % to be flexible, 45 % to be timely, 61 % to be useful, and 74 % to be simple. • Stakeholders with more years of experience were less likely to perceive the NDSS system as acceptable (OR 0.91, 95 % CI: 0.84–1.00, p = 0.041); those in disease detection were less likely to perceive it as timely (OR 0.10, 95 % CI: 0.01–0.96, p = 0.046) and those participating in National Outbreak Response Team were less likely to perceive it as useful (OR 0.38, 95 % CI: 0.16–0.93, p = 0.034).
• Using the three tracers of measles, meningococcal meningitis and typhoid, the comparative study found that notifications for all three tracer diseases were significantly lower compared to laboratory diagnosed cases • Completeness for the laboratory system was higher for measles (63% vs. 47%, p < 0.001) and meningococcal meningitis (63% vs. 57%, p < 0.001), but not for typhoid (60% vs. 63%, p = 0.082). • Stability was higher for the laboratory (all 100%) compared to notified measles (24%, p < 0.001), meningococcal meningitis (74%, p < 0.001), and typhoid (36%, p < 0.001). Representativeness was also higher for the laboratory (all 100%) than for notified measles (67%, p = 0.058), meningococcal meningitis (56%, p = 0.023), and typhoid (44%, p = 0.009). • The sensitivity of the NDSS was 50%, 98%, and 93%, and the PPV was 20%, 57%, and 81% for measles, meningococcal meningitis, and typhoid, respectively.
• The study found that 58% of HCPs (n=919) surveyed diagnosed a notifiable disease in the year preceding the survey. • Although the majority of these professionals (92%) indicated that they had reported the disease, only 51% of those notified the disease/s correctly to the Department of Health. • Factors influencing notification were HCPs perceptions of workload (OR 0.84, 95% CI 0.70 - 0.99, p=0.043) and that notification data are not useful (OR 0.84, 95% CI 0.71 - 0.99, p=0.040).
• 58% to 87%; of key stakeholders scored the level of NDSS organisation as poor or very poor; 54% to 68% scored human resource investment as poor or very poor, while 67% to 84% scored financial resource investment as poor or very poor, In contrast, 33% to 38% of HCPs scored the level of NDSS organisation as poor or very poor; 35% to 38%. scored human resource investment as poor or very poor, while 35% to 38% scored financial resource investment as poor or very poor,
• Key stakeholders rated the introduction of an electronic system as the best intervention to improve the NDSS, while HCPs rated the introduction of mobile technology as the best intervention to improve the NDSS

8.2.2 Performance of the NDSS against system attributes

An effective public health response, which is aimed at containing the spread of an outbreak of a communicable disease, is dependent on a NDSS that is acceptable, flexible, representative, sensitive, simple, stable, timely, useful, has quality data and with an appropriate positive predictive value (PPV) [9, 24, 25, 88, 89]. In this PhD, key stakeholders scored the NDSS in South Africa low on the attributes of acceptability, flexibility, simplicity, timeliness and usefulness. These findings were supported by the comparative study of notifications and laboratory surveillance for three tracer conditions of measles, meningococcal meningitis, and typhoid. The comparative study found that the NDSS performed poorly on data quality, representativeness, sensitivity, stability and PPV. The findings on the NDSS attributes are low when compared with South Africa's self-assessment surveillance scores of 100%, submitted for the period from 2014 to 2015 [27].

There are no international gold standards for the scores on these attributes [229], and comparisons with other countries should be treated with caution because of differences in context, disease profiles, resources and study methodologies [24, 88, 139]. Nonetheless, the attribute scores found in this study are a lower compared to those found in studies done in other countries [118-129]. In this PhD study, 25% of key stakeholders perceived the system to be acceptable, in contrast to Germany where 90% scored the NDSS as acceptable [130]. In Madagascar acceptability levels for influenza surveillance ranged from 84%-98% [134], albeit for a single disease. On the score of simplicity, 74% of South African stakeholders scored the NDSS as simple, which was lower than what was found in Madagascar where 94% of stakeholders scored the surveillance system as simple [134]. In a Ugandan study 68%-73% stakeholders scored the NDSS as timely [126], in contrast to my PhD study in which 45% of stakeholders regarded the NDSS as timely.

Given the difficulties with inter-country comparisons, it is more relevant to compare the study findings with similar studies in South Africa [24, 88, 139]. As indicated earlier, there is a dearth of NDSS evaluation studies in South Africa on the attributes of the NDSS, and these studies were limited in scope and scale. These other studies in South Africa found that the electronic TB surveillance system was acceptable and simple [86, 87], but the studies were contradictory on flexibility as the one scored it as flexible [87], whereas the other one found that the system did not adapt to changes, and hence was not flexible [86].

A direct comparison with my PhD study is not possible, as TB is a single disease, whereas my PhD focused on the NDSS as a whole.

My PhD study contributed new knowledge on the performance of the NDSS on the system attibutes. It should form the basis for future studies on the NDSS attributes. Importantly, the findings suggest that the entire NDSS should be reformed. As a minimum, the NDSS should make it easy for HCPs and laboratories to comply with notification of infectious diseases, in order trigger an appropriate public health response. The reforms of the NDSS should be implemented using a phased approach and in consultation with all the key stakeholders. This would also be in line with the WHO's 2020 strategic policy framework [112] which emphasises the importance of including all stakeholders in decision-making and health system reform initiatives [113]. Although the HCP survey found that training and experience had no influence on compliance, any NDSS reforms should be accompanied by a change management process that includes clear communication on the need for change, training and capacity building on new guidelines and protocols.

The study findings indicate a need for objective evaluations in support of annual IHR country submissions to the WHO. The tools used in this study could complement the JEE tool that has become the recommended

instrument for IHR objective assessments [79, 80, 276] because of their specific focus on the NDSS.

8.2.3 Comparing laboratory surveillance with the NDSS

The comparative study between the NDSS and laboratory surveillance found that notifications for all three tracer diseases, measles, meningococcal meningitis and typhoid, were significantly lower than cases that were laboratory diagnosed [57]. The NDSS also performed poorly on most of the system attributes of data quality, representativeness, sensitivity, stability and PPV, for all of the three tracers. The findings on the poor performance of the NDSS were underscored by the poor perceptions of key stakeholders on the system attributes (Chapter 4) and the poor compliance of HCPs with the NDSS (Chapter 6).

As indicated earlier there is a dearth of similar studies in the international literature. The sensitivity of 50% for measles in my study was lower than that in a similar 2005 Swedish study with sensitivities for salmonellosis of 99.9%, and meningococcal infection of 98.7% [142]. In this PhD study, the sensitivity for typhoid was 93%, for meningococcal meningitis 98% and these were comparable to the Swedish study. However, as indicated in Chapter 5, the calculation of sensitivity and PPV was negatively affected by the poor data quality in the notification and laboratory records, which prevented the matching of a sizeable number of records between the two systems. Defining minimum data requirements for laboratory requests and NDSS notifications, and building these into guidelines and protocols would assist in addressing the problem of poor data quality. Further studies on the attributes of sensitivity and PPV once data quality improvement measures have been implemented, are indicated.

A 1985 to 1988 South African study that compared notifications and laboratory surveillance for hepatitis B showed that 14% of hepatitis B cases

were notified [166]. Although this study was done more than 28 years ago and the South African health system has undergone major changes since then, it appears that under-reporting remains a serious problem as that only 1.5% of suspected measles and meningococcal meningitis cases were notified.

Based on my PhD study findings, mandatory laboratory notification is likely to enhance the effectiveness of the NDSS as was the case in other countries [140-144, 148]. The DOH should therefore take steps to ensure that appropriate regulations in this regard are developed and promulgated. In light of technological advances in laboratories in South Africa [277], an electronic system in the country should be instituted once regulations are promulgated. However, mandatory laboratory notification should not replace mandatory HCP notification, and should be implemented in tandem. The role of HCPs in implementation of NDSS reforms is critical because notification of diseases such as measles, meningococcal meningitis and cholera based on clinical suspicion is essential.

8.2.4 Compliance of health care providers (HCPs)

This PhD study found that 58% of HCPs indicated that they diagnosed a notifiable disease in the year preceding the survey and that 92% of these indicated that they have reported the disease. However, only 51% of those notified the disease/s correctly to the DOH. Hence compliance was not according to prescribed standards, supporting the finding in the comparative study that found that only 1.5% of suspected measles and meningococcal meningitis cases were notified [57]. The variations between self-reported compliance and the findings of the comparative finding could be due to differences in the denominator (the record reviews measured reporting per case while the survey computed this per HCP), and the social desirability bias of self-reported information. The self-reported timeliness of the notifications (67% within 24 hours) was also high and in contrast to

the poor perceptions on timeliness found amongst other key stakeholders, with only 45% scoring the NDSS as timely [56].

Underreporting in countries' NDSS is a common problem globally [140-143, 159, 160, 169-184], with similar low levels of HCP compliance of HCPs found in Nigeria and in Zimbabwe [185-187, 189]. The underreporting has implications for the optimal performance of an NDSS as it may result in the late detection of outbreaks.

In this PhD study, HCPs perceptions of workload and their opinions on the usefulness of notification were associated with their reported compliance with the system. This means that the DOH should address staffing levels, and give regular feedback and communicate to HCPs on the usefulness of notifications. Our study found that willingness to notify, training on the NDSS, understanding of the purpose of the NDSS, knowledge on what to notify, possession of notification forms and feedback did not influence HCP compliance with the NDSS. This was in contrast to other studies that have found these factors to be important determinants of compliance [84, 141, 160, 176, 177, 183, 184, 190, 191]. In Africa, two studies in Nigeria found that the most common reasons for lack of reporting were a lack of knowledge amongst HCPs and a lack of infrastructure or logistics for reporting [186, 187]. The differences in our findings and these studies may relate to differences in methodology, and do not mean that these factors are not important that require ongoing attention in ensuring an effective NDSS. In rural areas a lack of infrastructure may have contributed to the lower levels of compliance in our study. Steps should therefore be taken to ensure that infrastructure and forms are available to all HCPs to ensure that there are no barriers to notification.

Our finding that a high percentage of HCPs did not notify correctly indicates that clear guidelines are needed to ensure optimal functioning of the South African NDSS. The finding that paediatricians and rural private HCPs

notified fewer diseases correctly indicates the need for interventions to target paediatricians and rural areas. Apart from guidelines these interventions should include the introduction of a simplified notification system that makes it easy for clinicians to notify diseases to the correct authority, as well as appropriate training on the new system, both for HCPs in the public and private health sectors. In other countries, infection control nurses played a critical role in improving communicable disease reporting [234, 235]. In our study, a high percentage of HCPs reported notifiable diseases to them; hence infection control nurses should be targeted as part of the reforms of the NDSS.

8.2.5 Perspectives on reforms of the NDSS

My study found that different policy actors had different opinions on the level of organisation, resource investment and reforms needed in the NDSS. Key stakeholders, i.e., those at monitoring and evaluation level, regarded organisation and investments as poor, whereas HCPs, i.e. those at the coalface of service delivery level, regarded organisation and investments as satisfactory. Key stakeholders regarded the introduction of an electronic system as the best reform for the NDSS, while HCPs regarded the introducing of mobile technology as the best reform. The differences in context [243-245] with the longer NDSS training and experience that the key stakeholders had, may have contributed to the differences in opinion. The differences may also be because of different understanding or interpretations of the questions.

Poor human and financial resources are well-known problems of health care systems in LMIC [248-252]. Further studies are needed to assess current human and financial resources in all levels of the NDSS, and the knowledge and competencies of NDSS staff. This will enable costs of reforming the NDSS, which could be incorporated into a medium-term plan, and could feed into the overall discourse on the implementation of the NHI system.

The preference of key stakeholders for an electronic system is in line with global studies which have shown that electronic systems lead to improvement in the functioning of the NDSS [261-264]. The finding that HCPs rated the use of mobile technology highly is in line with the increased trend of using digital technology in health [266-273]. The implementation of an electronic NDSS with a mobile interface for HCPs is an appropriate recommendation for reform of the NDSS. The implementation of these reforms should be accompanied by stakeholder and HCP involvement, communication and awareness raising, appropriate training, dedicated budgets, guidelines and protocols, and monitoring and evaluation.

8.2.6 Summary of Recommendations

In this section, I have drawn on the study's conceptual framework presented in Chapter 1 and the key findings of the study to recommend essential NDSS reforms (Table 8.2). These proposed reforms should be led by the national Department of Health. The Department should involve, and be supported by the various role-players, as shown in Table 8.2.

Table 8.2: PhD Study Recommendations

Recommendation	Individual HCP	National Department of Health	Provincial, local and private health sector	National Health Laboratory Service
1. Provide leadership to implement NDSS reforms in South Africa	~	X	~	~
2. Use system attributes of usefulness, timeliness, simplicity, flexibility, acceptability, representativeness, stability, data quality, sensitivity and positive predictive value as a framework , to design a revitalised and reformed NDSS	~	X	~	~
3. Ensure that an electronic system with a mobile interface is incorporated into the design of the reformed NDSS	~	X	~	~
4. Ensure objective assessments of the NDSS during a five-year strategic planning cycle, drawing on the 2005 IHR, the IDSR, recommendations from the Joint External Evaluation (JEE) and the tools and findings of this PhD study	~	X	~	~
5. Adapt and implement the guidelines and protocols for the IDSR, addressing all organisational levels from the community to national		X	~	~
6. Develop and promulgate regulations in terms of the National Health Act to make it mandatory for all laboratories to notify listed infectious diseases		X	~	~
7. Conduct an audit of dedicated NDSS human resources in both the public and private health sectors, including relevant staff knowledge, competencies and skills	~	X	~	~
8. Conduct an audit of dedicated NDSS financial resources in both the public and private health sectors		X	~	~
9. Benchmark human and financial resource investments in the NDSS against those in other countries with similar levels of income		X	~	~
10. Use results of benchmarking, requirements indicated by audits and the reformed system to develop a business plan for NDSS reform implementation	~	X	~	~

Recommendation	Individual HCP	National Department of Health	Provincial, local and private health sector	National Health Laboratory Service
11. Reiterate the legal obligation of HCPs to notify communicable diseases in the regulations on mandatory laboratory notification	~	X	~	~
12. Emphasise the legal obligation of HCPs to notify communicable diseases in pre-service training in health science faculties and nursing colleges and in continuing professional development	~	X	X	~
13. Provide simple and clear protocols, guidelines and clinical management algorithms to HCPs, outlining the notification process and who to report to	~	X	X	
14. Educate and train all HCPs, in both the public and private health sectors, on the new reformed NDSS processes and tools, with particular attention paid to paediatricians and rural doctors	~	X	X	
15. Revitalise and emphasise the role and responsibilities of infection control nurses in hospitals	~	X	X	
16. Ensure regular feedback to HCPs on the use of notification data so that they appreciate the usefulness of their compliance with the NDSS		X	X	
17. HCPs should comply with their obligation to notify listed communicable disease	X			~

X-key responsibility; ~ NDSS reform involvement and/or support role

8.3 Scholarly contribution of the PhD study

8.3.1 Generating new knowledge

The PhD study has generated new knowledge on the performance of the NDSS in South Africa at a time when various infectious disease outbreaks (such as Ebola) underscored the importance of surveillance systems to national and global health security [209].

Study I involved all policy actors involved with the NDSS at a national and provincial level, and generated new knowledge on the performance of the NDSS against the attributes of acceptability, flexibility, simplicity, timeliness and usefulness. Study II was the first comparative study between the NDSS and laboratory surveillance, and it generated new empirical knowledge on the attributes of data quality, representativeness, sensitivity, stability and PPV of the NDSS that underscored the findings of the two surveys. Importantly, the comparative study was one of the first of its kind in a low and middle-income country setting, or in an African setting [210].

Study III on the compliance of HCPs with notification of infectious diseases was the first such representative study done in the country, covering both public and private health sectors, and different levels of the health care system. It generated new knowledge on HCP compliance with the NDSS and on factors associated with their compliance.

8.3.2 Methodological innovation

Studies I and II had a national coverage and are therefore representative of the entire country. Study III covered 77 randomly selected institutions, in the public and private health sectors, and 70 randomly selected GP practices in three randomly selected provinces. The cross-sectional surveys

conducted as part of the PhD obtained high response rates in excess of 80%, and the findings can be generalized to the rest of the country.

The methodology employed in the comparative study of notifications and laboratory surveillance was novel in South Africa, and can be used for similar studies in South Africa, and in other LMIC.

8.4 The Policy impact of the PhD study

The position I held as Chief Director: Communicable Diseases at the DOH and the publication of two papers in recognised peer-reviewed international journals, facilitated the provision of the recommendations of the research to decision makers in the country at an early stage of the PhD study. This allowed the study findings to inform some of the reforms that have begun to be implemented since the study was conducted.

In 2015, the directorate tasked with the surveillance function in the DOH was moved to the Chief Directorate: Communicable Diseases, which allowed me to be directly responsible for both surveillance and outbreak response in the country. This facilitated the implementation of an integrated epidemic preparedness and response training programme in all of the provinces in the country, as well as the development of an integrated strategy for disease surveillance and response by 2016 [278].

Following the adoption of the NaPHISA bill [53] that mandates the NICD to form the core of a future Institute, in 2016 the DOH entered into agreement with the NICD to assume responsibility for the implementation of the NDSS strategy in the country. In 2017, the draft regulations that make it mandatory for both the HCPs and laboratories to notify infectious were published for comments. Following the inputs of all policy actors these regulations were adopted in December 2017 [279]. An electronic notification system was also piloted under the auspices of the NICD in one institution in Gauteng province in 2017.

With regards to its IHR core competencies, South Africa underwent a JEE in December 2017, after the conclusion of the research for this PhD study. Subsequently, the WHO published their findings in a report [276].

8.5 Recommendations for further research

In light of the poor data quality found during the comparative study, there is a need to repeat the study, either using the same three tracers, or other conditions to recalculate sensitivity and PPV.

This PhD study used quantitative methods primarily. Qualitative studies among health care providers using in-depth interviews and focus group discussions on the reasons for non-compliance will add further insights into the performance of the NDSS.

This PhD study found that paediatricians and HCPs in rural areas had lower levels of compliance with the NDSS. Further studies amongst these groups to understand the reasons for their non-compliance should be conducted. Infection prevention and control nurses appear to play a central role in the NDSS as a high percentage of HCPs reported notifiable diseases to them. There is a need for further studies to understand the compliance of these professionals with the NDSS.

My PhD study showed that factors such as lack of infrastructure, forms and training did not affect the compliance of HCPs. These factors were shown to influence compliance in other countries. Further studies are needed in different provinces to confirm the factors that influence compliance of HCPs with the NDSS.

An empirical study is also needed to assess the resources (human, financial and equipment) invested in the NDSS at all levels of the health system. This would inform the resource requirements to address the gaps so identified. Lastly, policy analysis studies should be conducted to determine the impact

of the NDSS reforms on early detection of outbreaks, and the prevention of premature deaths due to infectious diseases.

8.6 Conclusion

A strong national NDSS is essential to ensure public health preparedness and response to epidemics. This PhD generated new knowledge on the performance of the NDSS in South Africa, and proposed a set of strategic recommendations for NDSS reforms.

A reformed NDSS is likely to revitalize public health capabilities of disease prevention, health promotion and health protection, provide the first line of defense against potential pandemics, and harness national leadership and coordination for epidemic preparedness and response [280]. The proposed reforms of the NDSS should be seen as an integral part of South Africa's quest for universal coverage.

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Appendix 1: Ethics Clearance

M140624

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M140624

NAME: (Principal Investigator)	Dr Frew Gerald Benson
DEPARTMENT:	School of Public Health NHLS, NDOH and Provincial Departments
PROJECT TITLE:	Analysing the South African National Notifiable Diseases Surveillance Systems (NDDS)
DATE CONSIDERED:	27/06/2014
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Prof L Rispel and Prof L Blumberg

APPROVED BY:

Professor PE Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 25/08/2014

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**.

Principal Investigator Signature M140624Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix 2: NDOH Approval

DIRECTOR GENERAL
HEALTH
REPUBLIC OF SOUTH AFRICA

PRETORIA
Private Bag X828, PRETORIA 0001, 27th Floor, Room 2710, Civitas Building, PRETORIA Cnr Thabo Sehume & Struben Street, PRETORIA, 0001 Tel (012) 395 8000 Fax (012) 395 8422

CAPE TOWN
P.O. Box 3875, CAPE TOWN, 8000, 6th Floor, Room 617, 103 Parliament Towers Plain street, CAPE TOWN 8000, Tel (021) 461 2040 Fax (021) 461 6864

Dr FG Benson
Chief Director: Communicable Diseases
National Department of Health
Private Bag X828
PRETORIA
0001

Dear Dr Benson

PERMISSION TO CONDUCT A RESEARCH STUDY: ANALYSING THE SOUTH AFRICAN NATIONAL NOTIFIABLE DISEASES SURVEILLANCE SYSTEM

Your request for permission to collect data towards a national PhD study on "Analysing the South African National Notifiable Diseases Surveillance System" refers.

Kindly note that permission for the study has been granted.

I wish you well with your research and request that you submit your research report to my office on completion of the research.

Kind regards

MS MP MATSOSO
DIRECTOR-GENERAL: HEALTH
DATE: 15/10/2014

Appendix 3: Provincial Approvals

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

OUTCOME OF PROVINCIAL PROTOCOL REVIEW COMMITTEE (PPRC)

Researcher's Name (Principal investigator)	Dr Frew Gerald Benson
Organization / Institution	University of Wits
Research Title	Analysing the South African National Notifiable Diseases Surveillance System (NDSS0)
Contact number	Tel: 011 7172119 Email: Thokozile.nhlapo@wits.ac.za
Protocol number	P01012015
Date submitted	
Date reviewed	19 December 2015
Outcome	APPROVED
Date resubmitted	N/A
Date of second review	N/A
Final outcome	APPROVED

It is a pleasure to inform that the Gauteng Health Department has approved your research on "Analysing the South African National Notifiable Diseases Surveillance System (NDSS0). The Provincial Protocol Review Committee kindly requests that you to submit a report after completion of your study and present your findings to the Gauteng Health Department.

Approves / not approves

Dr R Lebethe
Acting DDG: Clinical Services

Date 12/01/2016

health

Department:
Health
PROVINCE OF KWAZULU-NATAL

Health Research & Knowledge Management sub-component
10 – 103 Natalia Building, 330 Langalibalele Street
Private Bag x9051
Pietermaritzburg
3200
Tel.: 033 – 3953189
Fax.: 033 – 394 3782
Email.: hrkm@kznhealth.gov.za
www.kznhealth.gov.za

Reference : HRKM320/14
Enquiries : Mrs G Khumalo
Telephone : 033 – 395 3189

Dear Dr F G Benson

Subject: Approval of a Research Proposal

1. The research proposal titled **'Analysing the South African National Notifiable Diseases Surveillance System'** was reviewed by the KwaZulu-Natal Department of Health (KZN-DoH).

The proposal is hereby **approved** for research to be undertaken at KZN-DoH.

2. You are requested to take note of the following:
   a. **Make the necessary arrangement with the identified facility/department before commencing with your research project**.
   b. Provide an interim progress report and final report (electronic and hard copies) when your research is complete.

3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za

For any additional information please contact Mrs G Khumalo on 033-395 3189.

Yours Sincerely

Dr. E Lutge
Chairperson, KwaZulu-Natal Health Research Committee
Date: 12/12/14.

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Latif Shamila Ref:4/2/2

Benson F
National Department of Health

Greetings,

RE : Analyzing the South Africa National Notifiable Diseases Surveillance System

The above matter refers.

1. Permission to conduct the above mentioned study is hereby granted.
2. Kindly be informed that:-
   - Research must be loaded on the NHRD site (http://nhrd.hst.org.za) by the researcher.
   - Further arrangement should be made with the targeted institutions.
   - In the course of your study there should be no action that disrupts the services.
   - After completion of the study, a copy should be submitted to the Department to serve as a resource.
   - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
   - The above approval is valid for a 3 year period.
   - If the proposal has been amended, a new approval should be sought from the Department of Health.

Your cooperation will be highly appreciated.

pp Head of Department

10/03/2015
Date

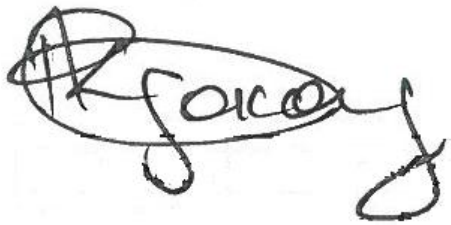
Appendix 4: NHLS Approval

Academic Affairs and Research Modderfontein Road, Sandringham, 2031 Tel: +27 (0)11 386 6142 Fax: +27 (0)11 386 6296 Email: babatyi.kgokong@nhls.ac.za Web: www.nhls.ac.za

05 February 2015
Applicant: Dr Frew Benson
Institution: National Department of Health
Faculty: Communicable Diseases
Tel: 012 395 8094
Email: frewbenson@gmail.com
Re: Approval to access National Health Laboratory Service (NHLS) Data
Your application to undertake a research project "**Analysing the South African National Notifiable Diseases Surveillance System**" using data from the NHLS database has been reviewed. This letter serves to advise that the application has been approved and the required data will be made available to you to conduct the proposed study as outlined in the submitted application.
Please note that the approval is granted on your compliance with the NHLS conditions of service and that the study can only be undertaken provided that the following conditions have been met.
• Full Updated Ethics clearance have been obtained from an approved local Ethics Committee and sent as proof.
• Processes are discussed with the laboratory manager and/or the Business Manager and/or the Unit Manager and are agreed upon.
• Confidentiality is maintained at participant and institutional level and there is no disclosure of personal information or confidential information as described by the NHLS policy.
• A final report of the research study and any published paper resulting from this study are submitted and addresses to the NHLS Academic Affairs and Research office and the NHLS has been acknowledged appropriately.

Please note that this letter constitutes approval by the NHLS Academic Affairs and Research. Any data related queries may be directed to Sue Candy, Manager NHLS Corporate Data Warehouse, Tel: (011) 386 6036 Email: sue.candy@nhls.ac.za

Yours sincerely,



Dr Babatyi Malope-Kgokong
National Manager: Academic Affairs and Research

Appendix 5: Private Hospital Approvals

From: Taylor,Steve

Sent: 01 December 2014 09:05 AM

To: frewbenson@gmail.com

Cc: Meyer,Andre; Kaseke,Lloyd; Cleghorn,Joy; Frankish,Trevor

Subject: Permission to conduct a research study: Analysing the South African National Notifiable Diseases surveillance system (NDSS)

Dear Dr Benson

Your letter dated 21 November concerning the abovementioned and received by our CEO on 26 November 2014 refers.

André Meyer has asked me to reply on his behalf.

We all agree that it would be a very valuable study and you are given permission to collect data from Life Healthcare facilities.

Please do not hesitate to contact myself, Trevor Frankish , Lloyd Kaseke or Joy Cleghorn when you commence the study so that we can give you ongoing assistance.

Kind regards

Steve Taylor

Dr Steve Taylor
MBChB(UCT); MMed (UCT); FFCH (CMSA)
Executive - Group Medical Director

+ 27 43 783 6004
+ 27 43 783 6004 / 0866865560
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steve.taylor@lifehealthcare.co.za
www.lifehealthcare.co.za

Life Healthcare Group (Pty) Ltd
Registration number: 2003/024367/07
This message and any attachments are confidential and intended solely for the addressee. The following link will display the full disclaimer: http://www.lifehealthcare.co.za/disclaimer/
The following link displays the list of Directors: http://www.lifehealthcare.co.za/IR/directors.aspx

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ETHICS LINE 0800 005 316

www.mediclinic.co.za

27 January 2015

Dr F Benson
National Department of Health
Pretoria

E-mail: BensonF@health.gov.za

Dear Dr Benson,

ANALYSING THE SOUTH AFRICAN NATIONAL NOTIFIABLE DISEASES SURVEILLANCE SYSTEM

Please be advised that Mediclinic hereby approves the application for the above-mentioned research.

Yours sincerely,

DR M S SMUTS
CHIEF CLINICAL OFFICER

RESEARCH OPERATIONS COMMITTEE FINAL APPROVAL OF RESEARCH

Approval number: UNIV-2015-0007

Dr FG Benson

E mail: bensonf@health.gov.za

Dear Dr Benson

RE: ANALYSING THE SOUTH AFRICAN NATIONAL NOTIFIABLE DISEASES SURVEILLANCE SYSTEM

The above-mentioned research was reviewed by the Research Operations Committee's delegated members and it is with pleasure that we inform you that your application to conduct this research at Private Hospital, has been approved, subject to the following:

i) Research may now commence with this FINAL APPROVAL from the Committee.

ii) All information regarding the Company will be treated as legally privileged and confidential.

Yours faithfully

12/2/2015

Prof Diondu Plessis
Full member: Netcare Research Operations Committee & Medical Practitioner evaluating research applications as per Management and Governance Policy

Shannon Nell
Chairperson: Netcare Research Operations Committee
Network Healthcare Holdings Limited (Netcare)
Date: 18/2/2015



Procedure Manual

Analysing the national notifiable diseases surveillance system in South Africa

Health Provider Survey and Record Review

23 March 2015

Introduction to the Procedure Manual

- This research study procedure manual sets out the procedures for the health care providers' survey and the district record review. Each fieldworker must carefully follow the manual to ensure success of the study.

- Every field worker must know all aspects of the procedure manual dealing with the health care providers' survey. The research manager must know all aspects of the manual in detail.

- We must all work together as part of a team. This means that staff stand in for, and help out other members of the staff when necessary

Remember

- ✓ **In any study, preparation is very important to ensure that the recruitment and data collection processes run smoothly.**
- ✓ **Before the actual start of the study, we should compile a checklist of all project forms, materials and equipment needed for the successful implementation of the study**

Ethics and maintaining confidentiality

This research has been approved by the Wits Research Ethics Committee. The steps that must be taken in the survey to ensure and maintain an ethical approach to the study, are listed below:

1. Potential participants must be informed that their participation in this study is strictly voluntary and that they are free to withdraw from the study at any time.

2. Following careful explanation of the survey, fieldworkers will give eligible health care providers the information sheet to read or, if necessary, the information sheet will be read to the survey participant by project staff.

3. A tamperproof box must be provided at all the relevant institutions for participants to insert completed questionnaires in.

4. Confidentiality must be maintained throughout the study. The tamperproof box with the completed questionnaires must be stored in a locked office or locked filing cabinet and handed to the principal investigator at the earliest opportunity.

5. All participant questions that arise must be addressed.

6. All participants will be given the name and telephone number of the principal investigator should they have any question about the study.

Remember

- ✓ **Professional behaviour of the research team is critical at all times**
- ✓ **Confidentiality, privacy and respect for individuals are not negotiable and must be adhered to**
- ✓ **The information sheet is critical to give to Health Care Providers even if they choose NOT to take it with them!**

Key Study Information

What is the study about?

The last decade has seen the global emergence of infectious disease epidemics, such as Severe Acute Respiratory Syndrome (SARS) in 2003, the influenza pandemic (H1N1) of 2009, and the recent Ebola Virus Disease outbreak of 2013-15. These emerging diseases have drawn attention to the importance of strong country-based Notifiable Disease Surveillance

Systems (NDSS) to ensure public health preparedness to respond to such outbreaks. Although the NDSS in South Africa has been in existence since the late 1970s, there is little information on its current status and there has been no systematic and objective evaluation of the national NDSS since its inception.

The aim of this study is to conduct a systematic, country-wide analysis of the national NDSS of South Africa

Who is doing the study?

The study is being done by Dr Frew Benson as part of a doctoral degree at the School of Public Health at the University of the Witwatersrand, Johannesburg. Dr Benson is supervised by Prof Laetitia Rispel, the Head of School, and Prof Lucille Blumberg of the National Institute of Communicable Diseases. All of their contact details are provided below.

Who will be our target population?

This procedure manual address two sub-studies of the research project with different target populations, namely a) a health providers' survey and b) a record review.

a) All health care providers (doctors and nurses) in City of Johannesburg and West Rand in Gauteng; eThekwini, uMgungundlovu and Ugu in KwaZulu-Natal; Capricorn and Vhembe in Limpopo, who are on duty at their institution on the day of the survey, will form the target population for this study.

b) Records of notifications on three tracer notifiable diseases, namely meningococcal meningitis, measles and typhoid for the year 2013, at the above mentioned district offices will be accessed and reviewed by the principal investigator or research manager in the province.

Where will the research study take place?

The survey will be done in a random sample of public facilities, as well as private facilities in the seven districts of the three provinces mentioned above. In hospitals, all professional nurses and doctors in the following divisions on the survey day, will be selected for study: internal medicine (including all outpatient departments and wards), medical casualty, paediatrics (including all outpatient departments and wards), paediatric casualty (where applicable) and infection control. In Primary Health facilities all professional nurses and doctors will be selected.

The record review will be done at the seven district offices.

Contact information

Principal Investigator
Dr Frew Benson
National Department of Health
Phone: 012 395 8094 or Cell: 0823724199
Fax: 012 395 8905
Email: frewbenson@gmail.com or bensonf@health.gov.za

Research Supervisors
Professor Laetitia Rispel
Centre for Health Policy, University of the Witwatersrand, Johannesburg
Tel: 011 717 3436 (office) or Cell: 082 372 0548
Fax: 011 7173429
Email : Laetitia.rispel@wits.ac.za

Professor Lucille Blumberg
National Institute of Communicable Diseases
Tel: 011 386 6337 (office) or Cell: 082 807 6770
Fax: 0867583326
Email : Lucilleb@nicd.ac.za

Procedure for Health Care Provider Recruitment

The Research Managers together with the fieldworkers will be involved in the recruitment of DOCTORS and PROFESSIONAL NURSES from the targeted facilities.

1. ON THE DAY OF THE SURVEY THE MANAGER/ FIELDWORKER Should be in possession of the following:

- **LIST OF RANDOMLY SELECTED FACILITIES**
- **INFORMATION SHEET**
- **QUESTIONNAIRE (WHICH CONTAINS THE CONSENT NOTE)-**
- **PENCIL AND ERASER AND A PEN**
- **TAMPERPROOF BOX (FOR THE INSERTION OF COMPLETED QUESTIONNAIRES)**
- **COPIES OF THE APPROVAL FROM THE RELEVANT PROVINCE AND PRIVATE HOSPITALS**

The MANAGER/ FIELDWORKER MUST present and introduce himself/ herself to the CEO/FACILITY MANAGER in charge of the hospital/clinic, explain the survey and present them with a copy of the relevant approval granted (for public hospitals, from the provincial department and from private hospitals, from their head office).

Greet the CEO/ FACILITY MANAGER and thank them for allowing us entry. Stress the importance of the study in generating information to improve the NDSS. **Remember first impressions are lasting impressions!**

Remember: Who is eligible to participate in the survey?

Must be a doctor or professional nurse working in one of the targeted areas i.e. not other categories of staff

- **Enrolled nurses, student nurses, and assistant nurses are excluded from the survey**
- **BUT Interns and Qualified nurses doing post-basic diplomas e.g. ICU are included in the study**

What is the procedure for recruiting health care providers in public facilities?

Script for manager/ fieldworker

*Hello, my name is……..I am pleased to meet you. Thanks for your willingness to receive us and assist us with the study '**Analysing the South African National Notifiable Diseases Surveillance System (NDDS).'** We are doing the study in seven districts in three provinces, namely Gauteng, Limpopo and KwaZulu-Natal. The study focuses on health care provider compliance with the NDSS and the factors influencing compliance. The aim of the study is to inform recommendations for policy improvements of the NDSS We are interested in doctors and professional nurses working in internal medicine (including all outpatient departments and wards), medical casualty, paediatrics (including all outpatient departments and wards), paediatric casualty (where applicable) and infection control. We will make sure that we do not interfere with the normal functioning of the health care workers and the units. If necessary, we will stay here for the whole day, to select the most convenient time to get the survey done. Thanks once again*

- After explaining the study, the CEO/ Facility Manager may refer the research team to the unit manager (s). It is preferable to talk to the managers responsible for these areas at the same time as talking to the CEO/Facility Manager.
- The Research Manager/Field Worker will introduce the study in the same manner as to the CEO/Facility Manager.
- In hospitals, the **targeted clinicians are doctors and professional nurses working in internal medicine (including all outpatient departments and wards), medical casualty, paediatrics (including all outpatient departments and wards), paediatric casualty (where applicable) and infection control**.
- In Primary care facilities (CHCs and clinics), **all professional nurses and doctors** are targeted.
- On the day of the survey, **every clinician in target group (excluding enrolled nurses, student nurses and assistant nurses)** will be asked to participate in the survey if they work in the areas mentioned above.
- The Research Manager/Fieldworker will approach nurses on duty at the most suitable/ convenient time and explain the study to them (use the fieldworker script).

What is the procedure for recruiting doctors and nurses in private hospitals?

Script for encouraging doctors and nurses to participate

My name is _____. I am from the School of Public Health. We are doing research on the Notifiable Diseases Surveillance System, which focuses on the detection, prevention and control of public health threats in South Africa. The aim of this research project is to inform policy and health system interventions for improvements in the system. We believe that you can help us by sharing with us your knowledge, views and experiences of the system. It will take about 15-20 minutes of your time.

We have obtained permission to conduct this study. Ethical approval for this study has been obtained from the University of the Witwatersrand Ethics Committee for Research on Human Subjects.

The questions are not a test, so there is no right or wrong answers. It is your opinions and experiences that are important. Everything that you say will be treated as private and confidential. .Your name will not be used in the study.

Your participation is completely voluntary. There will be no negative consequences if you do not want to participate. There will be no direct benefit to you if you participate in this study but we hope that the information collected will be helpful in improving nursing and health services in South Africa.

If you are willing to give your consent and take part, we will appreciate your participation and the information that you are willing to provide. This is an information sheet which explains the study in more detail **(GIVE THE CLINICIAN THE INFO SHEET).**

- After explaining the study, the facility manager may refer the research team to the unit manager (s).
- The Research Manager/Fieldworker will introduce the study in the same manner as to the CEO/Facility Manager.
- In private hospitals, the **targeted clinicians are doctors and professional nurses working in internal medicine, medical**

casualty, paediatrics, paediatric casualty (where applicable) and infection control.

- On the day of the survey, **every clinician in target group (excluding enrolled nurses, student nurses and assistant nurses)** will be asked to participate in the survey if they work in the areas mentioned above.
- The researcher/ fieldworker will approach clinicians on duty at the most suitable/ convenient time and explain the study to them (use the fieldworker script)
- Note that few doctors will be available in private hospitals. A list of 10 General Practitioners in each district will be randomly selected and provided to field workers to approach in their private practices at a time convenient to them.

Remember for some clinicians this may be their first time participating in a survey. Please explain the following to the participant

- **How to indicate an answer**
- **How the skip patterns work**
- **How to complete all the questions**
- **The importance of completing the questionnaire**
- **That she/he must ask any questions or assistance from you if needed**

Encourage the clinician to **complete the questionnaire on the same day**, insert the completed questionnaire **in the box provided** and say that you will be returning at a given time to collect the box. If the clinician **refuses to participate**, ask them to **Initial the statement of consent on the front of the questionnaire** and **return the form in the box** provided.

AFTER COMPLETION OF THE SURVEY

- Thank the clinicians for participating
- Collect the box with the completed questionnaires from the facility.
- **Note the date, name of the facility and district on a cover page and insert into the box**

Thank the manager on duty for assisting with the study

REMEMBER

PLEASE DO NOT FALSIFY INFORMATION OR COMPLETE THE QUESTIONNAIRE ON YOUR OWN.

GENERAL TIPS

1. **Planning-**make sure there are sufficient number of questionnaires and information sheets for clinicians. Do not make copies of the questionnaire at facilities.

2. **Working as a team and pro-active communication** are critical.

3. **Punctuality** is important-arrive early before the scheduled appointment with hospital management.

4. **Initial presentation to hospital CEO and particularly nursing management** is critical. We need to demonstrate enthusiasm for the survey, discuss why it is important, talk about planned feedback and acknowledge that people are doing us a great favour, often by giving us so much of their time and goodwill.

5. The survey requires **active management**- leaving questionnaires in wards do not work - the clinicians should be encouraged to complete the questionnaire as soon as possible.

6. Aim to have **100% response rate** in each facility - this means that you need to find out how many people are on duty that day and aim to
7. Get all the clinicians to complete the survey.

Remember

- ✓ **Please do not hesitate to contact the principal investigator or research manager if there are any queries or any problems.**

Randomly Selected Facilities

In each district, the health facilities are divided into public and private health facilities. Public facilities are in turn be divided into tertiary hospitals, regional hospitals, district hospitals, community health centers (CHC) and clinics (Specialised hospitals, satellite and mobile clinics are excluded from the study). Private hospitals with more than 100 beds will be divided according to ownership into the Netcare group, Life Healthcare and Mediclinic. Facilities were then selected randomly, proportional to the number in each stratum.

Table 1 below shows the sample size targets proportional to the number of Health Care Providers in each province, district and sector. Tables 2 to 4 show the facilities randomly selected in each stratum.

The Research Manager should plan to reach the respective targets in the different sectors.

Table1: Provincial Sample Size Targets			
	Public	**Private**	**Total**
Limpopo	121	52	181
KZN	249	146	416
Gauteng	272	160	454
Total	**642**	**358**	**1050**

Procedures to be followed with the Health Record Review

This section is applicable for the **Principal Investigator and Research Managers only**.

The MANAGER/ RESEARCHER MUST present and introduce himself/ herself to the DISTRICT MANAGER of the district, explain the survey and present them with a copy of the relevant approval granted from the provincial department. Preferably the District Surveillance Officer and Communicable Diseases Co-ordinator should be present in the meeting.

Greet the DISTRICT MANAGER and thank them for allowing us entry. Stress the importance of the study in generating information to improve the NDSS. **Remember first impressions are lasting impressions!**

Script for Researcher

*Hello, my name is……..I am pleased to meet you. Thanks for your willingness to receive us and assist us with the study '**Analysing the South African National Notifiable Diseases Surveillance System (NDDS).'** We are doing the study in three provinces, namely Gauteng, Limpopo and KwaZulu-Natal. The aim of the study is to inform recommendations for policy improvements of the NDSS. In this part of the study, we are interested in notifications on three tracer notifiable diseases, namely meningococcal meningitis, measles and typhoid for the year 1 Jan to 31 Dec 2013 . We will make sure that we do not interfere with the normal functioning of the officials in the relevant unit. Thanks once again for your assistance.*

The Research Manager should be in possession of the following:

- **RECORD REVIEW**
- **PENCIL AND ERASER AND A PEN**
- **COPIES OF THE APPROVAL FROM THE RELEVANT PROVINCE AND PRIVATE HOSPITALS**
- **A LAPTOP COMPUTER**

Ask politely to access the notification records for *1 Jan to 31 Dec 2013* for the three tracer diseases. The district may have a paper-based record system with a file for the notifications, or an Microsoft Excel spreadsheet based system or both. If they have both please ask to access both systems and compare which best represents all of the fields in the record review form.

Extract the records from the paper-based system and complete a review form per record (if the district only has a paper-based system). Where there is a Microsoft Excel spreadsheet system, obtain a soft copy and use the paper-based system to complete blank fields that were not recorded during data entry.

After completion of the review, thank the officials and Facility Manager for the co-operation and assistance.

Appendix 7: Information Sheet

Analyzing the National Notifiable Diseases Surveillance System in South African

Introduction

My name is Dr Frew Benson. I am a doctoral student in the School of Public Health at the University of the Witwatersrand in Johannesburg.

I am doing research on the Notifiable Diseases Surveillance System, which focuses on the detection, prevention and control of public health threats in South Africa.

Why are we doing the study?

The aim of this research project is to conduct an analytical study of the National Notifiable Diseases Surveillance System of South Africa in order to inform policy and health system interventions for improvements. We believe that you can help us by sharing with us your knowledge, views and experiences of the system.

What are we asking you to do?

We would like you to complete the questionnaire which will take you about 20 minutes. Alternatively, one of us could help you to complete the questionnaire. Your participation is voluntary. This is not a test, so there is no right or wrong answer. It is your opinions and experiences that are important. You may refuse to answer any questions that you don't feel comfortable answering.

Please insert the completed questionnaire in the box provided.

How do I know that the information I give you will not get out to others?

The information that you give in the questionnaire will be kept confidential. No one will know that it is you that have answered the questions. The information will not be given to your employer and will not affect your work. All questionnaires will be assigned a code. The answers given will be analysed and reported as group data.

Did you get permission to do the study?

Permission to carry out this project was obtained from the University of the Witwatersrand Research Ethics Committee. We have also obtained approval from the health authorities.

Are there any benefits and risks of participation?

Participation in this study is voluntary and there will be no direct benefits to anyone who completes the survey. Similarly there will be no negative consequences for individuals who do not want to complete the questionnaire. You will not be compensated for taking part in the study. You have the right not to answer any questions that make you feel uncomfortable or that you do not want to answer.

Whom do I contact if I want more information?

We will be happy to answer any question you have about this study. If you have any questions about your rights as a study participant, or questions or concerns about any aspect of the study, you may contact the University Ethics office on (011) 717 1234. If you have questions about the research, you may also contact the Principal Researcher or the Research Supervisor:

Principal Researcher	**Research Supervisor**	**Research Supervisor**
Dr Frew Benson	Professor Laetitia Rispel	Professor Lucille Blumberg
National Department of Health	School of Public Health	National Institute of Com Diseases
Phone: +27 12 395 8094	Phone: +27 11 717 2543	Phone: 011 386 6337
Email: frewbenson@gmail.com	laetitia.rispel@wits.ac.za	lucilleb@nicd.ac.za

Appendix 8: Key Stakeholders Questionnaire

Key Informants' Knowledge, Attitudes and Practices Questionnaire

For Official use only

1. **Questionnaire serial number**		☐☐☐☐
2. **Province ID**		☐☐
3. **District ID**		☐☐
4. **Sector**	☐ Public 1 ☐ Private 2	☐
5. **National Committee ID**		☐☐☐
6. Date of survey:	**DD/MM/YY**	☐☐☐☐☐☐
7. **Was the questionnaire completed?**	☐ No 0 ☐ Yes 1	☐
8. Date checked:	**DD/MM/YY**	☐☐☐☐☐☐

Consent To Participate

I have been given an information sheet and I understand the objectives of the study. I further understand that my responses will be kept anonymous and confidential and that it is up to me whether or not to complete the questionnaire. It has been explained to me that even if I choose not to complete this questionnaire, I should still return it to the box provided and indicate No in the space below. My refusal to participate will in no way prejudice me. I agree voluntarily to complete the questionnaire and to complete the survey only once.

(Please tick).

Yes ☐ No ☐

Initial : ……. Date: …….

Section A – Demographic Information

	Question	Official use
1.	In what professional category do you fall? (Only mark **one block** – that is most relevant) ☐ Communicable Disease Coordinator /Manager... 1 ☐ Surveillance Officer/Manager... 2 ☐ Malaria Coordinator /Manager... 3 ☐ EPI Coordinator /Manager... 4 ☐ TB Coordinator /Manager... 5 ☐ Medical Scientist... 6 ☐ Pathologist... 7 ☐ Epidemiologist... 8 ☐ Medical Officer... 9 ☐ Other… 10 Please specify……	☐
2.	How many years of experience do you have in your current portfolio?	☐
3.	What is your age (in years)?	☐
4.	In what sector are you employed? ☐ Private … 1 ☐ Public … 2	☐
5.	Did you ever receive training on Notifiable Communicable Diseases? ☐ Yes ... 1 ☐ No ... 2 ☐ Not certain ... 3	☐
6.	What was the duration of the training? (in weeks)	☐
7.	How long ago did you receive this training?	☐
8.	Did you receive any formal training in Epidemiology or Surveillance? ☐ Yes… 1 ☐ No… 2 (If No, go to question 10)	☐
9.	If yes, what level of formal training did you receive? ☐ Certificate… 1 ☐ Diploma… 2 ☐ Bachelor's degree… 3 ☐ Master's degree… 4 ☐ Doctorate… 5 ☐ Other… 6 Please specify……	☐
10.	When did you complete your formal training (date)?	☐
11.	How many years of experience do you have working with Notifiable Diseases?	☐

12.	Are you a member of: Provincial Outbreak Response Team… [Yes] [No] National Outbreak Response Team… [Yes] [No] South African Malaria Elimination Committee… [Yes] [No] National Surveillance Forum... [Yes] [No] ☐ Other Committee... Specify.....	☐
13.	Members of provincial health departments, please state in which province you work ☐ Eastern Cape... 1 ☐ Free State… 2 ☐ Gauteng… 3 ☐ KwaZulu-Natal… 4 ☐ Limpopo... 5 ☐ Mpumalanga… 6 ☐ Northern Cape... 7 ☐ North West… 8 ☐ Western Cape... 9	☐
14.	Members of district health departments, please state in which district you work ☐ City of Johannesburg ... 1 ☐ West Rand … 2 ☐ eThekwini… 3 ☐ uMgungundlovu… 4 ☐ Ugu... 5 ☐ Capricorn… 6 ☐ Vhembe... 7	☐

Section B –Knowledge and Skills on the Notifiable Diseases Surveillance System (NDSS)

Below is a list of skills that you need and use as part of your participation in the NDSS. For each, please indicate what your current level of skill is to perform the task on a scale of 1-10 (with 1 being Low skills, needing more support or training) and 10 being (Very high skills, no support or training needed). Circle the relevant block or mark with an X

	NOTIFICATION	**MY SKILLS Low Skills**									**Very High Skills**	**Office Use**
15.	I know what the purpose of the notifiable diseases surveillance is	1	2	3	4	5	6	7	8	9	10	☐
16.	I know which diseases should be notified immediately on clinical suspicion	1	2	3	4	5	6	7	8	9	10	☐
17.	I know which diseases should be notified within 24 hours of laboratory confirmation of diagnosis	1	2	3	4	5	6	7	8	9	10	☐
18.	I know which diseases can be notified after 24-48 hours after laboratory confirmation of diagnosis	1	2	3	4	5	6	7	8	9	10	☐
19.	I know what processes should be followed in notifying a disease	1	2	3	4	5	6	7	8	9	10	☐

20.	I am able to train other team members on the Notifiable Diseases Surveillance System	1	2	3	4	5	6	7	8	9	10	☐
	CASE MANAGEMENT	**Low Skills**					**Very High Skills**					☐
21.	I am confident in the management of meningococcal meningitis.	1	2	3	4	5	6	7	8	9	10	☐
22.	I am confident in the management of measles	1	2	3	4	5	6	7	8	9	10	☐
23.	I am confident in the management of typhoid	1	2	3	4	5	6	7	8	9	10	☐
24.	I am able to access the latest protocols and guidelines on notifiable diseases	1	2	3	4	5	6	7	8	9	10	☐
25.	I know who to consult if I am uncertain on the management of any notifiable disease	1	2	3	4	5	6	7	8	9	10	☐
26.	I am able to train other team members on the management of meningococcal meningitis	1	2	3	4	5	6	7	8	9	10	☐
27.	I am able to train other team members on the management of measles	1	2	3	4	5	6	7	8	9	10	☐
28.	I am able to train other team members on the management of typhoid	1	2	3	4	5	6	7	8	9	10	☐
	OUTBREAK RESPONSE	**Low Skills**					**Very High Skills**					
29.	I know what steps to follow in responding to an outbreak of a notifiable disease	1	2	3	4	5	6	7	8	9	10	☐
30.	I am confident on the basic elements of an epidemiological investigation	1	2	3	4	5	6	7	8	9	10	☐
31.	I am able to complete an outbreak investigation report	1	2	3	4	5	6	7	8	9	10	☐
32.	I am able to make appropriate recommendations to prevent outbreaks that are similar to the one I investigated	1	2	3	4	5	6	7	8	9	10	☐
33.	I am able to make appropriate recommendations to control outbreaks that are similar to the one I investigated	1	2	3	4	5	6	7	8	9	10	☐
34.	I am able to train other team members on the response to notifiable diseases	1	2	3	4	5	6	7	8	9	10	☐
	PREVENTION AND TRAINING	**Low Skills**					**Very High Skills**					☐
35.	I am knowledgeable on the prevention of notifiable diseases	1	2	3	4	5	6	7	8	9	10	☐
36.	I am able to educate the community on the prevention of notifiable diseases	1	2	3	4	5	6	7	8	9	10	☐
37.	I am able to train other team members on the prevention of communicable diseases	1	2	3	4	5	6	7	8	9	10	☐

Section C – Perceptions on attributes of the Notifiable Diseases Surveillance System

Listed below are statements on Attributes of the Notifiable Disease Surveillance. Using the provided scale state how strongly you agree or disagree with the statement.

PLEASE ANSWER ALL QUESTIONS – DO NOT LEAVE ANY OUT.

	Statement	Strongly Disagree	Disagree	Disagree slightly	Neither agree or disagree	Agree Slightly	Agree	Strongly agree
38.	The form used to notify diseases is easy to understand	1	2	3	4	5	6	7
39.	The form used to notify diseases takes a long time to fill in	1	2	3	4	5	6	7
40.	The notification process is easy to comply with	1	2	3	4	5	6	7
41.	Clinicians are not willing to participate in the notifiable disease surveillance system	1	2	3	4	5	6	7
42.	Clinicians do not notify meningococcal meningitis within 24 hours of clinical suspicion	1	2	3	4	5	6	7
43.	Clinicians notify measles within 24 hours of diagnosis	1	2	3	4	5	6	7
44.	Clinicians notify typhoid within 24 hours of diagnosis	1	2	3	4	5	6	7
45.	Outbreak response teams do not respond timeously to an outbreak	1	2	3	4	5	6	7
46.	Data obtained through the notifiable disease surveillance system is not used for outbreak response	1	2	3	4	5	6	7
47.	Data obtained through the notifiable disease surveillance system is used for policy and guideline formulation	1	2	3	4	5	6	7
48.	Data obtained through the notifiable disease surveillance system do not contribute to knowledge on the prevention and control of infectious diseases	1	2	3	4	5	6	7
49.	The notifiable disease surveillance system has been changed to meet changing circumstances and needs in the last decade	1	2	3	4	5	6	7
50.	The department provides regular feedback to doctors or nurses on notifiable diseases	1	2	3	4	5	6	7
51.	Lack of facility supervision does not impact on compliance with the system	1	2	3	4	5	6	7

Section D – Other Comments on the Notifiable Diseases Surveillance System

a. Please rate the availability of staffing for the notifiable diseases surveillance system at the following levels:

	Organisational level	Very Poor	Poor	Satisfactory	Good	Very Good
52.	National	1	2	3	4	5
53.	Province	1	2	3	4	5
54.	District	1	2	3	4	5
55.	Facility	1	2	3	4	5

b. Please rate the level of investment of funding for the notifiable diseases surveillance system at the following organisational levels:

	Organisational level	Very Poor	Poor	Satisfactory	Good	Very Good
56.	National	1	2	3	4	5
57.	Province	1	2	3	4	5
58.	District	1	2	3	4	5
59.	Facility	1	2	3	4	5

c. Please rate the organisational capacity for the notifiable diseases surveillance system at the following levels:

	Organisational level	Very Poor	Poor	Satisfactory	Good	Very Good
60.	National	1	2	3	4	5
61.	Province	1	2	3	4	5
62.	District	1	2	3	4	5
63.	Facility	1	2	3	4	5

d. Please indicate to what extent the following interventions would benefit the notifiable diseases surveillance system (on a scale of 1 -10, with 1= No benefit and 10 = Maximum benefit)

	Intervention	No benefit									Maximum benefit
64.	Addressing staffing gaps	1	2	3	4	5	6	7	8	9	10
65.	Addressing the gaps in the organisational capacity of the department	1	2	3	4	5	6	7	8	9	10
66.	Investing more financial resources in the system	1	2	3	4	5	6	7	8	9	10
67.	Introduction of the use of an electronic system	1	2	3	4	5	6	7	8	9	10
68.	Introduction of mobile technology	1	2	3	4	5	6	7	8	9	10

69.	Do you have any further comments on the Notifiable Diseases Surveillance System	☐

70.	Do you have any recommendations on how to improve the Notifiable Diseases Surveillance System	☐

Thank you for participating

Appendix 9: Record Review

Section A – General (Official use)

	Field	Code
1.	Source of Record: ☐ DOH… 1 ☐ NHLS… 2	☐
2.	Province where data is obtained (if DOH) _____ District where data is obtained (if DOH) _____	☐
3.	Communicable Disease Diagnosed ☐ Measles… 1 ☐ Meningococcal Meningitis… 2 ☐ Typhoid… 3	☐
4.	Record number	☐
5.	Date of review: DD/MM/YY	☐
6.	Completeness of record - Number of fields not completed	☐

Section B – Demographic Information

	Field	Code
7.	**Surname_____ Name_____**	
8.	Gender ☐ Male… 1 ☐ Female… 2	☐
9.	Age at time of occurrence *(in years)*	☐
10.	Population group ☐ Black… 1 ☐ Coloured… 2 ☐ Indian… 3 ☐ White… 4 ☐ Other… 5	☐
11.	Facility that patient presented to ……	☐
12.	District of residence at time of occurrence	☐
13.	Province of residence at time of occurrence ☐ KZN… 1 ☐ Limpopo… 2 ☐ WC… 3 ☐ EC… 4 ☐ NC… 5 ☐ North West… 6 ☐ Free state… 7 ☐ Gauteng… 8 ☐ Mpumalanga… 9	☐
14.	Travel history ☐ Yes… 1 ☐ No… 2	☐

	☐ Unavailable… 3 ☐ Where travelled to……..	

Section C – Medical Information

	Field							
15.	Date of onset of illness (DD/MM/YY)							☐
16.	Presenting symptoms and signs …… …… ……							☐
17.	Date of diagnosis (DD/MM/YY)							☐
18.	Date of notification (DD/MM/YY)							☐
19.	Outcome ☐ Recovered fully… 1 ☐ Developed complications… 2 ☐ Passed away… 3 ☐ Not known… 4 ☐ other… 5 Specify ……..							☐

Appendix 10: HCP Questionnaire

Health Care Providers' Knowledge, Attitudes and Practices Survey

Analysing the National Notifiable Diseases Surveillance System in South Africa

For Official use only

9. **Questionnaire serial number**		☐☐☐☐
10. **Province ID**		☐☐☐
11. **District ID**		☐☐☐
12. **Sector**	☐ Public 1 ☐ Private 2	☐
13. **Health Facility Type ID**		☐☐☐
14. Date of survey:	**DD/MM/YY**	☐☐☐☐☐☐
15. **Was the questionnaire completed?**	☐ No 0 ☐ Yes 1	☐
16. Date reviewed:	**DD/MM/YY**	☐☐☐☐☐☐

Please insert the completed questionnaire in the box provided.

Consent to Participate

I have been given an information sheet and I understand the objectives of the study. I further understand that my responses will be kept confidential and that it is up to me whether or not to complete the questionnaire. It has been explained to me that even if I choose not to complete this questionnaire, I should still return it to the box provided and indicate No in the space below. My refusal to participate will in no way prejudice me. I agree voluntarily to complete the questionnaire and to complete the survey only once **(please tick).**

Yes ☐ No ☐

Initial : ……. Date: …….

Section A – Demographic Information

	Question	**Official use**
1.	In what professional category do you fall? ☐ Professional Nurse...1……go to question 2 ☐ Doctor... 2…..go to question 3	☐
2.	If a Professional Nurse, are you : ☐ Primary Health Care Trained Nurse...1 ☐ Infection Prevention and Control Practitioner... 2 ☐ Paediatric Trained Nurse...3 ☐ Other... 4 Please specify.....	☐
3.	If a doctor, are you : ☐ Intern...1 ☐ Medical Officer ... 2 ☐ Private General Practitioner ...3 ☐ Registrar... 4 ☐ Infection Prevention and Specialist.... 5 ☐ Family Medicine Specialist.... 6 ☐ Specialist Physician... 7 ☐ Paediatrician... 8 ☐ Other… 9 Please specify……	☐
4.	Your age in years	☐
5.	What is your gender? ☐ Female… 1 ☐ Male… 2	☐
6.	In which sector are you employed? ☐ Private… 1 ☐ Public… 2	☐
7.	In what type of facility do you work? ☐ Central Hospital...1 ☐ Provincial Tertiary Hospital...2 ☐ Regional Hospital ... 3 ☐ District Hospital... 4 ☐ Private Hospital.... 5 ☐ Community Health Centre... 6 ☐ Clinic... 7 ☐ Private GP practice... 8 ☐ Other... 9 Specify:	☐
8.	Did you ever receive training on Notifiable Communicable Diseases? ☐ Yes ... 1 ☐ No ... 2……..go to Q11	☐

	☐ Not certain ... 3 .....go to Q11	
9.	What was the duration of the training?	☐
10.	How long ago did you receive this training? (In years and months)	☐
11.	Did you receive any formal training in Epidemiology or Surveillance? ☐ Yes… 1 ☐ No… 2 (If no go to question 14)	☐
12.	If yes, what level of formal training did you receive? ☐ Certificate… 1 ☐ Diploma… 2 ☐ Bachelor degree… 3 ☐ Master's degree… 4 ☐ Doctorate… 5 ☐ Other… 6 Please specify……	☐
13.	When did you receive your formal training? (Date- year)	☐
14.	How many years of experience do you have working with Notifiable Diseases? (answer 0 if less than one year)	☐

Section B – Practices related to the Notifiable Diseases Surveillance System

	Question	**Official use**
15.	Have you diagnosed any notifiable infectious diseases in the last year? ☐ Yes...1 (please answer all questions below) ☐ No... 2 (please go to question 20 and answer all questions after that) ☐ Unsure... 3 (please go to question 21 and answer all questions after that)	☐
16.	If yes, which notifiable infectious diseases did you diagnose? ……	☐
17.	Did you notify the infectious disease(s)? ☐ Yes… 1 ☐ No… 2 ☐ Unsure... 3	☐
18.	Who did you notify the disease(s) to? ……	☐
19.	How long after diagnosis did you notify the disease? ☐ Within 24 hours… 1 ☐ Within 48 hours… 2 ☐ Within 72 hours... 3	☐

	☐ Within 1 week... 4 ☐ Within 2 weeks... 5 ☐ Longer than 2 weeks... 6	
20.	If you did not notify the disease(s) diagnosed, please state the reasons for not notifying:	☐
21.	How many patients do you attend to personally per day?	☐
22.	Do you have notification forms available in your facility/practice? ☐ Yes… 1 ☐ No… 2 ☐ Unsure... 3	☐

Section C –Knowledge and Skills on the Notifiable Diseases Surveillance System (NDSS)

Below is a list of skills that you need and use as part of your participation in the NDSS. For each, please indicate what your current level of skill is to perform the task on a scale of 1-10 (with 1 being Low skills, needing more support or training) and 10 being (Very high skills, no support or training needed). Use X to mark the relevant block

	NOTIFICATION	**MY SKILLS Low Skills**									**Very High Skills**	**Office Use**
23.	I know and understand the need for a notifiable diseases surveillance system	1	2	3	4	5	6	7	8	9	10	☐
24.	I know which diseases should be notified immediately on clinical suspicion	1	2	3	4	5	6	7	8	9	10	☐
25.	I know which diseases should be notified within 24 hours of laboratory confirmation of diagnosis	1	2	3	4	5	6	7	8	9	10	☐
26.	I know which diseases can be notified after 24 -48 hours after laboratory confirmation of diagnosis	1	2	3	4	5	6	7	8	9	10	☐
27.	I know what process to follow in notifying a disease	1	2	3	4	5	6	7	8	9	10	☐
28.	I am able to train other team members on the notification of diseases	1	2	3	4	5	6	7	8	9	10	☐
	CASE MANAGEMENT	**Low Skills**									**Very High Skills**	☐
29.	I am confident in the management of meningococcal meningitis	1	2	3	4	5	6	7	8	9	10	☐
30.	I am confident in the management of measles	1	2	3	4	5	6	7	8	9	10	☐
31.	I am confident in the management of typhoid	1	2	3	4	5	6	7	8	9	10	☐
32.	I am able to access the latest protocols and guidelines on notifiable diseases	1	2	3	4	5	6	7	8	9	10	☐
33.	I know who to consult if I am uncertain on the management of any notifiable disease	1	2	3	4	5	6	7	8	9	10	☐

34.	I am able to train other team members on the management of meningococcal meningitis	1	2	3	4	5	6	7	8	9	10	☐
35.	I am able to train other team members on the management of measles	1	2	3	4	5	6	7	8	9	10	☐
36.	I am able to train other team members on the management of typhoid	1	2	3	4	5	6	7	8	9	10	☐
	PREVENTION AND TRAINING	**Low Skills**					**Very High Skills**					
37.	I am knowledgeable on the prevention of notifiable diseases	1	2	3	4	5	6	7	8	9	10	☐
38.	I am able to educate my patients on the prevention of notifiable diseases	1	2	3	4	5	6	7	8	9	10	☐
39.	I provide access for my patients to education material on the prevention of notifiable diseases in my facility	1	2	3	4	5	6	7	8	9	10	☐
40.	I am able to train other team members on the prevention of communicable diseases	1	2	3	4	5	6	7	8	9	10	☐

Section D- Perceptions on the Notifiable Diseases Surveillance System (NDSS)

Listed below are statements on Attributes of the Notifiable Disease Surveillance. Using the provided scale state how strongly you agree or disagree with the statement.

PLEASE ANSWER ALL QUESTIONS – DO NOT LEAVE ANY OUT.

	Statement	Strongly Disagree	Disagree	Disagree slightly	Neither agree or disagree	Agree Slightly	Agree	Strongly agree
41.	The form used to notify diseases is easy to understand	1	2	3	4	5	6	7
42.	The form used to notify diseases takes a long time to fill in	1	2	3	4	5	6	7
43.	The notification process is not easy to comply with	1	2	3	4	5	6	7
44.	Meningococcal meningitis does not need to be notified within 24 hours of clinical suspicion	1	2	3	4	5	6	7
45.	Measles must be notified within 24 hours of diagnosis	1	2	3	4	5	6	7
46.	Typhoid can be notified after 48 hours of diagnosis	1	2	3	4	5	6	7
47.	I am willing to participate in the notifiable disease surveillance system	1	2	3	4	5	6	7
48.	Data obtained through the notifiable disease surveillance system is not used for outbreak response	1	2	3	4	5	6	7
49.	Outbreak response teams do respond timely to most outbreaks	1	2	3	4	5	6	7

50.	Data obtained through the notifiable disease surveillance system is used for policy and guideline formulation	1	2	3	4	5	6	7
51.	Data obtained through the notifiable disease surveillance system do not contribute to knowledge on the prevention and control of infectious diseases	1	2	3	4	5	6	7
52.	The notifiable disease surveillance system has been changed to meet changing circumstances and needs in the last three years	1	2	3	4	5	6	7
53.	Lack of facility supervision do not impact on compliance with the system	1	2	3	4	5	6	7
54.	The department provided no feedback to providers on notifiable diseases over the last year	1	2	3	4	5	6	7
55.	A high workload prevents me from notifying diseases	1	2	3	4	5	6	7
56.	A lack of access to communication equipment prevents me from notifying diseases	1	2	3	4	5	6	7

Section E – Other Comments on the Notifiable Diseases Surveillance System

a. Please rate the availability of staffing for the notifiable diseases surveillance system at the following levels:

	Organisational level	Very Poor	Poor	Satisfactory	Good	Very Good
57.	National	1	2	3	4	5
58.	Province	1	2	3	4	5
59.	District	1	2	3	4	5
60.	Facility	1	2	3	4	5

b. Please rate the level of investment of funding for the notifiable diseases surveillance system at the following organisational levels:

	Organisational level	Very Poor	Poor	Satisfactory	Good	Very Good
61.	National	1	2	3	4	5
62.	Province	1	2	3	4	5
63.	District	1	2	3	4	5
64.	Facility	1	2	3	4	5

c. Please rate the organisational capacity for the notifiable diseases surveillance system at the following levels:

	Organisational level	Very Poor	Poor	Satisfactory	Good	Very Good
65.	National	1	2	3	4	5

66.	Province	1	2	3	4	5
67.	District	1	2	3	4	5
68.	Facility	1	2	3	4	5

d. Please indicate to what extent the following interventions would benefit the notifiable diseases surveillance system (on a scale of 1 to 10, with 1= No benefit and 10 = Maximum benefit)

	Intervention	No benefit									Maximum benefit
69.	Addressing staffing gaps	1	2	3	4	5	6	7	8	9	10
70.	Addressing the gaps in the organisational capacity of the department	1	2	3	4	5	6	7	8	9	10
71.	Investing more financial resources in the system	1	2	3	4	5	6	7	8	9	10
72.	Introduction of the use of an electronic system	1	2	3	4	5	6	7	8	9	10
73.	Introduction of mobile technology	1	2	3	4	5	6	7	8	9	10

74.	Do you have any further comments on the Notifiable Diseases Surveillance System	☐
75.	Do you have any recommendations on how to improve the Notifiable Diseases Surveillance System	☐

Thank you for participating

Appendix 11: Approval from BMC Public Health

Corbo, Jennilyn, BioMed Central Ltd. <jennilyn.corbo@biomedcentral.com> Fri, Oct 27, 2017 at 1:30 PM
To: Frew Benson <frewbenson@gmail.com>
PUBH-D-16-02033R1

Survey of the perceptions of key stakeholders on the attributes of the South African Notifiable Diseases Surveillance System
Frew Gerald Benson, MBBCh, MSc(Med) in Child Health, DTM&H; Alfred Musekiwa; Lucille Blumberg; Laetitia C Rispel

BMC Public Health

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Appendix 12: Approval from IJID

IJID (ELS) <IJID@elsevier.com> 11/1/17

to me

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Appendix 13 Turn-it-in Report

9011670d:Thesis_for_turn_it_in_16-3-18.docx Appendix 13

ORIGINALITY REPORT

13%	7%	10%	1%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	F.G. Benson, A. Musekiwa, L. Blumberg, L.C. Rispel. "Comparing laboratory surveillance with the notifiable diseases surveillance system in South Africa", International Journal of Infectious Diseases, 2017 Publication	4%
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5	F. G. Benson, A. Musekiwa, L. Blumberg, L. C. Rispel. "Survey of the perceptions of key stakeholders on the attributes of the South	<1%