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**Development and assessment of systems for population-
based estimation of neonatal and perinatal mortality
in The Gambia**

ANNE JEPTOO RERIMOI

Thesis submitted in accordance with the requirements for the degree of
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Department of Population Health
Faculty of Epidemiology and Population Health

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Hygiene & Tropical Medicine

Abstract

Background: Accurate data on perinatal and neonatal mortality in sub-Saharan Africa are scarce. This thesis assesses methods for their estimation in The Gambia.

Methods: Under-five mortality was estimated, comparing the results of the first Demographic Health Survey in 2013 with previous inquiries. Three studies collecting primary data were conducted to assess and develop systems to improve estimation of perinatal and neonatal mortality. First, a pregnancy history survey that employed female interviewers was conducted and the results were compared with those from routine health and demographic surveillance in Basse. A second study linked records of women visiting antenatal clinics (ANC) to the Health and Demographic Surveillance System (HDSS) and used the augmented data to re-estimate neonatal, infant mortality and stillbirth rates. Third, a qualitative study was embedded in the retrospective survey to explore reasons for under-reporting of neonatal deaths and stillbirths.

Findings: The DHS estimates of mortality for the recent past were consistent with those from other surveys. Age-disaggregated estimates for 2010-II reveal that neonatal mortality constitutes 40% of under-five deaths in The Gambia. Women reported significantly more pregnancies in the pregnancy history survey than the HDSS and, in particular, more adverse pregnancy outcomes. Thus, while collecting data prospectively in HDSS generally limits omissions of deaths and age/date reporting errors, it may yield less complete data than pregnancy histories on adverse perinatal outcomes. However, the ANC-HDSS linkage study improved the capture of pregnancies. Women whose pregnancy was only detected in the clinic were 2.5 times more likely to have had a stillbirth than women whose pregnancies were picked up by the HDSS. The qualitative study showed that the cultural practice of pregnancy concealment, reluctance to speak of the deceased and to be counted affect the accuracy of data on pregnancy outcomes and mortality in The Gambia. It also revealed the importance of identification and use of culturally-appropriate metaphors and idioms to discuss sensitive matters compared to training interviewers to ask standardised verbatim questions.

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Dedication

This thesis is dedicated to the memory of my sister Elizabeth Rerimoi-Kipchillat (1972-2016) whose unwavering belief in me gives me strength

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Abbreviations

AGA	Appropriate for Gestational Age
ANC	Antenatal Clinic
ARI	Acute Respiratory Illness
CHAMPS	Child Health and Mortality Prevention Surveillance
CMR	Child Mortality Rate
COD	Cause of Death
CRVS	Civil Registration and Vital Statistics
CSD	Central Statistics Department
DHS	Demographic Health Survey
EDC	Electronic Data Capture
EmONC	Emergency Obstetric and Neonatal Care
ENAP	Every Newborn Action Plan
ENMR	Early neonatal mortality rate
FGM/C	Female Genital Mutilation/Cutting
FGD	Focus Group Discussion
GBD	Global Burden of Disease
GBoS	Gambia Bureau of Statistics
GDP	Gross Domestic Product
GPS	Global Positioning System
HDSS	Health and Demographic Surveillance System
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome
ICD	International Classification of Diseases
IHME	Institute for Health Metrics and Evaluation
IMNCI	Integrated Management of Neonatal and Childhood Illnesses
INDEPTH	International Network for the Continuous Demographic Evaluation of Populations and Their Health
IMR	Infant Mortality Rate
LBW	Low Birthweight

LMICs	Low-and Middle-Income Countries
LGA	Local Government Area
LSHTM	London School of Hygiene and Tropical Medicine
MDG	Millennium Development Goal
MICS	Multiple Indicator Cluster survey
MIT	Minimally Invasive Tissue Sampling
MMR	Maternal Mortality Ratio
MRCG	Medical Research Council unit The Gambia
NMR	Neonatal Mortality Rate
PHC	Primary Health Care
PNMR	Post-neonatal Mortality Rate
PPS	Probability Proportional to Size
RMM	Real-Time Mortality Monitoring
SBR	Stillbirth Rate
SDG	Sustainable Development Goals
SGA	Small for Gestational Age
SRS	Sample Registration System
SSA	Sub-Saharan Africa
STI	Sexually Transmitted Infection
TBA	Traditional Birth Attendant
U5MR	Under-five Mortality Rate
UNICEF	United Nations Children's fund
UN IGME	United Nations Inter-Agency Group for Child Mortality Estimation
URR	Upper River Region
USAID	United States Agency for International Development
VA	Verbal Autopsy
WFS	World Fertility Survey
WHO	World Health Organization

Operational definitions

Live Birth: is the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of the pregnancy, which, after such separation, breathes or shows any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached; each product of such a birth is considered liveborn.

Neonatal death: deaths of live born babies occurring within 28 days of life, that is death on the day of birth (day 0) through 27 completed days of life.

Neonatal mortality rate: neonatal deaths per thousand livebirths.

Stillbirths: for international comparison, I use the World Health Organization definition of late foetal death after 28 weeks gestation or greater than 1000 grams birthweight

Stillbirth Rate: The number of stillbirths per thousand total births.

Perinatal deaths: deaths occurring from 28 completed weeks up to seven days of life.

Perinatal Mortality Rate: The number of perinatal deaths per 1000 total births.

Pre-term births: births of live babies occurring before 37 completed gestational weeks (or less than 259 days) from the first day of the last menstrual period

Post-term births: births of live babies occurring after 42 completed gestational weeks (294 days or more) from the first day of the last menstrual period

Post-neonatal mortality rate: deaths after 28 days of life to 1 year per 1000 livebirths

Infant mortality rate: deaths in children less than 1 year of age per 1000 livebirths

Child mortality rate: deaths in children surviving to one year but less than five years per 1000 population

Under-five mortality rate: deaths in children less than 5 years of age per 1000 livebirths

Chapter 1 Introduction

This thesis focuses on measurement of neonatal and perinatal mortality. It centres on measurement because major information gaps exist regarding neonatal and perinatal mortality metrics in developing countries, and on neonatal and perinatal mortality, as both stillbirths and neonatal deaths contribute almost equally large proportions of under-five deaths. Neonatal mortality has gained global visibility, but stillbirths are still inadequately addressed in most health management information systems¹. The thesis is based on existing health and demographic surveillance system (HDSS) data, and tailored survey and clinic data from The Gambia in West Africa.

The advent of the Sustainable Development Goals (SDGs) has brought into sharp focus the importance of accurate and timely metrics to evaluate whether agreed targets have been met². In September 2015, 193 member states of the United Nations adopted the 2030 sustainable development agenda as a sequel to the millennium development goals for progress by 2015. The number of goals was expanded from eight to seventeen, with the overall aims being the transformation of the planet and leaving no one behind³. Monitoring almost 40% of the 169 targets requires demographic data, and National Statistical Offices have been given primacy in the SDGs with calls for a data revolution⁴. For targets where mortality is the monitoring indicator, the gold standard for its measurement is complete vital statistics in a fully functional civil registration and vital statistics system (CRVS). The term “complete” not only implies that all vital events are registered, but also that timely and accurate information on the events is captured and analysed. However, even with the best of resources, this will not be achieved for every vital event. The United Nations (UN) utilizes a pragmatic definition that countries with more than 90% coverage of vital events have “complete” registration⁵. One indicator of progress toward SDG target 17.19 is the proportion of countries that achieve 100% coverage of birth registration and 80% of death registration⁶.

In sub-Saharan Africa (SSA), only Seychelles, Mauritius and Cape Verde have over 90% complete birth and death registration, whereas all European countries have complete

vital statistics systems⁷. This lack of complete registration in developing countries means that alternative methods such as censuses and surveys are the best available data sources for mortality measurement^{4, 8}.

Sub-Saharan Africa also has the highest under-five mortality rates of any world region, with west and central Africa worst affected⁹. Almost half of under-five deaths now occur in the neonatal period, suggesting the need to focus on neonatal mortality if under-five mortality is to reach the 2030 SDG target of less than 25/1000 livebirths⁹. Perinatal mortality is equally important because 2.6 million stillbirths occur annually, and yet, they are still unaccounted for in the new SDGs, despite the call to leave no one behind¹⁰. The causes of neonatal deaths, stillbirths and maternal deaths are interlinked in the intrapartum period, meaning that targeted prevention measures during this period will end up saving significantly more lives^{11, 12}. However, due to the very short perinatal and neonatal periods, there is only a narrow window within which to carry out interventions to save this highly vulnerable population¹³. This would require more timely and accurate turnaround of data, and therefore the time lags associated with surveys and censuses are sub-optimal for mortality measurement and evaluation of lifesaving interventions in this population.

In order to accurately report on neonatal and perinatal mortality in a timely manner, all pregnancies and their outcomes must be accounted for. Prospective follow up of pregnancy has been shown to yield higher stillbirth and neonatal death rates than data collected retrospectively¹⁴. In developing countries, HDSS that actively follow pregnancies may provide empirical data that are of better quality than official statistics as they tend to be better resourced than the national statistical organizations in their respective countries¹⁵. An additional benefit of following up pregnancies is that data from HDSS, especially those that follow pregnancy to outcome, may be used in modelling estimates of perinatal outcomes for larger populations¹⁶. However, HDSS carry out surveillance with differing frequencies, ranging from fortnightly to annual rounds of data collection, and it is not known how often this data should be collected for optimal yield and least cost¹⁷. Additionally, not all HDSS collect information on pregnancies and their outcomes.

A second consideration regarding the measurement of neonatal and perinatal mortality is how the information on pregnancy and pregnancy outcomes are collected. Most fertility surveys use either a pregnancy history questionnaire, which enumerates all pregnancies and includes all pregnancy outcomes, or a birth history questionnaire, which makes inquiry from a woman about her live born babies. For perinatal mortality, birth histories are not useful as they do not ask about stillbirths. However, if augmented with a reproductive calendar or additional questions, they can be used to estimate perinatal mortality¹⁸. In order to establish which method performs best for neonatal and perinatal mortality metrics, the gold standard of validation of demographic health surveys utilizing both questionnaires would be to compare findings from the survey to those from a complete vital statistics system. However, in developing countries, DHS are conducted to supplement lacking or inexistent CRVS and therefore no gold standard exists. Three studies have used the HDSS as a platform for such comparison¹⁹⁻²¹, while the DHS programme compared augmented birth histories to pregnancy histories using 168 surveys across all world regions¹⁸. Although pregnancy histories reported more pregnancy outcomes than either routine surveillance or augmented birth history, the difference was at best marginal and even conflicting in studies carried out in the same country. The DHS comparison concluded that neither the pregnancy history nor the augmented birth history was sufficient for reporting of stillbirths, as overall, they were under-reported based on low ratios of stillbirths to early neonatal deaths in over 90% of the surveys reviewed, and therefore more studies are needed for definitive conclusions¹⁸.

When collecting data of pregnancies and pregnancy outcomes, contextual considerations must be taken to account. For example, in the Gambia, a patriarchal society whose population is mostly (99%) Muslim²², there are strict norms regarding male-female interactions which may affect women's responses to questions asked by men. However, having a female fieldworker trained to create rapport and talk to women of reproductive age directly and privately, was shown to minimize missing of sensitive events in Tanzania which shares some cultural norms with The Gambia²³. Moreover, women in The Gambia tend to conceal pregnancy and there is cultural

secrecy surrounding death^{24, 25}. It is reported that, if women are asked about pregnancy within earshot of others, they will always reply in the negative. Additionally, the delay in accepting a newly-born child as a full person until the naming ceremony on the seventh day of life, and the religious practice of almost immediate burial may adversely affect counting of neonatal and perinatal outcomes²⁶⁻²⁸. Similar indifference to neonatal death has been described in Brazil, where only robust new-born babies are cared for, and mourning is frowned upon²⁹. Although it is often assumed that poor maternal recall is responsible for under-reporting of reproductive events, it may instead reflect women's reluctance to share personal and confidential information such as pregnancy loss or neonatal deaths with others²³. Thus, even with frequent surveillance visits in a HDSS, there is a chance that pregnancies are still not identified, and births or deaths not recorded.

Incomplete CRVS, alongside unsuitable censuses and untimely surveys, and the debate on methods of data collection, compounded by sociocultural factors that may affect data collection, leave many questions unanswered on how best to proceed with the measurement of neonatal and perinatal mortality in developing countries. Populations followed up in HDSS, who are usually exposed to interventions that may give them a survival advantage, and who are more experienced in being interviewed, are thought not to be nationally representative. However, some studies showed that this is not always true and that the HDSS population mirror those in neighbouring regions^{19, 30, 31}. Recent research also shows that, barring a few, HDSS broadly represent the regions within which they are located³². Some HDSS mortality estimates have been compared to national DHS and found to be similar, thus providing a useful source of rapid timely and accurate data^{33, 34}. One example of the utility of HDSS to support developments at the national level is the evidence from Agincourt HDSS in South Africa of improved national CRVS. Over two decades, data from the HDSS showed that birth and death registration had improved from as low as 8% to over 90%³⁵.

In The Gambia, civil registration data have not been utilized to generate vital statistics, and no data are provided to the *UN Demographic Yearbook*³⁶. However, based on the Africa Programme on Accelerated Improvement of Civil Registration and Vital

Statistics (APAI CRVS) resolutions, The Gambia now aims to improve CRVS through campaigns in urban and rural regions, to train institutes on CRVS, to enforce compulsory registration on attendance of clinics by children, to create standalone offices at regional administrative areas and to ensure birth certification is a prerequisite for entry into schools among other measures³⁷. This initiative remains at the planning stage and, as of 2018, the national coordinator was still to be appointed. Thus, given the potential of HDSS to be used as interim measures while CRVS is improved³⁸, this research proposed to use a Gambian HDSS which prospectively follows up pregnancies to assess whether HDSS are fit for measurement of neonatal and perinatal mortality. Gambian HDSS have previously provided estimates of neonatal mortality showing a slower decline compared to other child deaths, but also that they are potentially under-reported^{39, 40}. This thesis assesses the completeness of reporting of pregnancy outcomes using individually-matched pregnancy histories from women resident in the HDSS. It also assesses the utility of one approach to improve these metrics and investigates cultural factors that could affect data collection of pregnancies and perinatal outcomes.

1.1 Aims and Objectives

The overall aim of this thesis is to assess and improve existing population-based data sources in The Gambia for the estimation of neonatal and perinatal mortality. It focuses on censuses, the single-round surveys and HDSS as the civil registration system is not yet utilized for or capable of producing vital statistics. The following issues are investigated: First, what data sources are available for population-based estimation of under-five mortality in The Gambia, and can they be relied on? Second, as pregnancy and pregnancy outcome identification are central to accurate measurement of neonatal and perinatal mortality, estimates obtained by routine pregnancy surveillance in HDSS were compared with those obtained from retrospective pregnancy histories to identify the method that performs better. Third, the thesis investigates one approach that might improve the completeness of reporting of pregnancies and pregnancy outcomes in HDSS. Finally, the thesis explores Gambian

cultural attitudes, beliefs and practices which may represent a challenge to the accurate measurement of neonatal and perinatal mortality.

The specific objectives of this thesis are:

1. To assess the consistency and accuracy of the estimates of under-five mortality from the existing data sources and its age-specific components in rural Gambia and produce authoritative up-to-date estimates.
2. To compare at the individual-level the completeness with which pregnancy and pregnancy outcomes are reported in retrospect using pregnancy histories and during ongoing surveillance within a HDSS.
3. To assess whether linking antenatal clinic data to HDSS and active follow up pregnancies can improve detection of pregnancies and their outcomes and the estimation of perinatal and early childhood mortality.
4. To explore Gambian cultural attitudes, discourse and practices regarding pregnancies and perinatal outcomes, and the implications for data collection.

The hypotheses are:

- 1) Pregnancies that end in an adverse perinatal event are under-reported in HDSS, resulting in the underestimation of neonatal and perinatal mortality.
- 2) Although HDSS achieve more complete coverage of most types of vital events than other alternative designs where vital registration is incomplete, adverse perinatal events are an exception to this generalisation and are reported more fully in pregnancy histories collected from women in retrospect.
- 3) By linking of facility-based data on antenatal and perinatal care to population-based HDSS, one can collect data that are more complete on adverse perinatal events than from either information system alone.

The focus on the HDSS and DHS arises from the fact that perinatal outcomes are central to this thesis, and of the potential data sources, they are the only ones that provide this information. Whereas there are programmes being planned to improve

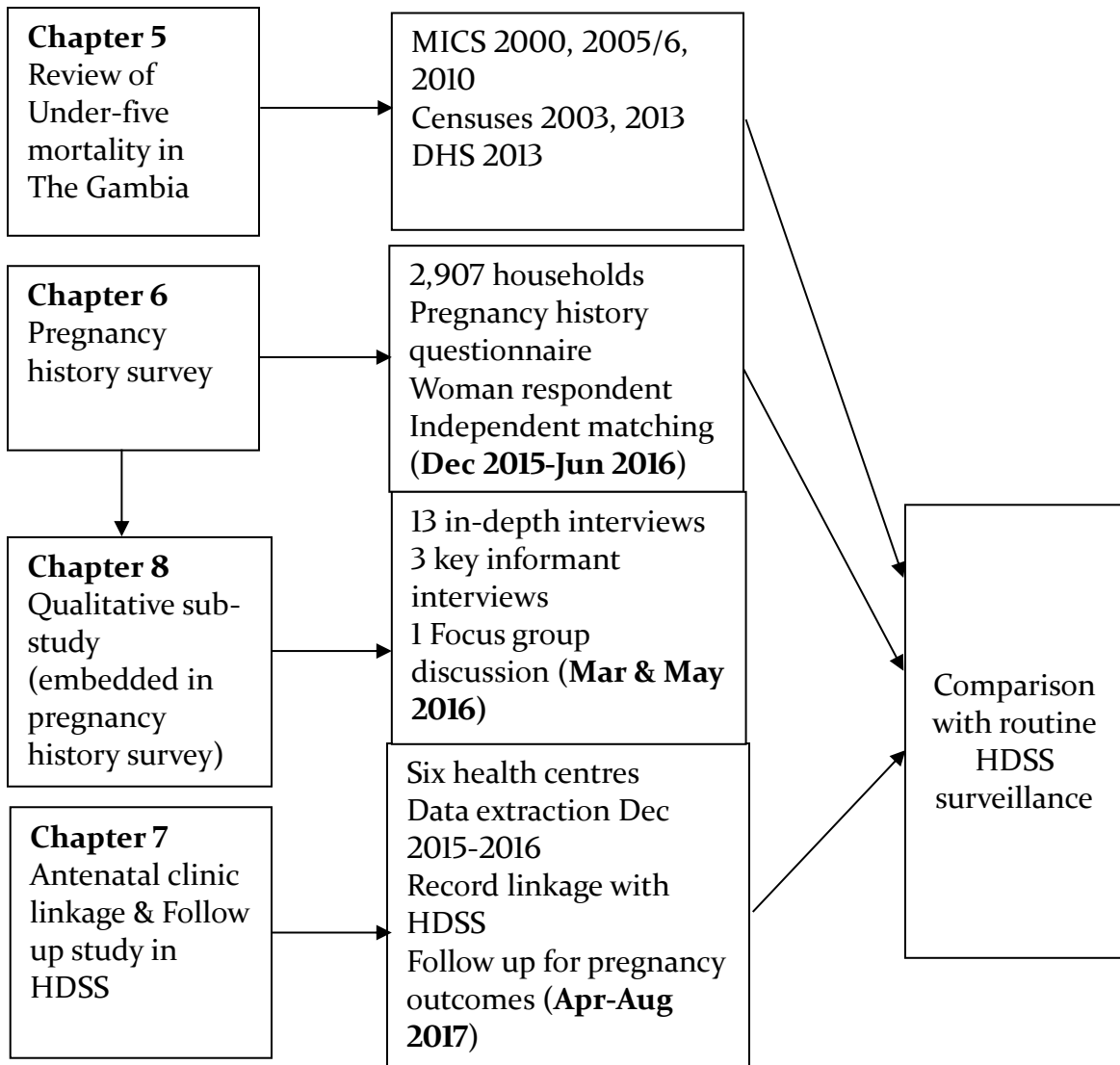
CRVS in The Gambia, particularly birth registration, no system yet exists for compiling a national register of certified deaths and no system exists for reporting stillbirths ⁴¹.

By comparing the 2013 Demographic and Health Survey to earlier national surveys and censuses and to HDSS in particular regions, the thesis first assesses the quality of the available data for under-five mortality estimation in The Gambia, and consistency of under-five mortality estimates from these data sources. Following the assessment, best estimates of under-five mortality rates in The Gambia are provided, alongside those of neonatal, post-neonatal and child mortality derived from the DHS as a baseline for this research.

To address the second and third objectives, longitudinal data from the demographic and health surveillance systems were used to assess data collection techniques that may improve estimation of neonatal and perinatal mortality. First, individually-matched reports obtained from a pregnancy history survey conducted within the HDSS were compared to those from the HDSS itself, with each woman acting as her own control. Second, I conducted a study that linked antenatal records from health facilities in the HDSS catchment area to women in the HDSS and tracked the pregnancy outcomes of the women to find out whether this form of linkage can be used to improve the surveillance of pregnancies by HDSS.

For the fourth objective, three methods of qualitative data collection (in-depth interviews, key-informant interviews and a focus group discussion) were used to gain an understanding of Gambian cultural factors surrounding pregnancy and perinatal outcomes.

1.2 PhD Components at a glance



1.3 Thesis Structure

This thesis uses the research paper format and includes four articles that have been submitted or are ready for submission to peer-reviewed journals. The papers are identified by headings in italics in the table of contents. Within each chapter, the article is prefaced by a research paper cover sheet which provides information about the publication including copyright information, author details, journal information, and outlines my role in a multi-authored paper. The papers also include acknowledgements of the contributions made by other people. The remaining sections contain material not included in the papers, but which contribute to achieving the objectives of the thesis. The four research papers variously draw on primary data, nationally-representative cross-sectional data from various surveys in The Gambia and qualitative data.

This initial chapter comprises an introduction to the thesis and its aims and objectives, and briefly outlines the candidate's role in the research, the structure of the thesis, ethical clearances and funding. It began by explaining why the thesis focuses on neonatal and perinatal mortality and discussing why their accurate measurement is important if countries aim to reduce under-five mortality even further.

Chapter 2 comprises an overview of the aetiology, prevention and global policies related to the reduction of neonatal and perinatal mortality. It also introduces the data sources available for population-based estimation of neonatal and perinatal mortality rates and causes of death, and briefly discusses of the advantages and disadvantages of these different types of data. HDSS are described, and their role as interim vehicles for the timely and accurate estimation of neonatal and perinatal mortality in settings with incomplete civil registration of vital events is discussed.

Chapter 3 gives the reader an insight to The Gambia where this study was carried out. First, it gives a brief description of the country's demographic profile and reviews the country's neonatal and perinatal mortality rates. Then, the state of the country's maternal and reproductive health care is summarized as well as the current national policies related to it. This chapter also introduces the Medical Research Council unit

The Gambia which funded this research, and which runs the HDSS where the studies were carried out.

Chapter 4 is the methods section. It includes a review of the Gambian national surveys and censuses used to achieve the first objective. A summary of the data extracted for the first paper on assessment of under-five mortality in The Gambia is presented. This section also describes the fieldwork processes for the pregnancy history survey, including sampling methods, training and the conduct of the fieldwork. The chapter also provides details of the antenatal clinic fieldwork, covering data collection and analysis. Lastly, the methods used for the qualitative studies are introduced.

Chapter 5 is an analytical research paper looking at the levels and trends of child mortality in the Gambia that addresses the first objective of the thesis. The 2000, 2005/6 and 2010 MICS, 2003 and 2013 censuses and 2013 DHS provide the data used for these estimates. This paper compares direct and indirect estimates from the multiple data sources and calculates neonatal, post-neonatal and child mortality rates from the DHS. The DHS estimates for two of the country's regions are also compared to those from the demographic health surveillance systems operating in those regions.

Chapter 6 is also a research paper that compares pregnancy history information obtained from the women in a single-round survey to their records in the Basse HDSS. It assesses pregnancy history vis-a-vis routine surveillance of pregnancy outcomes to address the second objective of this research regarding the completeness of pregnancy reporting in the two methods of data collection.

In Chapter 7, the third research paper discusses the utility of antenatal clinic record linkage to HDSS, to address the third objective of this research. This paper provides estimates of neonatal and infant mortality, and stillbirth rates from a compiled data set that utilized routine HDSS and a follow up study to provide pregnancy outcomes. The pregnancies were identified through routine pregnancy surveillance in the HDSS. Additional pregnancies were identified from antenatal clinics, and a follow up study conducted for those for whom no pregnancy outcomes were recorded in the HDSS.

The findings of the qualitative research are presented in Chapter 8. Data from in-depth interviews, focus group discussions and key informant interviews are analysed, comparing views from female and male participants as well as the young and old. Aspects of Gambian culture that impact on demographic research are highlighted and their implications for future research are discussed.

Chapter 9 discusses the findings of this research and its implications. It lists strengths and limitations of the research and highlights lessons for future research and for health policy. This is followed by a brief conclusion to the thesis.

All references have been listed in Vancouver style in each chapter. The appendices include ethical approvals and additional material relevant to this research.

1.4 Role of the candidate

AJR conceptualized this research and designed it with input from her supervisors. She obtained ethical approval from the joint Gambia government/Medical Research Council unit, The Gambia Ethics Committee as well as from the Research Ethics Committee of the London School of Hygiene and Tropical Medicine, United Kingdom.

She successfully completed the online demography course by the International Union for the Scientific Study of Populations, the Population Dynamics and Projections and Analysing Survey and Population Data courses offered by the London School of Hygiene and Tropical Medicine and the Qualitative and Mixed Methods in International Health Research course by the Institute of Tropical Medicine in Antwerp, Belgium to equip her with additional skills and knowledge necessary for carrying out the research.

She applied for and received the survey data used for the secondary analyses from the Gambia bureau of statistics, the UNICEF Gambia office and from the DHS programme. She designed the pregnancy history survey, trained and recruited with assistance the female interviewers and procured items such as tablets. She coordinated the community sensitization activities in the months before the actual survey, which

involved traversing the North and South Bank of the river Gambia, and meeting with village chiefs including such activities as presentation of kola nuts.

Having revised the proposals following her upgrading, the second and third year were spent in The Gambia carrying out the research. AJR organized the day-to-day fieldwork activities, including coordinating the drivers, allocation of households and resolution of challenges as well as administrative duties such as the payrolls for the fieldworkers and booking of vehicles.

For the qualitative work, AJR developed and constantly revised guidelines for in-depth interviews, key informant interviews and focus group discussions as the second set of primary data collected for this PhD. She conducted the key informant interviews and, together with a research assistant, the focus group discussion. She supervised the in-depth interviews.

Once the pregnancy history survey wound up, AJR met with the Basse regional health directorate and the medical officers in charge of the health centres where data for the antenatal clinic linkage data were to be collected. She trained two research assistants in photography and on the data that needed to be collected. She also introduced the team to the medical officers in charge in all six health centres. She accompanied the research assistants in the first month of data collection, and thereafter supervised and monitored data quality. This study also included active follow up of missing pregnancy outcomes carried out by HDSS fieldworkers and supervised by AJR.

With regard to the papers for publication included in the body of this thesis, AJR wrote the initial drafts and iteratively incorporated critical comments from the co-authors. AJR has disseminated results of the work through oral and poster presentations at the MRCG to peers in 2015 and 2016, and an oral presentation to the MRCG Scientific Advisory Board in April 2016. More recently, AJR presented a poster of the qualitative work at the British Society for Population Studies in September 2018.

Having been immersed in the Gambian environment for most of the PhD, AJRs understanding of the context and the combination of all the skills gained throughout the period has influenced the interpretation of the findings.

1.5 Ethical considerations

The HDSS is approved by The Gambia Government / MRC Joint Ethics Committee. AJR received ethical approval to conduct all studies for this research from both this committee and from the London School of Hygiene and Tropical Medicine. Children aged less than 18 years were considered mature minors if they were already married and written consent was obtained as adults^{42, 43}. Participation was voluntary and confidential (Appendix A-SCCI437v2 & LSHTM Ethics ref 10377).

Permission was also sought from the village chiefs (*Alkalolu*) and heads of households to interview females in their community and households.

The tablets used in recording data from the women respondents had the informed consent forms uploaded which were read verbatim to the respondents. This information included permission to access their information on antenatal clinic visits during the research period. The respondents' acquiescence/refusal was recorded in the tablet and a signature or thumbprint obtained, which was recorded in a quire book that was stored in a locked cabinet.

The data were uploaded on alternate days to a secure server at the base stations. Each of the tablets were encrypted and password protected, and confidentiality was emphasized to the fieldworkers. Only the candidate and the database managers had access to the data. The candidate stored the final decrypted data in an encrypted password-protected laptop as the names of the respondents were initially used to identify them during the linkage process. Thereafter, no identifying information was kept in the final datasets used in the analysis.

For the qualitative study, verbal consent was obtained, and permission sought to record the interviews for later transcription.

1.6 Funding

This work was supported by a PhD studentship awarded to AJR from the Medical Research Council unit, The Gambia.

Chapter 2 Background

There are two facets to the measurement of mortality. The first dimension requires that all events of death are captured completely and accurately, while the second deals with the causes of those deaths. This chapter describes the global burden of neonatal and perinatal mortality, their causes and what is known about how to prevent neonatal deaths and stillbirths. Then, it provides a description of the different data sources available to estimate neonatal and perinatal mortality, and associated challenges.

2.1 Overview of neonatal and perinatal mortality

Neonatal mortality has gained increased visibility in the global agenda over the past two decades as neonatal deaths are now the leading cause of mortality in children globally (Figure 2.1). Although the survival of mothers and children in the post-neonatal period has improved, progress has been slow in the neonatal period⁴⁴. Under-five mortality has fallen by 58% globally, from 93/1000 livebirths in 1990 to 39/1000 livebirths in 2017, while neonatal mortality dropped only moderately, from 36/1000 livebirths to 18/1000 livebirths over the same period⁹. It is estimated that approximately 2.5 million new-born babies die annually⁹. Approximately two million of these deaths occur in the first week of life and one million on the day they are born⁹. There is renewed urgency to reduce under-five mortality even further by 2030 to less than 25/1000 livebirths and neonatal mortality to less than 12/1000 livebirths¹³.

According to the UN Inter-agency Group for Child Mortality Estimation (UN IGME) estimates, Southern Asia and sub-Saharan Africa (SSA) have the highest levels of neonatal mortality (~30/1000 livebirths). In Africa, only Libya, Tunisia, Mauritius, South Africa and Seychelles have an NMR of less than 12/1000 livebirths, the global target level for 2030. West African neonatal mortality ranges from 40/1000 in Guinea Bissau to 12/1000 livebirths in Cape Verde⁴⁵.

Almost two-thirds of neonatal deaths occur in ten countries: India (695,900), Pakistan (244,700), Nigeria (240,100), the Democratic Republic of Congo (94,300), China (93,400), Ethiopia (87,400), Bangladesh (74,400), Indonesia (73,900), Angola

(53,200) and the United Republic of Tanzania (38,600)⁴⁵. These countries interchangeably have the highest number of stillbirths and maternal deaths as well.

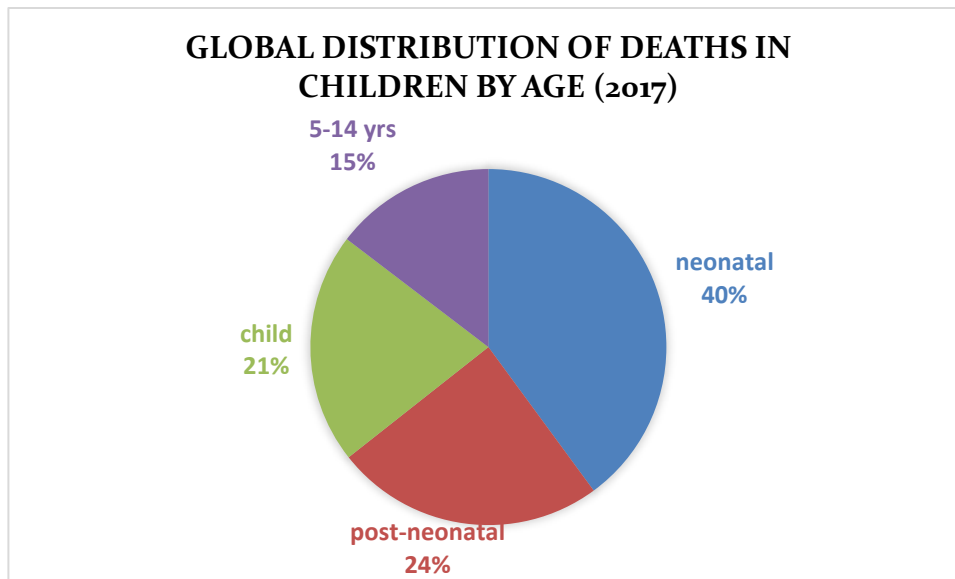


Figure 2.1: Timing of deaths in children <14 years. Adapted from the 2018 UN IGME Levels and Trends of Child Mortality report ⁹.

The definition of a stillbirth, as recommended by the World Health Organization (WHO) for international comparison, is a baby born with no signs of life at or after 28 weeks' gestation or birthweight of 1000 grams⁴⁶. The International Classification of Disease uses 22 weeks gestation and 500 grams birthweight⁴⁷. Recent research shows that the 28-week cut-off point misses out many stillbirths, and it is suggested that this is reduced to 24 weeks based on potential survival of these babies⁴⁸⁻⁵⁰.

Estimation of stillbirth rates is challenging in developing countries where more than half of the births occur at home and these early deaths may not be reported⁵¹⁻⁵⁴. Also, active identification of signs of life, such as the presence of a heartbeat (for example umbilical cord pulsation) and respiratory effort, critical for the distinction between a stillbirth and early neonatal death, is not usually done by traditional birth attendants or the woman's relatives who sometimes conduct deliveries. However, as the aetiology of stillbirths and early neonatal deaths are closely related, combining them is recommended to attenuate this conundrum, and therefore perinatal mortality is used^{55, 56}.

Developed countries use inconsistent definitions of stillbirths and over 35 different classification systems exist, making international comparisons challenging⁴⁷. This is further compounded by the overlap of definitions for early pregnancy losses where the upper boundaries are different depending on location and legal requirements⁵⁷. Early pregnancy losses are however divided into first trimester or second trimester losses universally. Around 10% of confirmed pregnancies are lost, with 80% occurring in the first trimester, and half of these due to chromosomal abnormalities for which there are no proven interventions for their prevention⁵⁸⁻⁶⁰. Although early pregnancy losses have significant effects on the health and wellbeing of mothers, first trimester losses in particular rarely cause maternal death (Figure 2.2). However, ectopic pregnancies, if poorly managed or misdiagnosed, have been associated with high mortality^{61, 62}.

On the other hand, preventable maternal, neonatal deaths and stillbirths are interlinked, with labour being the most dangerous time for both mother and child (Figure 2.2) ¹¹. In 2015, there were 2.6 million stillbirths, 98% of which occurred in LMICs, and 60% occurred in rural homes in south Asia and SSA. About half of stillbirths and neonatal deaths (each ~1.3 million), and 43% of maternal deaths occurred during labour, despite 67% of births worldwide now being in health facilities^{63, 64}. Although the SDGs do not mention stillbirths, the WHO and United Nations Children's Fund (UNICEF) every newborn action plan (ENAP) to end preventable deaths has a set stillbirth target of 12 per 1000 births or less by 2030¹³.

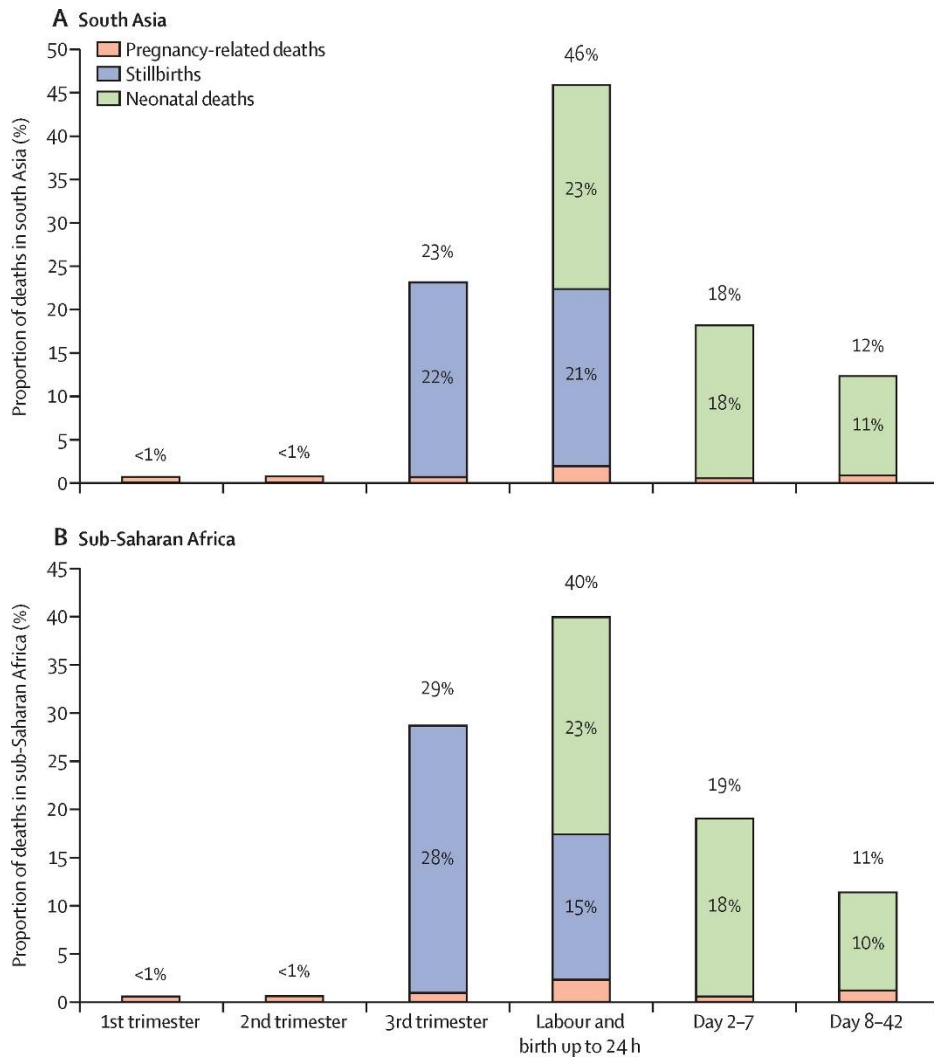


Figure 2.2: Population-based rates, timing, and causes of maternal deaths, stillbirths, and neonatal deaths in south Asia and sub-Saharan Africa: a multi-country prospective cohort study. Source- the Alliance for Maternal and Neonatal Health Improvement mortality study group⁶⁵

2.2 Causes of neonatal mortality

The global epidemiological transition in under-5 mortality has shifted the leading causes of death away from being infections in infants and older children, such as measles, pneumonia and malaria. Almost half of all under-five child deaths now occur in the neonatal period⁶⁶. Direct complications of preterm birth are estimated to have been the top cause of child deaths in 2015, followed by acute respiratory infections and intrapartum-related complications⁶⁶.

Huge data gaps remain for high mortality burden countries. However, methodological advances in data analysis, and progressively improving cause of death and mortality data make it possible to estimate causes of death in these countries⁶⁷. Regarding neonatal deaths globally and in sub-Saharan Africa, the main causes were direct complications of preterm birth, intrapartum complications and sepsis⁶⁶.

Approximately 15 million babies are born preterm annually, and in 2015, over one million died due to complications of preterm birth^{66, 68}. The mechanisms for preterm births include maternal, foetal and placental factors, for instance multiple pregnancies, infections like malaria, chronic illnesses like diabetes, and genetics, but often no cause is identified⁶⁹. Also, multifactorial causes in individuals may lead to preterm birth, and therefore phenotypic classification systems which acknowledge these variations are proposed^{57, 70-72}. Preterm births are further divided into extremely preterm (<28 weeks), very preterm (28 to <32 weeks) and moderate preterm (32 to <37 weeks)⁷³. However, the lower and upper limits of these boundaries are inconsistent, particularly in developed countries where the lower boundaries are set depending on the limit of viability, and for both boundaries, on country-specific legal requirements for registration^{74, 75}. This makes country comparisons challenging as estimates of prevalence of preterm births are affected. In developing countries, determination of gestational age relies on birthweight or recall of last menstrual period which have limitations, as ultrasounds which are recommended for dating of pregnancies are not widely available^{68, 75}. In these countries more than 90% of extremely preterm babies (<28wks) die, yet less than 10% die in high-income settings^{11, 74, 76}. Regional estimates of the incidence of preterm birth in SSA is 12%, almost double the level in Europe¹¹. However, as most of babies that are born too soon are moderately preterm, survival is possible even in developing countries with high neonatal mortality, if easily scalable and preventive interventions are carried out⁷⁷⁻⁷⁹. Of those who survive prematurity, some, especially those born extremely preterm, will face a lifetime of disability, including learning, visual and hearing challenges, and require resources to be directed towards rehabilitation and long-term follow up^{76, 80}.

The second most common cause of neonatal deaths is intrapartum complications, which in 2015 caused 691,000 of all under-five deaths⁶⁶. These complications are also responsible for an estimated 1.3 million stillbirths annually, mainly in Africa and southern Asia. Additionally, about ten million babies are born each year who do not breathe at birth and who could die without urgent care⁸¹. Newborn survival is closely linked to maternal care at birth and having skilled attendance at birth is associated with lower postpartum mortality⁸². Globally, skilled health personnel attend 80% of deliveries. In sub-Saharan Africa, however, where maternal mortality is highest, only 59% of births occurred with the help of skilled health workers⁸³. Additionally, although over 70% of women in SSA live within 2 hours of a health facility that can provide emergency services⁸⁴, proximity does not guarantee receipt of these services, as only one in three women who need emergency care actually get it^{85, 86}.

Having obstructed labour, a common maternal intrapartum complication, carries the highest risk of delivery resulting in a stillbirth or neonatal death, while also putting the mother at risk of death, vesico-vaginal fistula or incontinence^{87, 88}. Common causes of obstructed labour are cephalopelvic disproportion, poor uterine contractility, pelvic abnormalities and tumours. In Africa, female genital mutilation/cutting is prevalent in 28 countries including The Gambia, and its most severe form known as infibulation, may obstruct labour. Women who have undergone infibulation are also 30% more likely to have caesarean sections and 70% more will haemorrhage after delivery compared to women who did not undergo FGM. These women experience up to 55% more stillbirths and early neonatal deaths, and two-thirds of babies born to them will require resuscitation^{89, 90}.

Sub-Saharan Africa bears the highest maternal mortality burden in the world, contributing two-thirds of all maternal deaths. A review of 85 DHS in 34 countries from 1990 to 2014 revealed that in SSA, maternal deaths occurred throughout pregnancy, however in West Africa, intrapartum and antepartum deaths showed an increasing trend while South Africa had increasing intra-and post-partum maternal deaths⁸². In West Africa, haemorrhage was the leading cause of maternal morbidity alongside obstructed labour, uterine rupture and hypertensive disorders⁹¹. In East

Africa, mirroring the West, labour complications, particularly haemorrhage and obstructed labour caused over half of all perinatal deaths⁹².

The third most common cause of neonatal death is neonatal infections, most of which occur in South Asia and sub-Saharan Africa. In 2012, both these regions had over 6 million cases of possible serious bacterial infection (bacterial sepsis, pneumonia, meningitis)⁹³. In 2015, over 400,000 neonatal deaths were due to sepsis or meningitis. Other infections are of fungal and viral aetiology. Apart from death, infections also cause impairment and disability. Those most at risk of infection are preterm babies and/or low birthweight babies, with preterm babies having up to ten-fold higher incidence⁹⁴.

Although not a direct cause of neonatal deaths in low-and middle-income countries (LMICs), in 2012, over 600,000 (22%) neonatal deaths were attributed to small for gestational age (SGA), with nutritional deficiency being the largest contributor to this delayed intrauterine growth⁹⁵. Being small for gestational age is defined as weighing less than the 10th centile on reference growth charts for a given gestational age and sex, and this measure is used as a proxy for intrauterine growth restriction.

In sub-Saharan Africa, 13% of babies have a low birthweight (LBW), defined as less than 2500g⁹⁶. Having low birthweight may occur due to poor development in utero despite being born at term, or is due to prematurity, or both depending on the underlying aetiology^{11, 97}. Several permutations arise when gestational age and birthweight are combined to describe characteristics of babies at birth. Babies may be born at term and appropriate for gestational age (AGA) but either of low birthweight or not. Alternatively, they can be term and both small for gestational age (SGA) and LBW. Preterm babies are either AGA and have LBW or not, or are SGA with low birthweight⁹⁵.

There were slightly over 20 million SGA babies born in LMICs in 2012. 11 million were term and not of LBW, another 10 million were term and had LBW and 1.5 million were preterm as derived from the Intergrowth-21st standard which are based on multi-ethnic international data^{95, 98}. Babies born preterm and SGA have higher mortality risk

than those appropriate for gestational age both in the neonatal period up to the post-neonatal period. Besides poor nutrition, other causes of SGA include maternal infections, placental insufficiency, for example from maternal infections such as malaria and HIV, other morbidity during pregnancy and small maternal size^{11, 95}. The most common causes of neonatal deaths in The Gambia according to a 4-year audit of records in the country's only teaching hospital are complications of prematurity (39%), severe infection (25%) and intrapartum-related complications (24%)⁹⁹. In this study babies were more likely to be born SGA between August and December which is a period associated with increased agricultural activity and food shortage^{99, 100}. The causes of neonatal death according to the WHO Child Health Epidemiology Research Group estimates for The Gambia are similar albeit with intrapartum-related events ranked as the most common cause of neonatal death¹⁰¹.

2.3 Causes of stillbirths

The causes of stillbirths are similar to those that cause neonatal deaths. The most common being complications of childbirth and maternal infections in pregnancy, for example chorioamnionitis, malaria, HIV and syphilis⁶⁴. Recent research has also highlighted the importance of Group B *streptococcus* as a cause of perinatal mortality, particularly in SSA¹⁰². Other important causes include asphyxia associated with placental abruption, preeclampsia/eclampsia and umbilical cord complications. In high-income countries, maternal diabetes and obesity, advanced maternal age, post-term pregnancy and congenital anomalies play a bigger role, as preventable causes of intrapartum deaths have been reduced or eliminated^{47, 64, 103}. While there are no data on causes of stillbirths at national level in The Gambia, data from the country's three referral obstetric hospitals indicate that maternal haemorrhage, anaemia, sepsis, malaria, labour complications and hypertensive pregnancy disorders were associated with higher stillbirth rates^{104 105, 106}.

2.4 Prevention of neonatal and perinatal mortality

This section presents the prevention of neonatal and perinatal mortality as they are interlinked particularly regarding preventive measures around childbirth. Most of the

interventions carried out during antenatal care such as screening and treatment of HIV, malaria, syphilis, diabetes, anaemia and hypertension are geared towards the prevention of perinatal and neonatal mortality^{107, 108}. Use of vaccines in pregnancy such as tetanus toxoid, and in high income countries pertussis and influenza vaccines, have been of proven benefit. This is especially demonstrated with the achievement of elimination of maternal and neonatal tetanus in most countries¹⁰⁹. There are calls for the development of a vaccine for Group B *streptococcus* to be given during pregnancy, which has the potential to increase survival in the perinatal period^{102, 110}. The monitoring for growth restriction and the presence of foetal heart sounds in the antenatal period also aim to prevent stillbirths, as do the increasing numbers of caesarean sections when decreased foetal movement is detected or induction fails for post-term gestation⁴⁷.

Over the centuries, interventions have been developed to improve a baby's survival during labour. As far back as 600BC, operative delivery was done in India, and in the 16th century the Chamberlen family introduced forceps delivery in Europe¹¹¹. Subsequent economic development, improved health systems, decline in fertility and discovery of antibiotics among other innovations, have led to improved survival. Discoveries specific to neonatal survival for example are the discovery of surfactant and mechanical ventilation, use of folate to reduce congenital malformations as well as better surgical management for previously lethal congenital malformations. While many of these discoveries require facility care, there are promising interventions that can be carried out even in the community to reach the more than 70% of births to women in the poorest quintiles that happen at home in sub-Saharan Africa^{54, 112}.

Community-based interventions that have successfully been conducted in LMICs, and which prevent half of all neonatal deaths are; tetanus toxoid administration to the mother, clean and skilled delivery, newborn resuscitation, early and exclusive breastfeeding, clean cord care and management of neonatal infections^{113, 114}. Malaria prophylaxis, maternal education and giving mothers balanced protein energy supplementation have also been shown to be effective¹¹⁵. Recent reviews of data showed that community mobilization alongside antenatal and postnatal home

visitations significantly reduced neonatal mortality^{24, 114, 116-125}. Additionally, having women groups, where participatory learning and action takes place, and especially if about 30% of pregnant women participate, was associated with reduction in neonatal and maternal mortality in developing countries¹²⁶⁻¹²⁸.

Several interventions that can be provided at the facility level have survival benefits for mothers and their babies. For instance, delivering a baby in a health facility was found to reduce neonatal mortality by almost one-third¹²⁹. Additionally, cost-effective interventions are available in health facilities which can save more than 70% of premature babies¹³⁰. During the antenatal period, this includes administration of steroid injections to high-risk women. In the postnatal period, this is achieved through appropriate and timely antibiotic use for treatment of sepsis, and kangaroo mother care which involves continuous skin to skin contact between baby and parent, and is beneficial for cardiorespiratory and temperature regulation, improved neurodevelopmental and feeding outcomes^{131, 132}. Other effective interventions are safe oxygen use and treatments to assist respiration like continuous positive airway pressure. Additionally, mothers should be supported to breastfeed their babies within an hour of birth and babies should be kept warm^{63, 66}. A study into the effect of antenatal steroid injection in LMICs, however, revealed higher neonatal mortality and maternal morbidity as well as over-administration of steroids as only 16% of those given antenatal corticosteroids were eligible. These adverse effects were potentially due to lack of neonatal intensive care units in these settings where prophylactic and therapeutic use of surfactant and continuous positive airway pressure for neonatal resuscitation could have made a difference¹³³.

Skilled childbirth and Emergency Obstetric Newborn Care (EmONC) provide the largest, most feasible opportunity to save mothers and babies, so that if there were 90% coverage for pregnant African women, almost 400,000 neonates would be saved annually¹¹. EmONC is either basic or comprehensive; the difference being that basic EmONC does not include caesarean section deliveries and blood transfusions. The remaining components cover management of maternal complications at birth such as infection, bleeding, pre-eclampsia/eclampsia and obstructed labour. For newborns it

includes performing basic neonatal resuscitation. There are suggestions to include more neonatal components such as infection prevention, thermal protection and feeding among others¹³⁴.

Caesarean sections, also provided at the health facility level, are essential for the treatment of antepartum haemorrhage, prolonged or obstructed labour, eclampsia and intrapartum foetal distress, which if untreated lead to detrimental outcomes for mother and baby¹³⁵. A recent review reported that the average caesarean section rate in Africa in 2015 was the lowest globally, with West and Central Africa having a CS rate of 4%¹³⁶. In LMICs, a minimum rate of 9% was determined to be necessary in order to deal with six life threatening conditions; cord prolapse, severe antepartum haemorrhage, pre-eclampsia/eclampsia, transverse lie/breech presentation and uterine rupture^{137, 138}. Udo and colleague reviewed facility deliveries over the same period and found an inverse relationship between facility delivery and neonatal mortality¹³⁹.

Neonatal resuscitation is included in EmONC and is necessary for the over 10 million babies who do not breathe at birth⁸¹. Resuscitation ranges from as little as initial assessment of the newborn and stimulation, to bag and mask ventilation. For less than one per cent of births, advanced resuscitation consisting of chest compression, supplemental oxygen and drugs is needed. Lee and colleagues showed that stimulation alone would reduce 10% of intrapartum and preterm deaths, which is promising, as no equipment is needed. In addition, 30% of intrapartum neonatal deaths and 10% of preterm births could be prevented if resuscitation was done in facilities, and 20% and 10% respectively at community level¹⁴⁰. Across Africa, health facilities were found to be inadequate to offer emergency obstetric services and significant barriers ranged from lack of personnel to lack of equipment¹⁴¹⁻¹⁴⁸. For babies already sick, appropriate case management could prevent over 80% of neonatal infection deaths^{149, 150}.

Another critical intervention to prevent stillbirths and newborn deaths is delaying and spacing of pregnancy. Sub-Saharan Africa has the highest global fertility and

population growth rates with the lowest contraceptive use at only 25% regionally and 15% in West Africa¹⁵¹. Too frequent births, particularly inter-pregnancy intervals less than six months, for example following abortion/miscarriage, predispose to low birthweight through prematurity or uterine growth restriction and are associated with more neonatal deaths¹⁵².

If sub-Saharan African countries are to achieve SDG 3.2 which relates to reduction of under-five mortality, an unprecedented increase in the annual rate of reduction of U5MR will be needed in some countries. Most countries will need to sustain the acceleration that was seen with the MDGs³². This would require among other aspects such as financial investment, the scaling up of interventions that resulted in the falling child mortality rates, and investment in those that will reduce neonatal and perinatal mortality faster, such as increased access to EmONC, and training and recruitment of skilled midwives¹¹. While training of skilled birth attendants is crucial, a study on coaching them using the WHO safe birth checklist showed that despite better adherence to the checklist, there was no effect on maternal and perinatal mortality¹⁵³. This may indicate that additional factors influence provision of care such as inadequate staffing leading to overworking, demotivation and lack of well-equipped organised health facilities^{99, 154}.

For the wellbeing of mothers and children, governments need to invest in the intrapartum period, with a focus on improving quality and experience of care that is respectful^{155, 156}. They should ensure full integration of services for them across the continuum of care. In view of the limited resources available, this would mean focusing on health systems through strengthening of human resources, supplies and service efficiency, leading to increased coverage of essential services such as modern contraceptive use, antenatal care, birth with a skilled attendant, emergency services, newborn and postnatal care. Governments must also aim to sustain the existing workforce^{157, 158}.

The demand side must concomitantly be reinforced to reduce inequity in access and coverage of health services. Access to health services is commonly hindered by the

three delays, namely the delay in decision making to seek health care, in getting to the health facility and in the initiation of appropriate treatment. These delays need to be addressed by ensuring that decision-making is fast and includes empowerment of women to take decisions, quick referral to health facilities and no delay in initiating treatment. Parents, families and communities' support should be harnessed against the 'Fourth delay', which describes women's reluctance to visit health facilities following prior negative attitudes and experiences^{126, 159, 160}. Society also needs to act against dismissive attitudes by governments that put lifesaving equipment and drugs out of reach of those who need them most. For improved wellbeing of its members, increased advocacy for universal health coverage, education and good governance are critical¹⁶¹. It has been shown that removal of user fees, one major contributor to delay in accessing health facilities in LMICs resulted in increased access, particularly for poorer women^{162, 163}. This should go hand in hand with improved quality and availability of care in the health facilities if the benefits of health facility delivery are to be maximized¹⁶⁴.

Lastly, neonatal and perinatal mortality mostly occur in developing countries, yet they can be prevented with known and scalable interventions even in resource-poor countries¹⁶¹. However, in order to do this, it is vital to improve data on them so as to increase awareness and enable informed decision-making and accountability. Poor data quality characterises most developing countries for whom the data are most needed^{163, 161, 165, 166}.

Knowing the causes of neonatal and perinatal mortality, including through mortality audits, is critical for their prevention, while monitoring mortality accurately provides information on the extent of the problem¹⁶⁷. Evidence-based mortality estimation will be important in determining global, regional, national and local mortality rates, as well as tracking progress towards set targets¹⁶⁸.

While policymakers and researchers require these mortality metrics to evaluate utility and progress of interventions that aim to improve survival, high-level leadership is crucial if they are to be put to use¹⁶⁹. This information should be used to re-evaluate

strategies in place and to consider new interventions, thus the need for precision in measurement of neonatal and perinatal mortality¹⁶⁸.

The next section introduces population-based data sources for the estimation of neonatal and perinatal mortality, highlighting challenges associated with each data source. We present data sources for stillbirth rates where applicable. However, as previously mentioned, stillbirths have not been the focus for many developing countries and have only begun to receive attention in recent times.

2.5 Data sources for the measurement of neonatal and perinatal mortality

Accurate reporting on neonatal and perinatal mortality rates and causes of death requires complete registration of all births, deaths and causes of death^{170, 171}. Based on the axiom ‘what is measured influences what is done’, measurements need to be accurate in order to ensure proper allocation of resources and to target interventions based on the evidence¹⁷². The consequences of inaccurate data can be detrimental. For example, Vietnam did not qualify as a priority country with resultant exclusion from investment in newborn health, when the reported NMR of 4.2/1000 livebirths was used, instead of 16/1000 livebirths which was reported following rigorous examination and confirmation of accuracy of the data¹⁷³.

In the absence of complete vital registration data, other sources, such as surveys and modelling techniques for scarce data, have been used to obtain estimates of the NMR. WHO/UNICEF use alternative methods for global, regional and national estimates. All of these are inferior to complete empirical data but the situation in SSA requires their use, as complete data are lacking^{174, 175}. This underscores the need for a data revolution to improve the quality of statistics especially in the developing countries where a large population of the unreached people reside^{2, 174, 176}.

2.5.1 Civil Registration and Vital Statistics (CRVS) systems

Civil registration records births, deaths and their causes as well as changes in legal status. Complete civil registration is the gold standard of accurate and timely information gathering. Globally, death registration has improved from 28% in 1970 to

45% by 2013. SSA has consistently lower coverage with less than 10% of deaths registered between 1990-2013 and only the small islands having >90% level of completeness^{35, 67}. Civil registration is expensive to establish initially, but becomes an inexpensive source of statistical data when it is a by-product of routine administrative procedures and when it is passive, that is, does not require extensive human resource involved in actively searching for all vital event occurrences¹⁷⁷.

In developing countries, however, it would take a major financial commitment to set up vital registration as seen in Chile where the estimated annual cost of running a registration system is USD 45 million. However, if the data generated are utilized, and the financing raised from the system or through taxes, then the benefits to the economy outweigh the cost^{178, 179}. Other challenges are lack of political will, the use of outdated laws, poor organization, infrastructural problems and the absence of a culture of data utilization, fuelled by lack of capacity to analyse data¹⁸⁰. This is further complicated by the need to coordinate various departments to achieve complete registration, that is effectively linking the ministries of health and interior as well as the central statistical offices, with minimal disruption of their agency and respective functions^{166, 181}.

In less developed regions, no progress in improving the coverage of vital registration occurred over a period of 50 years (1946-1996). Sub-Saharan Africa and South Asia account for almost 80% of the world's unregistered births amounting to 48 million births¹⁸². Many developing countries have legislation about civil registration but do not routinely reinforce it. Births can go for years before finally being registered when the child joins the public education system, for example^{178, 183}. Two-thirds of newborns have their births registered, but only 5% of newborn deaths are registered and even fewer stillbirths⁶³. Overall, the WHO European region has 100% registration, while Africa has less than 10%. So, although vital registration is the recommended data source for accurate demographic statistics, it is not usable in calculating these rates in the African continent¹⁸⁴.

In Malawi, a real-time mortality monitoring (RMM) project was initiated to record births and deaths in the country. Districts usually employ health surveillance assistants to provide preventive care and community management of common illnesses. Each assistant covers approximately 1,000 people in a geographic area. As part of the RMM project, assistants were specially trained to record births and deaths. A mortality survey was then conducted in 12,000 households to provide a gold standard since vital registration data were unavailable. They found that under-five mortality was consistently under-reported by 16-44%, especially neonatal deaths. Births too were under-reported. Thus, although this method is potentially scalable in countries without complete vital registration, its lack of accuracy indicates that further innovative methods are required¹⁸⁵.

In The Gambia registration of births and deaths is within the mandate of the Ministry of Health and Social Welfare and is a centralised function³⁷. The primary registration units in The Gambia for births and deaths are health facilities. Those utilized for registration are 35 units countrywide which are within 7 km of each other. While this has the advantage of utilizing already available facilities and a wider coverage, the lack of civil registrars at each unit and the resulting additional burden on health workers may lead to a compromise in the quality of the data collected. Birth registration is free within 3 months of birth, thereafter a cost of one US Dollar is incurred.

Regarding death registration, monthly summary reports are prepared and transmitted to the national offices by health facilities. Therefore, only those deaths that occur in health facilities are registered. However, health facilities do not have the capacity to produce death certificates. There are only four hospitals where the cause of death can be ascertained, and post-mortems are only carried out at the country's sole teaching hospital – The Edward Francis Small Teaching Hospital. Death registration is a rare event due to cultural beliefs and religious practices, and death certificates are only prepared by the Births and Death Registry Unit at Medical Head Quarters in Banjul, The Gambia's capital city, which is out of reach for most of the population³⁷.

As of 2018 The Gambia had still to establish a coordinating body involving all the stakeholders in CRVS and thus the CRVS remains fragmented. With regard to perinatal mortality, no information on foetal deaths to the mother in her lifetime is collected ⁴¹.

The Gambia utilizes the MICS and DHS to make birth registration coverage estimates although these reports may be biased due to social desirability and recall bias. The country's first DHS was conducted in 2013.²² It suggests that about 80 per cent of births are registered eventually but that registration of the birth is often delayed until the child is several years old. As discussed in more detail in Section 8.5, newborn children in The Gambia are not named until they are a week old and remain secluded till then. Children who die during this period are unlikely to have their birth officially registered. Thus, even once The Gambia manages to establish a national system for certifying deaths, compiling a register and producing statistical reports based on it, CRVS is likely to remain particularly weak as a source of data on neonatal mortality. Neither MICS nor DHS ask about death registration coverage and therefore no quantitative information is available on this.

2.5.2 Sample Registration Systems (SRS)

Sample registration is similar to vital registration, the difference being that SRS is confined to a nationally-representative sample of the population. Biannual demographic surveys are carried out in conjunction with many SRS to complement the process and iron out any discrepancies. The major disadvantage of the approach is that it is expensive. Data are also not precise for small geographical regions such as districts, which may lead to poorly informed policy decisions at that level¹⁸³. The Indian SRS has been evaluated for completeness and accuracy by several researchers and found to underestimate births and deaths by around 10%. Completeness ranged between 77 and 99% but has been worsening over time, compounded by lack of records of missing data^{186, 187}. No SRS has been established in The Gambia.

2.5.3 Censuses

Data collected from well-conducted censuses are representative of the population and sampling error is avoided. However, they are costly and conducted decennially in most countries, with reports published 2-3 years after the event due to the large numbers involved. Regarding the SDGs, censuses would be ideal to provide base and end-line measures for many developing countries, as CRVS systems are not an option. However, the decennial nature of data collection means that they are unlikely to do so, as many censuses will have already been conducted too long before or after the start and endpoints of the goals, to be of much use⁴. Two main types of error are encountered in censuses – population undercount, although some cases of falsification resulting in more people than exist are encountered, and age-reporting errors.

Despite its comprehensiveness, some studies have estimated census under-enumeration to be about 3% in Asia, 4% in Latin America and 5% in Africa¹⁸². In South Africa, post-enumeration surveys report a population under-count ranging between 10 and 17%⁴. Most African countries do not conduct post-enumeration surveys and therefore the quality of censuses remain unknown. Nevertheless, the sheer complexity of the task and the lack of human resource points to poor data quality in African censuses⁴. Under-five mortality can be estimated from censuses if questions on births and deaths are asked, usually in the form of summary birth histories. Advanced modelling techniques can then be used on these summary birth histories to allow for neonatal and perinatal mortality estimation. The strengths and limitations of modelling are discussed in section 2.5.6 below. With regard to The Gambia, censuses have been conducted since 1881 and are the main source of population data in the country in addition to single-round surveys. More details are reported in Chapter 4 of this thesis.

2.5.4 Household Surveys

Household surveys have been used as early as the 1970's when the World Fertility Surveys (WFS) were conducted¹⁸². The WFS utilized verbatim translated pregnancy history questionnaires and employed well-trained female interviewers to interview

small samples of women. Although the WFS provided a few additional livebirths, there was evidence of under-reporting of abortions, miscarriages and stillbirths¹⁸⁸. A comparison of estimates from the WFS to a household survey showed consistent lifetime and current fertility estimates and that surveys utilizing birth history were considered adequate for measurement of infant mortality. It was concluded that the quality of data depended not on the data collection instrument but more on the skills and supervision of the fieldworkers¹⁸². Thereafter, for the last 30 years, demographic health surveys have mostly collected birth histories.

Household surveys now provide maternal and child health information for most developing countries. These include not only the United States Agency for International Development (USAID) sponsored DHS, but also the UNICEF-supported MICS^{189, 190}. They both use standard indicators and methodology enabling global comparisons. The population sampled is representative of the whole and data are easily accessible¹⁹¹. There is a time lag between collection of data and compilation of reports, and the fact that recent estimates are for five years prior to the survey, means that although the turnaround times are faster than censuses, they are still unsuitable for timely monitoring and effecting change on neonatal and perinatal mortality. Another major drawback is that MICS do not report on neonatal or perinatal mortality, but modelling of summary birth history data can provide these estimates¹⁹².

In single-round surveys, the information obtained relies on respondents' memory, with the possibility of recall bias^{193, 194}. This worsens with increasing passage of time as surveys involve recall of information for more than 15 years potentially resulting in inaccuracy of estimates obtained from them. Lastly, a recent review of DHS focusing on perinatal mortality showed that regardless of the exact data collection tool used, stillbirths are under-counted in these surveys¹⁸.

Under-five mortality estimates for The Gambia as well as other national demographic metrics have been derived mainly from these sources³⁶. They are discussed in detail in Chapter 4.

2.5.5 Health and Demographic Surveillance Systems

In the face of lack of timely, accurate and good quality data due to incomplete civil and vital registration in developing countries, health and demographic surveillance systems (HDSS) have been advocated as interim measures before vital registration systems are scaled up^{38, 195}. This section introduces HDSS and presents characteristics of HDSS that may make them suitable for measurement of neonatal and perinatal mortality.

Demographic surveillance is the process of defining risk and corresponding dynamics in rates of birth, deaths, and migration in a population over time¹⁵. HDSS are potentially capable of filling the existing data quality, accuracy and timeliness gaps¹⁹⁵. They follow up individuals within households in a defined geographical area over time, and demographic events are recorded through regular visits by trained interviewers. All HDSS regularly collect births, deaths and migration events as well as varied health, social, environmental and economic data of populations covered^{180, 196}. They can therefore provide data on long-term demographic trends and community health that are not possible to collect in rapid assessments or cross-sectional surveys¹⁹⁷. However, as they are limited by geographic boundaries, they do not provide representative data on national populations¹⁹⁸.

The International Network for the Continuous Demographic Evaluation of Populations and Their Health (INDEPTH) comprises over 40 HDSS sites in SSA, Oceania and SE Asia which share information and have standardized methodology to fill the data gaps in these regions¹⁹⁹. Continual surveillance is expensive; thus, most of these sites are confined to fairly small populations, but by pooling data across HDSSs, issues such as small sample sizes are mitigated¹⁵.

HDSS have been used as platforms for a broad range of research for example: on vaccines such as pneumococcal vaccine in Basse, The Gambia, on maternal mortality in Matlab, Bangladesh, on HIV/STI in Rakai, Uganda and malaria control in Ifakara, Tanzania, Kisumu Kenya, Farafenni, The Gambia and Oubritenga, Burkina Faso¹⁵ including the impact of social support grants in Agincourt, South Africa²⁰⁰. HDSS data

are highly suitable for clinical trials and understanding of causation based on their complete follow up of populations, provision of contextual knowledge, and reduction of omitted variable bias. The populations followed up are more likely to be homogenous and therefore confounding is less of a factor in such research. Follow up also allows provision of the proper sequence of events that are vital in establishing causality^{197, 201, 202}.

Additionally, relative to the countries where they are located, many HDSS have better data management and statistical capacity, resulting in faster and higher numbers of evidence-based outputs than the respective offices of national statistics¹⁵. Continuous follow up allows for verification of the events, potentially including immediate repeat field visits in cases where data quality is found to be poor. Some HDSS employ electronic data capture that provides a rapid and flexible data collection platform²⁰³. Inbuilt systems in electronic devices that prevent out of range or logically inconsistent responses further improve data quality. Electronic data capture through Global Positioning Systems (GPS), are useful in localizing mortality estimates, epidemics and socially vulnerable groups. GPS can also act as a quality control measure by monitoring fieldworker outputs to avoid data manipulation²⁰³⁻²⁰⁵.

While not all estimates from HDSS may be nationally representative, methods to extend their generalizability include comparison with national, hospital, census and survey data^{33, 206}. A comparison of DHS and HDSS in Ethiopia resulted in similar mortality patterns, with the DHS producing smoother estimates and being more liable to recall bias, while the HDSS estimates depicted local epidemics³³. Further validation, as with the INDEPTH network protocol in over 50 sites in Africa, Asia and Oceania, is through standardization of data collection methods, variables and analysis, and comparison with external estimates^{195, 196}.

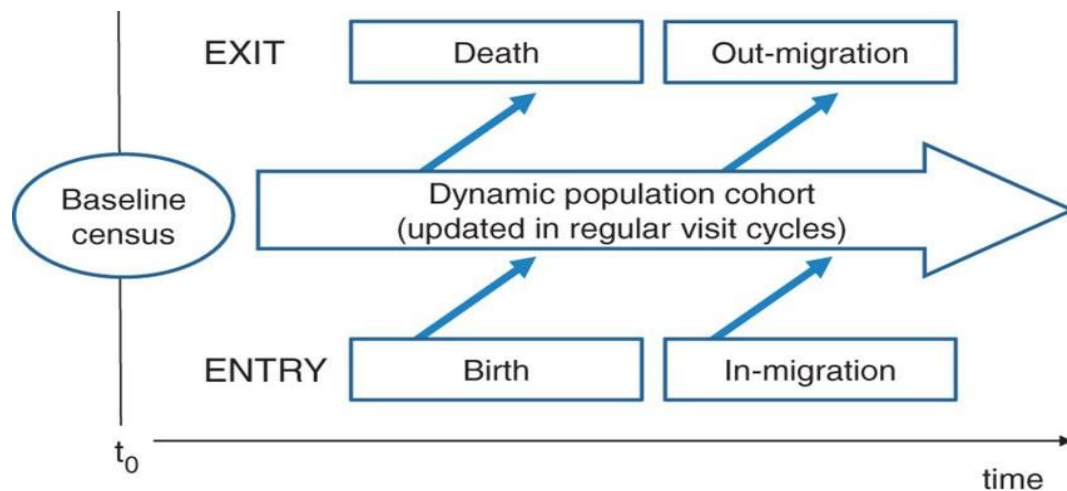


Figure 2.3: The structure of a health and demographic surveillance system adapted from INDEPTH ¹⁹⁶.

One study compiled data from 65 HDSS in SSA and analysed the variability of factors associated with under-five mortality in the HDSS relative to the populations within which they were located, at subnational level. These factors included female literacy, malaria prevalence, birth interval, stunting, and vaccine coverage among others. The researchers found little variation in birth interval, vaccine coverage and prevalence of stunting. For the remaining factors, combining HDSS data was useful for pinpointing regions with disparities in these risk factors, highlighting different geographical regions with similar risk, and informing on gaps which policy makers could fill. For instance, regions without HDSS but with similar risk could learn from those with HDSS. Also, in order to maximize information in the continent, if new HDSS were to be set up, regions like southern Niger, southern Mali, and parts of southern Zimbabwe, central Nigeria and eastern Kenya which were poorly represented by HDSS should be considered. Finally, the study highlighted the utility of HDSS for disease outbreak surveillance in view of HDSS coverage for a large part of the continent³².

For HDSS that are interlinked with health facilities or government agencies, this provides an avenue for more complete data since health information and vital registration respectively, combined with an individual's demographic data, enriches available information for analysis. As regards health facility linkage, one example is Kilifi HDSS in Kenya, which has conducted hospital-based clinical trials and followed up discharged patients to their homes in the ongoing HDSS to monitor outcomes such

as mortality²⁰⁷. In Kilifi, real-time linkage has proved challenging due to the time-consuming process of matching on an individual's names, age and names of household members to confirm identity. Other HDSS have generated their own identification cards, but their acceptability is context dependent. In Kilifi, for example, this method of identification is viewed with distrust. Alternative tools for improved linkage to health facilities or national data are use of national identity cards or biometric identification where acceptable and available²⁰⁷. However, in Kilifi less than half of the adult population have their national identity cards captured in the database, and slightly less than a quarter of young women have these cards, meaning that HDSS need to adapt to the local context. Agincourt HDSS reported challenges with biometric identification but found that using the first name of other members in the same household in addition to an individual's demographic data fared well²⁰⁸.

HDSS can also be used to depict progress at national level as shown by The Agincourt HDSS which highlighted South Africa's success story with regard to CRVS. Analysis of HDSS data between 1992 and 2014 showed that birth registration in Agincourt improved dramatically from 8% to 91% and death registration from 51% to 97%³⁵.

Specific to neonatal and perinatal mortality measurement, all INDEPTH members are required to prospectively follow up pregnant women and record pregnancy outcomes, duration of pregnancy, birthweights, place of delivery and whether the delivery was assisted by a skilled health care provider²⁰⁹. However, only about half actively do so, and the frequency with which such data are collected are varied, as are the data collected and the definitions used. Research is currently ongoing in five HDSS to address some of these issues¹⁷. Certain HDSS collect more detailed records on a woman's reproductive history and even an individual's genealogy²¹⁰. The follow up of pregnancies is mostly geared towards improving data quality by ascertaining that no livebirths are missed as they form the denominator for neonatal, perinatal, infant and under-five mortality estimates.

Few HDSS have published perinatal mortality estimates and report on verbal autopsies for stillbirths^{21, 196, 211, 212}. The frequency of follow up of pregnancies is a key issue when

considering using the HDSS for measurement as the neonatal period and intrapartum period can be easily missed if the pregnancy is not identified and if the delivery occurs between rounds¹⁷.

Lastly, there are cultural issues that affect perinatal and neonatal mortality data collection. In Kaya HDSS, Burkina Faso, deaths are under-reported due to cultural barriers²¹³. In Nahuche HDSS Nigeria, over 97% of the population are Hausa who have cultural taboos about reporting of neonatal and infant deaths²¹⁴. In addition, male fieldworkers are not allowed to interview females, limiting the follow up of pregnancies. Under-reporting of under-five mortality is also linked to low literacy levels in the region²¹⁴. While it would be important to understand the cultural barriers leading to under-reporting of these deaths, the details are not provided, yet this understanding may be key to mitigating the under-reported estimates.

In summary, the longitudinal and prospective nature of HDSS make them potentially suitable for reporting of trends of neonatal and perinatal mortality. The availability of electronic data capture, health facility linkage and verification procedures can improve data quality and timeliness if well implemented^{17, 203, 204}. Complete follow up of pregnancies and their outcomes, which are core to estimation of under-five mortality including perinatal mortality, indicate that they should be assessed as data sources for estimation of neonatal and perinatal mortality. This would also require consideration of cultural factors which have been shown to affect data collection particularly about pregnancies and deaths.

There are some challenges and ongoing debate with regard to HDSS. Those affecting the estimation of neonatal and perinatal mortality in particular are that first, HDSS are very costly to run, resulting in some HDSS reducing the number of update rounds. This has an adverse effect on data quality and completeness^{17, 15, 215}. Many HDSS, in an effort to ensure sustainability, have fees associated with their use as platforms for other studies, while others, for instance those in the Gambia, benefit from core funding through the Medical Research Council in the United Kingdom in addition to charging studies nominal fees for use of the HDSS resources¹⁹⁹. Second, as HDSS are run

independently, data collected by them may not be easily available to external researchers. This issue has been the focus of debate with calls for HDSS to consider their data as a public good that should be made available, especially in developing countries where data are scarce²¹⁶. The INDEPTH network ishare2 platform, that gives data access to external researchers, was initiated in response to such debate²¹⁷. For other HDSS outside of the network, applications may need to be made to justify the need for their data, to ensure confidentiality is maintained as well as to ensure that the data source is acknowledged in subsequent publications¹⁵. Having external researchers analysing and reviewing HDSS data can provide insights that may otherwise have been missed, but also indirectly contributes to improved data quality as they serve as audits which may reveal inherent quality issues in the data and motivate HDSS to utilize standardized data collection methods, definitions and tools²¹⁶.

A third challenge that some HDSS face regarding neonatal and perinatal mortality data is migration, which is a change in usual residence and can be broadly classified as internal, where individuals leave their usual residence and move to a different administrative region but remain within a country's borders, or international which involves movement outside of national boundaries. Migration is a key sociodemographic event whose determinants and effects are important for estimation of demographic parameters. Internal migration is more common, and both types of movement have been investigated for their effect on the migrants' health with regional and gender specific mortality differences between migrants and residents reported²¹⁸⁻²²⁰. There are theories that migration may affect health outcomes negatively due to potential lack of access to health care in destination areas during the adjustment period, as well as in original residences for return migrants. For instance, children born to women who migrated to an urban slum in Kenya while pregnant had significantly higher mortality risk compared to those born there^{221, 222}. Similarly, female children who transitioned to adolescence in slums entered into parenthood at an earlier age with resultant health risks and mortality that affects adolescent mothers and their

babies²²³. On the other hand, there may be positive health effects due to migration if health care is better in destination and origin areas respectively^{219, 222, 224}.

Not all HDSS follow up residents after they migrate, thus if a pregnant woman out-migrates, there is a high likelihood that the pregnancy outcome, particularly if adverse will be missed if she gives birth when outside the HDSS thus affecting the completeness and accuracy of neonatal and mortality data^{225, 226}. Although this list of challenges is not comprehensive, it highlights potential limitations when working with HDSS data. Nevertheless, it does not negate the fact that HDSS remain a good platform for methods to improve neonatal and perinatal mortality estimation and survival. Additionally, HDSS typically have close relationships with policymakers, universities, hospitals as well as with, more importantly, the community members who they monitor^{35, 207}. This means that dissemination of findings to change agents and champions (village leaders, government and non-governmental organizations and national statistics offices) is possible for most HDSS^{40, 200}.

2.5.6 Projections and Estimations

Projections and estimations of mortality are derived using standardized methods across countries that synthesize results from different data sources²²⁷. Modelling relies on data from countries with complete CRVS to guide estimation for countries without data, as well as on household surveys, censuses and surveillance systems, which all have their limitations. Modelling therefore emerged in an attempt to cover deficiencies in the available data sources. Two advantages of modelling are that it produces timely estimates and is inexpensive to conduct. Recent advances in modelling and in the data available also enable researchers to adjust mortality estimates to cater for epidemics such as HIV/AIDS and catastrophic events.

However, certain differences are seen when comparisons of estimates by different groups are made. A comparison of the UN IGME and the Institute for Health Metrics and Evaluation (IHME)'s under-five mortality estimates from 1990 to 2010 showed that in 2010, over 20% of all countries had absolute differences in U5MR greater than 10 deaths/1000 births. The differences between the groups originated in the modelling

techniques used and data handling methods²²⁸⁻²³⁰. For example, the UN IGME discarded incomplete data, thus potentiating under-estimation, while the IHME group had duplications from DHS birth histories that could distort mortality estimation^{228, 229}. More recently, using similar data sources to estimate stillbirths and neonatal deaths, the IHME estimated that there were 1.7 million stillbirths in 2016, whereas the Lancet Stillbirth Epidemiology investigator group estimated this figure at 2.6 million in 2015, a difference of almost one million stillbirths^{64, 67}. Similarly, IHME estimated 2.2 million neonatal deaths, while UN IGME estimated 2.6 million neonatal deaths in 2016^{67, 192}. These groups use different modelling techniques: UN IGME do not use covariates for their models generated using Bayesian Hierarchical Splines Regression, GBD use covariates and spatiotemporal Gaussian Process Regression and the Lancet stillbirth group use restricted cubic spline regression and predict estimates using covariates²³¹⁻²³³. Additionally, for the GBD, a change in method for estimating births through utilization of total fertility rates from censuses and surveys substantially impacted under-five mortality and stillbirth rates⁶⁷.

While these methods may work well for most countries, for others they may produce very inaccurate estimates so that national tailor-made analysis is necessary to improve them²³⁴. Modelling is remarkable but is not the remedy for the shortage of timely and complete empirical data which can provide true population estimates¹⁷⁴. The UN has put emphasis on the need for real time data to inform and adjust programs aimed at improving women's and children's health²³⁵. Modelling is also a big challenge in the developing world as the capacity to do it is largely located in the global North, and therefore without capacity building in statistics, the global South will be reliant on the former, contrary to the SDG partnership goals¹⁶⁶.

Table 2.1: Summary of data sources, strengths and limitations

Data Source	Strengths	Potential limitations/biases
CRVS	<p>Representative of total population</p> <p>Timely-continuous registration, compiled monthly, quarterly or annually</p> <p>Prospective</p> <p>Routinely producing statistics from a functioning system is inexpensive</p> <p>Data available for small subpopulations</p> <p>Death registration and establishment of cause of death are useful for prioritized effective health interventions</p> <p>Should be confidential</p>	<p>Initiation costly</p> <p>Incomplete in developing countries – particularly death registration</p> <p>Not all vital events are captured even in well-established systems</p>
SRS	<p>Representative of total population</p> <p>Timely-continuous registration, compiled monthly, quarterly or annually</p> <p>Prospective</p> <p>Data available for small subpopulations</p>	<p>Costly as not useful for administrative purposes</p> <p>Administratively complex (continuous registration and biannual surveys)</p> <p>Sampling bias</p>
Censuses	<p>Aims to count the total population</p> <p>Captures wide spectrum of population characteristics and variables e.g. housing, literacy</p> <p>Data available for small subpopulations</p> <p>Provides a sampling frame for other surveys</p> <p>Sampling error is avoided</p>	<p>Costly</p> <p>Not timely – decennial</p> <p>Under/over count of populations</p> <p>Due to the scale of the exercise, content and quality control may be limited</p> <p>Information may not be current at the time of reporting</p>
Surveys	<p>Representative of total population</p> <p>Flexible data collection (more variables collected)</p>	<p>Costly</p> <p>Not timely – quinquennial</p> <p>Retrospective -recall bias, omissions and displacement</p> <p>Sampling bias, selection bias (non-response, under coverage, volunteer response)</p> <p>Not suitable for population sub-group estimates</p> <p>Missing data (mitigated by imputation)</p>
HDSS	<p>Timely (continuous data collection)</p>	<p>Costly</p> <p>Non-representative of total population</p>
Modelling	<p>Representative of total population</p> <p>Timely (rapid turnover of results)</p>	<p>Dependent on quality of baseline data</p>

Table 2.1 summarizes the data sources for estimation of under-five mortality and lists some of the strengths and limitations of each source.

2.6 Data sources for cause of neonatal death and stillbirths

This section provides a brief overview of the data sources available for causes of stillbirths and neonatal deaths. Knowing the cause of death (COD) is dependent on knowing that an individual died, and therefore the true picture of causes of death relies on complete and accurate capture of deaths²³⁶. Currently, global reports on causes of neonatal deaths and stillbirths are generated using modelling of available data. In general, vital registration data are used for low under-five mortality settings and verbal autopsy data for high U5MR countries⁶⁷. In order to standardize definitions of causes of deaths, the WHO International Classification of Diseases (ICD) is recommended²³⁷.

2.6.1 Clinico-pathological autopsy in complete vital registration systems

The gold standard for establishing the cause of perinatal and neonatal death is physician certified, using ICD, through clinico-pathological autopsy. Autopsies or post-mortem examinations are the detailed external examination as well as dissection of organs after death for histopathological, toxicological and genetic testing where necessary to determine the cause of death. Clinico-pathological autopsies combine clinical information (patient's history, laboratory and radiological investigations) obtained prior to death, together with findings from autopsy for a definitive cause of death²³⁸. However, as these are hospital based, in LMICs, due to lack of personnel and sociocultural constraints, they are rarely done. Autopsies are also not a viable option for establishing the cause of death in resource poor settings where most deaths occur at home²³⁸⁻²⁴⁰. As mentioned in section 2.5.1 in this thesis, autopsies are only conducted at the Edward Francis Small Hospital in The Gambia, and are rarely done, and, therefore, are not used to generate information on causes of death.

2.6.2 Verbal and Social autopsy (VASA)

Verbal autopsy (VA) is a method that consists of interviewing relatives or caregivers about signs and symptoms experienced by the decedent prior to their death, as well as their medical history²⁴¹. They were introduced to fill the information gap for deaths that occur at home^{240, 242, 243}. Social autopsies complement VAs by gathering

information on social, behavioural, environmental and health system determinants that may have contributed to death^{244, 245}. VAs are interpreted to arrive at the cause of death by physicians or using computational algorithms^{246, 247}. This method has been in use for over half a century but renewed interest has resulted in their inclusion in household surveys and censuses^{240, 242, 243}. Verbal autopsies are also routinely carried out in HDSS. They have several limitations. For instance, they rely on accurate classification of symptoms and perform best when symptoms are distinct. However, cause-specific mortality fractions are easily distorted over time and between populations if there is misclassification of symptoms. For neonatal and perinatal mortality, verbal autopsies are useful for diagnosis of congenital malformations, perinatal asphyxia and neonatal tetanus, but may not be accurate in determining all causes of death, for example bacterial sepsis^{246, 248-252}. Also, the methods used for interpretation such as physician agreement further expose the method's weakness, thus novel methods have been proposed where VR is inadequate. In The Gambia, none of the national household surveys have incorporated verbal autopsies to establish causes of death. Additionally, at the time of data collection for this thesis, verbal autopsies had been newly introduced and were being tested out in the health and demographic surveillance systems. Thus, it was not possible to investigate the availability and quality of cause of death data based on the timelines of this PhD.

2.6.3 Minimally invasive tissue sampling and clinical verbal autopsy

The third source of cause of death data is through use of minimally invasive tissue sampling (MITS) by needle biopsy in combination with clinical verbal autopsy to yield cause-specific population-based mortality rates. This is conducted by a new surveillance system known as the Child Health and Mortality Prevention Surveillance network (CHAMPS)²⁵³. Results from MITS and verbal autopsies are assessed for each individual by a panel of experts in infectious disease, paediatrics, pathology and microbiology to arrive at a consensus on underlying COD and contributing factors²⁵³. It has been set up in seven sites in different countries: Bamako, Mali; Kisumu, Kenya; Manhica, Mozambique; Soweto, South Africa; Balikandi, Bangladesh; Harar, Ethiopia

and Maleni, Sierra Leone, most of which are HDSS. Some challenges envisaged include community hesitance and logistical issues surrounding the acceptability of, and the need for transportation of bodies to health facilities for the procedure preferably within 24hrs of death. However formative research showed that families are keen to know the cause of death of their loved ones²⁵⁴. Validation studies comparing MITS to the gold standard show high congruence of almost 80% for stillbirth and neonatal deaths, especially of infectious aetiology, but MITS fared poorly with congenital malformations²⁵⁵. If successful, this method will provide empirical accurate population-based causes of death. Scale up of MITS and verbal autopsies could be possible in HDSS but is unlikely to be adapted for household surveys or censuses in developing countries.

2.7 Summary

This chapter highlights that neonatal and perinatal mortality are a huge burden in developing countries. However, data on early childhood mortality tend to be in shortest supply in countries where the burden is highest. Moreover, although mentioned in the global agenda through the every newborn action plan for instance, stillbirths are not included in the SDGs despite being largely preventable. The causes of stillbirths and early neonatal deaths are similar and linked with maternal mortality in the intrapartum period, so that interventions in this period have high survival benefits for women and their babies^{10, 12, 63, 256}. To prevent stillbirths and neonatal deaths, it is important to know their causes. Unfortunately, in developing countries, data on COD are scarce although there are innovations currently being researched to fill this gap such as CHAMPS. Nevertheless, the most common causes currently known through modelling exercises can be prevented if there is a scale up of services such as appropriate ANC, nutrition including folate supplementation, EmONC, treatment of neonatal sepsis and, to a lesser extent respiratory support, to name a few.

However, in order to know the causes of death and prevent them, all deaths must be accounted for. Therefore, methods to improve measurement of mortality in developing countries are crucial if the true picture of mortality and causes of death is

to be ascertained. As highlighted in the MDG era, increased visibility resulted in improved funding towards areas deemed needful. The resultant achievements were therefore possible because the data directed policy makers and constrained resources in the right direction²⁵⁷⁻²⁶⁰.

I have highlighted data sources for national estimation of neonatal and perinatal mortality, some of which do not allow direct estimation. The main challenges faced in developing countries with incomplete CRVS, which rely on alternative data sources, are availability and timeliness of data as well as challenges associated with establishing the causes of death. In addition, modelling-based estimates of neonatal and perinatal mortality can differ depending on the data and techniques used. Although modelling of census and survey data provides a temporary solution to a huge problem, complete civil registration of vital events must remain the ultimate goal for developing countries³⁸.

This review also suggests that in the absence of complete vital registration, HDSS that actively follow up pregnancies and their outcomes may be a feasible interim measure to improve the estimation of stillbirth rates and neonatal mortality as well as provide data on cause of death through verbal autopsy and potentially MITS. These estimates and causes of death for closely followed populations can be further utilized in modelling to improve estimates for regions without good quality data. This research therefore focuses on improvement of measurement of neonatal and perinatal mortality using HDSS as a platform by first, evaluating the fitness of methods of pregnancy data collection, that is routine pregnancy surveillance in HDSS and pregnancy history survey of women resident in the HDSS, and second, testing whether the capture of pregnancies in the HDSS can be improved through antenatal record linkage. Box 1 summarizes current global policies directly related to neonatal and perinatal mortality.

Box 1. Global targets related to neonatal and perinatal mortality

Mortality targets by 2030:

SDG 3.2: 12 neonatal deaths or fewer per 1000 livebirths

ENAP: 12 stillbirths or fewer per 1000 total births in every country

Family planning:

By 2020, 120 million more women and girls with access to contraceptives

By 2030, universal access to sexual and reproductive health-care services and integration of reproductive health into national strategies and programmes

Antenatal care: by 2030, universal quality of care and comprehensive antenatal care for all women

Care during labour and birth: by 2030, effective and respectful intrapartum care to all women in all countries

Respectful care, including bereavement support after a death: by 2020, global consensus on a package of care after a death in pregnancy or childbirth for the affected family, community, and caregivers in all settings

Reduce stigma: by 2020, all countries to identify mechanisms to reduce stigma associated with stillbirth among all stakeholders, particularly health workers and communities

Modified and adapted from Lancet Stillbirth Series 2016 executive summary²⁶¹.

Chapter 3 Study Context

The Gambia (see Figure 3.1), where this research was conducted, is introduced in this chapter. The chapter provides a brief overview of neonatal and perinatal mortality in the country and of existing policies that address them. This section also summarizes the available data sources for national under-five mortality estimation. Then, it presents relevant background information on the Medical Research Council The Gambia, which runs the health and demographic surveillance system (HDSS) in which I undertook this research.



Figure 3.1: Map of The Gambia.

Sources www.geology.com and <https://www.mapsland.com/africa/gambia>

3.1 The Gambia

The Gambia is the smallest mainland country in Africa located in the West and covering 11,300km² with 1,857,181 inhabitants at the last census conducted in 2013²⁶². It is geographically surrounded by Senegal except for its Western border, which is the Atlantic Ocean. The current per capita income is \$450 (2005 international dollar) and the country derives its income from the services sector (62%) and agriculture (23%)²⁶³. About 55% of those over 7yrs old are economically inactive and the age dependency ratio is 85. Although the unemployment rate is only 6%, incomes are extremely low, as the majority of the workforce are farmers or petty traders²⁶³.

The Gambia has a hot rainy season from June to November and a cooler dry season from November to May. The main ethnic groups are the Mandinka, Wolof, Fulani, Jola, Serahule but the population also includes smaller groups like the Manjago, Aku, Bambara and non-Gambians. Over 95% of the population are Muslim²⁶². Gambia has a youthful population with 37% of the population aged between 13 and 30 years of age. The life expectancy at birth is estimated to be 65.9 years for women, 60.8 years for men and 63.4 years for both sexes. The 2013 Gambia Census gives the total fertility rate at 5.9 children per woman, with the age at first marriage at 22.5 years²⁶². According to 2013 DHS, the wanted fertility rate is 4.7 children per woman, but the current rate of contraceptive use is only 9%. A quarter of married women have unmet need for contraception, mainly for birth spacing purposes.

Antenatal care services are well-attended with almost universal coverage of at least one visit²². Pregnant women's intake of iron medication, provision of information on pregnancy complications as well as taking of vital signs and lab investigations is reported at 90% nationally²². Seventy percent of women received tetanus toxoid injections and about 60% of pregnant women had skilled attendance at birth. About 76% of women reported receiving postnatal care within 48hrs of delivery in stark contrast to only 15% of neonates being reviewed. For the five-year period before the 2013 Gambia DHS survey, only 59% of babies had their birthweight recorded and 12% of these had low birthweight²².

Regarding education, 58% of children aged 3-17yrs were attending school and an improvement in girl-child attendance to 31% was noted. Overall literacy is 55% and female literacy 51%. Twenty-five percent of children under five years of age in The Gambia are stunted, 12% are wasted and 16% are underweight²².

The cultural practice of Female Genital Mutilation (FGM) has a prevalence of 75% and almost two-thirds of women interviewed in the 2013 Gambia DHS think the practice should continue. The most common type of FGM/C performed in the Gambia is type I/II, however women with this less severe form of FGM/C were shown to have significantly higher odds of complications at birth such as perineal tears, prolonged

labour and need for caesarean sections^{22, 90}. A ban of FGM was legislated on 24th November 2015 by the then president Yahya Jammeh with a penalty of D50000 (\$1050) or 3 years in prison or both. However, after his ousting, the law is being laxly enforced based on a misconception in the community that Jammeh-led legislation would be repealed and a widespread belief that Islam requires FGM²⁶⁴. Non-governmental organisations are however campaigning to ensure this practice is stopped based on the considerable harm caused by it^{90, 265}.

3.2 Neonatal and perinatal mortality in The Gambia

Data on neonatal and perinatal mortality in The Gambia originate mainly from trials and longitudinal studies within the HDSS around the country and more recently from the first Demographic Health Survey conducted in 2013. Three rural villages in The Gambia have been followed up since 1950 by the United Kingdom Medical Research Council and provided information on neonatal mortality for over fifty years. Neonatal mortality was very high in the period 1951 to 1975 ranging from 85-50 per 1,000 livebirths²⁶⁶. However, neonatal mortality drastically dropped from 44/1000 before 1975 to 15/1000 livebirths by 1997²⁶⁷.

The MRC established a HDSS at Farafenni on the north bank of the river Gambia in 1981. The neonatal mortality rate was 41 per 1000 livebirths, stillbirth rate 34.9 and perinatal death rate 74.5 per 1000 births in 1982-83^{268, 269}. At this time, access to healthcare was poor as was the infrastructure in the region. The main causes of neonatal death were prematurity and infection. A significant decrease in neonatal mortality to 20 per 1,000 livebirths was observed from 1982-1996. This reduction has been attributed to the introduction of Primary Health Care (PHC) programme in the early eighties, particularly due to maternal tetanus toxoid vaccination, clean delivery and umbilical cord care which became widely available during this period of time²⁷⁰. By 2008, the fourth MDG target of reduction in under-five mortality by two-thirds had already been achieved in Farafenni HDSS, but the neonatal mortality rate lagged behind, dropping from 32 (95% CI 26-40) per 1000 person-years in the period 1989-1992 to 20 (95% CI 16-26) per 1000 person-years in 2004-2008. This is similar to the

drop recorded in the DHS of 31 to 22 per 1000 livebirths for the same period^{22, 40}. For the first time in 2001, national perinatal and neonatal estimates were provided through a national mortality and contraception prevalence survey. Perinatal mortality was estimated at 54.9 per 1000 births and neonatal mortality to have declined from 60 per 1000 live birth in 1996 to 31.2 per 1,000 livebirths. This survey did not investigate the causes of neonatal and perinatal deaths²⁷¹.

Two nationally representative household surveys – MICS 2010 and DHS 2013 – gave disparate results for the same measures and period. MICS estimated the under-five mortality rate for mid-2004 at 109 per 1000 livebirths and the infant mortality rate at 81 per 1000 livebirths, while for the period 2004-2008 the Gambian DHS reported an under-five mortality rate of 72/1000 livebirths and IMR of 46/1000 livebirths. The survey reports do not provide ranges within which these point estimates lie and it is difficult to decide which of them better depicts the child mortality picture in The Gambia^{22, 272}.

The leading causes of neonatal mortality in The Gambia are intrapartum related events, preterm birth and complications and neonatal infections based on modelled data²⁷³. These causes are mirrored at the country's only teaching hospital in Banjul. In this facility, however, preterm birth complications predominate, followed by infections and intrapartum-related events⁹⁹.

3.3 Current policy related to neonatal and perinatal health in The Gambia

The Gambia National Health Sector Strategic Plan 2014-2020 is the latest statement of policy to be produced by the Ministry of Health and Social Welfare²⁷⁴. Other policies related to maternal and child health include the National Health Policy 2012-2020 report and the National Reproductive Health policy 2007-14^{275, 276}.

None of these three policy reports mention stillbirth rates but all mention the use of perinatal audits in health institutions for monitoring and evaluation of maternal and newborn health. The policies related to neonatal and perinatal health are summarised in Box 2.

Box 2 Policies for perinatal and neonatal health by 2020 in The Gambia

- To reduce NMR to 15/1000 livebirths through provision of EmONC
- To increase early trimester attendance of ANC through incentivization and community sensitization
- To improve skilled birth attendance to 80% through human resource capacity building and advocacy especially by male community members among other strategies.
- To increase contraceptive prevalence rate to 25% through adequate supply, training of health workers on FP technology and behaviour change communication.
- To introduce perinatal audits in health institutions for monitoring and evaluation of maternal and newborn health

The Gambia health information system which is within the remit of the Department of State for Health and Social Welfare potentially has a central role in monitoring and evaluating the progress made towards achievement of targets set in the national policies such as those highlighted in Box 2.

Several reviews of the health information system, including that funded by the WHO Health Metrics Network, indicated that none of the data sources in the Gambia (censuses, population surveys, vital statistics and health and administrative records) were adequate in the measurement of vital statistics and policy targets, with the worst performing data source being the CRVS²⁷⁷. For instance, birth and death registration is still paper-based with reports of poor preservation of records making it essentially unusable for analysis. The civil registration and the vital statistics system in the Gambia is mainly used for certification purposes. Additionally, the reviewers indicate that access to HIS data is strictly controlled. Furthermore, the health information system is characterised by fragmentation, lack of capacity and resources so that, even if data are generated, they are of poor quality. Regarding inter-sectoral coordination, this is also non-existent as none of the hospitals send any reports to the central HIS²⁷⁸.

3.4 Maternal, Neonatal and Child Health (MNCH) services in The Gambia

This section presents an overview of MNCH services in The Gambia, which serve as a conduit for the achievement of national health targets. The Gambia health sector has a three-tier system comprising primary, secondary and the tertiary levels²⁷⁵. The primary level consists of the Village Health Services and Community clinics. The secondary level comprises the Minor and Major Health centres whilst the tertiary level consists of General Hospitals within local government areas and a teaching hospital, the Edward Francis Small Teaching Hospital located in Banjul, the capital city.

Although the Gambian government offers free maternal and under-five health care services as well as results-based financing in four local government areas, there is no universal health coverage as yet, and out of pocket expenditure on health through unofficial fees, estimated at 31% by the 2013 national health account survey and 80% in other sources, has contributed to impoverishment in the population^{274, 279}. As in many developing countries, health system funding is donor driven, accounting for over 60% of the health sector funding, with only 6% of GDP spent on health²⁷⁴. This has resulted in a flourishing of vertical programmes at the expense of non-funded health services.

The national health strategic plan reports that poor coordination of donor funds led to duplication of efforts, and Gambian health advocates are reported to have limited say in local priorities^{274, 279}. For example, while maternal mortality is high, and HIV low in the Gambia, funding is available for HIV through the global fund, GAVI, whereas MNCH, which requires health system strengthening and should be prioritized, is funded by the government and UNFPA, with the latter organisation funding the provision of family planning services²⁷⁹.

Table 3.1 below summarizes services provided at each level of the health system specific to neonatal and perinatal periods. MNCH services, also called reproductive child health services in The Gambia are provided at 256 outreach stations and their catchment areas, 41 Health Centres, 6 Major Health Centres, 6 general hospitals and 1 teaching hospital.

Table 3.1: Description of services provided at all levels of the Gambian Health System relating to Maternal, Neonatal and Child Health

VHS	Minor H/Centre	Major H/Centre	General Hospital	Teaching Hospital
Treatment of minor illnesses and referrals	Maternity care	All minor H/C services plus	All major H/C services plus	All health services at regional level plus
Maternity care*	Family Planning	Comprehensive EmONC	Specialist care services	Specialist in and out-patient care
Home visits	STI/HIV/AIDS prevention and treatment		Higher level referrals	Overseas referral
Community Health promotion activities	Maternal and Child nutrition Integrated Management of Neonatal and Childhood Illness (IMNCI) Basic Emergency Obstetric and Neonatal Care (EmONC) In-patient services Lab-HB, blood film, urinalysis, Syphilis & HIV screening Birth & death registration		Comprehensive lab services Radiology services	Post-mortem services

* Antenatal, Delivery and Postpartum Care²⁷⁵.

Compared to the WHO's recommended numbers of health professionals, The Gambia has fewer doctors, at 1.1 doctors per 10,000 population against the recommended 10 per 10,000 population^{274, 280, 281}. Following its adoption of the Alma-Ata declaration in 1979, deliveries in the 1990s were managed by trained TBAs but recently the policy has shifted in favour of health facility delivery, which is currently at 63% nationally²². Specially-trained maternal health nurses are deployed to all regions and conduct trekking clinics using vehicles sponsored by Riders for Health, a UK charity organisation^{275, 282}.

Half of the major health centres are equipped to provide comprehensive EmONC, but the national unmet need for emergency obstetric care was almost 80% in 2012^{274, 283}. In a nationwide health facility survey in 2009, 18/65 health facilities in the Gambia were found to have the capacity to provide surgical services. There was a striking shortage of skilled health personnel, with a total of 14 surgeons, 8 obstetricians/gynaecologists and four anaesthesiologists in the country. Mansakonko, Basse and Janjanbureh are three LGAs with the highest mortality in the Gambia. In Basse, where this study was conducted, there is only one doctor to cater for the population of almost 240,000 as at 2013²⁶². In light of this, most facilities utilized paramedics and midwives for minor surgeries²⁸³.

The referral system is to the Edward Francis Small Teaching Hospital in Banjul, but access is hampered by the River Gambia especially during the rainy season, and as a result of unreliable ferry services that do not work at night²⁸³. Past interventions that showed promise were river and horse-driven ambulances and maternity waiting homes, which were introduced in sections of the country in 1987 but did not work due to sustainability challenges. More recently, road ambulances covering the whole country were leased to the government by Riders for health^{279, 282, 284, 285}. Additionally, even if the referral hospital is accessed, it is overwhelmed due to capacity constraints and cannot serve the needs of the whole population²⁷⁴.

Over 80% of doctors are non-Gambian, but the University of The Gambia since 1999 has managed to graduate nine classes of over 200 local doctors as at 2018²⁸¹. However,

the health system is characterised by a high attrition rate and recruiting to posts in rural areas is difficult. Health care providers also face frustrations regarding lack of equipment and drugs⁹⁹.

Efforts have been made at improvement in maternal and neonatal health through external partnerships with donors, NGOs and local foundations. Citing an example, an ongoing partnership since 2005 between the Gambian Ministry of Health, WHO, Maternal Child Health Advocacy International and the Advanced Life Support Group led to the upgrading of three major health centres through structural renovations and establishment of blood banks²⁸⁶. In addition to improvements to infrastructure, nationwide training in emergency maternal and newborn care was started in 2010 and local trainers established for sustainability so that newly recruited health professionals are trained and refresher courses offered for those already in service^{286, 287}.

Nominally there are blood banks at the referral and two general hospitals, with a few major H/Cs having the capacity, but few voluntary donors despite public campaigns means that demand is always more than the supply. Additionally, the referral hospital is meant to supply blood to other health facilities, but the poor road infrastructure makes this difficult to do.

In summary, Gambian national policies have a focus on improving maternal and child health. However, problems with implementation, which relies on donor funding, have resulted in a reality that is substantially bleaker²⁷⁴. The ongoing training of health workers, infrastructural improvements and better funding of healthcare are critical to sustain and strengthen the health system which is relied on by over 95% of the population^{274, 287}.

3.5 The Medical Research Council, The Gambia

The MRC laboratories were founded in The Gambia in 1947. The main site lies on the Atlantic coast, the western border of the country. MRCG is financed by the United Kingdom and recently became part of the London School of Hygiene and Tropical Medicine²⁸⁸.

The unit conducts research under three main platforms: Disease Control and Elimination, Nutrition and Vaccines and Immunity. Additionally, MRCG is the Gambia's largest contributor of public health research²⁸⁹. The Gambia does not have a national medical research institute, although establishing one is one of its aims as stated in the National Science, Technology and Innovation policy under the mandate of the Ministry of Higher Education, Research, Science and Technology. Other institutions involved in medical research include the Edward Francis Small Teaching Hospital, specialized units within the Ministry of Higher Education, Research, Science and Technology and the university of The Gambia, the country's sole university. These institutions are underfunded and, while the University of the Gambia had a research and strategy committee that coordinated public health research, this was disbanded in 2009^{289, 290}. There are sentiments that research emanating from externally-funded institutions may not reflect the needs of the local scientific community. Nonetheless, efforts are being made to ensure that the Ministry of Health and Social Welfare and that of Higher Education and Research spearhead, coordinate and prioritize all research activities conducted in the country^{289, 290}.

The MRCG remains the foremost medical health research institute in The Gambia and enjoys a unique relationship with the Gambian Government. For instance, national scientific and ethical committees are constituted from the two institutions and the University of The Gambia. Also, research findings from MRCG are routinely shared with the government and have been used to aid in policy making^{40, 290-293}.

3.6 Health and Demographic Surveillance Systems run by MRCG at LSHTM

MRCG at LSHTM runs four HDSS, namely Farafenni, Basse, West Kiang and Bansang. However, only Farafenni and Basse HDSS were utilized for this research and are therefore introduced in this section. In general, one enters the population under surveillance by the HDSS through the initial enumeration, birth or in-migration. The HDSS provide precise estimates of the population denominator through visits to each household every 4 months (January-April; May-August; September-December)²⁹⁴. All deaths, births, in- and out-migrations, pregnancies and marriages, and the vaccination

status of the children, are recorded during visits by fieldworkers. The primary informants are the heads of household who are mostly male.

Verbal autopsies are also now being conducted, and all households have been mapped through global positioning. In addition, data collection is now through electronic data capture²⁹⁴.

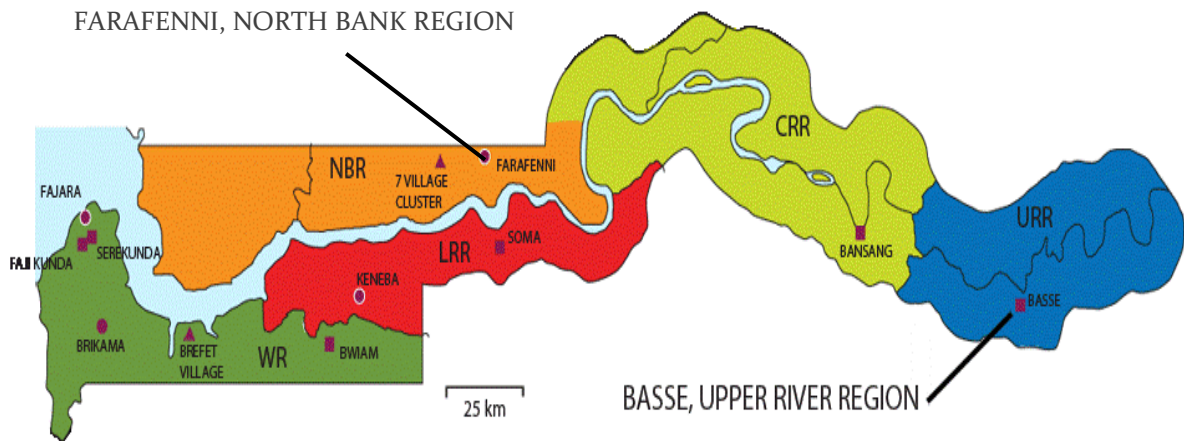


Figure 3.2: A map of The Gambia, depicting the Basse and Farafenni HDSS sites

3.6.1 Farafenni Health and Demographic Surveillance System

Farafenni HDSS is composed of Farafenni town, and two clusters of villages to the town's east and west. Farafenni HDSS is on the north bank of the Gambia River, and is the main connection between Dakar and the Casamance region of Senegal by ferry²⁹⁴. It is part of the Kerewan Local Government Area (LGA) or North Bank Region²⁶². The HDSS population is drawn mainly from the Wolof (41%), Mandinka (31%), and Fula (22%) ethnic groups, who are predominantly Muslim. The villages are poor, with incomes generated mainly through farming activities²⁹⁴.

The HDSS site was established in 1981 on request of the Government of The Gambia to evaluate Primary Health Care (PHC), which had been adopted and rapidly disseminated in 1978, following its recommendation by the WHO²⁹⁴. Surveillance began in April 1982 following completion of a baseline census and has been uninterrupted except for a 13-month hiatus in 2008 following the closure of the MRC station. Surveillance resumed thereafter operating out of the Armed Forces Provisional

Ruling Council General Hospital, which was commissioned in 1999 and has a 250-bed capacity. Since the resumption of surveillance in 2009, fieldworker visits have been conducted once every four months to update the survival and residency status of the population followed.

The total population under surveillance on December 31st, 2012 was 50,455 in 6,668 households and in 3,382 compounds²⁹⁴. Farafenni HDSS is part of the INDEPTH network.

3.6.2 Basse Health and Demographic Surveillance System

Basse, the eastern-most part of the country, is located 375 km from Banjul in the Upper River Region of the Gambia and is the least developed administrative region. Also known as the Upper River Region, Basse has a total population of 239,916²⁶². The main ethnic groups are the Serahule (39%), Fula (30%) and Mandinka (29%), and the main source of income for residents comes from agricultural activities³⁹.

Demographic surveillance commenced in July 2007 and was initially intended to support the Global Enteric Multicentre Study and the Pneumococcal Surveillance Projects, but has since hosted and continues to support several further studies²⁹⁵. The population under follow up is >170,000 living in 11,118 households in 225 villages in Fulladu East and Kantora Districts in Upper River Region, covering the entire region south of the River Gambia as at 31 December 2013³⁹. As in Farafenni, fieldworkers visit each household once every four months to update the vital events of the population followed. In both HDSS, pregnancies are identified, and their outcomes sought for and recorded in subsequent HDSS rounds. Basse HDSS, however, is not yet part of the INDEPTH Network.

Chapter 4 Data Sources and Methods

This chapter provides a detailed description of the data sources and methods of analysis used in this thesis, supplementing the sections on methods already included in the individual research papers. It also provides specific information on how the studies that I designed and managed for this research, for which no full reports have been published elsewhere, were carried out.

Formulae for estimation of perinatal and under-five mortality

The numerators for mortality estimation in this thesis include late foetal deaths (stillbirths), neonatal, post-neonatal, infant, child and under-five deaths. These adverse events were defined based on the ICD-10, the WHO system of disease classification²⁹⁶. For international comparison purposes, stillbirths were defined as late foetal deaths occurring at or after 28 weeks gestational age, and miscarriages/abortions as occurring before 28 gestational weeks. Perinatal, neonatal, infant and under-five mortality were based on the following timelines. The perinatal period covers ≥ 28 weeks gestation up to seven days of life; the neonatal period is defined as < 28 days; post-neonatal period (28 to < 365 days), infancy (less than one year), child (1 to 4 years) and under-five (less than 5 years). The neonatal period is further divided into two; early (< 7 days) and late (7 to < 28 days)²⁹⁶.

Mortality estimates were derived as follows throughout the thesis, unless otherwise stated:

$$\text{Perinatal mortality rate (PMR)} = \frac{\text{number of stillbirths} + \text{early neonatal deaths}}{\text{number of all births}} * 1,000$$

$$\text{Stillbirth rate (SBR)} = \frac{\text{number of stillbirths}}{\text{number of all births}} * 1,000$$

$$\text{Neonatal mortality rate (NMR)} = \frac{\text{number of neonatal deaths}}{\text{number of live births}} * 1,000$$

$$\text{Postneonatal mortality rate (PNMR)} = \frac{\text{number of postneonatal deaths}}{\text{number of live births}} * 1,000$$

$$\text{Infant mortality rate (IMR)} = \frac{\text{number of infant deaths}}{\text{number of live births}} * 1,000$$

$$\text{Child mortality rate (CMR)} = \frac{\text{number of deaths in under-fives surviving infancy}}{\text{mid – year total population}} * 1,000$$

$$\text{Under-five mortality rate (U5MR)} = \frac{\text{number of under-five deaths}}{\text{number of live births}} * 1,000$$

$$\text{Crude birth rate} = \frac{\text{number of births}}{\text{mid-year total population}} * 1,000$$

For the analysis in Chapter 7, fertility estimation based on the crude birth rate was calculated as above. The 2016 mid-year total population of the Health and Demographic Surveillance System (HDSS) was 142,714.

Indirect estimation of under-five mortality

In Chapter 5 of this thesis, both direct and indirect methods of estimation of under-five mortality are applied. This section describes the principles underlying indirect estimation methods. Such methods are termed ‘indirect’ as the estimation technique uses information that indirectly represents the parameter being measured. For example, the proportion dead of children ever-born is influenced by both existing mortality conditions and maternal age, among other variables, meaning that it is not a pure mortality estimate²⁹⁷. This method was pioneered by Brass and Coale and has been modified over time²⁹⁸. The data required for the method is the number of women, grouped by five-year age groups, duration of marriage, or time since first birth; the number of children ever born alive by women by relevant (age, time since first birth, or marriage duration) five-year group and the number of the children born alive that have died before (or, alternatively, are still alive at) the time of the survey, by relevant five-year group. The proportions dead of children ever born are then transformed into life table functions by adjusting for parameters other than mortality that influence them. The results are then expressed as probabilities of dying by exact ages of childhood²⁹⁹. A time location method was developed that estimates how many years previously each proportion dead approximates the period probability of dying to give a broad picture of trends in mortality over time³⁰⁰⁻³⁰³.

Model life tables (MLTS) are constructed to give plausible schedules of mortality by sex and age calculated from a small number of parameters that aim to capture the age pattern and level of mortality. Fundamentally, there is a U-shaped age pattern of mortality common to humans globally. Model life tables can be based on empirical data or mathematical models^{304, 305}. Crucial differences in model life tables reflect the overall level of mortality, the relationship between child and adult mortality and variations in the age pattern of mortality within childhood and old age mortality.

The most commonly used system is the Coale-Demeny model life tables. Others such as the UN MLTs, the Ledermann System of MLTs and the Brass Logit System have been developed but are less widely used^{297, 299}. The Coale-Demeny MLT system that was used for indirect estimation in Chapter 5 is classified into North, South, East and West (General) sets of models, which reflect mortality patterns derived largely from historical European data. The main differences between these four groups are in the relation between child, adult and overall mortality. The East model comes mainly from the Eastern European countries and is characterized by high child mortality in relation to infant mortality. The North model is based largely on the Nordic countries, and is characterized by low infant, high child and low old age mortality. The South model is based on life tables from Southern Europe and is characterized by high child mortality in relation to infant mortality at high overall mortality. The West model is based on the residual tables not used in the other regional sets and captures a wider range of scenarios^{305, 306}.

Although they remain widely used, the reduction in child mortality experienced globally means that these patterns may not accurately represent current mortality patterns. The choice of which MLT and pattern to use is pragmatic and depends on the best fit for the researcher's data, which is gauged here in terms of consistency between the series of estimates generated from different surveys. If a model is determined to closely represent reality, the characteristics of a given population can be summarized by the parameters of that model^{299, 305}. In The Gambia, prior to

2000, the Coale Demeny North MLT was used for indirect estimation of under-five mortality in the MICS and censuses, however this changed to the Princeton South thereafter in line with changing patterns of child mortality^{272, 307-309}

Other methodological considerations for Chapter 5 and 6

Accounting for clustering

The data sources available for under-five mortality estimation in The Gambia are introduced in section 4.1 and are surveys and censuses. Cluster sampling is employed in these data sources mainly for cost efficiency reasons. Thus, both MICS and DHS selected enumeration areas as primary sampling units. In Chapter 6, women are identified as the lowest-level clusters as their progeny may have similar characteristics and may have been exposed to similar risk factors, which must also be accounted for during analysis.

Analysing these data without considering the study design and the presence of clustering would result in overestimation of precision of the statistics. Traditional regression analysis relies on the assumption that individual units are independent. However, when individual units belong to the same group such as children from the same mother or people living in the same households or villages, they may be exposed to factors that make them similar or have correlated outcomes. Thus, the assumption of independence is violated. Accounting for clustering allows researchers to obtain valid standard errors and subsequently to make valid inferences³¹⁰. Making valid inferences was achieved in this thesis by using more complex survey analysis methods, such as by utilizing the SVY family commands in Stata, or via bootstrapping, as was employed in Chapter 5 for provision of robust standard errors for the DHS estimates^{311, 312}.

Flexible Parametric Survival analysis

In Chapter 5 of this thesis, this method was applied to the HDSS and DHS data used for direct estimation of under-five mortality. Flexible parametric survival analysis was chosen to predict smoothed child mortality rates and their confidence intervals. This method uses restricted cubic spline functions to model non-linear functions. Splines

are flexible mathematical functions defined by piecewise polynomials, with cubic splines being the most commonly used. The analysis done in this thesis utilized restricted cubic splines which force the first and last points at which the polynomials join (known as knots) to be linear and hence smooth. In STATA, there are default locations for the knots which are commonly used, however, researchers may choose the number and location of knots depending on whether the fitted values are sensitive to them, or based on sensitivity analysis or model selection methods³¹³.

4.1 Data sources for mortality estimation at the national level in The Gambia

Under-five mortality rates were estimated using either the direct or the indirect method of mortality estimation depending on the availability of data. For indirect mortality estimation, the data required were the number of children ever born classified by sex and by five-year maternal age groups; the number of children surviving (or the number dead) classified as mentioned and the total number of women irrespective of marital status by age group. For direct estimation, the dates of births and deaths of children and the total number of livebirths in a specified period were necessary²⁹⁷.

Mortality was estimated using eight data sources – MICS 2000, MICS 2005/6, MICS 2010, Census 2003 and 2013, DHS 2013 and Farafenni and Basse HDSS data. The following section presents a brief description of each of these data sources.

4.1.1 Multiple Indicator Cluster Surveys (MICS)

For the past two decades, over 300 MICS have been conducted in 112 countries to produce data on issues affecting lives of women and children¹⁸⁹. The first MICS in the Gambia was in 1996 and they have been carried out every five years. Survey questionnaires cover topics on households, women and children. The questionnaire of most interest for this thesis is the individual women's questionnaire for women aged 15-49 years that covers child mortality among other modules such as maternal and newborn health, desire for last birth, unmet need and the women's background. The MICS data are readily available on request¹⁸⁹ and we extracted information relevant for

indirect mortality estimation that is the number of women, children ever born and died per data source (Table 4.1) having selected the period from 2000 onwards. In The Gambia, the surveys covered all eight Local Government Areas (LGAs): Banjul, Kanifing, Brikama, Mansakonko, Kerewan, Kuntaur, Janjanbureh and Basse.

Table 4.1: Number of children and women of reproductive age by data source

Data Source	Women of reproductive age	Children ever-born	Children died
Census 2003			
Gambia	389348	846517	103750
Kerewan	48393	124290	16813
Basse	51820	128282	18437
Census 2013			
Gambia	534177	1120538	78648
Kerewan	13623	32425	2953
Basse	47908	114258	8851
MICS 2000			
Gambia	5976	17293	3019
Kerewan	657	2169	311
Basse	625	2389	633
MICS 2005/6			
Gambia	9982	27475	4034
Kerewan	1090	3643	490
Basse	1411	4451	895
MICS 2010			
Gambia	14685	42194	5575
Kerewan	1706	5602	721
Basse	2749	8572	1352
DHS 2013			
Gambia	10233	26601	2201
Kerewan	1448	4284	332
Basse	1269	3664	384

4.1.1.1 MICS 2000

The MICS 2000 survey was conducted between April and June 2000³⁰⁸. Sampling was done in two stages. First, 128 census enumeration areas were selected with probability proportional to size. Then, a systematic sample of households listed within the selected enumeration areas resulted in a final sample of 4,536 households.

From the MICS model English version, key terms in the questionnaires were translated into four Gambian languages: Mandinka, Wollof, Fula and Jola. The questionnaires

were pre-tested in March 2000 and modifications made to the wording thereafter. Fieldwork then began in earnest in May 2000 for two months³⁰⁸.

Of the 4,536 households selected, 4,492 (99%) were occupied and 4,478 were successfully interviewed for a household response rate of 99.7%. Of the 6,469 eligible women, 5,976 were successfully interviewed, yielding a response rate of 92%³⁰⁸.

4.1.1.2 MICS 2005/6

Fieldwork began in December 2005 and was completed in March 2006³⁰⁹. Sampling was by probability proportional to size where between 14 and 99 census enumeration areas were selected using the census 2003 as sampling frame. Household listing was done, and 6,175 households were selected. For this survey translated questionnaires were not produced but during training verbal translation was done to harmonize the questions put to the residents in three local languages (Mandinka, Wollof and Fula) spoken by the majority³⁰⁹. Because of the timing of the survey, data collection was characterized by numerous breaks. There were 10,252 women of reproductive age identified in the selected households and 9,982 were interviewed successfully, a response rate of 97%³⁰⁹.

4.1.1.3 MICS 2010

In 2010, MICS fieldwork began in April and was completed in August²⁷². Two stage sampling was done with LGAs as the main sampling domains, and between 44 and 60 census enumeration areas selected. Household listing was then carried out and systematic sampling done with probability proportional to size resulting in 7,799 households selected. Of these 7,791 (99.9%) households were successfully interviewed as well as 14,685 of the 15,138 (97.0%) eligible women²⁷².

4.1.2 Censuses

Population and housing censuses are usually conducted decennially to monitor changes in the population size, socio-economic characteristics of the population and the housing stock over time. Historical records show that a census was taken in The Gambia in 1881 and every tenth year thereafter³⁰⁷. The 1941 census could not be held

due to the Second World War and was deferred to 1944 when only a count of Banjul (then called Bathurst) was taken. The 1951 census covered only Banjul and Kombo St. Mary whilst the population of the rest of the country was based on estimates made by Travelling Commissioners. Due to general elections, the 1961 census could not be held on schedule and was deferred to 1963³⁰⁷. The 1963 census was thus the first modern count of the country's population.

Since then, The Gambia has successfully conducted population and housing censuses at intervals of ten years in 1973, 1983, 1993, 2003 and 2013³⁰⁷. Enumeration is done within the eight LGAs using household and group quarters questionnaires and recording building and compound structures. The household questionnaire is the main instrument and records members present and their social, economic and demographic data. For childhood mortality estimation in The Gambia censuses, women aged 12 years and over are asked to state the total number of children they have ever given birth to, how many are alive and how many died by the time of interview, disaggregated by sex. We present a brief account of the two censuses conducted during the period of interest for this PhD.

4.1.2.1 Census 2003

The 2003 census of The Gambia was the fifth complete census by the Gambian government³⁰⁷. In the Gambia, legal provision for conducting the census was contained in the Statistics Act, 1972 and the mandate lay with the Central Statistics Division (CSD). The 2003 census was carried out on the night of April 15th using a blend of *de facto* and *de jure methods* so that all persons were enumerated where they spent the night and usual household members absent on the night were also counted³⁰⁷.

4.1.2.2 Census 2013

The 2013 census was conducted under the legal framework of the Statistical Act 2005 that empowers the Gambia Bureau of Statistics (GBoS) formerly the CSD to conduct a population census in 2013 and every ten years thereafter²⁶². The 2013 census is the

sixth complete population and housing census. A *de facto* population enumeration began on April 15th and took 14 days to complete. This was the first Gambian census to include a maternal mortality module in addition to agriculture, information, and use of communication technology²⁶².

4.1.3 Demographic Health Survey (DHS) 2013

More than 300 DHS have been conducted in over 90 low and middle-income countries to provide representative population-based data on health, HIV and nutrition¹⁹⁰. The 2013 DHS was Gambia's first such survey and was carried out between February and April 2013. It used the 2003 census as a sampling frame. Two-stage systematic sampling with PPS resulted in selection of 281 enumeration areas and 6,217 households and 10,233 women were successfully interviewed. The DHS collected full birth histories and not pregnancy histories from women of reproductive age therefore enabling direct estimation of under-five mortality and its components. In addition to the birth history, the Gambia DHS also collected data on pregnancy outcomes in the five years prior to the survey when women were asked if they had had a pregnancy that ended in a stillbirth, miscarriage or abortion since January 2008. There were 89 stillbirths, 151 neonatal deaths and 7,995 births in the five-year period before the survey which were used to estimate perinatal mortality²².

4.2 Methods for the pregnancy history survey in the Basse HDSS area

4.2.1 Study Setting

The second component of the thesis involves the comparison of retrospective reporting of pregnancies, pregnancy outcomes and mortality in a DHS-type survey with the information that had been supplied by the same women in an ongoing HDSS. This survey had multiple objectives. One objective (which is reported on elsewhere) was to evaluate the accuracy of the HDSS listings of household members. Thus the survey enumerated a representative sample of HDSS households and the first stage of the analysis of the pregnancy data involved matching women enumerated in the survey with the HDSS records for the same women.

The Basse HDSS was selected for this research due to the large population followed up (~180,000) in 2015. It was also suitable for the ANC-HDSS linkage study that is also component of this thesis as there were health facilities that served the whole BHDSS and also provided antenatal care services. Twenty-one female fieldworkers were hired for a period of six months for the pregnancy history survey.

4.2.2 Routine surveillance activities in the Basse HDSS relating to pregnancy

The standard process of surveillance is 4-monthly visits to inquire about births, deaths and pregnancies in the HDSS. The head of household usually acts as a proxy, answering questions about women in the homestead who have gone for antenatal care. The woman thus identified is recorded as pregnant, and in subsequent update rounds, the fieldworker makes inquiries about the pregnancy until the pregnancy outcome (livebirth, stillbirth, miscarriage or abortion) is recorded.

If a pregnancy is visible, for instance in the last trimester, the fieldworker need not inquire about it, but records it as an observed pregnancy in the database and a similar process followed to that described to obtain the outcome.

However, not all pregnancies are picked up by the HDSS while the women are still pregnant. A review of the Basse HDSS pregnancy data revealed that over half of the pregnancies were captured in retrospect as follows. A fieldworker would arrive at a household and on finding a living baby, would then enumerate the infant as either born in the HDSS, or as an in-migrant if the mother had left for delivery and returned afterwards to the HDSS. The HDSS database does not allow for addition of an infant without a completed pregnancy episode. The practice therefore is to input the pregnancy end date as either a day before, or the same day as the baby's date of birth. The cultural practice of pregnancy concealment and the four-monthly update rounds play a role in the lack of capture of all pregnancies. For instance, pregnancies of five-month gestation are not easily visible, especially in The Gambia where flowing dresses are the norm and compounded by the fact that a woman will not reveal the pregnancy. Thus, an HDSS update round four months later will coincide with the delivery of a baby. Unobserved pregnancies that end in a pregnancy loss tend to be entirely missed

in the HDSS as residents are not followed once they out-migrate, and quick burial of stillborn babies or miscarried foetuses mean that they can go unnoticed and unreported. Although waning, the cultural practice of migrating to one's mother for delivery still exists. The Serahule ethnic group, who are mostly confined to Basse region in the Gambia in particular are highly mobile and tend to migrate to the north bank of the Upper River Region which is not part of the HDSS. Pregnant women have also been reported to migrate to the urban regions for delivery where their husbands reside and where health facilities are better equipped^{314, 315}.

Although a woman's marital status and type of marital union would have been of interest as an explanatory variable in this research, it was not possible to obtain this information. This is because data on marital status in the HDSS is only collected from women whose husbands are resident in the HDSS. Therefore, married women whose husbands live away can be classified as unmarried, and this is not reflective of the true situation. Additionally, as men are allowed up to four wives in The Gambia, not all their wives are resident in the HDSS, and a woman may be erroneously classified as being in a monogamous union.

Study participants in the pregnancy history survey

- i. Women of reproductive age
- ii. Willing to provide informed consent
- iii. Willing to be followed up at home
- iv. Not intending to travel out of the study area throughout the study duration

4.2.3 Sample size estimation

The literature suggested under-reporting of neonatal mortality in Basse HDSS^{22, 39}. The sample size calculation was based on the reporting of pregnancies which is core to measurement of both neonatal and perinatal mortality. A key objective of this thesis was to assess the completeness of pregnancy reporting in a survey utilizing pregnancy histories and in the HDSS. This was achieved by recruiting women of reproductive age

in the survey and contrasting their pregnancy histories with prospectively collected pregnancy reports in the HDSS.

Let $p_{0_{Survey}}$ and $p_{0_{HDSS}}$ be the proportions of unreported pregnancies in the survey and HDSS, respectively. The sample size is calculated using a formula by Gönen³¹⁶, which is based on McNemar's test for clustered data. The formula is as follows:

$$N = \frac{[z_{1-\alpha/2}\lambda + z_{1-\beta}\sqrt{\lambda^2 - \frac{1}{4}\delta^2(\lambda + 3)}]^2}{\lambda\delta^2/[1 + (L\lambda - 1)\rho]}$$

where $z_{1-\alpha/2}$ is the z-score corresponding to a type I error of α , $z_{1-\beta}$ is the z-score corresponding to a type II error of β , $\delta = p_{0_{HDSS}} - p_{0_{Survey}}$ is the minimum expected difference in the proportions of unreported pregnancies between HDSS and survey, $\lambda = p_{0_{HDSS}} + p_{0_{Survey}}$, ρ is the intra-cluster correlation and L is the number of pregnancies per woman.

Assuming $\alpha=5\%$, $\beta=20\%$, $\rho=0.5$, $\lambda =40\%$, $\delta = 3\%$ and $L=7$ corresponding here to the total fertility rate in Basse 2013 DHS report, the minimum number of women to be recruited was 6,619. Using the average number of women of reproductive age per household reported in the 2013 DHS for Basse of 2.7, the minimum number of households was estimated to be 2,452²². We included a 15% contingency to ensure we recruited enough number of households, resulting in a sample of 2,819 households.

4.2.4 Training of the interviewers

AJR together with the unit's staff development manager, a senior data manager and the HDSS supervisors sent out advertisements locally for the fieldworker position. With their help, AJR trained 55 females but recruited 31 based on their overall performance. Although AJR was running two surveys concurrently in Farafenni and Basse HDSS, the analysis presented in this PhD was based only on Basse, and therefore only this survey is reported on here. For the Basse survey, 21 fieldworkers were selected. The senior data manager was responsible for uploading the survey data collection instruments onto the tablets and ensuring that the tool was user-friendly. This meant that he ensured that the skip patterns were as in the paper questionnaire, and that a logical sequence

was followed in the tablets. He employed the open data kit system to upload the questionnaires and other study documents such as the training manual.

The training was based on the Demographic Health Survey manual which AJR, with suggestions from the trainers, modified to suit the study (See Appendix) and was conducted over a five-day period from the 18th to the 22nd of November 2015. The manual covered the following topics: definitions of a survey and sampling; study overview; survey questionnaires; the role of the interviewer and code of conduct and survey procedures.



Source AJR: The team getting introduced to the tablet

The trainees were required to read the manual which was provided before the training and were encouraged to ask questions. They were given a pre-test and after the training, the same test was administered.

During the training, the staff development manager and the HDSS supervisors with various assistants taught through demonstration interviews and a number of the trainees also practised to enhance adult learning. Rapport creation and sensitivity when interviewing the female respondents was emphasized, as this was especially important in rural Gambia where the culture is conservative and Islamic. The interviewers then went through each question in the questionnaire, with each explaining their understanding of it.

As they were native speakers of the major languages spoken in the Gambia – Mandinka, Wolof and Fula, the questions were verbally translated to each of the languages and again understanding of each evaluated by the team of trainers who are proficient and who use this method in routine surveillance activities. This was done because in the Gambia there is no official written form for the local languages and several attempts to translate forms in other studies have proved that equivalence is imperfectly achieved³¹⁷⁻³¹⁹. Finally, we adopted the MRCG unit's common medical terms in the local languages in order to standardize responses.



Source AJR: Training session on translation by experienced fieldworker and MRCG training and education staff

AJR specially trained the female interviewers to probe on neonatal status at birth, focusing on whether there was any cry or movement at birth, and the state of the baby's skin in an effort to distinguish between stillbirths and early neonatal deaths. This information is not routinely recorded, and it is challenging to distinguish between abortions, miscarriages and stillbirths in such settings. Training also emphasized using the last menstrual period to identify whether a woman was pregnant in order to circumvent the cultural reluctance to speak about pregnancy.

A pilot study was conducted with 55 households and evaluated for comparability to the HDSS as well as to modify the questionnaires to ensure that it was easily understood by the fieldworkers and the respondents in the community. This

modification was iteratively done in the initial months of the survey until it was agreed that what was asked was conveyed and understood correctly.

The recruitment criteria were that the trainee would be available for the duration of the study and had permission from her parents/husband in deference to the cultural requirements for women in the society.

They also had to have at least secondary-level education and the ability to use a smart phone. We selected 31 out of the 55 candidates with the highest scores and who had successfully completed the pilot.



Source AJR: Examination after training to conduct the survey

The best performers were assigned to be supervisors and the teams were made up of three. The supervisor's duty was to get consent to conduct the interview in the household and identify women of reproductive age. Once permission was given, the team leader asked the head of household to identify the members of his home using the household questionnaire. The name, age, education level and relationship to the head of the household for each member was recorded, regardless of duration of stay within the HDSS. The team leader during the survey then identified women of reproductive age and assigned the team members to interview them using the woman questionnaire. A full pregnancy history was taken from each woman in a private area as well as inquiry into her current pregnancy status once consent was obtained. Other duties assigned to the team supervisors included ensuring safekeeping and adequate

charging of the tablets as well as submission of data for uploading to the servers. These additional duties were commensurate with the compensation they were receiving.

4.2.5 Preparation for fieldwork

As part of the planning of the study, we conducted community sensitization activities which involved meeting the village chiefs (*Alkalolu*) and presenting 'Kola nuts' as is customary. The purpose of the study was explained, and permission sought to conduct the survey. An additional benefit to the survey was that the village chiefs agreed to provide accommodation to the fieldworkers at no cost as is also customary when there are visitors in the rural areas.

AJR requested and was given bed-nets from the National Malaria Control Programme as the survey was partly held in the malaria season. The fieldworkers were given mattresses so as not to over-stretch the accommodating households.



Source AJR: Pre-departure to the field

AJR was involved in the procurement of the tablets which were encrypted to ensure that confidentiality was maintained in the event of a loss. Additional safety measures included having a power bank and a solar panel as backup power sources to avoid delays in the work and loss of data due to power failure.

4.2.6 Experience with technology

From the outset, this project aimed to use electronic data capture (EDC) because overall it was cheaper, lighter and faster and was being considered as standard operating procedure for the HDSS within which the study is embedded. The HDSS had been planning to go 'paperless' so a pilot study to evaluate this transition was done for routine HDSS enumeration in September 2015. This required the male fieldworkers to carry both the paper folders, which are quite heavy as these are pre-printed forms containing information on the population followed, and a tablet to the field. No comparison of the protocols had been published but it took time to change over completely to EDC so, for a time, both methods were used in the HDSS. However, by December 2015, it was seen to be feasible to abandon the paper folders and go electronic, therefore this survey mainly utilized tablets.



Source AJR: Tablets being encrypted for data safety



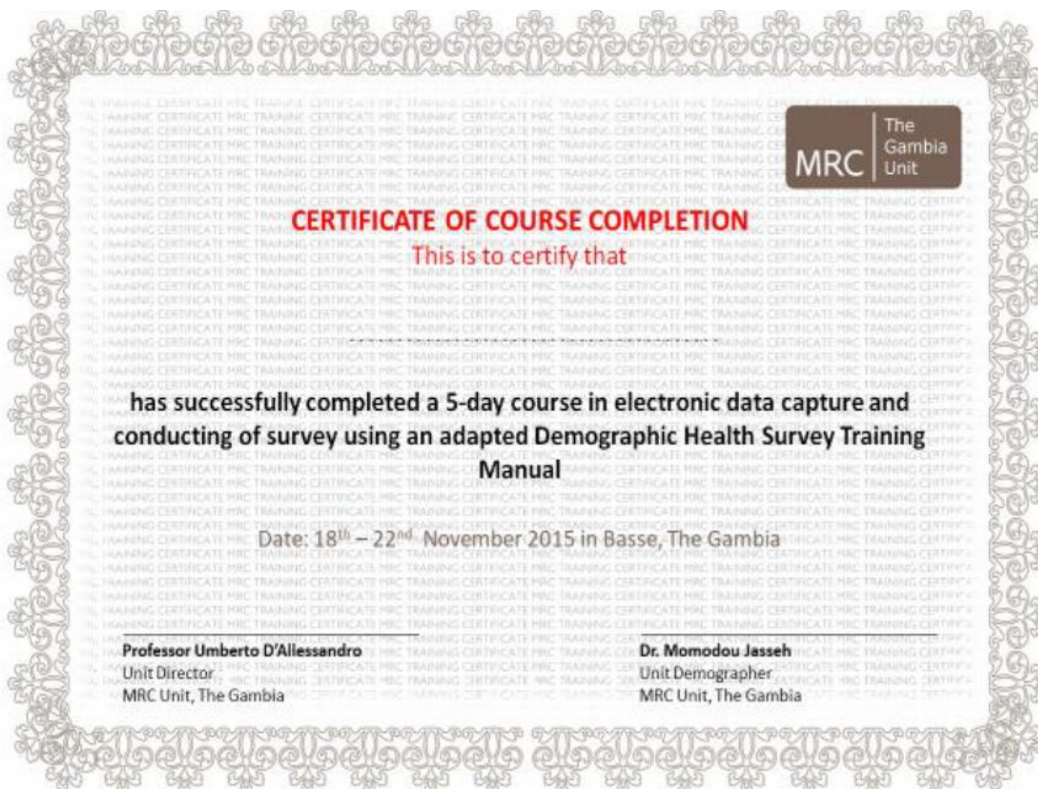
Power banks with solar panels for back up charging purposes

Nonetheless, each fieldworker in addition to the tablet, was given a ledger book as a back-up measure in the event of unforeseen complete electronic failure. For the team leader the ledger book was also used to do the initial listing of all household members. This listing was to enable her to quickly identify women eligible for the pregnancy history survey.

In rural Gambia electricity is rationed and is only available from 08:00-12:00hrs and 18:00hrs-01:00hrs. Further inland this supply is on alternate days. This had to be allowed for when planning, so each team had a power bank and solar panel (Power monkey). Back-up on the ledgers, although time consuming, was necessary because sometimes there was no electricity, or we did not have enough sockets for all the equipment. Each tablet and power bank had to be charged daily, this meant that at least forty electricity outlets were needed at a time. The solar panels proved to be too slow to charge the tablets and the power banks, so although it was an alternative energy source we did not find it to be efficient. Although a limited number of places exist inland where we could recharge the tablets, we were allowed to use health centres that had solar panels and compounds of the *Alkalolu* who also provided accommodation for the team. Apart from our difficulties with the power supply, the screens of three tablets cracked and three malfunctioned but were successfully repaired locally. No thefts occurred.

4.2.7 Conduct of the fieldwork

Fieldwork began on the 16th of December 2015 following a two-week delay in delivery of additional tablets, which had been bought in batches. This was because some airlines refused to transport lithium-based batteries. We started the survey in the urban sites as the female fieldworkers adjusted to the process and also for ease of uploading the data to the central server every two days. The data manager assisted with sorting out few problems but, after a slow start, the pace quickened as the team adapted to the interviewing process and the use of tablets. Three fieldworkers dropped out from Basse due to unforeseen circumstances. At the end of the survey, a handing-over ceremony for issuance of a certificate of completion of the five-day training was given to all those trained (55) as a female empowerment measure since these can be used when seeking employment (see below).



Source AJR: Certificate of training to conduct DHS type surveys

4.2.8 Enumeration of households

Through systematic random sampling, 2,819 households were selected in Basse HDSS and equally divided between the seven teams of three, with each individual assigned a list of households to visit, complete with HDSS IDs. Fieldwork began in Basse town for reasons stated above, and once the town was completed, we decided to start from Bakadagy which is to the east of Basse town, and head further inland to Koina, which is close to the Senegalese border. Part of the survey was conducted during the rainy season and soaring temperatures of up to 45 degrees Celsius were experienced. Although initially the plan was to complete survey in four months, due to difficulties associated with the location of households, the large household sizes



Source AJR: Basse terrain, a fieldworker experiencing high temperatures (up to 45 degrees Celsius)

and Serahule language barrier, as well as it being farming season, which made it difficult to find families in their homesteads, this was not achieved by end of April 2016. We therefore hired the fieldworkers from the Farafenni survey to assist in conducting the survey. The survey was completed on the 4th June 2016, at the beginning of the Islamic period of fasting, the Ramadan.

The village chiefs were extremely instrumental in community entry. The field teams always paid a courtesy call to the chiefs who then introduced them to the villagers, explaining what they were there to do. This was a follow on to the community sensitization conducted during the planning process. The village chiefs together with the HDSS fieldworkers also assisted in locating households, which sometimes proved

difficult due to the similarity of names in the community and in households where divorced women were unwilling to disclose this fact.

In some villages, despite getting consent from the women participants, permission needed to be sought from the heads of household first as they decided what questions could be answered. If the head was not around, the interviewers would have to wait or reschedule as doing otherwise meant that they could be expelled from the compound.

Finally, when the team was unable to get identification documents, they would approximate them, relating them to a standardized list of major local and national events that was prepared during the training period. This would enable them to get the year of the demographic event. Secondary to this, they would use the 15th as the date if the month was not known, and 15th of June if both the day and month was not known.

In rural areas, legal identification documents were not easily accessed, particularly in certain communities as they were kept by the heads of household who were not always available, making collection of the dates of events challenging.



Source AJR: Acceptable dressing according to the community. Female fieldworkers accompanied by AJR, and the data manager, who visited to ensure proper sequencing in the tablets.



Source AJR: Pregnancy history survey teams

By the end of the survey, 2,907 households and over 40,000 individuals were interviewed, making up approximately a quarter of the total population under follow up. Most of the respondents (99%) gave consent to be interviewed.

4.2.9 Pregnancy history survey - HDSS record linkage

The process of record linkage enables researchers to enrich their data by adding to the information they can access about individual study subjects. If unique identifiers exist for the same individuals in multiple datasets, the process of enjoining can use deterministic methods. In order to enable comparison of the survey data and the regular surveillance data, women surveyed were to be matched back to their unique HDSS identifiers. The Basse HDSS identification number is generated by combining the regional (5), compound (3), location (3) and individual (3) identifiers to create a unique number by which each individual that resides within its boundaries is identified. This fictional number is used to demonstrate; regional (50002) compound (001) location (101) and individual (001). Thus, the individual's identification number reads as 50002001101001; it cannot be exchanged and is stored permanently in the HDSS database. The numbers excluding the individual identifier represent the household identification number. For the survey, only the household identifiers were used but different individual identifiers were generated. This was because the survey

was a separate exercise from the regular surveillance activities and the survey had multiple objectives, including independently verifying the number of women of reproductive age resident in the HDSS (an analysis to be published elsewhere). In this thesis, the main focus is the pregnancy histories reported by surveyed women.

As the resulting survey data set did not have matching unique identifiers for the women, matching by the deterministic approach only would inevitably be incomplete as misspelling and typographic errors would disqualify true matches. Therefore, both probabilistic and deterministic linkage procedures were employed to ensure that the record linkage process was as complete as possible.

Deterministic matching procedure for matching IDs using the Basse HDSS

Personal identifiers or linkage characteristics in the survey data are: first name, surname, date of birth, age, sex, village name, household ID. For data preparation, all names were converted to lower case and parsed, with punctuation, prefixes and suffixes being removed. Issues related to the transposition of names and dates were reviewed, and their formats were standardised e.g. (Rerimoi A/ A Rerimoi) or (17/04/17 04/17/17).

Algorithm used to match Basse HDSS ID by data manager:

- Identify the household of each individual from the Women dataset and then
- Match with women name (full or partial match) of that household and sex=Female
- Match with date of birth
- Same date of birth
- Year and month of birth matched
- Month of birth within 6 months range plus matched name
- Year of birth only

This procedure yielded 2,600 matches based on the women's first and last names and household ID with at least the same year of birth from the 8,529 women of reproductive age recruited in the pregnancy history survey. Algorithms that tried to match on the exact date and month of birth of the women did not yield any additional matches as the dates of birth recorded in the pregnancy history survey and the Basse

HDSS data were not the same. The data were further interrogated, revealing the fact that women who were born into the HDSS were given IDs based on their father's household, but when they married retained their original IDs despite moving to the spouse's household. Thus, the original algorithm that combined region, compound and location was invalid. This led to the fourth step that involved linkage of mothers to their children in the Basse HDSS dataset and attaching the children's household IDs to the mother. Using the children's ID yielded an additional 236 matches on BHDSS IDs.

Probabilistic linkage of the survey data to the Basse HDSS data to obtain unique Basse HDSS identifiers

For the remaining unmatched records, probabilistic linkage was done using a record linkage programme in Stata v15.1 that is explained in the next section. A total of 3,455 women were identified through probabilistic matching and 1,005 by clerical review of the records independently, producing a total of 7,295 women in the survey that were positively linked to the BHDSS, a match rate of 86% (7,295/8,529).

4.3 Methods specific to the antenatal clinic (ANC) linkage to the Basse HDSS

A further aim of this thesis was to assess an approach to improving capture of pregnancy identification in the HDSS through antenatal clinic record linkage based on high antenatal coverage in The Gambia.

4.3.1 Situational analysis of antenatal coverage

The national coverage of the antenatal care system in The Gambia for at least one ANC visit is 99%. Antenatal care is provided at every level of the health system, with the primary level supported by health care workers based at the nearest health centres. At the health centres, maternal and child health units operate as standalone sections, with their own staff and resources, away from the clinics for sick children and adults. The primary level of support involves trekking clinics, which are trips made by nurses from the health centres to visit stations where village health workers are based. For this reason, each health centre has varying schedules for antenatal care provision to ensure that all outreach stations are visited at least once a month, in addition to regular ANC

services (see example of clinic schedule). These monthly clinics are well attended by women and children. The village health worker, supervised by a nurse carries out duties such as birth registration, weighing of children and assisting with immunization.



Photographs courtesy of Penda Johm (MRCG): Maternal and Child Health Clinic, The Gambia

GAMBISARA CLINIC DAYS 2016												
	JAN	FEB	MAR	APR	MAY	JUN	JUL	AUG	SEP	OCT	NOV	DEC
1ST MONDAY (BASE 1)	4	1	7	4	2	6	4	1	5	3	7	5
2ND MONDAY (BASE 2)	11	8	14	11	9	13	11	8	12	10	14	12
3RD MONDAY (BASE 3)	18	15	21	18	16	20	18	15	19	17	21	19
4TH MONDAY (BASE 4)	25	22	28	25	23	27	25	22	26	24	28	26

Source AJR: Antenatal Clinic schedule for 2016 at one of the health centres (also known as base clinic)

Regarding antenatal care, a nurse first registers the pregnant woman by collecting demographic information mostly in their local dialect. However, this information is recorded in the ANC registers in English. Vital measurements such as weight and blood pressure are also taken at this preliminary stage. In a separate room, the

pregnant woman's medical history is reviewed in addition to a clinical examination that includes fundal height measurement, listening for the foetal heart using a pinard horn and phlebotomy for HIV and Malaria testing. Ultrasounds and the VDRL test for Syphilis are only offered at Basse Major Health Centre. Therefore, women are referred there for these. If a woman is deemed high-risk, for example having high blood pressure or carrying twins, she is also referred.

In Basse, ongoing studies over the last eight years by teams from the Medical Research Council unit The Gambia (MRCG) have simplified the health workers workload as they have staff at all the health centres who assist with record keeping and procedures such as weighing and immunization for children aged under-five.

VARIABLE		COMMENT
AN REG. NO.		This sequence in which clients were entered into the register
NAME		This is the clients first name, median and family name
ADDRESS OF COMPOUND AND TELEPHONE		This is the client's residential address and contact telephone number
AGE		This is the client's age in years
GRAVIDA		This is the client's number of pregnancies
PARA		This is the client's number of deliveries and miscarriages
CHILDREN	ALIVE	This is the number of living children the clients have
	DEAD	This is the number of children who died (stillbirth and deaths)
DATE AGE AT LAST BIRTH		This is the last child's date of birth
LAST BIRTH A/D		This is the date of the last child either alive or death
FP METHOD PRACTICE AFTER LAST BIRTH		This is the last FP method used by client after the birth of the last child
DATE & FUNDAL HEIGHT FIRST VISIT		This is the first date that the fundal height was measured
RISK FACTORS	FIRST VISIT	This is the first time risk factor
	SUBSEQUENT VISIT	This is the identification of risk factors during subsequent visits
LAB Investigation	Unne	This is the result of urine analysis
	HB	This is the result haemoglobin test
	OTHERS	This is the results of other test including VDRL
	Sickle	This is the result of sickle test carried out on the client
MIP/IPT	IPT1	The date the first dose of IPT is given
	IPT2	The date the second dose of IPT is given
	Rec'd LLN	The LLN is given
MALARIA TREATMENT		This anti-malarial treatment given after IPT was given
STIs	VD	This is vaginal discharge seen during examination of AN clients
	GUD	This is genital and vaginal ulcers seen during examination of AN clients
	LAP IN PREG	This is low abdominal pain complained by client
DATE INDEX TREATED		Date the client was treated
DATE PARTNER TREATED		The date the partner was treated
DATE & FUNDAL HEIGHT EACH SUBSEQUENT VISIT		The date the fundal height was measured for each subsequent visit
		This is the column were the outcome of care is recorded

Source AJR: List in all ANC registers explaining what data are to be collected for each woman attending antenatal clinics

4.3.2 Preparation for data collection

In March 2016, AJR visited each of the six health facilities that were targeted for data collection and held sensitization meetings with the respective facility health workers. These meetings were held to give a brief on the proposed research and work plan. They were a follow up to meetings previously held with the regional health directorate, who had given permission for the work to be carried out, having been satisfied with the ethics documentation as well as the scientific proposal presented to them. The

regional health directorate had already disseminated the information about the upcoming research to the medical officers in charge of the health facilities, and therefore AJR re-emphasized the importance of keeping good records including completion of antenatal record data. The health workers were receptive to these visits and reported that the proposed work would also be beneficial to them in case they needed soft copies of the transcribed data for their use.

Fortuitously, the health facilities in Basse were part of the World Bank results-based financing programme that emphasized good record keeping as an aspect of the accountability of the health facility. For instance, for each woman's first antenatal clinic visit, she was entitled to receive 300 Gambian dalasi, and a further 300 when she completed the recommended four ANC visits. Thus, the health workers were required to record, in addition to a woman's name and age, her contact details, which included the name, address and telephone number of the head of the compound in which she lived, as well as her own number if she had a mobile phone (see image below of a sample page of ANC register). In The Gambia, compounds are normally named after their eldest male member. The largest of them accommodate hundreds of relatives. The information collected was designed to be used to trace a woman in the event that health workers needed to follow her up at home and to aid in confirmation of her identity for future visits. It was also the only information available to enable identification of the woman in the HDSS when we linked her back to the HDSS. Other methods of linkage such as national identity cards, biometric methods and HDSS identification cards were not available.

The research involved taking of photographs of antenatal clinic records from all health centres that serve the Basse HDSS, that is, the Basse major health centre and five minor health centres (Gambisara, Fatoto, Garawol, Koina and Demba Kunda). Use of photography was chosen as the most feasible method for this research as I neither had the capability to do real-time linkage nor the ability to hire a health records officer at each health facility due to resource constraints. The photographs were taken using mobile phones owned by the research assistants.

4.3.3 Fieldwork procedures

Training of fieldworkers

AJR and the two research assistants hired for this work visited the health centres in May 2016 for familiarization purposes. These visits also served to train the research assistants as to what was an acceptable quality of photography since the digital images were to be transcribed and used for record linkage. After the training, a pilot study was carried out and AJR found their work to be satisfactory.

The research assistants were selected because they were resident in Basse, were familiar with the HDSS and had good database management skills. Each of them was appointed to cover three health facilities, and they were to visit each of these clinics every month. The first two weeks of every month were set aside to take the photographs, and the remaining two weeks for transcription of the digital data to excel files for further data curation. This data collection method was retrospective in nature.

Data collection

Fieldwork began in June 2016 with the aim of collecting data covering 1st December 2015 to 31st December 2016. Initially, there were six months of data to collect (from December 2015-June 2016). Thus, for the first month of fieldwork, the research assistants concentrated on photography, while transcription was done in the second and third months concurrently with the respective photography. Thereafter, at the end of each month, the research assistant only needed to update the records for the preceding month. This process of data collection ended in January 2017.

Data quality was crosschecked each month by the research assistants (each checking the other's work) to ensure that the transcribed data were a replication of the digital images, and there were no duplicates. A third check for accuracy and completeness was done by AJR.

4.3.4 ANC-HDSS record linkage procedures

Following de-duplication of ANC registers, record linkage between the ANC records and HDSS was done in two stages. First, two research assistants familiar with the area used a clerical process to identify compounds where the village name and the name of the compound head recorded in the ANC registers matched the information stored in the HDSS database. Once the compounds were identified, women were matched based on their first and last name (including nicknames), age and parity. The upper threshold for the discrepancy in the age reported in the two sources was set at two years³²⁰.

For the remaining unmatched records, probabilistic record linkage was done^{321, 322}. With this method, two records in every matched pair identified from the different data sources are compared on each linkage identifier denoted i , producing an agreement pattern; i represents the woman's name, age and compound head name in our study. The weight assigned to agreement or disagreement on each identifier is assessed as a likelihood ratio, comparing the probability that true matches agree on the identifier (“ m -probability”) to the probability that false matches randomly agree on the identifier (“ u -probability”)^{323, 324}. Record pairs that agree are given a weight $\log_2 \frac{m_i}{u_i}$ while those that disagree are assigned weight $\log_2 \frac{1-m_i}{1-u_i}$. This weight gives the discriminatory power of the identifier chosen, but not the degree to which the matched pairs agree.

The degree of agreement is evaluated using the modified bigram string comparator. The string comparator helps to account for homonymous names, spelling errors and nicknames, and considers characteristics that would reduce the likelihood of matching, such as string length, number of transpositions of characters and location on the string where the nonmatching occurs. It assigns a string comparator value, which when combined with the agreement weight creates a partial agreement weight/score. Where the matching score was greater than 0.97, the ANC and HDSS records were automatically assigned as a match. Based on acceptable margins of error set by AJR, for those with a score between 0.80 and 0.97, the top 20 records generated

from the two databases (HDSS and ANC records) were reviewed manually, and the best match was identified.

4.3.5 Follow up study for pregnancy outcomes

Finally, following completion of record linkage, the outcomes of the pregnancies identified at the antenatal clinics were sought from the BHDSS. For those women whose pregnancy outcomes were not recorded in the BHDSS, AJR generated a list containing their names, ages and health facility attended and up to two follow up visits were made by the HDSS fieldworkers. They did this in the second round of HDSS updates as part of their routine surveillance activities. They used standard forms to collect data confirming whether the woman had been pregnant and the outcome of the pregnancy if indeed the woman was pregnant. On completion of follow up, any remaining identifying information for BHDSS residents were deleted prior to analysis. The follow up study was carried out between April and August 2017, and results are presented in Chapter 7 of this thesis.

4.4 Methods for the exploratory qualitative study

In the case of the qualitative study, a detailed explanation of the methods used is presented in Chapter 8 of this thesis. AJR and JN interviewed thirteen female fieldworkers and three key informants to learn about Gambian cultural practices, attitudes and discourse that could play a role in research on neonatal and perinatal mortality.

We also conducted a focus group discussion with male fieldworkers who routinely carry out surveillance in the HDSS in search of alternative views, increasing the diversity of the data sources. These methods and the interview guides were informed by informal conversations and observations AJR had while living in The Gambia as well as through a review of the literature about potential factors that could affect data collection on pregnancy and pregnancy outcomes in a socially conservative society.

Research paper cover sheet

Chapter 5 *Under-five mortality in The Gambia: Comparison of the results of the first Demographic and Health Survey with those from existing inquiries*

Evidence before this study. We screened articles based on inclusion criteria relating to neonatal and under-five mortality in The Gambia. We searched PubMed using the terms ("infant mortality"[MeSH Terms] OR ("infant"[All Fields] AND "mortality"[All Fields]) OR "infant mortality"[All Fields] OR ("neonatal"[All Fields] AND "mortality"[All Fields]) OR "neonatal mortality"[All Fields]) AND ("gambia"[MeSH Terms]. "under-five" [All Fields] AND ("mortality"[Subheading] OR "mortality"[All Fields] OR "mortality"[MeSH Terms]) AND ("gambia"[MeSH Terms] OR "gambia"[All Fields]) and found a total of 264 articles with 43 directly related to our research topic. 275 articles were identified in Web of science, of which ten were relevant using the terms "TOPIC: (child mortality OR under-five mortality OR neonatal mortality AND Gambia). In Scopus, 88 articles were extracted using TITLE-ABS-KEY (("neonatal mortality") OR ("child mortality") OR ("under-five mortality") OR ("under-5 mortality") OR ("complete birth histor*") OR ("summary birth histor*") OR ("health and demographic surveillance system*") OR ("HDSS") AND ("Gambia") OR ("The Gambia") OR ("Gambia*")). Additionally, we extracted information from national reports of the censuses, MICS and DHS. Only one report on global child mortality estimated national neonatal, post-neonatal and child mortality trends. It did not provide regional estimates and was conducted prior to 2013.

Added value of this study

This is the first study to estimate under-five mortality and its components at national and selected regional areas using multiple data sources including the 2013 DHS. We compared indirect and direct estimates and used flexible parametric survival methods to predict mortality rates for all empiric data points up to 2015.

Implications of all the available evidence. Disaggregated national estimates from the DHS, which approximates census and MICS data for recent years indicate the importance of neonatal mortality in The Gambia, and the need to focus on neonatal survival, while maintaining currently successful strategies to further reduce under-five mortality.

5.1 Abstract

Background: Prior to 2013, national estimates of under-five mortality (U5M) in The Gambia were from censuses and multiple indicator cluster surveys (MICS). The country's first demographic and health survey (DHS) in 2013 provided empirical disaggregated national estimates of neonatal, post-neonatal and child mortality trends and an opportunity to compare U5M with the existing inquiries.

Objective: To assess the consistency and accuracy of the estimates of U5M from the existing data sources and its age-specific components in rural Gambia and produce reliable up-to-date estimates.

Methods: Available national data on under-five mortality from 2000 onwards were extracted. Additionally, data from two DHS regions were compared to those from two health and demographic surveillance systems (HDSS) located within them. The quality of data was assessed, and indirect and direct estimates were compared.

Findings: Consistency checks on data quality for indirect estimation of U5M suggest that the data were plausible at national level once the 15-19yr age group was excluded. The DHS and HDSS data used to make direct U5M estimates were plausible, however HDSS data were of better quality. For the most recent five-year period, the DHS estimates agreed well with the census and MICS reports of U5M but was less accurate about the early births of older women. The most recent estimates from the 2013 DHS, which refer to 2011-12, are an U5M rate of 54/1000 livebirths (95% CI: 43-64) and a neonatal mortality rate of 21/1000 livebirths (95% CI: 15-27), contributing almost 40% of U5M in The Gambia. This indicates the importance of neonatal mortality in The Gambia, and the need to focus on neonatal survival, while maintaining currently successful strategies to further reduce U5M.

5.2 Introduction

Child mortality is an important indicator of a population's health and is strongly related to structural factors such as economic status, social wellbeing and environmental factors³²⁵⁻³²⁷. Sub-Saharan Africa (SSA) has the highest under-five mortality rates of any world region, with West and Central Africa worst affected. Almost half of under-five deaths (44%) occur during the first month of life and two-thirds of these neonatal deaths occur during the first few days of life (4). Global targets to reduce under-five mortality by two-thirds between 1990 and 2015 were set as part of the Millennium Development Goals. Although this target was not achieved by 2015, global under-five mortality was halved³²⁶; and some African countries registered significant gains in child survival^{328, 329}. Consequently, the new Sustainable Development Goals (SDGs) have set a target of reducing neonatal and under-five mortality rates by 2030 to 12 and 25 deaths per 1000 livebirths, respectively³. The monitoring and evaluation of these goals require accurate statistics for mortality measurement.

Measuring mortality is straightforward when vital registration is effectively complete. In SSA, vital registration is not fully functional in most countries^{227, 330, 331}, leaving the region dependent on alternative sources for estimating national-level mortality indices. These include national population censuses, Demographic and Health Surveys (DHS) and Multiple Indicator Cluster Surveys (MICS). Because of the relatively high cost and long periodicity of national censuses, DHS have become the main source for estimates of childhood mortality for use in national development planning and policy formulation³³². One advantage of the DHS over other sources of childhood mortality data is the detailed birth histories it collects. These data can be used to calculate the different age-specific indicators of childhood mortality, namely: neonatal (< 28 days), post-neonatal (1-11 months), child (1-4 years) and under-5 mortality rates.

Prior to its first DHS in 2013, The Gambia was one of very few continental sub-Saharan African countries that still depended solely on decennial censuses and MICS as sources

of childhood mortality data. Indirect estimates from successive decennial censuses since 1973, as well as three MICS enquiries between 2000 and 2010, document substantial decline in under-five mortality over the last four decades^{22, 262, 272, 307-309}. Also, longitudinal data from a health and demographic surveillance system (HDSS) suggest that child mortality fell below the MDG 4 goal seven years early⁴⁰. To date, no attempt has been made to systematically compare childhood mortality estimates derived from each of these sources.

The release of complete birth history data from the 2013 DHS therefore provides an opportunity to update and reassess mortality information from all available data sources. First, consistency checks are used to evaluate the quality of the DHS against existing Gambian mortality data, that is indirect estimates of under-five mortality from the MICS and the censuses, and direct estimates of under-five mortality and its constituents obtained from the HDSS. Then, new estimates are presented of under-five mortality and its components based on the conclusions reached about data quality and comparability of the DHS to existing sources.

5.3 Methods

Study setting

The Gambia is one of the smallest continental African countries. It is located in the middle of the bulge of the West African coast; and bound to the north, east and south by Senegal, and to the west by the Atlantic Ocean. With a total population of 1.85 million as at the 2013 national census²⁶², the country is divided for administrative purposes into two urban municipalities and five rural local government areas (LGAs). Two of these rural LGAs, Kerewan and Basse, host the Farafenni and Basse HDSS sites, respectively (see Figure 5.1).

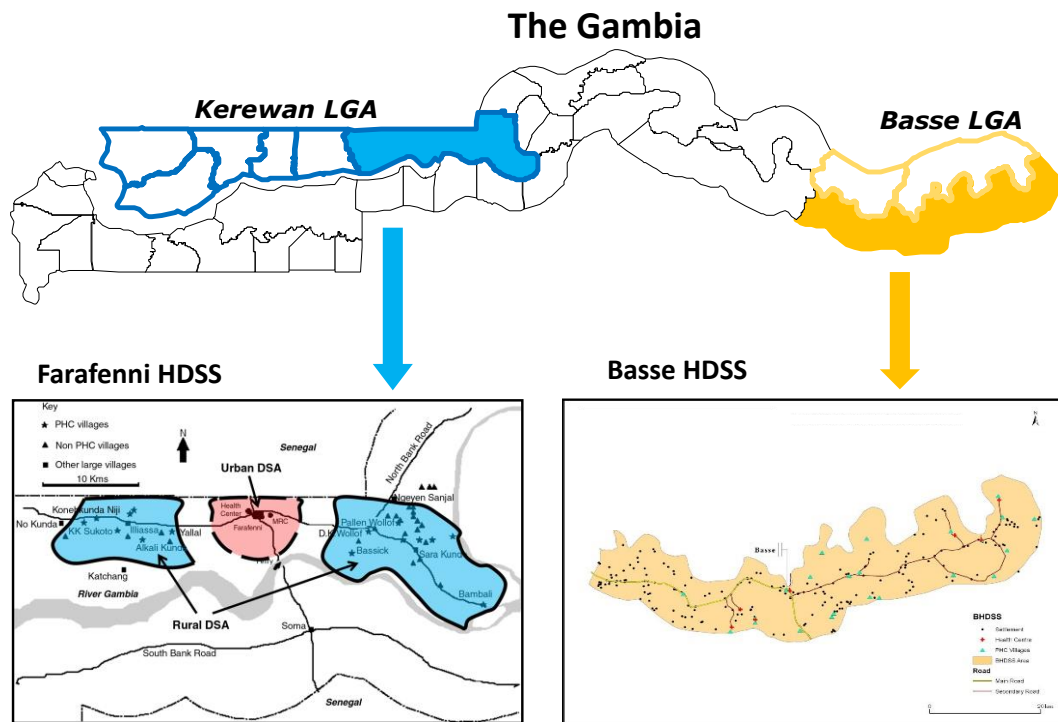


Figure 5.1: Map of The Gambia indicating the Farafenni and Basse HDSS sites located in Kerewan and Basse Local Government Areas, respectively.

Data sources

In addition to the 2013 DHS, five independent enquiries that collected childhood mortality data have been conducted by the Gambia Bureau of Statistics (GBoS) since 2000. These data comprise two sets of summary birth histories from the 2003 and 2013 national censuses, and three sets of summary birth histories from MICS 2000, 2005/6 and 2010. Whilst the DHS collected similar summary data, it also obtained data on person-time at risk and age at death by collecting full birth histories, thus enabling the *direct estimation* of mortality rates³³³. In contrast, the censuses and MICS asked women of reproductive age, about their numbers of children ever born and surviving, thereby providing the key information required for *indirect estimation* of childhood mortality²⁹⁸. Regional data were extracted from the DHS for Kerewan and Basse LGAs.

The individual-level data required to measure childhood mortality directly were also extracted from the Farafenni and Basse HDSS. The Farafenni HDSS has been in

operation since 1981 and covered a population of about 55,000 by December 2015. It is described in detail elsewhere²⁹⁴. The Basse HDSS started in 2007 and currently follows up about 180,000 people. It adopts the same procedures that apply in the Farafenni HDSS. In combination, the two HDSSs follow up about 13% of the Gambian population. Heads of household, or appropriate representatives, are interviewed at least once every four months about births, deaths, migrations and pregnancies that occurred in the period since the last visit. When pregnancies are identified, they are followed up in subsequent rounds of update to establish their outcomes²⁹⁴.

Data quality assessment

The accuracy of indirect estimates of childhood mortality²⁹⁸ depends, among other factors, on the quality of the data relating to children ever born, proportions dead, and the fertility experience of mothers by age group²⁹⁸. Consistency checks were therefore applied to ascertain the plausibility of the sex ratio of children ever born; the distribution of proportions dead of children ever born by age of mother; and the trend of average parities by age of mothers. As the natural sex ratio at birth is about 1.05, ranging between 1.03 and 1.07, male children born for every female in most populations around the world, the sex ratio at birth was examined for children ever born reported in the MICS, census and DHS datasets.

The quality of data used for direct estimation of mortality is usually assessed based on completeness of reporting of dates of births and deaths, and tests for omissions of births or deaths, birth displacement, age heaping and date preference. Assessment of these for the DHS data yielded similar outcomes as indicated in the report, that is, good quality of date reporting with less than 2% missing overall²². There was heaping of reported ages at death at 6 and 12 months, with only the latter likely to affect infant and child mortality estimates. The data from the two HDSS sites had complete dates of birth and death. However, inspection of the distribution of reported day of birth and death in the Basse HDSS data revealed that the first day of the month was by far the most frequently reported, suggesting that it was recorded when the actual day could not be ascertained (Figures 5.5 & 5.6). To minimise the potential impact on the

estimates that this issue might have had as a result of displacing neonatal deaths to the post-neonatal period, dates for births and deaths that occurred on the first day of the month were randomly imputed while preserving the reported month.

Estimation methods

Using the individual-level data from the HDSS, mortality rates were calculated directly for each period and year using Kaplan–Meier failure probabilities for each of the following age groups: <28 days for neonatal deaths; 28 days to <1 year for post-neonatal deaths; 1–4 years for child deaths; and <5 years for under-5 deaths. The HDSS data were extracted from 1990 to 2014¹ for Farafenni (excluding 2008/2009²) and from 2009 to 2014³ for Basse. The 2013 Gambia DHS was used to estimate both national mortality and mortality in the Kerewan and Basse regions using the synthetic cohort probabilities method employed by demographic health surveys³³⁴. For more accurate and conservative standard errors for the DHS data, clustering was accounted for, and 1000 sample replications used to generate bootstrapped standard errors and 95% confidence intervals for the mortality rates³³⁵.

The 2003 and 2013 censuses and the 2000, 2005/6 and 2010 MICS were analysed using the indirect method to estimate under-five mortality from the means of children ever-born and surviving for five-year maternal age groups²⁹⁷. The method incorporates assumptions about the age pattern of mortality. For this analysis, Princeton South model life tables were used to produce the estimates, which is consistent with previous analyses of the MICS and censuses. We do not report on rates generated from the 15–19 age group^{298, 334}. Indirect estimates from the DHS were compared to estimates obtained from these data sources in order to make a pure comparison of the completeness of death reporting in each inquiry.

¹ 1990 was chosen to reflect MDG trends in U5MR in view of good quality prospectively collected data from Farafenni HDSS

² The Farafenni field station was temporarily closed from April 2008 to March 2009 with resumption of surveillance activities thereafter. The quality of data for this period collected retrospectively was not reliable.

³ The quality of data from Basse HDSS in 2007 when surveillance began was unreliable but markedly improved by 2009

Having done this, the rest of the paper focuses on direct estimates from the DHS which, on the assumption that reporting of ages and dates is accurate, allows us to estimate the age pattern of mortality from the data. For the direct estimates only, we used flexible parametric survival methods to generate smooth mortality trends by calendar year³¹³. As more flexible models did not converge, the model was limited to one knot for neonatal and post-neonatal mortality, and to two for child mortality. Both smoothed and direct non-parametric mortality rates were plotted.

5.4 Results

Data quality assessment of data for indirect estimation of mortality

The results of data quality checks on MICS, censuses and DHS by means of sex ratio of children ever born, proportion dead of children ever born and average parity by mother at birth are presented in Figure 5.2. The sex ratio of children ever born at national level converged around 1.05 for older mothers, being erratic for the 15-19 year age group. In the regions, after excluding extremes of age (<20 and >40 years of age), the sex ratio at birth did not diverge much from 1.05. Although Kerewan DHS reported a SRAB less than 1.05 for all age groups, it was not far off from the expected SRAB.

The expected pattern of an increase in proportions dead of children ever born with maternal age was observed with few exceptions. At national level, proportions dead of children ever born were higher for the 15-19 year age group than the 20-24 year age group for the MICS in 2000 and 2010. In Basse, the DHS and MICS showed instances of lower proportions dead of children ever born in older age groups. For example, in Basse DHS, women aged 35-39 years had a higher proportion of dead children than those aged 40-44 years. Such fluctuations were also seen in the MICS data, occurring most often in the MICS in 2010. In Kerewan, this was only seen in the MICS conducted in 2005/6, with the remaining data sources depicting the expected pattern once the 15-19 year age group was excluded.

We observed expected trends in average parity per woman at national level from the DHS, while regionally, the 45-49 year age group registered slightly lower average parities than expected. Overall, the MICS had slightly higher average parity and higher

proportions dead of children than other sources, particularly the MICS in 2000 in Basse.

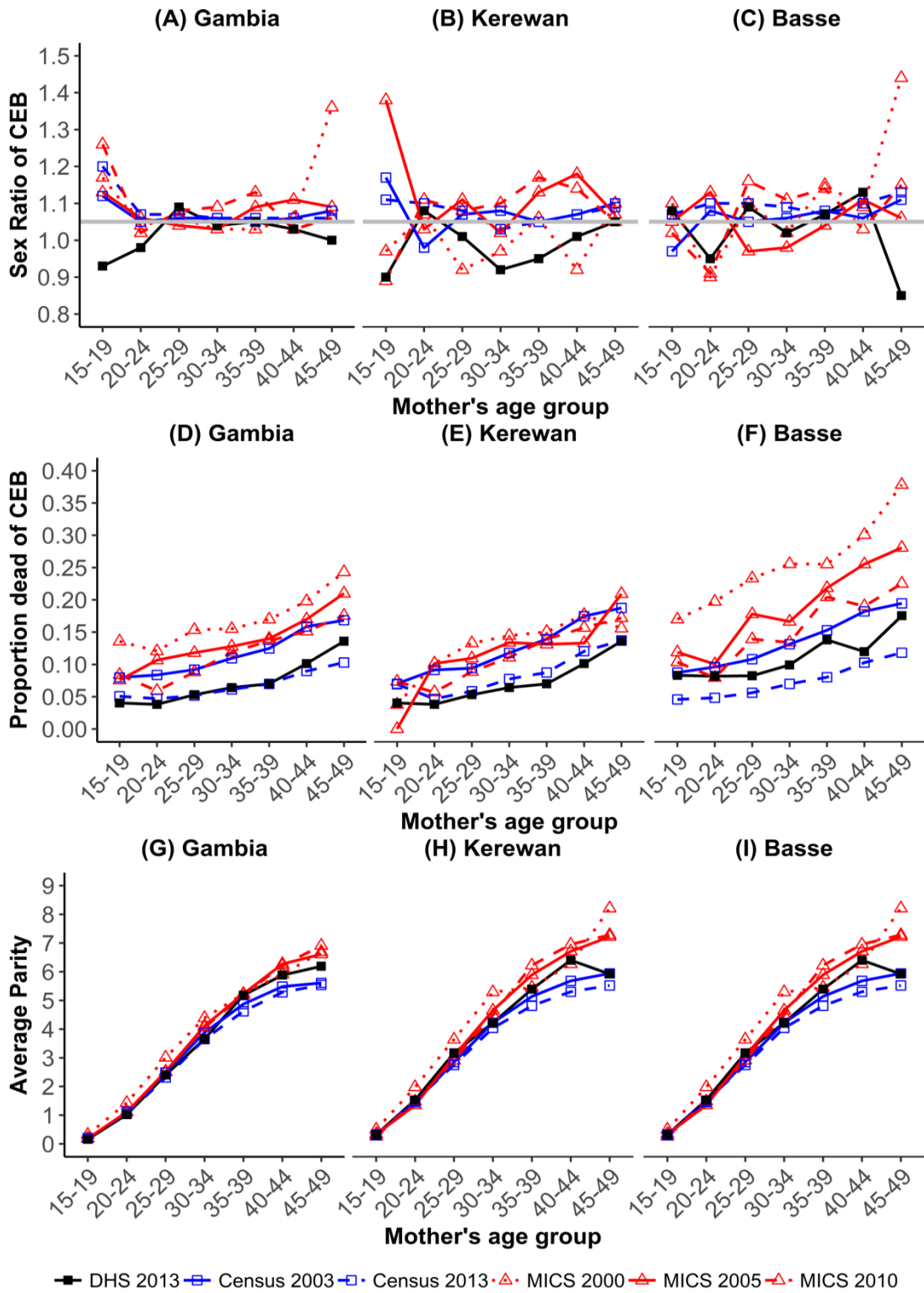


Figure 5.2: Assessment of the data on children ever-born (CEB) and dead children MICS 2000, 2005/6 & 2010, Census 2003, 2013 and DHS

Data quality assessment of data for direct estimation of mortality

Age heaping and date preference were assessed for both DHS and HDSS data. The ratios of under-five mortality indicators for DHS and HDSS data were also calculated. The age-heaping index for the neonatal period in the DHS was 1.15, while those for regions ranged from 0.85-1.71. For the HDSS, age heaping in the neonatal period was 0.90 and 0.94 for Basse and Farafenni respectively.

Table 5.1: Age heaping indices for the neonatal period - Gambia 2003-12

Neonatal age heaping	Gambia DHS	Kerewan DHS	Basse DHS	Basse HDSS	Farafenni HDSS
day7	32	7	4	19	21
day5-9	139	20	24	105	112
fifth of 5-9	27.8186	4.083	4.7166	21	22.4
heaping index	1.15031	1.714426	0.848069	0.904762	0.9375

In Figures 5.3 and 5.4, the age at death in DHS data indicates that more deaths occurred in the first week of life, mostly on the first day. Notably, there are very few neonatal deaths reported in the late neonatal period, and those that are recorded correspond to 14 days (2 weeks) and 21 days (3 weeks).

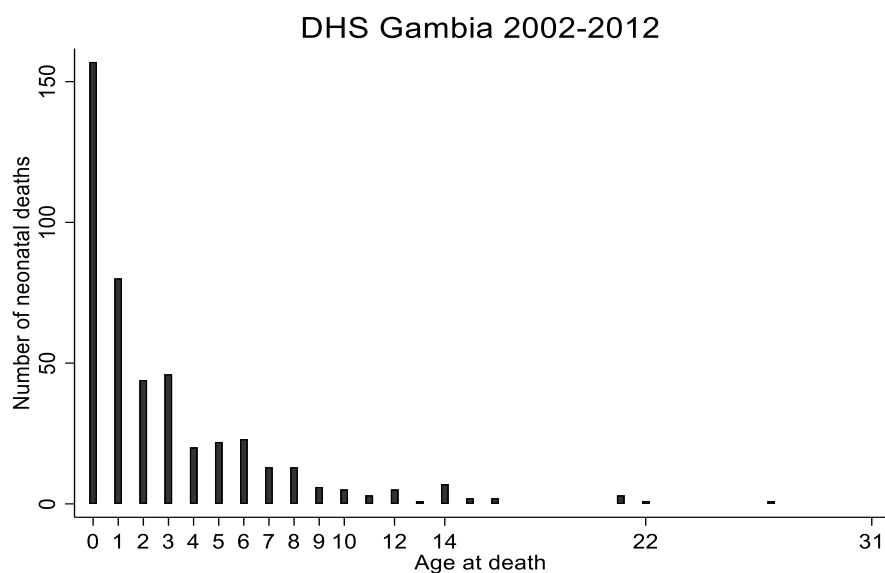


Figure 5.3: Age at death in days at the national level – 2013 Gambia DHS

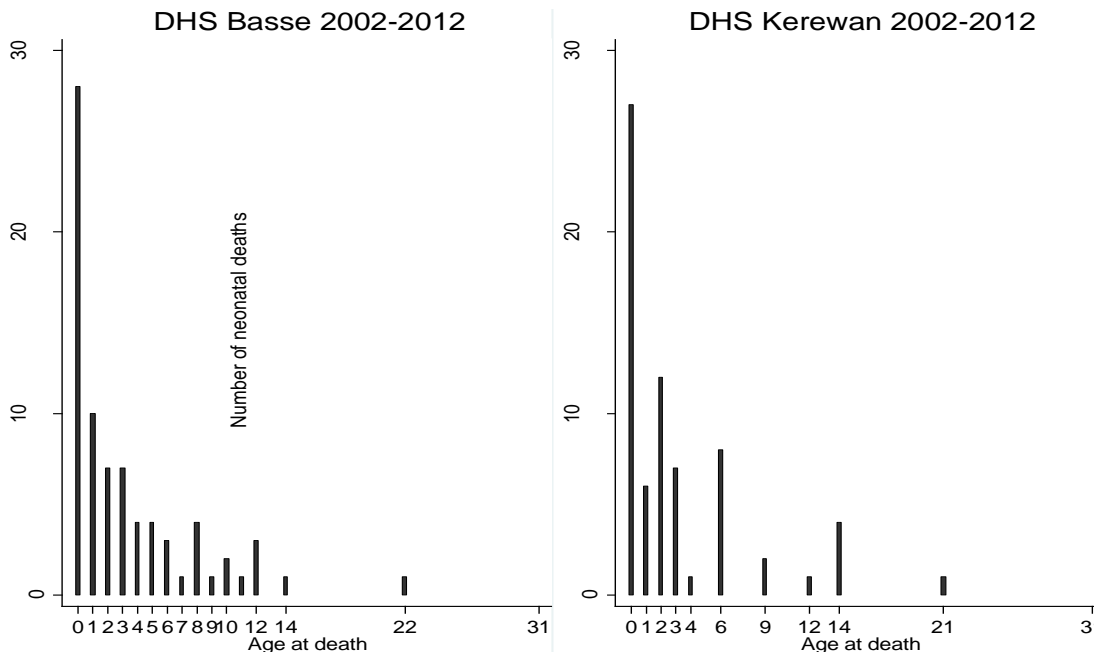


Figure 5.4: Age at death in days Basse DHS and Kerewan DHS regions

There were no missing dates in either the Basse or Farafenni HDSS. In the Basse HDSS, the 1st was the most frequently recorded date of birth and death as shown for deaths in figure 5.5, requiring a random imputation of day of birth and death with preservation of month and year of birth as indicated in the figures 5.5 & 5.6.

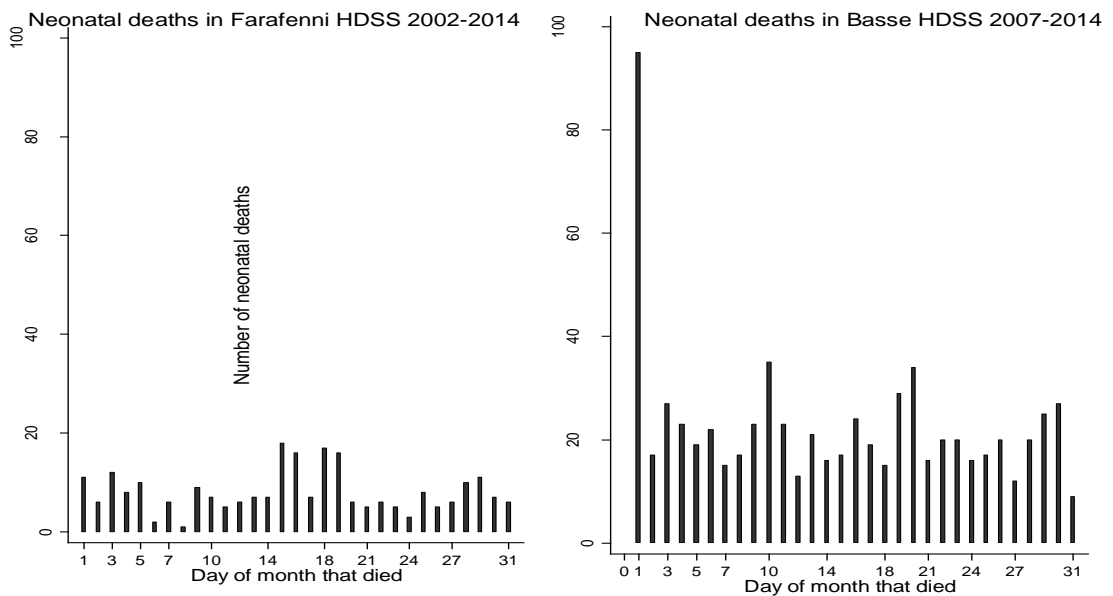


Figure 5.5: Unadjusted dates of deaths in Farafenni and Basse HDSS

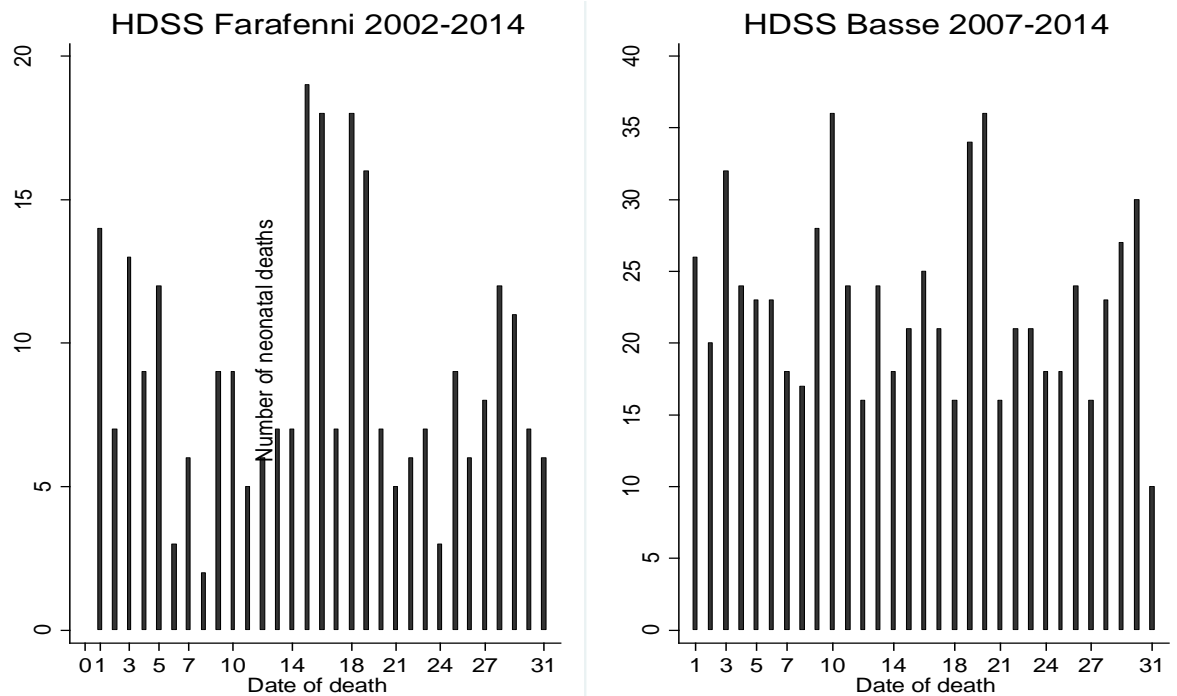


Figure 5.6: Adjusted date heaping in Basse HDSS

Regarding the ratios of under-five mortality indicators, these were to be compared to the expected sub-Saharan Africa ratios of NMR: IMR of 0.51 and NMR: U5MR of 0.34. This comparison was restricted to 2007 to 2012 based on availability of Basse HDSS data, and are presented in Figures 5.7 and 5.8 respectively. The values reported in this section are the average ratios for the period of analysis.

For the HDSS, NMR: IMR in Basse was 0.38 and in Farafenni 0.46. The NMR: U5MR in Basse HDSS was 0.31 and in Farafenni 0.23. In the DHS, at national level NMR: IMR was 0.6, in both Basse and Kerewan 0.7. NMR: U5MR was 0.43 at national level, 0.45 in Basse and 0.6 in Kerewan.

Farafenni HDSS most closely approximated the expected NMR: IMR, and Basse HDSS the NMR: U5MR. The DHS ratios over time had more fluctuations, while the HDSS estimates were more stable as would be expected.

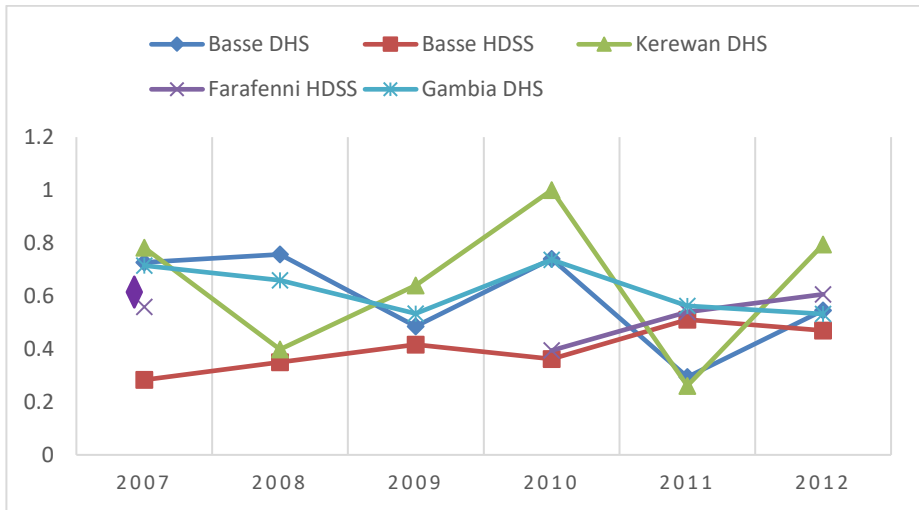


Figure 5.7: Neonatal to infant mortality ratios for DHS and HDSS data

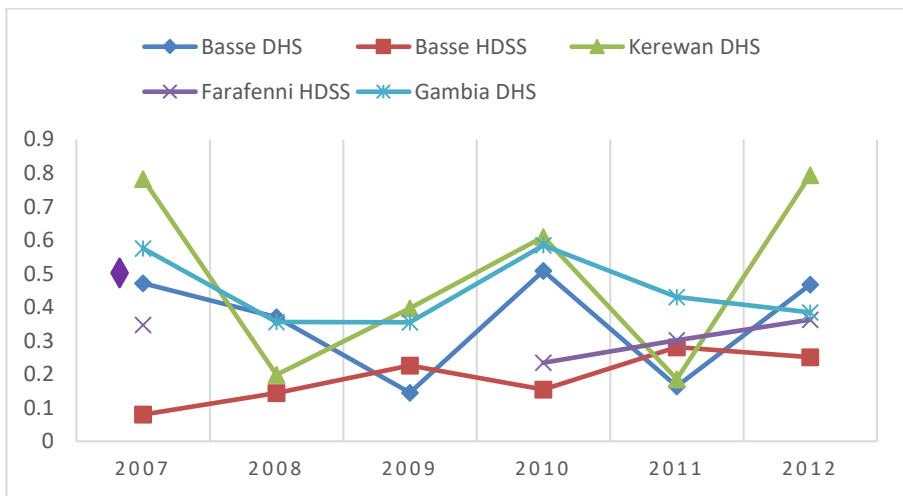


Figure 5.8: Neonatal to under-five mortality ratios for DHS and HDSS data

Consistency of estimates of under-five mortality from different inquiries

Direct and indirect estimates of under-five mortality at the national and selected regional levels are presented graphically in Figure 5.9 for all eight data sources (3 MICS, 2 Censuses, 1 DHS and 2 HDSS). All sources depicted a decrease in under-five mortality in The Gambia.

National level

At the national level (see Figure 5.9, Panel A), the estimates of under-five mortality from the two censuses are fairly consistent with each other and with the DHS, while the estimates from the MICS are much higher, especially before 2005. The estimated under-five mortality rates in 1999, for example, were 142, 90 and 108 per 1000 livebirths according to the MICS in 2010, the 2013 census and the 2013 DHS respectively, a gap of up to 50/1000 livebirths. The most recent estimates from the latest MICS survey, referring to 2006 to 2008, however, converge with those from the DHS (72/1000 livebirths and 73/1000 livebirths, respectively), although the census estimate was slightly lower (64/1000 livebirths). This discrepancy persists in the period 2009-2011, with DHS estimating under-five mortality at 69/1000 livebirths and the census at 57/1000 livebirths. The DHS direct and indirect estimates followed parallel trends.

Having ascertained that the most recent indirect estimates from the DHS were broadly comparable to those from other data sources, we calculated direct estimates from the DHS of the age-specific components of under-five mortality (details on point estimates and 95% CI from direct estimation of DHS data are presented in Table 5.2 and depicted in Figure 5.10, Panel E). The most recent estimates from the 2013 DHS, which refer to 2011-12, are an under-five mortality rate (U5MR) of 54/1000 livebirths (95% CI 43-64) and a neonatal mortality rate (NMR) of 21/1000 livebirths (95% CI 15-27), with the latter contributing almost 40% of under-five mortality. The DHS additionally showed that from ten years prior to the survey, child mortality dropped by 55% and neonatal mortality by 31% (Table 5.2).

Regional level

Panels B and C of Figure 5.9 present direct and indirect estimates of under-five mortality in Kerewan and Basse, the regions in which the two HDSS are located. The estimates for Kerewan show a high degree of congruence between the MICS, the DHS and the census especially in the most recent five-year period.

Direct estimates from Farafenni HDSS which is located within Kerewan region are also plotted and are almost congruent with the indirect data sources barring fluctuations in the early 1990's.

In Basse region, the census estimates are consistently lower than those from the other data sources, with a difference in point estimates of over 100/1000 livebirths in earlier periods. The 2000 MICS estimated U5MR at 284/1000 livebirths in 1988 while the census-based estimate was 170/1000 livebirths (Figure 5.9, Panel C). By 2007, the 2010 MICS estimate of the U5MR was 95, and that from the DHS 96 while the census report give one of 65/1000 livebirths. The MICS and DHS estimates are similar to each other from 2004 onwards. The direct Basse HDSS estimates are nearly congruent with the indirect estimates

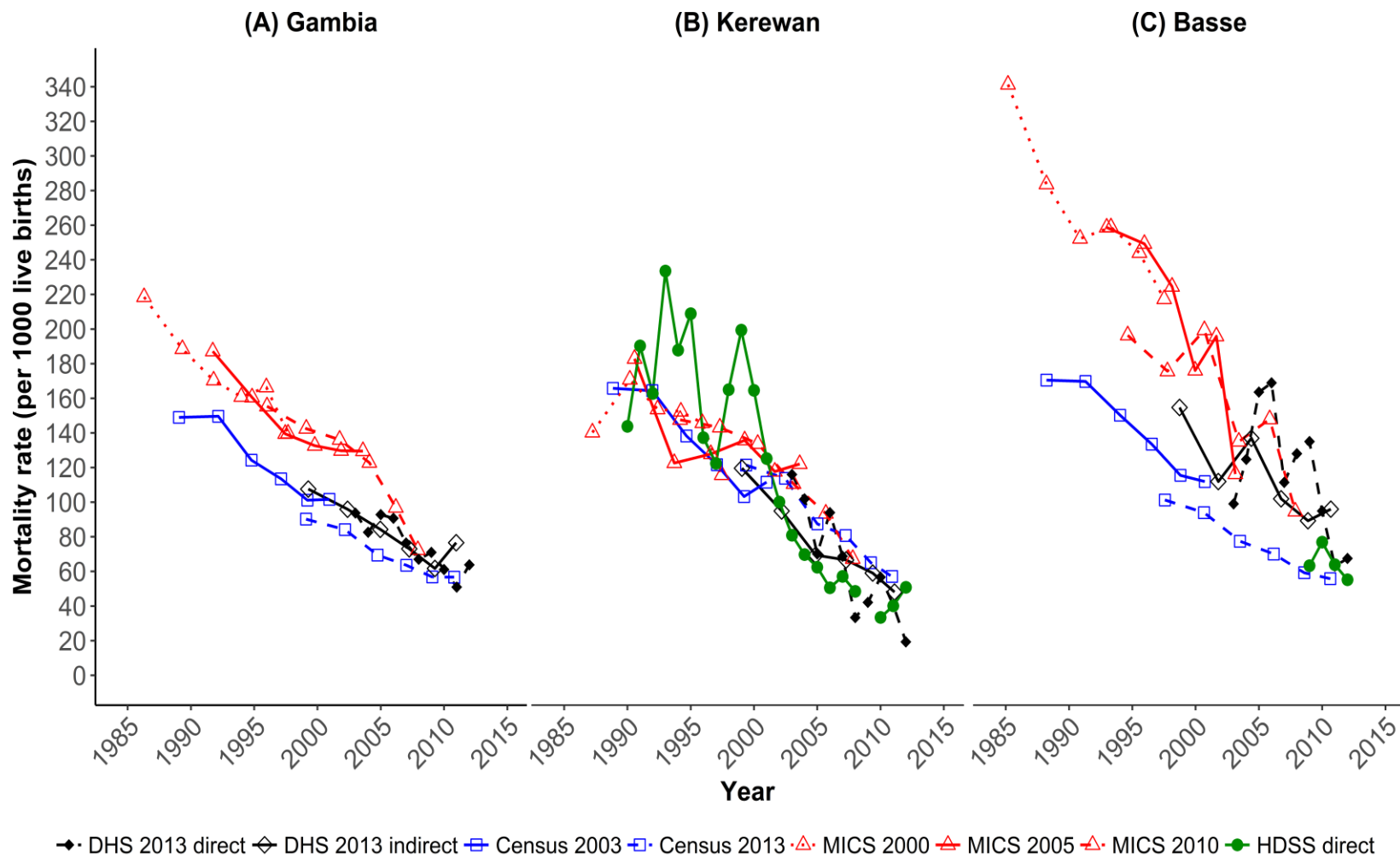


Figure 5.9: Under-five mortality estimates for The Gambia, Kerewan and Basse regions using data from 2003 and 2013 census, MICS 2000, 2005/6 and 2010, DHS 2013 and HDSS located within Basse and Kerewan Regions

Consistency of direct estimates of under-five mortality in the DHS and HDSS

To further evaluate the DHS data, consistency checks were performed by comparing disaggregated direct estimates of under-five mortality calculated from it to those from the Farafenni and Basse HDSS located in Kerewan and Basse DHS regions respectively. The results are shown in Table 5.2 and depicted in Figure 5.10 (Panels A-D). Flexible parametric survival methods were applied to predict trends and confidence intervals for NMR, PNMR and CMR and plotted alongside non-parametric point estimates of the mortality rates in the HDSS and DHS regions.

The DHS reported steeper declines in under-five mortality than the HDSS. According to the DHS, U5MR fell by 41% in the years 2009-2012 in Basse and by 74% in Kerewan from 2003-2012, with most of the decline being in child and post-neonatal deaths in the latter region. For the same periods, Basse HDSS reports a 15% reduction in the U5MR and Farafenni, a 44% reduction. Estimates of neonatal, post-neonatal, child and under-five mortality rates between 2009 and 2012 in Basse DHS and HDSS were similar, for all $p > 0.05$, the only significant difference being higher under-five mortality in 2009-10 in the DHS. On the other hand, prior to 2011, Kerewan DHS reported significantly higher estimates of neonatal mortality than Farafenni HDSS. Post-neonatal mortality rates were similar except in 2009-10 when they were higher in the HDSS. Regarding child mortality, there was no difference in estimates except in 2005-7 where the HDSS reported significantly higher rates ($p = 0.04$). There was no difference between the under-five mortality rates in Kerewan and Farafenni over the period 2003-2010. Under-five and post-neonatal mortality estimates for 2011-12 are significantly higher in Farafenni HDSS than in Kerewan DHS.

Regarding age patterns of mortality, child mortality shows the largest drop, starting earlier in Kerewan region. In both regions, neonatal mortality in DHS and HDSS in the most recent five years was less than 20/1000 livebirths. For the period 2011-12, NMR by data source were: Kerewan DHS NMR 9.1 (95% CI: 3.6-17.8); Basse DHS 16.4 (95% CI: 5.4-27.5); Farafenni HDSS 12.7 (95% CI: 9.6-16.8); and Basse HDSS 15.9 (95% CI: 14-18.1) per 1000 livebirths.

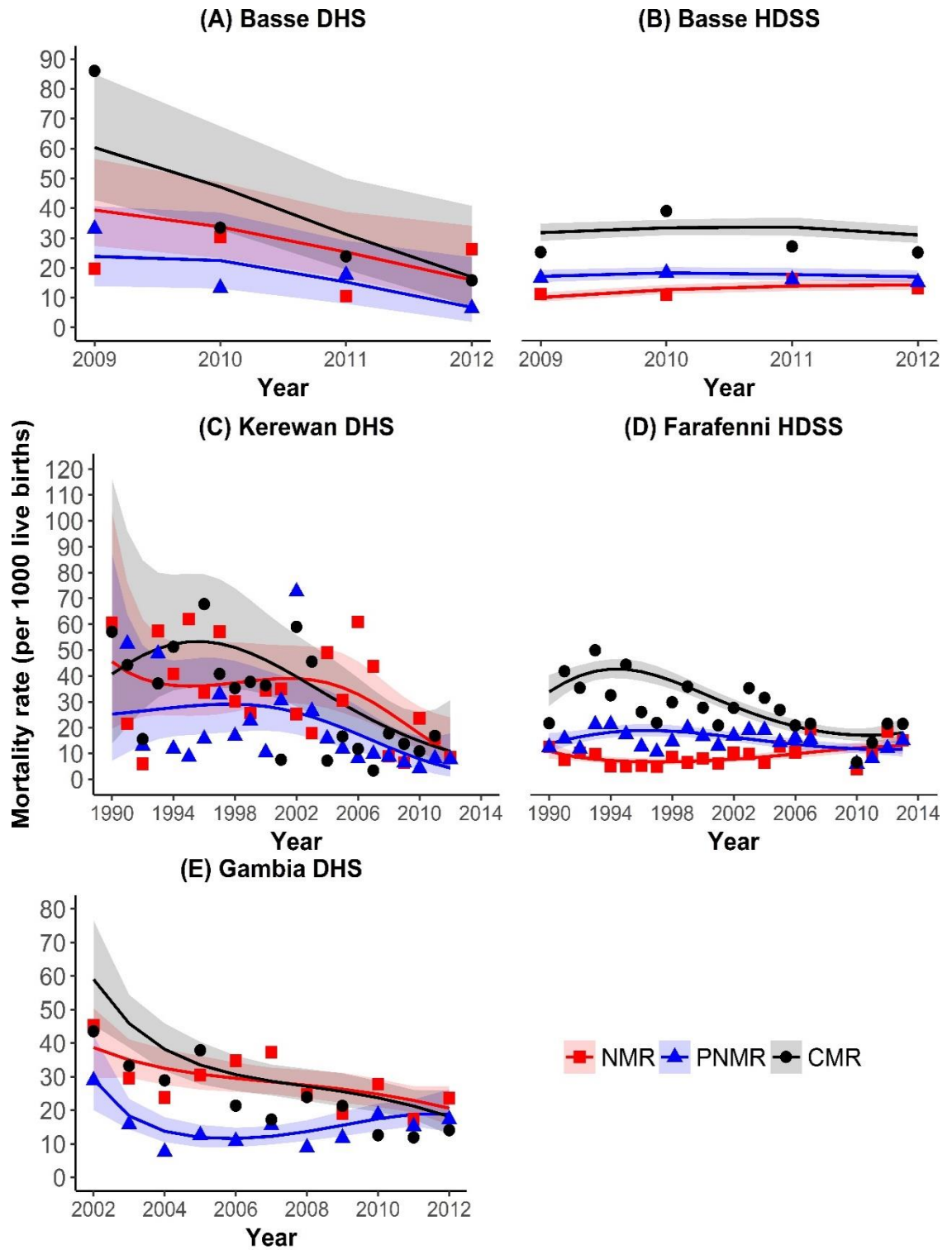


Figure 5.10: Direct estimates of neonatal, post-neonatal and child mortality rates in Basse and Farafenni HDSS, Basse and Kerewan Regions and the Gambia

Table 5.2: Neonatal, post-neonatal, child and under-five mortality rates and rate differences (95% CI) for HDSS and DHS regions and periods in the Gambia

Gambia	NMR (95% CI)		PNMR (95% CI)		CMR (95% CI)		U5MR (95% CI)		
2003-4	30.2	(20.7-39.7)	16.9	(10.7-23.0)	36.9	(27.4-46.3)	82.2	(67.4-97.1)	
2005-7	34.6	(27.1-42.0)	13.2	(8.5-17.9)	28.0	(20.1-35.9)	74.4	(62.4-86.5)	
2009-10	24.4	(17.4-31.5)	9.7	(5.1-14.2)	25.3	(16.1-34.5)	58.5	(47.3-69.7)	
2011-12	20.9	(14.5-27.2)	16.5	(7.4-25.6)	16.7	(11.3-22.1)	53.5	(43.0-64.0)	
Basse	NMR		PNMR		CMR		U5MR		Rate Difference
	DHS	HDSS	Rate Difference (95% CI)	DHS	HDSS	Rate Difference (95% CI)	DHS	HDSS	Rate Difference (95% CI)
2003-4	37.6			16.2			59.1		
2005-7	54.9			16.3			56.9		
2009-10	26.1	13.4	12.7 (-1.5;27)	18.9	20.7	-1.8 (-17.7;14.1)	56.2	37.4	18.8 (-5.9;43.5)
2011-12	16.4	15.9	0.5 (-10.6;11.8)	21.9	16.8	5.1 (-8;18.1)	21.2	27.8	-6.6 (-22.1;9.0)
Kerewan	NMR		PNMR		CMR		U5MR		Rate Difference
	DHS	HDSS	Rate Difference (95% CI)	DHS	HDSS	Rate Difference (95% CI)	DHS	HDSS	Rate Difference (95% CI)
2003-4	38.0	8.4	29.6 (6.7;52.5)	20.5	25.6	-5.1 (-23.1;13.1)	42.5	43.0	-0.5 (-23.7;22.7)
2005-7	43.5	12.1	31.4 (12.5;50.2)	14.8	18	-3.2 (-14;7.6)	13.7	27.7	-14 (-25.1; -2.9)
2009-10	20.5	2.7	17.8 (1.2;34.3)	2.1	8.3	-6.2 (-11.3;-1.1)	22.2	21.2	1 (-11.9;14)
2011-12	9.1	12.7	-3.6 (-13;5.8)	3.1	12	-8.9 (-14.5; -3.4)	13.3	21.5	-8.2 (-20.2;3.8)

5.5 Discussion

This paper aimed to assess the data quality of the first Gambian DHS and compare its estimates to those from the MICS and censuses in The Gambia. We first discuss the quality of data used for indirect and direct estimation of under-five mortality through consistency checks and compare the DHS to available data sources.

The internal consistency checks on the quality of data from six sources (MICS 2000, 2005 and 2010; Census 2003 and 2013 and DHS 2013) suggest that the data were plausible at national level once the 15-19 year age group was excluded. These estimates based on the 15-19 age group are probably biased upward compared to estimates for the population as a whole as very young mothers experience higher child mortality than older women. Additionally, a study conducted to evaluate the accuracy of estimates from responses by 15-19 year olds and 20-24 year olds in demographic health surveys conducted consecutively showed that there were marked differences in reporting by age group. Women aged 15-19 reported less accurately about their first births and first marriage, potentially due to social desirability and prevailing cultural, social and legal circumstances. Thus, estimates based on reports by younger women should be viewed with caution, particularly in sub-Saharan Africa ^{298, 334, 336}. It should be noted, moreover, that these consistency checks do no more than establish that the data are not grossly deficient as they only test for reliability of the data based on the expected patterns^{19, 297}. The regional data on average parities showed minor deviations from expected patterns, and in Basse inconsistencies in proportions dead of children ever born were observed, particularly in the MICS data. Data from both HDSS sites had complete dates of birth and death. However, inspection of the distribution of reported day of birth and death in the Basse HDSS data revealed that the first day of the month was by far the most frequently reported, therefore, to minimise the potential impact on the neonatal and post-neonatal mortality estimates, imputation was done preserving month and year data.

The Gambia DHS final report states that 87% of neonatal deaths occurred in the early neonatal period and is an indication that NMR was not under-reported; it however

failed to point out that late neonatal deaths were notably absent, skewing upwards the early neonatal mortality to neonatal mortality ratios (ENMR: NMR)²². This was also seen in Ethiopia, where health extension workers were found to report more early neonatal deaths³³⁷ contrary to 70-80% for early neonatal deaths in other low resource settings³³⁸. DHS have been found to underestimate early neonatal mortality, but in The Gambia, although neonatal mortality may be underestimated, it is the late neonatal mortality that appears more severely under-reported³³⁹.

The lack of reporting of late neonatal deaths is mirrored in many DHS, and several possibilities may explain the high ENMR: NMR ratios^{340, 341}. First, stillbirths may be misreported as early neonatal deaths thereby inflating deaths in the early neonatal period, or second, late neonatal deaths may be shifted to the post-neonatal period thereby underreporting neonatal mortality. It may also reflect a true picture of high early neonatal mortality whose aetiology and management differ from that of late neonatal mortality^{273, 341}. Although there was no evidence of age heaping in HDSS and DHS as our estimates fell within expected boundaries³⁴², the NMR: IMR and NMR: U5MR ratios in the DHS were incongruent and fluctuating compared to established patterns. Given that it is highly improbable that the sampled women in the DHS did not have late neonatal deaths yet there are virtually no late neonatal deaths recorded, both scenarios explained above, that is, that late neonatal deaths were reported as post-neonatal deaths, or that stillbirths were reported as early neonatal deaths are likely in the Gambia and contribute to the deviations from expected ratios of under-five mortality. However, in light of the very low national stillbirth rates, estimated at 11/1000 births for five years prior to the Gambia DHS²², it is likely that there is high early neonatal mortality in The Gambia and an undercount of stillbirths, as early neonatal deaths, stillbirths and maternal deaths are interlinked, and the number of stillbirths is expected to mirror the number of early neonatal deaths¹¹. According to the 2013 Gambia census, the maternal mortality ratio (MMR) was 861/100,000 livebirths in the year prior to the census, therefore the low stillbirth rates in the Gambia do not reflect the true situation³⁴³. Regionally, variability in the child mortality ratios were seen in both DHS and HDSS but were within expected values for the HDSS implying

better HDSS data quality. HDSS quality was also improved when imputation of data was done to counter date preference seen in Basse HDSS.

The consistency of the estimates from the different inquiries was also assessed. The MICS under-five mortality estimates for more than five years prior to the survey were higher than those from the DHS, while the national census estimates were lower than those from other data sources²⁷². The discrepancy between the MICS and DHS data of up to 50/1000 livebirths cannot be fully explained by misreporting of stillbirths as neonatal deaths. It is also unlikely that women reported deaths that did not occur in the MICS. This suggests that DHS data quality declines for earlier periods, that is, the data supplied by older women in the DHS are deficient, and significantly underestimate mortality. The low DHS mortality estimates in earlier periods should therefore be interpreted cautiously as dead children are likely omitted. At the regional level, census estimates for Basse were markedly lower than those from the other data sources, even in comparison to the lower census estimates at national level, pointing to inaccuracy of census data on child mortality in Basse region.

A comparison of direct and indirect estimates using DHS data suggested that the assumptions involved in making indirect estimates did not strongly distort the estimates and validates the choice of the Princeton South model. This in turn implies that the indirect estimates from MICS are indicative of the overall extent of decline in under-five mortality in The Gambia since the 1990s. Consistency of direct and indirect estimates also implies that no evidence exists of gross errors in reporting of dates and ages at death in the DHS in the last decade³⁴⁴. Because deaths of children of a cohort of women do not all occur at the same time but are spread over several years, the indirect estimates tended to smooth out the fluctuations in the direct estimates. According to Silva, direct and indirect methods of estimation for under-five mortality can be interchanged for populations that did not experience shocks in mortality and fertility for the five-year age groups between 25-39 years³⁴⁴.

The DHS and HDSS used to make direct under-five mortality estimates were of reasonably good quality for the recent past. In Basse, the DHS and HDSS estimates of

neonatal, post-neonatal and child mortality for 2009-2012 were similar. The estimates of under-five mortality from the Farafenni HDSS and for Kerewan region in the DHS are also comparable, but differences existed in those of neonatal and post-neonatal mortality. Using 2010 as the benchmark for the differences, we see that prior to 2010, the Kerewan DHS reported significantly higher neonatal mortality estimates, while after 2010, the Farafenni HDSS reported significantly higher post-neonatal mortality rates. The low HDSS 2009-10 estimate of NMR could be due to undercounting following recent resumption of surveillance activities after the station closure.

In particular, lower neonatal mortality rates in the HDSS could be a result of early deaths not being reported by male heads of households who act as respondents and who may choose to withhold information for instance if a pregnancy occurred out of wedlock or if the child died soon after birth without being named³⁴⁵⁻³⁴⁷. As the neonatal period is short, a neonate who is born and subsequently dies in the period between two rounds of fieldwork may be entirely missed if the pregnancy was not recorded and the death is not revealed. Regarding Kerewan DHS, the most recent under-five mortality estimates (2011-12), particularly in the post-neonatal period are uncharacteristically low, but the sample size on which it is based is quite small and thus caution is advisable when interpreting these differences.

Both the DHS and HDSS showed that child mortality was the major contributor of under-five deaths until recently. By 2011 however, neonatal mortality had gained prominence. High child mortality is consistent with other data for sub-Saharan data as infections in those aged 1 to 4 years still cause over 60% of under-five deaths in sub-Saharan Africa³⁴⁸.

Our assessment that the MICS can be used to measure the national trend in infant and child mortality implies that under-five mortality in The Gambia dropped from >200/1000 livebirths in the 1980's to 109/1000 livebirths in mid-2004. Although DHS estimates for earlier periods implied under-reporting of dead children by older women, for the most recent five-year period, the DHS estimates agreed well with the census and MICS reports of under-five mortality. According to these estimates, by

2011-12, a further drop in under-five mortality to 54/1000 live births occurred, and neonatal deaths comprised 40% of under-five mortality. As child mortality levels drop, neonatal mortality gains greater significance in under-five mortality^{235, 349, 350}.

Globally, in the past 25 years, progress against neonatal mortality has been slow, with only a 47% decline compared to the 58% decline in post-neonatal mortality and more than 50% reduction in overall under-five deaths³²⁶. The fourth millennium development goal aimed at reducing child mortality by two-thirds from 1990-2015 and the new targets set for 2030 by the sustainable development goals aim to further reduce under-five mortality to less than 25/1000 livebirths and neonatal mortality to less than 12/1000 livebirths³. In The Gambia, several targets for the MDGs were proposed depending on what estimate was adopted of under-five mortality in 1990. They ranged from 45-67.5/1000 livebirths^{351, 352}. As our estimates place the U5MR at 135/1000 livebirths for the year 1990, the 45/1000 target for under-five mortality seems most legitimate. Based on this, The Gambia almost achieved the fourth MDG, attaining a 60% reduction, compared to the targeted 67% reduction, in under-five mortality. This decline has been attributed to proper prevention and treatment of malaria, appropriate and timely case management of childhood illnesses and immunization where national measles coverage reached 95% by 2013^{353, 354}.

Neonatal mortality is gaining prominence as the mortality of older children drops in The Gambia. In the period 2009-2013, the three top causes of neonatal deaths in Gambia's teaching hospital were preterm birth complications, severe infection and intrapartum related events, while almost 50% of new-born babies seen in the hospital suffered from hypothermia at admission⁹⁹. Apart from over-administration of antibiotics for infection, other aspects of new-born care were found to be sub-optimal⁹⁹. In The Gambia inadequate human resources, deficient infrastructure and training of personnel, underfunding of health services and glaring health system inadequacies characterise health care^{287, 355, 356}.

The 2012-20 Gambian National Health Policy and 2014-20 Strategic Plans aimed to introduce free maternal and child health care, to improve doctor to patient ratios and

increase access to insecticide-treated bed nets to further improve child survival. These reports acknowledge that the bulk of under-five mortality in The Gambia consists of neonatal deaths. Several policies mentioned that relate to reduction of neonatal deaths include improvement in antenatal care through incentivization, skilled birth attendance, integrated management of neonatal illness and improved contraceptive use. None of these reports provide targets for stillbirths, but both mention perinatal audits in health facilities as strategies to improve maternal and newborn health. While this is encouraging, stillbirths and neonatal deaths that occur at home are unlikely to be captured^{274, 275}.

Other interventions that can greatly decrease intra-partum related neonatal mortality include availability of basic resuscitation in all birth settings and increased facility deliveries even in the current low coverage of emergency obstetric care³⁵⁷. Additional essential interventions include immediate thermal care and initiation of breastfeeding, hygiene and cord care, kangaroo mother care for preterm babies and medical interventions such as corticosteroid and surfactant use as well as case management of neonatal infections^{358, 359}. If they are scaled-up successfully, these interventions have been demonstrated to decrease neonatal mortality by up to 90% for neonatal infection and asphyxia-related deaths and prevent almost 60% of mortality related to complications arising from prematurity³⁶⁰.

5.6 Conclusion

The first Gambian DHS collected reasonably good quality data on infant and child mortality during the last decade, but less accurate data about the early births of older women. The availability of disaggregated estimates of under-five mortality from the DHS reveals that The Gambia has experienced a large decline in both under-five mortality and, more recently, neonatal mortality. Neonatal mortality now makes a substantial contribution to under-five deaths. Our DHS-based estimates of neonatal and under-five mortality for the period surrounding 2010 (average rates for 2009-2012) are 23 and 56/1000 livebirths respectively. The Gambia will need to halve both these rates over a twenty-year period if it is to achieve the SDG goal of neonatal

mortality of 12 per 1000 live births and an under-five mortality rate of 25/1000 livebirths by 2030.

As available interventions are under-utilized or lacking, The Gambia needs to initiate essential new-born care packages to improve neonatal survival on a country-wide basis, whilst maintaining or scaling up coverage of successful interventions that resulted in sustained decline in the other components of under-five mortality.

The HDSS data for The Gambia have improved over time, particularly since 2011 in Basse. The U5MR estimates derived from them are typical of the regions in which they are located. As about 13% of the country's population is under continuous surveillance, they are well placed for monitoring of SDGs. Recent advancements in Gambian HDSS include the introduction of electronic data capture which improves timeliness and quality of data. Measures that should improve data quality in the HDSS include improving the tracking of pregnancies and their outcomes, initiating direct interviewing of women, linking the HDSS data to health facility records, and further improve the training of fieldworkers. Effective tracking of pregnancy outcomes in the HDSS would also provide data for estimation of stillbirth rates which currently are under-reported in The Gambia.

5.7 Funding

The funder of the study had no role in study design, data collection, data analysis, data interpretation and writing of the report. AJR had full access to the data and had final responsibility to submit for publication.

5.8 Contributors

AJR managed the research process, including data curation, analysis and interpretation of the results and wrote the first draft. MJ contributed to data curation and data analysis. SCA contributed to data analysis and review of the manuscript. AR reviewed drafts and final paper. GR contributed to data analysis, revised drafts and the final paper. IMT contributed to the design of the study, data analysis, interpretation of results, and review and revision of drafts and the final paper.

Declaration of interests

We declare no competing interests.

5.9 Acknowledgements

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Research paper cover sheet

Chapter 6 On improving the reporting of pregnancy and its outcomes: A comparison of a pregnancy history survey and repeated cross-sectional follow up in The Gambia



6.1 Abstract

Background: In developing countries with incomplete civil registration and vital status systems, pregnancy information is commonly collected from women retrospectively through surveys and occasionally prospectively through surveillance. However, the mode of data collection and the context in which the research is conducted could affect the reporting of pregnancy and pregnancy outcomes.

Objective: This study assesses whether pregnancy histories and routine surveillance of pregnancies in HDSS are suitable for the capture of pregnancies and their outcomes, which are core to estimation of neonatal and perinatal mortality. It compares at the individual-level the completeness with which pregnancy and pregnancy outcomes are reported in retrospect using pregnancy histories and during ongoing surveillance within a HDSS

Methods: A pregnancy history survey was conducted by female interviewers in Basse HDSS. Women were then individually matched to their routinely collected pregnancy data and these reports were compared.

Results: 86% of surveyed women were matched to the HDSS. Both the HDSS and the Survey reported adequately on livebirths. However, 1,000 more live births and 700 more adverse pregnancy outcomes were reported in the pregnancy history survey compared to HDSS. The HDSS had complete date reporting unlike the Survey. Consistent reporting of the number of pregnancies was severely affected by the experience of a pregnancy loss or a child's death (AOR 0.10; 95% CI 0.08-0.13). Women with such experiences were up to 16 times more likely to report more pregnancies in the survey than in HDSS (RRR 15.5 (13.0-18.4)).

Conclusions: Both pregnancy histories and routine pregnancy surveillance in HDSS are suitable for the capture of livebirths, with HDSS having better data quality. However, pregnancy histories result in more complete data on pregnancy losses.

Contribution: The analysis of individually-matched data on pregnancies is the first in sub-Saharan Africa to our knowledge. This research represents the largest sample analysed relative to previous research. It shows that a pregnancy history questionnaire,

is valuable in identifying adverse pregnancy outcomes and child deaths. It also identifies that pregnancy loss and bereavement severely affects consistent reporting, and therefore surveys on mortality should take this into consideration.

6.2 Introduction

The 2015 deadline for achievement of the Millennium Development Goals (MDGs) brought into sharp focus the need for timely, reliable and actionable data with which to monitor progress. As a result, the Sustainable Development Goals (SDGs) include targets to improve data quality, availability, timeliness and accuracy by 2020². However, poor data quality remains a major problem in developing countries. Currently, the SDGs targets include the reduction of under-five mortality to less than 25 deaths per 1000 livebirths and neonatal mortality to less than 12 deaths per 1000 livebirths by 2030³. Nevertheless, despite the SDGs call to leave no one behind, 2.6 million families who have had stillbirths have been neglected as no targets for stillbirths are included³⁶¹. A more inclusive approach towards the health of mothers and their babies would encompass all the mother's pregnancy outcomes, including stillbirths and miscarriages or abortions, and not only focus on liveborn children. One step toward this holistic approach would be to account for stillbirths in the national and global statistics and specify targets for the reduction of perinatal mortality.

Africa still lags behind other regions in setting up and utilizing sustainable health information systems that encompass all health data sources required by a country to plan and implement its national health strategy⁸. Potential sources of data on mortality outcomes include population surveys, census data, health facility data, surveillance data and vital event records. Only Mauritius out of 46 WHO Africa region members collects high quality vital registration data useful for monitoring mortality^{227, 362}. The lack of existing or complete civil registration of deaths in the rest of Africa poses a big challenge to the timely and accurate measurement of mortality. Concerning perinatal mortality, although all African countries enforce birth registration in principle, only half monitor foetal deaths³⁸. Other aspects of health information systems such as health facility data are also unreliable and not comprehensive.

Achieving up-to date health information systems, and particularly vital registration systems, by 2020 is highly unlikely in low and middle-income countries, even with substantial investment. Thus, developing countries mostly rely on censuses and demographic health surveys⁸. Questions on children ever born and children surviving can be asked in censuses and used to calculate under-5 mortality¹⁸². However, no data are collected on stillbirths, and thus censuses are of little value for perinatal mortality estimation. Censuses are also costly. Hence in most countries they are conducted decennially and are therefore not timely for estimation of perinatal and neonatal mortality.

Demographic health surveys, on the other hand, use either birth or pregnancy history questionnaires to collect data for mortality estimation¹⁸. Birth history questionnaires only collect data on children ever born alive to a woman, whereas the pregnancy history retrieves information on all pregnancies and their outcomes. Surveys based on a birth history are ill-adapted to measure perinatal mortality, therefore, as they do not include stillbirths, unless the history is supplemented with additional questions or a reproductive calendar^{18, 53, 232}.

A number of previous studies have compared retrospective reporting of women's pregnancies or births with estimates from longitudinal Health and Demographic Surveillance Systems (HDSS). HDSS follow up a geographically-limited population over time, recording vital events among residents. Some HDSS carry out routine surveillance of pregnancies. The first study to evaluate the performance of pregnancy and birth history questionnaires compared child mortality estimates from the Matlab HDSS, Bangladesh to those from a survey that was conducted within it in 1994. The researchers randomly selected participants for interview using either questionnaire, and the HDSS was considered the gold standard. This study found some significant differences; pregnancy and birth histories both performed well in identifying livebirths, each having 99% completeness rates. However, the birth histories omitted more dead children (OR 22.5) and were twice as likely to omit livebirths as the pregnancy histories. Additionally, both pregnancy and birth histories had low levels of

completeness for early neonatal deaths. The researchers in Matlab did not report on perinatal mortality¹⁹.

In Africa, two further studies, both in rural Uganda, have similarly compared pregnancy histories from surveys to longitudinal surveillance. Researchers in Iganga-Mayuge HDSS asked women about their pregnancy histories and compared findings to routine HDSS for the period 2006-2011²¹. Overall, the pregnancy history was marginally better for reporting of pregnancy outcomes, with more adverse pregnancy outcomes reported in the year prior to the survey. However, even in this study, the HDSS performed better for earlier periods. The second study was in the General Population Cohort in Rakai. It utilized annual pregnancy data covering the period 1996-2013 and compared these data to a pregnancy history survey²⁰. This study focused on stillbirths and abortions and reported that routine surveillance and pregnancy history had similar abortion rates, but that the pregnancy history reported half of the HDSS stillbirth rates. This study also found that advanced maternal age and non-attendance of antenatal clinics were associated with higher risk of a lifetime experience of adverse pregnancy outcomes.

The DHS programme has compared estimates of neonatal and perinatal mortality from pregnancy histories against augmented birth histories, which are birth histories with additional questions asking about the number of stillbirths and miscarriages, in 168 demographic and reproductive health survey data sets across all world regions. This comparison showed that average stillbirth rates based on the pregnancy histories were 50% higher than those from augmented birth histories, but that both tools under-estimated stillbirths considering that over 90% of the surveys had stillbirth rates to early neonatal mortality rates lower than the expected 1.2:1 ratio. Only Ghana, Nicaragua and Paraguay had at least two surveys that utilized either birth or pregnancy history questionnaires, and for these countries no conclusion could be reached regarding the superiority of either tool for neonatal or perinatal mortality measurement¹⁸.

While it seems that in well-conducted surveys, livebirths are well captured by both pregnancy and birth histories, the contrasting findings on adverse pregnancy outcomes do not clearly indicate which of the two methods, pregnancy history or routine surveillance of pregnancies, is better suited for reporting of adverse pregnancy outcomes. It also points to the fact that reporting of adverse pregnancy outcomes could vary between contexts even within the same country. The Iganga-Mayuge researchers postulated that gender norms, sociocultural factors and choice of respondent may bias data collection of what may be legally or culturally sensitive information²¹.

Approximately half of the sites that are members of INDEPTH, a consortium of HDSS in low- and middle-income countries, actively track pregnancy and its outcomes. This surveillance of pregnancies is done to monitor neonatal health interventions and improve morbidity and mortality measurements²⁰⁹. However, few HDSS collect data on stillbirths, and those that do have data of varying quality¹⁷. In certain settings, sociocultural factors may influence data collection, for example where male fieldworkers are not allowed to interview females, or normative pressure is exerted on women to conceal pregnancy^{23, 214, 363}. Adopting a gender-sensitive data collection method in such settings may improve the quality of pregnancy information.

The focus of this paper is on the reporting of pregnancies by matched women, whereby each woman's pregnancies as reported retrospectively in the survey is compared to prospectively collected data on her pregnancies from the HDSS. This is done to provide insight into the ability of HDSS and pregnancy histories to capture of pregnancies and thereby the pregnancy outcomes that are key to measurement of neonatal and perinatal mortality.

6.3 Methods

Study setting

The Gambia is in West Africa and is the smallest country in continental Africa. Basse, where this survey was carried out, is in the eastern-most part of the country, about 375km from Banjul, the capital city.

It is the least developed administrative region and is one of the three regions with the highest maternal and peri/neonatal mortality rates²². Basse has a total population of 239,916²⁶². The main languages spoken are Fula, Serahule and Mandinka, and the main source of income for residents is agricultural activities. The Medical Research Council The Gambia at London School of Hygiene and Tropical Medicine runs an HDSS in Basse. Surveillance commenced in July 2007, mainly to support the Global Enteric Multicentre Study and the Pneumococcal Surveillance Projects, but the HDSS has hosted and continues to support several other studies.

HDSS update rounds are undertaken four-monthly in January-April; May-August and September-December. The population under follow up is about 180,000 in 225 villages in Fulladu East and Kantora Districts in Upper River Region, covering the entire region south of the River Gambia as at 31 December 2016.

Study design

A cross-sectional pregnancy history survey was conducted in Basse HDSS over a six-month period between 16th December 2015 and 4th June 2016. It employed female interviewers to interview women directly about their pregnancies and pregnancy outcomes to determine if this would yield more information. The survey used a modified backward pregnancy history questionnaire to ask women about each of her pregnancies in turn, starting with the most recent.

All households in Basse HDSS have an identification number that is generated by combining the regional, compound and location identifiers. For each individual, an additional three digits are added to the household identifier to create a unique number which is retained even if the individual migrates, and which can be reinstated on re-entry to the HDSS. Tablets were used for electronic data capture. Female interviewers were provided with listings of the household identifiers, which were preloaded in the tablets along with the pregnancy history questionnaires. They interviewed every woman of reproductive age that they found in the household. As residents of HDSS do not have their unique identification numbers with them, survey data were matched to the HDSS on completion of the study using the household identifiers to locate

households in the database first, and then matching the women within each household.

Figure 6.1 represents the flow of events as occurred in the survey. Although a total 8,529 women aged of reproductive age were recruited during the survey, 1,234 of them could not be traced in the BHDSS and therefore this study had a match rate of 86%. These women were excluded from further analysis. Also excluded were 899 women who were identified in both the survey and HDSS as being nulliparous, and 697 women who failed to report the year of occurrence of at least one of their pregnancies, all of whom were in the Survey data set as HDSS data did not have missing information. The 697 women were excluded from analysis to avoid inflating the number of pregnancies per woman resulting from merging both data sets. For women who were pregnant at the time of survey, only their previous pregnancies and outcomes were included in the analysis. Since we were comparing pregnancies among women based on the year of occurrence, the analysis was restricted to full year data covering the period January 2009 to December 2015. The HDSS pregnancy outcome data for the initial years of surveillance (2007-2008) were discarded, as they were grossly incomplete.

The pregnancies of the remaining 5,090 women with complete pregnancy information were matched on year of birth (the same as the year of pregnancy outcome; these terms are used interchangeably in the text) in two steps. First, pregnancies were matched using the reported year of birth in both Survey and BHDSS. However, to account for possible incorrect reporting of year of birth in the Survey, in a second step, unmatched pregnancies from the first step were re-matched in adjoining years, using the HDSS year of birth as the reference value as these were complete. Pregnancies reported to have occurred in 2008 in the Survey were included to allow them to be matched with 2009 BHDSS pregnancies. For this subset for instance, if a woman reported a pregnancy in 2010 in the Survey, but she had an unmatched pregnancy in the BHDSS in 2009, these two pregnancies would then be matched.

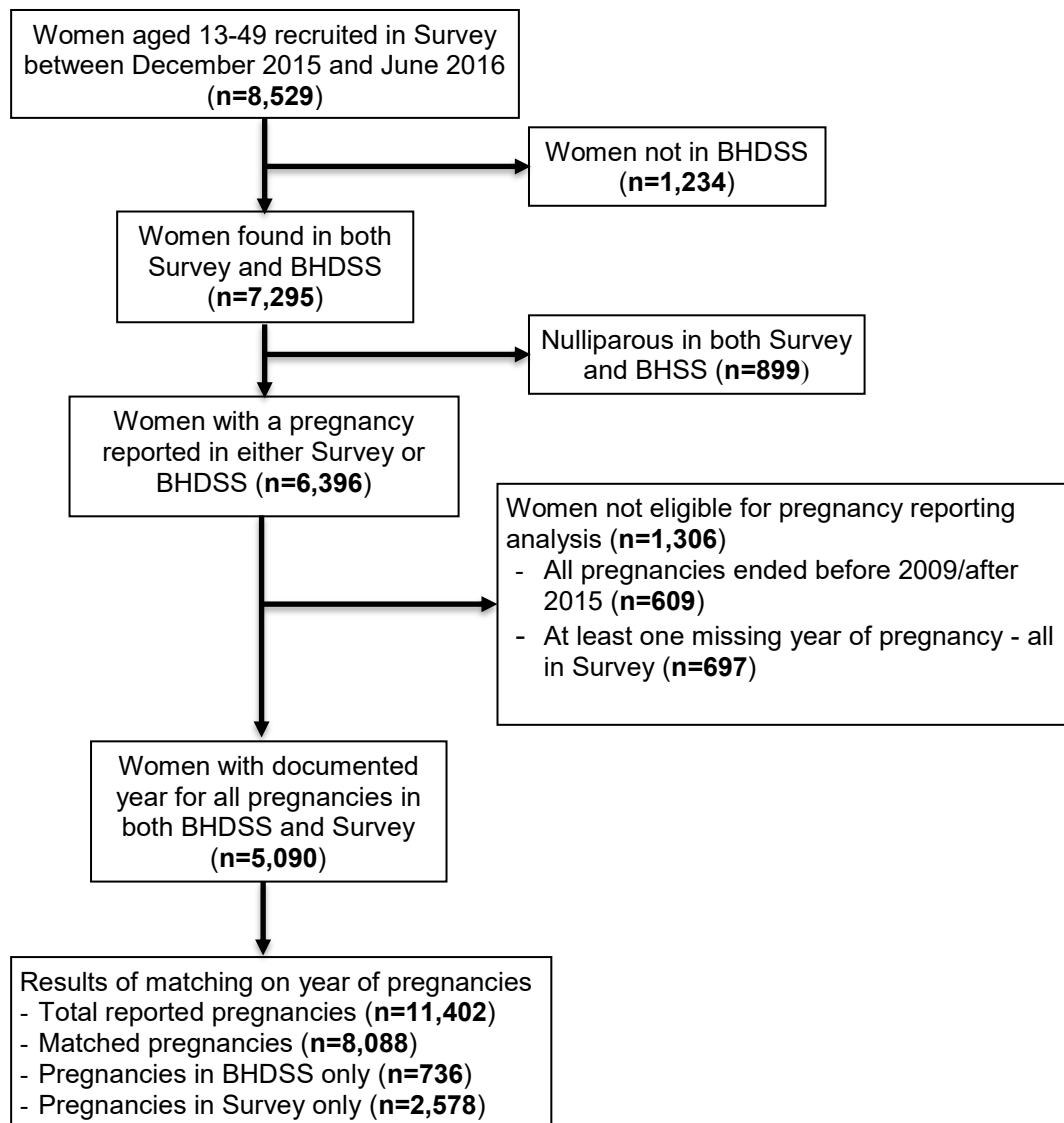


Figure 6.1: Flow diagram of derivation of sample included in the analysis.

To ensure that no double matching occurred in the event that two pregnancies in the Survey occurred within one-year of an unmatched pregnancy reported in the BDHSS, the pregnancy outcome and child's name was used to determine the more likely match. Pregnancies reported in 2008 in the Survey that were not matched to a 2009 pregnancy in the HDSS were excluded from this analysis.

The proportion of pregnancies that were matched per woman (the denominator being the number of pregnancies reported only in the HDSS database, plus those reported only in the survey database, plus the matched ones) was computed. Thus, the outcomes of interest at the woman level are the number of reported pregnancies in

each data source and maternal consistency of reporting of pregnancy defined as the proportion of matched pregnancy outcomes across both data sources. The outcome of interest at the child level is the reporting of a pregnancy outcome (livebirth, stillbirth, miscarriage or abortion) in any data source. Results of analyses strictly based on reported year of birth are presented after the analysis that accounts for misreporting of year of pregnancy outcome in Survey.

Statistical analysis

The number of reported pregnancies at the women level in the BHDSS and survey data sets were compared using a Wilcoxon matched-pairs signed-rank test. The positive percent agreement (PPA) was estimated while accounting for the clustering effect at the women level. The PPA was calculated assuming both the BHDSS and the Survey to be the reference source. When the HDSS is used as the reference source, the PPA provides the percentage of pregnancies identified in the survey out of all pregnancies in the HDSS. Likewise, using the survey as the reference source, the PPA corresponds to the percentage of pregnancies identified in the HDSS out of all pregnancies in the survey.

Then, univariable and multivariable fractional logit regression³⁶⁴ was used to model the proportions of matched pregnancies per woman. Conventional logistic regression is inappropriate because the proportions of matched pregnancies for each woman are quantities that vary between 0 and 1 (equal to 0 if there is no matched pregnancy across BHDSS and survey and equal to 1 if all reported pregnancies matched on their year of end). Fractional logit regression, however, accommodates dependent variables bounded by 0 and 1 with 0 and 1 included, and provides consistent estimates, that is, the estimates that get close to the true value as the sample size increases. When the dependent variable is a probability, as in this analysis, the fractional logit regression provides odds ratios (ORs) that have a similar interpretation to those obtained by means of conventional logistic regression. Factors influencing women's reporting of pregnancies by data source were sought using multinomial multivariable regression. Analysis was done in Stata v15.1.

6.4 Results

Characteristics of women in both the survey and HDSS compared to women in the survey

In total, 7,295 women were found in both HDSS and the survey. Table 6.1 displays the comparative characteristics of these women with those not in the BHDSS. We distinguish between women with complete pregnancy information, nulliparous women, those ineligible for further analysis as all their pregnancies were outside the study timelines, women with incomplete year of pregnancy information in the Survey, and those not found in the BHDSS. The age distributions in these groups differ but are plausible. For instance, 61% of nulliparous women in Survey and BHDSS are younger than 20 years.

Over 80% of women whose pregnancies ended before 2009 were older than 30 years, while it was mainly younger women who had all their pregnancies after 2015. Women eligible for analysis follow the expected age distribution, with younger and older women being fewer in number than those aged between 20 and 40 years. Of the surveyed women who were not found in BHDSS, over 30% had missing data on age, while most of the remaining women were young (<30 years of age). All groups found in the BHDSS had a similar distribution according to education and ethnicity, and most women belong to the Serahule or Fula ethnic groups. Three-quarters of women not found in BHDSS were classified as not having attended school or having a non-Islamic education. Almost a third did not report their ethnicity. Of those whose ethnic groups were reported, their ethnic distribution followed a similar pattern to the other groups.

Table 6.1: Characteristics of women of reproductive age recruited in Survey

Characteristics	Women eligible for pregnancy reporting analysis n=5,090 (100%)	Nulliparous women in both Survey and BHDSS n=899 (100%)	Women in both Survey and BHDSS, pregnancy ended before 2009/after 2015 n=609 (100%)	Women interviewed in Survey who had at least one missing year of pregnancy n=697 (100%)	Women interviewed in Survey but not found in BHDSS n=1,234 (100%)
Age					
Below 20	248 (4.9)	552 (61.4)	22 (3.6)	55 (7.9)	427 (34.6)
20-29	2,348 (46.1)	282 (31.4)	74 (12.2)	220 (31.6)	257 (20.8)
30 - 39	1,779 (34.9)	26 (2.9)	172 (28.2)	216 (31.0)	96 (7.8)
40 and above	695 (13.6)	16 (1.8)	339 (55.7)	204 (29.3)	54 (4.4)
Missing	20 (0.4)	23 (2.6)	2 (0.3)	2 (0.3)	400 (32.4)
Education					
Non-Islamic	3,221 (63.2)	617 (68.6)	357 (58.6)	452 (64.9)	910 (73.7)
Islamic	1,869 (36.8)	282 (31.4)	252 (41.4)	245 (35.1)	324 (23.3)
Ethnicity					
Mandinka	1,075 (21.1)	259 (28.8)	148 (24.3)	181 (26.0)	194 (15.7)
Serahule	2,152 (42.3)	298 (33.2)	242 (39.8)	228 (32.7)	340 (27.6)
Fula	1,740 (34.2)	309 (34.4)	200 (32.8)	270 (38.7)	295 (23.9)
Other	123 (2.4)	33 (3.6)	19 (3.1)	18 (2.6)	42 (3.4)
Missing	0 (0)	0 (0)	0 (0)	0 (0)	363 (29.4)

Agreement on the pregnancy reporting at the women level across data sources

Among 5,090 women with a documented year for all pregnancies in both the BHDSS and Survey, 3,035 (59.6%, 95% CI: 58.3-61.0) reported the same number of pregnancies. In an analysis that uses the data matched on exact year of pregnancy outcome, 2,959 (58.1%, 95% CI: 56.8-59.5) women reported the same number of pregnancies. Regardless of the matching method, the median number (range) of reported pregnancies per woman was 2 (0-7) and 2 (0-6) for the Survey and BHDSS, respectively. There was strong evidence that women reported more pregnancies in the Survey ($p < 0.001$).

Agreement in pregnancy reporting across data sources

In total, 11,402 pregnancies ending between January 2009 and December 2015 were reported after combining the BHDSS and Survey reports using the reported year of birth in the survey and allowing initially unmatched pregnancies to be matched to pregnancies in adjacent years. The first panel of Table 6.2 presents these results. The percentage of matched reported pregnancies was 70.9% (95% CI: 69.9-71.9). The Survey picked up 92% (95% CI: 91.0-92.2) of the pregnancies reported in the BHDSS, while the HDSS picked up 76% (95% CI: 74.8-76.8) of the pregnancies reported in the Survey. The second panel looks at the agreement in the reporting of pregnancies if only matching on the reported year of birth in the survey is used. Here, 12,261 pregnancies are reported, and the percentage of matched reported pregnancies was lower at 57% (95% CI: 55.9-58.1). The Survey picked up 80% (95% CI: 79.2-81.0) of the pregnancies reported in the BHDSS, while the HDSS picked up 66% (95% CI: 65.3-67.4) of the pregnancies reported in the Survey. If misreporting of year is allowed for in the survey, the values are higher than when it is ignored.

Table 6.2: Agreement between Basse HDSS and Survey data on pregnancies reporting by women

Pregnancy reporting in HDSS	Pregnancy reporting in Survey			Percentage of agreement (95% CI) ^a	PPA ^b using HDSS as reference (95% CI) ^a	PPA ^b using Survey as reference (95% CI) ^a	
	Reported	Not reported	Total				
Reported year of birth ± 1 year	Reported	8,088	736	70.9 (69.9-71.9)	91.7 (91.0-92.2)	75.8 (74.8-76.8)	
	Not reported	2,578	0				
	Total	10,666	736				11,402
Reported year of birth only	Reported	6,985	1,736	57.0 (55.9-58.1)	80.1 (79.2-81.0)	66.4 (65.3-67.4)	
	Not reported	3,540	0				3,540
	Total	10,525	1,736				12,261

^a 95% confidence intervals accounting for the clustering effect at the women level. ^b Positive percent agreement (PPA).

Factors associated with consistent reporting of number of pregnancies

The proportion of matched reported pregnancies (out of the pooled pregnancies across BHDSS and Survey) at the woman level was used as a measure of the consistent reporting of the number of pregnancies. Table 6.3 shows the results from the fractional logistic regression assessing the association between maternal characteristics and women's likelihood of consistently enumerating their pregnancies in both data sources (BHDSS and Survey) allowing for misreporting of year of pregnancy in the Survey. These women characteristics were maternal educational background, her ethnicity, age and parity at interview. Others were whether a woman had ever experienced an adverse pregnancy outcome or had a liveborn child who later died.

In the unadjusted model, there was no evidence of any association between maternal educational background and the consistency of reporting of pregnancies ($p=0.88$). Fula women were more likely than women from other ethnic groups to report the same number of pregnancies in the Survey and HDSS ($p=0.04$). However, the youngest and oldest women were least likely to report pregnancies consistently ($p<0.001$). No association was found between maternal parity and consistent reporting of pregnancies ($p=0.25$). The experience of an adverse outcome or a child's death was strongly associated with reduced consistency in reporting of pregnancies ($p<0.001$).

In the adjusted model, maternal ethnicity, age, parity and the experience of an adverse outcome or a child's death had significant associations with consistent reporting of pregnancy outcomes. Fula women were more consistent in reporting pregnancies than other ethnic groups (AOR 1.18; 95% CI 1.03-1.34). Compared to women aged 20-29, the odds of consistent reporting of pregnancy were reduced by 61% for women aged less than 20 years (AOR 0.39; 95% CI 0.30-0.50), and by a fifth for women older than 40 years (AOR 0.80; 95% CI 0.67-0.95). Likewise, women with three or more pregnancies had 25% lower odds of consistently reporting the number of pregnancies they have had than women with one or two pregnancies (AOR 0.75; 95% CI 0.67-0.83). Women who reported an adverse pregnancy outcome had 90% lower odds of consistently reporting their pregnancies than women whose children were still living (AOR 0.10; 95% CI 0.08-0.13).

The analysis based on reported year of birth only shows similar associations between maternal characteristics and consistent reporting of her pregnancies to the analysis allowing for misreporting of year of pregnancy. However, two exceptions are noted. First, in the unadjusted analysis women with three or more pregnancies have almost 40% lower odds of consistently reporting the number of her pregnancies (AOR 0.61; 95% CI 0.56-0.67) yet this is not significant in the analysis allowing for misreporting of year of pregnancy. Second, in the adjusted model fitted to these data, maternal ethnicity is not associated with consistent reporting of number of pregnancies, but the association appeared in the analysis of data that allows for misreported year of pregnancy occurrence in the survey.

Table 6.3: Association between women characteristics and proportion of matched pregnancies at the woman level

Woman characteristics	Year of Birth \pm 1 year		Year of Birth only		Year of Birth \pm 1 year		Year of Birth only	
	OR (95% CI) ^a	p ^b	OR (95% CI) ^a	p ^b	Adjusted OR (95% CI) ^a	p ^b	Adjusted OR (95% CI) ^a	p ^b
Education (ref. Non-Islamic)		0.88		0.83		0.84		0.80
Islamic	1.01 (0.90-1.13)		0.99 (0.89-1.10)		1.01 (0.90-1.14)		1.01 (0.91-1.13)	
Ethnicity (ref. Serahule)		0.04		0.05		0.04		0.34
Fula	1.18 (1.04-1.34)		1.14 (1.01-1.29)		1.18 (1.03-1.34)		1.08 (0.96-1.23)	
Mandinka/Other	1.08 (0.94-1.24)		0.97 (0.85-1.11)		1.11 (0.96-1.28)		0.99 (0.86-1.13)	
Women age (ref. 20-29)		<0.001		<0.001		<0.001		<0.001
Below 20	0.44 (0.34-0.56)		0.57 (0.45-0.73)		0.39 (0.30-0.50)		0.41 (0.32-0.54)	
30 – 39	1.16 (1.04-1.30)		1.04 (0.93-1.15)		1.29 (1.14-1.46)		1.16 (1.03-1.31)	
40 and above	0.75 (0.64-0.88)		0.79 (0.68-0.92)		0.80 (0.67-0.95)		0.79 (0.66-0.94)	
Number of pregnancies (ref. 1-2)		0.25		<0.001		<0.001		<0.001
3-7	0.95 (0.86-1.04)		0.61 (0.56-0.67)		0.75 (0.67-0.83)		0.54 (0.49-0.61)	
Pregnancy outcome (ref. Alive)		<0.001		<0.001		<0.001		<0.001
Born alive but died	0.46 (0.37-0.57)		0.43 (0.35-0.53)		0.58 (0.44-0.76)		0.54 (0.40-0.72)	
Stillbirth/miscarriage	0.11 (0.09-0.15)		0.09 (0.06-0.13)		0.10 (0.08-0.13)		0.06 (0.04-0.09)	

^a OR (95% CI): Odds ratio (95% confidence interval). ^b Wald overall significance test.

Factors associated with reporting of pregnancies in the HDSS alone or Survey alone

This section investigates the characteristics of women who reported their pregnancies in either just the Survey or just the HDSS, compared with those who reported the same number of pregnancies in both the BHDSS and the Survey. Table 6.4 reports associations between maternal characteristics and failure to report a pregnancy in the Survey only or in the BHDSS only. Using data that allows for misreporting of year of pregnancy occurrence, it shows that maternal education was not related to reporting of pregnancy in just the Survey (RRR 0.97; 95% CI 0.86-1.09) or just the BHDSS (RRR 0.99; 95% CI 0.84-1.17). Women of Serahule ethnicity were more likely to report a pregnancy in just the Survey or just the BHDSS than women of Fula and Mandinka/Other ethnicities relative to reporting of pregnancies in both the Survey and the BHDSS ($p=0.02$ & 0.05 , respectively). Maternal age was related to reporting of pregnancies in the Survey alone but not in the BHDSS alone. Compared to women aged 20 to 29 years of age, women less than 20 years of age (RRR 3.74, 95% CI 2.81-4.98) and older than 40 years (RRR 1.21, 95% CI 1.00-1.47) were more likely to report more pregnancies in the Survey than in the BHDSS. Likewise, women with three or more pregnancies had higher relative risk than those with two or less pregnancies of reporting more pregnancies in the BHDSS than in the Survey (RRR 1.83, 95% CI 1.53-2.19).

Women who had experienced an adverse pregnancy outcome were 16 times more likely to report more pregnancies in the Survey that they did not report in the BHDSS, than women with only living children (RRR 15.5, 95% CI 13.0-18.4). While this was also true for pregnancies reported in BHDSS but not in the Survey (RRR 4.14, 95% CI 3.05-5.63), more pregnancies with adverse outcomes were reported in the Survey alone (see Table 6.5), and when the relative risk was compared across BHDSS and Survey, the difference was strongly significant ($p<0.001$). Women who had liveborn children who later died were three times less likely to report one or more pregnancies in the BHDSS that they reported in the Survey (RRR 3.04, 95% CI 2.49-3.71). A similar result was found for

failure to report one or more pregnancies in the Survey that were reported in the BHDSS for women whose child had died (RRR 3.06, 95% CI 2.30-4.06).

Lastly, reporting of pregnancy outcomes improved over time whether a pregnancy was unreported in the BHDSS but reported in Survey (RRR 0.96, 95% CI 0.93-0.98), or vice-versa (RRR 0.91, 95% CI 0.87-0.95) rather than in both Survey and BHDSS and this improvement in reporting was more substantial in the Survey ($p=0.04$). In other words, recent pregnancies were more likely to be reported in either BHDSS or Survey.

Analysis of data that were strictly matched on the reported year of pregnancy outcome mostly found similar patterns of reporting by data source. However, according to these data maternal ethnicity was not a factor associated with the relative risk of failing to report pregnancies in the BHDSS that were reported in the Survey ($p=0.95$), but higher maternal parity was positively associated with incomplete pregnancy reporting in the BHDSS (RRR 1.57, 95% CI 1.41-1.75). On the other hand, for pregnancies reported in BHDSS but not in the Survey, fewer differences were noted between the two sets of analysis. Women of higher parity were more likely to report more pregnancies in the BHDSS than women with less than two pregnancies, but the estimated differential in the consistency of reporting was much higher in the analysis of the data that restricted matches to births with the same reported year of pregnancy (RRR 3.21, 95% CI 2.79-3.69). This as opposed to (RRR 1.83, 95% CI 1.53-2.19) in the analysis of the data that allowed for misreporting of year of pregnancy in the Survey.

Table 6.4: Multivariable multinomial logistic regression analysis for determinants of factors influencing failure to report pregnancies by data source

Women's Characteristics	Unreported in BHDSS				Unreported in Survey			
	Year of Birth ± 1 year		Year of Birth only		Year of Birth ± 1 year		Year of Birth only	
	RRR (95% CI)	p	RRR (95% CI)	p	RRR (95% CI)	p	RRR (95% CI)	p
Education (ref. Non-Islamic)		0.56		0.40		0.90		0.52
Islamic	0.97 (0.86-1.09)		0.96 (0.86-1.06)		0.99 (0.84-1.17)		0.96 (0.85-1.08)	
Ethnicity (ref. Serahule)		0.02		0.95		0.05		0.33
Fula	0.84 (0.74-0.96)		0.98 (0.87-1.11)		0.84 (0.69-1.01)		1.10 (0.96-1.27)	
Mandinka/Other	0.85 (0.74-0.99)		1.00 (0.88-1.13)		0.79 (0.64-0.97)		1.08 (0.94-1.26)	
Women age (ref. 20 – 29)		<0.001		<0.001		0.57		0.16
Below 20	3.74 (2.81-4.98)		3.40 (2.59-4.47)		1.10 (0.60-2.04)		1.37 (0.89-2.12)	
30 – 39	0.72 (0.64-0.82)		0.79 (0.70-0.88)		0.93 (0.77-1.11)		0.96 (0.85-1.09)	
40 and above	1.21 (1.00-1.47)		1.19 (1.00-1.41)		1.11 (0.85-1.46)		1.15 (0.95-1.40)	
Number of pregnancies (ref. 1-2)		0.31		<0.001		<0.001		<0.001
3-7	1.06 (0.94-1.20)		1.57 (1.41-1.75)		1.83 (1.53-2.19)		3.21 (2.79-3.69)	
Child status (ref. Alive)		<0.001		<0.001		<0.001		<0.001
Born alive but died	3.04 (2.49-3.71)		3.32 (2.73-4.03)		3.06 (2.30-4.06)		2.74 (2.18-3.44)	
Stillbirth/miscarriage	15.5 (13.0-18.4)		15.5 (12.7-18.9)		4.14 (3.05-5.63)		3.82 (2.93-4.98)	
Year of pregnancy outcome	0.96 (0.93-0.98)	0.001	0.92 (0.90-0.94)	<0.001	0.91 (0.87-0.95)	<0.001	0.90 (0.87-0.92)	<0.001

Table 6.5: Distribution of pregnancy outcomes from BHDSS and pregnancy history survey (2009-2015)

	Year of Birth \pm 1 year		Year of Birth only	
	BHDSS n (%)	Pregnancy history survey n (%)	BHDSS n (%)	Pregnancy history survey n (%)
Pregnancy outcomes				
Livebirths	8,671 (98.3)	9,774 (91.6)	8,895 (97.7)	9,986 (91.5)
Stillbirths	111 (1.25)	298 (2.8)	157 (1.7)	305 (2.8)
Miscarriages	38 (0.4)	586 (5.5)	45 (0.5)	612 (5.6)
Abortions	4 (0.05)	8 (0.1)	8 (0.1)	9 (0.1)
Total	8,824 (100%)	10,666 (100%)	9,105 (100%)	10,912 (100%)

Table 6.5 presents an itemisation of the pregnancy outcomes from the matched sample of women obtained from each data source separately for the period 2009-2015. There were more pregnancy outcomes reported in the Survey, regardless of whether misreporting of year of pregnancy was accounted for or not. In particular, disproportionately more stillbirths and miscarriages were reported in the Survey. Stillbirth rates derived from data allowing misreporting of year of pregnancy occurrence are; BHDSS 12.6/1000 births and Survey 29.6/1000 births. Those derived from strictly matching on reported year of pregnancy outcome are 17.3/1000 births for BHDSS and 29.6/1000 births for the Survey.

6.5 Discussion

This study compared the reporting of pregnancies in an ongoing HDSS with the pregnancy histories that the same women reported retrospectively in a single-round survey. It found that pregnancy histories included information on more pregnancies, and especially more adverse pregnancy outcomes, than had been detected by the HDSS, but that livebirths were well captured in both HDSS and pregnancy history survey. The HDSS collected complete and more accurate dates for events, despite the fact that it was the same woman interviewed. By virtue of conducting regular visits to each household, the HDSS can usually place any event within a four-month window of time. Moreover, the HDSS augments reporting of dates of events through use of clinic and national identification cards. Although the Survey sought to augment event reporting in a like manner, it proved to be

challenging. Almost 700 (8%) women in the survey did not report on the year of their pregnancies and had to be excluded from the analysis. Nevertheless, in the six-year window from 2009-2015, reporting of pregnancies in both the pregnancy history survey and in BHDSS improved.

It is likely that the dataset that matched pregnancies occurring in adjacent years when no exact match was available includes a high proportion of genuine matches and fewer false matches. Thus, the analysis that accounted for misreporting of year in the survey is discussed as it represents the more likely scenario based on the evidence of poor date reporting in the survey. In addition, the factors influencing reporting of pregnancies were largely similar in both datasets. Therefore, we focus here on the results of the analysis of the larger dataset. For women who had complete pregnancy information, the survey identified over 90% of all pregnancies reported in the BHDSS while the HDSS only picked up three-quarters of pregnancies reported in the survey. While some similar studies have treated the HDSS as a gold standard, these findings indicate that the assumption that HDSS are more complete can be misleading¹⁹. There was strong evidence that women in the extremes of the reproductive age range, and those who had experienced a child's death, stillbirth, miscarriage or an abortion were much more likely to have had pregnancies that were not reported to the HDSS than other women. For these women, significantly higher inaccuracies in reports of the numbers of their pregnancies were found. Our findings are in line with the study conducted by the Iganga-Mayuge HDSS, which reported that a pregnancy history identified more adverse pregnancy outcomes than the HDSS²¹. One advantage of the pregnancy history over the HDSS is that for the former, a woman's history over her lifetime is collected during the survey. However, as the HDSS is prospective, data are collected during ongoing rounds. In instances where a woman temporarily out-migrates from the HDSS, certain events may be missed out if she is not found. The risk factors identified in this study showed that women who experienced adverse outcomes were more likely not to be picked by HDSS, supporting this hypothesis. Additionally, younger women could be more likely to out-migrate in search of better economic prospects and thus would be less easily found during surveillance rounds³¹⁵. In addition, the practice of migration to maternal homes during

pregnancy persists in rural Gambia also contributing to the failure of fieldworkers to detect some events during HDSS rounds.

This study's findings are also consistent with an earlier study in the Gambia that asked couples to report on pregnancy outcomes. The Gambian study showed that while men and women did not differ in reporting livebirths or miscarriages, there was significant discrepancy in reports of perinatal mortality. In that study, the men reported more early neonatal deaths than their wives, but the women reported even more stillbirths, resulting in higher perinatal mortality estimates³⁶⁵.

While the HDSS does not collect pregnancy histories as the survey did, it prospectively collects information on all pregnancy outcomes of observed pregnancies and therefore in effect collects the same outcomes. It must be noted however that unobserved pregnancies that end in pregnancy loss are likely to be completely missed in subsequent HDSS update rounds. The better reporting of pregnancies in the survey, and in particular pregnancies with adverse outcomes, may have been a result of having females interviewing women in private in the survey, as opposed to the procedure used for routine surveillance where the head of the household or a proxy, usually any adult, is interviewed by mostly male interviewers. Although women in The Gambia are expected to conceal their pregnancies to protect them from harm, they may have been more open with the female interviewers as opposed to the male interviewers^{363, 366}. Preference for female interviewers especially for reproductive-related issues was reported by both male and female fieldworkers interviewed in a qualitative study discussed in Chapter 8 of this thesis. Better reporting in the survey may also have been due to the timing of data collection and sociocultural factors related to death and bereavement. In the Kaya HDSS in Burkina Faso, child deaths are under-reported due to cultural barriers²¹³. Garenne argues that women do not forget about their births but may be hesitant to provide information³⁶⁷. In addition, respondents may be unwilling to disclose information on death or pregnancy loss too soon after the event, resulting in under-reporting²⁴². Therefore, asking about recent pregnancies and recent death or pregnancy loss is likely to result in an undercount based on existing cultural norms. These norms and practices may not hold for past deaths,

pregnancies and losses, and perhaps give pregnancy histories an advantage over prospectively collected pregnancy data.

We evaluated the consistency with which women reported their number of pregnancies in the two data sources. Characteristics favouring consistent reporting were being of lower parity, and Fula ethnicity. It is logical that women with fewer children will find it easier to report their number of pregnancies accurately than women who have been pregnant many times. Fula women tend to display reluctance towards being counted, however these findings support literature that shows that they are numerate in their daily activities and can provide accurate answers despite the fact that they usually provide non-numerate responses in surveys³⁶⁸. This research also showed that women of higher parity were more likely to have had their pregnancies reported in the BHDSS as opposed to both data sources. Asking women of higher parity to retrospectively count all their pregnancies in the pregnancy history survey may result in omission of some of them due to issues such as the length of the interview, whether the question is considered sensitive and time pressure among others³⁶⁹.

The overall stillbirth rate in the HDSS is low pointing to under-reporting, however the stillbirth rate estimated from the pregnancy histories mirror those in sub-Saharan Africa^{10, 232, 338}. The likelihood of under-reporting is supported by the finding that reports of the number of pregnancies for women in extremes of the reproductive age range were highly inaccurate, yet they are most at risk of having adverse outcomes^{370, 371}. Lastly, 8% of surveyed women did not provide the year of pregnancy outcome for at least one pregnancy and were thus excluded from analysis, potentially contributing to under-reporting of both pregnancies and their outcomes. Their characteristics were similar to those who provided complete information in both survey and HDSS thus it is unclear why they did not report all dates of their pregnancies. It however suggests that women are still not accurate with reporting dates of events, and that the methods used by HDSS to augment event reporting are useful for this population. Additional methods that could be employed to improve date reporting would be to allow for imprecise dating, for instance where foetal losses occurred between live births of known dates, as well as having inbuilt field prompts especially where electronic data capture is used.

The generalizability of our findings beyond The Gambia may be limited. While this study found that pregnancy histories obtained more information, it did not have an arm testing birth histories, which would be ideal if one's objective is to identify which tool is superior to the other relative to a gold standard method. Testing both tools would also be important if the delineation of stillbirths and early neonatal deaths is crucial, as asking specifically about stillbirths in pregnancy histories could reduce the tendency to misclassify early neonatal deaths as stillbirths^{55, 56}. This study also did not set out to generate protocols for the use of pregnancy or birth history, nor for the utility of conducting one-off pregnancy surveys to evaluate pregnancy and outcome reporting in HDSS. However, it gives insight to the advantage of using pregnancy histories for improved yield of pregnancy information. In particular, pregnancy histories are comparable with HDSS on data for livebirths, but are more useful for information on stillbirths, most of which are preventable, yet they are generally under-reported and not included in the SDGs³. Regarding the role of interviewers, this study was conducted in a setting where sociocultural factors could affect data collection, such as restricted interactions between unrelated males and females, and the expectation that women should conceal their pregnancies³⁴⁵. It was also carried out where mortality is high³⁴³. The trained female interviewers obtained more information on adverse perinatal outcomes, necessary for perinatal mortality estimation, especially from adolescents and older women who are an at-risk population for having adverse outcomes. Greater sensitivity and empathy are needed when carrying out demographic and health surveys in areas experiencing high mortality if accurate and better-quality data are to be achieved. Future surveys in The Gambia should take into the account that experience of adverse events affects data accuracy, and innovative methods that actively consider respondents' psychological states, be employed.

6.6 Conclusion

This study set out to assess whether pregnancy histories and HDSS are fit for measurement of neonatal and perinatal mortality based on the capture of pregnancies and their outcomes. The HDSS was of better quality regarding event

date reporting and captured livebirths adequately which are crucial for measurement of neonatal mortality. HDSS was however deficient in the capture of stillbirths, and thus pregnancy histories outperformed it for measurement of perinatal mortality. The pregnancy history also captured livebirths adequately, but date reporting was poor, resulting in omission of potential pregnancy outcomes. In order to optimize HDSS, adjustment to the method of pregnancy data collection should include directly interviewing women and, in The Gambia, employing female interviewers. As the HDSS was shown to have improved the reporting of pregnancies and with the recent introduction of electronic data capture, the addition of the aforementioned adjustments would make it well placed to fill gaps in measurement of neonatal and perinatal mortality.

6.7 Acknowledgements

AJR is funded by a PhD Studentship awarded by the Medical Research Council Unit The Gambia at the London School of Hygiene & Tropical Medicine, who also fund the two HDSS.

6.8 Appendix: Under-five and perinatal mortality analysis of pregnancy history and HDSS data

This section presents the under-five and perinatal mortality analysis from the pregnancy histories obtained through the survey and is not restricted to matched women as in the previous sections in this chapter. Altogether, there were 28,906 pregnancy outcomes reported through pregnancy histories. These were 26,309 live births (91%), 1,019 stillbirths (4%), 1,549 miscarriages (5%) and 29 abortions (<1%).

Figure 6.2 shows mortality estimates restricted to the period when the BHDSS was established, that is 2007-2014 while Figure 6.3 shows the trends in under-five mortality in Basse since 1990 according to pregnancy histories.

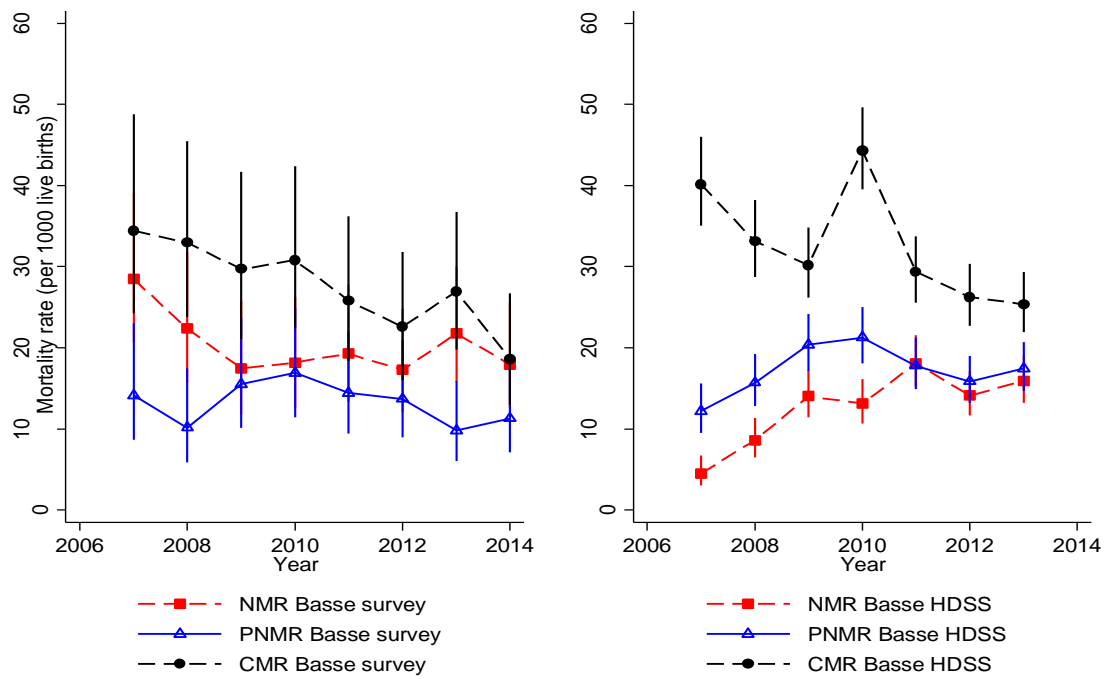


Figure 6.2: Comparison of neonatal, post-neonatal and child mortality rates in Basse HDSS and pregnancy history survey data from 2007-2014

Neonatal, post-neonatal and child mortality rates from each data source – the Survey and the BHDSS are compared in Figure 6.2 and Table 6.6. Child mortality is the largest contributor to under-five mortality in both data sources.

Table 6.6: Comparison of under-five mortality estimates from the pregnancy history survey and Basse HDSS

Basse	NMR		Rate Difference (95% CI)	PNMR		Rate Difference (95% CI)	CMR		Rate Difference (95% CI)	U5MR		Rate Difference (95% CI)
	SVY	HDSS		SVY	HDSS		SVY	HDSS		SVY	HDSS	
2007	28.5	4.5	23.9 (14.7;33.2)	14.1	12.2	1.9 (-5.6;9.5)	34.4	40.1	-5.7 (-18.9;7.5)	75.2	56.2	19.0 (2.0;36.0)
2008	22.4	8.6	13.7 (5.5;22.0)	10.2	15.7	-5.5 (-11.9;0.8)	32.9	33.2	-0.2 (-11.9;11.5)	64.2	56.5	7.6 (-7.4;22.7)
2009	17.5	14.0	3.4 (-3.9;10.8)	15.5	20.4	-4.9 (-12.3;2.6)	29.7	30.2	-0.5 (-11.4;10.5)	61.4	63.3	-1.8 (-16.4;12.8)
2010	18.2	13.1	5.1 (-2.1;12.3)	16.9	21.3	-4.4 (-11.8;3.0)	30.8	44.3	-13.5 (-24.5;-2.4)	64.5	76.9	-12.3 (-26.9;2.2)
2011	19.3	18.1	1.2 (-6.5;9.0)	14.4	17.8	-3.4 (-10.2;3.5)	25.8	29.4	-3.6 (-13.2;6.1)	58.4	63.9	-5.5 (-19.1;8.1)
2012	17.3	14.1	3.1 (-3.6;9.9)	13.7	15.9	-2.2 (-8.7;4.3)	22.6	26.3	-3.7 (-12.3;5.0)	52.6	55.2	-2.6 (-14.9;9.7)
2013	21.8	15.9	5.9 (-1.8;13.5)	9.8	17.4	-7.6 (-13.2;-2.0)	26.9	25.4	1.6 (-7.6;10.7)	57.4	57.6	-0.2 (-12.8;12.5)

The estimates of under-five and neonatal mortality in the survey in 2007 and NMR in 2008 are significantly higher than HDSS. From 2009 onwards, there is no evidence of a difference in these estimates in the two data sources.

There were no significant differences in other components of under-five mortality estimates from 2009 onwards except for higher child mortality rates and perinatal mortality rates reported in the HDSS compared to the survey in 2010 and 2013, respectively (see Table 6.6).

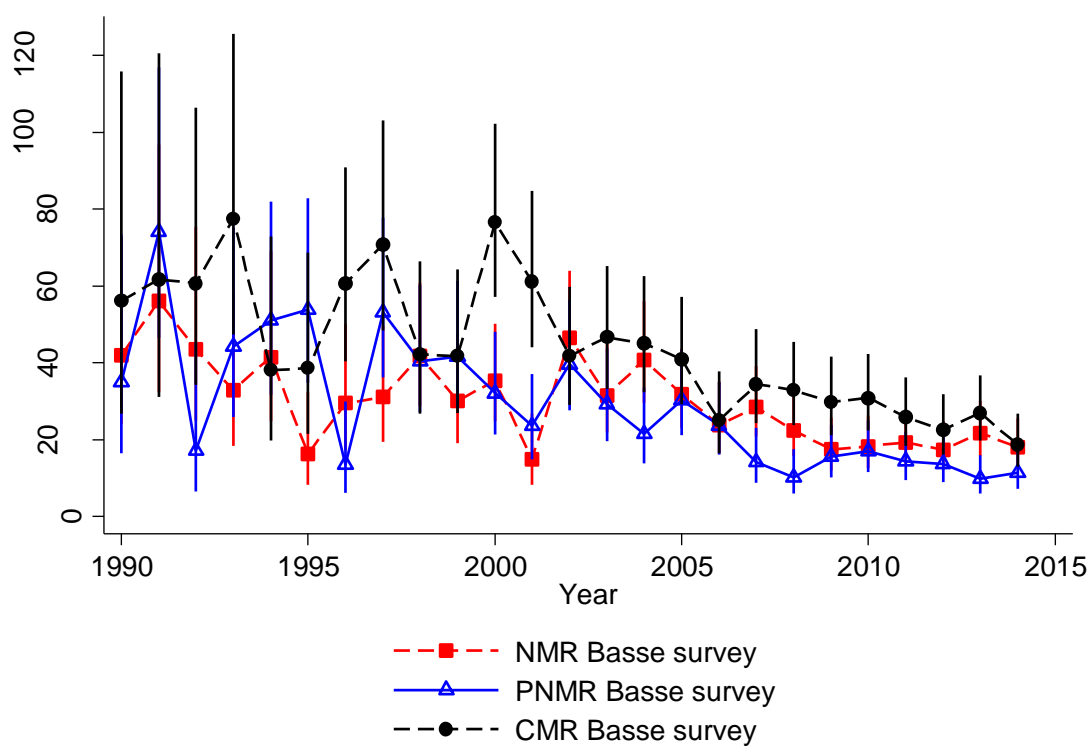


Figure 6.3 : Trend in neonatal, post-neonatal and child mortality rates in BHDSS using pregnancy history data

Figure 6.3 above depicts the trend in NMR, PNMR and CMR from the survey only from 1990 onwards, and shows an overall decline in under-five mortality, particularly in child and post-neonatal mortality, albeit with peaks seen in child mortality in 1993, 1997 and early 2000s. The proportion of neonatal mortality increases with the decrease in child and post-neonatal deaths.

Regarding perinatal mortality, for the period 1990 to 2014, the survey estimate was 49.3/1000 births. In 1990, perinatal mortality was estimated at 60.7/ 1000 births (95% CI 38.7-94.7). In subsequent decades perinatal mortality dropped, estimated at 58.0/1000 livebirths in 2000 (95% CI 44.4-75.6), in 2010 at 38.6/ 1000 births

(95% CI 30.2-49.4) and the latest estimates from the survey in 2014 showed a perinatal mortality rate of 38.8/ 1000 births (95% CI 30.7-49.1). The perinatal mortality rate for 2009-2013 was calculated at 43.3/1000 births (95% CI 39.1-48.0). For the same period, perinatal mortality from Basse HDSS was estimated at 31.4/1000 births (95% CI 29.7-33.0).

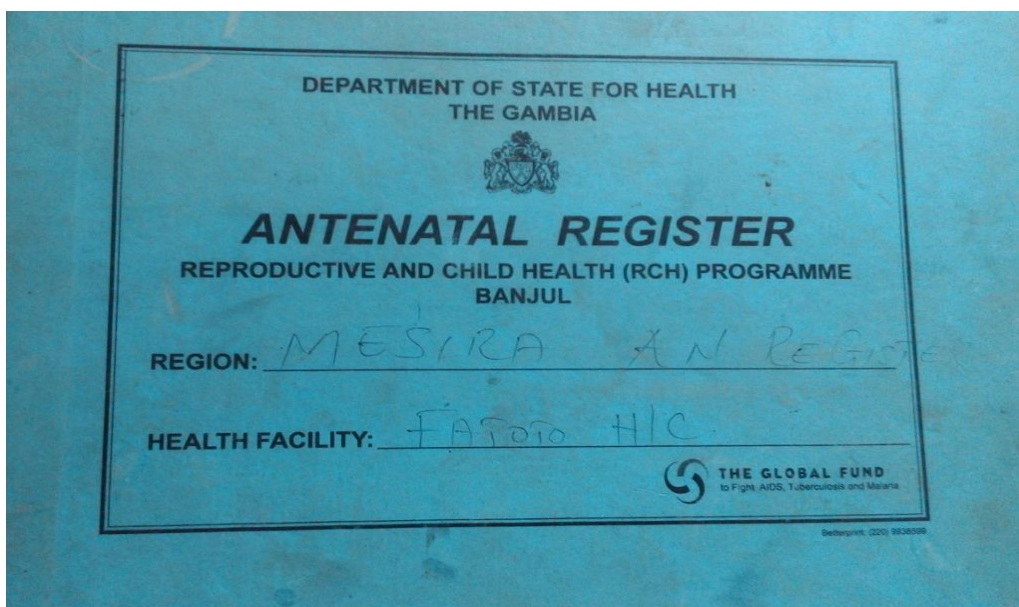
Summary

Under-five mortality estimates from the pregnancy history survey and Basse HDSS are largely similar for the period 2009-2013. As reported in Chapter 5 in this thesis, mortality estimates prior to 2009 in Basse HDSS were unreliable due to incomplete reporting of events during the initiation of surveillance in the HDSS. The drop in child mortality in The Gambia is also seen from the 1990-2014 survey estimates, as is the increasing importance of neonatal mortality.

Perinatal mortality has also declined, however the estimate from the survey for 2009-2013 (43/1000 births) is higher than that reported for The Gambia (30/1000 births) or Basse (27/1000 births) in the 2013 Gambia DHS report for the same period²². Basse HDSS estimates for the same period are closer to the national and regional estimates.

Research paper cover sheet

Chapter 7 Leveraging linkage with antenatal clinic records for improving the surveillance of pregnancy outcomes and early childhood mortality: a case study from a Health and Demographic Surveillance System in rural Gambia



Source AJR: The standard Antenatal Register in The Gambia



Photograph courtesy of Penda Johm (MRCG): Maternal and Child Health Clinic, The Gambia

7.1 Abstract

Background: Health and demographic surveillance systems (HDSS) prospectively follow up pregnancies and their outcomes, which are core to measurement of perinatal and under-five mortality. However, if tracking of pregnancies is suboptimal, accuracy of these estimates is compromised.

Objective: This study assessed whether pregnancy data obtained through routine surveillance in Basse HDSS in The Gambia could be improved through linkage with antenatal clinic (ANC) records.

Methods: Antenatal records from six health centres were extracted covering December 2015-December 2016 and matched back to women in the HDSS. Pregnancy outcomes were extracted from the HDSS database and follow up visits made for women without recorded pregnancy outcomes. Perinatal and early childhood mortality estimates were then compared between the routine HDSS data and those which included outcomes obtained through follow up visits, termed augmented HDSS data.

Results: 3,784 women in the HDSS were matched to their ANC records. Fifty five per cent had been identified as pregnant in the HDSS and 93% of their pregnancy outcomes were recorded. The follow up study identified 861 additional pregnancies, with disproportionately more stillbirths and neonatal deaths. Analysis of augmented HDSS data revealed higher estimates compared to routine HDSS. Perinatal mortality in augmented HDSS data was 47.0/1000 births (95% CI 39.3-54.7) and in routine HDSS, 33.0/1000 births (95% CI 25.3-40.7). The crude birth rate in the augmented HDSS data was 20.8 (95% CI 20.0-21.5) and 14.7 (95% CI 14.1-15.4) per 1000 population in routine HDSS data. Analysis of risk factors for infant but not perinatal mortality differed based on data source.

Conclusions: Linkage with antenatal clinic records and active tracking of pregnancy outcomes provide a viable method to improve the capture of pregnancies in HDSS particularly for adverse pregnancy outcomes. Fertility and mortality estimates from augmented data seem more plausible. Incomplete tracking of pregnancies and outcomes can lead to biased analysis of risk factors.

Contribution: This paper introduces the first approach of its kind to improve surveillance of pregnancies in HDSS through linkage with ANC and the resultant fertility and perinatal and early childhood mortality estimates.

7.2 Introduction

Maternal and under-five mortality rates are used to monitor the progress of countries in global health agenda such as the Sustainable Development Goals (SDGs)². One of the targets set in the third SDG goal is the reduction of Under-five Mortality Rates (U5MR) to 25/1000 livebirths or less and Neonatal Mortality Rates (NMR) to 12/1000 livebirths or less by 2030³. Although there are no targets set for stillbirths in the SDGs, the World Health Organization (WHO) every newborn action plan (ENAP) targets the reduction of stillbirth rates to 12/1000 births or less by 2030¹³. Sub-Saharan Africa bears a relatively large burden of early childhood mortality, yet timely and accurate monitoring systems are lacking. The most useful sources for under-five mortality estimation in African populations therefore remain nationally representative household surveys and censuses⁸, but these are not usually suitable for the estimation of perinatal mortality^{18, 182}.

Health and demographic surveillance systems (HDSS) fill some of these information gaps in low and middle-income countries¹⁹⁶. In most HDSS, surveillance of pregnancies is done to ensure that pregnancy outcomes are not missed, because a prior pregnancy report enables fieldworkers to probe for the pregnancy outcome in the following HDSS round. However, we suspect that pregnancies are not exhaustively reported, in part because the interviews are often done with one household representative who may not be aware of the pregnancy status of all women in the household. This was thought to be a reason for under-reported pregnancies in Iganga-Mayuge HDSS in Uganda when researchers compared pregnancy outcomes obtained from a pregnancy history survey to routine pregnancy surveillance²¹. Under-reporting of pregnancies may lead to under-reporting of adverse perinatal outcomes and neonatal mortality. Unreported pregnancies that result in a surviving child are less likely to go unnoticed as they tend to be identified in subsequent HDSS rounds.

In The Gambia, three HDSS in operation prospectively follow up pregnancies and their outcomes. However, neonatal mortality estimates from the HDSS are suspiciously low, which suggests that there is a need for improving the capture of pregnancies and their outcomes³⁹.

In this study, we proposed to improve pregnancy identification in the HDSS through record linkage with antenatal records from health facilities that serve the HDSS population. In addition, follow up interviews were organised for women whose ANC record was matched to an HDSS entry that lacked a pregnancy outcome. We compared estimates of perinatal and early childhood mortality in the original HDSS database and the data that were augmented with information from the follow up interviews. Further, we conducted and compared risk factor analyses of perinatal and early childhood mortality in the standard HDSS and augmented datasets.

7.3 Methods

Study area and population

The Gambia has one of the highest antenatal coverage rates in sub-Saharan Africa, being almost universal at 99% for at least one visit, and 78% for the recommended four visits²². Coverage may have been improved by the introduction of the Gambia Maternal and Child Nutrition and Health Results Project in the country's worst-performing regions in terms of health services and nutrition. The project aims to improve women and children's health by increasing both demand for, and supply of health and nutrition services through conditional cash transfers. Cash is transferred based on achievement of set targets that are monitored by the National Nutrition Agency and the World Bank. In this project, pregnant women receive 300 Gambian dalasi (equivalent to USD 6) for their first antenatal clinic (ANC) visit and another 300 dalasi on completion of four visits³⁷².

Our study was carried out in Basse located about 375 kilometres from Banjul, the capital city of The Gambia. Basse is the least developed administrative area of the country and was included in the Maternal and Child Nutrition and Health Results Project in 2014³⁷². Basse is partitioned by the River Gambia into north and south bank sections and has a population of 239,916 inhabitants²⁶².

The Gambian health sector has a three-tier system comprising primary, secondary and tertiary levels. The primary level consists of village health services and community clinics which make up the primary health care system. Minor and major health centres form the secondary level, and hospitals, including the country's sole teaching hospital, make up the tertiary level. All health facilities provide antenatal care services; however, ultrasound and laboratory facilities are only available from the secondary level and above²⁷⁵. Services that are provided at all levels include; weight and blood pressure measurement, palpation of fundal height to estimate gestational age, foetal heart monitoring using the pinard horn, prophylaxis for anaemia, malaria and tetanus and phlebotomy for HIV and malaria testing²⁷⁵. Since 2007, all maternal and child health services have been provided at no cost when a national identity card is presented as proof of citizenship. For pregnant women, her husband's card is sufficient, as few women have these cards due to the expenses and procedures associated with acquiring one; a national identity card costs 200 Gambian dalasi and must be renewed every five years. This is unaffordable for many households^{275, 314, 373}.

In Basse, there is only one major health centre (Basse health centre) and referrals are made to the nearest tertiary level Bansang Hospital which, although located in the Central River Region, also serves Basse²⁷⁵. In addition to providing antenatal services to women resident within their catchment areas, health facilities also cater for women from neighbouring Senegal. According to the 2013 Gambian demographic health survey, Basse had 99% ANC coverage for the 2009-2013 period²⁷⁴.

There are three HDSS in The Gambia, that cover almost 15% of the national population, one of which is the Basse HDSS^{40, 294}. The entire southern half of Basse (~180,000 population) is covered by the HDSS, which is run by the Medical Research Council unit The Gambia. There are seven health centres (1 major and 6 minor) within the area under study, as shown in Figure 7.1, although one was yet to start the provision of ANC services at the time of this study.

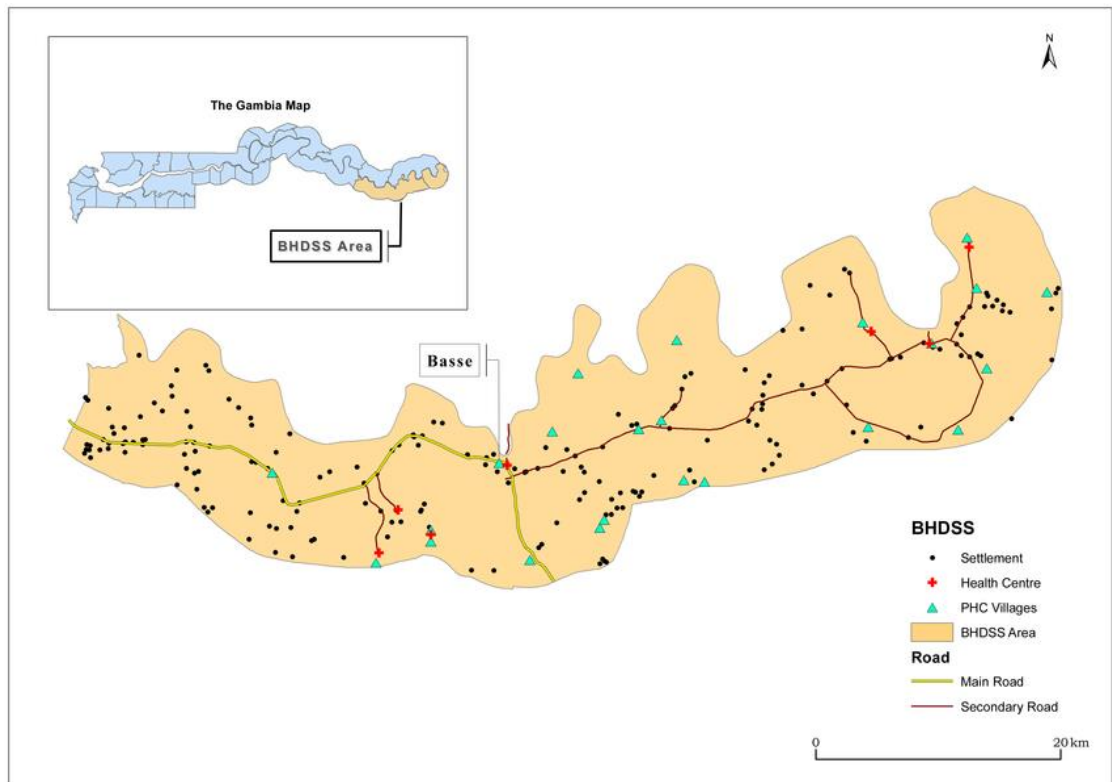


Figure 7.1: Map showing Basse HDSS and health facilities within it. Adapted from McKenzie et al 295.

Data sources

Three different data sources were used in this study. The first comprises records from six health centres (major and minor) that provide antenatal services to the Basse HDSS population. The ANC register data from the 1st December 2015 to the 31st December 2016 were photographed and independently digitized by two research assistants who reconciled any discrepancies in the transcription and de-duplicated the ANC records. This work was carried out retrospectively from June 2016 to January 2017.

The second data source is the routine HDSS information, which includes residency episodes in the HDSS area and vital events including births, deaths and pregnancy status measurements. The latter allowed identification of the date that a pregnancy was observed by the HDSS team, the outcome of the pregnancy and the date of the pregnancy outcome. Fieldworkers visit each household every four months and interview a household representative to record all vital events in the last four months²⁹⁴.

Further confirmation of vital events to ensure completeness of the data is done via a parallel reporting system, whereby volunteer village reporters, usually traditional birth attendants or leaders in the community, keep a record of vital events²⁹⁴.

The third data source results from follow up visits of women who attended ANC but whose pregnancy or birth was not captured in the HDSS. To that end, the ANC records were first matched to the HDSS using a record linkage procedure described below. For women without pregnancy outcomes in the HDSS, the fieldworkers conducted up to two visits between April and August 2017 to confirm the woman's identity, her pregnancy status and to record the pregnancy outcome.

ANC-HDSS record linkage procedures

Record linkage between ANC registers and HDSS was done in two stages. First, two research assistants familiar with the area used a clerical process to identify compounds where the village name and the name of the compound head as recorded in the ANC registers matched the information stored in the HDSS database. Once the compounds were identified using the village and compound head's name, women were matched based on their first and last name (including nicknames), and age.

Second, a probabilistic approach to find matches for the remaining set of ANC records was used. More specifically, we used the *relink2* package in Stata^{321, 322} to find the best match from the HDSS on the basis of a set of common identifiers in both datasets (woman's first name, woman's last name, her age in years, first and last name of compound head and village name), default match and unmatched weights as assigned by the programme, and their bigram scores³²². Record pairs with a match score greater than 0.97 (a value of 1 denotes a perfect match on all identifiers) were automatically classified as matches; record pairs with a match score between 0.80 and 0.97 were subjected to clerical review.

Data analysis

In the subset of women whose ANC records were matched to an HDSS database entry, the background characteristics of women whose pregnancy was identified in the HDSS were compared to those whose pregnancy was missed. To that end

univariable and multivariable logistic regressions were used, with maternal age, education, ethnicity and size of household introduced as covariates.

Second, estimates of fertility and early childhood mortality events in the HDSS and the HDSS after augmentation with the follow up interviews were compared. In accordance with the ICD-10 system of disease classification²⁹⁶, stillbirths were defined as late foetal deaths occurring at or after 28 weeks gestational age. Deaths before 28 weeks are classified as miscarriages or abortions. Perinatal deaths comprise those that occur in the late foetal period or in the first seven days of life. The neonatal period is defined as the first 28 days after birth and infancy as the first year of life. The denominator for computing rates is the total number of births for the Perinatal Mortality Rate (PMR) and the Stillbirth Rate (SBR), and the total number of live births for the NMR and Infant Mortality Rate (IMR). The estimate of the crude birth rate takes the mid-year population as the denominator.

Third, in both routine and augmented HDSS, maternal sociodemographic characteristics namely age, ethnicity and educational level were assessed for associations with perinatal and early childhood mortality to establish whether conclusions about these risk-factors differed by data source. This was done using univariable and multivariable logistic regressions. The estimated odds-ratios (ORs) were then compared across data sets. Crude and adjusted ORs are presented for all covariates for the two data sets (HDSS only, augmented HDSS). Information on more proximate risk factors of perinatal mortality, including birthweight and the circumstances of the delivery, were not available and therefore not included in the analyses. Data analysis was done in Stata v15.1.

Ethical approval

The Basse HDSS site has the MRC/ Government of Gambia ethical approval, and the community's permission to carry out longitudinal surveillance activities. Ethical approval was obtained for the antenatal clinic data extraction and follow up study from both the London School of Hygiene and Tropical Medicine and the joint MRC/Government of Gambia Ethics Committees (Appendix A-SCC1437v2 & LSHTM Ethics ref 10377). At regional level, the health directorate in Basse gave permission for data collection at the health facilities.

7.4 Results

A total of 7,383 women attended ANC in the six health centres and outposts from 1st December 2015 to 31st December 2016. At their first ANC visit, women were pregnant for a mean duration of 4.7 months and the mean parity was 4. The mean age for women attending ANC was 27.5 years and 28.6 years for pregnant women in the HDSS.

Figure 7.2 summarizes the data sources, the eligibility for a follow up interview and the outcomes of these interviews. A total of 3,784 women who visited an ANC between the 1st of December 2015 and 31st of December 2016 were matched to an HDSS record. Those not matched to the HDSS included 206 women who lived outside the HDSS area, of whom 110 were from Senegal. A further 2,421 women reported to be living in HDSS villages were not matched to an HDSS record. Additionally, there were 807 women who were matched to an HDSS individual who is no longer an HDSS resident (three of whom had died). This group includes cases that were erroneously matched as well as women who have genuinely moved out of the area (e.g. just after marriage). Four ANC records were matched to a male resident, which may be the result of a mismatch or an error in the record keeping at the health facility (e.g. registration of the ANC client under her husband's name). By the end of April 2017, 157 women had migrated out of the HDSS, while four women had died since their first antenatal visit.

Only 54.9% (2,079/3,784) of the ANC clients who were matched to a current HDSS record also had their pregnancy status reported in the HDSS. For the majority of these women (n=1,931 or 92.9%), the HDSS also captured a pregnancy outcome. Pregnancy outcomes were much less likely to be recorded in the routine HDSS if the pregnancy status was not captured in a previous HDSS round (173/1,705 or 10.1%).

Of the 1,680 women for whom no pregnancy outcomes were recorded, we selected 1,215 women for follow up. The remaining 465 women were not selected due to time and resource constraints. A pregnancy outcome was established for 70.1% (861/1,215) of the women who were followed up. The remainder were either not found after two visits (n=41), still pregnant at the time of the visit (n=21), which was

feasible as they may have been in the early stages of pregnancy at the tail end of data collection or, reported that subsequent antenatal clinic visits indicated that they were not or no longer pregnant (n=292).

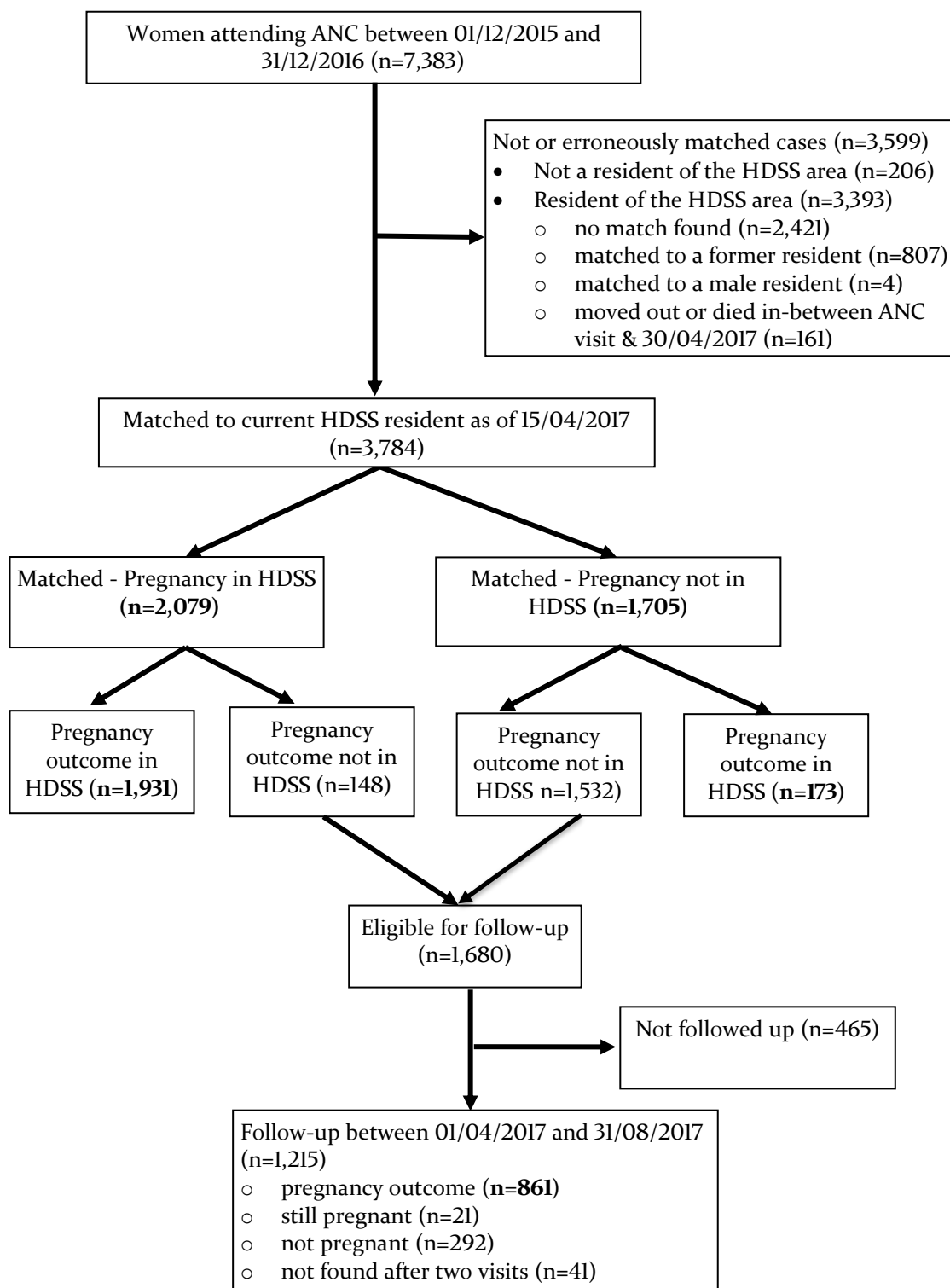


Figure 7.2: Study flow chart

This is plausible as biologic and non-biologic causes of amenorrhea can mimic pregnancy, and early pregnancy losses may not be noticed. The lack of pregnancy tests at the outposts and reliance on women's reports of missed menses to determine pregnancy status, as well as the financial incentives for antenatal visits could also contribute to this finding.

Some differences were found when the women that were followed up were compared to those that were not; i) women older than 30 years were more likely to be followed up compared to those aged between 20 and 29, while the odds were lower for adolescents ii) women with no formal education had almost twice the odds of being followed up than those that had Quranic education and iii) Mandinka women were most likely to have been followed up compared with women of other ethnicities (see Table 7.4).

Regression analyses of factors associated with pregnancy identification in HDSS

Table 7.1 explores socio-demographics associated with pregnancy capture in the HDSS among women whose ANC records were matched to the HDSS. In crude analyses, the pregnancies of relatively young and relatively old women were less likely to be reported in the HDSS ($p < 0.001$). Educational level appears to be negatively correlated with pregnancy capture in the HDSS, but this association only reaches statistical significance for women with tertiary education ($p = 0.01$). Pregnancies of Serahule women were less likely to be captured than those of other ethnic groups. While household size appeared to be negatively correlated with the completeness of pregnancy reporting in the HDSS, with larger households having less complete capture of pregnancy, this was not statistically significant.

In the adjusted model, compared to women aged 20-29, the odds of pregnancy capture in the HDSS were reduced by 74% for women aged less than 20 years (aOR 0.26; 95% CI 0.20-0.32), by 16% for women aged between 30 and 39 (aOR 0.84; 95% CI 0.72-0.97), and by 53% for women older than 40 years (aOR 0.47; 95% CI 0.36-0.62). Unlike in the crude analysis, the negative correlation between maternal educational level and pregnancy capture in HDSS did not reach statistical significance for women with tertiary education (aOR 0.76; 95% CI 0.58-1.01),

following adjustment for maternal age, ethnicity and household size. Finally, Mandinka women were twice as likely (aOR 2.02; 95% CI 1.68-2.42), to have their pregnancies identified in the HDSS than Serahule women. The odds that pregnancies of Fula women were captured in the HDSS were 37% higher than those of Serahule women (aOR 1.37; 95% CI 1.16-1.63).

Table 7.1: Socio-demographic covariates of pregnancy reporting in the HDSS (matched ANC-HDSS records)

Women in ANC	Matched - pregnancy in HDSS	Matched - pregnancy not in HDSS	Crude OR (95% CI)*	p	Adjusted OR (95% CI)*	p
Age				<0.001		<0.001
<20	142	327	0.26 (0.21-0.32)		0.26 (0.20-0.32)	
20-29 (ref.)	1,060	628	1		1	
30-39	758	533	0.84 (0.73-0.98)		0.84 (0.72-0.97)	
>40	119	145	0.49 (0.37-0.63)		0.47 (0.36-0.62)	
Missing	0	72				
Education				0.01		0.19
Primary/Secondary	58	51	0.76 (0.50-1.16)		0.77 (0.49-1.22)	
Tertiary	223	234	0.64 (0.49-0.83)		0.76 (0.58-1.01)	
Quranic (ref.)	257	172	1		1	
None/Other	1,541	1,248	0.83 (0.67-1.02)		0.92 (0.74-1.14)	
Ethnicity				<0.001		<0.001
Mandinka/Other	624	338	1.96 (1.66-2.31)		2.02 (1.68-2.42)	
Serahule (ref.)	783	831	1		1	
Fula	672	536	1.33 (1.15-1.55)		1.37 (1.16-1.63)	
Household size				0.10		0.98
<10/household(ref.)	128	94	1		1	
11-50	1,182	931	0.93 (0.70-1.23)		1.01 (0.75-1.36)	
51-100	630	534	0.87 (0.65-1.16)		1.01 (0.74-1.39)	
>100	139	146	0.70 (0.49-1.00)		0.96 (0.65-1.40)	
Total	2,079	1,705				

* OR (95% CI): Odds ratio (95% confidence interval).

Pregnancy outcomes, mortality and fertility analysis

In Table 7.2, we report the pregnancy outcomes (panel 1) and demographic rates (panel 2) in the different data sources. For the analysis of mortality, we use 2,104 pregnancy outcomes captured in the HDSS (1,931+173), and 861 pregnancy outcomes established through follow up interviews, making a total of 2,965 pregnancy outcomes.

Even though the large majority of pregnancy outcomes from the follow up study are livebirths (90%), miscarriages (one of these was reported as an abortion) and stillbirths are much more common in the subgroup of women whose pregnancy outcome was not captured by the routine HDSS.

Table 7.2: Pregnancy outcomes by data source and estimated stillbirth, perinatal, neonatal and infant mortality rates as well as crude birth rate from HDSS, the follow up study and the augmented HDSS data

	Sources		
	HDSS n (%)	Follow up n (%)	Augmented HDSS n (%)
Pregnancy outcomes			
Livebirth	2,040 (97.0)	773 (89.8)	2,813 (94.9)
Stillbirth	51 (2.4)	51 (5.9)	102 (3.4)
Miscarriage/Abortion	13 (0.6)	37 (4.3)	50 (1.7)
Total	2,104	861	2,965
Early neonatal deaths	18	17	35
Neonatal deaths	26	21	47
Infant deaths	39	29	68
Derived mortality and fertility estimates			
	Rate (95% CI)		
SBR/1000 births	24.4 (17.8-31.0)	61.9 (45.5-78.5)	35.0 (28.3-41.7)
PMR/1000 births	33.0 (25.3-40.7)	82.5 (63.7-101.3)	47.0 (39.3-54.7)
NMR/1000 livebirths	12.7 (7.9-17.6)	27.2 (15.7-38.6)	16.7 (12.0-21.4)
IMR/1000 livebirths	19.1 (13.2-25.1)	37.5 (24.1-50.9)	24.2 (18.5-29.8)
Crude Birth Rate/1000 population	14.7 (14.1-15.4)		20.8 (20.0-21.5)

The second panel of Table 7.2 contains fertility and early childhood mortality estimates from the HDSS data, the follow up data and the augmented or combined data set. The augmented HDSS data estimated the SBR at 35.0/1000 births which was significantly higher than SBR of 24.4/1000 births in the routine HDSS data. The PMR, a composite indicator for stillbirths and early neonatal deaths, followed a similar pattern to SBR.

The estimates of the NMR (16.7/1000 livebirths) and IMR (24.2/1000 livebirths) in the combined data set were higher compared to the estimates from the routine

HDSS information only; NMR (12.7/1000 livebirths) and IMR 19.1/1000 livebirths), but these differences do not reach statistical significance.

The estimated crude birth rate in the augmented data (20.8/1000 population) was significantly higher than in the routine HDSS (14.7/1000 population).

Analysis of risk factors of perinatal and infant mortality among women in HDSS

In Table 7.3, we explore whether conclusions about the risk factors of perinatal and infant mortality differ in the routine and augmented HDSS data that incorporate pregnancy outcomes that were observed by means of the follow up visits.

In both the crude and adjusted analyses of the routine and augmented HDSS data, maternal age was significantly associated with perinatal mortality; compared to women aged 20-29, women aged 30 or more have between 49 and 66 per cent elevated risk of perinatal mortality. Women aged 40 or more are three times more likely to experience adverse perinatal events compared to women aged 20-29 as corroborated by findings from other studies. There is no evidence of a difference in the association between age and adverse pregnancy outcomes between the routine and augmented HDSS using conventional levels of statistical significance as the confidence intervals overlap. Neither the level of maternal education nor maternal ethnicity was associated with the risk of having a stillbirth or experiencing an early neonatal death in either the routine or augmented HDSS data.

Whereas the risk factors of perinatal mortality in the routine and augmented HDSS are similar, they are quite different for infant mortality. Regressions that solely make use of the HDSS data, suggest that the odds of infant mortality are higher among Mandinka and Fula women than Serahule women ($p=0.04$). There is no evidence of association between maternal age, maternal education and infant mortality in these HDSS data.

Risk factors for infant mortality in the augmented dataset differ from those obtained from the routine HDSS alone. There is a positive association between maternal age and infant mortality ($p=0.01$). Compared to women aged 20-29, the odds of infant mortality are twice as high among women aged 30-39 (aOR 2.09, 95% CI 1.19-3.68), and three-fold higher in women over 40 years (aOR 3.37, 95% CI

1.51-7.51). In this analysis, unlike that of the routine HDSS, maternal ethnicity is not associated with infant mortality, but, as in the routine HDSS, maternal education does not appear to be associated with infant mortality.

Table 7.3: Risk factors for perinatal and infant mortality in Basse HDSS

Risk factors for perinatal mortality

Woman characteristics	HDSS only				Augmented HDSS			
	OR (95% CI)	p	aOR (95% CI)	P	OR (95% CI)	P	aOR (95% CI)	P
Age		0.04		0.03		<0.001		<0.001
<20	1.28 (0.49-3.38)		1.27 (0.48-3.34)		1.06 (0.52-2.19)		1.06 (0.51-2.18)	
20-29 (ref.)	1		1		1		1	
30-39	1.49 (0.87-2.55)		1.53 (0.89-2.62)		1.60 (1.09-2.36)		1.66 (1.13-2.46)	
>40	3.14 (1.44-6.85)		3.21 (1.47-7.05)		3.06 (1.76-5.31)		3.12 (1.79-5.44)	
Ethnicity		0.17		0.16		0.41		0.59
Mandinka / Other	1.43 (0.77-2.67)		1.35 (0.71-2.57)		1.33 (0.88-2.01)		1.23 (0.80-1.89)	
Serahule (ref.)	1		1		1		1	
Fula	1.75 (0.97-3.16)		1.81 (0.98-3.32)		1.15 (0.76-1.75)		1.19 (0.77-1.82)	
Education		0.88		0.95		0.49		0.43
Quranic (ref.)	1		1		1		1	
Primary/Secondary	0.86 (0.18-4.01)		0.87 (0.18-4.13)		1.36 (0.52-3.51)		1.54 (0.58-4.05)	
Tertiary	0.71 (0.25-1.97)		0.82 (0.28-2.35)		0.77 (0.38-1.55)		0.82 (0.40-1.69)	
None	0.83 (0.42-1.66)		0.81 (0.40-1.63)		0.78 (0.47-1.30)		0.79 (0.47-1.32)	

Risk factors for infant mortality

Woman characteristics	HDSS only				Augmented HDSS			
	OR (95% CI)	p	aOR (95% CI)	P	OR (95% CI)	P	aOR (95% CI)	P
Age		0.11		0.20		0.01		0.01
<20	2.15 (0.69-6.67)		2.12 (0.68-6.60)		1.67 (0.67-4.17)		1.65 (0.66-4.13)	
20-29 (ref.)	1		1		1		1	
30-39	2.10 (1.03-4.29)		2.11 (1.03-4.33)		1.98 (1.14-3.46)		2.09 (1.19-3.68)	
>40	2.09 (0.59-7.44)		1.99 (0.55-7.14)		3.26 (1.47-7.22)		3.37 (1.51-7.51)	
Ethnicity		0.01		0.04		0.47		0.80
Mandinka/other	3.53 (1.38-9.01)		3.18 (1.23-8.22)		1.44 (0.80-2.58)		1.23 (0.67-2.24)	
Serahule(ref.)	1		1		1		1	
Fula	3.16 (1.23-8.11)		2.96 (1.14-7.67)		1.25 (0.69-2.26)		1.14(0.63-2.08)	
Education		0.42		0.20		0.07		0.09
Quranic	1		1		1		1	
Primary/Secondary	0.86 (0.10-7.48)		0.81 (0.09-7.18)		2.48 (0.71-8.68)		2.93 (0.81-10.6)	
Tertiary	0.23 (0.03-2.02)		0.35 (0.04-3.10)		0.30 (0.06-1.44)		0.32 (0.06-1.55)	
None	1.05 (0.41-2.73)		1.10 (0.42-2.90)		1.21 (0.55-2.69)		1.23 (0.55-2.73)	

7.5 Discussion

This study demonstrated (i) that record linkage with antenatal records increased the identification of pregnancies in the Basse HDSS; (ii) that adverse pregnancy outcomes and early childhood mortality were more common for pregnancies that were not identified by routine HDSS operations, and (iii) that analyses of risk factors of early childhood mortality may be biased if the HDSS ascertainment of pregnancies is incomplete.

Most HDSS make use of a system of proxy respondent reporting whereby one household representative reports on the vital status and – importantly for the outcomes studied here – the pregnancy status of household members¹⁹⁶. Pregnancy status ascertainment is crucial because it allows fieldworkers to probe for the pregnancy outcome in the following HDSS round. Even though many HDSS closely space HDSS rounds to minimize the likelihood that pregnancies are missed, our analyses suggest that pregnancies are often not reported, either because the household representative is not aware of the pregnancy status of the women of reproductive age in the household, or, because he or she is not willing to disclose that information²¹. The reporting of pregnancy status information in the HDSS is not random, but tends to vary by maternal age, ethnicity and to a lesser extent also by education level. The large majority of pregnancies that were missed by the routine HDSS operations also missed a pregnancy outcome.

This study illustrated that record linkage with ANC registers could fill in for this missing information. In our study, slightly more than half of the matched records had a pregnancy outcome recorded in the HDSS, and through the follow up interview with a selection of these cases (n=1,215), we were able to establish a pregnancy outcome for 861 women. The proportion of stillbirths and estimates of perinatal mortality in the follow up sample were more than twice as high as those estimated on the basis of the routine HDSS dataset alone. Stillbirth rates (35/1,000 births) and perinatal (47/1,000 births) mortality estimates based on the combined HDSS and follow up data were also much higher than those reported at national level in the 2013 Gambia Demographic and Health Survey (11/1000 births and 30/1000 births, respectively)²².

Similarly, the follow up interviews combined with HDSS generated estimates of neonatal (16.7/1000 livebirths) and infant (24.2/1000 livebirths) mortality that were higher than in the routine HDSS, but these differences were only marginally significant. These estimates were lower than the 2013 DHS neonatal and infant mortality rates for The Gambia (22/1000 livebirths and 34/1000 livebirths respectively)²².

Pregnancies and pregnancy outcomes under-reporting may not only bias mortality estimates but could also lead us to draw inconsistent conclusions about their risk factors. Our analyses suggest that this is particularly the case for infant mortality. In contrast, the socio-demographic risk factors for perinatal mortality did not change after adding the information from the follow up interview, possibly because they are less susceptible to behavioural or environmental conditions^{20, 374-376}.

Even though most of the analyses focused on bias in perinatal and early childhood mortality estimates, under-reporting will also affect fertility estimates. Inclusion of the pregnancy outcome data from the follow up interviews increased the estimate of the crude birth rate for the Basse HDSS from 14.7 (95%-CI: 14.1-15.4) per 1,000 to 20.8 (95%-CI: 20.0-21.5) per 1,000 population.

An important limitation of this study is that it entirely relied on existing medical records that were retrospectively linked to the HDSS database using a combination of clerical and probabilistic methods. Among others, this resulted in low match rates, which together with pregnancies that were not followed up, suggests that our mortality estimates are still lower-bound estimates that could be further improved through better record keeping at medical facilities, or, the use of other matching approaches that tend to result in higher match rates and more complete tracking of pregnancies^{203, 208, 320}. Retrospective record linkage on the basis of existing medical records inevitably also leads to erroneously matched records, but the follow up interviews allowed us to resolve these and exclude them from further analysis. Other challenges associated with utilizing health facilities as data sources, in this case antenatal clinic records are that while women in the younger age groups tend to have a high attendance rate at ANC, not all women attend antenatal clinics, which may lead to a biased representation of the pregnant population. In The

Gambia in particular, older women of higher parity tend not to attend the clinics, especially those with children of childbearing age as this is linked to shame. These women do not want to be seen attending clinics with women who are their children's peers³⁷⁷. Additionally, there are instances where women may attend antenatal clinics in a different location and deliver elsewhere making follow up of pregnancy outcomes challenging in such settings.

While we did not conduct an economic evaluation of the linkage of HDSS, a study in Nouna HDSS in Burkina Faso that looked at the cost of routine HDSS and survey versus an integrated method that included survey questions into the HDSS rounds showed annual cost savings of about USD45,000 for the integrated approach³⁷⁸. In our study, even though the record linkage and follow up interviews increased operational costs in terms of hiring personnel to extract and link the two data sources, an integrated HDSS-health facility data platform may reduce the need to closely space HDSS rounds and could therefore entail costs-savings with the added benefit of better quality data. However, it is possible that reduced number of rounds may result in missing out pregnancy outcomes particularly in a setting of high out-migration rates during pregnancy. Therefore, further studies evaluating the cost-benefit of this approach would be needed to fully determine its utility, which should ideally include a component of follow up of emigrants.

Recent developments such as the call for a data revolution and the need to scale up health information systems (HIS) at regional and national levels have meant that countries have set out mechanisms to improve national data quality and use^{166, 379}. For instance, Kenya and Mozambique intend to leverage on their high coverage of maternal and child health services to improve civil registration and vital statistics systems (CRVS)³⁸⁰. In The Gambia, where attendance to ANC and delivery in health facilities is incentivized leading to high coverage of health services, there is a scope both for using these services to educate citizens about their rights and benefits attached to registration, and as a platform for birth and death registration.

Other alternatives that can be envisaged would be to develop a CRVS or sample registration system that is linked to health facilities and utilize ANC, immunization visits, morbidity and death registers which include cause of death information to bolster national data. Countries such as Uganda, Mozambique, Cameroon and

Guinea have proposed this latter approach that aims to make CRVS and HIS interoperable³⁸⁰. On the other hand, South Africa has harnessed their HDSS by bringing them under the national science and technology department's mandate and coordinating outputs that inform national policy and build capacity³⁸¹. Such developments indicate that record linkage has great potential in the sub-national, national, regional and global arena to improve quality of data particularly in regions with incomplete CRVS.

Regarding perinatal and early childhood mortality, the Alliance for Maternal and Newborn Health Improvement (AMANHI) study, which was carried out in eleven sites in south Asia and sub-Saharan Africa, followed a cohort of about 2 million pregnant women. It demonstrated the value of population-based surveillance of cohorts of pregnant women that included linkage with health facilities for morbidity and mortality data to produce estimates of maternal, neonatal and perinatal mortality^{65, 382}. In Zambia, as in our study, women were identified from the antenatal clinic as pregnant and followed up at home for outcomes by AMANHI as there was no population surveillance system established, unlike in other participating sites. Our study had the benefit of being conducted within an established HDSS, and in a setting where there was incentivization to attend antenatal clinics through unconditional cash transfers thus allowing for a high ANC coverage and for comparison of estimates based on routine surveillance with those augmented ANC linkage and follow-up of undetected pregnancies.

7.6 Conclusions

HDSS are an important and widely used resource for tracking population-level demographic trends in low and middle income countries where full-fledged vital registration systems remain deficient. In addition, they are often used as platforms for evaluating the effectiveness of interventions for improving population health. This study suggests that routine HDSS operations are likely to miss many pregnancies and pregnancies outcomes, which can result in biased estimates of fertility, perinatal and early childhood mortality and their risk factors. This can be remedied via individual-level record linkage between the HDSS database and ANC records from health facilities that serve the HDSS population. Over 80 percent of

women in sub-Saharan Africa nowadays visit an ANC at least once during their pregnancy³⁸³, and these data thus produce a quasi-exhaustive record of pregnancies that can be prospectively followed to ascertain outcomes. This model of integrated community and health facility-based surveillance not only has applications in the context of HDSS, but could also be applied in other surveillance platforms, including sample vital registrations systems.

7.7 Acknowledgements

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Supplementary analysis

Table 7.4: Demographic characteristics of women that were followed against those not followed up and regression analysis of differences in women characteristics in the two groups

Woman characteristics	Not followed up	Followed up	Crude OR (95% CI)	p	Adjusted OR (95% CI)	p
Age				<0.001		<0.001
<20	99	90	0.54 (0.38-0.75)		0.52 (0.37-0.73)	
20-29 (ref.)	205	347	1		1	
30-39	144	351	1.44 (1.11-1.87)		1.40 (1.07-1.82)	
>40	17	73	2.54 (1.46-4.42)		2.46 (1.40-4.30)	
Ethnicity				0.01		0.02
Mandinka (ref.)	81	200	1		1	
Serahule	222	415	0.76 (0.56-1.03)		0.76 (0.55-1.04)	
Fula	162	246	0.62 (0.44-0.85)		0.61 (0.44-0.86)	
Education				0.003		0.001
Quranic	64	83	1		1	
Primary/Secondary	11	21	1.47 (0.66-3.27)		1.77 (0.77-4.04)	
Tertiary	82	107	1.01 (0.65-1.55)		1.04 (0.66-1.62)	
None	308	650	1.63 (1.14-2.32)		1.76 (1.22-2.53)	
Total	465	861				

The characteristics of women who were not followed up in the HDSS (n=465) and therefore had no outcomes, were compared to those of women that were followed up with outcomes (n=861). Following adjustment for maternal age, education and ethnicity, this comparison showed that older women were more likely to have been followed up as opposed to those aged 20 to 29 years; for women between 30 and 39 years of age (AOR 1.40, 95% CI 1.07-1.82) and those aged 40 years and over, (AOR 2.46, 95% CI 1.40-4.30). On the other hand, adolescents were 48% less likely to be followed up as compared to those aged 20 to 29 years (AOR 0.52, 95% CI 0.37-0.73). Mandinka women were most likely to be followed up compared to the other ethnic groups (p=0.02). Regarding maternal education, those who had no formal education were almost twice as likely to be followed up compared to those with Quranic education (AOR 1.76 (95% CI 1.22-2.53)). There was no evidence of association for women with either primary, secondary or tertiary level education.

Research paper cover sheet

Chapter 8 *Gambian cultural beliefs, attitudes and discourse on women's reproductive health and mortality: Implications for data collection in demographic and health survey research from the interviewer's perspective*

The aim of this qualitative study embedded in the pregnancy history survey was to understand the societal constructs behind under-reporting of perinatal and neonatal outcomes among other demographic measures.



Photograph courtesy of JN: a team of female fieldworkers with JN in Basse

8.1 Abstract

Background: A community's cultural beliefs, attitudes and discourse can affect their responses in surveys. Knowledge of these cultural factors and how to comply with them or adjust for them during data collection can improve data quality.

Objective: This study describes implications of features of Gambian culture related to women's reproductive health, and mortality, for the collection of data on these topics in surveys through the interviewer's perspective.

Methods: 13 in-depth interviews of female interviewers and a focus group discussion among male interviewers were conducted in two rural health and demographic surveillance systems as well as three key informant interviews in three regions in The Gambia.

Results: From the fieldworker's viewpoint, questions relating to reproduction were best asked by women as culturally pregnancies should be concealed, and menstruation is considered a sensitive topic. Gambians were reluctant to speak about decedents and the Fula did not like to be counted, potentially affecting estimation of mortality. Asking about siblings proved problematic among the Fula and Serahule communities. Some ways to overcome these challenges include using culturally-appropriate metaphors and symbols to discuss sensitive matters and enumerating births/deaths singly instead of collecting summary totals, which had threatening connotations. Such strategies conflict with the practice of training interviewers to ask standardised and precise verbatim questions.

Contribution: This paper presents indigenous Gambian solutions devised by fieldworkers asking about culturally sensitive topics when collecting pregnancy outcomes and mortality data in demographic and health surveys. For researchers collecting maternal mortality data, it highlights the potential shortcomings of the sibling history methodology.

8.2 Introduction

The study of fertility and mortality is central to demography^{384, 385}. Statistical data on births and deaths are always reported retrospectively, which is inherently more challenging than collecting current status data. It can lead to problems of omission and misplacement in time of events, because respondents may never have known the answer, have forgotten it or be unwilling to provide it. Certain study designs experience less omissions or displacement than others, for example civil registration compared to retrospective surveys, but these problems are never entirely eliminated. The nature and severity of these problems is neither the same everywhere nor entirely idiosyncratic, but dependent on the context, including the cultural context.

In Africa, censuses and household surveys are the dominant vehicles for collecting demographic data, as civil registration is incomplete, particularly of deaths¹⁸². Data quality can be affected by almost every aspect of the research process. For example, if the information gathered relates to matters considered private and sensitive by respondents such as sexual activity, reproduction, illness and death, one could expect withholding of information³⁸⁴.

What is regarded as sensitive is varied and context specific and broadly grouped into three groups of factors. First, there are questions that are considered intrusive by nature of their content, for example, about income. Second, questions where disclosure may result in harm or perceived harm to the respondent, for example about HIV status. Third, there are questions which seek to elicit socially unacceptable answers^{386, 387}.

In addition to the type of information being gathered, interviewers play a role in data quality and accuracy. It has been suggested that eliminating interviewers and using self-interview methods is the best way to encourage honest responses to sensitive questions. Nevertheless, a large number of respondents in Africa are illiterate, and even less so computer-literate. This and attendant challenges such as power supply in remote areas leave face-to-face interviews as the most feasible mode of data collection³⁸⁸⁻³⁹⁰.

Interviewer characteristics such as age, ethnicity, gender, personality, attitudes and beliefs affect survey outcomes³⁹¹⁻³⁹⁴. Some characteristics are amenable to change through training, while others can be used to the research's advantage, for example gender matching. Further factors, such as the language in which the interview is conducted have been studied, indicating that use of the language the respondent is most comfortable with results in more accurate information regardless of differences in ethnicity between the interviewer and respondent³⁹⁵. While these characteristics are not exhaustive, they give an indication of what should be taken into consideration when planning and carrying out surveys.

The cultural context in which a survey is to take place is also crucial as it may influence responses to survey questions. Understanding it provides a background against which explanations of the study outcomes can be sought³⁹⁶. Culture is a social heritage that influences people's perceptions and responses during the process of communication. Certain cultural practices can affect data collection. For instance, post-partum confinement of new mothers and the belief that newly-born children are not yet fully human can lead to their omission by respondents, potentially resulting in underestimates of perinatal or neonatal mortality³⁹⁷⁻⁴⁰⁰.

This paper focuses on cultural beliefs, discourse and practices in The Gambia that relate to pregnancy and its outcomes, identifying sensitive matters for the community. It also describes cultural influences on respondents' attitudes towards interviewers, adaptive behaviours by interviewers, and how together, these factors may affect pregnancy data collection in survey research. The insights are based on learning from trained and skilled interviewers, who are an excellent source of qualitative information as they are the point of contact with community members⁴⁰¹. The interviewers observe the respondents' verbal and non-verbal responses as well as their surroundings and are the direct recipients of the community's responses as they usually hold conversations rich with information that is not recorded.

8.3 Methods

Study setting

The Gambia is the smallest country in continental Africa spanning 480km from east to west and on average 48km from north to south. It is surrounded by Senegal except at its western border which is the Atlantic Ocean. The River Gambia runs the entire length of the country and divides the country's land area almost equally into halves: The South Bank and the North Bank. The 2013 census enumerated almost 1.9 million citizens of whom 96% are Muslim²⁶².

The Medical Research Council Unit The Gambia (MRCG) at the London School of Hygiene & Tropical Medicine runs four health and demographic surveillance systems (HDSS) which cover almost 15% of The Gambia's population. HDSS are defined as highly monitored systems that gather longitudinal data of the total population within a geographically-specified area. Households within the HDSS are visited every four months by fieldworkers, all of whom are male, and pregnancies, births, deaths and movements in and out of the HDSS are recorded. HDSS also form a platform from which other studies are conducted.

The Farafenni HDSS has been in place since 1981 and is located 170km inland on the North Bank of the river Gambia from Banjul, the Gambia's capital city. There are three main ethnic groups – Wolof 41%, Mandinka (31%) and Fula (22%), whose primary occupation is farming (14). As at 31st December 2015, there were 55,209 individuals being followed up²⁹⁴.

The Basse HDSS established in 2007 is 375 kilometres away from Banjul on the south bank of the river Gambia³⁹. The Serahule, Fula and Mandinka are the major ethnic groups in Basse. As at 31st December 2015, a total of 179, 548 people were being followed up in the HDSS.

The qualitative study reported on here was embedded within two larger household surveys conducted from December 2015 to June 2016 in the two HDSS, each of which interviewed resident women about their pregnancies and outcomes.

The household surveys attempted to adopt a culturally-sensitive approach by training and employing 31 female fieldworkers and insisting that women were

interviewed in private using their preferred language. This was as a complement to the routine surveillance activities conducted by male fieldworkers described above.

The qualitative study was then conducted to find out about the female fieldworkers' experiences collecting the pregnancy history data. Specifically, we inquired about their thoughts on community members' conceptualization of cultural beliefs and discourse regarding reproductive issues, their attitudes towards them as female fieldworkers and how this shaped women's participation in the survey. This research also sought to get an external view from the male fieldworkers who regularly collect the demographic data in the HDSS, and who went back to the community after the female-only interviewer survey was completed).

Lastly, it aimed to identify cultural factors and mitigating factors, if any, that affected data collection during the main survey. These questions were founded on theoretical constructs of discourse and how it affects social relations, as well as gender roles, but allowed for discoveries about the communities' perceptions through the lens of the fieldworkers⁴⁰².

Study participants

The first group of study participants comprised 13 of the 31 female fieldworkers who conducted the pregnancy history survey (see Table 8.1). For the six months of the survey, the female fieldworkers were fed and accommodated in the community by the village chiefs at no cost, as is customary in The Gambia. They participated in daily activities of the community alongside the local women, including cooking, fetching water, grinding of cereals and washing, in addition to interviewing the women. The female fieldworkers each interviewed 332 women on average, although one of them interviewed 1,700 women. The female fieldworkers were mostly Mandinka and Fula, which are two of three most common ethnic groups in The Gambia, the third being Wollof. All fieldworkers spoke Wollof as it is the lingua franca in The Gambia.

All the female fieldworkers had completed secondary school education, two were in university and three had conducted nationwide surveys before. Although they had been born in the study areas, most of them no longer lived in the rural areas as they had left to study or work.

In addition, we interviewed three key informants, two of whom were community liaison officers and one who was a long-serving field worker having over twenty years of research experience all over The Gambia. The three key informants hail from three distinct regions in The Gambia. The third group of study participants were seven male fieldworkers and their supervisor, who live in the community and work in the HDSS, and who were responsible for follow up the residents in the HDSS both before and after the survey was completed.

Study design

Three research methods were used: in-depth interviews of the female interviewers, key informant interviews, and a focus group discussion (FGD) with a group of male HDSS field staff. AJR developed the question guides for all the interviews and FGD, after a cumulative process of information gathering during the two years she had worked in the HDSSs and lived in The Gambia. This involved observation and informal conversations about ways of communicating in the community that might affect the pregnancy history data that the female interviewers collected.

Some of the field team we interviewed had worked in both Farafenni and Basse, and thus provided different viewpoints covering the north and south bank communities, while others had worked only in Basse. AJR did not interview the female fieldworkers as the relationship was that of employer and employees, and this power dynamic would probably have constrained their responses, especially because they were being asked to evaluate their experiences in the field. Instead AJR arranged for the female fieldworker interviews to be conducted by JN. JN is white, and the interviews were carried out in English as all the participants were fluent. JN spent a week observing survey procedures as they were conducted in the field and the interactions of the fieldworkers with the community members and the community's reaction to both male and female fieldworkers. She is female and similar in age to most of the fieldworkers, which aided in building rapport.

While analysing the content of the initial interviews, AJR changed the interview guides used by JN as themes emerged that needed further investigation. The questions focused on the experience of the female fieldworkers and their understanding of the community members' attitude to being interviewed by a

female-only team and cultural beliefs that influenced the community's response. We stopped recruitment after no further emerging themes could be identified by JN and AJR. AJR and JN subsequently conducted the FGD with the male HDSS field staff, and AJR interviewed the key informants herself.

The female fieldworker interviews were conducted in Dampha Kunda and Gambisara, which are in Basse on the south bank of the river Gambia. The key informants were interviewed in Basse, Farafenni on the north bank of the river Gambia, and in Fajara on the coast, where the MRCG headquarters are located. The FGD comprising the male fieldworkers and their supervisors was conducted in the Armed Forces Provisional Ruling Council (AFPRC) General Hospital in Farafenni.

Sampling

Purposive selection was done to determine the experience of the female-only team that conducted the community survey, after which the snowball technique was applied to identify key informants⁴⁰³. The key informants were selected based on their knowledge of the Gambia as their main roles are to facilitate community entry for all projects by MRCG, the fact that they hailed from different regions in The Gambia, being multi-lingual, and their extensive experience doing research throughout the country. The FGD was held with all the male fieldworkers working on the Farafenni HDSS.

Data analysis

A reflective and iterative approach was used throughout the data collection and analytical period. Initial information from the informal conversations and observations was used to develop the interview guide, which was then cyclically refined as successive in-depth interviews were analysed.

The FGD guide also benefited from insights gained from the interviews and observations. The analytic phase started with the individual initial coding framework for each interview and the FGD. This included reading each transcript and field note, summarizing, designing tables with the contents and encoding material to emerging themes⁴⁰⁴. Relevant passages from the transcripts were added to the coding tables under the corresponding codes and recurring themes identified as follows: relationship with the community, female fieldworker

experiences and cultural influences on responses. Verification and validation of the themes through data and investigator triangulation were conducted by AJR and JN who compared their independent coding frameworks derived from responses from the different data sources and discrepancies between them were discussed and resolved.

All the in-depth and key informant interviews were digitally recorded and transcribed verbatim, using the software F4 and analysed using NVIVO 10 Qualitative Data analysis software (QSR International Pty Ltd. Cardigan UK). AJR and JN made expanded field notes after the FGD and recorded their reflection on the discussion immediately after its conclusion.

Ethical approval

The study was approved by the Gambia Government/ MRC Joint Ethics Committee and the London School of Hygiene & Tropical Medicine Ethics Committee (Appendix A-SCC1437v2 & LSHTM Ethics ref 10377). The participants were informed of the study and the main aim explained after which verbal consent was obtained. Study participants were reassured about confidentiality and informed of their right to withdraw at any time with no consequence.

Table 8.1: Demographic profile of the respondents interviewed

Participants	Age	Sex	Ethnic Group	Marital Status	Education Level	Fieldwork Experience
I1. interview_8II_0120	30	F	Mandinka	Married	Secondary	6 months
I2. interview_8II_0121	34	F	Fula	Single	Secondary	None
I3. interview_8II_0122	21	F	Mandinka	Single	Secondary	None
I4. interview_8II_0123	23	F	Mandinka	Single	Tertiary	None
I5. interview_8II_0124	27	F	Fula	Single	Tertiary	3 years
I6. interview_8II_0125 & 8II_0126	23	F	Fula	Single	Tertiary	None
I7. interview_8II_0127	22	F	Fula	Single	Secondary	None
I8. interview_8II_0128	38	F	Mandinka	Widow	Tertiary	3 years
I9. interview_8II_0130	29	F	Mandinka	Single	Tertiary	None
I10. interview_8II_0131	18	F	Wollof	Single	Secondary	None
I11. interview_8II_0132	23	F	Fula	Single	Secondary	None
I12. interview_8II_0133	24	F	Mandinka	Married	Secondary	None
I13. interview_8II_0134	26	F	Fula	Single	Tertiary	None
I14. interview_8II_0140	65	M	Fula	Married	Tertiary	22 years
I15. interview_8II_0141	57	M	Mandinka	Married	Tertiary	25 years
I16. interview_8II_0142	48	M	Fula	Married	Secondary	17 years
FGD_I	30	M	Mandinka	Married	Secondary	5 years
FGD_II	30	M	Mandinka	Married	Secondary	4 years
FGD_III	26	M	Mandinka	Married	Tertiary	1 year
FGD_IV	29	M	Mandinka	Married	Secondary	1 year
FGD_V	33	M	Mandinka	Married	Tertiary	7 years
FGD_VI	31	M	Mandinka	Married	Secondary	3 years
FGD_VII	48	M	Mandinka	Married	Tertiary	28 years

8.4 Results

We first present cultural beliefs and practices that the fieldworkers encountered that could affect data collection during surveys in The Gambia. Then we discuss how the fieldworkers utilized their knowledge of the Gambian culture and that acquired from our training to obtain the data required for the pregnancy history survey.

Table 8.2: Summary of findings, implications for surveys and proposed solutions by the interviewers

Cultural practices, discourse and attitudes	How it could affect data collection in surveys	Solutions proposed
Reluctance to be counted (Fula, Serahule)	Under-enumeration and underestimation of demographic parameters	Use of inanimate objects to enumerate (for instance ask how many 'sticks' instead of children)
Reluctance to speak of the deceased	Underestimation of mortality	Enumerate singly as opposed to totals Community entry using Alkalos
Pregnancy concealment and reluctance to speak about menstruation Stigma associated with pregnancy loss	Missed identification of pregnancies and their outcomes Omission of adverse pregnancy outcomes, underestimated perinatal mortality	Have women interview women directly about pregnancy and its outcomes Age matching for questions on menstruation which they termed a shared experience Use of a trusted interpreter especially as most interviewers did not speak Serahule
Hesitance in producing legal documentation – identity and health cards (Serahule community)	Poor date reporting	Use of a trusted interpreter Clearer explanation for the need for the legal documentation
Women's position in the community -defer to heads of households for decision making -female fieldworkers preferred and accepted especially if less 'westernized' -women's household responsibilities including farming and household chores	Reduced response rates -refusal by male and elderly female households to allow women in their households to participate -divorced women reluctance to reveal status Acceptance of female interviewers	In addition to individual consent from the women, permission needed to be sought from the mostly male heads of households Alkalos help in identifying households especially with extensive homonymy in The Gambia and dissolved households in the case of death or divorce Adherence to acceptable dressing norms Appropriate timing of surveys (avoid farming seasons and Ramadan) and having fieldworkers assist with chores while living in the community

Table 8.2 summarizes the cultural practices, discourse and attitudes that relate to women's reproductive health according to the fieldworkers. It also presents potential effects on data quality and accuracy in surveys and some proposed solutions as per this study's respondents. These are elaborated upon in the following sections.

For the most part, the female fieldworkers were well received in the community (II-II0, II2-II4). They reported that the community members were welcoming and

happy to meet them and that they gave of themselves wholeheartedly without expecting to be remunerated (I9, I5). When they encountered households that appreciated them and were friendly, the warm reception helped them to conduct the interview effectively. An example given was a woman who called 21 interviewers who were working in her region that day to the 'Bantaba', which is a meeting place for the community, and provided breakfast for all of them (I5). The positive attitude by the respondents was more notable in those households that benefited from trials and health care offered by MRCG at LSHTM (I2, I5, I6, I7, and III-II3).

In a few cases, however, households approached did not react well to the interviewing (I6- I9, II3) and because of this it was difficult to get information to complete the questionnaires from the respondents. For instance, some respondents had a "bad mind against MRC" with reference to taking people's blood," (I5) or would send the fieldworkers away (I6, I7). One villager saying that people from MRCG asked many questions and gave nothing in return (I8).

Some of those who resented being interviewed also complained that the interviews took too much time, and that they (the respondents) were busy (I6, I7, II3).

The team faced lengthy delays in completing the survey as it was partly conducted in the farming season and therefore, women could only be found either very early, before they left for the distant farms, or in the evening, at which time they were overwhelmed with the household chores of dinner preparation and fetching water (I4). This resulted in having to visit households up to at least three times and in the evenings in order to conduct the interviews. The initial survey period was meant to be four months but ended up taking six months to complete the minimum number of households.

Cultural beliefs and practices in The Gambia that may affect demographic research.

Respondents' reluctance to be counted and to enumerate their siblings

We found that the Fula, Wollof and Serahule exhibited a reluctance to be counted, unlike their Mandinka counterparts.

One of the key informants of Fula origin (community liaison officer), who speaks six local languages and is familiar with the Gambian culture reported that these groups of people held on to the belief that it was not good to be counted as it had been passed down generations. He suggested that they did not know the origin of this belief but still avoided being counted even after exposure to Western education. He said:

“As far as counting is concerned, the Fula will not want to use it for humans. Instead of asking ‘how many children do you have?’ you ask, ‘how many sticks does your mother have?’ They will then respond with a number. Even animals you do not count. The history goes back even before my ancestors. They do not like to count (II4).”

The female fieldworkers interviewed corroborated this view, saying that it was not culturally acceptable to count numbers of children because counting them would reduce their numbers, that is, increase their chances of dying. It is said that, if you know how many children someone has, it enables you to curse them and cause the children's death. The female fieldworkers attributed this to the low literacy level in the study areas and thought that, over time, this concept would change as more people were educated and therefore came to understand that counting people was not directly responsible for causing their deaths (II).

The fieldworkers encountered further resistance when asking about the respondents' siblings, especially if the siblings were deceased, as Gambians prefer not to dwell upon those who have died (I6). Most Fula and Serahule women interviewed refused to name their siblings. If the fieldworker probed for names, they would sometimes be told to ask their (the respondents') parents as a way of dismissing them. In some cases, their parents were not part of the study sample, or were resident elsewhere or deceased. Often, respondents would acknowledge

that they knew the number of their siblings, but some reported that they would never reveal this information, far less list their names. However, by gentle probing and by breaking down the question into two, starting by counting those who were alive first and then asking about those who had passed away, the team occasionally managed to get this information (I2).

A key informant reported that even Fula people from the neighbouring country of Guinea living in Basse have the same reticence, and that their reluctance was not related to fears about witchcraft.

Concealment of pregnancy

Women from all ethnic groups in The Gambia, seldom talk about or discuss their pregnancies, even when they are plainly visible. A well-known proverb that justifies this was provided by a key informant as follows: “If a snake wants to grow big it has to hide.” (I14). He further explained that hiding the pregnancy was a way of protecting it from harm from others who might cause the woman to miscarry by means of the evil eye or witchcraft. During the planning process and interviewer training, we included two questions to try to improve our success at detecting pregnancies. The women were first asked directly if they were pregnant. Regardless of the answer, they were then asked about their menstruation cycles. If a respondent reported that she had missed her period, she was further probed as to the reasons for the absence of her period while keeping in mind the sensitivity and cultural implications of revealing a pregnancy (I4). This was useful as many women readily reported missing their menstrual periods for months, but still said that they were not pregnant when asked directly. This was not always the case for older women however, as some of them felt offended at being asked about menstruation by our ‘younger’ fieldworkers. Analysis of the main survey reveals that approximately 9% of the respondents said they were pregnant and another 9% reported that they had not had their menses for months and, therefore, were probably pregnant (Table 8.3).

Table 8.3: Menstruation versus direct questioning about pregnancy in the women-only survey

LMP n (%)	Pregnant n (%)
Ongoing 389 (7.4)	Yes 456 (8.7)
Days 1266 (24.1)	No 4635 (88.4)
Weeks 1760 (33.6)	Unsure 122 (2.3)
Months 918 (17.5)	Missing 31 (0.6)
Hysterectomy 78 (1.5)	
Amenorrhea 30 (0.6)	
Menopause 65 (1.2)	
Postpartum amenorrhea 693 (13.2)	
Missing 45 (0.9)	
Total 5244	

The female fieldworkers reported that, in some instances, the woman's husband, mother or in-laws confirmed the pregnancy, even if she would not, despite attempts at privacy by the team such as interviewing the woman under a tree out of earshot. The woman's relatives knew that the survey was asking women about pregnancies and would tell the female interviewers that so-and-so was pregnant in spite of her reluctance to report this.

Although the women eventually responded, they found it difficult to report on dates of their last menstrual period, as asking about dates of menstruation is not an unusual practice in The Gambia. The female fieldworkers said that they would sometimes encourage the respondents to speak about periods and pregnancy on the basis that these were things that all women went through (I13).

Stigma about pregnancy losses

The pregnancy history survey (main study) included questions on miscarriages, abortions and stillbirths. Perhaps as a continuum of the reluctance to be counted noted previously, some women did not want to talk about their reproductive health problems and considered this information private. This was particularly so when the women were asked about pregnancy losses (I6, I7, I9, I12). The fieldworkers believed that younger women between 15 and 18 years of age found it most difficult to answer questions about pregnancy losses. For example, their standard response was that they were not married and therefore could not have had this experience

(I7). This reticence is probably compounded by the fact that the community frowned upon both women having children out of wedlock and upon them having an abortion.

Although respondents were hesitant to talk about pregnancy losses, there were a few exceptions to this. Some interviewers reported that although it took a lot of time to sit and listen to the respondents, the 'release' reported by the respondents after talking about their pregnancy losses was worth it. This was more so as they lived in the households that sometimes belonged to the respondents (I4, III). Unfortunately, some may have answered with the misconception that by giving out this information they would be helped to find a cure (II0). It was also difficult to capture accurate dates for stillbirths and miscarriages but not for livebirths, which were usually recorded on the child's health card (II, I4, III, II3).

Challenges specific to the fieldwork

Language barrier

The team encountered problems with language, particularly in Basse which is the main region in the country where the Serahule language is spoken (I9, II0). None of the fieldworkers spoke Serahule fluently and thus used a trusted interpreter. This meant that the female villager was asked to identify a woman she could trust with confidential information since we were asking about sensitive information such as miscarriages and abortions. Only when this person was identified and consented to keep confidentiality, was the interview conducted. Otherwise a repeat visit was arranged.

Challenges with legal documentation

In the urban area in Basse, people could clearly remember the dates of demographic events, and readily produced their identification documents. In the more rural areas, gaining access to documents proved difficult.

This sentiment is echoed by (I4, I9) and (II0), who mention that refusal to produce identification documents occurred more frequently among the Serahule community, who were concerned that the interviewers would take them.

How the team overcame the challenges

During fieldwork, the team learnt how to integrate into the communities. There were certain protocols that needed to be adhered to in order to gain community entrance and acceptance, which helped the team to get more information from the community members.

The village chiefs were extremely instrumental in facilitating entry to the community. The field teams always paid a courtesy call to the chiefs who then introduced them to the villagers, explaining what they were there to do (I8). This was a follow on to the community sensitization conducted during the planning process. The village chiefs (Alkalolu), together with the HDSS fieldworkers, also assisted in correct identification of the randomly selected households (III). This is vital because of homonymy in The Gambia, such that certain names are quite commonly used, making it difficult to differentiate between households. For example, twins are usually called Adama and Hawa and most firstborn males are Lamin, while females are commonly called Fatou. Also, in households where there was divorce, some of the women would not disclose that their husbands, who had been listed as the household head, had left, leading the fieldworkers to believe the women were not members of the selected households, when in fact they were (I6).

In some villages, in addition to getting consent from the women participants, permission needed first to be sought from the heads of household as they wished to decide what questions could be answered. If the household head was not around, the interviewers would have to wait or reschedule as doing otherwise meant that they could be expelled from the compound (II). We found that most refusals were by older women or male heads of households from the Serahule community.

The female fieldworkers also adhered to dress codes that were acceptable to the communities they visited. Being young, modern, educated women, sometimes they were met with disapproval when they wore 'western' attire such as trousers. They learned to ask about what way of dressing was acceptable in certain villages and adhered to it, reporting that this encouraged the community members to talk to them (I8).

Gambian culture dictates that hospitality offered by the community members should be accepted. It is customary to be offered food and drink when visiting homesteads. The team felt that they were well integrated and received more information because they lived in the community for the six months of the survey. They were hosted by residents in every village in which they were to conduct interviews as had been arranged by the *Alkalolu*. The villagers had been informed that they were conducting a survey that involved interviewing the women and, as per Gambian culture, hosted them at no cost. The female fieldworkers participated in daily activities including food preparation and eating from the same pot (I5). Doing chores with the women reduced the workload and time pressure faced by the female community members, who appreciated this and responded more positively during the interviews.

In The Gambia, women are required to live with their parents until they get married. For the female fieldworkers, living away from their parents was a challenge as most of them had never stayed away from their families before. Although they found this experience positive (I6, I9), they faced harsh weather conditions, and found the sleeping arrangements and food inadequate. Basse experiences the hottest temperatures in The Gambia, reaching over 40 degrees Celsius. The research team mitigated some of their discomfort by providing mattresses, insecticide-treated bed-nets, and bags of rice to supplement what the villagers provided. The hosts were also given a token of appreciation for providing accommodation.

Role of female fieldworkers

After the pregnancy-history survey was completed in Farafenni, we conducted an FGD with the male fieldworkers. This discussed their thoughts on the employment of female-only interviewers and what they had heard in the community about the female fieldworkers during their routine follow up visits so as to enable us to gauge the community's attitudes to having women interviewers. We also interviewed female fieldworkers from Farafenni who had moved to Basse to help complete the survey as it is a larger area.

Both the male and female fieldworkers reported that, in their opinion, female fieldworkers are the preferred choice for asking questions relating to pregnancy and menstruation as it was not culturally suitable to have men ask these questions (II-II4). The female fieldworkers reported that rapport between the women interviewed and themselves was further improved when they assured the former of the confidentiality of their responses and when they referred to their shared experience of menstruation and of pregnancy for those of them who were mothers (I4, I5). The male fieldworkers, on the other hand, confirmed their discomfort in asking about pregnancy, so much so that they had developed ingenious ways of doing so without compromising women's modesty. This they did, for example, by asking if the woman had a 'yellow card', which is a card given to women attending the antenatal clinic, thus alluding to her pregnancy without having to ask directly or make the woman respond directly. They also noted on their ledgers if the woman was visibly pregnant, thus eliminating the need to ask questions about this (usually in the late stages when it was obvious). It is important to note that male fieldworkers do not ask about menstruation during their routine HDSS rounds and they expressed great reluctance to ask a question about this if it was to be introduced, although they would do so if it were required. The male fieldworkers also felt that although the women in the community would answer questions about pregnancy when asked by men, social constraints made it difficult for them, whereas the female fieldworkers had no such constraint. Their visits to the community after the pregnancy history survey revealed that the female fieldworkers had left a good impression and the women had been happy to talk to them, stating that they were welcome to continue their surveys in the future.

Strengths and Limitations

This study focussed on finding out about the community's sensibilities and about the experiences of female fieldworkers conducting a pregnancy history survey. We were able to apply data triangulation by using three approaches to qualitative data collection, comparing views from different age groups, sex and different regions in The Gambia as well as investigator triangulation. This approach increased our confidence in our findings, resulting in a more comprehensive viewpoint of the cultural factors affecting data collection on pregnancies, births and deaths.

Although the employment of local interviewers is often advocated, we found that having most of our interviewers from urban areas did not hamper rapport building. A limitation of this study is that community members were not directly interviewed after the female-only survey, but information was gleaned by proxy via the male interviewers who went back to talk to them. Equally, in some regards, this may be a strength of the study as the male fieldworkers are insiders in the community and more frank information might have been given to them than would have been to the researchers, if we had asked community members about their thoughts on the survey and the interviewers⁴⁰⁵.

The female interviewers had all completed secondary education which enabled good communication between us. However, their educational level may have created a 'space' between them and the women in rural villages, who are unlikely to have had western education. This westernization may have affected the responses and attitudes of the community members, judging from the comments the interviewers received about their clothing. However, the fact that there were no other criticisms of, or sanctions against, the female fieldworkers from the community apart from the one occasioned by their 'westernized' dressing, which they subsequently corrected, suggests that it is unlikely that it resulted in significantly less information being given to them. However, inevitably, this paper represents the interviewers' views as modulated by their own beliefs and social constructs, as well as the researchers' interpretation based on their worldview, and may not fully depict the community's real perspective.

Reflexivity

Although AJR was a foreigner, she was easily integrated into the community as she apparently looked like a 'Fula' woman. The possibility of social desirability bias must be acknowledged as a potential limitation, however, as both AJR and JN were foreigners, and JN was white. This has been shown to influence responses in previous studies in The Gambia. Knowing that a researcher brings into the research their own perspectives allowed the first author to interrogate her views and how this is portrayed in the interpretation of the data. AJR is of nomadic origin from East Africa and could relate to the Fula reluctance to be counted, and to the use of metaphors when counting people. Being a medical professional enabled her to

access the key informants easily, as this status is highly-esteemed in The Gambia. Additionally, rapport was created through showing respect by adapting cultural etiquette surrounding greetings and gender relations. Being younger than the key informants reversed power dynamics, allowing the key informants to impart their cultural knowledge. The researchers showing interest, in turn, pleased them. In deference to the male fieldworkers and the key informants, the researchers went to their choices of meeting place, which were familiar to them. During the conversations, one of the key informants reiterated the importance of respect from the younger generation and the need to consult the elders before doing research in the community.

The researchers were keen not to push their agenda but instead to learn about the culture and articulate what was important to the community by proxy. However, we are aware that the agenda behind this work was distrust of the neonatal mortality estimates found when analysing mortality data from the HDSS as we thought they were too low. While the research would not directly benefit the community, as no medical care or other intervention was provided, we had the hope that with more insight into what underlay the under-reporting we suspected, our findings would eventually lead to more accurate estimates, thus the plight of the new-born babies would be highlighted.

8.5 Discussion

Demographic research often studies components of culture such as behaviour, knowledge and attitudes, with the aim of making these more quantifiable in order to explain demographic phenomena such as mortality and fertility⁴⁰⁶. We sought to understand how these factors influenced demographic field research in The Gambia and whether what we learned could be incorporated into data collection to enhance accuracy.

For research activities to be successful, researchers in Kenya have emphasised the need to move beyond insisting on individual consent to considering the influence of the community⁴⁰⁷. They note that having fieldworkers residing in the community, as well as having worked previously with the community, enhances the acceptability of a study. Similarly, it was important to have the heads of the

households involved in the research process, a sentiment echoed by other researchers working in The Gambia⁴⁰⁸. Certain characteristics affect responses in surveys, for instance the context in which it is carried out as well as the respondent and interviewer characteristics such as age, ethnicity, gender, personality, attitudes and beliefs. Our study identified additional culturally sensitive methods that could improve community relations, such as having women interviewing women about pregnancy and related outcomes and menstruation, using respondents' preferred language, employing metaphorical expressions to improve enumeration of people and vital events, and dressing appropriately. Although the majority of this study's respondents were from the country's largest ethnic group which may bias the lens through which their opinions are expressed, similar sentiments were expressed by the non-Mandinka respondents³⁴⁵. This study highlighted the fact that the timing of enumeration activities was key. It is important to avoid busy farming seasons and Ramadan (when people are fasting), and also to assist with chores if this was considered helpful.

In demographic and health surveys, the time needed to build rapport is lacking, making it a challenge to know whether the information that is gathered is true. Bleek cites examples of glaring misinformation when the relationship between the interviewer and the interviewee is biased⁴⁰⁹. There is also a need for close contact with the community to build trust, to encourage people to share confidential information willingly, rather than it being coerced from people. This is a time-consuming process, but effective in data collection for sensitive topics, and is one which could be adapted by HDSS, where more time is spent by fieldworkers in the community. As this is not tenable for large-scale single-round surveys, we find that the process of data collection may be enhanced by enrolling community gatekeepers such as village chiefs and household heads to assist with entry into the community, ensuring confidentiality, use of sensitive language and adherence to dress codes. Too much emphasis cannot be placed on training of fieldworkers as well as encouraging empathy, particularly when collecting mortality data. Ultimately, the community should be involved in the whole reiterative research process, which although time and resource consuming, has been found to be most effective. However, the issue of sensitive topics, as labelled by the respondents, is

more difficult to handle as they may require indirect inquiry in a circumscribed context which is often unmanageable. This then would require methodological advancement in analysis to cater for the missing information, potentially extrapolating it from closely followed populations.

The issue of concealing pregnancy for fear of harming oneself and the unborn child for example is widespread in Africa. In Mozambique and Liberia, women seek multiple protection methods to counter this 'reproductive vulnerability' and ensure they sail safely through the pregnancy, which is considered good fortune and thus may attract harm^{410, 411}. However, the protection methods sought do not normally include western medicine as the vulnerability is considered more spiritual in nature. In the Gambian context, bad *jinne*, the evil eye and spirit creatures, which are believed to be malevolent spiritual and physical beings, are thought to target vulnerable people like pregnant women^{412, 413}. Thus, a woman's duty is to conceal the pregnancy until such a time when it is physically impossible to do so^{410, 413, 414}.

Pregnancy concealment has several implications for research. Conducting research that requires identification of pregnancy in the first and second trimester, for example, may go against prevailing cultural practices as it potentially exposes women to occult forces to which they feel vulnerable. On the other hand, identification of all pregnancies in a HDSS is essential for accurate perinatal and neonatal mortality estimates. Therefore, innovative ways need to be developed to ensure that respondents and the interviewers can provide and collect this information respectively, without compromise of their values. Thirdly, women may delay antenatal visits in a bid to protect their pregnancies, contrary to clinical recommendations that advise early visits for protection. Lastly, rapport building, and culturally appropriate measures must be applied if truer outcome measures are to be obtained.

Idioms and proverbs were used by our informants to describe the pregnant state; for example, a snake having to hide to grow big. Research in Mozambique found that pregnancy was seen as a family secret. Revealing it was compared with revealing the hiding place of the house keys, the moral of the analogy being that, if you tell people about your hiding place, you may come and find the house empty⁴¹⁰. In one community in Nigeria, pregnant women were depicted as women carrying

pots of water, the pot here symbolizing the womb, and water- the unborn child. To speak of a miscarriage for example, they may describe a woman slipping and losing the water with the pot intact⁴¹⁵. Perhaps, the identification and application of idiomatic language when designing research instruments may be of use. Additionally, indirect methods may be employed for asking about pregnancy, such as asking a woman for her antenatal clinic card, the 'yellow card' as in the Gambian HDSS example.

We found that beliefs about being counted held by the Serahule, Fula and Wollof tribes, who comprise about 40% of Gambia's population, compounded by the stigma of having many deceased relatives, made data collection on mortality especially challenging²⁶³. Fula are also not allowed to utter certain names such as those of their spouses or their parents. Therefore, surveys that ask them to name certain members of their households go against the grain. O'Neill and colleagues noted this reticence to participate in research by the Fula who refused to have their blood taken due to a belief that their life force was getting drained⁴¹⁶. We know that the Fula are numerate. Therefore the practical implication of this reluctance to count up to the whole family's size would be to collect a birth history which individually enumerates each child, as opposed to asking summary questions such as those on children ever born and surviving used in censuses and multiple indicator cluster surveys^{368, 417}.

We were met with resistance by the majority of women when soliciting them for information on pregnancy loss, due to cultural hesitance and the stigma attached to women who had experienced multiple pregnancy losses. We did find, however, that some women were comforted when given space to speak of their pregnancy losses even if they occurred in the distant past. This highlights the fact that interviews on pregnancy losses may not be unwelcome and that there may be benefits to the affected women, particularly when they interact with empathetic interviewers. In The Gambia, carrying a pregnancy to term and having a healthy child are the woman's responsibility. Her status and security in the homestead are solidified even further if the child is a boy. On the other hand, pregnancy losses are blamed on the woman. Thus, by concealing the pregnancy and any losses, the woman protects herself from prejudice⁴¹⁸. Information on this did not reach

saturation, but it presents a platform for future research on the community's, particularly women's, wellbeing and coping mechanisms.

The combination of the community's reluctance to be counted and pregnancy concealment carries several implications for perinatal and neonatal mortality estimation. In Senegambia, there is a confinement period before the naming ceremony (on the 7th day of life) when strangers are not allowed to see new-born babies^{413, 414}. These first seven days of life are critical as most neonatal deaths occur during this period, with most deaths occurring on the day of birth⁹. In Ghana, after a baby survives the first week of life, a string of white beads is given to symbolize victory through this dangerous period, and is worn for a month, after which it is changed to blue to indicate different stages of the child's growth⁴¹⁹. In The Gambia, a fire may be kept continuously burning in the home during the first week of a baby's life as a precaution against harm towards the newborn baby and mother. Thereafter, an animal is slaughtered and the baby's head shaved followed by a large feast to celebrate and name the child³⁴⁵. These practices of confinement and celebration of survival highlight a community's awareness of the need to protect and enhance the neonate's survival. Equally, confinement clashes with contemporary methods of protection which require that the newborn baby visits the hospital.

Currently the Islamic religious practice of almost immediate burial compounded by the community members' reluctance to speak of the deceased could also detrimentally affect collection of neonatal and perinatal mortality data. The confinement period and lack of recognition of the neonate as an individual in this 7-day vulnerable period also serves to 'protect' the adults from pain in the event of death²⁹. The Mandinka call newborn babies 'angels' who go straight to heaven when they die, and people should therefore not be sad³⁶³.

Castle describes a rich Fula family in Mali that refused to have nutritional measures taken outside their home but were amenable to be measured at home as this would avoid supernatural reprisal³⁶⁸. Taking this into consideration to resolve the contemporary and cultural clash, postnatal home visits by health workers as recommended by WHO may remove the 'exposure' of the neonate to occult forces as the baby would remain confined and therefore protected³⁵⁹. These home visits

may also be helpful in prevention of early neonatal deaths through early recognition of neonatal illness and referral. If death has already occurred, the visits may be useful for enumeration of these deaths.

Self-reporting is the standard form of information gathering in most surveys including the demographic health surveys⁴²⁰. Existing translation policies emphasize the need for semantic equivalence, where the sentence structure and words in the translated question are the same. However, normative equivalence, which describes the ability of the translation to address social norms is required, but often missing. Also, in many contexts, particularly in sub-Saharan Africa, not every fieldworker will speak the language of the interviewee, as was seen in our case with the Serahule community. In The Gambia, as there is no standard written format for the spoken language, use of translated verbatim questionnaires in order to improve data quality, which is often recommended, is challenging^{319, 421}. In such situations, further research into what is suitable for the community and alternatives for research instrument development should be sought, keeping in mind cultural issues such as those described in this paper. Thus, ample time and resources need to be set aside for community-based research prior to the fieldwork, to properly identify these issues to avoid compromising data quality and committing injustices to the community to be studied.

Finally, to ably represent the community, the researcher is responsible for ensuring that the research is made available and used to address the struggles that the community confided in them^{422, 423}. In the global health culture, the need for accurate statistics has proliferated as the numbers are used for evidence-based policy making and as a leverage for financial investment to ensure that no one is left behind^{3, 424}. Statements such as ‘to count, you must be counted’ and ‘if it can’t be enumerated it won’t work’ enhance the hegemony of the quantitative. There is inherent danger in an over-emphasis on quantification, as people become neat numbers and attractive graphs that those being counted may not benefit from the counting. Thus, as we forge ahead with generating accurate statistics, the social reality of the people behind the numbers should repeatedly be brought back to the fore⁴²⁴⁻⁴²⁷.

8.6 Conclusion

Throughout the demographic research process, sensitive, nuanced and responsive qualitative inquiry into the cultural context of the participants yields information on the challenges faced by researchers. This can drive adjustments to the research process based on the findings from the formative research. Although formative research was not done in this study, prior knowledge of the cultural norms concerning interactions between male and females and the likely acceptability of using female fieldworkers to ask about pregnancy and pregnancy related outcomes, and the need for community consent and community entry through the village chiefs resulted in a smoother data collection process. One valuable lesson from this study is that cultural factors influence participants' response or non-response in surveys. Once they have been identified, such issues ought to be addressed. One example is to have women talk to women about pregnancy and menstruation. Another is to be aware that some groups are reluctant to be counted. This can be allowed for by using birth or pregnancy histories that count one by one, as opposed to summary questions on children-ever born, such as those used in censuses and multiple indicator cluster surveys. Alternatively, one can develop innovative questions that utilize idiomatic or metaphorical expressions such as 'how many sticks'. Identifying and addressing what is considered sensitive in a community is as critical as it is context specific. In The Gambia, understanding why pregnancies are concealed and neonates confined could stimulate advocacy for scaling up of interventions such as the home-based postnatal care visits. We also found in rural Gambia that talking about siblings was considered a sensitive topic. Sibling histories are a key method used to estimate maternal mortality, a critical health indicator, but little awareness exists among demographers that siblings can be an especially difficult group of relatives on which to collect data. Future studies should address this by conducting qualitative inquiries in other contexts into the reluctance to talk about siblings.

8.7 Acknowledgements

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Chapter 9 Discussion and Conclusion

This thesis has investigated the potential of health and demographic surveillance systems (HDSS) to contribute to accurate measurement of neonatal and perinatal mortality in low and middle-income countries. First, baseline under-five mortality in The Gambia was estimated after comparison of the country's first Demographic and Health Survey to earlier data sources, including data from two HDSS. The thesis then assessed retrospectively collected pregnancy histories relative to prospective routine surveillance of pregnancies and outcomes in HDSS to establish which of the two methods yielded more pregnancies and outcomes. Third, the thesis assessed the utility of linking antenatal clinics to a HDSS in identifying additional pregnancies and outcomes. Finally, it sought to understand aspects of Gambian culture that could affect the measurement of neonatal and perinatal mortality.

I postulated that a pregnancy history from the women would yield similar findings to the HDSS, basing this on the premise that women can recall their births. To alleviate some of the community members' reluctance to speak about their pregnancies, we employed only women to conduct these interviews. I also hypothesised that identification of pregnancies through antenatal records, with follow up visits in the HDSS, would increase the number of pregnancies and pregnancy outcomes identified, particularly where there was high coverage of antenatal clinic services.

This chapter summarizes the findings of the PhD and synthesizes these findings in line with the global health agenda and with other research. It then presents my reflections, before discussing the strengths and limitations of each study. Lastly, the implications for policy and future research are presented.

9.1 Overview of findings

This research focused on the development and assessment of systems for population-based neonatal and perinatal mortality measurement. The first paper presented in Chapter 5 of this thesis served to provide baseline measures of under-five mortality in the Gambia. The quality of data for under-five mortality collected

from the year 2000 onwards was assessed, after which under-five mortality estimates from MICS and census were compared to the country's first DHS data.

Regarding the quality of Gambian mortality data, the data were found to be plausible for indirect estimation of mortality based on standard reliability checks such as the sex ratio at birth and children ever born as well as proportions dead increasing with increasing maternal age. The main exceptions were that the DHS had very few neonatal deaths reported in the late neonatal period and that census data on Basse were of poor quality compared with those for the country as a whole. This did not affect overall under-five mortality as comparison of all sources showed that, although they were discrepant in the past, for recent years they yielded broadly consistent estimates of under-five mortality.

The advantage of DHS data is that the different age-specific indicators of childhood mortality, namely: neonatal (< 28 days), post-neonatal (1-11 months), child (1-4 years) and under-5 mortality rates are available. The availability of disaggregated estimates of under-five mortality has shown that The Gambia experienced a large decline in both under-five mortality, and more recently, neonatal mortality. However, neonatal mortality now makes a substantial contribution (40%) to under-five deaths. Our DHS-based estimates of neonatal and under-five mortality for the period surrounding 2010 (average rates for 2009-2012) were 23 and 56/1000 livebirths respectively. This means that The Gambia will need to halve neonatal and under-five mortality over a twenty-year period if it is to achieve the SDG goal of neonatal mortality of 12 per 1000 live births and an under-five mortality rate of 25/1000 livebirths by 2030.

SDG 3.2:

- Reduce NMR to $\leq 12/1000$ livebirths
- Reduce U5MR to $\leq 25/1000$ livebirths

The Gambia in context:

- NMR 23/1000 livebirths
- U5MR 56/1000 livebirths
- 40% of under-five deaths are in the neonatal period

Goal for The Gambia:

Halve NMR and U5MR in 20 years

Role of HDSS:

Utilize HDSS data for timely and accurate monitoring of SDG 3.2 mortality targets

Having established consistency at national level, we also compared under-five mortality estimates for the two regions within which the HDSS are located, to gain a picture of potential generalizability of HDSS data to the rest of The Gambia.

The HDSS data were of better quality based on congruence with expected ratios of under-five mortality in sub-Saharan Africa, that is, NMR: IMR and NMR: U5MR. The reported dates of events in the Basse HDSS were heaped on the

first day of the month, but this was adjusted for through imputation. The HDSS and DHS estimates were again similar for recent periods.

The decline in U5MR, especially in children aged one to four years, in The Gambia has been attributed to a reduction in infectious diseases through treatment and immunization, as well as malaria control⁴⁰. This is also the reason underlying reduced child deaths in West Africa, which has a unique Sahelian pattern of excess child mortality due to infectious causes. The unusual pattern of mortality in West Africa is associated with seasonal variation, with more deaths occurring during the rainy season^{267, 428-433}.

An important caveat to the preceding assessment is that consistency in measurement does not necessarily guarantee accuracy. The data sources may be consistently under-reporting neonatal and perinatal mortality. When compared to estimates for other West African countries, the Gambian rates seem low. In particular, the national stillbirth rate, at 11/1000 births, may be highly underreported considering Gambia's high maternal mortality and poor health systems^{99, 105, 143, 283, 287, 343, 355, 434-436}.

It is also likely that the DHS under-reported neonatal mortality, and therefore under-five mortality, based on our analysis that showed a notable absence of late neonatal deaths, and the high ENMR: NMR ratios in the final report. If a high ENMR: NMR ratio is not truly representative of the epidemiological situation in a

country, it means one of two things³⁴⁰. First, that early neonatal deaths have been shifted to the late neonatal period, which is not the case in The Gambia DHS data, or, second, that stillbirths were misreported as neonatal deaths, which is plausible as the reported stillbirth rates are very low³⁴⁰. If this is the case, the absence of late neonatal deaths remains unexplained and it is likely that overall omission of deaths occurred in the Gambian DHS.

Potential omission of child deaths in surveys is corroborated in several evaluations of DHS data, where omission of deaths is almost three times higher than that of births^{19, 437}. Possible reasons for omissions given are that respondents may not be willing to report on births that later resulted in a death, or that interviewers may be uncomfortable asking about deaths^{19, 438}. Also, the use of indicators for omissions in surveys such as NMR: IMR is a limitation in that they do not capture overall omission of death, as the ratios will remain within the expected distribution despite obvious omission of death as was seen in consecutive DHS surveys in Benin⁴³⁷. Thus, demographic health surveys in sub-Saharan Africa potentially underestimate under-five mortality as birth histories have consistently shown systemic omission of births, and logically deaths^{437, 439, 440}. Our results indeed showed that for earlier periods the DHS underreported child deaths when compared to other data.

One further consideration for under-reporting of neonatal and perinatal mortality in the Gambia is high maternal mortality, which is intricately linked with early neonatal deaths and stillbirths. In one study that used longitudinal data covering over 25 years in a rural region in The Gambia, researchers showed that children were 5 times more likely to die if their mother died. This risk was seven-fold higher for neonates whose mothers died during labour and shortly after¹². The DHS reported a pregnancy-related mortality ratio of 433/100,000 live births based on a sample of 91 maternal deaths over a period of seven years. The authors of the DHS report urged caution when quoting these estimates because of the small sample²². On the other hand, the recently published 2013 Gambia census reported a pregnancy-related mortality ratio of 861/100,000 live births based on 417 maternal deaths in the twelve months prior to the census³⁴³. In view of this more plausible estimate of maternal mortality, it is highly unlikely that both the stillbirth and

neonatal deaths are as low as are currently reported at either national or regional level including in the HDSS^{441 936}.

Active identification and follow up of pregnancies and pregnancy outcomes are crucial for ensuring the completeness and accuracy of neonatal and perinatal estimates. In The Gambia, two rural HDSS have followed up pregnancies and pregnancy outcomes for women residing in them. For Basse HDSS, this has been undertaken since its inception in 2007, and in the Farafenni HDSS, pregnancies have been tracked for two decades. Therefore, I used this opportunity to assess the Basse HDSS data on pregnancies using a mixed methods study approach. First, the Basse HDSS was assessed against a pregnancy history survey conducted within it. Second, I tested the hypothesis that linking the Basse HDSS to antenatal clinic records would improve the identification of pregnancies and reporting of pregnancy outcomes. Finally, a qualitative study was conducted to explore Gambian cultural attitudes and discourse on pregnancy and related reproductive health issues, as well as on issues surrounding data collection for neonatal and perinatal mortality.

Therefore, the second paper in Chapter 6 compared routine surveillance of pregnancy and outcomes in the HDSS to retrospectively reported pregnancy histories, to assess which of these approaches yielded more pregnancies and pregnancy outcomes. The data were matched at woman level and, to my knowledge, is the first such analysis in sub-Saharan Africa. Additionally, over 5,000 women were matched providing a larger sample than other surveys that have reported on individually-matched pregnancy outcome data, all of which were conducted in Bangladesh^{19, 30, 31}. Each woman was her own control in the sense that longitudinal data on her pregnancies in the Basse HDSS formed the comparator data to her pregnancy reports in the survey. The findings of this comparison were that pregnancy histories performed better than routine surveillance, particularly for adverse pregnancy outcomes. They yielded over 1,000 more livebirths and over 700 more adverse pregnancy outcomes than the HDSS ($p < 0.001$). These findings corroborate those in Bangladesh and rural Uganda as well as a DHS programme comparison of pregnancy histories with an augmented birth history^{18, 19, 21}. All these studies reported that pregnancy histories were superior to either routine

surveillance or augmented birth histories for the reporting of pregnancy outcomes. However, the DHS programme review reported that both pregnancy histories and augmented birth histories were underreporting stillbirths, and further research into better methods of data collection was needed¹⁸.

The women who were more likely to consistently report the numbers of their pregnancies in rural Gambia had fewer children (1 or 2) or were of Fula ethnicity. Conversely, women aged less than 20 years or more than 40 years and, significantly, those who had experienced a child death, or an adverse pregnancy outcome were the least consistent in reporting the numbers of their pregnancies by almost 80%. These findings highlight factors to be considered when collecting data. First, that mothers who experienced adverse outcomes could have been reluctant to speak about them. It is less likely that they forgot about their children^{23, 367}. Our findings in both the record linkage and pregnancy survey study confirm that the omissions in surveys and HDSS are disproportionately of births that ended in adverse outcomes^{19, 439}. Second, mothers tended to report more pregnancies in the survey, as opposed to the Basse HDSS.

The Matlab HDSS that conducted similar research utilized only female interviewers³¹. This was also the case in the pregnancy history survey. Moreover, the woman herself was always interviewed in the latter. In contrast, the reports were obtained by male interviewers in routine HDSS surveillance. In routine surveillance, the respondent can be any responsible adult. It is usually the head of household, who may not know the pregnancy status of women living with him, especially in polygynous communities like The Gambia^{442, 443}. A third reason for improved reporting of pregnancies in the survey is stated in the Iganga-Mayuge study in Uganda²¹. The researchers report that in retrospective surveys, mourning periods are likely to have passed, allowing respondents to speak of their loss with less constraint. This is a potential benefit of retrospective surveys that HDSS do not have, particularly those with frequent update rounds²¹. In the qualitative study for this research in Chapter 8 of this thesis, some women reported to the female interviewers that they felt released after having talked to them about their pregnancy losses. They had been allowed to speak of a matter that had been bottled up inside, pointing to their hidden emotional states.

These factors suggest that additional pregnancies were reported in the Basse pregnancy history survey not only because of the type of questionnaire used (the pregnancy history questionnaire), but also because women themselves were the only respondents, as no proxies were allowed, and because only women interviewed them. This conclusion is strengthened by the qualitative study, which found that women were the preferred interviewers for reproductive issues in The Gambia. The fact that the survey was retrospective in nature, and that most of the events being reported occurred well in the past, may also have played a role in enabling women to report more adverse pregnancy outcomes.

One further reflection on collecting pregnancy history data is based on the fact that women with three or more pregnancies tended to omit pregnancies from their survey reports that were picked up by the HDSS. This could be due to the pressure to recall all her pregnancies at once and provide information on details such as dates, reporting of which was shown to be poor in the survey^{369, 440}. It could also be other demands on women's time from their families, as we found in the qualitative study and in literature about The Gambia^{443, 444}. Here too the type of interviewer mattered and whether the question was considered sensitive^{384, 386, 391-394}. Common challenges associated with data collection by interviewers, such as their attitude to the interviewees were mitigated through the pre-survey training, which emphasized empathy as we were collecting mortality and pregnancy loss data. Other challenges were overcome by gender matching, as well as using the respondent's language of choice and conducting the interviews in private. The female interviewers also had to adjust their style of dressing to a less westernized look to facilitate data collection³⁴⁵. Some interviewer characteristics that are not amenable to change such as age did not present a problem, with the exception that some older women in the survey felt offended to be asked about menstruation by a younger woman. Thus, in the survey, the length of the interview and the characteristics of the respondent and interviewer could have influenced the quality of data collected. With the exception of gender matching, these factors are less prominent problems for HDSS. First, the interviewers live in the HDSS and are well known to the community members. Second, they need not conduct lengthy interviews, as they are able to return more frequently to complete updates

depending on the respondents' preference. This is advantageous for HDSS with regard to data quality, as was seen with event date reporting which was complete unlike the survey. Completeness in the HDSS was due to successful augmentation of event reporting through use of health cards and national identification documents, which are not easily available, especially in rural areas^{314, 445}. However, because they make regular repeat visits, the HDSS fieldworkers were able to obtain them.

In the Ugandan study, the HDSS was better for earlier periods, while the survey was better in the capture of more recent pregnancies²¹. In both the HDSS and the survey in our study, recent pregnancies were more likely to be reported, denoting an improvement in the capture of pregnancies especially in the HDSS. This was despite the fact that women do not usually speak of their pregnancies in The Gambia and they are expected to conceal their pregnancies and newborn babies in the first week of life to protect them from harm^{410, 412-414}. This resulted in estimates of the perinatal mortality rate for 2009-2013 as per the pregnancy history data of 43.3/1000 births. This is higher than DHS estimates at national level, where perinatal mortality is 30/1000 births, and for the Basse region, at 27/1000 births for the same period²². However, the HDSS stillbirth and perinatal mortality rates were lower than the pregnancy history estimates and indicated the need to improve the capture of pregnancies.

Pregnancy history survey and ANC-HDSS linkage

Vulnerable women:

Adolescent mothers
Pregnant women aged over 40 years

Why are they vulnerable?

Their pregnancies and outcomes likely to be missed in HDSS
Missed outcomes are mostly stillbirths, miscarriages and neonatal deaths
Mental health issues related to pregnancy losses and bereavement

In global agenda:

Pregnancy complications among top causes of adolescent and maternal mortality

Related global targets:

SDG 3.1: Reduce maternal mortality ratio to $\leq 70/100,000$ livebirths
SDG 3.7: Universal access to sexual and reproductive health-care services
SDG 3.8: Universal health coverage by 2030

SDG 4: Quality education for all

SDG 5: Gender equality, empowerment of women

Way forward for The Gambia:

Delay early pregnancies (through education, delayed marriage and increased uptake of family planning services)

Adolescent friendly services

Continued free MNCH but improve quality of health services (antenatal, intrapartum and postnatal)

The second component of the assessment of the HDSS aimed to find methods of improving the capture of pregnancy and therefore pregnancy outcomes. The findings are presented in the third paper from this research in Chapter 7 of this thesis. I chose to use antenatal clinic data from health facilities as it is estimated that this service achieves 99% coverage both nationally and in Basse²². Therefore, women's antenatal clinic records were linked to their records in the Basse HDSS. For women whose pregnancy outcomes could not be found in the existing HDSS database, up to two follow up visits were made, first to confirm the woman's identity and pregnancy, and second to collect data on the pregnancy outcomes. This is the first study to my knowledge that has linked women's antenatal clinic records to an HDSS record and used these data to track pregnancies in the HDSS for purposes of improving estimation of neonatal and perinatal mortality in the HDSS. It showed that as hypothesized, linkage of HDSS to antenatal clinics was a viable method to improve pregnancy capture in the HDSS in areas with high antenatal coverage. The follow up study based on the information captured in the antenatal clinics was able to provide information on 861 additional pregnancy outcomes to the Basse HDSS. As with the pregnancy history survey, these were disproportionately adverse pregnancy outcomes (stillbirths, miscarriages and abortions).

In this study, women older than 40 years of age had a higher risk of pregnancy loss and early childhood death. This was also reported in the General Population Cohort in Rakai, Uganda²⁰. Women in extremes of age (<20 and >40 years) and of Serahule ethnicity were least likely to have their pregnancies captured in routine surveillance. Adolescent mothers are a high-risk group for adverse pregnancy outcomes, and a study in rural Gambia also showed that their offspring were at a higher risk of dying^{207, 375}. The two top causes of death in adolescents are suicides and pregnancy complications, both of which are preventable with suitable and directed mental health care, delayed pregnancy as well as prevention of unwanted pregnancy⁴⁴⁶. The WHO has in place guidelines for management of pregnancies in adolescent mothers that includes having adolescent friendly services, delaying pregnancy and empowering women⁴⁴⁷.

Concerning Serahule women, who belong to fifth largest ethnic group in The Gambia, and who reside in Basse region, a few issues stand out. The Serahule are a wealthy and highly entrepreneurial ethnic group since historical times despite not being highly educated⁴⁴⁸. They are also part of a group of migrants who contribute to farming labour in Catalonia, Spain^{449, 450}. Additionally, non-Serahule people hardly speak Serahule⁴⁴⁸. These characteristics may play a role in their invisibility as found in the ANC-HDSS linkage study. The language barrier featured prominently in the qualitative study, as few interviewers were able to conduct the interview in the respondent's language of choice. Secondly, date accuracy could not be verified using national identification documents as the Serahule respondents refused to provide them. One reason given in the qualitative study was that they thought the female interviewers would confiscate their documents. This refusal could be linked to secrecy about documentation, particularly due to frequent emigration, which can involve different individuals using the same documentation⁴⁴⁹.

While ethnicity was found to be associated with the risk of infant mortality when routine HDSS were analysed, infants born to Serahule women had lower odds of dying compared to those born to women of other ethnicities, perhaps a representation of the higher income status among the Serahule. This finding is also documented in the national 2013 census mortality report³⁴³. However, this association was not significant when the fuller data set was analysed. Nonetheless, the finding that their pregnancies are less likely to be captured in the HDSS highlights that Serahule are a potentially marginalized group, even in regional and national estimates⁴⁵¹.

Regarding mortality estimates, the augmented HDSS data, which comprised of routine surveillance data and the follow up study data, had similar neonatal and infant mortality rates to the routine HDSS data. However, perinatal mortality at 47/1000 births was higher, as the follow up study of pregnancies identified in the antenatal clinics reported 2.5 times as many stillbirths per pregnancy as routine surveillance and these adverse pregnancy outcomes would otherwise have been missed. Using our estimates, the annual rate of decline needed for the ENAP

stillbirth target of $\leq 12/1000$ births to be achieved is 7.3%, whereas that for NMR is 2.4% for the SDG NMR target of $\leq 12/1000$ livebirths^{3,13}.

The fourth paper for this research was based on a qualitative study designed to gain understanding of the possible reasons for under-reporting of neonatal and perinatal mortality in The Gambia. Having lived in the Gambia during the formative stages of the PhD, I had learned through informal conversations and observation that there were strong social norms surrounding pregnancy, male and female interaction, and other matters. This informed the initial interview guides that were used, but which were continually revised as themes emerged in the field. I used in-depth interviews of female fieldworkers who had been employed specifically for the pregnancy history survey, key informant interviews, and a focussed group discussion with male interviewers who routinely collect HDSS data. This paper presented their views as constructed through their social lens, as well as my and JN's interpretation of what they said.

Gambia in context:

Pregnancy concealment and postnatal confinement of babies
Reluctance to be counted (Fula, Serahule)
Reluctance to speak of those deceased (it is the will of God)
Refusal to name or count their siblings
Men's difficulty asking about reproductive health issues

How to improve measurement of PNMR and NMR

-Formative research
-Pregnancy history
-Female fieldworkers
-Women as respondents
-Use of metaphors – Yellow card/sticks
-Use of two different questions for pregnancy (LMP and routine)
-electronic data capture

In global agenda:

-ENAP measurement improvement roadmap
-SDG 17: Data monitoring and availability

The main findings were that culturally a woman is expected to conceal her pregnancy as a way of protecting it from bad *jinne*, dwarf-like creatures, and the evil eye⁴¹³. The need to protect the child extends into the postnatal period with the baby being confined at home for seven days until it is given a name and ascribed a fully human status^{345, 363, 414}. Additionally, Fula and Serahule communities were reluctant to be counted, and further inquiry revealed that, to them, being counted was linked to potentially causing the death of someone. One explanation was that counting one's offspring could provide information about their

loved ones for a witch to use to cause them harm. Invariably though, it was said that

the reluctance to be counted had been passed down generations and that the original reason for it was unknown. Counting of the deceased members of the community was met with strong resistance as many of the community members would tell the informants that they were not willing to talk about them as it was God's Will, and nothing would bring them back. We also found that respondents were reluctant to name their siblings, as this is forbidden.

Fieldworkers suggested several methods to circumvent the various cultural factors, for instance use of metaphorical expressions to ask about pregnancy or children. They also asked about living siblings first, then those deceased to obtain this information. For pregnancy, two questions were asked, one asking the woman if she was pregnant directly, and another asking about her last menstrual period. There was a general reluctance to talk about pregnancy, but I learned that women were more willing to talk about menstruation than pregnancy. This is promising for surveys inquiring into pregnancies as questions can be formulated to identify pregnancies using the duration since the last menstrual period. However, this may be context specific and may suffer from errors in date reporting. Although questions on menstruation were not routinely asked in the HDSS, the male fieldworkers reported that they found it difficult to talk about either menstruation or pregnancy. While these findings are specific to The Gambia, similar concerns or other sociocultural factors probably affect data collection in other populations.

The endpoint of this research was to improve estimation of neonatal and perinatal mortality using HDSS as a platform. Better estimates and increased visibility of findings have an impact on what is done about the problem^{178, 452}. One lesson learnt from the MDGs was that those interventions or conditions that had the highest visibility also received the most funding²⁵⁷. This led to programmes with the highest national coverage rates and thus major improvements in survival, for example from malaria and HIV. This underscores the importance of increasing the visibility of key concerns using good data^{50, 178, 257}. Newborn health gained prominence in the decade prior to the advent of the SDGs, resulting in its inclusion for their first time as an indicator of good health in the global agenda¹. Increased visibility is critical for stillborn babies, who are not included in the SDGs, yet matter for families and should matter in the global agenda. Stillbirths are also excluded in

the denominator for maternal and child health indicators and as such, consideration should be made to include them⁵⁰. Persistently low funding for perinatal health has been documented, meaning that more advocacy is needed to bring the issue to the attention of funders and decision makers²⁵⁸⁻²⁶⁰. Globally, the West and Central African regions have the lowest coverage of interventions that improve survival of the mother-baby dyad, for example family planning services, exclusive breastfeeding and basic sanitation¹⁶⁵. Furthermore, adolescents, who are at risk of pregnancy complications and adverse outcomes, needed to get spousal or parental consent for access to family planning services, further compounding the problem.

For improved visibility, good quality data are needed. However, between 2010 and 2015, only eight SSA countries had over 90% coverage of birth registration, and only nine countries had more than 75% death registration⁴⁵³. It has been shown that several benefits accrue when there is reduced mortality and a good quality of life for a population. For instance, there is an increase in a country's economic growth by over ten per cent in LMICs⁴⁵⁴. Countries with reduced child mortality and reduced fertility, so long as the resulting youthful population are involved in income generating activities, could benefit from this demographic dividend^{454, 455}. Other factors that contribute to the reduction in mortality relate to socioeconomic aspects⁴⁵⁶. For more than half of the world's population, financial hardship is encountered when they need to access health services. This led to a global resolution to ensure universal health coverage that included alleviation of financial barriers^{457, 458}. The hardship experienced by families often leads to detrimental effects such as poverty and intimate partner violence, where over 30% of women of reproductive age report being abused at one point in their lives¹⁶⁴. However, interventions such as cash transfers have been linked with reduction of this type of violence⁴⁵⁹. Additionally, the latest efforts by the WHO are to ensure that one billion people benefit from universal health coverage, another billion are protected from health emergencies and one billion enjoy better health and wellbeing by 2023⁴⁵⁷.

The preceding discussion highlights the findings and implications of this research for The Gambia in the context of the global agenda. The Gambia needs to accelerate

the annual rate of decline of under-five mortality, particularly neonatal and perinatal mortality. This research has documented high perinatal mortality rates in The Gambia and shows that adolescent mothers and those over 40 years of age and their offspring are a vulnerable population. Thus, services targeting their survival will hasten achievement of both SDG and ENAP goals in The Gambia. This thesis brings to the fore the need for good quality timely data to inform policy makers as to where to allocate scarce resources^{168, 169}. Lastly, one benefit specific to The Gambia that might result from a reduction in child mortality could be a change in cultural beliefs and practices. Currently, data collection and accuracy are hampered due to fears of harm or death, so that pregnancies are concealed and being counted is unwelcome. However, if society learns that survival of its members is improving, then these fears could be allayed, and an enabling environment created for improved vital statistics measurement. This would potentially enable the population to reap the benefits of the resultant demographic dividend, if the focus shifts to ensuring gainful employment of its youthful population.

9.2 Reflections, strengths and limitations

9.2.1 Objective 1: Comparison of under-five mortality across different data sources

Analysis of secondary data limits one to the type of data available and to the quality of the data as is. For the purposes of comparison and establishing a baseline for this research, the data were adequate. The main limitations of the data sources are discussed in Chapter 5 of this thesis. The crucial one is the lack of data on perinatal mortality in any national survey other than the DHS. Therefore, no comparisons were possible. I could only compare the stillbirth rate with regional data to get a sense of the magnitude of reporting errors in The Gambia. Comparisons of surveys that have different objectives are challenging. Adding to the challenge is that the same pregnancies and deaths are not picked, and that migration is not accounted for, thus affecting the comparability.

9.2.2 Objective 2: Comparison of pregnancy outcomes reported through pregnancy history or routine surveillance

The pregnancy history survey was a primary data collection process conceptualized and conducted by AJR. This therefore provides an opportunity to reflect on its successes, limitations and what could have been done better. One achievement of this research is that it was conducted successfully as demonstrated by the analysis presented in the thesis. Additionally, the qualitative study affirmed AJR's instincts that cultural factors relating to male and female interactions could negatively affect data collection on pregnancy and its outcomes.

It was a privilege to conceptualize the study and go through the processes required to conduct a large-scale DHS like survey covering over 40,000 people, as I had not had this experience before. This gave me the opportunity to face the Scientific and Ethics committees and justify my study and allowed me to learn about precision in listing costs and justification of every item listed with the help of MRCG's research support unit. I learned that unforeseen circumstances could jeopardise one's research, for example, that transportation of lithium-based batteries could present a problem to airlines. This process also exposed me to work in an entirely different environment, from the work-ethos to the climate, and to the reality that what was on the ground could be different from one's mental concepts, including budgetary shortages despite planning for contingencies. These unforeseen circumstances developed my ability to be creative and to adjust, including learning patience. The ethos in The Gambia was also enlightening. For example, the *Alkalolu* (village chiefs) accommodated and fed over thirty fieldworkers asking for nothing in return^{345, 363, 414}. Additionally, I learned that the timing of data collection was important. Collecting data during the religious fasting period of Ramadhan or the rainy season increased the need for multiple visits with a rebound effect on resources available for the achievement of research objectives. These experiences highlighted sharply the need for formative research to provide contextual information when planning data collection.

While intended as a strength for this research, our use of electronic data brought out challenges in the field described previously⁴⁶⁰. Additionally, it highlighted the need for human resource capacity building in the form of data managers. Several

projects would share one data manager thus compromising the timeliness that would otherwise have been achieved by eliminating the need for double data entry and errors associated with it. Nonetheless, it is still a strength of this research because it demonstrated that young women, who had completed high school education, but whose prior interaction with information technology consisted only of use of smartphones, were capable of using tablets for electronic data capture with ease. This is hopeful for future research as it took only one week of training and a few field visits to ensure a smooth data collection process. An additional benefit for this research was the utilization of the open source software and the ability to put skips and logic checks in the questionnaire so that there were fewer implausible entries and less work for the fieldworker.

Regarding the data collected, the survey found it hard to collect dates despite attempts to use national identification and health cards as well as detailed event calendars to improve their accuracy. Almost 700 women had to be excluded from analysis because of this, and a third of women in the survey had missing data on age. However, it must be acknowledged that for the missing data on respondent's ages, interviewer errors are likely, as are data losses that were experienced in the initial stages of the research when data managers transferred data from the tablets to the servers. The HDSS on the other hand had complete data on the dates of events for the same women, indicating that the frequent update rounds as well as better access to health cards were critical to accurate reporting of dates in rural Gambia. No risk factors could be elicited for this inaccuracy in date reporting by the women. This showed that women in and of themselves were not accurate with reporting dates for events. This has implications for accuracy of neonatal and perinatal mortality measurement, especially if the last menstrual period dates are to be relied on for differentiating stillbirths from miscarriages or preterm births from term births. Inaccurate date reporting also affects delineation of neonatal and post-neonatal boundaries. Another limitation noted was that the women's length of residence in the HDSS was not collected, which would have aided in the analysis of migration patterns particularly with regard to out-migration during pregnancy and how this affected measurement of neonatal and perinatal mortality.

9.2.3 Objective 3: Utility of antenatal record linkage in pregnancy and pregnancy outcome identification

Having gone along with the Gambia MNCH staff for trekking clinics, I had noted that the staff were overwhelmed with the substantial amount of work that needed to be done during the once a month visits²⁷⁴. The two nurses assigned would cover up to hundreds of women and children over a period of at least six hours. Due to this heavy workload, priority was given to the more clinical aspects of antenatal care.

The initial plan I had for this work, if resources and time had allowed, was to have registry staff located in each of the health facilities in Basse. Their main duties would be to assist the short-staffed nurses in registering those attending the maternal and child health clinics. For my project, this would have involved linking the women to their HDSS unique identity numbers at the point of contact as has been done by the pneumococcal surveillance project in The Gambia and in the Kisesa HDSS in Tanzania^{295, 320}. This would then reduce the errors associated with retrospective linkage and remove the need to drop records of those who do not belong to the HDSS, as we had to do for ethical reasons in our study. Elsewhere, use of national ID cards and collecting the names of family members improves precision, but in The Gambia several challenges exist with regard to acquisition of national identity cards^{200, 208, 275, 314, 373}. An alternative method to improve record linkage for this study would have been to have all HDSS members issued with an identification card that has their number on it and included in their health records³¹. This can be quite tedious for the overworked clinic staff to implement and can be expensive to initiate, but in the long run, the benefits accrued due to better data may overshadow the cost²⁰⁷.

However, this study has shown that, even with resource and time constraints, innovative methods such as photography using mobile phones and transcription, despite the limitations mentioned in Chapter 7, can achieve useful levels of record linkage using procedures that are in line with the practical and financial constraints found in most developing countries. One other strength is that we were able to collaborate with the Ministry of Health to carry out the research.

My reflections on homonymy in the Gambia apply to both studies involving record linkage reported on in this thesis; the antenatal clinic study and the pregnancy history survey. Naming in The Gambia, as in many African cultures, follows tradition. Firstborn Mandinka males are inevitably called Lamin; twins will be Adama and Awa, with females also called Adama or Adam; Mamadou and Mamudou; or they will share the same first name, with a nickname differentiating the two, which is recorded as an alias in the HDSS. Females are usually called Fatou and its variations. The resultant homonymy is challenging, particularly for retrospective record linkage. In one household in our survey, for example, all the males were named Ali after the father. Therefore, to differentiate them we had to use their nicknames. The availability of aliases/nicknames in the BHDSS records was very valuable during matching process.

9.2.4 Objective 4: Qualitative study to understand cultural attitudes, practices and discourse that could affect data collection on pregnancy and its outcomes

At the outset, it was decided that only female fieldworkers would be employed to inquire from women resident in the HDSS about their pregnancy histories. This was based on the observations that limited interaction occurred between unrelated males and females and that women were reluctant to speak about pregnancies.

An MRCG staff member narrated to me that although she could see that her respondent was obviously pregnant, when she asked if the respondent was pregnant, the woman said she was not but proceeded to deliver a healthy baby two hours after the conversation.

This vignette is a small example of lengths that respondents may take to avoid revealing their pregnant state and shows the importance of adjusting study methods according to the cultural setting.

The findings from the qualitative study supported my initial hypothesis that more information would be elicited in The Gambia if women asked women about their pregnancies and sensitive topics such as menstruation. Our use of hearsay ethnography is a strength, in that we elicited information about the community

from community members with whom there would be more frankness and less social desirability bias.

9.3 Synopsis of current developments in health information systems (HIS) in developing countries

This section summarizes the current developments in HIS in developing countries and informs the recommendations made in the subsequent sections.

The SDGs call for a data revolution, particularly among developing countries that do not have adequate health information systems. This involves improving both the data quality in terms of completeness, accuracy, reliability and timeliness, and the demand for data use^{2, 379}. There have been several efforts to scale up civil registration and vital statistics systems at both regional and national levels in response to this call. Some of the regional bodies include the African program for accelerated improvement of CRVS, the regional initiative to improve CRVS in Asia and the Pacific and the Eastern Mediterranean regional strategy for the improvement of CRVS⁴⁶¹. Funders have also joined up in efforts to improve national and regional data. For instance, the World Bank Global Financing Fund in collaboration with the respective regional bodies encourages and funds individual nations to come up with ways in which they intend to improve or even initiate the CRVS, as in the case of Ethiopia, with their final goal being to enable those countries to eventually self-fund their CRVS. Some countries such as Mozambique and Kenya identified linkage of birth and death registration to maternal and child health services as a strategy to improve their CRVS, leveraging the high coverage of facility deliveries and immunization. Others such as Cameroon, Liberia and Sierra Leone opted to digitize historical records, while Uganda and Guinea sought to make the CRVS and the district health information systems interoperable³⁸⁰. One success story with regards to CRVS is South Africa which improved both birth and death registration, showing that it is indeed possible to achieve almost 100% birth registration and over 80% death registration as envisioned in SDG target 17.19. This progress was tracked in an HDSS which also identified main determinants of non-registration such as maternal age, level of education, refugee status and household

wealth. These gaps, of high national value, would otherwise not have been identified in the routine CRVS ^{3,35}.

The main challenge envisaged by many countries is the cost of setting up or scaling up CRVS. However, fully functional CRVS are considered superior to other data collection systems as they confer additional benefits to individuals for example a legal identity, which is a human right, and associated access to legal, health and social services. CRVS data are also prospectively collected, country-owned, comprehensive and can be used for proper planning and allocation of resources as well as governance. A review of the cost of alternative data collection systems to make the case for investing in CRVS was conducted as a means of indirectly determining savings that could be made were CRVS fully functional. This review showed that surveys, at US\$ 7.57-36.31 annualised cost per participant were the most expensive form of data collection to conduct, followed by censuses at US\$ 0.23-2 annualised cost per participant. Sample registration systems, which have been instituted as a form of continuous population surveillance and registration, ranged from US\$ 0.23-1 and HDSS, though geographically confined health information systems, were also costed and found to range from US\$ 0.80-3.08 annualised cost per participant ^{462, 463}.

Other developments regarding health information systems are exemplified by the South African Population Research Infrastructure Network (SAPRIN) ³⁸¹. This is an example of harnessing and coordinating available data sources in the country. SAPRIN is within the mandate of, and funded by the country's Department of Science and Technology. It harmonizes the country's health and demographic surveillance systems which are linked to the public health sector, schools and social protection measures. The main objective is to provide accessible, timely longitudinal data that can be used to calibrate national data. As the HDSS collaborate with universities and international networks, this platform brings together high calibre researchers with resultant high quality outputs. They also provide evidence-based, cost-evaluated data to guide policy making in the country and, finally, they serve to build research capacity in the country ³⁸¹. Thus, HDSS are able to play a role in generating data covering closely followed up populations spread out across the country and capturing the diversity of population

characteristics in both urban and rural domains. Another advantage that HDSS offer is the ability to follow up migrants. Currently, even well-developed CRVS and population registers do not record migration events or follow up migrants. This places HDSS in a unique position, as has been shown with the Multi-centre Analysis of the Dynamics in Migration and Health (MADIMAH) project and other centres which have been able to demonstrate the relationship between migrants' health and destinations, identifying vulnerable populations, the prevalence of non-communicable diseases and mortality outcomes^{218-220, 222}.

This thesis utilized HDSS in the Gambia which follow up approximately 15% of the total population to answer research objectives which are summarized in the box in section 9.4 below in the setting of an incomplete and unusable CRVS in The Gambia.

9.4 Study implications for policy, mortality metrics and practice

What is known about neonatal and perinatal mortality and its measurement?

Almost half (48%) of under-five deaths occur in the neonatal period (2.5 million neonatal deaths).

Around 2.6 million stillbirths occur annually, 1.3 million of them intrapartum, yet largely invisible in the global agenda.

The stillbirth rate in the Gambia is 11/1000 births – implausibly low in view of maternal mortality rate of 861/100,000 live births. The neonatal mortality rate is 22/1000 live births. Limited neonatal and perinatal data exist for developing countries, and recent estimates are from modelling, which ultimately relies on the quality of the input data.

The paper on the pregnancy history survey adds

Having women as informants and interviewers results in more pregnancy outcomes.

Pregnancy histories are better sources of data on adverse pregnancy outcomes - numerators for perinatal mortality measurement.

HDSS are of good quality and have potential for monitoring neonatal and perinatal mortality accurately if pregnancy capture is optimized.

Higher perinatal mortality rates of 43/1000 births compared to national and regional estimates (2009-2013).

The paper on the ANC-HDSS linkage adds

Better capture of pregnancies and adverse pregnancy outcomes in HDSS with ANC-HDSS linkage.

Improved estimates of perinatal mortality (47/1000 births) and fertility in augmented HDSS data.

Improved HDSS data accuracy and completeness through ANC linkage and tracking of pregnancies.

Overall thesis adds

HDSS useful for monitoring of SDGs in LMICs through improved inputs of data for modelling.

As standalone data sources, collated HDSS data can provide timely and accurate information for SSA.

Better quality data on stillbirths in The Gambia.

Implications of findings (Global, national, sub-national)

Survive^α

Highlighting the plight of still and newly born babies in The Gambia through better data may lead to redirected resources to enhance their survival.

Triple return of investment through saving mothers and their babies, especially adolescent and older mothers in The Gambia.

Scaling up of emergency obstetric and newborn care, improved infrastructure and strengthening of health systems.

Thrive^α

Highlights the need to advocate for empowerment of women through education of girls, adequate nutrition of mothers and their babies, and enabling spacing of families.

Continued momentum for child survival while investing in neonatal survival.

Transform^α

Encourage uptake of pregnancy histories as a data collection tool.

Employ women as interviewers and ensure woman respondent for reproductive issues.

Innovative culturally acceptable methods for asking sensitive questions.

Research priorities for neonatal and perinatal mortality measurement

Research into data collection tools

Formative research

Methodological advancement

^α *Survive, thrive and transform theme adapted from the Global Strategy for Women's, Children's and Adolescents' Health (2016-2030): Survive, Thrive, Transform⁴⁴⁶*

The following sections outline policies and research ideas that evolved from the findings in this research.

9.4.1 Implications for measurement of neonatal and perinatal mortality in surveys and HDSS

With regard to the survey process and utility of the pregnancy history, this research adds to the pool of knowledge on the benefit of using the pregnancy history in a conservative society. This research concurs that time and resource investment is crucial for better data quality, especially through skilled interviewers¹⁸². It also highlights that mental health plays a role in under-reporting of adverse pregnancy outcomes and this merits further research. The need for investment in research into what is sensitive in specific contexts when carrying out surveys cannot be understated as this can affect the quality of data collected if not considered³⁸⁶. The qualitative study identified sensitive questions in the community and provided suggestions on how to handle or mitigate for them. Country-specific formative research should be conducted to obtain more complete and accurate data. With regard to the collection of statistical data, we found that adolescent mothers and those aged more than 40 years were more likely to report their pregnancy and pregnancy outcomes in the survey, and it may be because we used female interviewers, most of whom were young, as seen in Matlab HDSS, Bangladesh³¹. Alternatively, women may find it easier to talk about pregnancies that occurred in the past, whose outcomes are already known and therefore no further protection is needed. One advantage of the retrospective survey over a HDSS could be that women may also be more willing to talk about their pregnancies that ended in loss, when they have grieved over them, or after the appointed mourning period is complete²¹.

The HDSS, however, was better for reporting the dates of events, and the survey was deficient despite using a detailed event calendar and attempts to use national identification and health cards. Thus, while HDSS are not considered nationally representative, findings from them and from studies such as the pregnancy history survey conducted within them can be used to adjust for underreporting in more nationally representative surveys. Recent advances in HDSS include the use of

electronic data capture, the availability of geospatial data and the advancement of methods to establish cause of death such as verbal autopsy and minimally invasive tissue sampling^{15, 203-205}. Additionally, HDSS tend to have better technical capacity within them relative to the countries in which they are located¹⁵. Last but not least, the fact that they are spread over the African and Asian continents means that they can be used as interim measures to provide good quality and timely data as developing countries accelerate towards achieving complete civil registration and vital statistics systems^{38, 195, 196}. For HDSS that do not actively track pregnancies and their outcomes for purposes of improving neonatal and perinatal mortality, this should be urgently instituted to further harness HDSS as a data resource^{17, 209}. For more complete data, tracking of pregnancies should include women who have out-migrated. This could be instituted through mobile phone follow up in this era of widespread mobile telephony. For return migrants, additional inquiries into events that occurred when they were away, in this case pregnancies and their outcomes, should be included in routine HDSS data collection.

9.4.2 Implications for policy makers in The Gambia

This research highlights the need for improved data on neonatal and perinatal mortality. Although attempts were made to improve measurement, our findings indicate that neonatal and perinatal mortality are potentially underestimated in a closely followed population. For The Gambia, which has a population of almost 1.9 million, I recommend the institution of sample registration systems alongside verbal autopsy for cause of death data as in Zambia, Malawi and Tanzania for improved measurement of these estimates as a stepping stone to complete CRVS. As indicated in the synopsis in section 9.3, the annualized costs per capita for sample registration systems were much lower than those of surveys. Thus, it makes financial sense to invest in SRS as a means of acquiring nationally representative data in The Gambia as CRVS is improved. Although The Gambia is currently not funded by the World Bank Global Financing Fund, policy makers should consider this opportunity to enable the initiation of these data collection systems which are costly, with the aim of self-funding over an agreed period of time⁴⁶⁴. Countries with SRS use statistical sampling techniques to produce nationally representative information on levels and causes of death. They mainly employ non-medical

personnel to enumerate births and deaths and to conduct verbal autopsies, although interpretation and assignment of cause of death is done by medical doctors. However, data quality for cause of death ascertainment could be further improved if minimally invasive tissue sampling is conducted, in addition to verbal autopsy²⁵³. In The Gambia, community acceptability and logistical challenges would be a major consideration as religious practices recommend burial within 24 hours of death, and autopsies are rare, yet MITS need to be done within 24 hours as well^{254, 445}. In order to extend the capture of deaths, data from hospital deaths should be included in national statistics. Regardless of whether it is a death in the community or in the hospital, all classification should be harmonized, for example through use of ICD-II²³⁷.

The Gambia has already been successful in near elimination of malaria through the concerted efforts of the Government, the Global Fund, MRCG the Catholic Relief Services, and other partners⁴⁶⁵. It is one of the countries identified for elimination of Malaria by WHO and Roll Back Malaria Partners⁴⁶⁵. This is a testament to the possibility of achieving complete CRVS in The Gambia if similar concerted efforts and funding are directed towards it. Currently birth registration is at 72%, although only 57% of children less than five years of age have a birth certificate²². Death registration is only done for hospital deaths at the country's sole teaching hospital. Foetal deaths are not registered. The SDG target 17.19, which aims for 100% coverage of birth registration can be achieved as issuing of birth certificates is decentralized to the village level^{274, 445}. It is unlikely that 80% of death registration will be achieved soon, as cultural norms surrounding death, including not talking about deaths and quick burial, as well as logistical difficulties associated with death certification are likely to be a hindrance. Also, many deaths in The Gambia occur at home⁶. However, SRS with verbal autopsies can overcome these challenges and should be considered by policy makers.

In light of the high population coverage by HDSS in The Gambia, the SAPRIN model could also be emulated. This would enable tracking of selected SDG indicators as HDSS generate annualized data that can be used to track progress, and is useful particularly as HDSS are costly to run and should therefore be utilized maximally and effectively. Coordination at national level, as well as linkage with

the national health management information system, in this case the district health information system 2 (DHIS2), schools and the CRVS, would be required for optimal performance. The Gambia for instance has almost universal coverage for antenatal care service attendance. Formation of a pregnancy cohort from the ANC and follow up in the community through HDSS as well as SRS would improve national estimation of neonatal and perinatal mortality in particular as has been shown in this and other research studies. It would also provide nuanced information from the HDSS that would otherwise not be available with routine CRVS, for instance, identification of marginalised and vulnerable populations. The benefits of adopting such a model include better, evidence based and scientifically sound national data, capacity building and improved use of scarce resources.

This research identified adolescent mothers as a highly vulnerable population as their pregnancies are most likely to be missed in the Gambia. Likewise, pregnancies of older women, who were also at risk of experiencing adverse pregnancy outcomes and child deaths, were likely to be missed, leading to under-estimation of under-five mortality. Adolescent friendly programmes, which have been successful in other countries, could be instituted in The Gambia for those who fall pregnant⁴⁴⁷. More importantly, continued advocacy for female education so that pregnancy is delayed should be prioritized. The government and partners should also improve availability and accessibility of family planning services through adolescent friendly health services⁴⁴⁷.

For the high-risk older women, they should be encouraged to attend antenatal clinics and have health facility deliveries^{435, 436}. At ANC, being relatively young or old should warrant closer follow up until the postnatal period. Notwithstanding this, the transportation infrastructure should be improved and the health system strengthened as the situation in The Gambia currently is dire^{148, 287, 355, 434, 436}. Harrowing tales are told of heavily pregnant women enduring three-hour donkey cart journeys on rough roads seeking help for complications in labour. Some have to wait overnight to cross the river Gambia because the ferry does not work at night or the river is flooded. The reliance on blood donation by relatives is unconscionable. So is the fact that lives are lost because there are no doctors, anaesthetists or fully operational theatres when emergency caesarean sections are

needed⁴³⁴. Unofficial fees for MNCH remain in The Gambia, hampering access to health facilities for the population^{274, 279, 314}. The Gambia has very few doctors, but has Africa's second highest rate of skilled emigration comprising mainly of doctors and nurses^{274, 280, 281, 450}. There is also an 80% unmet need for emergency obstetric care^{274, 283}. A further challenge is lack of coordination and prioritization of donor funds, which are directed to HIV for example, which is of low prevalence, and not towards maternal and child health, which is a priority in Gambian national policies²⁷⁴.

Nevertheless, the efforts underway to train doctors and more health professionals are laudable and in line with SDG targets 3.c.1 and 3.d.1⁶. Also commendable are the renovations of secondary-level health facilities to enable provision of emergency obstetric and newborn care services²⁸⁶. News of the upcoming bridge across the River Gambia in Farafenni is encouraging for women in labour⁴⁴⁵. Efforts should be made towards retaining healthcare professionals, for example by providing better remuneration and housing, and providing an enabling environment to work in by ensuring the hospitals are fully functional²⁸⁷.

Partners such as Riders for Health and Maternal & Child Health Advocacy International should be encouraged to introduce quad bike and river ambulances as a matter of urgency for women in rural Gambia^{285, 286}. The Ministry of Health and Social Welfare should scale up postnatal home visits for the mother-child dyad, especially in Basse where coverage is lowest. Postnatal visits are especially useful in The Gambia in two ways³⁵⁹. First, it enables women and their babies to remain within the seven-day confinement period as culture dictates, and which is conceived as a protective measure for the newborn³⁶³. Second, the first day and week of life are dangerous for newborns, therefore these visits serve to check on and refer sick babies⁹. Postnatal visits can also be used for data collection in the event that a death occurred.

The Gambia is one of 28 countries where the practice of Female Genital Mutilation/Cutting (FGM/C) is highly prevalent. Over three-quarters of women have undergone the cut, which can potentially lead to obstructed labour and other complications apart from psychological harm^{22, 90, 265}. The ban on FGM/C is in place

in The Gambia and it is hoped that it will be enforced and an end to this practice achieved in line with target 5.3 of the SDGs³.

Box 2 Policies for perinatal and neonatal health by 2020

- To reduce NMR to 15/1000 livebirths through provision of EmONC
- To increase early trimester attendance of ANC through incentivization and community sensitization
- To improve skilled birth attendance to 80% through human resource capacity building and advocacy especially by male community members among other strategies.
- To increase contraceptive prevalence rate to 25% through adequate supply, training of health workers on FP technology and behaviour change communication.
- To introduce perinatal audits in health institutions for monitoring and evaluation of maternal and newborn health

Finally, all targets set in the Gambian national policies in Box 2, which was presented in Chapter 3 of this thesis, should continue to be a priority as they all will improve the lives of mothers and their children with knock on effects for the country's economy and development in the long run, with up to a ten-fold return on investment⁴⁴⁶. This is in line with the first SDG goal of ending poverty through pro-poor and gender-sensitive development strategies⁶. To do this, The Gambia would need a multi-sectoral approach for optimized survival of mothers and their children. That is, further intensive efforts to improve social determinants of health such as hygiene and sanitation, nutrition and education⁴⁵⁶. Regarding water, sanitation and hygiene, this is exemplified by the Rural Water Supply and Sanitation Program funded by the African Development Bank operational in five rural regions⁴⁶⁶. This project has provided boreholes, almost 1,000 pit latrines and solar powered water supply including in rural health centres, so that over 95% of intervention villages now have access to water and sanitation facilities⁴⁶⁷. The ban on use of plastic bags since 2015 and the national cleaning days since 2007 are exemplary⁴⁶⁸⁻⁴⁷⁰. In terms of nutrition, the National Nutrition Agency's work is a

step in the right direction and needs to be stepped up alongside the World Bank funded Maternal and Child Nutrition and Health Results Project³⁷². The education of the girl child in The Gambia has improved with high net enrolment rates, and overall universal primary education has been achieved. However, girls are more likely to drop out of higher education for marriage and labour provision, and occasionally a girl may be removed if the school environment is considered unsafe, particularly by poorer families^{346, 471}. Despite free schooling, indirect costs make education unattainable for some children, and in The Gambia, religious preferences have been shown to play a role in poor school attendance and educational achievement. Thus, while there are positive achievements with regard to education in The Gambia, it remains among the bottom ten sub-Saharan African countries in terms of educational attainment⁴⁷¹. The recent 2016-2030 education strategic plan has taken this into consideration and includes conditional cash transfers as a pro-poor measure, with its main aim being improved quality and attainment of better education for Gambian children⁴⁷¹.

9.4.3 Recommendations for medical education and human resources for health

While these recommendations are particularly relevant for The Gambia, they are also applicable in most developing countries and deal with improved data quality and further thoughts on the retention of health workers. In terms of improving the quality of data, training of medical students and health care professionals on the international classification of diseases (ICD-II) and on completing death certificates correctly should be scaled up^{237, 472}. The vital strategies initiative with an e-learning Medical Certification for Cause of Death course for the African Region is one example of standardizing measurement⁴⁷³. The Gambia has successfully included training on ending female genital mutilation/cutting in medical curricula and should do the same for emergency newborn and maternal care and death certification⁴⁷⁴.

In addition to remuneration and providing enabling working environments, other methods of incentivization for health workers on data collection, analysis and use include professional development goals such as training, offering Masters or PhD

degrees and presentation of findings at both local and international conferences⁴⁷⁵⁻⁴⁷⁷.

9.5 Future research

9.5.1 Antenatal clinics - HDSS record linkage

This research did not set out to generate detailed protocols for record linkage. Nevertheless, based on the encouraging results from both linkage with antenatal clinic records and the follow up study in improving identification of pregnancy and its outcomes, I recommend that larger, well-resourced studies be done in other populations or HDSS where the level of ANC coverage is high. These studies could employ real-time linkage at the antenatal clinic using biometric identifiers for confirmation of identities during follow up of the pregnant women^{203, 208, 320}. This would provide further insights into the utility of antenatal clinic linkage and overcome record linkage errors, while also reconfirming active participation of the study respondents. Linkage with health facilities could also be integrated with population based data collection systems such as sample vital registration systems and utilized not only for pregnancy tracking, but also to provide clinical data useful for evaluation of population health including prevalence of diseases, their risk factors and monitoring of interventions.

9.5.2 Qualitative study

An incidental finding in the qualitative study was the reluctance of women to talk about their siblings. This has implications for demographic research that utilize the sibling history for mortality estimation as it has been shown that mortality estimates from sibling histories are likely to be under-estimated^{230, 478}. The qualitative research identified a general reluctance to speak about deceased relatives, but this reluctance was more severe when asking about deceased siblings as it was forbidden to speak of them. More research into the reasons for this hesitance is needed, and its implications for DHS and other estimates of adult and maternal mortality.

9.5.3 Maternal and perinatal audits in The Gambia

The Gambia 2020 National Health Strategic Plan includes the introduction of perinatal audits in all health institutions. Over 60% of births in The Gambia now occur in health facilities and the data generated from these audits would help fill the information data gap in The Gambia²². In the United Kingdom for example, there are nationwide maternal and perinatal audits that identify good practices for emulation, and areas of improvement so that each mother and baby gets the best care while attending maternal and child health services.

The Obstetricians/Gynaecologists in conjunction with Paediatricians and midwives conduct these audits^{479 978}. These data inform healthcare practitioners about the quality of care they provide. They also enable redirection of resources to health facilities lagging behind in terms of good quality care.

9.5.4 Surveys using pregnancy or birth history questionnaires

This research found that pregnancy histories performed better than routine pregnancy surveillance in HDSS for the identification of adverse pregnancy outcomes. Most DHS utilize birth histories that do not collect information on stillbirths. Some DHS include a reproductive calendar and specifically ask about stillbirths. These are known as augmented birth histories. In order to elucidate whether pregnancy histories are better than augmented birth histories for measurement of neonatal and perinatal mortality, research comparing the two tools to a gold standard is recommended. A further debate is whether to use backward or forward questioning, with the former asking from the latest pregnancy to the earliest and vice versa.

However, the gold standard for mortality metrics remains complete civil registration and vital statistics systems. In developing countries where CRVS are incomplete, these questions may be answered with well-designed surveys employing both pregnancy and augmented birth histories and backward and forward questions, using HDSS as a comparison as populations are closely followed up. These surveys should also collect data on the length of interviews using either questionnaire as part of the evaluation of the data collection tools. A mixed method study that includes qualitative research into which method was preferred and why,

would provide richer information, especially if a change of method of data collection were to be considered.

Outcomes of interest would be; i) whether the pregnancy history performed worse than the birth history in terms of the capture of livebirths, thereby providing cause to abandon it and retain the birth history ii) whether the length of the interview resulted in interviewee fatigue resulting in poor data quality and iii) whether the pregnancy history reduced the misclassification of stillbirths and early neonatal deaths which is a potential weakness of the more commonly used birth history. The benefits of such a study would be that the better tool could be adapted for national household surveys to improve reporting of pregnancy losses, and ultimately utilized to improve survival of babies both after birth and in utero.

Based on the findings from the qualitative study in Chapter 8 of this thesis, a cluster randomized trial testing out semantically equivalent versus normatively equivalent questionnaires should be carried out. The results from the qualitative study suggested that asking questions that required the respondent to enumerate their offspring was not culturally appropriate. However, if the questions were asked indirectly, it was suggested that more accurate responses would be received, particularly when asking about decedents. The proposed study would therefore compare responses based on a normative questionnaire, which ensures that translated questions consider social norms, with those from a semantic questionnaire, which strictly requires that translations are exactly as in the original language, to a gold standard. In the event that such a study is carried out where CRVS are mostly complete, this would form the gold standard. In the absence of this, alternative data sources such as HDSS or pregnancy history data would be considered. The likely confounding factors would be interviewer and respondent characteristics such as age, gender, ethnicity, and education level as well as the language of the interview among others. Information on all potential confounding factors should be collected and accounted for during analysis. Historically, during the World Fertility Surveys this concept was studied, and it was concluded that it was better to use standardized verbatim semantically equivalent questionnaires. However, in view of the cultural implications and the under-reporting of mortality noted in The Gambia, this issue warrants further study.

9.5.5 Methodological advancement in measurement of neonatal and perinatal mortality in HDSS

This research highlighted that capture of pregnancy outcomes in HDSS is not yet optimal. Studies into the frequency of update rounds are needed to determine the most effective and least costly number of update rounds needed to reduce the chances of missing pregnancies in the community. HDSS update rounds range from fortnightly to annually, with HDSS having the most frequent rounds performing better than those with spread out rounds¹⁷.

This research should also include methods to follow up pregnant women who migrate out of the HDSS. The widespread use of mobile technology in developing countries provides a means to do this cheaply. However, this may remain a challenge in areas where network coverage is weak. HDSS should also standardize forms for the collection of data on pregnancy outcomes. Those HDSS using electronic data capture could have a module specific for pregnancy tracking, so that each pregnant woman has a flagging mechanism that would require the fieldworker to inquire about the pregnancy outcome at every round. Those without EDC would need a pre-printed list of pregnant women included in the HDSS forms for every update round.

A second approach for advancement of measurement should be conducted in conjunction with statisticians whereby modelling techniques would be developed that utilize all available data in the HDSS and national data sources and adjust for missing information to predict accurate estimates. The aim of this would be to build capacity in low resource settings, while at the same time producing more plausible and accurate estimates. This training should include the HDSS networks so as to provide broader estimates for regions within which they are located.

9.6 Conclusion

This thesis aimed to answer four main questions. The first question related to the quality of data for under-five mortality estimation in The Gambia, and the reliability of estimates derived from them. We found that the data quality in the most recent surveys was plausible for both the indirect and direct estimation of under-five mortality. It could not assess the information on perinatal mortality due

to lack of stillbirth data in any of the available sources except for the DHS. The estimates derived from the DHS, which we found to be consistent with existing indirect data sources for recent periods, allowed the disaggregation of under-five mortality by age. This showed that child mortality has dropped significantly in The Gambia, although with a slower decline in neonatal mortality, which now contributes 40% of under-five deaths. While we could conclude something about the consistency of reporting of under-five mortality, we could only infer that the reported DHS stillbirth rate (11/1000 births), was probably an undercount based on comparison with regional estimates and on the stillbirth to neonatal mortality ratio, which was significantly low.

In view of this likely under-reporting, and the potential for HDSS to serve as interim measures for measurement of neonatal and perinatal mortality, the remaining research questions were based on HDSS. In the Gambia, the HDSS routinely follow up pregnancies and identify the pregnancy outcomes, which are central to the accurate measurement of neonatal and perinatal mortality. We therefore compared routine pregnancy surveillance in the Basse HDSS to pregnancy histories to identify the method that performs better. This showed that pregnancy histories outperformed routine pregnancy surveillance in the HDSS especially for adverse pregnancy outcomes. However, the HDSS was more accurate with regard to dating events and both ways of collecting data captured livebirths adequately. Thus, while collecting data prospectively in HDSS generally limits omissions of deaths and age/date reporting errors, it may yield less complete data than retrospectively-collected pregnancy histories on adverse perinatal outcomes.

The second study also related to the HDSS and aimed to find out if linkage to antenatal clinic records improved the capture of pregnancies in the HDSS. It took advantage of the almost universal antenatal coverage in The Gambia. This research found, albeit with several limitations, that linking of HDSS to antenatal clinic records resulted in the identification of a substantial number of otherwise unrecorded pregnancies, particularly those with adverse pregnancy outcomes. Incomplete tracking of pregnancies and their outcomes affected estimates of perinatal and early childhood mortality as well as fertility and led to different conclusions about their risk factors. The final aspect to this research was to

understand societal constructs that could affect collection of pregnancy and outcome data. Key findings were that women exhibited a general reluctance to being counted, that talking about deceased members of the family was difficult for the respondents, that pregnancy and menstruation were sensitive topics and that, invariably, women were preferred as interviewers for the discussion of reproductive issues. The respondents suggested using metaphorical expressions to obtain more accurate data.

The Gambia has been a success story regarding the survival of children⁴⁰. However, this research brings to light the largely untold story of newly-born and stillborn babies. Perinatal mortality is estimated at 43/1000 births and 47/1000 births in the pregnancy history survey and augmented HDSS data respectively. If we consider these estimates to be more representative of the situation in light of high maternal mortality, then neonatal mortality is likewise high^{10, 342, 343}. This means that for proper utilization of scarce resources, and for faster acceleration in the decline in under-five and maternal mortality, The Gambia should now focus on the survival of mothers and their babies around the time of giving birth.

This research also points to the value of HDSS for measurement of neonatal and perinatal mortality, all the more so with augmentation through antenatal record linkage and utilizing pregnancy histories within them. It first emphasized the importance of collecting all pregnancy outcomes. Therefore, the tracking of pregnancies in HDSS is crucial for improved accuracy in estimating neonatal and perinatal mortality. Also, pregnancies of women in extremes of age are likely to be missed in the HDSS and thus measures to improve pregnancy capture in this setting would need to pay special attention to this group. As this research showed, incomplete and inaccurate reporting of dates remains a major issue in Demographic and Health Surveys that tends to be concealed from view by the imputation of missing dates in standard recode files. HDSS provide a more suitable framework for collecting dated information on events, especially if data are collected using socially-acceptable methods and reproductive health data can be collected by female interviewers.

This also makes HDSS well situated for monitoring of SDG goals and ENAP targets, particularly if their scope is widened to follow individuals from conception to death, rather than birth to death, as is currently the norm.

It is my hope that mothers, and both born and unborn babies of The Gambia will benefit from findings presented in this thesis. If their survival status is more accurately documented, perhaps Gambian health policies will be urgently redirected towards their survival. For babies in other developing countries, this research has revealed possibilities that exist to improve measurement of neonatal and perinatal mortality in resource-poor settings. With better data and its proper use, more children can survive the perinatal period. Ultimately, stillbirths should be formally included in global, regional and national data systems, as well as in the denominators for maternal and child health indicators.

Chapter 10 References

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Chapter II Appendices

- A) Ethical approvals**
- B) Informed consent form**
- C) Pregnancy history questionnaire**
- D) Qualitative research field guides**
- E) Fieldworker Training Manual and Exam**
- F) Photographs from the fieldwork**

A) Ethical Approvals

The Gambia Government/MRC Joint

ETHICS COMMITTEE

C/o MRC Unit: The Gambia, Fajara
P.O. Box 273, Banjul
The Gambia, West Africa
Fax: +220 – 4495919 or 4496513
Tel: +220 – 4495442-6 Ext. 2308
Email: ethics@mrc.gm

14 October 2015

Dr Anne J. Rerimoi
Disease Control and Elimination Theme
MRC Unit, The Gambia
Fajara

Dear Dr Rerimoi

SCC 1437v2, Methods to improve the estimation of neonatal mortality in rural Gambia

Thank you for submitting your response letter dated 12 October 2015 addressing the issue raised by The Gambia Government/MRC Joint Ethics Committee at its meeting held on 02 October 2015.

I have reviewed the modified consent form that was requested by the Committee. This is satisfactory and I am happy to give Chair's approval. The project has now received full Ethics Committee approval and may proceed.

With best wishes

Yours sincerely



Mr Malamin Sonko
Chairman, Gambia Government/MRC Joint Ethics Committee

Documents submitted for review:-

- SCC Application Form, version 2.0 – 15 September 2015
- Response letters – 15 September 2015 & 12 October 2015
- Informed Consent Document, version 1.0 – 12 October 2015
- Work plan; in-depth interviews plan
- Questionnaire

The Gambia Government/MRC Joint Ethics Committee:

Mr Malamin Sonko, Chairman
Professor Ousman Nyan, Scientific Advisor
Ms Naffie Jobe, Secretary
Dr Roddie Cole
Dr Ahmadou Lamin Samateh
Mrs Tulai Jawara Ceesay

Prof. Umberto D'Alessandro
Dr Momodou L. Waggeh
Dr Kalifa Bojang
Dr Ramatoulie Njie
Dr Jane Achan
Dr Siga Fatima Jagne

London School of Hygiene & Tropical Medicine

Keppel Street, London WC1E 7HT

United Kingdom

Switchboard: +44 (0)20 7636 8636

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Observational / Interventions Research Ethics Committee

Dr Anne Rerimoi
LSHTM

23 October 2015

Dear Anne

Study Title: Methods to improve estimation of neonatal mortality in Rural Gambia

LSHTM Ethics Ref: 10377

Thank you for responding to the Observational Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

Approval is dependent on local ethical approval having been received, where relevant.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type	File Name	Date	Version
Covering Letter	LSHTM ethics 10377_Rerimoi		
Investigator CV	reniers- cv - 1507	01/12/2014	1.0
Information Sheet	ICD_Adult_CT_Rerimoi	24/06/2015	1.0
Local Approval	SCC 1437v2_Rerimoi_approved (subject to required change being made)_12Oct15	24/06/2015	1.0
Investigator CV	Anne Rerimoi CV	03/08/2015	1.0
Protocol / Proposal	Proposal_Rerimoi Anne	24/08/2015	1.0
Protocol / Proposal	pregnancy history questionnaire_Rerimoi	24/08/2015	1.0
Local Approval	SCC 1437v2_Rerimoi_approved_14Oct15	14/10/2015	1.1
Protocol / Proposal	Proposal_Rerimoi Anne v1.1	21/10/2015	1.1

After ethical review

The Chief Investigator (CI) or delegate is responsible for informing the ethics committee of any subsequent changes to the application. These must be submitted to the Committee for review using an Amendment form. Amendments must not be initiated before receipt of written favourable opinion from the committee.

The CI or delegate is also required to notify the ethics committee of any protocol violations and/or Suspected Unexpected Serious Adverse Reactions (SUSARs) which occur during the project by submitting a Serious Adverse Event form.

At the end of the study, the CI or delegate must notify the committee using an End of Study form.

All aforementioned forms are available on the ethics online applications website and can only be submitted to the committee via the website at: <http://leo.lshtm.ac.uk>

Additional information is available at: www.lshtm.ac.uk/ethics

Yours sincerely,



Professor John DH Porter
Chair

ethics@lshtm.ac.uk
<http://www.lshtm.ac.uk/ethics/>

Improving health worldwide

B) Informed Consent form

Identification code: SOP-CTS-015, Attachment 2a (Adult CT)
Version : 2.0 – 15 April 2013



PARTICIPANT INFORMATION SHEET

Version 1.1 Date 12/10/2015

Study Title: Methods to improve the estimation of neonatal and perinatal mortality in rural Gambia

SCC:		Protocol:	
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Sponsor: MRC

What is informed consent?

You are invited to take part in a research study. Participating in a research study is not the same as getting regular medical care. The purpose of regular medical care is to improve one's health. The purpose of a research study is to gather information that may be useful in future for the whole population. It is your choice to take part and you can stop any time.

Before you decide you need to understand all information about this study and what it will involve. Please take time to read the following information or get the information explained to you in your language. Listen carefully and feel free to ask if there is anything that you do not understand. Ask for it to be explained until you are satisfied. You may also wish to consult your spouse, family members or others before deciding to take part in the study.

If you decide to join the study, you will need to sign or thumbprint a consent form saying you agree to be in the study. You will receive a copy of this.

SCC:

Why is this study being done?

All over the world, for the past twenty years, survival of children to five years of age has been improving thanks to mothers having their children vaccinated, taking them to hospital early when sick, sleeping under bed nets among others. Unfortunately, the same cannot be said of newborn babies as more are dying especially in the first week of their lives. It is important to know to what extent your community is experiencing this in order to improve the survival of the babies. We will do this by having female fieldworkers come to ask you whether you are pregnant as well as how many pregnancies you have ever had and what their outcomes are. We understand that it is not easy to talk about pregnancy and loss, but we would kindly ask for your assistance in order to know the true numbers of pregnancy losses and newborn babies dying. We will also find out from you after one year what your thoughts are about being asked these questions. This will inform our leaders on the true situation in your community and how better to ask you about this information so that they will make decisions that will benefit mothers and their babies to help them survive. The results of the study will be made available to your community.

What does this study involve?

All selected women who are aged between 15 and 49 years of age will be interviewed separately. The first interview will be between October and December 2015 and then once more in October 2016. During this time, we would like you to allow our female fieldworkers to first ask you about all the pregnancies you have had and the outcomes and whether you are pregnant now. This information will help us know how many babies are born, how many pregnancies are lost and how many babies die.

If you get pregnant and go to the Antenatal clinic, we would like your permission to collect this information from the clinic which will mean that we will use your name to identify you there. The government team in Basse has been informed and they have

Version	1.1	Date	12/10/2015
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SCC:

allowed us to use their facilities, but we will only look at your information if you give us your permission.

Finally, after one year (October 2016), we will come again and ask some women about the outcome of their pregnancies and to find out how we can do better.

What will happen to the samples taken in this study?

No samples will be taken in this study.

What harm or discomfort can you expect in the study?

We do not expect any harm to come to you.

What benefits can you expect in the study?

This study will help health professionals and policy makers to know the true rates of newborn deaths. They will use this information to make decisions on what to do to improve the survival of mothers and their babies.

Will you be compensated for participating in the study?

You will not get paid for participation, but you will have played your part in helping others.

Are there other products or treatment?

No. We will only be conducting interviews for this study.

What happens if you refuse to participate in the study or change your mind later?

You are free to participate or not in the study and you have the right to stop participating at anytime without giving a reason. This will not affect any services that you would normally receive.

Should any new information become available during the study that may affect your participation, you will be informed as soon as possible.

Version	1.1	Date	12/10/2015
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SCC:

How will personal records remain confidential and who will have access to it?

All information that is collected about you in the course of the study will be kept strictly confidential. Your personal information will only be available to the study team members.

Who should you contact if you have questions?

If you have any queries or concerns you can contact Dr [[Anne Rerimoi](#)] or Dr [[Momodou Jasseh](#)] on [[+2202133078](#)] and you can always call the personal numbers of the study staff given to you.

Please feel free to ask any question you might have about the research study.

Who has reviewed this study?

This study has been reviewed and approved by a panel of scientists at the Medical Research Council and the Gambia Government/MRC Joint Ethics Committee, which consists of scientists and lay persons to protect your rights and wellbeing.

C) PREGNANCY HISTORY QUESTIONNAIRE



INTRODUCTION AND CONSENT

Hello. My name is _____. I am working with the Medical Research Council (MRC) The Gambia. We are conducting a survey of all women living in this area. The questions usually take about 20 minutes and will be mainly about your health. All of the answers you give will be confidential and will not be shared with anyone other than members of our survey team. You don't have to be in the survey, but we hope you will agree to answer the questions since your views are important. If I ask you any question you don't want to answer, just let me know and I will go on to the next question or you can stop the interview at any time.

In case you need more information about the survey, you may contact Anne Rerimoi (+2202133078).

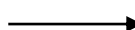
Do you have any questions? May I begin the interview?

Signature of the Interviewer _____ Date _____

Respondent accepts



Respondent refuses



END

NO.	QUESTIONS AND FILTERS	CODING	SKIP
	I would like to ask you about all the pregnancies that you have had during your life. By this I mean all the children born to you whether they were born alive or dead, whether they are still living or not, whether they live with you or somewhere else, and all the pregnancies that you have had that did not result in a live birth. I understand that it is not easy to talk about children who have died, or pregnancies that ended before full term, but it is important that you tell us about all of them, so that we can help develop programs to improve children's health.		
201	First I would like to ask about all the births you have had during your life. Have you ever given birth?	YES 1 NO 2	206
202	Do you have any sons or daughters to whom you have given birth who are now living with you?	YES 1 NO 2	204
203	How many sons live with you? And how many daughters live with you? IF NONE, RECORD '00'.	SONS AT HOME. DAUGHTERS AT HOME	
204	Do you have any sons or daughters to whom you have given birth who are alive but do not live with you?	YES 1 NO 2	206
205	How many sons are alive but do not live with you? And how many daughters are alive but do not live with you? IF NONE, RECORD '00'.	SONS ELSEWHERE . DAUGHTERS ELSEWHERE	
206	Have you ever given birth to a boy or girl who was born alive but later died? IF NO, PROBE: Any baby who cried or showed signs of life but did not survive?	YES 1 NO 2	208

PREGNANCY HISTORY QUESTIONNAIRE

207	<p>How many boys have died?</p> <p>And how many girls have died?</p> <p>IF NONE, RECORD 'oo'.</p>	<p>BOYS DEAD</p> <p>GIRLS DEAD</p>	
208	<p>Women sometimes have pregnancies that do not result in a live born child. That is, a pregnancy can end in a miscarriage, or the child can be born dead. Have you ever had a pregnancy that did not end in a live birth?</p>	<p>YES 1</p> <p>NO 2</p>	210
209	<p>How many pregnancies have you had that did not end in a live birth?</p>	<p>PREGNANCY LOSSES</p>	
210	<p>SUM ANSWERS TO 203, 205, 207 AND 209, AND ENTER TOTAL. IF NONE, RECORD 'oo'.</p>	<p>TOTAL PREGNANCIES</p>	
211	<p>CHECK 210:</p> <p>Just to make sure that I have this right: you have had in TOTAL _____ pregnancies during your life. Is that correct?</p> <p>YES NO PROBE AND CORRECT</p> <p>201-210 AS NECESSARY.</p>		
212	<p>CHECK 210:</p> <p>NO</p> <p>PREGNANCY ONE OR MORE PREGNANCIES</p>		234

PREGNANCY HISTORY QUESTIONNAIRE

212	213	214	215	216	217	218	219	220	221	222	222A
Did your (last/next to last/etc) pregnancy end in a live birth, stillbirth, miscarriage, or an abortion?	Was this a single or a multiple birth?	In what month and year (was this child born / did this pregnancy end?)	CHECK 212: RECORD SAME RESPONSE	What name was given to this child? WRITE 'BABY 1' 'BABY 2',	Is (NAME) a boy or girl?	Is (NAME) still alive?	IF ALIVE: How old was (NAME) on his/her last birthday? RECORD AGE IN COMPLETE YEARS	IF ALIVE: Is (NAME) living with you? RECORD	IF ALIVE: RECORD HOUSEHOLD LINE No. OF CHILD.	IF DIED: How old was (NAME) when he/she died? IF '1 YR', PROBE: How many months old was	Were there any other pregnancies between this and the pregnancy we were just talking about? IF YES, ADD IT
o1 LIVE BIRTH 1 STILL BIRTH 2 MISCARRIAGE . . . 3 ABORTION 4 GOTO 214	SING 1 MULT 2	MONTH YEAR	LIVE BIRTH 1 STILL BIRTH 2 MISCARRIAGE . . . 2 ABORTION . . . 3 4 GOTO 222A	NAME:	BOY 1 GIRL 2	YES . . . 1 NO 2 222	AGE IN YEARS YES . . 1 NO . . . 2	YES . . 1 NO . . . 2	HH LINE NO.: GOTO 222A	DAYS . . . 1 MONTHS 2 YEARS . . 3	YES . . 1 ADD PREGNANCY NO . . . 2 NEXT PREGNANCY
o2 LIVE BIRTH 1 STILL BIRTH 2 MISCARRIAGE . . . 3 ABORTION 4 GOTO 214	SING 1 MULT 2	MONTH YEAR	LIVE BIRTH 1 STILL BIRTH 2 MISCARRIAGE . . . 2 ABORTION . . . 3 4 GOTO 222A	NAME:	BOY 1 GIRL 2	YES . . . 1 NO 2 222	AGE IN YEARS YES . . 1 NO . . . 2	YES . . 1 NO . . . 2	HH LINE NO.: GOTO 222A	DAYS . . . 1 MONTHS 2 YEARS . . 3	YES . . 1 ADD PREGNANCY NO . . . 2 NEXT PREGNANCY

PREGNANCY HISTORY QUESTIONNAIRE

03 LIVE BIRTH 1 STILL BIRTH 2 MISCARRIAGE .. 3 ABORTION 4 GOTO 214	SING 1 MULT 2 YEAR	MONTH YEAR	LIVE BIRTH1 STILL BIRTH 2 MISCARRIAGE .. 3 ABORTION4 GOTO	NAME:	BOY 1 GIRL 2	YES 1 NO 2 222	AGE IN YEARS	YES .. 1 NO ... 2	HH LINE NO.: GOTO 222A	DAYS ... 1 MONTHS 2 YEARS .. 3	YES .. 1 ADD PREGNANCY NO ... 2 NEXT PREGNANCY
---	--------------------------	---------------	---	-------	-----------------	--------------------------------	-----------------	----------------------	---------------------------	--------------------------------------	--

04 LIVE BIRTH 1 STILL BIRTH 2 MISCARRIAGE .. 3 ABORTION 4 GOTO 214	SING 1 MULT 2 YEAR	MONTH YEAR	LIVE BIRTH1 STILL BIRTH 2 MISCARRIAGE .. 3 ABORTION4 GOTO 222A	NAME:	BOY 1 GIRL 2	YES 1 NO 2 222	AGE IN YEARS	YES .. 1 NO ... 2	HH LINE NO.: GOTO 222A	DAYS ... 1 MONTHS 2 YEARS .. 3	YES .. 1 ADD PREGNANCY NO ... 2 NEXT PREGNANCY
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05 LIVE BIRTH 1 STILL BIRTH 2 MISCARRIAGE .. 3 ABORTION 4 GOTO 214	SING 1 MULT 2 YEAR	MONTH YEAR	LIVE BIRTH1 STILL BIRTH 2 MISCARRIAGE .. 3 ABORTION4 GOTO 222A	NAME:	BOY 1 GIRL 2	YES 1 NO 2 222	AGE IN YEARS	YES .. 1 NO ... 2	HH LINE NO.: GOTO 222A	DAYS ... 1 MONTHS 2 YEARS .. 3	YES .. 1 ADD PREGNANCY NO ... 2 NEXT PREGNANCY
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PREGNANCY HISTORY QUESTIONNAIRE

212 Did your (last/next to last/etc) pregnancy end in a live birth, stillbirth, miscarriage, or an abortion?

213 Was this a single or a multiple birth?

214 In what month and year (was this child born / did this pregnancy end?)

215 CHECK 212: RECORD SAME RESPONSE

216 What name was given to this child? WRITE 'BABY 1' , 'BABY 2' ,

217 Is (NAME) a boy or girl?

218 Is (NAME) still alive?

219 IF ALIVE: How old was (NAME) on his/her last birthday? RECORD AGE IN COMPLETE

220 IF ALIVE: Is (NAME) living with you? RECORD

221 IF ALIVE: RECORD HOUSEHOLD LINE No. OF CHILD.

222 IF DIED: How old was (NAME) when he/she died? IF '1 YR', PROBE: How many months old was

222A Were there any other pregnancies between this and the pregnancy we were just talking about? IF YES, ADD IT

o6 LIVE BIRTH 1 STILL BIRTH 2 MISCARRIAGE .. 3 ABORTION 4 GOTO 214	SING 1 MULT 2	MONTH YEAR	LIVE BIRTH 1 STILL BIRTH 2 MISCARRIAGE 3 ABORTION 4 GOTO 222A	NAME:	BOY 1 GIRL 2	YES 1 NO 2 222	AGE IN YEARS	YES 1 NO 2	HH LINE NO.: GOTO 222A	DAYS 1 MONTHS 2 YEARS 3	YES 1 ADD PREGNANCY NO 2 NEXT PREGNANCY
o7 LIVE BIRTH 1 STILL BIRTH 2 MISCARRIAGE .. 3 ABORTION 4 GOTO 214	SING 1 MULT 2	MONTH YEAR	LIVE BIRTH 1 STILL BIRTH 2 MISCARRIAGE 3 ABORTION 4 GOTO 222A	NAME:	BOY 1 GIRL 2	YES 1 NO 2 222	AGE IN YEARS	YES 1 NO 2	HH LINE NO.: GOTO 222A	DAYS 1 MONTHS 2 YEARS 3	YES 1 ADD PREGNANCY NO 2 NEXT PREGNANCY

PREGNANCY HISTORY QUESTIONNAIRE

o8			LIVE BIRTH .	NAME:	BOY 1	YES 1	AGE IN	YES . . 1	HH LINE NO.:	DAYS . . . 1	YES . . 1
LIVE BIRTH	SING 1	MONTH 1				YEARS				ADD PREGNANCY
1			STILL BIRTH .		GIRL 2	NO 2		NO . . . 2		MONTHS 2	
STILL BIRTH	MULT 2	YEAR	. . . 2			222			GOTO 222A	YEARS . . 3	NO . . . 2
2			MISCARRIAGE								NEXT PREGNANCY
MISCARRIAGE 3								
3			ABORTION .								
ABORTION 4								
4			GOTO								
GOTO 214											

o9			LIVE BIRTH .	NAME:	BOY 1	YES 1	AGE IN	YES . . 1	HH LINE NO.:	DAYS . . . 1	YES . . 1
LIVE BIRTH	SING 1	MONTH 1				YEARS				ADD PREGNANCY
1			STILL BIRTH .		GIRL 2	NO 2		NO . . . 2		MONTHS 2	
STILL BIRTH	MULT 2	YEAR	. . . 2			222			GOTO 222A	YEARS . . 3	NO . . . 2
2			MISCARRIAGE								NEXT PREGNANCY
MISCARRIAGE 3								
3			ABORTION .								
ABORTION 4								
4			GOTO								
GOTO 214			GOTO 222A								

10			LIVE BIRTH .	NAME:	BOY 1	YES 1	AGE IN	YES . . 1	HH LINE NO.:	DAYS . . . 1	YES . . 1
LIVE BIRTH	SING 1	MONTH 1				YEARS				ADD PREGNANCY
1			STILL BIRTH .		GIRL 2	NO 2		NO . . . 2		MONTHS 2	
STILL BIRTH	MULT 2	YEAR	. . . 2			222			GOTO 222A	YEARS . . 3	NO . . . 2
2			MISCARRIAGE								NEXT PREGNANCY
MISCARRIAGE 3								
3			ABORTION .								
ABORTION 4								
4			GOTO								
GOTO 214			222A								

D) QUALITATIVE RESEARCH FIELD GUIDES

v1.3 FIELDWORKER INDEPTH INTERVIEW GUIDE
MRC UNIT, THE GAMBIA
MARCH 2016

Socio-demographic information

1). Where are you from in The Gambia?

P1: Where do you live right now?

P2: How long have you been there? Migrated?

P3: Do you originate from this village?

Relationship with community members

2). How would you describe your relationship with the other members of the community?

P1: Is it a good relationship?

P2: Is it a bad relationship?

3). How did the community react on your new responsibility?

P1: What is your impression?

P2: Did your being female have any influence on the responses from the community? How?

Are there certain people who find it more difficult (men, young ladies, very old ladies, people from a certain ethnic group)? Why do they find it difficult?

P3: Do you feel it is difficult for some women to tell you about their health information? If yes:

Why do you think it is difficult for them?

Are there certain people who find it more difficult (young ladies, very old ladies, people from a certain ethnic group)? Why do they find it difficult?

Fieldwork experience

4). Please tell me about your experiences during this fieldwork

P1: What do you think went well?

P2: What were the challenges?

P3: Did you have any positive experiences?

P4: Did you have any negative experiences?

P5: Do you have a suggestion about how this could be solved?

Socio-demographic characteristics

Which ethnic group do you belong to?

How old are you?

What is your marital status?

VI.3 FIELDWORKER FOCUS GROUP DISCUSSION GUIDE

MRC UNIT, THE GAMBIA

MARCH 2016

Socio-demographic information

1). Where are you from in The Gambia?

PI: Where do you live right now?

P2: How long have you been there? Migrated?

P3: Do you originate from this village?

Relationship with community members

2). How would you describe the female team's relationship with the other members of the community?

3). How did the community react to them?

PI: What is your impression?

P2: Do you think their being female had any influence on the responses from the community?
How?

Are there certain people who find it more difficult (men, young ladies, very old ladies, people from a certain ethnic group)? Why do they find it difficult?

P3: Do you feel it is difficult for some women to tell you about their health information? If yes:
Why do you think it is difficult for them?

Are there certain people who find it more difficult (young ladies, very old ladies, people from a certain ethnic group)? Why do they find it difficult?

Fieldwork experience

4). Have you conducted any interviews in the community after the female only team left?

PI: Can you describe your different experiences between the interviews before and after?

What was an especially good/bad interview? And where was the difference?

Socio-demographic characteristics

Which ethnic group do you belong to?

How old are you?

What is your marital status?

E) Fieldworker training manual and Exam

INTERVIEWER'S MANUAL

Introduction

The pregnancy history survey is a sample survey designed to provide information on pregnancy and pregnancy outcomes from women of reproductive age in the Basse health and demographic surveillance systems (HDSS). The survey will involve interviewing a randomly selected group of women.

You are being trained as an interviewer for the survey. After the training course, selected interviewers will be working in teams, going to different parts of the respective sites to interview households and respondents in these households. This is called fieldwork. Depending on the areas assigned to your team and on how well you perform the tasks given to you, you may be working on the survey for up to three months. However, we have recruited more interviewers to participate in the training course than are needed to do the work, and at the end of the course, we will be selecting the best qualified among you to work as interviewers.

During the training course, you will be listening to lectures about how to fill in the questionnaires correctly. You will also be conducting practice interviews with other trainees and with strangers. You will be given two tests, and the questionnaires that you complete will be edited to check for completeness and accuracy.

You should study this manual and learn its contents since this will reduce the amount of time needed for training and will improve your chances of being selected as an interviewer.

Survey objectives

The survey is designed to count pregnancies and pregnancy outcomes that a woman has had in her lifetime to help us find out the actual numbers. This information is useful so that policy makers and other users of this data can make well informed decisions.

Sample

There are several ways to gather information about people. One way is to contact every person or nearly every person and ask them questions about what you need to know. Talking to everyone is called a complete enumeration, and a national census is a good example of this type of information

Adapted from <https://dhsprogram.com/publications/publication-dhsm3-dhs-questionnaires-and-manuals.cfm>

gathering. This is very costly because it takes a lot of people to talk to everyone. However, in cases such as a national census, it is necessary to have a complete enumeration despite the cost.

Another way to collect information is through a sample survey. When it is not necessary to know exact total numbers, a sample survey can collect information about people much more quickly and cheaply. The sampling procedure allows us to collect data on a small number of people and draw conclusions that are valid for the region or country that is being studied.

The accuracy of a sample survey depends, among other things, on the size of the sample. The exact number to be interviewed for any survey is determined by statistical methods which we will not try to discuss in this training session. What you should know, however, is that the sample size for this survey reflects the number of interviews that are needed to provide an accurate picture of the situation in the survey area. Consequently, it is critical to a survey that fieldworkers try their hardest to complete all assigned interviews to ensure that the correct number of people are included in the survey.

The accuracy of a sample survey also depends on another major factor, the absence of bias that would affect the proportions found through the sample. To control or prevent bias from creeping into the results, the selection of people included in the sample must be absolutely random. This means that every person in the total population to be studied has the same opportunity to be selected in the sample. This is why it is so important to make call-backs to reach those people who are not at home, since they may be different from people who are at home. For example, it may be that women who have no children are more likely to be working away from the house, and if we don't call back to interview them, we may bias the fertility estimates.

For this survey, the sample consists of 2,780 households in Basse. The households in each of these clusters have recently been listed or enumerated. A sample of households was then scientifically selected to be included in the survey from the list in each of the clusters. Each of these households will be visited and information obtained about the household using the Household Questionnaire. Women age 15-49 years will be interviewed using the Pregnancy History Questionnaire. We expect to interview about 9,000 respondents in this survey.

Survey organization

During the survey fieldwork, you will work in a team consisting of two interviewers and a team leader. The team leader will administer the Household Questionnaire and identify women aged 15-

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49. Two interviewers in this team will then administer the Pregnancy History Questionnaire. You will be dropped off at the villages that you will survey for the week and at the end of the week, transported back to a central place.

There will also be a data manager who is responsible for uploading the data from the tablets to the central server. It is your responsibility to ensure that the tablets are in good care and shall not be shared. The data manager will monitor data quality.

Survey questionnaires in the tablets

The households that have been scientifically selected to be included in the sample will be visited and enumerated using a Household Questionnaire. The Household Questionnaire consists of a cover sheet to identify the household and a form on which all members of the household and visitors are listed. This form is used to record some information about each household member, such as name, sex, age, education, the ethnic group and survival as well as residence of parents. The Household Questionnaire also collects information on how many people have died in the household in the past 12 months. The Household Questionnaire permits the interviewer to identify respondents who are eligible for the individual interview. Women age 15-49 years in every selected household who are members of the households are eligible to be interviewed Pregnancy History Questionnaire.

After all of the eligible respondents in a household have been identified by the household interviewer, you will use the Pregnancy History Questionnaire on the tablet to interview the particular respondents you are assigned.

Interviewer's role

The interviewer occupies the central position in the SURVEY because she collects information from respondents. Therefore, the success of the survey depends on the quality of each interviewer's work. In general, the responsibilities of the team leader and the interviewer include the following:

- Locating the structures and households in the sample, and completing the Household Questionnaire
- Identifying all eligible respondents in those households
- Interviewing all eligible women in the households using the Pregnancy History Questionnaire
- Checking completed interviews to be sure that all questions were asked, and the responses properly recorded
- Returning to households to interview respondents that could not be interviewed during the initial visit

Adapted from <https://dhsprogram.com/publications/publication-dhsm3-dhs-questionnaires-and-manuals.cfm>

Training of interviewers

Although some people are more adept at interviewing than others, one can become a good interviewer through experience. Your training will consist of a combination of classroom training and practical experience. Before each training session, you should study this manual carefully along with the questionnaire, writing down any questions you have. Ask questions at any time to avoid mistakes during actual interviews. Interviewers can learn a lot from each other by asking questions and talking about situations encountered in practice and actual interview situations.

During the training, the questionnaire sections, questions, and instructions will be discussed in detail. You will see and hear demonstration interviews conducted in front of the class as examples of the interviewing process. You will practice reading the questionnaire aloud to another person several times so that you may become comfortable with reading the questions aloud. You will also be asked to take part in role playing in which you practice by interviewing another trainee.

The training also will include field practice interviewing in which you will actually interview household respondents and eligible women. You will be required to work as you would do in the actual fieldwork assignments.

You will be given tests to see how well you are progressing during your formal training period. At the end of the training course, the interviewers will be selected based on their test results and performance during the field practice.

The training you receive as an interviewer does not end when the formal training period is completed. Each time a supervisor meets with you to discuss your work, your training is being continued. This is particularly important during the first few days of fieldwork. As you run into situations you did not cover in training, it will be helpful to discuss them with your team. Other interviewers may be running into similar problems, so you can all benefit from each other's experiences.

Supervision of interviewers

Training is a continuous process. Observation and supervision throughout the fieldwork are a part of the training and data collection process. Your team supervisor and the data manager will play very important roles in continuing your training and in ensuring the quality of the SURVEY data.

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They will:

- Spot-check some of the addresses selected for interviewing to be sure that you interviewed the correct households and the correct women
- Review each questionnaire to be sure it is complete and consistent
- Observe some of your interviews to ensure that you are asking the questions in the right manner and recording the answers correctly
- Meet with you on a daily basis to discuss performance and give out future work assignments
- Help you resolve any problems that you might have with finding the assigned households, understanding the questionnaire, or dealing with difficult respond

Survey regulations

The supervisor may terminate the service of any interviewer who is not performing at the level necessary to produce the high-quality data required to make the survey a success. For the workload to be equally divided and the support equally shared, the following survey regulations have been established and will be strictly enforced:

Except for illnesses, any team member who is absent from duty during any part of the training or fieldwork without prior approval from her/his supervisor may be dismissed from the survey.

Throughout the survey training and the fieldwork period, you are representing the Medical Research Council (MRC). Your conduct must be professional, and your behaviour must be congenial in dealing with the public. We must always be aware of the fact that we are only able to do our work with the good will and cooperation of the people we interview. Therefore, any team member who is consistently overly aggressive, abrupt, or disrespectful to the people in the field may be dismissed from the survey team.

For the survey to succeed, each team must work closely together, sharing in the difficulties and cooperating and supporting each other. We will attempt to make team assignments in a way that enhances the cooperation and good will of the team. However, any team member who in the judgment of the survey director creates a disruptive influence on the team may be asked to transfer to another team or may be dismissed from the survey.

It is critical that the data gathered during the fieldwork be both accurate and valid. To control for inaccurate or invalid data, spot checks will be conducted. Interviewers may be dismissed at any time during the fieldwork if their performance is not considered adequate for the high quality this survey demands.

Survey data are confidential. They should not be discussed with anyone, including your fellow interviewers. Under no circumstances should confidential information be passed on to third parties. In keeping with this policy, it is also important that you never interview anyone you may know in the survey. Persons breaking these rules, and therefore the confidence placed in them, will be dismissed.

Conducting an interview

Successful interviewing is an art and should not be treated as a mechanical process. Each interview is a new source of information, so make it interesting and pleasant. The art of interviewing develops with practice but there are certain basic principles that are followed by every successful interviewer. In this section you will find a number of general guidelines on how to build rapport with a respondent and conduct a successful interview.

Building rapport with the respondent.

The team leader will make the first contact with each of the households selected for the survey. Any capable adult member of the household is a suitable respondent for the household interview. If at least one eligible woman is identified in the Household Questionnaire, the interviewer will go on to complete a Pregnancy History Questionnaire.

As an interviewer, your first responsibility is to establish a good rapport with a respondent. At the beginning of an interview, you and the respondent are strangers to each other. The respondent's first impression of you will influence their willingness to cooperate with the survey. Be sure that your manner is friendly as you introduce yourself. Before you start to work in an area, your supervisor will have informed the local leaders, who will in turn inform selected households in the area that you will be coming to interview them.

Make a good first impression.

When you arrive at the household, do your best to make a respondent feel at ease. With a few well-chosen words, you can put the respondent in the right frame of mind for the interview. Open the interview with a smile and greeting such as "good afternoon" and then proceed with your introduction.

Obtain respondent(s) consent to be interviewed.

You must obtain a respondent's informed consent for participation in the survey before you begin an interview. A special statement is included at the beginning of the household and of the respondent's questionnaires. This statement explains the purpose of the survey. It assures a respondent that participation in the survey is completely voluntary and that it is their right to refuse to answer any questions or stop the interview at any point. Be sure to read the informed consent statement exactly as it is written before asking a respondent to participate in a household or individual interview. Write the name of the respondent in the quire book that is provided and ask for a thumb print.

Always have a positive approach.

Never adopt an apologetic manner, and do not use words such as "Are you too busy?" Such questions invite refusal before you start. Rather, tell the respondent, "I would like to ask you a few questions" or "I would like to talk with you for a few moments."

Confidentiality of responses.

If the respondent is hesitant about responding to the interview or asks what the data will be used for, explain that the information you collect will remain confidential, and all information will be grouped together to write a report. Also, you should never mention other interviews or show completed questionnaires to the supervisor or field editor in front of a respondent or any other person.

Answer any questions from the respondent frankly.

Before agreeing to be interviewed, the respondent may ask you some questions about the survey or how he or she was selected to be interviewed. Be direct and pleasant when you answer. The respondent may also be concerned about the length of the interview. If she asks, say that the interview usually takes about [20] minutes. Indicate your willingness to return at another time if it is inconvenient for the respondent to answer questions then.

The respondent may ask questions or want to talk further about the topics you bring up during the interview. It is important not to interrupt the flow of the interview so tell her or him that you will be happy to answer questions or to talk further after the interview.

Interview the respondent alone.

The presence of a third person during an interview can prevent you from getting frank, honest answers from a respondent. It is, therefore, very important that the individual interview be conducted privately and that all questions be answered by the respondent.

If other people are present, explain to the respondent that some of the questions are private and ask to interview the person in the best place for talking alone. Sometimes asking for privacy will make others more curious, so they will want to listen; you will have to be creative. Establishing privacy from the beginning will allow the respondent to be more attentive to your questions. In all cases where other individuals are present, try to separate yourself and the respondent from the others as much as possible.

For the Household Questionnaire, it is usually not necessary to conduct the interview in private. In fact, it is sometimes helpful to ask other household members about information on age and/or education of other members. This is acceptable; it is only for the individual interviews that you should interview in private.

Tips for conducting the interview

Be neutral throughout the interview.

Most people are polite and will tend to give answers that they think you want to hear. It is therefore very important that you remain absolutely neutral as you ask the questions. Never, either by the expression on your face or by the tone of your voice, allow the respondent to think that she has given the “right” or “wrong” answer to the question. Never appear to approve or disapprove of any of the respondent’s replies.

The questions are all carefully worded to be neutral. They do not suggest that one answer is more likely or preferable to another answer. If you fail to read the complete question, you may destroy that neutrality.

If the respondent gives an ambiguous answer, try to probe in a neutral way, asking questions such as the following:

“Can you explain a little more?”

“I did not quite hear you; could you please tell me again?”

“There is no hurry. Take a moment to think about it.”

Adapted from <https://dhsprogram.com/publications/publication-dhsm3-dhs-questionnaires-and-manuals.cfm>

Never suggest answers to the respondent.

If a respondent's answer is not relevant to a question, do not prompt her by saying something like "I suppose you mean that. . . Is that right?" In many cases, she will agree with your interpretation of her answer, even when that is not what she meant. Rather, you should probe in such a manner that the respondent herself comes up with the relevant answer. You should never read out the list of coded answers to the respondent, even if she has trouble answering.

Do not change the wording or sequence of questions.

The wording of the questions and their sequence in the questionnaire must be maintained. If the respondent has not understood the question, you should repeat the question slowly and clearly. If they still do not understand, you may reword the question, being careful not to alter the meaning of the original question. Provide only the minimum information required to get an appropriate response. Please use the language translation agreed on during the training.

Handle hesitant respondents tactfully.

There will be situations where the respondents simply say, "I don't know," give an irrelevant answer, act very bored or detached, or contradict something they have already said. In these cases, you must try to re-interest them in the conversation. For example, if you sense that they are shy or afraid, try to remove their shyness or fear before asking the next question. Spend a few moments talking about things unrelated to the interview (for example, their town or village, the weather, their daily activities, etc.).

If the respondent is giving irrelevant or elaborate answers, do not stop them abruptly or rudely, but listen to what they have to say. Then try to steer them gently back to the original question. A good atmosphere must be maintained throughout the interview. The best atmosphere for an interview is one in which the respondent sees the interviewer as a friendly, sympathetic, and responsive person who does not intimidate them and to whom they can say anything without feeling shy or embarrassed. As indicated earlier, a major problem in gaining the respondent's confidence may be one of privacy. This problem can be prevented if you are able to obtain a private area in which to conduct the interview.

The interviewer **MUST** reiterate on confidentiality; that the respondents and all the project data will be highly confidential. The interviewer can honestly say, any breach of confidentiality from

their conversation can have [the interviewer] legal implication as the Gambia Health Services & MRC keep watch over the project's information confidential security.

If the respondent is reluctant or unwilling to answer a question, explain once again that the same question is being asked of women all over Basse, and that the answers will all be merged together. If the respondent is still reluctant, simply write REFUSED next to the question and proceed as if nothing had happened. Remember, the respondent cannot be forced to give an answer.

Do not form expectations.

You must not form expectations of the ability and knowledge of the respondent. For example, do not assume women and men from rural areas or those who are less educated, or illiterate do not know about dates of birth.

Do not hurry the interview.

Ask the questions slowly to ensure the respondent understands what they are being asked. After you have asked a question, pause and give them time to think. If the respondent feels hurried or is not allowed to formulate their own opinion, they may respond with “I don’t know” or give an inaccurate answer. If you feel the respondent is answering without thinking just to speed up the interview, say to the respondent, “There is no hurry. Your opinion is very important, so consider your answers carefully.”

Language of the interview

The questionnaires for the survey are in English however, when needed you shall use the terms agreed upon during training in Mandinka, Serahule, Fula and Wollof when interviewing will take place. One of the first things you will do when you approach a household to do an interview is to establish the language or languages that are spoken there. We will be arranging the field teams in such a way that you will be working in an area in which your language is spoken, so there should be few cases in which respondents do not speak your language. In such cases you might be able to find another language that both of you speak and you will be able to conduct the interview in that language.

In some cases, it will not be possible for you to find a language which both you and the respondent speak. If this happens, try to find out if the respondent speaks a language which another member of your team or the team leader speaks. If so, tell your team leader so that she can arrange for that person to conduct the interview.

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We will by all means try to avoid using interpreters since this not only jeopardizes the quality of the interview but also will mean that the interview will take more time to conduct and affects confidentiality. However, if the respondent does not speak a language which any of your team members speak, you will need to rely on a third person to translate for you. Since the interview involves some sensitive topics, it is best if you can find another woman to act as an interpreter if you are conducting the pregnancy history interview. You should not use the respondent's husband as an interpreter under any circumstances. Children are also unsuitable interpreters. Women from the same community are also not suitable unless expressly requested by the respondent. The default solution will be to ask a female interviewer from another team to come and conduct the interview.

We will be practicing interviews in the local languages during training. However, there may be times when you will have to modify the wording of the questions to fit local dialects and culture. It is very important not to change the meaning of the question when you rephrase it or interpret it into another language.

Fieldwork procedures

Fieldwork for the survey will proceed according to a timetable, and the survey will be successful only if each member of the interviewing team understands and follows correct field procedures. The following sections review these procedures and describe the proper procedures for receiving work assignments and keeping records of selected households.

Tracking the work assignments.

You are responsible for seeing that the questionnaires in the tablets are kept confidential. Do not share the results with other interviewers. You should never interview household in which you know one or more of the members, even if they are only casual acquaintances. If you are assigned to a household in which you know a person even if that person is not eligible for interview, you should notify your team leader, so she can assign that household to another interviewer. You should not attempt to see the completed questionnaires for that household nor discuss the interview results with your colleagues.

Making call-backs.

Because each household has been carefully selected, you must make every effort to conduct interviews with the eligible women identified. Sometimes a household member will not be available

at the time you first visit. You need to make at least 3 visits on three separate times of the day or days when trying to obtain an individual interview to maximize the possibility of successfully completing the individual interview.

At the beginning of each day, you should examine your quire books to see if you made any appointments for revisiting a household or eligible respondent. If no appointments were made, make your call-backs to a respondent at a different time of day than the earlier visits; for example, if the initial visits were made in the early afternoon, you should try to arrange your schedule, so you make a call-back in the morning or late afternoon. Scheduling call-backs at different times is important in reducing the rate of non-response (i.e., the number of cases in which you fail to contact a household or complete a woman's interview).

Supplies and documents needed for fieldwork.

Before starting fieldwork each morning, verify that you have everything you need for the day's work. Some necessary supplies include the quire book for consent, pens and a bag to carry the tablet and the ink used for fingerprint consent.

Contacting households and eligible respondents

Locating sample households.

The HDSS keeps up-to-date lists of all households and members that they continuously follow up. These households have numbers marked on the walls to aid in their identification. These are the definitions that we will use throughout the survey when contacting households.

A structure is a freestanding building, for a residential or commercial purpose. It may have one or more rooms in which people live; it may be an apartment building, a house, or a thatched hut, for instance.

Within a structure, there may be one or more dwelling (or housing) units. For instance, there would be one dwelling unit in a thatched hut, but there may be 50 dwelling units in an apartment building or five dwelling units in a compound. A *dwelling unit* is a room or group of rooms occupied by one or more households. It may be distinguished from the next dwelling unit by a separate entrance.

Within a dwelling unit, there may be one or more households. For example, a compound may have five households living in it, and each household may live in its own dwelling unit. By definition, a *household* consists of a person or group of persons, related or unrelated, who live together in the

same dwelling unit, who acknowledge one adult male or female as the head of household, who share the same living arrangements, eat from the same pot and are considered as one unit. In some cases, one may find a group of people living together in the same house, but each person has separate eating arrangements; they should be counted as separate one-person households.

Specific households have been selected to be interviewed, and you should not have any trouble in locating the households assigned to you if you use the structure number and the name of the head of the household to guide you. The structure number is usually written above the door of the house, but sometimes it may be on the wall. Although the supervisor of your team will be with you in the field, it is important that you also know how to locate the structures in the sample by using the sketch map.

Problems in contacting a household.

In some cases, you will have problems locating the households that were selected because the people may have moved, or the listing teams may have made an error. Here are examples of some problems you may find and how to solve them:

The household has moved away and a new one is now living in the same dwelling. In this case, interview the new household.

The structure number and the name of the household head do not match with what you find in the field. If you have located the correct dwelling, you should consider the household is living in the dwelling as the selected household.

The listing shows only one household in the dwelling, but two or more households are living there now. When the listing showed only one household and you find two households, interview both households. Make a note on the quire book of the household that was not on the listing. Your supervisor will assign this household a number, which you should enter on the questionnaire. If the listing shows two households, only one of which was selected, and you find three households there, only interview the one that had been selected and ignore the other two.

The house is all closed up and the neighbours say the people are on the farm (or away visiting, etc.) and will be back in several days or weeks. The house should be revisited at least two more times to make sure that the household members have not returned.

The house is all closed up and the neighbours say that no one lives there; the household has moved away permanently.

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A household is supposed to live in a structure that when visited is found to be a shop and no one lives there. Check very carefully to see whether anyone is living there.

A selected structure is not found in the cluster, and residents tell you it was destroyed in a recent fire.

No one is home and neighbours tell you the family has gone to the market. Return to the household at a time when the family will be back.

A fallen house structure especially as this will be just after the rainy season.

Discuss with your supervisor any problems you have in locating the households that you are assigned to interview. Remember that the usefulness of the sample in representing the entire survey area depends on interviewers locating and visiting all the households they are assigned.

Identifying eligible respondents.

To be “eligible” means to “qualify” for something. An eligible respondent is someone who is qualified to be included in our survey. You will use the Household Questionnaire to identify who is eligible to be interviewed with the Pregnancy History Questionnaire.

All women age 15-49 who are members of the household are considered eligible in the survey. It is very important that the team leader does not miss an eligible respondent when you fill in the Household Schedule in your quire book.

You must complete the first page of the individual questionnaire for each eligible respondent that you identify in the household before starting the interview and take consent. If you cannot finish the interview for whatever reason, type the reason on the cover page. Take care to note any information that may be useful when you contact the person later.

In some households, there will be no eligible respondents (i.e., there will be no usual household members or visitors of eligible age). For these households, you will have a completed Household Questionnaire, with no accompanying individual questionnaire.

Problems in obtaining interviews.

You may experience the following types of problems in obtaining an interview with an eligible respondent:

Eligible respondent not available. If the eligible respondent is not at home when you visit, you should contact the household at least three times, trying to make each visit at a different time of day. Under no circumstances is it acceptable to conduct all three visits on the same day and then stop attempting to contact the respondent.

Respondent refuses to be interviewed. The respondent's availability and willingness to be interviewed will depend in large part on the initial impression you make when you meet them. Introduce yourself and explain the purpose of the visit. Read the introduction on the questionnaire. You may emphasize the confidentiality of the information she provides, and/or the short duration of the interview. If the respondent is unwilling to be interviewed, it may be that the present time is inconvenient. Ask whether another time would be more convenient and make an appointment. If the respondent still refuses to be interviewed, report it to your supervisor.

Interview not completed. A respondent may be called away during the interview or they may not want to answer all the questions at the time you visit them. If an interview is incomplete for any reason, you should arrange an appointment to see the respondent again as soon as possible to obtain the missing information. Be sure that you record in the quire book that the interview is incomplete and indicate the time you agreed on for a revisit; you should also report the problem to your supervisor.

Respondent incapacitated. There may be cases in which you cannot interview a person because they are too sick, because they are mentally unable to understand your questions, or because they are deaf, etc. In these cases, make a note of it in your quire book.

The outcome of the final attempt to contact an eligible respondent should be noted in your notebook.

Returning work assignments.

At the end of fieldwork each day, check that you have filled out the listing of a Household Questionnaire for each household assigned to you, whether or not you managed to complete an interview. Check also that you have completed the cover sheet of the pregnancy history questionnaire of each respondent identified, whether you were able to interview them or not. For difficult cases, at least three visits will be made to a household in an effort to obtain a completed interview. Hand over the tablet to the data manager in order to upload the data.

Data quality

It is the responsibility of the data manager to review both the Household Questionnaires and the Pregnancy History Questionnaires from a sample cluster while the interviewing team is still in the cluster. It is especially important to conduct thorough edits of questionnaires at the initial stages of fieldwork. The supervisor will discuss with each interviewer the errors found in the collection of data. It may sometimes be necessary to send an interviewer back to a respondent in order to correct some data error.

General procedures for completing the Questionnaire

To collect the information, you must understand how to ask each question, what information the question is attempting to collect, and how to handle problems that might arise during the interview. You must also know how to correctly record the answers the respondent gives and how to follow special instructions in the questionnaire. This part of the training manual is designed to familiarize you with the questionnaire.

Asking questions.

It is very important that you ask each question exactly as it is written in the questionnaire. When you are asking a question, speak slowly and clearly so that the respondent will have no difficulty hearing or understanding the question. At times you may need to repeat the question to be sure the respondent understands it. In those cases, do not change the wording of the question but repeat it exactly as it is written.

If, after you have repeated a question, the respondent still does not understand it, you may have to restate the question. Be very careful when you change the wording, however, that you do not alter the meaning of the original question.

In some cases, you may have to ask additional questions to obtain a complete answer from a respondent (we call this 'probing'). If you do this, you must be careful that your probes are "neutral" and that they do not suggest an answer to the respondent. Probing requires both tact and skill, and it will be one of the most challenging aspects of your work as an interviewer.

Recording responses.

In this survey, all interviewers will use tablets that are programmed with the questionnaires. There are three types of questions in the questionnaire: 1) questions that have pre-coded responses; 2) questions that do not have pre-coded responses, i.e., that are ‘open-ended’; and 3) filters.

Questions with pre-coded responses.

For some questions, we can predict the types of answers a respondent will give. The responses to these questions are listed in the questionnaire. To record a respondent’s answer, you merely click on the code and select the number (code) that corresponds to the reply.

In some cases, pre-coded responses will include an ‘Other’ category. The ‘other’ code should be selected when the respondent’s answer is different from any of the pre-coded responses listed for the question. Before using the other code, you should make sure the answer does not fit in any of the other categories. When you select the code other for a particular question you must always type in the respondent’s answer in the space provided.

Recording responses that are not pre-coded such as names.

The answers to some questions are not pre-coded but require that you fill in write the respondent’s answer in the space provided.

Recording numbers or dates in boxes.

In some questions, you will record a number or date in the boxes provided. You will do this by clicking on the calendar and selecting the appropriate date or type in the appropriate number.

Correcting mistakes.

It is very important that you record all answers carefully. For pre-coded responses, be sure that you select the code for the correct response. For open-ended responses, the reply should be typed in accurately. If you made a mistake in entering a respondent’s answer or she changes her reply, be sure that you delete the incorrect response and enter the right answer.

Following instructions.

Throughout the questionnaire, instructions for the interviewer are printed in all CAPITAL LETTERS, whereas questions to be asked of the respondent are printed in small letters. You should

pay particular attention to the skip and filter instructions that have been programmed throughout the questionnaire.

Skip instructions.

It is very important not to ask a respondent any questions that are not relevant to her situation. For example, a woman who is not pregnant should not be asked for how many months she has been pregnant. In cases where a particular response makes subsequent questions irrelevant, the tablet will be programmed to direct you to skip to the next appropriate question. It is important that you carefully follow skip instructions.

Household Questionnaire

The purpose of the Household Questionnaire is to provide information on general characteristics of the population and their households. You will use it to identify individual household members who are eligible to be interviewed with the Pregnancy History Questionnaire.

Identification of household on the cover page.

Before you go to a selected household, fill in the identification information in the box at the top of the cover page. The identification information is obtained from the sample household listing and will be given to you by your supervisor. The following are key points in completing the identification section: Write the name of the HDSS; Record the household number; Type the name of the head of the household in which you are about to interview.

Completing the household questionnaire.

To complete the Household Questionnaire, you will need to find a suitable respondent. Any adult member of the household who is capable of providing information needed to fill in the Household Questionnaire can serve as the respondent. If an adult is not available, do **not** interview a young child; instead, go on to the next household, and call back at the first household later. Generally, you will ask a single individual in the household for the information you will need to complete the household questionnaire. However, as appropriate, you may need to consult other members of the household for specific information.

Household Schedule (Qs. 1-B)

After introducing yourself and explaining the purpose of your visit, you are ready to start the household schedule. Be sure to read the introductory sentence to inform the respondent that you

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are interested in getting information about all usual household members and any other persons who might have slept in the household the night before the interview.

Column (1): Line Number

In Column (1), each row of the household schedule is assigned a unique number. This number is referred to as the 'Line Number'. It is used to identify the person listed on that row and to link information collected in the household and individual interviews to that individual.

Column (2): Usual Residents and Visitors

The first step in completing the household schedule is to request a list of all persons who usually live in the household and any visitors. To get a correct listing, you will have to know what we mean by a member of the household and what we mean by a visitor:

Member of the household. A household may be one person or a group of persons who usually live and eat together. This is not the same as a family. A family includes only people who are related, but a household includes any people who live together, whether or not they are related. For example, three unrelated men who live and cook meals together would not be considered one family, but they would be considered to be members of the same household.

Visitor. A visitor is someone who is not a usual member of the household but who slept in the household the night before the day you are conducting the interview. If an individual slept in the household the previous night, he or she should be listed on the Household Schedule. Sometimes, it is not easy to know whom to include in the household and whom to leave out. Here are some examples:

Sometimes, people eat in one household and sleep in another. Consider the person to be a member of the household where he or she sleeps.

A person living alone is a household.

A servant is a member of the household if he or she usually lives in the household.

Anyone included in the household listing has to be either a usual resident of that household or has to have spent the previous night in the household.

As your respondent lists the names, write them down, one in each row in Column (2) of the table, **beginning with the household head**. The person who is identified as the head of the household has to be someone who usually lives in the household. This person may be acknowledged as the

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head on the basis of age (older), sex (generally, but not necessarily, male), economic status (main provider), or some other reason. It is up to the respondent to define who heads the household. There generally should not be a problem with this. If the person responding to the household interview is not the head of household then you may record this person on the second line.

After entering a name, the relationship of that person to the head of the household and the sex should be recorded in Columns (3) and (4) **before** going on to record the name of the next name.

Column (3): Relationship

Record how the person listed is related to the head of the household. Use the codes at the bottom of the page. **If the respondent is not the head of the household, make sure that you record the relationship of each person to the household head, not the relationship to the respondent.** *Example:* if the respondent is the wife of the head of the household and she says that Lamin is her brother, then Lamin should be coded as OTHER RELATIVE not BROTHER OR SISTER, because Lamin is a brother-in-law of the head of the household.

Column (4): Sex

Always confirm the sex of a person before recording it in Column (4) since there are many names that may be given to either a male or female. When you have written all the names, you want to be certain you have included everyone who should be listed before continuing with the rest of the questionnaire.

After completing Columns (2) through (4) for all household residents and any visitors, start with the person listed on Line 01 and move across the page, asking each appropriate question in Columns (5) through (13). When you have completed the information for the person on Line 01, move to the person listed on Line 02, etc.

Columns (5) and (6): Residence

In Column (5), record information on the person's usual residence. A usual member of the household may or may not have slept in the household the night. However, a visitor must always have stayed in the household the night before the interview. If after asking these residence questions you learn that the person does not usually live in the household, you will have to delete this person from the listing because he/she is neither a member nor a visitor.

Column (7): Age

You are to obtain each person's date of birth and age in completed years, that is, the age at the time of the last birthday.

Columns (8) and (9): Eligibility

Look at Column (7 & 8) and select the Line Number in Column (9) for all women who are between 15 and 49 years of age (including those who are age 15 and 49). These individuals are "eligible" women, and they qualify for an interview using the Pregnancy History Questionnaire. Alert your colleagues to start the individual questionnaires.

Columns (10) - (18): Ethnicity, Survivorship of Natural Parents

Select the appropriate ethnic group from the drop-down menu on Column 10. For Column 11-18, we want to know whether the respondent's natural parents are still alive.

Columns (19) and (20): Education

Questions on education are not to be asked for people who are younger than five years old. For anyone under five years old, simply leave these columns blank.

The term "school" means formal schooling, which includes primary, secondary, and post-secondary schooling, and any other intermediate levels of schooling in the formal school system. However, it does include technical or vocational training beyond the primary school level, such as long-term courses in mechanics or secretarial work.

If the person has never attended school, select No in column (18).

If the person has attended school, you will record the highest level of school the person has attained in the first box on the left in Column (19). Do this by using the pre-set codes. Then record the highest grade (form/year) the person completed at that level.

The last section of the household questionnaire asks about deaths in the household in the past 12 months. Remember this is a sensitive topic and you must show empathy and be gentle with the respondent.

Final Visit.

After you have paid your last visit to the household, you will fill in the the date on which you completed the household interview (recorded in the DAY, MONTH, YEAR boxes). For example, the last day in January 2016 would be DAY 31, MONTH 01, YEAR 2016. Record the result for the final visit and add up the number of visits you made for the household interview.

Total in household and total eligible women.

After you have completed the household interview, you will record the total number of people listed. You will also record the total number of eligible women.

Prepare an individual questionnaire for each eligible person.

After completing a household interview, interview each eligible respondent identified in the household. You will fill in the identification information on the cover sheet of the Pregnancy history questionnaire for each eligible respondent identified in the Household Schedule.

The identification information on the individual questionnaires is similar to the identification information on the Household Questionnaire. However, you must type the eligible respondent's name and the Line Number he/she was assigned in the Household Schedule in Column (1). If an eligible respondent is immediately available, proceed to interview them.

After completing the interviews with the eligible women, you will return the tablet with the completed Questionnaire to your supervisor with all of the individual questionnaires inside.

Pregnancy history questionnaire**Informed consent.**

The respondent's consent for participation in the survey must be obtained before you can begin the interview. Read the informed consent statement exactly as it is written. This statement explains the purpose of the survey. It assures the respondent her participation in the survey is completely voluntary and that she can refuse to answer any questions or stop the interview at any point.

After reading the statement, **you** (not the respondent) must sign in the quire book provided to affirm that you have read the statement to the respondent. If the woman does not agree to be interviewed, thank the respondent, and end the interview. Then write '3' (REFUSED) as the result on the cover sheet. In the quire book, for those who do give consent, record the name of the respondent and get a signature or a thumb print.

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General note about Qs. 201-210

Qs. 201-210 collect information about all births that the woman has had (no matter who the father is).

Q. 201: Ever given birth

This question serves two purposes: to introduce the section and to learn whether the respondent has ever given birth. Even if the woman tells you that she never gave birth (Q. 201 is NO), you must go on to ask Q. 206 since she may not have told you about children who died very young.

Q. 202: Any children living with her

Read the question slowly. The sons and daughters being considered are her OWN natural (biological) children who live with her in her household (which will usually be the household in which the interview is being held, except for women who are visitors).

Q. 203: Number of children living with her

Fill in the number of sons and daughters who live with the respondent. If she has only sons living with her, write '00' in the boxes for daughters, and vice versa. Remember that we are only interested in the respondent's OWN natural (biological) children and not foster children, children of her husband by another woman, or children of a relative.

Note that it is never correct to record '00' in the boxes for both sons and daughters since women who have no children living at home should not be asked Q. 203.

Qs. 204 and 205: Any children living elsewhere

These questions refer to the respondent's sons and daughters who are alive but not living with her. For example, they may be living with a relative, may be staying in a boarding school, may have been given up for adoption, or may be grown-up children who have left home. If she has only sons living elsewhere, write '00' in the boxes in Q. 205 for daughters, and vice versa. Make sure the respondent is not reporting dead children in this question.

Qs. 206 and 207: Children who died

These questions on children who have died are extremely important and are among the most difficult on which to obtain accurate data. Some respondents may fail to mention children who died very young, so if a woman answers NO, it is important to probe by asking, "Any baby who cried or

showed signs of life but survived only a few hours or days?” Some respondents may be reluctant to talk about this subject and may become sad or upset that you are asking such questions. Be sympathetic and tactful in such situations. Say that you know the subject is painful but that the information is important.

Q. 208: Total births

Add up the numbers in Qs. 203, 205, and 207 and enter the total in Qs. 208 and 209.

Q. 209: Checking total with respondent

Ask the respondent whether the total is correct. If she says NO, first check your addition, and then go through the list to check with the respondent whether you have obtained the information correctly.

Example: Starting with Q. 203, you would ask, “You have two sons and one daughter living with you. Is that correct?” Do the same for Qs. 205 and 207 and then enter the correct sum in Qs. 208 and 209.

Q. 209A, B and C: PREGNANCIES THAT DO NOT END IN LIVEBIRTHS

This section is also very sensitive, and you need to be sympathetic and tactful as well. You will need to ask the respondent about other pregnancies that ended up as stillbirths, abortions or miscarriage. It is especially important to conduct this interview in private as the presence of a third person will affect the answers given to you.

At this point, re-emphasize that this information will not be revealed to anyone other than the main researchers and that it is very important to know this sensitive information. Also remind them that no one will know who said what when the information will be analysed. Ask the questions in a neutral manner and withhold any expressions even if you may feel strongly about abortions for example, to ensure that the respondent does not feel judged.

Record the number of stillbirths, abortions and miscarriages a respondent has experienced in her lifetime and calculate the total in Q209D, confirm the numbers in Q210.

General notes about Qs. 212-222 (all pregnancies)

Qs. 212-222 collect additional information about the respondent’s pregnancies starting from the most recent one to her first one. It is important that you understand which events to include. We want to record information about the respondent’s pregnancies including abortions, stillbirths and

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miscarriages. We want to know about all the woman's pregnancies even if the child no longer stays in the household or if the child is no longer alive. If she has had twins or triplets, each one should be recorded in a separate line.

It is also important to understand which events should not be recorded. You must not record adopted or foster children or children of relatives who may be living in the households. You also should not include any of her husband's children to whom the respondent did not give birth herself.

Q. 211: Request for information on most recent pregnancies

Begin by informing the respondent that we would like to record the names of her children from her most recent pregnancies, from all marriages and unions, whether or not these children are still alive. Select the appropriate category of live birth, stillbirth miscarriage or abortion. Then select if the pregnancy was single or multiple. If multiple, ensure that you record each in a separate line. Remember to be gentle when asking these questions particularly if the respondent lost a child.

If at any time you find that the children are not listed in order (last, next-to-last, second-to-last), do not erase the information. Instead, go back and select the individual and change the birth order to the correct information.

Q. 212: Child's name

Record the name of the respondent's last pregnancy in the space provided in Q. 212. If the woman reports that she had a multiple birth (twins, triplets, etc.), record each of the children on a separate line.

Write the name that distinguishes that child from the others—in other words, if there are two children, Mariama Bah and Fatoumattah Bah, write “Mariama Bah” and “Fatoumattah Bah not “M. Bah” and “F. Bah.” If the baby never had a name, either because it is still very young or because it died very young, write “Baby” for the name.

Q. 213: Child's sex

Choose the appropriate code for the sex of the child. Although you can often tell the sex from the name, check with the respondent by saying, for example, “and Mariama is a girl?” Do not assume the sex of the child from the name.

Q. 214: Date of birth

When collecting information on a child's birth date, always look at any documents you collected for the child at the beginning of the interview (e.g., birth certificate or immunization record) to see whether a date of birth was recorded. Before entering a date from these documents, however, check with the respondent to determine whether she believes the date is accurate. In some cases, the information on the document may be the date when the birth was recorded and not the date when the child was born. If the respondent gives you a year of birth but does not know the month of birth, probe to try to estimate the month.

example: if a respondent says her daughter was born in 1987, but she does not know which month, ask her whether she gave birth in the dry or wet season, whether she remembers if she was pregnant at Tobaski, Koriteh, Christmas or Easter time, or during some other significant event/season of the year to try to determine the month of birth. Convert months to numbers, as before. If you cannot even estimate a month, write '98' for MONTH.

If the respondent cannot recall the year when the birth occurred, you need to probe carefully. See if the respondent knows a firm birth date for any other child in the household and relate it to that.

Example: if she knows the second child was born in 1985 and the first child was just a year old at that time, enter '1984'. You must enter a year for all children, even if it is just your best estimate. At all times do your best to get the exact date of birth.

Q. 215: Survival status

Choose the appropriate code for whether the child is still alive or not.

Other points about the most recent births

Recording of year of birth. For month of birth in Q. 214, it is permissible to record Code '98' for DON'T KNOW as an answer. However, for year of birth (Q. 214), you must record an answer. It is very important to obtain information for this question, so you must probe for this information and, if necessary, make your best estimate on the basis of the woman's answers.

Recording of information on twins (or triplets, etc.). If there are any twins, record the information about each twin on a separate line.

Correcting of reported sequence of births. If you find that the respondent has reported a birth out of the correct order, go back and change the child number.

Adapted from <https://dhsprogram.com/publications/publication-dhsm3-dhs-questionnaires-and-manuals.cfm>

Q. 223-225: Current pregnancy status

Ask about the last menstrual period and insert the date from the drop-down menu. If she cannot recall, select the most likely time in weeks, months or years as in Q223. Maintain the rapport created and ask if she is pregnant and how many months along. Congratulate her, and you can use this time to put her at ease and advice on antenatal care and preparedness. If the respondent does not know for certain whether or not she is pregnant, select '8' (UNSURE).

At this point, reassure the respondent that you will only take a few more minutes of her time and to please bear with you.

Q1101: Sibling history

This next section is to ask the eligible woman (age 15-49) about her brothers and sisters born of the same mother whether they are living together or apart and even those who have died. This asks for the total number of births to their natural mother.

Q1102 confirms the number and Q1103 asks how many are before the respondent.

In Q1104 type in the name of the sibling and proceed downward to select whether male or female, age and whether still alive.

If they have since died, Q1108 and 1109 are asked to establish when they died and their age at death. Please remember to be considerate as it is not easy to talk about loved ones that have passed on, and particularly since you had already asked her about her children who had died. Exercise patience, tolerance and empathy.

For all sisters to the respondents who died, Q1110-1112 are asked to find out if they died when pregnant, during childbirth or within two months of giving birth respectively. These questions are very important in helping establish maternal mortality rates in this area. It can be used to inform authorities on what they need to do to help mothers give birth safely and to help mothers and their babies to survive.

Q1113 asks about how many children the respondent's sister had in her lifetime and can be used to estimate orphanhood.

This is the end of the questionnaire. Thank the respondent for her cooperation and reassure her about the confidentiality of her answers.

FEMALE FIELDWORKER TRAINING

PRE AND POST-TRAINING TEST

NAME:

1. What is the title of the study you will be involved in? (3marks)
2. What is the purpose of the study you will be involved in? (5 marks)
3. Write down five things you must do before interviewing a respondent (5 marks)
 - a)
 - b)
 - c)
 - d)
 - e)
4. Write down five things you must not do while conducting an interview (5 marks)
 - a)
 - b)
 - c)
 - d)
 - e)
5. Who qualifies to answer the Household Questionnaire? (Write True (T) or False (F)) (4 marks)
 - a) Any adult person who is there when you visit
 - b) Any household member who is 15 or older
 - c) If no one is home after 3 re-visits, you can interview the neighbour
 - d) A child of the household of less than 12 years
6. If you get to a household and find out you do not know the language they are speaking. What will you do? (2 marks)
7. What are your responsibilities as an interviewer (5 marks)?
8. How shall you care for the tablets? (5 marks)
9. List five problems you may encounter when contacting a household (5 marks)
 - a)
 - b)
 - c)
 - d)
 - e)

FEMALE FIELDWORKER TRAINING

10. Define who is a household member (2 marks)

11. Who is the reference point of all relationships? (2 marks)

12. Write True (T) or False (F) for the following statements (5 marks)

- a) Always confirm the sex of the interviewees as names may be both male and female
- b) After listing, confirm whether you have the names of everyone in the household
- c) Always probe about dates of births or deaths and confirm using legal documents
- d) Record the age in completed years, age at last birthday
- e) Always tell the respondent you are in a rush and refuse to eat/drink what is offered

13. Why do you need the numbering of villages, compounds, households and personal identification? (2 marks)

14. Who should be given this unique identification numbers; (write True (T) or False (F)) against each question (5 marks)

- a) Births (Deliveries Occurring in the Demographic Surveillance Area)
- b) Out-migrants
- c) Deaths
- d) Stillbirths
- e) Abortions
- f) In-migrants

15. For those who died, do you give their unique identification numbers to their; (write True (T) or False (F)) against each question. (4 marks)

- a) Wives
- b) Children
- c) Husbands
- d) Visitors

16. If true, give a short explanation why (4 marks)

17. If false, give a short explanation why (4 marks)

FEMALE FIELDWORKER TRAINING



18. (4 marks)

Fill in the ages of the following people:	IN YEARS
A woman born in August 1986	<input type="text"/> <input type="text"/>
A man who says he doesn't know his age, but he was born in July 1948	<input type="text"/> <input type="text"/>
A child who was born in October 2000	<input type="text"/> <input type="text"/>
A man who was born in December 1977	<input type="text"/> <input type="text"/>

19. (10 marks)

For each person listed below, fill columns (16) and (17) for education: <u>LEVEL:</u> 1 = PRIMARY 2 = SECONDARY 3 = HIGHER 8 = DON'T KNOW <u>GRADE:</u> 00 = LESS THAN 1 YEAR COMPLETED 98 = DON'T KNOW	Has (NAME) ever attended school?		What is the highest level of school (NAME) has attended? What is the highest grade (NAME) completed at that level?	
	(16)		(17)	
	Y	N	LEVEL	GRADE
A woman who finished her third year in university.	1	2	<input type="text"/>	<input type="text"/> <input type="text"/>
A man who attended primary school, but never completed first grade.	1	2	<input type="text"/>	<input type="text"/> <input type="text"/>
A child who is currently in the third grade.	1	2	<input type="text"/>	<input type="text"/> <input type="text"/>

FEMALE FIELDWORKER TRAINING

Who should be listed on the Household Questionnaire: (ANSWER EACH ONE)	<u>YES</u> <u>NO</u>
a) The 14-year old niece of the head of the household who lives in the household during the week and returns to her village each weekend?	a) NIECE.....1 2
b) A cousin of the head of the household who came to visit yesterday, spent the night, but will return to his home this evening?	b) COUSIN.....1 2
c) The housemaid who comes to the house at 7 every morning and stays all day but does not sleep?	c) MAID.....1 2
d) The woman's husband who is the head of the household who works in town and comes home once a month and did not spend the previous night in the household.	d) HUSBAND1 2

20. Natoma has had three sets of twins in her lifetime.

- a) How many pregnancies has she had? (2 marks)
- b) If she tells you that in one set of twins, one was a stillbirth, how many children does she have alive? (2 marks)
- c) When you probe her further, she says that when she was six months pregnant, she lost twins. She had not told you this before. Now, how many pregnancies has she had in her lifetime? (2 marks)
- d) What is the total number of livebirths? (2 marks)
- e) What is the total number of stillbirths? (2 marks)
- f) What is the total number of pregnancy outcomes now? (2 marks)
- g) How will you record these pregnancy outcomes? (3 marks)

21. Select the correct answer (T/F)

- a) Fieldworkers must ensure that they settle disputes in villages where they work. T/F
- b) The best entry point in a village is the APRC chairman. T/F
- c) Community sensitisation means going out into the village community and talking to people individually. T/F
- d) *Alkalo* is the chief of the village. T/F

22. Define Stillbirth, Miscarriage, Live birth, Abortion (5 marks)

F) Photographs from the field courtesy of JN



Help from HDSS: One team of female fieldworkers and a male fieldworker, from the HDSS



Consent and Privacy: The team and a HDSS fieldworker ask for permission from woman to conduct the interview in a little store. (16.03.2016, Gambisara)



During the fieldwork around Basse temperatures of over 40 degrees are normal.



Completing information: The respondents offer seats and normally free water. Children are always interested in the work and watch. (16.03.2016, Gambisara)



JN with the Team in March Gambisara



Taking a break in the Bantaba: Gambisara



*Conducting the interview May 2016,
village between Basse and Fatoto*