Mixed-method research approaches within non-governmental programmes to improve maternal and child health in Zimbabwe

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Declaration of originality

I, Karen Myllynen Webb, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signed….[redacted]……… Date: December 15, 2023

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Abstract

Non-governmental organisations (NGOs) are key stakeholders in public health programmes in low resource settings. Despite known evidence-based interventions for improving maternal and child health (MNCH) and HIV outcomes, there remains an inequitable distribution of preventable and treatable maternal and infant morbidity and mortality within and between countries and regions globally. Through a scoping review and two published case studies, the aim of this research paper style thesis was to explore and critically reflect on how the use of theories, models and frameworks (TMFs) and mixed-method research approaches within NGO-implemented programmes can yield improved estimates of service uptake, clinical outcomes, and understanding of reasons for and consequences of failure to uptake evidence-based prevention of mother to child transmission (PMTCT) of HIV and MNCH services in Zimbabwe. Scoping review findings demonstrate that NGOs are central actors in the HIV response as catalysts of change through advocacy and activism, direct service delivery providers and technical partners in low resource settings. Limited evidence of application of scientific methods by NGOs through transdisciplinary research collaborations indicate missed opportunities for strengthening evidence-based practice in context. In the first case study, an observational, multisite, cohort study used sampling-based methods to actively trace a random sample of 371 HIV positive mothers in Mashonaland East Province Zimbabwe with no documented uptake of recommended Early Infant Diagnosis (EID) HIV testing for their HIV-exposed infants. Corrected estimates of EID uptake following tracing almost doubled, from 31.2% of infants with documented EID in routine records to a cumulative incidence of EID with death as a competing risk of 60.0% (95% CI: 58.7% to 61.3%) after contact tracing. Findings highlight significant underreporting of both infant HIV testing and mortality in routine data sources. The second case study explored the lived experience of ‘non-adherers’ to recommended HIV/MNCH services. A qualitative study among women with a recent non-institutional birth was conducted with 71 women (30 in-depth interviews; 41 in focus group discussions) who had delivered at home in the previous 6 months in Mashonaland Central Province, Zimbabwe. Narratives of women’s birth and postpartum experiences following a home delivery highlighted a coalescing of structural inequality and vulnerability at the time of delivery which prevented access to institutional delivery. Social norms for ‘facility delivery for all’ produced through health promotion initiatives to increase skilled attendance at birth, created unintended social consequences (shaming, blaming) and punishments (fines, reduced quality of healthcare) for home delivery which introduced additional risk to women at the time of delivery and in the postnatal period. Women’s narratives underscore the importance of understanding social norms, contextual vulnerabilities and potential unintended consequences of health policy translation on the most vulnerable who are unable to comply to recommended public health practice. Embedding mixed-method research within routine NGO programmes in this thesis yielded improved estimates of service uptake and outcomes; provided additional insights into the reasons for suboptimal uptake of PMTCT/MNCH services among rural women in Zimbabwe; and, led to the expansion of existing TMFs. The scoping review and case study findings provided critical insights to inform adaptation of NGO programme strategies that have improved programme performance and been adopted into national policy and programmes at scale in Zimbabwe. Transdisciplinary programme science embedded within NGO

programmes has the potential to optimise coverage and effectiveness of evidence-based interventions that are equitable and contextually relevant.

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Acronyms

ACT	Advocacy Core Team
ART	Antiretroviral therapy
BEmONC	Basic Emergency Obstetric and Newborn Care
CeSHHAR	Centre for Sexual Health and HIV AIDS Research Zimbabwe
CWH	Children with HIV
DFAT	Australian Department of Foreign Affairs and Trade
DHIS	District Health Information System
EBI	Evidence-based Intervention
EID	Early Infant Diagnosis
FACE-HIV	Families and Communities for the Elimination of HIV
FBD	Facility-Based Delivery
GHI	Global Health Initiative
GFTAM	The Global Fund to Fight AIDS, Tuberculosis and Malaria
HIS	Health Information System
HIV	Human Immunodeficiency Virus
IFRC	International Federation of Red Cross Societies
i-PARIHS	Integrated-Promoting Action on Research Implementation in Health Services
IS	Implementation Science
JAIDS	Journal of Acquired Immune Deficiency Syndromes
LMIC	Low- and Middle-Income Country
LSHTM	London School of Hygiene and Tropical Medicine
LTFU	Loss-to-follow-up
MDGs	Millenium Development Goals
MER	Monitoring, Evaluation and Reporting
MMR	Maternal Mortality Ratio
MNCH	Maternal Newborn and Child Health
MOHCC	Ministry of Health and Child Care (Zimbabwe)
MRF	Monthly Return Form
NAT	Nucleic Acid Test
NGO	Non-governmental Organisation

OPHID	Organisation for Public Health Interventions and Development
PCR	Polymerase Chain Reaction
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PLHIV	People Living with HIV
PMTCT	Prevention of Mother-to-Child Transmission
POC	Point-of-care
SDGs	Sustainable Development Goals
SMS	Short Message/Messaging Service
SSA	Sub-Saharan Africa
STI	Sexually Transmitted Infection
TASQC	Target Accelerate and Sustain Quality Care for HIV Epidemic Control
TMF	Theories Models and Frameworks
UCSF	University of California San Francisco
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
VHW	Village Health Worker
WHO	World Health Organisation
ZNNP+	Zimbabwe National Network of People Living with HIV

Definitions

Many of the concepts and terms used throughout this thesis do not have agreed upon, standardised definitions. To aid in interpretation of the works in this thesis, the following operational definitions have been used:

Embedded Research – research conducted by those who work inside host organisations as members of staff, while also maintaining an affiliation with an academic institution.[1] In the context of this thesis, embedded research refers to NGO implementers working together with researchers and health systems stakeholders to undertake scientific research embedded within ongoing public health programmes. This research is conducted in order to generate evidence to inform practices to address the most pressing challenges to public health programme performance.

Implementation Science (IS) - the scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices into routine practice, and, hence, to improve the quality and effectiveness of health services and care. IS is the scientific investigation of factors associated with effective implementation, where the roles of context, actors, ideas, institutions and power are central to analysis.[2]

Improvement Science - improvement science focuses on iteratively measuring and improving the efficiency, quality, safety, effectiveness, timeliness and patient-centeredness of health care processes and systems.[3] The areas of focus of improvement science are intended to evaluate standards of care and are closely aligned to service outcomes within implementation science.[3] While the dimensions of improvement science were not specifically measured as part of this thesis, they form an important part of facilitation activities of NGO programmes. Such factors influence engagement in health care studied within the case studies in this thesis through the lens of the grounding conceptual framework – Health Equity Implementation Framework.[4]

Non-governmental Organisation (NGO) – self-governing, private, not-for-profit organisations that are geared to improving the quality of life for disadvantaged people.[5] NGOs represent a wide range of organisations involved in development and public health action.[6] In the context of this thesis, NGOs refer to non-state actors supporting governments to implement public health programmes to increase access to and quality of health services.

NGO Programme - portfolio comprised of multiple projects that are managed and coordinated as one unit for planning, delivering, assessing, and adapting development programming in a given region or country.[7] In this thesis, NGO programmes refer the provision of technical, financial and material support towards the management, coordination and provision of comprehensive HIV and MNCH clinical care services. This support includes community-based projects to increase demand and improve equitable access to health services.

Programme Science – the systematic application of theoretical and empirical knowledge to optimise the scale, quality and impact of public health programmes.[8] Programme science employs the systematic combination of the programme cycle with a research strategy, by embedding research within programmes and having programmes set and drive the research agenda.[9] The work in this thesis represents an example of programme science within an NGO programme, whereby implementation gaps and research priorities have been derived from routine programme data, with scientific methods employed to prioritise research questions informed by TMFs.

Routine Data - Routine data are collected and reported at regular intervals to monitor programme performance for purposes other than research or without specific a priori research questions developed before collection.[10] In the context of this thesis, routine data refers to data routinely collected and analysed by NGOs to monitor programme performance through various sources including clinic registers, health information systems, bespoke programme activity monitoring indicators (i.e., data collected by community health workers or NGO programme officers) as well as routinely reported data to programme funders such as U.S. President's Emergency Plan for AIDS Relief (PEPFAR) Monitoring, Evaluation and Reporting (MER) indicators.

Theories, Models and Frameworks (TMFs) – this thesis employs Nilsen's[11] conceptualisation of TMFs within implementation science, whereby:

Theory: implies some kind of predictive capacity and attempts to explain the causal mechanisms of implementation.

Models: describe and/or guide the process of translating research into practice rather than to predict or analyse what factors influence implementation outcomes.

Frameworks: have a descriptive purpose by pointing to factors believed or found to influence implementation outcomes.

Transdisciplinary Research – problem-focused, participatory and contextualized research characterized by an interpenetration of disciplinary epistemologies, viewed as necessary for generating evidence required to solve complex social problems such as inequitable access to EBIs.[12] A specific feature of transdisciplinarity is developing new TMFs across disciplines. Specifically, reference to transdisciplinary research within this thesis refers to the collaboration between NGOs, health systems stakeholders and scientists to prioritise, design, analyse and disseminate public health research, whereby NGOs both increase use of TMFs in their evaluation strategies, but also contribute to the expansion or development of TMFs.

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SECTION I: INTRODUCTION

1. Introduction

1.1 Background

Despite known evidence-based interventions (EBIs) and existence of global and national public health policy frameworks and global health and development initiatives such as the Sustainable Development Goals (SDGs), there remains an inequitable distribution of preventable and treatable morbidity and mortality within and between countries and regions globally.[1] Such disparities are increasingly recognised as attributable to social determinants of health, driven by harmful gender norms, and inequities in power, money and resources.[2-4] The disproportionate burden of HIV and poor maternal, newborn and child health (MNCH) outcomes in sub-Saharan Africa (SSA) are poignant examples of such inequities.

A child born in SSA is 10 times more likely to die in the first month than a child born in a high-income country.[5] SSA also has the highest maternal mortality ratio globally[6] and is home to 55% of all people—and two thirds of all children living with HIV.[7] Women are disproportionately affected by HIV in SSA, which has lead to a concomitant epidemic of vertical transmission[8] and excess maternal and infant deaths in many high prevalence countries,[9] including Zimbabwe.[10,11] Developing contextually relevant implementation strategies to overcome barriers and increase the speed, fidelity, efficiency, and equitable coverage of evidence-based maternal and child health interventions (EBIs)[12] are public health research and programmatic priorities.[13]

Non-governmental organisations (NGOs) are recognised non-state actors supporting governments to implement public health programmes.[14] Public health programmes implemented by NGOs most frequently focus on the primary drivers of morbidity and mortality in a given population, with a particular focus on improving equity of access to evidence-based health interventions.[10] NGOs are recognised to play diverse roles in public health including advocacy, mobilization, consensus building, provision of medical services, standard setting, self-regulation and fostering social partnerships to improve equity and quality of universal health coverage[15]

Although they are critical implementers of public health interventions in low and middle-income countries (LMICs), as with many public health interventions, NGO programmes are often 'packaged', with poorly defined implementation strategies.[16,17] Due to limited human and financial resources, outcomes measured in NGO programmes typically comprise of aggregate observational data on service outcomes against donor-driven programmatic targets, as opposed to measurement of implementation outcomes or population-level impact. For example, number of institutional deliveries/number of women registered for antenatal care (ANC) at a health facility for which the denominator represents those in care and is not a reflection of the population. Accordingly, NGO programme data frequently lack evidence on individual-level or conceptually distinct implementation outcomes as proximal indicators of intervention success.[18] While NGOs as public health programme implementers are uniquely placed to contribute to developing and testing strategies to improve implementation processes, and measure client and service outcomes, poor coordination in evidence generation and programming results in missed opportunities for optimising evidence-based public health practice.[19,20]

Programme, improvement and implementation science (IS) utilise a range of TMFs to ask and answer questions about how to improve the delivery of EBIs and what works in populations who need it.[21-23] Where IS focuses on "getting research into policy", programme science focuses on "getting research out of practice".[22] The use of TMFs has the potential to improve the fidelity, effectiveness and equity of impacts of routine programmes.[24] However, such conceptual frameworks and methods are rarely used by NGOs within routine health programmes to strengthen evidence-based practice. This is primarily due to lack of capacity and too little emphasis on the "pull" for IS or practice-based research through training of practitioners/implementers.[25,26] As noted by Brownson and colleagues, "too often capacity-building efforts have been built around pushing out research-based evidence without accounting for the pull of practitioners, policy makers, or community members, or accounting for key contextual variables (e.g., resources, needs, culture, capacity)".[26]

Strengthening the integration of pragmatic programme improvement and IS approaches within routine NGO programmes has the potential to improve the effectiveness and equity of evidence-based interventions and attainment of health policy objectives.[27-28] Further, gaining a better understanding of the emerging and evolving roles of NGOs within local, regional and global health initiatives; and, optimising the potential contributions of NGO programmes to both consume and produce evidence are vital for improving global public health.[29,30]

Successful and sustainable models for collaboration between programme and implementation scientists and frontline programme implementers are required to close the gap between evidence and practice.[31] Transdisciplinary research, "problem-focused, participatory and contextualized research characterized by an interpenetration of disciplinary epistemologies" is viewed as necessary for generating evidence required to solve complex social problems such as inequitable access to EBIs.[32]

Persistent disparities in access to EBIs leads to inequitable distribution of preventable and treatable morbidity and mortality among women and children in SSA. NGOs are key stakeholders in public health programmes in low resource settings, although their role in public health practice is not clearly defined. There is limited use of TMFs in routine public health programmes or transdisciplinary collaboration between implementers and scientists. This separation between routine programmes and science results in missed opportunities for generating evidence to enhance equity and quality of programmes that are implemented by NGOs.

1.2 Research aims and objectives

Through a scoping review and two published case studies, this research paper style thesis aimed to explore and critically reflect on how the use of TMFs and mixed-method transdisciplinary research approaches within NGO-implemented programmes can yield improved estimates of service uptake, clinical outcomes, and understanding of reasons for and consequences of failure to uptake evidence-based PMTCT and MNCH interventions.

Through a transdisciplinary collaboration between a local Zimbabwean NGO, health system stakeholders and researchers, this aim will be achieved through 3 key objectives to:

1. Describe available evidence on the role of the NGO sector in the HIV response through a scoping review.
2. Use sampling-based methods to improve estimates of cumulative incidence of timely early infant diagnosis (EID) and mortality among a clinic population of HIV-infected/HIV-exposed mother-baby pairs lost to follow up (LTFU) from routine care, and theoretically informed qualitative methods to explore reasons for no EID.
3. Explore and describe the reasons for and experiences of non-institutional birth among rural women who deliver at home.

As with many NGO-delivered public health programmes, the objective of the NGO programme through which this applied research was embedded was to reduce health disparities by facilitating equitable access to services and enhance the quality of care received through iterative improvement practices.[33] Developed for healthcare and practice settings to explore determinants believed to predict successful and equitable implementation, the Health Equity Implementation Framework[34] is employed as the grounding conceptual framework for synthesis of research conducted in this thesis. This determinant framework is well suited for research aiming to explore the role of NGO implementers and factors influencing uptake of essential PMTCT/MNCH services for two key reasons.

First, the Health Equity Implementation Framework provides a conceptual scaffolding which explicitly recognises the role of 'facilitation' (such as NGO-implemented programmes) in successful implementation and improving equitable access to EBIs in context.[34] Second, the Health Equity Implementation Framework recognises the dynamic interaction between recipients, intervention characteristics, contextual and societal influences for understanding how best to modify implementation frameworks to better address health equity determinants.[35] Supporting theory and frameworks are employed in each case study to further understand the influence of socioecological factors[35] and social norms[36] influencing engagement in integrated PMTCT and MNCH care among rural women in Zimbabwe.

This programme science and IS-informed thesis is based on applied research embedded within the activities of the local NGO, Organisation for Public Health Interventions and Development (OPHID), that implements sub-national integrated HIV and MNCH programmes in Zimbabwe.

1.3 Rationale for the scoping review and case studies

In countries such as Zimbabwe, progress towards national PMTCT and MNCH programme performance is commonly measured by NGOs along aggregate cascades of care of evidence-based interventions. In the case of PMTCT and MNCH, this continuum of care ranges from pregnancy through to delivery and the postnatal period.[37] Facility-based delivery with a skilled birth attendant and access to basic emergency obstetric and neonatal care (BEmONC) form part of the core package of MNCH services recommended by the World Health Organization (WHO)[38] and have been adopted within national reproductive health strategies to reduce preventable maternal and newborn deaths, including in Zimbabwe.[39-41] Similarly, since 2010 the WHO's infant HIV testing algorithm recommended HIV testing with Nucleic Acid Tests (NATs) for all HIV-exposed infants at four to six weeks postnatally as standard of care in high HIV prevalence settings.[42-44]

Zimbabwe adopted the same infant testing algorithm,[45] aligning the maternal and infant HIV (re)testing algorithms with other reproductive, maternal, newborn and child health service uptake schedules such as immunizations and growth monitoring.[46] Despite efforts to decentralise access to MNCH and PMTCT services within walking distance of all women in Zimbabwe,[47-49] existing programme and survey data identified low uptake of facility-based delivery[50-53] and low coverage of early infant diagnosis among HIV-exposed infants[54,55] as key areas compromising PMTCT and MNCH programme cascade performance in select OPHID geographies.

Within this context, this PhD research sought to critically reflect on the role of the NGO sector within global public health and explore how the integration of transdisciplinary research collaboration and use of IS TMFs within NGO programme evaluations can improve evidence on the rates and reasons for suboptimal uptake of essential PMTCT/MNCH health services in a high HIV prevalence setting. This is presented as a scoping review examining available evidence the role of NGOs within the HIV response and two case studies of mixed-method research within an ongoing NGO programme to improve estimates of service uptake and mortality, and understanding of reasons for disengagement from care among rural women in Zimbabwe.

1.4 PhD research context

This research was embedded within the local NGO, OPHID's, Families and Communities for Elimination of Pediatric HIV (FACE HIV; 2012-2020) and follow-on Target, Accelerate and Sustain Quality Care for HIV epidemic Control (TASQC; 2020-2025), and Australian NGO Cooperation Program (ANCP) MNCH Access and Quality Improvement (2012-2015; 2016-2018) programmes in Zimbabwe. These programmes, operating at a sub-national level, aimed to contribute to the achievement and sustainability of HIV epidemic control in Zimbabwe through the provision of technical, financial and material support towards the management, coordination and provision of comprehensive clinical care services within the Zimbabwe national HIV programme, including integrated MNCH health services.

OPHID collects age and sex-disaggregated aggregate data at facility, district, provincial and national level at over 315 public health facilities in line with the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) Monitoring, Evaluation, and Reporting (MER) Indicators[56] as well as MNCH indicators on health service uptake collected on Zimbabwean Ministry of Health and Child Care (MOHCC) Monthly Reporting Forms (MRFs) for data verification and supporting MOHCC to monitor programme progress.[57,58] Data are analysed on a monthly basis along aggregate care cascades, with gaps in performance (primarily calculated as the proportion of eligible individuals in a clinic population (i.e., pregnant women registered in ANC) that uptake essential MNCH services (i.e., facility-based delivery; EID)) triggering targeted programme remediation. There are noted limitations in routine data sources including lack of individual-level data and final clinical outcomes across the

PMTCT/MNCH cascade (i.e., proportion of HIV-exposed infant HIV negative at cessation of breastfeeding/exposure).[59-61]

Programme 'packages' include both community- (health promotion, facilitation of birth planning, male partner and traditional leadership engagement) and facility-based strategies (training in BEmONC, standards of care, algorithms and standard operating procedures (SOPs) for HIV testing and treatment). Quality improvement practices include clinical mentorship on new MNCH/HIV guidelines to strengthen evidence-based practice during the clinical encounter, and standardised documentation and reporting and data use at primary, secondary and tertiary healthcare facilities.

Improving quality of implementation evidence and strengthening the effective translation of EBIs into equitable public health practice requires an increased emphasis on practice-based evidence, and a greater focus on external validity which recognises the importance of context.[62] OPHID had not previously integrated programme science approaches or use of TMFs to explore true rates of service uptake, service outcomes, as well as context-based evidence on the barriers and facilitators for maternal health service uptake. With a focus on health disparities, the applied research in this thesis sought to embed mixed-method, theoretically informed research within OPHID's existing programmes. Each case study sought to better understand the barriers and facilitators to PMTCT/MNCH service uptake from the 'non-user perspective' (i.e., those women identified has having failed to access recommended services) as to better understand their lived realities. Embedded within an existing NGO programme, the research also sought to pragmatically inform the strengthening of improvement practices in context by understanding true service uptake, and why these women and children have been left behind.

1.5 Thesis outline

This thesis follows the "research paper style" in accordance with the London School of Hygiene and Tropical Medicine (LSHTM) guidelines. The thesis is made up of one unpublished scoping review and two manuscripts that have been published and one that has been prepared for publication. The outline of the chapters is as follows:

SECTION I INTRODUCTION

Chapter 1 (this chapter) contains an overview of the research background, gaps in knowledge, study rationale, the research aim and objectives and the outline of the thesis.

Chapter 2 provides a review of the literature on the role of NGOs in the global public health response, MNCH and HIV, the epidemiology of HIV, the evolution of MNCH PMTCT programming and the barriers to facility-based delivery and early infant diagnosis HIV testing in Zimbabwe. Key issues related to the measurement of peripartum and PMTCT outcomes in NGO programmes, including strengths and limitations of available data sources are reviewed. The intersection between programme, improvement and implementation science within NGO programmes along the evidence translation pathway is discussed. Conceptual definitions in programme, implementation, improvement and translation science and the role of TMFs for improving evidence-based practice are overviewed. The grounding conceptual framework for this thesis, the Health Equity Implementation Framework is described and framed within the context of the problem of suboptimal uptake of EBIs along the PMTCT/MNCH cascade within NGO-implemented programmes.

Chapter 3 (thesis Objective 1) is an unpublished manuscript for Current HIV/AIDS reports. This scoping review explores recent evidence on the role of the non-governmental sector in the HIV response and implications for transdisciplinary programme and implementation science.

SECTION II IMPROVING ESTIMATES & UNDERSTANDING OF TRUE UPTAKE, OUTCOMES & REASONS FOR FAILURE TO UPTAKE FBD AND EID IN ROUTINE PROGRAMMES

Chapter 4 (thesis Objective 2) is the full paper of a published brief report entitled "*Improving Early Infant Diagnosis Observations: Estimates of Timely HIV Testing and Mortality Among HIV-Exposed Infants*".[63] This report was published in the Journal of Acquired Immune Deficiency Syndromes (JAIDS) and assesses the impact of employing sampling-based methods and active tracing of HIV positive mother-HIV-exposed infant pairs with no documented uptake of EID upon corrected estimates of EID incidence and infant mortality, as well as caregiver reasons for no EID.

Citation (Research Paper 1): **Webb, K.,** Chitiyo, V., Mahachi, N., Huruva Mukungunugwa, S., Mushavi, A., Zizhou, S., Engelsmann, B., Abbas Ferrand, R., Neuman, M., Hartogensis, W., Geng, E.. Brief Report: Improving Early Infant Diagnosis Observations: Estimates of Timely HIV Testing and Mortality Among HIV-Exposed Infants. J Acquir Immune Defic Syndr. 2020;83(3):235-9. doi: 10.1097/QAI.0000000000002263

Chapter 5 (thesis Objective 3) is a published qualitative study that explores the reasons for and experiences of home delivery among women living in rural Zimbabwe. The paper is titled "*'I was trying to get there, but I couldn't': social norms, vulnerability and lived experiences of home* *delivery in Mashonaland Central Province,* Zimbabwe" and was published in Health Policy and Planning.[64]

Citation (Research Paper 2): **Webb, K. A.,** Mavhu, W., Langhaug, L., Chitiyo, V., Matyanga, P., Charashika, P., Patel, D., Prost, A., Ferrand, R. A., Bernays, S., Cislaghi, B., Neuman, M.'I was trying to get there, but I couldn't': social norms, vulnerability and lived experiences of home delivery in Mashonaland Central Province, Zimbabwe. Health policy and planning. 2021. Doi: 10.1093/heapol/czab058

SECTION III DISCUSSION & RECOMMENDATIONS TO IMPROVE DATA, IMPLEMENTATION & OUTCOMES OF EVIDENCE-BASED INTERVENTIONS

Chapter 6 is a discussion of each of the study findings, strengths and limitations of the research, and the implications of this research in the context of MNCH and HIV programmes in Zimbabwe. Evidence from the scoping review and two case studies in this thesis is synthesised within the Health Equity Implementation Framework as to contextualise and reflect on the role of NGOs as facilitators of EBIs, and factors influencing engagement with PMTCT/MNCH services in rural Zimbabwe.

Chapter 7 is a synthesis and critical reflection on the experience of conducting embedded research within an ongoing NGO programme and implications of research findings upon the feasibility and sustainability of transdisciplinary IS collaboration in NGO programmes. Remaining evidence gaps are explored and recommendations to support NGOs to use IS TMFs and engage in transdisciplinary research partnerships for the improved adaptation of evidence-based practice in context and enhance equity and outcomes of routine public health programmes provided. Additional examples of implementation research embedded within OPHID's routine programmes, informed by this PhD research, are provided.

Chapter 8 is the overall summary of thesis findings and conclusion and recommendations for future research on the integration of TMFs and mixed-methods programme science within NGO MNCH and HIV programmes.

1.6 Contribution of the author

NGO sector in HIV response scoping review: I conceived the review and was responsible for the development of the review methods and search strategies. I created the analysis framework and conducted searches, article review, charting and analysis and wrote the manuscript draft.

Loss-to-follow-up (LTFU) for EID Study: I was responsible for the development of the study protocol under the supervision of Professor Geng. I designed the study methods, outcomes, data collection tools, topic guides and standard operating procedures. I applied for all the ethical approvals for the study in Zimbabwe.

I developed the protocol training curriculum for Village Health Workers (VHWs). I participated in VHW protocol training. I trained and supervised all OPHID research assistants that supervised data collection by VHWs, who conducted community tracing and enrolled participants into the study and collected both the quantitative and qualitative data. Research assistants were working within OPHID's Operations Research (OR) Department and not involved in OPHID programme implementation at study sites. I conducted daily field debriefs with field research assistants during training and data collection. The study database was managed by myself and Vivian Chitiyo (OPHID Zimbabwe) and Wendy Hartogensis (University of California San

Francisco (UCSF) who also did the data cleaning. Together with Prof Geng and Dr Hartogensis, I prepared the quantitative analytical plans and data analysis and performed the qualitative analysis. I led the write up of all publications with support from Dr Neuman and Prof Ferrand, my academic supervisors at LSHTM, together with my UCSF and Zimbabwean collaborators at OPHID and MOHCC.

Home Delivery Study: I was responsible for the development of the study protocol. I designed the study methods, data collection tools, topic guides and standard operating procedures. I applied for all the ethical approvals for the study in Zimbabwe. I trained and supervised the two Shona-speaking female research assistants that enrolled participants into the study and collected qualitative data. Research assistants were members of OPHID's OR Department and not involved in OPHID programme implementation in study areas. I led daily and weekly debriefs with research assistants during data collection. I developed transcription and translation guides and managed the transcription and translation of manuscripts that were checked by Vivian Chitiyo and Priscilla Matyanga for completeness. Qualitative analysis plans, coding frameworks, and analysis of key themes were supported by Drs Mavhu and Langhaug under the supervision of Dr Neuman.

I wrote the complete drafts of all research papers included in this thesis under the supervision of Dr Neuman and Prof Ferrand and was responsible for submission to the journals and responding to the reviewer comments.

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2. Literature review

2.1 NGOs in global public health

2.1.1 Definition of NGOs

Non-governmental organisations (NGOs) can be defined as "self-governing, private, not-for-profit organizations that are geared to improving the quality of life for disadvantaged people".[1] While the presence of NGOs has become ubiquitous within global public health, humanitarian and development responses,[2] it is a poorly defined and incredibly diverse sector.[1] NGOs are composed of charitable, religious and volunteer associations, and other community-oriented organisations, that mobilise resources for and act to address a wide range of public health issues. These issues include but are not limited to health promotion and disease prevention, food security and nutrition, protection of social structures, improvement of the environment, and advocacy for positive social change and policies.[3] While there is a recent evolution of the traditional NGO structure through multisectoral strategies and partnerships such as social enterprises, which seek to achieve sustainable social impact through for-profit commercial activities,[4,5] for the purposes of this PhD thesis, the term NGO will refer to not-for-profit organisations.

Even through a non-profit lens, the collection of organisations, networks and alliances in the non-governmental sector engaged in global public health is highly heterogeneous,[6] and they go by many other names than NGO.[7] Depending on their funding sources, orientation and affiliation, NGOs can self-identify within various subcategories such as private voluntary organisations, faith-based organisations, community-based health organisations, AIDS service organisations and civil society organisations, among others.[7] Relatedly, NGOs may also range in size from individual community-based organisations led by volunteers and activists, to local NGOs operating within national contexts, to complex international organisations with a global footprint.[8]

Acknowledging the diversity of size, geographic scope, areas of implementation and organisational structure among NGOs, this PhD purposefully uses the term NGO as an umbrella term for the range of not-for-profit organisations working within the field of global public health.

2.1.2 NGOs' role in global public health programmes

The role of NGOs in global public health has evolved and been shaped by prevailing sociopolitical events and global public health threats, as well as the micro and macro politics of health and the institutions holding power within them. The historical antecedents of the imperial system of colonisation, tropical medicine, industrialisation, the age of post-war development, globalisation, emergent pandemics, and the rise of NGOs within global public health overlap and converge.[9]

While the growth of the NGO sector within public health is generally poorly documented, the earliest involvement of NGOs within the health sector, occurring as early as the 19th century in some developing countries, was via Christian missionary organisations based within European colonies.[10] Such mission-based health care most frequently involved infrastructural development of health facilities and training of local staff as part of mission activities,[10] and caring for illnesses, debilities and other iatrogenic health consequences,[11] many of which were indirectly or directly attributable to the structural violence of colonialism.[12,13]

With the rise of urbanisation and conditions of structural inequity, coupled with overpopulation in the early 1900s, local and national NGOs were created in many Western nations to increase awareness of and public health responses to outbreaks of transmissible diseases including tuberculosis, poliomyelitis and cholera.[14] Following the First and Second World Wars, NGOs such as the International Federation of the Red Cross Societies (IFRC) began to play an increasing role within humanitarian emergency contexts to support the health and development needs of those injured or displaced through war.[15,16] Given this increasing role in supporting health, development and peace building, the term non-governmental organisation was first officially used in Article 71 of the Charter and Statute of the International Court of Justice of the newly formed United Nations in 1945 as a means of establishing lines of communication with organisations that are not part of governments.[17]

The number of international NGOs expanded in the 1970s and 1980s as war-time NGOs such as the IFRC transitioned into public health, welfare and disaster management, and new international NGOs such as Médecins Sans Frontières began providing public health responses in regions experiencing humanitarian emergencies such as famine, natural disasters and conflict.[14]

With the rise of global health initiatives (GHIs) in the early 2000s to achieve universal health coverage and reduce infectious, child and maternal mortality rates, it was recognised that policy goals could not be achieved through ministries of health alone in low- and middle-income countries (LMICs).[18,19] NGOs became increasingly recognised as critical 'third sector' actors for localising GHIs and implementing programmes to achieve policy targets in resource-limited settings.[20] GHIs including the President's Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund to Fight AIDS, TB and Malaria (GFATM) and the health goals of the Millennium Development Goals and subsequently the Sustainable Development Goals in the 2000s have resulted in an 'NGO boom' in many low-resource settings over the past two decades,[20-22] as NGOs have become some of the primary recipients of global health funding.[23] With a lack of uniform taxonomies to categorise the number and activities of NGOs in the health sector, estimates of the number of organisations receiving health and development funding currently range between 1 million and 10.3 million NGOs worldwide.[24]

Through endorsement of the 1978 Declaration of Alma-Ata, and the subsequent 2018 Declaration of Asanta, WHO member states prioritised the strengthening of primary health systems as an essential step to achieving universal health coverage, and the achievement of GHI goals.[25] Recent calls for increased use of human-centred designs to improve equity of health programmes and narrow the 'know–do' gap between efficacious interventions and impact at scale promote further decentralisation of public health programme delivery into communities.[26,27] Given the disproportionate burden of disease and poor health outcomes in SSA, coupled with constrained human resources for health and limited domestic financing,[28,29] the majority of GHI funding has been channelled to priority countries in SSA,[30] where a large proportion of it is now spent by NGOs.[23,31] In SSA, the greatest proportion of this assistance, by health focus area, is provided for HIV/AIDS and MNCH,[32] because SAA is the epicentre of the HIV pandemic and the region with the worst maternal and child health outcomes globally.

While NGO contributions have been credited with accelerating progress onGHIs,[7] the proliferation of global health actors, coupled with problems of global leadership, divergent donor interests and problems of power relations and accountability, has also led to fragmentation in global health efforts, which may undermine the effectiveness of local health programmes.[33]

2.1.3 NGO health programmes

The linkage between GHIs and the growth of the NGO sector in global health has translated to a focus on reaching vulnerable and hard-to-reach populations to achieve universal health care coverage as a defining feature of NGO programmes within global public health.[34] Most frequently operating in countries with constrained health systems and high disease burden, NGOs are recognised non-state actors supporting governments to implement public health programmes to improve access to and uptake of essential health services and continuity of integrated community- and facility-based health services in most LMICs.[35]

The broad nature of organisations that fall under the umbrella of NGOs, which include interest groups, professions, a large set of very diverse community-based organisations (faith, identity, locality, social and health-condition), and local and international NGOs, is equally reflected in the diversity in size, coverage and content of NGO-implemented programmes.[7,36] In their framework of health activities among different types of civil society organisations, Greer and colleagues outline policymaking (including evidence generation, policy development, advocacy, mobilisation, consensus building and watchdog/accountability), service delivery (to members and to the public) and governance (standard setting, self-regulation and social partnerships) as core activities of NGOs in health.[36] The specific activities of NGO-delivered programmes depend not only on the size and composition of the organisation but also on the donor priorities and contextual drivers of poor health within the populations being served.[37,38]

Related to their role in promoting equitable health access, a critical function of NGOs within global health programmes, particularly within LMICs, is their decentralised community-based activities providing health information, direct service delivery, and strengthening community- and health-facility linkages.[35,39] As trusted non-state actors, often represented by members of affected populations, NGOs drive advocacy, mobilisation, consensus building, promotion of standard setting, self-regulation and fostering of social partnerships in global public health that is well recognised.[40]

Based on their established role implementing programmes at all levels of global health and development initiatives, NGOs also play important roles in providing technical assistance and advising national governments, international donors and public health agencies on policy and programme processes, particularly in LMICs.[41] Evidence of NGO engagement in global accountability mechanisms includes the establishment of the NGO Major Group, a global network of NGOs that consolidates expertise to identify barriers to achievement of the SDGs to feed into the direct and indirect processes of the High-Level Political Forum.[42] NGOs and civil society actors also play important roles in the global and national multi-constituency consultations around disease-specific areas such as the Partnership for MNCH (PMNCH) alliance,[43] as well as participating in global and national HIV planning processes with PEPFAR,[44] GFATM[45] and the UNAIDS Programme Coordinating Board.[46]

While the contribution of NGOs to the discipline of global health and to improvements in health equity worldwide is well acknowledged, the lack of a standardised classification system and challenges with coordination of NGO activities by local authorities and between NGOs operating at local and national levels have been noted as leading to delayed responses, inefficiencies and poorly coordinated public health responses, particularly in emergency settings.[47] Given the growing heterogeneity of multilateral, bilateral and NGO donors operating in many LMIC settings, there are concerns that the aims of health care reform to improve the efficiency, effectiveness and equity of global health will not be met if coordination of external efforts is not improved.[48]

2.1.4 NGO programme evidence

2.1.4.1 Routine data and improvement practice

NGOs working in public health routinely collect and generate vast amounts of potentially rich data, most of which are not used or reported for research purposes.[24] These data often mirror the routine indicators within host ministry of health information systems (HIS).[49] Dependent on the aims and scale of the programme implemented, data may be collected at community, health facility, District, Provincial and national-levels at regular intervals. NGO data are frequently input into large donor-managed electronic systems and have given rise to the use of care cascades for tracking of progress towards policy objectives.

First used to evaluate HIV care,[50-52] care cascades provide a model for evaluating patient retention across sequential stages of evidence-based care required to achieve a desired health outcome. Care cascades are composed of aggregate, cross-sectional, observational data from routine data sources, trace a population eligible for a service or intervention (denominator) through a series of 'steps' and progress towards GHIs such as the UNAIDS '90-90-90': 90% of all people living with HIV (PLHIV) know their HIV status; 90% of those diagnosed are initiated on antiretroviral therapy (ART); 90% of those are virally suppressed.[53]

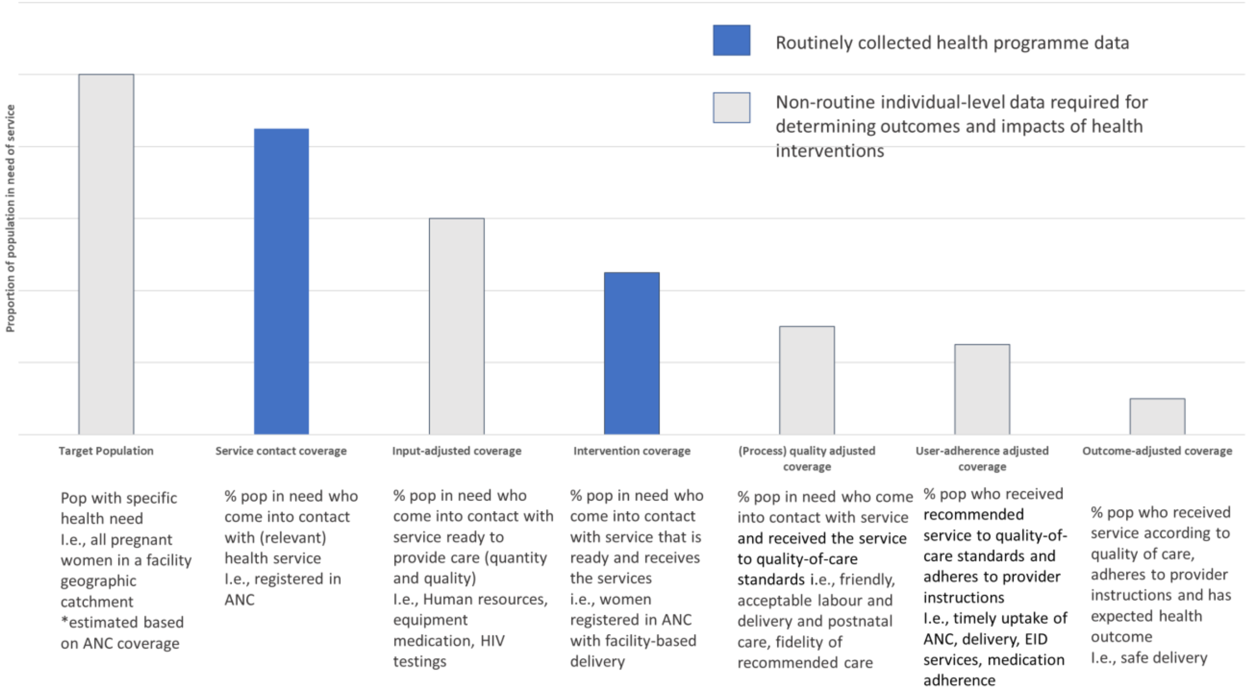
Care cascades are intended to act as a quantitative tool to both measure coverage of health interventions, as well as monitor performance and trigger targeted programme remediation and quality improvement where there are 'leakages' between steps which indicate loss-to-follow-up.[53,54] Cascades have now become the primary tool for measuring progress towards multiple GHIs. Accordingly, NGO routine programme reporting, currently collects and tracks routinely reported aggregated data across a range of programmes in TB[55], viral hepatitis[56], MNCH[57] , non-communicable diseases,[58] to substance use disorders using the cascade approach.[59] Further, 'sub-cascades' are frequently used to monitor specific policy objectives among targeted sub-populations. For example, in the field of HIV, progress towards GHI towards MTCT[60] and end of paediatric AIDS, mean that countries and NGOs implementing partners routinely monitor PMTCT[61] and early infant diagnosis (EID) of HIV using cascades.[62]

The activities of NGOs in supporting public health programmes can therefore largely be characterised as improvement practice interventions to enhance quality of care within a specific setting (i.e., community- or facility-based MNCH services) to increase the likelihood of desired health outcomes. Cascade analysis using routine data is a systematic, cyclical approach for identifying performance gaps in the coverage or outcomes of EBIs within improvement practice. However, replicable, generalisable evidence in support of the effectiveness of improvement tools and methods is limited.[63]

2.1.4.2 Limitations of aggregate cascades

Routine data which form the basis of NGO reporting have noted limitations. Aggregate routine data are not population representative, cross-sectional in nature, and are collected at such a frequency and scale that routine programmes often lack the capacity and resources to comprehensively clean and check data.[64] Collected by non-research health facility or NGO staff and lay cadres, in the absence of unique identifiers or inter-facility linked electronic medical records, it is recognised that routine programme data may be incomplete and/or inaccurate.[65]

Aggregate data and limitations of routine data sources are problematic for reporting of individual-level clinical outcomes in health programmes, where rates require information from two or more time points for which the denominator (those at risk) and the numerator (those with the event) may be documented in multiple paper-based registers and/or at different facilities. [66] Individuals who are documented as lost to follow up from care at one facility, for example, may have re-engaged at another, stopped care, or have died. If not captured within routine data, lack of population representativeness and lack of quality and outcome data within these aggregate ‘coverage cascades’ may lead to bias of outcome and effect estimates of public health interventions and inappropriate programme responses.[67,68] Routine programme data collection frequently ends at intervention coverage, lacking evidence regarding quality or specificity to measure outcomes of intervention coverage (Figure 2.1).



Abbreviations: Pop: population; ANC: antenatal care; HIV: human immunodeficiency virus; BEmONC: Basic Emergency Obstetric and Newborn Care

Figure 2.1. Example of gaps in routine NGO programme data cascades for measuring quality, outcomes and impact. Adapted from Exley et al. and Marsh et al.[57,69]

2.1.4.3 Community needs and preferences

Translation of evidence-based interventions at the individual level to effectiveness and scale at the population level requires recognition of risk heterogeneity.[70] This is acknowledged as requiring work with target populations as essential for ensuring representation within public health intervention design for equitable and rights-based public health programming and commensurate gains in population health.[70-72]

Due to their often highly decentralised operational presence and relationships with health system stakeholders and as service providers, NGOs frequently engage with affected subpopulations such as pregnant and lactating women (PLW), PLHIV and community leaders and gatekeepers (such as male partners of PLW) in the adaptation of programme and policy guidelines and evidence-based interventions to context so that they are feasible, acceptable and culturally appropriate.[73,74] Given their often decentralised presence at community, district, provincial and national levels, NGOs have an opportunity to build bridges between grassroots organisations and local and national-level systems, structures and processes[75]

However, the limited use of established TMFs for specifying and reporting strategies or evaluating implementation processes, outcomes and impact of complex public health interventions and community based participatory research (CBPR) methodologies within routine NGO programmes is limited.[76,77] The qualitative evidence and implementation lessons produced through such efforts is frequently not reported, or perceived as anecdotal and of insufficient quality to inform national health policy or practice.[78] NGO programme evidence is perceived as a source of supporting evidence and not as primary source data, however it is recognised that NGO data has potential to facilitate research in under-researched marginalised groups and in contexts that are hard-to-reach by academics an operational presence or community ties, such as conflict-affected areas.[24]

2.1.4.4 NGO participation in evidence generation and translation

Given their ubiquitous role in global public health, NGOs are acknowledged as directly or indirectly contributing to all stages of the global health research cycle, fostering the relevance and effectiveness of the research, priority setting, and knowledge translation to action.[79] The ability of NGOs to pursue health research based on observations in routine programme data and service delivery depends on NGO capacity to use scientific TMFs; exert control over their research agendas; relationships with external actors and financial autonomy of NGOs to undertake the research activities.[80]

The expansion of the global health metrics enterprise and increased generation of 'big data' through NGO programme activities is credited for bringing greater efficiency, objectivity and accountability to the use of routine data in policy and programme decision-making. However, critics of global health metrics enterprises emphasise these systems are promoted and funded by among the richest and most powerful organisations in the global health field. Such universal public health indicator systems lead to the transfer of information from institutions in low-income countries to ones based in high-income countries, hampering the development of national health information systems, and privileging certain forms of knowledge over others.[81] Given their primary role in health advocacy, health promotion and routine programme implementation, NGOs have a particularly important role in evidence stewardship (promoting and advocating for relevant global health research), and health systems research on programme design and innovations.[79]

However, the core business of the vast majority of NGOs is in the 'doing' (programme implementation) and not in the 'knowing' (research and evidence generation). Accordingly, NGOs may lack the methodological expertise and infrastructural capacity to lead robust improvement and implementation science endeavours.[82] NGO-led research on their own programmes may also introduce potential selection, observational and response biases, where research participants are also beneficiaries of NGO programmes.[24,83]

Further, NGO funding is inherently tied to implementation timelines and programme deliverables. As such, NGOs must continually move forward to achieve programmatic coverage and quality, and will rarely have dedicated resources to invest in the intensive processes of rigorous research including the selection and application of appropriate research questions and TMFs[84], writing protocols, and data collection, entry, management and analysis, resulting in missed opportunities for evaluation.[85]

Thus, the heterogeneity which poses a challenge to the development of a unifying framework for the role of NGOs in global public health extends to the role and engagement of NGOs in evidence production, dissemination and translation. The health evidence-policy-implementation continuum has been noted to be fragmented due to practitioners operating across various paradigms, organisational structures and tiers, translating to evidence production that is not always aligned with priority knowledge gaps.[86] The fragmentation in health research as depicted by Nathan Caplan's theorised 'two communities': the research community (knowledge producers) and the policy/practice community (knowledge consumers), each with intrinsically different perspectives and priorities.[87] A juxtapose exists where institutionalised knowledge producers (scientists) may consider their research relevant for the policy and practice community but knowledge consumers (NGOs, local health systems) often question the utility and scalability of the resulting evidence within the constraints of real-world resource constrained policy and programme contexts.[88]

Collaborative research between programmers and researchers has the potential to play a critical role in improving health, equity and development in the context of growing health inequities.[85,89] Currently, the focus of many North-South collaborations to build health systems and services research (HSSR) and research on social determinants of health have focused on building the capacity of LMIC universities and research institutions as opposed to implementing organisations.[90-92] Where research collaborations exist, NGO involvement in research is typically downstream from knowledge production. There is a recognised need to involve NGOs in all aspects of health research in order to maximize the potential benefits of research *in* practice and rapid translation of research evidence *to* practice.[79] The full benefit of engaging NGOs in health research in LMICs is therefore seen as largely untapped, with the need for research and evaluation of practice models for partnering with NGOs in biomedical research as a scientific imperative in the developing world.[93]

2.1.5 Intersection between programme, implementation, improvement and translation science with NGO programmes

When choosing appropriate TMFs for embedded mixed methods research within routine NGO programme practice, it is important to make conceptual distinctions between programme, implementation, improvement/operational and translation science approaches.

2.1.5.1 Programme science

Programme science is the systematic application of theoretical and empirical knowledge to optimise the scale, quality and impact of public health programmes.[100] Programme Science cycles involve strategic planning, programme implementation and program management and evaluation using routine indicators and reporting tools to examine data quality, evaluate trends over time, and assess programme achievements to target.[101] These cycles are aligned to the routine monitoring and evaluation (M&E) processes employed within NGO programmes.

However, distinct from routine M&E conducted by NGOs, the programme science approach systematically applies scientific theory and empirical knowledge to answer critical programmatic questions.[100] Programme science endeavours to embed research within programmes based on routine performance data and having programmes set and drive the research agenda.[100] In addition to optimizing implementation, programme science emphasizes “getting research out of practice” and formulating new hypotheses and theoretical contributions as a strategy for improving population impact of public health interventions, whereby practice informs research and research informs practice and policy.[101]

2.1.5.2 Implementation Science

Implementation science is “the scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices into routine practice, and, hence, to improve the quality and effectiveness of health services and care”.[106] The field of IS focuses on improving the delivery of evidence-based interventions (EBI) to maximize their potential impact across heterogeneous settings.[82] EBIs are broadly defined as “programmes, practices, processes, policies, and guidelines that have proven efficacy or effectiveness in a population and setting”.[112] Despite the existence of many EBIs to improve health outcomes, many go unused in practice, partly due to the fact that EBIs rarely fit seamlessly into a context or setting that is different from the one in which they were originally developed and tested.[113]

Implementation strategies, defined as methods or techniques employed to improve adoption, implementation, and sustainability of a clinical program or practice[114], are a major focus of IS as they present the ‘how to’ component to changing and improving evidence-based healthcare practice.[115] This involves recognition of the factors influencing the system as a whole and specific aspects of that system upon EBIs. Linked to the need for specification of intervention strategies is the need to clearly define implementation outcomes in IS. Proctor et. al’s conceptual framework for implementation outcomes distinguishes between three distinct but interrelated types of outcomes[96]:

1. **Implementation outcomes**: implementation outcomes are the effects of deliberate and purposive actions to implement new treatments, practices, and services. These may include proximal outcomes such as acceptability (satisfaction with aspects of the innovation), adoption (uptake, utilisation), appropriateness (suitability, practicability), feasibility (suitability for everyday/routine practice), fidelity (quality of program delivery to defined standards), implementation cost (cost-effectiveness), penetration (level of institutionalisation, access) and sustainability (maintenance).
2. **Service Outcomes**: are intermediate outcomes aligned to the dimensions of QI within improvement practice and science and encompass outcomes related to standards of care.
3. **Client Outcomes**: may include client satisfaction with services, function (quality of life, or reduction of barriers to access facility delivery), and symptomatology (clinical data, linkage, retention and clinical outcomes such as ART for HIV positive pregnant mothers, PMTCT among exposed infants).

In low resource settings, NGOs are central actors in leading the dissemination and implementation of public health programmes and efforts to adapt and improve quality and implementation fidelity of EBIs and contribute evidence on outcomes through routine programme data. However, many public health interventions, including NGO implemented programmes are part of 'packaged' approaches that are inconsistently labelled, poorly described, rarely justified theoretically[116], and specific elements and mechanisms of action poorly understood.[115]

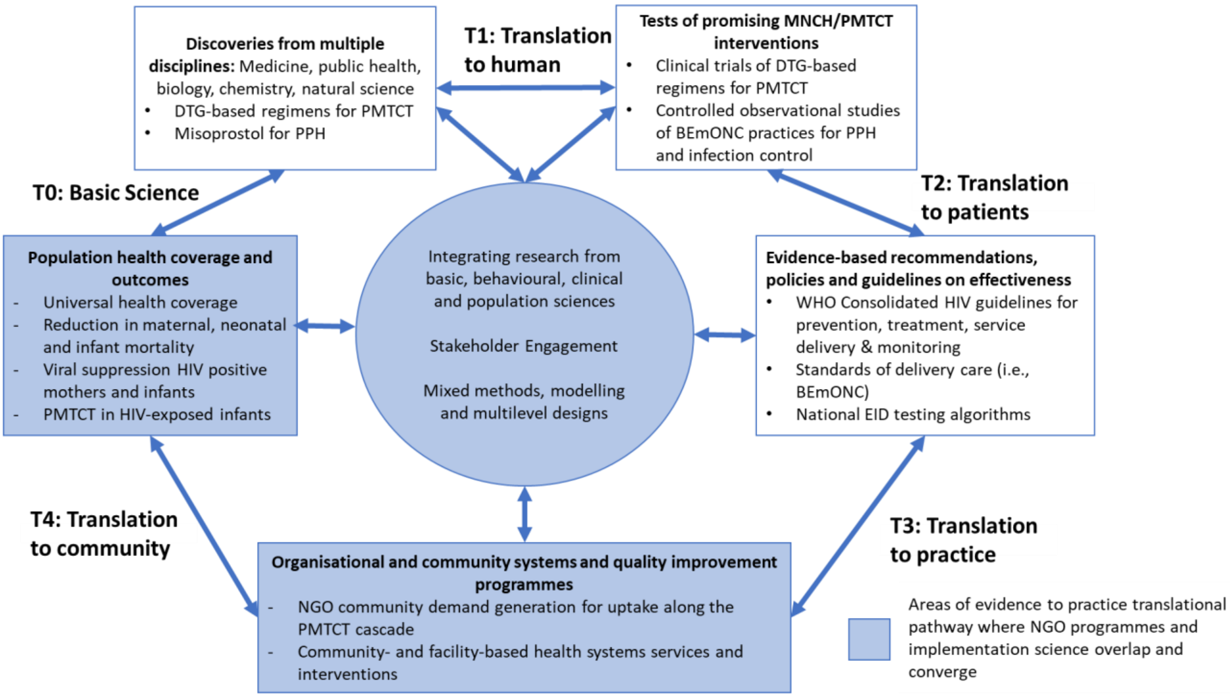
2.1.5.3 Improvement science and operations research

Implementation science focuses on increasing the systematic uptake of evidence-based interventions (EBIs) into real world practice, whereas improvement science focuses on iteratively measuring and improving the efficiency, quality, safety, effectiveness, timeliness and patient-centeredness of health care processes and systems.[94] The areas of focus of improvement science are intended to evaluate standards of care[95] and are closely aligned to service outcomes within implementation science.[96]

Improvement science has its foundation in the field of improvement practice. Improvement practice is distinct from improvement science in that its goal is to produce the local (rather than generalizable) knowledge needed to improve care in a specific setting and is often referred to as quality improvement (QI).[97,98] NGO programme activities including infrastructural improvements, hiring personnel with expertise in improvement models, and training providers and staff in clinical guidelines and strategic information and evaluation data tools such as root cause analysis, process flow diagramming, cascade analysis, and Plan-Do-Study-Act (PDSA) cycles[63] are common improvement practices in public health.

2.1.5.4 Translational research

Translational research focuses on how to get scientific “evidence into practice”.[108] The implementation work of NGOs and the evidence produced by improvement and implementation science overlap and converge along the research translation pathway (Figure 2.2). NGO programmes frequently focus on translating evidence-based interventions into organisational and community systems and quality improvement programming in context (T3) so as to improve population health coverage and outcomes (T4).[107,108] Similarly, implementation science seeks to promote the systematic uptake of research findings and other evidence-based practices into routine practice, and, hence, to improve the quality and effectiveness of health services and care.[106,109] Programme science emphasises the bi-directional nature of evidence translation and seeks to use routine data to inform research for strengthening programmes to improve population health impacts and correspondingly, feed back practice-informed research into public health policy and programmes.[100]



Abbreviations: DTG: dolutegravir; PMTCT: Prevention of Mother to Child Transmission; PPH: Postpartum haemorrhage; HIV: Human immunodeficiency virus; BEmONC: Basic Emergency Obstetric and Newborn Care; EID: Early Infant Diagnosis; NGO: non-governmental organisation

Figure 2.2. Intersection of NGO MNCH/PMTCT Programmes with Implementation Science along the research translation pathway *Adapted from Kroelinger et al.[108] and Glasgow et al.[107]

While the convergence between the objectives of implementers (NGO programmes) and implementation science in the translation pathway is clear, the role of NGOs in contributing to implementation science evidence in the fields of HIV and MNCH is poorly documented and requires specification in order to develop evidence on effectiveness and impact dissemination and implementation in routine programmes.[108] Strengthening translation of research evidence into practice requires partnerships between researchers and those for whom evidence is ultimately meant to be of use and who contend with the real-world needs and constraints of health systems (including NGO implementers, communities, providers and patients).

There are currently missed opportunities for the establishment of multi-disciplinary partnerships between NGOs and implementation scientists to improve the co-design and rigorous evaluation of the processes, implementation and evaluation and translation of EBIs into practice.[111]

2.1.6 TMFs, health inequity and NGOs programmes

2.1.6.1 Theoretical perspectives on optimising NGO evidence through IS-informed approaches

Global public health evidence generation and programme implementation are influenced by a wide range of ecological levels from individual, household, communities, implementing organisations and political and economic historical, structural and systems determinants.[82] Such dynamic influences necessitate a relativist rejection of a pure biomedical knowledge or empirical observational 'truth' in the translation of EBIs into public health implementation.[117-119] Recognising the complexity of 'real life' public health practice, IS utilises theories and methods from social, behavioural, epidemiological and biological sciences.[120]

Holistic approaches to exploring and mitigating the causes of suboptimal implementation of EBIs are therefore aligned to epistemic foundations within both social constructionist and constructivist paradigms.[121] First, social constructionism places social context at the centre of meaning and 'knowing' in EBIs. This includes the process of dissemination and translation of knowledge about evidence-based practice in public health in context and across a wide range of actors (policy, provider, users).[122] Conversely, social constructivism involves meaning making and learning that takes place because of an individual's interactions within a particular social context.[123] Due to their emphasis on knowledge and meaning within context, constructivist and constructionist social, behavioural, learning and organisational theories provide a useful grounding for operationalising the use of TMFs in understanding factors influencing evidence-based practice in routine NGO programmes. Such theoretically-informed approaches are particularly important in guiding efforts to explore health disparities in context from the user perspective.

Such paradigms emphasise positioning of public health investigations into: 1) the socioecological factors[124] that influence ability to translate evidence-based practice into equitable health coverage and outcomes; 2) the importance of reflexivity;[125] and, 3) the influence of implicit cognitive biases of stakeholders in interpretation and translation of evidence-based practice. In LMICs, the impact of systemic gender, racial and socioeconomic injustice upon structural determinants of health highlight the need to embed intersectionality and recognition of power in the generation, translation, and adaptation of evidence-based practice.[126] The dynamic influences of structural determinants of health[127], social norms[128], and differential vulnerability within conditions of poverty[129] should be acknowledged and explored when employing IS-informed approaches to understanding and intervening on global health inequalities.

2.1.6.2 Theories, models and frameworks

Just as the role of NGOs in public health programme implementation and evidence generation lacks specificity, standardised terminology and reporting frameworks,[47,48] consensus about conceptualization and reporting of implementation research does not yet fully exist. This lack of consensus and use of standardised frameworks in IS has been noted as potentially undermining the reproducibility, transparency, and generalizability of research in IS.[130]

To overcome this, a range of TMFs have been developed across research disciplines. Within IS, there are three overarching approaches: *process models* to guide process of translating research into practice; *determinant frameworks* to understand or explain what influences implementation outcomes; and, *evaluation frameworks* to explore intervention effectiveness and impact of implementation.[97] Given that programme science initiatives encompass many key elements of other evidence-to-practice research disciplines (Figure 2.3), it draws on the TMFs of these disciplines to answer key programmatic questions.[100] Selection of the most appropriate TMF for use is determined by the IS research question, levels and perspectives being explored (individual, provider, system); depth of analysis ; and orientation (policy, program, specific EBI).[131]

As NGOs programmes frequently involve translating research on EBIs into practice, understanding the contextual factors influencing implementation outcomes, and evaluating the success of such programmes in improving universal health coverage and improved health outcomes, the work of NGOs is closely aligned to the aims of many IS TMFs.[97] However, there is limited evidence of the use of IS TMFs among implementers. In a recent review conducted by Kemp and colleagues exploring application of implementation science methods to integration of non-communicable disease services into HIV care settings in SSA, among 26 projects reviewed, only one used a theoretical framework for IS research.[132]

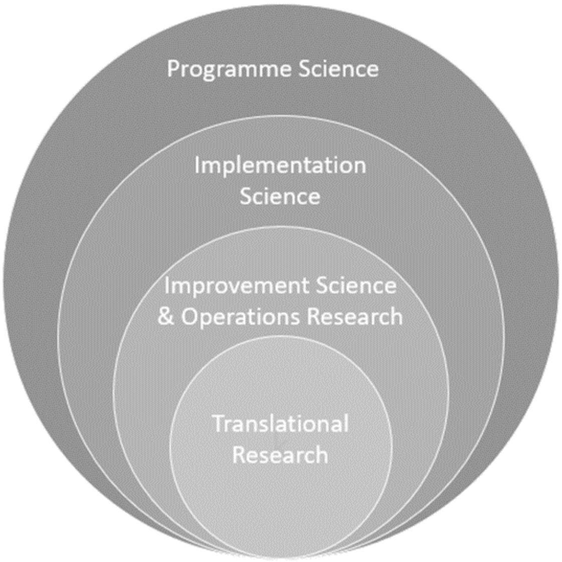


Figure 2.3 Programme science and its relationship with other research frameworks*from Becker et al.[100]

2.1.6.3 Health inequity and TMFs

Existing IS frameworks have been criticised for failing to adequately focus on inequities within health care delivery,[133] inequities in access, uptake and quality of health services which many NGO programmes specifically seek to address among underserved, vulnerable and hard-to-reach populations.

The determinants of healthcare inequities are complex, multifactorial and involve the intersection of clients, family members, providers, healthcare organizations, and communities. Disparity research often follows three steps: detecting (Phase 1), understanding (Phase 2), and reducing (Phase 3), disparities.[134] IS can help address the gap between EBI implementation and equitable uptake and benefit by studying the factors, processes, and strategies at multiple levels of a system of care that influence the (sustained) uptake among vulnerable populations.[133] Brownson and colleagues note that IS research processes often fail to adequately consider context and do not always align with priorities of those experiencing inequities and recommends more practice-based evidence and the need to engage public health organisations (such as NGOs) in order to identify root causes of inequity and direct resources to those most in need.[135]

2.1.6.4 Health Equity Implementation Framework

It is acknowledged that successful implementation of public health interventions requires understanding of the environment (vulnerable individuals, households, communities, health systems) and how target populations (such as P&L women for MNCH and PMTCT programmes) live and function in order to identify the causes of disparities in access, uptake and outcomes of EBIs in context, and facilitators to address inequities.[72,108] Implementation determinant frameworks provide a structure to explore and understand why disparities exist in access, receipt, use, quality or outcomes of healthcare.[97,136] However, existing IS frameworks are viewed as falling short of assessing health equity determinants.[137] Health equity challenges require special attention to the clinical encounter because of unique patient and provider factors which may influence the access, uptake, experience of, and outcomes of healthcare among vulnerable groups.[137]

The Health Equity Implementation Framework integrates implementation science and healthcare disparities conceptual frameworks to understand an implementation problem and select evidence-based and contextually appropriate implementation strategies.[137] It is a modification of the Integrated-Promoting Action on Research Implementation in Health Services (i-PARIHS) framework that explains implementation elements of context, recipients and characteristics of the innovation as levels of implementation elements that are influenced through a set of evidence-based implementation strategies, or implementation facilitation.[138] i-PARIHS was combined with the Health Care Disparities Framework, which explains health disparities at multiple levels including patients, providers, clinics and the health care system.[137,139]

The Health Equity Implementation Framework provides a pragmatic tool for conceptualizing how implementation factors and health care disparities factors can be simultaneously studied and intervened upon (Figure 2.4).[137] Use of the framework is particularly encouraged for use to explore healthcare disparity implementation problems[137] and accordingly, has some overlap with improvement practice of NGO programmes and quality improvement approaches. The Health Equity Implementation Framework can be adapted to any population where implementation disparities exist.[136]

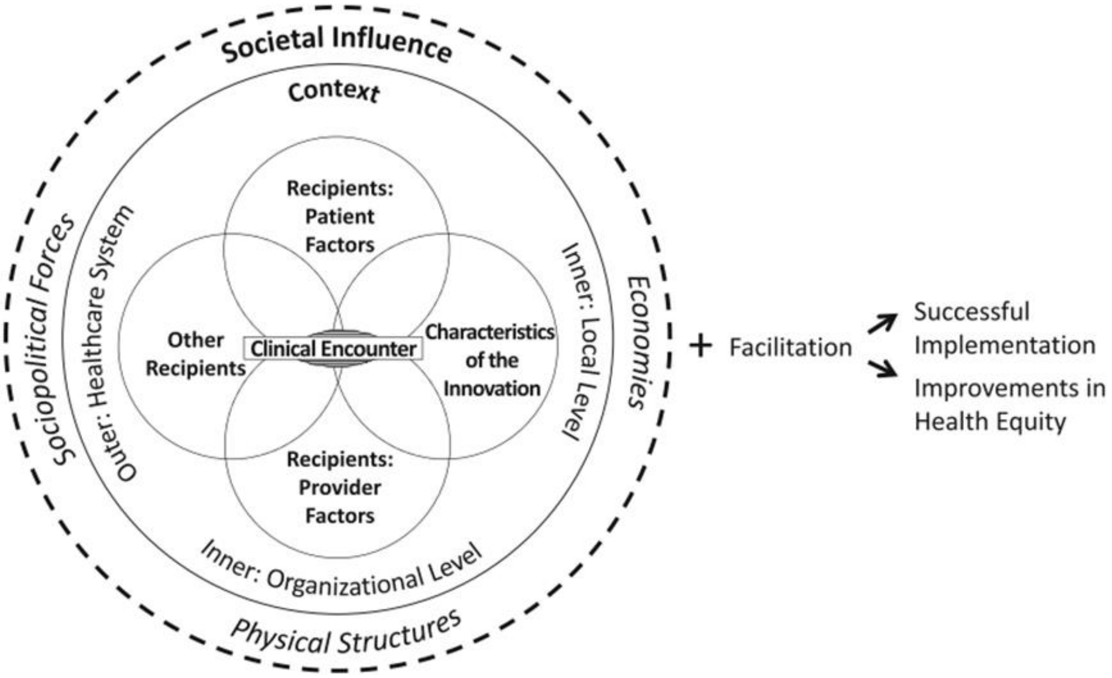


Figure 2.4 Health Equity Implementation Framework. From Woodward et al.[136]

This framework is particularly relevant for exploring service outcomes (the clinical encounter), and barriers and facilitators to access EBIs. Facilitation within the Health Equity Implementation Framework encompasses a "multi-faceted process of enabling and supporting individuals, groups and organizations in their efforts to adopt and incorporate clinical innovations into routine practices".[140] Within the i-PARHIS framework, facilitation is the active ingredient in the implementation process; facilitators such as NGO program designers and implementors engaged in cascading new EBIs into practice, and improving access and quality of existing EBIs need to assess and respond to the characteristics of the innovation being implemented, the individuals and teams involved in or affected by innovation implementation, and the organizational context.[140,141] Implementation strategies associated with facilitation may include audit and feedback, education and training, clinical mentorship and stakeholder engagement.[140]

2.1.7 Summary

The role of NGOs in global public health has evolved and expanded over the past century. The emergence of GHIs to attain universal health coverage and control of communicable disease epidemics, has established NGO's as recognised 'third state actors' in the public health response of many LMICs. The geographic areas of operation, programme aims and monitoring frameworks of NGOs are led by the demands of their funders, which largely mirror the primary drivers of excess morbidity and mortality. Accordingly, over the past two decades, the majority of GHI funding channelled to NGOs has been invested into HIV and MNCH programmes in SSA designed to reach HIV epidemic control and reduce maternal newborn and child morbidity and mortality.

The diverse and heterogeneous programmes implemented by NGOs within global health are characterised by poorly defined roles, fragmentated action due to disease-specific programme siloes and donor-driven implementation priorities.

While their activities are most commonly aligned to improvement practice, the activities of NGOs in translating evidence-based recommendations, policies and guidelines into practice (T3), and from practice to communities for improved health coverage (T4) mirror the part of the research translation pathway occupied by IS. NGOs are involved in the generation of volumes of routine observational data, which are most frequently used within care cascades, but these data are underutilised within IS endeavours. Conversely, NGO programmes are frequently implemented as 'packages' and rarely make use of IS TMFs which have the potential to provide ‘clarity out of chaos’[142] by providing standardised methods for designing, reporting and evaluating the implementation strategies and outcomes of NGO programmes. NGO health programmes are most often focussed on identifying and addressing health disparities and improving equity of access, uptake and outcomes among vulnerable and underserved populations. Accordingly IS determinant frameworks that integrate equity domains such as the Health Equity Implementation Framework,[136] have particular promise for integration of IS TMFs within routine NGO programmes.

2.2 Maternal, newborn and child health

2.2.1 Global status of MNCH

Recent years have seen substantial gains in maternal and child survival: between 2000 and 2017, the global maternal mortality ratio (MMR) (number of maternal deaths during a given time period per 100,000 live births during the same time period) fell by 38%,[143] and neonatal deaths (probability of dying during the first 28 days of life, expressed per 1,000 live births) by 60%.[144] Such gains can in large part be attributed to the impact of GHIs to improve maternal and child health under the Millennium Development Goals (MDGs) (MDG goal 4: Reduce child mortality, and 5: Improve maternal health) and current Sustainable Development Goals (SDGs) aiming to reduce the global MMR to less than 70 per 100,000 live births (SDG indicator 3.1.2 under goal 3, target 3.1) and the neonatal mortality rate to ≤12 deaths per 1,000 live births (indicator 3.2.2, target 3.2) by 2030.[145] The Global Strategy for Women’s, Children’s and Adolescents’ Health (Global Strategy) further translated SDG goals on maternal and child health to promote accountability and support countries and their partners (i.e., NGOs) to translate the SDGs into concrete guidance and monitoring frameworks on how to accelerate and measure progress through a multisectoral approach.[146]

Despite strong political commitment and substantial progress, the United Nations Maternal Mortality Estimation Interagency Group (MMEIG) estimated that in 2017 up to 295,000 mothers died from complications of pregnancy and childbirth, the majority due to preventable causes.[147] The average annual rate of reduction of MMR (2.9%) is less than half the 6.4% annual reduction rate needed to attain SDG target 3.12.[143,148] Recent models estimate that of the projected 48.1 million deaths among children under five between 2020 and 2030, almost half will occur during the neonatal period.[149] Fifty-four countries are currently off track to achieve targeted reductions in the neonatal mortality rates,[148] which have declined more slowly than among children aged 1–11 months or 1–4 years.[150]

The state of global maternal and child health is one marked by regional and country-level inequities. Nearly all maternal (94%) and neonatal (>85%) deaths occur in LMICs.[143,151] A child born in SSA is 10 times more likely to die in the first month than a child born in a high-income country,[152] and the region accounts for 41% of global neonate deaths.[150] At 542 maternal deaths per 100,000 live births, compared to a global ratio of 216 deaths per 100,000 live births, SSA also has the highest maternal mortality ratio globally.[143]

2.2.2 Causes of maternal and neonatal mortality

Globally, three quarters of maternal deaths are attributable to just five major complications: 1) severe bleeding (mostly bleeding after childbirth); 2) infections (usually after childbirth); 3) high blood pressure during pregnancy (pre-eclampsia and eclampsia); 4) complications from delivery; and 5) unsafe abortion.[153] The majority of maternal deaths occur during labour, delivery or the immediate postpartum period.[154] The indirect causes of maternal death differ by region, with HIV-related maternal deaths highest in SSA, while other medical causes are highest in developed regions and Eastern Asia.[155] Maternal health and newborn health are closely linked in both causation and timing, with up to half of newborn deaths occurring within the first 24 hours after birth.[154] Preterm birth, intrapartum-related complications (birth asphyxia or lack of breathing at birth) and infections account for 90% of infant deaths.[156,157]

The distribution of MNCH outcomes globally is marked by inequity: 34 of 36 countries with extremely high (>1,000), very high (500–999) and high (300–499) maternal mortality are in SSA, where a woman's lifetime risk of a maternal death is 1 in 37, as compared with 1 in 4,800 in Europe and North America.[143,148] Regional inequalities in mortality levels are consistent with patterns in other key development indicators, and maternal and child morbidity and mortality rates are reflective of the intersection between biomedical and social determinants of health including sociocultural gender inequities, urban–rural residence, educational disparities and economic inequality.[155,158] Sexual and reproductive health inequalities in SSA are rooted within sociocultural[159] and economic spheres that influence the future prospects, decision-making power and autonomy of women and girls.[160]

Illustrative of the complex interaction between socioecological and biomedical determinants of maternal and child health are the links between age at first childbirth, poverty, and maternal and infant morbidity and mortality in LMICs. The risk of maternal mortality is highest for adolescent girls under 15 years old, and complications in pregnancy and childbirth are higher among adolescent girls aged 10–19 (compared to women aged 20–24).[143] In SSA, the median age at first birth is 19.9 years and young women have limited access to sexual and reproductive health services and disproportionate risk of HIV infection.[161] Differential vulnerability is a recognised driver of poor health outcomes among women and children and critical for understanding and addressing health inequalities, with emphasis on the importance of viewing vulnerability as a contextual phenomenon.[162,163] Accordingly, developing contextually relevant strategies to improve equity of health access is the focus of many NGO programmes seeking to improve MNCH outcomes in LMICs.[34]

2.2.3 Place of delivery

Much of the global maternal and neonatal mortality occurs among women and children who die in the first week following home deliveries[164] conducted without a skilled birth attendant, access to a clean birth or basic emergency obstetric and neonatal care (BEmONC), or effective referrals in the event of complications.[155,165,166] The inclusion of skilled birth attendance in the Millennium

Development Goal (MDG) and Sustainable Development Goal (SDG) frameworks was expected to accelerate universal coverage with skilled delivery care by 2030 and reduce the global MMR (SDG indicator 3.1.2 under goal 3, target 3.1) to less than 70 per 100,000 live births by 2030.[145] Skilled attendance at birth is also seen as a critical SDG strategy for reducing the global neonatal mortality rate (indicator 3.2.2, target 3.2) to ≤12 deaths per 1,000 live births.[145]

Despite such commitments, striking disparities in access to quality health services and skilled attendance at birth persist. All regions, with the exception of SSA and South Asia, have reached universal coverage (95% or higher) of skilled birth attendance, and these are the two regions where maternal and neonatal mortality are highest.[167] Skilled birth attendance in SSA in 2018 was only 59%[168] and rates of non-institutional delivery remain unequal.[169] In SSA, more than half of women who deliver at home do so alone, without a skilled birth attendant.[154]

Among the 60 million non-facility births occurring worldwide every year, outcomes are worst among the poorest; more than 70% of all births in the lowest two wealth quintiles take place at home without skilled help.[170,171] Key risk factors for non-institutional delivery mirror those of maternal and neonatal mortality, including low maternal education, high parity, low household wealth, distance to the nearest health facility and low number of antenatal care visits.[172,173] This dynamic interaction, where vulnerability factors limit individual capacity for maternal health service uptake, has been described by others,[174] who acknowledge that a 'pro-poor path' to universal coverage of safe delivery requires identification and intensive outreach among the most vulnerable households.[175]

While the sociodemographic determinants of home delivery are well documented, it is recognised that quantitative methods alone are insufficient for explaining women's health-seeking behaviours, particularly among vulnerable women in low-resource settings.[176,177] Among other contextual factors, social norms – unwritten rules of behaviours shared by members of the same social network – are known to affect women's preferences and choice of delivery location.[164,178,179]

The three delays model is a conceptual model that outlines three levels of delay: 1) time between onset of complications and recognition of the need to access health services; 2) time between leaving home and reaching the facility; and 3) time between reaching the facility and receiving appropriate treatment.[164,180] The model posits that the majority of maternal and infant morbidity and mortality is accrued due to emergency complications that are not predictable, although largely preventable with access to quality BEmONC.[155] The variation in the association of facility-based delivery with maternal and neonatal survival within and across regions and by facility type underscores the importance of adequate training, equipment and referral systems in realising the potential benefits of facility-based delivery for maternal and child health.[181-183]

2.2.4 HIV and PMTCT programmes

The morbidity and mortality associated with home deliveries in low-income countries is further exacerbated in countries with a high prevalence of HIV. While MTCT of HIV has been virtually eliminated in industrialised countries, it remains common in Africa.[13] The Joint United Nations Programme on HIV/AIDS (UNAIDS) has led a GHI to virtually eliminate vertical transmission of HIV (defined as MTCT transmission of less than 5%) and to reduce AIDS-related maternal mortality by half by 2015 through enhancing the coverage of PMTCT programmes.[14]

Home delivery is known to limit the coverage of PMTCT of HIV programmes.[15] Even when HIV status is known and HIV positive mothers are enrolled in PMTCT programmes, home delivery is associated with non-adherence to ARVs to prevent vertical transmission.[16–19] Strengthening the continuum of care between the home and health facilities during pregnancy, childbirth and the period is not only important for reducing anti-, peri- and postpartum infant and maternal mortality and morbidity[7] but is also an important approach for reducing vertical transmission of HIV in high-prevalence countries.

2.3 HIV and MNCH in high-burden countries

2.3.1 HIV infection

HIV transmission occurs in three ways: through unprotected sexual (vaginal or anal) intercourse, from blood products or from an infected mother to her child.[184] In part, the disproportionally high HIV prevalence in SSA has been attributed to high prevalence of ulcerative sexually transmitted infections (STIs) and multiple concurrent sexual partnerships.[185,186] Heterosexual transmission is the predominant mode of transmission in SSA, with an associated epidemic in children as result of vertical (mother-to-child) transmission in countries with generalised HIV epidemics.[185,187] Incident HIV infection in mothers can cause extremely high viral loads, making routine HIV retesting during pregnancy, labour and delivery and in the postnatal period while breastfeeding a priority programmatic action for improving maternal and child health in HIV-endemic settings.[188]

2.3.1.2 Prevention of mother-to-child transmission of HIV

Over the last 20 years there have been a number of approaches developed for prevention of mother-to-child HIV transmission (PMTCT).[189] Before the development of effective preventive interventions, the rate of transmission from mother to child ranged from 15% to 25% among infants who were formula-fed and from 25% to 40% among infants who were breastfed.[190] Key among the PMTCT strategies is the use of ART for pregnant mothers,[191] and ART has been recommended as a strategy for PMTCT since 2006.[189]

2.3.2 HIV diagnosis

Viral detection methods involve detection of viral nucleic acid using polymerase chain reaction (PCR).[192] PCR testing requires laboratory infrastructure and is mainly used for early infant diagnosis (EID) of HIV, where HIV antibody tests cannot be used due to the passive transfer of maternal antibodies to the infant.[192]

2.3.2.2 Infant HIV diagnosis

Infants born to HIV-positive mothers are recommended to have an HIV test within four to six weeks of birth. However, according to UNAIDS, in 2019 only 60% of children eligible for HIV testing at birth had received an HIV test within six weeks globally.[191,193]

Therefore, up to 18 months of age, diagnosis of HIV requires viral detection (rather than antibody detection) methods such as DNA PCR.[194-196] Virological tests detecting DNA PCR are costly and require much more infrastructure and sophisticated laboratory capacity, resulting in HIV testing being restricted to central laboratories. Turnaround of test results (from the laboratory to the health facility or to the patient) can often take several months, meaning delayed diagnosis for infants who do return for results, but also many infant–mother pairs are lost to follow-up.[194] In an observational study of eight African countries, 98.3% of infants who had point-of-care (POC) HIV tests in 2017 received their results within 30 days. In comparison, only 18.7% of infants receiving virological HIV testing from 2014 to 2017 received their results within 30 days.[197]

Additionally, the result-return time for infant testing varies widely, often up to two months, and 30–50% of patients never receive the results.[13] Gaps in the testing of infants and children exposed to HIV have left more than two fifths of children living with HIV (CHW) undiagnosed.[14] Consequently, only 43% of CWH initiate antiretroviral therapy (ART), a percentage far lower than in adults.[15,16] Given this, strategies that have been used to try to improve uptake of EID include alignment of HIV testing with routine child health visits, use of SMS reminders and community follow-up of infants who are lost to follow-up.[194]

More recently, several POC HIV testing platforms for EID have been evaluated and demonstrated to be feasible and to improve rates of results return and ART initiation rates, but they have not been implemented widely to date.[194,198] This may be due to the costs associated with rollout of the POC EID testing platforms or delays in their introduction into the market, whereby only two EID POC testing platforms had been prequalified by WHO by January 2019.[196] Evidence indicates over 92.3% of HIV-positive infants who received POC HIV testing were initiated on ART within 60 days, while only 43.3% of infants receiving conventional EID were initiated.[197] Current WHO guidance is that HIV-exposed infants should also be tested for HIV again at nine months. However, often children do not return for repeat HIV testing.[199]

HIV prevention efforts must focus on infants who test negative in order to minimise transmission through breastfeeding,[200,201] which accounts for a growing fraction of infections among infants.[202,203] The completeness of EID and the proportion of infants testing positive are correspondingly used as cardinal indicators of the success of PMTCT programmes.[62,200,204]

2.4 HIV and MNCH programme integration

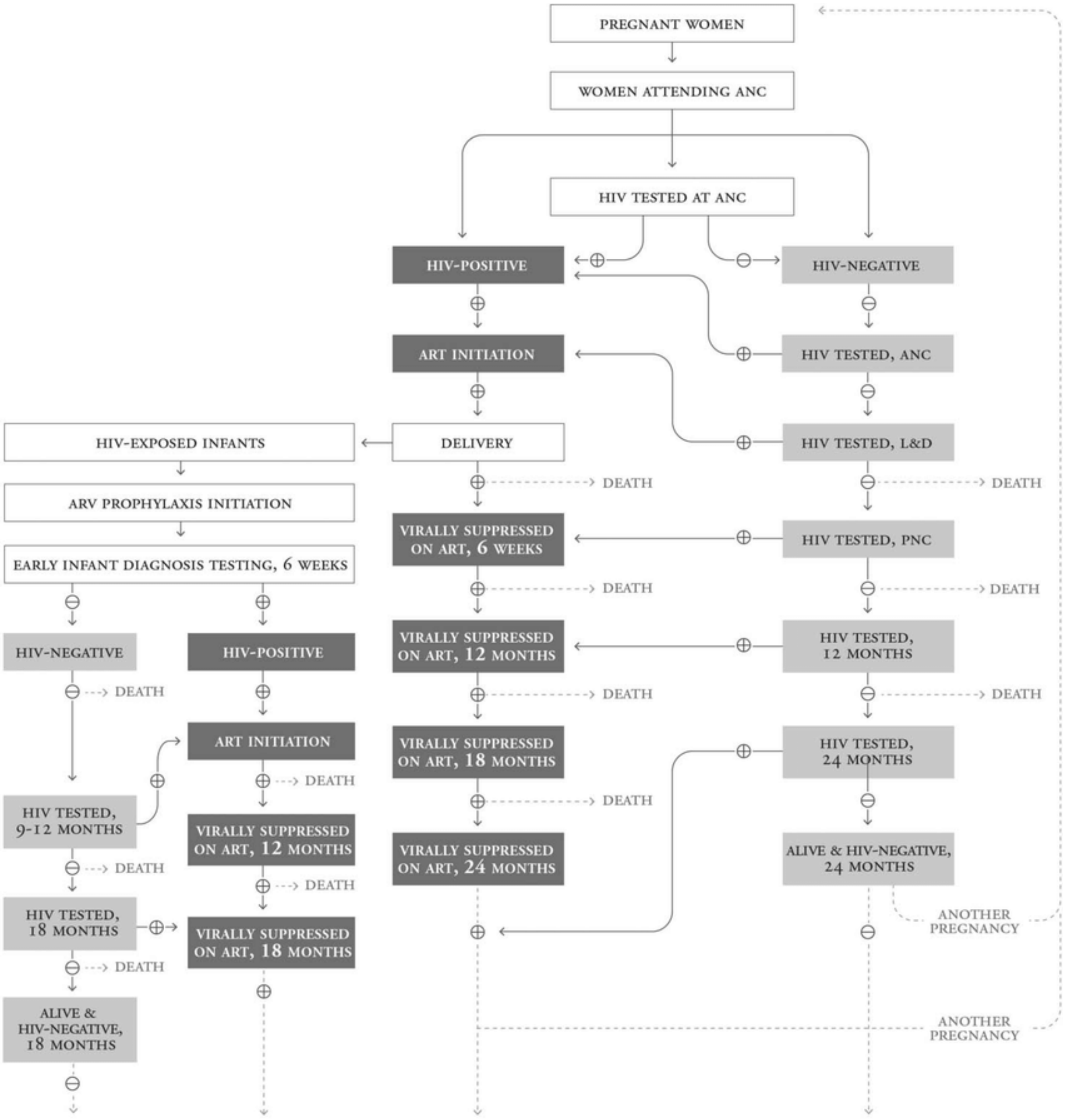
2.4.1 PMTCT and MNCH

In high-HIV-prevalence settings, the integration of HIV prevention, care and treatment into existing MNCH services is an established strategy to strengthen systems, improve efficiencies, ensure sustainability and broaden the impact of health investments.[205]

Utilising a public health approach to integrating health services is proposed as one way for LMIC health systems to make progress towards the goal of universal health coverage by lowering incremental cost-effectiveness ratios (ICERs), by "either improving health outcomes due to increasing coverage rates, or through lower costs through more efficient use of resources by exploiting economies of scale and/or benefiting from economies of scope, or both".[206,207]

Service delivery models to improve individual and programmatic outcomes along the PMTCT/MNCH cascade include integration of comprehensive HIV treatment and care into routine antenatal, labour and delivery and postnatal care at decentralised, primary care levels.[208] This integrated PMTCT and MNCH care cascade includes services for both HIV-positive and HIV-negative mother–baby pairs in high-prevalence settings, with HIV testing and retesting in ante- and postnatal care, provision of HIV care and treatment services within routine care, and diagnostic testing of HIV-exposed newborns scheduled to coincide with the regular immunisation schedule in most national programmes (Figure 2.5).[61,200,209] The 'bundling' of multiple evidence-based interventions and integration of HIV services within routine MNCH has been demonstrated to improve HIV service uptake and outcomes while ensuring progress towards preventing maternal and infant deaths.[210,211]

Figure 2.5 Expanded PMTCT cascade, which includes essential services for HIV-positive and -negative women from pregnancy through to cessation of breastfeeding. From Hamilton et al.[61]



2.4.2 PMTCT/MNCH cascade through an IS lens

Within the frame of IS, each step of the PMTCT/MNCH cascade represents a series of discrete EBIs known to contribute to PMTCT and maternal and infant survival (health outcomes).[61] Implementation strategies aimed to increase uptake of EBIs along the PMTCT cascade include a constellation of community- and facility-based strategies as well as policies and health system strengthening. Examples of strategies employed by NGOs to strengthen PMTCT/MNCH cascade interventions include: sensitisation and engagement with traditional leaders and male partners to support women's uptake of essential health services, community- and facility-based health education with pregnant women to promote sustained and timely utilisation of maternal, neonatal and infant health services, offer of free MNCH services including facility birth, HIV testing and treatment to all pregnant women and HIV-exposed infants, counselling of women in ANC to promote facility-based delivery and early HIV testing of exposed newborns, clinical mentorship and follow-up the mother-baby pair across the PMTCT cascade of care to identify MB pairs lost to follow up until determination of the child's final HIV status at 18–24 months.[212]

Implementation research outcomes of evidence based strategies for PMTCT and MNCH can be measured and analysed at various levels from individual users (i.e., P&L women) and providers (i.e., health care worker, NGO programme officers), to organisations (NGO or health system structure) and settings (policy context, societal influences) using routine administrative data, surveys, observation, self-reports and qualitative methods such as interviews and focus groups.[96]

2.4.3 Integrated MNCH and PMTCT programme coverage

Policy and programmatic efforts have intersected with social, demographic and economic changes to dramatically increase access to and uptake of integrated PMTCT/MNCH services over the past two decades. This progress is attributable to increased resources provided through GHIs, and NGO-implemented programmes.[7] However, suboptimal uptake, poor quality of services and loss-to-follow-up of mother–infant pairs at each step of the PMTCT/MNCH cascade remain significant contributors to preventable maternal and newborn morbidity and mortality in LMICs.[57,211,213]

Antenatal care

First, not all women enter into the PMTCT/MNCH cascade of care through ANC registration and access to HIV testing and other evidence-based interventions for improving MNCH outcomes.[191,214] Late or no registration for ANC has been attributed to structural barriers such as costs of accessing facilities, limited access to health facilities due to the need to travel long distances, and also long waiting times at facilities.[215,216] Individual barriers also exist, such as lack of knowledge about the need to register for ANC early to access PMTCT, and lack of male partner involvement in ANC.[215-217] Once women are in care, poor implementation fidelity of recommended services such as maternal HIV testing results in missed opportunities to initiate women on HIV treatment for their own health and for PMTCT.[218]

Improved coverage of HIV programmes and increased availability of ART has resulted in reduced maternal mortality due to HIV/AIDS, which peaked in 2005 and showed signs of decline in 2010 and 2015.[155] Attributable to investments of GHIs such as PEPFAR and the GFTAM and activities of NGOs and host governments to decentralise access to PMTCT services, global coverage of maternal ART improved from 17% in 2010 to 85% by 2019.[191] However, disparities persist, with 85% of HIV-related maternal deaths[155] and 88% of child deaths occurring in Sub-Saharan Africa. Further, there is heterogeneity in coverage, with highly affected regions such as West and Central Africa having under 60% coverage, while some regions, such as Eastern and Southern Africa, have successfully and consistently reached almost all pregnant women, with 95% coverage in 2019.[191] Importantly, the gaps in coverage of maternal ART within PMTCT programmes mean that new infections in children continue to occur.

Skilled attendance at birth

Since 2010, births in SSA have been 85% more likely to occur in facilities than those in the 1990s.[219] Global and national policy and programme focus has increased skilled attendance at birth, increasing normalisation of facility-based delivery in both urban and rural LMIC settings[173,220,221] and commensurate reductions in maternal and neonatal morbidity and mortality. Despite progress, high mortality clusters and between- and within-country inequalities in MNCH outcomes persist.[143,151]

Timely, evidence-based intervention is a critical factor in mitigating preventable maternal and infant deaths. The three delays model is a commonly used framework to describe delays that lead to maternal deaths: 1) delays in deciding to seek appropriate medical help for an obstetric emergency; 2) delays in reaching an appropriate obstetric facility; and 3) and delays in receiving adequate care when a facility is reached.[164,180] Structural inequities drive the three delays and access to quality MNCH services, with recent analyses estimating that up to 58% of child deaths between 2000 and 2017 could have been averted in the absence of geographic inequality.[222] Further, inequalities in determinants of institutional delivery such as wealth, place of residence and education are widening in many LMICs.[223]

The impacts of COVID-19 further exacerbated disparities in access to quality MNCH services, which translated to significant increases in the incidence of stillbirth, maternal death and ruptured ectopic pregnancy.[224] Over the pandemic, LMICs had an almost 50% reduction in hospitalisation and emergency visits, with increases in stillbirths and maternal deaths attributed to increases in unattended birth.[225]

Postnatal care

Postnatal care is a critical juncture for maternal and child health for timely prevention, diagnosis and treatment of complications and infections that lead to maternal and child morbidity and mortality and suboptimal development outcomes. Postnatal care consistently has some of the lowest interventions coverage on the continuum of maternal and child care.[169,226] Recent WHO guidance (2022) provides recommendations for a human-rights-based approach to support quality of evidence-based care and promote positive postnatal experience.[227] However, inequities that limit access to antenatal and delivery care persist in the postnatal period and require contextual evidence on vulnerabilities and attention to structural determinants.[228]

In HIV-endemic settings, all HIV-exposed children are recommended to receive EID HIV testing between four and six weeks of age to enable timely HIV treatment of infected infants and HIV-negative mothers should be retested for HIV for maternal health and early ART initiation and PMTCT through breastfeeding.[229] Improved access to early infant diagnosis is a critical part of child-centric prevention of mother-to-child transmission,[200] although up to 70% of infected children are not receiving live-saving HIV care and treatment.[230]

2.4.4 Interventions to prevent maternal and neonatal mortality

Prevention of maternal and neonatal mortality can occur at three levels: prevention of pregnancy, prevention of obstetric complications and prevention of maternal or infant death once complications have arisen. Prevention includes both clinical and non-clinical interventions.[231] In terms of isolated interventions, the Lives Saved Tool (LiST) computer-based model, which estimates the impact of scaling up interventions on stillbirths and maternal, neonatal and child health, identifies safe labour and delivery with a skilled attendant as the most impactful intervention for averting maternal and neonate morbidity and mortality.[183] Long-term goals of public health programmes emphasise the importance of a life course approach, and the fact that the greatest gains in maternal and child health will require sustained uptake of a continuum of quality health services.[32,169,232] Decentralising services to primary care level and ensuring adequate resources to administer evidence-based treatment with adequate medical equipment and avoidance of drug stock-outs are essential interventions for achieving effective and equitable health coverage.[190,233-236]

2.5 Measurement issues in routine PMTCT/MNCH programmes

2.5.1 Intervention coverage as a flawed metric for MNCH outcomes

Intervention coverage, the proportion of the population with a health care need who receive care, is the primary metric used by NGO-delivered PMTCT/MNCH health programmes. Measurement of coverage alone (access and uptake of essential health services such as FBD or EID), however, does not account for intervention quality or health outcomes, and is acknowledged to potentially overestimate the health benefits of services provided to populations.[69] Coverage metrics oversimplify complex realities and displace other forms of knowledge, particularly those that cannot be quantified.[81] Failure to measure client outcomes such as patient satisfaction, function and symptomatology[96] may result in neglected equity and rights concerns as NGOs "play the numbers game" and advance a technocratic, medicalised agenda in order to meet the performance targets of donors.[237]

While the development of cascades was intended to standardise reporting and monitoring performance on attaining GHI goals, without a commitment to ensuring standardised measurement and reporting methodologies, international comparisons are complex.[53] There is currently no standardised definition of 'integration', established framework or country information source that captures all elements and processes of PMTCT/MNCH integration, making rigorous analysis and country comparisons difficult.[238]

Further, the use of aggregate, cross-sectional data in integrated PMTCT/MNCH cascades presents challenges in LMIC settings with high mobility and weak systems to track women and children across services. Weak postnatal follow-up and losses at each step of the cascade have limited use of the PMTCT cascade for evidence-based programme and policy decision-making.[61] As cross-sectional, observational data are frequently derived from multiple paper-based registers, and in the absence of unique identifiers to track women and children across the journey of ANC, labour and delivery and postnatal care, true rates of service uptake and retention along the cascade in routine programmes are subject to considerable bias and lack of population representativeness. [66,239-242]

Routine programme data also fail to systematically and routinely document the perceptions and experiences of women regarding the quality of care received, or reasons for failure to take up services, in order to promote equity and inform contextually relevant programme strategies to address the needs and preferences of the most vulnerable.[243] Rather than using coverage as a central metric of success, there are calls for health systems and programmes to better specify implementation strategies,[115,244] outcomes[245] and impacts, including better health and its equitable distribution; on the confidence people have in them; and on their economic benefit, and processes of care, consisting of competent care and positive user experience.[246]

2.5.2 Measurement of peripartum outcomes in the integrated MNCH/PMTCT cascade

In an attempt to standardise definitions, improve quality and optimise use of routine programme data, WHO and bilateral funders of GHIs produce detailed guidance on strategic information and evaluation,[247-250] and investments have been made in electronic data systems such as the District Health Information System (DHIS2).[49] However, the persistent fragmentation of global public health[33] is similarly evidenced in the fragmentation of monitoring and evaluation systems of routine public health programmes, as seen in uncoordinated parallel data collection systems, analysis of multiple data sources focusing on single diseases, and the lack of resources provided to NGOs for other non-programmatic funding for alternative improvement and implementation research.[251,252]

In routine programme settings, completion of service uptake is assessed at individual facilities, tabulated from information across several paper-based registers, which may be incomplete and/or inaccurate.[66,239-242] Monitoring completion of the PMTCT/MNCH cascade rates requires information from two (or more) time points for which the denominator (those at risk) and the numerator (those with the event) may be documented at different facilities. Mother–baby pairs who are documented as lost to follow-up at one facility may have re-engaged at another, stopped care or died.[66,253] As with other routinely reported data on uptake of and retention in HIV care and treatment in resource-constrained settings,[65] there is a lack of confidence in available estimates of maternal and neonate service uptake, health outcomes and survival. These estimates are required to guide ongoing quality improvement and inform national modelling estimates, which become increasingly important as countries seek to validate attainment of GHI goals to reduce maternal and infant mortality, HIV epidemic control, and elimination of mother-to-child transmission (EMTCT).[239,254,255]

2.5.3 Limitations of routine MNCH data

The often intensive process and context of collecting routine programme data, excessive data requirements by donors, misconceptions regarding frequently changing indicator definitions and the limited use of data among those generating the data result in missed opportunities to use routine data for decision-making.[65] This becomes further complicated in PMTCT and MNCH integration contexts, where health information for maternal and child health and HIV services is recorded separately. For example, in its subnational HIV care and treatment programme in Zimbabwe, OPHID works with community- and facility-based cadres to collect routine programme data from 40 separate paper-based registers and reporting tools (Table 2.1) at 320 public health facilities for reporting under PEPFAR

Monitoring, Evaluation and Reporting (MER) indicator guidelines.[248] Approximately 1,500 individual data points are collected and reported each month by OPHID from each supported health facility, totalling to over 3.7 million data points annually, further disaggregated by geography (facility, district, provincial and national), sex and five-year age bands. A task-oriented job analysis that mapped out the administrative tasks and responsibilities that primary care nurses (responsible for both provision of care, documentation and reporting) undertake to capture services in a single PMTCT ANC care visit identified that a median time of 30 minutes was required to complete documentation in an average of 10 registers for a single care visit.[256] These data are then tabulated and transferred to a Monthly Progress Return Form, which is then manually entered into DHIS2 and into the PEPFAR Data for Accountability Transparency Impact Monitoring (DATIM) system. While the investment of bilateral donors in routine data systems has contributed to the training and expansion of an M&E workforce in LMICs, concerns have been raised regarding routine processes for assessing and ensuring data quality, the development of disease-specific data systems, the increasing burden on health care workers to comply and the ability of those at implementation level to appropriately and effectively analyse the volume of data produced.[257]

In addition to uncertainty regarding the true outcomes of mother–baby pair service uptake across integrated PMTCT/MNCH cascades, the true extent of maternal and infant mortality is also unknown, given the problems with definitions and measurement.[155] WHO has called for countries to improve their vital registration and death surveillance systems; however, it is estimated that in some LMICs, it is not uncommon for more than two thirds of maternal deaths to go unreported in

Table 2.1. Routine data sources for reporting in the OPHID TASQC Programme

1	HIV Monthly Progress Return Form
2	HIV Testing Services: HTS Register
3	HIV Self-Testing Register
4	Pre-Exposure Prophylaxis: PREP Register
5	Sexually Transmitted Infections: STI Register
6	Tuberculosis: TB Register
7	HIV Testing and Counselling: HTC Intake Forms
8	Antenatal Care: ANC Booking register
9	Postnatal Care: PNC Register
10	Delivery Register
11	ART Pharmacy Dispensing Register
12	AIDS and TB Programme Referral Transfer Form
13	Infant PMTCT Dispensing Register
14	Mother–Baby Pair Register
15	HIV DNA PCR Laboratory Request Form (for EID)
16	Tuberculosis Preventive Therapy Register for PLHIV and TB Contacts
17	HIV Infant Diagnosis Clinic Register
18	Chronic HIV Care Pre-ART Register
19	Chronic HIV Care ART Register
20	Patient Opportunistic Infection/ART (OI/ART) Care Booklet
21	National Cervical Cancer Screening Register
22	Defaulter Tracking Register
23	Modified Standard Operating Procedure for defaulter tracking in Zimbabwe
24	Appointment Diary
25	Defaulter Tracking Flow Chart
26	HIV Contact Tracing Register
27	OPHID TASQC Community Output Monitoring Tool
28	TASQC Facility Output Monitoring Tool
29	Differentiated Service Delivery Register
30	Facility Viral Load Register
31	Determined, Resilient, Empowered, AIDS-free, Mentored, and Safe (DREAMS) Monitoring Form
32	Monthly Progress Return Form (MRF)
33	MoHCC Facility–Community Referral Tool (for use by MoHCC village health workers)
34	OPHID TASQC Community and Facility Referral Tool (for use by OPHID-supported community health workers)
35	Family Planning Register
36	Essential Changes Register
38	Client ART Preparedness Application Tool
39	Infant Child HIV and Congenital Syphilis Case Investigation Form
40	Intimate Partner Violence Screening Tool
41	PrEP Screening Tool

official records.[258] This ‘scandal of invisibility’ renders the births, deaths and causes of death among most of the world's poor as unseen, uncountable and hence uncounted.[259] Engaging community health workers in routine health programmes in a formalised death review process through verbal and social autopsy and documenting reasons for loss-to-follow-up are promising methods for improving programme evidence in context on the rate and causes of loss-to-follow-up[260] and maternal and infant deaths.[261] However, such interventions are not implemented at scale in routine programmes. The extension of participation and inclusion of bilateral donors, funds, foundations, non-governmental organisations, the private sector, academic institutions and civil society in civil registration and vital statistics systems is proposed as a key strategy to optimise resources and strengthen the global evidence base.[262]

2.6 Zimbabwe

Zimbabwe is a land-locked country in Southern Africa that has 10 administrative provinces, eight of which are rural. Of a total population of 15,178,979, the majority of Zimbabweans, 61.4%,[263] live in rural areas, where the poverty rate is 86.0%.[264]

2.6.1 The economy, public health system and public health response in Zimbabwe

In Zimbabwe, the level and quality of health care delivery have been drastically affected by a progressively weakened economic and political environment over the past 30 years. This decline over time has negatively impacted the delivery of and funding for public health services.[265]

Following independence in 1980, in an attempt to correct historical inequities in the distribution and quality of health care under Rhodesian rule, the government of Robert Mugabe invested in the decentralisation and expansion of rural primary care services, establishment of the village health worker programme and a strong network of teaching hospitals.[266] The country operates a four-tier health care system, consisting of rural hospitals, public and private health centres providing preventive and curative services, district hospitals, provincial hospitals, general hospitals, and central hospitals located in major cities.[267] Although there are currently over 1,500 health facilities around the country, there are still hard-to-reach rural areas that are not yet serviced, and inequalities persist in achieving universal health coverage.[268] This focus on improving equity of access to health care shows a rapid growth in the number of secular NGOs in Zimbabwe, with 50% of them being formed post-1979.[269]

Figure 2.6 Map of Zimbabwe (Source: cia.gov)

From the mid-1990s, a collapsed economy, HIV and TB endemicity, seasonal malaria and cholera, mass emigration of medical professionals, poverty and food insecurity coalesced and took their toll on the public health system and Zimbabwe's population health.[265,270] The combined impacts of health system collapse precipitated by Zimbabwe's deepening socioeconomic crisis, together with the impacts of the HIV epidemic, were most notably reflected in the reduction in life expectancy of Zimbabwean men from 61 years to just 37 years for men and to 34 years for women in just 10 years (1997–2007).[271]

2.6.2 Maternal, newborn and child health and facility-based delivery in Zimbabwe

The collapse of the Zimbabwean health system was also reflected in rates of non-institutional delivery or 'home delivery' in Zimbabwe, losing gains towards prevention of maternal and infant morbidity and mortality. Between 1999 and 2009 home delivery rates increased from 23%[272] to 39%.[273]

As in most settings, risk factors for failure to take up recommended MNCH services and adverse maternal and neonatal health outcomes in Zimbabwe are driven by inequity. The characteristics of mothers who have delivered at home captured by previous surveys suggest that the majority of mothers who give birth in the home in Zimbabwe belong to the lowest wealth quintile (53.5%), have no education (65.5%), attended no ANC visits (70.2%) and parity of the highest birth order category of 6+ (54.6%).[274]

In Zimbabwe, the available data on reasons for failure to make use of institutional maternity services include women's minimal expectations of cleanliness and non-interference during labour and delivery; institutional delivery costs including travelling expenses; loss of family support and the inability to meet cultural expectations; women's lack of knowledge about danger signs of pregnancy; women's negative perceptions of nurses working at institutions;[275] previous delivery at home; belonging to the Apostolic Faith;[276,277] non-use of maternity waiting shelters; unemployment; being without a husband; and use of traditional care.[30] More recent qualitative data suggest that the lack of available health care providers; lack of access to drugs; shortage of equipment;[31] the high costs of transport; upkeep costs at health institutions; and other constraints may be inhibiting factors for women to access maternity care.[13] Many of these findings are consistent with the three delays model, in which individual decision-making, reduced access to affordable services and a lack of skilled personnel at birth are proposed as the main factors that can delay access to effective interventions to prevent maternal mortality.[278]

Government and NGO responses have been mobilised to redress increases in maternal and infant mortality in Zimbabwe observed following the economic and health system collapse of the late 2000s. National strategies guiding NGO programmes are outlined by MOHCC in the maternal and neonatal health roadmap[279] and led by donor priorities through the multi-donor pooled Transition Fund for Health in Zimbabwe (2011–2015),[280] and World Bank results-based financing[281] aimed specifically at improving access, uptake and quality of care of essential MNCH services. Interventions included abolishing MNCH user fees; decentralising training of primary health workers in comprehensive and basic emergency obstetric and newborn care and WHO-integrated management of childhood illness standards; improving availability of essential medicines and equipment; and building of maternity waiting homes to support rural women (particularly those with risk factors) to stay close to the facility at the time of delivery. Many MNCH interventions in facilities and communities have been implemented through support from NGO implementing partners.[282,283]

Investments and policy commitments to improve maternal and child health in Zimbabwe have yielded results. Zimbabwe's MMR declined between 2007–2008 and 2018–2019 from 657 (95% CI: 485 to 829) to 217 (95% CI: 164 to 269) deaths per 100,000 live births.[284] Prior to increases in ART access through Option B+ (universal HIV testing and treatment for pregnant and lactating women) from 2011,[285] HIV was the leading cause of maternal deaths In 2018–2019, HIV dropped to fourth cause (2 deaths per 10,000). Leading direct causes of maternal deaths in Zimbabwe include eclampsia (3 deaths per 10,000), abortion-related complications (4 deaths per 10,000) and postpartum haemorrhage (3 deaths per 10,000).[286] Similarly, the IMNCI was significantly associated with a reduction in neonatal mortality (adjusted odds ratio (95% CI): 0.70 (0.50, 0.98)) and infant mortality (adjusted odds ratio (95% CI): 0.69 (0.54, 0.91)) and also helped increase institutional deliveries significantly (adjusted odds ratio (95% CI): 1.95 (1.67, 2.28)).[287]

While Zimbabwe has experienced declines in both direct and indirect causes of pregnancy-related deaths and neonatal mortality over the past decade, it remains among the countries with the highest maternal and neonatal mortality ratios globally.[148] Achieving universal health coverage in Zimbabwe is recognised as requiring programmes, primarily delivered through NGOs, that are able to identify and reach the most vulnerable, and incorporate their needs and preferences into program strategy to improve equity of coverage and outcomes of EBIs.[288]

2.6.3 The HIV epidemic and PMTCT in Zimbabwe

Zimbabwe has had an early-onset generalised HIV epidemic. Despite reductions in HIV prevalence from a peak of 29% in 1997[289] to 12.9% in 2020,[290] HIV programming has remained one of the top health priorities in Zimbabwe. An estimated 1.3 million Zimbabweans were living with HIV in 2020, 94% of whom were accessing ART,[291] although inequity persists in both the distribution of HIV incidence and treatment outcomes. As compared to men of the same age, women of childbearing age (15–49 years) in Zimbabwe experience disproportionate annual HIV incidence (0.67%; 95% CI: 0.39–0.99 vs 0.23%; 95% CI: 0.01–0.44) and have a higher overall prevalence (15.3%; 95% CI: 14.4–16.1% vs 10.2%; 95% CI: 9.5–11.0). Maternal and pediatric ART treatment coverage also lags behind: 87.21% maternal ART coverage in ANC and 72.68% pediatric ART coverage respectively. The poorest quintile of people living with HIV have lower levels of viral suppression.[292]

HIV testing, treatment initiation and viral load monitoring services are most frequently provided in nurse-led primary care health facilities. HIV programmes also include primary care counsellors (who mainly provide HIV testing and counselling services), and community or village health workers who follow up clients defaulting on HIV or TB treatment and refer clients from the community to the facility.[293]

To increase efficiency in implementation and resource utilisation and address the gaps in maternal and pediatric HIV care cascades as required to achieve the goal of virtual elimination of pediatric HIV, defined as MTCT < 5% in breastfeeding populations,[294] HIV services have been fully integrated within routine MNCH services in Zimbabwe.[295] Despite decentralisation and integration of PMTCT and MNCH services, performance on WHO process indicators for validation of EMTCT and ending of pediatric HIV, which require ANC, HIV testing and ART coverage among pregnant and lactating women, and performance along the EID cascade for recommended HIV testing of all HIV-exposed infants 4–6 weeks after birth ≥ 95%[294,296] lag behind.

Spectrum model HIV estimates indicate an increasing MTCT rate, from 6.4% in 2015[297] to 8.9% in 2021.[298] Increases are at least partially attributable to reduced access to health services during COVID-19.[299] MOHCC HIV Positive Child Case Investigation forms completed following an HIV-positive EID HIV test result, together with Spectrum data, indicate early and sustained maternal ART and incident HIV infection in mothers during pregnancy or lactation as primary drivers of MTCT in Zimbabwe.[64,298,300] Strengthening timely and sustained uptake of integrated PMTCT/MNCH services for mothers and infants at each step of the cascade, from pregnancy, labour and delivery to the breastfeeding period, is seen as critical to preventing MTCT and improving maternal and infant survival.[301,302]

2.6.4 Role of NGOs in provision of integrated MNCH/PMTCT services

Funding for HIV services in Zimbabwe is largely though international donors such as PEPFAR and the Global Fund, but also includes some domestic funding through the national AIDS levy, which was introduced by the Zimbabwean government in 1991.[303,304] The HIV response in Zimbabwe is coordinated by the National AIDS Council (NAC) in collaboration with the MOHCC.[303]

In response to a collapsed health system and increasing rates of maternal and infant mortality, funding from donors increased from $167 million in 2009 to $361 million in 2015, with concerns regarding capacity and corruption, and the majority of funds being channelled to NGO programmes.[305] External funding from donors, including PEPFAR, GFTAM, the World Bank and various UN agencies, has been essential for health system strengthening, retention of health workers, procurement and distribution of commodities coordinated and managed through NGO implementing partners.[305]

With the majority of bilateral donor funding being provided to NGOs, a diverse network of NGOs has developed in Zimbabwe. As of June 2022, the National Association of Non-Governmental Organisations (NANGO),the official voluntary coordinating body of registered NGOs operating in Zimbabwe, had a current membership of 1,246 NGOs.[306] A mapping of civil society organisations in Zimbabwe conducted by UNDP and UNAIDS in 2019 identified 327 HIV/AIDS and integrated health service organisations.[307]

NGO programmes have been engaged in all levels of HIV and MNCH programming in Zimbabwe, including training of health care workers, support for management of commodity chains, and community-based interventions to improve access and uptake to essential health services across the integrated PMTCT/MNCH cascade.

2.6.5 OPHID programmes, PhD research starting points and grounding determinant framework

2.6.5.1 NGO programme

The Organisation for Public Health Interventions and Development (OPHID) is a local organisation that develops and implements innovative approaches and strategies to strengthen HIV and MNCH services in Zimbabwe, providing enhanced access for communities to comprehensive HIV and complementary MNCH and SRH services. OPHID, previously known as the Institute of Public Health, Epidemiology and Development (ISPED) of Bordeaux, France, has been supporting the MOHCC in the implementation of the national PMTCT and related MNCH programmes since 2001. OPHID has a Memorandum of Understanding (MOU) with the Zimbabwean MOHCC to improve people's access to quality public health services as outlined in the National Health Strategy[293] and works embedded within MOHCC structures, with an emphasis on strengthening of community-based and health system structures at all levels.

OPHID programmes are implemented at both facility- and community-based levels, with geographic scope and programme content determined by MOHCC and funding agency priorities. OPHID's primary source of funding comes from USAID through PEPFAR to support subnational programmes to enhance the provision of comprehensive HIV prevention and care services in high-burden priority districts, first through the Families and Communities for Elimination of Pediatric HIV (FACE HIV; 2012–2020) programme and then the follow-on Target, Accelerate and Sustain Quality Care (TASQC) for HIV epidemic control (2020–2025) programme in Zimbabwe. These programmes were aimed/aim to contribute to the achievement and sustainability of HIV epidemic control in Zimbabwe through the provision of technical, financial and material support for the management, coordination and provision of comprehensive clinical care services within the Zimbabwe national HIV programme, including integrated maternal, newborn and child health services.

Over this same period, additional funding from donors including UNICEF, the Australian Department of Foreign Affairs and Trade (DFAT) and the European Commission supported programmes to strengthen continuity of care across the PMTCT/MNCH cascade of care and improve community–facility linkages and quality of services received. These programmes conduct community-based health promotion and outreach, building capacity of both OPHID-supported community cadres, Community Outreach Agents, and MOHCC VHWs to strengthen community-facility referrals and linkages.

2.6.5.2 PhD research starting points

It is in this context that, in 2012, I led a descriptive retrospective study of reasons for home delivery in Mashonaland Central Province, the province with the highest rate of non-institutional births in Zimbabwe,[308] to identify gaps and missed opportunities in order to inform PMTCT/MNCH programme implementation to increase facility-based delivery. This operational research study administered a standardised questionnaire among 360 women who had delivered at home in the previous six months at OPHID-supported facilities to capture the characteristics of and self-reported reasons for home delivery.[309] Findings highlighted discrepancies between women's responses, existing policy and expressed intentions to take up facility-based delivery vs behaviours at the time of delivery.[310] Despite policies to abolish maternal user fees, the most frequently cited reason for home delivery was user fees (52.1%). The study provided useful evidence regarding conditions of limited infection control or safe delivery practices and unskilled birth attendance (traditional birth attendants or untrained VHWs were present at 58.9% of home births) to inform the health promotion strategies of OPHID's community-based MNCH and PMTCT programmes. However, the study had multiple limitations, which restricted translation of the Home Delivery Study findings into evidence-informed programme action. These limitations included the limited use of theoretical frameworks in the study design and the use of a structured questionnaire to capture the broad range of social, structural, economic and individual circumstances, and lack of in-depth qualitative data to better understand the possible permeations of the combined effects of vulnerability across socioecological domains.

Over this same period, the coverage of EID by six weeks of age was estimated to be as low as 45%,[311] with documented disparities in uptake of services across the PMTCT cascade in both population-based surveys[312,313] and routine programme data. Given this, improving the accurate determination of EID completion among HIV-positive mother-HIV-exposed infant pairs was a programme priority.

Methodological challenges in for reliably ascertaining individual-level service outcomes across the PMTCT/MNCH cascade at the facility-level included missingness and quality of health register completion and inability to reliably trace mother–baby pairs across multiple registers due to reasons detailed in Section 2.5.3. At community-level, weak systems, training and capacity for timely identification of defaulters for tracing and standardised documentation of tracing outcomes by village health workers precluded true rates and reasons for suboptimal uptake of services by pregnant and lactating women, used to measure the performance of OPHID programmes and national policy goals.

Further, despite suboptimal programme performance for these critical PMTCT/MNCH cascade services, no robust programmatic or research evidence existed from the user perspective on the reasons for failure to uptake services. Or more specifically, the non-user perspective of women who failed to uptake facility-based delivery for a recent birth or failed to bring their HIV-exposed infant to the clinic for EID testing, despite large scale community- and facility-based programmes to support access, uptake and quality of care. The perceived reasons for failure to uptake services among women with poor care or treatment adherence are essential for NGO programme remediation in context to support care engagement.[314,315]

2.6.5.3 Grounding determinant framework for this thesis

This research in this thesis is informed by both improvement, programme and implementation science approaches. Specifically, this thesis uses the Health Equity Implementation Framework as a grounding determinant framework to explore the persistent challenge of rural women's suboptimal access to EBIs along the MNCH/PMTCT in rural Zimbabwe. With research embedded within OPHID's existing PMTCT/MNCH programmes the scoping review and two case studies in this thesis seek to explore the role of the NGO response in maternal and child health. Theoretically informed embedded research sought to improve accuracy of estimates on service and client outcomes and expand upon existing determinant frameworks to explore the mediating factors for uptake of essential maternal health services from the user perspective (Figure 2.7).[134]

To better understand the true uptake, reasons and experiences of women who had had a non-institutional birth or failed to uptake EID for their HIV-exposed infants, the PhD thesis first employed steps in health disparity research as outlined in Section 2.1.7.3:

Phase 1: detecting – use of routine OPHID programme data to identify geographies implementing PMTCT/MNCH programmes with high rates of non-institutional deliveries and low coverage of EID for HIV-exposed infants as justification for selected EBIs for IS-informed embedded research on true outcomes, reasons for non-use and lived experiences of women.

Phase 2: understanding – scoping review of the role of NGOs and two case studies sampling 'non-adherers' of recommended practice to better ascertain true service outcomes and understand the experiences and reasons for failure to uptake services despite NGO programmes to support access and uptake.

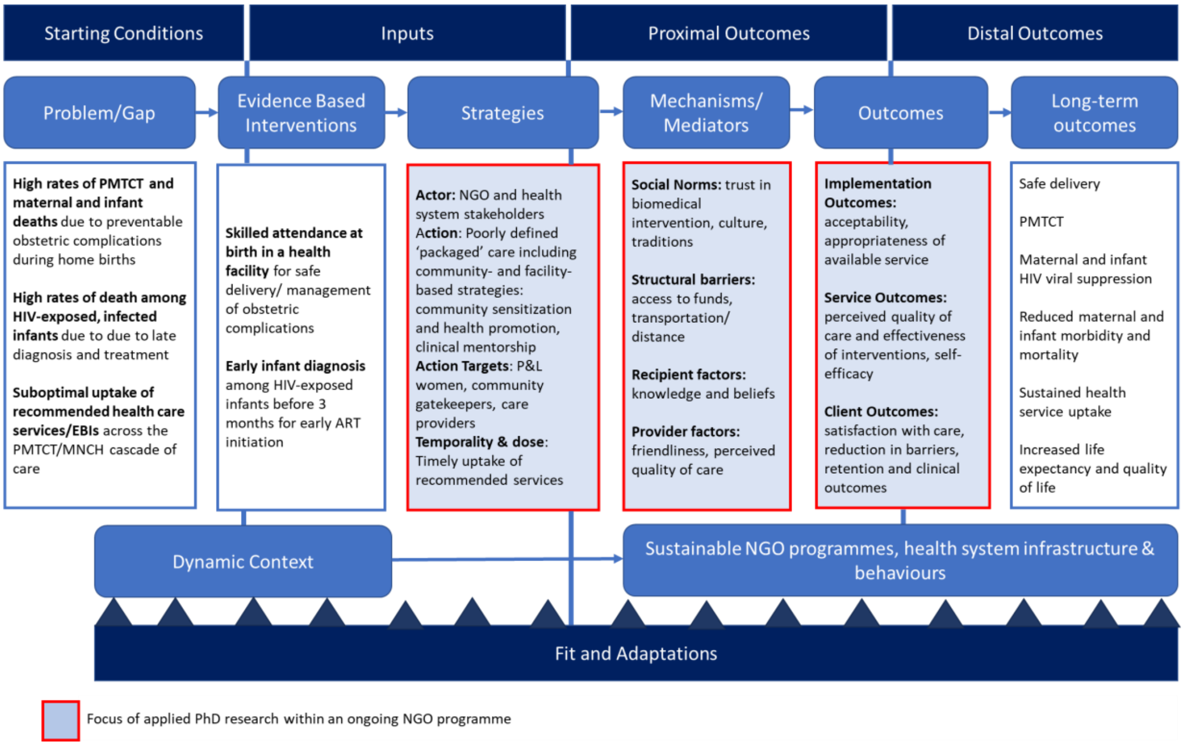


Figure 2.7 Logic model of dissemination and implementation PhD thesis project *Adapted from Proctor et al[96,115]; Woodward et al[136]. Figure adapted from planning tools at https://dissemination-implementation.org[316]

The purpose of the applied research in this thesis is two-fold:

1) To generate evidence for **Phase 3** research and actions to **reduce health disparities**[134] within an existing NGO programme and expedite the research-to-practice timeline. The research sought to utilise evidence to develop context-appropriate adaptations of implementation processes and strategies that may be beneficial for vulnerable pregnant and lactating rural women at risk of suboptimal uptake of EBIs across the PMTCT/MNCH cascade.

2) To contribute to evidence and operational models on the role of NGOs within HIV and programme/IS and advancement of determinant TMFs through IS-informed

research grounded in the Health Equity Implementation Framework. This framework is appropriate as can be used to systematically assess health equity and implementation determinants simultaneously.[137]

Table 2.2 provides operational definitions for each of the elements of the Health Equity Implementation Framework[136] in reference to this PhD research project.

Table 2.2 Matrix of determinant factors within the Health Equity Implementation Framework as grounding framework for research in this thesis[137]

Health Equity Implementation Framework element	Definition for purposes of this PhD research
Innovation factors	Evidence based interventions along the MNCH/PMTCT cascade (i.e., skilled birth attendance to reduce birth complications that contribute to maternal and infant morbidity and mortality, timely EID at 6 weeks for all HIV-exposed infants for early identification and initiation of HIV positive infants) that is delivered in a clinical encounter. Measurement of successful implementation done by NGOs may be done through programme science using routinely collected programme data. Implementation science methods measure three distinct but interrelated implemented outcomes including implementation, service and client outcomes.[96]
Clinical encounter	Includes the interaction between a P&L woman and the provider of the evidence-based intervention (i.e., clinic nurse) and all communication during that visit. This may include experience of antenatal care or previous childbirth at the clinic, or counselling provided to HIV positive women regarding timing and importance of EID services.
Facilitation	Intervention facilitation is an essential active process to ignite change to any of the elements or factors. Facilitation in the context of this PhD research represents NGO-delivered programmes to enhance coverage and equitable access to evidence-based MNCH/PMTCT interventions. Specification of NGO intervention facilitation requires clearly defining the role of NGO in EBI delivery, and specification of intervention strategies. NGO facilitation includes developing and implementing implementation strategies to overcome identified barriers to access and uptake EBIs through NGO-delivered programmes.[115] For example, OPHID community-based programmes to increase demand and uptake of facility-based delivery which include health education and promotion

	on PMTCT cascade and importance of timely EID, to programmes to identify and support vulnerable P&L women at increased risk of defaulting from care or non-adherence to recommended treatments.
Recipient factors	
Patient factors	Beliefs, preferences, culture and community strengths or limitations, health literacy or biology of pregnant and lactating women that may influence their ability to access and uptake essential health services. Individual sociodemographic determinants (age, wealth quintile, religion, parity) and access to social support of rural women that act as barriers to service uptake.
Provider factors	Health care worker and other MNCH/PMTCT service providers (such as Village Health Workers) skills, capacity, knowledge and beliefs influence on the clinical encounter. This might include training and competency to provide quality BEmONC for safe deliveries, knowledge about vulnerable pregnant and lactating women in their community that may be at increased risk of home delivery or failure to uptake health services such as EID in a timely manner, attitudes or bias towards groups and competing demands in low resource context.
Other recipients	Other recipients include individuals who affect the delivery of an intervention. In the context of this thesis, other recipients may include both health system stakeholders and decision-makers (i.e., provincial medical directors, or district medical officers who manage health care workers and monitor quality and implementation fidelity during the clinical encounter). Other recipients may also include community-based gatekeepers (i.e., male partners, traditional and religious leaders) that are custodians of social norms and control resources required for women to access and uptake MNCH services.
Context factors	
Inner context	
Local level (clinic or unit or ward depending on facility size and infrastructure)	Clinic-level inner context factors include facility-based influences which may impact the client encounter. This may include available both human (availability and number of trained staff in BEmONC) and infrastructural or material resources (i.e., POC machine for EID, blood availability for maternal hemorrhage during childbirth, maternity waiting homes, consistent access to power or water for machine functionality and maintaining hygiene and infection control), or operational characteristics (clinic operating hours to conduct deliveries at night), and implementation dynamics (i.e., management style of nurse in charge, interpretation and operationalization of new program and policy guidance in practice).

Organisational level	This can include national and district leadership support for feedback processes (reporting requirements into national health information systems), the structure of a system, or any formal policies to embed change within a practice (such as new EID testing algorithms, or MNCH policies banning training of traditional birth attendants) and interpretation of those policies.
Outer context	
Heathcare System	Outer context factors might include incentives or mandates (such as removal of user fees for maternal health and HIV services) and environmental (in)stability of a political, economic, or cultural nature within the healthcare system (i.e., domestic and international donor funding, political appointments or changes in leadership within the health system).
Societal influence	Societal influence includes the economies, policies, and sociopolitical forces within which rural women, communities, health care providers and other community-level actors providers are living and influence attempt to be healthy or provide healthcare (i.e., Zimbabwe hyperinflation, political instability)

It is in this context that my PhD research was conducted.

2.7 Summary

The role of NGOs in global public health has evolved and expanded over the past century. The emergence of GHIs to attain universal health coverage and control of communicable disease epidemics has established NGOs as recognised ‘third state actors’ in the public health response of many LMICs. The geographic areas of operation, programme aims and monitoring frameworks of NGOs are led by the demands of their funders, which largely mirror the primary drivers of excess morbidity and mortality.

Despite their important supporting attainment of GHI goals, the heterogeneity of the organisations and their roles generally, and within defined areas of public health action, have resulted in fragmented public health responses and siloing of programmes into disease-specific areas. Limitations of routine data sources and limited use of IS theories, methods and frameworks to guide and document outcomes and impact of NGO programmes result in missed opportunities to improve evidence-based practice.

Over the past two decades, the majority of GHI funding has been invested in HIV and MNCH programmes in SSA designed to reach HIV epidemic control and reduce maternal, newborn and child morbidity and mortality. Accordingly, based on research embedded in the routine HIV and MNCH programme activities of a local NGO in Zimbabwe, this thesis will focus on two priority programme areas: increasing uptake of facility-based delivery, and early infant diagnosis. I will first seek to explore and better define the role of NGOs in the HIV response. Case studies presented will demonstrate the use of mixed-method IS-informed research embedded in routine NGO programmes to improve evidence on the rates of and reasons for suboptimal uptake of evidence-based public health interventions to inform programme strategies improve maternal and child health in Zimbabwe.

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3. Exploring recent evidence on the role of the non-governmental sector in the HIV response

3.1 Introduction

As detailed in my literature review chapter; while NGOs play a prominent role in the global health funding and implementation landscape, this role is poorly defined and lacks methodological rigour to meaningfully contribute to the global health evidence-base both across and within disease-specific responses, such as HIV.[1,2] As such, there is need to systematically explore the evidence-base on the role of NGO-implemented programmes as facilitators of public health interventions.[3] This evidence is required to optimise NGO programmes intended to enhance the coverage, quality and equity of EBIs and their public health impact.

The case studies within this PhD Thesis are embedded within the routine HIV and maternal, newborn and child health programme activities of a local NGO based in Zimbabwe. Accordingly, the aim of this scoping review was to broadly explore the recent role and contribution of the non-governmental sector in the HIV response. There is noted inequity in the global health metrics enterprise which transfers power from institutions in low-income countries to ones based in high-income countries privileges certain forms of knowledge over others.[1] Given such inequities limiting engagement of NGOs and local stakeholders in global public health research, this review engaged a multidisciplinary group of activists, advocates, local NGO programmers and scientists in the design, analysis and interpretation of key themes and their implications for public health action.

The findings from this unpublished scoping review will be used as a guiding framework to inform methodological approaches of case studies integrating programme science and relevant TMFs into routine NGO programming and inform the critical analysis of the role of NGOs in the global health response in the chapters that follow.

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3.3 Research paper 1: Role of the non-governmental sector in the HIV response and implications for transdisciplinary implementation science: a scoping review

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First Name(s)	Karen		
Surname/Family Name	Myllynen Webb		
Thesis Title	Mixed-method implementation science approaches within routine non-governmental programmes to improve maternal and child health in Zimbabwe		
Primary Supervisor	Dr. Melissa Neuman		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

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Stage of publication	**Not yet submitted**

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For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	I was first author of this paper. I wrote the first draft and did led on the study design, implementation and analysis plan for the manuscript. I incorporated all the feedback from co-authors and will lead on the submision of the manuscript to the journal. I will be responsible for responding to all the reveiwer comments and resubmission after peer review.

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COVER PAGE

Title: Role of the non-governmental sector in the HIV response and implications for transdisciplinary implementation science: a scoping review

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ABSTRACT

Purpose of Review:

Non-governmental organisations (NGOs) have been central actors in the HIV response since the start of the HIV epidemic, though the role of NGO sector is broad and poorly defined. We searched PubMed, in addition to hand-review of key journals identifying research pertaining to the relative contribution of the non-governmental sector to the HIV response over the past 7 years from 2015-2022.

Recent Findings:

The non-governmental sector has catalysed advocacy and activism for marginalised and key populations; provided direct provision of HIV prevention, care and treatment services; and implementation and technical assistance to national HIV responses. There is limited representation of NGOs, particularly local NGOs, within published evidence reporting on the design, adaptation, translation, dissemination and implementation of evidence-based HIV interventions.

Summary: Transdisciplinary implementation science frameworks provide an opportunity for specifying and optimising the important roles of the non-governmental sector in the HIV response, to bridge the gap between evidence-based interventions and programme practice, and enhance implementation, service and client outcomes to reach and maintain national and global HIV epidemic control.

Keywords: Non-governmental organisation, HIV, transdisciplinary, implementation science

1.0 INTRODUCTION

Early in the epidemic, the impact of the HIV upon not just the health, but economic and social wellbeing of affected nations and regions was recognized as requiring a multi-sectoral response.[1] Non-governmental Organisations (NGOs), defined as "self-governing, private, not-for-profit organisations that are geared to improving the quality of life for disadvantaged people",[2] are recognised key third sector actors in development and public health action.[3] The contribution of NGOs to the multi-sectoral HIV response is wide-ranging and evident at multiple levels, from community-based support through local grassroots organisations, to large national, regional and international policy, programme and research initiatives.[4]

While the presence of NGOs has become ubiquitous within global public health, humanitarian and development responses; it remains a poorly defined sector.[5] The NGO sector is highly heterogeneous, composed of a diverse collection of organisations, networks, and alliances.[1] They range in size from individual community-based organisations led by volunteers and activists, to complex organisations with global footprint and annual revenues of $1 billion or more.[6] While there are few comprehensive or reliable global statistics, estimates of the number of NGOs receiving funds from a range of philanthropic and bilateral donors are upwards of 200,000 organisations, but if including informal/community-based NGOs could be more than one million organisations worldwide.[7]

The non-governmental sector has been at the core of the HIV response from its inception. This is evidenced by the UNAIDS Programme Coordinating Board being the only governing body in the UN system that includes formal participation by civil society.[8] The scale up of United States Government's President's Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund to Fight AIDS, TB and Malaria (GFATM) in the 2000s resulted in a 'NGO-boom' in many high prevalence settings over the past two decades.[9] In 2019, 77% of the PEPFAR 6.9-billion-dollar global investment towards the HIV response was distributed bilaterally,[10] with the majority of these funds channelled to non-governmental partners implementing field and country programmes.[11]

Given increasing calls for the use of implementation science within routine programmes to promote evidence-based interventions (EBIs) and document and disseminate adaptations in context,[12] NGOs also act as critical stakeholders for the translation (and potential production) of scientific evidence.

As global and national health initiatives strive to reach the end of AIDS and shift towards sustainable investment in local organisations and national health system strengthening, a review of recent evidence on the contributions made by NGOs in the HIV response, and lessons for optimising equity and impact of evidence-based HIV programmes is both timely and necessary. Accordingly, the aim of this scoping review was to identify and thematically map the available evidence on the non-governmental sector's contribution to the HIV response from January 2015 to July 2022. A secondary objective was to collate lessons learned to identify gaps and opportunities for optimising the contribution of the non-governmental sector towards evidence generation and implementation of effective and equitable evidence-based interventions (EBIs).

2.0 METHODS

Review Approach

We conducted a scoping review[13-15] to identify existing evidence of the role of the non-governmental sector in the HIV response. The primary research question was: *What is known about the role and contribution of the non-governmental sector in the HIV response from January 2015 to July 2022?* Given the rapidly evolving landscape of HIV as countries approach attainment of policy goals of HIV epidemic control and elimination of mother to child transmission,[16,17] our objectives were to identify and explore emerging themes related to the nature of NGO involvement, and reflect on existing evidence in terms of promising practices, gaps and opportunities for future research and practice. Recognizing the diversity of actors within the NGO sector and to minimize the influence of situated intersectionality[18] upon researcher bias in the selection and interpretation of articles reviewed, we engaged a multidisciplinary research team. As such, this paper is equally directed at a wide audience of actors working in the field of HIV including policymakers, implementation researchers and health system stakeholders and NGO practitioners.

We followed established methodological frameworks for conducting scoping reviews through a five-step procedure that involved articulating a research question, identifying relevant studies, selecting studies, charting the data, and summarizing the findings[19] and reporting guidelines using the PRISMA Extension for Scoping Reviews (PRISMA-ScR).[20]

Identifying Relevant Studies

We adopt the structural and organisational features for the definition of NGOs used by Masefield and colleagues: private or non-state; self-governing; formalised; and not-for-profit organisations.[21] Expert consultation was conducted with co-authors who have knowledge of health systems, research, advocacy and NGO programming, and pilot searches were conducted in several domains to refine key terms. Given that the non-governmental sector is generally poorly defined and includes a diverse membership, we used broad methodology and search terms (Table 3.1), while recognizing this list is not exhaustive and includes purposive exclusions. For example, while not-for-profit universities and research institutes can be included within a broad definition of non-governmental organisations, these bodies focus on scientific inquiry as opposed to routine HIV programme implementation, and as such are more traditionally associated with the published research and literature in the field of HIV. Similarly, articles describing multilevel and intergovernmental humanitarian organisations' role in the HIV response (United Nations Agencies, World Health Organization, and International Federation of Red Cross/Red Crescent) were excluded.[21]

Table 3.1 Scoping review search terms
Search terms "non-governmental organisation" OR "NGO" OR "non-profit organisation" OR "not-for-profit organisation" OR "private voluntary organisation" OR "faith-based organisation" OR "civil society" OR "community-based organisation" OR "grassroots" OR "charity organisation" OR "social movement organisation" OR "implementing partner" **AND** "HIV" OR "AIDS" OR "HIV/AIDS"

The Pubmed Database was searched and peer-reviewed articles published in English from January 2015 to July 2022 describing HIV programmes or interventions implemented by NGOs, outcome or impact evaluations from NGO programmes or interventions were included. To capture the breadth of evidence, we did not restrict our inclusion criteria based on article type (review, commentary, editorial, research), study methodology (quantitative or qualitative) or geography (high-, low- and middle-income countries). Included articles references were manually searched to identify additional articles or grey literature through pearling. Highly relevant research articles and evidence reviews identified through manual searches and other sources that specifically explored the role of NGOs in the HIV sector were included in the analysis even if they fell outside of the recent period of interest.

Searches were conducted by KAW in Pubmed (last searched 1 November 2022). The Pubmed data was searched and was restricted by year of publication (January 2015-July 2022). From the search, identified peer-reviewed citations were abstracted, uploaded and organised in EndnoteX5.0.1. Following de-duplication, titles and abstracts were screened for eligibility. Distinct from systematic reviews in the absence of a priori article criteria; our scoping review inclusion criteria was purposefully broad and intended to gain an appreciation of the breadth of available evidence on the role of NGOs in the HIV response. Articles that reported NGO involvement in HIV-related programming, research or policy initiatives were included. Articles that did not report on NGO activities and/or were not related to the field of HIV were excluded.

With the purpose of mapping and exploring the published evidence base, scoping reviews do not generally include a formal assessment of methodological limitations or risk of bias.[22] Further our objective was to explore the roles of NGOs as opposed to the effectiveness of NGO programmes which would should necessitate quality assessments in systematic reviews.[23,24] Accordingly, we did not include an assessment of quality as part of our inclusion/exclusion criteria, however, we did document reported limitations in articles reviewed within our charting framework.

Charting Data

We exported key characteristics of selected articles (title, authors, journal, publication type, year of publication, region and country) into an MSExcel spreadsheet for data abstraction and charting. We applied additional charting of abstracted data into the following coding categories: Year of Publication, Region, HIV Response Role, NGO Role in Publication, Key Findings/Lessons and Limitations. Charting data were imported into StataSEV15 for descriptive quantitative analysis.

Analysing and Summarising the Data

Directed content analysis was employed to group articles into key emergent themes relative to the non-governmental sector's role in the HIV response through analytical techniques including textual searches and contextual analyses including historical and stakeholder reflection[24,25] Additional emergent themes were coded into sub-themes through deductive reasoning. Given the broad nature of search terms as a multidisciplinary analysis team we individually and collectively reflected on the findings and identified other known sources of evidence relevant to our research question not captured through our search strategy relative to our areas of expertise and experiences supporting the Zimbabwean national HIV prevention, care and treatment programme.

3.0 FINDINGS

We identified 1,211 peer-reviewed abstracts and 692 were advanced to a full-text review. Of the 692 articles that underwent full-text review, 38 met the inclusion criteria (Figure 3.1). An additional 39 papers were identified through manual searches and reviewer recommendations.

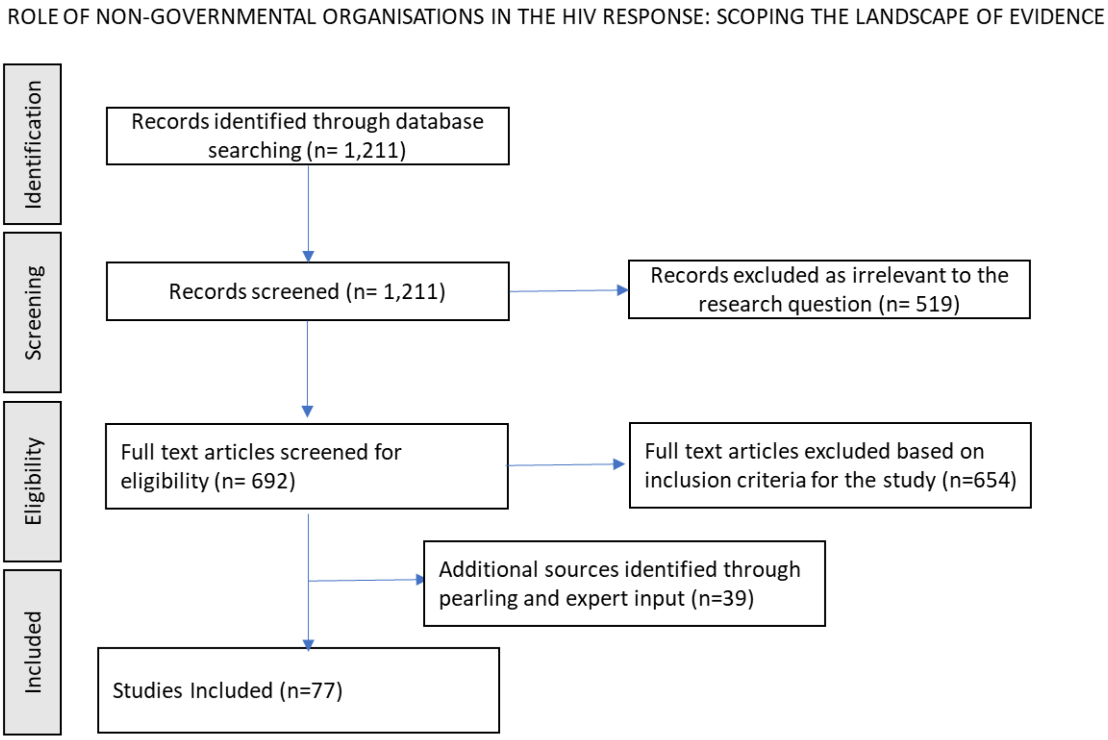

Figure 3.1 PRISMA flow diagram of the research review process

Among the 77 fully reviewed articles, the majority were linked to NGO programmes implemented in Africa (42/77; 55%), followed by global systematic review or editorials (20/77; 26%).

Emerging Themes

We identified three overarching themes representing a typology of roles played by the non-governmental sector in the HIV Response as: 1) Catalysts; 2) Implementing Partners, and 3) Evidence- and Policy-Users and Makers.

THEME ONE: NGOs as CATALYSTS

Subtheme 1.1 NGOs as Advocates and Activists

The non-governmental sector's involvement in the HIV response was borne from activism and civil society mobilization, primarily led by civil society organisations (CSOs). Parker outlines three historical phases of advocacy within the HIV movement: from initial activism to mobilise government action and decrease HIV-related stigma which lasted into the mid-90s, to advocating for treatment access and health equity, to more diffuse global and localized advocacy platforms for treatment scale-up and increased representation among key affected populations.[26] The impact of activism-elevated awareness of HIV treatment literacy and treatment access movements on a global scale played a large part in prompting the remarkable surge of international HIV funding between 1999 and 2008 through mechanisms including GFATM and PEPFAR.[27]

More recently, Williamson & Rodd[28] reported that non-governmental sector advocacy generally fell into two broad categories: organisations providing a mix of advocacy and service provision, such as the Planned Parenthood Federation, and networks of CSOs such a Networks of People Living with HIV that provide peer-based support and community-based monitoring of HIV service access and quality. NGOs involved in HIV advocacy work are recognized as playing an important role in ensuring meaningful representation and sharing the lived experiences, needs and preferences of PLHIV for socially and culturally relevant HIV programming and peer support.[29] While evidence exists on the impact of HIV advocacy efforts on shifts in social norms, there is a noted lack of methodologically rigorous published evidence on the effectiveness of such efforts upon individual-level clinical outcomes such as HIV transmission risk or treatment adherence.[28] In their case study of Vietnamese NGO involvement in transnational HIV advocacy, Pallas and Ngyuen[30] highlight what evidence does exist often reports North-South partnerships and while Southern NGOs have expanded their advocacy, research capacity and resource base over the past two decades, little research has been done on their potential to target non-domestic actors without the aid of Northern NGOs or academics.

The evolution of HIV advocacy from "case advocacy" to "cause advocacy", most often led by people living with and other key affected and at-risk populations is also acknowledged as possessing important lessons for other areas of public health with growing disease burden and barriers to care driven by stigma and marginalisation, such as non-communicable diseases.[31] However, the dangers of wholesale adoption of HIV/AIDS advocacy strategies and inappropriately 'universalising' global health strategies has been noted, when HIV, as with other areas of global health concern, consists of a multitude of diverse epidemics which require nuanced advocacy and activism in context.

Subtheme 1.2: NGO Autonomy for Advocacy in Context of Political and Donor Demands

As international funding has increased, multiple articles articulated concerns regarding the capacity of NGOs to maintain their advocacy and activist standpoints while meeting the ‘conditions’ of governments and donors. Such conditions may limit the involvement of NGOs and civil society engagement in some settings in rights- and equity- advocacy.[32] A poignant recent example of this tension was the impact of the Protecting Life in Global Health Assistance (PLGHA) – an expansion of the Mexico City Policy (MCP), or “Global Gag Rule”, - which prohibited non U.S.-based NGOs from funding if they advocated, provided, counselled, or referred clients for abortions, or crucially for advocacy organisations, lobby for the liberalisation of abortion law.[33,34]

The impact of PLGHA upon NGO funding and activities resulted in the reported “chilling effect”,[35] the reduction and fragmentation of HIV and sexual and reproductive health service delivery globally, with examples cited in Africa[36] and Asia,[37] as well as the reduction in advocacy and coalition spaces for reproductive health and rights.[38] A risk index analysis of de-integration of family planning and HIV services conducted by Sherwood et al, demonstrated countries with the highest risk scores were also in the top quartile of PEPFAR countries for HIV prevalence and unintended pregnancies among young women.[39] Kavakli and Rotondi’s recent analysis of country-level data from 134 countries between 1990 and 2015 demonstrated both macro country-level and micro individual-level effects of the MCP including significantly higher maternal mortality and HIV incidence and reduced exposure to individual-level information on family planning and HIV when MCP was in effect, a relationship magnified by greater dependence of many NGOs in LMICs on US funds.[40]

Linked to issues of autonomy and donor dependency is the documented climate of funding competition created between local NGOs which may compromise collaboration and pursuit of local priorities. An ethnographic study among 26 NGOs working on gender and HIV programming in South Africa noted how funding insecurity and competition leads NGOs to forego interventions informed by knowledge of local context in order to meet the needs of international donors.[41]

Subtheme 1.3 Critical role of NGO and Civil Society Advocacy in Reaching and Maintaining Epidemic Control

In their review of the role of civil society for demanding accountability for reaching UNAIDS 90-90-90 (now 95-95-95) goals in East and Southern Africa, Russel and colleagues outline three vital functions NGOs/CSOs play: unlocking decision-making processes monopolized by powerful funders through North-South networks; challenging dominant ideas that justify status-quo policies; and 'venue shifting' to institutionalize new, more open spaces for policymaking.[42] Indeed, the International AIDS Society (IAS) and Lancet Commission on advancing global health and strengthening the HIV response in the era of the Sustainable Development Goals identified the rejuvenation and empowerment of a new ‘wave of HIV activism’[43] as a critical element of the future of the HIV response.[44]

The success of such renewed activism will in part be determined by the democratic and rights-based views of NGO and civil society’s acceptable role within national HIV responses, such as holding governments accountable for providing services, ensuring equity of access among key and marginalised populations, and donor support to promote policy changes based on emergent expressed needs of the most affected. In their examination of the GFATM programme management in Botswana, Molosiwa and colleagues[45] emphasise there is a delicate balance to enable the nimbleness and capacity of NGOs and civil society to respond and effectively coordinate national HIV programmes and avoid bureaucratisation of the HIV response.

THEME TWO: NGOs as IMPLEMENTING PARTNERS

Subtheme 2.1 NGOs as Direct Service Providers & Technical Assistance Partners

The majority of published literature reviewed (n=41/77; 53%%) described the role of NGOs in reaching vulnerable and key populations to provide co-located HIV awareness and stigma reduction, and improve linkages to HIV prevention, testing and treatment services. Articles reviewed most frequently cited the role of NGOs within intervention studies as providing outreach and community-based HIV services for key populations facing stigmatisation, systemic exclusion and/or criminalisation, and those in remote or underserved areas.[46]

Published examples of NGOs as insiders with capacity to reach hidden or vulnerable populations including HIV outreach and services were reported in multiple settings. These described NGO-led implementation within communities to improve equitable access to services, and in the creation of safe-spaces. Examples include NGO involvement in community-based outreach for men who have sex with men (MSM) in China,[47,48] transgender women in Latin America,[49] integrated HIV testing and treatment at addiction treatment centres in Ukraine,[50] support groups for adolescents living with HIV,[51] for female sex workers in South Africa and Zimbabwe, [52,53] among disenfranchised, minority and diasporic communities in Canada,[54] to

HIV service provision to remote communities via a mobile ship clinic 'The Amazon Hope' in Peru.[55]

The current emphasis on scale up of differentiated service delivery (DSD) models that provide patient-centred, decentralised services to achieve sustained engagement in HIV care, is recognised as requiring task-shifting and the increased involvement of community-based organisations and health systems.[56] Given their ability to access affected communities, NGOs are reported as playing a central role in leading the expansion of DSD models at scale, and strengthening linkages between community- and facility-based services across the HIV care cascade. Recent examples include NGO involvement in the community-based distribution of over half a million HIV self-test (HIVST) kits in Malawi, Zambia and Zimbabwe through the Self-Testing AfRica (STAR) Initiative, reaching a high proportion of men, young people and first-time testers;[57] efforts to improve cumulative linkages between HIV testing and treatment in South Africa and Uganda;[58-60] and index-based HIV testing;[60] active defaulter tracing and return to care of mother-infant pairs lost to follow up for early infant diagnosis for improved outcome estimates; [61] and synthesis of routine data for improved estimates of performance across the HIV care cascade and clinical outcomes.[62,63]

While NGOs, particularly community-based NGOs, play a critical role in scaling DSD models, an important caveat in the literature is the ability of small, grassroots NGOs to build the capacity to meet the conditions to apply for and access funds. In their survey of 212 NGOs working within the HIV sector within 8 provinces of China, Wang and colleagues suggest that lack of social capital among unregistered NGOs reduces perceived legitimacy among donors and their capacity to manage funding, which limits NGO access to funding and ability to implement needed community-based programmes.[64]

NGOs are also actively involved in the provision of technical assistance and health systems strengthening within large-scale programmes, particularly in resource constrained settings. NGOs also play an important role in providing comprehensive care where HIV services have not been decentralised, or capacity within the health workforce is lacking. Examples include private voluntary clinics in Harare, Zimbabwe managing patients switching to third-line antiretroviral therapy,[65] multi-dimensional case management models for improving ART linkages and treatment outcomes,[66] and provision of dedicated PrEP, HIV testing and treatment services for key populations including female sex workers (FSW), men who have sex with men (MSM), transgender people (TG), persons who inject drugs (PWID), and people in prisons and other closed settings through community-based and dedicated NGO-run private clinics across sub-Saharan Africa.[67]

In a qualitative examination of the limits of neoliberalism upon health systems for HIV and COVID-19 care and treatment in Malawi, Zhou[68] highlighted how parallel NGO systems of care have become grafted onto public healthcare in many high prevalence settings, with NGO activities managing HIV supply chains, management, data systems, and providing services which are confined within donor priorities. Such NGO-health systems functional dependencies underscores the need and challenge faced by health systems to coordinate a wide range of implementing partners and ensure centralised reporting.

Subtheme 2.2: NGOs as decentralised actors for ensuring continuity of HIV care in emergent crises

Evidence of NGO activities during the COVID-19 epidemic further underscored their critical role. In particular, due to their highly decentralised and community-based presence, NGOs play an important role for ensuring continuity of HIV prevention and treatment services in the context of emergent epidemics, or other conditions that may limit human movement or disrupt service provision (i.e., political unrest, climate change effects). During COVID-19 lockdowns, NGOs facilitated rapid programme innovation and adaptations for case-finding, acceleration of DSD approaches such as multi-month dispensing, expansion of community-based ART delivery, and decongestion of health facilities sought to both limit SARS-CoV-2 transmission while ensuring the continuity of prevention and treatment access.[69] Specific examples reviewed included community-based HIV prevention and treatment services for sex workers in India and Thailand,[70,71] while protecting the immense gains towards HIV prevention, testing and treatment policy objectives.[72] Indeed, in their editorial to a JIAS supplement on differentiated service delivery (DSD) for HIV during COVID-19, Grimsrud and colleagues note one of the few 'silver linings' of the COVID-19 pandemic, was the rapid expansion of DSD models for client-centred HIV care and treatment services including virtual support through mobile phones, extended ART refill as new standard of care, and demonstration of value of DSD for not just HIV care and treatment.[73] Such programmes primarily implemented through NGOs working in collaboration with national health systems.

Subtheme 2.3: Sustainability of NGO-led HIV programme implementation

Multiple papers reviewed raised questions regarding the sustainability of NGO's central role in national HIV responses in the face of global reductions in HIV funding from international donors. Pfeiffer and colleagues highlight that austerity constraints on public sector health systems and channelling of funds through NGOs in Mozambique, while yielding policy gains towards 90-90-90, have also resulted in the stagnation of public sector health system coverage and workforce/population ratio.[74] The authors emphasise that sustaining HIV epidemic control in countries dependent on donor funds will require rechannelling of aid away from NGOs and towards the public health systems.

While NGO support as implementing partners is recognised as strengthening health systems, Munjangaju and colleagues[75] cite the influence of NGO recruitment leading to 'internal brain drain' in Mozambique, where health care workers in the public system seek out higher paying jobs within NGOs. Similarly, Bemelman et al's review detailing the important role of NGO-supported programmes in supporting lay cadres to expand HIV testing and counselling and adherence support in eight sub-Saharan African countries, found that formal integration of community-based outreach cadres into national health systems is limited, as lay counsellors are usually not included in national strategies or budgeting.[75]

Subtheme 2.4 – NGOs & transitional funding plans

In efforts to build sustainable transition plans and country ownership of the HIV response, in 2018, the U.S. State Department's Office of the Global AIDS Coordinator announced a target that 70% of funding received by a country from a PEPFAR implementing agency must be provided to local prime implementing partner, primarily NGOs.[76] While the total proportion of PEPFAR partners that are local reached the 70% benchmark by 2020, the proportion of PEPFAR funds going to local partners lagged at 54%.[77]

Challenges onboarding of new local partners can be linked to structural inequalities between large international NGOs and smaller local NGOs and CSOs, who often lack the infrastructure, administrative and technical capacity receive funding from large donors.[78] Capacity building, institutionalizing mechanisms for civil society participation, planning for information needs, and flexible funding are priority actions.[79] Donors such as USAID and PEPFAR are responding through initiatives such as their Accelerating Support to Advance Local Partners (ASAP) initiative which provides customized risk and capacity development support to local organisations and government entities to prepare them to manage and implement USAID/PEPFAR programmes as prime partners.[80]

Further, and at the core of the sustainability of epidemic control, is not just the transition of funding to local NGOs, but the impact of withdrawal of funding to NGO-run programmes. Documented impacts in articles reviewed include significant effects upon staff shortages and reduced supervision,[81] reductions in viral load testing, defaulter tracing systems and prevention services,[82] and patient perceptions of reduced quality of care when transferred from private NGO-operated clinics back into the public sector.[83]

The large injection of community-based health workers through NGO programmes have demonstrated effectiveness of task-shifting for improving access and quality of HIV care.[84] However, reduced donor funding to NGOs for supporting lay cadres, paired with limited inclusion of lay counsellors within national budgeting for human resources for health posed a threat for reaching and sustaining 90-90-90.[85] In their qualitative investigations of harmonisation of CHW programmes in 4 countries across Southern Africa, De Neve and colleagues note many CHW programmes are fragmented, poorly integrated, and lack ownership and accountability once funding ends.[86]

Published evaluations of large donor-funded programme transition processes and outcomes highlight the interrelated complexities of achieving the important goal of local ownership and self-sustained national HIV responses and the central role of NGOs within this current and future landscape. In their evaluation of the transition of the Bill and Melinda Gates Foundation HIV/AIDS prevention initiative in India, Bennett et al highlight the importance of building local NGO/CBOs capacity to run HIV programmes independently, and also ensure awareness and timing of funding transitions within all levels of NGO staff, including community-based cadres.[87] In their mixed-method examination of impact of transition of NGO-supported direct service delivery in 61 clinics in the Western Cape, South Africa, Chiliza and colleagues'[87] framework to maximize large-scale HIV programme sustainability promotes NGO involvement in planning for funding transition together with all levels of government and ministry of health 2-5 years before transitions occur, as stakeholders who will be the ultimate custodians of HIV programmes when donors pull away.

In their comprehensive paper on recommendations for countries transitioning from donor funding to domestic reliance for HIV responses, NGO sustainability is outlined by Burrows et al as one of 4 critical factors which should be considered when determining the timing of transitions from donor funding to domestic reliance for HIV responses.[88] Countries where NGOs still largely depend on external funding to do their work are proposed by authors to be included in the final of three 'waves' of transitions (2024-2029) to avoid hasty defunding of NGOs in the transition to domestic funding and disruption of outreach and prevention services, particularly for key and vulnerable populations.[89] Two important considerations among frameworks by Burrows and colleagues include the critical importance of increased multisectoral engagement for private-sector and philanthropic funding of NGOs, and need to improve in-country capacity for advocacy based on data collection and analysis by NGOs.

THEME THREE: NGO's Generation and Use of Evidence

Subtheme 3.1 NGO participation in evidence generation

In addition to published literature reporting NGO involvement in advocacy and implementation, a key theme arising from the literature regarding the important role NGOs play in national HIV responses is evidenced through their frequent participation as key informants in qualitative research seeking stakeholder perspectives on the impact of HIV policies and programmes. Examples include NGO worker perceptions regarding the provision of mental health support during HIV counselling and testing services in Uganda,[90] scale up of new or emerging HIV programming areas such as regulation of HIV self-testing or expansion of Pre-Exposure Prophylaxis (PrEP),[91-94] and National Institutes of Health's Fogarty

International Center the Adolescent HIV Prevention and Treatment Implementation Science Alliance (AHISA) platform to facilitate better utilization of scientific evidence in adolescent HIV programming.[95]

Many large international NGOs supporting HIV programmes in multiple countries support dedicated research and evaluation units, primarily located at Northern headquarters, and collaborate with academic partners to produce peer-reviewed evidence. Recent examples reviewed include Population Services International (PSI)'s work to explore costing and operational models for community- and facility-based HIV self-test distribution in The Self-Testing AfRica (STAR) Initiative,[96] the Clinton Health Access Initiative (CHAI)'s technical assistance to countries to forecast demand for HIV diagnostics and treatment,[97] Médecins Sans Frontières (MSF)'s work adapting DSD models to provide HIV care in fragile and conflict settings,[98] and the Elizabeth Glaser Pediatric AIDS Foundation's evaluation of routine point-of-care intervention for early infant diagnosis on HIV test result return and timely ART initiation in HIV infected infants.[99]

In response to the increasing demand by funders for evidence-based intervention models, local NGOs are increasingly partnering with researchers to rigorously evaluate HIV programme model outcomes and impact. Published example include evaluation of the Zvandiri adolescent peer support group impact on improved virological suppression in Zimbabwe,[100] improved retention of mother-baby pairs in in HIV care in Uganda enrolled in a mothers2mothers (m2m) programme,[101] to exploring the impact of the Mbereko+Men gender-synchronised community-based intervention for increasing male participation and uptake of services across the

PMTCT cascade.[102] While NGOs are credited for their role in identifying and developing innovations such as sports-based HIV/AIDS awareness programmes, there is recognised the need to improve the use of implementation, service and client outcome and impact indicators, and better define implementation strategies and mechanisms of action for evaluation of effectiveness.[103]

Subtheme 3.2 NGO representation in HIV evidence-base – whose evidence 'counts'?

Despite NGO representation as key informants and stakeholders in HIV programming and research, mapping of author affiliations among all articles under review demonstrated only one quarter had NGO-affiliated first authors (25%; 19/77) or even as members of the research team as co-authors (21%; 16/77).

An important consideration noted in the literature for NGO-produced evidence is 'whose voice counts' and the decolonisation of HIV evidence. Munro[104] describes 'technocratic racism' whereby global HIV interventions authorize certain actors, knowledge, priorities and methods over others, to the exclusion of indigenous workers and knowledge systems for service provision. In his paper exploring evidence and AIDS activism, Colvin[105] emphsises the need to recognise the politics of knowledge and promote the production and deployment of new forms of activist-led evidence that are critical in perspective and independent of existing institutional and hegemonic modes of knowledge production. In Zimbabwe, the Zimbabwe Network of People Living with HIV (ZNNP+)'s community treatment observatory model Client Satisfaction and HIV Stigma Index Surveys[106] are examples of local advocacy groups, monitoring accountability, documenting and communicating the needs and preferences of their members for improving equitable access to quality HIV services.

DISCUSSION

Through this scoping review the role of NGOs within the HIV response is explored and critically analysed. Based on findings, we reflect on opportunities to optimise the equitable impact of NGO contributions towards reaching and the sustainable maintenance of HIV epidemic control and the “end of AIDS” through transdisciplinary implementation science.

Current evidence on NGO roles in the HIV response

We identified three key thematic areas of evidence on the role of NGOs as catalysts, implementing partners and evidence users and makers in the HIV response. Each highlight the fundamental role of NGOs in HIV programme implementation and promoting equity and facilitating access to HIV prevention, care and treatment services globally.

As catalysts, we find evidence that NGO advocates and activists not only contributed to treatment literacy and awareness that gave rise to global treatment literacy and access, but continue to play critically important roles in advocacy and activism for key populations, particularly in countries and regions where LGBTQ+, MSM, IDUs, sex workers, and other at-risk groups such as adolescent girls and young women may be marginalised and have limited access to HIV prevention and treatment services. Evidence reviewed on the infringements of NGO autonomy to integrate essential sexual and reproductive health and rights-based approaches under the constraints of international funders and host governments, should act as an important red flag regarding the potential catastrophic impact of restrictive funding conditions and implementation spaces upon not just HIV policy objectives but global health and rights under the Sustainable Development Goals. Further, our findings suggest there is need to make important changes in aid architecture for NGOs who are often in competition for support, which has been documented as causing resentment and limited collective action, further weakening capacity for effective advocacy.[107]

The majority of evidence reviewed reported on the role of NGOs as programme implementers and providers of technical assistance to national HIV responses from national to community-level. Specifically, NGOs play a critical role in promoting equity of access to HIV care and co-located anti stigma and HIV prevention and treatment services through the provision of facility- and community-based direct service delivery.

As non-state actors, NGO activities are particularly critical for reaching marginalised and underserved key populations where policies and laws criminalise, or otherwise pose a barrier to service uptake among the most vulnerable. The ability of NGOs to rapidly mobilise to reach recipients of HIV care with differentiated services and ART distribution during COVID-19, is an important example of the current and future role of community-based and local NGOs for supporting provision of patient-centred DSD and continuity of HIV care. NGOs' decentralised presence and localised knowledge will become increasingly critical in the face of emergent pandemics, conflict and climate change that will impact human movement and ability to access HIV prevention, care and treatment services.

While we found evidence of NGO involvement in HIV research initiatives, articles reviewed highlight important issues of equity that require redress for meaningful participation and representation of NGOs as implementers within implementation science, and realise their potential contribution to the HIV evidence base. The influence of structural racism, postcoloniality and Western ethnocentrism within IS theories, methods and outcomes has noted that racism can indeed be reinforced through the research process.[106,108] Our findings reinforce and extend such challenges to the epistemological assumptions that knowledge production is a neutral endeavour,[109] by highlighting that the primary 'doers' in the HIV response, NGOs, and specifically local NGOs, were underrepresented in scientific reporting. This indicates a bias towards evidence generated by Western academics, framed within Western theories, methods and frameworks, while the locus of the epidemic is in the global south,

Our evidence is aligned with increasing recognition that implementers and affected populations are not only critical for sustainable achievement of the 'do' in addressing the 'know-do' gap within HIV programmes, but also in generating the research questions themselves for producing meaningful evidence in context.[110] We propose that realising the equity and scale of evidence-based HIV interventions will require accelerated support for building the capacity of NGOs actors (particularly local and community-based) in implementation science theories, models and frameworks.[111] As noted by Nilsen and colleagues, such efforts should include building the awareness on and appropriate use of process models, determinants frameworks, classic theories, implementation theories, and evaluation frameworks[112] in both NGO programme design and evaluation. Such investments should be regarded as decolonising the knowledge bearers of the HIV evidence-base, while also ensuring the tools and local capacity to robustly monitor the attainment and maintenance of HIV epidemic control as part of sustainable transitional funding.

Within transdisciplinary action research paradigms, individuals from different fields collaborate to build upon discipline-specific TMFs and create new models and knowledge that transcend disciplinary boundaries.[113] Our findings suggest the potential of transdisciplinary implementation science (IS) and social and behavioural science (SBS) partnerships to both contribute to the improved use of TMFs in routine NGO programmes, as well as generate new contextually relevant TMFs to meet the dual purpose of achieving health equity to end the HIV epidemic.[108] Our findings highlight the existing situatedness of NGOs within existing IS determinant frameworks as facilitators of the equitable and effective implementation of evidence based interventions.[114] NGOs clearly play a central role in the implementation strategies that may best address contextual determinants.[115,116] They also collect routine programmatic data that has potential for contributing to the evidence-base on the implementation, service, and client outcomes[117] and understanding of the inner and outer level factors that influence implementation success.[109,118-120]

Our findings suggest that meaningful involvement of NGO insiders and community stakeholders will become increasingly important in the context of rapidly emergent scientific evidence and guidelines which may necessitate changes to implementation (or de-implementation), where community involvement is essential to support change in practice and identify and mitigate dynamics of medical mistrust.[121] We propose further specification and expansion of transdisciplinary IS frameworks for HIV science to purposively map the potential contribution of NGOs and other local actors[122,123] in the HIV ecology for both formulating meaningful research questions and contributing to the research process for generating type 1 (aetiology and burden), type 2 (intervention effectiveness) and particularly, type 3 (implementation and context) evidence.[124]

Optimizing NGO contributions to the HIV response

Based on the findings from this scoping review, we propose a typology of the potential role of NGOs in national HIV responses (Figure 3.2) to maximize impact and address key anticipated needs as countries reach 95-95-95**.**

While NGOs currently act as primary implementing and technical partners of national HIV programmes, this role can/should be anticipated to reduce through successful health system strengthening and transition to domestically funded programmes. Community-based Direct Service Delivery will be remain critical for sustaining equitable access to HIV prevention and treatment services but may need to remain outside of the bounds of state-run programmes. Context-based advocacy and activism for promoting accountability for equitable access to quality HIV services and representation of key and vulnerable populations at greatest risk of new infections will therefore increase in importance at 95-95-95 as epidemic drivers becoming increasingly localised.

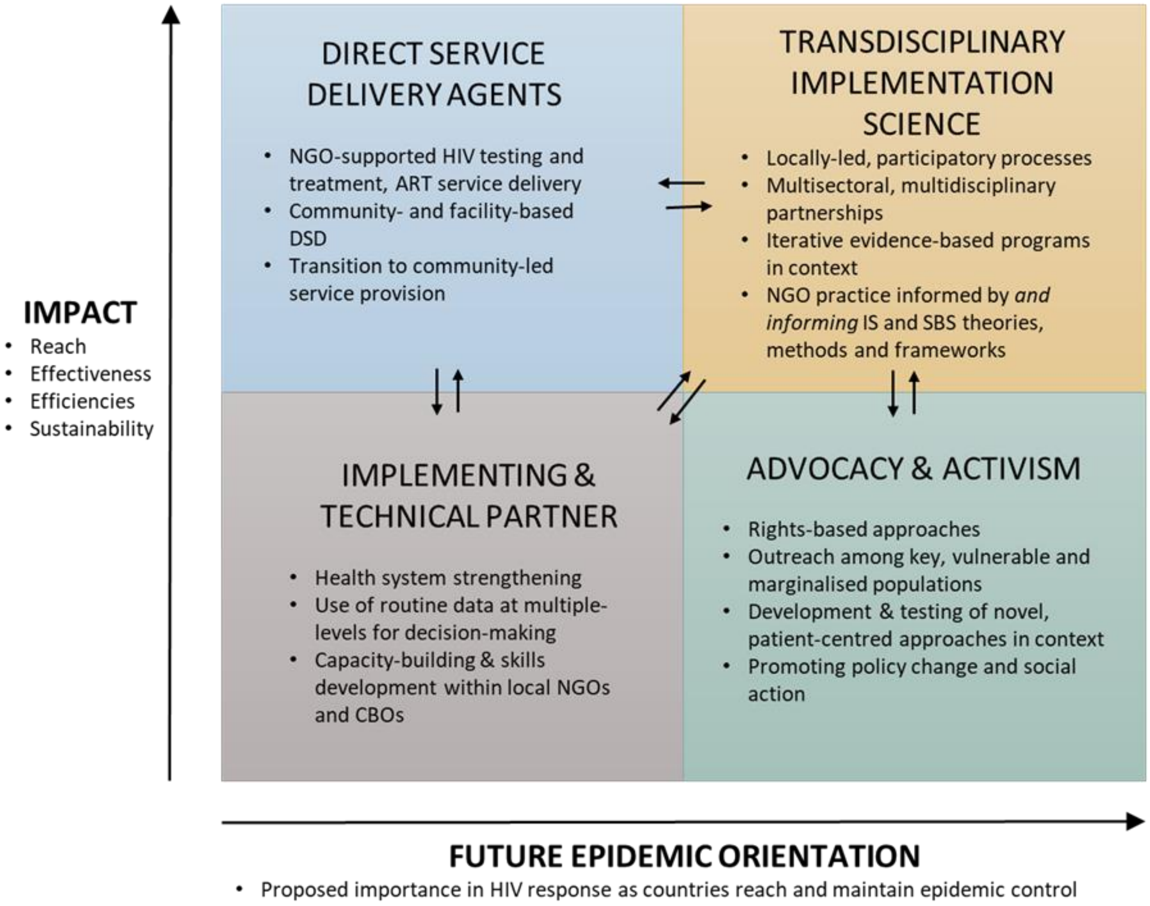

Figure 3.2 Typology of roles of NGOs for optimizing national HIV responses towards attainment and maintenance of HIV epidemic control. The vertical axis represents impact of NGO activities interventions upon national HIV program performance in terms of reach, effectiveness, efficiencies and sustainability. The horizontal access represents importance for the future of the HIV epidemic as countries seek to reach and maintain epidemic control. NGOs as primary implementing and technical partners Adapted from Anderson et al.[125] and Geng et al.[126]

The findings of this scoping review underscore that the evaluation work of NGOs typically falls under program science, or improvement practice, focused on improving the scale, quality, and impact of public health programmes.[122,123] While such quality improvement initiatives generate evidence and knowledge for local improvement practice, they do not establish generalizable knowledge within established TMFs.[123] Inadequate training in IS TMFs and too little emphasis on the "pull" for implementation science (e.g., training implementers, practice-based research) has been noted as limiting the expansion of the field's approach to evidence.[124]

Underreporting of implementation strategy characteristics and outcomes contribute to missed opportunities for strengthening implementation guidelines for evidence-based HIV service delivery.[127] Recent evidence regarding ''data velocity'' of IS findings indicate integration of IS findings into policies and/or guidelines and actual adoption in practice at the patient-level remains unacceptably protracted.[128] Addressing bottlenecks in the production and dissemination of HIV-related implementation research by NGOs would accelerate translation into practice and strengthen programmatic and policy-relevance.

We propose that NGO contributions towards reaching and maintaining HIV epidemic control can be optimised through multidisciplinary collaborations in context-relevant transdisciplinary IS. NGOs should work alongside academics and health system stakeholders to improve the use IS TMFs to design and implement EBIs in real-world settings. Such collaborations have the potential to advance IS TMFs and improve practice through production of locally-led, theoretically informed, and scientifically sound evidence in context.

Meaningful transdisciplinary IS efforts require recognition that the core function and priorities of NGOs in the field of HIV are on the 'doing' (programme implementation). At present, NGO programmes are inadequately resourced (capacity building, time or research funding) to design, implement and disseminate high quality embedded-IS. Optimising the potential impact of NGO participation in transdisciplinary IS will necessarily require investment and meaningful partnerships between scientists, NGO implementers and the affected communities, households and individuals they serve. Such partnerships and local capacity building of NGOs to generate relevant IS research questions and use of appropriate IS TMFs has the potential to not only enhance the impact of NGO-delivered programmes, but also fast-track the translation of EBIs to practice at scale.

LIMITATIONS

There are a number of important limitations to note. First, the abstract screening, full text review, and data charting processes in scoping reviews are inherently subjective. The findings reported are the result of a single, defined search process and snowballing through expert consultation. The majority of articles were reporting evidence from Africa or global systematic reviews or commentaries that were not geographically defined, with the remainder reporting NGO programmes in Asia, Europe, North and South America. As we restricted our scoping review to articles and reports published in English, research published in other languages from other geographies may have added to a greater diversity of regions included and expansion of the key themes and findings reported in this paper or not.

While we are confident our review captures key themes and illustrative evidence on the role of NGOs in the HIV response, we recognise these are not exhaustive of the global evidence-base in this area and likely exclude important contributions due to lack of standardization of definitions or systematic inclusion of NGO within keywords of published evidence. Similar to efforts required to improve the definitions of implementation science within HIV,[129] improvements to standardizing the nomenclature and definitions within the nongovernmental sector will be required for future investigations into the effectiveness of NGO programmes.

Related to the above, we recognise that the emergent thematic categories in our review are overarching and do not capture the breadth and nuance of the HIV programmes and activities of NGOs which are as diverse as the types, size and focus of NGOs that work within the field. Indeed, in their review of interventions targeting the adult HIV care cascade in LMICs, Hickey and colleagues identified 6 intervention approaches, with 34 distinct intervention types,[130] each of which may be represented as discrete contributions of NGOs. As nomenclature and indexing of NGO contributions to the HIV response improves, more targeted reviews of evidence by region, NGO- and intervention-type, and more importantly, their effectiveness, can and should be pursued. Our typology of roles offers a first step in the process of systematically indexing the broad contributions of NGOs to the HIV response within the evidence-base.

Finally, as a scoping review, we did not systematically grade the quality of the published research included in our review, but rather sought to explore the breadth of available evidence. We do however, report limitations in articles reviewed relevant to understanding strengths and limitations of NGO contributions to the evidence-base.

Limitations notwithstanding, to our knowledge, this is the first review attempting to capture evidence of the NGO sector's contribution to the HIV response as a whole.

We sought to employ reflexivity in our analysis, and limit subjective evidence selection and interpretation biases through the inclusion of a diverse, multidisciplinary team in the design and analysis of this review. Situating our review and discussion through an intersectional lens allowed us to critically reflect on how and why given their acknowledged fundamental role in the HIV response, NGO advocate and implementer contributions have (or have not) contributed to or been recognised within the evidence-base.

Conclusion

Our scoping review on the role of NGOs in national HIV responses highlighted their critical role as advocates, programme implementers and providers of technical assistance. Despite their vital function in the HIV response, we identify a lack of NGO representation (particularly among local NGOs) as co-producers of evidence in the published literature or evidence of the use of implementation science TMFs in the design and evaluation of routine programme interventions. We provide a typology for optimising the roles of the non-governmental sector to optimise sustainability and impact, and meet current and future programming needs to reach and maintain national and global HIV epidemic control. We propose the expansion of transdisciplinary IS TMFs to better articulate role of NGO advocates, implementers and service providers in both use and generation of TMFs and enhance evidence-based practice within local HIV responses.

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SECTION II: IMPROVING ESTIMATES & UNDERSTANDING OF TRUE UPTAKE, OUTCOMES & REASONS FOR FAILURE TO UPTAKE FBD AND EID IN ROUTINE PROGRAMMES

4. Improving estimates of cumulative incidence of timely Early Infant Diagnosis and mortality among HIV-exposed infants in routine programmes

4.1 Introduction

This chapter aims to build upon evidence from the previous two chapters emphasising the role of NGOs as facilitators to improve access to and quality of HIV and maternal EBIs and also the suboptimal use of implementation science (IS) theories, methods and frameworks by NGOs to improve the quality of evidence in routine programmes.

Specifically, this chapter provides an applied case study in response to literature and scoping review findings highlighting limitations of data sources (paper-based registers, lack of unique identifiers) and routine aggregate data in NGO programmes for accurately reporting individual-level service outcomes. Further, lack of evidence on client outcomes regarding reasons for failure to uptake health services limits design of context-appropriate interventions to improve coverage and quality of EBIs across the PMTCT cascade. Scoping review findings highlighted that multidisciplinary NGO-researcher collaborations and the integration of embedded research into NGO programmes have the potential to generate more robust programme evidence and also fast track the translation of EBIs into routine practice at scale. This case study uses a sampling based approach in an observational, multisite, cohort study to improve accuracy of estimates of service outcomes and explores the medical, structural, clinic-based and psychosocial reasons[2] for failure to uptake.

The OPHID Families and Communities for Elimination of Pediatric HIV (FACE HIV; 2012-2020) programme aimed to contribute to the achievement and sustainability of HIV epidemic control in Zimbabwe national HIV programme, including strengthening of integrated maternal, newborn and child health services along the prevention of mother to child transmission of HIV (PMTCT) cascade. All HIV-exposed infants are recommended to receive Early Infant Diagnosis (EID) HIV testing at 4-6 weeks,[1,2] however available evidence from routine programmes estimated coverage as low as 45%.[3]

This chapter presents the published findings from a mixed-methods study tracing a random sample of HIV positive mother-HIV-exposed infant pairs for recommended EID HIV testing from routine health facility-based data in Mashonaland East Province, Zimbabwe. Findings from community-based tracing to assess infant and maternal vital status and timely uptake of EID were incorporated into corrected estimates of infant mortality and timely EID in the entire clinic population. Although this sampling-based approach has been used in clinic-based cohorts of adult patients in HIV treatment programmes in Africa and found to alter estimates of retention and mortality substantially,[4-7] this chapter represents the first time the approach had been used in routine PMTCT programmes in a high HIV-prevalence setting.

By adapting and replicating scientific methodologies for studying LTFU rates and implemented in collaboration with researchers from LSHTM and UCSF, this case study also provides an example of an NGO-researcher collaboration to strenthen evidence on service outcomes (EID uptake) as well as qualitative evidence of contextual, patient and provider recipient factors influencing successful implementation and equity of access to health services as to inform synthesis within the grounding conceptual framework, Health Equity Implementation Framework.[8]

4.2 Citation

This chapter provides the full text version of a manuscript submitted to JAIDS that was eventually published as a brief report (see Appendix 1).

Webb, K., Chitiyo, V., Mahachi, N., Huruva Mukungunugwa, S., Mushavi, A., Zizhou, S., Engelsmann, B., Abbas Ferrand, R., Neuman, M., Hartogensis, W., Geng, E.. Brief Report: Improving Early Infant Diagnosis Observations: Estimates of Timely HIV Testing and Mortality Among HIV-Exposed Infants. J Acquir Immune Defic Syndr. 2020;83(3):235-9. doi: 10.1097/QAI.0000000000002263

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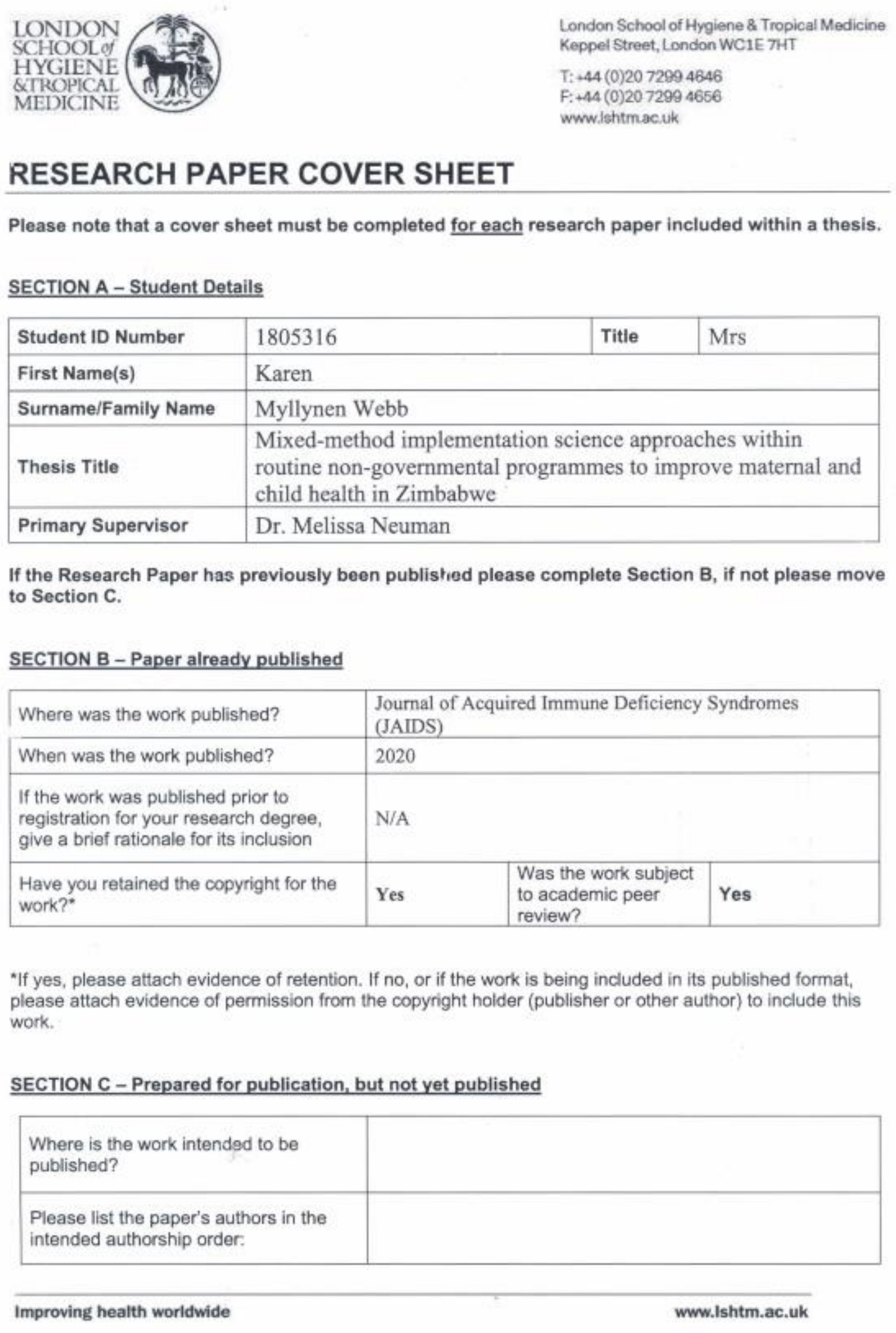
4.4 *Research Paper 2: Improving Early Infant Diagnosis Observations: Estimates of Timely HIV Testing and Mortality Among HIV-Exposed Infants*



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SECTION A – Student Details

Student ID Number	1805316	**Title**	Mrs
First Name(s)	Karen		
Surname/Family Name	Myllynen Webb		
Thesis Title	Mixed-method implementation science approaches within routine non-governmental programmes to improve maternal and child health in Zimbabwe		
Primary Supervisor	Dr. Melissa Neuman		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?	Journal of Acquired Immune Deficiency Syndromes (JAIDS)		
When was the work published?	2020		
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SECTION E

Student Signature	[redacted]
Date	11/02/2023

Supervisor Signature	[redacted]
Date	12/1/23

Improving Early Infant Diagnosis Observations: Estimates of timely HIV testing and mortality among HIV-exposed infants in rural Zimbabwe

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3. 21st International AIDS Conference (AIDS 2016), 18-22 July 2016, Durban, South Africa; Abstract: LBPE036.

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Running head:

Loss to follow up for Early Infant Diagnosis

ABSTRACT/KEY WORD PAGE

Background: Improving efforts towards elimination of mother-to-child transmission of HIV requires timely early infant diagnosis (EID) among all HIV-exposed infants, but the occurrence of timely EID and infant survival may be under-ascertained in routine, facility-bound programme data.

Methods: From March 2015 to May 2015, we physically traced a random sample of HIV-positive mother and HIV-exposed infant pairs lost to follow-up for EID in facility registers in Zimbabwe. We incorporated updated information into weighted survival analyses to estimate incidence of EID and death. Reasons for no EID were surveyed from caregivers.

Results: Among 2651 HIV-positive women attending antenatal care, 1823 (68.8%) infants had no documented EID by 3 months of age. Among a random sample of 643 (35.3%) HIV-exposed infants lost to follow-up for EID, vital status was ascertained among 371 (57.7%) and updated care status obtained from 256 (39.8%) mothers traced. Among all HIV-infected mother–HIV-exposed infant pairs, weighted estimates found cumulative incidence of infant death by 90 days of 3.9% (95% confidence interval: 3.4% to 4.4%). Cumulative incidence of timely EID with death as a competing risk was 60%. The most frequently cited reasons for failure to uptake EID were “my child died” and “I didn’t know I should have my child tested.”

Conclusions: Our findings indicate uptake of timely EID among HIV-exposed infants is underestimated in routine health information systems. High, early mortality among HIV-exposed infants underscores the need to more effectively identify HIV-positive mother–HIV exposed infant pairs at high risk of adverse outcomes and loss to follow-up for enhanced interventions.

Keywords: HIV-exposed infants, early infant diagnosis, loss to follow-up, prevention of mother-to-child HIV transmission, retention

INTRODUCTION

HIV testing for exposed infants six to eight weeks after birth – early infant diagnosis (EID) – is the cornerstone of public health strategies to improve coverage of pediatric antiretroviral therapy (ART) and prevent mother to child transmission (PMTCT) in the postnatal period. HIV-infected infants who are not promptly identified after birth and started on ART experience 30% mortality by their first birthday.[1] HIV prevention efforts must focus on infants who test negative in order to minimize transmission through breastfeeding,[2.3] which accounts for a growing fraction of infections among infants.[4]The completeness of EID as well as the proportion of infants testing positive are correspondingly used as cardinal indicators of the success of PMTCT programmes.[5,6]

In routine programme settings, completion of infant HIV testing is assessed at individual facilities, tabulated from information across several paper-based registers on HIV infected mother-HIV exposed baby (MB) pairs, which may be incomplete and or inaccurate.[7-10] Completion of EID or mortality rates require information from two (or more) time points for which the denominator (those at risk) and the numerator (those with the event) may be documented at different facilities. Mother-baby pairs who are documented as lost to follow up at one facility may have re-engaged at another, stopped care, or have died.[11,12] As with other routinely reported data on uptake of and retention in HIV care and treatment in resource-constrained settings,[13] there is a lack of confidence in available estimates of infant HIV testing and survival of HIV-exposed infants. These estimates are required to guide on-going quality improvement and inform national modelling estimates, which become increasingly important as countries seek to validate elimination of mother to child transmission (EMTCT).[14,15]

In this study, we randomly selected a sample of lost-to-follow up MB pairs from routine health facility-based data in Mashonaland East Province, Zimbabwe. We actively traced and located MB pairs in the community to assess infant and maternal vital status and timely uptake of EID. Finally, we incorporated these findings to correct estimates of infant mortality and timely EID in the entire clinic population using a probability weight. Although this sampling-based approach has been used in clinic-based cohorts of adult patients in HIV treatment programmes in Africa and found to alter estimates of retention and mortality substantially,[16-19] our study represents the first time the approach has been used in PMTCT programmes in high HIV-prevalence settings. We reflect on key lessons from our research on programme progress and persisting gaps for strengthening EID coverage on the path to elimination of MTCT in Zimbabwe.

METHODS

Participants and setting

We evaluated all women with HIV who accessed antenatal care (ANC) at all public sector health facilities (referral sites excluded) in Mashonaland East Province in Zimbabwe, supported by the Organization for Public Health Interventions and Development (OPHID) through their Families and Communities for Elimination of Pediatric HIV (FACE-HIV) programme.

We used a multi-stage clustered survey sampling approach. PMTCT Programme data indicate that in 2013, 6,512 HIV positive women accessed antenatal care in Mashonaland East at eligible health sites (referral sites excluded). To promote equity of programmatic action within each supported District, in the first stage of sampling, we selected 5 clinic sites from each of the 9 Districts within the Province based on probability proportional to size, making use of existing data on the number of HIV positive women accessing ANC at each facility over the previous year. One site was omitted as its data capture system precluded linking of HIV positive mothers with HIV-exposed infants receiving EID, leaving 44 clinics participating in the study. In the second stage of sampling, patients lacking documented evidence of EID for their exposed infants in clinic registers were identified and a random sample was selected for active physical tracing to determine outcomes through direct patient interviews.

Phase I: Register Tracing. In the absence of inter-facility electronic patient monitoring systems in all- sites, a combination of individual identifiers including clinic-allocated PMTCT number, patient name and date of birth, were used to trace each identified HIV positive pregnant woman in ANC and her HIV-exposed child through five paper-based registers (ANC register, Delivery Register, HIV Exposed Infants Register, Clinic Register, HIV Infant Diagnosis and EID Lab Request Form Booklets) to determine loss to follow up (LTFU) for EID. LTFU was defined as no documented DNA polymerase chain reaction (PCR) sample taken for EID among HIV-exposed infants of HIV positive ANC patients within 90 days of delivery. Mothers with locator information recorded in ANC registers but no documented EID for their infants were classified as LTFU and eligible for tracing.

We targeted a random sample of at least 10% of lost HIV positive mother-HIV exposed infant pairs based on practical considerations regarding limitations of completeness and accuracy of patient information in multiple paper-based registers,[20] and available resources to intensively trace those identified as LTFU for EID over the study timeframe. Based upon known challenges in tracing defaulters from HIV care and treatment,[21,22] we over-sampled by 100% as a contingency to meet our target of obtaining direct patient interviews from a random sample of 10% of those lost.

Phase II: Physical tracing of LTFU MB Pairs. Village health workers (VHWs), the MOHCC cadre tasked with strengthening community-facility linkages, were chosen as ascertainers due to their familiarity with the surrounding community and existing role to support health facilities with community education, patient referrals, and defaulter tracing.[23,24] Engagement and training of VHWs for tracing of LTFU MB pairs by local non-governmental organization (NGO) was intended to increase probability of successfully tracing selected mothers, as well as to use research activities to build capacity of existing community health workers in processes and documentation of active client tracing.

Working in collaboration with MOHCC District Nursing Officers, OPHID operational research personnel trained 197 VHWs working in the geographical catchment of selected health facilities on: the importance of EID for PMTCT and pediatric HIV treatment; study procedures; confidentiality, and informed consent processes. Ten 2 day trainings were conducted in March 2015, grouping VHWs for training by geographic cluster.

Following training, VHWs were assigned selected patients residing within their geographical catchment area for tracing. If the individual was unable to be located, VHW-ascertainers sought to determine both mother and infant vital status from informants (friends, neighbors or relatives). Tracing often required multiple household visits, with VHWs typically traveling by foot or bicycle to locate the patient. Written, informed consent was obtained once contact was made, and HIV positive mothers were interviewed in a location of their choosing.

Figure 4.1 Village health worker training on procedures for LTFU study tracking and tracing, Marondera District Hospital, March 2015 (NB. Photo taken with written informed consent)

Measurements

Clinical and demographic characteristics obtained from facility registers included date of first ANC, gestational age (GA) at booking, infant date of birth, knowledge of HIV status in ANC, evidence of HIV-exposed infant DNA PCR sample (EID) drawn by three months of age, and availability of locator information to be used in tracing. Among the random sample of LTFU mother-baby pairs selected for tracing, VHWs ascertained mother and infant vital status through patient or informant interviews where possible. Directly interviewed patients were administered a standardized questionnaire to ascertain postnatal care outcomes, including EID status and timing as well as socio-demographic information not available from routine registers such as education, marital status, religion, distance from nearest health facility, and uptake of other antenatal and postnatal health services across the PMTCT cascade. The VHW ascertainers also surveyed reasons for failure to obtain EID or for self-transfer of care to another facility ('silent transfer') using a standardized form. Data were entered into Open Data Kit (ODK) and analyses were conducted using Stata v.13.1 (Stata Corp., College Station, TX). This study was approved by the Medical Research Council of Zimbabwe (MRCZ/A/1844) and Ministry of Health and Child Care (MOHCC) health authorities.

Analyses

We estimated the incidence of EID using (1) data abstracted from the routine health information system, and (2) data from tracing patients in the field who had undocumented EID status. In the first instance, we used EID outcomes based only on clinic registry data, but with the application of facility weights (inverse to the probability of clinic selection) to yield an estimate of EID completion in the entire province based purely on paper registers kept at the facilities.

EID estimates: First, the influence of facility and individual factors on documented completion of EID was explored using Poisson regression with robust standard errors adjusted for confounders to estimate risk ratios.[25,26] Second, as described in previous work,[19] we generated corrected estimates of EID completion and mortality that used data obtained from clinic registries as well as data ascertained through interviews with a random sample of mother-baby pairs missing EID in the paper registers kept at each facility. For the corrected estimate of the cumulative incidence of EID, deaths before EID (including fetal deaths) were considered as competing risks. To obtain an estimate corrected for outcomes not captured in the facility registers, we used additional sampling weights inverse to the probability of being successfully sought to represent all LTFU HIV-infected pregnant women at each clinic.

Among women with no documented EID in facility registers who were traced and interviewed, univariate analysis was used to describe baseline socio-demographic and clinical characteristics, with chi-squared tests of differences between the EID and the no EID groups. Informed by the Behavioral Model for Vulnerable Populations,[27,28] reasons for silent transfer to a different clinic from antenatal care for EID and for not bringing HIV-exposed child in for HIV testing (no EID) were grouped into four categories: structural (external factors such as transportation costs, family, mobility); clinic-based (long waiting times, staff friendliness); psychosocial or patient-related (knowledge, attitudes or beliefs); or medical (too sick to get to clinic, infant died).

Mortality estimates: For the weighted mortality estimate, the traced patients contributed time from the delivery date to the date of the patient interview or the date of the death of the infant at any time prior (i.e., all deaths including those later than 90 days were included in the mortality estimate); the patients with EID documented in phase I contributed time from the date of delivery to the date of the 6-week postnatal visit, which is the latest date at which we have confirmed vital status for those infants. Kaplan-Meier methods were used to estimate mortality.

RESULTS

Phase I: Facility Register Data

Participant characteristics

Between 1 April 2012 and 1 May 2013, among the 18,065 women who registered for ANC, 2,651 (14.7%) were HIV positive. The majority tested HIV-positive in ANC (n=1,621; 61.1%), and 38.9% entered ANC with a known HIV-positive status. The median Gestational Age (GA) at ANC booking was 25 weeks (IQR: 19-31).

Uncorrected estimate of the occurrence of EID based on review of facility registers

Among all HIV positive women, 31.2% (95%CI: 29.5%-33.0%) had documented uptake of EID for their infant within three months of delivery in clinic registers (Figure 4.2). Among the 1,823 HIV positive women with no documented EID for their exposed infants, 90.6% had locator information documented for tracing. After adjustment for available register information and site characteristics, factors associated with documented EID completion in original facility registers included earlier gestational age at presentation (Risk Ratio (RR): 0.97 per two weeks; 95%CI:0.95-0.99; p=0.013), later calendar time of ANC presentation (RR: 1.04 per 30 days; 95%CI:1.02-1.06, p= 0.011) and smaller site volume (Table 4.1). There was large variability in the probability of EID completeness within groupings by site size, indicating facility-level quality factors influencing proportion of patients with documented EID (Figure 4.3).

Phase II: Community Tracing LTFU

Outcomes of Tracing

Among the 1,652 HIV positive mother-HIV exposed infant pairs identified as LTFU with documented locator information in Phase I, a random sample of 643 (38.9%) were selected for tracing. Tracing was carried out between March and May 2015. In 371/643 (57.7%), updated information about vital status or EID status was obtained; 22.5% (371/1,652) of the total LTFU sample. The primary reason for failure to locate clients was insufficient detail of locator information documented in facility registers to enable tracing of MB pairs (Figure 4.1). Among the 371 successfully traced patients, 256 (69.0% of located) mothers were interviewed directly and for the remaining 115 (31.0%), informants were interviewed. Among the 371 mother-baby pairs for whom vital status outcomes were determined, 66 infants (17.8%; 95% CI: 14.0 – 22.1%) and 18 mothers (4.9%; 95% CI: 2.9%-7.6%) were found to be deceased.

Corrected estimate of EID and survival

To maintain confidentiality among women whose HIV disclosure status was unknown, infant HIV testing status was only ascertained among the 256 mothers who were successfully located and provided informed consent for participation (HIV testing status was not discussed with informants). Median age of mothers traced was 31 years (IQR:27-35yrs). The majority of women indicated they had disclosed their HIV status (227/256; 88.7%), with male partners being the person most frequently disclosed to (156/227; 68.7%). Uptake of services along the PMTCT cascade was generally high: the majority reported having a CD4 test during pregnancy, delivering in a health facility and being on antiretroviral therapy at the time of interview (Table 4.2).

Among those mothers traced, 190/256 (74.2%; 95% CI: 68.4% - 79.5%) indicated their infant had actually received HIV testing; though fewer than half of those received EID testing prior to three months of age (92/190; 48.4%; 95%CI: 41.1% - 55.8%). Among those with timely EID, the majority, 61/92 (66.3%) accessed EID at the same clinic where ANC was accessed, with the next most common location being District Hospital (12/92; 13.0%). Compared to our uncorrected estimate of EID of 31.2% from Phase I, our Phase II corrected estimate of timely EID following tracing resulted in a cumulative incidence of timely EID with death as a competing risk of 60.0% (95%CI: 58.7% - 61.3%). We estimated a cumulative incidence of mortality among HIV-exposed infants of 3.9% (95%CI: 3.4% - 4.4%) at three months and a weighted estimate of one-year infant mortality of 7.7% (95%CI: 4.7% - 13.5%).

Reasons for no EID vs. Silent Transfer

The most frequently cited individual reason for failure to have exposed infants tested for HIV at any time was ‘my child died’ (26/71; 36.6%) (Figure 4.3 A). Among infants with timing of death ascertained, the majority did not survive to the age when EID testing is recommended (6 weeks) (26/42; 61.9%). Among mothers of living infants, ‘I didn’t know I should have my child tested’ was the most frequently cited reason for lack of EID (16/45; 35.6%). Relocation to a different area (17/78; 21.8%) and transport being easier/cheaper at new clinic (16/78; 20.5%) were the most commonly reported reasons for silent transfer (Figure 4.3 B). Medical and psychosocial factors were the predominant categories of reasons that HIV-infected mothers did not obtain HIV testing for their exposed infants at any time (53/71; 74.6%), whereas clinic or structural factors were given as the reason for silent transfer in the majority of instances (70/78; 89.7%). Sociodemographic characteristics between MB pairs who obtained HIV testing for their infant and those who did not were not significantly different. As expected, uptake of antenatal, delivery, and early postnatal HIV services was greater among women who obtained EID for their infants than among those who did not. Interestingly, there were no statistically significant differences between these groups in rates of attending the general 6-week postnatal care visit or receipt of infant vaccinations (Table 4.2).

DISCUSSION

In 44 health facilities representing all of Mashonaland East Province of Zimbabwe, we found only 31.2% of infants born to HIV infected mothers had documented early infant diagnosis testing in facility registers. After incorporating self-reported EID outcomes obtained through community tracing of a sample of individuals without previously documented EID, the corrected estimate of EID rose to 60.0% (95%CI: 58.7% - 61.3%). These findings underscore the risk of equating loss to follow up of mother-baby pairs in health information systems with attrition from care where health information systems do not facilitate electronic, longitudinal tracing of mother-baby pair service uptake within and between different health facilities.[21,22]

We not only improved our understanding of 'true EID' rates in Mashonaland East, but also developed evidence for informing quality improvement within an existing NGO programme. Phase I processes identified facilities with low proportion of clients with documented EID for targeted technical assistance to strengthen documentation; and in Phase II, we built capacity of existing MOHCC VHW-ascertainers for identifying and tracing clients with unknown outcomes *within* existing health system structures, and supported return to care among disengaged clients.

We found an alarmingly high incidence of mortality among HIV exposed infants of 3% by 3 months and 7% by one year among infants whose outcomes could be ascertained. The large number of MB pairs that were untraceable may also result in underestimation of maternal and/or infant mortality. Under-reporting of infant mortality in high HIV burden settings is acknowledged to bias child mortality estimates downward.[29-31] Indeed, studies among adults have shown that routine death documentation underestimates mortality by between 2-fold to over 10-fold, and that deaths on ART may be widely under-appreciated.[32,33] High observed mortality emphasizes the need for PMTCT programmes to effectively identify HIV positive mother-exposed infant pairs at high risk of adverse clinical outcomes (e.g. those with high viral loads) followed by targeted differentiated interventions, such as birth testing, increased frequency of routine follow-up and enhanced adherence counselling to improve PMTCT and infant survival.[34,35] Furthermore, our findings support investment into continued efforts to routinely implement longitudinal case-based surveillance among all HIV-positive mother and HIV-exposed infant pairs.[7,15,]

Finally, we report both facility- and patient-level factors influencing timely infant HIV testing rates. High volume facilities had the lowest rates of documented EID. A high proportion of women traced had silent transfers and/or indicated their infants received timely EID from the same facility where ANC was accessed, yet documentation did not enable linkages between HIV positive mothers in ANC and EID for their exposed infants through existing paper-based health information systems.

At patient-level, the predominance of psychosocial reasons (‘I didn’t know’) for failure to uptake EID among mothers of living infants emphasizes the need to provide HIV positive women with information about the importance of timely infant HIV testing during initial engagement in antenatal care and continued emphasis at every subsequent visit. [36,37] Consistent with previous studies of LTFU in PMTCT programmes, our findings reinforce that ‘uptake begets uptake’ for HIV services along the PMTCT cascade.[38-41] Infants of HIV positive mothers who made consistent use of other ANC, delivery and post-natal HIV services, were more likely to receive EID. However, the high rates of general six week checkups and immunizations among those with no EID underscores need to strengthen integration of PMTCT within routine postnatal maternal and child health services, including screening of HIV-exposure and EID status of all infants in high prevalence settings.[42] Once engaged in care, HIV positive mothers indicate retention orbits around issues of service quality and convenience. Reasons for silent transfers are consistent with studies of adult ART retention and highlight the role of structural (mobility, transportation, livelihoods and food insecurity)[43] and clinic-based factors (waiting times, caregiver attitudes)[44] for optimizing retention in care.

Conducted within an NGO programme context together with Ministry of Health and Child Care, each of these findings have guided programme planning and actions to strengthen quality of care and increase service uptake, patient education and problem solving, appointment monitoring, active follow-up and outcome documentation in Zimbabwe and other settings.[37,45-47]

Limitations

The large number of clients sampled that were untraceable due to incomplete documentation of locator details in source registers underscores known challenges to the use of routine programme and other forms of observational data for ascertaining true outcomes.[48,49] While oversampling enabled achievement of our targeted tracing of a random sample of at least 10% of clients LTFU for EID, we acknowledge non-response may introduce some uncertainty in the resulting estimates. However, we used an entire province as a sampling frame, and employed an approach that documents the probability of selection at each stage, therefore offering a reasonable population-based estimate over a large geographic area. Documented characteristics and service uptake of MB pairs traced, and corrected estimates of EID are consistent with other large-scale surveys in

Zimbabwe,[40] yet also yield important facility- and patient-level reasons for no EID that have guided programmatic responses.[45-47]

Our findings provide a pragmatic answer to the call for collaborative implementation research to strengthen outcome estimates and identify specific barriers to uptake of HIV testing and treatment among children required to reach super-fast track targets and EMTCT.[36,37,47] In the absence of robust inter-facility electronic patient monitoring systems, our findings support calls for improved use of observational data and leveraging of routine HIV programme data in 'real-life' programme settings for identifying bottlenecks and programmatic actions at local level, while strengthening national and regional estimation efforts.[50-54]

Conclusions

Our findings suggest that routinely reported EID completion in public health information systems may be substantially underestimated. Accurate determination of mother-infant pair outcomes in PMTCT programmes is complicated by resource-constrained health information systems that involve multiple paper-based registers, lack of unique patient identifiers and challenges with completeness and accuracy of information recorded. We demonstrate the value of sampling-based approaches in pediatric HIV research for providing important, context-based evidence for policy and programmes.

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613-A-12-00003, FACE HIV) (OPHID); K24 AI 134413 (E.G.); CFAR ISWG (P30 AI027763) (E.G.). R.A.F. is funded by the Wellcome Trust (206316/Z/17/Z).

Figure 4.2 Flowchart of outcomes in the study population (N=18,065)

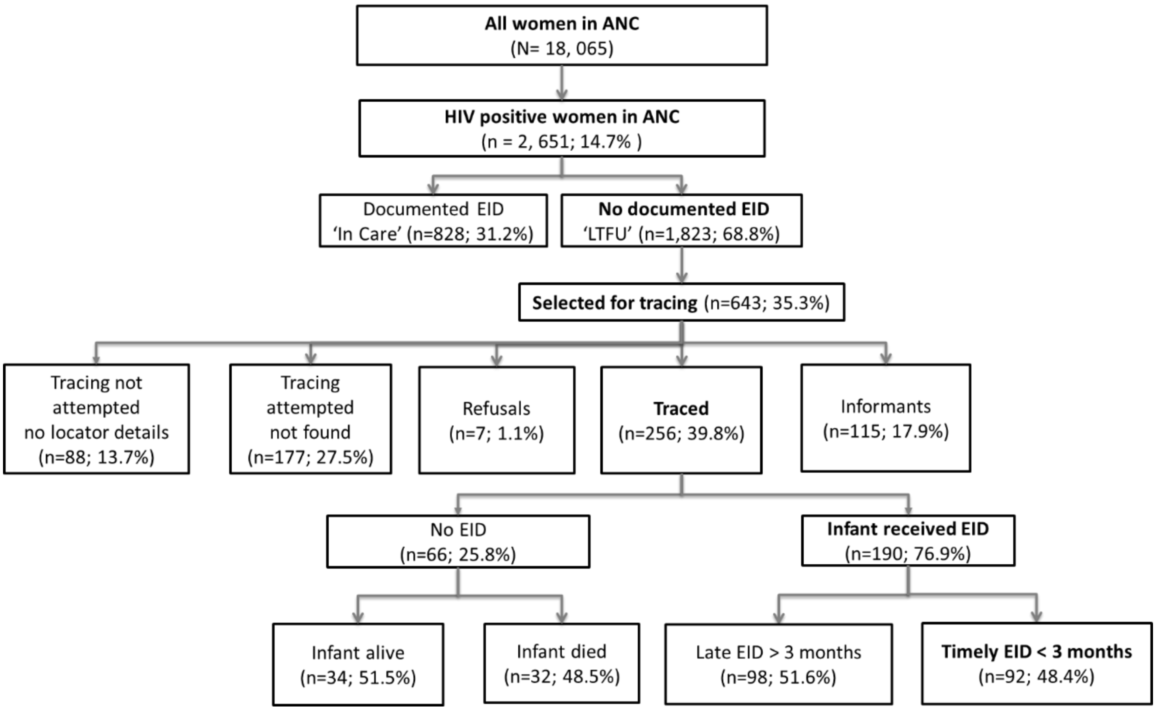

Figure 4.2

Title: Flowchart of outcomes in the study population (N=18,065)

Caption:

Abbreviations: ANC, antenatal care; HIV, human immunodeficiency virus; EID, early infant diagnosis.

Figure 4.3 Proportion documented EID among HIV positive women in ANC by site volume (N=44)

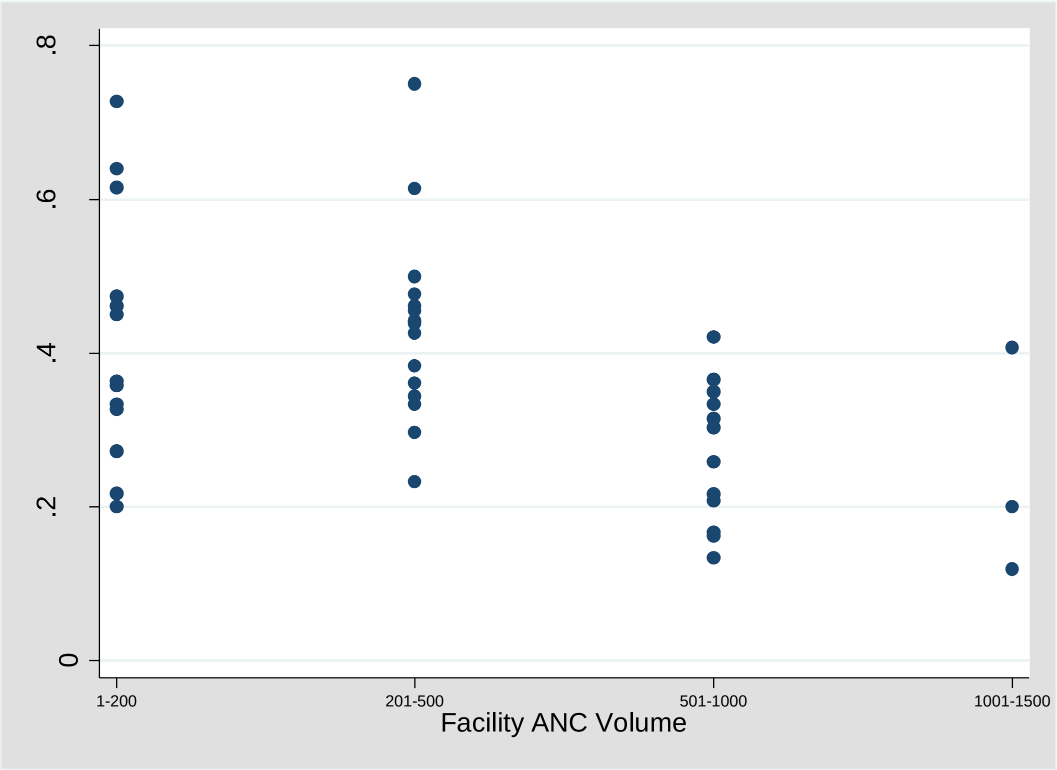

Figure 4.3

Title: Proportion documented EID among HIV positive women in ANC by site volume (N=44)

Caption:

Abbreviations: ANC, antenatal care; HIV, human immunodeficiency virus; EID, early infant diagnosis.

Table 4.1 Facility volume and documented EID completion

Variable **ANC Volume**	**Risk Ratio**	**p-value**	**95% CI**
High: 1001-1500 (referent)	1	-	-
Med-High: 501 – 1000	1.23	0.05	(1.00, 1.52)
Med-Low: 201 – 500	1.78	<0.001	(1.45, 2.19)
Low: 0 – 200	1.85	< 0.001	(1.44, 2.38)

Poisson regression showing association of site ANC volume on the probability of documented EID completion. Association is adjusted for gestational age at presentation and calendar time.

Abbreviations: ANC, antenatal care; CI, confidence interval

Table 4.2 Characteristics of women traced (N=256)

Sociodemographic Characteristics	Total n (%) N=256	No EID n (%) N=66	EID n (%) N=190	P
Age (years)[a]				
≤20	10 (4.0)	3 (4.7)	7 (3.7)	0.37
21 – 30	93(36.8)	25 (39.1)	68 (36.0)	
> 30	150 (59.3)	33 (51.5)	114 (60.3)	
Total pregnancies[b]				
1	19 (7.5)	6 (9.2)	13 (6.9)	0.28
2-3	103 (40.6)	21 (32.3)	82 (43.4)	
4+	132 (52.0)	38 (58.5)	94 (49.7)	
Residential status[c]				
Urban	35 (13.7)	16 (16.9)	24 (12.6)	0.40
Rural	220 (86.3)	54 (83.1)	166 (87.4)	
Marital status[d]				
Never married	7 (2.8)	1 (1.5)	6(3.2)	0.90
Married monogamous	195 (76.8)	52 (80.0)	143 (75.7)	
Married polygamous	11 (4.3)	3 (4.6)	8 (4.2)	
Divorced or separated	29 (11.4)	6 (9.2)	23 (12.2)	
Widowed	12 (4.7)	3 (4.6)	9 (4.8)	
Residing with partner	196 (77.2)	53 (81.5)	143 (75.7)	0.32
Highest level of education[e]				
None	3 (1.2)	0 (0)	3 (1.6)	0.23
Primary	83 (32.7)	25 (38.5)	58 (30.7)	
Secondary	168 (66.1)	40 (61.5)	128 (67.7)	
Religion[f]				
Apostolic	131 (52.6)	37 (56.1)	94 (49.5)	0.50
Christian	102 (41.0)	22 (33.3)	80 (42.1)	
Traditional or other	16 (6.4)	4 (6.1)	12 (6.3)	
None/No response	7 (2.7)	3 (4.6)	4 (2.1)	
Distance from facility[g]				
<1km	24 (9.5)	3 (4.8)	21 (11.1)	0.24
1-5km	107 (42.3)	28 (44.4)	79 (41.8)	
6-10km	72 (28.5)	20 (31.8)	52 (27.5)	
10km+	49 (19.4)	12 (19.1)	37 (19.6)	
HIV Disclosure[h]				
Disclosed to anyone	227(89.4)	55 (84.6)	172 (91.0)	0.32
Pregnancy outcome				
Live birth	242 (94.5)	52 (78.8)	190 (100)	
Still birth	3 (1.2)	N/A[i]	N/A	
Miscarriage	11 (4.3)	N/A	N/A	
Health Service Uptake	**Total, n(%)**	**No EID, n (%)**	**EID, n (%)**	**P**
Attended ANC 4 or more times[c]	209 (82.0)	40 (61.5)	169 (89.0)	<0.0001
CD4 in pregnancy[c]	194(76.1)	38 (58.5)	156 (82.1)	<0.0001

Facility delivery[j]	200 (81.6)	38 (62.8)	162 (81.8)	0.006
Maternal ART	180 (70.3)	27 (40.9)	153 (80.5)	<0.0001
Infant ARV prophylaxis[k]	198 (81.8)	21 (42.0)	177 (94.2)	<0.0001
6 week PNC visit[l]	218 (94.8)	33 (94.3)	185 (98.4)	0.131
Infant 6 week immunization[l]	221 (96.1)	34 (97.1)	187 (99.5)	0.180

Abbreviations: EID, early infant diagnosis; km, kilometre; ANC, antenatal care; PNC, postnatal care; HIV, human immunodeficiency virus; ART, antiretroviral therapy; ARV, antiretroviral

[a] Missing in 3 (1.2%); [b] Missing in 2 (0.8%); [c] Missing in 1 (0.4%); [d] Missing in 2(0.8%); [e] Missing in 2(0.8%); [f] Missing in 7 (2.7%); [g] Missing in 4 (1.6%); [h] Missing in 2(0.8%); [i] N/A as infant death prior to recommended date for HIV testing; [j] excluding miscarriages; [k] excluding miscarriages and still birth; [l] excluding miscarriages, stillbirth and infant death prior to 6 weeks

Figure 4.4 Prevalence patient-reported reasons for no EID (N=71) (A) and switching site of EID from ANC care (N=78) (B)

Caption:

Prevalence of patient-reported reasons for no Early Infant Diagnosis (EID) (A) and switching site of care (B). Structural barriers stem from material conditions of life in resource-limited settings (e.g., transportation cost and availability, family conflict, not enough money) and are shown in red bars. Psychosocial barriers are related to knowledge, beliefs, or attitudes of the patients in the given social setting (e.g., ‘didn’t know’ child should be tested, fear of disclosure, preference for spiritual healing) and are shown in yellow bars. Clinic-based barriers are related to delivery processes at a clinic site (e.g., long waiting times, healthcare worker friendliness, quality of care) and are shown in green bars. Medical barriers related to health status (such as infant death or mother too sick to bring child to clinic) are shown in blue bars.

Abbreviations: ANC, antenatal care; HIV, human immunodeficiency virus; EID, early infant diagnosis.

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5. Expanding knowledge on reasons for failure to uptake MNCH/PMTCT EBIs: social norms, vulnerability and lived experiences of home delivery in Mashonaland Central Province, Zimbabwe

5.1 Introduction

Chapter 4 presented corrected estimates of the uptake and mortality of HIV-exposed infants lost-to-follow (LTFU) up for Early Infant Diagnosis (EID) testing.[1] Through actively tracing a random sample of HIV-infected mother-HIV-exposed infant pairs without no documented EID in a routine NGO programme, the corrected estimate of EID almost doubled (from 31.2% to 60.0%). Reasons for failure to uptake EID and silent transfer to a new clinic after birth within socioecological domains[2,3] (structural; clinic-based; psychosocial or patient-related; or medical factors) highlighted the importance of understanding lived experience and context within determinant frameworks.

Coupled with findings from a survey on reasons for home delivery,[4,5] the use of structured questionnaires for describing reasons for failure to uptake services in the previous Chapter's study provided insufficient depth on the dynamic interaction of societal, inner and outer contextual influences and influence of patient, provider and other recipients involved in supporting uptake of MNCH and PMTCT services within the Health Equity Implementation Framework.[6] Nor did the research provide insight into the lived experiences of rural women who fail to uptake recommended services.[7] Such evidence is required to inform specification of contextually relevant adaptations to NGO programme strategies to address barriers to accessibility and utilization of maternal and newborn healthcare services in context.[4,8]

In this chapter the reasons for and experiences of non-facility birth among rural women who deliver at home are evaluated.[9] Using data from 30 semi-structured interviews and five focus group discussions, this manuscript builds on the findings from Chapter 4 by further exploring the patient, provider, community, social and cultural factors that affect uptake of recommended MNCH services from the perspective of women who experienced a recent non-institutional delivery.

The study found dynamic interaction of factors at each layer of the Health Equity Implementation Framework (societal, contextual, and recipients) as having influenced the ability of rural women to access and uptake institutional deliveries, despite the existence of community- and health facility-based NGO programmes to support maternal health service uptake. Specifically, translation of global health targets supported by NGO programmes promoting health service uptake created social norms for women to deliver at facilities, yet vulnerability factors coalesce at the time of delivery to prevent access to facility-based services. In an attempt to "follow the rules" many women delivered at home alone or on the way to the facility in unsafe settings and experienced punishments following home delivery which further increased vulnerability of women and their infants across all socioecological domains. Cislaghi and Heise's Dynamic Framework for Social Change was used as complementary theoretical framework to specifically explore the impact of social norms on the experiences and narratives of women who deliver at home. This facilitated theoretical advancement and evidence on the influence of social norms to create unintended consequences among vulnerable non-adherers of promoted health practice in NGO programmes.

This study highlights the importance of considering the dynamic interaction of vulnerability and community context of intended recipients of care in the design, implementation and evaluation of public health programmes, including the identification and mitigation of unintended consequences. The findings from this study underscore how community-based participatory engagement and storytelling through qualitative research (particularly with 'non-adherers') can inform evidence-based 'facilitation'[10] strategies within NGO programmes aimed at enhancing equity of access and outcomes in maternal and child health programmes.

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5.2 Citation

Webb, K. A., Mavhu, W., Langhaug, L., Chitiyo, V., Matyanga, P., Charashika, P., Patel, D., Prost, A., Ferrand, R. A., Bernays, S., Cislaghi, B., Neuman, M.'I was trying to get there, but I couldn't't': social norms, vulnerability and lived experiences of home delivery in Mashonaland Central Province, Zimbabwe. Health policy and planning. 2021. Doi: 10.1093/heapol/czab058

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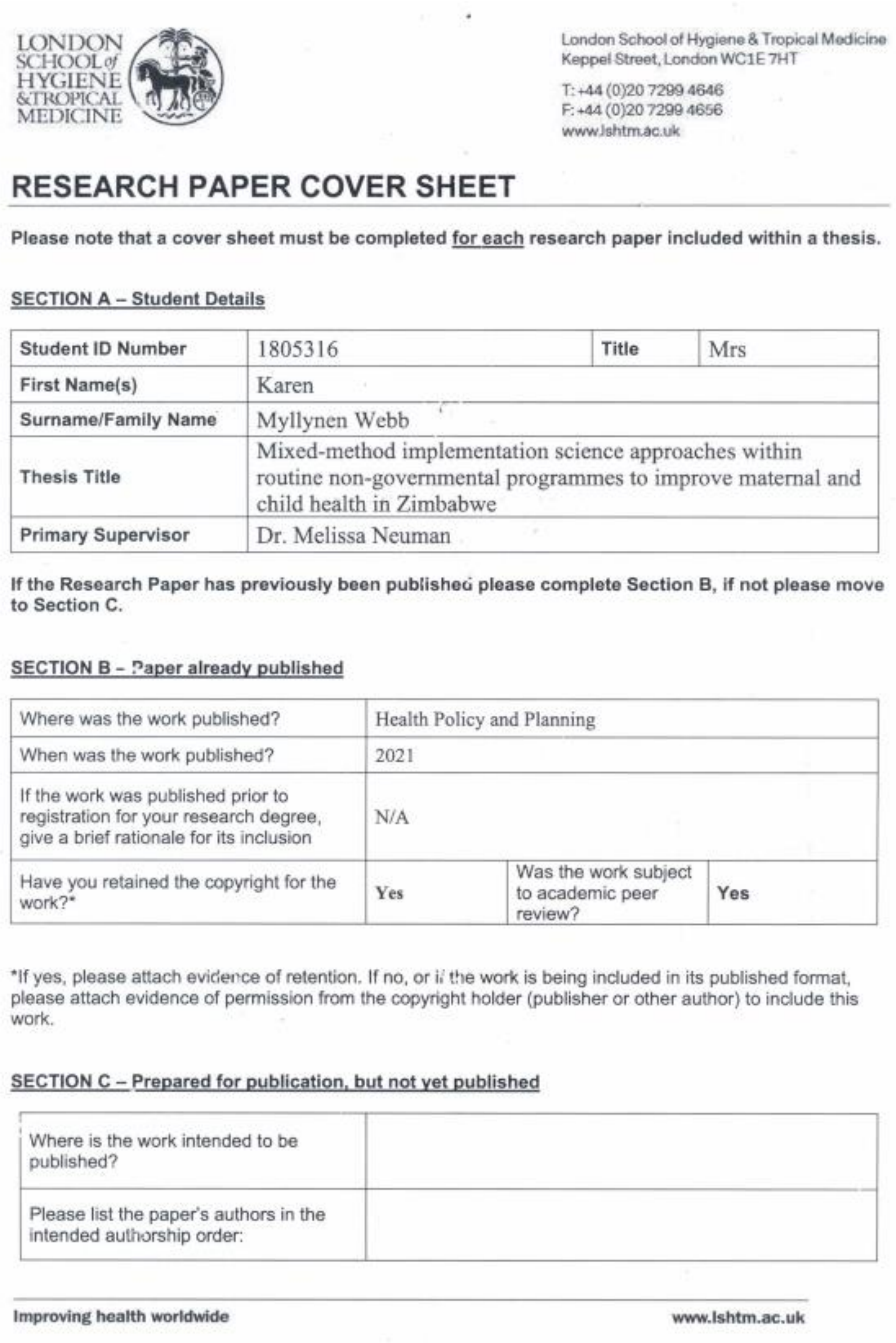
5.4 Research Paper 3: 'I was trying to get there, but I couldn't': social norms, vulnerability and lived experiences of home delivery in Mashonaland Central Province, Zimbabwe



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Surname/Family Name	Myllynen Webb		
Thesis Title	Mixed-method implementation science approaches within routine non-governmental programmes to improve maternal and child health in Zimbabwe		
Primary Supervisor	Dr. Melissa Neuman		

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For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	I was first author of this paper. I wrote the first draft and led on the study design, implementation and analysis for the manuscript. I incorporated all the feedback from co-authors and led on the submision of the manuscript to the journal. I was responsible for responding to all the reveiwer comments and resubmission after peer review.

SECTION E

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Original Article

‘I was trying to get there, but I couldn’t’: social norms, vulnerability and lived experiences of home delivery in Mashonaland Central Province, Zimbabwe

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Abstract

Increasing facility-based delivery rates is pivotal to reach Sustainable Development Goals to improve skilled attendance at birth and reduce maternal and neonatal mortality in low- and middle-income countries (LMICs). The translation of global health initiatives into national policy and programmes has increased facility-based deliveries in LMICs, but little is known about the impact of such policies on social norms from the perspective of women who continue to deliver at home. This qualitative study explores the reasons for and experiences of home delivery among women living in rural Zimbabwe. We analysed qualitative data from 30 semi-structured interviews and 5 focus group discussions with women who had delivered at home in the previous 6 months in Mashonaland Central Province. We found evidence of strong community- level social norms in favour of facility-based delivery. However, despite their expressed intention to deliver at a facility, women described how multiple, interacting vulnerabilities resulted in delivery outside of a health facility. While identified as having delivered ‘at home’, narratives of birth experiences revealed the majority of women in our study delivered ‘on the road’, en route to the health facility. Strong norms for facility-based delivery created punishments and stigmatization for home delivery, which introduced additional risk to women at the time of delivery and in the postnatal period. These consequences for breaking social norms promoting facility-based delivery for all further increased the vulnerability of women who delivered at home or on the road. Our findings highlight that equitable public health policy and programme designs should include efforts to actively identify, mitigate and evaluate unintended consequences of social change created as a by-product of promoting positive health behaviours among those most vulnerable who are unable to comply.

Keywords: Facility-based delivery, home delivery, health inequities, social norms, maternal health, health policy, Zimbabwe

Introduction

Over the past two decades, increasing skilled attendance at birth has been the fulcrum of global health efforts to reduce maternal and neonatal morbidity and mortality in low- and middle-income countries (LMICs; Doctor *et al.*, 2018). Given that almost all neonatal deaths occur in LMICs, with two-thirds of these occurring on the first day after birth (Sankar *et al.*, 2016), skilled attendance at birth is a critical strategy for reaching Sustainable Development Goals (SDGs) to reduce the global neonatal mortality rate to ≤12 deaths per 1000 live births (United Nations General Assembly (UNGA), 2015).

Across sub-Saharan Africa (SSA), risk factors for non-institutional delivery include low maternal education, high parity, low household wealth, distance to the nearest health facility and low number of antenatal care (ANC) visits (Moyer and Mustafa, 2013). Social norms—unwritten rules of behaviours shared by members of the same network—are also known to affect women’s preferences and choice of delivery location (Bohren *et al.*, 2014).

Since 2010, births in SSA were 85% more likely to occur in facilities than those in the 1990s (Doctor *et al.*, 2018). Global and national policy and programme focus has increased skilled attendance at birth, expanding the normalization of facility-based delivery in both urban and rural LMIC settings (Montagu *et al.*, 2017) and decreasing maternal and neonatal morbidity and mortality.

Despite such progress, coverage of skilled attendance in SSA in 2018 was only 59% (Sachs *et al.*, 2019), and rates

Key messages

- Understanding the reasons for and experiences of home delivery from the perspective of women who deliver at home is critical for informing context-sensitive policy and programmes.
- Rural women who delivered at home in Zimbabwe described multiple, intersecting vulnerabilities that resulted in home delivery.
- Social norms promoting facility-based delivery for all created perverse incentives, which introduced consequences dur- ing and after home delivery that further increased women's vulnerability.
- Public health policies and programmes promoting social change should actively identify and mitigate unintended consequences among the most vulnerable who are unable, or unwilling, to comply.

of non-institutional delivery remain unequal (Boerma *et al.*, 2018). Understanding the reasons for and experiences of home delivery through an approach that purposively seeks to elevate women's voices is critical for informing context-sensitive policy and programmes (Langlois *et al.*, 2018). However, few qualitative studies have explored the influence of social norms upon the experience of home delivery among women who deliver at home.

We present the findings of a qualitative study exploring the lived experiences of women who have had non-institutional, or 'home', deliveries in rural Zimbabwe. We aim to both provide empirical data on women's experiences of home delivery and expand the conceptual literature, building upon existing frameworks to describe the influence of social norms on the reasons for and consequences of home delivery among vulnerable rural women.

Theoretical framework

Social norms govern appropriate actions in a given situation and can either constrain or motivate positive action and health behaviours in a dynamic fashion, shifting over time (Legros and Cislaghi, 2020). Norms are fundamental when understanding health behaviours as they influence people's beliefs about what others do (descriptive norms) and what others approve or disapprove of and expect of them (injunctive norms; Cialdini *et al.*, 1991).

Despite the abundance of social norms theories, few conceptual frameworks seek to operationalize social norms theory to support the design of health promotion policy and programmes. Cislaghi and Heise's Dynamic Framework for Social Change (2019) draws on Bronfenbrenner's (1979) ecological framework by stressing the overlapping and dynamic interaction of global, institutional, material, social and individual factors influencing health-related choices and actions. Social norms operate at intersection points of each ecological domain, where they exert their greatest influence (Cislaghi and Heise, 2019). We draw from the Dynamic Framework as a conceptual scaffolding to explore how public health initiatives can create and reinforce social norms supporting facility-based delivery but also result in negative consequences for women delivering at home.

Context

Facility-based deliveries in Zimbabwe increased from 65% in 2010 to 77% in 2015 (ZIMSTAT and ICF International, 2013; 2016). Over the same period, Zimbabwe's maternal mortality ratio decreased from 960 deaths to 651 deaths per 100 000 live births (2010–2015). Neonatal mortality, however, only declined from 31 deaths to 29 deaths per 1000 live births.

Increases in access to facility-based delivery are linked to efforts to improve equity of access and quality of healthcare through national health policies and programmes (Zimbabwe MOHCW 2009; MOHCC 2016a). These have included making maternal health services free of charge, results-based financing initiatives and public health campaigns discouraging traditional birth attendants (TBAs) from assisting with home deliveries. Despite gains, Zimbabwe's maternal and neonatal mortality remain well above SDG targets.

Mashonaland Central Province, the study setting, has one of the lowest rates of institutional delivery in Zimbabwe, with only 68.5% of women delivering in a health facility (ZIMSTAT and ICF International, 2016). Rural residents make up 92% of the population (ZIMSTAT, 2018). The province also has the highest rate of extreme poverty (41.2%; ZIMSTAT, 2018) and long distances between many households and the closest health facility.

Methods

Study setting

Our qualitative study was conducted from February to June 2016 in Mashonaland Central Province. We purposively selected five communities in five of eight districts, with health facilities serving as the focal point of our sampling strategy. All communities selected were rural, although purposively chosen to provide a relative diversity of rural communities within the province in relation to transportation access, existence of maternity waiting homes and community context (Table 1).

Study design and participants

We sought to explore women's experiences of home delivery, a term commonly used in context to refer to any delivery outside of a health facility, and the influence of social norms on these experiences. Our approach was influenced by the interpretive perspective of social constructivism, which acknowledges that meanings attributed to an experience are subjective and socially negotiated by both participants and researchers (Gergen, 2001). While we recognize non-institutional births may occur both at 'home' and 'in another place' (ZIMSTAT and ICF International, 2016), in this study, the use of the term 'home delivery' denotes any birth outside of a health institution.

We planned 30 semi-structured in-depth interviews (IDIs) and five focus group discussions (FGDs) with rural women identified as having delivered at home in the previous 6 months, as to explore how both personal lived experiences and peer- and community-level norms may mediate reported reasons for and experiences of home delivery. Recognizing that home deliveries among the most vulnerable and isolated may go unregistered (United Nations Children's Fund (UNICEF), 2016), we utilized a multi-stage purposive

Table 1. Community characteristics

District	Proximity to main road	Maternity waiting home	Community context
Bindura	Road access	No	Farming community, limited transportation availability
Mazowe	Near main road	No	Farming community on periphery of Harare, some industry (brickmaking), mobile community
Mbire	Very remote	Yes	Remote rural settlement, border community, high poverty
Mt. Darwin	Very remote	No	Rural resettlement, seasonal access challenges (washout of roads/bridges)
Rushinga	Road access	Yes	Remote rural district close to Mozambican border/seasonal migration with active non-governmental organization maternal health programme

sampling strategy using both community- and facility-based registries and peer referral. We selected women residing in the catchment of five rural health facilities through a three-stage sampling process: (1) village health workers (VHWs) conducted community enumeration of women with home deliveries during the previous 6 months, cross-referenced against facility records. Snowballing techniques were also used: women identified by VHWs were asked if they knew of any other women in their community who had experienced a recent home delivery; (2) women were purposively selected from this sampling frame, with attempts made to prevent over-representation of any characteristic among participant IDI or FGD groups; (3) selected women were asked by VHWs to participate in a study to discuss their recent home birth. Women consenting to participate were either requested to attend FGDs at a central community location or interviewed individually. All chose to be interviewed at their homestead.

Data collection

The first author designed the study protocol and tools. IDIs and FGDs were conducted by experienced and trained female research assistants in the local language (Shona). Interviews averaged 50 minutes in length (range 32–68 minutes). FGDs included an average of 8 women (range 7–10) and averaged 80 minutes in length (range 68–92 minutes).

Discussions were guided by pre-tested topic guides exploring women's reasons for delivering outside of a health facility, probing their experiences, reactions of others and emotions during and after birth. Interviews and FGDs were audio-recorded, transcribed verbatim and later translated into English. Translated transcripts were proofread against Shona transcriptions and audio-recordings, with corrections made by consensus. In addition to audio-recording, notes were taken during each IDI/FGD to document key impressions, non-verbal behaviour and descriptive information about the environment and atmosphere in which the discussion was conducted. Daily and weekly debriefs with KW were conducted during fieldwork to discuss emergent themes and any required changes to the topic guides.

Data analysis

To minimize bias and encourage reflexivity throughout the research process, data generation and analysis began at the point of collection, following an iterative process. Contact summaries, field notes and minutes from research team debriefs were included as data sources in the analysis. Data were imported into NVivo 10 software (QSR International; Melbourne), and analysis was conducted using a grounded analytic approach to thematic analysis (Corbin and Strauss, 2008).

Cognizant of implicit relationality and power dynamics in discourse, the analysis focused on participant language and patterns, in terms of what participants said and how they said it, including moments of silence, non-verbal communication and events in the interview environment (Fairclough, 2003). First-level or open coding drew upon a combination of a priori themes reflected in the study interview guide and inductive or *in vivo* codes based on participant narratives (Charmaz, 2014). Investigators met to discuss initial codes and themes collaboratively, with an initial start-list combined from a selection of 10 transcripts (n =5 IDIs; n =5 FGDs).

Inter-rater reliability was established using the full coding framework through a combined analysis of 6/30 (20%) randomly selected transcripts. Theoretical nodes were revised after a series of discussions between co-authors in which they were compared, contrasted and iteratively refined until consensus was reached, to avoid personal bias.

Additional analysis was conducted by the principal investigator (PI), with the coding framework adapted as analysis progressed. Emerging linkages between codes were explored through iterative comparisons and corroborated by exploring negative cases where responses by research context (IDI/FGD) and women's narratives differed or counteracted the emerging themes and explanations.

Ethical considerations

Ethical approvals were received by the author's institute. Written informed consent, including for audio-recording, was obtained from all respondents prior to their participation in the study, with those aged 16–18 independently consenting as emancipated minors as they had children and were married and/or heads of household (MOHCC, 2016b). Names and other personal identifiers were removed from transcripts before analysis.

Results

Seventy-one participants with a median age of 27 (range 16–44 years) and median parity of 3 (range 1–7 children) were interviewed (n = 30) or participated in FGDs (n = 41). In addition to their recent home delivery (N = 71), over half of the women reported experiencing a home delivery in a previous pregnancy (n = 39; 55%; Table 2). Two women participating in FGDs did not know their exact date of birth and did not have identity documents. Among women participating in IDIs for whom additional demographics were recorded (N=30), most (n=25; 83%) were married. One

Table 2. Participant characteristics (*N* =71)

Characteristics		Interview *N* (%), *n* =30	Focus group *N* (%), *n* =41
Age (years)	≤18	5 (17)	3 (7)
	19–29	14 (47)	19 (46)
	30–39	9 (30)	15 (37)
	40+	2 (6)	2 (5)
Religion	Apostolic	21 (70)	25 (61)
	Pentecostal	3 (10)	5 (12)
	Other Christian	3 (10)	5 (12)
	None	3 (10)	6 (15)
Education	Secondary (any)	10 (33)	16 (39)
	Primary only	18 (60)	22 (54)
	None	2 (7)	3 (7)
Parity	1	6 (20)	5 (12)
	2–3	13 (43)	20 (49)
	4+	11 (36)	16 (39)
Previous home delivery	Yes	17 (57)	22 (54)
	No	7 (23)	14 (34)
	Not applicable (first child born at home)	6 (20)	5 (12)

Table 3. Place of recent non-institutional delivery, interview participants (*N* =30)

Place of delivery	At own home unskilled assistance (friend, relative)	7 (23%)
	At home of neighbour or relative	2 (7%)
	At own home alone	4 (13%)
	'On the road'—en route to health facility	17 (57%)

woman reported being in a polygamous marriage. All but two women reported using ANC services in the recent pregnancy that ended with home delivery. Women with more than four children more frequently described having experienced a previous home delivery (9/11; 82%). Despite self-identifying as having experienced a home delivery, description of birth experiences revealed that more than half of women interviewed (*n* = 17/30; 57%) delivered 'on the road', en route to the health facility (Table 3); the majority of whom delivered at home in a previous pregnancy (12/17; 72%). Nearly all participants 18 years and below delivered at home with the assistance of a relative (4/5) with one delivering on the road.

Home delivery—a discourse influenced by social norms, vulnerability, gender and power

An early reflective finding was that through their lived experiences of home delivery as well as subsequent interactions with health services and community members, women had already constructed narratives to rationalize and justify having 'broken the rules'. Research participation not only represented a moment of self-formation and identity work between researchers and participants (Riessman, 2008) but the continuation of an ongoing social process to validate their social reality and limit damages (Rhodes *et al.*, 2010).

Qualitative data analysis led to the identification of three emergent, inter-related themes: (1) social norms in favour of facility-based delivery, (2) overlapping vulnerabilities across ecological domains as the reason for home delivery and (3) enforcement of social norms around facility-based delivery leading to consequences during and after home delivery, which further increased vulnerability. Additional illustrative quotes under each theme can be found in Supplementary Table S1.

Social norms regarding place of delivery

Respondents described a recent evolution of prevailing social norms on preferred place of delivery—a lived historical period when home delivery was accepted due to poverty, distance, user fees and the existence of trained TBAs. The removal of user fees, building of maternity waiting homes, health education campaigns and the 'banning' of TBAs were described as contributing to a shift in social norms regarding acceptability of home delivery in terms of 'then' and 'now':

> *Those older people are used to delivering at home and being assisted by people in the community…they never used to go to the clinic* (IDI 203, 20 years, parity of 1, recent birth at home assisted by mother).

Current social norms reinforced the expectation of facility-based delivery for all women. Women's narratives provided examples of both descriptive (belief that the majority of women in their community deliver at health facilities) and injunctive norms (perception that others in their social networks and community wanted them to deliver at a facility) regarding facility-based delivery. These social norms were so strong that they were frequently referred to in absolute, moralistic terms, with facility-based delivery described as 'good' and home delivery as 'bad' and, in many instances, as 'law' (Table S1; Section 1.5).

All respondents expressed having had no intention to deliver at home, many citing their uptake of ANC services during pregnancy or previous facility-based delivery as 'proof' of their intention for a facility birth. Women expressed valuing facility-based delivery, and many linked having a facility-based delivery with access to skilled help or emergency care, while home delivery was linked to being isolated and helpless in the event of complications:

> *Aah it is bad to deliver at home…if you deliver at home sometimes no one will come to help you. You can die - as well as the baby- because you may be alone* (IDI 102, 18 years, parity of 1, recent birth at home assisted by aunt).

Intersecting vulnerability as reason for home delivery

Women's narratives identified three overlapping themes for their recent home delivery: (1) material vulnerability, (2) social vulnerability and (3) individual vulnerabilities related to lack of knowledge.

Material vulnerability

A strong emergent theme from the narratives of women was how vulnerability begets vulnerability, or, 'I couldn't do because I didn't have'. Women described how despite their intention to deliver at a facility, they were unable to plan for or reach the clinic during labour without the necessary resources. The influence of material vulnerability on women's decision-making and agency was multi-faceted, compounding and heightened at the time of delivery.

Among the most remote and vulnerable households, respondents described the need to prioritize resources for household survival as negating any opportunity to save or make preparations for facility-based delivery:

> *I didn't have the money because the moment you get money you buy mealie meal for the family to eat* (FGD 401, remote community on Mozambican border).

Lack of personal transportation or resources to hire transportation at the onset of labour was a dominant reason for home delivery during both interviews and focus groups. Women living near road networks described not having money to hire vehicles, whereas the most remote and vulnerable women described lack of livestock and/or scotch carts (oxen/donkey drawn carts; Table S1; Section 2.1).

Despite describing how material vulnerability resulted in seemingly inevitable home delivery, few women described a belief that their own or another's vulnerability was an acceptable justification for their failure to deliver at a health facility.

> *Aah, every woman ..., rich or poor, all must deliver at the clinic* (IDI 505, 33 years, parity of 4, all home births, recent birth on the road).

Social vulnerability

Many women described how being alone in the homestead, working in the fields, collecting water/firewood and/or being solely responsible for dependent household members (children and elders) contributed to delays that led to home delivery. Despite the majority of women self-identifying as married, few male partners were present at the onset of labour. Social isolation and household responsibility were particularly noteworthy for vulnerable women with high parity. The importance of social support at the time of delivery was described by a 24-year-old mother of three:

> *I wanted to [deliver at the facility] but I don't have a father or mother so I didn't have anyone to look after my children while I was away…In the future my children will be grown up [sic] so I can go and stay at the hospital* (IDI 506, 24 years, parity of 3, previous facility births, recent birth on the road).

Despite their desire to deliver at a health facility, at the onset of labour, women described a lack of agency to either access or control the resources required to uptake facility-based delivery. Within a community context of generalized poverty, participant narratives emphasized how vulnerability factors coalesce and the sense of helplessness experienced by these most insecure households to 'achieve' facility delivery:

> *Some of the transport owners demand a goat as payment, but you may not have the goat. He asks for a chicken and the only chickens you have are to sell [so that you can] buy soap for home use. Some people may offer you a scotch cart, but you don't have the cattle. The husband runs around looking for cattle, someone may offer him one only, [but] you need two to pull a scotch cart…He goes to the next house, [and] some say, "We don't have cattle." All this time, labour is progressing, so by the time he comes back home the wife has delivered already* (FGD 401, remote community on Mozambican border).

Despite existing within poor communities, women described stigmatization and shaming experienced by the most vulnerable. This was most often referred to during FGDs as opposed to IDIs, and even then, most often in the third person as 'other women's' experience as opposed to their own. In remote areas with maternity waiting homes, these poorest women were described as rejecting stays at maternity waiting homes to avoid the social consequences of having their extreme poverty gossiped about by others:

> *Some don't have baby preparation clothes and food so they can't stay at [a] mother's shelter because they are embarrassed [that] they don't have anything to cook. Some women want to show off what they have, so you feel out of place* (FGD 501, remote community with high rates of poverty).

Individual vulnerability

The third dominant theme from women's narratives regarding reasons for home delivery was related to individual-level vulnerability factors, specifically, knowledge and understanding of signs of labour and undue reliance on the exact nature of their expected delivery dates (EDDs).

Women described interpreting their EDD as a fixed date, so were often not expecting to go into labour and dismissed symptoms at onset of labour. This led to delays in notifying others until labour had progressed so much it was too late to reach the facility (Table S1; Section 2.3).

Social norms mediate the experience and consequence of home delivery

The contradictory interplay between vulnerability and social norms ('I couldn't get to the facility because I didn't have … yet everyone must deliver at the facility') permeated respondents' descriptions of their experience of home delivery. Women expressed personal shame and discomfort for having broken widely held community norms through silence, expressions indicating hesitation or discomfort ('aahh/eii'), as well as body language (looking down at the ground or their hands) when discussing their birth experiences. This was particularly poignant during IDIs, where women's narratives were concentrated upon their individual experience as opposed to FGDs that discussed a shared experience of home delivery. Many women expressed gratitude to research assistants for 'listening to their stories' without judgement.

Experience of home delivery

Women described home delivery as imbued with fear and worry by both themselves and others anticipating the negative repercussions for breaking widely accepted rules discouraging home delivery or seeking assistance from TBAs. This was a particularly strong narrative among women who gave birth at the home of a neighbour or relative. One woman described the reaction of her aunt during home delivery:

> *Aah she was afraid. She said, "You should have gone to the clinic because here at my home people will scold me." She wanted these people with the bag [with baby items] to arrive so that we [could] go to the clinic but I told her I couldn't get there now* (IDI 406, 20 years, parity of 2, previous facility delivery, recent birth on the road).

Despite that respondents described lack of agency to make decisions or access resources required to reach the health facility during labour, many women described the 'blame' for home delivery and onus to ensure safe delivery as falling onto them solely. One participant described how she was chastised by a relative for her failure to reach the health facility, even during the act of childbirth:

> *She was standing there telling me that what I did is not allowed. I said, "What could I do, I didn't know I was in labour?" I pushed the baby alone* (IDI 504, 24 years, parity of 2, previous facility delivery, recent birth on the road).

Norms promoting facility-based delivery and 'banning' of TBAs resulted in some women being refused assistance from friends, relatives or elders and delivering alone:

> *People are now afraid. I gave birth by myself…They [TBAs] are afraid of being arrested because everyone now is aware that they have to go to the clinic* (IDI 402, 33 years, parity of 7, no antenatal care, recent birth at home alone).

The majority of respondents described delivering their infants 'on the road', en route to the health facility (Table 3). Delivery at home without demonstrated attempts to reach the health facility incurred the risk of being accused of planning home delivery by healthcare workers or community members. Of note, women who delivered on the road described delays that made the perceived likelihood of reaching the facility unlikely, yet set out for the facility regardless. The dissonance between the desire/expectation to deliver at a health facility and structural reality of vulnerability was a common theme (Table S1; Section 3.1).

A number of respondents described a practice where, following delivery, they wrapped the baby with the umbilical cord still attached to the placenta and travelled to the clinic for the cord to be cut by a healthcare worker as a demonstration of their intention to deliver at the health facility:

> *When I delivered on the road I took everything (placenta with cord still attached to the infant), they [health care workers] cut the cord. I told them I had [a] short labour and I miscalculated my dates, they accepted me and said it was "not a problem at all; it happens. Let us prepare the baby."…they didn't scold me* (IDI 405, 39 years, parity of 6, previous facility delivery, delivered on the road).

Consequence of home delivery

During interviews and focus groups, nearly all respondents described numerous explicit and implicit consequences for breaking community codes of conduct by having a non-institutional birth.

Women described feelings and experiences of shame and ridicule for being known in their community as someone who delivered at home. Women's narratives emphasized that as home delivery is no longer accepted, 'committing' the act of home delivery reflects poorly on the household, but especially on the mother.

> *The one who delivers at home… many stories are told about her and the baby…if you hear what people say, it is better to go to the clinic* (IDI 506, 24 years, parity of 3, previous facility birth, delivered on the road).

Another mother described her infant being labelled with a derogatory name after delivering on the road:

> *When they came to see the baby, some said, "Hi chenzira" ("baby born on the street" - a derogatory term in Shona). Some were joking but it was annoying me because it was not my fault that I delivered on the road because I was going to the clinic…there was nothing else that I could have done* (IDI 201, 28 years, parity of 3, first two home deliveries, delivered on the road).

Due to widely held community beliefs that home delivery threatens the health of mothers and infants, many women described social sanctioning by community members for having delivered outside of a health facility:

> *When I delivered my child I was staying with my sister so when I saw people at the well fetching water, they were not happy that I delivered at home. They didn't see it as a good thing. They shouted at me saying, "You will kill the baby!". They didn't even ask if I [had] delivered safely or if I [had] encountered any problems* (FGD 101, commercial farming area close to urban centre).

Due to continuous reinforcement of messages to deliver at the facility by healthcare providers, many women described being fearful or ashamed to present to the health facility after home delivery. Once at the clinic, while not formalized or uniformly applied, women described punishments imposed by healthcare workers, including being shouted at, separate queues and longer wait times for postnatal care, and being 'fined' to receive the infant's health information card.

> *Those that deliver at home are punished at the hospital. They are made to sit for some time and explain why they chose to deliver their babies at home* (IDI 201 28 years, parity of 3, first two home deliveries, delivered on the road).

Discussion

In this article, we have explored the reasons for and experiences of home delivery from the perspective of rural women who delivered at home in Zimbabwe. By elevating the voices of the affected, we gained insights into how social norms influence the narratives and lived experiences of vulnerable women who deliver outside health facilities through three key findings. First, we found strong social norms in favour of facility delivery. Second, intersecting vulnerabilities coalesced across multiple ecological domains to result in seemingly inevitable home delivery among the most vulnerable. Finally, 'zero tolerance' for home deliveries resulted in consequences that further increased the vulnerability of women who deliver at home. Drawing on and extending Cislaghi and Heise's Dynamic Framework for Social Change (2019), we explore implications of these findings for policy and practice.

First, we add to an existing body of literature documenting shifting social norms in favour of facility-based delivery across Africa (Montagu *et al.*, 2017; Shifraw *et al.*, 2016). Changes in social norms can be subtle and progressive, inculcated through socialization, or more overt and sudden, imposed by more powerful authorities (Cislaghi and Heise, 2019). The potential of norms-based interventions for affecting widespread and lasting community-based health promotion and reducing harmful gender-related practices is being increasingly recognized (Cislaghi and Heise, 2019).

In our study, women's narratives provide evidence of social norms on facility-based delivery being recently evolved and widely shared across their social networks. This is an important example of successful 'organized diffusion' of public health messaging for achieving the normative change for health promotion (Cislaghi *et al.*, 2019). Social norms in favour of facility-based delivery were pervasive, expressed both descriptively and injunctively, the fear of sanctions for breaking them so strong that even TBAs were described as telling women 'everyone must deliver at the facility now'. Recent policy and programs effectively increased community support for facility-based deliveries. However, local interpretation and 'enforcement' of policy transitions such as those that once promoted training of TBAs and subsequently banned their involvement in community births, have been noted as creating punitive measures which disadvantage the poorest rural women (Choguya, 2014; Uny *et al.*, 2019).

As proposed by our expanded theoretical framework, such evidence demonstrates how global policy commitments to reduce maternal and neonatal mortality have influenced national and local policy and programmes and in turn fundamentally altered social norms around such culturally entrenched practices as childbirth. We suggest the relationship between global health policy and social norms is bi-directional, with widely diffused social norms also acting to reinforce existing policy and programmes, further establishing their value as priority public health actions over competing alternatives (such as training TBAs in safe deliveries or distribution of safe delivery packs among women at high risk of home delivery).

The more women deliver at health facilities, the stronger the social norm becomes, behaviours are reinforced and, our study suggests, so are the consequences for non-compliance. This shift of social norms that stems from global health initiatives can be at least partly attributed to dramatic increases in facility-based delivery rates in many LMIC settings over the past decade (Montagu *et al.*, 2017). An important caveat to the success story of increased facility-based delivery is the simultaneous need to ensure the availability of quality obstetric services to meet the increasing demand. Increases in facility-based delivery have not always translated to improved maternal and neonatal survival, with differences within and across African countries, and by facility type (Montoya *et al.*, 2014; Moyer *et al.*, 2013).

The second key finding was the role of intersecting vulnerabilities that aggregated and prevented reaching the 'tipping point' for being able to access facility-based delivery. Women's narratives captured how material (food insecurity, available household assets and access to transportation), social (isolation, distance and lack of agency for decision-making) and individual-level (knowledge of signs of labour or EDD leading to delays) vulnerabilities coalesce at the time of labour to result in home delivery. This dynamic interaction of vulnerability as a reason for home delivery is consistent with the literature on determinants of home delivery in Africa (Moyer and Mustafa, 2013). Our findings highlight a dissonance between the pace of progress in transforming social norms promoting facility-based delivery and improving structural conditions to ensure no one is left behind.

Differential vulnerability as a driver of poor health outcomes is a theme commonly explored by social epidemiologists as important for understanding and addressing health inequalities, stressing the importance of viewing vulnerability as a contextual phenomenon (Diderichsen *et al.*, 2019). Importantly, women in our study live in a context where 82% of households live in generalized poverty (ZIMSTAT, 2019), and while they shared vulnerabilities, they were not all vulnerable in the 'same way'.

This dynamic interaction where vulnerability factors limit individual capacity for maternal health service uptake has been described by others (Storeng *et al.*, 2013), with a 'pro poor path' to universal coverage of safe delivery requiring identification and intensive outreach among the most vulnerable households (Kruk *et al.*, 2015). Our findings underscore that identifying the most at risk in the context of generalized poverty will require community participation and critically the active involvement of the vulnerable and affected (Hargreaves *et al.*, 2007). With a protracted socioeconomic crisis and severely constrained health system, most recently exacerbated by the COVID-19 pandemic that has further disrupted access to and availability of maternity services (Murewanhema *et al.*, 2020), the importance of understanding contextual vulnerability and structural inequalities will remain a critical component in the design and implementation of public health interventions in Zimbabwe for the foreseeable future.

Our final key finding was that the enforcement of social norms related to place of delivery introduced both additional risk at the time of delivery and consequences after delivery that further increased women's vulnerability across all ecological domains. Strong social norms resulted in communities viewing home delivery on moralistic and even legal terms. To have or assist in home delivery was 'bad' or 'unlawful' and resulted in increased risk at the time of delivery. Many women delivered without assistance, on the road and even carried their infants wrapped with the placenta to the clinic after delivery, as evidence that the home delivery was not planned. While rates of non-institutional delivery in Mashonaland Central declined from 48.4% to 26.8% from 2010/11 to 2015, the proportion of women who delivered in places other than a health facility or home rose from 1.1% to 4.8% (ZIMSTAT and ICF International, 2012; 2016).

After 'committing' a home delivery, women described consequences including ridicule, shaming, fines and reduced quality of care. This clash between maternal health policies and programmes that promote universal uptake of skilled delivery against local realities to create contexts that may endanger the most vulnerable and further enhance inequities has been previously documented (Greeson *et al.*, 2016; Rishworth *et al.*, 2016; Sochas, 2019).

The contradictory impact of social norms, which both promote community support and value for facility birth and simultaneously increase vulnerability among the most vulnerable through punishments for home delivery, provides a powerful example of perverse incentives, or 'cobra effects', of public health policy implementation. Described by Merton (1936) as the 'unanticipated consequences of purposive social action', perverse incentives are unintended and undesirable consequences that are contrary to the intentions of policymakers and programmers. Such cobra effects have been noted as an unintended by-product of 'travelling models' of public health generated through global health initiatives, where the interaction between standardized interventions and implementation contexts may produce unexpected, invisible or perverse effects (De Sardan *et al.*, 2017). Our findings support assertions that universal population measures may widen inequalities for some and that such measures should be combined with strategies that target vulnerable groups (Frohlich and Potvin, 2008). We demonstrate that programmes integrating social norms for positive health behaviours, such as skilled attendance at birth, should actively guard against dogmatic interpretation and implementation. Policies and programmes seeking to create positive social change should equally embed and enculturate principles of compassion and empathy (Fotaki, 2015) for the vulnerable minority who may be unable or unwilling to comply.

Too often, perverse incentives are identified as artefacts of public health policy and programmes (or not at all). While certainly unintended and perhaps unavoidable by-products of public health policy implementation, perverse incentives may be anticipated and mitigated in context. Evidence-informed decision-making can involve intentional articulation of mechanisms for both positive change and harm from a single policy or intervention during the design phase (Oliver *et al.*, 2019). The starting point of efforts to identify and mitigate perverse incentives should be the experiences, needs and preferences of the most vulnerable and affected to understand the local context and lived realities (Larson *et al.*, 2015). Qualitative research should be paired with robust quantitative investigations to understand who will bear the greatest risk from unintended consequences of appropriate public health policies. Mixed-method implementation science approaches are critical for bridging the gap between those who could potentially benefit from an evidence-based intervention and those who actually do benefit and improve the equity of these benefits (Eccles and Mittman, 2006; Geng *et al.*, 2017).

Our expanded framework (Cislaghi and Heise, 2019) provides a pragmatic tool to consider how mechanisms for achieving social change at local levels may adversely affect vulnerable members of a community who do not adhere to the 'rules' (Figure 1).

Strengths and limitations

Our methodology included multiple measures to minimize the risk of bias and enhance the quality and transferability of our findings to other rural settings and vulnerable populations. Limiting the reference time for retrospective questions to 6 months since delivery to minimize recall bias, the use of a purposive sampling of rural communities with different characteristics and a diverse group of women, researcher reflexivity at each stage of data collection and analysis, comparisons within and between cases and triangulation of data

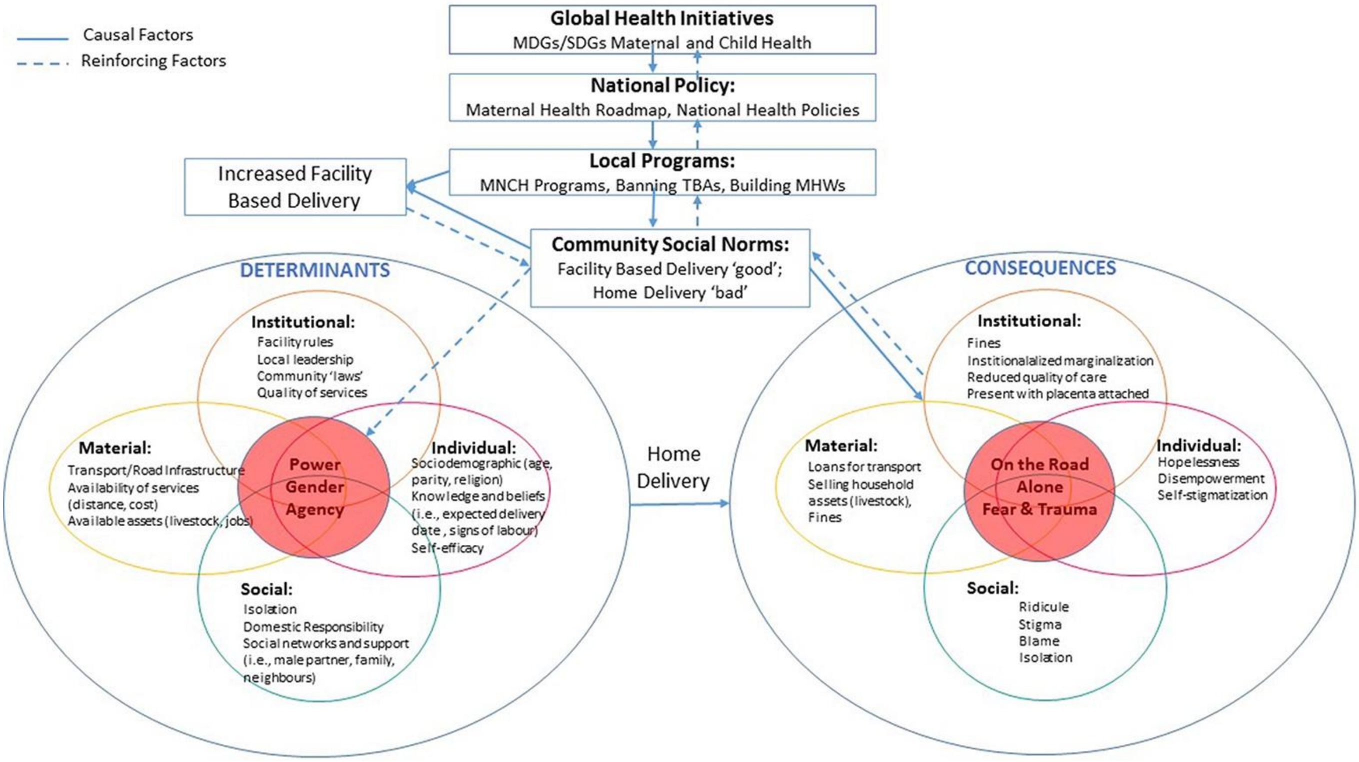

Figure 1. Conceptual framework of generation and impact of social norms upon the determinants and consequences of home delivery. Adapted from Cislaghi and Heise (2019)

sources were intended to improve the internal and external validity of our findings.

We, however, recognize that the narratives of women in our study were socially constructed. The potential for social desirability bias to create an unwillingness to report a planned home delivery or dissatisfaction with health facilities has been noted in other studies of home delivery in Africa (Hill *et al.*, 2019). Despite this limitation, the consistency of our findings with recent quantitative and qualitative evidence on home delivery in Africa gives us confidence that our key findings and expanded theoretical framework are transferrable to other settings and capture important lessons regarding the interaction of social norms, vulnerability and public health policy and programmes.

Finally, the appreciation expressed by women for being able to share their experiences indicates the potential transformative impact of storytelling as both a research tool and an intervention (McCall *et al.*, 2019). Our research not only allowed us to better understand the dissonance between social norms promoting health-seeking and the reality of structural inequality but also provided women 'left behind' with an opportunity to re-engage with the system in a way that promoted empathy and appreciated theirs as part of a valuable landscape of birth experiences in their community. Programmes seeking transformational change in public health should continue to reach out to and learn from 'non-adherers' of promoted health practice.

Conclusion

By exploring reasons for and experience of home delivery among women in rural Zimbabwe, we found that the translation of global and national health initiatives to attain universal access to facility-based delivery influenced and interacted with social norms at the community level. Social norms created perverse incentives through which the most vulnerable women who delivered outside of a health facility were made more vulnerable. We propose policy and programme processes that purposefully identify and mitigate unintended consequences to strengthen evidence-informed decision-making in context and safeguard the most vulnerable.

Supplementary data

Supplementary data are available at *Health Policy and Planning* online.

Data availability statement

The data will be shared on reasonable request to the corresponding author.

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Conflict of interest The authors declare that they have no conflict of interest.

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SECTION III: DISCUSSION & RECOMMENDATIONS TO IMPROVE DATA, IMPLEMENTATION & OUTCOMES OF EVIDENCE BASED INTERVENTIONS

6. Discussion of Key Findings

6.1 Research aims and studies conducted

The aim of this research was to explore and critically reflect on how the use of TMFs and mixed-method transdisciplinary research approaches within NGO-implemented programmes can improve estimates of service uptake, clinical outcomes, and understanding of reasons for and consequences of failure to uptake evidence-based PMTCT and MNCH interventions. This research used the Health Equity Implementation Framework as a grounding conceptual framework for exploring the role of NGOs as facilitators of EBIs and the factors influencing engagement with essential PMTCT/MNCH services from the perspective of rural women who had no documented uptake of care.

The following studies were undertaken:

1. A scoping review to synthesize available evidence on the role of the NGO sector in the HIV response.
2. An observational, multisite, cohort study using sampling-based methods to actively trace a random sample of HIV-infected/HIV-exposed mother-baby pairs lost to follow up from routine care to improve estimates of cumulative incidence of timely EID and mortality and reasons for no EID.
3. A qualitative study exploring reasons for and experiences of non-facility birth among rural women who delivered at home in the previous 6 months..

In this chapter, the key findings, the strengths, limitations and implications of the research findings are discussed. The findings from each study will be critically reflected upon in reference to my grounding determinant framework, the Health

Equity Implementation Framework,[1] and implications for improving the strategies employed by NGOs to optimise implementation, service and client outcomes discussed.[2] The chapter also includes a description of how the findings have been disseminated and opportunities for future research. A synthesis of the research experience and recommendations for strengthening use of transdisciplinary implementation science approaches within NGO programmes in low-resource, high prevalence settings will build on findings from my scoping review and case studies in Chapter 7.

6.2 Discussion of findings

6.2.1 Role of NGOs in Global Public Health

Scoping review findings clearly demonstrated the increasing role of NGOs within HIV programmes in LMICs over the past 20 years. Three key themes emerged with regards to the specific role of the NGO sector in the HIV response: 1) NGOs' role acting as catalysts through advocacy and activism for marginalised and key populations; 2) NGOs' role as implementing partners through direct service provision of HIV prevention, care and treatment services and technical assistance to national HIV responses; and, 3) NGOs as key stakeholders in the generation and use of evidence in the HIV response. While the scoping review was conducted in the specific context of the role of NGOs in the HIV response, these themes are reflective of the ever-changing and increasingly broad role of NGOs over time. Beginning with policy-level commitments of the 1978 Alma Alta and follow on Asanta Declaration in 2018[3] to improve access to primary health care, and extending through to global health initiatives such as millennium and sustainable development health goals and control of infectious disease pandemics and epidemics, the role of NGOs in public health continues to change and expand.[4]

Review findings clearly identified the critical role of NGOs as decentralised actors in the HIV response in communities, health facilities, health systems and advocacy forums. COVID-19 demonstrated the role of NGOs in rapid response and supporting continuity of care and community-based health services in the event of emergent pandemics, conflict or effects of climate change that affect access to health services.[5] In relation to the Health Equity Implementation Framework,[1] the grounding conceptual framework employed in this thesis, scoping review findings provide evidence regarding the role of NGOs in the facilitation of public health EBIs in context (Figure 6.2). NGO programmes seek to improve the clinical encounter through quality improvement and facilitating access to EBIs by identifying and addressing contextual factors that may act as barriers or facilitators to equitable access to EBIs.

Despite the current importance of NGOs as facilitators in the field of HIV and global public health, the review also identified limited representation of NGOs, particularly local NGOs, within published evidence reporting on the design, adaptation of EBIs in context despite their role in developing intervention strategies to improve the uptake and quality of EBIs in context. Specifically, the scoping review themes emphasised the role of NGO translation of EBIs into organisational and community systems and quality improvement programming in context as to improve population health coverage and outcomes.[6,7] However, despite the clear overlap between the objectives of NGOs programmes and those of IS, findings emphasised the limited use of TMFs for the specification and reporting of intervention strategies[8] and outcomes.[2] These findings are reflective of both criticisms regarding the lack of robust evidence produced through NGO programmes[9] and also suboptimal use of ‘big data’ produced through NGO programmes within IS.[10,11]

The review highlighted that the failure to adequately capacitate and engage the ‘doers’ of public health, NGOs and communities, in programme, implementation and improvement science is a cross-cutting theme in recent reviews of missed opportunities for the use of IS to enhance equity and quality of evidence-based interventions in modern public health.[12,13] The findings and critical analysis of the role of NGOs within the HIV response underscore the need to improve the standardization of definitions for NGOs and further specification of the roles and contributions of NGOs to avoid competition between NGOs for funding which results in lack of coordination, sharing of lessons on ‘what works’ and operational fragmentation between NGOs by geography, donor and health issue.[14]

Scoping review findings contributed to: 1) Improving specification of the role that NGOs play as facilitators within the HIV response; 2) Highlighting the existing gaps and opportunities for use of TMFs in NGO programmes; and, 3) Informing a typology of roles of NGOs for optimising national HIV responses (Figure 3.2) in which collaborative transdisciplinary IS between NGOs and implementation scientists is suggested as having the greatest potential impact (reach, effectiveness, efficiencies, sustainability) as countries reach and maintain HIV epidemic control.

6.2.2 Mixed-method implementation science for improving estimates of uptake and outcomes in routine NGO programmes

This research showed that within routine programme data sources, among 2,651 HIV-exposed infants, only 31.2% had documented EID HIV testing. Likelihood of documented EID was higher at low volume health facilities where mothers receive their MNCH and HIV care from the same primary care provider (RR: 1.85 1-200 ANC patient volume, 1001-1500 volume referent; 95% CI: 1.44 to 2.38, P< 0.001).

Community-based tracing of a random sample of those identified LTFU almost doubled the corrected estimate of EID HIV testing (60.0% (95%CI: 58.7% - 61.3%). Corrected estimates of EID HIV testing were similar to population-based PMTCT survey findings over a similar time period of 57%.[15]

The study also identified high rates of undocumented maternal and infant deaths; 17.8% of infants and 4.9% of mothers were found to be deceased. Weighted estimates found cumulative incidence of HIV-exposed infant death by 90 days of birth of 3.9% (95% confidence interval: 3.4% to 4.4%) and 7.7% (95% CI: 4.7% to 13.5%) by one year. These findings support larger studies demonstrating underreporting of adult and infant deaths in high HIV burden settings such as Zimbabwe as biasing mortality estimates downward between two and ten-fold.[16-19] High observed mortality rates among infants in this study underscore evidence that the benefits of successful EID are substantial, not only for HIV-infected infants, in whom morbidity and mortality can be reduced with early ART initiation, but also for HIV-negative infants and their caregivers, as an opportunity for reinforcing PMTCT messages during the postnatal exposure period through breastfeeding.[20]

The documentation of reasons for no EID uptake, or silent transfer within socioecological determinant frameworks identified routine programmatic areas in need of strengthening to prevent in missed opportunities for early identification of HIV positive infants. Among mothers with living infants the most frequent reason for no EID was individual, "I didn't know I should have my child tested" indicating missed opportunities for health education during contact with mothers in ANC and delivery.[21] Silent transfers were described as primarily structural: maternal mobility and transport being easier/cheaper at a new clinic accounting for 43% of reasons for silent transfer. Given the increasing burden of chronic conditions in LMICs with high levels of internal and external migration due to socioeconomic vulnerability, study findings are supported by recent calls for more research on the reasons for and outcomes of transfers to improve processes and data systems for measuring health outcomes.[22]

This case study provides an example of how transdisciplinary research collaborations between NGOs, health system stakeholders and scientists using mixed-method theoretically informed approaches can improve evidence on service outcomes (improved estimates of EID uptake and mortality among a clinic population of HIV positive mothers and their HIV-exposed infants). The study also provided important insight into the contextual barriers to service uptake using expanded upon socioecological frameworks to better understand the medical, structural, clinic-based and psychosocial barriers to engagement in care.[23]

6.2.3 Reasons for failure to uptake essential PMTCT/MNCH Services

Findings from the second case study integrating qualitative research within routine NGO programmes in an area with high rates of non-institutional deliveries provided further in-depth insights into the importance of inclusion and engagement with 'non-adherers' of recommended public health practice for equitable, evidence-based and contextually appropriate public health programmes. Qualitative interviews and focus group discussions with rural women who delivered at home in the previous 6 months in Mashonaland Central Province identified strong community-level social norms in favour of facility-based delivery.[24] These are consistent with evidence across sub-Saharan Africa of shifting cultural norms on place of delivery, partially attributable to local policy and NGO programme translation of global health initiatives to reduce maternal and infant mortality that have led to substantive increases in facility-based delivery rates in Africa.[25]

Building on observed discrepancies in descriptive survey data on reasons for home delivery in 2012,[26,27] despite their expressed intention to deliver at a facility, this study revealed how multiple, interacting vulnerabilities resulted in delivery outside of a health facility. This is consistent with evidence of the influence of vulnerability across socioecological domains on place of delivery.[28] Importantly, study results showed while all women were vulnerable, they were not all vulnerable in the same way. By focusing on the lived experiences of women before, during and after home delivery, the study provided new insights into how differential vulnerabilities coalesce at the time of labour and delivery for women and will require community participation in contexts of generalised poverty to understand vulnerability in context and appropriate and acceptable interventions.[29] Both case studies emphasise how structural inequalities have not kept pace with the ambition of GHIs among the most vulnerable women and children.

Almost 30 years from the seminal article by Thaddeus and Maine, it is still ‘too far to walk’ for many women in Zimbabwe,[30,31] and resulted in delays to accessing timely care-seeking by mothers and infants in the critical intrapartum period to access EBIs to prevent maternal and infant deaths.

Figure 6.1. Road to access primary health care in PhD study intervention community

Strong norms for facility-based delivery, in part attributable to NGO community-based health promotion programmes intended to improve maternal and child health, created a ‘zero tolerance for home deliveries’ climate. Social norms for facility delivery for all introduced punishments and stigmatisation for home delivery, which presented additional risk to women at the time of delivery (delivery alone or enroute to health facilities in unsafe conditions) and in the postnatal period (shaming, stigmatisation and reduced quality of postnatal care) that have also been observed in other settings.[32-34]

Scoping review findings highlighted that NGOs programmes often focus on improving health equity among the most vulnerable and hard-to-reach for improving universal health coverage and achievement of public health policy objectives. Findings from the home delivery case study emphasised that local translation of Global Health Initiatives to improve maternal and child health promoting 'universal coverage for all' enhanced the vulnerability of some women unable to comply through unintended consequences of changes to social norms on place of delivery.[35] This study demonstrated the importance of embedding theoretically informed qualitative evaluation of service and client outcomes which include patient perspectives and identification of unintended consequences of evidence-based public health programmes upon the most vulnerable.

Use of qualitative methods was also able to indicate the value of storytelling as a strategy for re-engaging and understanding the perspectives of 'non-adherers'[24] as an important finding with implications on NGO practice. Mentorship of NGO and health providers on the importance of compassion and empathy as part of quality of MNCH care in context is recognised as important.[36,37] NGOs will not feasibly have the resources or capacity to trace and utilise storytelling as a programme strategy for re-engaging all women who fail to uptake essential services across the MNCH cascade. However, these findings support evidence regarding the importance of client-centred care and quality of counselling by health care providers to utilise active reflection and empathy for changing life circumstances as part of counselling among patients who return to care.[38]

The utilisation of the Dynamic Framework for Social Change[39] to explore the influences of social norms on the reasons for and experiences of home delivery across socioecological domains enabled not only a richer understanding of the determinants of engagement from the perspective of these vulnerable women, but also the expansion of an existing theoretical framework. This provides an example of the potential of transdisciplinary programme research within NGO programmes to both utilise TMFs to frame process, implementation and evaluation efforts, and strengthen rigour of resulting evidence; but also to expand and/or develop new TMFs across disciplines.[40]

6.2.4 Synthesis of findings within the Health Equity Implementation Framework

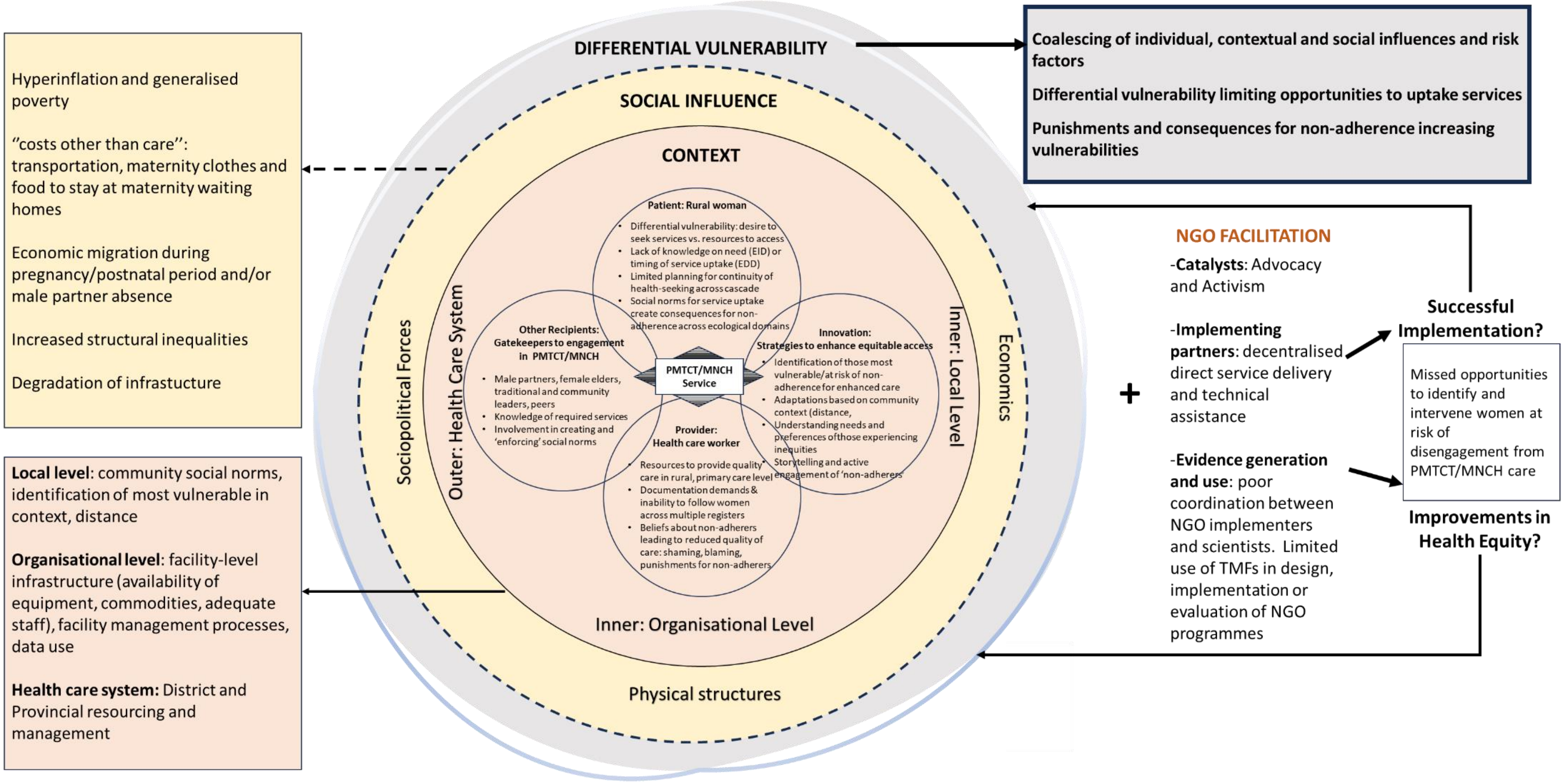
The Health Equity Implementation Framework was employed as the grounding conceptual framework for this thesis to explore and critically reflect on how the use of TMFs and mixed-method transdisciplinary research approaches within NGO-implemented programmes can yield improved estimates of service uptake, clinical outcomes, and understanding of reasons for an consequences of failure to uptake evidence-based PMTCT and MNCH interventions. The scoping review and case studies conducted through this PhD research project yielded important insights into the specification of the Health Equity Implementation Framework from the perspective of ‘non-adherers’ of promoted health practice (Figure 6.2).

First, scoping review findings provided valuable insights into the role of NGOs as facilitators of EBIs in low resource settings as catalysts of public health action through advocacy and activism, as implementing partners supporting direct service delivery and technical assistance, with potential contributions to the generation and use of evidence through transdisciplinary research collaborations. Key strengths of NGOs as facilitators include their decentralised structure and knowledge of community context for accessing hard-to-reach and vulnerable populations. Weaknesses include questions of sustainability of their role in facilitation of EBIs in the absence of external donor funding, and limited evidence of the use of TMFs for the design, implementation and evaluation of EBIs.

Second, given the limitations of routine programme data, PhD research yielded improved evidence on estimates of service uptake, or the ‘clinical encounter’. Such evidence is required to accurately measure improvements in health equity through coverage of EBIs.

Finally, by focusing on the user perspective, case study findings yielded important evidence regarding the societal, contextual, and recipient influences of engagement in care among rural women in Zimbabwe. These findings highlighted the importance of contextual factors and recognition of differential vulnerabilities among intended recipients of care, and need to strengthen identification of women who may be at greater risk of disengagement in care for enhanced counselling and support.

Figure 6.2 Synthesis of PhD research project findings within Woodward et al's Health Equity Implementation Framework



6.3 Strengths and Limitations of NGO data and this research

6.3.1 Strengths of routine NGO programme data and evidence

A major strength of this PhD research was the use of programme science approaches within an iterative, multi-phase research process utilising routine NGO programme data together with mixed-method research.

Routine NGO programme data are collected at community, District, Provincial and national levels at regular (weekly, monthly, quarterly) intervals and input into large donor managed electronic systems. These data repositories are used for tracking of national and global progress towards HIV epidemic control and have given rise to the globally standardised use of HIV prevention and treatment cascades to monitor progress towards policy level objectives such as 95-95-95.[41] Global health metrics of including PEPFAR MER indicators.[42] Global Fund performance management frameworks[43] and UNAIDS Global AIDS Monitoring (GAM) shape the indicator definitions, reporting frequency and timelines of care cascades in Zimbabwe. These are intended to streamline and standardise indicators within age, sex and key population disaggregates.

Donor-managed systems such as PEPFAR's Data for Accountability, Transparency and Impact Monitoring (DATIM) act as data repositories to assist in targeting where HIV resources are needed through geospatial information systems and performance monitoring by donors and NGOs of supported healthcare site level for rapid program remediation. These routine data systems can be used to identify 'leakages' across the HIV care cascades,[44,45] measure the impact of targeted interventions implemented by NGOs to strengthen cascade performance such as clinical mentorship on HIV program performance,[46] and inform regional and global analyses such as the joint PEPFAR and Global fund cascade analysis of programming for key populations.[47]

A specific strength of routine programme data identified through this research is that in addition to programmatic uses in strategic planning, programme implementation, management and evaluation, it can also be used to prioritise research questions and populations to conduct embedded research in NGO programmes. Within the context of this PhD, routine programme data was used to identify key services and geographies with low performance on the PMTCT/MNCH cascade and develop timely and context-relevant research to provide evidence not available through routine reporting. This research provides a worked example of a programme science cycle as an iterative process that allows for the re-development and re-design of programmes to respond to programme indicators and outcomes and to evolving epidemics, structures and drivers of an epidemic.[48]

A recent example of use of routine data to track impact of emergent epidemics or other disruptions on HIV prevention and treatment access, was a difference-in-differences analysis conducted by Harris et al, which showed initial declines in HIV service access at the start of the COVID-19 epidemic, but rapid rebound in HIV testing and treatment cascade performance across 11 countries in sub-Saharan Africa.[49] Programme science approaches where 'big data' from programmes drive scientific inquiry will remain critical for tracking attainment and maintenance of Global Health Initiatives including but not limited to SDG targets for reductions in maternal and infant mortality, HIV epidemic control and elimination of mother to child transmission of HIV.

Due to OPHID's highly decentralised structures and positions of trust as community 'insiders', another important strength of embedding research within an existing NGO programme was access to affected communities and health systems.[50] This translated to familiarity with routine data sources, systems and power hierarchies/protocols and cultural considerations within a fragile, resource-constrained context. NGOs frequently engage with individuals and communities in the adaptation of evidence-based interventions so that they are culturally appropriate and acceptable through modified community-based participatory research processes,[51,52] and accordingly are uniquely placed to employ culturally and contextually appropriate methods for engaging with research participants.

Given this privileged position of working with people and systems in context, an important strength of this research was the ability for research itself to become an intervention within routine programmes. Women who had 'defaulted' from care in the home delivery and LTFU for EID studies frequently thanked interviewers for listening to their stories at the end of their interviews and expressed motivation and interest to re-engage with health services. Utilisation of the Health Equity Implementation Framework and culturally grounded mixed-methods research highlights the importance of mixed-methods using quantitative data to understand and target most affected populations, but then looking beyond and into community context and the importance of lived experiences and individual context in providing person-centred and equitable care.[53,54] While resources have shifted towards 'leaving no woman and child behind', the research in this thesis emphasises the importance of empathy and storytelling among the vulnerable minority who remain left behind as a method of problem-solving therapy.[53] Peer-delivered community-based problem solving therapy approaches have been demonstrated to be successful approaches in Zimbabwe.[55]

To maximise benefits of embedding programme science approaches within routine NGO programmes requires equal attention to rigour, and more intentional use of TMFs to improve the quality of this evidence.[56] The use of TMFs within this PhD research provide applied examples of the benefits of TMFs to both enhance quality of research, as well as contribute to the expansion and contextualisation of existing TMFs. Use of the Behavioural Model for Vulnerable Populations[23] to explore the medical, structural, clinical, and psychosocial barriers for failure to bring HIV-exposed infants for EID testing and/or for silent transfer to a new clinic in the postnatal period not only provided important evidence in context regarding reasons for disengagement in care, but also a structure to evidence generation to enable comparisons with other studies on reasons for LTFU in Africa.[57,58] The use of the Dynamic Framework for Social Change allowed the expansion of current theoretical frameworks on the influence of social norms on the health-seeking behaviours, and unintended consequences of influencing social norms in health promotion.[59] Use of the Health Equity Implementation Framework[1] as a grounding conceptual framework has enabled use of a practical, theory based tool for exploring equity domains within a determinant framework and synthesis of PhD research findings on the role of NGOs as facilitators of EBIs and factors influencing access to and experience of the clinical encounter among rural women in Zimbabwe.


[redacted]

Figure 6.3: Home Delivery Study interviewer together with participant in a location of the mother's chosen time and location, de-emphasizing implicit power dynamics created through systemic inequity and respecting local cultural customs*NB photo taken with written informed consent.

Finally, a key strength of this research has been its embedded nature in ongoing NGO programme, communities and health systems that enabled rapid translation into improved programme practice and translation into local policy and practice (See Section 8.2).

6.3.2 Limitations of this research

The great paradox of NGO participation in programme and implementation science, and of the strengths and limitations of this PhD research, is that the documented strengths of routine data and positionality of NGOs are simultaneously the source of limitations of the evidence produced through embedded research.

Data sources: Aggregate routine data are not population representative, cross-sectional in nature, and are collected at such a scale that implementers often lack the resources to comprehensively clean and check data.[11] Information bias results from incorrect determination of exposure, outcome, or both.[60] Collected by non-research health facility staff or lay cadres, in the absence of unique identifiers or inter-facility linked electronic medical records, it is recognised that routine programme data may be incomplete and/or inaccurate.[61] This PhD highlighted how routine programme data are problematic for reporting of individual-level clinical outcomes across longitudinal cascades of care.[62] Ehrenkranz and colleagues highlight the limitations of a linear and unidirectional HIV care cascade in capturing lifetime care pathways as requiring cyclical cascades that more accurately capture the lifetime care pathways of engaging and re-engaging in HIV care as both explicit and expected.[63]

Observational data: While this PhD research provides evidence of the benefit of embedding mixed-methods research to verify data, these efforts remain subject to established internal and external validity biases of observational research.[60] Research embedded within routine NGO programmes is done within prioritised implementation areas of greatest need, selection bias stems from an absence of comparability between groups being studied and limited generalizability. While the methods used in this PhD were intended to minimize known biases associated with each approach, it is recognised that while important and meaningful in context, it is not generalisable evidence (nor was it intended to be). Rather embedded mixed-method research has the ability to inform evidence-based practice and provide important contribution to TMFs and identify potential context-appropriate innovation strategies for adaptation, replication and evaluation within routine NGO programmes to support enhancing of implementation outcomes as proposed in Figure 6.2 .

Respondent and researcher bias: Embedded within an epistemic foundation of social constructivism and contextualism, the influence of social and individual context upon understanding, implementation and behavioural adoption, and interpretation of knowledge of evidence-based interventions is subject to bias in response, analysis and interpretation. Study procedures were designed to minimise social desirability or sponsor bias associated with research being led by an NGO with existing programmes in study communities: ensuring all study interviewers were not members of programme staff in study areas/known to study communities; training which focussed on de-roling and minimising power dynamics between researchers and participants (I.e., appropriate cultural dress and adherence to customs with regards to greetings, discussions between women, and local language - Figure 6.3); and, detailed informed consent procedures which emphasise the purpose of the research was to learn from study participants' unique and important experiences without judgement, that all information discussed was confidential and would not have any implications on current or future access to health services or other programme benefits.

Efforts to minimise researcher bias among included: engagement with research teams to control for confirmation bias by ensuring a diversity of perspectives to minimise positionality and use of reflexivity within case study activities. The epistemological grounding of this research recognises and findings underscore that truth is socially constructed and also subject to internal biases of the observer based on their own position of power and/or historical antecedents of experiences of inequity.

Finally, there are important and legitimate questions around potential biases of NGO involvement in conducting research and evaluation of their own programmes. Multiple measures were employed to attempt to minimise any observational or interpretation biases associated with research being embedded within an existing NGO programme including: the use of established TMFs in study design and analysis, replication of existing methods (in the LTFU study), establishment of detailed standard operating procedures to minimise subjectivity and establishing multi-investigator research teams of diverse NGO, public health stakeholders and academics.

With the objective of generating new knowledge for – and from programmes, programme science intends to address the disconnect between the perspectives and priorities of scientists, programme implementers and policy makers.[64] This PhD represents an applied example of programme science within existing NGO programmes. Risks of potential bias related to the process of getting research *out* of programmes and *into* practice through programme science endeavours[48] are acknowledged. However, the improved evidence for programming and resultant impact of this PhD research upon NGO-delivered programmes ''in real time'' (see Section 8.2) indicate that with transparent acknowledgement of limitations and appropriate steps to minimise bias, the potential benefits of involving NGOs in programme science for leap-frogging the evidence-to-practice gap and generating context relevant evidence outweigh the risks if documented and managed transparently and scientifically.

NGO research capacity and knowledge brokering: A final limitation of this PhD research is grounded in the use of "packaged" interventions by NGOs. This results in the limited capacity and use of TMFs structured process evaluations, or fully elucidated implementation strategies, mechanisms of action, or reporting on process or implementation outcomes by NGOs. However, this is also an area requiring redress within the field of implementation science itself. In a recent review conducted by Kemp and colleagues exploring application of implementation science methods to integration of non-communicable disease services into HIV care settings in SSA, among 26 projects reviewed, only one used a theoretical framework for implementation science research.[65]

Scoping review and case study findings further support the assertion of an underutilisation of existing program data. Few scoping review articles reported cost-effectiveness analyses of NGO programmes,[66,67] or use of sampling-based methods or advanced statistical methods to elucidate greater insight into programme performance such as loss to follow up[68,69] or guideline changes.[70] While the use of TMFs and mixed-method research in this PhD thesis demonstrates the feasibility of embedding programme science within NGO programmes, in the absence of additional resources to support robust research activities and build the capacity of NGO practitioners to conduct such research the quality and impact of such research on policy and programme practice at scale will remain limited.

To strengthen the intentional use of programme science in public health and to strengthen the capacity and generation and use of evidence, Becker and colleagues propose processes for knowledge brokering in programme science in which programme, policy and research stakeholders engage in routine processes of strategic planning related to the drivers of infectious diseases and identification of where burden of disease is a priority; public health responses and interventions; and monitoring and evaluation programmes and policies.[71] The rapid translation of PhD research findings into programme innovations, adaptative strategies in context and within national policy and programmes, indicate such processes would not only improve strategic and routine integration of programme science within practice, build on learnings and knowledge in context, but also build capacity and consensus on public health responses based on evidence.

Findings and lessons from this PhD research have identified a gap in existing programme, implementation, improvement and translation TMFs to help guide meaningful inclusion of NGOs within global health research. This thesis has demonstrated the benefits of embedded programme science for generating theoretically informed, contextually relevant evidence on rates of uptake, outcomes and experiences of the most vulnerable required to improve the equity and coverage of integrated PMTCT/MNCH services in Zimbabwe.

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7. Role of NGOs in Advancing Transdisciplinary Programme Science

7.1 Findings related to programme science

This research paper style thesis aimed to explore and critically reflect on how the use of TMFs and mix-method transdisciplinary research approaches within NGO-implemented programmes can yield improved estimates of service uptake, clinical outcomes, and understanding of reasons for and failure to uptake evidence-based PMTCT and MNCH health services in Zimbabwe. The research process also provided important lessons on the use of programme science approaches and TMFs within routine programmes.

7.1.1 Nomenclature and NGO evidence

While clearly demonstrating the important role of NGOs in the HIV response, scoping review findings revealed inconsistencies in the definition of NGOs and lack of standardised terminology for identifying or categorising NGO contributions to national HIV responses within the published literature. Much like the lack of standardization of definitions within the field of implementation science itself,[1] varying definitions and classifications for the nongovernmental sector means that generating a reliable taxonomy of the wide range of NGOs and their unique roles and contributions to the evidence base is challenging.[2] Collective efforts have been made to produce codes of conduct for NGOs engaged in health, development and humanitarian work responding to HIV/AIDS[3] and health system strengthening.[4] However, I could find no source document providing guidance and definitions on the various sub-categories of NGOs involved in the HIV response to use as a guiding framework for the scoping review. For example, while recommendations for text entry terms for NGOs are included in the Medical Subject Headings (MeSH) thesaurus for indexing journal articles and books in the life sciences[5] under the broad entry term “Organisations”, non-governmental organisations or the sub-classifications included as part of my scoping review search term were rarely listed within the keywords of articles reviewed. Optimising involvement of NGOs within programme, implementation, improvement and translation science for improved evidence and evidence-based practice will require standardisation of nomenclature and definitions.

7.1.2 NGO-led Programmes and Programme Science

While the vision is for locally-led IS to be conducted by NGO practitioners within existing programs with domestic funding, scoping review findings highlight that given the current dependency of NGOs upon external donors and prescribed conditions of such funding, this will be a process rather than a short-term reality. Local, and community-based organisations are particularly vulnerable, facing barriers to registration, capacity and long-term financial support.[6] Further, NGOs are primarily funded to ‘do’ - implement HIV programmes and collect routine data, as opposed to undertake the involved process of designing and implementing rigorous IS.

As such, NGOs as non-academic partners lack the required resources to support the training, personnel (data managers, translators, statisticians, social scientists, epidemiologists) and systems (data collection and entry, cleaning and management) to design, implement, analyse and disseminate rigorous peer-reviewed research outputs.[7] The most feasible and sustainable response to generation of programme science in practice is to collaborate and share resources between NGOs, health systems stakeholders and academics with complementary expertise and interest in pursuit scientific research to improve cost efficiency and effectiveness of resulting evaluations.[8]

Within the context of the research conducted in this thesis, with leveraged levels of effort on local and international investigators and activity costs in-country embedded within existing decentralised HIV and MNCH programmes, the total costs of both studies combined did not exceed USD$30,000. Such transdisciplinary research collaborations represent a productive and cost-efficient approach to pursuing programme and implementation science.

Researchers gain access to local routine data sources to support identification of appropriate research questions and sampling. Partnering with local institutions saves researchers time required to build networks and trust with local authorities. Working with NGOs with existing decentralised operations also offsets costly travel, data collection and entry costs by working with local partners. Further, NGOs can provide important contextual information for prioritising research questions and understanding processes and data flows within public health programmes.

These benefits are bi-directional. With limited resources to invest in methodological expertise in the use of TMFs, research design, analysis and scientific write up with programmes funds, NGOs gain access to scientific expertise and skills building of local staff, and build needed capacity to self-direct future research projects.[9] Equitable research partnerships also enable NGOs to prioritise research questions of greatest importance to advancing programme performance and public health impact in local populations and/or developing evidence for justifying funding requests for new programme areas, or innovations within existing programmes which are known to be required, but lack robust evidence for justification.

Finally, transdisciplinary research partnerships including health system stakeholders facilitate local priority setting and evidence generation in resource-limited health systems. Engagement with health systems stakeholders also has the potential to increase the speed and adoption of evidence into policy and programmes, as was the case with research conducted in this PhD thesis (See Section 8.2).[10] Engagement with health systems stakeholders in IS, has the potential to improve the 'implementability' of research at scale for public health impact.[11]

The need to find pragmatic ways to bring global public health efforts into alignment as evidenced in this thesis is expressed by Dhillon and Karan as the blind man and the elephant parable,[12]

> "*…each blind man feels only one part of the elephant — a trunk, a tusk, an ear, a tail — and is convinced he's confronting a certain sort of creature. Ultimately, they're informed that each has only a piece of the puzzle, and together they can appreciate the whole elephant.*"

Through collaboration between 'non-adherers' of recommended MNCH practice, community- and facility-based health care workers, health system stakeholders, local NGO implementers and researchers, this thesis employed multidisciplinary mixed-method implementation science approaches to improve evidence on the true rates and reasons for suboptimal MNCH service uptake within routine programme settings. The case studies in this thesis not only provide meaningful evidence for achieving the primary research objective, but also a pragmatic example of the bi-directional benefits of transdisciplinary implementation science endeavours that not only translate the 'science-derived knowledge' from researchers to evidence users, but also converts this to the 'practical art of implementation' required for public health impact.[13,14]

The potential benefits of transdisciplinary programme science partnerships led by NGOs do not come without caveats. As the 'outputs' of NGOs are programmatic actions and based on achievement of performance targets derived from routine data, securing protected resources and time to design, analyse, and write up research can be compromised and diverted by donor-driven priorities. A prime example of this was the documented impact of the 'Global Gag Rule' within scoping review findings, which limited integration of sexual and reproductive health services within HIV programmes reliant on US government funding.[15] Capacity building of local implementers is seen as critical for achieving the vision of IS to facilitate widespread and equitable adoption, delivery, and sustainment of scientific advances into routine programme practice. However, findings similarly underscore that without dedicated funding for such capacity-building initiatives, academics many not have the protected time or resources to invest in the level of capacity building that NGOs require to lead high quality research outputs.[16]

7.1.3 Reflection on findings within existing TMFs

The Health Equity Implementation Framework has provided a meaningful conceptual scaffolding to examine the role of NGOs as facilitators of public health programmes and of strategies to enhance individual decision making, health-seeking and delivery and evidence-based PMTCT/MNCT interventions.[17] Scoping review findings showed the routine use of TMFs by NGOs is lacking. As implementers of public health programmes, case study findings demonstrate the benefit of theoretical grounding of NGO research for theory-informed consideration of the dynamic interaction of the determinants of health inequities. Specifically, this thesis demonstrates the importance of mixed-methods and employment of constructivist grounded theory[18] in context to identify unintended consequences of promoting positive health seeking behaviours for MNCH service uptake upon non-adherers.

Embedding considerations of sustainability of NGO programmes in the implementation and maintenance of EBIs is a critical but under-researched area of implementation science in the context of attainment and maintenance of the goals of global health initiatives, such as HIV epidemic control. Evidence on dissemination, implementation, scale-up and sustainability are areas where NGOs can make a significant contributions to global public health research agendas and guide evolution of equitable evidence-based practice. Routine programme science processes such as those proposed by Becker et al in which available evidence is reviewed, research topics are chosen through a consensus-based process based on national infectious disease priorities, while taking into consideration heterogeneity and epidemic changes at the provincial and regional level (such as with HIV) show promise for building an evidence base and long term vision for programme science in low resource settings.[19]

The appropriate TMF employed should necessarily be guided by the research question under study.[16] Findings from this thesis highlight the utility of extensions of programme and implementation science to address dynamic context, sustainability and maintenance of equitable health benefits of EBIs as a potentially useful unifying framework for use by NGOs in practice.[20-23] The contribution of evidence from research in this thesis to the contextualisation of the Health Equity Implementation Framework to the role of NGOs and user perspective of factors influencing access to PMTCT/MNCH services in Zimbabwe is such an example. Such models emphasise that EBIs are not static and require continuous iterative application to guide adaptations and evolve implementation strategies within changing contexts.[21] Despite their ubiquitous presence in public health programming in low resource settings, many existing TMFs fail to articulate the role of NGOs in each stage of evidence generation to support operationalisation of research findings and guide intentional multidisciplinary collaboration.[16]

7.1.4 Transdisciplinary Programme Science

Each of the research pieces in this thesis provide examples of the use of transdisciplinary programme science paradigms in routine NGO programmes, where individuals from different fields collaborate to build upon discipline-specific TMFs and create new models and knowledge that transcend disciplinary boundaries.[24] The generation of new TMFs to meet the dual purpose of achieving health equity and achieving the goals of GHIs through greater inclusion of communities and affected populations are key characteristics of transdisciplinary research.[17] Meaningful involvement of NGO insiders and community stakeholders becomes increasingly important in the context of rapidly emergent scientific evidence and guidelines which may necessitate changes to implementation (or de-implementation), where community involvement is essential to support change in practice and not further dynamics of medical mistrust.[25]

7.2 Operational framework for NGO involvement in programme science

Findings from this thesis highlight a pervasive 'know-do' gap not only in evidence-based practice, but also in the use of programme, implementation, improvement or translation science methods within NGO programmes. This thesis identified the need for further specification and expansion of transdisciplinary programme science frameworks to provide an operational framework for use *by* NGOs (as opposed to "on" NGOs to describe or evaluate their role as facilitators, as in the scoping review and adapted Health Equity Implementation Framework employed in this thesis) to improve use of TMFs and specification of programme strategies and process, implementation, service and client outcomes in routine programme practice.

Findings from research in this thesis highlight that GHIs can serve to entrench both inequitable relationships and unfair distributions of power, resources, and wealth within and between countries (and individuals, households, and public health implementers and researchers) if inequitable power relationships are left undocumented and unmitigated.[26] Engagement of all levels of the global public health ecology (Figure 7.1) in programme science has the potential to disrupt epistemic power imbalances and inequities identified in this research with regards to whose knowledge is valued and considered valid, and foster meaningful involvement of local actors, including recipients of care, in the generation and selection of evidence to inform implementation and policy.[27]

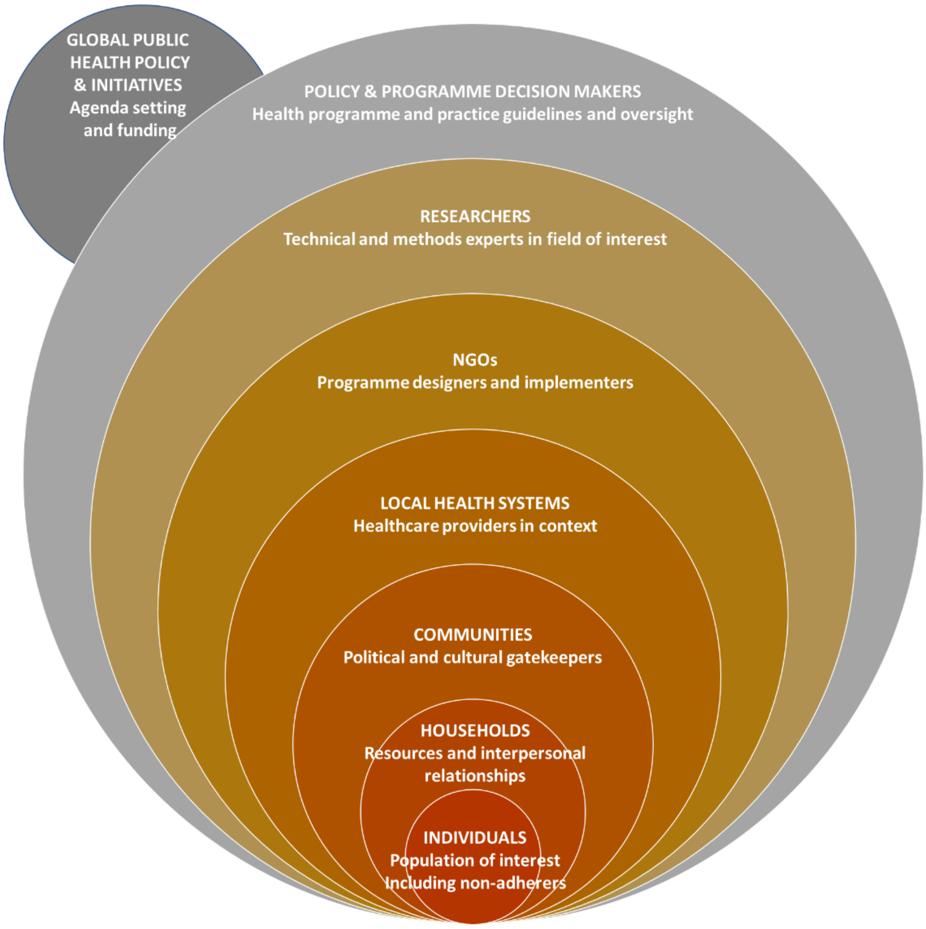

Figure 7.1. Transdisciplinary programme science ecology in public health*Adapted from Bronfenbrenner's socioecological model[28]

The proposed operational framework for improving participation of NGOs in transdisciplinary programme science incorporates key learnings from this thesis and is intended to improve the relevance and rigor of NGO implementation and evaluation for advancing GHIs for equitable and universal health coverage. The need for an operational framework was derived from scoping review findings regarding the low visibility of NGOs in the scientific literature and limited use of TMFs within routine programmes, as well as my own observations and experiential learning from embedding applied mixed-methods transdisciplinary research within an ongoing NGO programme.

Two critical observations from this PhD research process that informed the operational framework development were: 1) NGOs like OPHID recognise they have a role within evidence generation, particularly with increasing demands of donors for ‘evidence-based programmes’ and ‘data-driven programme strategies’[29]; and 2) While NGO practitioners have confidence and capacity to implement programmes in context, they are not structured or funded to have the same capacity or expertise in production of rigorous implementation science design or outputs. Nor do NGOs know where to access the available tools or networks to support independent learning and/or engage in transdisciplinary programme and implementation science endeavours.

The operational framework informed by the experience and findings of research conducted as part of this thesis seeks to lend itself to the operational and implementation strengthens of NGOs by providing a pragmatic ‘checklist’ of key considerations for optimising NGO contributions to the research process for generating type 1 (Etiology and burden), type 2 (intervention effectiveness) and particularly type 3 (implementation and context) evidence (Figure 7.2).

NGO programmes implement multilevel interventions strongly mediated by local context. Accordingly, implementation of this framework by NGOs should be utilised in conjunction with other established frameworks such as the UK Medical Research Council (MRC) framework for researchers and research funders on developing and evaluating complex interventions.[30,31] These frameworks provide evidence-based guidance on how to generate questions about complex interventions on design and conduct research with a diversity of perspectives and appropriate choice of methods.[30]

Collaborations characterised by trust, transparency, respect, solidarity, and mutuality contribute to the development of successful and sustainable NGO–Researcher partnerships.[32] Equitable public health and transdisciplinary programme science also involves active involvement and communities and beneficiaries of GHIs to acknowledge and correct power imbalances where in the interest of serving global and national policy objectives, NGOs may undermine or otherwise violate cultural norms, values, and practices in order to receive much-needed aid.[33] Additional research will be required to test the effectiveness of transdisciplinary research models intended to engage NGOs in programme and implementation science endeavours.

7.3 Summary

This chapter critically discussed thesis findings from a methodological perspective. Integration of mixed-method implementation science not only improved evidence on uptake, outcomes and reasons for defaulting from routine care, but also provided valuable lessons on how to address the 'know-do' gap of use of theories, methods and frameworks by NGOs. An operational framework for the integration of transdisciplinary IS into routine programme activities is provided, with key future directions for advancing both knowledge on effective integration models, as well as key research areas for contributing to the evidence-base and equitable health programmes.

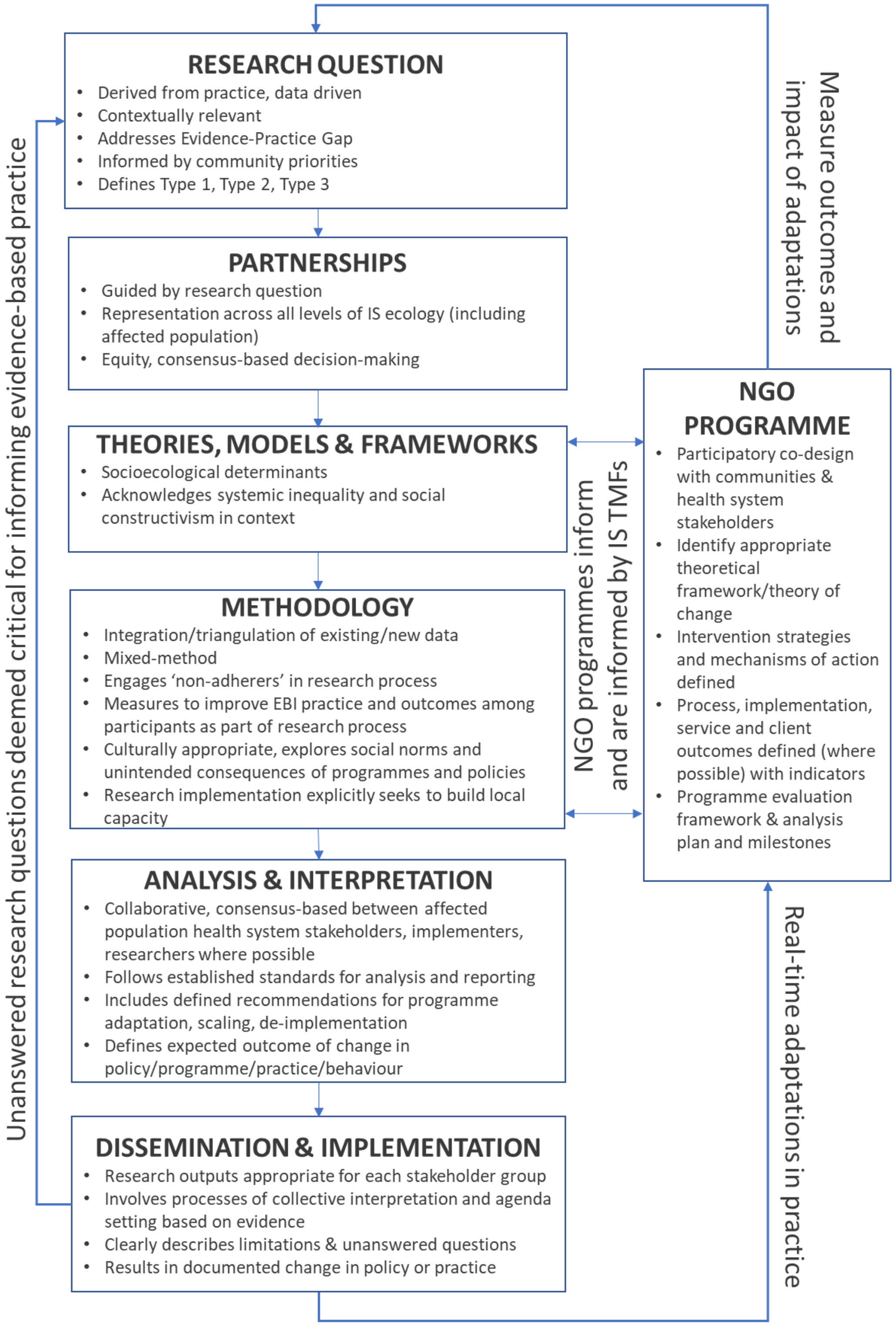

Figure 7.2. Operational framework for improving participation of NGOs in transdisciplinary programme science for improved programme practice and equity of health outcomes

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8. Thesis Summary, Impact & Dissemination

8.1 Summary of key findings

NGOs are key stakeholders in public health programmes in low resource settings, although their role in public health practice is often not clearly defined. In addition, there is a missed opportunity for generating evidence to inform practice within public health programmes that are implemented by NGOs. The 'know do' gap, or failure to implement evidence-based public health at scale interventions leads to preventable morbidity and mortality through suboptimal programme implementation. This PhD combined a scoping review of the role of NGOs within the HIV response and two case studies utilising mixed-methods research embedded within an existing NGO programme to evaluate rates and reasons for suboptimal uptake of essential HIV and MNCH health services in Zimbabwe.

Scoping review findings established that NGOs are central actors in the HIV response at all levels within advocacy, direct service delivery, technical assistance and evidence use and generation. implementation and evidence. However, lack of definitions and taxonomies, poor coordination and limited application of programme science methods results in missed opportunities for improving evidence-based practice. Synthesis of findings was used to develop a typology of key roles of NGOs for optimising the HIV response towards attainment and maintenance of HIV epidemic control. The proposed typology of roles outlined the future orientation of NGO direct service delivery, advocacy and activism and implementation along a continuum of impact. This typology places transdisciplinary implementation science involving communities, NGOs and researchers for improving equity of evidence based interventions as having the highest potential impact.

Two case studies explored the integration of mixed-methods research within routine PMTCT/MNCH programmes to explore the true outcomes, reasons for failure to uptake services and lived experience of women who failed to uptake recommended HIV/MNCH services for themselves or their child. In the first case study, sampling-based methods were employed to actively trace a random sample HIV positive mother-HIV-exposed infant pairs with no documented uptake of recommended EID for HIV testing. Corrected estimates of EID following active tracing by VHWs increased from 31%-60%. Reasons for failure to uptake EID were informed by previous research and the Behavioural Model for Vulnerable Populations[1] and Socioecological Models.[2] The most common reason for failure to uptake EID was medical, 'my child died', with an estimated cumulative incidence of HIV-exposed infant mortality by 3 months of 3.9%.

The second case study conducted qualitative interviews and focus groups with women who had experienced a recent home delivery and used the Dynamic Framework for Social Change as a grounding TMF.[3] Women described how structural inequality and vulnerability factors coalesce at the time of delivery limiting access to institutional birth. Further, social norms for 'facility delivery for all' produced unintended social consequences (shaming, blaming) and punishments (fines, reduced quality of healthcare) which introduced additional risk to women at the time of delivery and in the postnatal period across all socioecological domains.

Embedding mixed-method IS within routine NGO programmes using transdisciplinary research partnerships and established TMFs has the potential to optimise coverage and effectiveness of evidence-based interventions that are equitable and contextually relevant. Case studies provided critical insights to inform development of an operational framework for the pragmatic integration of transdisciplinary IS into routine NGO programmes.

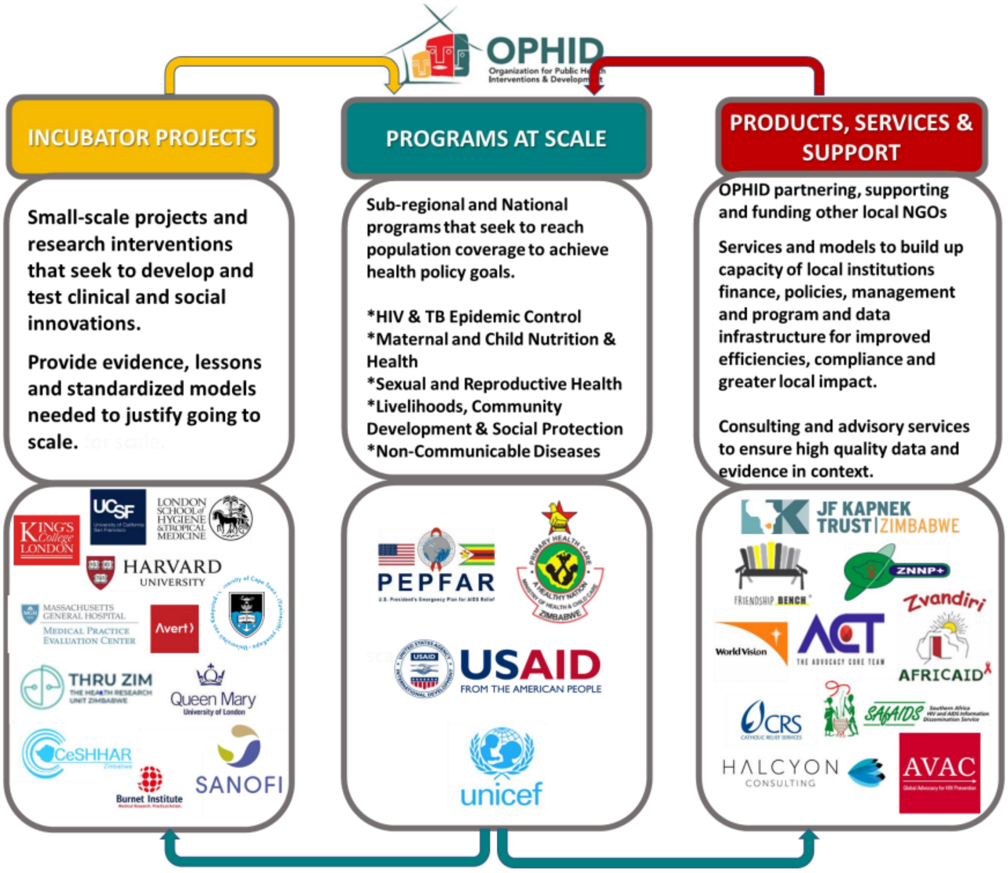
8.2 Contribution of the thesis to improving integrated PMTCT/MNCH programmes in Zimbabwe

The results of these case studies reinforce findings regarding the importance of understanding of the socioecological determinants and context for improving equitable and evidence-based programme practice. In the absence of mixed-methods research that engaged the 'non-adherers' of recommended health practice, key contextual determinants (i.e. unintended consequences and influence of social norms) would have gone unaddressed in the march to 'universal health coverage'. Implemented within the context of an existing NGO programme resulted in this PhD research rapidly informing adaptations within a sub-national PMTCT/MNCH programme. The findings also expanded both the programme design and evaluation methodologies of OPHID and resulted in justification for new programme strategies that have had demonstrated effectiveness and been adopted within national policy.

First, findings from the scoping review and operational framework for integration of transdisciplinary research into NGO programmes have been adopted by OPHID as a core strategy in its current 5 year strategic plan (2020-2025).[4] I have simplified the integration of transdisciplinary implementation science model presented in this thesis as OPHID's 'incubator' project model (Figure 8.1), which has been approved by our Executive Committee as a core strategy for evaluating and identifying innovations within OPHID's programmes. The model has been extended to include OPHID, a local organization, providing services to other local organisations to become learning organisations and make use of similar strategies to improve evidence-generation and programme performance.

This model has resulted a formal Memorandum of Understanding with The Health Research Unit Zimbabwe (THRU-ZIM) and the on-boarding of numerous new academic partners to build upon the work presented in this thesis and pursue additional transdisciplinary IS to improve evidence-based practice and programme outcomes. Working in over 315 health facilities and communities in 4 provinces of Zimbabwe and serving a population of over 329,000 people living with HIV, the potential impact of learnings from use of this operational framework upon maternal and child health in Zimbabwe is significant.

Due to its large core funding from PEPFAR through USAID, OPHID is able to support personnel with a wide range of clinical, epidemiological and social science backgrounds. While these roles are supported for programmatic and not research purposes, it is recognized they play an important potential role in facilitating successful locally-driven research partnerships. Smaller, community-based NGOs would be less able to implement this incubator project model due to limited human and financial resources. OPHID has therefore included the provision of products, services and support into the incubator model to support other local NGOs with technical capacity building.



INCUBATOR PROJECTS

Small-scale projects and research interventions that seek to develop and test clinical and social innovations.

Provide evidence, lessons and standardized models needed to justify going to scale. for scale.

PROGRAMS AT SCALE

Sub-regional and National programs that seek to reach population coverage to achieve health policy goals.

*HIV & TB Epidemic Control
*Maternal and Child Nutrition & Health
*Sexual and Reproductive Health
*Livelihoods, Community Development & Social Protection
*Non-Communicable Diseases

PRODUCTS, SERVICES & SUPPORT

OPHID partnering, supporting and funding other local NGOs

Services and models to build up capacity of local institutions finance, policies, management and program and data infrastructure for improved efficiencies, compliance and greater local impact.

Consulting and advisory services to ensure high quality data and evidence in context.

Figure 8.1. OPHID Incubator Projects Model which makes explicit integration of transdisciplinary programme science as a strategy for improving OPHID programmes at scale.

Specific examples of how the research in this thesis has contributed to maternal and child health programmes and evidence strategies in Zimbabwe are summarised below.

1. Cost-effectiveness and Location Optimisation Modelling for Improved EID Coverage: Success of building capacity of VHWs to trace mother-baby pairs LTFU for EID using routine data sources in the first case study was further explored using mathematical modelling. This analysis utilised routine programme data to model the clinical and cost-effectiveness of a one-time VHW intervention to improves retention in care for EID testing among HIV-positive mother-HIV-exposed infant pairs with undocumented EID using costing and tracing outcome probabilities from this PhD research. Findings demonstrated the intervention is very cost-effective at scale, but emphasized importance of longitudinal retention across the PMTCT/MNCH cascade to retain benefits (see Appendix 2).[5] Follow on work has involved use of routine programme data on EID test coverage and outcomes to inform location optimization models for EID point-of-care placement to enhance equity of access and early ART initiation in HIV-infected infants in Matabeleland South Province, Zimbabwe.[6,7]

While the research in the LTFU for EID case study demonstrated underestimation of EID uptake,[8] programme remediation actions to improve implementation fidelity and expansion of POC for EID and introduction of integrated sample transportation systems have dramatically increased documented EID coverage in Zimbabwe to >90% (OPHID Programme data, 2022). In the absence of routine population-based surveys to establish precise estimates of EID among all HIV-exposed infants (not just among clinic population of HIV positive mothers registered in ANC), given Zimbabwe's high coverage of ANC uptake and PMTCT/MNCH programme integration, this work has demonstrated the value of novel uses of routine data. Site-level programme data on the number of EID samples processed relative to the number of HIV-exposed infants and infant test positive rates represent novel uses of data through location optimisation modelling useful tools for decision-making. Such tools demonstrate that programme science approaches and relevant research questions should necessarily evolve with changes in performance, policy and practice, while noting limitations.

2. Strengthening of routine data for decision making in MNCH/PMTCT: with high rates of ANC uptake, but low rates of facility based delivery and EID HIV testing, findings from both case studies highlighted missed opportunities to identify vulnerable mothers in ANC which require enhanced support for retention across the MNCH/PMTCT cascade and client-specific vulnerabilities for problem-solving using existing resources. This evidence prompted three specific actions. First, an HIV Positive Child Case Investigation Form piloted by OPHID to develop further routine evidence on sociodemographic and service uptake histories of mothers of infants diagnosed with HIV.[9] The tool was further refined by MOHCC based on pilot evidence is now standard of care in MOHCC and has been incorporated into Zimbabwe's DHIS2 system and is intended to support information Zimbabwe's tracking of areas for programme strengthening.

Second, to maximize use of available data, together with a colleague from the Centre for Sexual Health and HIV AIDS Research Zimbabwe (CeSHHAR) I chaired a data integration technical working group (TWG) hosted by MOHCC together with NAC and other implementing partners through UNICEF support. The TWG conducted a data integration exercise to explore available evidence and gaps (in performance and evidence) across the PMTCT/MNCH cascade in Zimbabwe. The purpose of the TWG was to review and synthesise research, programmatic and health system data sources on MNCH/PMTCT cascade performance to better identify priority areas for action (co-first authored publication in JIAS, see Appendix 3).[10] The evaluation identified specific evidence gaps in monitoring of the postnatal PMTCT cascade, and monitoring of the PMTCT cascade among women testing HIV negative in ANC in need of additional evidence and strategies to improve implementation fidelity of recommended EBIs.

In addition, data from this thesis together with subsequent efforts described above was used to engage pregnant and lactating women, community gatekeepers, and health systems stakeholders in the participatory co-design[11] of a Risk Awareness and Action Tool to support identification of risk factors for MTCT in routine ANC and appropriate referrals and clinical action to strengthen access to EBIs.[12] The tool has demonstrated increased implementation fidelity of recommended care and improved perceptions of quality of routine care among pregnant and lactating women. The MTCT Risk Assessment for HIV negative and HIV positive pregnant and breastfeeding women tools have now being incorporated into standard of ANC care by MOHCC in the 2022 Operational Service Delivery Manual for the Prevention, Care and Treatment of HIV in Zimbabwe (Appendix 4).[13]

3. Improving social support for pregnant and lactating mothers: Finally, findings regarding the intersecting vulnerabilities across all socioecological domains including lack of male partner support and the home delivery study, including lack of male partner support, social isolation, limited birth planning and multiple intersecting vulnerabilities informed the adaptation of OPHID’s Mbereko Women’s Empowerment Group Model. The model was expanded to include +Men (Men’s dialogue forums) and pregnant and lactating women received health information through facilitated problem solving to identify barriers to service uptake along the MNCH/PMTCT cascade of care and problem solve using available resources using the Action Birth Card, service referrals and training in income generating activities. To promote robust evidence on the model's effectiveness for improving service uptake using embedded implementation science approaches, an integrated cluster randomized controlled pragmatic trial to evaluate community-level impacts demonstrated significant improvements in maternal mental health and MNCH service uptake in intervention communities.[14] The Mbereko+Men Model was promoted as a strategy for enhancing human rights, gender and community engagement in Zimbabwe's National Plan for Elimination of Mother to Child Transmission and Syphilis (2018-2022).[15] Further, evidence from an oral presentation at the International Pediatric HIV Workshop[16] was included as a selected abstract of key evidence presented on PMTCT, Pediatric, Adolescent, and Maternal/Adult Abstracts at the AIDS 2022 conference in Montreal, Canada.[17]

Findings from this PhD research have resulted in the development of successful models for transdisciplinary research collaboration within OPHID programmes, design of evidence-based interventions and tools that have been incorporated into national policy as standard of care, and tangible and wide ranging programme and policy and contributions to maternal and child health in Zimbabwe, and the local, regional and international evidence-base through publications and presentations. Such impacts provide strong evidence for the utility of utilising the operational framework generated through this PhD work as part of a continuous cycle of iterative evidenced-based programming and the potential of strengthening transdisciplinary implementation science in routine NGO programmes.

8.3 Dissemination

The findings of this research have been disseminated at local, regional and international platforms that included various stakeholders including researchers, study participants, national and international policy makers, programmers and donor organisations. Summarized below are key fora where I have presented the research findings.

8.3.1 Academic conferences and meetings

I presented oral and poster presentations during the course of my PhD at the following academic conferences and meetings:

1. 8th IAS Conference on HIV Pathogenesis, Treatment and Prevention (IAS 2015), Vancouver Canada, 19-22 July 2015; Poster Abstract: MOPED747.
2. Strengthening Epidemiology and Strategic Information in the Republic of Zimbabwe under PEPFAR (SEAM) Scientific Seminar, 1 October 2015, Harare, Zimbabwe. Oral Presentation.
3. 18th International Conference on AIDS and STIs in Africa (ICASA 2015), Harare, Zimbabwe, 29 November – 4 December 2015; Oral Abstract: THUAC1105.
4. 21st International AIDS Conference (AIDS 2016), 18-22 July 2016, Durban, South Africa; Late Breaker Abstract: LBPE036.
5. 12th IAS Conference on HIV Science (IAS 2023), 23-26 July 2023, Brisbane, Australia; E-poster: EPE0995 and EPE0997.

8.3.2 Dissemination meetings

During the course of my PhD, I disseminated the preliminary and final research findings at the following meetings and directly to the following organizations:

1. MOHCC Mashonaland East Provincial Health Team Meeting, Marondera 2016
2. MOHCC Mashonaland Central Provincial Health Team Meeting, Bindura 2017
3. MOHCC National PMTCT Partnership Forum Meeting, Harare 2016, 2017
4. MOHCC District Health Executive Meetings (LTFU for EID and Home Delivery Study Districts:
5. FACE-HIV Programme Data Review Meeting: Harare, 2018
6. PEPFAR/USAID Partners Meeting and Annual Reports: 2017, 2018

The findings of my PhD case studies have been published in peer -reviewed journals (2020, 2021) – See Chapter 5 and Appendix 1.

The scoping review will be submitted to a peer-reviewed journal.

Following submission of an abstract, I have been invited to submit a commentary by series editors for review entitled "Is it time to put implementers at the fore of HIV implementation science?" based on analysis and reflections derived from this PhD research to the JIAS Special Issue: "Implementation research and the HIV response: Taking stock and charting the way forward" to be launched at the International AIDS Conference in July 2024.

A policy brief and paper on the topic of transdisciplinary programme science is in preparation and will be shared with the Ministry of Health and Child Care in Zimbabwe, PEPFAR, USAID, CDC, WHO, UNAIDS, UNICEF and Heads of Agencies (NGOs, Funders and Bilateral Agencies) in Zimbabwe.

8.4 Opportunities for future research

As detailed in Section 6.4, the embedded nature of this PhD research within routine NGO programmes has resulted in significant opportunities to pursue additional research in 'real time'. Additional areas of research that my findings indicate are required for strengthening TMFs on translational programme, implementation, improvement and translation science and evidence on the role (and impact) of NGOs in global public health include:

8.4.1 Improved scientific nomenclature

I propose that lack of standardization is in part due to the fact that while NGOs have clearly acted as a centre pin in the public health response in LMICs over the past two decades, as scoping review findings demonstrate, NGO actors are not equitably represented as scientific collaborators in the resulting evidence outputs.

These findings suggest that advancing the evidence-base on NGO contributions in global health will require use of standardised definitions, major and sub-classifications to more accurately catalogue the body of evidence on the role of NGOs within the HIV response. To address issues of scientific indexing, I propose a simplified structure for future authors reporting evidence on (preferably in collaboration with) NGO programs and activities within the scientific literature (Table 8.1). We recognise these categories are not exhaustive and should be iteratively refined through a consensus-based processes with representation from the wide range of stakeholders the form the composite of NGOs working in the field of HIV.

Table 8.1 Recommendations for keywords for indexing evidence on NGO involvement in the HIV response

What	Keyword to be provided for all submissions to peer-reviewed publications reporting on, or involving, NGO activities. Suggested classification of keywords to specify subcategory of NGO for indexing specificity.
Definition of NGO	**Organisations** are groups of people working together in a structured manner to pursue common goals and objectives. [18] **NGOs** are private or non-state; self-governing; formalised; and not-for-profit organisations. [19]
Suggested keywords for NGO*	Non-Governmental Organizations Nongovernmental Organizations Organizations, Nongovernmental Non-Governmental Organisations Nongovernmental Organisations Organisations, Nongovernmental
Suggested NGO sub-category keywords	Faith-based Civil society Community-based Social movement Advocacy group Activist group Network
Suggested NGO intervention category keywords	See Hickey[20] for list of 6 intervention categories and 36 sub-categories.

* United States National Library of Medicine Medical Subject Headings (MeSH) Descriptor Data Entry Terms[18]

8.4.2 NGO Capacity Building & Transdisciplinary Models

Making use of the proposed Operational Frameworks for NGO Participation in Transdisciplinary IS will require targeted investments to build the capacity of public health practitioners, including NGO implementers and communities in TMFs and research methods. As Brownson states in his comprehensive review of concepts of evidence in implementation science, there has been inadequate training of implementers and too little emphasis on the “pull” for implementation science in low-resource setting which results in missed opportunities for achieving equitable and sustained improvements in population health. [21]

While not exhaustive, important recent examples of such initiatives to increase IS capacity within health system and implementation stakeholders include the INtegrating and Scaling up PMTCT Through Implementation REsearch (2011-2016) [22]; USAID's Project Strengthening Operational AIDS Research Project (2014-2019) [23]; the Structured Operational Research and Training IniTiative (2009-present) [24] and Massive open online course [25] on implementation science led by the Special Programme for Research and Training in Tropical Diseases (TDR). In addition, recent and ongoing open-access web-based resources to improve the use of standardized tools and rigorous methodologies in the indicators, data infrastructure, collection and use by countries and non-governmental HIV implementing partners include WHO's Consolidated HIV Strategic Information Guidelines[26], the USAID-funded MEASURE Evaluation and Data 4 Impact, [27] PEPFAR Solutions platform[28], the HIV Coverage, Quality, and Impact Network[29] and the International AIDS Society's differentiatedservicedelivery.org[30] to promote evidence-based DSD. Despite such efforts, the available opportunities for training in IS are insufficient to meet demand within the scientific and practitioner community.[31,32] Further, what is less clear from the literature is the level of awareness and coverage of available capacity building initiatives in reaching NGOs, and in particular, local and community-based NGOs in resource-limited settings.

Programme science, by definition, is a science of practice. Therefore the models of successful mentorship, on-the-job experience and professional education for programme, implementation, improvement and translational science training need to be developed and tested.[33] OPHID is currently supporting other local organisations to strengthen the use of transdisciplinary programme science in routine programs. However, the effectiveness and impact of such models upon the activities, outputs and improved fidelity of evidence-based practice are require further research.

8.4.3 Priority transdisciplinary programme science

The operational framework for integrating transdisciplinary programme science resulting from findings and experiences of conducting research in this PhD thesis will require testing, specification and evidence of outcomes in context. Key areas for testing and documentation of lessons for expanding transdisciplinary partnerships and testing models of implementation include routine data strengthening, community-based participatory research on knowledge translation of evidence based practice.

This thesis demonstrated evidence produced by NGOs through routine programmes is often compromised by lack of unique identifiers, data missingness, inaccuracies and lack of population representativeness as to determine coverage as well as individual-level outcomes and impact of public health interventions.[34-36]

Transitioning towards interoperable digital health systems is pivotal for overcoming the limitations of aggregate cascade data and achieving person-centred HIV strategic information in routine health programmes[37]. In their *Consolidated guidelines on person-centred HIV strategic information: strengthening routine data* *for impact*, WHO highlights achieving digital health systems will require integration, collaboration and partnership between national HIV programmes, internal NGO partners and external funders, technical collaborators and academic institutions.[37] In resource limited settings, NGOs play an important role in informing evidence on best practices for building capacity in the use of new data systems and strategies for pursuit of interoperability of systems as programs go to scale.[38]

Further, this thesis demonstrates the potential of NGO-researcher collaborations in the improving the quality and more robust secondary analysis of routine data through integration of mixed-methods research. Improved data use and secondary data analysis of NGO programme data has the potential to optimise information for decision making at multiple programmatic levels. Quasi-experimental methods such as difference-in-differences and regression discontinuity[39,40] analysis hold promise for controlling confounding within NGO research, but will require building of capacity of implementers.

Review findings and implementation experiences in this thesis highlight the important role NGOs play in reaching the most vulnerable and affected for equitable health programmes. Increased use of community-based participatory research and human centred design approaches have the potential to improve tailoring of public health innovations to end-user needs and preferences and reduced the gap between evidence and impact. More flexibility from donors, increased use of digital technology, and more transparency on if and how data is being used would help NGOs with their M&E process.[41-43]

Finally, NGOs are uniquely positioned to address the deficit in quantity and quality of 'type 3' (dissemination and implementation) evidence in programme, implementation, improvement and translation sciences.[44] Working at the frontlines of translation of evidence based policies to practice, NGOs have much to contribute to TMFs within knowledge translation science broadly, and differentiated adaptation of EBIs and intensification of monitoring and support based on characteristics between high and low performing sites as well as to highlight factors that can be manipulated throughout the implementation process to improve success.[45]

8.5 Conclusion

Through a scoping review and two published case studies, this thesis explored and critically reflected on how the use of TMFs and mixed-method transdisciplinary research within a routine NGO programme can improve estimates of service uptake, clinical outcomes, and understanding of reasons for and consequences of failure to uptake evidence-based PMTCT and MNCH interventions.

This thesis employed the Health Equity Implementation Framework as a grounding conceptual framework to explore the role of NGOs in the facilitation of EBIs and societal, contextual and recipient factors influencing engagement in care. Scoping review findings on the role of NGOs in the HIV response demonstrated the important role of NGOs as advocates, implementing partners and identified potential for strengthening use and generation of evidence through practice.

Two case studies on the integration of mixed-method research within OPHID's routine PMTCT/MNCH programme strengthened available evidence on coverage and outcomes along the PMTCT/MNCH service cascade and identified missed opportunities to prevent maternal and child deaths through timely service uptake. By purposefully engaging with women who had home deliveries or failed to access EID testing for their HIV exposed infants regarding their reasons for no uptake and lived experiences, this thesis provides evidence on the importance of understanding influence of vulnerabilities in context and importance of participatory co-design of health interventions and evaluations.

The use of the Health Equity Implementation Framework and complementary socioecological and social norms theories enabled the advancement of evidence for programmatic action. Innovations and program adaptations developed as a result of evidence produced have been adopted by MOHCC as standard of care in national PMTCT and HIV Care and Treatment Guidelines and implemented by OPHID and other NGOs at scale. The evidence produced in this thesis has also enabled advancement of existing theory related to barriers to accessing EBIs among rural women, greater understanding of the influence of translation of GHIs for universal health coverage upon community-level social norms, and the role of intersecting vulnerability as a critical factor influencing the ability to uptake and adhere to recommended public health practice.

Programmatically, the process of utilising programme science to prioritise research questions test innovations, integrating resulting evidence into programmes at scale, and build the capacity of other NGOs in programme science has been adopted as

OPHID’s incubator model in its five-year strategic plan. Additionally, a critical reflection on lessons from integration of mixed-method transdisciplinary research within routine NGO programmes in this thesis led to the generation of an operational framework to guide the future integration and expansion of transdisciplinary research methods in the NGO sector.

This PhD research provides timely evidence to justify and inform the expansion of transdisciplinary programme science involving NGOs as a targeted strategy for strengthening the equity of evidence-based public health interventions and achievement of Global Health Initiative goals to reduce maternal and infant mortality and reaching HIV epidemic control in Zimbabwe and other low resource settings.

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SECTION IV: APPENDIX

Appendix 1 Improving estimates of cumulative incidence of early infant diagnosis and mortality among HIV-exposed infants

OPEN

Improving Early Infant Diagnosis Observations: Estimates of Timely HIV Testing and Mortality Among HIV-Exposed Infants

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Background: Improving efforts toward elimination of mother-to-child transmission of HIV requires timely early infant diagnosis (EID) among all HIV-exposed infants, but the occurrence of timely EID and infant survival may be underascertained in routine, facility-bound program data.

Methods: From March 2015 to May 2015, we traced a random sample of HIV-positive mother and HIV-exposed infant pairs lost to follow-up for EID in facility registers in Zimbabwe. We incorporated updated information into weighted survival analyses to estimate incidence of EID and death. Reasons for no EID were surveyed from caregivers.

Results: Among 2651 HIV-positive women attending antenatal care, 1823 (68.8%) infants had no documented EID by 3 months of age. Among a random sample of 643 (35.3%) HIV-exposed infants lost to follow-up for EID, vital status was ascertained among 371 (57.7%) and updated care status obtained from 256 (39.8%) mothers traced. Among all HIV-infected mother–HIV-exposed infant pairs, weighted estimates found cumulative incidence of infant death by 90 days of 3.9% (95% confidence interval: 3.4% to 4.4%). Cumulative incidence of timely EID with death as a competing risk was 60%. The most frequently cited reasons for failure to uptake EID were “my child died” and “I didn’t know I should have my child tested.”

Conclusions: Our findings indicate uptake of timely EID among HIV-exposed infants is underestimated in routine health information systems. High, early mortality among HIV-exposed infants underscores the need to more effectively identify HIV-positive mother–HIV exposed infant pairs at high risk of adverse outcomes and loss to follow-up for enhanced interventions.

Key Words: HIV-exposed infants, early infant diagnosis, loss to follow-up, prevention of mother-to-child HIV transmission, retention

(*J Acquir Immune Deﬁc Syndr* 2020;83:235–239)

INTRODUCTION

The timeliness of early infant diagnosis (EID)—HIV testing of exposed infants 6–8 weeks after birth—and proportion of infants testing positive are cardinal indicators of prevention of mother-to-child transmission (PMTCT) program success.[1] However, in routine program settings, completion of EID is assessed at individual facilities, from information across several paper-based registers, which may be incomplete and/or inaccurate.[2,3]

New approaches are needed to improve confidence in estimates of EID completion and survival of HIV-exposed infants to guide on-going quality improvement and inform national modeling estimates. These become increasingly important as countries such as Zimbabwe, with an HIV prevalence of 16.0% among women,[4] seek to validate elimination of mother-to-child transmission.[5]

In this study, we randomly sampled lost-to-follow-up (LTFU) HIV-positive mother, HIV-exposed baby pairs (MB), pairs from routine health facility-based data. We actively traced MB pairs in the community to assess infant and maternal survival and EID uptake. Finally, we incorporated these findings to correct estimates of HIV-exposed infant mortality and timely EID in the entire clinic population of MB pairs using a probability weight. Although this sampling-based approach

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has been used in clinic-based cohorts of adult patients in HIV treatment programs and found to alter estimates of retention and mortality,[6,7] our study represents the first time the approach has been used in PMTCT programs. We reflect on key lessons from our research on program progress and persisting gaps for strengthening EID coverage on the path to elimination of MTCT in Zimbabwe.

METHODS

Study Design

We defined LTFU as no documented sample taken for EID polymerase chain reaction testing among infants of HIV-positive antenatal care (ANC) patients within 90 days of delivery. At the time of study, Zimbabwe HIV care and treatment guidelines recommended HIV testing of all exposed children 6 weeks postnatal.[8] Our sample included all women with HIV who accessed ANC at public sector health facilities in Mashonaland East Province (referral sites excluded), using a multistage clustered survey sampling approach.

Phase I: Register Tracing

We selected 5 clinics from each of the 9 districts within Mashonaland East Province based on probability proportional to size, using program data on HIV-positive women accessing ANC over the previous year. In the absence of interfacility-linked electronic patient monitoring systems, we used a combination of individual identifiers including clinic-allocated PMTCT number, patient name, and date of birth to trace each identified HIV-positive pregnant woman in ANC and her HIV-exposed infant through 5 paper-based registers (ANC, delivery, HIV-exposed infants, clinic registers, HIV infant diagnosis, and EID lab request form booklets) to determine LTFU for EID status. We targeted a random sample of at least 10% of lost MB pairs based on practical considerations regarding limitations of completeness and accuracy of patient information in multiple paper-based registers[9] and available resources to intensively trace those identified as LTFU for EID over the study timeframe. Based on known challenges in tracing defaulters from HIV care and treatment,[10–12] we over-sampled by 100% to ensure we met our target sample.

Phase II: Tracing of LTFU MB Pairs

In the second stage of sampling, a random sample of patients identified as lacking documented EID in Stage 1 was selected for active tracing to determine outcomes through direct patient interviews. We trained MOHCC village health workers as ascertainers due to their familiarity with the surrounding community and existing role to support health facilities with defaulter tracing.[13,14]

Village health workers were assigned selected LTFU patients residing within their geographical catchment area for tracing. If the individual was unable to be located, mother and infant vital status was obtained from informants (friends, neighbors, or relatives); however, to maintain confidentiality, informants were not asked any specific questions related to HIV services. Successfully traced and consenting mothers were interviewed using a standardized questionnaire to ascertain survival outcomes, EID status and timing, and reasons for failure to obtain EID or for self-transfer of care to another facility. Analyses were conducted using Stata v.13.1. This study was approved by the Medical Research Council of Zimbabwe (MRCZ/A/1844) and MOHCC authorities.

Analyses

EID Estimates

First, we estimated EID incidence based on clinic registry data only, using facility weights inverse to the probability of clinic selection to yield an estimate of EID completion based purely on paper registers kept at the facilities. Facility and individual factors on documented completion of EID were explored using Poisson regression with robust standard errors adjusted for confounders to estimate risk ratios (RRs).[15,16]

Second, we generated corrected estimates of EID completion using data from clinic registries as well as data ascertained through interviews with a random sample of MB pairs missing EID in facility-based registers.[7] Deaths before EID (including fetal deaths) were considered as competing risks. To obtain an estimate corrected for outcomes not captured in the facility registers, we used additional sampling weights inverse to the probability of being successfully sought to represent all LTFU HIV-infected pregnant women at each clinic.

Among women with no documented EID in facility registers who were traced and interviewed, reasons for silent transfer to a different clinic from ANC for EID and for not bringing HIV-exposed child in for HIV testing (no EID) were grouped into 4 categories informed by a socioecological framework[17,18]: structural; clinic-based; psychosocial or patient-related; or medical factors.

Mortality Estimates

For the weighted mortality estimate, the traced patients contributed time from the delivery date to the date of the patient interview or the date of the death of the infant at any time prior (ie, all deaths including those later than 90 days were included in the mortality estimate); patients with documented EID contributed time from the date of delivery to the date of the 6-week postnatal visit, which is the latest date at which we have confirmed vital status for those infants. Kaplan–Meier methods were used to estimate mortality.

RESULTS

Phase I: Facility Register Data

Among 18,065 women registered for ANC between April 2012 and May 2013, 2651 (14.7%) were HIV positive and 31.2% [95% confidence interval (CI): 29.5% to 33.0%] had documented uptake of EID for their infant within 3 months of delivery in clinic registers. After adjustment for register information and site characteristics, factors associated with documented EID completion included earlier gestational age at presentation (RR: 0.97 per 2 weeks; 95% CI: 0.95 to 0.99; P = 0.013), later calendar time of ANC presentation (RR: 1.04 per 30 days; 95% CI: 1.02 to 1.06, P = 0.011), and smaller site volume (RR: 1.85 1-200 ANC patient volume, 1001-1500 volume referent; 95% CI: 1.44 to 2.38, *P* , 0.001).

Phase II: Community Tracing LTFU

Among 1652 mother–baby pairs identified as LTFU with any documented locator information, a random sample of 643 (38.9%) was selected for community tracing between March 2015 and May 2015. In 371/643 (57.7%), updated vital or EID status information was obtained (22.5%; 371/1652 of the total LTFU sample). The primary reason for failure to locate clients was insufficient location information. Among 371 successfully traced patients, 256 (69.0% of located) mothers were interviewed directly on infant vital status and EID uptake, and for the remaining 115 (31.0%), informants were interviewed regarding MB pair survival outcomes (not HIV-related) (Fig. 1). Among the 371 mother–baby pairs for whom vital status outcomes were determined, 66 infants (17.8%; 95% CI: 14.0% to 22.1%) and 18 mothers (4.9%; 95% CI: 2.9% to 7.6%) were found to be deceased.

Most mothers interviewed (190/256; 74.2%; 95% CI: 68.4% to 79.5%) reported their infant had received HIV testing; although fewer than half received EID testing before 3 months of age (92/190; 48.4%; 95% CI: 41.1% to 55.8%). Our corrected estimate following tracing resulted in a cumulative incidence of EID with death as a competing risk of 60.0% (95% CI: 58.7% to 61.3%). We estimated a cumulative incidence of mortality among HIV-exposed infants at 3 months of 3.9% (95% CI: 3.4% to 4.4%) and at 1 year of 7.7% (95% CI: 4.7% to 13.5%). Among the 66 infants with no EID at any time, the most frequently cited reason for failure to have EID was “my child died” (36.6%; 95% CI: 25.8% to 49.0%), Figure 2A. Among infants with timing of death ascertained, most did not survive to the age of recommended EID testing (6 weeks) (26/42; 61.9%). Among mothers of living infants, “I didn’t know I should have my child tested” was the most frequently cited reason for no EID (16/45; 35.6%). Relocation to a different area (21.8%; 95% CI: 13.2% to 32.6%) and transport being easier/cheaper at new clinic (20.5%; 95% CI: 12.2% to 31.1%) were the most commonly reported reasons for silent transfer (Fig. 2B).

DISCUSSION

In a representative sample of Mashonaland East Province of Zimbabwe, after tracing a sample of MB pairs identified as LTFU for EID, our corrected estimate of EID almost doubled (from 31.2% to 60.0%). These findings underscore the risk of equating LTFU of MB pairs in health information systems with disengagement from care where such systems do not facilitate electronic, longitudinal tracing of service uptake within and between health facilities.[19] MOHCC is currently expanding efforts to strengthen facility-based documentation, retention monitoring, and longitudinal outcome reporting through use of the Mother-Baby Pair Register to track longitudinal outcomes of MB Pairs, together with appointment diary systems.[20] As Zimbabwe

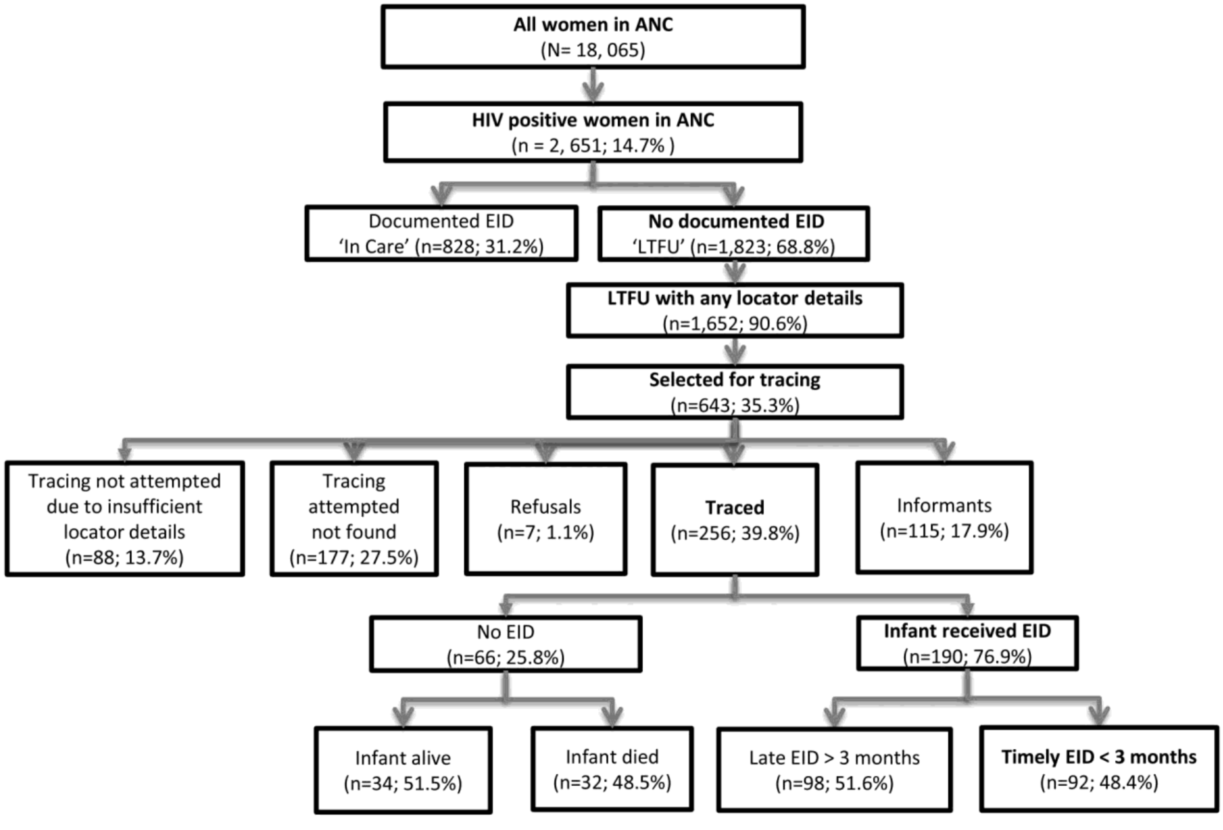

FIGURE 1. Flowchart of outcomes in the study population (N = 18,065).

FIGURE 2. Prevalence of patient-reported reasons for no Early Infant Diagnosis (EID) (N = 71) (A) and switching site of EID from ANC care (N = 78) (B). Structural barriers stem from material conditions of life in resource-limited settings (eg, transportation cost and availability, family conflict, or not enough money). Psychosocial barriers are related to knowledge, beliefs, or attitudes of the patients in the given social setting (eg, "didn't know" child should be tested, fear of disclosure, or preference for spiritual healing). Clinic-based barriers are related to delivery processes at a clinic site (eg, long waiting times, healthcare worker friendliness, and quality of care). Medical barriers related to health status (such as infant death or mother too sick to the bring child to the clinic). full color online

transitions toward electronic health record systems, we indicate the value of sampling-based methods for improving accuracy of EID coverage estimates and informing current progress toward EMTCT validation.[21]

We found high mortality among HIV-exposed infants, with "my child died" being the most frequently cited reason for no EID testing. Passive facility-based monitoring may underestimate true mortality by up to 80%,[22] and under-reporting of infant mortality in high HIV burden settings is acknowledged to bias child mortality estimates downward.[23,24] Our findings reinforce the need to act early among HIV-positive mother–exposed infant pairs at high risk of defaulting or adverse clinical outcomes with enhanced PMTCT inter- ventions.[25,26] Subsequent MOHCC guidelines recommending prioritization of viral load monitoring for pregnant and lactating mothers, birth testing for high-risk infants,[20,27] and case-based surveillance of infants testing HIV positive[20,28] are intended strengthen program evidence and action among high-risk MB pairs. Our findings emphasize that monitoring of facility-level implementation fidelity, data quality, and robust analysis of resulting data will be central to realizing the benefit of such efforts for improved PMTCT program strategies and impact.

Finally, we not only improved our understanding of "true EID" rates but also developed evidence on factors influencing timely infant HIV testing for informing quality improvement. At patient-level, the predominance of psychosocial reasons ("I didn't know") for failure to uptake EID among mothers of living infants emphasizes need to provide information about the importance of timely infant HIV testing during the initial engagement in ANC and continued emphasis at every subsequent visit. Reasons for silent transfer are consistent with studies of adult ART retention and highlight the role of structural[29] and clinic-based factors[30] for optimizing retention in care along the PMTCT cascade. Findings have guided PMTCT program planning and actions including strengthening of patient education and problem solving, appointment monitoring, active follow-up, and outcome documentation in Zimbabwe and other settings.[20,31–33]

Limitations

Although oversampling enabled achievement of our targeted sample of at least 10% of MB pairs LTFU for EID (we traced 22%), our findings highlight need to strengthen routine documentation and other forms of observational data to ascertain uptake of services and mortality.[34] We acknowledge nonresponse due to incomplete tracing details may introduce some uncertainty in the resulting estimates. However, our findings of lower LTFU and higher mortality after tracing are concordant with larger, more robust LTFU studies.[35] In the absence of effective interfacility electronic patient-monitoring systems, we demonstrate the value of leveraging routine observational data in "real-life" program settings for improving accuracy of estimates, identifying bottlenecks and guiding programmatic actions at the local level.[34,36,37]

CONCLUSIONS

Our findings suggest that routinely reported EID completion in public health information systems may be substantially underestimated. Accurate determination of mother–infant pair outcomes in PMTCT programs is complicated by resource-constrained health information systems that involve multiple paper-based registers, lack of unique identifiers, and challenges with completeness and accuracy of information recorded. We demonstrate the value of sampling-based approaches in pediatric HIV research for providing important, context-based evidence for policy and programs.

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Appendix 2 Optimising Zimbabwe’s National PMTCT Programme: Cost-effectiveness of a planned VHW based intervention to improve linkage to postnatal care

Optimizing Zimbabwe's National PMTCT Program: Cost-effectiveness of a planned village health worker (VHW)-based intervention to improve linkage to postnatal care

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BACKGROUND

- In September 2013, the Zimbabwe Ministry of Health and Child Care (MOHCC) transitioned to Option B+ (lifelong ART).
- Low retention of mother-infant pairs in postnatal care (PNC) reduces the effectiveness of PMTCT programs offering Option B+.
- Village Health Workers (VHWs) are the established community-based cadre supporting MOHCC to strengthen linkages between community and healthcare facilities in Zimbabwe.
- The National PMTCT Program seeks to enhance the VHW program to identify mother-baby pairs defaulting after delivery, trace them, and support their return to care.

OBJECTIVE

- To project the clinical and economic impact of a planned VHW-based intervention to re-engage mother-infant pairs who fail to link to PNC after delivery in Zimbabwe.

METHODS

The Cost-Effectiveness of Preventing AIDS Complications (CEPAC) Model:

- The CEPAC-International model (Monte Carlo simulation of HIV disease) was linked to a validated decision analytic model of MTCT (TreeAgePro).

Population: Pregnant Zimbabwean women and their infants

- Pregnant women identified as HIV-infected during antenatal care and treated with ART
- Mean maternal age: 24 years
- Mean maternal CD4: 451/μL
- Mean gestational age at ANC booking: 26 weeks
- Breastfeeding duration: 18 months

PMTCT strategies:

1. *No antenatal ARVs*: as comparator; with access to Option B+ in postnatal period if in PNC.
2. *Current national program*: Option B+.
3. *Current program plus a planned VHW-based intervention*: to identify and re-engage in care mother-infant pairs who fail to link to PNC by 6 weeks postpartum.

Data inputs: We derived clinical and economic inputs from trials and cohort studies (Table 1).

Table 1. Selected Model Input Parameters

Mother-to-child transmission risks					**Source**
	Intrauterine/intrapartum period (one time risk)		*Postpartum period (monthly risk)*		Published PMTCT trials and cohort studies
	CD4 >350/μL	CD4 ≤350/μL	CD4 >350/μL	CD4 ≤350/μL	
No ART	0.175	0.27	0.24-0.40%	0.76-1.28%	
3-drug ART	0.01	0.033	0.19%	0.33%	
Clinical inputs					
OI risk, children (per month, range)				0.5-11.6%	IeDEA
OI risk, adults (per month, range)				0.025-2.4%	Cape Town AIDS Cohort
ART efficacy (% with RNA <400c/ml at 24 weeks)					
Children (1st-line, 2nd-line ART)				75%, 91%	P1060; PENPACT-1
Adults (1st- and 2nd-line ART)				75%	Gallant, Johnson
Loss to follow-up from HIV care (per year)				2.5%	Sutcliffe
Cost inputs				**Value (2013 USD)**	
Medication costs, per month					
Pediatric ART					
1st-line				6.11-13.66	Clinton Foundation
2nd-line				27.50-41.56	
Adult ART					
1st-line				10.90	
2nd-line				32.60	
Clinical care costs					
Direct treatment, children (per month, range by age)				32.27-45.04	Zimbabwe AIDS Spending Report
Direct treatment, adults (per month, range by CD4)				31.37-43.78	
CD4 assay				5.68	Clinton Foundation

VHW program impact:

Effectiveness: After delivery, 6-week PNC linkage was modelled as:

- *Current program (Option B+)*: 43% (Zimbabwe Demographic Health Survey 2010-11)
- *Current + planned VHW Intervention*: 71.5%
  - 57% of cohort assumed to be traced (100-43%)
  - 50% of these (28.5% of total) assumed to be linked to PNC

Costs: $35 (range, $10-400) per mother-infant pair traced, regardless of linkage to PNC, assumed based on preliminary VHW cost data.

Model outcomes:

Clinical outcomes: Infant HIV infection risk at weaning, maternal life expectancy (LE) from delivery, and pediatric LE from birth.

Economic Outcomes: PMTCT program costs, maternal HIV-related healthcare costs, and pediatric healthcare costs (2013 USD).

- Incremental cost-effectiveness ratios (ICERs) using combined antenatal, maternal and pediatric care costs, discounted at 3%/year.
- We defined "very cost-effective" as ICER <US $950/YLS (Zimbabwe 2013 per-capita GDP).

RESULTS

Table 2: Results of model-based analysis: impact of planned VHW intervention in Zimbabwe

Strategy	**Pediatric outcomes after birth (all HIV-exposed)**			**Maternal outcomes after delivery (HIV-infected women)**		
	MTCT risk (18m, %)	**Lifetime cost/ person (USD)**	**Life expectancy (years)**	**Antenatal care + VHW cost/ person (USD)**	**Lifetime cost/ person (USD)**	**Life expectancy (years)**
I. Base-case model results: impact of planned VHW intervention in Zimbabwe						
No antenatal ARVs	26.0	3,110	48.79	245	8,230	15.38
Current program	8.8	1,270	57.36	280	8,230	15.38
VHW intervention	7.2	1,100	58.11	300	10,000	17.24
II. Selected Sensitivity analyses (Comparison of current program to current + VHW program[c])						
Lower efficacy: 20% return to care	8.1	1,360	57.66	300	8,940	16.13
Higher cost: $100/ mother-infant pair traced	7.2	1,100	58.11	340	10,000	17.24
Increased late-LTFU (10%/year)	7.2	500	57.69	300	5,410	12.56

Impact of current national program Option B+ (Table 2, Section I):

- Compared to no antenatal ARVs, the current national program was projected to:
  - Reduce MTCT and increase pediatric LE among all exposed infants.
  - Reduce total costs, due to averted healthcare costs for HIV-infected infants.

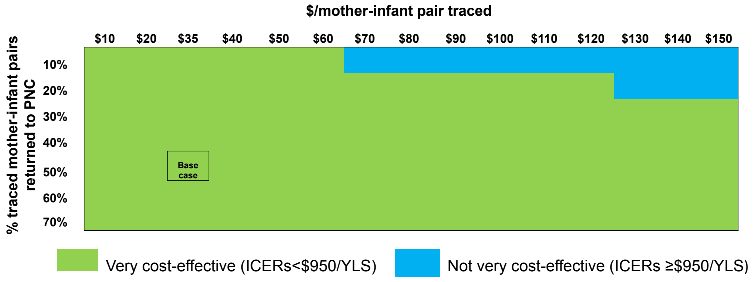
Impact of possible VHW-based intervention (Table 2, Section I):

- Compared to the current national program, the VHW program was projected to:
  - Further reduce MTCT and increase pediatric LE among all exposed infants.
  - Increase maternal LE after delivery by 1.86 years.
  - Further reduce pediatric care costs (due to averted HIV infections), but increase maternal care costs (due to greater participation in care), leading to higher total costs.
  - Lead to an **ICER of $840/YLS**, considered "very cost-effective" by WHO standards for Zimbabwe.

Sensitivity analyses (Table 2, Section II):

- The VWH program remained "very cost-effective" (ICERs <$950/YLS) **when program efficacy decreased** from 50% to 20% return to care, or **program cost increased** from $35 to $100 per mother-infant pair traced.
- The VHW program was not effective or "very cost-effective" when **loss to follow-up after linkage to PNC** increased to 10% per year for mother-infant pairs. Although program cost was lower because fewer people remained in care, pediatric and maternal LE both decreased substantially.

Figure 1. Two-way sensitivity analysis: VHW program effectiveness and cost



- The VHW program remained "very cost-effective" under a wide range of cost and efficacy values (Figure 1).

CONCLUSIONS

- Our pre-program analysis demonstrates that a one-time intervention that improves retention in care and use of ART among HIV-infected mothers is very cost effective.
- VHW-based interventions to improve linkage to postnatal care in Zimbabwe will increase maternal and pediatric life expectancy, and will provide good value for investment by the national PMTCT program.
- Long-term retention of mother-infant pairs in care is critical to realize the benefits of early linkage and to optimize outcomes of Option B+.

Appendix 3 Use of data from various sources to evaluate and improve the prevention of mother-to-child transmission of HIV programme in Zimbabwe: a data integration exercise

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RESEARCH ARTICLE

Use of data from various sources to evaluate and improve the prevention of mother-to-child transmission of HIV programme in Zimbabwe: a data integration exercise

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Abstract

Introduction: Despite improvements in prevention of mother-to-child transmission (PMTCT) of HIV outcomes, there remain unacceptably high numbers of mother-to-child transmissions (MTCT) of HIV. Programmes and research collect multiple sources of PMTCT data, yet this data is rarely integrated in a systematic way. We conducted a data integration exercise to evaluate the Zimbabwe national PMTCT programme and derive lessons for strengthening implementation and documentation.

Methods: We used data from four sources: research, Ministry of Health and Child Care (MOHCC) programme, Implementer – Organization for Public Health Interventions and Development, and modelling. Research data came from serial population representative cross-sectional surveys that evaluated the national PMTCT programme in 2012, 2014 and 2017/2018. MOHCC and Organization for Public Health Interventions and Development collected data with similar indicators for the period 2018 to 2019. Modelling data from 2017/18 UNAIDS Spectrum was used. We systematically integrated data from the different sources to explore PMTCT programme performance at each step of the cascade. We also conducted spatial analysis to identify hotspots of MTCT.

Results: We developed cascades for HIV-positive and negative-mothers, and HIV exposed and infected infants to 24 months post-partum. Most data were available on HIV positive mothers. Few data were available 6-8 weeks post-delivery for HIV exposed/infected infants and none were available post-delivery for HIV-negative mothers. The different data sources largely concurred. Antenatal care (ANC) registration was high, although women often presented late. There was variable implementation of PMTCT services, MTCT hotspots were identified. Factors positively associated with MTCT included delayed ANC registration and mobility (use of more than one health facility) during pregnancy/breastfeeding. There was reduced MTCT among women whose partners accompanied them to ANC, and infants receiving antiretroviral prophylaxis. Notably, the largest contribution to MTCT was from postnatal women who had previously tested negative (12/25 in survey data, 17.6% estimated by Spectrum modelling). Data integration enabled formulation of interventions to improve programmes.

Conclusions: Data integration was feasible and identified gaps in programme implementation/documentation leading to corrective interventions. Incident infections among mothers are the largest contributors to MTCT: there is need to strengthen the prevention cascade among HIV-negative women.

Keywords: PMTCT; PMTCT cascade; prevention cascade; data integration; data triangulation; data layering; HIV

Additional Supporting Information may be found online in the Supporting Information tab for this article.

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1 | INTRODUCTION

Although significant gains have been made in reducing mother to child transmission (MTCT) of HIV globally, there still remains an unacceptably high number of transmissions estimated at 170,000 and 160,000 new infections in 2017 and 2018 respectively; with all infected infants requiring antiretroviral therapy (ART) for life [1,2] and facing an increased risk of significant morbidity and mortality that persists into adulthood [3]. To date very few countries have attained MTCT elimination status according to WHO validation criteria (≤50 new infections per 100,000 live births and a transmission rate of <5% in breastfeeding populations and <2% in non-breastfeeding populations) [1,4,5]. Success in delivery of prevention of mother-to-child transmission (PMTCT) programmes is typically evaluated according to the PMTCT cascade – a series of sequential steps that need to be implemented to optimise care and prevention outcomes among HIV-positive women, HIV-negative women at risk of infection, and their babies [6]. Indicators to measure success have evolved over time in parallel with knowledge and WHO PMTCT guideline updates [6]. Although the importance of primary prevention among mothers has always been recognized (UNAIDS PMTCT prong 1) [7], to date cascade reporting has largely focused on MTCT outcomes (UNAIDS prongs 3 and 4). Given the growing proportion of MTCT occurring postnatally, with significant contribution from mothers who previously tested HIV negative [2], it is critical to pay attention to HIV prevention outcomes among pregnant or breastfeeding women in high prevalence settings. Both research studies and programme evaluations have documented losses to follow-up at different steps along the cascades [8-11]. The value of PMTCT cascade analysis for reporting PMTCT programme performance [12,13], and for identifying gaps and appropriate interventions to strengthen quality of facility-based PMTCT services [14,15] is well established [6] and has informed use of other prevention, care and treatment cascades in the HIV field [11,16-20].

The Global Plan to eliminate new HIV infections among children and keep their mothers alive (2010) [21] stimulated analyses of country PMTCT gaps and bottlenecks at each step of the cascade to strengthen programming. However, previous PMTCT cascade analyses have primarily utilised aggregate cross-sectional data from routine programme reporting with known limitations and importantly, not reported HIV status of either HIV-negative women in antenatal care (ANC) through delivery and postnatal period or exposed children at 18 to 24 months, or the proportion with HIV-free survival at 24 months [6].

Together with implementing and research partners, Ministry of Health and Child Care (MOHCC) in Zimbabwe is tracking the progress towards elimination of MTCT (EMTCT) using a range of platforms. Although these data are shared, there has been no formal process to systematically integrate these data and maximise the learning they can provide. Public health triangulation/data integration is a process for reviewing, synthesizing and interpreting secondary data from multiple sources that bear on the same question to make public health decisions [22,23].

In this study, we report on the process and results of a "data integration initiative" undertaken by MOHCC in partnership with implementing partners and researchers which aims to integrate data from different sources in order to give a fuller picture of performance of the national PMTCT programme. Results will be used to strengthen the impact of the PMTCT programme in Zimbabwe. Additionally, this process aims to identify data gaps required to inform programming and modelling across the region more broadly.

2 | METHODS

The data integration working group comprising individuals from MOHCC, National AIDS Council, research and implementing partner organisations met biweekly from May to September 2019 to: (i) identify relevant data (ii) develop a system for integration (iii) develop cascades using integrated data (iv) identify data gaps (v) identify areas for programme improvement, and (vi) identify geographies/facilities for specific intervention.

2.1 | Data sources

We triangulate data from four sources: MOHCC, research, programme and modelling (Figure 1). Each source includes multiple types of data, providing individual, facility and population level evidence, with different strengths and weaknesses. For example, the research is population-representative, used robust methods for data collection and cleaning, and, importantly, includes mother-baby (MB) pairs who are lost to follow-up from the health system. However, unlike programme data where health outcomes are verifiable on medical record, some survey outcomes are self-reported. See Table 1 for detailed description of the data sources.

The data collection process for each is given below.

2.1.1 | Research

Between 2012 and 2018, researchers partnered with MOHCC to conduct an external evaluation of Zimbabwe's PMTCT programme. Three representative, cross-sectional, population-based surveys were conducted in catchment areas surrounding the same 157 randomly selected health facilities in five of Zimbabwe's ten provinces. Multi-stage sampling was used to select facilities and MB pairs for inclusion. The study population consisted of infants born 9-18 months before the survey and their biological mothers or caregivers aged ≥16 years old. Infants 9-18 months old were selected to be able to detect HIV transmissions occurring during pregnancy, delivery and breastfeeding. Importantly, the survey aimed to include mothers or infants who had died since delivery, in which case verbal autopsy data were collected. All mother/caregiver participants completed an interviewer administered questionnaire and provided a dried blood spot sample for HIV testing. Details of survey methods have been published previously [24]. In 2017/2018, the survey was extended to include MB pairs where babies were 19-36 months old specifically to explore retention of mothers and babies in the later post-partum period. In depth data on PMTCT services offered at facilities were also collected.

2.1.2 | MOHCC

Through the National PMTCT Programme, MOHCC collects a wide range of programmatic data at 1560 health facilities across Zimbabwe into multiple paper registers that track engagement of mothers/infants at different cascade points including antenatal, delivery and postnatal service uptake and clinical outcomes. In 36 Districts, MOHCC has piloted the MB Pair register which tracks all MB (HIV positive and negative) from birth to 24 months. For each MTCT that is recorded, MOHCC recently introduced detailed case investigation and documentation of potential causes of transmission. This is recorded on paper then entered into a national database. At 624 high volume facilities, MOHCC enters data aggregated from Patient OI/ART Care Booklets into an Electronic Patient Monitoring System. Data entered onto monthly return forms are entered into the District Health Information System 2 (DHIS2) on a monthly basis with centralized data entry and retrieval at district level. MOHCC data are recorded by health workers who have a high workload and typically do not have time for routine quality assurance and data validation.

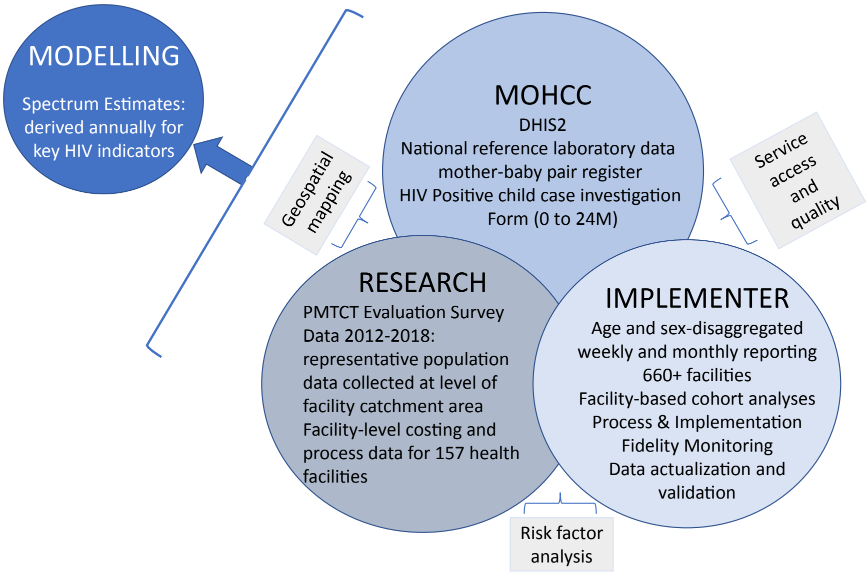


Figure 1. Data sources and domains.
DHIS2, District Health Information System 2; MOHCC, Ministry of Health and Child Care; PMTCT, prevention of mother-to-child transmission.

2.1.3 | *Implementing partner*

The local implementing partner, Organization for Public Health Interventions and Development (OPHID), has supported MOHCC with implementation of the National PMTCT Programme since 2001. Through President's Emergency Plan for AIDS Relief (PEPFAR)/USAID funding, OPHID currently provides support at multiple health system levels to strengthen HIV Care and Treatment at over 660 health facilities in six Provinces through the Families and Communities for Elimination (FACE HIV) Programme. This support includes weekly, monthly and quarterly data collection and analysis of PEPFAR Data Accountability Transparency and Impact Measurement (DATIM) indicators, age- and sex-disaggregated cross-sectional service indicators, and targeted process and cohort-based programme assessments. The data sources for OPHID's programme mirror MOHCC data sources, but the frequency and granularity of targeted analysis is more intense. In addition, OPHID actively engages in data strengthening and strategic utilisation at health facilities through monthly facility-level data consolidation and visualization activities, district level data triangulation meetings and annual data actualization.

2.1.4 | *Modelling*

United Nations Programme on HIV/AIDS (UNAIDS) supports national Programmes to make annual estimates of key HIV indicators. These estimates rely on national surveillance and survey data, national programme data as well as epidemic patterns derived from scientific studies. The Spectrum software is used to combine this information under specific assumptions to produce estimates of key indicators, including the number of people living with HIV by age and sex, new infections, AIDS deaths, AIDS orphans, the need for treatment and prevention, including PMTCT. In this study, we report Spectrum estimates on PMTCT outcomes.

2.2 | Data handling and analysis

Drawing on previous work in data triangulation and evidence-informed intervention design [22,25], we followed four stages in the data triangulation: (1) Evidence attribute mapping; (2) Data quality assessment; (3) PMTCT Cascade Data Layering Analysis; and, (4) Data-Driven Intervention Design. The cascade data layering analysis was conducted at geographic level rather than individual level because unique identifier data were not available for programme data.

2.2.1 | *Evidence attribute mapping*

We mapped the data to understand attributes of each source including defining the population, period covered, data collection methods, geographical coverage, and relative strength and weaknesses [23]. We then determined the availability of data for each step along an expanded PMTCT cascade that includes infant HIV status at 18-24 months and HIV-free survival [6].

2.2.2 | *Data quality assessment*

We assessed the relative strengths and weaknesses of each data source according to four major categories: conformance of data values to intended format and allowed values (e.g. for survey data we verified that numeric data, such as age, appeared as such, and we did additional checks if age of mother did not fall between 16 and 55 years. For programme data which were aggregate, examples of conformance checks included application of validation rules that numerators were smaller than denominators along the cascade and that historical trends in reporting were realistic with data verification for outliers). We also checked for completeness (extent of missingness), plausibility, for example verifying that dates of birth/delivery and early infant diagnosis made temporal sense, and

Table 1. Data sources and attributes for the integration exercise

	Research	Programme				Modelling
	PMTCT survey	**DHIS2**	**PEPFAR DATIM**	**MB Pair register**	**Case investigation forms**	**Spectrum**
Population	Representative, population level MB pairs 9-18 and 19-36 months	Attendees of health facilities	Attendees of health facilities	Attendees of health facilities	MB pairs where MTCT is recorded	
# Records (N)	2018: 7709 MB 9-18 months; 1221 MB 19-36 months 2012: 8800 2014: 10,404	448,475 women registered in ANC	177,706 women registered in ANC	Aggregate MB pair patient entries not documented	271 newly diagnosed infant-HIV positive MB pairs	
Period covered	2017-2018	2018-2019	2018-2019	2018-2019	January 2018-September 2019	
Data collection method	Population based survey in catchment areas of health facilities	Collation of data originally recorded on programme forms	Collation of data originally recorded on programme forms	Register completed longitudinally for each MB pair	Forms completed for each MTCT that is recorded	
Data type	Individual level	Aggregate at the facility level	Aggregate at the facility level	Individual level	Individual level	Population level
Geographical coverage	Catchment areas of 5 of 10 Zimbabwean provinces	National	669 health facilities in 24 districts	36 districts	669 health facilities in 6 Provinces	National estimate
Strengths	Robust data collection and cleaning Inclusion of MB pairs not currently in care (including if either M or B have died) Population-representative estimates	National-level data Objective data reporting using programme forms Monthly reporting for continuous performance monitoring Outcomes verifiable with source documents	Monthly reporting for continuous performance monitoring (support for rapid course correction) Outcomes verifiable with source documents	Longitudinal follow-up of MB pairs	Detailed investigation of each MTCT	Population level impacts and outcomes
Weaknesses	Some outcomes are self-reported Expensive Does not facilitate real-time quality improvement	Aggregate cross sectional data Limited resources to validate/clean the data	Aggregate data	Paper registers with incomplete abstraction to electronic format	Incomplete data and low coverage (completed and entered form for each laboratory diagnosis)	Informed by programme data which may not be accurate/complete
Summary of data quality assessment	Good	Fair	Fair	Poor	Good	Fair

ANC, antenatal care; DHIS2, District Health Information System 2; MB, mother-baby; MCTC, mother-to-child transmission; MOHCC, Ministry of Health and Child Care; PEPFAR/DATIM, President's Emergency Plan for AIDS Relief/Data Accountability Transparency and Impact Measurement; PMTCT. prevention of mother-to-child transmission.

relevance of data values. See Appendix for the framework that was used [26].

2.2.3 | *PMTCT cascades data layering analysis*

We constructed mother and infant cascades according to a comprehensive cascade framework [6], indicating engagement of (i) HIV-positive women, (ii) HIV exposed infants and (iii) HIV-negative women according to each of the four data sources. For the research we used data from the 2017/2018 survey. For MOHCC and OPHID data, proportions were calculated for 2018. We used the latest modelling estimates that were based on 2017/2018 data.

For each data source, we examined risk factors for poor programme performance such as poor health service uptake, ART initiation and MB retention using different methods according to available data. We only performed univariable analysis to determine risk factors for MTCT from survey data because there were too few MTCTs (25 in total) to conduct multivariable analysis. For the survey, we conducted a spatial analysis of MTCT hotspots using MTCT data. We layered this with MOHCC data on new positives so as to identify geographic target areas for enhanced prevention interventions. Risk factors for MTCT were further explored through analysis of detailed case investigation of MTCT that was supported by OPHID, and also through analysis of modelling outcomes.

Using patterns determined from geographic regions where data from all sources were available, we determined the feasibility and utility of extrapolating to regions/facilities with missing data. Although each data source was analysed individually, for the integration exercise we evaluated concordance in cascade indicator data across available sources, and identified information gaps and areas of poor performance across the PMTCT cascade.

2.3 | Ethical considerations

The research (serial surveys) had ethical approval from Medical Research Council of Zimbabwe, reference numbers MRCZ/A/1655, MRCZ/A/ 1826, MRCZ/A/2162 for 2012, 2014 and 2017 surveys respectively. Approval was also obtained from the following ethics committees: University College London (2517/004), University of California Berkeley (2014-02-6038) and Liverpool School of Tropical Medicine (16-063). Written informed consent was obtained from survey participants before study procedures were done. MOHCC and OPHID data were collected programmatically with verbal consent; with all but PMTCT case investigation (where names were necessary for follow-up but was de-identified at data entry and in generated reports) using deidentified data.

3 | RESULTS

Table 1 shows a summary of the data that were available for triangulation. Data came from similar periods which made comparisons feasible, except for prior survey rounds which albeit provided important baseline and midline comparisons prior to HIV care and treatment guideline changes including Option B+ and Treat All. We recruited 8800; 10,404 and 7709 mother/caregiver infant dyads from the 2012, 2014 and 2018 surveys respectively. For women attending ANC, in DHIS2 and OPHID DATIM, 448,475 and 177,706, records were used respectively.

3.1 | Engagement at different steps of the cascade

We present separate cascades for HIV-positive women (Figure 2a), HIV-exposed infants (Figure 2b) and HIV negative women (Figure 2c) constructed using data from the four sources. Each cascade is constructed up to 24 months postnatal as median duration of breastfeeding, and consequent risk of MTCT in Zimbabwe (and elsewhere in the region) is 18 months. Overall, the different data sources showed similar trends, with data gaps later in all three cascades. The exception is for HIV testing in labour and delivery among eligible women. While available evidence on antenatal and perinatal cascade indicators is relatively complete, there are information gaps in all cascades during the postnatal period. For example, there are more data points from more sources for HIV infected women. There are few data on MTCT following early infant diagnosis (6-8 weeks postnatal) in the infant cascade. While MOHCC has introduced a MB pair register to track individual outcomes of MB pairs from birth to 24 months, there are no reported data available for HIV-negative mothers from any source in the post natal period resulting in poor understanding of coverage and outcomes of HIV re-testing intended to identify maternal incident infection in the postnatal period. At present, cascade data on primary prevention for pregnant and lactating women testing HIV negative (i.e. referral and linkage rates of HIV-negative women to HIV prevention services such as pre-exposure prophylaxis (PrEP)) is completely lacking. Importantly, no data are routinely reported on the final outcomes for: HIV positive mothers alive on ART at 24 months (Figure 2a), HIV-exposed infants at cessation of breastfeeding (Figure 2b) or among HIV negative women in the post-partum period (Figure 2c). There are gaps in reporting viral load monitoring cascades among HIV-positive pregnant and lactating mothers.

3.2 | MTCT of HIV

Survey data showed that MTCT by 9-18 months post-partum decreased from 9.5%, 5.1% and 3.4% in 2012, 2014 and 2018 respectively, while Spectrum showed estimates of 7.78% in 2018 by end of breastfeeding. Analysis of trends of MTCT by province showed heterogeneity across and within provinces (data not shown) [27]. Layering of survey and MOHCC data shows that similar geographical areas are hot spots for MTCT (Figure 3). MOHCC data includes data from all ten provinces, showing regions where it is most critical to intervene.

Risk factor analysis in the 2018 survey (which covered five of ten provinces) found that a higher prevalence of partner accompaniment for first ANC was associated with a decrease in MTCT, as was knowledge of an HIV-positive status before pregnancy and receipt of antiretroviral prophylaxis for the baby, Table 2. Women who travelled (received care at more than one facility) more than doubled the risk of MTCT. Of note, out of 25 MTCTs in the 2018 survey, 12 were among MB pairs where the mother had previously tested HIV negative. Programme data on HIV Positive Child Case Investigation found that the majority of mothers that transmitted HIV to their infants booked for ANC late, with a median of

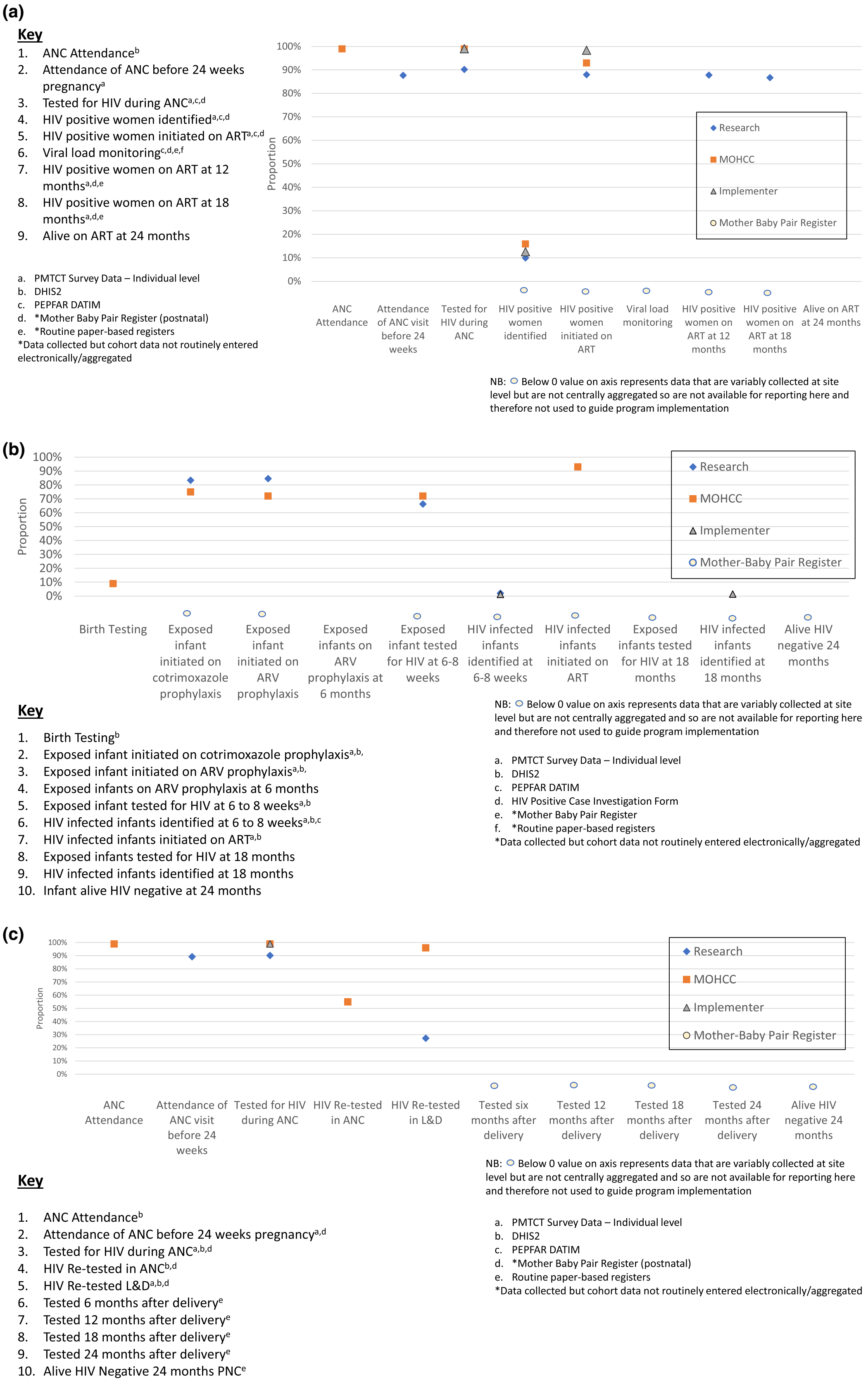


Figure 2. Cascade for (a) HIV-positive women; (b) HIV-exposed infants; (c) HIV-negative women.
ANC, antenatal care; ART, antiretroviral therapy; DHIS2, District Health Information System 2; MOHCC, Ministry of Health and Child Care; PEPFAR/DATIM, President's Emergency Plan for AIDS Relief/Data Accountability Transparency and Impact Measurement; PMTCT, prevention of mother to child transmission.

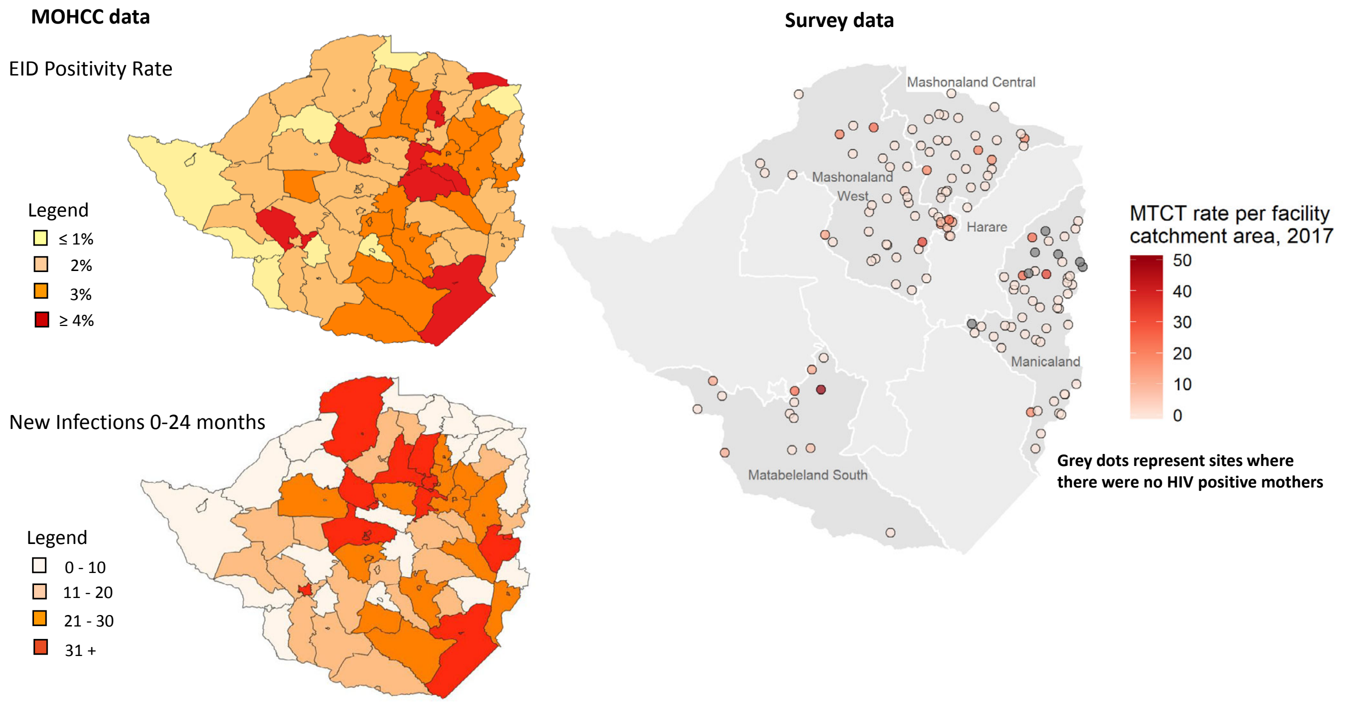


Figure 3. Spatial representation of MTCT across the country.
MOHCC, Ministry of Health and Child Care; MTCT, mother-to-child transmission.

Table 2. Univariable analysis of factors associated with MTCT in 2018 survey

Factor	Number (%) MTCT	Odds ratio (95% confidence interval)	*p*
Timing of ANC registration/month	–	1.20 (0.96-1.52)	0.11
Partner accompaniment to ANC			
No	14 (5.45)	1	0.01
Yes	3 (1.30)	0.23 (0.065-0.81)	
No partner	1 (25.00)	5.79 (0.56-59.25)	
HIV status before pregnancy			
Negative	14 (6.6)	1	0.01
Positive	7 (2.1)	0.32 (0.13-0.81)	
Baby received ARV prophylaxis			
No	14 (7.9)	1	0.003
Yes	11 (2.4)	0.29 (0.13-0.65)	
Received care at more than one facility			
No (one facility)	11 (2.6)	1	0.03
Yes	12 (6.5)	2.55 (1.10-5.89)	

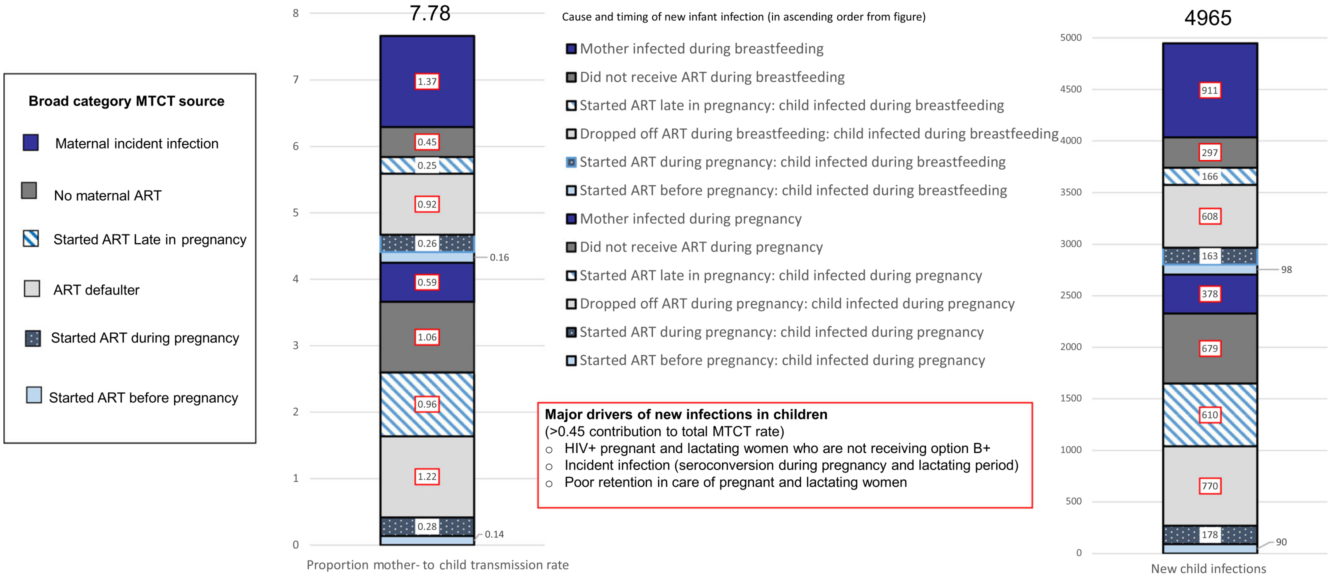
ANC, antenatal care; ARV, antiretroviral; MTCT, mother-to-child transmission.

Table 3. Descriptive analysis among case investigation form respondents (N = 271 HIV-positive infants)

Factor	Number (%) or parameter
Timing of ANC registration/month	Median 23.5 weeks/5.4 months (N = 96)
Male partner HIV status	
Negative	20 (7.4)
Positive	104 (38.4)
Unknown	109 (40.2)
Not Documented	37 (13.7)
HIV status before pregnancy	
Negative	143 (52.7)
Positive	81 (29.9)
Not documented	47 (17.3)
Baby received ARV prophylaxis	
No	67 (24.7)
Yes	166 (61.2)
Not documented	38 (14.0)
Received care at more than one facility	48/219 (21.9) - maternal mobility noted in free text comments

ANC, antenatal care; ARV, antiretroviral.

23.5 months, and 40% were unaware of their partner's HIV status, Table 3. Additionally, 53% of infected babies were born to mothers who were reported to be negative before pregnancy. Case investigation data also demonstrate MTCT was explained by late HIV diagnosis and limited time on ART among mothers before delivery. In addition, as reported in all survey rounds, the case investigation process revealed that maternal mobility increased transmission risk.



Major drivers of new infections in children
(>0.45 contribution to total MTCT rate)

- HIV+ pregnant and lactating women who are not receiving option B+
- Incident infection (seroconversion during pregnancy and lactating period)
- Poor retention in care of pregnant and lactating women

Figure 4. Modelling of MTCT rate by source.
ART, antiretroviral therapy; MTCT, mother to child transmission.

Box 1. Data integration leads to programme strengthening – maternal mobility during perinatal care and risk of postnatal transmission Preliminary analysis of the *2018 survey* data showed that MTCT was higher in the group who visited >1 facility (6.5% vs. 2.6%, odds ratio 2.55 (95% confidence interval 1.10-5.89), $p = 0.03$).

MOHCC HIV Positive Child Case Investigation Forms documenting maternal and infant characteristics of new paediatric diagnoses were submitted by 118/669 OPHID-supported sites from January 2018 to September 2019 and were electronically entered and analysed centrally. During form review, free text comments reported maternal travel during antenatal/postnatal HIV care among 21.9% (48/219) of HIV-positive women who transmitted to their infants 0-24 months.

Travel during infant exposure period has been recommended as a standardized indicator on a revised *MOHCC HIV Positive Child Case Investigation Form* for implementation at all health facilities in Zimbabwe.

Based on these findings, OPHID is working with MOHCC to implement the Strengthening of Information Systems for Elimination of MTCT (SISTEM) – to strengthen PMTCT Programme implementation fidelity and documentation in high MTCT incidence health facilities. SISTEM includes routinely asking and documenting travel plans during the antenatal and postnatal period and strengthened referral systems for women reporting an intention to travel. OPHID is also contributing to the development of a standardized MOHCC Differentiated ART Service Delivery model for mobile and migrant populations, with special considerations for pregnant and lactating mothers.

Of note, modelling indicated that the majority of MTCTs are attributable to mothers who become infected during breastfeeding (Figure 4), pointing to the need to strengthen HIV-retesting, risk screening, primary prevention and follow-up care of HIV-negative mothers postnatally (in addition to the care for HIV-positive mothers which has been more optimally given).

A key finding is the variable coverage and completeness of MTCT case investigation: some health facilities complete this comprehensively for all newly diagnosed infants, while in many facilities there were gaps which did not allow elucidation of the cause of transmission.

The data integration process led to decisions on how programmes/data systems could be improved. See Figure 5 and Boxes 1 and 2 for examples of such decisions/effects.

4 | DISCUSSION

We describe a process for integrating data from different sources to evaluate the PMTCT programme and formulate interventions for strengthening both the data and implementation processes. We found that across datasets, ANC coverage is high, although women generally present late. Uptake of HIV testing among women who present to health facilities is near universal. There are gaps in viral load monitoring of mothers, which may impact MTCT rates. There is variability in PMTCT programme success, with clear MTCT hot spots identified. Investigation of MTCT cases is a recently introduced intervention; we found that this intervention has not yet been adopted across all sites and those sites that implement do so with variable fidelity. Risk factor analysis of MTCT found that late

Box 2. Data integration leads to programme strengthening – postnatal MTCT is increasingly important *UNAIDS SPECTRUM modelling* in Zimbabwe (and globally) suggests that 40% of transmissions are occurring postnatally during breast feeding with a substantial proportion of infections among mothers who were HIV negative at the time of delivery (Figure 4). However, to date there has been limited empirical evidence to support this. In the *2018 PMTCT impact evaluation survey* 12 of the 25 transmissions (48% 95% CI 28.4-67.6) identified had occurred in mothers reporting that they were HIV negative in ANC.

Furthermore, analysis of *MOHCC HIV Positive Child Case Investigation Forms* in OPHID-supported facilities revealed that 23% (61/271) of mothers that transmitted HIV to their infants were only diagnosed in the postnatal period.

MOHCC has introduced a *post natal MB Pair register with electronic data entry into DHIS2* which tracks all mother infant pairs from 0 to 24 months postnatally to ensure timely retesting, retention in HIV prevention and care and final outcome ascertainment of both HIV-positive and HIV-negative MB pairs. Entry and analysis of MB service uptake and outcomes will be critical for informing PMTCT programme efforts as Zimbabwe approaches EMTCT.

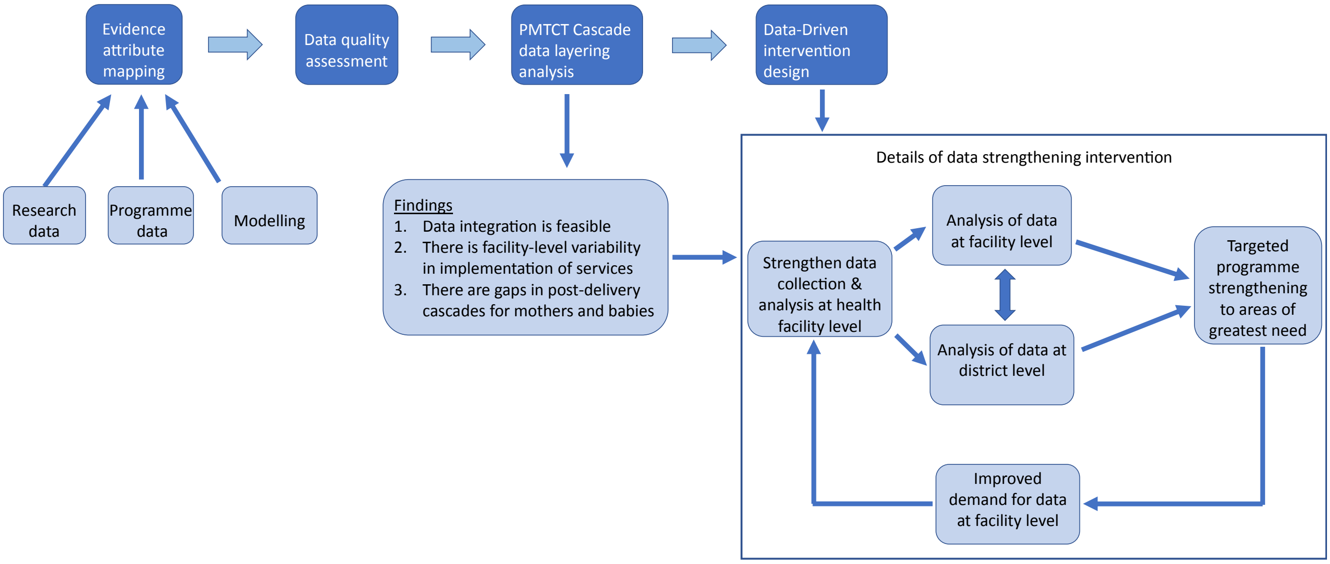


Figure 5. Process of data integration and summary of findings and resulting intervention.
PMTCT, prevention of mother-to-child transmission.

ANC registration with corresponding delay in initiation of ART was critical. Other factors associated with MTCT include mobility of mothers and accompaniment to HIV testing or ANC by partners. Of note, estimates of MTCT differ between Spectrum and survey data (7.78% and 3.8% in 2018), likely because the survey measured MTCT up to a median of 11.5 months postnatally whereas Spectrum estimates MTCT at cessation of breastfeeding. Both modelling and research data suggest that the largest source of MTCT is among women who have tested HIV negative during ANC but who seroconvert and transmit during breastfeeding, but there are currently no programme data showing follow-up of HIV-negative women postnatally.

Lack of follow-up data of HIV-negative women in the face of high HIV incidence in this group calls for strengthening of implementation and documentation of prevention interventions in this group: there is need to increase the demand, supply and optimal use of both retesting and prevention methods among HIV-negative women postnatally. Women need to receive information/education on existing prevention methods, with tailored messaging according to type of woman, for example, young women may be told about mentored mothers programmes [28] while other women may benefit from PrEP or circumcision of their partners. The PMTCT cascade would therefore need to be extended to capture engagement with prevention: (i) how many women know of prevention methods; (ii) how many took up prevention methods, and, (iii) how many optimally used the methods; see Figure 6. In pursuit of ensuring better follow-up of HIV-negative women MOHCC are currently rolling out guidelines to routinely support and document engagement of individual MB pairs to 24 months postpartum regardless of maternal HIV status. All

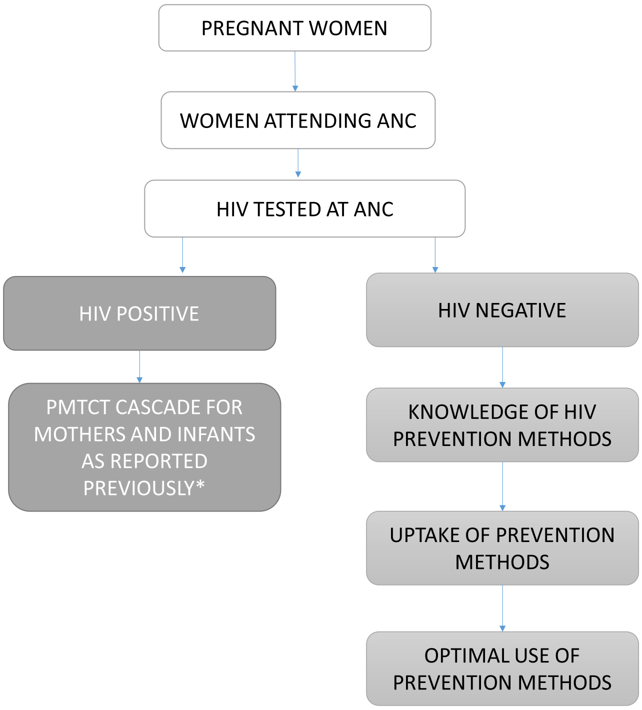


Figure 6. Expanded PMTCT Cascade to include the prevention cascade among HIV-Negative Women.
*Hamilton *et al*., JAIDS 2017. ANC, antenatal care; PMTCT, prevention of mother-to-child transmission.

MB pairs living in a facility catchment area are entered into a mother infant care register to facilitate tracking and early identification of loss to follow-up, with data entered electronically into DHIS2. This process could be strengthened through training and mentoring of health workers to implement with fidelity and regularly review and act on their programme data to optimize maternal retention in the primary prevention cascade of recommended services.

Similarly, facilities need to be supported to improve and act on results of their MTCT case investigation to provide learning on where gaps/bottlenecks are. Although MOHCC has introduced MTCT case investigation it has not yet been widely implemented. Health facilities need capacity building to strengthen their use of data to ensure timely improvements in implementation, which may include training and mentorship as well as providing feedback on performance. In addition, given the negative impact of mobility of women during pregnancy on MTCT, interventions to strengthen engagement and ensure between facility referral are being considered. Together with MOHCC, OPHID are planning to pilot a differentiated service delivery model for mobile and migrant pregnant and lactating women living with HIV, which includes data strengthening for documentation of referrals and confirmed uptake.

There is need to promote early registration for ANC. Previous qualitative research in Zimbabwe has shown that although demand for ANC among women is high, they may face personal/family barriers such as fear of HIV testing and lack of male partner support [29], and supply-side barriers such as reluctance to engage with unfriendly health workers. Many suggestions on how uptake of ANC can be improved have been made [29], including improvement of male partner support and removal/abolition of user fees [30], which MOHCC has adopted.

The strengths of this paper include the comprehensive data that comes from four sources, giving us deeper understanding of the PMTCT programme in Zimbabwe. Combining data from different sources potentially allows us to overcome the inherent limitations/weaknesses of each individual data source. For example, while survey data on timing of testing and engagement of services are limited by self-reporting, programme data are generally objectively (if incompletely) collected. Our survey data have robust numerators and denominators, while programme data have incomplete data on denominators. The systematic process by which we conducted the integration/triangulation exercise gives us confidence in the results. Also, the triangulation process has potential utility for extrapolating missing data, which may prove important when data are not immediately available.

Limitations of the data integration exercise include the use of different sampling and data collection methods, with sampling occurring at different time periods which limits the ability to compare with certainty. The quality and completeness of data varied by data source. Indicators were not always measured in the same way (for example some were measured through self-report during the survey but by clinic record from programm). Spectrum estimates of post-partum transmission relied on transmission rates pre-ART. Although there was overlap of geographic regions covered in many instances, in some cases there was poor or no overlap. Despite all these weaknesses, integration ensured that weaknesses in one data source were compensated for to a certain extent by the other sources, and we showed similar findings where data across sources were available.

5 | CONCLUSIONS

By systematically integrating data from multiple sources, a number of areas for PMTCT programme strengthening were identified. In addition, important data gaps became apparent. The data integration working group is developing a package of data strengthening interventions informed by this work for rollout and evaluation and proposes that the cascades be extended to fully capture PMTCT and maternal and infant survival.

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COMPETING INTERESTS

No competing interests are declared.

AUTHORS' CONTRIBUTIONS

ELS, KW, FMC, SM, NP and AM formulated the research study and design. CW, JD, MD, IT, AC, KW, AM and SM collected data and informed design of data collection methods. IT, AC, MD, JD, MKD, CF and SIM analysed data or contributed to analysis. ELS and KW wrote the first draft of the manuscript. FMC, KW, ELS, NP, EG, SIM, CF, MKD, SM and AC substantial intellectual input to manuscript.

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SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article:

Appendix 4 MOHCC MTCT Risk Assessment for HIV negative and HIV positive pregnant and breastfeeding women in Zimbabwe

Appendix 2: MTCT Risk Assessment for HIV negative pregnant and breastfeeding women

What: This tool should be used as a counselling aide to identify personal risk factors, provide information, and prompt risk reduction actions among all pregnant and breastfeeding women for MTCT risk at each antenatal (ANC) and post-delivery care appointment and/or child health appointments (growth monitoring, immunizations).

Who: Health care workers administer the tool during routine ANC and post-delivery (infants <24 months) consultations.

When: At the start of every care visit, ask women the relevant care questions and offer appropriate follow up support, services and referrals as recommended in MOHCC guidelines and service delivery standards

HIV NEGATIVE: WOMEN MTCT RISK SCREENING		
PART I: Priority MTCT Risks – check appropriate responses. Any response with * indicates woman is at high risk of MTCT and should receive immediate intervention.	**YES**	**NO**
1. Have you been HIV tested during the current pregnancy/breastfeeding period? **Key message:** Women who are HIV infected during pregnancy and breastfeeding are at increased risk of MTCT – timely HIV (re)testing is important for PMTCT.		*
2. Is your partner HIV positive and/or are you unaware of your partner's HIV status? **Key message:** HIV negative women in discordant couples or unaware of their partners status are at increased risk of HIV infection.	*	
3. Are you currently using an HIV prevention method (if pregnant) or dual protection method (if post-delivery)? **Key message:** All women should be supported to select and HIV prevention method that works for them and counselled on how to use it correctly and consistently.		*
4. Will you be travelling between now and your next scheduled ANC/PNC appointment? **Key message:** women who travel during pregnancy and breastfeeding may experience delays in accessing services that increase MTCT risk. If you will be travelling notify your home facility for a transfer letter.	*	
PART II: MTCT Red Flags – check appropriate responses. Any response with * indicates increased MTCT risk. Provide key messages, services and referrals to reduce risk as appropriate.	**YES**	**NO**
1. Are you less than 24 years of age? **Key message:** Young women may face challenges to access to information about HIV prevention, PMTCT, service uptake and ART adherence that may increase personal HIV risk and MTCT risk.	*	
2. Have you been accessing ANC and PNC services as recommended? **Key message:** Delayed/no uptake of essential PMTCT services during pregnancy and breastfeeding period can increase MTCT risk – refer to motivation package for schedule of services and planning tools.		*
3. Has your partner attended ANC or PNC with you? **Key message:** Male involvement in service uptake and couples HIV testing reduces MTCT risk.		*
4. Have you recently had or experienced any of the following signs or symptoms in the past month?		
i. Do you have a cough, night sweats, fever, weight loss? (assess for TB/Refer to TB screening tool)	*	
ii. Do you have vaginal/urethral discharge or genital sores? (assess for STI)	*	
iii During the past month, have you: Felt like you were losing interest or pleasure in doing things? **AND/OR Have you felt down, depressed or helpless?** (assess for depression or anxiety SSQ14)	*	
Key message: Clients with TB, STIs, Depression or Anxiety may have reduced immune functioning or prevention behaviours and be at increased of HIV infection and MTCT. Screen and refer as appropriate.		

IMPORTANT: All MTCT Risk areas should be addressed with client and referrals and services provided documented as appropriate – with confirmation/follow-up on next appointment. Complete for all clients:
Action taken:
Referral made: Yes / No Referred to:____

Appendix 3: MTCT Risk Assessment for HIV positive pregnant and breastfeeding women

What: This tool should be used as a counselling aide to identify personal risk factors, provide information, and prompt risk reduction actions among all pregnant and breastfeeding women for MTCT risk at each antenatal (ANC) and post-delivery care appointment and/or child health appointments (growth monitoring, immunizations).

Who: Health care workers administer the tool during routine ANC and post-delivery (infants <24 months) consultations.

When: At the start of every care visit, ask women the relevant care questions and offer appropriate follow up support, services and referrals as recommended in MOHCC guidelines and service delivery standards

HIV POSITIVE: WOMEN MTCT RISK SCREENING		
PART I: Priority MTCT Risks – check appropriate responses. Any response with * indicates woman is at high risk of MTCT and should receive immediate intervention.	**YES**	**NO**
1. Are you taking HIV treatment (ART) as recommended? **Key message:** HIV positive women not on ART, or experiencing ART adherence challenges are at high risk of MTCT. If not on ART, initiate ART as soon as possible. If having adherence challenges refer for Enhanced Adherence Counselling immediately.		*
2. Does your partner know your HIV status (disclosure)? **Key message:** Women who have not disclosed their HIV status may face challenges to taking their ARVs as required and be at increased risk of MTCT. Male involvement in ANC and PNC helps to reduce MTCT risk. Discuss options for partner engagement.		*
3. Assess Viral Load Status of Clients **Key message:** Clients with a high viral load are at increased risk for MTCT. Pregnant and lactating women are priority populations for viral load monitoring for their own and the infant's health.		
Viral Load Sample Taken		*
Viral Load Result Received		*
Viral Load Suppressed (<1000 copies/mL)		*
4. Will you be travelling before your next scheduled appointment/medication pick-up? **Key message:** Women who travel away from their home area during pregnancy and breastfeeding are more likely to experience challenges to ART and service uptake which may increase MTCT risk. Let health care workers know of any plans to travel to ensure ART stocks and transfer letters		
PART II: MTCT Red Flags – check appropriate responses. Any response with * indicates increased MTCT risk. Provide key messages, services and referrals to reduce risk as appropriate.	**YES**	**NO**
1. Are you less than 24 years of age? **Key message:** Young women may face challenges to access to information about PMTCT, service uptake and ART adherence that may increase MTCT risk.	*	
Have you been accessing ANC and PNC services as recommended? **Key message:** Delayed/no uptake of essential PMTCT services during pregnancy and breastfeeding period can increase MTCT risk – refer to motivation package for schedule of services.		*
2. Has your partner attended ANC or PNC with you? **Key message:** Male involvement in service uptake and couples HIV testing reduces MTCT risk.		*

	YES	NO
3. Have you recently had or experienced any of the following signs or symptoms in the past month?		
i. Do you have a cough, night sweats, fever, weight loss? (assess for TB/Refer to TB screening tool)	✱	
ii. Do you have vaginal/urethral discharge or genital sores? (assess for STI)	✱	
iii During the past month, have you: Felt like you were losing interest or pleasure in doing things? **AND/OR Have you felt down, depressed or helpless?** (assess for depression or anxiety SSQ14)	✱	
Key message: Clients with co-morbidities (TB, STIs, Depression or Anxiety) may have reduced immune functioning or face challenges to ART adherence and be at increased MTCT risk. Screen and refer as appropriate.		
4. Are you currently involved in any support groups or receiving psychosocial support? **Key message:** social support from friends, relatives, partners, or peers is very important to maintain good physical and mental health for ART adherence to reduce MTCT risk.		✱
IMPORTANT: All areas with ✱ MTCT Risk should be addressed with client and documented as appropriate (counselling, services, referrals) and confirmation/follow-up on next appointment. **Action taken:** **Referral made: Yes / No Referred to:**______________________________		