POST-DISCHARGE CARE FOR BABIES BORN SMALL OR SICK IN KENYA: UNDERSTANDING HEALTHCARE PROVIDER CHALLENGES AND REDESIGNING DOCUMENTATION TO SUPPORT CARE

Gulraj Grewal

Green Templeton College

Nuffield Department of Medicine

University of Oxford

A thesis submitted for the degree of

Doctor of Philosophy

Hilary 2025

Abstract

Low-and-middle-income countries (LMICs) have a high burden of small and sick newborns. Previous research has focused on care received within hospitals, but there are growing concerns over poor outcomes after discharge. More attention is needed on post-discharge care to improve delivery and lead to better outcomes. My thesis specifically examines how post-discharge care continuity for babies born small or sick may be better supported within the Kenyan health system.

I conducted a scoping review on interventions used to improve post-discharge care continuity in LMICs, followed by empirical research including 180 hours of ethnographic observations, 19 qualitative interviews and five participatory workshops with healthcare providers in two county referral hospitals in Kenya. I supplemented this with interviews with mothers and key informants. I used reflexive thematic analysis to analyse my data, and the goal-directed design process to guide redesign of a hospital form (discharge summary).

My scoping review extended an established care continuity typology to highlight the importance of relationships between mothers and family members or people within the community ("interpersonal continuity"). My empirical work showed healthcare providers faced numerous continuity challenges, including poor documentation, multiple providers involved in care journeys with poor linkages between them, and time and staffing constraints leading to interns conducting tasks with minimal supervision. Viewing post-discharge care continuity as a sociomaterial practice enabled examination of the assemblage of human, material and institutional components necessary for the enactment of care continuity. Based on this analysis, I redesigned the discharge summary form with

healthcare providers, focusing on their priorities (intuitive for interns to fill in, and concise for paediatricians to follow after discharge).

Continuity of post-discharge care is complex. Other interventions are needed in addition to form redesign, such as creating a role for care coordination post-discharge and improving support mechanisms for mothers.

Acknowledgements

Thet last four-and-a-bit years have simultaneously flown by and felt like a lifetime. It took a village to help get me here, and I'm grateful for every person.

I must start by thanking my incredible supervisors. Dr Chrysanthi Papoutsi, thank you for being a kind and supportive supervisor. You are a brilliant thinker, and it has been a joy learning how to be a better researcher from you. Dr Chris Paton, thank you for your patience and expertise as you taught me a new methodology. Dr Sebastian Fuller, thank you for your insightful comments and constant encouragement. You made the DPhil process enjoyable for me and the other students. Dr Michuki Maina, thank you for all your input and encouragement. Your insights as a paediatrician were invaluable and you were calming and steadying influence throughout - I took your advice and enjoyed the journey. Prof Mike English, thank you for always emailing relevant articles at the most opportune times, and for giving me a chance on this project.

Thank you to my incredibly supportive parents, Gurminder Grewal and Pardeep Grewal, for always believing in me and encouraging me to pursue my dreams. To my family in the UK who made this process a little easier and a lot more joyful, Gursharan Sahota, Gurdhir Pandhal, Jugraj Pandhal, Reena Pandhal, Sahib Pandhal, Mala Singh, Aloke Singh, Kulveer Mangat, and Harjit Grewal. To my paternal grandmother, Gurdev Grewal, who is like a second mother to me. I love that in your mind I remain a school kid, I wish you could know that I finally finished studying. To my maternal grandmother, Narinderjit Pandhal, thank you for (over)feeding me, and showing me the meaning of resilience. Whenever I hit a milestone in life I think of my late grandfather, Jasmer Grewal. He was my favourite person in the world, and was always very proud of me. I hope today his little monkey has made him just a little prouder.

To my cousin, Pria De Eyto Grewal, I am so lucky to have grown up with a built-in best friend. Thank you for guiding me through life and for always being a phone call away. To my bonus cousin, Will Nicholson, thank you for letting me third wheel and looking after me.

I was lucky to work with an exceptional group within the Nuffield Department of Medicine and appreciate every member of the HSC team for their support. I am grateful for my fellow

HIGH-Q students, who walked this journey with me. Thanks to Dr Abdulazeez Imam for all the insightful questions and for leading the way. I would also like to especially thank Frances Simpson and Holly Blades for all their help with logistics and budgets. You both made the DPhil process so much easier, and your hard work is much appreciated.

To Dr Katherine Kalaris and Dr Claire Keene, I am so grateful we started our DPhils at the same time. Thank you for always inspiring me and pushing me beyond my limits, both within the DPhil and in life. You are both intelligent, hard-working and gifted women, and I am excited to see what this next chapter holds for all of us. To Na'ima Nasir, thank you for being a constant companion over the last few months of the DPhil. If it were not for you, I am not sure I would have made it. I think we finally chose peace and not problems. Dr Natalie Tegama I am so grateful for our friendship, the sound of your laughter in the office brightened up the dull days. Thank you Immy Brown for all the tea, both herbal and verbal.

To my UCL friends, George Forsyth, Anoushka Handa, Emily Atalar, Lara Houchou and Dr Laurel Schofield. Thank you for being there for me, and for all the laughter. I am grateful for your friendship over the last 11 years as we all navigate our twenties together.

To my friends in Nairobi, Anisha Singh and Dr Edwige Marty thank you both for your friendship and encouragement. Yasmeen Iraqi, it's strange to think our mothers were our age when they became friends at Braeburn. Thank you for being a good friend, reconnecting with you has been a source of great joy.

To the friends who have been there since high school. Diellza Gojani, I wish everyone had someone like you in their life, a friend who is happier for you on your good days and sadder on your bad ones. Your work ethic and incredible talent are an inspiration to me. I am grateful for your friendship. Peter Wekesa, Ahmed Bulhan and Eldar Thomas – thank you for providing much-needed comic relief and memes throughout this process.

I would like to give a special thank you to everyone at KEMRI-Wellcome Trust. I would especially like to thank Kenneth Karumba for all of his work making this project as seamless as possible. HIGH-Q would not have bene the same without you. Thank you to Caroline Waithera, Nancy Odinga and Onesmus Onyango for all their help with data collection and translating transcripts. Dr Jalemba Aluvaala and Prof Fred Were – thank you for your

feedback and advice. Dr Naomi Muinga, thank you for the insightful discussions and your guidance, I hope to pay it forward.

Thank you to the National Institute of Health and Care Research (NIHR) for the funding that made this work possible. I would also like to thank to the Nuffield Department of Medicine and Green Templeton College for their support. Thank you to my examiners Dr Lisa Hinton and Dr Jacinta Nzinga for the lovely discussion about my research, your feedback and comments were much appreciated.

For the doctors, nurses, occupational therapists, interns and mothers who so generously allowed us access to their lives. I am forever grateful. My sincere hope is that this work will be taken forward and make a small difference in each of your lives.

Dedication

For the children of Kenya, those who are given the opportunity to meet their potential and those who are not.

Declaration

I declare that this thesis is a presentation of my original research work and has not previously been submitted for a degree from any other university. To the best of my knowledge, this thesis does not contain any material previously published or written by another person except where duly acknowledged in the text.

List of Figures and Tables

Chapter One

Figure 1: Salisbury et al.'s continuity of care framework

Figure 2: Meiqari et al.'s continuity of care framework

Figure 3: Bahr and Weiss' continuity of care framework

Table 1: Different levels of healthcare facilities in Kenya

Chapter Two

Table 2: Overview of selected county referral hospitals

Figure 4: Overview of data collection

Figure 5: Overview of how each form of data collection iteratively informed future data collection

Table 3: Characteristics of caregivers from county 2

Table 4: Characteristics of caregivers from county 1

Table 5: Healthcare workers interviewed

Figure 6: Goal-directed design process

Table 6: Overview of workshops

Figure 7: Eight-step process for persona development

Chapter Three

Figure 8: PRISMA chart

Chapter Four

Figure 9: James' post-discharge story

Figure 10: Michael's post-discharge story

Figure 11: Original discharge summary

Table 7: Different informational tools used post-discharge

Table 8: Overview of continuity of care logics

Chapter Five

Table 9: Behavioural variables for COIs

Table 10: Behavioural variables for paediatricians

Figure 12: Mapping behavioural variables

Table 11: Characteristics and goals of COIs

Table 12: Characteristics and goals of paediatricians

Figure 13: Examples of discharge summary prototypes

Figure 14: Redesigned discharge summary

Abbreviations

BA	Birth Asphyxia
CHW	Community Health Worker
CHAIN	Childhood Acute Illness and Nutrition
CIN	Clinical Information Network
COI	Clinical Officer Intern
CP	Cerebral Palsy
CPAP	Continuous Positive Airway Pressure
E-record	Electronic record
HIGH-Q	Harnessing Innovation in Global Health for Quality Care
HRIO	Health Record Information Officer
IVR	Interactive Voice Response
KWTRP	KEMRI Wellcome Trust Research Programme
GDD	Goal-Directed Design
LBW	Low Birthweight
LMIC	Low-and Middle-income-countries
MCH	Maternal and Child Health
MoH	Ministry of Health
MOI	Medial Officer Intern
MVP	Minimal Viable Product
NGO	Non-Governmental Organisation
NHIF	National Health Insurance Fund
NOPC	Neonatal Outpatient Clinic
OT	Occupational Therapist or Occupational Therapy
POPC	Paediatric Outpatient Clinic
SDG	Sustainable Development Goal
SMS	Short Message Service
UNICEF	United Nations International Children’s Emergency Fund
WHO	World Health Organisation

Table of Contents

Abstract **2**
Acknowledgements **4**
Dedication **7**
Declaration **8**
List of Figures and Tables **9**
Abbreviations **11**
Table of Contents **12**
Chapter 1: Introduction **15**
Introduction 15
Background 17
Continuity of Care 18
Sociomaterial Lens 23
Participatory design 26
Post-discharge care in LMICs 28
Justification of the Research Setting 30
Overview of Neonatal and Paediatric Care in the Kenyan Health System 31
Post-discharge Care 34
Health Technology Landscape 38
Relevant Political Context 40
Overview of HIGH-Q 41
Thesis Aim, Research Questions and Structure 42
Chapter 2: Methodology **45**
Introduction 45
Philosophical Assumptions and Research Paradigm 46
Scoping review 47
Search strategy 48
Eligibility criteria 49
Data charting and synthesis 50
Rationale for Qualitative Methods 52

Study Setting 53
County 1 55
County 2 56
Empirical data collection 57
Ethnographic observations 61
Semi-structured In-depth Interviews 64
Participatory Workshops 67
Qualitative data management and analysis 72
Qualitative Analysis 72
Goal-Directed Design Analysis 73
Ethical considerations 77
Positionality and Reflexivity 79
Chapter summary 81
Chapter 3: Scoping Review Findings 83
Introduction 83
Results 85
Search results 85
Overview of the Studies Included 86
Interventions 87
Participatory studies 89
Small or sick babies only 90
Continuity logics 92
Discussion 98
Chapter 4: Post-Discharge Care Continuity 102
Introduction 102
Results 104
Stories to Illustrate Disruptions to Care Continuity 104
The Discharge Process 111
Overview of the organisation of post-discharge care 116
Continuity of care 120
Discussion 135
Chapter 5: Co-design of a package of interventions 142

Introduction 142
Results 144
Research 144
Modelling 146
Requirements 157
Framework 164
Discussion 170
Chapter 6: Discussion 178
Introduction 178
Summary of findings 178
Personal Reflections 182
Contributions to the research literature 183
Strengths and limitations 187
Implications for policy and practice 190
Documentation 190
Communication with mothers 192
Creating a role for care coordination 193
Support for Mothers 194
Directions for future research 195
Conclusion 199
References 201

Appendices 220

Chapter 1: Introduction

Introduction

Post-discharge care for babies born small or sick is a critical yet neglected area in low-and-middle-income-countries (LMICs), despite growing concern over the outcomes for this vulnerable group (1). A significant number of deaths occur within the first 30 days after discharge (2), underscoring the urgency of strengthening care continuity. Follow-up care refers to provision of care for babies born small or sick after discharge from hospital, and can include tracking growth, continued monitoring of symptoms, and treatment for illness, including visits to clinics (3). Previous research in LMICs has identified high rates of discontinuation in follow-up care after delivery in contrast to antenatal care (4-6). Robust follow-up systems for babies born small or sick in LMICs have been identified as essential for monitoring outcomes and linking caregivers to existing support systems (7). Improving continuity of care has recently been suggested as a way of reducing neonatal mortality for this group by linking pregnancy, delivery, and postnatal care, as well as strengthening communication between households and hospitals (8, 9).

Despite its importance, limited data exists on post-discharge outcomes for small and sick newborns specifically. However, it is likely that the same factors which affect paediatric outcomes, such as weight-for-age, young age, previous hospitalisations, financial and cultural barriers, will also affect newborn outcomes (2, 10). Post-discharge care is an essential part of care, as the period after discharge from the paediatric unit has been shown

to be high risk, with high readmission and fatality rates (11, 12). The Childhood Acute Illnesses and Nutrition (CHAIN) study which followed up on children aged 2-23 months who were admitted for acute care in Sub-Saharan Africa and South Asia found that almost a fifth of children had at least one readmission, with infants under six months experiencing higher mortality rates (10). Health systems in LMICs have largely prioritised reducing neonatal mortality through investments in newborn units (NBUs) (13), while the post-discharge period has received comparatively little attention. As a result, there remains no universally endorsed guidance for discharge and follow-up care for small and sick newborns in these settings (14).

In this thesis, I focus on how post-discharge care for babies born small or sick may be better supported within the Kenyan health system. I have taken a qualitative approach to explore challenges and potential solutions primarily with healthcare workers, but also with mothers, leaders of support organisations and academics. My empirical research includes observations of discharge and post-discharge care provision in two public county referral hospitals in Kenya, interviews and participatory workshops with healthcare providers, supplemented by interviews and observations with mothers in the homes in which babies born small or sick were discharged. Based on this analysis I argue that continuity of post-discharge care needs to be viewed as a sociomaterial practice, with consideration needed for both the people involved, and the artefacts used to enact provision of care. As such, I worked with healthcare providers to redesign discharge documentation specific to small and sick newborns to better meet continuity needs and improve the provision of care post-discharge.

For the purposes of this study, I have used the following definitions from the World Health Organisation (WHO). Newborn babies are defined as those within the first 28 days of life (15). Small newborns are defined as a baby who is preterm, low birthweight (LBW) or small for gestational age, and sick newborns as those who also require medical care (16). Prematurity is defined as 28-37 completed weeks of gestation and low birthweight (LBW) is defined as a baby weighing less than 2500g, regardless of gestational age (17). My work does not just include small or sick babies within the first 28 days of life, as I have looked at experiences of healthcare workers with post-discharge care for older babies and children, provided they were born small or sick and were admitted to hospital as newborn babies.

In the rest of the chapter, I provide an overview of the literature that has informed my research, including on continuity of care, sociomateriality and participatory design. I then describe how these lenses can be used to inform post-discharge care in LMICs and discuss my choice of Kenya as a research setting. I provide an overview of the Kenyan health system with a particular focus on post-discharge care, the healthcare providers involved in care provision, disability services the relevant technological landscape and wider political context, with a focus on newborn and paediatric care. I also describe The Harnessing Innovation in Global Health for Quality Care (HIGH-Q) project within which my research was nested. Finally, I provide an overview of the thesis, including my aim and overarching research questions.

Background

In this section I will describe literature on continuity of care, sociomaterality and participatory design that I drew on to inform my work to explore and further thinking around post-discharge care continuity in public hospitals in Kenya.

Continuity of Care

The concept of continuity of care is essentially concerned with the care of an individual patient and care delivered over time. In the context of neonatal and child health, continuity has been characterised as involving time (the period from pregnancy to childhood) and space (care from facilities to community-based care) (18). Care continuity has also been applied to primary care, disease management, mental health and nursing (19). I defined continuity of care as "the provision of coordinated care and services over time and across levels and disciplines, which is coherent with the patient's health needs and personal circumstances" (20), as this definition considers time, space and professional disciplines, and is developed as a result of research in resource-constrained settings.

There are a variety of continuity of care frameworks. In this thesis I used the continuity of care typology developed by Haggerty et al. (19), which proposed there are three types of continuity – informational, management and relational. Informational continuity refers to the use of information on past care and personal circumstances to make current care appropriate for each individual. Management continuity is a consistent and coherent approach to the management of a health condition that is responsive to a patient's changing needs. Relational continuity is an ongoing therapeutic relationship between a patient and one or more providers (19).

I also considered the Salisbury et al. framework (21) for conceptualising continuity in primary care, shown in **Figure 1**, which suggested a critical aspect of improving continuity of care is using a small number of health professionals to provide care, as this builds a caring relationship between the healthcare provider and patient (21). Yet, Salisbury et al. acknowledged that primary care is increasingly made up of a variety of healthcare professionals, and it would not be possible to see the same provider for every issue at follow-up (21). In resource-constrained settings it would be difficult to implement a system where the same doctor is available for all follow-up care due to the shortage of healthcare providers and care being received in different facilities (22). In addition, The conceptual framework on continuity of care in resource-constrained settings shown in **Figure 2** was useful, as it highlighted the importance of access to care and quality of care, which is not uniform across hospitals (20).

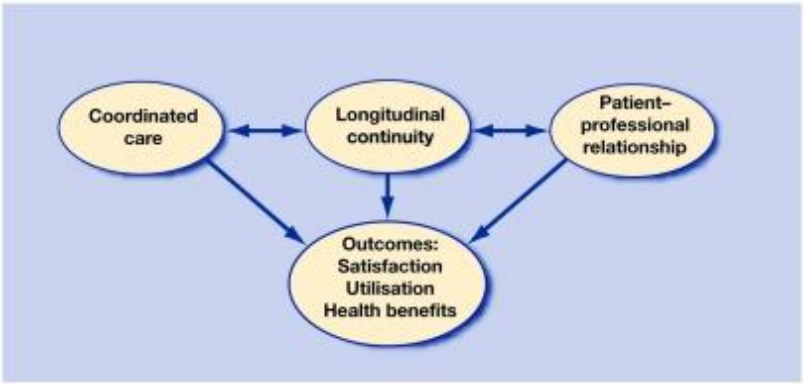

Figure 1: Salisbury et al.'s conceptual framework on continuity of care. Longitudinal continuity is defined as repeated consultations with as few providers as possible. Patient-professional relationship refers to a caring relationship between the health professional and patient. Coordinated care is defined as seamless care between professional and organisations, and encompasses informational, management or team continuity (21)

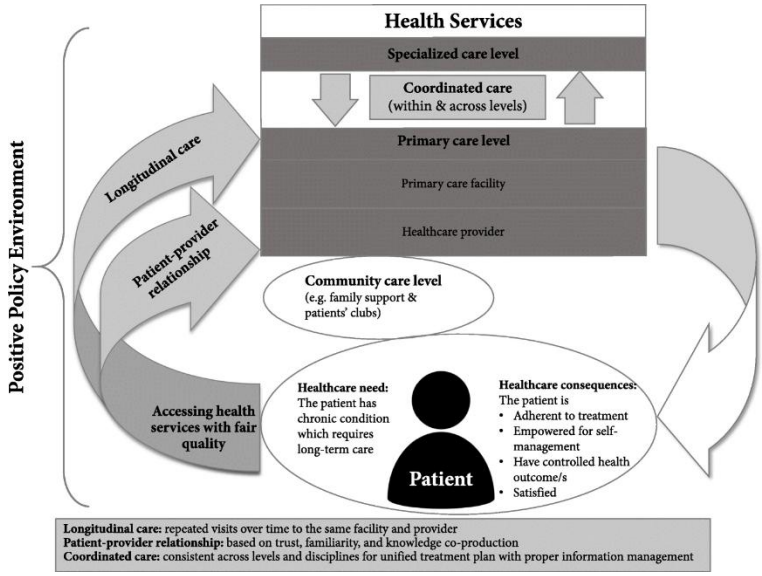

Figure 2: Meiqari et al.'s continuity of care framework adapted from the WHO's innovative care for chronic conditions and Salisbury et al. (21)

The continuity of care framework by Bahr and Weiss (23) shown in **Figure 3** showed how the three continuity concepts by Haggerty et al (19) related to reach other. While these frameworks could have been used to conceptualise care continuity, I found they did not adequately differentiate between the components of care continuity. For example, I found Bahr and Weiss' (23) idea of any one form of continuity being foundational to the others problematic, as each component is required for care continuity to be enacted. All three frameworks included longitudinal continuity as a key component of the continuity of care framework; however, I agree with Haggerty et al.'s argument that longitudinal continuity is not a dimension of care continuity, but rather an intrinsic part of continuity as a practice (19). In addition, Meiqari et al.'s and Bahr and Weiss' frameworks mention coordinated care as a type of care continuity, defining it as including informational and management continuity (20, 21). I found this concept too broad and instead found it useful to break down care coordination into separate forms of continuity, as described below.

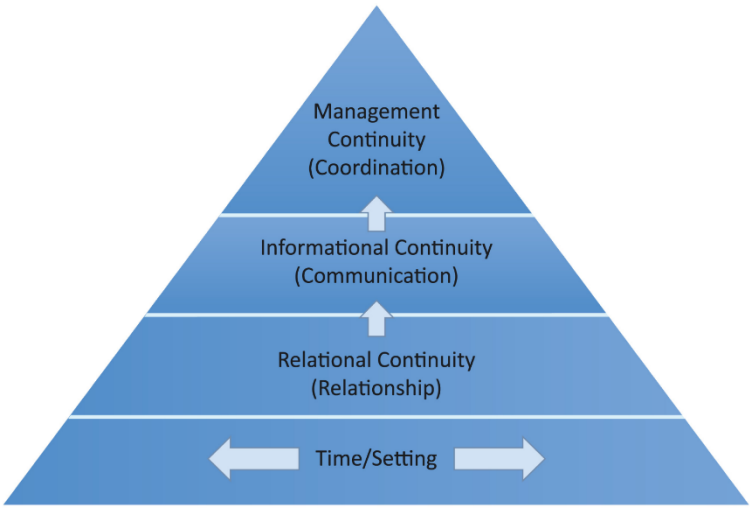

Figure 3: Bahr and Weiss' (23) continuity of care framework, showing a hierarchical relationship between Haggerty et al's (19) three forms of continuity.

The Haggerty et al. typology has been widely used in other similar studies, including a review on the effects of continuity of care on the health of the mother and babies in the postnatal period, though this focused on babies born full-term (24). A commentary on continuity of primary care in LMICs used the typology to describe examples of each type of continuity, arguing for community-based follow-up to improve continuity and development of metrics to measure continuity (25). A study on weaknesses of continuity of care for pre-term babies discharged from the NBU in Brazil used Haggerty et al.'s typology to examine continuity challenges faced by healthcare providers (26). Another study in Italy used the typology to categorise families' experiences on continuity of care in children with special healthcare needs and found the importance of the type of continuity varied between hospitalisation, discharge and after discharge (27). However, frameworks on continuity of care are often based on high-income settings (19, 21, 28), and are therefore not directly

transferable to lower-income settings, where the health system challenges are different (20).

I used this typology as it enabled me to distinguish between different ways in which continuity could be achieved, or disrupted, and provided guidance on how to focus my data collection and analysis. For example, I found that understanding care co-ordination from the perspective of informational and management continuity as discreet dimensions was a helpful conceptualisation, while still sustaining a sense of how the different types of continuity overlapped and influenced each other. Through my scoping review (Chapter 3) I developed the typology by adding interpersonal continuity which enabled me to elaborate on relevant aspects in my empirical research (Chapter 4).

Studies examining outcomes from improved care continuity have had mixed results. One review on the association between continuity of care and outcomes across medical conditions found most studies focus on provider continuity, paying little attention to management and information continuity (29). The review found increase provider continuity was associated with improved patient outcomes and satisfaction (29). Another study in Canada found that post-discharge care continuity for medical or surgical admissions could be improved, i.e., the risk of readmission or death was lowered, if follow-up appointments were conducted with the clinicians who had provided care during admission, rather than a patient's regular primary care physician (30). Improved continuity of care can have a positive effect on maternal and child health care, including improving breastfeeding initiation and duration, and outcomes related to maternal and newborn health status, such as improved maternal mental health (24). One review on continuity of midwifery care found that despite the benefits of this model, most countries had not

managed to scale up this approach (31). However, both reviews included mostly high-income countries, further emphasising the need for research in LMICs on the effects of strengthening care continuity (24, 31).

Previous research on experiences of care continuity during the transition from NBUs to homes has focused on mother's experiences in Kenya (32), mothers' and babies' health in the postnatal period (24) and parent's experiences in Uganda (33). The conceptualisation of care continuity in resource-constrained settings highlighted that while care continuity may be experienced by patients, there was a need to consider providers, systems and policies that support care continuity (20). As such, my research aimed to examine the experience of continuity from the perspective of healthcare providers, a perspective which is lacking in the literature. There was one similar study in Brazil which used interviews to explore weaknesses of care continuity from the perspective of healthcare providers for pre-term babies once they are discharged (26). My study extended this work by including observations of care within wards and using participatory workshops with healthcare providers to explore solutions to the challenges. The literature on care continuity primarily focuses on the people involved, i.e., healthcare providers or patients/families, and hardly mentions the tools used by these groups to enact continuity. As I explain in the next section, in addition to using the Haggerty et al (19) typology, I have also conceptualised post-discharge care as a sociomaterial practice involving both human and non-human actors (e.g. material artefacts), to further thinking around care continuity.

Sociomaterial Lens

Sociomateriality is defined by Leonardi (34) as the enactment of a particular set of activities that merge materiality with institutions, norms, discourses, and all other phenomena

typically defined as social. As pointed out in the seminal paper by Orlikowski and Scott, the sociomaterial approach challenges the assumption that technology, work and organisations should be conceptualised separately and instead posits there is inherent inseparability between the technical and social (35). Materiality is defined as "the arrangement of an artefact's physical and/or digital materials into particular forms that endure across differences in place and time and are important to users" (34). Insight can be gained by departing from the notion that materiality is simply about artefacts, i.e., physical objects, and instead focus on the effects of these artefacts (36). Sociomateriality provides a useful theoretical perspective when examining how an enactment such as completion of clinical documentation tools is performed into existence by an entanglement of human and non-human factors, i.e., healthcare workers, expectations about professional roles, established norms, local routines, and material characteristics of artefacts such as the discharge summary (a one-page document used in Kenya to summarise the care provided during admission to the NBU). Although sociomateriality and materiality are terms often associated with information technology, they can be applied to non-technological artefacts too (37-40).

A useful lens proposed by Zammuto, Griffith (41) considers the affordance perspective, which recognises how the materiality of an object favours, shapes, or invites, and at the same time constrains, a set of specific uses. For example, one study found that digitising physical forms removed some of their affordances, such as the ability to take notes on the side of the form, erase things and move the forms around in different settings (40). Artefacts are meant to reduce the need for "articulation work", i.e., the effort of coordination of tasks and responsibilities between distributed collaborators (40). The effect of humans and technologies on each other leads to tools acquiring a certain form,

attributes and capabilities, and how an artefact is constructed is as important as the artefacts themselves (42).

The sociomaterial lens has been applied to continuity of care in several ways. For example, in an inpatient medicine teaching unit in Canada, the authors examined how the assemblages of various human and non-human factors produce progressive collaborative refinement, i.e., teams working together to produce safe and effective care as patients move through the system (37). The authors found that coordination of care is an ongoing practice rather than a single achievement, and focusing on building capacity amongst the healthcare professionals alone would be insufficient in increasing quality of patient care, as the non-human factors (policies, schedules, electronic records, paper records etc.), are intricately entangled with interprofessional collaboration and must be considered (37). In another example on the review of medications in a hospital in Sweden, examining practices and artefacts built an understanding of the enactment of medication review and how sustaining coordination required ongoing work and was not a state to be achieved by only having the right people and artefacts in place (43). A study in Saudi Arabia that introduced e-records to improve information flow over time for patients found that a sociomaterial approach helped explain how nurses and doctors re-negotiated their professional roles as a result of the implementation of a new e-record system in a hospital ward, highlighting the nuance of intervention implementation and the importance of non-human actors (38).

I found that using a sociomaterial lens helped to explore the complex and ongoing practices of post-discharge care in public hospitals in Kenya by showing that material artefacts and how they are used is crucial to enacting post-discharge care. Participatory design has long embraced the sociomateriality of how work is conducted within a system, i.e., considering

artefacts as well as people (44, 45) and within design, i.e., how the use of physical artefacts as tools for thinking tools and forms of expression can aid design (44, 46).

Participatory design

Participatory design is a design approach aimed at developing artefacts with close involvement from those most affected by the artefact (47). Participatory design originated in Scandinavia in the 1970s and 1980s, where it was used to enable workers to determine the shape and scope of new technologies introduced into the workplace (48, 49). Over time, participatory design has evolved away from its Marxist underpinnings, but its core has remained the same – focusing on designing artefacts or work environments with participants (48). Participatory design gained interest from researchers and companies as a method to create artefacts, due to the assumption that it increases utility and use (50-53), which makes it enticing for health systems.

Participatory design is increasingly being used in public health contexts (54) and can play a role in designing innovative solutions to the complex and persistent public health challenges faced by low-resource settings (55, 56). By considering the context in which an intervention is being implemented, participatory design questions the assumption that what works in one setting can be imported to another (57), an approach which I think is particularly salient in global health to avoid waste in lower-resource settings. Co-production, co-design and co-creation are all participatory approaches which place emphasis on the genuine participation and inputs from service users in the design, delivery and evaluation of services or innovations (49, 57). These approaches developed out of different disciplines but are used interchangeably. Involving the people who will be affected

by an intervention is a key component of participatory design (46, 47, 49, 50, 53, 58), though the level of participation can vary within the different stages of the research process and between studies – ranging from tokenistic participation to participants leading research decision-making (59). Another key tenet is the recognition that participants are experts (46, 49), and therefore placing value in their tacit knowledge of the system (56). As such, decisions should be made democratically between researchers and participants, rather than by designers alone (46, 49, 58).

Participatory design is an iterative process, often using prototypes and user feedback to enhance an artefact or system (48, 53). It requires researchers spending time with users in their environment to gain an understanding of the way they work (53, 58), and as such often uses ethnographic approaches, such as observations, interviews with key stakeholders and workshops. Good quality participatory design takes time and resources, which can be a challenge (50, 51), particularly in low-resource environments where healthcare workers are extremely time constrained. In addition, participatory design needs to consider the power dynamics between participants, participants and non-participants and participants and researchers (51, 52, 57). Hierarchies amongst participants can create tension and make it uncomfortable for suggestions for improvement to be made openly (53). Those who are involved in the design process may be seen to be favoured, as they get time away from work to participate in design activities and influence service improvement, thus it is important to include a wide array of participants and provide feedback about the process (51). There is an inherent tension in design between researchers and participants, with each bringing their own knowledge and experiences together to create something new; it is important to not favour one form of knowledge over another, and to democratically make decisions (52).

Participatory design approaches have been used in LMICs to design information tools, such as using participatory workshops to develop the MCH (Maternal and Child Health) handbook in Angola (60), iterative prototyping of the newborn clinical audit tool with healthcare providers in Kenya (61), co-design workshops to develop a nursing documentation tool in NBUs in Kenya (62) and co-design "sprints" to create paper-based information systems in Nigeria, Mozambique and the Ivory Coast (63). Another application of participatory design in LMIC settings included the NeoRoo mHealth application, which was used to improve kangaroo mother care provision by family and healthcare providers in Kenya (64). NeoRoo was iteratively designed by the research team with input from healthcare workers in Kenya. Berg suggested exploring seemingly mundane "infrastructural" technologies, such as records and information systems, which can have a great impact on the quality of care provided (65).

In summary, participatory design has value as an approach to strengthening continuity of post-discharge care because it is a democratic process, involving the people who will be directly affected by introduction of an artefact. While it is hard to gauge the success of participatory design regarding individual interventions, as a method it has been shown to foster engagement and buy-in from participants, which can help with implementation and sustaining an intervention (66, 67).

Post-discharge care in LMICs

Having described the theoretical literature I drew on for my study, I will now provide a more detailed overview of neonatal mortality and morbidity, and of post-discharge care in LMICs. According to the WHO, in 2000 there were 4.1 million newborn deaths globally, with this decreasing to 2.3 million 2024 (13). However, progress has been much slower in sub-

Saharan Africa, which bears a higher burden of neonatal mortality (13). Most pre-term babies are born in Sub-Saharan Africa and South Asia, and the pre-term newborns who survive are at higher risk of short-term and long-term morbidities (68). The WHO estimates that 13.4 million babies were born pre-term in 2020, and nearly 1 million of those babies died of pre-term complications (69). Of these surviving children, it is estimated that 345,000 will have moderate to severe neurodevelopmental impairment and 567,000 have mild impairments (70). The morbidity of low birthweight (LBW) babies is undetected and unaddressed in many developing countries (71), and a review of outcomes for pre-term babies in LMICs has called for more robust studies assessing the outcomes of babies who survive the immediate newborn period (72). One study in Uganda showed that barriers to utilisation of post-discharge follow-up care for newborns included parents not wanting to spend money on returning to the facility if the child was stable; limited partner support; inadequate communication from healthcare providers about the need for returning for care, and distance to the facility due to transportation costs (73).

The WHO-UNICEF recommend that post-discharge follow-up care of small and sick newborns include home-based care and facility-based follow-up to monitor medical conditions, growth and cognitive and motor development (74). They emphasise that this requires interprofessional systems and teams which coordinate from inpatient care onwards, and that the schedule and content of follow-up visits should be well defined (74). The WHO recommends care for pre-term babies should include family involvement in care provision during admission and preparation for discharge, family support such as education, counselling and peer support and home visits by trained healthcare professionals (75). A review on existing practices of following up women and newborns post-discharge found that home-visits by trained professionals and visits at facilities were

commonly used, and suggested phone and internet-based methods could be used for screening but need to be verified and followed-up appropriately (76). To achieve the WHO's goal for people-centred care, locally designed technologies and financial protection to transform care for small and sick newborns, there needs to further research into how care for small and sick newborns is organised, the challenges involved and ways to improve care provision (16).

Justification of the Research Setting

I chose to conduct my research in Kenya because previous literature on continuity of care for newborns has focused primarily on high income countries (24). In addition, my work could build on studies that have focused on post-discharge care for children (10, 11). Mortality rates of small and sick newborns post-discharge from the NBU are unknown in Kenya, however, these studies on infants indicate that outcomes are poor, and readmission is common (10, 11). A study on infants aged less than 60 days who were admitted to the paediatric units in Kilifi found neonatal sepsis, preterm complications and birth asphyxia accounted for 83% of admission. This study followed discharged infants for one year and found that 49% of deaths occurred one month post-discharge and 49% of deaths occurred at home (1). In addition, very low birthweight newborns still make up a disproportionate amount of infant mortality post-discharge in Kenya (77). These studies advocate for the need for better continuity of care post-discharge (1, 10).

I also chose Kenya as my research setting as interventions and policies in Kenya have focused on antenatal and facility-based delivery, with moderate success, but the journey post-discharge has been somewhat neglected (78, 79). With more babies surviving the neonatal period with longer term conditions, there must be a shift in focus to provision of

continuous care after discharge (78). The Kenyan government introduced a free maternity care service in 2013 which led to increased antenatal care and facility-based delivery (80). One study showed an increase in the level of deliveries in hospitals, with limited effect on antenatal and postnatal care attendance due to a lack of clarity on their inclusion in the maternal care policy (81). The increased facility attendance and provision of hospital-based care have led to modest reductions in neonatal mortality, which means babies are more likely to survive prematurity and early neonatal morbidities, such as congenital conditions, birth asphyxia and serious infections (82, 83). As such, the health system needs to shift the focus onto building robust follow-up mechanisms to ensure these newborns receive the care required (16, 78).

Other reasons that led me to focus on Kenya include that the Nuffield Department of Medicine in Oxford has established links with KEMRI-Wellcome Trust Research Programme (KWTRP) - a research organisation in Kenya - and hospitals in Kenya. The HIGH-Q project, which provided me with a studentship to conduct my research, was part of this collaboration, as discussed in further detail later in this chapter. Being Kenyan myself and having conducted research in the country I am familiar with the setting; I describe this further in my positionality statement in Chapter 2.

Overview of Neonatal and Paediatric Care in the Kenyan Health System

The Kenyan health system comprises of public, private and faith-based health facilities; public facilities account for 52% of all facilities, private for 37% and faith-based for 11% (84). In 2010 a new constitution was passed which led to the devolution of the Kenyan health

system, meaning each of the 47 counties were charged with managing health services in their area, while the national government remained in-charge of producing policies and managing national referral hospitals (85).

The public facilities are divided into six levels, as shown in **table 1** below.

Table 1: An overview of the level of health facility in Kenya and the care provided (86, 87)

Level of public health facility	Care provided	Staffing and Care Provided
1	Community health services	CHWs (Community Health Worker) and CHEWs (Community Health Extension Worker)
2	Dispensaries and clinics	Nurses and clinical officers
3	Health centres	Nurses, clinical officers, doctor
4	Sub-county hospitals	Specific specialised services: internal medicine, general surgery, gynaecology obstetrics and paediatrics
5	County referral hospitals	Specialised services, training facilities for primary care staff, internship centre for all staff, research centre
6	National referral hospitals	Highly specialised services, research centre providing training and research services for issues of national importance

In 2020 the number of qualified and registered healthcare workers in Kenya stood at 110,000 nurses, 12,792 medical doctors, of which 7884 were generalist medical practitioners and 343 were paediatricians, 25,400 clinical officers (tasked with patient management and care, including taking patient histories and prescribing medication), and 553 occupational therapists (88). The density of doctors, nurses or clinical officers is 30.14 per 10,000 people, which is below the threshold of 44.5 per 10,000 people recommended

to achieve selected tracer indicators of the sustainable development goals (SDGs) (89). These poor staffing numbers lead to an overwhelmed workforce (78), and healthcare worker burnout (90), which exacerbate the gaps in the provision of continuous care post-discharge (78). Other challenges faced by healthcare providers within the Kenyan health system include frustration with existing systems, including a lack of drugs and supplies (90), and poor documentation systems (91). These challenges, as well as additional challenges, apply to the post-discharge context, and are described in more detail in Chapter 4.

The clinicians that provide post-discharge care for newborns and children include paediatricians, medical doctors, clinical officers, medical officer interns (MOIs), clinical officer interns (COIs), nurses, nurse interns, occupational therapists, occupational therapy interns, nutritionists and social workers. COIs have completed three years of university education (92), while MOIs have completed five to six years of medical school. Both are then required to conduct a year-long internship programme (92, 93).

When interns are sent to placements they are expected to carry out the same work as qualified professionals, such as guiding patients and relatives with regards to diagnosis, treatment and follow-up, documenting and regularly updating patients' notes, writing accurate and informative case summaries and appropriate handing over patients, but under direct supervision from a trained and qualified healthcare provider (94). However, most hospitals in Kenya do not have adequate staffing to provide this supervision, and as a result interns can become the only available person for care provision and do so without appropriate supervision (95). The lack of qualified staff also results in documentation of care in hospitals being delegated to interns, and as a result the quality of data documented

is variable (78). I describe the challenges around documentation further in Chapter 4. However, efforts to improve documentation of neonatal care specifically have been done via standardised inpatient forms and feedback to hospitals on completeness of forms, which changed the hospital culture over time and enabled hospital staff to track outcomes for patients (96).

To support administration and service delivery, health record informational officers (HRIOs) are employed at county and national referral hospitals. Their tasks include receiving and registering patients, booking appointment for specialty clinics, storing and retrieving medical records, preparing clinics, editing of patient cases records, maintaining record safety and confidentiality directing patients to relevant clinics, entering patient data into medical records management systems and compiling medical records reports (97). In regards to the care small or sick newborns receive, this means HRIOs store and retrieve NBU files for follow-up visits at the paediatric outpatient clinic (POPC), book POPC appointments and create reports which are sent to the county government (98). However, in terms of where resources are invested records departments are often neglected, leading to poor documentation practices (91), and as described in Chapter 4 this can affect the provision of long-term care, including babies born small or sick.

Post-discharge Care

Post-discharge care visits for all newborns in Kenya currently consist of check-ups at 1-2 weeks, 6 weeks and 6 months after birth, in addition to routine vaccinations and weight checks (99, 100). To the best of my knowledge, there are no national guidelines on the frequency of visits for small and sick newborns, though guidelines exist specifically for

babies admitted to the kangaroo mother care (KMC) unit, with weekly visits recommended until the baby attains a weight of 2500g (101). An expert consultation between WHO and UNICEF recommends a well-defined schedule with clear content for each follow-up visit (74). Post-discharge care provision is complicated by poor documentation of care in NBUs in Kenya (102-104), and is attributed to poorly designed documentation tools and clinicians' lack of time (62, 104).

There are no estimates of national prematurity rates in Kenya, but one study in the largest teaching and referral hospital in Kenya found the prevalence of pre-term babies to be 183 per 1000 live births (105). Another cause of complication post-discharge is birth asphyxia. The WHO defines birth asphyxia as the failure to establish breathing at birth, usually caused by complications during childbirth (106). The prevalence of birth asphyxia is also unknown in Kenya, with one study of 237 babies in a Kenyan hospital finding that 5.1% had birth asphyxia (107). One study found that 40.3% of babies discharged from NBUs in 23 public hospitals in Kenya required at least one speciality post-discharge follow-up appointment, of which 91.9% required two or more follow-up appointments (78). These authors emphasised the importance of care coordination and suggested a multi-disciplinary team should be available for follow-up to ensure carers do not need to return to the hospital at multiple points (78). An important factor to consider during the post-discharge journey is the mother's experiences, as they are often the primary caregiver. Mothers are excited to be discharged but find adapting to life away from the hospital and medical expertise stressful, and face challenges such as a lack of information on feeding and danger signs and stigma at follow-up appointments (32).

There is little literature on neonatal post-discharge care, but the issues are likely similar to paediatric post-discharge care, as the same healthcare providers are involved and neonates are often readmitted to the paediatric ward. A mixed-methods study including surveys and semi-structured interviews examining knowledge, attitudes and practices of healthcare workers in Kenya regarding paediatric discharge from hospital, focusing on children aged 1-59 months, found participants felt their training lacked in this area, especially around how many deaths occurred post-discharge (108). The period post paediatric discharge is high-risk (2), with high readmission rates and an eight times higher fatality rate than similarly aged peers (12, 109). Paediatricians underestimated the higher risk faced by children who had been admitted, with only 3% guessing that these children had an eightfold risk of dying in the 12 months following discharge compared to their community peers (108).

Governmental Disability Services for Children

Earlier in this chapter I mentioned that Kenya has a high number of premature births. As more small and sick newborns survive, there is likely to be an increased rate of disabilities, which should be identified early to mitigate poor outcomes (16). In one study in Migori county in Kenya followed pre-term and LBW infants up to two years of age found that 8.6% of children had delays or disabilities and 2% of children showed concerns for being unable to walk (110). Similarly, a study in Burundi that followed-up small and sick newborns for two years found that 1 in 3 children had at least one developmental impairment and one in ten posed an additional burden in the family, defined as five or more impairments, consistent assistive care required and families routines organised around the sick child, with very low birthweight (VLBW) babies having a significantly higher risk of multiple

impairments (7). As newborn mortality reduces and more sick newborns survive, they will require more services, including links to occupational therapy and paediatric services.

The exact number of children living with disabilities in Kenya is unclear, with the 2019 census reporting that 2.2% or around 0.9 million Kenyans over the age of 5 were living with disabilities (111). The Kenya National Survey for Persons with Disability estimated the total number of people living with disabilities as 4.6% in 2007 (112), and states the most common causes of disability are disease and congenital conditions (112). Without clear data there cannot be accurate projections of the resources required to support families with disabled children due to issues during the neonatal period.

Despite the lack of data on the number of children living with disabilities, the government does offer some support. A government disability card entitles families to 2000KES per month, which is paid by an appointed agent (113). To receive this card, carers of children with disabilities must get an assessment conducted by an occupational therapist (OT). The disability card programme suffers from low levels of coverage, and as such many families requiring social support are excluded (113). With a Kenyan MoH survey showing that 12.7% of households experienced catastrophic health expenditure in 2013 (114), more thought needs to go into how to support families with children with long-term care conditions.

There are some organisations offering support to people living with disabilities or their carers. For example, the cerebral palsy society of Kenya provides free therapy and aims to

create awareness of cerebral palsy (115) and the Association of the physically disabled of Kenya provides assistive technology, such as wheelchairs, therapy and economic empowerment programs (116). However, the reach and support available from these organisations remain low (115, 116).

Health Technology Landscape

Increasingly, health technology is posited as a solution to improve care. Potential access to technology, such as mobile phones, is important to understand before digital interventions can be considered. In Kenya, 86% of households own a mobile phone, this is split into 94.2% in urban areas and 80% in rural areas (117). One study in Northern Kenya showed that mobile phone ownership and use was increasing, but phone sharing remained common (118). Phone sharing can improve spousal communication, but it can also exacerbate relationship issues by upholding men as sole decision makers; these gendered dynamics are not always considered at the outset of the design of mHealth interventions (119). In addition, most of the phones in use are not smartphones, even in urban areas close to Nairobi (120), meaning people cannot access apps or services using videos and photos. mHealth interventions are favoured by implementors due to the high coverage of mobile health networks and the lower cost, compared to other ICT systems (121). mHealth interventions such as short message service (SMS) have been used to improve knowledge of postpartum danger signs and uptake of family planning in Kenya, though effects on postnatal care were limited due to a high baseline knowledge of danger signs (120). One study in Kenya acknowledged that clinical visits are short and proposed complementing them with SMS to share informational messages and provide appointment reminders and

an artificial intelligence (AI) powered help-desk to triage cases based on risk for pregnant and post-partum women (122). The study showed an effect on the maternal care received postpartum, but there was no effect on care seeking for neonatal danger signs.

A scoping review found that Kenya has 67 digital health interventions for health system strengthening, the third highest in Africa (123). mHealth and eHealth interventions need to be cognisant of where they are implemented; the literature shows underserved communities are often neglected, leading to an increased divide in access to healthcare (121, 124). Technology based solutions within hospitals often focus on electronic health records (e-records) (123). Based on studies from the USA and UK (125, 126), it is estimated that implementing an e-record system in Kenyan hospitals would cost about 2.5% of Kenya's GDP, something which is not feasible given the current economic state of the country (127). Systems for e-records are costly to implement and difficult to sustain; as such, implementation of co-designed standardised forms is recommended as an initial step (98, 103).

Despite the challenges mentioned, there is a positive policy environment for digitalised health services in Kenya. The Kenyan government recognised digital transformation as a key enabler of healthcare by enacting the Digital Health Act 2023, which mandated the establishment and maintenance of a Comprehensive Integrated Health Management Information System (128). This system is meant to enable the flow of health information via E-Systems and promote patient centred care for all Kenyans (128). In addition, a growing number of counties in Kenya are utilising digital health systems for accounting and reports to the Ministry of Health (MoH), though poor documentation of clinical data, issues around

usability and lack of infrastructure (availability of information technology and electricity) remain (129).

Relevant Political Context

In August 2022 Kenya held elections, which fell between my first and second round of data collection. Since the new regime has taken over, there has been confusion about the Linda Mama program, the maternal and child health policy introduced in 2016 which provides free care for antenatal visits, delivery and two postnatal visits (130, 131). The MoH says the program remains open and has expanded the available services offered (132), yet there are media reports indicating mothers are being asked to pay for services and held in hospitals when they cannot do so (133). As I explain in more detail in Chapter 4, the confusion around the availability of services is especially disrupting for mothers of children with long-term conditions, as they require regular appointments, and the cost can be prohibitive if it needs to be paid out-of-pocket.

Kenya has experienced multiple strikes since devolution, with healthcare providers being unhappy with their salary and working conditions (86, 134). Doctors and interns working in the public sector regularly experience delayed salary payments (135) and often work in the private sector to supplement their income and have access to organisational resources and an improved working environment (136). These challenges create a strained workforce, where delayed payment of salaries for staff, failure to hire trainee doctors, and lack of comprehensive health insurance for doctors (137) has contributed to poor mental health for healthcare providers, and a worrying trend of doctors taking their own lives (138). In

Chapters 4 and 5 I describe how these challenges affect the provision of care for small and sick babies specifically

The strikes have led to reduced health seeking for antenatal, delivery and postnatal care, with delayed immunisation (134, 139). In Kilifi County a study found a 75% increase in mortality among children aged 12-59 months during the strike period (140). Despite the government agreeing to the doctors conditions in 2024, the situation remains precarious, especially with the government increasing taxation and a rising cost of living (141). This precarity was demonstrated by countrywide protests in 2024 against increased taxation policies (142).

Overview of HIGH-Q

My research was part of a larger project, called Harnessing Innovation in Global Health for Quality Care (HIGH-Q). HIGH-Q addressed questions focused on how introducing essential technologies affects neonatal care quality, including how increasing nurse and nurse assistant staff numbers affected care quality and technology adoption, and how we might better support the delivery and integration of post-discharge care for families in Kenya (143). The programme involved five DPhil students, including myself, working across three different work packages. When the project was devised, the work-package to which my DPhil was linked was meant to focus on the design of a minimal viable product (MVP), digital or physical, to improve care continuity post-discharge. One of the other students on the HIGH-Q project focused on mothers' experiences of post-discharge care and their information needs. HIGH-Q is a collaboration between the University of Oxford and KEMRI Wellcome Trust Research Programme (KWTRP). Kenya Medical Research Institute (KEMRI)

was founded in 1979 and is a well-recognised and respected parastatal organisation which conducts clinical and social science research in the country.

The hospitals in the HIGH-Q study were also part of the clinical information network (CIN), a hospital surveillance platform which collects routine admission and discharge data from NBUs and paediatric wards in 19 of the 47 counties in Kenya (144). CIN was an ongoing collaboration between KWTRP, the Kenya Paediatric Association, the Kenyan MoH and public county hospitals. As such, CIN often organised meetings in Nairobi with healthcare providers from various counties, which I was able to leverage for my workshops.

I conducted my data collection in two different county referral hospitals, both of which were intervention hospitals for HIGH-Q, meaning they received extra nurses and nurse assistants in the NBU during the project. This intervention is unlikely to have affected the results of my research, as it was focused on care received from nurses and nurse assistants during admission in the NBU, rather than care provided post-discharge. Being embedded in a large programme was helpful because we had administrative help from Oxford and KWTRP that eased the logistical burden. Working with other DPhil students and postdoctoral researchers enabled a supportive environment, with strong peer support as well as learning across work packages, including some sharing of data. There were also some disadvantages, such as challenges coordinating fieldwork to ensure we were not overly burdening one ward or hospital, and ensuring the scope of our work was not similar.

Thesis Aim, Research Questions and Structure

The overall aim of my thesis is to explore how continuity of care for small and sick newborns post-discharge may be better supported within the Kenyan health system. To achieve this

aim, I have organised the thesis around three main research questions (with related sub-questions presented in each of the empirical chapters):

1. What types of interventions, innovations or support mechanisms have been proposed to support continuity of post-discharge care for newborns in LMICs?
2. What continuity challenges do healthcare providers encounter when providing post-discharge care for babies born small or sick in Kenya?
3. How can participatory design inform improvements on documentation artefacts used to promote continuity of post-discharge care for small and sick newborns in Kenya?

As mentioned earlier in this chapter, there is scarce literature on post-discharge care for small and sick newborns. As such, I focused my questions on this group. In addition, the literature has tended to focus more on the experience of patients, or mothers and parents of sick babies, rather than healthcare providers. Earlier in this chapter I described how I drew on literature on continuity of care, sociomateriality and participatory design, which helped frame and address my questions.

My thesis is divided into six chapters. This first chapter describes the literature that my work aims to build on and sets the scene for the following chapters. The second chapter describes the hospitals where data was collected, and the qualitative and design methodologies employed. This chapter includes reflections on my positionality and the ethical challenges faced during data collection. My first research question is answered in chapter three, which shows the results from my scoping review, including an expansion of Haggerty et al.'s (19) continuity of care typology. My second research question is addressed in chapter four, which shows the challenges with providing care continuity, highlighted by

stories from two mothers of children with long-term conditions. This chapter argues that continuity of post-discharge care is a sociomaterial practice, and as such the artefacts involved in care provision need to be duly considered. These artefacts and how they are used (or not) play a major role in disruptions to informational continuity. Chapter five addresses my third research question and describes the redesign of the discharge summary using goal-directed design as a specific approach to participatory design. This approach uses personas and context scenarios to guide the direction of design. Chapter six is the discussion chapter and includes a summary of the thesis, the strengths and limitations of the study, my contributions to the research literature and a reflection on the journey I took conducting the research. This final chapter argues that participatory design to improve documentation is an important task, but tackling the complex problem of post-discharge care will require more than just the presence of a redesigned artefact.

Chapter 2: Methodology

Introduction

My DPhil comprises of three components. A scoping review on the types of interventions, innovations or support mechanisms that have been used to support continuity of post-discharge care for newborns in LMICs addressed my first research question. The qualitative research on the challenges faced by healthcare workers when caring for babies born small or sick after discharge from hospitals, especially around care continuity, addressed my second research question. The qualitative research and participatory workshops on improving documentation artefacts used to promote care continuity for small and sick newborns addressed the third research question.

In this chapter I describe how an interpretivist paradigm underpinned my research, followed by my rationale for selecting a scoping review, qualitative methods and participatory workshops to answer my research questions. I describe both settings of my research, public level 5 facilities. I describe the process I undertook for my scoping review, which followed the five steps outlined by Arksey and O'Malley (145). I describe the methods used in my empirical data collection, including semi-structured qualitative interviews, ethnographic observations and participatory co-design workshops with healthcare providers in two public level 5 facilities. I outline how the qualitative data underwent quality checks and was securely stored and transferred. I describe how I used

reflexive thematic analysis, and the continuity of care typology developed in the scoping review to analyse the interviews and ethnographic data, and how I used the goal-directed design process to analyse qualitative data and data from participatory workshops. I also discuss ethical considerations that arose, such as compensation of participants, and end with a reflexive discussion of my positionality and how it influenced my research.

The methods presented in this chapter, and the results in the following chapters, may seem linear, but findings from one method or round of fieldwork iteratively informed my interpretations of the data and next steps in this research.

Philosophical Assumptions and Research Paradigm

The term research paradigm was coined by Kuhn (146) to differentiate between different scientific research practices; paradigms are concerned with the beliefs about how problems should be understood and addressed. Each paradigm has its own assumptions about epistemologies and ontologies. Epistemology can be thought of as "a set of rules determining how we can learn about the social world or phenomena being studied, and what counts as valid evidence about these phenomena" (147). Ontology is concerned with the nature of the world and "requires researchers to consider whether the social phenomena they are studying are independent of human thinking and interpretation, or whether such phenomena exist only as a result of a process of construction by researchers" (147).

For my research I adopted an interpretivist paradigm, which argues there are multiple realities constructed through experience and interactions, and as such people perceive issues differently and give them different weight (148). Interpretivism recognises that the researcher is inherently part of the investigation process (147). The researcher's style of

involvement and gaining and maintaining access to organisations are important aspects of doing interpretive research (149). As such, I was critical about how my positionality affected my data collection and analysis, and how I engaged with the healthcare workers, as described later in this chapter.

Interpretivism also recognised the importance of understanding phenomena from the perspectives of those involved in these processes (147, 150). My methods (interviews, observations and participatory workshops) aimed to build an understanding of post-discharge care from the perspective of those involved in care provision at the hospitals, i.e., the healthcare providers. Interpretivism rejects the idea of an objective or factual account of events, instead seeking a shared understanding of phenomena (150). My research was informed by the concept of subtle realism (151), which is consistent with interpretivism, and acknowledges that there is an external social world that can only be accessed through the different interpretations or subjective perspectives that we all have. I discuss this later in this chapter when I explore my positionality.

Scoping review

I conducted a scoping review of academic and grey literature to understand what interventions have previously been used in LMIC settings to improve care continuity for newborns, with a focus on post-discharge care. Scoping reviews are good for gaining a broad understanding of a topic area (152) and identifying gaps in the literature (145) (153). I used the five-step scoping review approach outlined by Arksey and O'Malley (145) which included setting the research questions; identifying relevant studies; study selection; data charting; collating, summarising and reporting the results. I incorporated the updates by

Peters et al. (152), hence the population, concept, context (PCC) framework was used to guide the inclusion and exclusion criteria.

The review has been published as a journal article in BMJ Global Health (154), but this does not include the grey literature which I searched for and incorporated in the thesis after the article was published. The grey literature included digital health interventions, which broadened the scope of the review. The following sections have been adapted from the published article.

Search strategy

The sections below describe the search strategy used for both academic literature and grey literature.

Academic literature

I initially conducted exploratory searches to gain familiarity with the literature, define key terms and develop the search strategy. Search terms and information sources were selected based on key words and databases used in previous reviews in similar topic areas (20, 121, 155, 156). Two librarians reviewed the search strategy (Appendix 1) to confirm all relevant terms had been included. I searched seven databases: MEDLINE, CINAHL, Scopus, Web of Science, EMBASE, Cochrane library and (Ovid) Global health. The search was limited to papers published in English between 2001-2021.

Grey literature

The importance of searching for grey literature when working on mHealth and eHealth has been previously highlighted (121). I searched databases recommended by an academic working in the health intervention space in Kenya. These included websites such as the digital health atlas, the digital public good alliance, center for health market innovations and health e-net. Concurrently, I looked up reports by relevant organisations such as: UNICEF (United Nations Children's Fund), CHAI (Clinton Health Access Initiative), WHO (World Health Organisation), Bill and Melinda Gates, Kenyan Ministry of Health, Reliefweb, USAID (United States Agency for International Development) and FCDO (Foreign Commonwealth and Development Office). In addition, I reached out to organisations in Kenya that were known to be working on newborn health and digital technology, including AMREF, IntelliSOFT and World Friends.

I used the search terms "newborn" and "post discharge" for my searches on the grey literature websites. I limited my search for interventions on the digital health atlas and digital public goods alliance databases to those in Kenya. I reviewed the interventions available and aimed to capture the range of interventions, and the interventions in Kenya were representative and fed into ideas for improvement of care continuity.

Eligibility criteria

I screened the titles and abstracts of retrieved articles using Rayyan (systematic review management platform). A fellow DPhil student (AR) reviewed a random 10% sample of articles to refine the process of article inclusion and exclusion; disagreements in 26 of the academic articles reviewed were resolved through discussion with reference to the inclusion and exclusion criteria. Subsequently, I retrieved and read the full texts of all

articles remaining after title and abstract screening to assess them for inclusion. Articles had to meet the PCC criteria: the population under investigation was newborn babies (defined as babies under 28 days of age) (15), the concept was defined as continuity of care after discharge and the context was LMICs. There were no limits on the study design if primary data was used. Articles were only included if there was a clearly defined intervention to improve continuity of care for newborns in LMICs. Grey literature was considered relevant if the reports included a significant post-discharge care component.

Data charting and synthesis

I extracted descriptive information for each of the academic articles included in the review using an Excel spreadsheet (**Appendix 2**). AR charted data from a random 10% sample of articles to get a second opinion on data abstraction; differences were resolved through discussion. The table provides an overview of study characteristics such as author, title, year of publication, study location, study design, aim, type of intervention, methods and sample size.

I prioritised a set of 28 core academic articles (which provided rich descriptions of intervention, results, contexts, and outcomes) and used these as a starting point for iterative analysis of the 65 articles. Detailed analysis of the articles was underpinned by the continuity of care typology by Haggerty et al. (19), which distinguishes between informational, management and relational continuity. Informational continuity is defined as information being shared and used appropriately; management continuity as managing an illness in a consistent and coherent manner; and relational continuity as the ongoing relationship between a patient and one or more providers (see Chapter 1). I treated these

different facets of continuity as distinct logics, i.e., assumptions underpinning how continuity might be achieved. In reviewing these papers, I sought to interpret how different logics of continuity underpinned and informed different interventions in each of the studies. Multiple continuity logics could underpin a single intervention, e.g., informational continuity might be attempted as part of an intervention while explicitly or implicitly supporting relational continuity. The logics underpinning continuity were not always clearly articulated by study authors, therefore interpretation and judgment was needed. I conducted an inductive analysis of extracted data to compare findings across studies, interventions and continuity logics and produce summaries, which were then reviewed and discussed with co-authors. The analysis of core articles resulted in the addition of 'interpersonal continuity' as a new category, highlighting the importance of relationships between family members, between healthcare workers or between people within the community (see Chapter 3).

The methods used in papers were assessed to see if they were participatory. Participatory studies are defined as involving the community (157, 158) and designing interventions with people, not for them (159). However, there are different levels of participation, for example, who is included (community members vs end-users vs stakeholders) and when they are involved (problem definition through to assessment of the project) (160). I applied the classification by Vaughn and Jacquez (59) to differentiate the participatory studies. The authors defined 'empowerment' of participants as the community leading research decision making, while 'informing' participants was defined as information being provided to the community and 'involvement' of participants as researchers working directly with the community.

I defined opportunities as structural or behavioural levers to continuity of care in the post-discharge period, and challenges as structural or behavioural challenges that are barriers to continuity of care in the post-discharge period. I extracted information on opportunities and challenges from the studies that was considered pertinent to the implementation of the intervention, then conducted an inductive thematic analysis.

The extracted information from the grey literature reports were placed in an Excel sheet provided in **Appendix 3**. The table provides an overview of the website the intervention was found, the organisation implementing the intervention, study location, type of intervention, aim, target, continuity logic and whether there was a participatory component.

Rationale for Qualitative Methods

Qualitative research is an interpretive and material practice that makes the world visible, which means studying things in their natural settings and interpreting events (161). Ethnography is a qualitative method that can be used to identify complex social problems by discovering what people actually do and why (162). By observing and speaking to healthcare providers, I learned how they carried out their day-to-day work and where there may be challenges (148). I acknowledge that no one can have a truly neutral stance, and the researcher is the primary means through which data is collected in ethnography (162), as discussed in my positionality and reflexivity section. I conducted semi-structured in-depth interviews as there is little published literature on continuity of post-discharge care for babies born small or sick. As such I wanted to explore the topic during in-depth discussions with healthcare workers and mothers to gain an understanding of their

experiences, practices and frustrations, and develop a nuanced account of how care is organised and how care continuity might be improved (163). I chose the semi-structured approach for flexibility to talk openly and probe some of the responses from participants (147, 163). Different forms of qualitative data were collected to access different perspectives and therefore generate more useful insights (158).

A participatory design approach was suitable for the purposes of my research as it enables those who are using an intervention to be involved in determining what the intervention looks like, especially as the intervention involved a physical artefact, i.e. designing a discharge summary (164, 165). Other studies have shown that a participatory approach can create buy-in from potential users (166, 167), which can make them feel a sense of ownership over artefacts that fosters continued support (60, 67). As such, I chose to conduct participatory workshops with the healthcare workers to be able to design the intervention with their input as they are the experts in providing post-discharge care (164). Involving the "end-users" in this democratic process ensures that the intervention meets their needs, and is more likely to be used (168).

Study Setting

As mentioned in Chapter 1, the hospitals I conducted my research in were part of the HIGH-Q project. I selected two hospitals for my research, which I shall refer to as Twiga and Ndovu to maintain their anonymity. I selected Twiga and Ndovu as they served urban and rural populations respectively. The county served by Twiga, herein referred to as County 1, was much smaller than the county served by Ndovu (County 2), which also served populations in neighbouring counties. **Table 2** provides an overview of the referral hospitals in each

county. I wanted to observe whether the challenges faced by these differing populations were similar, and how this would affect development of an intervention.

Engagement with the county government and hospital management and healthcare workers was conducted as part of the HIGH-Q project and began in September 2021. Site visits to each study site were conducted by Kenneth Karumba, the project manager for HIGH-Q at KEMRI-Wellcome Trust Research Programme (KWTRP). Each study site was introduced to the research project, memoranda of understanding were signed, and researchers were introduced to hospital staff. Handouts were given to the NBU with HIGH-Q researchers faces and research aims and were placed on the wall so all staff could see them; this ensured healthcare workers were aware of who we were. During my first visit to each hospital, I was introduced to the heads of the relevant wards by research assistants (RAs) who had been conducting observations as part of the HIGH-Q project and had already established rapport with hospital staff. Both study sites were aware that I would be collecting data from various wards within the hospital and were receptive to my presence. Relevant stakeholders were engaged throughout the project – details on the engagement process and how it was maintained throughout the project have been published elsewhere (169).

Table 2: An overview of key characteristics from the referral hospitals within each county.

	County 1	**County 2**
Population Served	2.5 million	750,000
Distance to Nairobi (km)	15	153
Annual births	9865	600
Annual neonatal admissions	2514	1299
NBU Paediatricians	4	2

County 1

County 1 is in the Central region of Kenya about 15km away from Nairobi. The county has a population of about 2.5 million, making it the second most populous county (170). On average, women complete 10.1 years of education and men complete 10.5 years (117).

County 1 contributes 5.5% to Kenya's GDP making it the 3rd highest performing county (171). The county makes most of its money from agriculture, forestry and fishing; followed by construction, and manufacturing. County 1 has the highest access to media for any county, with 26.7% of women in county 1 are likely to access newspapers, watch TV and listen to radio at least once per week (117). 56.4% of men have read newspapers, watch TV and listen to radio at least once per week (117).

In county 1 only 1.7% of mothers who had a live birth in the last 5 years did not access any antenatal care and 97.9% received antenatal care from a skilled provider. 93.4% of women delivered their baby in a public or private hospital. 20.1% of deliveries are by C-section (117).

Twiga hospital

Twiga was upgraded in 2017 from a level 4 to a level 5 facility. Unpublished health facility assessments from NEST 360 and the Kenyan Ministry of Health show that the newborn unit consists of 40 cots, with 2514 annual neonatal admissions and 9865 births annually. There were 12 nurses assigned exclusively to the newborn unit (NBU). There were also 4 paediatricians assigned to the NBU.

County 2

County 2 is also in the Central region of Kenya, about 153km from Nairobi. Towns within the county are urban, but most of the population lives in rural areas (117). The county has a population of about 750,000 (170), predominantly from the most populous tribe in Kenya, the Kikuyu. On average, women complete 9.2 years of school, with men completing 9.3 years (117).

County 2 contributes about 2.2% of Kenya's GDP, making it Kenya's 14th highest performing county out of 47 (171). The county has fertile land and makes most of its money from agriculture, forestry and fishing; financial and insurance activities and transport and storage are the next highest sources of revenue (172). The county has amongst the highest access to media in the country, with 21% of women and 71% of men in County 2 likely to read newspapers, watch TV and listen to the radio at least once per week (117).

In County 2, only 2.8% of mothers who had a live birth in the last five years did not access any antenatal care and 96.7% received care from a skilled provider; 89% of women delivered their baby in a public or private hospital (117). 13.5% of deliveries are via C-section (117).

Ndovu hospital

Ndovu is a level 5 public facility. The hospital was founded in the 1930s under colonial rule and offered maternity services and primary healthcare services (173). Today, the hospital is one of the largest in the region and provides care to patients in neighbouring counties too. There are 530 members of healthcare staff, including cleaning crew (173).

Unpublished health facility assessments from NEST 360 and the Kenyan Ministry of Health show that the newborn unit in Ndovu hospital consisted of 32 cots, with 1299 annual neonatal admissions (newborns are admitted to the paediatric unit if they have previously been discharged) and 600 births annually. There were 12 nurses, 2 doctors, a technician and a data clerk assigned to the newborn unit. From observations and discussions on the ward there is also one nutritionist attached to the neonatal unit.

Empirical data collection

My empirical data was used to answer my second and third research questions. Data collection involved: semi-structured interviews with healthcare workers, mothers, and key informants; observations within hospital wards and mothers' homes, and participatory workshops with healthcare workers. **Figure 4** provides an overview of the three rounds of data collection, and **Figure 5** provides a more detailed description of how the different forms of data collected iteratively informed subsequent phases of data collection. The first round of data collection took place between March and June 2022 and involved interviews, observations in Ndovu and one participatory workshop with healthcare workers from Twiga, Ndovu and two other hospitals that are part of CIN. The data collected was exploratory, as I was trying to build an understanding of how post-discharge care was organised, the artefacts used, and the healthcare providers involved. My second round of data collection was informed by the continuity of care typology (19) used in the scoping review, including the new concept of interpersonal continuity. During this round of data collection, I focused observations and questions around informational continuity, management continuity, relational continuity and interpersonal continuity. The third round

of data collection took place in March 2024 and involved a participatory workshop with COIs from Twiga.

I conducted most of my interviews with mothers in the first round of data collection, when my research was exploring challenges with care continuity both from the perspective of mothers and healthcare providers. Continuity of care cannot be created by healthcare workers alone; mothers play a central role and care continuity is a joined effort involving a variety of artefacts. After the first round of fieldwork, it became clear that designing an artefact to meet both the needs of healthcare providers and mothers would not be possible. As such, to build a deeper understanding of how continuity of care was provided and the artefacts involved I needed to focus on one group. I chose to focus on healthcare providers as their perspective is lacking from the literature, with only one study using a similar approach (26). One of the other DPhil students on HIGH-Q, as described in Chapter 1, focused on the experiences and information needs of mothers.

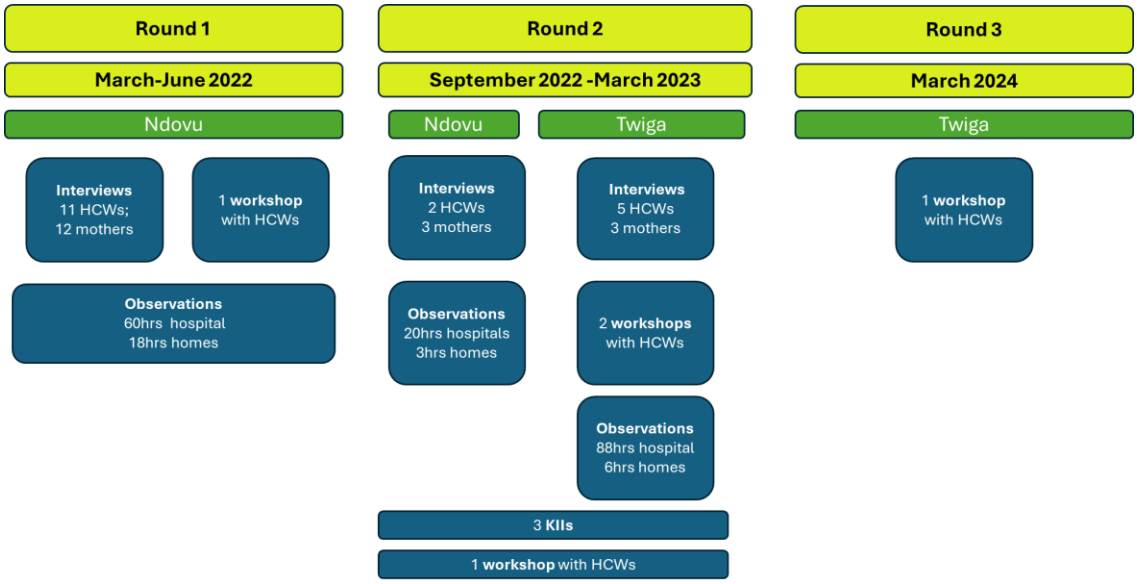

Figure 4: An overview of the data collected during the three rounds of data collection

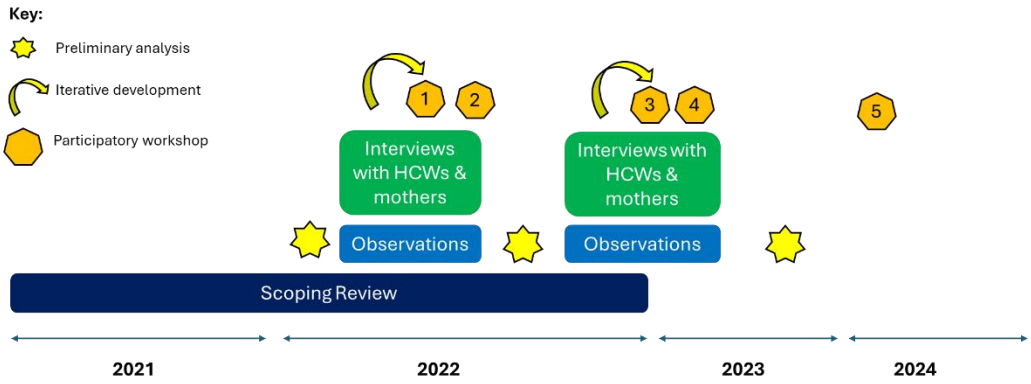

Figure 5: A visual representation of the different data collected and how it was used to inform further rounds of data collection. Preliminary analysis is represented by a star and represents when there was significant time for analysis of all available data to inform further rounds of data collection. The arrows represent iterative development of data collection guides, which is typical of qualitative data collection, where data collected within a round of data collection could inform who was included, interview guides, observation guides or the structure and content of workshops.

In Figure 5 I illustrate how analysis took place iteratively before and after each round of empirical data collection, with data from one phase informing the next, both in terms of data collection but also recruitment. The iterative development of interview and observation guides is not novel to qualitative research. I also recruited participants based on analysis of interview and observation data. For example, I conducted an interview with a social worker in Ndovu as their involvement in post-discharge care was mentioned by paediatricians and OTs and sounded like it required follow up. I also conducted observations in the MCH clinic in Ndovu as healthcare workers described this as a key site where mothers received information related to post-discharge care.

I had done the bulk of my analysis for my scoping review in Chapter 3 before starting my data collection and was completing my writing while collecting empirical data. The continuity of care typology, which I extended in the review, informed my data collection, as my interview guides and observations were broadly structured around informational, management, relational and interpersonal continuity. In turn, the qualitative data I

collected was used to inform the co-design workshops; for example, I presented scenarios I had commonly observed and initial sketches of personas.

Between the first and second round of data collection I was able to read through the interview transcripts and my observation and workshop notes, and I found that Informational continuity was a salient challenge. I realised any intervention would not be able to meet the informational needs of both healthcare providers and mothers, and there was a need to focus on one group. As described in further detail in Chapter 3, I chose to focus on healthcare providers as their perspective was lacking in the literature. This resulted in my interviews, observations and workshops in my second round of data collection focusing on informational continuity. For example, I spent more time in the occupational therapy ward, as I realised this was a crucial place for the provision of long-term care. During my time in the occupational therapy ward and the paediatric outpatient clinic (POPC) I focused my observations on the various artefacts used to document care, and communication between healthcare workers and healthcare workers and mothers. I also asked healthcare workers about the challenges they faced in terms of informational continuity. The qualitative data I gathered led to the focus of workshops 3 and 4 being on redesign of existing artefacts.

As I can understand some Kiswahili but cannot speak fluently, I was assisted with my data collection by three RAs – Onesmus Onyango, Caroline Waithira, and Nancy Odinga. The RAs were based at KWTRP, the organisation mentioned in the previous chapter that conducts social science research throughout Kenya and which Oxford has a historical relationship. Onesmus, Caroline and Nancy are Kenyans with years of research experience in qualitative research, including interviews and observations, and transcription. Onesmus is a qualified

nurse, Caroline has a bachelor's degree in Sociology and Economics and had previously worked on two maternal and child health projects; Nancy has a master's degree in Sociology.

During the HIGH-Q project the RAs collected quantitative and qualitative data, mostly focused on the NBU, analysed data and produced academic publications. KWTRP provided training to each of the RAs on qualitative methods, including how to conduct interviews and a practical training session on conducting observations. Onesmus and Caroline introduced me to clinical staff at each facility and helped me recruit mothers. I trained Onesmus, Caroline and Nancy on the purpose of my data collection, and on how to use the interview guides I developed. We conducted mock interviews and debriefs with each other, and they provided feedback on re-wording questions to make them more understandable (174). The RAs were not simply data collectors; their experience with mothers from the NBU and the way they approached the field shaped the quality of the data collected, and they acted as cultural brokers between me and the mothers (174). I provide a deeper reflection on the role of RAs in the positionality section.

Ethnographic observations

Ethnographic observations were selected to observe the healthcare workers and mothers in their "natural state" (158) to understand the process of post-discharge care and the setting it takes place in. In addition, observations allowed me to capture social dynamics and the practices of the various cadres of care providers, which enabled me to develop a deeper understanding of post-discharge care provision. I used the suggestion from Orlikowski and Scott (35) to look at practices, i.e., to examine how sociomateriality is enacted in the workplace. Ethnographic observations allowed exploration of how work is

organised in a way that may be “taken for granted”. This allowed me to observe how design and use are related, including the ways in which people get work done in their own way and the agency of artefacts (45). My observations started broadly – I wanted to understand how the discharge process and post-discharge care was organised, which healthcare providers were involved and what information tools were used. I observed how healthcare workers interacted with each other, parents and the documentation tools during the consultation; how healthcare workers went about their everyday work, and how they exchanged information. Observations allowed me to see what people actually do in their daily routines to understand how healthcare is organised and provided (147). Ethnographic observations are subjective by their nature, and therefore heavily involved myself and my perspective (175), which has implications for what was considered important.

In total, I conducted around 92 hours of observations in Ndovu (including 12 hours conducted by Caroline) and 88 hours in Twiga. Observations at the hospitals were conducted within the NBU, occupational therapy (OT) department, daily paediatric outpatient, paediatric ward, maternal and child health (MCH) clinic and paediatric outpatient clinic (POPC). I spent time in different wards to build a fuller view of how post-discharge care is provided. However, I am aware that I cannot draw conclusions from every ward I attended. When Caroline and I visited mothers in their homes for interviews, I conducted further observation to understand family dynamics and living conditions (4.5 hours in county 1 and 21 hours in county 2).

During the first round of data collection, I did not enter the field with an observation guide. Instead, my observations were open and unstructured, as I aimed to gain how post-discharge care was provided in this specific setting (158). In the second round, I had more

focused and structured observations. My focus was on information flow, i.e., how information is shared between healthcare workers. Information flows could be in the form of verbal communication, but was often in the form of physical artefacts such as discharge summaries, NBU files, outpatient files etc. I would observe who filled in the various documents, how they were used by healthcare workers and any disruptions to the flow of information. As I narrowed my focus in round 2, I decided not to spend as much time in the NBU or observe social workers as I did in round 1. I wrote fieldnotes in a notebook in situ and typed them into a Word document within one day of the observation.

It was clear that my presence caused the Hawthorne effect – people changing their behaviour when they are observed (158) – especially when I was in a new ward. For example, while conducting observations of the check-ups mothers and babies attend in the MCH clinic I noticed the nurse spending a lot of time with each mother-baby dyad, which was unusual because the waiting room was full, and all the babies would need to be seen by the nurse on that day. She also conducted all the follow-ups in English, presumably for my benefit, as all other follow-ups I observed in other wards were in Kiswahili. Another example is the reaction of clinical officer interns (COIs) when I started observations in the postnatal ward. Without realising that I understood Kiswahili one of them said *"Huyu mzungu yuko hapa kutujaribu"* [this white person is here to test us]. The Hawthorne effect is a common phenomenon, and once people got used to my presence this effect reduced over time (147). The healthcare providers became used to my presence after two or three days in a ward and were happy to answer questions as they completed their tasks.

Semi-structured In-depth Interviews

Interviews allowed me to deepen my understanding of how discharge and post-discharge care was organised, and provided insight into participants' views and experiences, especially around the challenges they faced around care provision. I conducted 13 interviews in English with healthcare workers in Ndovu and two interviews in Twiga. By the second round of data collection the paediatricians expressed interview fatigue, therefore I used three interviews conducted by a DPhil colleague in Twiga as secondary data. I conducted three key informant interviews with an academic with experience in paediatric care in Kenya, and two people who organised support groups for mothers born pre-term or with cerebral palsy.

Due to my language constraints, I required help with the interviews with mothers, and the logistics involved with organising these interviews. Caroline conducted interviews in Kiswahili and Kikuyu with mothers while I was present. The interviews were translated afterwards by the RAs or an external translating service as opposed to in situ, to avoid taking too much time, disrupting the flow and shifting the focus away from the mothers (176). Nancy and Caroline conducted quality checks on the transcripts from interviews with mothers and healthcare workers. 15 interviews were conducted with mothers in Ndovu and three interviews were conducted with mothers in Twiga. This reflects the shift in focus towards an intervention for healthcare workers, with the data from mothers providing contextual information. The inclusion criteria for mothers started broadly, i.e., anyone who was admitted to the NBU. As the project progressed, I started to focus on babies with long-term conditions, particularly birth asphyxia (BA), as these children have continuous long-term interactions with the health system, i.e., there are more opportunities for enactment

of continuity and discontinuity of care. Caroline conducted follow-up phone calls with one mother of a child with long-term conditions in each county, which I was not present for. I provided a brief guide on questions to ask the mother, but Caroline was free to use her perceptions of what information was needed to guide the discussion (177).

For healthcare workers and mothers, the interview guides used for the first round of data collection were broad and focused on understanding how post-discharge care was organised and mothers' experiences respectively. During the second round of data collection the guides used the continuity of care typology to guide questions, such as information flows, how relationships were built, how cases were managed, and what support was available to mothers. Healthcare workers described the challenges they experienced during their work and suggested possible solutions.

The interview guides for mothers, healthcare workers and key informants are provided in **Appendix 4**.

Recruitment for Interviews

Mothers were recruited by Caroline, Onesmus, or me from the NBU, paediatric ward, OT department or POPC. During the first round of data collection, we recruited mothers of any babies born small or sick during observations. After a potential participant was identified, we would approach the parent, introduce ourselves and describe the study. We told the parents it was okay to say no, and that would not affect the care provided for their child. If parents agreed, we asked for their phone numbers and called to arrange an interview at a time and place of their choosing, which was usually at their homes. During the second round of data collection, I told the RAs that I was interested in children with longer term conditions, such as birth asphyxia (BA). We would still recruit parents while conducting

observations, but this included mothers who the RAs had met while doing HIGH-Q observations in the NBU. Before the interview we would explain the study again, ask if there were any questions and emphasise that participation was voluntary before having the consent papers signed. I had a positive experience with recruitment, most parents were willing to take part in the study and share their experiences. **Tables 3 and 4** below describe the characteristics of the mothers. Our ethics approval covered mothers who were at least 18 years of age.

Table 3: Characteristics of caregivers recruited from Ndovu

	Age	Education	Marital status	Occupation	Parity	Condition of baby
1	25	Form 3	Married	Unemployed	2	Infected cord
2	--	College	Single	Unemployed	1	Jaundice
3	24	Form 4	Married	Farm work	2	BA
4	30	Form 4	Married	Farmer	2	BA
5	21	In college	Single	Farm work	1	Pre-term, BA, jaundice
6	26	Form 4	Single	Farmer	3	Pre-term
7	32	Form 4	Single	Beautician	4	Pre-term, BA, sepsis, anaemia
8	44	Standard 8	Married	Farmer	1	Pre-term
9	26	Class 8	--	Hotel worker	4	Mild/moderate BA
10	35	Form 4	Married	Agribusiness	--	Mother passed away
11	20	Form 4	Married	Salon owner	1	Pre-term and BA
12	38	Form 4	Divorced	Businesswoman	3	Pre-term and BA
13	--	College	Single	Unemployed	2	LBW
14	24	College	Married	Unemployed	1	LBW and jaundice
15	22	Form 3	Married	Unemployed	2	Breathing problems

Table 4: Characteristics of caregivers recruited from Twiga

	Age	Education	Marital status	Occupation	Parity	Condition of baby
1	25	Form 4	Married	Unemployed	2	LBW
2	23	Form 4	Married	Businesswoman	1	Mild BA
3	28	Class 3	Married	Businesswoman	3	Severe BA

I recruited healthcare workers from the wards where observations were conducted. I explained the purpose of my study and asked if they had time to participate in an interview. I provided an information sheet and in-depth explanation of the study before formal interviews took place. **Table 5** shows the healthcare providers interviewed in each hospital. I interviewed a variety of healthcare providers to get a wide range of opinions to better understand the system and care provided.

Table 5: Professional roles of healthcare workers interviewed.

	Paediatrician	OT	Nurse	Social worker	COI	Nutritionist	Total
Twiga	2	2					4
Ndovu	3	2	4	1	2	1	13

Key informants were recruited from within the wider HIGH-Q study, or recommendations from KWTRP researchers involved in researching mothers' experiences of care. Informants included a senior professor from a Kenyan university, and two founders of organisations to support mothers of pre-term babies and babies with birth asphyxia respectively. I asked them to participate and gave an outline of what the interview would entail and provided information sheets and a chance to ask questions before the formal interview.

The information sheet given to participants is provided in (Appendix 5). We emphasised that participation was voluntary and written informed consent was obtained from all participants.

Participatory Workshops

As described in Chapter 1, I was planning on collecting information on the context and challenges faced so I could develop a minimal viable product (MVP) of an artefact to help with post-discharge care. I used goal-directed design (GDD) to address this research

question as it is a method used to develop tools, which can be software or paper-based tools, by building empathy with people who are going to use the tools (178). GDD does this by using the qualitative data to create personas, which are "fictional, detailed archetypical characters that represent distinct groupings of behaviours, goals and motivations observed and identified during the research phase" (179, 180). Personas are created in a precise manner by following the GDD method, whereas other methods lead to creation of personas based on assumptions or limited data, as discussed in Chapter 5. Personas are a useful tool as it is easier to build empathy with a persona than with statistics, and personas build empathy with end-users without being based on one specific "user" but are representative of a good proportion of overall "end-users" (178). I use the term "user" in quotation marks as Cooper suggests not using the term and instead building personas which become the focus of design; these personas should be thought of as real individuals (181).

I used workshops to sense-check findings and receive input from healthcare workers to further refine personas, context scenarios and the initial design framework i.e., visual and physical design of the discharge summary, shown in **Figure 4**. Context scenarios are written from the persona's perspective and describe how the artefact can be used to create the ideal experience for the persona (178). I used RAs to assist with facilitating the breakout groups, with one facilitator per a group of 3-5 people, as has been done in another study in an LMIC (182). The workshops involved design facilitation, i.e., applying design approaches to enable dialogue and ideas to emerge in the workshops, to develop novel solutions to complex problems (183). An outline of the workshops and participants in provided in **Table 6**.

I adopted the GDD method described by Cooper (178) to structure the design process, as shown in **Figure 6**. GDD originated in industry (184) and is widely used to design digital systems however it is also being used in research studies where new digital interventions are being designed with participants (185-187). In workshop 1 healthcare providers created process maps of post-discharge care in each facility, including the relevant wards, who was involved, and which information tools were used. Process maps engage stakeholders to create a visual diagram of a shared understanding of the process under review (188). I chose to use process maps in this workshop to ensure I had built an understanding of the way discharge and post-discharge care was organised that represented healthcare worker's experiences. The data from this workshop was combined with observations of discharge and post-discharge care being provided within the hospitals and interviews with healthcare workers and mothers to build knowledge on the "users", the problem and the context. In workshop two, I presented personas I created based on observations and interviews to healthcare providers for sense-checking, to ensure they were accurate representations of end-users. These personas were further refined, as described later in this chapter. I provided scenarios for these personas, such as having insufficient information at a POPC follow-up and seeing a baby at POPC with insufficient weight gain and clear financial difficulties. I asked healthcare providers if these situations resonated with their experiences, how they thought the personas would behave and how the situation could be improved. Based on the qualitative research and the workshops, it became clear that information tools were important artefacts in the provision of post-discharge care and needed to be redesigned to better meet the needs of healthcare workers. As such, in workshops three and four I asked healthcare workers what information it was important for them to have to provide care and then asked them to design prototypes of artefacts,

the OT initial assessment and the discharge summaries, by themselves, before a group discussion. Based on that, I created a redesigned discharge summary. In workshop five the COIs and medical officer interns (MOIs) used real cases of sick babies currently in the NBU to fill in the newly designed discharge summary. One baby had birth asphyxia, and the other was born pre-term and had been admitted to the NBU for over a month. Workshops had to remain flexible in terms of the time available for each activity as there were tight time constraints, as documented in another study on participatory design in an LMIC (182).

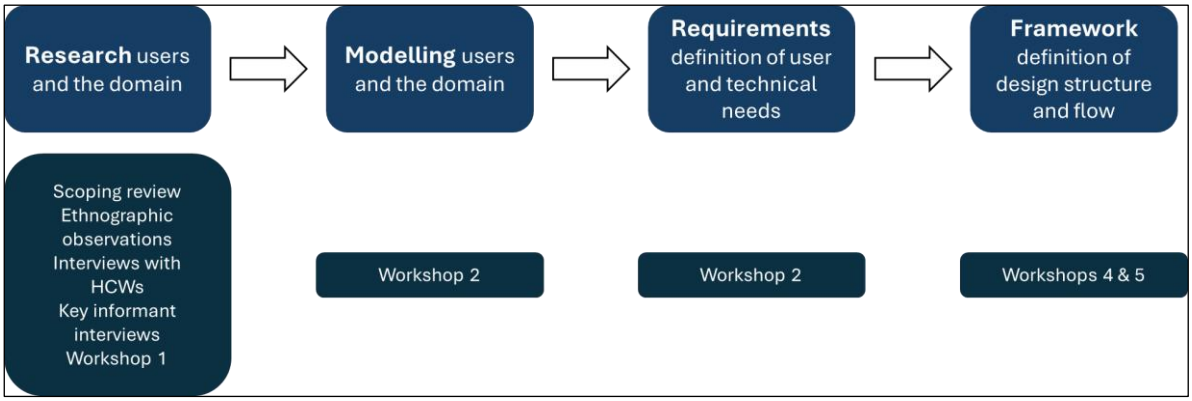

Figure 6: The adapted version of the goal-directed design process, including the methods used at each stage to re-design the discharge summary. Workshop 3 was excluded from this description as it was used to design the occupational therapy initial assessment tool with OTs.

Recruitment for Workshops

Healthcare workers for the first and second workshops were recruited from ongoing CIN workshops in Nairobi, but in workshops 3, 4 and 5 healthcare workers from Twiga were recruited for workshops in the hospital. Workshops were attached to ongoing meetings to reduce the time providers were away from their patients (189). Workshops 3 and 4 took place in Twiga and were conducted with healthcare workers and interns from the NBU/paediatric unit and the OT unit respectively. Workshop five was conducted with COIs and MOIs from Twiga, as these were the groups who would normally complete documentation. The workshops were enabled by building relationships with healthcare

providers over time and having support from the heads of the relevant departments. For example, the respective heads of department directed interns and staff to attend workshops 3, 4 and 5. Guides for the workshops are provided in **Appendix 6**.

Table 6: An overview of the focus of participatory workshops and attending participants.

Workshop	Focus	Date	Participants	Facilitators
1	Process map	6th May 2022	Nurses from: Twiga (3), Hospital 1 (3), Hospital 2 (3), Ndovu (3)	Gulraj, 2 HIGH-Q DPhil students, 2 senior HIGH-Q academics
2	Personas and context scenarios	22nd November 2022	Twiga: nurse in charge of NBU. Ndovu: 5 (OT, HRIO, nurse in charge NBU, paediatricians (2). Non-HIGH-Q hospital: 2 (nurse in charge NBU, paediatrician)	Gulraj, 2 RAs, Caroline (RA)
3	Designing the artefact	21st February 2023	Twiga: OTs (5); OT students (5)	Gulraj and Caroline (RA)
4	Designing the artefact	9th March 2023	Twiga: Paediatricians (3); MOIs (7); CO (2); clinical pharmacist (1)	Gulraj and Caroline (RA)
5	Testing the re-designed discharge summary	February 2024	Twiga: MOIs (7); COIs (10); nurses (4)	Gulraj and Caroline (RA)

Qualitative data management and analysis

Transcriptions for interviews and workshops were completed by a professional transcription service third party sourced by KWTRP. The audio files were de-identified, and then securely transferred for transcription and translation, where interviews were held in Kiswahili. To comply with KWTRP's data management policies, de-identified data shared with KWTRP was stored in secure servers with password-protected access. Data held on these servers is backed up in similar password protected mirror servers at another location within the KWTRP. Quality checks were conducted by Caroline, Nancy and me. Transcripts were typed on Microsoft Word and imported into NVivo (Version 12). Transcripts were labelled according to the hospital they were conducted, the interviewee (healthcare worker vs mother), date, name of interviewer and work package under the HIGH-Q program.

To ensure the resulting transcripts was secure we transferred our recordings to a shared OneDrive folder on the KWTRP server. Every six weeks our access to the folder was renewed via our Oxford single sign-on. As such, only the HIGH-Q team, including DPhils, had access to this data.

Qualitative Analysis

I started analysing data during my fieldwork, reviewing my observation notes and transcripts. Initial analyses were used to see which ideas and concepts I wanted to explore further during data collection and build a conceptualisation of how discharge and post-discharge care were organised, including the people and artefacts involved. My analysis was abductive (147), i.e., it switched between inductive and deductive analysis. I used reflexive thematic analysis (190) to analyse my data. I started by reading the transcripts and

observation notes to re-familiarise myself with the data. During my second reading I started to create codes and wrote notes about points I thought were interesting.

The next stage of analysis was more interpretive. I used the one sheet of paper (OSOP) method and wrote all my codes onto one piece of paper to better visualise how they might group together in broader themes (191). As I looked at the codes I generated and started thinking about grouping them into themes, I realised my findings fit into Haggerty et al.'s continuity of care typology (19) which I extended during my scoping review. As such, I coded the data to each of the continuity dimensions. After adopting this typology, I re-analysed the interviews, and observation notes to see if there was anything that had not been coded or did not fit into the typology and found that all the codes fit into the extended typology.

The findings from my qualitative analysis were also used during the first step of the GDD process, research, as shown in **Figure 6**.

Goal-Directed Design Analysis

The analysis of the workshop data followed the GDD process (178), as shown in **Figure 6** above. The research phase included the findings from the scoping review, ethnographic observations and interviews. The research phase created an understanding of discharge and post-discharge care, the people and artefacts involved, and the challenges faced.

The modelling phase involved analysing the results from the observations and interviews in the research phase, and the workshops, to create personas. Personas are a composite sketch of a person and not based on any one individual. I followed the eight-step process outlined by Cooper and shown in **Figure 7**. In step 1, I grouped the interview subjects by

role, i.e., COIs and paediatricians. In step 2, I identified behaviour variables by considering people's activities [what the "user" does and how frequently], attitudes [how the "user" thinks about the artefact domain and technology], aptitudes [What education or training the "user" has, and their ability to learn], motivation [why the "user" is engaged in the artefact domain] and skill ["user" abilities related to the artefact domain and technology]. In step 3 I mapped the healthcare providers I interacted with to the behavioural variables identified in step 2 using visual diagrams – most of the behaviours were discrete choices as opposed to a range. In step 4 I identified behavioural patterns based on the visuals. In step 5 I created goals and characteristics for my personas by synthesising the following details from my data:

- The behaviours themselves (activities *and* the motivations behind them)
- The use environment(s)
- Frustrations and pain points related to the behaviour using current solutions
- Demographics associated with the behaviour
- Skills, experience, or abilities relating to the behaviour
- Attitudes and emotions associated with the behaviour
- Relevant interactions with other people, artefacts, or services
- Alternate or competing ways of doing the same thing, especially analogue techniques

In step 6 I checked for any redundancies by going back to my data and seeing if there were any characteristics or goals that I had missed. In step 7 I assigned the roles of primary and secondary persona. Finally, in step 8 I used the previous steps to create a persona narrative,

which included most of my research in a succinct description of a typical day in the life of the persona.

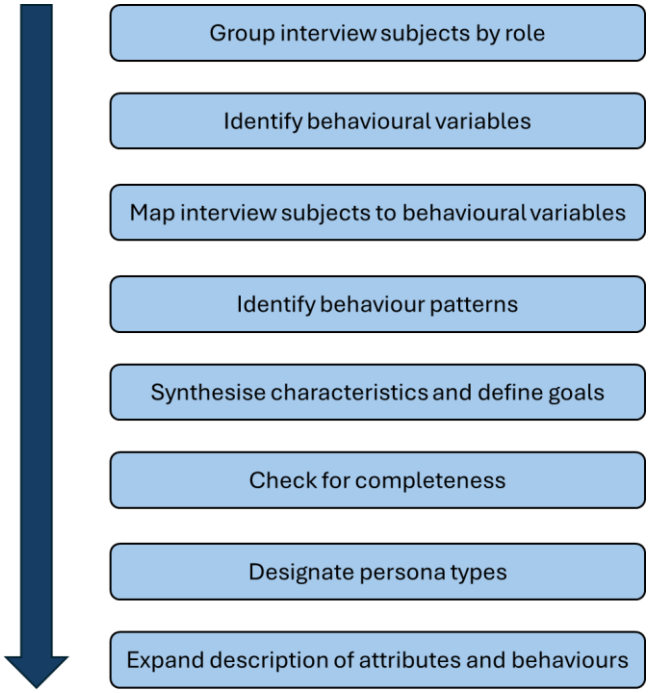

Figure 7: An overview of the persona creation process (178)

I designed context scenarios during the requirements phase, based on observations, interviews and the previously created personas. Defining requirements was a five-step process

1. Create problem and vision statements
2. Explore/brainstorm
3. Identify persona expectations
4. Construct context scenarios
5. Identify design requirements

Problem and vision statements direct the researcher. The problem statement defines the purpose of the research and reflects a situation which needs to be changed, and the vision statement is a high-level objective or mandate. Brainstorming requires a switch from understanding problems, to becoming solution oriented. All ideas should be considered,

and exploratory concepts can be shared with stakeholders for feedback. Persona expectations are about how the design of an artefact presents itself, and whether this aligns with the mental models of “users”. This stage of the process shows what the personas expect from the artefact, their desired experiences of using the artefact and how the personas think about the elements of the artefact. The scenarios consisted of a narrative describing the persona’s job and lifestyle and highlighting a typical day at work. The scenarios focused on how the newly designed artefact could help the persona achieve their goals, rather than representing behaviours around the artefact as they currently are. Context scenarios inform the design requirements the intervention needs to meet the personas’ goal and conclude with a sentence on what the persona is looking for from an intervention. Design requirements consider the data, functional and contextual requirements. Data requirements consist of the informational needs of the persona; functional requirements are the places where information must be displayed; contextual requirements consider the environment where the artefact is being used, and the skills and capabilities of the persona using the artefact.

The framework phase involved creation of a prototype of the intervention, in this case a paper-based artefact. Creation of the artefact was based on the previous GDD process and workshop four, where paediatricians, COIs and MOIs created mock discharge summaries, explained what information they needed and how best to display the information. The mock discharge summaries were synthesised to create a final prototype, which was tested with a group of COIs in workshop five.

Ethical considerations

Ethical approval for this study was obtained via approvals for the HIGH-Q programme, from the Oxford Tropical Research & Ethics Committee (OxTREC ref: 26-21) and the KEMRI Scientific and Ethics Review Unit (SERU) CGMR-C/229/4203. Further approval for the study was obtained from the National Commission for Science, Technology and Innovation (NACOSTI), Licence number NACOSTI/P/21/11580.

Debrief sessions were held fortnightly while conducting fieldwork and led by two experienced postdoctoral qualitative researchers from KWTRP. They used a framework based on previous experience of data collection to discuss ethical and operational challenges. The sessions aimed to identify issues that needed to be addressed immediately and what feedback to provide the hospitals. Each person conducting fieldwork would submit slides according to the framework, which included: a general update, operational challenges, things that were hard to watch but there was nothing to be done, things which required immediate intervention and things that should be fed back more generally to the hospitals.

Compensation of participants was discussed in the debrief sessions. Healthcare workers were compensated according to the KWTRP guidelines and were paid 650KES (£4) per interview and 1000KES (~£6.25) for workshops. However, for mothers we discussed whether compensation should be monetary or provision of goods. We decided to compensate mothers with a pack of 64 diapers worth 1400KES (~£8.75) due to KWTRP having concerns about staff safety if substantial cash was taken to the field. In addition, there may be unintended consequences related to gender in terms of who receives and decides how the money is used. Compensation is necessary as households are facing

economic difficulties and we are taking up their time for interviews, it would be unethical not to compensate them (174).

Another recurring dilemma related to healthcare workers' lack of time, as they were overburdened in the wards, an issue which has been previously documented in Kenyan hospitals (189). During the second round of data collection the paediatricians expressed annoyance when I came to the hospital and openly said they hoped I was not there for interviews. This interview fatigue has been documented previously (192), and given the long-term engagement during the HIGH-Q project this was navigated by trying not to overburden one particular hospital and using other DPhil students' interview data where possible. I navigated this challenge by opting to prioritise workshops with paediatricians and COIs in my second round of data collection as opposed to interviews, as I had access to interviews from other students.

The support we could give to the participants was a concern. During one interview where the family expressed frustration with their child's arduous journey, Caroline and I decided to call a senior researcher/paediatrician at KWTRP for advice. He advised the family to attend the referral hospital and said a colleague was expecting to see them; the family seemed visibly relieved. In a study on costs and coping with illness Molyneux, Goudge (174) noted that an RA intervened in a patient's care journey but did not document this as they did not think it was important; the authors highlighted that such information that arises in debriefs is valuable information rather than an RA "just assisting this person in his personal capacity".

Positionality and Reflexivity

Positionality is the researcher's position in relation to the sociocultural and political setting of the study, and how the researcher engages with the setting and the people within it (193). Reflexivity is a critical part of qualitative research and refers to how research is conducted and explains the way knowledge is generated (147, 193). In this section I discuss how my background impacted the way I conducted my research and analysis.

Using the definitions laid out by Adler and Adler (194) about the different forms participation can take when conducting research, I categorise myself as a peripheral member. While I was present in the various clinics and homes and empathetic to what was observed, I did not engage in any core activities of the people I was observing. However, even a "neutral" observer (one who is not aligned with a particular group within the organisation) cannot be unbiased, as my background and knowledge made me see things in a certain way (149).

During data collection it was clear that I was simultaneously an insider and an outsider. I am neither a healthcare worker nor a parent, and this would have labelled me as an "outsider", yet I also hold "insider" status by being Kenyan and having worked in healthcare research in Kenya for three years prior to the start of my DPhil. I disagree with the comments from Burgess that maintaining membership in the culture you are reared and establishing membership in the group you are studying makes you "alienated from both worlds" (194). I believe one can straddle the insider-outsider paradigm of two different settings without necessarily settling in either group, and that binary of in or out is unduly narrow (195). During this project I used my dual "insider/outsider" status to my advantage – my "insider" status made participants more relaxed. In addition, my grounding in the

Kenyan context made it easier to integrate into the hospitals for data collection, as I was familiar with how hospital care was organised and could understand cultural nuances. The "outsider" status allowed me to ask questions about the ways in which healthcare workers conduct their work, and the medicalised terminology they used on documents intended for dual use by healthcare workers and mothers. Healthcare workers and carers in the hospital often called me "*mzungu*" (white person) and would speak Kiswahili in front of me, unaware that I can understand the gist of conversations in Kiswahili. However, I am a Kenyan Indian who has only been educated in the British system, which further labelled me as an "outsider". This "outsider" status came with the assumption that I had power and influence over how the hospital operated. For example, healthcare providers would suggest changes such as extra staff or uniforms, which I had to clarify were outside of my control. This misconception may be aided by the HIGH-Q project itself, which was introduced to staff at the facility as a large study nested within a well-known University and well-known research organisation in Kenya.

My limited Kiswahili meant I needed an RA to conduct the interviews with mothers. She put the mothers at ease as she had recruited some of them, from the NBU or within the hospital. The mothers were comfortable with me sitting in to observe the interviews, and I understood most of the interview and could ask the RA to ask probes. Using a translator can provide challenges in terms of power dynamics and control of the research process (196). As mentioned earlier in the chapter, rather than controlling the use of an interpreter, I trusted Caroline as an "active interpreter" (176) as she had experience conducting qualitative interviews, was given an induction to the study, and so could ask relevant questions and probes outside of the interview guide. However, by having a basic understanding of Kiswahili I avoided being excluded from the interview, a key tension

highlighted by Pitchforth and Van Teijlingen (176). Though we did not explicitly discuss Caroline's positionality as suggested by Edwards (196), I was aware that the ethnicity of a RA can also influence data collection by whether the researcher is seen as an "insider" or an "outsider" (197). Her shared vernacular, being a mother, and the time she spent in the NBU during HIGH-Q were assets and made the mothers more comfortable and marked her as an "insider".

During data collection I tried to step back and analyse the various sources of data to create a coherent narrative. While speaking to healthcare professionals as an outsider, it was easy to take their word for how care was organised and the challenges faced. However, I had to go beyond what was said and interrogate some of the assumptions created by simply listening to the healthcare providers' stories, as their narrative was from their perspective. By asking probes, observing how care was provided in practice and consulting with clinicians in the KWTRP team I was able to build a more holistic idea of how care continuity was enacted, and the challenges faced by healthcare providers.

Chapter summary

In this chapter, I have described the overall design of my research, which was underpinned by an interpretivist paradigm. I used a scoping review to understand what interventions on care continuity had previously been implemented in resource constrained settings to answer my first research question. My second research question was addressed by using ethnographic observations and semi-structured interviews to understand the challenges faced by healthcare providers around providing care continuity post-discharge. My third research question was addressed using the GDD process, combining the qualitative research and participatory design workshops. I used reflexive thematic analysis for my

qualitative data in Chapter 3, and followed the steps outlined in the GDD process in Chapter 4. I describe my dual position as both an “insider” and “outsider” affected data collection, and some of the ethical considerations that arose during the project, such as participant’s compensation and time constraints on healthcare providers. In the following chapter I present the results of my scoping review.

This chapter draws on and expands on a scoping review that has been published. Sections on grey literature have been added to the chapter.

Publication: Grewal G, Fuller SS, Rababeh A, Maina M, English M, Paton C, Papoutsi C. Scoping review of interventions to improve continuity of post discharge care for newborns in LMICs. *BMJ Glob Health*. 2024;9(1):e012894. Published 2024 Jan 10. doi:10.1136/bmjgh-2023-012894

Chapter 3: Scoping Review Findings

Introduction

In previous chapters I provided the background literature informing this work, including my theoretical perspective, and presented the relevant context of postnatal and post-discharge care, both in LMICs and specifically in Kenya. In Chapter 2 I explained the methodological approach I followed, including this scoping review which followed the five-step method outline by Arksey and O'Malley (145) with the updated from Peters et al. (152) which included the PCC framework which was used to guide the inclusion and exclusion criteria. I searched seven databases (MEDLINE, CINAHL, Scopus, Web of Science, EMBASE, Cochrane library and (Ovid) Global health). I drew on relevant theoretical frameworks and classifications to assess the extent to which interventions adopted participatory methods and how they attempted to establish continuity, as described below and in Chapter 2.

This chapter provides the findings of the scoping review, i.e. the interventions and approaches that have been used in LMICs to improve care continuity for newborns, with a focus on the period after discharge from healthcare facilities. At first, I focused my scoping review on small and sick newborns, however, after an initial search I learned that were not

many papers focusing exclusively on this population, so I broadened the review to include all babies, with a view to draw relevant learning from a wider literature. I chose to conduct a scoping review as continuity of post-discharge care has not been well explored, and I wanted to be able to summarise findings from a range of studies and identify existing research gaps (145). Below I revisit some contextual information on post-discharge care to justify how I developed several secondary questions guiding the review, present findings related to my review questions and synthesise learning in the final discussion section.

I used the definition of continuity of care mentioned in the previous chapter, "the provision of coordinated care and services over time and across levels and disciplines, which is coherent with the patient's health needs and personal circumstances" (20). The review was informed by the continuity of care typology developed by Haggerty et al. (19), where care continuity is conceptualised as informational, management and relational, and I extended the typology by developing the concept of interpersonal continuity.

I used the participation framework by Vaughn and Jazquez (59) to categorise what type of participation the authors described in their studies, as described in Chapter 2. Participatory approaches involve engaging with the people who will ultimately interact with an intervention and have drawn interest in recent years. These approaches aim to form collaborations with stakeholders and participants as opposed to viewing participants as research subjects (59). While participatory approaches hold promise, it is worth noting that few published studies mention power and control, which can hinder the egalitarian principles participatory approaches are based on (198).

This scoping review aims to map and describe interventions and approaches that have been used in LMICs to improve care continuity for newborns, with a focus on the period after discharge from healthcare facilities.

To address this, I answered the following (overarching and secondary) review questions:

RQ1. What interventions, innovations or support mechanisms have been proposed to support continuity in post-discharge care for newborns in LMICs?

a. What are the different logics (premises or assumptions) that underpin interventions to establish continuity?
b. To what extent have participatory methods been used to develop these interventions?
c. What opportunities and challenges for improving continuity of newborn care within the period after birth have been identified in previous studies?

Results

Search results

Figure 8 outlines the process of searching and screening articles from academic databases and grey literature sources. Of the 2404 academic records that remained after deduplication, 65 met the inclusion criteria after a full-text review. Of the 195 reports retrieved from grey literature sources, 13 met the inclusion criteria.

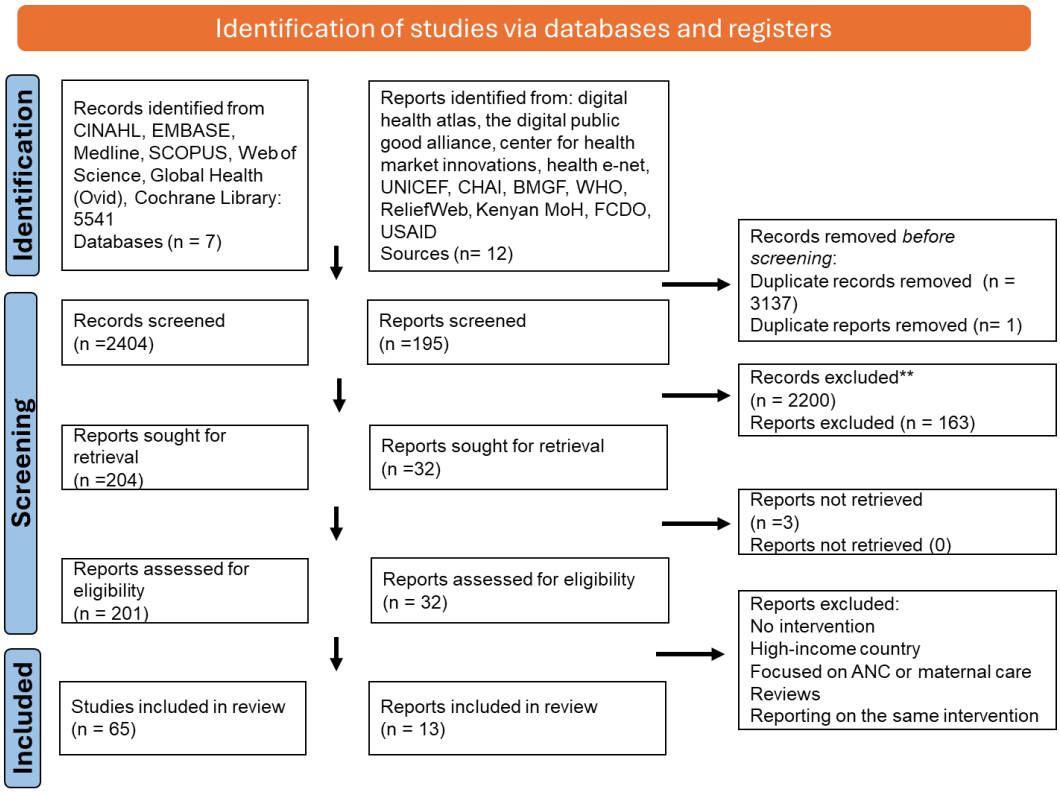

Figure 8: PRISMA (Preferred Reporting Items for Systematic Reviews and Meta -Analyses) chart demonstrating the sources of data selected for review.

Overview of the Studies Included

The following sections provide an overview of the studies included in the review. First, I provide a description of the interventions, and their characteristics as discussed in the articles, then I focus on how participatory approaches have been embedded in intervention design or delivery and next I specifically emphasise findings that relate to vulnerable babies. In the sections that follow I draw on the continuity of care typology (19) to explain with which continuity logics the interventions were most aligned, and how these interventions aimed to improve continuity of post-discharge care. The findings are separated into academic and grey literature in each section.

Interventions

More than half (56.9%) of the 65 interventions in the academic articles reviewed involved home visits from community health workers (CHWs), and a small number (4.6%) involved home visits from midwives (199-201). About 20% of all studies (18.5%) focused on newborn care education during home visits, such as informing mothers about danger signs, care-seeking and thermal care (201-212). A further fifth (18.5%) of studies focused on providing community-based newborn care during home visits, which could include administration of antibiotics or resuscitation, management of newborns or referrals to care (202, 213-223). Nine interventions (13.8%) involved group-based activities such as plan-do-study-act (PDSA) or participatory action cycles. (224-232). Seven studies (10.8%) included healthcare worker training as an intervention (233-239);

Most of the 65 interventions (56.9%) involved CHWs. Other healthcare workers such as doctors, nurses and midwives, were involved in seventeen studies (26.1%) (6, 200, 201, 233-237, 239-246), and eight studies (12.3%) involved facilitators who were locally recruited and trained (224, 225, 227, 228, 230-232, 245).

About a third of academic studies (36.9%) targeted pregnant women (224, 225, 227, 228, 230-232, 245), and another third focused on mothers of term babies (35.3%) (202, 207, 209, 211, 218, 219, 223, 225, 229, 245-255). 36 studies (55.4%) aimed to modify behaviours that contribute towards reducing neonatal mortality, such as breastfeeding and KMC (199, 201-203, 205, 207-210, 212, 218, 221, 226, 229, 233-239, 241, 243-249, 251, 254, 256-260). 15 studies (23.1%) explicitly targeted neonatal mortality as an outcome (204, 211, 213-217, 223, 225, 232, 252, 253, 255, 261, 262) and four studies (6.2%) targeted both neonatal mortality and behaviours that contribute towards reducing neonatal mortality (206, 222,

227, 231). Ten studies (15.4%) focused on the implementation process itself (200, 219, 220, 224, 228, 230, 240, 242, 263, 264).

In contrast, about half of the interventions in the grey literature included an mHealth component (7/13 50%) (265-271). The mHealth component included an app for CHWs to report on care continuity (271) or to communicate with each other (270), pre-composed messages and communication with an AI help-desk (272) or with a healthcare provider (265), tracking and measuring feeding of vulnerable newborns in real-time (266), women sharing audio information about maternal and newborn health with each other (267), and a mobile channel providing information to mothers via edutainment (269). Four studies included home visits; two studies included home visits with CHWs (273, 274), one study included home visits with nurses using an MNCH app to access diagnostic tools and communicate with each other (270) and another included home visits and follow-up reminders via text messages and phone calls (275). One program included one-to-one and peer counselling (276), and another was a peer-support group on EBF (277).

Most grey literature interventions targeted mothers, with four focusing purely on mothers (267, 269, 272, 277), two on mothers and healthcare workers (265, 266) and two on mothers and their families, such as husbands and mothers-in-law (268, 276). Four interventions targeted CHWs (270, 271, 273, 274) and one targeted healthcare providers (275).

Participatory studies

Of all academic studies, 16.9% (11/65) were defined by study authors as participatory (**Appendix 7**), and 3.1% (2/65) were not defined as participatory, but used participatory elements in intervention design to different degrees, for example, consulting with key stakeholders, such as district health management, before implementing KMC interventions and essential newborn care (205). Participatory learning and action cycles were used most to facilitate participation (6/11; 54.5%) (226-228, 230-232), with only two studies (2/11; 18.2%) using PDSA cycles (224, 225). The participatory learning and action cycle activities led to interventions such as disseminating information via counselling women in their homes or in community centres (224), bicycle ambulances (225) and health education on postnatal care (224, 225). A small number of studies (2/11; 18.2%) focused on community mobilisation (226, 229).

Stakeholder participation varied: six of the 11 studies defined by authors as participatory (54.5%) included women from villages where the intervention was taking place, i.e., pregnant women, recently delivered women or women of reproductive age (225, 227-232). A few studies (3/11; 27.2%) involved representatives from the community such as CHWs, teachers and community leaders without always including women from the community (222, 224, 226). Using the classification by Vaughn and Jacquez (59), we found that seven studies aimed to 'empower' participants by engaging with them to define local problems, coming up with solutions, implementing them and evaluating whether they were effective (224, 225, 227, 228, 230-232). Two studies aimed to 'inform' participants via online social networks about breastfeeding (256) and community health education about danger signs via women's groups, farmers groups and village coordination committees (229). Two

studies aimed to 'involve' participants, one by designing a behaviour change intervention via input from participants on current newborn care practices, designing behaviour change messaging, optimising available resources and providing viable alternatives (222). Another study set up community support groups to implement activities supporting postnatal care, neonatal care counselling and referrals (226).

Only one of the grey literature reports mentioned using a participatory approach (275). The authors described a design workshop which included government facility providers and relevant national stakeholders to develop the implementation strategy. As such, this study aimed to 'involve' participants, as they helped plan the implementation but were not involved in defining the problem or coming up with solutions.

Small or sick babies only

In the academic literature, only eight studies (12.3%) exclusively targeted mothers of babies who were high risk i.e., low birthweight (LBW) or pre-term (200, 213, 215, 238, 239, 242, 260, 262). These studies focused on home visits post-discharge by CHWs (200, 213, 215), KMC exclusively (239, 262), KMC and breastfeeding (238), telemonitoring high-risk neonates (242)and breastfeeding peer counselling (260).

From the grey literature only two reports focused exclusively on small and sick babies. One of these described a program that focused on improving post-discharge follow-up of babies discharged from the NBU, with a specific component on those who needed KMC, including phone calls and text reminders (275). The other report described a program which

conducted data collection and visualisation of the breastfeeding of vulnerable babies so healthcare workers and mothers could adapt their feeding practices in real-time (266).

Continuity logics

We viewed each of the interventions as underpinned by specific assumptions (implicitly or explicitly) in terms of how to establish the conditions necessary for improving continuity of care for newborns in the community. Some interventions were underpinned by multiple, overlapping continuity logics. Looking at the most dominant logic from each paper, most interventions from the academic literature (53/65; 81.5%) targeted informational continuity, followed by relational continuity (33/65; 50.8%), the new category of interpersonal continuity (24/65; 36.3%) and management continuity (15/65; 23.1%).

Most interventions from the grey literature targeted informational continuity (8/14; 57.1%), followed by management continuity (5/14; 35.7%), interpersonal continuity (5/14; 35.7%), and relational continuity (2/14; 14.3%). Results are presented under each of these categories below, for both academic and grey literature.

Informational continuity

Informational continuity refers to information being shared and used appropriately, which includes considering patient preferences, values and context, as well as medical records (19). This approach to organising care was the most dominant, used in 81.5% of studies (53/65). Informational continuity was evident in interventions that focused on sharing information via education sessions between CHWs, who had received training, and the community (23/53; 43.4%). The interventions attempted to improve neonatal outcomes by increasing knowledge on essential newborn care (209, 213, 216, 222, 228, 229, 231, 258), danger signs (214, 219), exclusive breastfeeding (EBF), KMC (239, 244, 251, 262), the importance of postnatal visits (243) and providing referrals to care (217, 220, 221, 252),

which could include referral cards which mothers were encouraged to take to each visit (220, 221).

In the grey literature an informational continuity logic mostly underpinned information sharing interventions with mothers via mHealth, which could include messages on newborn care (268), such as generic messaging that was pre-composed based on the gestation or age of the baby, and dialogue with a healthcare worker (265) or AI help-desk (272), a mobile phone channel providing information to women (269), or using social networks to encourage mothers to share audio information with other mothers (267). Other interventions focused on informational continuity used counselling, either one-to-one and group lactation and nutrition counselling (276) or at discharge from the NBU (275). The interventions tried to improve neonatal outcomes by improving tracking of small and sick newborns (266), equipping mothers with information (265, 267, 269, 272) and encouraging mothers to seek care at the right place and time (265, 272).

Opportunities

Interventions underpinned primarily by an informational logic intended to improve the way information was shared, and studies reported they were more accepted in regions where CHWs were well established. Publications reported information sharing was easier because the community trusted CHWs and the content of the health messages they delivered (209, 217, 219, 248). Information sharing was also reportedly improved by these interventions in settings where seeking care at facilities, for example for deliveries or postnatal care, was uncommon (213, 214, 216, 217, 222, 228, 231, 239, 251). Publications reported information sharing was easier because home visits provided information to families where previously they would have received nothing.

Challenges

Sharing information was less easy in circumstances with patriarchal gender norms because men or mothers-in-law were considered the custodians of women's access to health (228, 229, 251, 258). However, two studies focused their education sessions on men, with the aim of increasing their knowledge and improving their decision-making ability (258) or improving healthy behaviours and communication between couples (243).

Relational continuity

Relational continuity refers to the ongoing relationship between a patient and one or more provider, with the understanding that consistency of core staff can provide a sense of coherence (19). This approach to organising care was evident in interventions that focused on repeated interactions (13/33; 39.4%), i.e., home visits by care providers (200, 209, 213, 215, 216, 219, 221, 222, 234, 239, 248, 251, 262) because they attempted to build trust with families and improve access to care for communities who would not otherwise receive a post-discharge follow-up.

In the grey literature interventions promoting relational continuity focused on communication between mothers and facilities and having CHWs conduct home visits (274, 275). This approach improved contacts between communities and the health system and encouraged referrals to care where required.

Opportunities

These interventions intended to improve the patient-provider relationship and it was reported they were easier to implement in communities where there was greater acceptance of CHWs as they were carefully selected from and resided within the community (209, 213). Some studies reported that the patient-provider relationship was

improved by home visits by CHWs, as these communities reported a common practice of confining mothers and babies at home for 4-6 weeks after delivery, which is the period when babies are most likely to experience issues (222, 262).

Challenges

However, it was difficult to improve the patient-provider relationship in communities that faced difficulties physically accessing facilities due to geographical barriers such as mountains (215), distance to the facility (221) and weak transport links (251, 264). Relational continuity was also disrupted by women returning to their parental home for delivery, which may be far from their antenatal care facility (231).

Interpersonal continuity

Interpersonal continuity refers to relationships between family members, between healthcare workers or relationships within the wider community. Building these relationships outside of the "patient-provider" dyad can foster support systems and lead to improvements in care. This approach to organising care was evident in interventions that focused on healthcare workers working together (2/24; 8.3%) because they attempted to improve communication between different cadres of staff (217, 219). Interpersonal continuity was seen in interventions that used CHWs to foster supportive relationships within families (7/24; 29.2%) to promote gender equity via shared household chores (234), supportive relationships from husbands (199, 258) and joint decision making between couples (243). Interpersonal continuity was encouraged by interventions which involved community mobilisation (8/24; 33.3%), which aimed to improve discussions within the wider community on localised issues related to maternal and newborn health (214, 216, 224, 228-230, 239, 256).

In the grey literature creating interpersonal continuity was shown in interventions that increased community engagement, improved interdepartmental communication (275), encouraged women to share information within their community (267), encouraged nurses to communicate with each other via an MNCH app (270) and an EBF peer support group (277).

Opportunities

More participatory than non-participatory studies reported improvements among interpersonal relationships within the community, though this was only evident in studies that involved communities, as opposed to a focus on key stakeholders only. Improving relationships within the community via participatory methods was easier as facilitators were selected from the community to guide contextual intervention creation, and members of the community who were part of the intervention would often help those who were not (228, 230).

Challenges

Although these interventions intended to improve interpersonal relationships, findings show that they were less able to do so in communities with patriarchal cultures. This was reportedly due to women's low levels of education and perceived low social standing (229), women's access to health being gatekept by men (and therefore often not prioritised) (258) and sociocultural norms against women seeking care (231).

Management continuity

Management continuity refers to managing an illness in a consistent and coherent manner, which is particularly important when there are multiple care providers and there is a need

for complementary and timely provision of care (19). This approach to organising care was evident in interventions that focused on introducing algorithms for CHWs based on national or WHO guidelines on when to treat or refer sick newborns (214, 220, 252) or introducing protocols on the management of illness for healthcare workers (217, 219, 264) (6/15; 40.0%). These interventions attempted to standardise and make consistent the care that newborns would receive.

In the grey literature interventions focused on management continuity by improving referral networks and provider capacity (278), changing the post-discharge and follow-up processes (275), giving CHWs an mHealth app to track post-discharge visits (271) or that included diagnostic aids (270) and training CHWs to recognise symptoms and provide care (273).

Opportunities

Although these interventions intended to improve the way illnesses were managed, publications reported they were high rates of acceptance in circumstances where relationships had been previously built with the community because CHWs had been well-established in the community for over 20 years (213). An example of ready acceptance is the community appreciating the care received by CHWs, expressed via provision of gifts, lifts or money (219). In addition, interventions were reported to be easier to implement when researchers had been collecting data and running programs for years (252).

Challenges

There were no challenges associated with management continuity reported in the publications.

Discussion

This review aimed to map and describe interventions used in LMICs to improve continuity of care for newborns by examining: which interventions have been used; to what extent participatory methods were employed to develop these interventions; how interventions attempted to establish continuity (i.e., through what logics and assumptions); and what opportunities and challenges they encountered. Home visits were the most common intervention and usually focused on providing education for mothers or community-based care for newborns. Other reviews have also recognised the importance of community-based care (279, 280) and CHWs as a valuable resource that need to be empowered and integrated into health systems to help reduce neonatal death (281). Most interventions targeted pregnant women; however, one study suggested the optimal time to begin the continuum of care is pre-pregnancy (282).

In my analysis I used the continuity typology by Haggerty et al. (19) which distinguishes between three types of continuity logics (informational, relational and managerial). The literature on post-discharge care emphasised informational continuity more by focusing on information flow between the health system and carers i.e., education of mothers and families via CHWs. Although the Haggerty et al. typology covers relational continuity in terms of patient-provider relationship, this does not extend to relationships between healthcare workers, family members and mothers and the wider community. These relationships may impact continuity of care in LMICs, where men and mothers-in-law often have the final say in care-seeking (228, 229, 251, 258). Recently literature has focused on people outside the mother-child dyad, with growing recognition that including men is important (283, 284). Involving men in postnatal care is recommended by the WHO (285)

and can help tackle stereotypical gender norms (286). Therefore, I have extended the continuity typology by adding interpersonal continuity as a new category to emphasize that newborn care involves multiple complex relationships which need to be supported. Although a previous typology on continuity of care also recognises the importance of co-ordination between healthcare workers (20), the importance of family and community members in decision-making and care-seeking has been less explored.

The grey literature included more interventions with a digital component, which is expected given the nature of the start-up and non-governmental organisation (NGO) sector in Kenya. While technological innovations in maternal and newborn health have received much attention in the last few decades, they have produced mixed results, and there is limited evidence on the use of information and communication technology in neonatal health (287). Text message interventions have proven to be effective reminders for other illnesses, such as getting healthcare workers to follow malaria guidelines (121) and bi-directional messages for adherence to HIV medication (288) (289). One study highlighted that the bi-directional texting was meant to enhance the patient-provider relationship and build trust (289), a feature which would improve relational continuity for post-discharge care. One review on treatment adherence for non-communicable and communicable diseases highlighted that combining more than one mHealth tool is the most effective way of making the intervention more interactive, for example, combining short message service (SMS) and interactive voice response (IVR) (290). Most studies showed text messages improve adherence, and these improved with personalised messages, tailored messages and bidirectional messages, as opposed to daily messages (291). However, adherence to medication cannot be conflated with continuity of care for babies born small or sick who may have complex conditions.

Technological innovations also need to be careful not to widen the access/inequality gap by serving a select few and leaving out those in most need (292). For example, most eHealth and mHealth studies are conducted in urban settings rather than underserved counties in Kenya; in addition, interventions are often donor or aid funded, and as such do not integrate into the public health system (121). It is also important to note that people are likely to resist technology that is viewed as inadequate or interferes with their values, aspirations or role (293). As such, participatory approaches are key in creating technologies that aid those on the frontline, rather than hindering them.

In the participatory studies included in the review, the level of participant engagement varied, and it was not always clearly described, with the lowest level of engagement focusing on how to "inform" i.e., provide information to participants. Studies need to provide more detail on participant engagement and its role in study design and co-production of interventions. Across the academic and grey literature, detailed information for replicability is lacking, such as how specific interventions were developed by groups (231, 232) and participatory involvement processes were not well described (222, 229). These findings echo the call for future research papers to adequately describe the process of using participatory approaches for research, especially in LMICs (294).

This scoping review considers how different continuity interventions may best meet needs in specific context(s) and what assumptions need to underpin these interventions. For example, home visits were the most popular intervention in the literature, but best outcomes were achieved in contexts where CHWs were well established and trusted within the community (i.e., using informational and interpersonal continuity logics). In addition, some interventions faced challenges with implementation in contexts with patriarchal

gender norms, hence more effort may be required for community engagement or interventions should be designed to include male-identifying community members in these settings.

The academic and grey literature included in this review highlights the paucity of studies in LMICs focusing exclusively on small and sick babies, despite this group disproportionately contributing to neonatal mortality (295). Some studies suggest focusing on babies at higher risk post discharge to improve outcomes (1, 79) and to be cost-effective (296). Further research is required on how to develop interventions to specifically meet continuity needs of high-risk newborns. Continuity of care can be examined from the perspective of healthcare providers or mothers, and I opted to focus on healthcare providers as this perspective was lacking in the literature. I used qualitative methods to develop a deep understanding of the context in which care is provided, as described in Chapter 2. I used participatory design to develop an artefact with the healthcare providers to ensure their needs were met, as described in Chapter 5.

In the next chapter I present and discuss the findings from my qualitative research, which aimed to provide insights on the context of discharge and post-discharge care for babies born small or sick, and the challenges with provision of continuous care.

Chapter 4: Post-Discharge Care Continuity

Introduction

In Chapter 3 I highlighted what interventions and mechanisms have previously been described in the literature to improve care continuity in LMICs, with informational continuity between healthcare providers and mothers being the focus of most interventions. The chapter also highlighted the importance of interpersonal relationships in fostering continuity of care. These relationships include those between family members, between healthcare workers or between people within the community.

In this chapter I describe the different ways in which continuity became disrupted, or sustained, in the post-discharge care of babies born small or sick in Kenya. My analysis was guided by the following overarching and secondary research questions:

RQ2. What continuity challenges do healthcare providers encounter when providing post-discharge care for babies born small or sick in Kenya?

a. How is post-discharge care (including discharge processes) organised and delivered?
b. What disruptions to care continuity influence the post-discharge journeys of small and sick babies?
c. What sociomaterial practices are involved in enacting post-discharge continuity?

In my analysis of qualitative data for this chapter, I applied the continuity of care typology by Haggerty et al. (19) with the additional facet of interpersonal continuity developed in

Chapter 3. In addition, I drew on sociomateriality as a novel lens for conceptualising care continuity post-discharge from a hospital in an LMIC (as explained in Chapter 1). Previous studies using a sociomaterial lens to examine continuity of care have focused on care received within hospitals alone, such as examining how e-records affect workflows within a hospital in Saudi Arabia (38), exploring the influence of sociomateriality on how interprofessional collaboration is affected in an inpatient unit in Canada (37) and how coordination of medication review in a hospital in Sweden is connected to the artefacts involved (43). All these examples are from high-income settings, and the technological artefacts they focus on are not commonly used in Kenya, or other LMIC settings. As such, I used a sociomaterial lens to explore how continuity of post-discharge care in Kenya is enacted.

I open the chapter with two striking stories of mothers seeking post-discharge care for their babies - these stories illustrate the complexity of their journeys, indicate how families are affected and help set the scene for the analysis of continuity challenges from the perspective of healthcare workers which is the focus of the chapter. Next, I provide an overview of how NBU discharges and follow-up processes were organised in the two hospitals where I carried out my research. Drawing on a sociomaterial lens alongside the expanded continuity of care typology, I then set out my analysis of data from interviews and observations of care provision in different wards in each of the hospitals. I argue for an understanding of post-discharge care continuity as a sociomaterial practice, to place more emphasis on the complex interactions between human factors and non-human artefacts, institutional norms and established ways of organising that lead to communication and co-ordination between healthcare workers being becoming a major challenge. In addition, I highlight how disruptions in one type of continuity affect other types of continuity,

demonstrating that there are no straightforward solutions to the challenge of establishing good post-discharge care.

Results

In this section I describe the results of my qualitative analysis, drawing on 180 hours of observations, 19 interviews with healthcare workers, three interviews with key informants, and two workshops with healthcare providers. To supplement my understanding, I also conducted 18 interviews with mothers, including two mothers who were followed up via phone call after interview. Further details on the methods used are provided in Chapter 2.

Stories to Illustrate Disruptions to Care Continuity

To provide some context for my secondary research questions (see b and c above), I have compiled two stories from the perspective of the families looking after and seeking care for their sick babies. In these stories I draw on data from interviews with mothers, observations in their homes and follow-up phone calls. Field notes have been italicised. All names are fictional, and facilities have been anonymised.

Both stories illustrate the effects of care continuity breakdowns on the baby and family. The stories emphasise that the facilitator of care continuity is the carer themselves, which is often the mother. Mothers attend the various follow-up appointments, feed and monitor the baby, and provide home-based care. As such, mothers have a crucial role in the accomplishment of care continuity. Although Chapter 3 described interventions with CHWs as common, both mothers, and all the other mothers interviewed, did not report interacting with a CHW once they were discharged to the community.

James

James was three months old when we interviewed his family.

[October, 2022] We visited baby James' home, located about half an hour from town. James' parents live on a shared compound with the rest of his father's family. During the interview James' mother, father, paternal grandparents, uncle and aunt were present. I gather that James' family is relatively comfortable financially compared to the other homes we visited given the assets on the compound.

Figure 9 illustrates James' journey. James' parents said he was referred at birth from a health centre to a public level 6 referral hospital in the county with breathing difficulties. His parents said they understood the referral, as they noticed James had challenges. Two weeks later James attended a follow-up at the same hospital. During the interview we saw the documents his parents were given. *The discharge summary shows he was admitted in the NBU for nine days. During the interview, James' parents said they were not sure what was written on this discharge summary. The terms written were medicalised and barely legible, the only thing I could make out was the return date for the follow-up appointment.*

James' mother said two weeks later they went to an outpatient clinic at a health centre where James was hardly examined and prescribed basic medication. They were told James may have epilepsy and a stomach issue. The issue persisted, and James continued convulsing; a week later the family contacted a family friend who is a doctor, who recommended going to Ndovu. James was seen by a paediatrician who examined him and said he had to be admitted, the discharge summary from the level 6 facility corroborates this. *The discharge summary showed that James was admitted for three and a half weeks, though the discharge summary from Ndovu had a date of birth that did not match with the*

discharge summary from the level 6 facility, illustrating a break in informational continuity. The family felt that if the health centre had examined James properly and referred him, an admission may have been avoided. James' mother said that period was difficult, as James looked shocked whenever he convulsed and was not breathing comfortably. *The conditions written on the discharge summary from Ndovu were convulsive disorder and meningitis.* However, James' father said lab tests for meningitis were negative, and he did not know what James was being treated for. According to James' parents, X-Rays, blood tests and a CT scan during admission to the paediatric ward did not reveal that anything was wrong. His parents said doctors told them James had Meconium Aspiration Syndrome, resulting in convulsions. While at home, they gave the recommended anti-convulsant medication and two weeks later they returned for POPC, where I recruited them. The family reached out to their family friend again to understand James' diagnosis and medication, demonstrating another break in informational continuity.

"You would know that I am suffering from Malaria or another disease, but with James we don't even know, we still don't know but he is still taking medicine." ***James' Mother***

During the interview James was still convulsing. His parents said they had a POPC appointment at Ndovu in six weeks but felt this was a long wait given James' condition. *During our home visit we saw that the family kept a notebook documenting the date and duration of his convulsions. It was unclear if this was recommended, or their choice.* During the first follow-up phone call [February, 2023], we learned that James was readmitted to the paediatric unit in Ndovu. His mother said no tests were done, but he was given tuberculosis medication. James was discharged home, but was then admitted to a different facility, where his fever went down but his convulsions continued. A week after being

discharged he was readmitted to the same facility; his mother said the doctors said James had an eye issue linked to his brain issues and recommended an MRI. His parents tried to get National Health Insurance Fund (NHIF) coverage, but insurance was needed for a year before making a claim. Instead, they raised the money and were planning on going to the national referral hospital. James' mother was exhausted by the constant hospital visits, and the family were facing financial difficulties.

During the second follow-up phone call [June, 2023] James' mother said he was better. He had gotten the MRI, and a doctor told them that James' brain was shrinking, hence the convulsions, and that he would develop slower than other babies. James' mother was happy to finally have a diagnosis. A friend introduced her to a facility that provides free therapy and support tools, which James received. However, during a follow-up appointment James was readmitted, and the doctors recommended an echocardiogram.

At the point of last contact [September, 2023], James' mother called Caroline (research assistant) to give an update. At this time, he was 14 months of age. She was trying to raise money for an echocardiogram. She had moved to her mother's house as James' father was no longer in the picture. James' mother felt this was due to interference from his family.

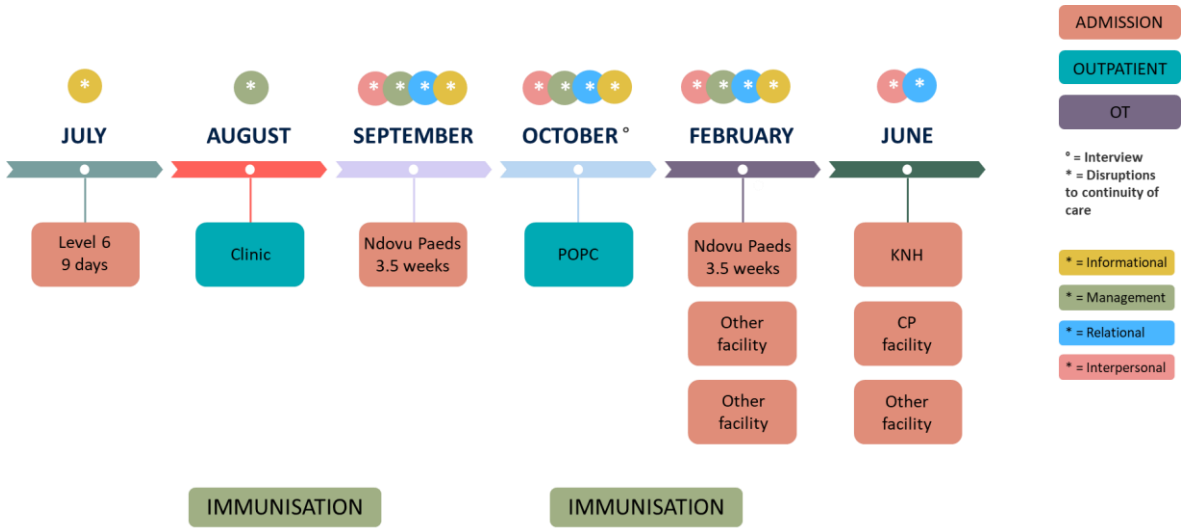

Figure 9: James' post-discharge journey. The abbreviations stand for: paediatric outpatient clinic (POPC), Kenyatta National Hospital (KNH) and cerebral palsy (CP)

Michael

We estimated Michael was around three months old when we conducted the interview. **Figure 10** illustrates Michael's post-discharge care journey. Caroline recruited Michael's mother from the NBU in Twiga, where he stayed for a long time due to severe birth asphyxia, which distressed Michael's mother. *It is unclear how long Michael spent in the NBU as his discharge summary was missing both the dates of admission and discharge, which affected informational continuity.* Michael's mother felt guilty about his illness, as her other two children were healthy.

"… having a baby is a blessing, every parent loves to get a baby and leave with the baby to go home while it is healthy. When I entered NBU, it was a challenge because it was something I had never heard of... I would never have known that someone could not be able to breathe." ***Michael's mother***

We interviewed Michael's mother after a hospital appointment in December 2022. She said during the first six months of Michael's life she could not afford formula milk and gave

Michael diluted baby cow's milk to help with weight gain, indicating financial distress. Michael's discharge summary cited his conditions as BA and Erbs Palsy. Michael was likely born in September 2022. Michael's first POPC visit was scheduled for 27th September, but he was admitted to the paediatric ward on 23rd September and discharged on October 1st. *The discharge summary from the paediatric ward says he had neonatal sepsis.* However, Michael's mother said she did not understand the doctor's explanation. She found the doctors rude, and the ward dirty.

"…the doctors… should know how to communicate well. There is no one that asks to be sick… But you find that when you go there, someone talks to you like you wanted that disease." ***Michael's mother***

Six days after discharge from the paediatric unit Michael had an OT session at Twiga. *Based on Michael's outpatient card, we can see that Michael's mother attended all the recommended OT appointments*, before asking for a referral to another OT clinic due to challenges with relational continuity. She said she told the OTs it was due to the distance to the clinic. However, Michael's mother told us during the interview that she was unhappy that interns were conducting therapy unsupervised, Michael was given the same therapy each week, and she was not taught new home therapies. She also did not want to pay for the outpatient card as nothing was written on it.

Michael's mother said she found therapy expensive, as she had to pay for transport and oil for massages, but she was focused on making Michael well. She described caring for him as a full-time job, and she could not leave him alone. She wanted someone to explain why Michael cried so much and what his future held, another disruption to informational continuity.

During the first follow-up call with our research team [February, 2023], we learned that Michael had attended another OT clinic, and his mother was happy that qualified OTs provided therapy, and the same therapists were present each time. She recorded a video of a new therapy she thought was beneficial and used it, showing improved management continuity. During the second follow-up call in June, Michael was able to swallow food which made her happy. A friend recommended another different OT clinic. She planned to take him to therapy sessions in both facilities. In September, Michael's mother contacted Caroline. She had moved out of the family home, as Michael's father was no longer in the picture, and now struggled with transport costs to the OT clinics.

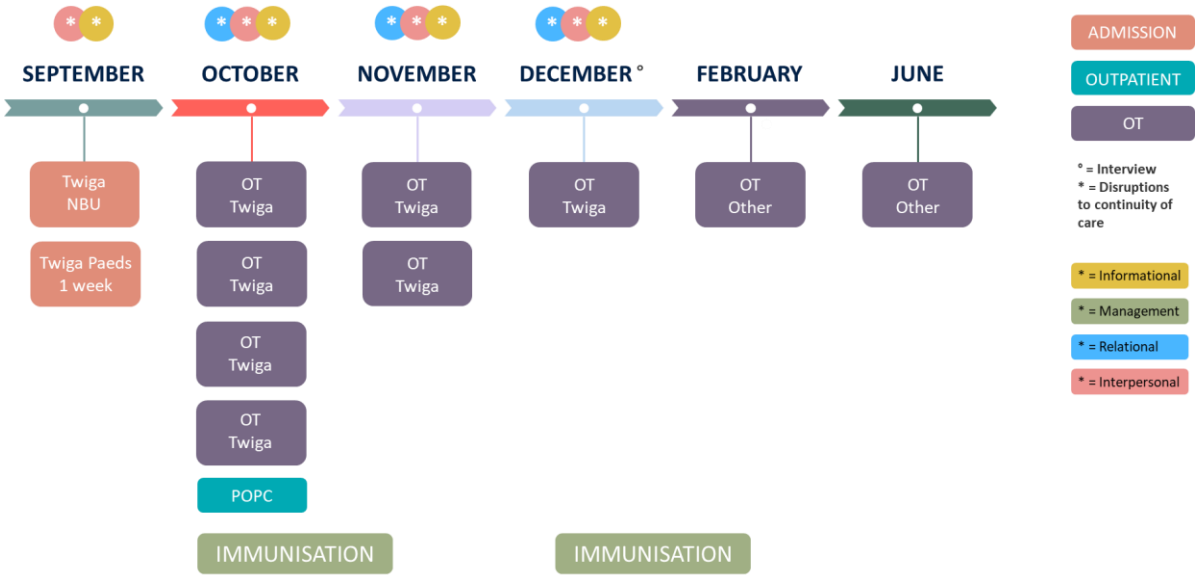

Figure 10: Michael's post-discharge journey. OT stands for occupational therapy.

In both cases, carers were distressed by being unsure about the condition of their baby, reflecting breaks in informational continuity between healthcare providers and carers. In both cases the artefacts used to document provision of care were poorly utilised leading to

disruptions in post-discharge care continutiy; James' documents had conflicting dates of births, and dates for Michael's admission and discharge were missing. The documentation issues clash with the protocols from the Ministry of Health (MoH), which state that accurate, standardised medical records should be available (297).

James saw multiple different healthcare providers at different facilities, which disrupted relational continuity. Combined with poor use of documentation artefacts this affected management continuity i.e., the consistency and coherence of care provided, as new healthcare providers did not have a clear history of James' condition. Michael's mother was happy with his treatment when he was seeing the same OT, as this built relational continuity and they were aware of his condition and could provide different forms of therapy, ensuring management continuity. Interpersonal continuity was disrupted for both cases due to financial constraints and the mothers becoming single parents.

These stories emphasised how taking a sociomaterial approach to post-discharge care continuity of would enable a broader understanding of the multiple social and material elements that are enacted in order to achieve continuity.

The Discharge Process

Having illustrated the discontinuities from the perspective of the families, and the effects this has on the babies and families, I will now discuss my observations in healthcare settings. Understanding discontinuities from the perspective of families helped me contextualise my findings with healthcare providers. The following description of the discharge process from NBUs is based on my ethnographic observations and informal conversations with healthcare providers in the two hospitals where I conducted my research. I focused on the discharge process, as good discharge was crucial for mothers to

understand what care was needed, and for artefacts such as the discharge summary to be completed. This affected what information was available at follow-up. Based on my observations and interviews a baby could only be discharged from the NBU after the clinical team (paediatricians, MOIs, nurses and nutritionist) decided that a baby was well enough to leave the hospital. I found and compared the national guidelines produced by the MoH in Kenya for when a baby can be discharged (297) with the observed discharge process. Discharge criteria in these guidelines include a completed discharge summary including the baby's weight at discharge; home care being considered safe; carers receiving a comprehensive management plan and being competent in the care of their newborn; the carer being counselled on breastfeeding practices, appropriate sunlight exposure and how to recognize danger signs in a sick newborn (297). The guidelines state every small and sick newborn needs to have a complete, accurate, standardised, up-to-date medical record, which is accessible throughout their care, i.e. follow-up (297). However, documentation was an issue. Paediatricians also highlighted that the guidelines could be adapted by individual hospitals. For example, the guidelines say that a baby must weigh a minimum of 1800g before discharge, however, in Twiga a paediatrician explained that they opted to increase this to 2000g after noticing readmissions of many pre-term babies.

Nurses said they could override a discharge directive if they felt the baby's condition had deteriorated since the discharge notice was given, or if they thought the baby required further monitoring. The nurse said they would write a note in the NBU file and discuss it with the paediatrician, medical officer or MOI during their next ward round. The NBU file was used by nurses, clinicians and OTs to document the care provided during NBU admission and communicate with each other via written documentation.

The discharge summary was one material artefact in an assemblage of tools that aimed to enact care continuity. The discharge summary was a single A4 sheet of paper with one side requiring information to be filled in, as shown in **Figure 11.** The form shaped and constrained the way information was entered via the domains and spaces available for information. A copy of this summary was given to mothers at discharge, and a copy was kept in the NBU file. Paediatricians told me during a workshop that the form must be one page due to how it was photocopied and attached to the NBU files. The discharge summary was the only document with space for the file number (IP number), which was used to retrieve the file at paediatric outpatient clinic (POPC) appointments. The discharge summary was meant to provide an overview of the baby's admission in the NBU which could be used by any clinician to get the information required to provide care at follow-up. While paediatricians or MOIs initiated discharge, the discharge summary was usually completed by COIs, as paediatricians did not view completion of the discharge summary as their task. During my observations, I did not see these forms being checked by anyone before discharge. The lack of checks and feedback led to incomplete forms, or incorrect information, which affected post-discharge follow-up care as described in further detail in this chapter. In addition, it hindered interns learning how to improve their documentation skills.

I observed nurses or nurse interns conducting discharge discussions one-to-one with mothers. Another family member was required to be present for discharge, but they were usually moving between the hospital administration office and the NBU to get the required documents before the mother and baby could be released. As such, they were not usually present for the discussion with the nurse. Based on national and international guidance the nurse was meant to speak to mothers about the condition of their child; check the cord for

any infection and explain cord care; check that the mother can breastfeed; immunisations have been given; let the mother know when to return for a follow-up at the POPC and answer any questions that the mother may have (74, 298). However, during my observations the discharge conversation was usually completed in about five minutes, which did not allow for this level of interaction.

Nurses, COIs and MOIs said mothers were very excited when they were discharged, particularly if they had spent a lot of time in the NBU, as this could be a stressful experience. I observed a couple of mothers receiving news that they would be discharged, and they were visibly happy. Nurses told mothers which date to return to the hospital for check-ups at the POPC, and this date was documented in the discharge summary, though usually in medicalised terms, for example, 2/52 (meaning review in two weeks) followed by a date. Before mothers were discharged from the hospital they needed to go to the records office and have the health records and information officer (HRIO) confirm the date for their follow-up POPC appointment. In Ndovu the POPC follow-ups were scheduled for two weeks after discharge, whereas in Twiga the POPC visits could happen at one week if deemed necessary by the discharging paediatrician. In both hospitals, if the baby experienced an issue in-between discharge and the scheduled follow-up, they could attend the outpatient clinic at the hospital, also called a filter clinic, or visit another facility. I did not observe mothers being given this information at discharge.

[Hospital Name] Newborn Unit Exit Form

Infant Name				**IP No.**			
Age	days	**Sex**	**F□ M□ Indeterminate□**	**Birth wt**	grams	**Exit wt**	grams
Mode of delivery		SVD □ CS □ Breech □ Vacuum □ Forceps □		**Date of Admission**			dd/mm/yyyy
Infant HIV sero-exposed?		**Y□ N□**	**If *yes* ARVs given? Y□ N□**	**Date of Discharge/ Referral / Death**			dd/mm/yyyy
Outcome		Died□ Alive□	***If alive*** Discharged □ Absconded □ Referred □				
Referred to			**Reason**				

Neonatal Diagnoses: Select ONE *primary diagnosis (tick 1) and for secondary diagnoses (tick 2)*

Birth asphyxia Severe/Encephalopathy□ Mild/Moderate □	**1□**	**2□**	***Neonatal sepsis***	**1□**	**2□**	***Jaundice***	**1□**	**2□**	Highest bilirubin =_____
			Meningitis	**1□**	**2□**	***Anaemia***	**1□**	**2□**	Discharge HB **=_____**
			Multiple Delivery	**1□**	**2□**				
Preterm	**1□**	**2□**	***Other diagnoses-name and indicate if primary(1) or secondary(2)***						
Newborn RDS	**1□**	**2□**		**1□**	**2□**		**1□**	**2□**	
Meconium aspiration	**1□**	**2□**		**1□**	**2□**		**1□**	**2□**	

Supportive Care given

KMC	**Y□ N□**	**CPAP**	**Y□ N□**	**Phototherapy**	**Y□ N□**	**Transfusion**	**Y□ N□**

Preventive Care given

OPV	**Y□ N□**	**BCG**	**Y□ N□**	**TEO**	**Y□ N□**	**Vit K**	**Y□ N□**	**Chlorhexidine**	**Y□ N□**

Feeding at Discharge	Breast Milk only□ Formula only□ Formula&Breastmilk□ Fortified breastmilk□

Summary of Key Investigations, Interventions, Progress & Needs at Discharge

Condition on D/C	Normal□ Neuro Sequelae□ Other Complication□ =
Follow up	None□ POPC/NOPC□ KMC Clinic□ Physio/OT□ PMTCT□ Other facility□
	Weeks after discharge = ***Date:*** ***Time:***
Discharge Drugs:	

Name of Clinician Discharging: ***Signature:***
Consultant in-charge:

Figure 11: A copy of the NBU discharge summary (2019 version). One copy was retained in the NBU file, and another was given to mothers on discharge.

Overview of the organisation of post-discharge care

Having described the discharge process, I will now continue to address my first research sub-question as set out in the introduction of this chapter by describing how post-discharge care was organised and delivered. The description of the post-discharge process is based on my ethnographic observations, interviews and informal conversations with healthcare providers and mothers, and workshops with healthcare providers. Multiple artefacts were used during post-discharge care, and each served a different purpose as described in **Table 7** below.

Table 7: The different information tools, or artefacts, used during post-discharge care

Document	Intended purpose	Storage
MCH Handbook	Providing mothers with information on care for the baby; documenting care, including antenatal care, delivery, postnatal care, immunisation and growth and monitoring	Mothers
Discharge Summary	Summary of the condition of the baby in the NBU and the care received	Mothers + Records office
NBU File	Medical notes from NBU admission to discharge, and notes from POPC visits	Records office
OT initial assessment	Initial assessment of an OT case, used during ongoing therapy provision	OT department
OT outpatient document	Documenting ongoing progress of therapy	Mothers
E-records	Documenting care provision for children in outpatient clinics	Outpatient clinic
Referral form	Summary of the case from the referring hospital and reason for referral	Mothers

POPC visits

The post-discharge journey varied depending on the baby's condition. During observations, the COIs and paediatricians explained that after attending the first POPC follow-up, scheduled for two weeks from discharge, the mother will be told to bring the baby back for another POPC in four weeks. If the baby was progressing well the baby will be classed as a

well-baby and continue with the routine checks for a healthy child. I observed that in both facilities the POPC happened once per week in the morning - Tuesday morning in Twiga and Wednesday morning in Ndovu. The paediatricians said ideally there would be a separate neonatal outpatient clinic (NOPC), but this was not possible due to staff shortages.

When mothers attended a POPC appointment they would first go to the records office to retrieve the NBU file via the NBU file number written on their discharge summary. The NBU file was used to document information from the POPC visit. As mentioned earlier, the discharge summary was one artefact used towards the sociomaterial accomplishment of care continuity. One of the features of this artefact was that it was a loose piece of paper (**Figure 11**). As such, it could easily be lost or damaged, causing issues at follow-up. I observed that Twiga did not have computers in the POPC rooms, however, in Ndovu the POPC and filter clinic had a computer-based e-record system. The material properties of these information tools, the NBU file and e-record, affected how they were used. I observed that the NBU file was prioritised for the documentation of detailed information, while the e-record was used to record basic information. This was explained by a COI's comment that the NBU file was a legally binding document, and a paediatrician expressing frustration that their work was duplicated by having to fill the same information in both the NBU file and e-record. As such, the paediatrician said they filled e-records with minimal details and instead used the e-record system to check the medication stocked in the hospital pharmacy. If the medication required was out of stock carers would be advised to go to another pharmacy.

I observed differences between the two hospitals in how delivery of care was organised and prioritised. This was especially apparent in different responsibilities for different cadres

of healthcare providers. For example, during the POPC in Ndovu the paediatrician would see new cases, i.e., referral cases from other facilities or from within the facility. COIs would see the repeat visitors. However, in Twiga, the paediatricians would see babies discharged from the NBU and the COIs and MOIs would see older children.

I observed that paediatricians often commented to mothers during POPC that it was not necessary to get all their baby's care at the same facility - immunisation and growth monitoring could be conducted at lower-level facilities closer to their homes. The information from these visits should be recorded in the dedicated section of the MCH (maternal and child health) handbook. The handbook was provided for mothers when they attended their first antenatal appointment to document the health journey of the child, including information about delivery and postnatal care. The handbook also contained important health messages for mothers, including tips on breastfeeding, nutrition and danger signs. The MCH handbook was an artefact used by mothers, paediatricians, nurses and nutritionists, and was meant to provide a holistic overview of the baby's health. However, I observed that only the antenatal care, delivery and immunisation sections were usually completed. The growth and monitoring sections were more scantily filled, and only a couple of MCH handbooks had postnatal visits documented.

OT clinic

Paediatricians or MOIs would refer the baby to the OT department for follow-up if they had birth asphyxia, a congenital abnormality, or any neuromuscular abnormality. During the first OT appointment an initial assessment was conducted. The assessment was meant to document basic information about the child, their diagnosis and plans for therapy. Disability assessments were conducted by the OT department, which enabled carers to get

a disability card entitling them to a monetary stipend from the government. Most of the information required for the initial assessment by OTs was included within the MCH handbook. Having multiple documents requiring the same information led to frustration amongst healthcare providers. In both hospitals this assessment was noted on blank pieces of A4 paper that were stored in files based on the assessment date within the OT department. During observations at the OT department in Twiga I noticed carers were given an outpatient card, whereas in Ndovu carers were told to purchase a notebook. The affordances of these two different documents affected how information was recorded and led to disruptions in information flow. For example, in Twiga the card provided by the hospital was folded with use, resulting in damage. Mothers had to pay for the outpatient card, thus the OTs wrote minimal information – notes included the date, therapy provided, and a follow-up date. In Ndovu the blank notebook had different affordances - the OT could write more detailed information about the therapy provided, but there were no directions on what data to include. As such, the data recorded was highly dependent on the OT.

Other outpatient clinics

Post discharge the baby may be referred to the laboratory or radiography department for tests or referred to another facility if specialised care was not available within the same facility. During discussions with paediatricians, MOIs and COIs, they said if a baby was not adequately gaining weight the mother would be referred to a nutritionist. If a baby needed to be readmitted, they were placed in the paediatric ward, not the NBU, even if the baby was still classed as a neonate. The NBU file from their previous admission would not be used, instead a new inpatient file was created. In both hospitals, the same paediatricians

attended the NBU, POPC and paediatric ward. The MOIs rotated between wards every three months, and COIs rotated every three weeks.

Continuity of care

Having explained some of the key processes related to discharge and post-discharge care, I will now move on to discuss how care continuity was disrupted, drawing on the typology by Haggerty et al. (19) that I extended in Chapter 3. The dynamics of care continuity can occur between mothers and healthcare workers, between healthcare workers and sometimes in a three-way dynamic, i.e., healthcare worker-mother-healthcare worker. As mentioned in Chapter 1, I drew on the sociomaterial lens to understand how care continuity was enacted in practice by people and artefacts. **Table 8** at the end of the section provides an overview of the key findings.

Informational continuity

As mentioned in Chapters 1 and 2, Haggerty et al. defined informational continuity as information being shared and used appropriately to make current care appropriate for each person; the typology suggests that while documentation tools focus on the medical condition, it is also important to consider patient preferences, values and context (19). Below, I have presented my findings about the challenges with informational continuity in three different sections.

Challenges with Documentation

In my fieldwork I found that informational continuity was affected by incomplete or missing documentation. The discharge summary was often filled by interns and not checked by paediatricians or nurses, leading to gaps, omissions and inaccuracies. During observations in the POPC in Twiga, a paediatrician said "*look at this*", as she showed me an incomplete

discharge summary and complained that it was scantily filled. The discharge summary showed malnutrition was an issue, but the notes section had no details to elaborate further. She had to ask the mother questions to get more information, such as the weight of the child.

"…if I give an appointment to a patient two months later… I am not the person who is going to be here, so if I document nothing or do the bare minimum the next person who is going to come here is going to really struggle..." ***COI 1, Ndovu***

During observations in Twiga, one paediatrician said with the limited time at POPC appointments she must quickly scan the NBU file, saying "*you learn with time*". She said "*the history is there*" and pointed at the NBU file when I asked if there were issues with information, indicating that if information was missing from the discharge summary, a shorter documentation artefact, it was available in the NBU file, which could be much longer.

"I know there are days when you… have the time to do the [weight gain] calculation and then there are days when… you don't even have time to calculate because you are just thinking the queue is so long… you are like okay no major concerns,… it's like you are just working mechanically so those are some of the challenges." ***Paediatrician 2, Twiga***

Informational continuity was also disrupted by mothers forgetting to bring their documents to POPC or OT appointments. If informational continuity was disrupted by missing or incomplete documents at POPC, a new patient history was taken, which was time consuming. However, bringing these artefacts alone was insufficient. Michael's story touched on the affordances of the OT outpatient card in Twiga; if a new OT saw the patient,

they would be unable to determine what care was provided and whether any progress had been made due to minimal note-taking or damaged documents.

"If their card is missing, then there is no progress note. Maybe the therapist who has taken over from the one who was in the outpatient has not seen this client for so long. Now it's like they will start reassessing the child again." ***OT 1, Twiga.***

My observations and interviews showed that healthcare providers did not fill or use every documentation artefact as recommended in the national guidelines (297), and each filled in the form in a different way. For example, in Twiga the OTs made an initial assessment of each patient, which was stored in the OT room. However, I did not observe these documents being brought out of storage to guide therapy during any follow-ups, and instead OTs relied on their knowledge of patients who visited frequently.

"…As we achieve our objectives or goals we are supposed to note that in the file... So that when finally the child is able to walk, we can trace that from the progress that we have been achieving every time the client comes to the clinic. But because of the workload, we are not able, but we can always tell, because we know all our clients because of the frequent visit." ***OT 1, Twiga***

Healthcare workers had to record the same information in multiple artefacts which posed a challenge, as there was insufficient time at follow-up visits. The MCH handbook had a section for post-discharge visits which was rarely filled. During observations in the POPC in Twiga, I noticed a paediatrician filled in the MCH handbook for a patient. I asked why they did this for this specific patient. The paediatrician said they were filling the developmental milestones and should have done this with the other patients but forgot, and did not have the time required to make this a routine practice. E-records were another artefact requiring

duplication of documentation. Clinicians in Ndovu only used e-records to check pharmacy stock and record the baby's condition, as detailed information needs to be written in the NBU file.

"…the manual file remains by law what is recognized…, we find that we actually use the e-records more or less to help us to get to prescriptions… otherwise the real details, the real examination findings, you will find that most of the time are doing the manuals [manual documentation in the NBU file]. Of course, it's a tedious process because you are entering two records…" ***Paediatrician 1, Ndovu***

Regulations on document storage and use caused disruptions to informational continuity. For example, the OT departments and outpatient clinics in both hospitals did not use the NBU files to document information. During observations in Twiga an OT told me this was due to the file being viewed as a medical file, and their work was considered physical work. However, there was only one HRIO in the records department and the more likely reason for this arrangement was an inability to get files to the ward in a timely manner. Regardless, due to this system, the clinicians who saw the baby at POPC were unaware of any outpatient care provided by other healthcare providers.

"…the information that we have in our outpatient clinic, may not be directly transferred into their POPC files, because those are two different setups." ***Paediatrician 3, Ndovu***

Although healthcare providers suggested there was significant emphasis on ensuring informational continuity during clinical care provision, this seemed hard to realise in practice.

"From this hospital as we are discharging, the incomplete is close to none, since if its incomplete it will be returned... We are not going to continue with the discharge process if part of it is not complete or not satisfactory…" ***COI 1, Ndovu***

Communication Challenges Between Healthcare Workers

Inter-facility communication was mostly via referral forms, though much like discharge summaries, I found these were often scantily filled and seemed to disrupt informational continuity. Although a paediatrician mentioned phone calls between facilities being an option for further communication, this was not something I observed in my fieldwork.

"I think under continuity of care the referral system should be a bit more aggressive. Because I've had cases where… children are not referred. I had to talk to the doctor and tell them these children that are not being referred, they'll come to us a year later. And still, this child will not have attained the milestones. Now we will start working on the milestones at one year." ***OT 2, Twiga***

"The communication [between facilities] is something we can do, maybe we have not yet developed a very clear mechanism… so it's about just the linkages [between facilities] which maybe they have not been exploited." ***Paediatrician 1, Ndovu***

In both hospitals, intra-facility communication was aided by in-person and telephone communication between OTs and paediatricians during admission in the NBU. However, there was little coordination between paediatricians and OTs for post-discharge care plans. As mentioned earlier, while conducting observations I noticed that in Twiga and Ndovu the records for OT visits and POPC visits were separate. This separation meant paediatricians could not monitor the child's progress in OT and the OTs could not see the child's progress

in the POPC. As such, the two provider groups would not be able to communicate with each other if there was a need to adjust care plans due to an illness or setback.

Communication Challenges Between Healthcare Workers and Mothers

To make care appropriate for each individual, communication between healthcare workers and mothers of babies born small or sick was needed to understand patient preferences, values and context. Mothers often asked paediatricians how to care for pre-term babies at home. OTs dealt with the long-term care of the patient, thus were regularly asked questions about the child's developmental milestones. Healthcare providers tried to answer parent's questions but were time constrained. One OT in Ndovu suggested parents should seek information online. However, a paediatrician from Twiga said this would cause distress, and sometimes there was a need to withhold information from parents for their own benefit.

"When I come to the NBU, I want to talk to the mother... I feel happier talking to the mother, not just seeing a baby and writing things. I want to talk to the mother, hear their problem, and tell her what to do." ***Paediatrician 2, Twiga***

"Imagine if you are writing the patient has severe birth asphyxia [BA]… the patient can see the diagnosis, and then they go Google severe BA and then they start wondering like oh my baby has severe BA … they will start saying my baby has a poor outcome. Sometimes you don't tell them the baby has severe BA but you will just be like you know your baby got extreme lack of oxygen when they were being born and there will be delay in the milestones and therefore they will have to go for OT, you see there is a way you are putting it?" ***Paediatrician 2, Twiga***

Communication with mothers needed to consider tone, as well as the content of information being shared. Healthcare workers said lay language must be used so mothers could understand what was needed.

"Because the moment you do POPC 2/52? Does that mama out there understand what that is? A medical person will understand this paediatric outpatient clinic in two weeks. So, you find also information, the way the information is relayed to the mother also contributes."

OT 2, Twiga

During observations one paediatrician in Twiga suggested providing a general phone number for mothers to call and ask questions after discharge, as mothers often sought care elsewhere if their POPC appointment was far away.

Management continuity

Management continuity refers to managing an illness in a consistent and coherent manner, which is important with multiple care providers and when complementary and timely provision of care is needed (19).

Babies discharged from the NBU with long-term conditions often had multiple conditions and were complex cases. If specialist care was required but unavailable, they were referred to other facilities with these services. As such, mothers usually saw multiple care providers at multiple facilities. Coupled with disruptions to informational continuity, this led to inconsistent treatment. The example below was a rare case of good management continuity, as the same specialist worked at both facilities which aided consistent management of the baby's condition.

"Fortunately, I was still the cardiologist [when the baby was moved from one facility to another], so she missed nothing, even in [private facility] I was still the cardiologist and so we did the surgery at [private facility] and then we came back to Twiga [the original hospital] afterwards." ***Paediatrician 1, Twiga***

During my discussions with the OTs they highlighted that they would like to see patients weekly for therapy, but could not due to their workload. To provide adequate treatment continuity for children with cerebral palsy, mothers must be involved in care provision. OTs, and OT interns, would tell mothers to provide their baby with daily therapy to improve muscle tone and achieve developmental milestones. This home program was demonstrated to mothers, but not written down, and therefore parents could not refer to it later. The OTs said at follow-up appointments they asked mothers to demonstrate the therapy provided at home to monitor whether it was correct, but I did not observe this in either hospital. Instead, at follow-ups the OTs and OT interns provided therapy for 30-40 minutes, asked the mothers questions, and wrote notes in the follow-up document and ward-based documents.

To manage an illness consistently, follow-up appointments must be maintained. However, in some cases, mothers did not return and there was no system for follow-up. In Ndovu a nurse and a paediatrician mentioned the social worker being involved in follow-up care. However, as discussed further below, this was not part of their job description. One paediatrician highlighted that when patients missed follow-ups they eventually returned when they were very sick. The OTs echoed this, saying it was common for mothers to seek second opinions about their child's condition due to denial. As such, conditions were not treated, causing delayed achievement of developmental milestones.

"We do not have a way of knowing exactly how they responded if they didn't show up in the clinic. We are yet to come up with a way of ensuring they are followed up and this might involve us getting the social workers and all those other people." ***Paediatrician 1, Ndovu***

Relational continuity

Relational continuity refers to the ongoing relationship between a patient and one or more providers, with the understanding that consistency of core staff can provide a sense of coherence (19).

During observations, when I asked a paediatrician in Twiga how they built relationships with mothers, they said "*there's no relationship to be honest*" due to insufficient time with mothers at follow-up appointments. Based on my observation, in both hospitals POPC visits lasted an average of 11 minutes.

However, paediatricians found it easier to build a relationship with mothers whose babies were in the NBU or paediatric ward for longer periods, as they interacted with them frequently during admission. Similarly, OTs in both hospitals found it easy to build relationships with parents post-discharge as they saw them regularly and the visits were longer. OTs bonded with mothers by providing counselling and support as they come to terms with their baby's condition.

"We are very close to our parents… When you give birth to a child that you do not expect, a lot of things happens to you emotionally, psychologically… So, we have to step in now, encourage them and bring them closer to us, encourage them and give them reassurance so we are close to them. They open up to us…" ***OT 1, Twiga***

During one POPC consultation we observed a mother who was unhappy because she was told her baby needed a head scan; she wanted to see the same paediatrician she saw during NBU admission as they understood the baby's history. When we saw the mother again later that day, she explained that the same paediatrician managed to see the baby, and said the baby was well and did not need the scan. In this case relational continuity worked well, but it was not always feasible; a paediatrician in Twiga said it was not logistically possible for mothers to opt to see the same paediatrician at every follow-up appointment.

Relational continuity was also disrupted by the turnover of interns in both hospitals, as interns are heavily involved in care provision.

"… you train them [interns] and the interns change rotations every month, even the medical officers, there is this thing which I don't like that every six months the medical officers are rotated. I have refused with mine, because we have invested so much in her, she has become almost like a consultant then you take her away…" ***Paediatrician 2, Ndovu***

Healthcare providers said their medical education was focused on diagnosis, and not on building relationships with patients, stating that they were not taught how to speak to patients. As such, they learned about building relationships with caregivers on-the-job. Coupled with their workload this made relationship-building difficult. Yet, healthcare workers were aware of the importance of building rapport and trust with mothers to create relational continuity.

"…you communicating to the mother the benefits the baby is going to get from whatever I'm doing, that relationship becomes very smooth… If you approach her as if you want to help the baby, well and good, if you approach her with that lion heart, you get nothing.

Because if she tells you don't touch my baby there is nothing you can do and she will have a negative attitude towards you." ***COI 1, Ndovu***

To build a trusting relationship, healthcare providers played a supportive role for caregivers, as they recognised the critical role mothers play during long-term care. This built confidence in the mothers' abilities to provide care.

"I always think the mothers are the main people who are involved in the care... In that clinic, how long are you seeing this patient for? Maybe 10-15 minutes, most of the time it's the mother who is going to be with that baby… you know, sometimes you want to reassure them, give them confidence, keep them confident, tell them that they are doing well, encourage them. If the baby is doing well tell the mother..." ***Paediatrician 2, Twiga***

To maintain relationships with mothers, some healthcare providers gave mothers their personal phone numbers so they could support them and provide advice. However, one OT noted that mothers who had not accepted their child's condition may feel that calls were invasive.

"We are always free. They call us. I usually give them my number... And I don't put my phone off, even at night. Cause sometimes they get anxious, especially if it is the first child. So, you have to continue reassuring them, talking to them, reminding them, because sometimes we, you can lose them." ***OT 1, Twiga***

Interpersonal continuity

Interpersonal continuity was a concept I developed to extend Haggerty et al.'s framework which I used in the scoping review; it refers to relationships between groups outside of the "patient-provider" dyad which can improve care provision. This includes relationships

between family members, between healthcare workers or relationships within the wider community (154).

Healthcare Providers

Relationships between healthcare workers faced several challenges in both hospitals. One of the main challenges was the role of each healthcare provider was not clearly defined, and they made assumptions about the roles of other cadres. As such, discrete care tasks could remain incomplete.

Healthcare providers described working as a team during discharge and across the post-discharge journey. The teams were multi-disciplinary, across cadres and wards within the hospital, hence coordination between these groups was needed.

"Taking care of the babies cannot be done by any one person or any one cadre…" ***Paediatrician 1, Ndovu***

For example, in Ndovu there was an assumption by clinicians that follow-up of babies born small or sick was conducted by the social worker. However, when I spoke to the social worker, they said they dealt with issues around inability to pay, ensuring babies who lost their mothers had adequate support, and facilitation of referrals to other hospitals. They did not follow-up small and sick babies discharged from the NBU. Ndovu had three social workers; the social worker assigned to the NBU also dealt with several other wards, as such, their workload was high.

"The social worker is whom we depend on to get to the roots because… when they go out of the facility, who is there to look after her… the social worker is going to be the link between the patient at home, or the community, and the hospital." ***COI 1, Ndovu***

Qualified healthcare providers and interns built a relationship via supervision. Healthcare providers had to balance the role of supervision with their own patient workload. Interns often completed tasks due to healthcare worker shortages, but supervision was crucial for their learning and maintaining patient safety.

"… as an intern you are still a learner, it's not like you are really qualified as such to be able to perform this. So, wherever you are not able to give the correct information there is always room for consultation and we have a very wide amount of staff here who are willing to help you…" ***COI 1, Ndovu***

Family members

When mothers returned home, they depend on their family to provide a supportive environment. Healthcare providers mentioned the importance of involving fathers in the care journey as early as possible, so they could be informed, involved and supportive.

"When they come for assessment, we encourage them to come with their partner. So that they can be given that supportive care because emotionally and psychologically they'll be focused now to effectively attending to their children." ***OT 1, Twiga***

Yet, mothers were often blamed for their child's condition, resulting in frayed familial relationships. Mothers also faced social issues within their family, including financial difficulties; fathers leaving the family due to the baby's health condition; and competing priorities within the household, such as the needs of other children. These social difficulties made it harder for mothers to provide the continuous care required.

"Normally you talk to the mother, find out what the problem is. Because there's… the support system. This mother could be a single parent, or the moment she got a child with

an issue, the father of the child left, this mother might not be earning anything economically... Now, if she was supposed to come to clinic today, she was told there is no money, and she does not have any money. You see, that already is a challenge." ***OT 2, Twiga***

Disruptions in continuity due to financial difficulties experienced by families were exacerbated by new measures I saw during my second round of data collection, where mothers were required to pay for OT services which were previously free. Healthcare workers thought family financial difficulties could be alleviated by financial tools.

"The [disability] card entitles the mother and child to a stipend of I think 2000KES every month?... it will enable the mother to come for the clinic, fare, to buy olive oil [for therapy], pay for the clinic, though we are encouraging these mothers to enrol in NHIF… Because the moment you enrol on NHIF you don't come with any money." ***OT 2, Twiga***

Wider community

Communities in Kenya are tight-knit and support each other during difficulties. Mothers who had babies together in the NBU bonded, often keeping in contact beyond their time in the hospital. The same was true for mothers who attended OT appointments together. The key informants echoed the importance of creating a supportive community.

"… what I do with the community is I have a support group of caregivers who raise children with special needs… we offer a support system… we also try to talk to each other, maybe just encourage each other on a day-to-day basis." ***Key informant 3***, ***founder of a parental peer support group***

However, when mothers of babies born small or sick were discharged, they were often blamed by community members for their child's condition, which caused distress.

"Mothers are told they have brought home rats or kittens, they are told they tried to get an abortion hence the small size of the baby, or that they did not eat enough to save their figure, hence the baby is small." ***Key informant 1, founder of a parental peer support group***

Healthcare providers highlighted that misinformation could easily be shared amongst mothers in the community, which affected care-seeking.

"…in the community, we have some people who have little knowledge but it's dangerous. They tell you, you don't need to go to the hospital, they are only going to eat your money… you can buy a packet of flour rather than going to talk to a doctor who is going to say the same thing that I'm going to tell you… that is another challenge - they like listening to each other." ***COI 1, Ndovu***

Table 8: An overview of the facets of continuity of care and how they manifest in the empirical data.

Informational continuity	**Relational continuity**
• Disruptions were caused by damaged documents, incomplete documentation and multiple documents requiring the same information. • Interns completed paperwork with limited supervision. • When informational continuity was disrupted a new patient-history must be elicited, which takes time. • Communication can occur between healthcare workers within the same facility, intra-facility, or in different facilities, inter-facility.	• Paediatricians had difficulties building relationships with mothers due to time constraints at POPC visits. Whereas OTs found it easier to build relationships as they saw patients regularly. • Some mothers preferred to see the same paediatrician at POPC visits, but this was not always feasible. • COIs said medical training did not equip them with the skills to build relationships with patients. • Healthcare workers said building trust and rapport with mothers was important.
Management continuity	**Interpersonal continuity**
• Small and sick newborns often have multiple conditions and require follow-up visits with multiple providers.	**Healthcare providers:** • Roles were not well defined. • Mothers were active care providers.

• Mothers were an integral part of continuous care provision and are provided therapy at home. • There was no follow-up system for babies who don't return for care.	• Co-ordinating post-discharge care between different cadres of healthcare worker was challenging. • Interns must learn on the job with minimal supervision. **Family members:** • Mothers were blamed for their child's condition. • Social issues (financial capability and other care duties) led to disruptions. • Healthcare providers encouraged father's involvement. **Wider community:** • Mothers experience stigma within their communities. • Mothers who stayed in the NBU for longer formed bonds and supported each other post-discharge.

Discussion

In this chapter I described the post-discharge journeys of babies and mothers, how post-discharge care continuity was a sociomaterial practice involving an assemblage of artefacts, and outlined the challenges faced by healthcare providers when providing post-discharge care continuity. The results from this chapter show that continuity of care was interlinked, with disruptions to one type of continuity causing knock-on effects to other types of continuity. Relational continuity was disrupted as seeing the same healthcare provider for each follow-up visit was not feasible, thus having good inter- and intra-facility documentation and communication was critical for management continuity. The materiality of information tools affected the quality of documentation, which disrupted information flow and reduced relational continuity as providers had to elicit patient histories instead of spending time with patients. The two stories demonstrated care

continuity was an ongoing effort, in a context where mothers often had to bear the burden of care with little emotional or financial support, which disrupted interpersonal continuity.

Healthcare workers acknowledged the hospital to community link was an issue, but neither hospital had a robust follow-up system. Even though most interventions included in the scoping review (Chapter 3) focused on CHWs, none of the mothers interviewed reported interacting with CHWs. The WHO and the UNICEF suggest using CHWs for postnatal home visits for low birthweight and pre-term infants where trained healthcare workers are not available (299). In another study, healthcare providers in Kenya suggested that CHWs could be used to conduct follow-ups with paediatric patients as they are embedded in the community (108). One review found CHWs may be useful in LMIC contexts to help relieve anxiety in parents, promote parental self-efficacy, and improve feeding and developmental outcomes in newborns, however CHWs would need to be adequately trained (300). The Kenyan government has a Community Health Strategy, implemented in 2020, where CHWs are key (301), but there are variations in how each county has deployed CHWs. As such, it is likely that the two counties studied did not have a robust CHW program, whereas other counties may be engaging CHWs for follow-up care. Home-based support for babies with long-term conditions also requires adequate training, thus CHWs may not be best placed to provide this service.

Discharge was an important process and set up mothers' post-discharge journey by providing information about newborn care. My findings about discharge resonate with a recent study in Kenya that found discharge from the NBU was treated as an event, rather than a process (32). Other studies found that postnatal education should begin pre-discharge and continue post-discharge, ideally involving the whole family (300, 302), rather

than focusing on the point of discharge. Studies in high-income countries have shown that strengthening discharge preparation was important (303), as at discharge women reported a lack of confidence, particularly for breastfeeding and unpreparedness for physical or psychosocial health problems (304, 305). One review of high-and-low-income countries found that emotional and psychosocial support was crucial postnatally (306). Discharge was a multi-factorial process: checklists, medication, educations of carers and moving the patient record to the appropriate location all need to be completed correctly (37).

My findings align with a review on the effects of continuity of care on the physical and mental health of mother and child which showed that when informational, management and relational continuity were in place, results were better in the postnatal period for breastfeeding and health status (24). My findings also highlight the importance of interpersonal continuity in post-discharge care provision. Families are usually living in poverty; thus, health shocks cause financial difficulties. Other studies have shown financial difficulties are a major constraint for follow-up care (108). The two stories demonstrated the need for additional support systems for the emotional needs of the mother. These could help manage mothers' expectations of how their child's growth and development will progress and address stigma (32).

My research found paediatricians were frustrated by forms which did not contain all the relevant information needed to assess the child. However, documentation was seen as the remit of interns, who did not usually provide follow-up care. Other studies highlighted similar issues, in that the person entering data on an artefact may not be the same person using that data later in the patient's care journey (37). Poor documentation at one time point may lead to issues around care provision at follow-up visits due to a lack of knowledge

about the patient journey (43). The lack of checks or feedback for interns completing documentation was also an issue, as they left forms partially filled. Other studies in high-income countries demonstrated similar issues. An Australian study showed interns indicated they wanted feedback on the quality of their notes and to learn how to critique theirs and their colleagues' notes (307). One study from Sweden showed documentation checks were not completed before discharge (43) and another showed a lack of clarity on whose role it was to review patients pre-discharge (37). Healthcare providers have limited time at the POPC, which has been shown in other studies (26, 308). To maximise the limited time at POPC, improved documentation could provide more accurate patient histories in a concise way and increase the amount of patient-facing time. The materiality of tools can affect documentation; making forms shorter and more intuitive to fill can alleviate issues. When artefacts require the same information repeatedly it frustrates healthcare providers and wastes their time. Increasing workload via poorly conceptualised interventions may lead to burnout, further highlighting the need to create artefacts which lessen the burden of healthcare providers (308). These studies and my findings highlight that care continuity is a sociomaterial practice, as material artefacts alone are insufficient, social aspects must also align for continuity to happen effectively.

My findings showed continuity was disrupted by poor communication and co-ordination of care, either between healthcare providers or healthcare providers and parents. This aligns with a study on weaknesses of continuity of care of pre-term newborns in Brazil, where the authors found that communication between healthcare providers at different facilities and coordination within facilities was a major challenge, partly due to lack of availability of complete information about the care received by the newborn (26). One review highlighted the need to develop novel interventions to promote interdisciplinary teamwork when

caring for high-risk infants (300). The literature shows communication and co-ordination of care are generated by assemblages of human and non-human actors, or artefacts, which need to be given their due consideration (37, 38, 43).

The separation of documentation between the OT ward and POPC highlights the challenge of using different artefacts between different cadres, as management continuity can be affected by an incomplete history of the baby. Progressively developing an understanding of the patient's medical condition and documenting this on an artefact that was shared across different cadres should be a goal for continuity of care (37).

A consultation between the WHO and UNICEF recognised the interprofessional teams that provide follow-up care and highlights the importance of systems that connect inpatient care with outpatient care (74). The latest WHO recommendations on care for pre-term or LBW babies echo this, saying careful coordination of care was needed post-discharge (309). One review suggests that e-records can contribute to collaborative care models between multidisciplinary teams (24). However, my findings showed e-records were not used as intended. This aligns with a study in Kenya which showed that e-records for antiretroviral therapy were not accessed in real time during patient visits, and instead were used for monitoring and evaluation rather than enhanced clinical care (288). The authors suggested employing technology that people use in their daily life rather than introducing new technology (288), indicating that improving established practices, which use paper-based artefacts, is a good first step before introducing new technology.

My findings showed that improving intra and inter-facility communication should provide clarity on the patient's journey. A study in Kenya showed a barrier to post-discharge paediatric care was ineffective communication between different healthcare providers

(108). Yet, communication between cadres has also been highlighted as an issue in Australia, leading to poor interprofessional relationships (310). One study highlighted communication gaps between different cadres within a hospital can arise due to different artefacts being used by the healthcare providers, and inconsistencies in the quality of data entered (37). To improve communication, the literature suggests employing care coordinators, as their role includes being a communication link between the interprofessional team, including family, and following up on care provision (37, 43). If care coordinators were to be used in Kenya, the literature suggests using different follow-up mechanisms for high-risk cases (1, 108), including tailored interventions for families with a complex social background (24). However, efforts to improve collaboration need to consider artefacts as well as human interactions (37).

In this chapter, I built an understanding of the way discharge and post-discharge care was organised, and the challenges healthcare providers faced, with the aim to ensure any future intervention to support continuity can be designed for the existing context. As mentioned in Chapter 1, one of the aims of my research was to develop an intervention that had the potential to lead to improvement in care continuity post-discharge. For feasibility in terms of resources available, and the ability of the hospitals to sustain an intervention long-term, I decided my intervention should aim to improve informational continuity between healthcare providers by focusing on improving existing documentation artefacts, in a way that makes them both intuitive to fill in and to read at follow-up. I specifically focused on redesigning the discharge summary and engaged healthcare workers in this process through participatory workshops. Information tools need to be redesigned in a participatory manner, particularly those that aid communication between cadres, as introducing new artefacts can lead to unintended consequences, such as extra time being

taken for documentation and uncertainty around how the artefact changes enactments of healthcare provider's roles (38). Roles must be considered given the high staff turnover, and that interns fill the discharge summary but paediatricians are the ones who use artefacts at follow-up visits (37). Unavoidably, new ways of doing paperwork and checks for paperwork will lead to some re-enactments of work and renegotiation of roles (38). In the next chapter, I describe how the results from this chapter were combined with the results from participatory workshops to develop a redesigned discharge summary.

Chapter 5: Co-design of a package of interventions

Introduction

In Chapter 3 I found that most interventions on continuity of care focused on informational continuity between healthcare providers and carers and highlighted the importance of interpersonal continuity, i.e., relationships between healthcare providers, and between mothers and family members and the wider community. In Chapter 4 I discussed how discharge and post-discharge care is organised, and the challenges faced with provision of continuity of care. Informational continuity between healthcare providers was a challenge due to interns being unsure what to write, and completing documentation with minimal supervision, resulting in incomplete documentation. The disruption to informational continuity was problematic, as relational continuity was disrupted, i.e., a different care provider, usually a paediatrician, used the document at follow-up. As a result, the consistent and coherent management of the child (management continuity) was disrupted. The previous chapter also highlighted how the sociomateriality of continuous care provision could be impacted by the design of information artefacts. This chapter aims to address my third research question and the secondary research questions, outlined below.

RQ3. How can participatory design inform improvements on documentation artefacts used to promote continuity of post-discharge care for small and sick newborns in Kenya?

a. How can we describe typical roles and behaviour patterns of healthcare workers involved in enacting care continuity post-discharge?

b. How can we imagine a redesigned discharge summary may be used by healthcare workers supporting care continuity?
c. What features does the discharge summary require to meet the needs of the healthcare providers using it?

I will provide a brief reminder of the methods I used to re-design the discharge summary following the goal-directed design (GDD) process (178), an approach that helps with product development, as shown in **Figure 6** in Chapter 2.

GDD consists of six phases: research, modelling, requirements, framework, refinement and support. I incorporated participatory design workshops into the GDD process to engage the healthcare workers who ultimately use the artefact. To complete the research phase in my project, I drew on data from the scoping review and qualitative research as described in Chapters 3 and 4, as well as discussions during my first workshop with nurses from four different clinical information network (CIN) hospitals. The modelling stage of the GDD process involved building personas. I built initial versions of the personas based on the qualitative data from the research phase and presented them to paediatricians, nurses, health records information officers (HRIOs) and occupational therapists (OTs) in workshop 2 for feedback. After this workshop, the personas were further refined. There are multiple different providers involved in the post-discharge journey of a small or sick newborn; I chose two key personas – the primary persona is Martin, a clinical officer intern (COI), and the secondary persona is Mary, a paediatrician. These personas were created using the eight-step process outlined in Chapter 2. The requirements definition stage involved creation of context scenarios, which I created from qualitative data from the research phase and workshop 2. The scenarios presented in the workshop described experiences and

activities that I commonly observed or were mentioned by healthcare workers in interviews; the context scenario was meant to explore how an artefact could meet the needs of the personas (178). The framework stage involved designing the artefact and testing it with COIs during workshops 4 and 5. The discharge summary was designed based on suggestions from healthcare providers.

Results

This chapter does not cover the final stages of the GDD process, refinement and support, and instead suggests these as areas for future research.

Research

The scoping review (Chapter 3) examined existing interventions in low- and middle-income countries (LMICs) and how they improved continuity of post-discharge care. It found that informational continuity between healthcare providers and carers was the most prevalent continuity domain in the literature. The review also highlighted that interpersonal continuity was important to consider, as relationships between healthcare providers, or between carers and family members or people within the community, can affect care provision for newborns.

The results in Chapter 4 echoed the results from the scoping review, by showing that informational continuity between healthcare providers and mothers was an issue. Communication was a recurring theme brought up by healthcare providers. They acknowledged that better communication between healthcare providers and mothers was needed so mothers knew what care to provide at home post-discharge care and when to return for follow-up appointments.

In addition, informational continuity was also disrupted between healthcare workers within facilities and between different facilities due to poor documentation. This disruption meant healthcare workers needed to elicit new patient histories from mothers who were often unsure about their child's condition and what care had been provided. Management continuity was impacted by the disruption to informational continuity. As mentioned in Chapter 4, healthcare providers had up to 11 minutes per patient at follow-up, and disruptions to informational continuity meant less patient-facing time. Healthcare providers said there was a need to communicate with each other within facilities and between different facilities to promote management continuity. The discharge summary was a salient artefact as it provided a summary of the care received in the newborn unit (NBU) and was brought to every follow-up appointment. As such, the discharge summary provided the background of the patient and oriented future care provision. In addition, it was the only document with the file number (IP number) written on it, which allowed the NBU file to be brought to the paediatric outpatient clinic (POPC), where information about follow-up visits was recorded.

My qualitative findings about how post-discharge care was organised were sense-checked in the first workshop with paediatricians, nurses, and HRIOs. They emphasised that each child's journey was different and depended on their condition(s) and social circumstances. The workshop showed that multiple artefacts and healthcare providers are involved during discharge and post-discharge care, making the process complex. The discharge process itself is time-consuming for the healthcare workers, and they acknowledged that there was inadequate time for communication with mothers at discharge.

Based on my scoping review and the qualitative data, an intervention targeting informational continuity between healthcare providers seemed the most feasible in terms of the resources available within the hospitals. I previously described how the facets of continuity of care were interlinked; meeting the information needs of the healthcare providers could also improve management and relational continuity as a comprehensive history of the care received would be available, and healthcare providers could spend less time extracting information and more time building relationships with mothers. As such, the focus of the rest of the GDD process became the redesign of the discharge summary.

Modelling

I built personas based on my observations and interviews, while following the eight steps outlined in the GDD process, as shown in Chapter 2.

Step 1: Group interview participants by role

I grouped my interview and observation subjects by role, which matched with job descriptions – COIs and paediatricians

Step 2: Identify behavioural variables

I used my fieldnotes and interview data to build descriptions of COIs (**Table 9**) and paediatricians (**Table 10**).

Table 9: The behavioural variables of COIs.

Clinical Officer Intern (COI)	
Activities What the user does; frequency and volume	• Attend weekly CMEs and ward rounds write patient notes, laboratory and radiology requests and discharge summaries • Provide care in the NBU, and sometimes at the POPC • Speak to the mothers in the NBU daily • Refer for follow-ups e.g., nutritionist, OT etc.

	• Ask for guidance from paediatricians when unsure what to do.
Attitudes How the user thinks about the artefact domain and technology	• Paperwork is not a priority due to the heavy workload • On rotations – learning new things on each ward [overwhelmed] • Taking time on paperwork in the NBU does not benefit them – it only benefits whoever provides care in the future [unmotivated]. • Not taught how to do paperwork at university, learning on the job.
Aptitudes What education and training the user has; ability to learn	• Medical training • CME • Willing to learn
Motivations Why the user is engaged in the artefact domain	• Interns must fill in the discharge summaries • In their own interest to have a summary which is easy to complete i.e., intuitive and does not take much time. • Some interns see people at follow-up: it would be in their interest to have a complete and accurate medical history.
Skills User abilities related to the artefact domain and technology	• Need to learn documentation skills on the job, do not have them as they start
CME: continuous medical education | NBU: newborn unit | OT: occupational therapist | POPC: *paediatric outpatient clinic*	

Table 10: The behavioural variables of paediatricians.

Paediatrician	
Activities What the user does; frequency and volume	• Lead CMEs • Lead audits • Supervise interns • Discharge decisions for NBU and paediatric wards • Prescribe medication • Provide referrals to other wards or hospitals • Weekly follow-up at POPC • Speak to mothers • Documentation in the NBU files during follow-ups • Uses notes from previous care [referral, NBU file, discharge summary] when providing follow-up care • Managerial duties including sitting in for the medical director when they are away

Attitudes How the user thinks about the artefact domain and technology	• Unhappy with the discharge summaries when they lack information • Doesn't like the large spaces on the discharge summary – leads to variable notes; prefers tick boxes and spaces for short answers • Hospital 2 – EHRs viewed as an extra piece of work, as the NBU file still must be completed
Aptitudes What education and training the user has; ability to learn	• Medical training, including specialisation • CME • Willing to learn • Previous experience with co-design
Motivations Why the user is engaged in the artefact domain	• The paediatricians see patients at follow-up and end up wasting time getting new patient histories – complete and accurate medical information would save them time. • Mothers also often do not know the condition of their child so the history you get from them is unreliable, it would be preferable to have a healthcare provider write down the history for you.
Skills User abilities related to the artefact domain and technology	• Able to complete documentation accurately and read artefacts quickly to get the information required. • The paediatricians are looking for a way to get interns to document sufficient information for follow-ups not to require new patient histories from parents.
CME: continuous medical education | EHR: electronic health records | NBU: newborn unit | POPC: *paediatric outpatient clinic*	

Step 3: Map interview subjects to behavioural variables

I created **Figure 12** by mapping healthcare providers I observed to key behaviours in the provision of post-discharge care. Each icon in the first three behavioural variables represents a healthcare worker I observed. In the fourth behavioural variable, each icon represents a version of the discharge summary created by a healthcare provider during workshop four. As the map shows, most healthcare providers opted for a completely structured form, though two COIs preferred a less structured form.

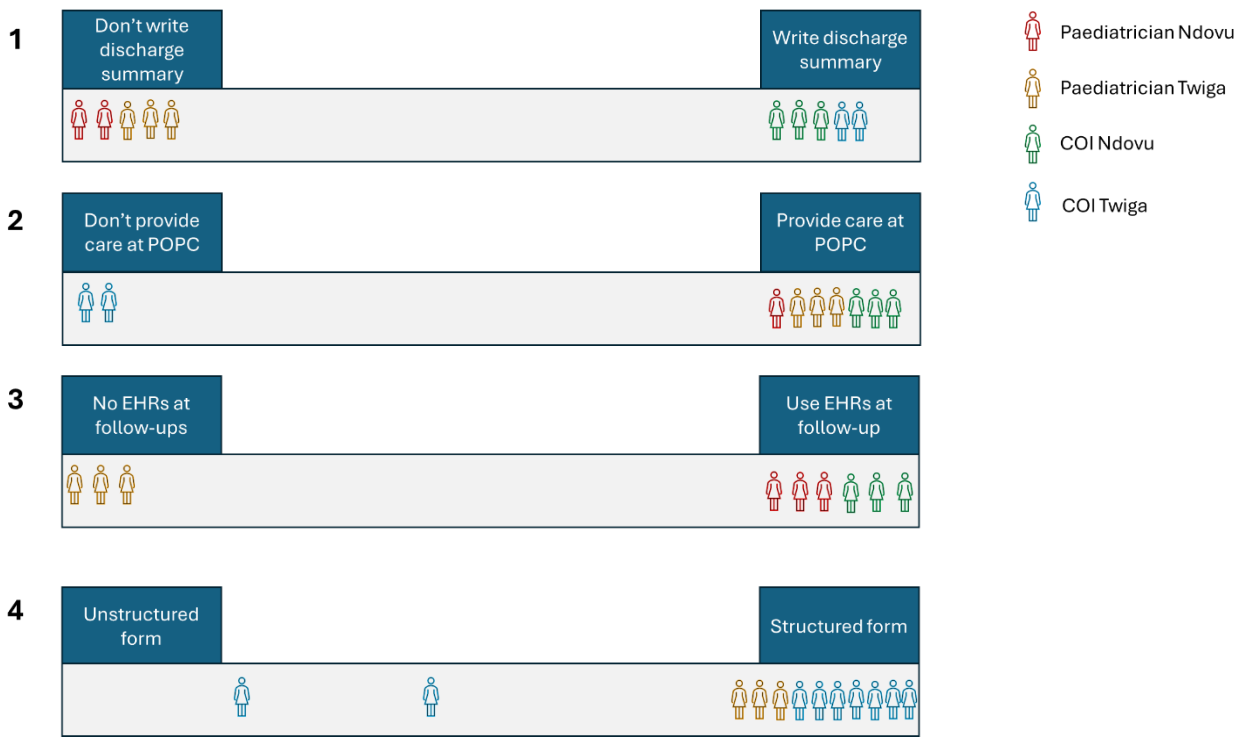

Figure 12: Mapping the behavioural variables of healthcare providers. Each icon in behavioural variables 1-3 represents an observation of a healthcare provider. Each icon in variable 4 represents a version of the discharge summary created by a healthcare provider.

Step 4: Identify significant behaviour patterns

Based on **Figure 12**, there were several distinct behaviour patterns. First, interns were the ones writing the discharge summaries. These summaries were used by paediatricians in both hospitals at the POPC appointments, and by COIs in hospital 4. Another difference was the use of e-records, both COIs and paediatricians in hospital 4 used e-records, whereas hospital 1 did not have them available for POPC. Finally, there was a preference for structured forms, i.e., checkboxes and spaces for short answers, as opposed to blank spaces.

Step 5: Synthesize characteristics and define goals

The descriptions below (Tables 11 and 12) are based on data from observations, interviews and workshops.

Table 11: Characteristics and goals of COIs

Clinical Officer Interns (COIs)	
The behaviours themselves (activities *and* the motivations behind them)	Discharge summaries must be filled before discharge and interns must complete them
The use environment(s)	NBUs are hot, noisy and there are frequent interruptions from colleagues or mothers asking questions
Frustrations and pain points related to the behaviour using current solutions	Unclear what to write on the discharge summary due to lack of training and the form not being intuitive No feedback is provided on documentation, so interns do not learn from their mistakes Interns are on rotations and are constantly learning
Demographics associated with the behaviour	Young
Skills, experience, or abilities relating to the behaviour	No training on documentation, either in university or on the job No experience with documentation No feedback given about documentation
Attitudes and emotions associated with the behaviour	Confusion – interns do not know how to complete documentation Stress because of their workload Deprioritising documentation due to other competing demands, such as providing direct care to babies
Relevant interactions with other people, artefacts, or services	Interns interact with each other for help and support Interns also seek help from other healthcare providers when they are unsure what to do

	Artefacts they interact with: discharge summary, NBU file, e-records [Ndovu], handbooks
Alternate or competing ways of doing the same thing, especially analogue techniques	Discharge summaries must be filled before discharge
NBU: newborn unit	

Table 12: Characteristics and goals of paediatricians

Paediatricians	
The behaviours themselves (activities *and* the motivations behind them)	Providing follow-up care for newborns at POPC – paediatricians want better outcomes for the babies and fewer readmissions Training interns – it is part of their duties to guide interns during their rotations
The use environment(s)	Busy and noisy NBUs Crowded waiting room at POPC Interruptions from interns and mothers asking questions in the NBU and POPC
Frustrations and pain points related to the behaviour using current solutions	Paediatricians are frustrated when they get partially/poorly filled discharge summaries, as they need to elicit a new patient history or spend time looking through the NBU file Paediatricians cannot rely on mothers for an accurate history, as they often do not know their child's condition or the treatment received

Demographics associated with the behaviour	Older, more educated and more experienced
Skills, experience, or abilities relating to the behaviour	Advanced medical training Experience providing care on wards Experience supervising interns
Attitudes and emotions associated with the behaviour	Paediatricians do not view documentation as their job, hence they expect interns to do it Paediatricians have time constraints – they do not check the documents before they are filed and given to mothers; they do not have sufficient time at POPC visits
Relevant interactions with other people, artefacts, or services	Paediatricians interact with each other and COIs when providing care for newborns. They also interact with nurses, OTs and nutritionists in the NBU and at POPC Artefacts they interact with: NBU file, discharge summary, e-records [hospital 4]
Alternate or competing ways of doing the same thing, especially analogue techniques	Paediatricians can use the NBU file instead of the discharge summary to get an understanding of a child's history, but this takes time
COI: clinical officer intern | NBU: newborn unit | OT: occupational therapist | POPC: paediatric outpatient clinic	

Step 6: Check for completeness and redundancy

My personas were distinct as they varied by at least one behaviour, which is a requirement for persona development in GDD (178). I examined my observations, interviews and workshops again, but did not find any additional behavioural traits or characteristics.

Step 7: Designate persona types

My primary persona was Martin, the COI, as interns are the ones required to complete documentation. My secondary persona is Mary, the paediatrician, as paediatricians oversee supervising interns and use the discharge summary to provide care at the POPC visits.

Step 8: Expand the description of attributes and behaviours

Using the data from step 5, I developed the descriptions below of my primary and secondary personas.

Primary Persona: Martin the COI

Martin is a 24-year-old COI in Ndovu in Kenya. He has completed three years of diploma level training in clinical medicine and surgery at a medical training college. He is currently completing his internship, which lasts for one year, and is on a six-week paediatric rotation with some of his friends from college. During this rotation he provides care for babies in the NBU and POPC. Martin is enjoying this part of his internship, but he finds the commute to the hospital long and has not received his salary for the last four months due to delays. He wakes up at 6am and walks to the hospital from a nearby estate where he shares a house with some colleagues. He is meant to be at the hospital by 7am to review patients and prepare for the major round with the paediatrician at 9am. He is always tired during these rounds but does his best to write notes in the NBU file for the paediatrician, who asks him questions to test his knowledge about how care is provided. He listens to the

paediatrician discuss how decisions are made about when to discharge the small and sick newborns. Martin likes working with babies, but he does not spend enough time with them or the mothers to get to know them very well, as he has many tasks to complete.

Once a medical officer intern (MOI) or paediatrician decides that a newborn will be discharged, Martin must write the discharge summary. He has not received any training on how to write these forms at university or during his rotation, so he is learning as he goes. Martin struggles with the forms as he was tasked with writing discharge summaries for actual patients from his first day in the NBU, and he does not receive much guidance or support. There are multiple babies being discharged every day, so writing the discharge summaries is a daily task for Martin. Martin can only ask his fellow COIs for assistance, as the nurses, paediatricians and MOIs are too busy, and they do not view documentation as part of their job description. The form has a large, blank space where he is meant to complete a summary of the care provided. Without adequate training or guidance on what information is critical to write on the form, he is not sure exactly what to write in this space. In addition, he does not have much time for documentation as he has many other tasks to complete while on the ward, including procedures like drawing blood. As such, Martin does not write too much on the forms – he tends to write one or two sentences in the summary space at most, and he sometimes skips sections when he is busy. Instead, he prioritises providing care directly to the babies and speaking to mothers. Martin usually has at least four discharge summaries to write per day, and while he is completing the forms he is interrupted by other interns asking for advice on their forms, and mothers asking questions about their babies. This makes the task of documentation take longer, and he worries that because of the interruptions he may get distracted and make mistakes on the form.

Secondary Persona: Mary the Paediatrician

Mary is a 35-year-old paediatrician working in Twiga in Kenya. She chose to specialise in paediatrics after completing her rotation in the NBU, as she felt very strongly about providing the best care possible for the small and sick babies she saw. Mary met her husband while they were completing medical school at the University of Nairobi. They have a 3-year-old baby girl, called Nancy, who she adores. Mary loves spending time with her daughter, especially reading her stories at bedtime. She lives in a 2-bedroom house about a half hour drive from Twiga. She goes to church every Sunday with her family, and afterwards they get Nancy a treat. Mary has not received her salary for the last two months due to financial challenges within the county government. She therefore needs to do some private practice in her limited free time to supplement her family's income.

Mary has been working in her current role in Twiga for five years. Before this, she was practicing as a paediatrician in a different hospital. In Twiga, she works across the NBU and paediatric ward and provides care at follow-up visits in the POPC. Mary usually starts her day at 9am, where she conducts a ward round in the NBU. Sometimes mothers are present on the ward rounds and ask her questions, and she does her best to answer them in the limited time available. During these rounds Mary takes COIs and MOIs around to see the newborns and discuss their care. She likes to ask them questions about how they would provide care, so that they learn. During the round in the NBU, she decides who is going to be discharged, before heading to the paediatric ward for another ward round there. She is not keen to write discharge summaries and feels documentation could be delegated to the interns as part of their learning process. She also expects the nurses to communicate with the mothers at discharge, as she will not be in the NBU in the afternoon when discharges

occur. She does not have time to check the discharge summaries before the mothers and babies are sent home, and based on her experience in the POPC she knows the interns sometimes take shortcuts and do not fill in the required information, which leads to disruptions in information flow. She thinks the missing information on the discharge summary is due to the discharge summary form not providing enough guidance to COIs on what information is required, and a lack of training on proper documentation. The form has large blank spaces for a summary of care, and the interns often do not write much in this space. She also knows that communication at discharge is not standardised, and nurses or nurse interns may not always pass on every piece of information to the mothers. This means mothers may not know when to come back, what danger signs to look out for, or where to receive care if the baby gets ill before the scheduled POPC visit.

One day per week, she attends the POPC. Mothers are told to arrive at 8am, but she usually shows up to the clinic at 10am as she must attend the compulsory weekly continuous medical education (CME) session or pass by the ward to review a sick baby. There are long queues by the time she arrives, and as a result she does not get much time with each patient. She has her own small space to see patients, which is separated from the waiting room by a curtain. The area can become noisy, and she is sometimes interrupted by interns asking questions, either in-person or on the phone, when they are unsure what to do. She gets a bit frustrated by the constant interruptions. Mary must also document the patient visit on the e-records system, despite having to fill the in-patient file. The e-records system was only added a couple of months ago, and the duplication of work annoys her as she already has too many tasks to juggle. Instead of typing everything onto the e-record system, she only writes the condition of the child and uses it to check what medication is in stock. She advises the parents on where to receive medication if the hospital is out of stock. Mary

gets frustrated when the discharge summary does not have all the information she needs to provide care at a follow-up visit. She either must look through the NBU file, which can be thick, or ask the mother for a patient history, which can be unreliable. Both solutions take time, and mean she has less time to examine the baby or see her other patients. Mary needs to be out of the POPC by midday, so she can make it to the private practice that she works in.

Requirements

To learn more about the requirements of an intervention, I used fieldnotes from my observations in the NBU in Ndovu and the POPC in both hospitals to create context scenarios, which are described below. To create the scenarios, I reviewed my observation notes, and much like the personas, created a composite sketch of a normal day in the hospital. These were sense checked with participants during the second workshop. Context scenarios tell the story of a particular persona using the future version of the developed artefact in a manner that is typical for that persona (178). Based on my observations and the feedback from the workshops, I refined the context scenarios to focus on how the artefact design could help Martin and Mary, the personas described previously, achieve their goals. The process of creating the personas showed that to design an intervention that could be used in both hospitals, it would be pertinent to focus on a paper-based tool, as these were the artefacts currently being used in both hospitals to provide informational continuity.

Step 1: Create problem and vision statements

The following statements are based on the previous steps of the GGD process. The statements define which direction the scenarios should be moving towards.

Problem statement: Informational continuity post-discharge from NBUs is disrupted by an artefact, the discharge summary, not being completed properly, leading to issues with providing quality care at follow-up visits.

Vision statement: The new design of the discharge summary will help guide COIs to complete documentation with greater accuracy and efficiency, removing confusion over what to write on the form. Paediatricians will then have all the information required to provide care at follow-up, reducing the need to elicit patient histories from mothers, which are often inaccurate, and guess about what care has been previously provided. As a result, informational continuity will improve, as will the quality of care provided to newborns.

Step 2: Explore/brainstorm

Initial thoughts for interventions early in the project included e-records and mHealth tools, but for feasibility within the public hospitals "blue sky" thinking was not considered the best avenue, as the infrastructure to make the interventions feasible would not be readily available. Thus, altering an existing artefact involved in informational continuity was considered pertinent and therefore limited to paper-based designs. During workshop 4 the participants chose which artefact they wanted to redesign, and they opted to redesign the discharge summary. They debated between re-designing the referral form and the discharge summary, opting for the latter as they said most referrals end up in the NBU and they previously co-designed the admission summary which was working well. In addition, they acknowledged there were issues with the discharge summary.

Step 3: Identify persona actions

Most of the expectations of the personas can be elicited from the persona descriptions themselves. Below is a summary of what the personas expect from the artefact, their desired experiences of using it, and how they think about the basic elements.

Martin the COI:

Martin is looking for a way to quickly document information, i.e., spend as little time as possible on documentation in the NBU, so that he can spend more time providing care directly to the babies or communicating with their parents. He expects the discharge summary to be intuitive to fill; the process of completing the documentation should feel easy and not stressful. Martin thinks the large spaces for the summary of care are confusing, and he does not know what information to put in this section, as he has no previous training or experience with documentation and has not received feedback about previous forms that he has completed.

Mary the paediatrician:

Mary expects the artefact to contain complete, concise and easily readable information about newborn patients so that she can conduct a thorough follow-up visit and provide quality care. She wants her experience of providing care at a POPC visit to be seamless so she can use the discharge summary to understand what care the baby received in the NBU, without needing to refer to the NBU file. Mary thinks checkboxes and spaces for short answers will ensure the forms are completed and are easier to read at follow-up visits. She also thinks COIs need to be careful to write legibly and there needs to be a mechanism to provide feedback to the interns, so they improve their documentation skills.

Step 4: Construct context scenarios

In this section I will provide two context scenarios for each persona. Context scenarios are stories about how the persona will use a future version of the artefact in a way that is typical for that persona.

Context scenario 1: COI – primary persona

- Martin is on a paediatric rotation in the NBU. He is told by the paediatrician that four babies will be discharged today, and he will need to complete the discharge summaries for each of them.
- Martin brings the NBU files of the babies being discharged to the desk which MOIs, COIs and paediatricians use for documentation. These files will be used to complete the discharge summary. A carbon copy of the summary is kept in the NBU file, and one discharge summary will be given to the mother. The NBU file number is only written on the discharge summary, so the mother needs to bring it back at follow-up for her baby's file to be retrieved for the visit. There are three other interns with Martin, each completing their own discharge summaries, but sitting together at the desk.
- The file Martin has is thick, the baby was admitted to the NBU for over a month as the baby was pre-term and had a low birthweight. He is worried that providing a summary of the baby's care will be difficult. As he starts filling in the discharge summary, he notices that it consists of tick boxes and spaces for short answers in the diagnosis, treatment, and follow-up care sections. In addition, he finds the summary is succinct, i.e., there is no space for unnecessary information. As such, Martin knows what information needs to be filled, and he does not take long to complete the form.
- At a couple of points Martin is unsure what information to write. For example, the baby was on and off oxygen during the duration of their admission and he cannot see the date that the baby stopped receiving oxygen. He speaks to another COI who helps him and advises Martin to record the days based on the last date that oxygen was provided to the baby, as sometimes people forget to explicitly write that oxygen treatment has stopped. One intern is confused about what to note down as the primary condition, and Martin advises that they write down the condition with which the baby was referred to the NBU.
- After completing the first discharge summary, Martin moves on to the second discharge summary. This baby developed neonatal sepsis and was hospitalised for seven days, so their file was not long.
- Martin can complete the discharge summary quicker than the previous one, as there were fewer details to note down. The checkboxes and spaces for short answers in the diagnosis, treatment, and follow-up care sections of the form helped guide him on what information to include, and he has gained a bit of confidence after completing the previous discharge summary.

- Martin finds it easy to note the treatment provided as there is a separate antibiotics section, which is intuitive. The treatment and antibiotics sections include a column where the duration of each of the treatments is meant to be noted, which makes it clear what care was provided to the baby during their admission.
- Martin completed the remaining two discharge summaries and before the discharge summaries are given to the mothers an MOI looks over the documents to ensure the details are correct. She tells Martin that he has forgotten to complete a couple of data points on the sheets; she explains that even if the baby never received the treatments listed, he still must circle the "No" option.
- Martin makes the necessary changes and is grateful for the feedback. He will not make the same mistake in the future. The discharge summaries are given to the nurse, who uses it to complete the discharge discussion with the parents.
- As Martin spends less time than expected on the paperwork, he can complete the blood draws he is meant to do in a timely manner and follow up on radiology reports.

Martin is looking for a way to quickly document information, i.e., spend as little time as possible on documentation in the NBU, so that he can spend more time providing care directly to the babies or communicating with their parents.

Context scenario 2: Paediatrician – secondary persona

- Mary has just arrived at the POPC after attending the weekly CME. She finds a long queue of patients in the waiting room. She goes into the room where she conducts follow-ups. The NBU files for the patients she needs to see have been brought to the room by a nurse.
- Mary opens the first file and calls in the mother. Based on the size of the file Mary knows the baby was admitted to the NBU for a while. She is worried the baby will have a complicated history. This is the baby's first visit back to the hospital after being discharged.
- When Mary reads the discharge summary, she finds it provides a succinct, detailed, and accurate description of the care received while the baby was in the NBU. Despite being admitted for a long time, Mary can clearly tell the history of the child. Due to the layout of the form, she can see that the baby was initially admitted because of being pre-term and low birthweight, then later developed sepsis during the admission. The baby received CPAP (continuous positive airway pressure) and oxygen throughout their admission, and second-line antibiotics as treatment for sepsis. The form shows that the baby was then discharged when well and healthy two weeks ago.
- It is just the mother and Mary in the room, so Mary can ask questions in privacy. Mary asks follow-up questions based on the baby's history, such as whether the baby can breastfeed or has any difficulties breathing. The mother has good knowledge of the child's condition, and the follow-up care required. She asks Mary about the supplemental medication and is concerned about whether she is breastfeeding correctly.

- Mary has enough time to ask the mother to demonstrate how she feeds the baby and provides some advice on positioning and the mother's nutrition. Mary also advises the mother about supplemental feeding, i.e., expressing milk and feeding the baby via a cup.
- The mother thanks Mary for her time and does not have any other follow-up questions.
- Mary documents the discussion notes in the NBU file then calls in the next patient. The discharge summary having all the information required for a quick follow-up saved her time and made the follow-up quicker than she expected.
- The next mother comes in with her baby. The discharge summary shows that the baby had congenital clubfoot and had been referred to another facility for surgical correction. The baby is returning for their third follow-up visit as they had poor weight gain. The discharge summary is complete and has a report from the referral facility. Mary can easily see the baby's condition. She feels she has a good understanding of the baby's history and goes on to ask the mother some questions about the care she is providing at home.
- Mary sees from the baby's history and examination that the baby has delayed milestones and refers them to the OT department for therapy.
- Mary can see from the discharge summary that the baby was meant to be given calcium supplementation for one month. She asks about the supplements, and the mother seems confused; she said she only gave the baby calcium for two weeks.
- Mary says the supplements are meant to be topped up during follow-ups and learns that there was a stockout at the hospital. She gives the mother a prescription to get the calcium from a nearby drugstore.
- Mary has some time left at the end of the appointment, so she asks the mother if she has any questions or queries. The mother says she does not, and Mary thanks her for coming to the appointment. Mary then calls in the next patient.

Mary is looking for a way to receive complete, concise and easily readable information about newborn patients so that she can conduct a thorough follow-up visit and provide quality care.

Step 5: Identify design requirements

Design requirements are extracted from context scenarios and are separated into data, functional, and contextual requirements.

Data requirements

Data requirements are the information needs that should be met by the artefact. During the workshops, the paediatricians and MOIs said the discharge summary needs to contain

the following information for the newborn: name, age, file number/IP number, mode of delivery, health conditions [primary and secondary], duration of admission, treatment received during admission, date for POPC, other clinics required for follow-up, medication given on discharge, and signature.

Functional requirements

Functional requirements are the places where the information must be displayed. The discharge summary should contain all the data requirements and must be one page only, on an A4 sheet of paper. The discharge summary should not have large blank spaces for unstructured writing; instead, there should be spaces for short answers and checkboxes. A copy is given to mothers, and a copy is kept in the NBU file.

Contextual requirements

Contextual requirements include considerations about the physical environment, and the skills and capabilities of the personas using the artefact. The discharge summary needs to be easy to complete in a busy and noisy environment (the NBU). As Martin had likely not had training on documentation, the form must guide him with the prompts and layout. Martin should be able to get the relevant information from the NBU file and accurately summarise it in the discharge summary. Mary should be able to read the discharge summary at a POPC visit, where there are time constraints and it can be noisy, in a couple of minutes, and have all the information she needs to understand the child's history and what care they require at follow-up. As a trained paediatrician with experience, this should be easy if the form is completed correctly.

Framework

As described above, during workshop three and four we asked healthcare providers which forms they thought it would be most useful to redesign, and the paediatricians chose to redesign the discharge summary. The paediatricians mentioned that newborn follow-up was conducted by paediatricians and interns were tasked with writing the discharge summaries. The redesigned form can be considered a two-sided intervention: the form contains the necessary information for the paediatrician at follow-up and acts as a guide for the COI during discharge.

A design framework includes the underlying organising principles and the arrangement of functional elements on the tool, interactive behaviours and the visual format used to express information (178). I developed the design framework by compiling the findings from the previous stages of the GDD process, i.e. research, modelling and requirements, and workshop four. Paediatricians and MOIs participated in the fourth workshop and discussed the physical characteristics the discharge summary required to meet their information needs. The workshop started by asking what information paediatricians and interns would require when seeing newborns at follow-up. Afterwards, the paediatricians thought it would be most helpful to examine the existing discharge summary and see how it could be better adapted, rather than starting the design process from scratch. The paediatricians mentioned that sometimes discharge summaries were not adequately filled, and instead they would refer to the admission summary within the NBU file.

"… because even the current information [for the discharge summary] is not so much, yet it is not filled. So, we want to find out what is the problem, why aren't we filling everything. But the discharge summary is definitely a problem." **Paediatrician, Twiga**

The paediatricians said the discharge summary needs to provide a summary of the baby's stay in the NBU that can be examined at follow-up, and that paediatricians should not need to keep referring to the notes in the NBU file to get the information needed. Their recommendations for the re-designed discharge summary included:

1. Removing large blank spaces, and instead providing direction on what needs to be filled
2. Using a checklist format
3. The APGAR (Appearance, Pulse, Grimace, Activity, and Respiration) score being included in the form
4. Taking learnings from the success of the admission form, such as not requiring too much writing
5. Keeping the discharge summary as a one-page, one-sided document, as it needs to be carbon copied and added to the NBU file

Figure 13 shows some of the prototypes the healthcare workers produced when redesigning the discharge summary in workshop 4.

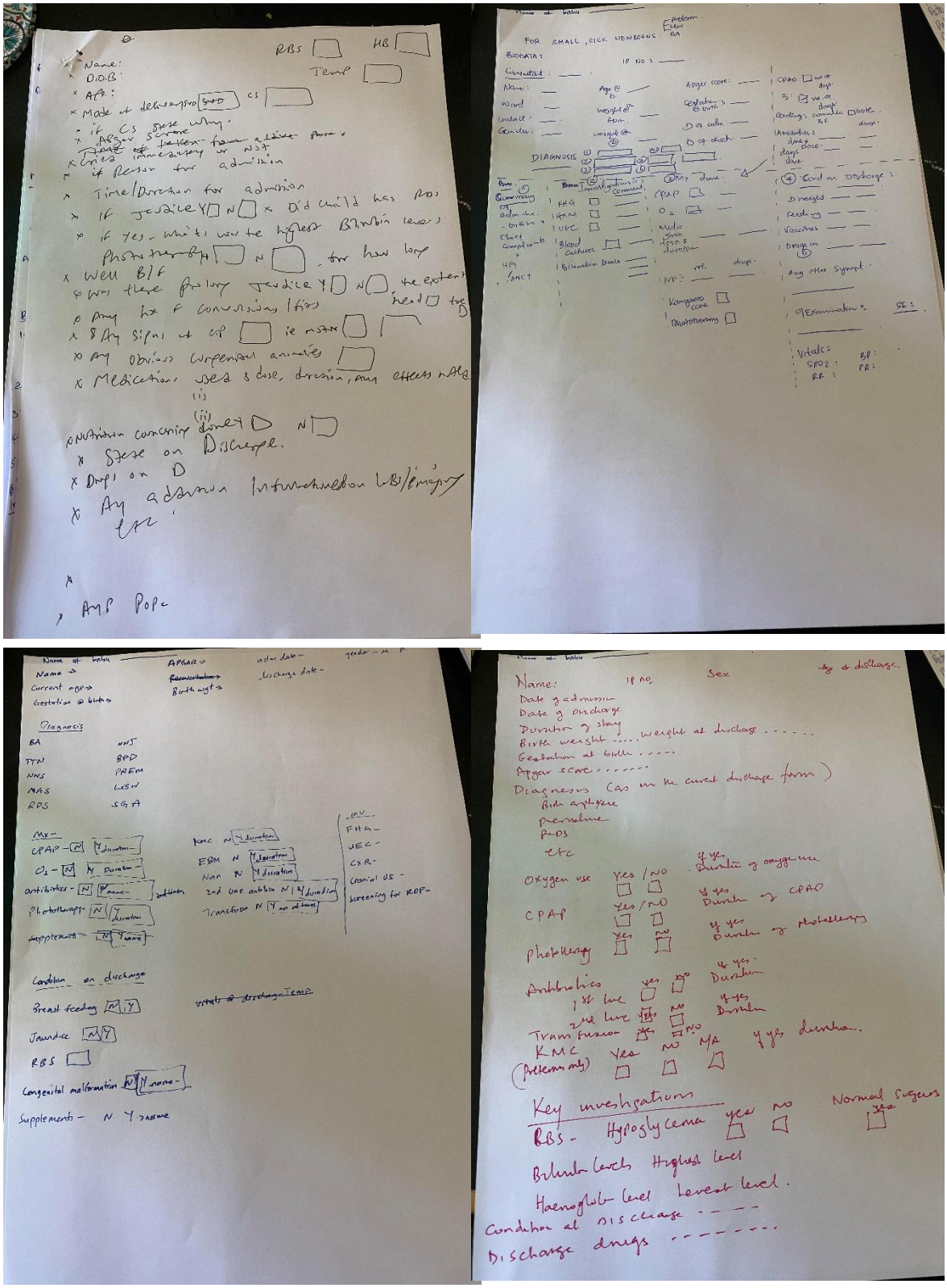

Figure 13: Examples of the prototypes of the discharge summary created by healthcare providers in workshop 4

The discharge summary I redesigned based on the GDD process and feedback from workshop four is shown in **Figure 14**. The discharge summary was tested in workshop 5.

NBU Discharge Summary

Name: IP No.: Sex: M/F

Age at discharge (days): Date of admission: Date of discharge:

Duration of stay (days): Birth weight (g): Weight at discharge:

Mode of delivery: Gestation age: Apgar score (1, 5,10):

Sero-exposed: Y/N ARVs started: Y/N

Neonatal Diagnoses

Primary diagnosis at admission (put 1), secondary diagnoses (put 2 for all that apply)

Prematurity		Birth asphyxia		Meningitis		BPDysplasia		
Newborn RDS		Meconium aspiration		Anaemia		Encephalopathy grade		1 2 3
Neonatal sepsis		Jaundice		Multiple delivery		Other diagnosis		

Treatment

Oxygen	Y/N	Duration (days)		KMC	Y/N/NA	Duration (days)	
CPAP	Y/N	Duration (days)		Transfusion	Y/N	Duration (days)	
Phototherapy	Y/N	Duration (days)		Nutrition counselling	Y/N	Duration (days)	
Mechanical ventilation	Y/N	Duration (days)		Exchange transfusion	Y/N		
OT/physio	Y/N			Surgery (If Y, specify)	Y/N		

Medication	**Y/N**	**Medication name**	**If yes, duration (days)**
1st line antibiotics	Y/N		
2nd line antibiotics	Y/N		
Other	Y/N		

Follow-up care

POPC date:	
Other follow-up care (include clinic and date, e.g., OT, nutrition, lab tests, surgical clinic, HIV clinic):	
Discharge drugs	

Name: Signature:

Designation:

Figure 14: Mock NBU Discharge Summary. The original discharge summary is provided in Chapter 4.

During the fifth and final workshop I tested the redesigned discharge summary. I visited hospital 1 with the HIGH-Q project manager from KEMRI-Wellcome Trust Research Programme (KWTRP) Ken Karumba, who had done community engagement with each of the hospital sites and built relationships with the facility staff. A couple of days before the workshop we had requested two files from the nurse-in-charge of the NBU, one baby with birth asphyxia (BA) and another who had been admitted for longer and therefore had a thicker file. These were two common scenarios I saw during data collection, and I wanted to test how the form could be used for them. Paediatricians, COIs and MOIs were present for the workshops.

During the workshop I emphasised that all feedback was welcome, that the form was a first draft, and that the aim was to make it as useful as possible to the people filling in the form. The COIs were happy with the key investigations section being removed, as they said it was confusing, and they were unsure what to say in that section as the condition of the child can change daily. They also said the form was more comprehensive, easier to fill, and captured common conditions in the NBU. One COI said the form makes life easier for the person at follow-up as it is “a screenshot of how the baby is”. However, despite being comprehensive and saying it would save time for the provider at follow-up, the participants said it would take time to fill for the person writing the discharge summary in the NBU. I noticed that the interns filling the discharge summary for the larger NBU file had to flip through the file and have discussions amongst themselves more often than the group with the smaller NBU file. As a result, they took longer to fill the discharge summary.

The participants had some feedback on how to improve the redesigned form. Minor feedback included clarification on whether supplements counted as “discharge drugs” and

providing more space for the section on discharge drugs. The COIs also wanted space for additional information, such as relevant tests and investigations, and a section for vaccinations, as those who are in the NBU for over six weeks may not have their MCH handbook filled with vaccinations. The final suggestion was changing the metric for transfusions from days to number of transfusions. Some of the information the COIs wanted the form to include, such as the mother's diagnosis, should be available from other sources.

The COIs pointed out that filling in the number of days for treatment can be difficult as they need to look through the notes in the NBU file which can be time consuming. They also said that people may not make consistent notes about the provision of treatment, and therefore they must make assumptions that an intervention has been stopped when it is no longer noted in the file. Further discussions around this section and the relevance of the duration of treatment could lead to a refined version that is more straightforward to fill and less time consuming. One COI highlighted that the discharge summary takes time to fill when the NBU file is thick, saying "If you have 10 discharges in a day it will be hectic to fill the nitty gritty". Similarly, I noticed that one of the COI groups working on the thicker NBU file filled in the discharge summary quicker than the first group but missed some information. A COI in this second group admitted that he had miscalculated the duration of the hospital stay after looking at his colleague's form. To avoid such errors and documentation on the form taking too much time, further iterations and training would be required.

Discussion

Based on the findings from Chapters 2 and 3 and the first two workshops, there were a variety of challenges raised with promoting care continuity. Addressing the larger scale

issues, such as healthcare workforce shortages and the poverty experienced by mothers, are important but were not feasible within the scope of this project. However, there were existing system-based issues which could be improved, without vastly increasing the cost of care and at the same time potentially reducing workload for healthcare workers. One of the recurring issues from the data was communication between healthcare workers. Informational continuity between healthcare providers was often disrupted by missing or incomplete documentation. Other studies have tried to address the documentation issues by redesigning forms used in the NBU with healthcare providers in Kenya (61, 62). One study in Angola also used participatory workshops to design and implement a mother and child health (MCH) handbook; the workshops were with key stakeholders, including frontline staff, technical advisors from global organisations, and the Ministry of Health (MoH) (60). A systematic review on MCH home-based records in LMICs suggested that involving frontline healthcare providers in the design of new records, or re-design of existing records, would enable their use in routine practice (311). While simply redesigning forms will not be a solution to all the issues at hand, it is a start to improving information flow and communication, which can improve care continuity.

This chapter focused on the redesign of the discharge summary in conjunction with the COIs, MOIs and paediatricians from Twiga. The redesigned form was created with a focus on existing practices, as I wanted the discharge summary to match the interns' and paediatricians' current behaviours and mental models (178). My findings showed that COIs complete the discharge summary, but experience challenges with time constraints, being unsure what information to write and receiving minimal supervision or feedback. This is consistent with research in Malawi which showed that the time taken to complete forms

was an issue, with the average electronic admissions form taking 37 minutes to complete, and disruptions from fellow healthcare providers were common (312).

My findings showed that like the COIs, paediatricians also experience time constraints and are frustrated by disruptions to informational continuity at the POPC. Issues around completion of documentation in LMIC settings have been noted in other studies, with another study in Malawi showing that over half the documents for a paediatric audit had deficiencies (313). If information is easier to access at the POPC visits, the paediatrician may be able to spend more time with the mothers and babies. One observational study in Israel found that the more time a clinician spent reading and documenting on an information tool, the less time there was for dialogue with patients (314). The lack of dialogue deters relationship building, which is important given the anxiety most mothers face over their children's care.

The introduction of a new form warrants training on how it is expected to be completed before introduction into NBUs. The literature suggests training on documentation could be done pre-service (315, 316), or post-service (60). Continuous training on ward specific documentation is important in the Kenyan context, as the COIs who are charged with completing the discharge summaries are on rotation. One study in Kenyan NBUs conducted training using sample-filled paper-based charts, a poster, a training sheet describing all the fields on the inpatient chart, and a slide deck to be used by nurses to train staff (317). This approach could be adapted for the discharge summary. In addition, the COIs do not currently receive any feedback or behavioural redirections when completing the form. A study on the implementation of a newly designed MCH handbook in Angola emphasised the importance of monitoring and supervision to review the recording in the handbook and

assess user acceptance (60). Use of a paediatric admission record in Kenya was improved by ongoing training sessions and feedback, though active supervision was suggested to address the issue of people delaying training attendance (318). Adding a mechanism whereby the discharge summaries are checked by an MOI, paediatrician, or nurse before being given to mothers and placed in the NBU files, would help flag issues in situ and provide learning opportunities for the COIs. Feedback could also be provided to hospitals on their documentation practices. For example, after implementing a standardised paediatric admission record the CIN hospitals had audit reports with indicators on documentation sent to hospitals every 2-3 months showing how well the hospital was doing and how it compared to other hospitals (319). Using the admission record and audit and feedback led to improved documentation of clinical signs for babies aged 2-59 months (319).

In this chapter I discussed several changes to the discharge summary that were suggested by the COIs and paediatricians, including removing large spaces for notes and replacing them with spaces for short answers and checkboxes, and showing the history of care provided in the NBU. Structured forms have been shown to improve the quality of documentation (96, 318), and have been associated with increased generation of useful data when compared to unstructured forms (320). One study in Nigeria and Cote D'Ivoire found similar preferences for checkboxes to save time during documentation (63). After testing the newly designed form with these changes, the COIs had further suggestions such as increasing the amount of space available for the discharge drugs. They also highlighted that writing the number of days a baby has been on treatment would be difficult, as this would take time to calculate, and some people do not document when treatment has ended. This feedback is important in ensuring the form is intuitive, meets current needs,

and does not take too much additional time to complete (63). A scoping review on the design of paper-based inpatient charts found that design issues discovered during piloting could have been minimised or averted by using a systematic design approach and considering users and their context (294). Before a new discharge summary is implemented, I would suggest further rounds of refinement and completion of the final stages of the GDD process. I was unable to complete the process as I prioritised spending time in the hospitals to build an understanding of the discharge and post-discharge process, and building relationships with the healthcare providers so they were engaged with my work.

GDD has been used in other studies to improve mHealth by focusing on the goals and needs of users (186, 187, 321). To the best of my knowledge, this was the first instance of GDD being used to inform the development of a paper-based tool. The methods employed during the GDD process (ethnography, personas, and context scenarios) are suited to the design of a paper-based tool as they focus on user needs and the implementation context. One other study described how using personas helped to guide the design of an mHealth app by focusing on functionality and ensuring this met the needs of an elderly population (186). Another study observed how a prototype of their mHealth tool was used by children and used data from interviews with the children to improve their tool (187). Besides the qualitative data I collected, I used participatory workshops to ensure my findings were aligned with the needs of healthcare workers.

While personas can be a useful tool, there have been several critiques to the approach. Personas are created by designers or researchers, and can therefore be biased, and used to justify preconceptions and stereotypes (322, 323). There are also concerns about the

validity of personas and how representative they are, as the data they are based on may be insufficient or biased (324). Another common criticism is that creating good quality personas takes time, and personas are often ignored in the design process (323). However, by following a well-defined process, using in-depth qualitative research, and sense-checking findings with healthcare providers, I have mitigated many of these pitfalls.

My findings show that engaging healthcare workers in the participatory design of artefacts that are critical to their work is well accepted and can improve the functionality of the artefact. One study on routine data collection tools for malaria in Kenya echoed these findings, showing that involving frontline staff in the design of the data collection tools, or artefacts, could significantly improve their relevance and utility (66). Previous studies have found that using participatory design can build a sense of ownership (67), and shift healthcare provider's perspectives about artefacts and their importance (63). Other studies have employed similar approaches, i.e. observing how coordination work is conducted before designing an artefact (63, 325). However, the design process was a balance between ensuring the artefact had sufficient detail while also being conscious of the time available for documentation, and the environment in which documentation is completed (61).

Participatory workshops can provide crucial insights for design, but they are not a panacea. A major criticism of participatory workshops is that it can serve particular participants while ignoring others (48), with those who are more vocal being favoured. Participatory design should focus on those who are underserved and less powerful to ensure the specific challenges they face are met (326). What participants say in a workshop may not be a viable solution and incorporating their feedback into existing theoretical and empirical research can be challenging (283). Power dynamics also have an important role, which is rarely

explicitly discussed (327). The level of engagement is often at the discretion of the researcher, who may favour their own ideas over those of the "end-user" (52). Another tension can be understanding the current processes and designing a different system (52), with participatory design being dubbed as "evolution not revolution" (48).

I addressed these challenges by reflecting on my positionality, as discussed in Chapter 2, and trying to encourage participation from a wide range of healthcare providers, including interns. I kept participants engaged by sense-checking my findings with them in workshops and receiving their input in the design of the discharge summary.

It is worth noting that design requirements include budget and resource constraints (178) (328). Long-term sustainability of an intervention, including ongoing costs and maintenance costs, is an important consideration and those in charge of finances need to be engaged (124, 326, 329). In one study development partners paid the printing and distribution costs for the MCH handbook (60), an approach which is not sustainable long-term. In Kenya, post devolution it is counties that pay for the forms used within the hospitals, and stockouts are a common issue (66, 317). There have been instances of national stockouts of the MCH handbook in Kenya between 2014-2016 (330), and the literature suggests these issues are linked to vulnerable financing mechanisms (331). This reality limited the discharge summary to a one-page form that could be easily duplicated.

In this chapter I described the results of the goal-directed design process, which combined the qualitative research from the previous chapter and my scoping review with participatory design workshops. I created two personas from the data, Martin the COI and Mary the paediatrician, and described a typical day at the hospital for each of them. I then created two context scenarios, which depicted the way the redesigned discharge summary

would be used to improve Martin and Mary's work. Healthcare providers opted to re-design the discharge summary, and I took their input and created a redesigned discharge summary, which was tested with COIs. They provided feedback on what they liked and potential alterations. In the next chapter, I provide a summary of the findings from my thesis, discussion and conclusion.

Chapter 6: Discussion

Introduction

In this final chapter I will provide a summary of my findings, discuss contributions to the research literature, the strengths and limitations of the study, implications for policy and practice and suggestions for areas for future research. I will then provide a brief conclusion.

Summary of findings

In my thesis I aimed to explore how continuity of care for small and sick newborns post-discharge may be better supported within the Kenyan health system. To achieve this aim, I organised my research around three overarching research questions:

1. What types of interventions, innovations or support mechanisms have been used to support continuity of post-discharge care for newborns in LMICs?
2. What continuity challenges do healthcare providers encounter when providing post-discharge care for babies born small or sick in Kenya?
3. How can participatory design inform improvements on documentation artefacts used to promote continuity of post-discharge care for small and sick newborns in Kenya?

As explained in Chapter 1 my work drew on three distinct bodies of literature: continuity of care, and particularly the typology by Haggerty et al. (19); sociomateriality as the study of the entanglement of material artefacts with institutions, norms, discourses, and all other phenomena typically defined as social (34), and participatory design to place emphasis on involving the people who will use an artefact. In Chapter 2 I described the qualitative

methods I used to answer my research questions, described the study sites and discussed my positionality and how this affected my research.

In Chapter 3 I presented the findings of my scoping review on the types of interventions, innovations or support mechanisms have been used to support continuity of post-discharge care for newborns in LMICs. In conducting the review, I primarily drew on the continuity of care typology by Haggerty et al. (19) and extended this to include 'interpersonal' continuity, defined as continuity achieved through relationships between healthcare providers, family members and mothers and the wider community. Coordination between healthcare workers is not a novel concept (20, 21), but considering the relationship between family and the wider community is especially important in LMIC settings, where mothers often do not have the final say in care-seeking (228, 229, 251, 258). The review showed there was limited attention to interventions specifically targeting small and sick newborns. Most interventions included in the review focused on informational continuity between healthcare providers and mothers and used home visits by CHWs to improve care continuity. The scoping review also showed that participatory approaches were not often used, and when they were they were not described in adequate detail.

In Chapter 4 I provided my analysis of qualitative data from two county referral hospitals in Kenya, where I conducted 92 hours and 88 hours of observations in various wards in Ndovu and Twiga respectively. My qualitative data included 19 interviews with healthcare workers, supplemented by interviews with 18 mothers, including two mothers who were followed up via phone calls, and three key informants. I conducted a reflexive thematic analysis of the qualitative data and used the extended typology for continuity of care created in Chapter 3 to frame my findings. The chapter focused on the continuity challenges

healthcare workers encountered when providing post-discharge care for babies born small and sick in Kenya. I argued for the importance of understanding continuity in post-discharge care as a sociomaterial practice involving an assemblage of people and artefacts. The material properties of these artefacts affected informational continuity, which in turn affected other continuity domains. For example, management continuity required coherent management of a condition, which could only be achieved when an accurate patient history was provided. In addition, there was limited time available at POPC visits, and if there were breaks in informational continuity healthcare providers had to spend time eliciting a patient history instead of examining the baby and building a relationship with the mother, which affected relational continuity. Interns were charged with documenting on discharge summaries, and this artefact was not checked before being given to mothers, nor were interns given feedback about their documentation skills. Paediatricians were meant to be use the discharge summary at follow-up and were frustrated when poor documentation led to disruptions to informational continuity. There were multiple facilities and cadres involved in post-discharge care of small and sick newborns, and communication between these groups was poor. In Chapter 4 I also presented two stories synthesised through interview data and fieldnotes to highlight the impact that discontinuity of care has on families, which showed that mothers were important care providers and integral to the provision of continuous care. The stories highlighted the importance of interpersonal continuity, with mothers being the sole providers for their children and facing difficulties both financially and emotionally. When thinking about potential interventions to support post-discharge care continuity, the complexity of the issue meant that one intervention alone would not solve all the challenges, but that informational continuity between healthcare providers could be improved by better design of documentation artefacts.

Informational continuity was the focus of most interventions in the scoping review (Chapter 3), but I chose to do this using participatory design, which was a method less commonly applied.

In Chapter 5 I addressed my third research question on how participatory design could be used to inform improvements on documentation artefacts used to promote continuity of post-discharge care. I described the results from the goal-directed design (GDD) process, which is used in product development. I followed the first four steps: research, modelling, requirements and framework. The GDD process included my scoping review, qualitative research and five participatory workshops with a variety of healthcare providers from both hospitals, including paediatricians, clinical officer interns (COIs), medical officer interns (MOIs), occupational therapists (OT) and OT interns. My qualitative work showed that informational continuity between healthcare providers was a challenge, thus I focused on redesigning a key artefact in post-discharge care, the discharge summary. This artefact was used to provide a summary of the care received in the NBU to orient healthcare providers on what care was required at follow-up. I used the interviews with healthcare providers and observations in both hospitals and the data from the first two workshops, which included paediatricians and COIs, to build two personas, Martin the COI and Mary the paediatrician, which guided my redesign of the discharge summary. The redesigned form focused on being short and easy to fill for COIs and provide adequate information in a readable format for paediatricians at follow-up. To achieve this, the redesigned discharge summary had no large spaces for notes and instead had checkboxes and sections for short answers. I tested the redesigned form with COIs using two real cases from the NBU and received feedback.

Personal Reflections

As mentioned in my positionality section in Chapter 2, I was familiar with qualitative research and research on healthcare in Kenya before embarking on the DPhil due to my previous work experience. However, over the course of this study, I gained skills in design research and application of participatory methods. My skills as a qualitative researcher developed with practice, and I felt a noticeable difference between my first and second round of data collection. I had not previously worked on projects with children under the age of five, and my understanding of newborn and child health grew. My understanding of continuity of care evolved over time. Conducting the scoping review extended the Haggerty et al. (19) typology on care continuity to include interpersonal continuity, which made me consider the context in which the newborns were being discharged, and how this could affect their care-seeking journey. For example, I learned during my empirical work the effects that lack of support can have on the mothers and newborns and realised this was an important aspect of care continuity. In addition, I learned to think in a more theoretical way and not assume that the presence of tools alone can bring change, as they are embedded in sociomaterial practices.

There were some findings that I did not expect, given my previous experience. I expected documentation to be checked by a nurse or paediatrician before being given to mothers or placed in the NBU file, especially as these were small and sick newborns. I was surprised by how much direct care was provided by interns, whether COIs, nurses or in the OT wards, and how little supervision was provided. I was also surprised that documentation skills were not taught to interns before they started providing direct care to patients.

By spending time on the various wards, I saw very sick babies, which was distressing at times. Visiting homes was emotionally challenging, as I could see the poverty and difficult circumstances in which mothers tried to provide care continuity. It was hard to hear how the mothers struggled as their partners had left them to cope alone with a very sick child, particularly when mothers would reach out to me or the research assistants after interviews to request additional financial support. The fortnightly debriefs held by the HIGH-Q team provided outlets for discussing these challenging issues as they arose, and having other DPhil students in similar positions provided an informal support network.

As a result of this research my understanding of the complexity of health systems deepened, as even a seemingly simple paper-based intervention is incredibly difficult to design, implement, evaluate and sustain. I knew the conditions in which healthcare workers worked were difficult, but this project showed me how strained they were for time and resources, and how they try their best despite the difficult circumstances. In the future, as a researcher I expect the work I conduct to be influenced by this study, as I will continue to be a proponent of the importance of understanding the system in which an intervention is being implemented, including both human and non-human artefacts, and using participatory design.

Contributions to the research literature

This research contributes to several bodies of literature spanning post-discharge care, continuity of care, sociomateriality, and participatory design.

As discussed in Chapters 1 and 3 the journey for babies born small or sick post-discharge from the NBU has not been well documented (16, 78, 154). To address this gap, Chapter 3 presents a detailed account of how post-discharge care is currently organised, drawing on

interview and observational data from two public county referral hospitals in Kenya. Complementing this systems-level perspective, I included stories from two mothers whose babies required long-term care. These stories illustrated how breakdowns in care continuity affected families and provided the background against which I described the challenges faced by healthcare providers in providing care continuity.

While existing literature predominantly focused on the experiences of mothers and parents, (24, 32, 33), my work foregrounds the often-overlooked perspectives of healthcare providers involved in delivering post-discharge care. By addressing this gap, my work provides valuable insights into how post-discharge care for babies born small or sick was organised, and the challenges faced by healthcare providers. Although my findings were rooted in the Kenyan context, the challenges identified, such as fragmented referral systems, weak communication between providers, and limited support for families, are likely shared across other under-resourced health systems. Similar dynamics have even been documented in high-income countries; for instance, a study in the United Kingdom found that parents of children with complex health needs often assume a coordinating role across fragmented services, and that financial and peer support play an important role in their caregiving capacity (332).

My research also contributes to conceptual literature on continuity of care, which has historically been shaped by frameworks developed in high-income settings (19, 21, 23). I drew on Haggerty et al.'s widely used continuity of care typology to inform my analysis (19), and provided a powerful extension by adding the concept of interpersonal continuity. The concept of relationships between healthcare providers being an important part of care continuity is not novel and is referred to as care coordination or team continuity (21).

However, the addition of relationships between patients, in this case babies and their mothers, and their other family members and relationships between patients and community members being key for care continuity was a useful addition to the typology. This extension is particularly salient in contexts where conditions such as low birthweight or cerebral palsy may be stigmatised, and where caregiving decisions are influenced by individuals beyond the mother, such as fathers or in-laws (228, 229, 251, 258). In Chapter 3 I described how these patriarchal systems can hinder care-seeking and therefore care continuity for mothers. By extending the continuity of care framework to account for these relational dynamics, my research offers a more culturally sensitive model that may be relevant in LMICs. This model can be used to better inform interventions to improve post-discharge care continuity by focusing on things outside of clinical care, such as improved care coordination and support mothers – which are described in further detail in the implications for policy and practice section below.

In addition, my research advances sociomaterial understandings of continuity of care by bringing together an analysis of social and material practices and applying this lens to an LMIC context. My research has built on previous studies which have used a sociomaterial lens for continuity of care. For example, a study in Canada found that assemblages of human and non-human actors enabled teams to work together as patients moved through the system (37). A study in Sweden showed that the presence of the right people and artefacts was not enough, and sustained work was required for care continuity to be enacted (43). While most studies focused on high-income settings (37, 38, 43), I applied this lens in an LMIC context, framing post-discharge care continuity as a sociomaterial practice. This perspective shifts the focus away from common narratives of workforce shortages (22), or implementation of innovative new technology (287), and towards a more

grounded consideration of the artefacts currently used by healthcare providers. This application of a sociomaterial lens to a resource-constrained setting is important, as it shifts the focus from human factors alone, to non-human factors such as artefacts, guidelines and the space in which care is provided. In addition to enabling consideration of the material artefacts used to enact care, sociomateriality is closely linked with participatory approaches and centres how artefacts are designed and for whom. In this context, the sociomaterial perspective encouraged exploration of what could be improved within the existing system, i.e., the discharge summary, rather than introduction of a novel artefact. While systems theory can be useful at shifting the care perspective from individual cases and healthcare providers to the wider system that provides care (333), it does not draw enough attention to artefacts, and how they are involved in assemblages with human actors to produce care continuity. As such the sociomaterial perspective is a useful lens, as it shows improvement of post-discharge care should consider the design of non-human artefacts involved in care and engage healthcare providers to ensure their needs are met.

Finally, this thesis contributes to the design literature by applying participatory design methods to develop a prototype of an artefact, a redesigned discharge summary, to support post-discharge care. Co-designing interventions with healthcare providers has been suggested in a study on vulnerability and treatment seeking journeys of acutely ill children (334). Previous design studies in Kenya have focused on redesigning documentation tools for care within the NBU (61, 294). I extended these studies by focusing on an artefact used during post-discharge care. My workshops included healthcare providers with an array of experience and training. While a similar approach was used in the redesign of a clinical audit tool in hospitals in Kenya (61), the development of the NeoRoo application did not include interns, and engaged healthcare workers as advisors rather than participants (64).

To the best of my knowledge, this was the first time GDD was used for the design of a physical artefact. GDD is an established process for the design of products, usually software, but the principles can be applied to physical artefacts too. The GDD process uses a robust mechanism to form personas, which guide the design of an artefact. In my research, personas and contextual scenarios, central elements of GDD, were co-developed with healthcare providers through participatory workshops. These participatory workshops not only refined the personas to reflect real-world constraints and experiences but also led to the creation of initial prototypes by the providers themselves. Though in-depth testing was beyond the scope of this thesis, there are ongoing plans to test the artefact in real world settings, with the long-term goal of integration into routine documentation by the Ministry of Health (MoH) in Kenya.

Strengths and limitations

This study exhibited several strengths. The use of multiple data collection methods (interviews, observations and participatory workshops) enabled a deep and rich understanding of how discharge and post-discharge care was organised, and the challenges faced by care providers. The level of participation of healthcare providers in the design of artefacts was also a strength. My research benefitted from the buy-in from healthcare providers for interviews and workshops created by the Clinical Information Network (CIN), a 10-year programme which created strong links between researchers and hospitals. In addition, the community engagement done by the HIGH-Q programme was thorough (169) and enabled me to be seamlessly introduced to the hospital staff.

Another strength of my study was that I used established frameworks and theories which enhanced the analytical approach and explanatory power of my research. In addition, I

conducted my research iteratively which enabled me to progressively focus in ways that were useful both from a theoretical and a practical perspective.

A strength of my scoping review was that it included a broad range of interventions from LMICs, which benefitted from the addition of grey literature. My study also benefitted from a diverse sample, including both urban and rural hospitals. Including two diverse hospitals gave a general overview of how post-discharge care was organised in Kenya, and the challenges faced. Ultimately, the challenges were similar.

Lastly, the study included a diversity of perspectives by including a variety of healthcare providers and key stakeholders. I applied recommendations for conducting participatory design in low resource settings, including building rapport with participants and making the purpose of the artefact specific and relatable to the healthcare workers involved (335). In addition, I included healthcare providers with an array of experience and training. Though my research was focused on understanding the challenges faced by healthcare workers and designing an artefact that meets their needs, my work also benefitted from the perspectives of mothers. The stories from James' and Michael's families in Chapter 4 demonstrated the impacts of care (dis)continuity on newborns and their families. As my findings in Chapter 4 demonstrated, mothers are the key providers of care continuity, thus it was important to capture their experiences to contextualise the experiences of healthcare providers.

There were some limitations to my research. In terms of my scoping review, there may be some interventions that I inadvertently missed. However, by searching several databases, seeking grey literature and trying to connect with organisations working on the ground, a wide array of interventions has been included. My thesis focused on babies who are born

pre-term and sick, however most of the included studies and grey literature focused on term and healthy babies. I drew on this literature to understand what was relevant for small and sick babies. Lastly, most of the grey literature did not mention the results of interventions, but simply described them, and often not in sufficient detail. However, the included reports allowed me to learn about existing interventions, and what may be adapted for the Kenyan context which informed my empirical research.

My empirical work had limitations too. Although healthcare workers were engaged with the participatory design of the tool, they also experienced interview fatigue by the second round of data collection. As part of the larger HIGH-Q study it was expected that interview fatigue would occur, as paediatricians were interviewed multiple times, and may also have been involved in other studies. To mitigate this, care was taken to spread the work packages amongst different facilities within the HIGH-Q project, and to spread the interviews over time. I adopted a flexible approach, for example, rescheduling interviews to avoid interrupting patient care or workflows, as has been advised in other studies (189). This approach was successful, as I had good engagement and collected rich data.

Another limitation was that workshops did not involve hospital administrative staff who are involved in the printing and distribution of forms. Handling the logistics of getting an artefact into the system, such as the costs and organising continuous supply and distribution is critical, as is engaging with the stakeholders involved in that process. However, unpublished CIN data showed that there are examples of hospitals sustaining single page forms. Including frontline staff who engage with the tool is also critical. As such, I focused my research on co-designing the artefact with healthcare workers, though engaging other stakeholders is part of the plan for taking this research forward.

The redesigned discharge summary considered the documentation practices of COIs, and the information needs of paediatricians at follow-up, but it did not cover the information needs of mothers. Based on my observations, the discharge summary is a medical information tool that is used to communicate between healthcare providers. The only information intended for mothers on the form is the date of return for the first POPC visit. As such, I did not receive input from mothers, though this could be an area for further exploration. If a tool has dual use it should be designed considering the capacities of both sets of users (316), such as the MCH handbook, which contains sections for medical information and information on newborn care for mothers.

Implications for policy and practice

Changes to policy and practice should focus on improving follow-up care for babies born small or sick, ultimately reducing readmissions and post-discharge mortality. Multiple changes will be required to address the challenges highlighted in Chapters 3-5, as described below. Other studies have shown that reduction of neonatal mortality and morbidity is complex and using multi-pronged approaches may be more effective than focusing on single interventions (336, 337). In this section, I describe how my findings have implications for documentation, communication with mothers, care coordination and support for mothers.

Documentation

One of the key implications from my findings relates to the importance of improving informational continuity between healthcare providers by improving documentation. While there has been a focus on improving data collection and quality of care during neonatal admission to hospitals in LMICs (338), this needs to be extended post-discharge.

Linking follow-up visits with data from previous admissions and visits provides the healthcare provider with a more accurate patient history. One study found that healthcare workers rate inpatient tasks as more important than tasks such as documentation (108). There needs to be a shift in this mindset, with documentation given due consideration. Involving healthcare workers in a participatory manner highlighted that they recognised informational continuity between providers was an issue, and that artefacts needed to be designed to meet their realities. In essence, forms needed to be short and intuitive to fill, and easy to read at follow-up. The MoH is keen to introduce digitalised information systems (128), which will need to consider some of the design requirements mentioned in Chapter 5 to ensure healthcare providers information needs are met, and documentation does not become time-consuming or a duplication of work. My findings also showed that there was no feedback mechanism for letting interns know when documentation was poor. Creating a robust data system with supportive supervision would be important for scaling up care for small and sick newborns (74). Having a more senior healthcare provider read the forms before they are given to mothers to ensure completeness, and provide feedback to interns, should be considered. Optimising discharge summaries, and other forms of data collection, in hospitals could lead to better national routine information systems (339), which in turn could improve national statistics and disbursement of funds. In addition, future iterations of the MCH booklet should include a strong participatory design component, with input from paediatricians, MOIs, COIs, nurses and nutritionists, to ensure the artefact meets their needs.

Communication with mothers

My empirical work (as presented in Chapter 4) showed that discharges were quick events, and mothers were often unaware of the condition of their baby. Besides being distressing for mothers, this also meant it was common for mothers to struggle to provide a patient history for their child when they saw new providers. Other studies have highlighted the importance of communication, with one study in Uganda showing that healthcare providers communicating with mothers had a strong influence on mother's preparedness for going home and caring for their pre-term babies (33). A study in South Africa highlighted the importance of health information for parents, with parents suggesting both digital and non-digital solutions (283). Clarity of communication and compassionate communication can have effects on the care provided to children post-discharge, as mothers are often given conflicting advice at different facilities (334). As such, how mothers are given information needs to change. In addition, a study on parents of pre-term babies in the UK found that knowing discharge dates helped parents better prepare for transitioning to home-based care, though the trend of moving discharge dates earlier meant parents had less time to gain the necessary skills and knowledge to care for newborns post-discharge (340). My findings in Chapter 4 aligned with a qualitative study in Kenya showed that mothers of pre-term babies were anxious about their baby's condition when they returned home, anxieties which could be alleviated with improved communication during admission and at discharge (32). Guidance on how to provide care should be given while mothers are in the NBU, and discharge should be used by healthcare providers to check that mothers know what to do and where to go. Mothers should also be made aware of where to access reliable information once they are at home. To address the issues around communication that I observed participatory training programmes such as the one conducted with nurse

managers in CIN hospitals, which made nurses aware of the importance of communication skills and emotional awareness when dealing with parents (341), can be adapted to improve the information given to parents at discharge. The training was acceptable, and healthcare workers reported an increased ability to provide respectful care, stronger relationships with colleagues and more confidence. As such, this approach could be scaled up to include more facilities. In addition to healthcare providers communicating with mothers, mHealth platforms can be leveraged. Jacaranda Health in Kenya and MomConnect in South Africa provide information for pregnant women and new mothers and are well accepted by both groups, with postnatal care attendance improving in Kenya (122) and informational messages leaving women feeling empowered in their role as mothers in South Africa (342).

Creating a role for care coordination

Providing continuous home-based care for babies born small or sick with long-term conditions is challenging. One intervention that could alleviate this challenge is creating a designated role for care co-ordinators in the NBU, whereby they bring together the various healthcare providers involved in caring for the newborn within the hospital and at home to create a care plan (343). This strategy has been employed in other settings to improve communication between interprofessional teams and with families (37) and communication between facilities (43). However, I am aware that adding a new member of staff is complex and may not be feasible for most counties in Kenya, due to budgetary constraints. An alternative would be designating someone on the clinical team as the person in charge of discharge and care coordination. However, the care coordinator would still require adequate time for the task, as one study in Uganda found that adding an

education component to paediatric discharge made discharges take 30 minutes (296). Applying a sociomaterial lens shows that multiple changes to the discharge process would be required, including changes to job descriptions and institutional norms, supervision, managing parents' expectations and availability of time for tasks. Regardless of who gets allocated the discharge and care coordination role, the Ugandan study suggests using a clinical prediction tool to follow up on vulnerable cases, as follow-up of all children would not be feasible or necessary (296).

Support for Mothers

My research focused on challenges faced by healthcare providers, but there were several findings related to policy and practice that would affect mothers. For example, my findings showed that mothers needed several support mechanisms to achieve care continuity for their child. Similar findings, i.e., the need for financial, emotional and practical coping, were raised in a study on maternal and child health solutions in South Africa (283) and children who require complex medical care in the United Kingdom (332). Financial difficulties were common in my research. Two studies in rural Kenya found that lack of spousal support for transport costs to facilities was a major barrier to accessing healthcare (334, 344). Another study on cash transfers and access to maternity care in Nairobi found that 60% of mothers reported not being able to afford 1000KES for medical treatment if it was needed (345). While there is a governmental financial support programme in place for children with disabilities (113), the amount provided (2000KES) is insufficient and should be increased.

Studies in Kenya and Uganda on post-discharge care for children found the role of fathers, family members and the community, i.e. interpersonal continuity, must be considered when planning interventions (33, 334). In Uganda, fathers also wanted support to provide

care, and negative comments from community members on the survival and development of the child upset mothers (33). Whereas in Kenya, fathers could be sources of advice and funds, or delay care-seeking, be violent or absent (334). Another study on formal care seeking during pregnancy, delivery and postnatal care in Kenya found that fathers and mothers-in-law influenced decisions around money and postnatal visits (344). My findings showed that mothers needed social support to keep them motivated while providing care, echoing findings from NBUs in Kenya (32, 346). Key informants and healthcare workers highlighted the importance of social support from caregivers who have experiences similar journeys. Peer support has been shown to be effective in both high-income and low-income settings when dealing with long-term conditions, which could be due to shared social identity, a sense of belonging and empowerment and learning from others' experiences (347). In one study in Uganda on young children with developmental disabilities, peer support was found to play an important role in keeping parents motivated (348). However, another study in Kenya found that while breastfeeding peer support worked well in inpatient settings, the gains diminished post-discharge as the support ended, highlighting the need for sustained support (349). These findings echo the latest WHO recommendations, which proposed extra support, including education, counselling, discharge support and peer support, starting from facilities and continuing post-discharge (75). As such, formalised social support should be implemented in each county for parents of babies born small or sick.

Directions for future research

There are several different ways to extend my research. I will present the areas I think are most pertinent. My main suggestion is for studies to focus on completing the goal-directed

design process, i.e. including the refinement and support stages, and testing iterations of the discharge summary until it meets the needs of COIs and paediatricians. In addition, completion of the goal-directed design process for the OT initial assessment form should be considered. I also suggest involving hospital management in this process so that budgets and supply of the forms can be discussed. Once the form is redesigned, I suggest evaluating the implementation process. This will be important for learning, as the literature shows the organisation of care will be altered by the artefact, and the artefact itself will likely require further refinement to meet the needs of healthcare workers (38, 63, 350). Evaluations should include qualitative data and quantitative data on the completeness of information tools. Developing metrics on informational continuity and acting on the resulting data will be important for improving continuity of care. In addition, evaluations should consider monitoring continuous support from healthcare workers and management alike, as this will be required for sustained use of the artefact (65).

My research focused on re-designing a physical artefact, however, the use of technology for documentation in post-discharge care is expected. For example, there is ongoing unpublished work at KWTRP on digitalising newborn records via photo and using artificial intelligence to examine trends in disease and progress. Given the likely digitalisation of forms, future research should consider using participatory design to adapt physical artefacts to digital settings. In addition, there are existing digital information systems documenting inpatient care for babies. For example, Liveborn is an mHealth application which has been used to document resuscitation actions in real-time within delivery rooms in the Democratic Republic of the Congo, Nepal, Norway and Tanzania (351). The NeoTree application was used in NBUs in Malawi to collect digital data at the point of admission and discharge, demonstrating that mHealth can be used in facilities low-resource settings (312).

Research should explore extending these digital interventions to collect data at follow-up visits for babies born small or sick, so that a record of all historical care received is available.

My research showed there are multiple facilities involved in care provision but the linkages between facilities were poor, which hindered care continuity. As also suggested by Hedqvist, I suggest future research should explore communication between healthcare providers in different facilities to understand the various modes of communication (343) and how this can be optimised to provide care continuity for small and sick newborns. Such research would extend existing recommendations and guidelines, such as the WHO-UNICEF recommendation on improving coordination of communication between facilities to achieve a functional referral system (74). In Kenya the national referral guidelines similarly emphasise that a well-functioning referral system—with efficient linkages and consistent information flow—is essential to ensuring continuity of care across all health system levels (352). These guidelines provide minimum requirements for referral and feedback documentation. However, empirical research is needed to examine how these processes function specifically for small and sick newborns. A promising direction would be to apply a network of care approach, which has previously been used in maternal and child health to assess and strengthen inter-provider collaboration (353). Additionally, recognising that care continuity is shaped not only by people but also by material artefacts, future studies should adopt a sociomaterial perspective. This would allow researchers to explore how communication is enacted in practice, and how various artefacts—such as referral forms, mobile phones, and institutional norms—contribute to or hinder care continuity. Qualitative and ethnographic methods could provide nuanced insights into existing practices, identify gaps, and inform both the redesign of communication artefacts and institutional protocols to better support inter-facility coordination.

As noted earlier in this chapter, resource limitations and clinical prioritisation make it neither feasible nor necessary to follow up with every newborn discharged from the NBU. A precision public health approach has been proposed to identify which newborns and mothers require additional post-discharge support (79). Developing such an approach would entail the creation of a comprehensive risk metric—one that extends beyond clinical indicators to incorporate socioeconomic and contextual vulnerabilities, such as financial constraints and the need for social support. My findings suggest several potential support mechanisms for families of babies born small or sick, including peer support and financial assistance—both of which warrant further exploration. Peer support has been shown to enhance learning and emotional support of mothers of pre-term babies during NBU admission in government hospitals in Kenya (346). However, this social capital is often lost after discharge (32), leaving a critical gap in the continuity of support. While the WHO recommends family support interventions for parents of pre-term babies, it also noted the current evidence base is limited (75). Further research is needed to build a stronger case for such interventions.

One promising avenue could be a mixed-methods evaluation of existing peer support groups for caregivers of preterm infants or children with cerebral palsy in Kenya. The evaluation should include the costs and resources needed to maintain these groups, so scalability can be considered. Such evaluations should examine not only the impact of these groups but also the financial and logistical requirements for their maintenance, to assess their scalability and sustainability. In parallel, studies should investigate the financial needs of mothers caring for children with long-term health conditions, to inform the design and adequacy of government support schemes, such as disability stipends or conditional cash transfers. Evaluating the impact of these financial interventions on care-seeking behaviours

and child health outcomes is critical. This would build on existing evidence, such as an evaluation of Kenya's largest social protection program, the Cash Transfer for Orphans and Vulnerable Children (CT-OVC), which reported reduced illness among children over the age of seven, but no significant difference for children under the age of five, and no significant impact on health-seeking behaviours (354).

Conclusion

In this thesis, I explored how continuity of care for small and sick newborns post-discharge may be better supported within the Kenyan health system. Post-discharge care continuity is a sociomaterial practice, involving a variety of people and artefacts which enable the enactment of care provision. Healthcare providers faced numerous challenges, including lack of informational, relational and management continuity due to poor documentation, multiple providers being involved in care journeys with poor linkages between them, and time and staffing constraints leading to interns conducting tasks with minimal supervision. To begin tackling these issues, I redesigned an artefact, the discharge summary, in a participatory manner with healthcare providers. COIs were tasked with filling the artefact and needed a form that was quick and intuitive to fill. Paediatricians used the artefact at POPC and needed complete and concise information in a way that was easily readable. The redesigned form was well accepted by COIs, but they had suggestions for changes. Iterative design of the form should be conducted with healthcare providers before implementation. I also recommend implementing other interventions to improve continuity of care post-discharge in addition to form redesign, such as creating a role for care coordination post-discharge, improving communication between healthcare providers and mothers, and providing support for mothers.

References

1. Talbert A, Ngari M, Obiero C, Nyaguara A, Mwangome M, Mturi N, et al. Trends in inpatient and post-discharge mortality among young infants admitted to Kilifi County Hospital, Kenya: a retrospective cohort study. BMJ Open. 2023;13(1):e067482.
2. Wiens MO, Pawluk S, Kissoon N, Kumbakumba E, Ansermino JM, Singer J, et al. Pediatric Post-Discharge Mortality in Resource Poor Countries: A Systematic Review. PLOS ONE. 2013;8(6):e66698.
3. Cutting WAM. Pocket Book of Hospital Care for Children. Guidelines for the Management of Common Illnesses with Limited Resources. WHO Geneva, 2005. Price CHF 20.00/US$ 18.00 Developing countries: CHF 10.00 English 2005 377 pp. (ISBN 924 154670 0, Order Number 11500626). 2007. p. 487-.
4. Bittencourt SDdA, Cunha EM, Domingues RMSM, Dias BAS, Dias MAB, Torres JA, et al. Nascer no Brasil: continuity of care during pregnancy and postpartum period for women and newborns. Rev Saúde Pública. 2020;54(100):1-11.
5. Tiruneh GT, Demissie M, Worku A, Berhane Y. Predictors of maternal and newborn health service utilization across the continuum of care in Ethiopia: A multilevel analysis. PLOS ONE. 2022;17(2):e0264612.
6. Kikuchi K, Yasuoka J, Nanishi K, Ahmed A, Nohara Y, Nishikitani M, et al. Postnatal care could be the key to improving the continuum of care in maternal and child health in Ratanakiri, Cambodia. PLOS ONE. 2018;13(6):e0198829.
7. van den Boogaard W, Zuniga I, Manzi M, Van den Bergh R, Lefevre A, Nanan-N'zeth K, et al. How do low-birthweight neonates fare 2 years after discharge from a low-technology neonatal care unit in a rural district hospital in Burundi? Trop Med Int Health. 2017;22(4):423-30.
8. Tinker A, ten Hoope-Bender P, Azfar S, Bustreo F, Bell R. A continuum of care to save newborn lives. The Lancet. 2005;365(9462):822-5.
9. Kerber KJ, de Graft-Johnson JE, Bhutta ZA, Okong P, Starrs A, Lawn JE. Continuum of care for maternal, newborn, and child health: from slogan to service delivery. The Lancet. 2007;370(9595):1358-69.
10. Hama Diallo A, Shahid ASMSB, Khan AF, Saleem AF, Singa BO, Gnoumou BS, et al. Hospital readmission following acute illness among children 2–23 months old in sub-Saharan Africa and South Asia: a secondary analysis of CHAIN cohort. eClinicalMedicine. 2024;73:102676.
11. Snow RW, Howard SC, Mung'ala-Odera V, English M, Molyneux CS, Waruiru C, et al. Paediatric survival and re-admission risks following hospitalization on the Kenyan Coast. Tropical Medicine and International Health. 2000;5(5):377-83.
12. Nemetchek B, English L, Kissoon N, Ansermino JM, Moschovis PP, Kabakyenga J, et al. Paediatric postdischarge mortality in developing countries: a systematic review. BMJ Open. 2018;8(12).
13. WHO. World health statistics 2024: monitoring health for the SDGs, Sustainable Development Goals. Geneva: World Health Organisation; 2024.
14. Lawn JE, Cousens S, Zupan J. 4 million neonatal deaths: When? Where? Why? The Lancet. 2005;365(9462):891-900.
15. WHO. Newborn health in the Western Pacific [Available from: https://www.who.int/westernpacific/health-topics/newborn-health.
16. WHO. Survive and thrive: transforming care for every small and sick newborn. Key findings. Geneva: WHO; 2018.
17. WHO. International Classification of Diseases 10th revision (ICD-10). WHO; 2010.
18. Kikuchi K, Ansah EK, Okawa S, Enuameh Y, Yasuoka J, Nanishi K, et al. Effective Linkages of Continuum of Care for Improving Neonatal, Perinatal, and Maternal Mortality: A Systematic Review and Meta-Analysis. PLOS ONE. 2015;10(9).

19. Haggerty JL, Reid RJ, Freeman GK, Starfield BH, Adair CE, McKendry R. Continuity of care: a multidisciplinary review. BMJ. 2003;327(7425):1219.
20. Meiqari L, Al-Oudat T, Essink D, Scheele F, Wright P. How have researchers defined and used the concept of 'continuity of care' for chronic conditions in the context of resource-constrained settings? A scoping review of existing literature and a proposed conceptual framework. Health Research Policy and Systems. 2019;17(1):27.
21. Salisbury C, Sampson F Fau - Ridd M, Ridd M Fau - Montgomery AA, Montgomery AA. How should continuity of care in primary health care be assessed? Br J Gen Pract. 2009(1478-5242 (Electronic)).
22. Naicker S, Plange-Rhule J, Tutt R, Eastwood J. Shortage of Healthcare Workers in Developing Countries—Africa. Ethnicity & disease. 2009;19:S1-60.
23. Bahr SJ, Weiss ME. Clarifying model for continuity of care: A concept analysis. International journal of nursing practice. 2019;25(2):e12704.
24. D'Haenens F, Van Rompaey B, Swinnen E, Dilles T, Beeckman K. The effects of continuity of care on the health of mother and child in the postnatal period: a systematic review. Eur J Public Health. 2020;30(4):749-60.
25. Schwarz D, Hirschhorn LR, Kim J-H, Ratcliffe HL, Bitton A. Continuity in primary care: a critical but neglected component for achieving high-quality universal health coverage. Continuity in primary care: a critical but neglected component for achieving high-quality universal health coverage: BMJ Publishing Group Ltd; 2019.
26. Tanaka MC, Bernardino FBS, Braga PP, Alencastro LCdS, Gaíva MAM, Viera CS. Weaknesses in the continuity of care for preterm infants discharged from the neonatal unit. Revista da Escola de Enfermagem da U S P. 2024;58:e20230228-e.
27. Zanello E, Calugi S, Rucci P, Pieri G, Vandini S, Faldella G, et al. Continuity of care in children with special healthcare needs: a qualitative study of family's perspectives. Ital J Pediatr. 2015(1824-7288 (Electronic)).
28. Pereira Gray DJ, Sidaway-Lee K, White E, Thorne A, Evans PH. Continuity of care with doctors—a matter of life and death? A systematic review of continuity of care and mortality. Continuity of care with doctors—a matter of life and death? A systematic review of continuity of care and mortality: BMJ Publishing Ltd; 2018.
29. Van Walraven C, Oake N, Jennings A, Forster AJ. The association between continuity of care and outcomes: a systematic and critical review. Journal of Evaluation in Clinical Practice. 2010;16(5):947-56.
30. Van Walraven C, Mamdani M, Fang J, Austin PC. Continuity of Care and Patient Outcomes After Hospital Discharge. J Gen Intern Med. 2004;19(6):624-31.
31. Bradford BF, Wilson AN, Portela A, McConville F, Fernandez Turienzo C, Homer CSE. Midwifery continuity of care: A scoping review of where, how, by whom and for whom? PLOS Global Public Health. 2022;2(10):e0000935.
32. Maluni J, Oluoch D, Molyneux S, Boga M, Jones C, Murila F, et al. After neonatal care, what next? A qualitative study of mothers' post-discharge experiences after premature birth in Kenya. International Journal for Equity in Health. 2025;24(1):17.
33. Nalwadda C, Tusubira AK, Nambuya H, Namazzi G, Muwanguzi D, Waiswa P, et al. Transition from hospital to home care for preterm babies: A qualitative study of the experiences of caregivers in Uganda. PLOS Glob Public Health. 2023;3(5):e0000528-e.
34. Leonardi PM, Nardi BA, Kallinikos J. Materiality and Organizing: Social Interaction in a Technological World. 1 ed. Oxford: Oxford University Press; 2012. xiv-xiv p.
35. Orlikowski WJ, Scott SV. Sociomateriality: Challenging the Separation of Technology, Work and Organization. The Academy of Management annals. 2008;2:433-74.
36. Orlikowski WJ. Sociomaterial Practices: Exploring Technology at Work. Organization studies. 2007;28(9):1435-48.

37. Burm S, Faden L, DeLuca S, Hibbert K, Huda N, Goldszmidt M. Using a sociomaterial approach to generate new insights into the nature of interprofessional collaboration: Findings from an inpatient medicine teaching unit. Journal of interprofessional care. 2019;33(2):153-62.
38. Introna LD, Hayes N, Al-Hejin Z. The negotiated order and electronic patient records: A sociomaterial perspective. Journal of information technology. 2019;34(4):333-49.
39. Xiao Y, Lasome C, Moss J, Mackenzie CF, Faraj S. Cognitive Properties of a Whiteboard: A Case Study in a Trauma Centre. In: Prinz W, Jarke M, Rogers Y, Schmidt K, Wulf V, editors. ECSCW 2001: Proceedings of the Seventh European Conference on Computer Supported Cooperative Work 16–20 September 2001, Bonn, Germany. Dordrecht: Springer Netherlands; 2001. p. 259-78.
40. Bardram JE, Bossen C, editors. A web of coordinative artifacts: collaborative work at a hospital ward. GROUP '05 : proceedings of the 2005 International ACM SIGGROUP Conference on Supporting Group Work : November 6-9, 2005, Sanibel Island, Florida, USA; 2005 2005; New York, NY, USA: ACM.
41. Zammuto RF, Griffith TL, Majchrzak A, Dougherty DJ, Faraj S. Information Technology and the Changing Fabric of Organization. Organization science (Providence, RI). 2007;18(5):749-62.
42. Whyte J, Harty C. 10 Socio-material Practices of Design Coordination: Objects as Plastic and Partisan. Oxford: Oxford University Press; 2012.
43. Reichenpfader U, Wickström A, Abrandt Dahlgren M, Nilsen P, Carlfjord S. 'Our surgeons want this to be short and simple': practices of in-hospital medication review as coordinated sociomaterial actions. Studies in Continuing Education. 2018;40(3):323-36.
44. Eriksen MA, editor What triggers us?: A close look at socio-material situations of co-designing services. ServDes2014 Service Futures Proceedings;No 4; 2014 2014.
45. Ehn P, editor Participation in design things2008 2008; Indianapolis, IN, USA: Indiana University.
46. Dell'Era C, Landoni P. Living Lab: A Methodology between User-Centred Design and Participatory Design. Creativity and Innovation Management. 2014;23(2):137-54.
47. Wacnik P, Daly S, Verma A. Participatory design: A systematic review and insights for future practice2024.
48. Spinuzzi C. The Methodology of Participatory Design. Technical Communication. 2005;52(2):163-74.
49. Sanders EBN, Stappers PJ. Co-creation and the new landscapes of design. CoDesign. 2008;4(1):5-18.
50. Gulliksen J, Göransson B, Boivie I, Blomkvist S, Persson J, Cajander Å. Key principles for user-centred systems design. Behaviour & information technology. 2003;22(6):397-409.
51. Bodker S. Creating Conditions for Participation: Conflicts and Resources in Systems Development. Human-computer interaction. 1996;11(3):215-36.
52. Steen M. Tensions in human-centred design. CoDesign. 2011;7(1):45-60.
53. Robertson T, Simonsen J. Challenges and Opportunities in Contemporary Participatory Design. Design Issues. 2012;28.
54. Teal G, McAra M, Riddell J, Flowers P, Coia N, McDaid L. Integrating and producing evidence through participatory design. CoDesign. 2023;19(2):110-27.
55. Bazzano AN, Martin J, Hicks E, Faughnan M, Murphy L. Human-centred design in global health: A scoping review of applications and contexts. PLoS One. 2017;12(11):e0186744-e.
56. Rousseau N, Turner KM, Duncan E, O'Cathain A, Croot L, Yardley L, et al. Attending to design when developing complex health interventions: A qualitative interview study with intervention developers and associated stakeholders. PLoS One. 2019;14(10):e0223615.
57. Singh DR, Sah RK, Simkhada B, Darwin Z. Potentials and challenges of using co-design in health services research in low- and middle-income countries. Glob Health Res Policy. 2023;8(1):5-
.
58. Aitamurto T, Holland D, Hussain S. The Open Paradigm in Design Research. Design issues. 2015;31(4):17-29.

59. Vaughn LM, Jacquez F. Participatory Research Methods – Choice Points in the Research Process. Journal of Participatory Research Methods. 2020;1(1).
60. Kuramata M, Mochida K, Fukushima S, Sadamori T, Suzuki M, Francisco KR, et al. Development and implementation of the maternal and child health Handbook in Angola. BMJ Global Health. 2022;7(10):e010313.
61. Ogola MA-O, Wainaina J, Muinga N, Kimani W, Muriithi M, Aluvaala JA-O, et al. Development of a small and sick newborn clinical audit tool and its implementation guide using a human-centred design approach newborn clinical audit process and design. PLOS Global Public Health. 2023(2767-3375 (Electronic)).
62. Muinga N, Paton C, Gicheha E, Omoke S, Abejirinde I-OO, Benova L, et al. Using a human-centred design approach to develop a comprehensive newborn monitoring chart for inpatient care in Kenya. BMC Health Services Research. 2021;21(1):1010.
63. Ekpenyong N, Heitz Tokpa K, Nwankwo O, O'Donnell D, Rodriguez Franco D, Berté S, et al. Using and improving the PHISICC paper-based tools in the health facility laboratories: Examples of Human Centered Design taking systems thinking into practice, in Côte d'Ivoire and Nigeria. Front Public Health. 2022;10:916397-.
64. Bucher SL, Young A, Dolan M, Padmanaban GP, Chandnani K, Purkayastha S. The NeoRoo mobile app: Initial design and prototyping of an Android-based digital health tool to support Kangaroo Mother Care in low/ middle-income countries (LMICs). PLOS Digit Health. 2023;2(10):e0000216-e.
65. Berg M. Implementing information systems in health care organizations: myths and challenges. International journal of medical informatics (Shannon, Ireland). 2001;64(2-3):143-56.
66. Okello G, Molyneux S, Zakayo S, Gerrets R, Jones C. Producing routine malaria data: an exploration of the micro-practices and processes shaping routine malaria data quality in frontline health facilities in Kenya. Malaria Journal. 2019;18(1):420.
67. Muinga N, Magare S, Monda J, Kamau O, Houston S, Fraser H, et al. Implementing an Open Source Electronic Health Record System in Kenyan Health Care Facilities: Case Study. JMIR Med Inform. 2018;6(2):e22.
68. Chawanpaiboon S, Vogel JP, Moller AB, Lumbiganon P, Petzold M, Hogan D, et al. Global, regional, and national estimates of levels of preterm birth in 2014: a systematic review and modelling analysis. Lancet Glob Health. 2019(2214-109X (Electronic)).
69. 152 million babies born preterm in the last decade [press release]. WHO2023.
70. Britto P, Chai V, Day LT, Durairaj A, Franck LS, Kak L, et al. Survive and thrive: transforming care for every small and sick newborn. Survive and thrive: transforming care for every small and sick newborn: World Health Organization; 2019.
71. Namiiro FB, Mugalu J, McAdams RM, Ndeezi G. Poor birth weight recovery among low birth weight/preterm infants following hospital discharge in Kampala, Uganda. BMC Pregnancy Childbirth. 2012;12(1):1-.
72. Gladstone M, Oliver C, Van den Broek N. Survival, Morbidity, Growth and Developmental Delay for Babies Born Preterm in Low and Middle Income Countries - A Systematic Review of Outcomes Measured. PloS one. 2015;10(3):e0120566-e.
73. Namiiro FB, Nolens B, Rujumba J, Kiguli S, Batte A, Akker T. “My baby is fine, no need for more clinic visits.” Facilitators and barriers for utilisation of follow-up services for children born preterm in low-resource setting: Parents' perceptions. Trop Med Int Health. 2023;28(3):194-202.
74. Group W-UEaCCoSaoSNC. A comprehensive model for scaling up care for small and/or sick newborns at district level-based on country experiences presented at a WHO-UNICEF expert consultation. J Glob Health. 2023(2047-2986 (Electronic)).
75. Darmstadt GL, Al Jaifi NH, Arif S, Bahl R, Blennow M, Cavallera V, et al. New World Health Organization recommendations for care of preterm or low birth weight infants: health policy. EClinicalMedicine. 2023;63:102155-.

76. Pepper M, Campbell OMR, Woodd SL. Current Approaches to Following Up Women and Newborns After Discharge From Childbirth Facilities: A Scoping Review. Glob Health Sci Pract. 2024;12(2):e2300377.
77. Were FB, N. O. The Contribution of Very Low Birth Weight Deaths to Infant Mortality. East African Medical Journal. 2009;86:374-7.
78. Wainaina J, Lee E, Irimu G, Aluvaala J, English M, Group TCINA, et al. Identifying and quantifying initial post-discharge needs for clinical review of sick, newborns in Kenya based on a large multi-site, retrospective cohort study. Frontiers in Pediatrics. 2024;12.
79. Wiens MO, Kissoon N, Kabakyenga J. Smart Hospital Discharges to Address a Neglected Epidemic in Sepsis in Low- and Middle-Income Countries. 2018(2168-6211 (Electronic)).
80. Lang'at E, Mwanri L, Temmerman M. Effects of free maternity service policy in Kenya: an interrupted time series analysis. The Lancet Global Health. 2019;7:S21.
81. Orangi SA-O, Kairu A, Malla L, Ondera J, Mbuthia B, Ravishankar N, et al. Impact of free maternity policies in Kenya: an interrupted time-series analysis. LID - 10.1136/bmjgh-2020-003649 [doi] LID - e003649. (2059-7908 (Print)).
82. Wilson-Costello D, Friedman H Fau - Minich N, Minich N Fau - Siner B, Siner B Fau - Taylor G, Taylor G Fau - Schluchter M, Schluchter M Fau - Hack M, et al. Improved neurodevelopmental outcomes for extremely low birth weight infants in 2000-2002. Pediatrics. 2007(1098-4275 (Electronic)).
83. Kumar P, Jeeva Sankar M, Sapra S, Agarwal R, Deorari AK, Paul VK. Follow-up of high risk neonates. The Indian Journal of Pediatrics. 2008;75(5):479-87.
84. Group P. A closer look at the healthcare system in Kenya. 2016.
85. Kenya Go. The Constitution of Kenya, 2010. Kenya: National Council for Law 2010.
86. WHO. Primary health care systems (PRIMASYS): case study from Kenya, abridged version. Geneva: World Health Organisation; 2017.
87. The Health Act, 2017 (2017).
88. Okoroafor SA-OX, Kwesiga B, Ogato J, Gura Z, Gondi J, Jumba N, et al. Investing in the health workforce in Kenya: trends in size, composition and distribution from a descriptive health labour market analysis. LID - 10.1136/bmjgh-2022-009748 [doi] LID - e009748. (2059-7908 (Print)).
89. Organisation WH. Health workforce requirements for universal health coverage and the Sustainable Development Goals. WHO; 2016.
90. Afulani PA, Ongeri L, Kinyua J, Temmerman M, Mendes WB, Weiss SJ. Psychological and physiological stress and burnout among maternity providers in a rural county in Kenya: individual and situational predictors. BMC Public Health. 2021;21(1):453.
91. Kihuba E, Gathara D, Mwinga S, Mulaku M, Kosgei R, Mogoa W, et al. Assessing the ability of health information systems in hospitals to support evidence-informed decisions in Kenya. Glob Health Action. 2014(1654-9880 (Electronic)).
92. Oginga FO, Kulimankudya VD, Okila CS. Integrating Clinical Officers into Primary Healthcare Delivery in Kenya: Challenges, Innovations, and Future Directions. International Journal of Research and Scientific Innovation (IJRSI). 2024;XI.
93. Mbindyo P, Blaauw D Fau - English M, English M. The role of Clinical Officers in the Kenyan health system: a question of perspective. Human Resources for Health. 2013(1478-4491 (Print)).
94. Board MPaD. National Guidelines for Internship Training of Medical and Dental Officer Interns. Kenya2019.
95. Zhao Y, Osano B, Were F, Kiarie H, Nicodemo C, Gathara D, et al. Characterising Kenyan hospitals' suitability for medical officer internship training: a secondary data analysis of a cross-sectional study. 2022.
96. Tuti T, Bitok M, Malla L, Paton C, Muinga N, Gathara D, et al. Improving documentation of clinical care within a clinical information network: an essential initial step in efforts to understand and improve care in Kenyan hospitals. BMJ Glob Health. 2016(2059-7908 (Print)).
97. THE HEALTH RECORDS AND INFORMATION MANAGERS ACT, (2022).

98. Hagel C, Paton C, Mbevi G, English M. Data for tracking SDGs: challenges in capturing neonatal data from hospitals in Kenya. BMJ Glob Health. 2020;5(3):e002108-e.
99. Warren C, Mwangi A, Oweya E, Kamunya R, Koskei N. Safeguarding maternal and newborn health: improving the quality of postnatal care in Kenya. International Journal for Quality in Health Care. 2010;22(1):24-30.
100. sanitation Mopha. National Orientation Package for Targeted Postnatal Care. Kenya: Ministry of public health and sanitation; 2011.
101. Health Mo. Kangaroo Mother Care: Clinical Implementation Guidelines. In: Health Mo, editor. Nairobi 2023.
102. Aluvaala J, Nyamai R, Were F, Wasunna A, Kosgei R, Karumbi J, et al. Assessment of neonatal care in clinical training facilities in Kenya. Archives of Disease in Childhood. 2015;100(1):42.
103. Gathara D, Opiyo N, Wagai J, Ntoburi S, Ayieko P, Opondo C, et al. Quality of hospital care for sick newborns and severely malnourished children in Kenya: A two-year descriptive study in 8 hospitals. BMC Health Services Research. 2011;11(1):307.
104. Michuki M, Jalemba A, Paul M, Olga T-A, Catherine M, Beth M, et al. Using a common data platform to facilitate audit and feedback on the quality of hospital care provided to sick newborns in Kenya. BMJ Global Health. 2018;3(5):e001027.
105. Wagura P, Wasunna A, Laving A, Wamalwa D, Ng'ang'a P. Prevalence and factors associated with preterm birth at kenyatta national hospital. BMC Pregnancy and Childbirth. 2018;18(1):107.
106. WHO. Perinatal asphyxia Geneva [Available from: https://www.who.int/teams/maternal-newborn-child-adolescent-health-and-ageing/newborn-health/perinatal-asphyxia.
107. Daniel Muturi Gichogo FM, Micah Matiang'i, Wycliff Ndege, Kefa Bosire. Prevalence of asphyxia and readiness for neonatal resuscitation in Kenya. African Journal of Midwifery and Women's Health. 2018;12.
108. Paul S. Knowledge, Attitudes, and Practices of Kenyan Healthcare Workers Regarding Pediatric Discharge from Hospital. In: Denno D, Anderson L, editors.: ProQuest Dissertations Publishing; 2019.
109. Moïsi J, Gatakaa H, Berkley J, Maitland K, Mturi N, Newton C, et al. Excess child mortality after discharge from hospital in Kilifi, Kenya: a retrospective cohort analysis. 2011;89(10).
110. Martin-Herz SA-O, Otieno P, Laanoi GM, Moshi V, Olieng'o Okoth G, Santos N, et al. Growth and neurodevelopmental outcomes of preterm and low birth weight infants in rural Kenya: a cross-sectional study. (2044-6055 (Electronic)).
111. Statistics KNBo. 2019 Kenya Population and Housing Census. Nairobi: Kenya National Bureau of Statistics; 2019 December 2019.
112. Statistics NCAfPaDaKNBo. Kenya National Survey for Persons with Disabilities. Kenya; 2008.
113. Ministry of Labour and Social Protection SDfSP. Kenya Social Protection Sector Review. Kenya: Ministry of Labour and Social Protection, State Department for Social Protection; 2017.
114. Kenya Ministry of Health U, Kenya National Bureau of Statistics. Kenya Household Health Expenditure and Utilization Survey. Nairobi, Kenya: Ministry of Health; 2013.
115. CPSK. Kenya [Available from: https://cpsk.or.ke/.
116. APDK. Kenya [Available from: https://apdk.org/.
117. Kenya National Bureau of S, Ministry of HK, National ACCK, Kenya Medical Research I, National Council for P, Development/Kenya. Kenya Demographic and Health Survey 2014. Rockville, MD, USA; 2014.
118. Parlasca MC, Mußhoff O, Qaim M. How mobile phones can improve nutrition among pastoral communities: Panel data evidence from Northern Kenya. 858 ed. St. Paul: Agricultural & Applied Economics Association (AAEA); 2018.
119. Kirkwood EA-O, Clymer CA-O, Imbulana KA-OX, Mozumder SA-O, Dibley MA-O, Alam NA-O. The Role of mHealth Interventions in Changing Gender Relations: Systematic Review of Qualitative Findings. JMIR Hum Factors. 2022(2292-9495 (Electronic)).

120. Jones RM, Kimenju G, Subbiah S, Styles A, Pearson N, Rajasekharan S. A Short Message Service (SMS) increases postpartum care-seeking behavior and uptake of family planning of mothers in peri-urban public facilities in Kenya. PLOS ONE. 2020;15(9):e0239213.
121. Njoroge M, Zurovac D, Ogara EAA, Chuma J, Kirigia D. Assessing the feasibility of eHealth and mHealth: a systematic review and analysis of initiatives implemented in Kenya. BMC research notes. 2017;10(1):90.
122. Vatsa R, Chang W, Akinyi S, Little S, Gakii C, Mungai J, et al. Empowering patients across the maternal-newborn care continuum: A cluster randomized controlled trial testing a digital health platform in Kenya. medRxiv. 2024:2024.06.03.24308340.
123. Karamagi HC, Muneene D, Droti B, Jepchumba V, Okeibunor JC, Nabyonga J, et al. eHealth or e-Chaos: The use of Digital Health Interventions for Health Systems Strengthening in sub-Saharan Africa over the last 10 years: A scoping review. (2047-2986 (Electronic)).
124. Nyatuka DR, De La Harpe R. Design considerations for patient-centered eHealth interventions in an underserved context: A case of health and wellbeing services within Nairobi's informal settlements in Kenya. The Electronic journal of information systems in developing countries. 2021.
125. Clarke A, Watt I, Sheard L, Wright J, Adamson J. Implementing electronic records in NHS secondary care organizations in England: policy and progress since 1998. British Medical Bulletin. 2017;121(1):95-106.
126. Fleming NS, Culler SD, McCorkle R, Becker ER, Ballard DJ. The financial and nonfinancial costs of implementing electronic health records in primary care practices. Health Aff (Millwood). 2011;30(3):481-9.
127. Tuti T. Data BRIDGE: Building reliable information from data generated in everyday clinical practice for newborn care in sub-Saharan Africa. In: Institute T, editor. Cambridge2023.
128. Waiyaiya E, Nyangena J, Nyotu R, Wamicwe J, Nyaga N, Wanyee S, et al. Digital Health Convergence Workshop: The Kenyan experience. Oxford Open Digital Health. 2024;2:oqae014.
129. Muinga NA-O, Magare S, Monda J, English M, Fraser H, Powell J, et al. Digital health Systems in Kenyan Public Hospitals: a mixed-methods survey. BMC Medical Informatics and Decision Making. 2020 (1472-6947 (Electronic)).
130. Orangi SA-O, Kairu AA-O, Ondera JA-OX, Mbuthia BA-O, Koduah AA-O, Oyugi BA-O, et al. Examining the implementation of the Linda Mama free maternity program in Kenya. (1099-1751 (Electronic)).
131. NHIF. Expanded Programme for Free Maternity Package Benefits. In: Health Mo, editor. Kenya: Ministry of Health; 2021.
132. Kenyans Embrace SHA Rollout with High Registration Turnout [press release]. Kakamega county, Kenya, 1st October 2024.
133. Kahenda M. SHA: Linda Mama now covers more than just free deliveries. The Standard. 2025.
134. Scanlon ML, Maldonado LY, Ikemeri JE, Jumah A, Anusu G, Bone JN, et al. A retrospective study of the impact of health worker strikes on maternal and child health care utilization in western Kenya. (1472-6963 (Electronic)).
135. Nyawira L, Tsofa B, Musiega A, Munywoki J, Njuguna RG, Hanson K, et al. Management of human resources for health: implications for health systems efficiency in Kenya. BMC Health Serv Res. 2022(1472-6963 (Electronic)).
136. Muruga K. Perception of Health Care Practitioners on Dual Practice in Kenya. Journal of e-health Management,. 2022;2022.
137. Nakweya G. Doctors in Kenya end strike after threat of court action. BMJ. 2024;385:q1088.
138. Muia W. 'Thankless job' - why trainee Kenyan doctors are taking their own lives. BBC News. 2024.

139. Mohiddin A, Langat E, Orwa J, Naanyu V, Temmerman M. Exploring the impact of health worker strikes on maternal and child health in a Kenyan county. BMC Health Services Research. 2022;22(1):1139.
140. Ong'ayo G, Ooko M, Wang'ondu R, Bottomley C, Nyaguara A, Tsofa BK, et al. Effect of strikes by health workers on mortality between 2010 and 2016 in Kilifi, Kenya: a population-based cohort analysis. 2019(2214-109X (Electronic)).
141. Rukanga B. Why Kenya's president wants people to love the taxman. BBC 2024 8 June.
142. Muia W. New faces of protest - Kenya's Gen Z anti-tax revolutionaries. BBC. 2024 20 June
143. Were MEaF. Learning to Harness Innovation in Global Health for Quality Care (HIGH-Q). Kenya: NIHR; 2020.
144. Trust KW. Kenya [cited 2025 7th Feb]. Available from: https://kemri-wellcome.org/clinical-information-network-cin/.
145. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. International Journal of Social Research Methodology. 2005;8(1):19-32.
146. Kuhn TS. The structure of scientific revolutions. Chicago ;: University of Chicago Press; 1962.
147. Pope C, Mays N. Qualitative research in health care. Fourth edition. ed. Hoboken: John Wiley and Sons Ltd; 2020.
148. Creswell JW, Poth CN. Qualitative inquiry & research design : choosing among five approaches. Fifth edition. ed. Thousand Oaks, California ;: Sage; 2024.
149. Walsham G. Doing interpretive research. European Journal of Information Systems. 2006;15(3):320-30.
150. Orlikowski WJ, Baroudi JJ. Studying Information Technology in Organizations: Research Approaches and Assumptions. Information systems research. 1991;2(1):1-28.
151. Hammersley M. What's wrong with ethnography? : methodological explorations. London ;: Routledge; 1992.
152. Peters MDJ, Marnie C, Tricco AC, Pollock D, Munn Z, Alexander L, et al. Updated methodological guidance for the conduct of scoping reviews. JBI Evidence Synthesis. 2020;18(10).
153. Munn Z, Peters MDJ, Stern C, Tufanaru C, McArthur A, Aromataris E. Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. BMC Medical Research Methodology. 2018;18(1):143.
154. Grewal GA-O, Fuller SA-O, Rababeh A, Maina MA-O, English MA-O, Paton C, et al. Scoping review of interventions to improve continuity of postdischarge care for newborns in LMICs. LID - 10.1136/bmjgh-2023-012894 [doi] LID - e012894. 2024(2059-7908 (Print)).
155. Amoakoh-Coleman MA-O, Borgstein Ab Auid- Orcid: --- Fau - Sondaal SF, Sondaal Sf Auid- Orcid: --- Fau - Grobbee DE, Grobbee De Auid- Orcid: --- Fau - Miltenburg AS, Miltenburg As Auid- Orcid: --- Fau - Verwijs M, Verwijs M Auid- Orcid: --- Fau - Ansah EK, et al. Effectiveness of mHealth Interventions Targeting Health Care Workers to Improve Pregnancy Outcomes in Low- and Middle-Income Countries: A Systematic Review. (1438-8871 (Electronic)).
156. van Zyl C, Badenhorst M, Hanekom S, Heine M. Unravelling 'low-resource settings': a systematic scoping review with qualitative content analysis. BMJ Global Health. 2021;6(6):e005190.
157. Brocklehurst PR, Baker SR, Langley J. Context and the evidence-based paradigm: The potential for participatory research and systems thinking in oral health. Community Dent Oral Epidemiol. 2021;49(1):1-9.
158. Green J, Thorogood N. Qualitative methods for health research. London: SAGE Publications; 2004.
159. Langley J, Wolstenholme D, Cooke J. 'Collective making' as knowledge mobilisation: The contribution of participatory design in the co-creation of knowledge in healthcare. BMC Health Serv Res. 2018;18(1):585-.
160. Unertl KM, Schaefbauer CL, Campbell TR, Senteio C, Siek KA, Bakken S, et al. Integrating community-based participatory research and informatics approaches to improve the engagement

and health of underserved populations. Journal of the American Medical Informatics Association. 2016;23(1):60-73.
161. Denzin NK, Lincoln YS. The SAGE handbook of qualitative research. Fifth edition. ed. Thousand Oaks, CA: Sage; 2018.
162. LeCompte MD, Schensul JJ. Introduction. Designing and Conducting Ethnographic Research. 1. United States: AltaMira Press; 2010.
163. DeJonckheere M, Vaughn LM. Semistructured interviewing in primary care research: a balance of relationship and rigour. Semistructured interviewing in primary care research: a balance of relationship and rigour: BMJ; 2019.
164. Sanders EBN, Stappers PJ. Probes, toolkits and prototypes: three approaches to making in codesigning. CoDesign. 2014;10(1):5-14.
165. Simonsen J, Robertson T. Routledge international handbook of participatory design. New York: Routledge; 2013.
166. Waller A, Franklin V, Pagliari C, Greene S. Participatory design of a text message scheduling system to support young people with diabetes. Health Informatics Journal. 2006;12(4):304-18.
167. Scholl J, Syed-Abdul S, Ahmed LA. A case study of an EMR system at a large hospital in India: Challenges and strategies for successful adoption. Journal of Biomedical Informatics. 2011;44(6):958-67.
168. LaFond A, Cherney M. A Theory of Change for Guiding the Integration of Human-Centered Design into Global Health Programming. Glob Health Sci Pract. 2021;9(Suppl 2):S209-S16.
169. Karumba K, Oluoch D, Mutua E, Gathara D, Fuller S, English M, et al. Engaging stakeholders in embedded newborn health services/systems research in Kenya; a continuous process involving multiple actors. [version 1; peer review: awaiting peer review]. NIHR Open Research. 2024.
170. Statistics KNBo. VOLUME I: POPULATION BY COUNTY AND SUB-COUNTY. Kenya National Bureau of Statistics; 2019.
171. WANKURU PC. World Bank Blogs: World Bank. 2019. [cited 2022]. Available from: https://blogs.worldbank.org/africacan/for-the-first-time-the-relative-economic-size-of-kenyas-counties-is-clear.
172. Services O. Kenya - Gross County Product (GCP) by Economic Activities per county 2019 [Available from: https://data.humdata.org/dataset/kenya-gross-county-product-gcp-by-economic-activities-per-county.
173. Unit GsP. Nyeri County Weekly Review. County Government of Nyeri; 2021.
174. Molyneux C, Goudge J, Russell S, Chuma J, Gumede T, Gilson L. Conducting health-related social science research in low income settings: ethical dilemmas faced in Kenya and South Africa. Journal of international development. 2009;21(2):309-26.
175. Dourish P, editor Implications for design. Conference on Human Factors in Computing Systems; 2006; New York NY: ACM.
176. Pitchforth E, Van Teijlingen E. International public health research involving interpreters: A case study from Bangladesh. BMC Public Health. 2005;5(1):71-.
177. Nguyen P, Scheyvens R, Beban A, Gardyne S. From a Distance: The 'New Normal' for Researchers and Research Assistants Engaged in Remote Fieldwork. SAGE Publications Inc; 2022.
178. Cooper A. About face : the essentials of interaction design. Fourth ed. Indianapolis, Indiana: Wiley; 2014.
179. Calde S, Goodwin K, Reimann R. SHS Orcas: The First Integrated Information System for Long-Term Healthcare Facility Management. 2002.
180. Cooper A. The inmates are running the asylum. Indianapolis, Ind: Sams; 1999.
181. Blomkvist S. Persona–an overview. Retrieved November. 2002;22(2004):15.
182. Ortega Roman D, Bartolini, Rosario, Pareja, Rossina, Creed-Kanashiro, Hillary M., Stawarz,, Katarzyna H, Michelle, Rousham, Emily and Verdezoto Dias, Nervo. Barriers and Facilitators to Participation when Involving Caregivers and Healthcare Workers in Co-design Workshops in Peruvian Low-resource Settings. The 22nd European Conference on Computer-Supported

Cooperative Work; Rimini, Italy2024.
183. Mosely G, Markauskaite L, Wrigley C. Design facilitation: A critical review of conceptualisations and constructs. Thinking skills and creativity. 2021;42:100962.
184. Williams A, editor User-centered design, activity-centered design, and goal-directed design: a review of three methods for designing web applications. Proceedings of the 27th ACM international conference on Design of communication; 2009 2009; New York, NY, USA: ACM.
185. Fore D, Goldenhar LM, Margolis PA, Seid M. Using Goal-Directed Design to Create a Novel System for Improving Chronic Illness Care. JMIR Res Protoc. 2013;2(2):e43.
186. Duan H, Wang Z, Ji Y, Ma L, Liu F, Chi M, et al. Using Goal-Directed Design to Create a Mobile Health App to Improve Patient Compliance With Hypertension Self-Management: Development and Deployment. JMIR Mhealth Uhealth. 2020;8(2):e14466.
187. Pratama MSP, Effendy V, Junaedi D, editors. Modeling Reproductive Health Educational Games For Early Childhood using Goal-Directed Design. 2021 International Conference on Software Engineering & Computer Systems and 4th International Conference on Computational Science and Information Management (ICSECS-ICOCSIM); 2021 24-26 Aug. 2021.
188. Antonacci G, Lennox L, Barlow J, Evans L, Reed J. Process mapping in healthcare: a systematic review. BMC Health Services Research. 2021;21(1):342.
189. Jepkosgei J, Nzinga J, Farsides B, Marsh V, Molyneux S, McKnight J. Maintaining distance and staying immersed: Practical ethics in an underresourced new born unit. 2019.
190. Braun V, Clarke V. Thematic analysis : a practical guide. London: SAGE Publications Ltd; 2021.
191. Ziebland S, McPherson A. Making sense of qualitative data analysis: an introduction with illustrations from DIPEx (personal experiences of health and illness). Med Educ. 2006;40(5):405-14.
192. Clark T. 'We're Over-Researched Here!' Exploring Accounts of Research Fatigue within Qualitative Research Engagements. Sociology (Oxford). 2008;42(5):953-70.
193. Corlett S, Mavin S. Reflexivity and Researcher Positionality. 55 City Road, London: SAGE Publications Ltd; 2018. p. 377-99.
194. Adler PA, Adler P. Membership roles in field research. Newbury Park, Calif. ;: SAGE; 1987.
195. Dwyer SC, Buckle JL. Reflection/Commentary on a Past Article: "The Space Between: On Being an Insider-Outsider in Qualitative Research". International journal of qualitative methods. 2018;17(1).
196. Edwards R. A critical examination of the use of interpreters in the qualitative research process. Journal of ethnic and migration studies. 1998;24(1):197-208.
197. Stevano S, Deane K, Liamputtong P. The Role of Research Assistants in Qualitative and Cross-Cultural Social Science Research. Singapore: Springer Singapore; 2019. p. 1675-90.
198. Egid BR, Roura M, Aktar B, Amegee Quach J, Chumo I, Dias S, et al. 'You want to deal with power while riding on power': global perspectives on power in participatory health research and co-production approaches. BMJ Global Health. 2021;6(11):e006978.
199. Bich TH, Long TK, Hoa DP. Community-based father education intervention on breastfeeding practice-Results of a quasi-experimental study. Matern Child Nutr. 2019;15 Suppl 1(Suppl 1):e12705.
200. de Vries I, Abu Hamad B, Gurp Mv, Alba S, Khammash U, Baatsen P. Key lessons from a mixed-method evaluation of a postnatal home visit programme in the humanitarian setting of Gaza. Eastern Mediterranean Health Journal. 2021;27(6):546-52.
201. Bashour HN, Kharouf MH, Abdulsalam AA, El Asmar K, Tabbaa MA, Cheikha SA. Effect of postnatal home visits on maternal/infant outcomes in Syria: a randomized controlled trial. Public Health Nurs. 2008;25(2):115-25.
202. Choi Y, El Arifeen S, Mannan I, Rahman SM, Bari S, Darmstadt GL, et al. Can mothers recognize neonatal illness correctly? Comparison of maternal report and assessment by community health workers in rural Bangladesh. Trop Med Int Health. 2010;15(6):743-53.

203. Goel AD, Gosain M, Amarchand R, Sharma H, Rai S, Kapoor SK, et al. Effectiveness of a Quality Improvement Program Using Difference-in-Difference Analysis for Home Based Newborn Care - Results of a Community Intervention Trial. Indian J Pediatr. 2019;86(11):1028-35.
204. Boone P, Eble A, Elbourne D, Frost C, Jayanty C, Lakshminarayana R, et al. Community health promotion and medical provision for neonatal health-CHAMPION cluster randomised trial in Nagarkurnool district, Telangana (formerly Andhra Pradesh), India. PLoS Med. 2017;14(7):e1002324.
205. Waiswa P, Pariyo G, Kallander K, Akuze J, Namazzi G, Ekirapa-Kiracho E, et al. Effect of the Uganda Newborn Study on care-seeking and care practices: a cluster-randomised controlled trial. Glob Health Action. 2015;8(1):24584-.
206. Bhandari N, Mazumder S, Taneja S, Sommerfelt H, Strand TA, Group IES. Effect of implementation of Integrated Management of Neonatal and Childhood Illness (IMNCI) programme on neonatal and infant mortality: cluster randomised controlled trial. BMJ. 2012;344:e1634.
207. Ayiasi RM, Kolsteren P, Batwala V, Criel B, Orach CG. Effect of Village Health Team home visits and mobile phone consultations on maternal and newborn care practices in Masindi and Kiryandongo, Uganda: A community-intervention trial. PLoS One. 2016;11(4):e0153051-e.
208. Hodgins S, McPherson R, Suvedi BK, Shrestha RB, Silwal RC, Ban B, et al. Testing a scalable community-based approach to improve maternal and neonatal health in rural Nepal. J Perinatol. 2010;30(6):388-95.
209. Nsibande D, Doherty T, Ijumba P, Tomlinson M, Jackson D, Sanders D, et al. Assessment of the uptake of neonatal and young infant referrals by community health workers to public health facilities in an urban informal settlement, KwaZulu-Natal, South Africa. BMC Health Serv Res. 2013;13(1):47-.
210. McConnell M, Ettenger A, Rothschild CW, Muigai F, Cohen J. Can a community health worker administered postnatal checklist increase health-seeking behaviors and knowledge?: Evidence from a randomized trial with a private maternity facility in Kiambu County, Kenya. BMC Pregnancy Childbirth. 2016;16(1):136-.
211. Bhutta ZA, Soofi S, Cousens S, Mohammad S, Memon ZA, Ali I, et al. Improvement of perinatal and newborn care in rural Pakistan through community-based strategies: a cluster-randomised effectiveness trial. Lancet. 2011;377(9763):403-12.
212. Mannan I, Rahman SM, Sania A, Seraji HR, Arifeen SE, Winch PJ, et al. Can early postpartum home visits by trained community health workers improve breastfeeding of newborns? J Perinatol. 2008;28(9):632-40.
213. Bang AT, Baitule SB, Reddy HM, Deshmukh MD, Bang RA. Low birth weight and preterm neonates: can they be managed at home by mother and a trained village health worker? J Perinatol. 2005;25 Suppl 1:S72-81.
214. Baqui A, Williams EK, Rosecrans AM, Agrawal PK, Ahmed S, Darmstadt GL, et al. Impact of an integrated nutrition and health programme on neonatal mortality in rural northern India. Bull World Health Organ. 2008;86(10):796-804, A.
215. Neupane D, Dawson P, Houston R, Dhakal L, Sharma J, Gargi KC, et al. Lower mortality is observed among low birth weight young infants who have received home-based care by female community health volunteers in rural Nepal. BMC Pregnancy Childbirth. 2017;17(1):218-.
216. Rasaily R, Saxena NC, Pandey S, Garg BS, Swain S, Iyengar SD, et al. Effect of home-based newborn care on neonatal and infant mortality: a cluster randomised trial in India. BMJ Glob Health. 2020;5(9).
217. Soofi S, Cousens S, Turab A, Wasan Y, Mohammed S, Ariff S, et al. Effect of provision of home-based curative health services by public sector health-care providers on neonatal survival: a community-based cluster-randomised trial in rural Pakistan. Lancet Glob Health. 2017;5(8):e796-e806.

218. Ndaba T, Taylor M, Mabaso M. Training and Evaluation of Community Health Workers (CHWs): Towards Improving Maternal and Newborn Survival in an Urban Setting in KwaZulu-Natal, South Africa. The Open Public Health Journal. 2019;12(1):406-13.
219. Kayemba CN, Sengendo HN, Ssekitooleko J, Kerber K, Källander K, Waiswa P, et al. Introduction of newborn care within integrated community case management in Uganda. Am J Trop Med Hyg. 2012;87(5):46-53.
220. Darmstadt GL, El Arifeen S, Choi Y, Bari S, Rahman SM, Mannan I, et al. Household surveillance of severe neonatal illness by community health workers in Mirzapur, Bangladesh: coverage and compliance with referral. Health Policy Plan. 2010;25(2):112-24.
221. Manu A, Hill Z, Ten Asbroek AH, Soremekun S, Weobong B, Gyan T, et al. Increasing access to care for sick newborns: evidence from the Ghana Newhints cluster-randomised controlled trial. BMJ Open. 2016;6(6):e008107.
222. Kumar V, Mohanty S, Kumar A, Misra RP, Santosham M, Awasthi S, et al. Effect of community-based behaviour change management on neonatal mortality in Shivgarh, Uttar Pradesh, India: a cluster-randomised controlled trial. Lancet. 2008;372(9644):1151-62.
223. Hailegebriel TD, Mulligan B, Cousens S, Mathewos B, Wall S, Bekele A, et al. Effect on neonatal mortality of newborn infection management at health posts when referral is not possible: A cluster-randomized trial in rural Ethiopia. Glob Health Sci Pract. 2017;5(2):202-16.
224. Eriksson L, Huy TQ, Duc DM, Ekholm Selling K, Hoa DP, Thuy NT, et al. Process evaluation of a knowledge translation intervention using facilitation of local stakeholder groups to improve neonatal survival in the Quang Ninh province, Vietnam. Trials. 2016;17:23.
225. Colbourn T, Nambiar B, Bondo A, Makwenda C, Tsetekani E, Makonda-Ridley A, et al. Effects of quality improvement in health facilities and community mobilization through women's groups on maternal, neonatal and perinatal mortality in three districts of Malawi: MaiKhanda, a cluster randomized controlled effectiveness trial. Int Health. 2013;5(3):180-95.
226. Gai Tobe R, Islam MT, Yoshimura Y, Hossain J. Strengthening the community support group to improve maternal and neonatal health seeking behaviors: A cluster-randomized controlled trial in Satkhira District, Bangladesh. PLoS One. 2019;14(2):e0212847.
227. Lewycka SP, Mwansambo CF, Rosato MP, Kazembe PF, Phiri TM, Mganga AB, et al. Effect of women's groups and volunteer peer counselling on rates of mortality, morbidity, and health behaviours in mothers and children in rural Malawi (MaiMwana): a factorial, cluster-randomised controlled trial. Lancet. 2013;381(9879):1721-35.
228. Morrison J, Thapa R, Hartley S, Osrin D, Manandhar M, Tumbahangphe K, et al. Understanding how women's groups improve maternal and newborn health in Makwanpur, Nepal: a qualitative study. Int Health. 2010;2(1):25-35.
229. Dongre AR, Deshmukh PR, Garg BS. A community based approach to improve health care seeking for newborn danger signs in rural wardha, India. Indian J Pediatr. 2009;76(1):45-50.
230. Rath S, Nair N, Tripathy PK, Barnett S, Rath S, Mahapatra R, et al. Explaining the impact of a women's group led community mobilisation intervention on maternal and newborn health outcomes: The Ekjut trial process evaluation. BMC Int Health Hum Rights. 2010;10(1):25-.
231. Azad K, Barnett S, Banerjee B, Shaha S, Khan K, Rego AR, et al. Effect of scaling up women's groups on birth outcomes in three rural districts in Bangladesh: a cluster-randomised controlled trial. Lancet. 2010;375(9721):1193-202.
232. Fottrell E, Azad K, Kuddus A, Younes L, Shaha S, Nahar T, et al. The effect of increased coverage of participatory women's groups on neonatal mortality in Bangladesh: A cluster randomized trial. JAMA Pediatr. 2013;167(9):816-25.
233. Callaghan-Koru JA, Estifanos AS, Sheferaw ED, de Graft-Johnson J, Rosado C, Patton-Molitors R, et al. Practice of skin-to-skin contact, exclusive breastfeeding and other newborn care interventions in Ethiopia following promotion by facility and community health workers: results from a prospective outcome evaluation. Acta Paediatr. 2016;105(12):e568-e76.

234. Coutinho SB, de Lira PI, de Carvalho Lima M, Ashworth A. Comparison of the effect of two systems for the promotion of exclusive breastfeeding. Lancet. 2005;366(9491):1094-100.
235. Mulupuru S, Siddu A, Murki S, Saikiran D, Reddy A. Breast crawl at birth, effect on breastfeeding rate and infant growth in infants delivered at an urban tertiary care public hospital: A randomized controlled trial. Journal of neonatal nursing : JNN. 2019;25(5):236-9.
236. Senarath U, Fernando DN, Rodrigo I. Newborn care practices at home: effect of a hospital-based intervention in Sri Lanka. J Trop Pediatr. 2007;53(2):113-8.
237. Shah MH, Roshan R, Parikh T, Sathe S, Vaidya U, Pandit A. LATCH Score at Discharge: A Predictor of Weight Gain and Exclusive Breastfeeding at 6 Weeks in Term Healthy Babies. J Pediatr Gastroenterol Nutr. 2021;72(2):e48-e52.
238. Zhang B, Duan Z, Zhao Y, Williams S, Wall S, Huang L, et al. Intermittent kangaroo mother care and the practice of breastfeeding late preterm infants: results from four hospitals in different provinces of China. Int Breastfeed J. 2020;15(1):64-.
239. Mony PK, Tadele H, Gobezayehu AG, Chan GJ, Kumar A, Mazumder S, et al. Scaling up Kangaroo Mother Care in Ethiopia and India: a multi-site implementation research study. BMJ Glob Health. 2021;6(9).
240. Jeganathan S V, R, Germans T. Linking Home Based New Born Care to the Existing Government Health system in Tamil Nadu - Pilot Study. Pediatric Oncall Journal. 2015;12(2):34-9.
241. Jennings L, Yebadokpo A, Affo J, Agbogbe M. Use of Job Aids to Improve Facility-Based Postnatal Counseling and Care in Rural Benin. Matern Child Health J. 2014;19(3):557-65.
242. Madireddy AL, Swapna. Telemonitoring of High-Risk neonates discharged from SNCU using a novel device a pilot study. Perinatology. 2019;20:38-42.
243. Sahip Y, Turan JM. Education for expectant fathers in workplaces in Turkey. J Biosoc Sci. 2007;39(6):843-60.
244. Thapa K, Mohan D, Williams E, Rai C, Bista S, Mishra S, et al. Feasibility assessment of an ergonomic baby wrap for kangaroo mother care: A mixed methods study from Nepal. PLoS One. 2018;13(11):e0207206.
245. Turan JM, Say L. Community-based antenatal education in Istanbul, Turkey: effects on health behaviours. Health Policy Plan. 2003;18(4):391-8.
246. Vanhuyse F, Stirrup O, Odhiambo A, Palmer T, Dickin S, Skordis J, et al. Effectiveness of conditional cash transfers (Afya credits incentive) to retain women in the continuum of care during pregnancy, birth and the postnatal period in Kenya: A cluster-randomised trial. BMJ Open. 2022;12(1):e055921-e.
247. Ijumba P, Doherty T, Jackson D, Tomlinson M, Sanders D, Swanevelder S, et al. Effect of an integrated community-based package for maternal and newborn care on feeding patterns during the first 12 weeks of life: a cluster-randomized trial in a South African township. Public Health Nutrition: PNH. 2015;18(14):pp2660-8.
248. Kimani-Murage EW, Norris SA, Mutua MK, Wekesah F, Wanjohi M, Muhia N, et al. Potential effectiveness of Community Health Strategy to promote exclusive breastfeeding in urban poor settings in Nairobi, Kenya: a quasi-experimental study. J Dev Orig Health Dis. 2016;7(2):172-84.
249. Kimani-Murage EW, Kimiywe J, Mutoro AN, Wilunda C, Wekesah FM, Muriuki P, et al. Effectiveness of the baby-friendly community initiative on exclusive breastfeeding in Kenya. Matern Child Nutr. 2021;17(3):e13142-n/a.
250. Manandhar DS, Osrin D, Shrestha BP, Mesko N, Morrison J, Tumbahangphe KM, et al. Effect of a participatory intervention with women's groups on birth outcomes in Nepal: cluster-randomised controlled trial. Lancet. 2004;364(9438):970-9.
251. Quasem I, Sloan NL, Chowdhury A, Ahmed S, Winikoff B, Chowdhury AM. Adaptation of kangaroo mother care for community-based application. J Perinatol. 2003;23(8):646-51.
252. Rahman M, Jhohura FT, Mistry SK, Chowdhury TR, Ishaque T, Shah R, et al. Assessing Community Based Improved Maternal Neonatal Child Survival (IMNCS) Program in Rural Bangladesh. PLoS One. 2015;10(9):e0136898.

253. Sloan NL, Ahmed S, Mitra SN, Choudhury N, Chowdhury M, Rob U, et al. Community-based kangaroo mother care to prevent neonatal and infant mortality: a randomized, controlled cluster trial. Pediatrics. 2008;121(5):e1047-59.
254. Tylleskar T, Jackson D, Meda N, Engebretsen IM, Chopra M, Diallo AH, et al. Exclusive breastfeeding promotion by peer counsellors in sub-Saharan Africa (PROMISE-EBF): a cluster-randomised trial. Lancet. 2011;378(9789):420-7.
255. Rahman A, Moran A, Pervin J, Rahman A, Rahman M, Yeasmin S, et al. Effectiveness of an integrated approach to reduce perinatal mortality: recent experiences from Matlab, Bangladesh. BMC Public Health. 2011;11(1):914.
256. Cavalcanti DS, Cabral CS, de Toledo Vianna RP, Osorio MM. Online participatory intervention to promote and support exclusive breastfeeding: Randomized clinical trial. Matern Child Nutr. 2019;15(3):e12806.
257. Modi D, Dholakia N, Gopalan R, Venkatraman S, Dave K, Shah S, et al. mHealth intervention "ImTeCHO" to improve delivery of maternal, neonatal, and child care services-A cluster-randomized trial in tribal areas of Gujarat, India. PLoS Med. 2019;16(10):e1002939.
258. Nasreen HE, Leppard M, Al Mamun M, Billah M, Mistry SK, Rahman M, et al. Men's knowledge and awareness of maternal, neonatal and child health care in rural Bangladesh: A comparative cross sectional study. Reprod Health. 2012;9(1):18-.
259. Bhandari N, Bahl R, Mazumdar S, Martines J, Black RE, Bhan MK, et al. Effect of community-based promotion of exclusive breastfeeding on diarrhoeal illness and growth: a cluster randomised controlled trial. Lancet. 2003;361(9367):1418-23.
260. Agrasada G, Gustafsson J, Kylberg E, Ewald U. Postnatal peer counselling on exclusive breastfeeding of low-birthweight infants: A randomized, controlled trial. Acta Paediatrica. 2005;94(8):1109-15.
261. Baqui AH, El-Arifeen S Fau - Darmstadt GL, Darmstadt Gl Fau - Ahmed S, Ahmed S Fau - Williams EK, Williams Ek Fau - Seraji HR, Seraji Hr Fau - Mannan I, et al. Effect of community-based newborn-care intervention package implemented through two service-delivery strategies in Sylhet district, Bangladesh: a cluster-randomised controlled trial. (1474-547X (Electronic)).
262. Mazumder S, Taneja S, Dube B, Bhatia K, Ghosh R, Shekhar M, et al. Effect of community-initiated kangaroo mother care on survival of infants with low birthweight: a randomised controlled trial. Lancet. 2019;394(10210):1724-36.
263. Yeboah-Antwi K, Hamer DH, Semrau K, Waltensperger KZ, Snetro-Plewman G, Kambikambi C, et al. Can a community health worker and a trained traditional birth attendant work as a team to deliver child health interventions in rural Zambia? BMC Health Services Research. 2014;14(1):516.
264. Kikuchi K, Gyapong M, Shibanuma A, Asah E, Okawa S, Addei S, et al. EMBRACE intervention to improve the continuum of care in maternal and newborn health in Ghana: The RE-AIM framework-based evaluation. J Glob Health. 2021;11:04017-.
265. WACh G. 2022. [cited 2024]. Available from: https://depts.washington.edu/globalwach/2022/08/03/mobile-wach-neo-randomized-controlled-trial-achieves-milestone-to-enroll-5020-research-participants/.
266. Consulting I. NewBorn Nutrition Digital Adaptation Kit (NNDAK) 2022 [Available from: https://www.intellisoftkenya.com/intellisoft-in-action/.
267. Foundation BaMG. Pay it Forward Maternal Health Model: Bill and Melinda Gates Foundation; 2011 [Available from: https://gcgh.grandchallenges.org/grant/pay-it-forward-maternal-health-model.
268. Aponjon. 2015 [Available from: http://www.aponjon.com.bd/aponjon_inner.
269. Development Z. MOBILE INTEGRATED RESOURCES FOR AURAT-WOMEN (MIRA) CHANNEL: Providing critical MNCH services to women at the bottom of the pyramid ZMQ Development; 2011.
270. Worldwide C. May 13th 2016. [cited 2024]. Available from: https://concernusa.org/news/innovations-community-health-nurses-on-the-go/.

271. Achieng W. Equipping CHWs with tools in Kitui County, Kenya2022 [cited 2024 14th June]. Available from: https://medic.org/stories/equipping-chws-with-tools-in-kitui-county-kenya/.
272. Health J. PROMPTS [Available from: https://www.jacarandahealth.org/prompts.
273. Health M. [cited 2024 14th June]. Available from: https://www.musohealth.org/the-muso-model.
274. ARTH. ARTH; [Available from: https://www.arth.in/.
275. USAID. USAID's MaMoni Maternal and Newborn Care Strengthening Project. 2021 September.
276. Thrive A. Infant and Young Child Feeding. Alive & Thrive; 2014.
277. Hasanah DR, Putri NK, Pramono AY. EFFECTIVENESS OF FORMING BREASTFEEDING SUPPORT GROUP PROGRAM TO IMPROVE EXCLUSIVE BREASTFEEDING. Jurnal administrasi kesehatan Indonesia (Online). 2020;8(1):5-19.
278. USAID. USAID MOMENTUM Joint Fact Sheet. USAID; 2022.
279. Schiffman JBA, Darmstadt GLMDMS, Agarwal S, Baqui AHMDMPH. Community-Based Intervention Packages for Improving Perinatal Health in Developing Countries: A Review of the Evidence. Semin Perinatol. 2010;34(6):462-76.
280. Sacks E, Freeman PA, Sakyi K, Jennings MC, Rassekh BM, Gupta S, et al. Comprehensive review of the evidence regarding the effectiveness of community-based primary health care in improving maternal, neonatal and child health: 3. neonatal health findings. J Glob Health. 2017;7(1):010903.
281. Negero MG, Sibbritt D, Dawson A. How can human resources for health interventions contribute to sexual, reproductive, maternal, and newborn healthcare quality across the continuum in low- and lower-middle-income countries? A systematic review. Human Resources for Health. 2021;19(1):54.
282. Kikuchi K, Okawa S, Zamawe COF, Shibanuma A, Nanishi K, Iwamoto A, et al. Effectiveness of continuum of care - Linking pre-pregnancy care and pregnancy care to improve neonatal and perinatal mortality: A systematic review and meta-analysis. PLoS One. 2016;11(10):e0164965-e.
283. Klingberg S, Motlhatlhedi M, Mabena G, Mooki T, Verdezoto N, Densmore M, et al. "Must you make an app?" A qualitative exploration of socio-technical challenges and opportunities for designing digital maternal and child health solutions in Soweto, South Africa. PLOS Global Public Health. 2022;2(12):e0001280.
284. Muraya K, Ogutu M, Mwadhi M, Mikusa J, Okinyi M, Magawi C, et al. Applying a gender lens to understand pathways through care for acutely ill young children in Kenyan urban informal settlements. International Journal for Equity in Health. 2021;20(1):17.
285. WHO. WHO recommendations on Postnatal care of the mother and newborn. WHO; 2013.
286. Uddin MF, Molyneux S, Muraya K, Hossain MA, Islam MA, Shahid ASMSB, et al. Gender-related influences on adherence to advice and treatment-seeking guidance for infants and young children post-hospital discharge in Bangladesh. International Journal for Equity in Health. 2021;20(1):64.
287. Duran P, Sommer JA, Otero P, Daus M, Benitez S, Serruya S, et al. Information and communication technologies in neonatal health. Revista Panamericana de Salud Pública. 2020;44(123).
288. Jongbloed K, Parmar S, van der Kop M, Spittal PM, Lester RT. Recent Evidence for Emerging Digital Technologies to Support Global HIV Engagement in Care. (1548-3576 (Electronic)).
289. Aunon Fm Fau - Okada E, Okada E Fau - Wanje G, Wanje G Fau - Masese L, Masese L Fau - Odeny TA, Odeny Ta Fau - Kinuthia J, Kinuthia J Fau - Mandaliya K, et al. Iterative Development of an mHealth Intervention to Support Antiretroviral Therapy Initiation and Adherence Among Female Sex Workers in Mombasa, Kenya. (1552-6917 (Electronic)).
290. Mwangi CW, M Mukanya CM. Does Message-Based Communication Through Mobile Phones for Medication and Treatment Adherence Improve Health Outcomes? A Systematic Review. Journal of Pharmaceutical Care & Health Systems. 2017;04(03).

291. Hall AK, Cole-Lewis H Fau - Bernhardt JM, Bernhardt JM. Mobile text messaging for health: a systematic review of reviews. (1545-2093 (Electronic)).
292. Lupton D. Digital Health : Critical and Cross-Disciplinary Perspectives. 1st ed: Routledge; 2017.
293. Cresswell K, Sheikh A. Organizational issues in the implementation and adoption of health information technology innovations: an interpretative review. (1872-8243 (Electronic)).
294. Muinga N, Abejirinde IOO, Paton C, English M, Zweekhorst M. Designing paper-based records to improve the quality of nursing documentation in hospitals: A scoping review. J Clin Nurs. 2021;30(1-2):56-71.
295. WHO. Newborn Mortality Geneva: World Health Organisation; 2022 [Available from: https://www.who.int/news-room/fact-sheets/detail/levels-and-trends-in-child-mortality-report-2021.
296. Wiens MO, Kumbakumba E, Larson CP, Moschovis PP, Barigye C, Kabakyenga J, et al. Scheduled Follow-Up Referrals and Simple Prevention Kits Including Counseling to Improve Post-Discharge Outcomes Among Children in Uganda: A Proof-of-Concept Study. 2016(2169-575X (Electronic)).
297. Kenya MoH. Comprehensive Newborn Care Protocols: Integrating Technologies with Clinical Pathways. Ministry of Health Kenya; 2022.
298. Organisation WH. Standards for improving quality of care for small and sick newborns in health facilities. Geneva; 2020.
299. UNICEF W. Home visits for the newborn child: a strategy to improve survival. World Health Organisation; 2009.
300. Maraschin FG, Adella FJ, Nagraj S. A scoping review of the post-discharge care needs of babies requiring surgery in the first year of life. PLOS Global Public Health. 2023;3(11):e0002424.
301. Ministry of HK. Kenya Community Health Strategy 2020-2025. Kenya: Ministry of Health; 2020.
302. Subramanian L, Murthy S, Bogam P, Yan SD, Marx Delaney M, Goodwin CDG, et al. Just-in-time postnatal education programmes to improve newborn care practices: needs and opportunities in low-resource settings. BMJ global health. 2020;5(7):e002660.
303. Smith H, Harvey C, Portela A. Discharge preparation and readiness after birth: a scoping review of global policies, guidelines and literature. BMC Pregnancy and Childbirth. 2022;22(1):281.
304. Brown SJ, Davey M-A, Bruinsma FJ. Women's views and experiences of postnatal hospital care in the Victorian Survey of Recent Mothers 2000. Midwifery. 2005;21(2):109-26.
305. Barimani M, Oxelmark L, Johansson S-E, Langius-Eklöf A, Hylander I. Professional support and emergency visits during the first 2 weeks postpartum. Scandinavian Journal of Caring Sciences. 2014;28(1):57-65.
306. Sacks E, Finlayson K, Brizuela V, Crossland N, Ziegler D, Sauvé C, et al. Factors that influence uptake of routine postnatal care: Findings on women's perspectives from a qualitative evidence synthesis. PLOS ONE. 2022;17(8):e0270264.
307. Isoardi J, Spencer L, Sinnott M, Nicholls K, O'Connor A, Jones F. Exploration of the perceptions of emergency physicians and interns regarding the medical documentation practices of interns. Emergency Medicine Australasia. 2013;25(4):302-7.
308. Irving G, Neves AL, Dambha-Miller H, Oishi A, Tagashira H, Verho A, et al. International variations in primary care physician consultation time: a systematic review of 67 countries. 2017.
309. WHO. WHO recommendations for care of the preterm or low birth weight infant. Geneva: World Health Organisation; 2022.
310. Psaila K, Schmied V, Fowler C, Kruske S. Discontinuities between maternity and child and family health services: health professional's perceptions. BMC Health Services Research. 2014;14(1):4.
311. Joseph L, Lavis A, Greenfield S, Boban D, Jose P, Jeemon P, et al. A systematic review of home-based records in maternal and child health for improving informational continuity, health

outcomes, and perceived usefulness in low and middle-income countries. PLOS ONE. 2022;17(8):e0267192.
312. Crehan C, Kesler E, Chikomoni IA, Sun K, Dube Q, Lakhanpaul M, et al. Admissions to a low-resource neonatal unit in Malawi using a mobile app: Digital perinatal outcome audit. JMIR Mhealth Uhealth. 2020;8(10):e16485-e.
313. Fitzgerald E, Mlotha-Mitole R, Ciccone EJ, Tilly AE, Montijo JM, Lang H-J, et al. A pediatric death audit in a large referral hospital in Malawi. BMC Pediatrics. 2018;18(1):75.
314. Margalit RS, Roter D, Dunevant MA, Larson S, Reis S. Electronic medical record use and physician–patient communication: An observational study of Israeli primary care encounters. Patient Educ Couns. 2006;61(1):134-41.
315. Osaki K, Hattori T Fau - Kosen S, Kosen S. The role of home-based records in the establishment of a continuum of care for mothers, newborns, and children in Indonesia. Glob Health Action. 2013(1654-9880 (Electronic)).
316. Osaki K, Aiga H. Adapting home-based records for maternal and child health to users' capacities. Bull World Health Organ. 2019(1564-0604 (Electronic)).
317. Muinga N, Abejirinde I-OO, Benova L, Paton C, English M, Zweekhorst M. Implementing a comprehensive newborn monitoring chart: barriers, enablers, and opportunities. 2022.
318. Mwakyusa S, Wamae A, Wasunna A, Were F, Esamai F, Ogutu B, et al. Implementation of a structured paediatric admission record for district hospitals in Kenya – results of a pilot study. BMC International Health and Human Rights. 2006;6(1):9.
319. Gachau S, Ayieko P, Gathara D, Mwaniki P, Ogero M, Akech S, et al. Does audit and feedback improve the adoption of recommended practices? Evidence from a longitudinal observational study of an emerging clinical network in Kenya. 2017.
320. Jawhari B, Ludwick D, Keenan L, Zakus D, Hayward R. Benefits and challenges of EMR implementations in low resource settings: a state-of-the-art review. BMC Medical Informatics and Decision Making. 2016;16(1):116.
321. Subiyakto A, Adhiazni V, Nurmiati E, Hasanati N, Sumarsono S, Irfan M, editors. Redesigning User Interface Based On User Experience Using Goal-Directed Design Method. 2020 8th International Conference on Cyber and IT Service Management (CITSM); 2020 23-24 Oct. 2020.
322. Joni S, Bernard JJ, Jisun A, Haewoon K, Soon-Gyo J. Are personas done?: Evaluating the usefulness of personas in the age of online analytics. Persona Studies. 2018;4(2):47-65.
323. Hill C, Haag M, Oleson A, Mendez C, Marsden N, Sarma A, et al. Gender-Inclusiveness Personas vs. Stereotyping: Can We Have it Both Ways?2017. 6658-71 p.
324. Chapman C, Milham R. The Personas' New Clothes: Methodological and Practical Arguments against a Popular Method. 2014.
325. Gurses AP, Xiao Y, Hu P. User-designed information tools to support communication and care coordination in a trauma hospital. Journal of Biomedical Informatics. 2009;42(4):667-77.
326. Roder-DeWan S, Madhavan S, Subramanian S, Nimako K, Lashari T, Bathula AN, et al. Service delivery redesign is a process, not a model of care. BMJ. 2023;380:e071651.
327. Beatrice RE, María R, Bachera A, Jessica Amegee Q, Ivy C, Sónia D, et al. â□□You want to deal with power while riding on powerâ□□: global perspectives on power in participatory health research and co-production approaches. BMJ Global Health. 2021;6(11):e006978.
328. Papoutsi C, Wherton J, Shaw S, Morrison C, Greenhalgh T. Putting the social back into sociotechnical: case studies of co-design in digital health. 2020.
329. Andersson SR, Hassanen S, Momanyi AM, Onyango DK, Gatwechi DK, Lutukai MN, et al. Using Human-Centered Design to Adapt Supply Chains and Digital Solutions for Community Health Volunteers in Nomadic Communities of Northern Kenya. Global Health: Science and Practice. 2021;9(Supplement 1):S151.
330. Brown DW, Gacic-Dobo M. Occurrence of home-based record stock-outs—A quiet problem for national immunization programmes continues. Vaccine. 2018;36(6):773-8.

331. Young SL, Gacic-Dobo M, Brown DW. Results from a survey of national immunization programmes on home-based vaccination record practices in 2013. Int Health. 2015(1876-3405 (Electronic)).
332. Page BF, Hinton L, Harrop E, Vincent C. The challenges of caring for children who require complex medical care at home: 'The go between for everyone is the parent and as the parent that's an awful lot of responsibility'. 2020.
333. Anderson BR. Improving health care by embracing Systems Theory. J Thorac Cardiovasc Surg. 2016(1097-685X (Electronic)).
334. Zakayo SM, Njeru RW, Sanga G, Kimani MN, Charo A, Muraya K, et al. Vulnerability and agency across treatment-seeking journeys for acutely ill children: how family members navigate complex healthcare before, during and after hospitalisation in a rural Kenyan setting. International Journal for Equity in Health. 2020;19(1):136.
335. Corsini L, Aranda-Jan CB, Cassi H, Moultrie J. Recommendations for participatory design in low-resource settings. 2019.
336. Shukla V, Carlo WA. Technology-driven Neonatal Health Care in Low-resource Settings: Expectations and Reality. EClinicalMedicine. 2019;12:2-3.
337. Dol J, Hughes B, Bonet M, Dorey R, Dorling J, Grant A, et al. Timing of neonatal mortality and severe morbidity during the postnatal period: a systematic review. Timing of neonatal mortality and severe morbidity during the postnatal period: a systematic review: Wolters Kluwer; 2023.
338. Stevenson AG, Tooke L, Edwards EM, Mangiza M, Horn D, Heys M, et al. The use of data in resource limited settings to improve quality of care. The use of data in resource limited settings to improve quality of care: Saunders; 2021.
339. Day LT, Sadeq-ur Rahman Q, Ehsanur Rahman A, Salim N, Kc A, Ruysen H, et al. Assessment of the validity of the measurement of newborn and maternal health-care coverage in hospitals (EN-BIRTH): an observational study. The Lancet Global Health. 2021;9(3):e267-e79.
340. Fleming PJ, Ingram J, Johnson D, Blair PS. Estimating discharge dates using routinely collected data: improving the preparedness of parents of preterm infants for discharge home. Estimating discharge dates using routinely collected data: improving the preparedness of parents of preterm infants for discharge home: BMJ Publishing Group Ltd & Royal College of Paediatrics and Child Health; 2017.
341. Musitia P, Boga M, Oluoch D, Haaland A, Nzinga J, English M, et al. Strengthening respectful communication with patients and colleagues in neonatal units — developing and evaluating a communication and emotional competence training for nurse managers in Kenya. Wellcome Open Res. 2022;7:223-.
342. Skinner D, Delobelle P, Pappin M, Pieterse D, Esterhuizen TM, Barron P, et al. User assessments and the use of information from MomConnect, a mobile phone text-based information service, by pregnant women and new mothers in South Africa. BMJ Glob Health. 2018;3(Suppl 2):e000561-e.
343. Hedqvist A-T, Lindberg C, Hagerman H, Svensson A, Ekstedt M. Negotiating care in organizational borderlands: a grounded theory of inter-organizational collaboration in coordination of care. BMC Health Serv Res. 2024;24(1):1438-17.
344. Ochieng CA, Odhiambo AS. Barriers to formal health care seeking during pregnancy, childbirth and postnatal period: a qualitative study in Siaya County in rural Kenya. BMC Pregnancy and Childbirth. 2019;19(1):339.
345. Cohen J, Rothschild C, Golub G, Omondi GN, Kruk ME, McConnell M. Measuring The Impact Of Cash Transfers And Behavioral 'Nudges' On Maternity Care In Nairobi, Kenya. 2017(1544-5208 (Electronic)).
346. Oluoch D, Hinton L, English M, Irimu G, Onyango T, Jones COH. Mothers' involvement in providing care for their hospitalised sick newborns in Kenya: a focused ethnographic account. 2023.

347. Heys M, Lakhanpaul M, Allaham S, Manikam L, Owugha J, Oulton K, et al. Community-based family and carer-support programmes for children with disabilities. Paediatrics and child health. 2020;30(5):180-5.
348. Nanyunja C, Sadoo S, Kohli-Lynch M, Nalugya R, Nyonyintono J, Muhumuza A, et al. Early care and support for young children with developmental disabilities and their caregivers in Uganda: The Baby Ubuntu feasibility trial. Front Pediatr. 2022;10:981976-.
349. Mwangome M, Murunga S, Kahindi J, Gwiyo P, Mwasho G, Talbert A, et al. Individualized breastfeeding support for acutely ill, malnourished infants under 6 months old. Maternal & Child Nutrition. 2020;16(1):e12868.
350. Carboni C, Wehrens R, van der Veen R, de Bont A. Conceptualizing the digitalization of healthcare work: A metaphor-based Critical Interpretive Synthesis. Soc Sci Med. 2022;292:114572-.
351. Bucher SL, Cardellichio P, Muinga N, Patterson JK, Thukral A, Deorari AK, et al. Digital Health Innovations, Tools, and Resources to Support Helping Babies Survive Programs. Pediatrics. 2020;146(Suppl 2):S165.
352. Health Mo. Kenya Health Sector Referral Implementation Guidelines. Nairobi: Ministry of Health; 2014.
353. Kalaris K, Radovich E, Carmone AE, Smith JM, Hyre A, Baye ML, et al. Networks of Care: an approach to improving maternal and newborn health. 2022.
354. Huang C, Singh K, Handa S, Halpern C, Pettifor A, Thirumurthy H. Investments in children's health and the Kenyan cash transfer for orphans and vulnerable children: evidence from an unconditional cash transfer scheme. Health Policy and Planning. 2017;32(7):943-55.

Appendices

Table of Contents

Appendices 220
Appendix 1: Search Strategy for Academic Literature for the Scoping Review 221
Appendix 2: Data Charting Table for Academic Literature in the Scoping Review 224
Appendix 3: Data Charting Table for Grey Literature 241
Appendix 4a: Interview Guide for Healthcare Workers 247
Appendix 4b: Interview Guide for Mothers 250
Appendix 4c: Interview Guide for Social Worker 252
Appendix 4d: Interview Guide for Follow-up Phone Calls 252
Appendix 5a: Information and Consent Form for HCWs (Interview or Group Discussion) 254
Appendix 5b: Information Sheet and Consent Form for Mothers Interviews 259
Appendix 5c: Information Sheet and Consent Form for Key Informants 263
Appendix 6a: Guide for Workshop 1 267
Appendix 6b: Guide for Workshop 2 271
Appendix 6c: Guide for Workshop 3 274
Appendix 6d: Guide for Workshop 4 274
Appendix 7: Participatory Studies in the Academic Literature in the Scoping Review 276

Appendix 1: Search Strategy for Academic Literature for the Scoping Review

The table below shows the search terms applied across the databases. The list of LMICs was created according to the World Bank classification. Van Zyl et al. highlighted that LMIC rankings are based on economic measures which can mask strained health systems in a “developed” country (1), thus their search terms were added.

Concept 1	“continu* of care” OR “continu* care” OR “care retention” OR “long term care” OR “follow up care” OR “coordination of care” OR “continuity of patient care” OR “care continu*” OR “comprehensive healthcare” OR “comprehensive care” OR “patient centred care” OR “person centred care” OR “patient focused care” OR "post discharge continu*" OR "post discharge care" OR "post discharge follow up" OR “post discharge” OR “discharge planning” OR “hospital discharge” OR “transition*” OR “integrated care” OR “home-based care” OR “community care” OR “community based care” OR “informational continuity” OR “management continuity” OR “patient-provider relationship*” OR “longitudinal care” OR “coordinated care” OR “relational continuity”
Concept 2	"postnatal care" OR “postpartum care” OR “post partum care” OR “postpartum period” OR “postpartum visit” OR “neonatal care” OR “neonatal health” OR “newborn care” OR “new born care” OR “newborn health” OR “perinatal care” OR “peri natal care” OR “maternal-child health service*” OR “newborn healthcare” OR “perinatal service*” OR “post natal service” OR “postnatal service*” OR “postnatal health service*” OR “post natal health service” OR “infant health” OR “perinatal mortality” OR “neonatal mortality” OR “infant mortality” OR “paediatric care”
Concept 3	afghanistan OR albania OR algeria OR “american samoa” OR angola OR "antigua and barbuda" OR antigua OR barbuda OR argentina OR armenia OR armenian OR aruba OR azerbaijan OR bahrain OR bangladesh OR barbados OR “republic of Belarus” OR belarus OR byelarus OR belorussia OR byelorussian OR belize OR “british Honduras” OR benin OR dahomey OR bhutan OR bolivia OR "bosnia and herzegovina" OR bosnia OR herzegovina OR botswana OR bechuanaland OR brazil OR brasil OR bulgaria OR “burkina faso” OR “burkina fasso” OR “upper volta” OR burundi OR urundi OR “cabo verde” OR “cape verde” OR cambodia OR kampuchea OR “khmer republic” OR cameroon OR cameron OR cameroun OR “central african republic” OR “ubangi shari” OR chad OR chile OR china OR colombia OR comoros OR “comoro islands” OR “iles comores” OR mayotte OR “democratic republic of the congo” OR “democratic republic congo” OR congo OR zaire OR “costa rica” OR "cote d’ivoire" OR "cote d’ ivoire" OR “cote divoire” OR “cote d ivoire” OR “ivory coast” OR croatia OR cuba OR cyprus OR “czech republic” OR czechoslovakia OR djibouti OR “french Somaliland” OR dominica OR “dominican republic” OR ecuador OR egypt OR “united arab republic” OR “el Salvador” OR “equatorial guinea” OR “spanish guinea” OR eritrea OR estonia OR eswatini OR swaziland OR ethiopia OR fiji OR gabon

	OR “gabonese republic” OR gambia OR "georgia (republic)" OR georgian OR ghana OR “gold coast” OR gibraltar OR greece OR grenada OR guam OR guatemala OR guinea OR “guinea Bissau” OR guyana OR “british Guiana” OR haiti OR hispaniola OR honduras OR hungary OR india OR indonesia OR timor OR iran OR iraq OR “isle of man” OR jamaica OR jordan OR kazakhstan OR kazakh OR kenya OR "democratic people’s republic of korea" OR “republic of korea” OR “north korea” OR “south korea” OR korea OR kosovo OR kyrgyzstan OR kirghizia OR kirgizstan OR “kyrgyz republic” OR kirghiz OR laos OR “lao pdr” OR “lao people's democratic republic” OR latvia OR lebanon OR “republic of north Macedonia” OR macedonia OR madagascar OR “malagasy republic” OR malawi OR nyasaland OR malaysia OR “malay federation” OR “malaya federation” OR “indian ocean islands” OR “indian ocean” OR mali OR malta OR micronesia OR “federated states of micronesia” OR kiribati OR “marshall islands” OR nauru OR “northern mariana islands” OR palau OR tuvalu OR mauritania OR mauritius OR mexico OR moldova OR moldovian OR mongolia OR montenegro OR morocco OR ifni OR mozambique OR “portuguese east Africa” OR myanmar OR burma OR namibia OR nepal OR “netherlands Antilles” OR nicaragua OR niger OR nigeria OR oman OR muscat OR pakistan OR panama OR “papua new guinea” OR “new guinea” OR paraguay OR peru OR philippines OR philipines OR phillipines OR phillippines OR poland OR "polish peoples republic" OR portugal OR “portuguese republic” OR “puerto rico” OR romania OR russia OR “russian federation” OR ussr OR “soviet union” OR “union of soviet socialist republics” OR rwanda OR ruanda OR samoa OR “pacific islands” OR polynesia OR “samoan islands” OR “navigator island” OR “navigator islands” OR "sao tome and principe" OR “saudi arabia” OR senegal OR serbia OR seychelles OR “sierra leone” OR slovakia OR “slovak republic” OR slovenia OR melanesia OR “solomon island” OR “solomon islands” OR “norfolk island” OR “norfolk islands” OR somalia OR “south Africa” OR “south sudan” OR “sri lanka” OR ceylon OR "saint kitts and nevis" OR "st. kitts and nevis" OR “saint lucia” OR "st. lucia" OR "saint vincent and the grenadines" OR “saint Vincent” OR "st. vincent" OR grenadines OR sudan OR suriname OR surinam OR “dutch guiana” OR “netherlands guiana” OR syria OR “syrian arab republic” OR tajikistan OR tadjikistan OR tadzhikistan OR tadzhik OR tanzania OR tanganyika OR thailand OR siam OR “timor leste” OR “east timor” OR togo OR “togolese republic” OR tonga OR "trinidad and tobago" OR trinidad OR tobago OR tunisia OR turkey OR turkmenistan OR turkmen OR uganda OR ukraine OR uruguay OR uzbekistan OR uzbek OR vanuatu OR “new hebrides” OR venezuela OR vietnam OR “middle east” OR “west bank” OR gaza OR palestine OR yemen OR yugoslavia OR zambia OR zimbabwe OR “northern Rhodesia” OR “global south” OR “africa south of the sahara” OR “sub-saharan Africa” OR “subsaharan Africa” OR “africa, central” OR “central Africa” OR “africa, northern” OR “north Africa” OR “northern Africa” OR magreb OR maghrib OR sahara OR “africa, southern” OR “southern Africa” OR “africa, eastern” OR “east Africa” OR “eastern Africa” OR “africa, western” OR “west Africa” OR “western Africa” OR “west indies” OR “indian ocean islands” OR caribbean OR “central America” OR “latin America” OR "south and central america" OR “south America” OR “asia, central” OR “central asia” OR “asia, northern” OR “north asia” OR “northern asia” OR “asia, southeastern” OR “southeastern asia” OR “south eastern asia” OR “southeast asia” OR “south east asia” OR “asia, western” OR

	“western asia” OR “europe, eastern” OR “east Europe” OR “eastern Europe” OR “developing country” OR “developing countries” OR “developing nation?” OR “developing population?” OR “developing world” OR “less developed countr*” OR “less developed nation?” OR “less developed population?” OR “less developed world” OR “lesser developed countr*” OR “lesser developed nation?” OR “lesser developed population?” OR “lesser developed world” OR “under developed countr*” OR “under developed nation?” OR “under developed population?” OR “under developed world” OR “underdeveloped countr*” OR “underdeveloped nation?” OR “underdeveloped population?” OR “underdeveloped world” OR “middle income countr*” OR “middle income nation?” OR “middle income population?” OR “low income countr*” OR “low income nation?” OR “low income population?” OR “lower income countr*” OR “lower income nation?” OR “lower income population?” OR “underserved countr*” OR “underserved nation?” OR “underserved population?” OR “underserved world” OR “under served countr*” OR “under served nation?” OR “under served population?” OR “under served world” OR “deprived countr*” OR “deprived nation?” OR “deprived population?” OR “deprived world” OR “poor countr*” OR “poor nation?” OR “poor population?” OR “poor world” OR “poorer countr*” OR “poorer nation?” OR “poorer population?” OR “poorer world” OR “developing econom*” OR “less developed econom*” OR “lesser developed econom*” OR “under developed econom*” OR “underdeveloped econom*” OR “middle income econom*” OR “low income econom*” OR “lower income econom*” OR “low gdp” OR “low gnp” OR “low gross domestic” OR “low gross national” OR “lower gdp” OR “lower gnp” OR “lower gross domestic” OR “lower gross national” OR lmic OR lmics OR “third world” OR “lami countr*” OR “transitional countr*” OR “emerging economies” OR “emerging nation?” OR "low-resource*" OR "low resource*" OR "resource-limited" OR "resource* limited" OR "resource poor" OR "resource-poor" OR "resource* constrain*" OR "resource restrict*" OR "resource-restrict*" OR "low-resource*" OR "low resource*" OR "resource-limited" OR "resource* limited" OR "resource poor" OR "resource-poor" OR "resource* constrain*" OR "resource restrict*" OR "resource-restrict*"

References

1. van Zyl C, Badenhorst M, Hanekom S, Heine M. Unravelling ‘low-resource settings’: a systematic scoping review with qualitative content analysis. BMJ Global Health. 2021;6(6):e005190.

Appendix 2: Data Charting Table for Academic Literature in the Scoping Review

Title of Paper	Author	Intervention	Aim	Who implemented the intervention?	Target of Intervention	Purpose/Focus of intervention	Continuity logic
Intermittent kangaroo mother care and the practice of breastfeeding late preterm infants: results from four hospitals in different provinces of China	Zhang et al.	HCW training	Behaviour change	HCWs in hospitals	Mothers of late pre-term babies	KMC and BF	Informational
Breast crawl at birth, effect on breastfeeding rate and infant growth in infants delivered at an urban tertiary care public hospital: A randomized controlled trial	Mulupuru et al.	Breast crawl (immediate skin to skin contact until breastfeeding)	Behaviour change	HCWs in hospitals	Mothers of term babies	BF	Interpersonal
Lower mortality is observed among low birth weight young infants who have received home-based care by female community health volunteers in rural Nepal	Neupane et al.	Home visits by CHWs	NMR	CHWs	Mothers of LBW babies	Community-based newborn care, including administering antibiotics and referrals	Relational
Effect of community-based newborn-care intervention package implemented through two service-delivery strategies in Sylhet district, Bangladesh: a cluster-randomised controlled trial.	Baqui et al.	Home visits by CHWs	NMR	CHWs	Married women of reproductive age (15-49) (community-based care) Pregnant women	Community-based newborn care, including community mobilisation, administering antibiotics and referrals	Informational, Management, Interpersonal

Title of Paper	Author	Intervention	Aim	Who implemented the intervention?	Target of Intervention	Purpose/Focus of intervention	Continuity logic
					(home-based care)		
Process evaluation of a knowledge translation intervention using facilitation of local stakeholder groups to improve neonatal survival in the Quang Ninh province, Vietnam.	Eriksson et al.	Group-based activities	Process	Trained facilitators from the Women's Union	Local healthcare staff and local key stakeholders (trained professionals, influential commune members)	Identify local problems and solutions	Interpersonal
Low birth weight and preterm neonates: can they be managed at home by mother and a trained village health worker?	Bang et al.	Home visits by CHWs	NMR	CHWs	Mothers of babies who are pre-term or LBW	Health education, management of newborns and referrals to care	Informational, Relational
Effects of quality improvement in health facilities and community mobilization through women's groups on maternal, neonatal and perinatal mortality in three districts of Malawi: maiKhanda, a cluster randomized controlled effectiveness trial	Colbourn et al.	Group-based activities	NMR	Volunteer facilitators	Pregnant women	Identify local problems and solutions	Informational, Management, Interpersonal

Title of Paper	Author	Intervention	Aim	Who implemented the intervention?	Target of Intervention	Purpose/Focus of intervention	Continuity logic
Effect of community-initiated kangaroo mother care on survival of infants with low birthweight: a randomised controlled trial	Mazumder et al.	Home visits by intervention workers	NMR	Intervention workers	Mothers of LBW babies	KMC	Informational, Relational
Effect of provision of home-based curative health services by public sector health-care providers on neonatal survival: a community-based cluster-randomised trial in rural Pakistan	Soofi et al.	Home visits by CHWs	NMR	CHWs	Mothers of term babies	Community-based newborn care, including resuscitation, management of newborns, administering antibiotics and referrals	Informational, Management, Interpersonal
Online participatory intervention to promote and support exclusive breastfeeding: randomized clinical trial	Cavalcanti et al.	Facebook Group	Behaviour change	Research team	Mothers of term babies	BF	Informational, Relational, Interpersonal
Effect of home-based newborn care on neonatal and infant mortality: a cluster randomized trial in India.	Rasaily et al.	Home visits by CHWs	NMR	CHWs	Mothers of term or LBW babies	Health education, management of newborns, treatment for minor illnesses and referrals	Informational, Relational, Interpersonal

Title of Paper	Author	Intervention	Aim	Who implemented the intervention?	Target of Intervention	Purpose/Focus of intervention	Continuity logic
Training and evaluation of Community Health Workers (CHWs): towards improving maternal and newborn survival in an urban setting in KwaZulu-Natal, South Africa.	Ndaba et al.	Home visits by CHWs	Behaviour change	CHWs	Pregnant women	Assess and support the mother during post-discharge, including newborn management and encouraging follow-ups	Informational, Relational
Strengthening the Community Support Group to improve maternal and neonatal health seeking behaviors: a cluster-randomized controlled trial in Satkhira District, Bangladesh.	Gai Tobe et al.	Group-based activities	Behaviour change	Community Support Groups (representatives from across the community)	Women who had given birth in the last year	Community mobilisation activities, planning for care (ANC to postnatal), referrals, education amongst residents	Informational, Interpersonal
Newborn care practices at home: effect of a hospital-based intervention in Sri Lanka.	Senarath et al.	Training hospital HCWs	Behaviour change	Hospital HCWs	Mothers of term babies	Education on newborn care	Informational
Adaptation of kangaroo mother care for community-based application	Quasem et al.	Home visits by CHWs	Behaviour change	CHWs	Expectant or recently delivered women	KMC	Informational, Relational

Title of Paper	Author	Intervention	Aim	Who implemented the intervention?	Target of Intervention	Purpose/Focus of intervention	Continuity logic
Can mothers recognize neonatal illness correctly? Comparison of maternal report and assessment by community health workers in rural Bangladesh	Choi et al.	Home visits by CHWs	Behaviour change	CHWs	Pregnant women	Education on neonatal danger signs, and CHW management of newborns including administering antibiotics or referrals to facilities	Informational, Management
Introduction of newborn care within integrated community case management in Uganda	Kayemba et al.	Home visits by CHWs	Process	CHWs	Pregnant and recently delivered women	Essential newborn care, encourage follow-ups at facilities, identify newborn danger signs, advise on healthy newborn practices	Informational, Management, Relational, Interpersonal
Can a community health worker and a trained traditional birth attendant work as a team to deliver child health interventions in rural Zambia?	Yeboah-Antwi et al.	Pairing CHWs and TBAs	Process	CHWs and TBAs	CHWs and TBAs	Improved teamwork between CHWs and TBAs	Relational, Interpersonal
Effectiveness of the baby-friendly community initiative	Kimani-Murage et al.	Home visits by CHWs and	Behaviour change	CHWs	Pregnant women ages 15-49	BF	Informational

Title of Paper	Author	Intervention	Aim	Who implemented the intervention?	Target of Intervention	Purpose/Focus of intervention	Continuity logic
on exclusive breastfeeding in Kenya		support groups					
Community-based father education intervention on breastfeeding practiceâ€"Results of a quasi-experimental study	Bich et al.	Home visits, monthly meetings and media campaigns	Behaviour change	Midwives and CHWs	Expectant fathers	Education on BF	Informational, Interpersonal
EMBRACE intervention to improve the continuum of care in maternal and newborn health in Ghana: The RE-AIM framework-based evaluation.	Kikuchi et al.	CoC cards, training HCWs on CoC, retaining women for 24 hours after delivery and home visits	Process	HCWs in hospitals	Recently delivered women	Increasing completion of CoC	Management, Relational
Scaling up Kangaroo Mother Care in Ethiopia and India: a multi-site implementation research study	Mony et al.	Maximising access to KMC facilities, training and supporting facility staff, supporting KMC at home post-discharge	Behaviour change	HCWs in hospitals and CHWs in the community	Mothers of LBW babies	KMC	Informational, Relational, Interpersonal

Title of Paper	Author	Intervention	Aim	Who implemented the intervention?	Target of Intervention	Purpose/Focus of intervention	Continuity logic
Effectiveness of a Quality Improvement Program Using Difference-in-Difference Analysis for Home Based Newborn Care - Results of a Community Intervention Trial.	Dhanesh Goel et al.	Home visits by CHWs and group based activities	Behaviour change	CHWs	Pregnant or recently delivered women	Health education on newborn care, including breastfeeding and danger signs	Informational, Relational, Interpersonal
mHealth intervention "ImTeCHO" to improve delivery of maternal, neonatal, and child care services—A cluster-randomized trial in tribal areas of Gujarat, India	Modi et al.	mHealth service	Behaviour change	CHWs and HCWs	Mothers of children under the age of 2	Videos with health messages for family members, screening checklist and referrals. HCWs can track high risk cases.	Informational, Relational
LATCH Score at Discharge: A Predictor of Weight Gain and Exclusive Breastfeeding at 6 Weeks in Term Healthy Babies	Shah et al.	Recording LATCH scores at discharge and giving extra support to mothers who need it	Behaviour change	Lactation nurse	Mothers of term babies	BF	Informational
Telemonitoring of high-risk neonates discharged from SNCU using a novel device: a pilot study	Madireddy and Lingaldinna	mHealth service	Process	Nurses	Parents of high risk neonates	Monitoring high risk babies and referrals	Management

Title of Paper	Author	Intervention	Aim	Who implemented the intervention?	Target of Intervention	Purpose/Focus of intervention	Continuity logic
Community health promotion and medical provision for neonatal health-CHAMPION cluster randomised trial in Nagarkurnool district, Telangana (formerly Andhra Pradesh), India	Boone et al.	Home visits by CHWs	NMR	CHWs	Women in the community	Education on newborn care and increasing awareness of available services. Tracking high risk mothers and referrals	Informational
Potential effectiveness of Community Health Strategy to promote exclusive breastfeeding in urban poor settings in Nairobi, Kenya: a quasi-experimental study	Kimani-Murage et al.	Home visits by CHWs	Behaviour change	CHWs	Pregnant women (12-49)	BF	Informational, Relational
Effect of the Uganda Newborn Study on care-seeking and care practices: a cluster-randomised controlled trial	Waiswa et al.	Home visits by CHWs	Behaviour change	CHWs	Pregnant women	Education on newborn care including breastfeeding, skin-to-skin care, delayed bathing and care-seeking for illness	Informational
Effect of implementation of Integrated Management of Neonatal and Childhood Illness (IMNCI) programme on neonatal and infant mortality:	Bhandari et al	Home visits by CHWs	NMR and behaviour change	CHWs	Recently delivered women	Education on newborn care practices, including breatfeeding, thermal care,	Informational, Management

Title of Paper	Author	Intervention	Aim	Who implemented the intervention?	Target of Intervention	Purpose/Focus of intervention	Continuity logic
Cluster randomised controlled trial						cord care, care seeking for illness. Newborns were assessed for signs of illness and referred.	
Household surveillance of severe neonatal illness by community health workers in Mirzapur, Bangladesh: coverage and compliance with referral	Darmstadt et al.	Home visits by CHWs	Process	CHWs	Pregnant women	Identifying severely ill newborns and referring them to care	Informational, Management
Increasing access to care for sick newborns: evidence from the Ghana Newhints cluster-randomised controlled trial	Manu et al.	Home visits by CHWs	Behaviour change	CHWs	Recently delivered women	Promoting early newborn care practices and providing referrals for sick babies	Informational, Relational
Effect of women's groups and volunteer peer counselling on rates of mortality, morbidity, and health behaviours in mothers and children in rural Malawi (MaiMwana): a factorial, cluster-randomised controlled trial	Lewycka et al.	Group-based activities and home visits	NMR and behaviour change	Facilitators and peer counsellors	Pregnant women	Identify local problems and solutions. Promoting early newborn care practices including care seeking	Informational, Interpersonal

Title of Paper	Author	Intervention	Aim	Who implemented the intervention?	Target of Intervention	Purpose/Focus of intervention	Continuity logic
Understanding how women's groups improve maternal and newborn health in Makwanpur, Nepal: a qualitative study	Morrison et al.	Group-based activities	Process	Local female facilitators	Women in the community	Identify local problems and solutions	Informational, Interpersonal
A community based approach to improve health care seeking for newborn danger signs in rural wardha, India	Dongre et al.	Group-based activities	Behaviour change	Community based organisations	Pregnant women	Community mobilisation and health education on care seeking	Informational, Interpersonal
Community-based antenatal education in Istanbul, Turkey: Effects on health behaviours	Mulzan Turan and Say	Group education sessions	Behaviour change	Nurse, facilitator and trained community member	Pregnant women	Education on newborn care practices	Informational
Feasibility assessment of an ergonomic baby wrap for kangaroo mother care: A mixed methods study from Nepal	Thapa et al.	Ergonomic KMC wrap	Behaviour change	HCWs at the hospital	Family of LBW babies	KMC	Informational, Management
Linking Home Based New Born Care to the Existing Government Health system in Tamil Nadu - Pilot Study	Jeganathan et al.	Integrated care	Process	HCWs and CHWs	Recently delivered women	Linking CHWs to facilities for referrals. Extra nurses, equipment (including ambulances) were provided at the hospitals	Informational, Relational, Interpersonal

Title of Paper	Author	Intervention	Aim	Who implemented the intervention?	Target of Intervention	Purpose/Focus of intervention	Continuity logic
Effect of community-based behaviour change management on neonatal mortality in Shivgarh, Uttar Pradesh, India: a cluster-randomised controlled trial	Kumar et al.	Home visits by CHWs	NMR and behaviour change	CHWs	Community stakeholders and pregnant women and their families	Essential newborn care, including breastfeeding, thermal care, cord care, care seeking from professionals	Informational, Relational
Key lessons from a mixed-method evaluation of a postnatal home visit programme in the humanitarian setting of Gaza	de Vries et al.	Home visits by nurses and midwives	Process	Midwives and nurses	First time mothers and mothers of high risk babies	Improving continuity of care post-discharge	Relational
Explaining the impact of a women's group led community mobilisation intervention on maternal and newborn health outcomes: the Ekjut trial process evaluation	Rath et al.	Group-based activities	Process	Local facilitators	Women in the community	Identify local problems and solutions	Interpersonal
Effect of Village Health Team home visits and mobile phone consultations on maternal and newborn care practices in Masindi and Kiryandongo, Uganda: a community-intervention trial	Ayiasi et al.	mHealth service Home visits by CHWs	Behaviour change	CHWs	Pregnant women	Education on essential newborn care	Informational, Relational

Title of Paper	Author	Intervention	Aim	Who implemented the intervention?	Target of Intervention	Purpose/Focus of intervention	Continuity logic
Men's knowledge and awareness of maternal, neonatal and child health care in rural Bangladesh: a comparative cross sectional study.	Nasreen et al.	Group activities	Behaviour change	Program organisers	Married men	Education on essential newborn care and referrals	Informational, Interpersonal
Effectiveness of an integrated approach to reduce perinatal mortality: recent experiences from Matlab, Bangladesh.	Rahman et al.	Home visits by CHWs	NMR	CHWs	Pregnant women	Improving links between communities and facilities via CHW counselling and referrals	Informational, Management
Assessing community based improved maternal neonatal child survival (IMNCS) program in rural Bangladesh	Rahman et al.	Home visits by CHWs	NMR	CHWs	Pregnant women	Improving the continuum of care via CHW counselling and improving services at facilities	Informational, Relational
Testing a scalable community-based approach to improve maternal and neonatal health in rural Nepal	Hodgins et al.	Home visits by CHWs	Behaviour change	CHWs	Mothers and family members	Education on essential newborn care	Informational, Relational
Effect of scaling up women's groups on birth outcomes in three rural districts in Bangladesh: a cluster-randomised controlled trial	Azad et al.	Group-based activities and health system strengthening	NMR and behaviour change	Local facilitators	Recently delivered women (15-49)	Identifying local problems and solutions. Refresher training for HCWs	Informational, Relational, Interpersonal

Title of Paper	Author	Intervention	Aim	Who implemented the intervention?	Target of Intervention	Purpose/Focus of intervention	Continuity logic
Effect of community-based promotion of exclusive breastfeeding on diarrhoeal illness and growth: a cluster randomised controlled trial	Bhandari et al	Group education	Behaviour change	TBAs, CHWs and other health workers	Recently delivered women	Education on BF	Informational, Interpersonal
Comparison of the effect of two systems for the promotion of exclusive breastfeeding	Coutinho et al.	Baby friendly hospital initiative and home visits	Behaviour change	HCWs and CHWs	Recently delivered women	BF	Informational, Relational, Interpersonal
Exclusive breastfeeding promotion by peer counsellors in sub-Saharan Africa (PROMISE-EBF): a cluster-randomised trial	Tylleskar et al.	Home visits	Behaviour change	Peer counsellors	Pregnant women	BF	Informational, Relational
Can early postpartum home visits by trained community health workers improve breastfeeding of newborns?	Mannan et al.	Home visits by CHWs	Behaviour change	CHWs	Pregnant women	Essential newborn care with a focus on BF	Informational, Relational
Community-Based Kangaroo Mother Care to Prevent Neonatal and Infant Mortality: A Randomized, Controlled Cluster Trial	Sloan et al.	Home visits by CHWs	NMR	CHWs	Pregnant women and their families	KMC	Informational
Postnatal peer counselling on exclusive breastfeeding of low-birthweight infants: A randomized, controlled trial	Agrasada et al.	Home visits by CHWs	Behaviour change	CHWs	Mothers of LBW babies	BF counselling	Informational, Relational

Title of Paper	Author	Intervention	Aim	Who implemented the intervention?	Target of Intervention	Purpose/Focus of intervention	Continuity logic
Impact of an integrated nutrition and health programme on neonatal mortality in rural northern India	Baqui et al.	Home visits by CHWs	NMR	CHWs	Mothers who had given birth in the last 2 years	Information to encourage behaviour change for essential newborn care	Informational, Relational
Education for expectant fathers in workplaces in Turkey	Sahip et al.	Group education sessions	Behaviour change	Doctors attached to companies	Men working in large offices	Education on antenatal care, supporting partners, breastfeeding, postnatal check ups	Informational
The Effect of Increased Coverage of Participatory Women's Groups on Neonatal Mortality in Bangladesh A Cluster Randomized Trial	Fottrell et al.	Group-based activities	NMR	Local facilitators	Women in the community	Identifying local problems and solutions	Interpersonal
Effect of Postnatal Home Visits on Maternal/Infant Outcomes in Syria: A Randomized Controlled Trial	Bashour et al.	Home visits by midwives	Behaviour change	Midwives	Recently delivered women	Education on newborn care, including breastfeeding, uptake of newborn care and immunisation	Informational, Relational

Title of Paper	Author	Intervention	Aim	Who implemented the intervention?	Target of Intervention	Purpose/Focus of intervention	Continuity logic
Improvement of perinatal and newborn care in rural Pakistan through community-based strategies: a cluster-randomised effectiveness trial	Bhutta et al.	Home visits by CHWs	NMR	CHWs	Women in the community. Pregnant women	Education on newborn care, including identification of danger signs, and promotion of care seeking	Informational, Relational
Practice of skin-to-skin contact, exclusive breastfeeding and other newborn care interventions in Ethiopia following promotion by facility and community health workers: results from a prospective outcome evaluation	Callaghan-Koru et al.	Counselling and home visits	Behaviour change	HCWs, CHWs and HEWs	Recently delivered women	KMC and BF	Interpersonal
Use of Job Aids to Improve Facility-Based Postnatal Counseling and Care in Rural Benin	Jennings et al.	Job aids for postnatal care	Behaviour change	Nurse-midwives	Recently delivered women	Education on immediate newborn care, including danger signs	Informational, Management
Effect on Neonatal Mortality of Newborn Infection Management at Health Posts When Referral Is Not Possible: A Cluster-Randomized Trial in Rural Ethiopia	Degefie Hailegebriel et al.	Home visits by CHWs and health system strengthening	NMR	CHWs and HEWs	Pregnant women	Essential newborn care, including referrals. Health centres were given job aids, antibiotics and	Management

Title of Paper	Author	Intervention	Aim	Who implemented the intervention?	Target of Intervention	Purpose/Focus of intervention	Continuity logic
						HCWs received training	
Effect of an integrated community-based package for maternal and newborn care on feeding patterns during the first 12 weeks of life: a cluster-randomized trial in a South African township	Ijumba et al.	Home visits by CHWs	Behaviour change	CHWs	Pregnant women (over 17)	BF	Informational, Relational
Can a community health worker administered postnatal checklist increase health-seeking behaviors and knowledge?: evidence from a randomized trial with a private maternity facility in Kiambu County, Kenya	McConnell et al.	Home visits and phone calls by CHWs using a checklist	Behaviour change	CHWs	Recently delivered women	Education on danger signs and referrals	Informational, Management, Relational
Assessment of the uptake of neonatal and young infant referrals by community health workers to public health facilities in an urban informal settlement, KwaZulu-Natal, South Africa	Nsibande et al.	Home visits by CHWs	Behaviour change	CHWs	Pregnant women	Education on danger signs and referrals	Informational, Management, Relational

Title of Paper	Author	Intervention	Aim	Who implemented the intervention?	Target of Intervention	Purpose/Focus of intervention	Continuity logic
Effectiveness of conditional cash transfers (Afya credits incentive) to retain women in the continuum of care during pregnancy, birth and the postnatal period in Kenya: a cluster randomised trial	Vanhuyse et al.	Cash transfer	Behaviour change	Nurses	Pregnant women	Increased care attendance	Relational

Appendix 3: Data Charting Table for Grey Literature

Website	Organisation	Country	Intervention	Aim	Target	Continuity logic	Participatory
USAID	USAID - MaMONI	Bangladesh	KMC register with phone numbers for follow-up calls, posters to indicate where KMC follow-up happens, two-way communication between patients and providers (counselling provided), home visits by CHWs, post-discharge process changed for high-risk and low-risk babies, NBU discharges are prioritised at follow-up to reduce waiting times, phone-based reminders for follow-up,	Aims: To learn how to improve tracking of preterm/LBW (<2kg) newborns through inpatient and post-discharge hospital and community follow-up in the current system To understand how to improve tracking of sick newborns using registers in inpatient and post-discharge hospital follow-up in	Healthcare providers	Relational, management, informational, interpersonal	The orientation package was developed based on the baseline assessment and the recommendations drawn from design workshop

			improved inter-departmental communication	the current system			
Digital health atlas	Medic Mobile	Kenya	Register new pregnancies, track ANC visits, flag danger signs, report on deliveries, report on post-partum visits via an mHealth platform. Facilities which can provide care have been pre-approved	Provide evidence-based tools to quickly reach health workers as they provided quality antenatal care, postnatal care, immunization delivery, and referrals to health facilities.	CHWs	Management	No
Digital health atlas	Jacaranda Health	Kenya	mHealth - PROMPTs text messaging platform. Behavioral	Empowering mothers to seek care at the right place and time	Mothers	Informational	No

			nudge messages , and an AI-supported helpdesk service that triages responses and questions to flag for clinical urgency				
Digital health atlas	Mobile Solutions for Women and Children's Health (Mobile WACh) University of Washington	Kenya	mHealth. Mobile WACh sends pre-composed messages to clients at scheduled times. Clients may send messages at any time and a live healthcare worker (HCW) answers incoming messages, leading to personalized dialogue.	Reduce NMR, determine the effect of WACh on care-seeking behaviours for sick newborns, determine effects on maternal social support, self-efficacy and depression.	Mothers and Healthcare workers	Informational	No
Digital health atlas	IntelliSOFT - Newborn Nutrition Reference Application (Neonatal Nutrition	Kenya	mHealth.	Equip mothers and healthcare providers with information and real-time	Mothers and healthcare workers	Informational	No

	Digital Adaptation Kit			feedback to adapt practices to optimize the provision of lifesaving milk to newborns			
R4D	Malezi-Bora	Kenya	Women sharing audio information on newborn care - mHealth	The aim is to leverage social networks in villages and understand who the key people are to share critical information.	Mothers	Informational, interpersonal	No
R4D	Aponjon	Bangladesh	Stage-based information via text messages - mHealth	Provide important weekly health messages to pregnant women, mothers with newborn babies and their family members.	Mothers; fathers and mothers in law are secondary	Informational	No
R4D	Project Muso	Mali	Train CHWs to identify symptoms and provide basic care.	To create a cure for delay because no one should	CHWs	Management	No

				die waiting for health care.			
R4D	Mat Troi Be Tho	Vietnam	Lactation and nutrition counselling - group classes or 1:1	To provide good quality infant and young child feeding at health facilities at all levels	Pregnant women, lactating mothers and their families	Informational	No
R4D	MIRA Channel (Women mobile lifeline channel)	India	Mobile phone channel providing information to women - mhealth	To bridge the information gap among rural women, help them connect with health services, and empower their decision-making abilities related to critical health issues.	Mothers	Informational	No
R4D	Action Research and Training for Health (ARTH)	India	Home visits to provide care	To help communities access and manage health care according to their needs and capacity,	CHWs	Relational	No

				by using research and training initiatives.			
R4D	Community Health Nurse on the Go (CNH)	Ghana	App for MNCH for CHWs - mhealth	Technology to help Ghana's frontline nurses go the extra mile.	CHWs	Interpersonal, Management	No
R4D	Rumah ASI: Exclusive Breast Feeding Peer Support Group	Indonesia	Exclusive Breast Feeding Peer Support Group - voluntary peer support group established by mothers to mothers.	The aim is to highlight the importance of breastfeeding during the first 6 months and up to 2 years where possible	Mothers	Interpersonal	No

Appendix 4a: Interview Guide for Healthcare Workers

IDI Guide: Healthcare workers

Thank you for taking the time to speak with me today. My name is Gulraj, I am a student from KEMRI and I am interested in continuity of care post-discharge for small and sick newborns, that is, babies that are born pre-term, LBW or have birth asphyxia, sepsis, jaundice, pneumonia etc. within the first 28 days of life. I am here to learn from you and better understand how things work. I am not here to judge you or your work, and everything you say will be confidential and private. If there are any questions you do not feel comfortable answering, please let me know, and we can move on to the next topic. If at any point you want to end the interview, please let me know. Do you have any questions for me?

Intro

1. Could you please tell me about your role within the hospital?
2. How long have you been working in that position?
3. What are the main responsibilities that your work involves?

1. What information are mothers given during their stay on the ward that they continue to use at home? For example, KMC or breastfeeding
    a. What questions/concerns are common from the mothers?
    b. How do you build a relationship with the mothers?
    c. Have you received any training/guidance on what to do during admission? *(Looking out for information given to mothers, building relationships, how to speak to mothers).*
2. Could you please explain the process of babies being discharged from your ward? (*Probes: is there a designated person, time of discharge, what happens on weekends/public holidays*).
    a. How are you involved in the discharge process and in follow-up of small and sick newborns?
3. What works well when it comes to discharge of these babies?
    a. What information are mothers given when they are being discharged from this ward?
    b. In what format do they receive this information? (Written, verbal, any reference to the MCH booklet or discharge summary).
    c. What questions/concerns are common?
    d. For mothers who don't seem so confident caring for their child, is there anything you do to provide some extra support or encouragement?

    e. Do you have any sources of support while discharging the baby? (Previous training, checklists)
4. Is there anything that doesn't work well when it comes to discharge?
    a. What would you like to change/do differently during this process?
    b. Do you have any ideas for how this could be implemented?
5. Can you tell me about the training you received on how to discharge a baby?
    a. When did you receive the training?
    b. What did it consist of?
    c. Did you feel it was helpful/useful?
    d. How could it be improved?
6. Let's say a mother is seropositive or has lost their baby, where would you have a discussion with her?
    a. Do you feel this works well?
    b. What could be done differently?
7. Could you explain the process of what happens when a baby dies?
    a. Who informs the mother and family?
    b. What documentation in involved?
    c. What kind of information do you provide for such a couple?)

For those who do check-ups

(For people interviewed previously) For this next section I want to focus on the care received after babies are discharged, such as the routine follow-ups.

(For people where the interview starts now). Thank you for taking the time to speak with me today. My name is Gulraj, I am a student from KEMRI and I am interested in continuity of care post-discharge for small and sick newborns, that is, babies that are born pre-term, LBW or have birth asphyxia, sepsis, jaundice, pneumonia etc. within the first 28 days of life. I am here to learn from you and better understand how things work. I am not here to judge you or your work, and everything you say will be confidential and private. If there are any questions you do not feel comfortable answering, please let me know, and we can move on to the next topic. If at any point you want to end the interview, please let me know. Do you have any questions for me?

- What is your role in the process of follow-up care for small or sick newborns?
- Which wards do you work in?

8. What are the most common issues babies born small or sick have during check-ups?
    a. Why do you think these issues happen?
    b. What do you do if the mother has not brought the discharge summary or MCH booklet?

    c. How do you manage babies that may not have records at the hospital?
    d. Is there anything you think could be done to reduce these issues?
9. What are some of the challenges you face with providing continuous care post-discharge?
    a. How would you improve the process?
    b. If you could create an intervention to help with these issues, what would the intervention include?
10. Are there things that are working well in the system, i.e., that make your work easier?
    a. Why do you think these features are working well?
    b. How could we make other parts of the system similar to this?
11. How do families engage with follow-up checks? For example, in terms of attendance etc.
    a. Is there a particular group of mothers/carers that struggles to make follow-ups?
    b. What do you think could be the reason for this?
    c. Is there anything you think could make the process easier for them?
12. Can you tell me about the training you received on how to manage a baby at a follow-up appointment?
    a. When did you receive the training?
    b. What did it consist of?
    c. Did you feel it was helpful/useful?
    d. How could it be improved?

Conclusion

Thank you for taking part in this study, I know you are very busy so it's much appreciated. Is there anything else you think it's important for me to know? Do you have any questions for me? Thank you.

Appendix 4b: Interview Guide for Mothers

Thank you for taking the time to speak with me today. My name is Gulraj, I am a student from KEMRI and I am interested in learning about how you look after your baby at home, and some of the things you may find challenging. I am not here to judge you or how you look after your baby, this is not a test. I won't use your name or anything that could lead someone to trace what you have said back to you. If there are any questions you do not feel comfortable answering, please let me know, and we can move on to the next topic. If at any point you want to end the interview, please let me know. Do you have any questions for me?

Intro

- Please tell me a bit about yourself and your family.
- How long have you lived in this area?
- What does a normal day look like for you?

1. Please tell me about your baby.
    a. Is this your first child?
    b. How long did the baby spend in the hospital?
    c. What care does your baby need now? (*Medication, breastfeeding, KMC, follow-up appointments)*
2. How was your experience at the hospital?
    a. Were you happy with the care provided? (why/why not)
    b. Did you feel supported by the staff?
    c. Do you think you were given enough information about how to care for your baby?
    d. Is there anything which could have been better?
3. Have you been to any follow-ups at the facility yet?
    If yes:
    a. Please tell me about your experience at follow-ups.
    b. Which facility did you go to?
    c. How did you get to the hospital?
    d. What did the doctors/nurse tell you?
    e. Were you happy with the care provided for your baby?
    f. Did you feel like you could ask any questions?
    g. Is there anything you would have liked them to do differently?
    If no:
    h. When is the next follow-up scheduled?
4. Do you feel confident caring for your baby?
    a. What would help you feel more confident?
    b. Were you given any information/advice at discharge?

    c. Is there any information you want to have on caring for your baby?
    d. If you needed advice on caring for your baby, what would you do/where would you go?
5. If you were unsure about what to do and needed some help/advice about looking after your baby, what would you do? (*Probe around whether they speak to other mothers, family members, refer to the MCH booklet, or have other resources*)
6. Where do you keep medical information, like the MCH booklet or discharge summaries?
    a. Have you ever used the booklet?
    b. Have you read the book or looked at the pictures?
7. What are the biggest difficulties you have faced while caring for your baby at home?
    a. Is there anything that could make this easier? Please tell me more

Conclusion

Thank you for taking part in this study, I know you are very busy so it's much appreciated. Is there anything else you think it's important for me to know? Do you have any questions for me? Thank you.

Appendix 4c: Interview Guide for Social Worker

Clarify that the focus is on small and sick babies.

1. Could you please tell me about your role in the discharge of mothers with small or sick babies?
    a. Who alerts you to a case?
    b. How do you decide whether you need to get involved? (criteria)
    c. At what point do you get involved?
    d. Who do you report to?
    e. How do you feel about the way things are done?
    f. Could anything be done to make things better?
2. Is there a particular group of mothers that you work with?
    a. Teen mothers
    b. Socioeconomic difficulties
    c. Mothers with mental health difficulties
3. What is your role in the follow-up of small or sick babies?
    a. What happens if a baby doesn't come back for a check-up?
4. Please tell me about your involvement with CHVs.
    a. Do you interact with CHVs at the hospital? What about CHVs in the rural communities?
    b. What is their role?
    c. Are these interactions formally documented?
5. Is there anything you think could make your work easier, or help mothers more?
6. Please tell me about a case that really stands out to you (can be good or bad).

Appendix 4d: Interview Guide for Follow-up Phone Calls

Please start the follow-up by asking the mother how she is, and any other questions that make her comfortable.

<u>Follow-up Questions</u>

1. How is your baby doing?
2. Have you been to any facilities since we last saw each other/spoke to each other?
3. Please tell me about your experience at these facilities (*the probes below are in case the mother doesn't give a long answer)*
    a. How did you feel? Happy, unhappy, angry, frustrated, judged, comfortable
    b. What do you think of the healthcare workers at the facility?
    c. What did you like/dislike

4. Please tell me about your experience providing care for the baby at home (*the probes below are in case the mother doesn't give a long answer)*
    a. How did you feel? Happy, unhappy, angry, frustrated, judged, comfortable
    b. What do you think of the healthcare workers at the facility?
    c. What did you like/dislike
5. Is there anything they would change about their experience?

Appendix 5a: Information and Consent Form for HCWs (Interview or Group Discussion)

HCW (interview or group discussion) information and consent

HIGH-Q Study Form 2a - <u>Information sheet and consent form for health care workers (adapted to either an individual interview or a small group)</u>

Title: Evaluating the effects of technology and workforce enhancement to support neonatal hospital care in Kenya.

Lay Title: A study to learn if and how the introduction of new technologies and service delivery innovations improves the quality of care provided in newborn units

Institution	Investigators and Collaborators
KEMRI Wellcome Trust Research Programme	Dr. Michuki Maina, Dr. Dorothy Oluoch, Dr. David Gathara, Prof. Mike English, Prof. Sassy Molyneux, Prof. Caroline Jones, Joyline Jepkosgei, Dr. Jalemba Aluvaala, Dr. Tim Tuti, Ms. Edith Gicheha, Mr. John Wainaina, Mr Livingstone Mumelo, Peris Musitia, Edna Mutua
University of Nairobi	Dr Jalemba Aluvaala, Prof Grace Irimu, Prof Fred Were, Dr Brian Maugo
Ministry of Health	Dr Caroline Mwangi, Dr Laura Oyiengo
Moi University	Prof Fabian Esamai
Nursing Association of Kenya	Edna Talam
Neonatal Nurses Chapter	Josephine Bariu
Preemie Love Foundation	Ruby Kimondo
Nuffield Department of Medicine, University of Oxford, UK	Dr. Chrysanthi Papoutsi, Dr Chris Paton, Dr. Lisa Hinton, Ms. Gulraj Grewal, Dr. Abdulazeez Imam, Dr. Gloria Ngaiza, Ms. Naima Nasir, Dr Sebastian Fuller, Dr Jacob Mc Knight, Ms. Asma Rababeh, Ms. Christiane Hagel

You are being asked to take part in a study. The box below tells you important things you should think about before deciding to join the study. We will provide more detailed information below the box. Please ask questions about any of the information before you decide to participate. You may also wish to talk to others (for example, your line manager, family, or friends) about this study, before agreeing to join.

Key Information for You to Consider
• **Voluntary Consent**. You are being asked to volunteer for a research study. You can choose whether you would like to participate or not. If you do agree, you can

change your mind at any time and withdraw from the research. This will not affect you now or in the future.

- **Purpose**. We are doing this research to find better ways of integrating necessary technologies into Kenyan health systems. In this study, we want to understand how the introduction of new technologies affect how nurses go around their work of caring for the newborns and if increasing the nursing workforce improves how the care is provided. Additionally, we aim to better understand if family experiences as their babies are treated will improve the acceptability of these technologies and improve patient care and follow up. We also aim to understand the governance structures that assess the safety and authorise the introduction of new technologies in the county
- **Duration.** Your participation in this study will last less than one and a half hours.
- **Procedures and Activities.** We will ask you to take part in an in-depth interview or a small group discussion with 6-8 healthcare workers.
- **Risks or disadvantages.** We do not believe there is risk to you if you join. In this study, there is a possibility that you might be a little bit inconvenienced by the time it takes to complete the interview.
- **Benefits**. There are no direct benefits in this study. However, the outputs from this study will contribute to the improvement of hospital care for newborns. If the interventions are successful, the strategies that we are testing could be adopted much more widely across Kenya.

Who is carrying out this study, and what is this study about?

This study is being carried out by KEMRI in collaboration with the University of Oxford, University of Nairobi, Moi University, Nursing Association of Kenya, Neonatal nurses' chapter, Preemie Love Foundation and the Kenya paediatric association. KEMRI is a Kenyan government organization that carries out medical research to find better ways of preventing and treating illness in the future for everybody's benefit.

In this research, we want to learn more about how to help hospitals use some technologies and health workers to provide better care for the sick babies that need to stay in the hospital for treatment soon after they are born. We are doing this by working with four other hospitals. We will work with the doctors and nurses from your hospital to find better ways of working that improve quality and safety. We will learn how to measure some aspects of babies' care and progress and use this information to promote improvements in care, and better prepare for your babies care once they are discharged from the hospital. To do this, we would like to hear the views of health care workers who have been treating the babies in the hospital's newborn unit. We will talk to people at their own convenient time.

Why do you want to talk to me (us) and what does it involve?

- We are interested in the experience of nurses/doctors/hospital managers with an understanding of / experience of health care provision in newborn units, MCH and

outpatient clinics as exploring these experiences can help us understand how things really are and whether efforts to make improvements are working or not.

- I would like to ask you some questions about your role in the newborn unit /in hospital management and how things work in this hospital and how you think things may have changed.
- If you are willing, interviews/discussions will be audio-recorded to assist later in fully writing up the information. No one will be identified by name in the recordings or in the writings.
- If you are invited to an interview: The interview will take between 40-60 minutes. If you do not want to answer any of the questions, you may say so, and the interviewer will move on to the next question. The interview will take place here. No-one else but you and the interviewer(s) will be present unless you would like someone else there.
- If you are invited to a small group discussion: The discussion will take about 90 minutes. You do not have to answer any question that you don't want to. The discussion will take place here. There will be 6-8 healthcare workers and the interviewer(s) present during the discussion.

Are there any risks or disadvantages to me taking part?

- If you are invited to an interview: The interview will take less than an hour of your time. We do not believe there are any risks to your taking part as we aim to ensure the confidentiality of all participants so that no comments can be directly linked to any person in recordings or written records of the interview.
- If you are invited to a small group discussion: The group discussion will include 6-8 healthcare workers and take less than 90 minutes of your time. Before the discussion begins, we will discuss the importance of keeping what is said in the group private to help ensure confidentiality of what is discussed. Once the discussion is over, the researchers aim to ensure the confidentiality of all participants so that no comments can be directly linked to any person in recordings or written records of the discussion.
- If the interviews are conducted outside your duty station/facility, you will be reimbursed for your out of pocket study related expenses. This will include reimbursement of any necessary travel (range 200-1000 KES), based either on receipts, or as a flat rate based on area and distanced travelled (whichever is the greater amount will be reimbursed). In addition, an out-of-duty station allowance will be given to you (1000 KES) for your participation.

Are there any advantages to me taking part?

There are no individual benefits to taking part. In talking to us, you will contribute to knowledge on how efforts to improve care on newborn units in Kenyan hospitals can work best. This may help other people in Kenya and elsewhere in the future, for example, through making the current approaches to improvement better or developing new strategies to improve care.

Who will have access to the information I give?

- All of our documents/ recordings are stored securely in locked cabinets and on password-protected computers. The knowledge gained from this research will be shared in summary form, without revealing individuals' identities, with study participants, hospital managers, policymakers and professional regulatory bodies.
- In future, information collected or generated during this study may be used to support new research by other researchers in Kenya or other countries on improving newborn service delivery. In all cases, we will only share information with other researchers in ways that do not reveal individual participants' identities. For example, we will remove such as their names and where they live and replace this information with number codes. Any future research using information from this study must first be approved by a local or national expert committee to make sure that the interests of participants and their communities are protected.

The University of Oxford is responsible for ensuring that Oxford staff involved in the study in Kenya adhere to the safe and proper use of any personal information you provide, solely for research purposes.

Who has allowed this research to take place?

All research at KEMRI has to be approved before it begins by its Scientific and Ethical Review Unit who look carefully at planned work. They must agree that the research is important, relevant to Kenya and follows nationally and internationally agreed on research guidelines. This includes ensuring that all participants' safety and rights are respected.

What will happen if I refuse to participate?

All participation in research is voluntary. You are free to decide if you want to take part or not. If you do agree, you can change your mind at any time without any consequences.

What if I have any questions?

You are free to ask me any question about this research. If you have any further questions about the study, you are free to contact the research team using the contacts below:

Dr. Michuki Maina, KEMRI Wellcome Trust Research Programme, P.O. Box 43640, Nairobi 00100. Telephone: 0722248890

If you want to ask someone independent anything about this research, please contact:

Community Liaison Manager, KEMRI Wellcome Trust Research Programme, P.O. Box 230, Kilifi. Telephone: 041 7522 063, Mobile 0723 342 780 or 0705 154 386

And

The Head, KEMRI Scientific and Ethics Review Unit, P. O. Box 54840-00200, Nairobi; Telephone numbers: 0717 719477; 0776 399979 Email address: seru@kemri.org

KEMRI-Wellcome Trust Research Programme consent form for a study to learn if and how the introduction of new technologies and service delivery innovations improves the quality of care provided in newborn units

I have had the study explained to me. I have understood all that has been read/explained and had my questions answered satisfactorily. And I agree to take part in this research

I agree for the interview/discussion to be recorded -- Yes -- No

I understand that I can change my mind at any stage, and it will not affect me in any way.

Signature: _____ **Date:** _____

Participant Name: _____ **Time:** _____

(Please print name)

(Please print name)

THE PARTICIPANT SHOULD NOW BE GIVEN A SIGNED COPY TO KEEP

Appendix 5b: Information Sheet and Consent Form for Mothers Interviews

HIGH-Q Study Form 2c - Information sheet and consent form for Mothers interviews

Title: Evaluating the effects of technology and workforce enhancement to support neonatal hospital care in Kenya.

Lay Title: A study to learn if and how the introduction of new technologies and service delivery innovations improves the quality of care provided in newborn units

Institution	Investigators and Collaborators
KEMRI Wellcome Trust Research Programme	Dr. Michuki Maina, Dr. Dorothy Oluoch, Dr. David Gathara, Prof. Mike English, Prof. Sassy Molyneux, Prof. Caroline Jones, Joyline Jepkosgei, Dr. Jalemba Aluvaala, Dr. Tim Tuti, Ms. Edith Gicheha, Mr. John Wainaina, Mr Livingstone Mumelo, Peris Musitia, Edna Mutua
University of Nairobi	Dr Jalemba Aluvaala, Prof Grace Irimu, Prof Fred Were, Dr Brian Maugo
Ministry of Health	Dr Caroline Mwangi, Dr Laura Oyiengo
Moi University	Prof Fabian Esamai
Nursing Association of Kenya	Edna Talam
Neonatal Nurses Chapter	Josephine Bariu
Preemie Love Foundation	Ruby Kimondo
Nuffield Department of Medicine, University of Oxford, UK	Dr. Chrysanthi Papoutsi, Dr Chris Paton, Dr. Lisa Hinton, Ms. Gulraj Grewal, Dr. Abdulazeez Imam, Dr. Gloria Ngaiza, Ms. Naima Nasir, Dr Sebastian Fuller, Dr Jacob Mc Knight, Ms. Asma Rababeh, Ms. Christiane Hagel

You are being asked to take part in a study. The box below tells you important things you should think about before deciding to join the study. We will provide more detailed information below the box. Please ask questions about any of the information before you decide to participate. You may also wish to talk to others (for example, your line manager, family, or friends) about this study, before agreeing to join.

Key Information for You to Consider

- Voluntary Consent. You are being asked to volunteer for a research study. You can choose whether you would like to participate or not. If you do agree, you can change your mind at any time and withdraw from the research. This will not affect you now or in the future.
- Purpose. We are doing this research to find better ways of integrating necessary technologies into Kenyan health systems. In this study, we want to understand how the introduction of new technologies affect how nurses go around their work of caring for the newborns and if increasing the nursing workforce improves how the care is provided. Additionally, we aim to better understand if family experiences as their babies are treated will improve the acceptability of these technologies and improve patient care and follow up. We also aim to understand the governance structures that assess the safety and authorise the introduction of new technologies in the county
- Duration. Each interview will take between 40-60 minutes of your time.

- Procedures and Activities. We will ask you to take part in an in-depth interview at discharge. We may also ask you to take part in a follow-up interview about 3 weeks after you have brought your baby home.
- Risks or disadvantages. There are no known harms/disadvantages in this study that could happen to you if you join. In this study, there is a possibility that you might be a little bit inconvenienced by the time it takes to complete the interview.
- Benefits. There are no direct benefits in this study. However, the outputs from this study will contribute to the improvement of hospital care for newborns. If the interventions are successful, the strategies that we are testing could be adopted much more widely across Kenya.

Who is carrying out this study, and what is this study about?

This study is being carried out by KEMRI in collaboration with the University of Oxford, University of Nairobi, Moi University, Nursing Association of Kenya, Neonatal nurses chapter, Preemie Love Foundation and the Kenya paediatric association. KEMRI is a Kenyan government organization that carries out medical research to find better ways of preventing and treating illness in the future for everybody's benefit.

In this research, we want to learn more about how to help hospitals use some technologies and health workers to provide better care for the sick babies that need to stay in the hospital for treatment soon after they are born. We are doing this by working with four other hospitals. We will work with the doctors and nurses from this hospital to find better ways of working that improve quality and safety. We will learn how to measure some aspects of babies' care and progress and use this information to promote improvements in care, and better prepare for your babies care once they are discharged from the hospital. To do this, we would like to hear the views mothers who have babies in the NBU. We will talk to people at their own convenient time.

Why do you want to talk to me, and what does it involve?

We feel that your experience as a mother whose baby has been admitted in a newborn unit immediately after their birth can contribute much to our understanding of your experiences with the introduction of new technologies during the time that your baby was admitted.

We would like to interview you since your experience will help us improve our understanding of newborn care, to explore the implementation dynamics of new technologies and to identify contextual and other broader contextual and health system factors affecting adoption and uptake of new technologies within newborn units as well as inform our understanding of workforce interventions on teamwork.

If you agree, we will request your participation in an interview. The interview will take between 40-60 minutes. If you do not want to answer any of the questions we ask, you may say so, and we will move to the next question. No one else but the people conducting the interview will be present unless you would like someone else there. We may follow up with you about 3 weeks later, by phone, for another interview to understand how your experiences might have changed.

If you are willing, interviews will be audio-recorded to assist later in fully writing up the information. No one will be identified by name in the recordings or in the writings.

Are there any risks or disadvantages to me taking part?

The interview should take approximately 40-60 minutes. We recognize that some of the answers can be confidential or sensitive to some individuals.

You will be reimbursed for your out-of-pocket study related expenses. This will include reimbursement of any necessary travel (between Ksh 200-1000), based either on receipts, or as a flat rate based on your area and the distanced you need to travel (whichever is the greater amount will be reimbursed). In addition, an out-of-pocket allowance of between Ksh 350 and 1000 depending on the geographical location of the interviews will be given to you for your participation.

Are there any advantages to me taking part?

There are no individual benefits to taking part. In talking to us, you will contribute to our understanding of how to integrate necessary technologies into Kenyan health systems better and improve newborn and post discharge care.

Who will have access to the information I give?

All our research records are stored securely in locked cabinets and password protected computers. Only a few people who are closely concerned with the research will be able to view information from participants.

In future, information collected or generated during this study may be used to support new research by other researchers. In all cases, we will only share information with other researchers in ways that do

not reveal individual participants' identities. For example, we will remove information that could

identify people, such as their names and where they live and replace this information with number codes. Any future research using information from this study must first be approved by a local or national expert committee to ensure that the interests of participants and their communities are protected.

We will share anonymized individual and summary information we collect or generate with the University of Oxford in ways that do not reveal individual participants' identities.

The University of Oxford is responsible for ensuring that Oxford staff involved in the study in Kenya adhere to the safe and proper use of any personal information you provide, solely for research purposes. Who has allowed this research to take place?

All research at KEMRI has to be approved before it begins by its Scientific and Ethical Review Unit who look carefully at planned work. They must agree that the research is important, relevant to Kenya and follows nationally and internationally agreed research guidelines. This includes ensuring that all participants' safety and rights are respected.

What will happen if I refuse to participate?

All participation in research is voluntary. You are free to decide if you want to take part or not. If you do agree, you can change your mind at any time without any consequences.

What if I have any questions?

You are free to ask me any question about this research. If you have any further questions about the study, you are free to contact the research team using the contacts below:

Dr. Michuki Maina, KEMRI Wellcome Trust Research Programme, P.O. Box 43640, Nairobi 00100. Telephone: 0722248890

If you want to ask someone independent anything about this research, please contact:

Community Liaison Manager, KEMRI Wellcome Trust Research Programme, P.O. Box 230, Kilifi. Telephone: 041 7522 063, Mobile 0723 342 780 or 0705 154 386

And

The Head, KEMRI Scientific and Ethics Review Unit, P. O. Box 54840-00200, Nairobi; Telephone numbers:

0717 719477; 0776 399979 Email address: seru@kemri.org

Appendix 5c: Information Sheet and Consent Form for Key Informants

HIGH Q Study Form 2o - Information sheet and written informed consent for key informants on post-discharge care for newborns

Title: Learning to Harness Innovation in Global Health for Quality Care (HIGH-Q)

Lay Title: A study to learn if and how the introduction of new technologies and service delivery innovations improves the quality of care provided in newborn units Institution	Investigators
KEMRI Wellcome Trust Research Programme	Dr. Michuki Maina, Dr. Dorothy Oluoch, Dr. David Gathara, Prof. Mike English, Prof. Sassy Molyneux, Prof. Caroline Jones, Joyline Jepkosgei, Dr. Jalemba Aluvaala, Dr. Tim Tuti, Ms. Edith Gicheha, Mr. John Wainaina, Mr Livingstone Mumelo, Peris Musitia.
University of Nairobi	Dr Jalemba Aluvaala, Prof Grace Irimu, Prof Fred Were, Dr Brian Maugo
Ministry of Health	Dr Caroline Mwangi, Dr Laura Oyiengo
Moi University	Prof Fabian Esamai
Nursing Association of Kenya	Edna Talam
Neonatal Nurses Chapter	Josephine Bariu
Preemie Love Foundation	Ruby Kimondo
Nuffield Department of Medicine, University of Oxford, UK	Dr. Chrysanthi Papoutsi, Dr Chris Paton, Dr. Lisa Hinton, **Ms. Gulraj Grewal**, Dr. Abdulazeez Imam, Dr. Gloria Ngaiza, Ms. Naima Nasir, Dr Sebastian Fuller, Dr Jacob Mc Knight, Ms Katherine Kalaris, Ms. Asma Rababeh, Ms. Christiane Hagel

You are being asked to take part in a study. The box below tells you important things you should think about before deciding to join the study. We will provide more detailed information below the box. Please ask questions about any of the information before you decide to participate. You may also wish to talk to others (for example, your line manager, family, or friends) about this study, before agreeing to join.

Key informant interviews information and consent. Key Information for You to Consider (Not more than 500 words)

• **Voluntary Consent**. You are being asked to volunteer for a research study. You can choose whether you would like to participate or not. If you do agree, you can change your mind at any time and withdraw from the research. This will not affect you now or in the future.

• **Purpose**. We are doing this research to find better ways of integrating necessary technologies into Kenyan health systems. In this study, we want to understand the process of delivering and implementing technologies. We are keen to understand how technologies were installed, and training conducted support post-implementing and the use and adoption (or lack) of technologies in routine practice. Additionally, we aim to understand how the implementation of technologies might have influenced changes in the hospital, such as the provision of essential resources, improved staffing or infrastructure changes.

- **Duration.** Your participation in this study will last 40-60 minutes.
- **Procedures and Activities.** We will ask you to take part in an in-depth interview.

Who is carrying out this study, and what is this study about?

This study is being carried out by KEMRI in collaboration with the University of Oxford, University of Nairobi, Moi University, Nursing Association of Kenya, Neonatal nurses' chapter, Preemie Love Foundation and the Kenya paediatric association. KEMRI is a Kenyan government organization that carries out medical research to find better ways of preventing and treating illness in the future for everybody's benefit.

In this research, we want to learn more about how to help hospitals provide better care for the sick babies that need to stay in the hospital for treatment soon after they are born. We are doing this by working with four hospitals. As part of this work, we will introduce existing technologies; educate health care providers; and provide supportive supervision and mentorship. We will assess the implementation process and the effects of these technologies on the care provision process and quality of newborn care. We will use this information to better understand to promote improvements in care and better design intervention implementation activities. To do this, we would like to hear the views of stakeholders from organizations that in charge of approving new technologies. We would like to talk to people at their own convenient time.

Why do you want to talk to me (us) and what does it involve?

- We are interested in the experience of key stakeholders with an understanding of / experience of improving post-discharge care for vulnerable babies.
- I would like to ask you a number of questions about your role as a stakeholder in post-discharge care. The interview will take between 45 minutes to 1 hour. If you do not want to answer any of the questions, you may say so, and I will move on to the next question. The discussion will take place here. No-one else but you and the interviewer(s) will be present unless you would like someone else there.
- If you are willing, discussions will be audio-recorded to assist later in fully writing up the information.
- No one will be identified by name in the recordings or in the writings.

Are there any risks or disadvantages to me taking part?

- If you are invited to an interview: The interview should take about an hour of your time. We do not believe there are any risks to your taking part as we aim to ensure the confidentiality of all participants so that no comments can be directly linked to any person.

- If the interviews are conducted outside your duty station/facility, you will be reimbursed for your out of pocket study related expenses. This will include reimbursement of any necessary travel, based either on receipts, or as a flat rate based on your area and the distance you need to travel (whichever is the greater amount will be reimbursed). The out-of-duty station allowance given to you will be (1000 KES) for your participation. If you agree to participate in a video call, you will be reimbursed and an additional 250 KES for a 1GB data package.

Are there any advantages to me taking part?

There are no individual benefits to taking part. In talking to us, you will contribute to knowledge on how to introduce and oversee technologies in newborn units as part of efforts to improve care on newborn units in Kenyan hospitals can work best. This may help other people in Kenya and elsewhere in the future, for example, through making the current approaches to improvement better or developing new strategies to improve care.

Who will have access to the information I give?

- All of our documents/ recordings are stored securely in locked cabinets and on password-protected computers. The knowledge gained from this research will be shared in summary form, without revealing individuals' identities, with study participants, hospital managers, policymakers and professional regulatory bodies.
- In future, information collected or generated during this study may be used to support new research by other researchers in Kenya or other countries on improving newborn service delivery. In all cases, we will only share information with other researchers in ways that do not reveal individual participants' identities. For example, we will remove such as their names and where they live, and replace this information with number codes. Any future research using information from this study must first be approved by a local or national expert committee to make sure that the interests of participants and their communities are protected.
- The University of Oxford is responsible for ensuring that Oxford staff involved in the study in Kenya adhere to the safe and proper use of any personal information you provide, solely for research purposes.

Who has allowed this research to take place?

All research at KEMRI has to be approved before it begins by its Scientific and Ethical Review Unit who look carefully at planned work. They must agree that the research is important, relevant to Kenya and follows nationally and internationally agreed research guidelines. This includes ensuring that all participants' safety and rights are respected.

What will happen if I refuse to participate?

All participation in research is voluntary. You are free to decide if you want to take part or not. If you do agree, you can change your mind at any time without any consequences.

What if I have any questions?

You are free to ask me any question about this research. If you have any further questions about the study, you are free to contact the research team using the contacts below:

Dr. Michuki Maina, KEMRI Wellcome Trust Research Programme, P.O. Box 43640, Nairobi 00100. Telephone: 0722248890.

If you want to ask someone independent anything about this research, please contact:

Community Liaison Manager, KEMRI Wellcome Trust Research Programme, P.O. Box 230, Kilifi. Telephone: 041 7522 063, Mobile 0723 342 780 or 0705 154 386

And

The Head, KEMRI Scientific and Ethics Review Unit, P. O. Box 54840-00200, Nairobi;
Telephone numbers: 0717 719477; 0776 399979 Email address: seru@kemri.org

---

KEMRI-Wellcome Trust Research Programme consent form for a study to learn if and how the introduction of new technologies and service delivery innovations improves the quality of care provided in newborn units

I have had the study explained to me. I have understood all that has been read/explained and had my questions answered satisfactorily. And I agree to take part in this research

I agree for the interview/discussion to be recorded -- Yes -- No

I understand that I can change my mind at any stage, and it will not affect me in any way.

Signature: _____ **Date:** _____

Participant Name: _____ **Time:** _____

(Please print name)

(Please print name)

THE PARTICIPANT SHOULD NOW BE GIVEN A SIGNED COPY TO KEEP

Appendix 6a: Guide for Workshop 1

Attendees: HRIOs and Nurses from CIN facilities.

What do we want to get out of it as WP2?

- Process map and information tools used at the post-discharge/follow-up stage
- See similarities/differences between the maps from each facility
- See similarities/differences between the process map I've created from Nyeri and the map created in the workshop.
- Understand what works well (or less well) from their perspective when it comes to discharge and follow-up care.
- Understand where there are challenges and how we can improve the process.

I will have a slide deck to aid with the workshop. The slides will be used throughout, mainly as reference for participants about what the activities are about.

Introductions (5 mins)

"Hello everyone, thank you for coming to this session today. My name is Gulraj, but GG is usually easier for people. I am a PhD student working with KEMRI. I have no medical background so forgive me if I need to ask what certain terms mean. This is my colleague Asma. Hi I am Asma. I am also a DPhil student form Oxford University working with KEMRI. My background is in nursing and health informatics, and I am very happy to meet you all. We have some of our colleagues helping us with the session today, Christiane and Naima. My research looks at how to improve continuity of care for small and sick babies post discharge. Asma wants to understand healthcare workers and families' experiences and perspectives on post-discharge care for these vulnerable newborns, and the information tools used. Small and sick newborns include babies which are pre-term or LBW or develop an illness within the first 28 days of life, such as jaundice, birth asphyxia, sepsis or pneumonia. We are very excited to have you with us for this session and look forward to learning from you. We'll explain each of the activities as we start them, if you have any questions please feel free to ask us, or the facilitators in your group."

Process mapping (75 mins)

We will have 4 groups, one facilitator per group (Gulraj, Asma, Naima, Christiane, Michuki?)

Resources required: Large cardboard sheets, flipcharts, pens, sticky notes, projector, markers.

Explanation [5 minutes]

"By the end of this session I would like each group to have produced a process map. A process map helps us understand the workflows within hospitals and the processes that you have in place for discharge and follow-up care. The maps are meant to be visual, so we want you all to get creative. To give you an idea of what the maps should look like, here are examples. Your maps can look like this, or you can draw them out however is easiest. You will be working as a group so feel free to discuss how to draw the map between yourselves. Remember that our focus is on small and sick newborns. We also want to understand what happens when the babies come back to the facility for these follow-ups – where they go, who sees them and what information tools are used. The materials on the table are for you to use however you like. I would suggest using sticky notes so you can move things around and add new notes easily. Does anyone have any questions?"

Discharge process + follow up [25 mins]

We're going to start by looking at the process of discharge and follow-up. Can you put your hand up if you have conducted discharges for small and sick babies from hospital? What about follow-ups? If you haven't done discharges or follow-ups yourself, are you familiar with the process? [*facilitators note down how many people are familiar, if there is lack of familiarity with follow-ups focus on discharge care*]. Okay, I would like you map out that process. Please write down the wards that are involved, and how babies may move between the wards.

Probes:

- What happens if a healthy baby develops a septic cord?
- What about cases which are referred to your facility?
- Where do babies receive their vaccination?
- What happens to the baby's medical record when it is discharged?
- Where do small and sick babies go for follow-up?
- What if a small or sick baby has a problem before their next follow-up?
- What if a baby needs to be admitted after follow-up?

People involved [15 mins]

Now I would like to add to the maps. Could you please write down who is involved at each stage? This can be the person doing the work, or the person supervising them. Remember that this isn't a test, there's no right or wrong answer, we just want to understand how things work.

Probes:

- What roles do doctors have in discharges and follow-ups?
- What roles do nurses have in discharges and follow-ups?
- How are MOIs and COIs involved?
- How are HRIOs involved?
- In one facility I saw nursing students carrying out discharges, have you ever seen this?

Information tools [15 mins]

Thank you for your engagement so far! For this activity we want to add a bit more detail to the maps. Could you please write down what kind of information tools are used? An information tool is anything that is used to document or provide information, for example, the MCH booklet. We're also interested in any verbal information that may be given to the mothers/carers.

Probes:

- What are mothers/carers told at discharge from the NBU? What about the postnatal unit? Paediatric unit?
- When are discharge summaries given? What is written in them?
- Are electronic records used?
- I've observed mothers coming for check-ups with their own notebooks, have you seen this?
- Are there any guidelines that you can refer to?
- I saw some interns using the basic paediatric protocols booklet, have you ever used it?

Would you do things differently if you had time/resources? [15 mins]

For this activity we'll just have everyone participate in one group.

To conclude I would like to hear about how things could be different. Maybe if you had more help, or more time with patients or resources. Imagine you could change the process to make things better for you and for mothers/carers. How would you like to do things differently? Please spend 5 minutes writing down your ideas. We'll discuss the ideas after

everyone is done. Please feel free to refer to the maps you have drawn to show us where you think a change would be helpful.

Probes:

- Is there anything you already do to make things easier for you or for mothers at discharge? What about follow-up?
- Have you heard of other facilities doing something you think your facility should adopt?
- What are some of the challenges you face?
- How can we make that better?

Conclusion [10 mins]

Ask people to summarise their process maps (2 mins per groups).

“Thank you so much for taking part in the workshop today! We know it can be a bit intense, and we really appreciate your time and energy. I believe we have a well-earned break after this. Please don’t forget to leave any of the papers you have written on, all your ideas are important to us. If anyone has any questions about the workshop, please feel free to speak to one of us.”

Appendix 6b: Guide for Workshop 2

Time: 2-3 hours

Attendees: Paediatricians and nurses from Ndovu, Twuga and other CIN hospitals

What do I want to get out of the workshop?

I want to know what part of post-discharge care faces the biggest challenges with care continuity and receive suggestions for solutions from those who are involved and familiar with the organisational system.

Planned Activities

Introduction – 5 mins

I will introduce myself and the activities we will be going over. I will emphasise that the focus is on continuity of care after small and sick newborns have been discharged from the hospital.

Process maps – 30 mins

The first activity will involve sense-checking the process maps that have been created in a previous workshop and based on discussions with healthcare workers. Any changes will be noted.

Questions:

1. Is this how the process works in your hospital? (fact-check the previous process maps with new participants)
2. Is the process working well?
3. Where are there difficulties? (where do patients drop off, where do clinicians find it difficult to do complete their tasks)

Personas – 30 mins

Personas that have been created beforehand will be used for this exercise. These personas will be presented to the participants for sense-checking followed by a discussion.

HCW personas: COI, paediatrician, nurse, nurse student, nutritionist(?), social worker(?)

1. What is this persona's goal?
2. How do they achieve this goal? (i.e., are there any tools or people who support them)
3. What part of their role caring for small and sick newborns is difficult?

Context scenarios and brainstorming – 1hr 45 mins

We will run through a few different scenarios and see how the selected persona would respond.

Scenario 1

Martin is a COI in a referral hospital. He is currently on a paediatric rotation, which he is enjoying. He sees a young mother who has brought her baby in for a POPC check-up. He is having a busy day, he started with CME, and this is the tenth baby he is attending to and there are more patients in the waiting room. As he sees each patient, he tries to document everything, but he is interrupted by colleagues and other mothers. The baby was born pre-term in a peripheral facility, so there is no medical record available at this hospital. The mother has not brought her discharge summary with her but has a partially filled MCH booklet.

1. What kind of product do you think would help?
2. Will this product be used for a long time?
3. Is the COI interrupted during this consultation?

Scenario 2

A first-time mother with form 4 education brings her baby to the filter clinic at the hospital. The baby has not been feeding properly and has not being gaining weight adequately. The mother is scared because she has already been told off for having a baby who is not gaining weight. Her husband is a casual labourer, but he does not have work all the time, and they are struggling financially.

1. Have you seen this before/does this resonate with you?
2. What support exists for this mother?
3. How would you like to help this mother?
4. Given this is a first-time mother, how complex do you think an intervention could be?

Scenario 3

A mother who has been in the NBU with her baby for 2 weeks is keen to get discharged and go back home to her other children. A nurse goes over the discharge summary and tells her when to come back for a check-up. The nurse is not able to cover all the relevant discharge information as she has other discharges to complete and needs to observe the nurse students.

1. What could improve the discharge experience for this nurse?

Reflection (5-10 mins)

How did it feel to discuss personas/process maps?

Have you been involved in something like this before?

Etc.

Conclusion – 5 minutes

Thank you all so much for your time and participation! We really appreciate the ideas you brought. Is there anything you would like to add before we wrap up?

Appendix 6c: Guide for Workshop 3

Time: 1 hour

Introduction (5 mins)

Today we will go through some interactive activities before going for a short snack break. The session will last 1 hour and we will go through 3 activities as a groups. I've got Caroline to help me lead this session (Caroline introduces herself). Let's remember that this workshop is about improving continuity of care for babies who are born pre-term or sick. You are the experts in this field, I want to hear your experiences and opinions about things you think will work in this hospital.

Based on the observations and interviews, I would like to discuss improving information flow, so that you can easily get accurate information that you need, when you need it.

Activity 1: Doctors to OTs (15 mins)

What information do you need when a patient first comes to see you?

Activity 2: OTs to doctors (15 mins)

There are multiple healthcare workers working with each child. What information would you like to give the doctors about your patients?

Activity 3: What would the form look like? (25 mins)

Data requirements, functional requirements, contextual requirements

- How would you like the information to be passed on?
- How would you like the information to be displayed?
- What size would you like it to be?
- Who should store the information?

Appendix 6d: Guide for Workshop 4

Time: 1 hour

Introduction (5 mins)

Today we will go through some interactive activities before going for a short snack break. The session will last 1 hour and we will go through 2 activities as a groups. I've got Caroline to help me lead this session (Caroline introduces herself). Let's remember that this workshop is about improving continuity of care for babies who are born pre-term or sick. You are the experts in this field, I want to hear your experiences and opinions about things you think will work in this hospital.

Based on the observations and interviews, I would like to discuss improving information flow, so that you can easily get accurate information that you need, when you need it.

Activity 1 (30 mins)

What information do you need when a patient comes to see you at the POPC?

This can be a patient returning after being discharged from the NBU or a referral. Please think about all the information you would. Now that you have completed that, please think about the **key** information you need. Remember, your fellow healthcare workers would have to be the ones filling in these forms, so think about the time they have to do this.

Activity 3: What would the form look like? (30 mins)

Data requirements, functional requirements, contextual requirements

- How would you like the information to be passed on?
- How would you like the information to be displayed?
- What size would you like it to be?
- Who should store the information?

Appendix 7: Participatory Studies in the Academic Literature in the Scoping Review

Author	Self-defined as participatory?	Method	Who was involved?	Level of involvement	What was done?	What was the outcome?	How was the outcome measured?
Eriksson et al.	Yes	Plan-do-study-act	Facilitators were recruited from the Women's Union and had to be mothers. Each group included: the vice chairperson of the people's committee (responsible for education and health in the commune), three members of staff from the community health centre, one CHW and a Women's Union representative from the commune or village, and a population collaborator (responsible for collecting population data and performing family planning.	Empower	Maternal and neonatal health groups were created, facilitators helped in monthly meetings. Members were meant to be supported and empowered to identify local problems and actions related to neonatal health.	In both groups with facilitators (low and high ratings) the NMR was lower than control, but the high group had a significantly lower odds ratio of neonatal mortality.	Process data was taken from notes by facilitators, at meetings and supervisor's records of meetings with facilitators.

Author	Self-defined as participatory?	Method	Who was involved?	Level of involvement	What was done?	What was the outcome?	How was the outcome measured?
Colbourn et al.	Yes	Plan-do-study-act	Pregnant women from the community, volunteer facilitators, maternal and neonatal health task force (unlcear who was involved in this)	Empower	Participatory women's groups were created to mobilise communities around maternal and newborn health. The groups followed an action cycle to identify and prioritize maternal and neonatal health problems, decide upon local solutions, advocate for, implement and evaluate such strategies (Facility improvement was also done. The study followed a 2*2 factorial cluster RCT.	NMR was 22% lower in facility and community intervention than control clusters, and the perinatal mortality rate was 16% lower in community intervention clusters	Village volunteers collected data on pregnancies, miscarriages, abortions, stillbirths, live births, neonatal deaths, maternal deaths and place of delivery using standardised forms

Author	Self-defined as participatory?	Method	Who was involved?	Level of involvement	What was done?	What was the outcome?	How was the outcome measured?
Cavalcanti et al.	Yes	Participatory intervention using an online social network	The research team (academics in nutrition, nursing, social work, and psychology; nutritionists; paediatricians; professors). Brazilian MoH and WHO recommendations were used.	Inform	The research group created a booklet on BF with the MoH and WHO. The intervention was a Facebook group where topics from the booklet were posted each week and discussion was encouraged. The research team responded to any questions.	EBF rates were higher throughout the study compared to the control group. The median number of days of EBF was higher in the intervention group than in the control.	Surveys via phone calls with mothers (self-reported)
Gai-Tobe et al.	Yes	Participatory learning action cycle	Facilitators (government CHWs), community support groups (housewives, persons with disabilities, elderlies, adolescents, religious leaders, and freedom fighters), the wider community (educated by CSG), pregnant women	Involve	Community support groups were set up to implement activities to support safe motherhood, including promoting birth planning, ANC, PNC, and neonatal care counselling and referrals. Outside	Home deliveries decreased in the intervention group. ANC, PNC provided after 42 days, and care for sick newborns from skilled professionals increased	Baseline and endline surveys

Author	Self-defined as participatory?	Method	Who was involved?	Level of involvement	What was done?	What was the outcome?	How was the outcome measured?
					of the group community diagnosis and resource mapping exercise and advocacy and planning meetings were held at union level.		
Mony et al.	No	Formative research was used to inform an intervention to scale up use of KMC	State and district government health managers and a local research institution	Consult	Discussions were held with government officials about policies, experiences and required resources.	Coverage was 25% after model 1, 40% after model 2, close to 55% with model 3. KMC was initiated for 82% eligible infants overall, 52% continued to receive KMC after discharge.	Qualitative data on feedback from programme learning (managers, health providers and women/family responses) and quantitative data on KMC coverage
Waiswa et al.	No	Design workshop and formative research	National policymakers, experts and the district health management teams	Consult	A design workshop was held with national policy makers and experts and the district health	Significant improvements in birth preparedness and essential newborn care	Baseline and endline surveys

Author	Self-defined as participatory?	Method	Who was involved?	Level of involvement	What was done?	What was the outcome?	How was the outcome measured?
					management teams of the trial districts. The intervention was then piloted.	practices, including breastfeeding, hygienic cord care, and thermal protection practices associated with reduced neonatal mortality.	
Lewycka et al.	Yes	Participatory action cycle	Local facilitator, pregnant women, men from the community	Empower	The facilitators used a manual to implement the cycle with participatory rural appraisal methods and picture cards of maternal and newborn health problems to guide discussion. Members identified and prioritised maternal and child health problems, identifi	Women's group interventions reduced MMR, PMR and NMR in years 2 and 3. EBF also increased.	Questionnaires used during home visits

Author	Self-defined as participatory?	Method	Who was involved?	Level of involvement	What was done?	What was the outcome?	How was the outcome measured?
					ed strategies to implement, planned and implemented them, and assessed them and made plans for the future		
Morrison et al.	Yes	Participatory learning action cycle	Local facilitator, women in the community	Empower	Women's groups were created to discuss and exchange ideas around maternal and newborn health.	30% reduction in neonatal mortality in intervention areas. The groups learned, developed confidence, disseminated information within communities and increased community capacity to take action. Women's groups were a source of support, people could	FGDs (including photoelicitation) with women in the groups, women not in the groups, mother-in-law, men and CHWs. Observations of group sessions. Interviews with facilitators, CHWs and community leaders.

Author	Self-defined as participatory?	Method	Who was involved?	Level of involvement	What was done?	What was the outcome?	How was the outcome measured?
						share ideas and experiences and learn. Participants become confident, expressed themselves openly and without shame. Some evidence of standing up to norms, e.g., inter-caste marriage. Women spread information in the community to non-group members, which improved hygiene and immunisation.	

Author	Self-defined as participatory?	Method	Who was involved?	Level of involvement	What was done?	What was the outcome?	How was the outcome measured?
Dongre et al.	Yes	Participatory community mobilisation	Women, adolescents, farmers, local female CHW, local self-government	Inform	Women's self-help groups, adolescent girls groups, farmers groups and village coordination committees (made up of community groups) to form a platform at community level for action. Capacity of the VCC members was strengthened during their monthly village-based meetings to develop their gender sensitive village health plan with culturally appropriate solutions to local problems and develop emergency transport plan. The trained social	Women's membership in self-help group and health insurance coverage of family significantly improved from 8% to 16.9% and 23.3% to 58.6% respectively. There was significant improvement in mothers' knowledge regarding newborn danger signs.	Lot Quality Assurance Sampling (LQAS) method - quant surveys.

Author	Self-defined as participatory?	Method	Who was involved?	Level of involvement	What was done?	What was the outcome?	How was the outcome measured?
					worker facilitated Community's Action Experience Learning Cycle (CAELC) through VCCs to explore and collectively act upon their priority maternal and child health issues.		
Kumar et al.	Yes	Co-development of a community-based intervention for behaviour change management	Village heads, community leaders, respected members, priests, teachers, traditional newborncare providers and birth attendants, unqualified medical practitioners, and health system workers, pregnant woman or mother, mother-in-law, father-in-law and husband	Involve	A community-based intervention for behaviour change management was designed. Researched aimed to understand existing practices, design relevant behaviour change messages, create a shift in reasoning in favour of improved	NMR reduced in both intervention groups by over 50%. Significant improvements were seen with targeted newborn-care practices. Commencement of early BF was higher in the intervention groups than in	Baseline and endline surveys

Author	Self-defined as participatory?	Method	Who was involved?	Level of involvement	What was done?	What was the outcome?	How was the outcome measured?
					practices, negotiate barriers to change by optimising available resources and providing viable alternatives, equip households with necessary skills, build self-confi dence, and create a supportive environment	the control. Care seeking from unqualified medical practitioners decreased in the intervention group.	
Rath et al.	Yes	Participatory learning and action cycle	Women from the community, local facilitators	Empower	Groups met monthly to discuss issues around pregnancy, childbirth, and the post-natal period. The cycle emphasised collective problem solving and planning and was divided into four phases. Group members	Reduction in NMR. The interventions were locally accepted, used participatory approaches to develop knowledge, skills and "critical consciousness" , community involvement beyond the	Case studies, direct observation of meetings and FGDs, quantitative data such as women's group meeting attendance records and data from the trial's main monitoring and evaluation

Author	Self-defined as participatory?	Method	Who was involved?	Level of involvement	What was done?	What was the outcome?	How was the outcome measured?
					organised community meetings at specific times during the cycle to share their learning with the wider community and enlist their support in implementing strategies to address problems in pregnancy and childbirth.	groups occured. The intervention was successful because facilitators were local, locally appropriate discussion materials were used, and timing and content of meetings were flexible.	questionnaire for information on group membership status.
Azad et al.	Yes	Participatory learning and action cycle	Local facilitator, women who has recently given birth	Empower	The facilitator activated and strengthened groups, to support them in identifying and prioritising maternal and neonatal problems, to help to identify possible strategies, and to support the	Participatory women's groups did not significantly reduce neonatal mortality	Prospective monitoring system with TBAs

Author	Self-defined as participatory?	Method	Who was involved?	Level of involvement	What was done?	What was the outcome?	How was the outcome measured?
					planning, implementation, and monitoring of strategies in the community		
Fottrell et al.	Yes	Participatory learning and action cycle	Women whose childbirth or death was recorded, men, TBAs, health service providers, teachers, and community leaders	Empower	New groups were formed and old groups (previous study) were involved. New groups had meetings on maternal and newborn health, old groups expanded into health for children under 5.	NMR was lower in the intervention group than clusters	A prospective surveillance system recorded all deaths during pregnancy and for up to 6 weeks postpartum and all births taking place in the study areas and their outcomes