Ebola outbreaks, community needs, response priorities: Case studies of community engagement in Ebola responses in Sierra Leone and the Democratic Republic of the Congo

Gillian Lee McKay

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Declaration

I, Gillian McKay, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, it has been appropriately referenced.

Signed: Gillian McKay

Date: Sept 1, 2022

Dedication and acknowledgements

I dedicate this thesis to the many individuals who gave me their time and energy in recounting their stories of Ebola in Sierra Leone and the DRC as part of this research. I was asking them to talk about challenging and even traumatic times in their lives, and I hope that in some small way I am repaying them by continuing to advocate for and influence change in response policy and practice.

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And to my cat Finn: head bonk, bum scratch.

Abstract

This DrPH thesis takes a social science lens to examine how communities engaged with Ebola responses, and how responses engaged with the knowledge and experiences of communities, in the Sierra Leone and North-Kivu, DRC outbreaks. A single case of Ebola is considered an outbreak, and generally results in a massive mobilization of human, financial, logistical and technical resources. These large scale responses, made up of many actors, can overwhelm local health systems and communities with activities intended to end transmission of the virus. Communities living through Ebola outbreaks have the capacity and drive to stop the spread of the disease and to maintain health through engagement with health services, but only when the policy environment of the broader Ebola response facilitates such action.

This thesis took a case study approach to answer the overarching question about how communities engage with Ebola responses. The first case study examined women's perceptions of seeking (or not seeking) women's gendered health care services during the Sierra Leone Ebola outbreak, and is used as a lens to understand decision making and health care access in the midst of a widespread epidemic. The second case study was conducted in 2018-2020 Ebola outbreak in North-Kivu, Democratic Republic of the Congo and investigated how the Red Cross' new system of collecting and analysing community feedback was utilized by the Ebola response.

Both case studies used qualitative methods to collect data, predominantly in-depth interviews and focus group discussions. The studies have been grounded in literature reviews to contribute to the ongoing academic and operational discussions relating to community needs in outbreak situations. The two case studies are brought together in this thesis to make the wider argument that the needs and experiences of communities in Ebola-affected spaces are often discounted in favour of the needs of the response, to the detriment of the overarching aim: to stop the spread of Ebola.

Acronyms

CDC: Centers for Disease Control

CF: Community Feedback

CFR: Case Fatality Ratio

DRC: Democratic Republic of the Congo

DrPH: Doctorate of Public Health

ETC: Ebola Treatment Centre

FGD: Focus Group Discussion

FP: Family Planning

IASC: Inter-Agency Standing Committee

IDI: In Depth Interview

IFRC: International Federation of the Red Cross

MoH: Ministry of Health

MoHS: Ministry of Health and Sanitation

MSSL: Marie Stopes Sierra Leone

NGO: Non-Governmental Organisation

OPA: Organisational Policy Analysis

PPE: Personal Protective Equipment

RA: Research Assistant

RCCE: Risk Communication & Community Engagement

SDB: Safe and Dignified Burials

UK: United Kingdom

UN: United Nations

WHO: World Health Organization

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1.0 Introduction

"Before applying this to another illness, we have to correct these mistakes first, and if it works, we can apply the system to another illness." This was said to me in Goma, North-Kivu, when I was interviewing community engagement volunteers working for the Red Cross. My question was about how the Red Cross' community feedback system could be adapted to other illnesses, but the volunteer wanted to be clear with me that before it was possible to adapt the system, we had to reframe our thinking about the system's purpose. The Ebola response had made mistakes, usually because they had not really listened to communities before acting. Before we could learn how to adapt the community feedback system, first we had to correct our mistakes. The response had not engaged with intent to change response policy. It had engaged with the intent to change the behaviour of community members.

Communities living through Ebola outbreaks have the capacity and drive to stop the spread of the disease and to seek to maintain health through engagement with health services, but only when the policy environment of the broader Ebola response facilitates such action. Ebola outbreaks are intensely disruptive events, with wide ranging impacts on those living in the outbreak area, but studies have shown that it is the response to these outbreaks that can be more disruptive to people's lives. Past research has commented on the (often negative) changes to health care access (Jones and Ameh 2015, Elston, Cartwright et al. 2017, Nuriddin, Jalloh et al. 2018, McKay, Black et al. 2019), the impacts on mental health (Van Bortel, Basnayake et al. 2016), the interruptions to economic opportunities (Glennerster, Suri et al. 2016, Gatiso, Ordaz-Nemeth et al. 2018), the disproportionate impacts on women and girls (Minor 2017, The International Rescue Committee 2019) and the social impacts of school closures, religious activities and funeral rites (Nuriddin, Jalloh et al. 2018). In the low income country contexts in which Ebola outbreaks generally occur, already stressed communities must navigate these challenges, alongside the risks of the virus itself, a herculean task.

Community engagement, the process of working with communities to manage health issues and improve health, is an essential aspect of outbreak response for all the reasons provided above, and yet is often conducted in a manner that assumes little pre-existing knowledge on the part of those being “engaged”. Despite significant research into how best engage communities in Ebola outbreaks, there remain gaps in knowledge and practice about how responses can best support communities to engage with health services in a way that respects their heterogeneous needs, and in how response leadership can be receptive to the needs of communities affected by such outbreaks.

This public health thesis uses a social science lens to address the question of how communities in Ebola outbreak settings are engaged, how they engage with outbreaks, and how their knowledge and experiences are taken up, or not, by the Ebola response apparatus. To answer this question I undertook a research study comprised of two case studies, one in the Sierra Leone Ebola outbreak of 2014-2016, and one in the Democratic Republic of the Congo North-Kivu & Ituri Ebola outbreak of 2018-2020.

This work, offered as the capstone to my Doctorate of Public Health programme, brings together my academic, professional and personal experiences over the last 7 years working in and researching outbreak responses. To start, I present two vignettes.

1.1 Vignette 1: Aisha’s story

It’s February 2018 and my research assistant Masi and I are sitting under a tree near the health centre in a mid-size town in Kambia, Sierra Leone, talking with a young woman, about 20 years old, about her reproductive choices now, in the ‘post-Ebola time[1]’ and before, during the outbreak. Aisha (not her real name) came to the health centre to get pills because she is now ready to have another baby with her husband, after preventing pregnancy the last 4 years. She’s rather shy to talk to me, but after some gentle back and forth chat, she tells me that the reason she did not want to have a baby in the ‘Ebola time’ was because she was worried about

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[1] Ebola struck Sierra Leone between 2014 and 2016. This interview took place in 2018, and the terms “post-Ebola” or “after-Ebola” was often used in common parlance, as it had been a highly significant period in the lives of many people.

having to go in a health facility for care and believed she would not be treated well by the health staff, because at that time, everything was focused around Ebola. She tells me that she knows women in her area who went to the facility for pregnancy-related reasons, and they were sent to the Ebola Treatment Centre because they were considered “suspect” Ebola cases. She made the decision to take contraception during the outbreak against the wishes of her husband, as he was concerned that by seeking family planning at the hospital, that she would be infected with Ebola. Aisha went to the pharmacy in secret to buy injectable contraceptive medication and then waited for her local area nurse to give her the injection after she was done at the hospital, at a safer location away from the perceived place of infection. She chose to pay privately for the medication and the administration of the injection, even though family planning services are meant to be free in Sierra Leone. Aisha minimized her risk of infection through these actions, revealing her own, carefully calculated, risk analysis, in the face of a very complex outbreak scenario.

Aisha’s story about her resilience, resourcefulness and intensive efforts to get contraception during such a challenging time demonstrates her realistic assessment of how dire the country’s maternal health system had become during Ebola. She engaged with health services even during a time of such disruption, using her knowledge to seek out help in a way that felt safe to her.

1.2 Vignette 2: Ebola’s resurgence in Beni town

In the town of Beni, in the North-Kivu province of DRC, I was out doing home visits with the local Red Cross team in November 2019 as they engaged households in discussion of the resurgence of Ebola in the town. The role of the Red Cross volunteers was twofold. They were there to record the questions, perceptions and concerns of those that they spoke to, for aggregation and presentation to the Ebola response; and they were also there to try to answer questions and share knowledge about how to protect against Ebola.

At many of the homes, the questions and comments were the same. “Why has Ebola returned? Is it because of the many bodies left behind by the massacres?” “Why have I not been offered the vaccine if it is such a dangerous disease? I am a pregnant woman and my children would be alone if I died. I hear you have to pay to be vaccinated.” “Why do all of the international agencies care so much about Ebola, and not about the violence and killings that we live with every day?” “Why do you burn the belongings of those with Ebola? How are we meant to replace these items? We are very poor here.”

These questions are emblematic of a context where townspeople had been terrorized by armed groups for so many years, where a feeling of abandonment by the national government and the international community was strong. The Ebola response’s official communication approach with the local population was often very poor, with limited information provided about vaccination and response interventions that were highly disruptive and disrespectful to local communities. The people asking these questions were seeking to engage with the response, but often their feedback did not result in changes to response actions, leaving them to feel that their experiences and efforts were being disregarded.

1.3 The disease of interest: Ebola

First identified in the DRC in 1976, there have been 41 known outbreaks of Ebola, with the majority in central Africa. The two largest outbreaks to date have been the 2014-2016 West African epidemic, with 28 601 cases and 11 308 deaths across Sierra Leone, Guinea and Liberia, and the North-Kivu & Ituri outbreak from 2018-2020, with 3481 cases and 2299 deaths (World Health Organization 2021).

Ebola virus disease (EVD) is a viral infection thought to be hosted in an animal species that makes the jump to humans often through hunting activities. The virus is transmitted through body fluid contact, either directly through caregiving activities, sexual transmission, or though contact with the dead body of a person who has died of Ebola, or indirectly through contact with surfaces contaminated with body fluids (World Health Organization 2021).

The case fatality rate (CFR) for Ebola has varied widely in the many outbreaks since discovery, with a CFR of 88% in the first known outbreak (1976 Zaire), and a CFR of 42% in the most recent completed outbreak (2020 DRC). The West African epidemic had low reported CFRs (Sierra Leone 28%, Liberia 45%, Guinea 67%)(World Health Organization 2021), but these numbers are thought to be inaccurate due to challenges with laboratory confirmed diagnosis, missing data and poor reporting. CFR estimates using modelling techniques estimated CFRs of 89.1% for Sierra Leone, 79.2% for Liberia and 65.6% for Guinea (Donnelly, Dorigatti et al. 2020). The North-Kivu and Ituri estimated CFR was 66% (World Health Organization 2021).

The West African epidemic led to the rapid testing of new vaccines and therapeutics that were then rolled out on a larger scale and validated in the North-Kivu outbreak. There are currently 2 vaccines and 2 therapeutics approved for use in Ebola, and improvements in prevention and supportive care are also helping to reduce transmission and mortality (World Health Organization 2021).

1.4 Responding to an Ebola outbreak

The organisation of an Ebola outbreak plays a large role in how quickly it can be brought to an end. There are often large numbers of domestic and foreign actors involved in the response, from the Ministry of Health (MoH) of the country, to international and national NGOs, the Red Cross and Red Crescent societies, UN Agencies and funding bodies (governmental and private) that require coordinating. Depending on the size of the outbreak, there could be multiple districts, provinces or countries involved, with the consequent complexities of varying administrative bodies for health, social care, security etc (Ross 2017, Crawford, Holloway et al. 2021).

The Sierra Leone and North-Kivu Ebola responses that this thesis focuses on had similar organisational structures, with a number of pillars representing varying thematic areas important to outbreak response: Surveillance, Case Management, Community Engagement, Logistics and others. The overall response coordination structure (pillars) are determined by the particular needs of the disease and response environment (World Health Organization 2017). The context of the North-Kivu outbreak in an active conflict zone necessitated the addition of a Security pillar, and the extensive roll out of vaccines also brought forth a Vaccination pillar. This pillar-type approach is generally led by the Ministry of Health of the affected country, with named partners providing technical and operational assistance for their assigned pillars (eg. World Health Organization (Surveillance, Vaccination, Case Management), UNICEF (Community Engagement and Risk Communication), the World Food Programme (Logistics)). NGOs supporting the response will fit into one or more pillars, depending on the services they are providing.

Strategic oversight for the response is led by the government, alongside technical and operational partners (often UN agencies) and donors. Operational level activities are often assigned to NGOs, and they are responsible for carrying out the activities in line with the overall strategic guidance and to a similar technical standard. The Overseas Development Institute have done comprehensive reviews of coordination structures for both the West Africa and North-Kivu Ebola responses (DuBois, Wake et al. 2015, Crawford, Holloway et al. 2021).

1.5 My history in Ebola outbreaks and responses

My path to outbreak response and outbreak research started in August 2014, as I was working for an NGO in their roving health team. The West African Ebola outbreak hit our programme in Sierra Leone hard, and the country team needed someone with a health background to come in and conduct risk assessments for the programming that had been put on hold. It was an eerie emergency to be stepping into, as it felt as though the humanitarian “cavalry” had not yet arrived. Coordination meetings were sparsely attended and were endlessly “mapping” who was doing what where, with no strategic oversight. Key NGOs had evacuated many of their staff, leaving gaping holes in the response. Among many organisations there was a sense that Ebola was a terrifying disease that only Médecins Sans Frontières could handle, with their extensive clinical and logistical apparatus, and that the rest of us non-medically specialized NGOs were better off either staying out of it or being highly peripheral.

But peripheral we did not remain, first my role involved setting a programme of training for the security services (police and military) to help them stay safe as they secured Ebola Treatment Centres (ETCs), quarantined homes, roadblocks and hospitals. This work jump started a consortium focused on community engagement in Ebola, that became the primary government partner for messaging and two way communications. Following that I led a clinical team running a 100-bed Ebola Treatment Centre in Port Loko, testing and treating patients, and then I moved into surveillance, working with the local MoH staff to find cases in the community early enough to try and get them to the centre to increase their chances of survival, and to reduce the transmission in the community. It was in doing this work that I realized the huge indirect impacts that so many of the Ebola response policies were having on communities, and particularly on pregnant women, who had faced huge barriers to seeking basic ante-natal and delivery care.

I started my DrPH with the intention to focus on women's perceptions of health seeking in Ebola outbreaks, and I collected data to address this question, but it was following a deployment with the World Health Organization (WHO) to the North-Kivu Ebola outbreak in 2019 that the breadth of my DrPH research became clear. Having worked with WHO in Infection Prevention and Control (IPC) and witnessing just how harmful many IPC practices were, particularly the burning of people's belongings following a positive Ebola test, I was eager to learn more about how response leaders engage with community experiences and make changes to response policy. An LSHTM research project with the International Federation of the Red Cross (IFRC) fit exactly with this broader interest, as I was able to study how the Red Cross' community feedback mechanism, that had been rolled out in the North-Kivu Ebola response, contributed to response decision-making.

Through nearly 8 years of working in outbreaks, including most recently in the Covid-19 pandemic, I developed a passion to make sure that communities affected by the infectious disease are not just presented with one way communication, but to ensure that their needs, experiences and knowledge are heard, valued and acted on by the disease response itself.

1.6 Community roles in Ebola outbreaks

Communities in Ebola are constantly being “engaged”. Usually with the intention of changing their behaviour to reduce human to human transmission of the virus, and to encourage health-seeking behaviour to catch cases of the virus early (World Health Organization 2018). Communities members are often seen as passive recipients of information, with “ignorance” or “cultural factors” seen as the reason why they are not engaging with the science of the Ebola response (Piot, Muyembe et al. 2014, Koroma and Lv 2015). They are not often seen as heterogenous entities, with essential local knowledge and experiences that can contribute to ending the outbreak and improving health, but also having internal power dynamics that can make engaging a fraught exercise if not done through a critical social lens (Wilkinson, Parker et al. 2017).

In contrast to how communities are often “seen” by some in the response, prior experience and research has shown that communities under outbreak stresses are highly dynamic, change behaviour rapidly and often organically, and are eager to engage with the response to help end the outbreak and contribute to scientific advancements, and find innovative ways of accessing the care they need despite the barriers put up by outbreak mitigation measures (Richards, Amara et al. 2015, Richardson, Barrie et al. 2015, Enria and Lees 2018). This thesis will seek to contribute to the evidence base about community engagement through research into community knowledge and experiences in outbreaks of Ebola.

1.7 Thesis aims and objectives

This research project is made up of two case studies, that, in combination, seek to address the below aim and objectives.

Overarching aim:

To understand how communities engage with Ebola outbreaks, and how their knowledge and experiences were integrated by responses to those outbreaks.

Objectives:

1) To understand how a particular group, women, navigated a gendered form of non-Ebola health care, family planning, during the Sierra Leone Ebola outbreak.
2) To understand how communities were heard, and how action was taken based on that knowledge, in the North-Kivu & Ituri outbreak of Ebola in the Democratic Republic of the Congo.
3) To develop recommendations for improved community/response engagement in future outbreaks of Ebola.

1.8 Thesis overview

This thesis is organized into 7 chapters. The first chapter introduces the disease of interest, Ebola, gives some background on responses to Ebola outbreaks and introduces the research topic: community engagement in such outbreaks. This chapter also introduces the researcher and explains the aims and objectives of the study. Chapter 2 provides the background literature to situate why understanding how communities engage in outbreaks of Ebola is important. In this chapter I also introduce the two case studies for the research project, and provide additional information on the literature gaps that the research seeks to contribute to. The third chapter, methodology, provides a detailed explanation of the methods employed in the two case studies, and reflections on the researcher's positionality and fieldwork. Chapters 4 and 5 comprise case study 1 (fulfilling Objective 1), about family planning in Sierra Leone's Ebola outbreak, with chapter 4 a detailed contextual analysis of the setting, and chapter 5 the research paper that was published in August 2022 in the journal Studies in Family Planning. Chapters 6 and 7 comprise the context and research paper for case study 2 (fulfilling Objective 2): community feedback in the North-Kivu Ebola outbreak. The paper for case study 2 was published in BMJ Global Health in February 2022. Chapter 8 of this thesis brings together the findings from the two case studies to make a broader argument about how community engagement is hampered due to responses to Ebola having mismatched priorities to the needs of Ebola-affected communities. The discussion chapter also makes clear how this thesis contributes to public health knowledge and practice through the advancement of thinking about mismatches between response priorities and community priorities, how hierarchies of knowledge can determine who and what is heard and done, and the challenges of health care seeking and evidence based responses in highly complex outbreak crises. Chapter 8 also presents recommendations for how community engagement could be improved in future outbreaks, in fulfillment of Objective 3. Chapter 9, the final chapter of this thesis, is my DrPH integrating statement where I reflect on my learning over the 3 components of the DrPH programme: 1) the coursework modules; 2) my Organisational Policy Analysis; and 3) this thesis.

2.0 Background

The following chapter will review the literature on community engagement, perceptions and experiences of Ebola outbreaks to situate the aim of the thesis in pre-existing knowledge. This chapter will also include literature review sections specific to the two case studies: on seeking women's gendered health care in outbreaks of disease, and on feedback and accountability approaches in humanitarian crises.

2.1 Community engagement

The importance of community participation "*in the planning and implementation of their health care*" has been enshrined in public health since Alma-Ata in 1978 (World Health Organization 1978). A review into the concept of community participation by Morgan described how the reasoning for undertaking such efforts can be classed into two models. The first, a utilitarian model, presumes that community participation is a means by which donors and governments can reduce the costs and efforts of providing health services by having communities invest their own resources. The second model is one of empowerment, where community participation creates an opportunity for communities to define and action their own solutions to their health problems (Morgan 2001).

WHO's guide to community engagement in universal health coverage aims for empowerment as the highest level of participation, and links it to the ideals of autonomy and a change in power dynamics allowing for greater citizen control. WHO uses the term community engagement which they describe as "*a process of developing relationships that enable stakeholders to work together to address health-related issues and promote well-being to achieve positive health impact and outcomes."* (World Health Organization 2020, p.vii) This thesis will observe the WHO's definition.

2.2 Community perceptions, knowledge and experiences in Ebola outbreaks

There is ample evidence of the importance of community engagement in Ebola outbreaks, from the necessity of engagement to reduce viral transmission, to reducing the risk of violence against Ebola responders, to increasing early presentation to reduce overall mortality (not to mention the importance of communities in the long-term building and strengthening of the health system on which they depend) (DuBois and Wake 2015, World Health Organization 2018, Dewulf, Ciza et al. 2020). Unfortunately in many cases community engagement staff are siloed into a role of reactive firefighting, trying to fix “problems” with communities that are “resistant” to the Ebola responders, instead of seeing community engagement as a proactive process to bring communities on board and to understand their perspectives (Dewulf, Ciza et al. 2020, Lees, Palmer et al. 2020). In the DRC response, a new structure, the social science analysis cell, performed the new and essential role of gathering structured community perceptions data and integrating this with the epidemiological data, with the aim of influencing both policy level decision making, and also helping guide the community engagement approach and messaging (Carter, Ahuka-Mundeke et al. 2021). The two largest Ebola outbreaks in known history, in West Africa and North-Kivu, produced many papers and studies on community engagement and community experiences, which this literature review will narratively summarize.

The very term “community” was critiqued in Wilkinson and colleagues’ article, which advocated for a more nuanced understanding of the social dynamics of groups of individuals living in outbreak affected areas. They argue that idea of a “community” does not take into account varying social, economic and political realities (Wilkinson, Parker et al. 2017), a finding echoed by Enria and colleagues in relation to setting up a vaccine trial in an outbreak context (2016).

The ability of communities to engage with the response was deepened when response apparatuses were brought closer to their homes, when they considered the response work to be part of their responsibility as members of society, or when there were associated bylaws giving local people authority. An evaluation of Ebola “community care centres” in Sierra Leone (small spaces providing basic health care and Ebola testing), found that these structures were associated with positive feelings, especially given the free health care that was offered in these spaces, and were appreciated for their role in providing care closer to home for those who might have Ebola (Oosterhoff, Mokuwa et al. 2015). This was echoed by Gray and colleagues, who also found that when Ebola care became more proximate, people were more willing to seek it out (Gray, Stringer et al. 2018). Community members' engagement with the response could also manifest through participating in vaccine trials, as a way of demonstrating their relationship and responsibility to their country, and to contribute to ending the outbreak by giving of themselves to the scientific effort, which was no easy thing in a context where there were persistent rumors that biomedical activities for Ebola were in some way malicious (Enria and Lees 2018). The imposition of bylaws by local community leaders was felt by some to be a positive way of engaging with the response, as it set out clear expectations for behaviour (Gray, Stringer et al. 2018), though this was not universally agreed, as the imposition of fines for breaking bylaws led some to hide or otherwise conceal when they did not abide by them (Wilkinson, Parker et al. 2017).

Engaging with the response could be hindered however when acts by the response were felt to be damaging to social ties or when economic benefits of the response were believed to be flowing only towards those with power, damaging trust in institutions. The management of dead bodies of those who had died during the outbreak was a particularly challenging aspect of the West African response, as the infection control procedures put in place limited (or even in some cases eliminated) the roles of families and friends in the care of the bodies, leaving many grieving not only their loved one, but also their inability to be involved in their preparation and burial. These restrictions caused strife between and within communities, and was a significant barrier to engagement with the response for those who felt their customs had not been respected (Lipton 2014, Oosterhoff, Mokuwa et al. 2015, Lipton 2017, Wilkinson, Parker et al. 2017, Nuriddin, Jalloh et al. 2018). In the DRC response this was improved, with greater respect for local customs, and a concerted effort to enable families to be involved in burial practices and rites (Sikakulya, Ilumbulumbu et al. 2021).

Further hindrance was related to the perceptions of how funds were disbursed in the response, as concerns about corruption and the vast amount of money spent on Ebola responses were widespread, with those in power being perceived to have unjustly benefited from the response, while the majority of the population suffered privations due to the economic contracture (DuBois, Wake et al. 2015, Shepler 2017, Crawford, Holloway et al. 2021, Nyenyezi Bisoka, Vlassenroot et al. 2021). In the case of the DRC, an area already managing a long standing conflict pre-Ebola, the additional mistrust and corruption related to the Ebola response likely contributed to attacks on health workers and Ebola infrastructure (Crawford, Holloway et al. 2021, Nyenyezi Bisoka, Vlassenroot et al. 2021).

These opportunities and challenges to community engagement call up broader debates in the development and humanitarian sectors, relating to localization, participation and the challenges of medical humanitarianism. These conversations link to this thesis in considering how community-derived knowledge and experience is valued by response actors and funders. Major events such as the West African Ebola outbreak brought forth many critiques of medical humanitarianism, with the weaknesses of the response, particularly in relation to the early limited engagements with communities and the lack of funding directly allocated to local organisations often raised as key failings (DuBois and Wake 2015, Colombo and Pavignani 2017, Lees, Palmer et al. 2020). The Grand Bargain, initially launched in 2016, has 65 signatories, including donors, NGOs and UN agencies, and aims to make humanitarian action more efficient and effective, in part by addressing some of the critiques around localization and community engagement. Two workstreams in the Grand Bargain speak directly to these concerns: Workstream 2 which commits to funding and supporting local and national responders and response agencies; and Workstream 6 which commits to including those in need of aid in decision making through improved participatory action (Grand Bargain Secretariat 2022). These efforts are to be lauded, but as critiqued by Roepstorff, the very definition of local is not sufficiently explained or explored, resulting in confusion about where localized funding should be directed, should it go to sub-national organisations or also to those working at the national level? Or to only those headquartered in the Global South, when this would exclude organisations working with refugees in high-income countries? (Roepstorff 2019). When aiming for increased participation in humanitarian action by those most affected by the crisis, a question remains, as was raised by Wilkinson and colleagues, of who to include in participation efforts when communities are not homogenous entities (Wilkinson, Parker et al. 2017). These ongoing conversations about localization and community engagement are plentiful, with the relationships between responses to Ebola outbreaks and the populations in the affected areas at the centre of these debates.

The negotiated relationship between communities and the outbreak response (and the international structures of global health) will impact on the effectiveness of the response to stop transmission, and the ability of community members to both participate in the response and to work to maintain their own health in the midst of such an event. With these essential outcomes in play, it is critical that we better understand how communities are engaged in outbreaks of Ebola, and how their knowledge and experiences are factored into responses. Two areas that have been under researched within the community engagement field, and thus demonstrate gaps in outbreak preparedness and response policy and implementation, are: 1) how women use their knowledge and experience to engage with women's gendered health care during outbreaks; and 2) how community feedback, a system of collecting experience and knowledge from affected individuals, is used by the outbreak response to make change. It is critical to better understand these areas as the participation of communities, in all of their heterogeneity, is critical if we seek to prevent and end outbreaks in future. Listening and responding to the diversity of community needs, and building on the knowledge and experiences of those in the affected area builds trust at the local level, and enables a response that is more tailored to people affected by crisis. The following sections will summarize the current knowledge in these areas.

2.3 Accessing women’s gendered health care in outbreaks

A key motivation for community engagement in outbreaks is to improve health care-seeking, often with the intent of identifying potential cases of the virus, but also to reduce the impacts of the outbreak on the health of individuals by encouraging ongoing access of health services (World Health Organization 2018). This is especially important as it has been well documented that an often unintended consequence of outbreaks is a reduction in essential health care access (Jones and Ameh 2015, Sochas, Channon et al. 2017, Yerger, Jalloh et al. 2020).

In the case of women’s gendered health care, this reduction has both demand and supply side reasons, as has been well explained by Yerger and colleagues in their systematic review of seeking maternal health services in Ebola outbreaks. On the demand side, health care services and health care workers can be considered by health care consumers as possible loci of infection, thus reducing interest in attending services. Transport challenges due to local restrictions can make it difficult to travel to health care services, and in countries where health care requires user fees, reduced economic activities caused by the outbreak can make it difficult for some to afford services. On the supply side, health workers are often reallocated to outbreak response work, instead of day to day health care provision, supplies of personal protective equipment are often prioritized for those treating those with the outbreak disease, leaving little for other services, and health workers themselves may fear providing maternal care in times of Ebola due to the risk of infection (Yerger, Jalloh et al. 2020). These varied reasons (in addition to others) can make accessing any non-outbreak health care difficult, even more so when the health care is highly gendered and may be considered by the health services and the outbreak response apparatus as non-essential, given the large number of other priorities. Family planning (FP) is one of those services that, unfortunately, is often dropped off the priority list in times of crisis, though not by the women and families who rely on this service to plan their futures.

At the start of the COVID-19 pandemic in 2020, there were highly concerning estimates about the impacts of the pandemic disruption on essential FP services. Riley and colleagues modelled that a 10% decline in short and long term contraceptives could result in more than 48 million additional women with an unmet need for contraceptives, and 15 million unintended pregnancies (Riley, Sully et al. 2020). As will be shown below, these projections do not seem to have been borne out in such severity, however, one year after the start of the pandemic, WHO did still report that more than 40% of countries continued to report disruptions to essential FP and contraceptive services, indicating that these challenges were widespread and ongoing due to the impacts of the pandemic (World Health Organization 2021).

There have been several studies that have looked at the impacts of Covid-19 on FP, with the majority identifying either a reduction in utilization, or little or no impact. Data from a community-based health promoter programme in Mozambique found that the imposition of a state of emergency for Covid-19 (in March 2020) resulted in a short term reduction in utilization and provision of the FP service, but that it rebounded quite quickly (Leight, Hensly et al. 2021). A multi-country study (Kenya, Burkina Faso, Nigeria and DRC) used multiple surveys to investigate the impacts of Covid-19 on contraceptive need and use (measured separately). In all contexts the need for contraception increased (though only significantly in the urban setting of Lagos, Nigeria), and contraceptive use increased in Burkina Faso and Kenya (rural settings). The authors interpret these findings that there has not been an overall negative effect of the pandemic on contraceptive use and need. However, they also bring forward findings particular to sub-groups, including that nulliparous women showed an increased need for contraceptives during Covid-19 compared to baseline, and that rural women who had suffered income loss were more likely to use contraceptives in Covid-19 (again compared to baseline)(Wood, Karp et al. 2021). In Gauteng, South Africa, a study looking at FP during the lockdown in 2020 identified that injectable methods that required a health provider for administration declined, and the use of oral contraceptives increased (Nqeketo, Mapanga et al. 2020). These varying findings indicate that while the severe disruptions that were anticipated may have not been borne out at the population level, there is still research work to be done to understand how women at the individual level are making decisions to either access or choose not to access family planning, in this pandemic context.

Prior to the Covid-19 pandemic, there were a very few studies that investigated the impacts of acute outbreaks of infectious disease on family planning services. Of those that had been done, there were several that looked at Ebola. In a 2020 paper, Bietsch and colleagues conducted a retrospective analysis of FP provision in Sierra Leone and Liberia in the West Africa Ebola outbreak, and identified that distribution of modern FP methods declined by 65% in Liberia and 23% in Sierra Leone at the peak of the epidemic. But this paper is also a lesson in post-Ebola recovery, in that it also showed an increase (above pre-outbreak levels) of 39% in Liberia, and 27% in Sierra Leone 2 years after the epidemic (Bietsch, Williamson et al. 2020). Another study, focused on Guinea during the same outbreak, found a decrease of 51% in FP visits during the peak of the Ebola outbreak period (from pre-Ebola levels), which then rebounded to 98% in the post-Ebola period. This study showed an interesting, but not further discussed finding, that in the 3 months prior to the worst of the outbreak that there was a 47% increase in FP visits (Camara, Delamou et al. 2017). In 2019, a report that colleagues and I wrote for the International Rescue Committee, identified that in the North-Kivu Ebola outbreak the trends for FP visits had remained generally stable. This report also identified from interviews and focus group discussions that FP was desired by both men and women, out of concern that the outbreak had made it a particularly dangerous time to be pregnant. Furthermore, some women who had sought out modern methods of FP preferred to go to the pharmacy to get these, as seeking care at the hospital came with stigma that the care-seeker might have Ebola (McKay, Black et al. 2019). A narrative synthesis including these studies, but also including other disruptive events including natural disasters, found that the most impacted methods of family planning were those that required a health care worker to administer (intra uterine device, implant, injectables) (Loewen, Pinchoff et al. 2021), similar to the findings from Covid-19 (Nqeketo, Mapanga et al. 2020). Women’s experiences of using their knowledge and skills to decide if and how to engage with the health care system to seek out a form of essential health care, FP, within the constraints of an Ebola outbreak, has not been previously studied, and understanding this is essential to ensure community engagement plans are responsive to the needs of women of reproductive age. Objective 1 of this thesis attempts to address this literature gap.

2.4 Feedback and accountability mechanisms in humanitarian crises

In seeking to understand the engagement of communities in Ebola outbreaks, studying community feedback is essential, as these relatively new approaches for listening and responding to communities can potentially facilitate or impede community engagement with the response. Risk communication and community engagement (RCCE) is a key pillar of Ebola responses, and comprises of two-way communications, rumour management, participation and engagement of communities (World Health Organization 2018). In the DRC North-Kivu Ebola response, RCCE as a pillar had been developed further since the West African Ebola outbreak to include "*strong elements of community ownership in preventing, preparing for and responding to a health crisis, partly through community feedback approaches to inform decision-making processes for the response and closing the feedback loop."* (Dewulf, Ciza et al. 2020, p. 12). However Dewulf et al's report identified that the RCCE pillar of the response struggled to put in place a collective approach to working with communities, likely contributing to community frustrations (Dewulf, Ciza et al. 2020).

Feedback mechanisms are a community engagement tool and accountability mechanism intended to reduce power asymmetries between responding agencies and affected populations, allowing for greater community input into decision making, however the process by which they collect and manage feedback is critical to effectiveness. Processes for feedback collection have included mechanisms like complaint boxes, call centres, help desks and open meetings. Per the humanitarian learning NGO ALNAP, effectiveness of feedback mechanisms depends on two things: the first is that the information gathered through the approach is used by the response to change the programme for the better, or if it is not possible to change things, then there must be a clear response to the feedback; the second is that the mechanism must be easily accessible to affected populations, including those with additional vulnerabilities (Bonino, Jean et al. 2014). A case study in from Typhoon Haiyan in the Philippines in 2013 found that a new digitized system of mobile phone feedback collection did not always appropriately respond to feedback collected, frustrating community members, and queried the point of such systems if they do not help to rebalance power asymmetries (Madianou, Ong et al. 2016). In outbreaks, where power and information is often held by governments, technical agencies and responders (not communities), feedback mechanisms are acknowledged to be important, and yet studies of such systems are few and far between, with the exception of the Red Cross' system. Objective 2 of this thesis seeks to address the literature gap relating to how feedback mechanisms are used in outbreaks of Ebola.

2.5 Research significance and approach

Outbreaks, epidemics and pandemics of infectious disease are all the more likely in our increasingly interconnected world, as evidenced by Covid-19's disruptions to lives worldwide. The impacts of climate change, global travel, urbanization, health worker shortages and human-animal interactions may well result in the emergence of more infectious agents (GAVI 2020). Since the West Africa outbreak of Ebola in 2014, there have been a further 8 outbreaks of the disease (US Centers for Disease Control and Prevention 2022), requiring responders to learn from and apply lessons from the previous outbreaks.

Part of this ongoing process of learning and improving outbreak response requires that we better understand people's agency in, and engagement with, outbreaks, as this will help responding agencies and the global outbreaks community to strengthen and tailor community engagement efforts. The gaps identified in the literature review, relating to engagement with communities, women's health care seeking and how communities are heard or not in Ebola outbreaks, are all questions that social science methods are best suited to answer, as they seek to understand people's experiences of a highly disruptive time. I contribute to these debates through two case studies, each of which offers a unique lens by which to examine community engagement in Ebola outbreaks. These two case studies come together to fulfill the overarching aim of understanding how communities engage with Ebola outbreaks, and how Ebola responses engage with the knowledge and experience of communities.

Case study 1 seeks to understand how women engaged with the Ebola-affected health care system through the lens of navigating family planning services during the outbreak in Sierra Leone. Case study 2 seeks to understand how communities in the North-Kivu Ebola outbreak were heard, via a new community feedback mechanism, and how their feedback was used by decision makers in the response. Both case studies help to fill the evidence gap in the field of community engagement in outbreak settings, and the papers resulting from these case studies will contribute to the ongoing conversation about improving outbreak responses in times to come.

3.0 Methodology

A Doctorate of Public Health (DrPH) seeks to contribute to the furtherance of knowledge in the academic space, but also seeks to produce lessons for public health practice. How public health authorities position communities, engage their knowledge and experiences, and develop policies and protocols in response to outbreaks of Ebola that threaten affected populations is inherently a public health question. This practice of this public health question is to improve the lives of people living in outbreak-prone geographies, and to encourage an inward look at outbreak response actors to critically review how they interact and work with communities.

Outbreaks and outbreak response are inherently complex phenomena, with a multitude of actors, systems, contexts and populations involved, notwithstanding the impacts of the infectious agent on the human body itself. Qualitative research lends itself well to such complex events, as it allows those involved in the response, either as affected individuals or as responders to speak about their own perspectives and experiences. As described by Sofaer, qualitative work can "*allow people to speak in their own voice…giving voice, in particular, to those that are rarely heard…*" (Sofaer 1999, p.1105) and can also "*…enhance the capacity not only to describe events but to understand how and why the "same" events are often interpreted in a different, sometimes even conflicting manner, by different stakeholders."*(Sofaer 1999, p.1106).

Outbreaks of infectious disease are often characterized by their intense focus on quantitative data, with daily updates of case counts, numbers of contacts followed, health facilities decontaminated, vaccinations given and so on. These quantitative measures are generally reported on daily, in coordination meetings, and represent the key performance indicators to which response leadership will be held accountable. As will be further discussed in chapter 7, the use of qualitative data for decision-making has not traditionally formed a large part of outbreak response, as has been raised by anthropologists in the public health field, though this type of data offers a unique way of assessing and documenting the impact of outbreaks and the outbreak responses on those living in the outbreak geography (Abramowitz 2014, Lees, Palmer et al. 2020)

My thesis took a qualitative lens to answering the objectives, with the main methods employed being in-depth interviews, focus group discussions and observations. Qualitative methods were chosen as they allowed for a broader, more narrative engagement with the subject matter, and to bring out stories that had not been recorded or documented in the numbers-focused epidemic curves and quantitative reports of the outbreak and that could allow for policy-relevant findings. In case study 1, the research participants were community women, who were unlikely to have had the chance to participate in the Ebola response in any kind of policy or decision making way. By using qualitative methods to interact with them, the women were offered the opportunity to provide their history of health care in the outbreak, and offer a new perspective on the response, one that would not be captured by the case counts of the infection, or even by the quantitative numbers of women seeking family planning services. In case study 2, the Ebola response decision makers interviewed were able to recollect the last 15 months of the response, and to reflect on how community feedback data was or was not used. Through a qualitative approach the decision-makers were able to provide examples of good practice and recommendations for future use of the community feedback tool, allowing the final product of the research to be a practical, operational and future-thinking article. The methods used to conduct the case studies have been described in the research papers in the results chapters, but these methods are described in this section in greater detail.

3.1 Case study contexts

Sierra Leone and the DRC have commonalities besides both being countries with large Ebola outbreaks in the recent past. Both countries have a colonial history, British in Sierra Leone's case and Belgian in the case of the DRC, and achieved independence in 1961 and 1960 respectively. The two countries post-independence struggled to establish stable democratic governmental systems, with one-party autocratic rule and civil war featuring in the modern histories of both nations. Sierra Leone and the DRC both have extensive natural resources, including the minerals diamonds, iron ore, gold and coltan, though both states struggle to exploit these resources for the good of their populations (Wong 2012). In the 1980s the two countries significantly contracted their public sectors due to the conditionalities of structural adjustment programmes, resulting in poorly resourced health sectors, the legacies of which are still shown in the poor health indicators of both countries (Wong 2012, Benton and Dionne 2015, Kentikelenis, King et al. 2015, Aembe and Dijkzeul 2019). The contexts of the two case studies will be explained in much greater depth in the chapters preceding each result chapter, with the inclusion of some data from the case study research to add additional context.

3.2 Case study 1: Women's perspectives of family planning in Sierra Leone's Ebola outbreak

This case study employed in-depth interviews, focus group discussions and participant observation as the main research methods. Following a country visit in October 2017 to engage stakeholders and apply for in-country ethics approval, primary data collection began in early 2018, and continued until August of the same year. In-country fieldwork took place from January 24 – February 28; April 4 – May 13; and August 19-29, 2018.

3.2.1 Ethical review

Ethical approval for this study was received from the Sierra Leone Ethics and Scientific Review Committee dated November 14, 2017, with an amendment approval on March 27, 2018. LSHTM Ethics Committee approval was received January 9, 2018 (ref: 14552), with amendment approved on June 1, 2018 (ref: 14552-1). Local permissions were granted by the District Medical Officer of Kambia District, the Paramount Chief of Magbema Chiefdom (where Kambia town is located), and local Headpeople of villages visited for data collection.

3.2.2 Data collection locations & partnerships

The main location for data collection was Kambia District, with some additional interviews undertaken in Freetown with national level stakeholders.

Kambia, a district in the north-west of the country, was one of the last districts of the country to end transmission of Ebola, following a recorded 286 cases of the disease (Sandi, Barrie et al. 2017). The district is primarily rural, and is on the border with Guinea with significant migration between the two countries. Kambia has also been the site of other LSHTM projects including the EBOVAC-Salone Ebola Vaccine trial. The EBOVAC trial had an integrated social science component (and thus team) and as such there was good research infrastructure present, including availability of trained research assistants and a highly engaged Paramount Chief who was supportive of research efforts. Languages spoken in the district include Themne, Susu, Limba, Fula and Krio.

At the time of this research, FP services in Kambia were provided by the Ministry of Health and Sanitation (MoHS) at the clinic-level and by Marie Stopes Sierra Leone (MSSL) in outreach settings. MSSL provided logistical project support to data collection by transporting the research team to locations where FP outreach clinics were being run, introducing the research team to potential interviewees, and by providing access to some health care staff for interviews.

Three interviews took place in Freetown, the country capital, with health policy stakeholders who worked at the national level to further contextualise the Kambia case study. Freetown is an urban setting, where the Ebola outbreak faced a unique trajectory in the urban informal settlements, with 2131 recorded cases of the disease (World Health Organization 2016). It is often said in Sierra Leone that “*Freetown is not the rest of the country*”, as indeed it is comprised of a mix of language groups, who generally converse in Krio.

3.2.3 Research team

The research team was made up of a Research Assistant (RA), Maseray Fofanah, two transcribers and myself. The RA was identified as she had worked with a member of my thesis advisory team in research and community engagement in 2017, and had direct experience in working in the Ebola response in community engagement during the period of the outbreak.

Maseray (Masi) provided support with the identification of research participants, participant screening, consent form completion, interview and focus group interpretation and also with community engagement and contextual understanding. I trained Masi through a two day intensive session on participant selection, ethics, the topic guide and the consent form, and then her development continued as we worked together through daily debriefings following interviews and focus group discussions and adjustments to our approach. Masi was instrumental in contextualizing data within the Kambian and Sierra Leonean settings, and she also provided critical support in situating events within the Ebola outbreak of the local environment. Masi and I jointly reflected back on every interview and focus group discussion and wrote notes capturing the main points and emerging themes. Masi has been included as a co-author in the published research paper (research paper 1) given her essential contributions to this work.

Two local transcribers supported with translation and transcription of interviews and focus group discussions. These assistants were identified through contacts at LSHTM's EBOVAC research site, located in Kambia town. One assistant required a 2 day training on how and what to transcribe and how to maintain confidentiality. The other research assistant had been working with the EBOVAC project for three years and thus was able to start work with just an orientation to the new terminology that had not come up in his prior transcription work.

The RA and transcriptionists were compensated for their time and efforts monetarily and through small gifts.

3.2.4 Data collection

The primary data collection consisted of three different approaches:

- FP clinic visits
- In-depth interviews
- Focus group discussions

3.2.4.1 FP clinic visits

The initial research plan included conducting clinic consultation observations of FP service delivery. While the research team was able to go out with both the MSSL outreach teams and to visit the MOHS clinics where FP takes place, it was not possible to undertake formal clinic consultation observations. MSSL's clients were almost exclusively under the age of 18, meaning that on the 3 occasions when the author did go out to the field with the outreach team, it was not possible to gain appropriate consent to observe a client consultation. I was however able to observe the entire process of an outreach clinic, from the selection of location, set up of consultation rooms and data recording spaces. While I did spend several days visiting MOHS FP clinics, as there is no specific day or time for women to come to request FP, I was unsuccessful at identifying a woman over 18 who was willing to be observed during the FP consultation. However, I was able to be present in the FP health promotion sessions, where method choices were discussed. I took extensive field notes during her FP clinic and outreach visits and these notes were coded and integrated into this thesis as observations and helped with analysis.

3.2.4.2 In-depth interviews

A total of 19 interviews were completed for this research project, 10 women who had received FP during Ebola and 9 who did not receive FP during Ebola. While it would have been ideal to conduct follow up interviews with participants, as a form of longitudinal qualitative research (Calman, Brunton et al. 2013), this was not possible, as many of the women were not contactable or had travelled away from Kambia.

Selection criteria included women between the ages of 18 and 40 years of age, with purposive sampling to identify women who were users of FP during the Ebola outbreak and those who were non-users during the outbreak. Women FP users and non-users were recruited in two ways. Initially Masi and I intended to interview FP users who were attending MSSL outreach clinics, but as stated above, nearly all clients of those clinics were under 18 years of age, so this method did not bear fruit. We therefore visited under 5 clinics where women of childbearing age would congregate, Masi would approach women to ask them if they were interested in being a part of the research project after asking some basic screening questions about FP practices during the outbreak. After completing 5 interviews, we reworked the topic guide, and changed the recruitment approach as some of those early interviews were quite stilted. The new approach involved connecting with local women's group leaders, who then facilitated the introduction to women who might be interested in being a part of the research. Women were given information about the project informally, and then those who were interested were then screened for being FP users and non-users. This approach to recruitment was more successful and resulted in richer, more open conversations during the interviews.

Interviews with women all took place with the translation assistance of Masi as the interviews did not take place in English. All interviews except two were digitally recorded and translated and transcribed into English. For the two interviews where consent for recording was not granted, detailed notes were taken.

To inform the literature review and to provide insight into the context of how FP services were provided during the outbreak, and the challenges that health workers and policy makers experienced while trying to ensure FP was included in operational priorities, background interviews took place with health care workers (7 participants) and stakeholders (6 participants). These participants were purposively selected as they had all been involved in delivering or facilitating FP services in the outbreak, either at the frontline, in policy, or through their role as key community leaders. Health care workers were largely female nurses from the Ministry of Health and NGOs, with experience providing FP services in Kambia during the outbreak. The stakeholders included health policy leaders from the Ministry of Health and health NGOs, and local leaders including village heads and religious leadership. Health care worker and most stakeholder interviews took place in English, and thus did not require the assistance of Masi. Two stakeholder interviews did require translation support and so were supported by Masi. All interviews were recorded and transcribed (and translated if necessary).

All IDI participants were offered a nominal sum as compensation for their time in local currency (valued at approximately £1.) The amount of this sum was chosen as it was felt to cover both transportation costs to and from the interview venue, and to compensate for the opportunity cost of the participants not using the interview time for either income-generating activities or household work, as they might have otherwise done. A further reflection on compensation to research participants can be found in the reflective section at the end of this chapter.

Topic guides for the IDIs can be found in Appendix A.

3.2.4.3 Focus group discussions

At the end of the data collection period the research team undertook two focus group discussions with women of childbearing age to triangulate findings from the IDIs. Women were selected for these FGDs through similar methods to those for the IDIs, through engagement with local women's groups. One FGD was made up of 10 women largely from Kambia town, a more urban environment, and one with 8 women from a rural village approximately 40 minutes from Kambia town. Both groups comprised of women who were FP users and non-users during the outbreak.

The FGDs began with two participatory learning and action exercises: 1) problem ranking; and 2) barriers on the road to health care. These exercises were adapted from HIV sensitization participatory learning and action tools (International HIV/AIDS Alliance and Frontiers Prevention Project 2006). The FGDs commenced with the problem raking exercise, where women were asked to first free list their major concerns during Ebola, following the identification of concerns, women voted for which were their most significant concerns. The second activity involved drawing a road from a woman's home to the FP clinic, and asking participants to travel along the road and either draw or name barriers that would make it difficult for the woman to get to the clinic to get her FP. Both activities generated significant interest and excitement among the women, and catalyzed a very interesting discussion about barriers and facilitators to seeking FP during Ebola, that were further probed during the remainder of the FGD. Both FGDs were audio recorded, and the two participatory learning and action tool outputs (on flipchart paper) were photographed.

All FGD participants were offered a nominal sum as compensation for their time in local currency (valued at approximately £1.)

The topic guide for the FGDs can be found in Appendix A.

3.2.5 Risks to participants

Given the sensitive nature of the topics that were discussed in the IDIs and FGDs, I anticipated that these could trigger emotional responses in participants. To mitigate this I had a three part approach. First, I completed an online course by Johns Hopkins University on Psychological First Aid. This course introduced me to their RAPID (Reflective listening, Assessment, Prioritization, Intervention, Disposition) model (Everly, Lee McCabe et al. 2014), which I employed in all interviews and FGDs. I followed this up by providing all participants with my local Sierra Leone number so they could contact me to talk further if they wished to. Secondly, I attempted to connect with local Community Based Organisations in Kambia to identify suitable psychosocial support groups, but unfortunately no free formal services were identifiable in the areas of data collection. Therefore I was prepared to ask any participant who became distressed (during the interview or after) if they had a local community leader or religious leader or women's group they might like to speak to for follow up support, and I would offer to call this person to make a referral. I was also ready to refer to the local public health clinic for support as needed on the recommendation of the Sierra Leone Ethics committee. Throughout the period of the data collection none of the participants requested follow up support.

3.2.6 Informed consent

All interviewees and FGDs participants were provided with an information sheet that Masi provided translation and clarification on in the local language. All participants were asked to sign consent forms, or if they were non-literate they provided a thumbprint and we obtained a witness' signature. All participants had the opportunity at all times to refuse to participate or to leave the interview/FGD at any time, without any penalty. If they left prior to the completion of the activity they would have still received their financial compensation, though no participant requested to end the interview.

3.2.7 *Confidentiality*

All data gathered through interviews, FGDs and observations was kept anonymous and confidential using coded identifiers. Data have been presented in an aggregated form except where quotes were used, which have only been identified with the age range of the participant, the rural or urban geography, and if they were a user or non-user of FP services. Consent forms for stakeholders did include a note that role titles (but not organisation names) could be included with quotes.

3.2.8 *Data analysis*

Data analysis initially followed Braun and Clark (2006)'s six steps for thematic analysis: 1) familiarizing with data by reading and rereading transcripts; 2) generating a first set of codes based off of early ideas; 3) bringing together codes into early patterned themes; 4) checking themes against coded extracts and considering the themes against the entire dataset; 5) repeated analysis to refine themes and build the story of the analysis; and 6) writing up the article for publication. In the latter stages of the analysis, I read an article that described fear related to Ebola outbreaks as being "locative", defined by the authors as "*concern for one's personal well-being in spaces where microbial threats are, have been or might be."* (Shrum, Aggrey et al. 2020, p.7). This concept of locative fear helped me develop the overarching framework of analysis for this dataset, grouping identified themes into either proximal to disease or distal to disease, terms which will be defined in chapter 5.

The analysis process was supported by the co-authors of the paper, with each co-author reviewing, providing reflections and revisions and, in the cases of Maseray Fofanah and Dr.

Sulaiman Conteh, critical contextual knowledge of the Kambian Ebola outbreak and the overarching Sierra Leone family planning situation during the outbreak.

3.2.9 Limitations

The relatively small sample of participants across rural and more urban environments meant it was not possible to identify particular barriers or opportunities unique to those environments. It would have been advantageous to re-interview more of the women, to elicit further experiences and as they may have felt more comfortable with the research team the second time, but as discussed above this was not generally possible due to the women not being contactable. The interviews and focus groups took place in English, and were translated in real-time by Masi, and then responses were interpreted back into English, making the interviews and focus groups sometimes rather stilted, as there was a time lag between question and answer. The interpretation process also made it challenging to ask new questions that were not in the topic guide, as Masi would have to consider carefully how to accurately translate the new question, but as more interviews were done Masi became very adept doing so, as she was involved in debriefing following each interview and thus learned to identify areas to follow up. A final limitation may be that by asking women to provide information about their experiences from three to four years prior, that they may have struggled to recall their decisions or challenges, though in general it appeared that the Ebola outbreak was a major event for many of the women interviewed, and thus they did have vivid stories to share, even if occasionally they were not able to remember approximate dates of events.

3.3 Case study 2: Integrating community feedback into the North-Kivu Ebola response

The research methods for this case study were key informant interviews, focus group discussions and meeting observations, along with documentary analysis. I had worked in this Ebola response as a deployee with the World Health Organization via the Global Outbreak and Alert Response Network, and thus had a network of contacts that facilitated the research. Furthermore, I had completed essential security training and was thus able to travel outside of

Goma to conduct the research. Primary data collection took place in November 2019 over a ten day period.

3.3.1 Ethical review

This study was ethically reviewed and approved by the ethics board of the Faculty of Medicine, University of Kinshasa in the DRC (October 30, 2019, ref: ESP/CE/264/2019), as well as by the London School of Hygiene and Tropical Medicine ethics committee (August 7, 2019, ref: 17762). Local permissions were granted by the Ebola response coordination bodies in Goma and in Beni.

3.3.2 Partnerships & data collection locations

This research was undertaken in partnership with the International Federation of the Red Cross (IFRC), as part of a wider research project evaluating the work of the IFRC and the DRC Red Cross on the North-Kivu Ebola response. The US Centers for Disease Control (CDC) were also involved in the overall project, as they were a key partner in the IFRC's community feedback mechanism, of which the project aimed to evaluate. The IFRC and CDC were involved in the grant application process, the research design and in identifying potential interviewees. Both partners also reviewed the final submitted paper, though only team members from the IFRC were involved sufficiently for co-authorship credit.

Data was collected in two locations, chosen as these were locations where key informants could be found, while also taking into account substantial security restrictions as well as the ability of our research partner, the Red Cross, to provide logistical support. Goma, the main coordination hub of the North-Kivu and Ituri Ebola response, is a large city located on Lake Kivu, bordering Rwanda, with an international airport and a population of approximately 600,000 people (Macrotrends 2021). Goma has long been the main staging location for humanitarian responses into the conflict-affected North-Kivu province, and thus has bases for many international NGOs, the UN's MONUSCO forces and government bodies for the provinces of North-Kivu and Ituri. Goma was thus the location whereby many of the senior strategic decision-makers of the response were found and interviewed. The second data collection site was in Beni, North-Kivu province, the coordination hub of the Ebola response (prior to it being moved to Goma in February 2019 (Crawford, Holloway et al. 2021)), and where a large number of field-level decision makers continued to be based. The two fieldwork sites were also locations where the Red Cross had substantial coordination structures and fieldwork operations, thus enabling me to have logistical and security support as well as access to key Red Cross informants.

3.3.3 Research team

The core research team for this study was made up of myself as the main researcher and Dr. Hana Rohan (co-investigator of the overarching project and qualitative lead). As discussed in the introduction, I already had experience in the North-Kivu response, and so had a strong network of potential interviewees on which to draw. I drafted out the tools for data collection, worked with the project partners to identify interviewees, collected the data, led the analysis and wrote up the paper for submission.

Dr. Rohan had not worked in this Ebola response, but had extensive experience with the West African Ebola response and with other outbreak responses in Africa including Lassa Fever. She reviewed the data collection tools, advised on interviewees, provided remote support to data collection and early analysis through review of the main researcher's field notes and through calls, provided support with analysis including identification of overarching themes, and supported writing of the final paper.

Three staff members from the IFRC also contributed to the research. Ombretta Baggio, community engagement and accountability senior advisor, supported grant writing and study design, and was present during fieldwork to help set up interviews and to provide contextual analysis of the Red Cross' Ebola work. She was not present during any interviews to maintain confidentiality. She also reviewed the final manuscript. Cheick Abdoulaye Camara, community engagement officer, provided support with fieldwork, including participant identification and contextual analysis, and reviewed the final manuscript. Eva Erlach, community engagement and accountability delegate, and Lucia Robles, information management coordinator, were both involved in grant writing and study design, participant identification, and reviewed the manuscript.

3.3.4 Data collection

The primary data collection consisted of five different approaches:

- Meeting observation
- Document review
- Key informant interviews
- Focus group discussions
- Field notes

3.3.4.1 Meeting observation

A total of 7 meetings were observed, two in Beni and five in Goma. The meetings were chosen though a combination of practicality (happening in the field location, on days when I was available), appropriateness (I could secure an invitation to attend), and relevance (focus on community feedback or communications with communities, different levels of coordination). At all meetings the researcher was introduced as such, and took extensive fieldnotes but did not record quotes or meeting participant identifying details. For a list of meetings please see Appendix C.

3.3.4.2 Document review

Eight documents relevant to the Ebola response, the community feedback mechanism or the safe and dignified burial programme were reviewed. These documents were either suggested and provided by the IFRC, or were identified and obtained by the main researcher through web-searches or by asking key informants to provide them. These documents were read and provided critical background information that helped to guide interview questions and were also used at the analysis stage of research. For a list of documents reviewed please see Appendix C.

3.3.4.3 Key informant interviews

A total of 30 interviews were completed for this research project, with the profiles of the interviewees and their type of organisation listed below. Key inclusion criteria were for Ebola response workers who were involved in either strategic or field-based decision making, they could be from government, UN agencies, NGOs (international or national) or funding bodies. I worked with the project partners to identify key individuals or role profiles (eg. field coordinator, community engagement manager) to be interviewed, aiming to have a mix of different organisations and organisation types. Once potential interviewees were identified, individuals were approached either initially by IFRC staff or myself, were given a copy of the info sheet and consent form to review and sign, and given time to ask questions prior to commencing the interview. Interviewees were interviewed in private spaces. In most cases interviews lasted no more than 40 minutes, and an effort was made to keep them short and targeted as research participants were all extremely busy individuals. Unfortunately, in two instances potential interviewees declined to be interviewed following preliminary discussions due to the lack of financial compensation for the interview. Compensation had not been budgeted for nor planned for these interviews in the project preparation phase. As a research team we agreed that as response decision-makers, all interviewees were in paid employment, and as we would be interviewing them at their place of work, during their standard workday, there would be no incurred transportation costs.

All interviews took place either in English or French, per the preference of the interviewee. Interviews were digitally recorded on a password-protected encrypted device, and the recordings were then transcribed (and translated if necessary) by an external specialist agency based in the UK.

The topic guide for the interviews was iterated over time, and was adapted in real time given the profile of the individual being interviewed. The original topic guide can be found in Appendix B. A table laying out the types of organisations and profiles of interviewees is available in Appendix C.

3.3.4.4 Focus group discussions

Two focus group discussions were held with Red Cross staff and volunteers, one with a community engagement and accountability team in Goma, and one with a safe and dignified burial team in Beni (done in two parts). These focus group discussions were set up by the local Red Cross leadership in the two field sites, and followed meetings that these two groups already had so as not to burden the participants with additional travel. All focus groups were digitally recorded on an encrypted device, and transcribed (from the original French) by an external agency. The topic guides for these focus groups are in Appendix B. The data from these focus groups has been included in the results chapter, but also has informed the context section of the background chapter.

3.3.4.5 Field notes

I wrote up field notes at the end of each day of data collection and shared these with Dr. Rohan. These notes included early analytical thoughts on meetings attended, or on interviews completed. Challenges involved in the data collection, from security concerns, to issues with participant recruitment were also recorded. These field notes were used in the analysis stage to provide additional context.

3.3.5 Risks to participants

There were very limited risks to participants in the KIIs and FGDs, though it was possible that speaking about the Ebola response and the use of evidence in the response could have been traumatic for some. All participants were provided with the contact details for the main researcher so that they could follow up with any concerns or issues following their involvement in the research, but none chose to do so.

3.3.6 Informed Consent

All participants in both the KIIs and FGDs were provided with an information sheet and consent form in either French or English per their preference. They were provided the opportunity to review the information and ask questions prior to signing the consent form.

3.3.7 Confidentiality and anonymity

All interviews and FGDs took place in private spaces to preserve confidentiality. Prior to commencing FGDs, participants were asked to verbally agree to keep all shared information private. Coded identifiers were used to anonymize participant information from interviews and FGDs. For any quotes in the results section, the role profile of the respondent was included (e.g. community engagement specialist), but these role profiles have purposely been modified so that they cannot be linked to any particular organisation (thus preventing backwards identification).

3.3.8 Data analysis

Data analysis followed the approach of framework analysis (Gale, Heath et al. 2013). This process involved four distinct stages: 1) transcription (and translation) of the audio recordings of interviews and FGDs. This stage was done by external agencies. 2) familiarization with the transcripts by reading and rereading them, alongside reviews of the collected documents, field notes and meeting notes. 3) applying and coding the data into the analytical framework, whereby the framework used was initially the topic guide, but which also branched out to inductive coding when extracts or ideas came up that did not apply to existing codes. This was done initially on only 5 transcripts, at which point Dr. Rohan and I reviewed the codes and identified potential categories, which were included as additional codes. Once all transcripts and fieldnotes had been coded, key categories were identified by the main two researchers. This work was done using Nvivo 11. 4) the final stage was that of interpretation of the data, where key categories were considered, prioritized, developed and discussed, working memos were written bringing together representative quotes in these categories, and the final paper was written up, including data-driven recommendations for future outbreak responses.

3.3.9 Limitations

There were several high level Ebola response leaders that the research team had hoped to interview, however due to the extremely high workload brought about by another flare of Ebola in a remote location away from the locations of fieldwork, these individuals were not available for interview. Attempts to connect with them by teleconference following the in-country fieldwork were unsuccessful. It would have been very interesting to assess community member perspectives on how their feedback was being used by the Ebola response, but this question was out of scope for this project, as the aims focused on how leadership were using the community derived feedback.

Potential bias could have been introduced into this study as I had previous experience working for the Ebola response, and thus may have been positively biased towards it. This was mitigated by having Dr. Rohan critically review field notes and provide ongoing teleconference support to interrogate assumptions that could have come up during the data collection.

3.4 Positionality of the researcher

As an individual with both a professional background and a research interest in outbreak response, the work of Mosse on insider-outsider perspectives resonated with me strongly in writing up this thesis. Mosse comments on how anthropologists working now (as compared to previous eras) are closer to the "other" that they are studying than ever before (Mosse 2006). In my case, as in Mosse's, we are both writing from an "insider" perspective, as researchers studying an institution that we had also been employed by, in my case, the Ebola responses of Sierra Leone and the DRC. In the two case studies, my role as a researcher was similar, in that I was studying an outbreak in an context in which I had been an "insider" in the past. However, the two cases were also different, in how I was likely to be perceived by research participants.

The organisational linkages I carried with me while conducting these two case studies required ongoing reflection during data collection and in the write up. As discussed by Lewis et al, when researchers affiliate with humanitarian organisations in the midst of a crisis they gain security, logistics and often can piggyback on the long-established relationships that the organisation has built with the population they serve (2019). In this case I may have been perceived to be wearing "*humanitarian clothes*", as Lewis et al had described researchers who conduct their work under the banner of humanitarian organisations (Lewis, Banga et al. 2019, p.203). Having a responder background I often played up my experiential background while speaking with research participants, to create some sense of shared experience and identity.

In Sierra Leone, I was quite independent, while in some cases I went out with Marie Stopes Sierra Leone, the majority of time Masi and I went out by ourselves, using local transport and only under the "umbrella" of LSHTM as a research institution. LSHTM seemed to have a largely positive reputation in Kambia, thanks to the work on the Ebola vaccine trial, and it may be that this opened some doors for me. But overall, most participants likely did not see me as affiliated with any one organisation, and thus I would not have come with as much institutional baggage as had I been directly linked with either an Ebola-responding or reproductive health organisation. However I generally did introduce myself as having been in Sierra Leone during the outbreak, so that the people I spoke to would hopefully feel comfortable sharing their experiences and details, secure that I could relate, even if only in a small way.

In the DRC I was affiliated with the IFRC, both for security and logistical reasons, and in many cases for the introductions to potential interviewees. While I did my utmost to demonstrate independence from my host organisation, it is not unlikely that some interviewees may have given a more positive emphasis of the community feedback work that was IFRC led. I found when interviewing participants it was essential to give some background about my experience in the North-Kivu response, as I did not want to be perceived as a "parachute" researcher, just coming in to collect what I could without having any connection to the context.

Returning to Mosse' insider-outsider framework, I acknowledge that I am also writing from an "outsider" perspective (Mosse 2006). In both Ebola responses when I was employed as a responder I held incredibly privileged positions, from my position as an educated, western, white woman coming into the space with the backing of my academic and professional experience and the mantle of "health expert". I worked closely with health workers and policy-makers from Sierra Leone and the DRC with decades more experience than I, yet my international contracts granted me a salary and position that was often disproportionate when compared to my national colleagues. In this time where demands for the decolonization of global health, humanitarianism and the academy are finally being heard, I continue to be reflexive of how my position of power and privilege may have changed or influenced the stories of my research participants.

3.5 Reflections on fieldwork

My fieldwork as written up in this methodology section comes off as a very well planned and executed journey, and while I did not experience major challenges or disruptions, there are some issues that emerged that deserve reflection.

The challenges of recruitment in Sierra Leone required me to lean heavily on my research assistant. As a woman from the local area, she had insider knowledge of how to find potential participants, and I am sure that without her I would not have been able to have the conversations that I had with women in Kambia. It was her idea to engage with local women's groups to create a connection before asking them to participate in the study, and this approach was very successful in the end. Pre-data collection I had not given due consideration to how strange it would be for an outsider white woman to come into the local area to interview women about their health care decision making. I had spent much of my time concerned with formal approval processes, from ethical boards and local leaders, but these approvals had largely come from men. What Masi taught me was that women's leadership is less formal, more relational, and that if I wanted to really hear women's stories, I had to go through their organisational structures.

The second issue I would like to reflect on is the financial incentivization of research participants. I chose to compensate participants in my research in Sierra Leone, and the decision was made for the DRC research not to compensate. In Sierra Leone I was generally interviewing women in the local community, many who would have been facing an opportunity cost to speaking with me, as their time could have been spent in income-generating activities or in their daily tasks (childcare, home-making). And in some cases the women had travelled from their homes to a central location to speak with me (in the case of the FGDs). The health workers I interviewed at their places of work, but generally after the workday was completed as I did not want to take them away from their patients, so I felt a payment was fair as they were staying late at work. None of the health policy stakeholders accepted the small payment, suggesting that they saw the interview as a part of their engagement with research and learning following Ebola, and as salaried individuals the small sum was likely not of large value to them. In the DRC all research participants were salaried staff working for the Ebola response in some capacity, and all were interviewed at their places of work, during the standard workday. I had not considered that anyone would be asking for compensation for the interviews, and so had not come prepared to provide any. Two potential participants declined to participate when I informed them that there would not be “prime” (incentive). My fieldnotes from that day include some of the language they used with me, about how “*you people up in London*” do not consider the “*delicate economic situation of the Congo, and the socio-cultural expectations of providing soda, food and money when you are asking something of someone. Other researchers provide prime, and so should you*.” It was true that I had not considered this, but I had been involved in research activities in my previous role in the response and had not been asked by any of my participants for compensation, though I clearly should have done more background work. The complexities of conducting research in low-income countries requires an ongoing process of enquiring after local norms, but also critically reflecting on who these norms benefit. Researchers must respect the time they take from research participants, and consider if compensation is warranted, but also remain true to the ethical requirements of research by not coercing participation through financial means.

As a final reflection on my research fieldwork experiences, I have come to recognize that my experiences in both places of having been a responder made some aspects of fieldwork easier, and some likely harder. Having worked in the responses, I did have some internalized ideas about what had worked well in the response and what had not. In both responses, in my experience, community engagement had been done poorly (in the case of DRC), or at least had been started too late and was not given the prioritization it deserved (Sierra Leone). These feelings of not having worked hard enough or of feeling ineffective in my efforts to improve the responses on these fronts may have spilled over into my research interests and foci. Several years after these responses I continue to reflect on the distress that I personally experienced in those spaces. I often wonder if by taking the opportunity to conduct research in these settings, and my drive to contribute to making future outbreaks better for communities and responders, is my way of making up for my own failings and contributes to my healing journey.

4.0 Introduction and context for case study 1

Family planning in Sierra Leone's Ebola outbreak

While the advent of new vaccines and therapeutics for Ebola is positive and may well help to lessen mortality in future outbreaks, it remains that Ebola outbreaks disrupt health services and systems. For future outbreak planning, it is critical to understand how communities continue to engage with their health during times of epidemic stress. In low income countries where outbreaks of Ebola occur, gender disparities in health are sadly common, and therefore understanding the additional burden that outbreaks place on access and engagement with women's health services is important to minimize the impacts of outbreak responses and to enhance community engagement. The case study to follow looks at women's health care engagement through the lens of family planning in outbreaks of Ebola, with this chapter (4) focused on the setting and context of family planning in the outbreak, including some research data from health policy stakeholders and health workers, and the following chapter (5) presenting the final published article.

4.1 Pre-Ebola context

Sierra Leone's health system pre-Ebola was in poor condition, a legacy of structural adjustment, a shrunken public sector and an 11 year long civil war (that ended in 2002) that had killed some 70,000 and displaced a further 2.8 million people (Kaldor and Vincent 2006, Benton and Dionne 2015, Kentikelenis, King et al. 2015). As in many low-income, post-conflict health systems, there was a dearth of qualified health workers, demotivated and poorly paid staff, poor health infrastructure and a funding system that was highly dependent on user fees to function (McPake, Witter et al. 2015, Pieterse and Lodge 2015, Witter, Wurie et al. 2016). Sierra Leone's health system may have been further weakened by a health policy environment heavily influenced by outside actors, with donors, large international NGOs and government all involved in agenda-setting, in a sometimes often un-coordinated fashion (McPake, Witter et al. 2015). That much of health delivery was provided by health staff funded directly by NGOs or faith organisations also limited the government's oversight of facilities and staff (DuBois and Wake 2015).

The Free Health Care Initiative, largely funded by international donors including the UK and the Global Fund, aimed to reduce the barriers to health care by providing free care to children under the age of 5 and pregnant and lactating women, and also sought to rationalize health care expenditure and staffing. This initiative, a massive undertaking, showed successes in improving staffing numbers and satisfaction, monitoring and evaluation, infrastructure, and overall seems to have resulted in increased utilization of services for the priority groups. However in some ways Free Health Care struggled, most notably in the area of drug procurement and distribution, resulting in out of pocket payments still being required for holistic care (Witter, Brikci et al. 2016). When asked about this deficiency, health policy stakeholders interviewed as part of this thesis admitted the challenge in relation to FP commodities, but also emphasized that good efforts were being made in the pre-Ebola era to improve the supplies of drugs, and to provide additional training to all cadres of staff to enable women to be provided with the FP method of their choice at their local health unit. Overall, the pre-Ebola health system in Sierra Leone did have challenges, but the situation had improved since the war, and the increase in use of modern methods of contraception from 8.2% in 2008, to 20.9% in 2013 is one indicator of this improvement in the realm of women's health (Statistics Sierra Leone and ICF Macro 2009, Statistics Sierra Leone (SSL) and ICF International 2014).

4.2 Ebola context and FP in Ebola

The Sierra Leone health system (and response to Ebola) in the context of the outbreak showed the cracks of longstanding under investment in health, management and technical capacity, though as stated by Dubois and colleagues: "*It would be unfair to condemn Liberia, Sierra Leone and Guinea for being unable to deal with an epidemic that, by the summer of 2014, might have challenged the health systems even of wealthy nations"* (DuBois and Wake 2015, p. v). From the start of the outbreak, coordination structures were unsettled, with the implementation of different response structures[2], and abrupt replacement of both the national health minister

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[2] March – July 2014: National Ebola Task Force; July – October 2014: Ebola Operations Centre; October 2014 – onwards: National Ebola Response Centre.

and the WHO representative, before the responsibility for the outbreak landed with the Minister of Defense and the establishment of a National Ebola Response Centre at the strong urging of the United Kingdom (UK). The leadership of the UK in the Sierra Leonean response was related to the long standing historical, post-colonial and bilateral relationship of the two countries, and the UK ended up as a key financial, operational and strategic partner in the response (Ross 2017).

Sierra Leone had a long history of managing viral hemorrhagic fevers, as Lassa fever is endemic to the region, with one of the foremost research centers for the disease based in the town of Kenema, formally run by Dr. Sheik Umar Khan[3], an expert hemorrhagic fever virologist (BBC 2014). However Ebola was to prove another thing entirely, with the much higher mortality rate, extensive human to human transmission and wide geographic spread, leading to an epidemic that lasted from 2014 to 2016, and killed at least 3,955 people (though this is highly likely to be an underestimate) (World Health Organization 2016).

The health system struggled to manage the combination of day to day health needs, alongside the Ebola-specific health infrastructure and programming that had become of overwhelming importance (DuBois and Wake 2015, Jones and Ameh 2015, Jones, Gopalakrishnan et al. 2016). As several health policy stakeholders agreed in interviews, the system struggled to prioritize any health activities that were not directly related to Ebola, and this included reproductive health services.

"*The reason why we left [FP] out was because at that time all we were thinking was to treat Ebola. So, because we were just thinking of treating Ebola, we forgot about every other thing. It was only when we saw that women were bleeding giving birth at home and nobody could attend to them because everybody was afraid of touching blood. So, if someone started bleeding in a car, people would just run away. So, that was the time we came back and we*

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[3] Dr. Khan died of Ebola in July 2014, a major loss for the Ebola response and for the medical research community.

programmed ourselves to go and provide services for the reproductive health care." (health policy stakeholder).

This concern was echoed by health care providers at the clinic level, who had often been reallocated to work in the Ebola response, leaving their communities with limited support, thus undermining the routine health system. As one health worker stated: "*We stopped the family planning but [organisation] got involved in another activities which was very vital to the country and it was very successful…we were part of the Ebola fighting…as a surveillance officer."* Health workers also raised concerns that while working in family planning services they felt their needs for personal protective equipment were at the bottom of the list when distributions were being done, again pointing to the deprioritization of some services in the Ebola outbreak.

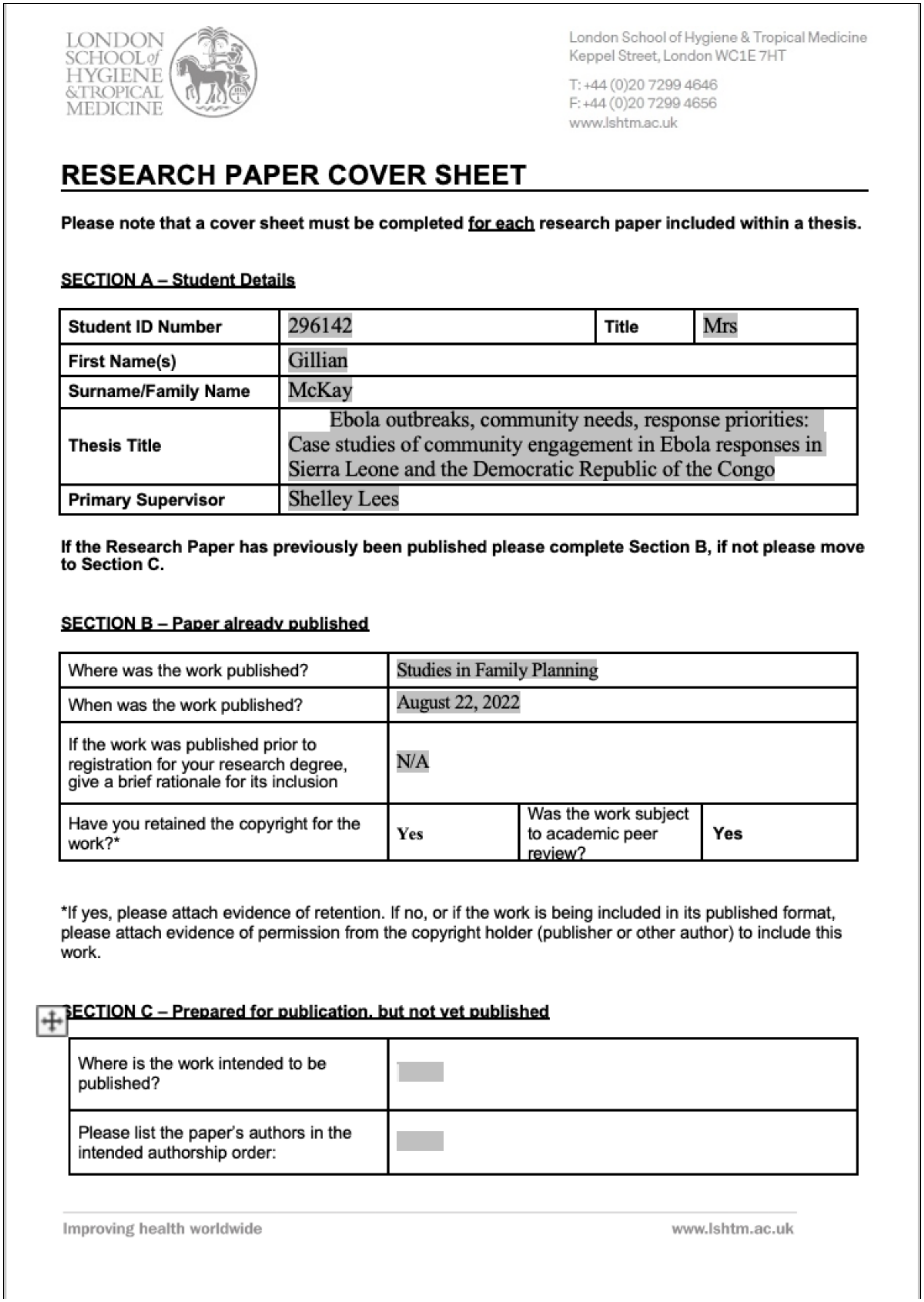
Infection Prevention and Control (IPC) measures (including appropriate Personal Protective Equipment (PPE)) at the health facility level were put in place to reduce the transmission of Ebola from patients to health care providers and vice versa, though the completeness and availability of these supplies were highly variable temporally as well as geographically (Pathmanathan, O'Connor et al. 2014, DuBois and Wake 2015, Shoman, Karafillakis et al. 2017). Health policy stakeholders at district and national levels stated that reproductive services were often prioritized for implementation of IPC training and PPE provision (after Ebola-specific environments like Ebola treatment centres), given the risks of transmission of the virus in childbirth and to reduce the impacts of the outbreak on maternal mortality. However FP was not included in this prioritization. "*Delivery was the most important, I think family planning actually fell below that [for PPE]."* (health policy stakeholder). Health workers commented frequently on the IPC measures, stating that they felt safer when they'd been trained on IPC and had adequate supplies of PPE, but that there had been stock-outs so they had to provide care in sub-optimal situations in some cases.

Provision and access to health care were also impeded by the "no-touch" (or avoid body contact) public health directive that had been put in place, which had been widely communicated to emphasize the exceptionalism of the Ebola situation and to reduce transmission through physical contact. While "no-touch" was not intended for health care settings where personal protective equipment was available, the messaging slipped into the health care environment, resulting in patients and health care providers being wary of physical contact, making many examinations and procedures difficult if not impossible (Siekmans, Sohani et al. 2017, Yerger, Jalloh et al. 2020). "*This was because people were afraid to touch patients…the health workers did not trust the patients. So, like the best thing was 'don't touch' and don't go closer to the patient*" (health policy stakeholder). Several health workers stated that they struggled with this directive, as they felt that they were unable to establish the therapeutic relationship with their clients that they, and their clients, really valued.

"*They say we should not touch…It changes the relationship also but when it came back, when the family planning service came back, I think no touch was still kind of there, people were still scared…maybe if the client is explaining, crying, the nurse [should] console her like [holding her hand]. So, if the client is talking to you maybe you are far away maybe the client will feel that you are not paying attention to her or you are discriminating her. So, even if the client wants to be open up to you to tell you something, that will block it, that barrier will be there."* (health care worker).

As previously discussed, engaging communities is essential to maintain health seeking behaviour during outbreaks of Ebola both to prevent onwards transmission and mortality from the virus itself, but also to prevent morbidity and mortality from non-Ebola causes (World Health Organization 2018). Understanding how women engaged in seeking support with their health, in the face of all of the challenges of a chronically underfunded health system, and the additional barriers of the Ebola outbreak and response, opens new avenues for two-way community engagement, but first further research and analysis into this question is required, to which the research paper to follow contributes.

5.0 Research paper 1



LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

London School of Hygiene & Tropical Medicine
Keppel Street, London WC1E 7HT

T: +44 (0)20 7299 4646
F: +44 (0)20 7299 4656
www.lshtm.ac.uk

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Student ID Number	296142	**Title**	Mrs
First Name(s)	Gillian		
Surname/Family Name	McKay		
Thesis Title	Ebola outbreaks, community needs, response priorities: Case studies of community engagement in Ebola responses in Sierra Leone and the Democratic Republic of the Congo		
Primary Supervisor	Shelley Lees		

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

SECTION B – Paper already published

Where was the work published?	Studies in Family Planning		
When was the work published?	August 22, 2022		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion	N/A		
Have you retained the copyright for the work?*	**Yes**	Was the work subject to academic peer review?	**Yes**

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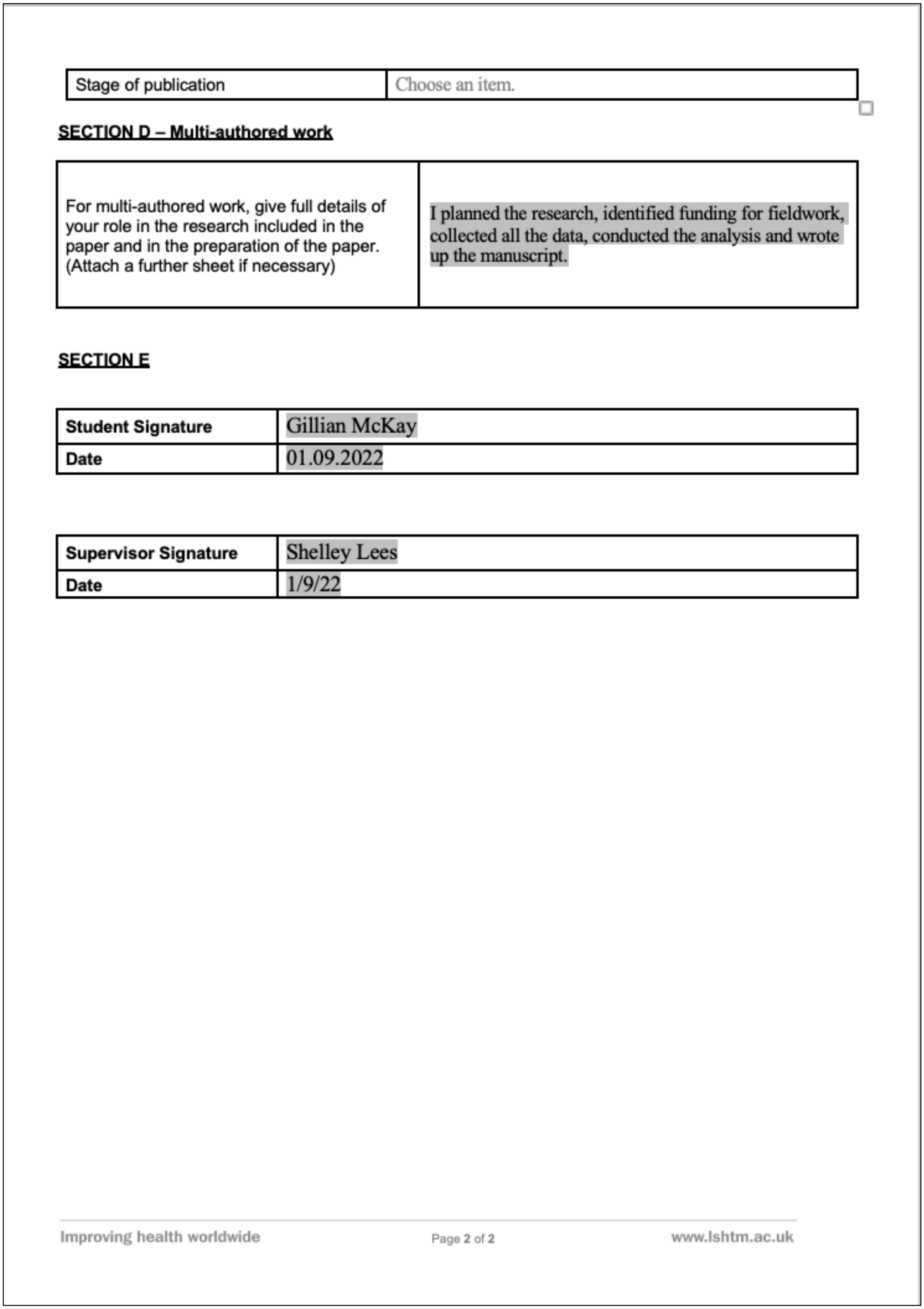

Stage of publication	Choose an item.

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	I planned the research, identified funding for fieldwork, collected all the data, conducted the analysis and wrote up the manuscript.

SECTION E

Student Signature	Gillian McKay
Date	01.09.2022

Supervisor Signature	Shelley Lees
Date	1/9/22

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Family Planning in the Sierra Leone Ebola Outbreak:
Women's Proximal and Distal Reasoning

Author Names:

Gillian McKay

Luisa Enria

Sara L Nam

Maseray Fofanah

Suliaman Gbonnie Conteh

Shelley Lees

Author Affiliations:

Gillian McKay (corresponding), Luisa Enria, Shelley Lees: Department of Global Health and Development, The London School of Hygiene and Tropical Medicine, 15-17 Tavistock Place, London, UK, WC1H 9SH. gillian.mckay@lshtm.ac.uk; luisa.enria2@lshtm.ac.uk; shelley.lees@lshtm.ac.uk. Sara L Nam: Independent Consultant. sara.globalhealth@gmail.com. Maseray Fofanah: Independent. masi.fofanah@gmail.com. Suliaman Gbonnie Conteh: University of Sierra Leone College of Medicine and Allied Health Sciences, A.J. Momoh Street Tower Hill, Freetown, Sierra Leone. University of Sierra Leone. conteh4722@gmail.com.

Abstract

Sierra Leone was highly impacted by the 2014–2016 West Africa Ebola outbreak, with 3,955 recorded deaths. Already stressed maternal health services were deeply affected by the outbreak due to fears of viral transmission, reallocation of maternity staff, and broader policies to stop transmission including travel restrictions. This research sought to explore women's perspectives on delaying pregnancy during the Ebola outbreak using family planning methods. Qualitative data collection took place in Kambia District in 2018 and included 35 women participants, with women who were either family planning users or nonusers at the time of the outbreak. Women reported a variety of reasons for choosing to take or not to take family planning during the outbreak, which we categorized as proximal (directly related to the outbreak) or distal (not directly outbreak related). Proximal reasons to take family planning included to avoid interacting with health care spaces where Ebola could be transmitted, to avoid the economic burden of additional children in a time when economic activities were curtailed and to return to school when education resumed postoutbreak. Distal reasoning included gender roles affecting women's decision making to seek family planning, concerns related to the physiological side effects of family planning, and the economic burden of paying for family planning. Women's perspectives for choosing to take or not take family planning during the Sierra Leone Ebola crisis had not been explored prior to this paper. Using the lens of family planning to consider how women choose to access health care in an outbreak gives us a unique perspective into how all health care interactions are impacted by a generalized outbreak of Ebola, and how outbreak responses struggle to ensure such services remain a priority.

Introduction

Amid a global pandemic of Covid-19, women's ability to seek family planning (FP) services have been negatively impacted across the world due to restrictions in availability of health services and commodities, out of fear of contagion at clinics and due to lockdown or movement restrictions (Cousins 2020, Riley, Sully et al. 2020, World Health Organization 2020). Crises such as outbreaks and pandemics can cause an increase in unintended pregnancies, making the need for FP all the more acute (Riley, Sully et al. 2020). These challenges have been foreshadowed in previous outbreaks, including in the large West African Ebola outbreak that started in 2013 and continued until 2016, where a total of 14,122 people were infected and 3,955 died of the disease (World Health Organization 2016).

The impacts of the West African outbreak of Ebola on reproductive health have been well documented (Jones, Gopalakrishnan et al. 2016, Sochas, Channon et al. 2017, Yerger, Jalloh et al. 2020). Following the outbreak there were intensive processes of reflection in numerous "lessons learned" fora into how the tunnel-visioned focus on stopping transmission of the virus was highly detrimental to the overall health care system, thus impacting on non-Ebola health services (including reproductive health care). Part of these analyses included how the already weakened health care systems of the 3 most affected countries (Sierra Leone, Guinea and Liberia) likely contributed to the extent of the crisis (Shoman, Karafillakis et al. 2017). Prior to the outbreak, Sierra Leone (the country in which this research took place) had 0.2 physicians and 1.7 nursing or midwifery staff per 10,000 citizens, and only paid 12 dollars per head for health out of the government budget (World Health Organization 2015). McPake and colleagues explain how the fragility of Sierra Leone's post-conflict health system, plagued by challenges including poor human resources for health and lack of trust in institutions, likely contributed to the extended outbreak and high death toll (McPake, Witter et al. 2015).

The Ebola outbreak, in such a context, can be thought of in terms of syndemics, a "*clustering of two or more diseases within a population; the biological, social, and psychological interaction of those diseases; and the large-scale social forces that precipitate disease clustering in the first* *place."* (Mendenhall 2017, p.889). The complexity of accessing maternal health care during Ebola in a syndemic environment meant that while 3,955 people died in Sierra Leone from Ebola itself (World Health Organization 2016), it has been estimated that there were an additional 549-714 maternal deaths due to the weakened health system (Sochas, Channon et al. 2017), compounded by the deterioration in trust between women, health providers and the health system (Nam, Thomas et al. 2016). These additional maternal deaths were in a country where in 2013, the year before the Ebola outbreak, the Sierra Leone demographic and health survey (DHS) estimated the maternal mortality rate among the highest in the world at 1,100 per 100,000 live births (Statistics Sierra Leone (SSL) and ICF International 2014).

Pregnant women are particularly vulnerable during Ebola outbreaks (McKay, Black et al. 2019). Pregnancy complications and Ebola symptoms are very difficult to differentiate even by medical experts, and the Ebola-positive body fluids from complicated deliveries or maternity procedures can cause infection in the health provider especially when personal protective equipment (PPE) is in short supply (Black 2015, Black, Caluwaerts et al. 2015). These challenges led many health providers to restrict their work with pregnant women, at least in the early stages of the Ebola outbreak before there was sufficient PPE to allow pregnant women to be cared for safely (Jones and Ameh 2015, Strong and Schwartz 2016, Jones, Sam et al. 2017, Yerger, Jalloh et al. 2020).

The well-documented and acknowledged risks associated with pregnancy in Sierra Leone during the Ebola outbreak raises the question of why there was not a concerted effort to implement programmes to prevent unintended pregnancy, in line with the standard practice in the Minimum Initial Service Package (MISP) for reproductive health care in humanitarian crises (Inter-Agency Working Group on Reproductive Health in Crisis 2010). While the MISP that in 2014 did not include prevention of unintended pregnancy as a lone key objective in crises, this activity was included under Objective 5: Plan for the provision of comprehensive RH services integrated into primary care, and therefore the global policy framework was present to encourage FP service provision. Further to this, the Interagency Standing Committee reference group for gender in humanitarian action at UN Women issued a gender alert that without increased attention paid to FP services, there was risk of an increase in unintended pregnancies (2015).

Quantitative analyses demonstrated that while there was a decline in FP service provision, it was less than may have been expected and bounced back to near pre-Ebola levels quickly (Bietsch, Williamson et al. 2020). Other research has shown that the decrease in service utilization for FP and other reproductive health services was due to a decrease in demand and access issues and less due to supply side issues or a decrease in provision of care (Jones and Ameh 2015). These studies however do not explain individual motivations for seeking (or avoiding) FP services during the outbreak.

This paper investigates women's decision making whether to seek out FP services or not during the Ebola outbreak. While we explore women's "individual" decision making, we acknowledge, and will provide evidence in this paper, that women's agency to seek FP in this context is influenced by broader economic realities, political factors and family dynamics. This paper contributes to the scarcity of evidence on FP in outbreak settings and strives to provide insights that will support demand creation for modern FP in future outbreaks of infectious disease, including the current Covid-19 pandemic.

Methods

All data collection took place in Kambia District, Sierra Leone, where a protracted Ebola outbreak with 286 confirmed Ebola cases occurred from September 2014 to September 2015 (Sandi, Barrie et al. 2017). Kambia is a rural district, sitting on the border with Guinea with significant migration and circulation for reasons of trade and family ties between the two countries. This district is also the site of other London School of Hygiene and Tropical Medicine projects including the EBOVAC Ebola vaccine studies. This site had good research infrastructure, including availability of trained research assistants and a highly engaged Paramount Chief who was widely supportive of research efforts and thus provided local approvals. The fertility rate in Kambia for three years preceding the 2014 DHS was 5.8 children per woman compared 4.9 for the country, and among all districts, Kambia had the lowest rate of modern methods of contraception use in the country, at 5.4% compared to 20.9% for the country overall (Statistics Sierra Leone (SSL) and ICF International 2014).

The primary investigator (GM) on this study had spent time in Kambia in 2014 and 2015 during the Ebola outbreak while working for an international non-governmental organisation on a surveillance project, and then returned in 2018 to conduct this research. The main research assistant (MF) was a female in her early-thirties, a native-born Kambian, with language skills in most of the languages spoken in the District (Themne, Susu, Fula and Krio), as well as English, and worked during the outbreak for NGOs on community engagement projects.

From January to August 2018 a total of 35 women were interviewed for this research, 19 through semi-structured interviews and the remaining 16 in two focus group discussions (FGDs). Interviewed women were identified following FP clinics run by a national family planning NGO, or as they were leaving under 5 clinics. Focus group women were identified through engagement with local women's groups. Among the interviewees, 10 women had been using modern FP during the Ebola outbreak, and 9 had not been. The focus group discussions were a combination of FP users and non-users, with one group made up of women from the semi-urban area of Kambia Town and the other group with women from a more rural area. Women in interviews and FGDs were mixed between married and unmarried, all were between the ages of 18-40 at the time of interview and identified as either Muslim or Christian. The PI also conducted observations of outreach and static FP clinics and held interviews with health workers about provision of FP services during Ebola.

The topic guide was developed and piloted in the first few interviews, and was adapted over time to further develop themes as they emerged. The FGD topic guide was developed following the interviews to allow the PI to probe areas of interest that had come up in the preliminary analysis of the interviews. During FGDs, the research team employed participatory learning and action tools, including health care journey mapping and a ranking exercise, to help women explain how they prioritized family planning and reproductive health during the outbreak. Analysis took place through free coding of interviews and FGDs using Nvivo 11, followed by thematic grouping of codes to identify factors that influenced women's decision making to take or not take FP during the Ebola outbreak.

Ethical approval was received from the London School of Hygiene and Tropical Medicine ethics committee and from the Sierra Leone Scientific and Ethical Review board. Local permission was granted from the District Medical Officer and from local traditional authorities (Paramount Chief, local Chiefs and village Headpeople). All women were consented in Krio or their local language, were offered the opportunity to ask questions prior to accepting or declining to participate, and were provided with contact details of the PI and local health services should they have questions or need follow up support.

Findings

A lack of availability of FP methods as a barrier to uptake has been documented in Sierra Leone as a key reason why individuals do not use modern pregnancy-prevention methods (Shirley, Lilley et al. 2014, Labat, Medina et al. 2018). However prior to the start of the outbreak there had been a significant increase in women using modern FP, from 8-21% from 2008-2013 (Statistics Sierra Leone (SSL) and ICF International 2014), indicating that availability was improving, along with uptake. Observations during this research identified that while FP was meant to be available in static clinic settings, supply chain availability of specific FP methods and trained staff to provide them was not guaranteed. Conversations with health workers identified that FP services had become less available during the Ebola outbreak, as there were reductions in staff numbers and in services offered, which is backed up by research showing a FP distribution decrease of 23% (Bietsch, Williamson et al. 2020). Outreach services provided by a national family planning NGO were better supplied with FP commodities so offered a greater range of methods, but staff from the NGO reported that these services also were also reduced during the outbreak for staff safety reasons.

In setting the scene in the FGDs, the research team asked women to free list and rank their concerns during the outbreak, to better elicit where concerns around pregnancy and FP would fall. The findings from these exercises identified that the top concerns of women were not directly health related, with main issues such as a lack of prayer and group gatherings (including funerals) being banned, schooling for children being stopped and trading and other money-generating activities being impacted. Some of these issues can be indirectly linked to health, as despite efforts by the Sierra Leone government to provide free health care as part of the Free Health Care Initiative for pregnant and lactating women and children under age 5, informal payments are still often required at the point of care (Pieterse and Lodge 2015, Witter, Brikci et al. 2016) meaning the inability to earn money would make seeking health care more difficult. Concerns related to fear of catching Ebola were mentioned and ranked highly, as were concerns about being quarantined for possible Ebola exposure, and the subsequent economic impacts on livelihoods. While pregnancy and FP were not the most critical concerns of the women in our FGDs, these issues did come up without prompting, and were said to be linked to not wanting to get pregnant during the outbreak, due to their fear of attending health facilities.

Proximity to Disease

Many of the factors that women reported that impacted on their decisions to take (or not take) FP related to the proximity to the disease either in the form of people (like health care workers) or geographic locations (like health care centres). This is a similar idea to that described by Shrum et al when discussing Ebola across many countries, who used the term “locative” which they defined “*as concern for one’s personal well-being in spaces where microbial threats are, have been or might be.”* (Shrum, Aggrey et al. 2020). This framework is particularly useful in thinking about Ebola given how it is transmitted, through contact with bodies or body fluids, and the role of health care facilities in the potential mitigation or spread of the infection.

Taking FP to mitigate the risk of Ebola

The case definition in 2014 for Ebola included unexplained bleeding, vomiting, diarrhea and other symptoms that could be confused with early pregnancy symptoms, and symptoms of complications of pregnancy (Black 2015). This was of concern to participants who believed it could lead to women being identified as suspect Ebola cases and being sent to an Ebola treatment centre, far from their homes and families, possibly not to return.

"Because the signs and symptoms of pregnancy are similar to Ebola. Some women do get sick from one month to five months when they are pregnant. So, during Ebola when one vomits they will just call 117[4] for you, and they come and take you the Ambulance will again say good bye by saying "owa-o! owa-o! owa-o[5]!" (FGD with rural women).

Fear of the potential negative outcomes of pregnancy and delivery was a large driver for many women to go on or continue with FP. The perception of poor care being provided at the health centre was common, many women told stories of friends and family members who had been treated badly or died while delivering their babies, or who had been taken away to an Ebola treatment centre and had never returned.

"Because during the Ebola if you get pregnant you will not get care because at any time you visit the hospital the nurses are scared to touch you, the people will think you are an Ebola patient. That is why we are scared to [go to the hospital]." (FP user, 18-25 years old).

Even women who had not taken FP during Ebola felt that these concerns justified them advising others to take FP. *"I will advise [my daughters] to take it because I will make reference to that pregnant woman who was vomiting and when they carried her [to the Ebola treatment centre] she did not [return to her family]."* (FP non-user, 26-40 years old).

Contagion and distrust leading to the avoidance of FP spaces and providers

Seeking out FP by going to the clinic was believed to put women at risk for catching Ebola. Therefore, some women felt it was better to see health workers privately, at the provider's home or outside the clinic setting.

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[4] The Ebola alert line that could be used to report possible Ebola cases.

[5] The ambulance that takes you away makes a noise like "owa-o", which also means "goodbye" in Themne.

“Our people were not allowing us to go to the hospital and they always advise us that when you go to the hospital they will do this or do that [test you for Ebola]. Because of that, we will wait until the area nurse is off from work then we go there [to their home] and take [FP].” (FP user, 18-25 years old).

In some cases, it was the health workers who were perceived to be carrying or spreading the infection, thus they were to be feared or avoided.

“As for me, my neighbour is a nurse and was working at the centre, when she came home and washed, she will call me to play [a game], I always said no. So, at one time some spots began to appear on her face, I became afraid of her, when she comes and sit down I will go inside and sleep. After the Ebola she was laughing at me saying that she noticed that I was afraid of her.” (FGD with urban women).

“They were afraid of the nurses, because some people do not even believe/trust the nurses… and people were afraid of Ebola and because we heard that a lot of health workers died during Ebola.” (FP non-user, 18-25 years old).

This distrust of health workers also manifested in relation to what FP method was considered safe to take. Prior to Ebola the most commonly used method was injectable contraception (Bietsch, Williamson et al. 2020). However for some women, this method was no longer acceptable, as there were persistent rumours that health workers used injections to give people Ebola (Dynes, Miller et al. 2015, Jones, Sam et al. 2017).

“Because during that time we were afraid, we felt they were giving Ebola [injections] or if you go to seek prevention[6], you might not know the person who is treating you, they might give you

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[6] A commonly used term to mean contraception.

another injection that is not prevention, so that was why we were afraid during that time." (FGD with urban women).

One way for women to overcome this concern about injections was in choosing FP methods that did not require physical contact between the health provider and the woman's physical body.

"For me, I prefer the pills because it will not give reason for somebody to touch me like it happens in the case of the injection. When I buy [pills], I will go to my house and take and nobody will touch me to give me injection at that time." (FP user, 18-25 years old).

The challenges women faced in trusting their health providers was often related to PPE. PPE at the primary health care level was not the head to toe, anonymizing, yellow PPE worn in Ebola treatment centres, and yet it was still fear inducing for many women:

"That is why some are afraid to go to the centre because of the PPE…because when they wear the PPE is like a ghost, even if you know someone, when they wear the PPE, you will not recognize the person." (FGD with rural women).

Overcoming fears through interpersonal relationships and confidence in known health workers

PPE could however contribute to increasing trust between health provider and some women when they sought out FP or other clinical care, because in the "no-touch environment[7]", PPE allowed for greater physical contact between patient and health care worker and induced a sense of reassurance.

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[7] A key message in Ebola-time was "no-touch", intended to reduce physical contact between people to prevent transmission of Ebola.

"I felt good because since they said we should not touch and the protective gears she put on will help to protect herself and me because we both did not know our status at the time. That's why I felt good because they put on their PPEs." (FP user, 18-25 years old).

While proximate fears of contagion from health workers could lead to women choosing not to take FP, these fears could be overcome with a sufficient level of trust and engagement with health workers from their local area, especially if these workers spoke the same language and came from the same geography.

"Like, I got used to so many nurses in the community because some of them are native born of the land. If I am a native born of [town] and they brought me here as a health worker, if my sisters see me they will have confidence to go take the prevention [FP]." (FGD with rural women)

This familiarity with the health worker may have also helped to overcome women's fears of PPE, as the worker is less anonymous even when masked and gowned when they are a person the woman already knows.

Concerns about side effects of FP mimicking Ebola symptoms

How women saw their bodies during Ebola may have had an effect on their willingness to take FP. Common side effects of FP (like breakthrough bleeding) could be considered a signal indicator of potential Ebola infection, and may have caused some women to rethink taking FP, out of concern that they could end up in an Ebola treatment centre.

"It is because some women, when they take prevention they will bleed too much, but during Ebola when you bleed they will say it is Ebola, and some say they get stomach pain and during Ebola even if your stomach ached they will call 117 for you and if you go [to the Ebola treatment centre], you will not come home again." (FGD with rural women)

Abstinence as a way to prevent Ebola

A number of women stated that they did not need to use FP as they chose to limit sexual contact with their partner in order to comply with the emphasized message of "no-touch" to prevent Ebola transmission. Further to this, sexual transmission of Ebola has been documented (Schindell, Webb et al. 2018), and this risk was well publicized during the Ebola outbreak with Ebola survivors given supplies of condoms on discharge from an Ebola Treatment Centre.

"The reason why people were afraid of 'mami en daddy bisnes' [sex], why I was afraid of sex, because they said during the Ebola, we should not touch one another. So, my husband used to go out to work, so I might not know if he met with somebody who has Ebola and then he comes and touches me, so there was that fear, so I did not allow him." (FGD with urban women).

"But some of the boyfriends now, they can leave you and have another woman, so you might not know the person he is going out with is sick, so that is at the time when Ebola came, I closed my door on all of my boyfriends, I didn't have boyfriends again, I was afraid." (FGD with urban women).

Some women interviewed, located in a village that had been entirely quarantined near the end of the Ebola outbreak, spoke about how they chose to completely avoid sexual relations during the 21-day quarantine period. The Ebola narrative in this village was that a woman who passed away from Ebola had contracted it from sexual contact with a known male survivor, leading to many women in the village refusing to sleep in the same beds as their husbands. The agency that these women were able to show is in contravention of typical gender norms in Sierra Leone (see below section on gender relations) with regards to who holds the sexual power in couples (almost always the men) in Sierra Leone (Fofana Ibrahim 2017), and demonstrated the exceptionality of Ebola.

Preventing economic burden through FP

The additional stresses of the impact of Ebola on the economy was a driver for some women to take FP, or to prevent pregnancy through other means including abstinence. Many markets were closed restricting petty trading, and large mining companies also closed, putting many people out of work and plunging them into economic hardship.

"…when there is no money and you have to go to clinic it is difficult. Even if they say free health care[8], you [pay a small amount]. There are some medicines that are not under free health care, you have to buy them. So, if you are pregnant during [Ebola] you have to spend money. So, when you give birth to the baby you have buy things for the baby, so that is why when there is no money child bearing is not sweet." (FGD with urban women).

The impacts of the economic decline due to Ebola among women were more severe than among men due to women's higher presence in highly-Ebola impacted sectors including markets, cross-border trading, hospitality and farming (African Development Bank 2016).

Attaining educational goals through FP despite Ebola

To stop or restrict transmission during the Ebola outbreak the government closed all public and private schools for a year. The closure of schools was a motivating factor for many women to take up or continue with FP, as they did not want to become pregnant during the school closure as they could have difficulty completing their schooling or exams when they reopened. The following respondent had a daughter at the age of 15, causing her to leave school early but she returned to finish her studies before the outbreak began. In this quote she explains how FP was important to her to enable her to continue her studies.

"No, I was never afraid [to take FP]. The moment it got expired I will immediately go again and take after my menses…I was preparing to take my [examination]. The schools were closed but I was taking extra lessons, so you know when schools reopened I could go back. There were

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[8] Sierra Leone Free Health Care Initiative

rumors that schools were about to reopen so I was taking extra lessons to catch up so that when the schools reopen, I would have got some good preparation. (FP user, 26-40 years old).

Choosing to have children amid the Ebola outbreak

Decision making was for many women related to their own personal circumstances and their support networks that could facilitate having a first or additional child. While most women did not wish to become pregnant during the Ebola outbreak, other women did desire to have more children, and this was the major factor in their decision not to take FP.

"Because my husband had no child at that time that is what I decided to get a child for him. I wanted also to have a baby. I did not have fear about having a baby during Ebola time." (FP non-user, 18-25 years old).

Fertility intentions have been studied in other crises, and it appears the type of crisis may contribute to women's desire to have future children. Following the Angolan war, women in less-affected areas were more likely to wish for a pregnancy, compared to women in more-affected areas (Agadjanian and Prata 2002). During the Zika outbreak in Brazil, in areas with more cases of microcephaly (the birth defect caused by in-utero exposure to Zika virus) there was a corresponding decrease in childbearing, indicating women were preventing pregnancy (Diaz-Quijano, Pelissari et al. 2018). Following the 2004 Indian Ocean Tsunami, women in areas with higher mortality were more likely to have additional children than in areas that were less affected (Nobles, Frankenberg et al. 2015).

Distal to Disease But Still Affected by Ebola

Outside of the proximate reasoning that drove women to choose to take or not take FP, there were also additional reasons that emerged from this research. These reasons are not as "Ebola-specific" in that they are chronic challenges that women face, but were amplified during the Ebola crisis. We have termed these "distal" as while they are further away from the locus of the virus itself and the concerns around contagion, these reasons are still affected by the context of the Ebola outbreak.

Gender roles determining choice to take or not take FP

For many women, the unequal gender relations common in Sierra Leone were highly influential in their decisions either to take or not to take FP. These challenges were not unique to the Ebola context, but instead they highlight the background against which Ebola compounded pre-existing, often structural, challenges to seeking FP.

For some women, their reasoning to avoid future pregnancy was due to having unreliable partners, who would not be supportive of them or their children. Choosing to take FP was because *"men of this generation are not serious"* (FP user 18-25 years old) or that the men were in relationships with other women, or that they would not care for the baby *"my husband does not care about me and the child"* (FP user, 18-25 years old). Women's role as the primary caregivers for children, and as the member of the couple responsible for obtaining FP (when the man has no responsibility to wear a condom) has been further discussed in research by Fofana Ibrahim (Fofana Ibrahim 2017).

Other family pressures could also work against a woman choosing to take FP, if, for example, her husband did not want her to be on a method to control her sexuality.

"One of my friends told her husband that she wanted to go and take prevention, her husband said no, because she wants to prostitute that is why she wants to go and prevent. So, they quarreled." (FGD with urban women).

The control that men have over women's sexuality is in contrast to how men were able to go about their sexual lives, even during Ebola. Fofana Ibrahim describes a case of a woman who caught Ebola following sex with her husband. She believed he had been in an Ebola Treatment Centre, but he told her that he had simply been living with his other wife in another town, and when she challenged him he became angry and threatened to leave her, with no financial support, so she complied and had unprotected sex resulting in her illness (Fofana Ibrahim 2017).

Concerns related to potential physiological effects of FP

Many women interviewed had concerns about FP side effects. Concerns about changes in menstruation, either excess or reduced bleeding, were common. While this was made more acute during the outbreak out of fear of being sent away to an Ebola treatment centre if the bleeding was thought to be "unexplained", the side effects alone were also reason enough to avoid FP.

"When I was taking family planning, it was stopping my menses and it caused me daily abdominal pain. So after several struggles with it, I eventually experienced shortness of blood and for that reason, I had to remove it." (FP user, 18-25 years old).

Other women recounted stories of side effects that their friends or family members had perceived they'd suffered due to FP. While it must be noted that these are not biologically supported side effects, these do reveal real anxieties and the importance of prior narratives and experiences of women or others that influence decision making.

"I decided not take family planning because my Aunty had taken family planning when she was young, she took an implant. So, when the war came, she was not able to go to the hospital again for them to remove it, so the implant remained inside her and it later turned cancer, and stated eating into her body and she died of that." (FGD with urban women).

"Why some women do not take this prevention is that they say when they take it, it blocked their womb not to give birth and that they will never give birth again." (FGD with urban women).

This concern over side effects also came into play when women were discussing the potential impact on children, namely on babies still breastfeeding as one woman who was not on FP during Ebola (but who later took injectable FP) stated *"They said the prevention [FP method] will affect the child."* (FP non-user, 18-25 years).

Economic burdens factoring into decisions to take or not take FP

While FP is meant to be free in Sierra Leone, many women reported having to pay at the public health unit or at a private clinic. This has been documented previously, and often stems from the lack of a "whole of the health system" approach to resourcing such an initiative, where health workers salaries are not guaranteed, leaving patients to pick up the costs, and where overworked staff are thought to provide poorer care especially in rural areas (Pieterse and Lodge 2015, Witter, Wurie et al. 2016, Wurie, Samai et al. 2016). The amount women reported having to pay ranged from 5,000-10,000 Sierra Leone Leones (approximately 1-2 USD at time of interview). The financial cost of getting FP for some women did factor heavily into their decisions, as the reported cost could represent an entire day's earnings, or even more if the woman's earnings had been reduced due to Ebola's impact on the economy.

"I stopped taking injection before Ebola because I hadn't money to pay and by the time I got the money, I was already pregnant with my first child, but it was miscarried and it was during the Ebola." (FP non-user, 18-25 years old).

Though economic hardship was also in some cases a driver for women to take FP, if they perceived that times were difficult and therefore it would be better not to have another child.

"It's all about hardship, my child has to go to school and I have nothing, I have to dress him, I have to please him. If I have plenty of children and things are difficult, it will be difficult to meet their demands and it will lead them to the street to beg. That is why I gave birth to the number I can care for. (FP user, 18-25 years old).

Again, these economic burdens were increased during the Ebola period, however the quotes above represent the reality that for many women, regardless of crisis, economic reasoning is critical in their decision-making process around FP.

Discussion

Women's individual decisions and agency that enabled her to choose to take or not take FP during the Sierra Leone Ebola crisis had not been explored prior to this paper. These findings show the significance of proximal and distal reasons for choosing or choosing not to take FP, and that, while difficult to differentiate at times, looking at both types of reasons demonstrates a holistic view of how FP care seeking was disrupted or adapted to in the outbreak. Using proximal and distal framing allows for the impacts directly related to the virus (proximal) to be differentiated from the chronic and structural challenges of seeking gendered health care in a country with a stressed health system such as Sierra Leone (distal). Furthermore, the framing of distal allows us to keep sight of how while these reasons may have preceded the outbreak, the outbreak itself added additional pressures to health and social systems, making these challenges more acute. Using the lens of FP to consider how women choose to access health care in an outbreak gives us a unique perspective into how all health care interactions are impacted by a generalized outbreak.

Proximal fears including concerns around hygiene and contagiousness of staff directly impacted on women's decision making to seek services. Hospitals and health facilities are meant to be places of cleanliness, healing and safety, yet even in "normal" or non-outbreak times they can be sites of contamination and disease (Nejad, Allegranzi et al. 2011, Abdullah and Kamara 2017). However, the Ebola outbreak amplified any pre-existing concerns women may have had about catching disease from a health facility setting, possibly due to the overwhelming messaging from government, NGOs and the overall Ebola response about the importance of handwashing and "no-touch" in the prevention of Ebola.

On a physical level, women's fears and concerns about how their own bodies could be seen as sources of contamination or disease by health workers, especially in cases of "unexplained bleeding" during menstruation or due to side effects of many FP methods, were legitimate given a context with broader narratives of people being sent away to an Ebola Treatment Centre. While "unexplained bleeding" was not restricted to blood from the womb, as any kind of bleeding was potentially an Ebola sign, women and girls are unique in that they bleed regularly, and while this should be seen as "explained" physiological bleeding, menstrual blood is widely seen as a contaminant in many societies (Hoskins 2002, Tan, Haththotuwa et al. 2017). The negative connotations of menstrual and FP side effect blood may thus have been (inappropriately) aligned with blood resulting from a spontaneous miscarriage, of which Ebola infection can be an inciting factor (Black 2015). Mary Douglas' concept of "*matter out of place*", the idea that blood should be on the inside, applies here (Douglas 1966, p.44). As menstruation implies "*bleeding without injury*" this bodily function could be misinterpreted by health workers as an Ebola sign that would justify sending a woman away to an Ebola Treatment Centre, reinterpreting a normal bodily process as one that is threatening. This disruption of the body's normal processes is mirrored in the societal disruption of Ebola time, leading women to possibly consider their bodies as abnormal or contaminated, to be feared or as a source of disease and infection to their loved ones.

This fear of women infecting health workers with Ebola was mirrored with women's fears about health workers as a potential source of contamination. This fear, however, could be mitigated (though not eliminated, given how the nature of the outbreak response negatively impacted on confidence and trust in health services) through a social connection with the worker themselves, helping to increase trust in safe care. Abstractly women reported that health workers could infect them, either intentionally through injection with Ebola (as they perhaps had heard through circulating rumours) or unintentionally through unsafe care. On a more personal level, women acknowledged that when they knew the worker and/or when the worker was from their local area, they were more able to trust them and this abstracted fear was reduced. The importance of having trusted health workers delivering services during an outbreak cannot be understated, especially when there are increased fears related to unfamiliar practices like the wearing of PPE, concerns around Ebola-injections and a generalized environment of suspicion and rumour. However it must be acknowledged that this trust can be misplaced in cases where a health worker is in fact ill, is not well trained and equipped with PPE, and continues to provide care, thus infecting their patients, as was sadly seen in some cases during the outbreak (Manguvo and Mafuvadze 2015).

Building rapport and developing familiarity with health workers has been shown in other studies of the Sierra Leone Ebola outbreak to increase trust even in potentially risky situations. For example, Ronse's research identified trust in national and international trial staff and a sense of social responsibility as key in the decision of Ebola survivors to be plasma donors in the search for a treatment for the disease (Ronse, Sáez et al. 2018). Additionally, Enria et al (Enria and Lees 2018) found that participants agreed to take part in an Ebola vaccine trial when they felt connected to the staff of the trial, either personally or through close social networks.

The factors influencing decisions around whether to choose to become pregnant or avoid pregnancy during an outbreak are complex and touch on both proximal and distal reasoning. Some women had to overcome concerns of contamination, family and partner pressures, and economics. For others, the outbreak was simply not a large factor in their decision making, possibly due to the long period in which the outbreak took place, from approximately March 2014 – June 2016. For these women, life had to go on, it could not be put on hold indefinitely waiting for the virus to be overcome, a finding also described in Lipton's (Lipton 2019) chapter about pregnancy in Freetown during the outbreak. As discussed by Vigh in his 2008 paper about crisis and chronicity, for those who live in unstable contexts where crises are endemic, the external framing by crisis responders is that these huge upheavals in society will change the lives of all, yet for individuals living through the crisis, they may see it as just one more event that must be adapted to (Vigh 2008). Outbreak responders tend to see the crisis as all encompassing, not recognizing that for many people, the chronic concerns of daily life, including challenges and difficulties in accessing health care (whether economic, social or physical), have been amplified by the outbreak, and so efforts must be made to reduce additional barriers that have been created due to outbreak response policies.

Some women were able to, in a way, take advantage of the Ebola situation to assert a different form of power in the household in relation to their reproductive and sexual decision making in contrast to findings by Fofana Ibrahim (Fofana Ibrahim 2017) that women had no choice with regards to sex with their partners. In this research some respondents reported being able to tell their partners that they were not available for sex due to the no-touch policy and their concerns about partners bringing Ebola into the home. In this way they asserted their rights and authority using pragmatic means mid-outbreak. How their partners responded to this was not investigated in this research but it was the older women in the FGDs and KIIs who described such powerful interactions, implying a different family dynamic than may exist among younger women. This pragmatism also applied to women who chose to seek out FP, in spite of concerns about potential contamination, out of their desires to complete schooling or maintain some economic stability in a time of intense economic disruption. As one respondent stated in an assessment from the 2018-2020 Ebola outbreak in the DRC, "*Ebola-time is a good time to plan your family*", further evidencing that women and their partners should be offered the opportunity to prevent conception if they so desire, to assert agency over their lives during and after the crisis (McKay, Black et al. 2019, p.27).

Unfortunately, amid highly complex public health crises like Covid-19 and Ebola, FP often becomes considered a non-essential service as health workers are reassigned and service availability is restricted for safety and capacity reasons. A 2020 survey on essential services in Covid-19 found that 68% of countries reported a partial or severe disruption in FP (World Health Organization 2020). The rationale for the non-essential-ness of FP is likely due to the service being considered (by some in the humanitarian space) as part of development and long term programming, not part of humanitarian or emergency programming. There are constant tensions between when development actions (including FP) cease or are deprioritized during a humanitarian crisis, to the detriment of those who depend on such services and may even need these services more during the crisis itself given social upheavals. This mismatch in perspectives between the lived experience and needs of women in the Ebola outbreak, and the response structure's ability to identify, integrate and respond to these needs demonstrates how emergency responses, like outbreaks, struggle to address health problems that are not directly outbreak related, especially in fragile health systems.

It is not possible to separate the long-term and chronic needs that women have for quality reproductive health services (especially in a state of health system fragility) from the acute challenges that are amplified during a public health emergency, for example when health workers are reassigned away from reproductive health areas, thus reducing service availability. These issues reflect ongoing conversations, and academic critiques, of the humanitarian-development nexus, wherein the humanitarian principles of immediate and needs-based response are at odds with an approach focused on long-term, rights-based development. Expanding the "humanitarian present" (the immediacy of the response environment) to encompass preventive and recovery stages aims to bring together humanitarianism and development, aiming to reduce the disruptions of crises on populations (Lie 2020). These ideas, if they can be successfully implemented (which is an ongoing challenge) would acknowledge and react to the reality that women's decision-making is not done purely in the moment in a crisis, as the long-standing impacts of the context in which she lives will inevitably impact on her choices of how, from who and where to seek care. Real, practical actions to reduce the chasm between humanitarian and development are not always easy to identify, but FP advocacy seeking to ensure that FP services are ring-fenced in current and future outbreak responses, as has been argued in a recent paper about essential services in Covid-19 (Blanchet, Alwan et al. 2020), could be a step in the right direction.

Limitations

There are several limitations to this research. First, by recruiting women outside health clinics we may have biased the sample towards women who were more likely to be engaged with health services (including FP). Some women declined to participate in the interviews but we did not record their reasons for non-participation, so it is not possible to know how this may have impacted the sample. Secondly, the relatively small sample of participants across rural and more urban environments meant it was not possible to identify particular barriers or opportunities unique to those environments. A final limitation may be that by asking women to provide information about their experiences from several years prior, that they may have struggled to recall their decisions or challenges. Though in general it appeared that the Ebola outbreak was a major event for many of the women interviewed, and thus they had vividly recalled stories to share, even if occasionally they were not able to remember the dates of the events they described.

It is difficult to say if similar findings would be found in other areas of Sierra Leone. The extent of widespread Ebola transmission varied across the country, with some regions experiencing much less, and others much more. Women in areas with less transmission may have not experienced quite as much disruption to their health care access, though some level of disruption is to be assumed given national policies related to the Ebola case definition and PPE. Kambia district, even in urban areas, is still quite a rural environment, and thus the findings may be less generalizable to highly urban spaces, like the capital city Freetown, where the trust in health workers may be different, as the local health clinic staff may not be as well known to those frequenting it.

Conclusion

In the midst of the widespread Ebola outbreak in Sierra Leone, policies to stop transmission of the virus and fears of contamination impacted on health care seeking, including for non-Ebola care like FP. All interactions with the health care system were touched by the outbreak itself, from the process of deciding to seek care when contamination was possible (and negotiating with family to do so), to the reporting of Ebola-associated symptoms (like vaginal bleeding), to the choice of method, to the confidence to engage with a health worker. While some facets of health care interactions are more proximal than others (eg. fears of contamination), even distal interactions (like the economics of paying for FP) were amplified by the Ebola outbreak.

Women's perspectives of engagement with the health care system in this time of crisis demonstrates how they married their previous experiences with the new environment of Ebola to decide how best to manage their reproductive lives. The Ebola response's ability to engage with women's needs at this time was lacking, and generally added further barriers to care seeking, fueling the critique of health responses divorced from day to day lived reality.

Data availability statement: The data that support the findings of this study may be made available on request from the corresponding author. The data are not publicly available for research participant privacy reasons.

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Patient consent statement: All research participants signed a consent form prior to being interviewed.

Permission to reproduce material from other sources: Not applicable

6.0 Introduction & context to case study 2

Community feedback in the North-Kivu Ebola outbreak

In the North-Kivu and Ituri outbreak the Red Cross rolled out a community feedback mechanism to engage communities in the response in a particularly complicated context with a long history of conflict and distrust of authorities (Crawford, Holloway et al. 2021). The mechanism sought to improve relations between communities and the response through listening to community needs and experiences and responding through changes to Ebola response activities (Baggio, Camara et al. 2019). This case study sought to understand how this feedback system worked, and how evidence from the feedback was used to change decisions at the Ebola response policy levels to contribute to the overarching aim of understanding how response actors engaged with community knowledge and experience. This chapter (6) provides additional information on the Ebola outbreak in North-Kivu, as well as a detailed description of the Red Cross' community feedback mechanism and is supported with some primary research data to add contextual depth. The research paper presented in chapter 7 presents the final published version of the case study research.

6.1 The North-Kivu Ebola outbreak

The DRC's 10th Ebola outbreak was largely situated in North-Kivu province, and started in August 2018, only weeks after the DRC's 9th outbreak in the west of the country had been declared over. After the West African outbreak, this is the second largest known outbreak of Ebola, as the outbreak spilled over into multiple provinces, including Ituri and South-Kivu, and also into Uganda. The epidemiological record totaled 3470 cases of Ebola, and 2287 deaths (World Health Organization 2020, US Centers for Disease Control and Prevention 2022). While all Ebola outbreaks are unique, the North-Kivu outbreak took place in a conflict-affected area, where dozens of armed groups, government forces and United Nations peacekeepers continue to engage in confrontations, which dramatically increased the complexity of the Ebola response (Rohan and McKay 2020, Crawford, Holloway et al. 2021, James, Kasereka et al. 2021, Nyenyezi Bisoka, Vlassenroot et al. 2021). Key challenges that the response faced included a long history of mistrust in government and external bodies manifesting in violence against Ebola health infrastructure and staff, and the silo-isation of the vertical response to Ebola from the broader humanitarian response.

As explained by Nyenyezi Bisoka and colleagues in their brief, the populations of North-Kivu have long felt that conflict-mitigation activities in the province, whether by the DRC government, humanitarian organisations or UN peacekeepers, have been largely ineffective at preventing violence against civilians. The huge response to Ebola, that in the early days seemed to consider only Ebola-related health impacts, was entirely dissociated from the paramount concern of the local people, which was for improved security (Nyenyezi Bisoka, Vlassenroot et al. 2021). As stated by a research participant in a focus group in Goma: *"And especially because the region has been experiencing security issues for several decades. Why do we mobilize against a single illness that could kill about 3000 people over the course of a year, when someone can come and butcher 50 people in one night?"*

In the first half of the outbreak the WHO framed the response as being a disease-specific health security emergency, and thus there was limited engagement with the wider humanitarian community who had been working on public health in the region for decades. It was only later in the outbreak when a change in coordination structure brought in a UN Ebola Emergency Response Coordinator that a more integrated approach came into being. This inclusive, consultative, "big tent" type system brought in many more partners, including local NGOs, who were able to represent their local communities, thus ensuring that there was greater heed played to local needs, including for security, food assistance and other priorities (Dewulf, Ciza et al. 2020, Crawford, Holloway et al. 2021).

The lack of alignment between the needs of the people and the responses' priorities in much of the outbreak was further amplified by persistent rumours that the Ebola outbreak had been brought into North-Kivu to eliminate the local Nande population, to stop them voting in the long-delayed presidential elections[9], to test new vaccines or drugs on the local people, and/or for elites and NGOs to make as much money as possible from the donors funding the response[10] (Dewulf, Ciza et al. 2020, Freudenthal 2020, Crawford, Holloway et al. 2021, James, Kasereka et al. 2021, Nyenyezi Bisoka, Vlassenroot et al. 2021). This mistrust and disaffection was to spill over into violence against the response, with the February 2019 attacks on the Médecins Sans Frontières-run Ebola treatment centres in Butembo and Katwa being the most well publicized (MSF 2019). It was in the efforts against this misinformation and alienation that the Red Cross community feedback intervention was created and implemented.

6.2 The Red Cross' community feedback mechanism

The Red Cross are a worldwide humanitarian organisation, and in the countries in which they operate they are generally one of the first responding agencies to outbreaks. The North-Kivu Ebola outbreak was no exception, with the DRC Red Cross specializing in community engagement and safe and dignified burials, in coordination with the Ministry of Health, other NGOs and UN agencies. The DRC Red Cross' community engagement response relied on the efforts of more than 800 volunteers, who worked across all areas of the outbreak conducting house to house visits and community meetings with at-risk and outbreak-affected communities to ask questions and provide information about Ebola. This face to face dialogic approach was not new in the North-Kivu response, but it was through this method that the community feedback system came to be put in place (Baggio 2020).

The community feedback system relied on the volunteers collecting unstructured feedback from their visits, including rumours, concerns, questions, complaints and suggestions. This feedback was then translated from the local language and transcribed into a living Excel document, and then coded according to defined themes (using an iteratively developed

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[9] The populations of Beni and Butembo were disenfranchised in the 2018 elections, with the risk of Ebola transmission given as the main reason for postponing the vote in those areas.

[10] A legitimate concern, as journalists and internal UN reports found significant levels of corruption and sexual abuse across the Ebola response by all types of response staff including government officials, NGO and UN agency workers.

codebook) (Baggio 2020, Dewulf, Ciza et al. 2020, Earle-Richardson, Erlach et al. 2021). Initially the analysis was done at the international level, but as one focus group participant explained, over time the analysis came to be done at the local level:

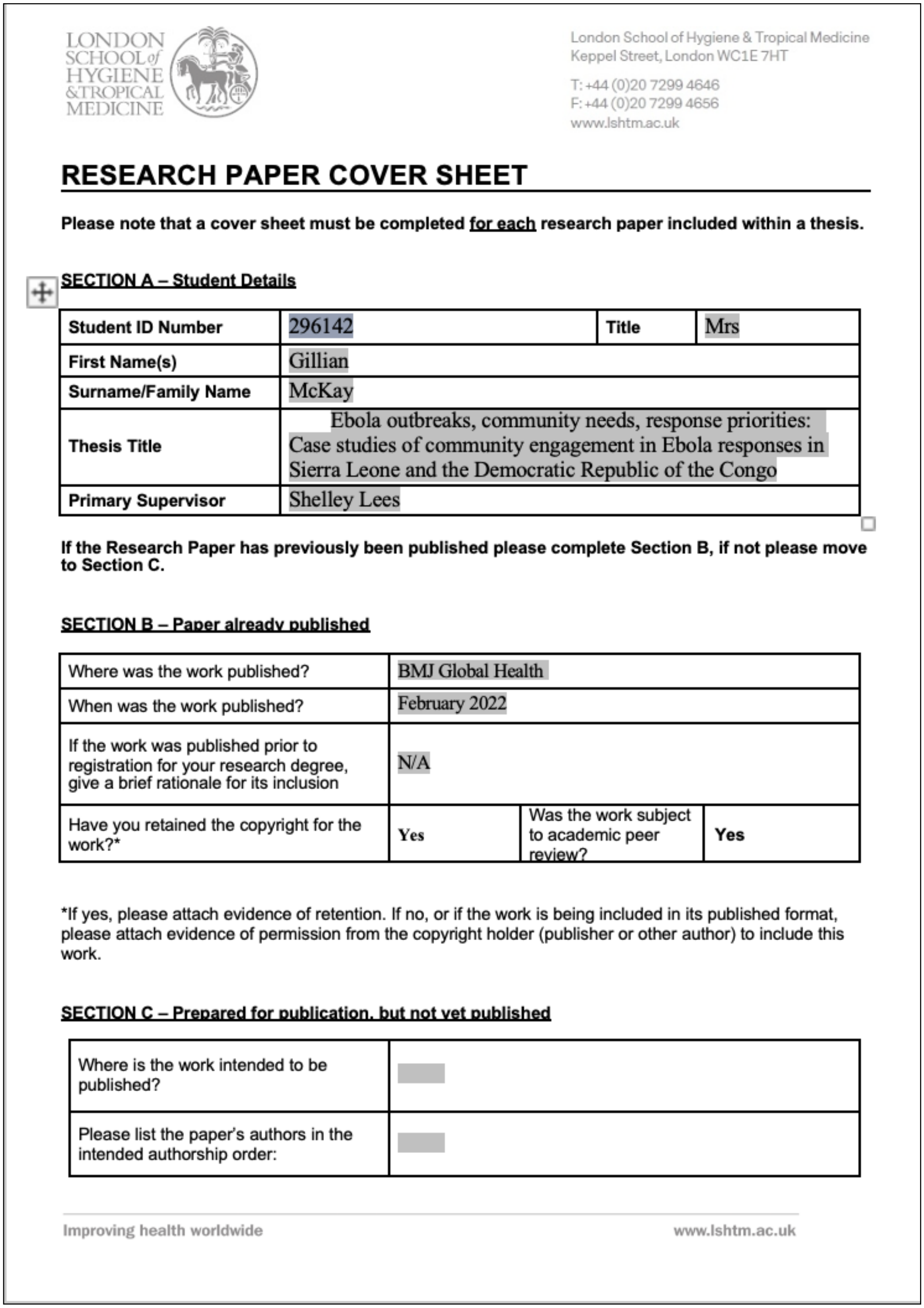
“The team in Beni does the coding, and that’s reported to Nairobi, I think. And then to Atlanta. But, for quite some time now, at the Communications sub-committees at every base, I think it would be better if we could not have to wait for the analyses to arrive about a week later, in order for us, at the base level, to be able to analyse this feedback in order to redirect activities on the ground. So, in Goma, for example, we already analyse the information internally first.”

“Deep-dives” into particular areas of interest (eg. vaccination) were also conducted, with briefs being generated analyzing these findings and triangulating them against other sources of data in the response (Baggio 2020, Dewulf, Ciza et al. 2020, Earle-Richardson, Erlach et al. 2021).

The local DRC Red Cross system was supported by the International Federation of the Red Cross (IFRC), and by the US Centres for Disease Control and Prevention (CDC). The IFRC (with CDC support) has since taken the system and further developed it, and adapted it for a respiratory illness, and it was rolled out in the 2020 Covid-19 pandemic by national Red Cross societies in 40 countries in Africa (Erlach, Nichol et al. 2021).

Community feedback is an essential component of community engagement, but collecting the data is insufficient, it must also be analysed and responded to. The research paper to follow contributes to understanding how responses use community knowledge and experience by studying the Red Cross’ mechanism, but also by using the system as a lens through which to understand how community derived evidence is taken up by response structures.

7.0 Research paper 2



LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

London School of Hygiene & Tropical Medicine
Keppel Street, London WC1E 7HT

T: +44 (0)20 7299 4646
F: +44 (0)20 7299 4656
www.lshtm.ac.uk

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Student ID Number	296142	**Title**	Mrs
First Name(s)	Gillian		
Surname/Family Name	McKay		
Thesis Title	Ebola outbreaks, community needs, response priorities: Case studies of community engagement in Ebola responses in Sierra Leone and the Democratic Republic of the Congo		
Primary Supervisor	Shelley Lees		

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

SECTION B – Paper already published

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When was the work published?	February 2022		
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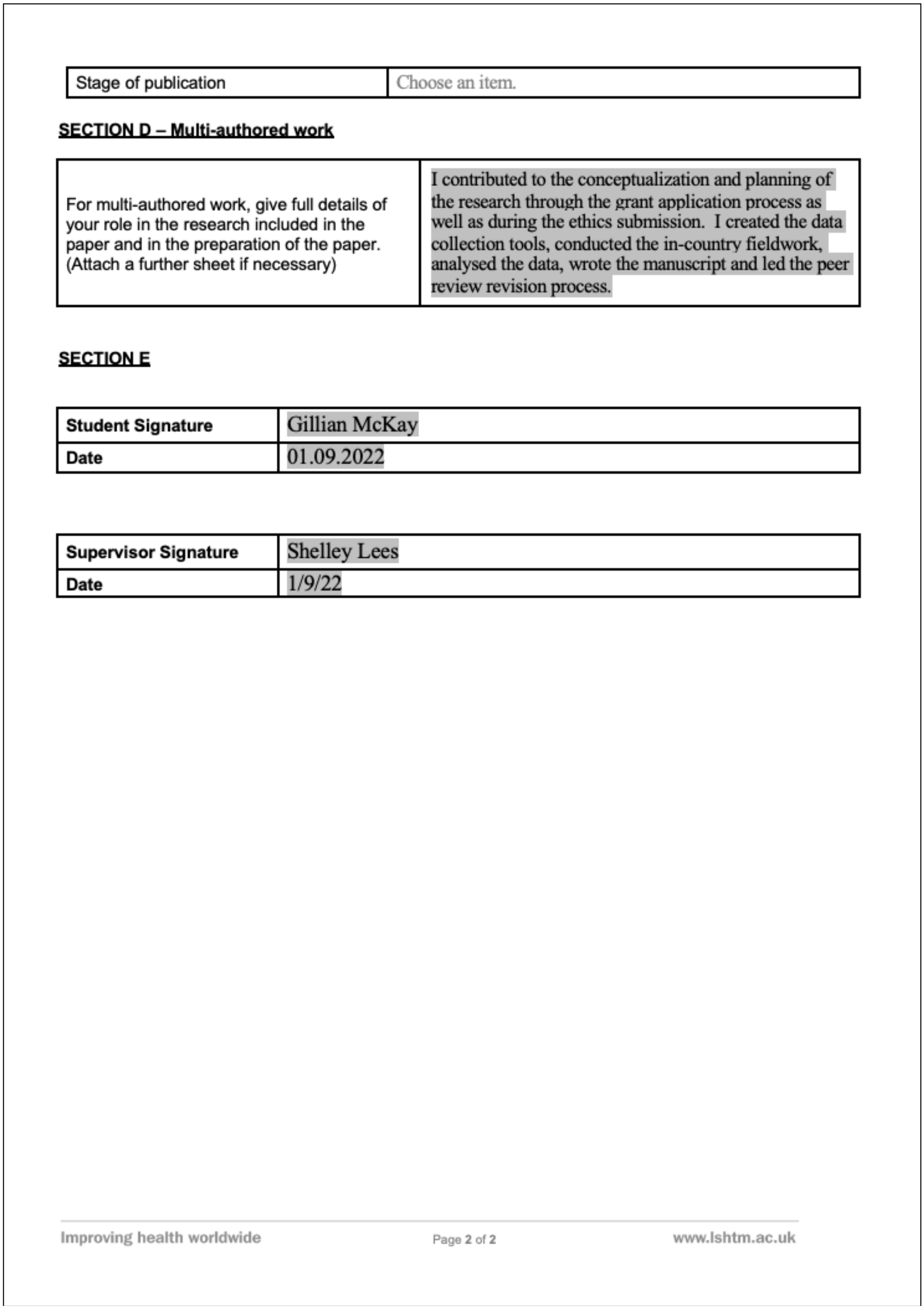

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For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	I contributed to the conceptualization and planning of the research through the grant application process as well as during the ethics submission. I created the data collection tools, conducted the in-country fieldwork, analysed the data, wrote the manuscript and led the peer review revision process.

SECTION E

Student Signature	Gillian McKay
Date	01.09.2022

Supervisor Signature	Shelley Lees
Date	1/9/22

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“The Response is Like a Big Ship”: Community Feedback as a Case Study of Evidence Uptake and Use in the 2018-2020 Democratic Republic of the Congo Ebola Epidemic

Authors

Gillian McKay[1], Ombretta Baggio[2], Cheick Abdoulaye Camara[3], Eva Erlach[2], Lucia Robles[2], Francesco Checchi[4], Hana Rohan[5]

Author Affiliations

1. Department of Global Health & Development, London School of Hygiene and Tropical Medicine, UK
2. International Federation of the Red Cross, Switzerland
3. International Federation of the Red Cross, Guinea
4. Department of Infectious Disease Epidemiology, London School of Hygiene and Tropical Medicine, UK
5. UK Public Health Rapid Support Team, London School of Hygiene & Tropical Medicine, London, UK

Address for Correspondence

Gillian McKay, Department of Global Health & Development, London School of Hygiene and Tropical Medicine, 15-17 Tavistock Place, London, UK. +44 75 3156 3763
gillian.mckay@lshtm.ac.uk

ABSTRACT

Introduction: The 2018-2020 Ebola outbreak in the Democratic Republic of the Congo took place in the highly complex protracted crisis regions of North-Kivu and Ituri. The Red Cross developed a community feedback data collection process through the work of hundreds of Red Cross personnel, who gathered unprompted feedback in order to inform the response coordination mechanism and decision-making.

Aim: To understand how a new community feedback system was used to make operational and strategic decisions by Ebola response leadership.

Methods: Qualitative data collection in November 2019 in Goma and Beni (DRC), including document review, observation of meetings and community feedback activities, key informant interviews and focus group discussions.

Findings: The credibility and use of different evidence types was affected by the experiential and academic backgrounds of the consumers of that evidence. Ebola response decision makers were often medics or epidemiologists who tended to view quantitative evidence as having more rigour than qualitative evidence. The process of taking in and using evidence in the Ebola response was affected by decision-makers' bandwidth to parse large volumes of data coming from a range of different sources. The operationalization of those data into decisions were hampered by the size of the response and an associated reduction in agility to new evidence.

Conclusion: Community feedback data collection has both instrumental and intrinsic value for outbreak response and should be normalized as a critical data stream however a failure to act on those data can further frustrate communities.

KEYWORDS

Decision-making
Policy Making
Outbreaks
Viral Hemorrhagic Fever
Accountability
Evidence Based Policy

Sub-Saharan Africa

North-Kivu

Ituri

SUMMARY BOX

What is already known about this subject?	Decision makers in outbreaks are besieged by data from many sources and find it challenging to integrate evidence given many competing priorities.
What are the new findings?	The Red Cross' community feedback system provides a lens by which to look into how new forms of evidence (particularly qualitative evidence) was taken up and integrated into the North-Kivu Ebola response. Decision makers largely had medical or epidemiological backgrounds, and tended to prefer quantitative evidence types, therefore qualitative evidence had to be presented in a "quantified" way to be taken in by this audience. Evidence-based policy and practice change in the Ebola response was hampered by the geographic scale and large numbers of responding actors resulting in an insufficiently nimble response, frustrating communities who were providing feedback.
What are the recommendations for policy and practice?	Community feedback systems like that of the Red Cross' are an important mechanism to gather and present community views to decision making bodies in the midst of a public health crisis, and should be rolled out for future outbreaks.

INTRODUCTION

The tenth known Ebola outbreak in the Democratic Republic of the Congo (DRC) was announced on August 1st 2018, and declared over nearly two years later on June 25, 2020 with a total of 3470 cases and 2287 deaths (World Health Organization 2020). The outbreak took place in a highly complex environment, including active conflict, displaced populations, inaccessible terrain and porous borders. It was characterized by unprecedented violence against staff and assets involved in the Ebola response and consequently a marked securitization of response operations (Moran 2018, Rohan and McKay 2020).

The way that decisions are made in the midst of infectious disease outbreaks has been studied in both high- and low-income settings (Rull, Kickbusch et al. 2015, Kapiriri and Be LaRose 2018, Salajan, Tsolova et al. 2020). A recent scoping review from a variety of infectious disease outbreaks in high, middle and low income countries, including from the West African Ebola outbreak (Salajan, Tsolova et al. 2020) found that decision-makers are challenged by multiple competing priorities, struggle with uncertainties and different interpretations of evidence, and often prioritize quantitative (epidemiological and mathematical modelling) evidence types to make their decisions. To challenge this epistemic hierarchy, in this study, the authors used Rycroft-Malone et al's 2004 definition of evidence-based practice in health care, which "*does not presuppose the value of a particular evidence source or study design over another, but instead highlights the importance of ensuring that the evidence used to inform practice (and policy) has been subject to scrutiny*." (Rycroft-Malone, Seers et al. 2004).

One important domain of evidence for responding appropriately to epidemics, involves the collection and use of community feedback (CF) to identify community concerns and incorporate these into decision-making. While the goal is to improve interventions and help ensure accountability to local populations, these aims are not always achieved (Madianou, Ong et al. 2016). Traditionally, feedback mechanisms have included feedback boxes, help desks and community meetings (Bonino, Jean et al. 2014). In one example of its importance to humanitarian effort, CF makes up two (commitments four and five) of the nine commitments of the Core Humanitarian Standard, which humanitarian response agencies can commit to in order to improve accountability to affected populations (CHS Alliance, Groupe URD et al. 2014).

In 2018, as part of the DRC Ebola response, the DRC Red Cross Society and International Federation of the Red Cross and Red Crescent Societies (IFRC), in collaboration with the United States Centers for Disease Control and Prevention (CDC), set up a programme to routinely and systematically gather CF through its network of Red Cross community volunteers (Baggio, Camara et al. 2019). This feedback was intended to be used: 1) to help the Red Cross better understand community concerns to guide their internal weekly planning, and 2) by the wider Ebola response coordination and decision-making bodies to ensure that community perspectives, perceptions and disease understandings were at the centre of epidemic response strategies, a major recommendation arising from lessons learned during the West African Ebola epidemic (DuBois, Wake et al. 2015, Gillespie, Obregon et al. 2016). Additional detail about the system itself is described elsewhere (Baggio 2020, Dewulf, Ciza et al. 2020, Earle-Richardson, Erlach et al. 2021).

The structure of the DRC Ebola response changed over time, but remained organized around technical “commissions” or pillars (see Figure 1), based on the WHO’s Incident Management System (World Health Organization 2017). These pillars were largely the same at all levels of the DRC Ebola response. For a comprehensive review of coordination of the Ebola response over time, see the Humanitarian Policy group’s report on the 10th DRC outbreak (Crawford, Holloway et al. 2021).

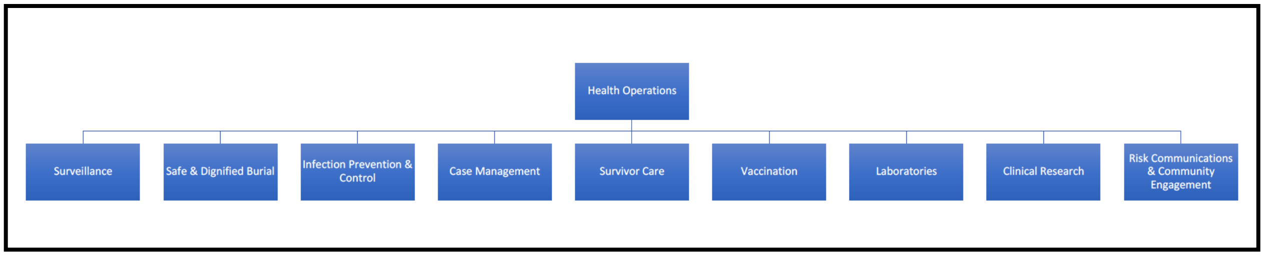

Figure 1: Ebola response structure (simplified)

Decision-making in the Ebola response was somewhat decentralized, with coordination hubs at multiple geographic levels and operational coordination at aggregated health zone levels and at sub-coordination levels (see Figure 2 below). At all levels, decision-making was led by Ministry of Health (MOH) staff, with technical support and advice from UN Agencies, the IFRC, DRC Red Cross, donors and NGO partners. Decision-makers were faced with an often-overwhelming volume of data to sift through and prioritize to make strategic and operational plans. At the strategic level (in Goma), decision-makers also had to balance the immediate priorities of outbreak control with other more distal challenges, including security and access, the economic fallout of disease spread, political pressures to bring the outbreak under control and the wider humanitarian needs of the local population.

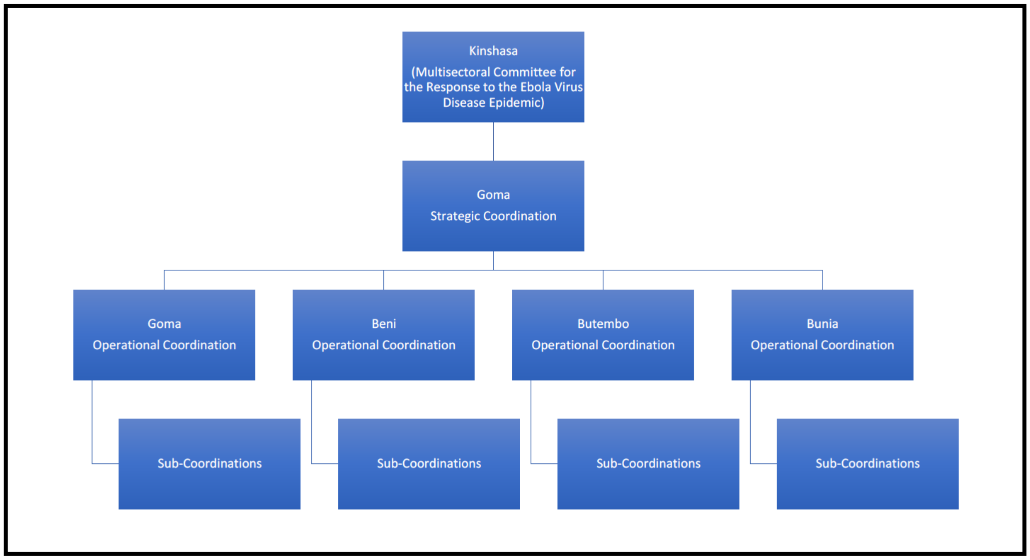

Figure 2: Ebola response coordination levels (simplified)

In this paper, we present a summary of the way that CF evidence was taken up by the Ebola response, grounded in data from interviews conducted with a cross-section of Ebola response staff and volunteers. These results highlight the highly complex nature of this particular outbreak response context. We do not attempt to provide a comprehensive account of evidence use in outbreaks, as that is beyond the scope of this paper.

INTERVENTION & METHODS

Red Cross Community Feedback System

The Red Cross CF data collection and analysis process started with having Red Cross volunteers note down unstructured feedback from community members in the course of their daily work engaging with communities[11]. While the term "community" is a contested term, in this research study we interpreted community in the same way as the Red Cross CF system to ensure consistency of interpretation across both intervention and evaluation (Council of Delegates of the International Red Cross and Red Crescent Movement 2019). This feedback was classified by the field volunteers on a collection form: 1) Questions; 2) Statement (rumour, belief, observation); 3) Suggestion/Request; 4) Sensitive or Violence related; 5) Appreciation; 6) Other (refused dialogue). The feedback was then passed to local field teams so that the classification could be validated for subsequent data entry. Following this, feedback was then coded thematically with more granularity by IFRC staff and Red Cross volunteers, and then quality checked by US CDC staff. Any discrepancies or coding scheme adjustments were reviewed in weekly teleconference calls between the partners. In the early days of the intervention the CDC provided substantial support on coding, but this skill was then transferred to the local level once the project was more established; CDC then took on more of a quality assurance role.

The granular themes applied by these teams were developed using an iterative approach over many months of data collection and analysis. The analytical process was detailed and was enhanced through the involvement of multiple teams ostensibly acting as multiple coders validating each other's work. This work of data collection, coding and thematic analysis allowed for the creation of weekly briefs by geographical zone, deep-dive briefs, trend analyses and specialized presentations for field-level and strategic decision-making. A dashboard of the CF (coded) was also made available to all response partners (Earle-Richardson, Erlach et al. 2021).

At the time of data collection, CF was collected and analysed under the Risk Communications and Community Engagement (RCCE) pillar, one of several technical response pillars (Figure 1). As part of this Red Cross initiative, CF meetings were established where organisations contributing CF could present their latest community collected information for discussion and analysis (see Figure 3), with escalation to decision-makers as needed.

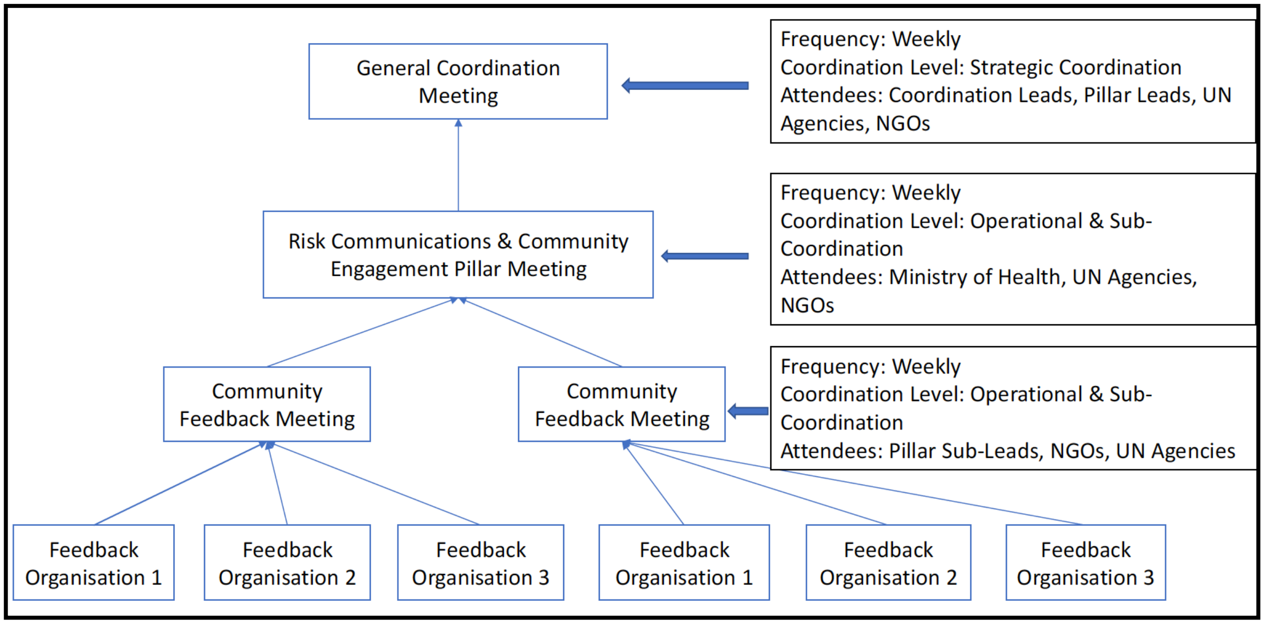

Figure 3: community feedback information flows (simplified)

The Red Cross community feedback system is, to our knowledge, unprecedented in scope and breadth, generating (between August 2018 and June 2020) approximately 300,000 individual verbatim records of feedback received by over 800 Red Cross volunteers during their routine fieldwork in 29 health zones. In a separate paper, we will analyse patterns in the Red Cross CF across time and by stage of the epidemic, and evaluate its potential accuracy for providing early warning of attacks against Ebola responders, a common feature of the Eastern DRC epidemic. Here, we examine qualitatively the utility of the Red Cross CF system for decision-making, and, more broadly, how CF evidence was used during the response to inform strategy.

The study encompasses the epidemic period up to October 2019. Data collection took place in two locations: 1) Goma, the capital of North-Kivu with a population of approximately 630,000, is a large city on Lake Kivu with an international airport and easy access via land border to Rwanda. Goma was not heavily affected by local Ebola cases but was established as the coordination hub for the response; and 2) Beni: a city of approximately 230,000 people, the main city of the “Grand-Nord” region of North-Kivu, an early epicenter of the Ebola outbreak and a frequent site of militia attacks on Government, UN forces and civilian populations.

Study methods

This study used qualitative data collection methods, including document review, CF collection observation, meeting observation, key informant interviews (KIIs) and focus group discussions (FGDs). Data collection for this study was conducted in November 2019, with 17 KIIs and 1 FGD conducted in Goma, 13 KIIs and 1 FGD in Beni in the DRC, and one additional interview conducted remotely from London, UK. The lead researcher (GM) is a nurse and was herself previously deployed to the DRC for the Ebola response, though working for different response pillars and with no interaction with the Red Cross CF system.

Documents reviewed included policies and strategies relevant to CF and Safe and Dignified Burials (SDB), along with the multi-sectoral strategic Ebola response plans that encompass all components of the Ebola response (see list of coordination meetings and key documents in Appendix A). Observations of 8 meetings took place, including general coordination, CF and community engagement, as well as internal Red Cross meetings. Meetings were not recorded, but detailed written notes about meeting processes and engagement with CF were taken by the researcher.

A total of thirty KIIs were conducted with staff from the national Red Cross, the IFRC, the MOH, the Ebola response coordination, NGOs, UN Agencies and funding bodies (see Appendix B). The interviews utilized a semi-structured interview guide that was iterated over time as new findings and themes emerged (see appendix C for topic guides). Three FGDs were held with Red Cross volunteers, one with community engagement personnel and two with SDB personnel (see appendix D for topic guides). All interviews and FGDs were recorded using an encrypted audio recorder, and were then translated (where French was the language of the interview) and transcribed by a professional agency. Observation of the Red Cross CF system took place through a field visit with CF teams collecting data, and during CF analysis meetings and coordination meetings where the feedback was discussed.

All data were analysed in Nvivo using a thematic analysis framework approach (Gale, Heath et al. 2013), where codes derived from the interview topic guide were assigned to lines of text in a small sample of interviews. Following review of the initial coding by two experienced social scientists (GM & HR), a working analytical framework made up of codes and categories was applied to the remaining transcripts and field notes, while allowing for novel concepts in later transcripts to be coded and categorized. After completion of all coding, the two main authors identified the key categories and further developed them to form the basis of the results section of this paper.

Ethical approval was received from the ethics committees of the London School of Hygiene and Tropical Medicine and the Faculty of Medicine, University of Kinshasa, DRC. All participants were provided with a study information sheet, given time to review it and ask questions, before being asked to sign a consent form.

It was not possible or appropriate to involve patients or the public in the design, conduct or reporting of our research. We do intend to involve the public (defined in our case as outbreak and humanitarian actors in the DRC) in the dissemination phase, but this has been put on hold due to the Covid-19 pandemic.

RESULTS

We describe, in order, the process by which CF was produced, the extent to which it was valued by the Ebola response, its uptake for decision-making and its operationalisation as concrete changes to interventions or strategy. These over-arching themes were prioritized as they offer opportunities to highlight barriers and facilitators to the CF process and use, so that recommendations could be generated for its use in future outbreaks.

Production of Evidence

Observations showed how the raw feedback was analysed and developed into recommendations for the various consumers of the data, including Ebola response leadership (MOH, WHO and UNICEF), response partners (including DRC Red Cross, NGOs and additional UN agencies) at multiple levels of the response.

Production of Community Feedback

Observations of the CF data collection and analysis process found the fieldwork component to be adhering well to the written operating protocols, which had been changed and adapted over time as the CF mechanism and the Ebola response evolved over the course of the 17 months of the outbreak. Some key changes that had been made to the system included fieldworkers taking on analysis of feedback at their administrative level (to increase the system's timeliness and sustainability for localized action, and to ensure geographical nuances weren't lost), the identification of new thematic codes in response to changes in key operational priorities (i.e. perceptions of Ebola survivors) and the institutionalization of CF meetings with members of the various pillars of the Ebola response to jointly develop recommendations that were then "owned" by the pillar leads for implementation.

The IFRC and DRC Red Cross were not the only group engaged in CF data collection. Other NGOs had different but complementary methodologies, and all formally collected CF was fed into the RCCE pillar. However, proposed approaches to aggregate CF collected via different organisations and methodologies were not welcomed by all actors. Reasons for this were that different approaches to data collection were not felt to be equivalent in terms of the rigour of field worker training and feedback analysis, nor in terms of the geographic coverage or quantity of feedback collected. Organisations were often protective of their own CF approach, and wanted to ensure that "their" feedback was presented as coming from their organisation, perhaps to demonstrate their value to the Ebola response.

Branding of Evidence

The Red Cross, while respected for their role in SDB and in community engagement, were initially not perceived to be a data generating organisation by the RCCE pillar of the Ebola response, and as a result, some of the evidence that they were trying to bring to decision-makers was not initially trusted or welcomed by the MOH-led Ebola response coordination.

"…people don't see IFRC as a data organisation, they're a service organisation, they're a volunteer organisation…So I think the fact that it's branded as IFRC data actually affected it and I think once people became familiar that CDC was doing the analysis and that we were part of the analytic process…and really meeting with the [RCCE pillar] and finally getting [CF] on the agenda of a [RCCE pillar meeting]." (foreign advisor, Goma).

The reputation of the CDC as being analytically skilled supported the Red Cross and the IFRC to further develop their CF system and imbued Red Cross with the data legitimacy they needed to highlight CF data as critical evidence for decision-making in the Ebola response.

Another challenge with how CF was 'branded' was that it was often thought to only have relevance for the RCCE pillar, with the consequence that other pillars (including Infection Prevention and Control, Vaccination, and Case Management) didn't always see the applicability of the feedback to their own operations. As stated by one Goma-based individual closely involved in the CF process:

"…I think one of the biggest challenges is just that this feedback mechanism is then associated with the [RCCE] pillar, this is like touchy-feely stuff that people don't care [about].*"* (community engagement engagement specialist, Goma)

Some respondents also reported that the CF data were sometimes perceived negatively by specific Ebola response pillars:

"they see it as an accusation… Because if we really wanted to manage [CF], or implement recommendations deriving from community feedback, everyone would have to know and accept that there's a problem, and this is the solution." (RCCE specialist, Beni)

In these ways, both the branding or positionality of the organization collecting data, and of the value of the data itself, affected perceptions of the Red Cross CF system, and therefore its ability to influence decision-making.

Value of Evidence

How different types of evidence were perceived in the Ebola response was found to be dependent on the experiential and academic backgrounds of the consumers of that evidence.

Hierarchies and Cultures of Evidence

KIIs identified that different types of evidence were viewed as more or less valuable, usable and valid than others in the decision-making for the Ebola response. Often this was perceived to be linked to Ebola response leadership who were predominantly clinicians or epidemiologists for whom quantitative data were seen to be at the top of a hierarchy of evidence types.

"… whether or not we want it or say it, epidemiological data are used much more than social sciences or qualitative data. …we chase numbers when we say "There's one confirmed case", or when we say "There are ten confirmed cases." … Certainly, qualitative data are used, but not as much as the quantitative data…when there is a confirmed case, or this and that happens, that sets a lot of things in motion. But you can be sure that qualitative data are also used every day through the community feedback escalated by the [RCCE pillar]." (area coordinator, Beni).

This quote illustrates the hierarchical approach to evidence types within the response, as well as the perception that qualitative data was not seen to reliably portray the magnitude of the problem or issue that it described. When feedback was presented in a quantitative format (e.g. by tabulating the frequency of certain feedback themes), it was better received by the Ebola response coordination leads, as opposed to when quotes from feedback were presented:

"…because they're scientists. They need advanced analyses with probable results. When you present [CF] data for the sake of it... But when you present data that seems to imply an advanced analysis, the work is taken into account. If you say, "The community says this or that" and you stop at that, it's a bit complicated. But we present recommendations backed by what the community has said, and we consider the rate of repetitions, so it seems more scientific to the people involved in this response. It gets more attention." (RCCE coordinator, Beni).

Respondents felt that a purely qualitative approach to presentation of feedback findings might be perceived to contain bias and was a confusing way of presenting findings for an audience that had largely been trained in quantitative disciplines. Taking a quantitative lens to qualitative data is not a gold standard approach to the presentation of this type of evidence, and so it took several iterations of presentation formats before a compromise between qualitative and quantitative presentation was reached.

The method by which CF was collected also led some quantitatively trained response staff to dispute how robust the data were; the feedback wasn't representative of the community, given that it had not been collected using a random sample.

"*I think that community feedback…you can't go and see the same person every day for feedback. They're going to repeat the same thing. Or you can't go and see just one category of people…In my opinion, community feedback needs to establish a randomised selection system for people that give their opinion. For example, we know what Beni's population is, we know how many homes there are here, and we know how to elaborate a stratified, random sample...*

in a sequential manner... so that community feedback represents community opinion. And think about how different groups can be included in that." (area coordinator, Beni).

This epistemological difference between the perceived value of qualitative and quantitative data was felt by some research participants to be emblematic of the power differentials between the Ebola response leadership (who were nearly always clinical and/or epidemiologists) and those with "softer" social science skills. Some respondents felt that due to outbreaks nearly always being led by clinicians or epidemiologists, the Ebola response inherently became too narrowly focused on biomedical interventions, even in the midst of a highly complex humanitarian context like North-Kivu and Ituri. As one communications expert stated:

"The response, despite it being a health response, I personally think that …it wouldn't be adequate to let the WHO direct a health response. I'd rather we chose someone from the social sciences, someone with another profile, to direct a response like this one, a response to an epidemic. Because when it's directed by someone from social sciences, he could tell the epidemiologist that he's not doing his job well. But when the epidemiologist runs things, he thinks that he's the only one who understands reality." (RCCE specialist, Beni).

CF data had to be presented in atypical formats and were downgraded within evidence hierarchies because of its non-statistical approach to sampling. The epistemological perspective of the majority of clinical or epidemiological Ebola response decision-makers was seen by respondents to accentuate this issue and further limit the value and uptake of CF data.

Decision-makers and Evidence Uptake

The process of taking in and using evidence in the Ebola response was affected by decision-makers' time and bandwidth to parse the large volumes of data coming from a range of different sources. Furthermore, the size and the organisational structure of the response affected its momentum, insofar as changes to policy and strategy required buy-in from a large number of individuals and agencies and extensive retraining of staff on new policies and SOPs, negatively impacting the speed of changes.

Bandwidth of Decision-makers to Absorb Evidence

Amid an Ebola response that spread across multiple districts, with more than ten technical pillars and dozens of responding agencies, Ebola response decision-makers were felt to be incredibly busy and there was compassion for their workloads and the challenges they faced in trying to consider data and evidence from a wide variety of sources, including CF. Engaging with routinized systems of CF was quite new for many in the response:

"..to be fair to us and all of us who are working this response and to the people who are working in the response, they are not used to having this data in a response, they are not used to having to process CF…so this is a new data stream for epidemiologists and everybody in the response but they're like, what the heck are we supposed to do with this! …so we've had to learn how to make [CF data] meaningful and then trying to balance, how do you make recommendations from the data..." (technical advisor, Goma).

In a landscape of highly competing agendas and with an overwhelming number of data points, sources and recommendations, greater "community resistance" to outbreak response interventions was found to guarantee the attention of decision-makers.

"*If the community complains, for example…you have to wait for the number of complaints to be flagrant enough to get the attention of the decision-makers. That's an important element, because the more resistance there is, the more the decision-makers pay attention. And you have to wait for the resistance to multiply in order to consider the feedback."* (RCCE coordinator, Beni).

In a context with ongoing conflict, where Ebola responders were not infrequent targets of violence, respondents felt that decision-makers were more likely to engage with feedback data when it was negative, but (as illustrated by the above quote) only when a certain threshold of negative feedback had been reached.

Evidentiary Inertia

The overall culture of DRC's Ebola response operated under the assumption that decision-making and the response structure itself were largely driven by evidence. However, the ability of the Ebola response to use evidence with sufficient agility, or indeed at all, was contested by some interviewees, particularly those who had been working in the response for many months. The repetition of old problems in new areas was a source of real frustration to many:

"I don't agree that it's an evidence-based response because often at times I mean we're finding … other health zones… that become hot spots are going through the exact same challenges previous ones have and are not applying lessons learned, which is …so important." (technical advisor, Goma).

This was expanded upon by another individual, who felt that the perception that the response was evidence-based and community-led was tokenistic, since they felt that the CF was insufficiently acknowledged and acted upon:

"… it's been ridiculous that in all documents it says that communities are at the forefront of the response and putting people centre, and it's just not happening at all… there is more demand now so I think that I see a bit of a shift…and I think this is why this went so slowly, because people would not think that [feedback] is relevant…but even though we are working in such a complex situation where it's all about security and access, which is often like an argument for people to look at the [CF] data." (technical advisor, Goma)

This perceived sluggishness in accepting the utility and value of the CF data contributed to an overall concern that the Ebola response was not evidence-based in its approach, even when that evidence could have security implications.

Once a particular strategy had been put in place, even if found to be ineffective or if new evidence did not support its continued implementation, it was felt to be very hard to change course:

"In my opinion, we have community feedback that indicates we should spend some time on community dialogue before deploying response measures; otherwise, they won't be as effective as we want them to be. I think that's something that's changing very slowly, but it takes time, because the response is like a big ship, and when you want to turn the rudder, by the time you do, and the response shifts, a long time has passed. We have to find a more agile way, a faster one, so that our strategic changes can become operational ones." (programme coordinator, Beni).

While the DRC's Ebola response was positioned externally as evidence-based in its approach, many respondents felt that this wasn't the case: lessons were not learnt and applied in new outbreak areas, and that this was particularly the case for CF data. While lip service was paid to the importance of CF and dialogue, some respondents saw this as tokenistic, particularly when it was ignored even in the face of insights into potential security risks for health and humanitarian responders.

Integrating Evidence at the Operational Level

Strategic decision-making was operationalized into action by a variety of different coordination hubs. These actions could be hampered by a number of factors, from the large number of actors involved in the response, lack of technical know-how, or insufficient coordination. However, respondents did identify good examples of CF evidence use which could be built upon to develop recommendations for outbreaks in future.

Challenges to Implementing Change

The slow speed of change of the Ebola response was a frequent concern for many respondents, though the reasons for the delays in implementation of evidence-based change were often beyond the control of any one actor. These were sometimes reported to be related to a lack of resources, as exemplified by challenges associated with developing and reviewing communications materials:

"For example, imagine: there's no leaflet on Ebola [in the response]… Because the Communications pillar and the Coordination don't have the resources…Because if we had resources, we'd be able to hire experts to provide some interesting support…Because expertise, in Communications is... I wouldn't say it doesn't exist, but it's rare." (communications expert, Beni)

At other times delays were attributed to the lengthy process of validation to ensure the right actors were involved in making a change. One respondent discussed the challenges with long timelines in generating evidence for action in the context of the RCCE pillar, and the ways in which the bureaucracy inherent to Ebola response decision-making sometimes made it difficult to make operational changes at any appropriate speed:

"[The RCCE pillar] validate the data [and recommendation]… So we adopted their recommendation and worked on revising our messages...It took a long time because there was data collection, which was then shared on another level, and that's when we decided to organize a workshop for revising the messages, because we couldn't do that ourselves...The government has to approve it. So we set up a workshop, and after it was over, we made drafts, and after those drafts were done, the corrections were done, we'd send them to the Coordination for approval. After that, we started the production process, and its development on the ground. It took us from May to August to finish that process." (RCCE specialist, Beni).

New approaches to operations were often also not well communicated to response field staff, which could act as a direct barrier to the implementation of change:

"There are decisions made by the [government body]. They issue memos. But I've never seen the coordinators go on the ground to instruct the departments on the memos. Ever. We see the memos in our inbox. Those of us on the ground have to take those memos and meet with the Communications Sub-pillar, and ask them, "Have you seen this?" They never have. So we're the ones who have to say, "Listen, this is a circular from the [government body]. And now, we have to adapt to it." (RCCE specialist, Beni).

This issue of communication between strategic and field levels also reflects poor coordination between those levels, requiring the intervention of additional actors, further adding to the challenges of timely implementation.

Strategies for successful uptake of community feedback data

Respondents discussed ways in which CF data were more likely to result in direct operational changes, and these varied in approach from ad hoc to more strategic engagement with different pillars.

Creating demand for CF data was found to be helpful in gathering the support needed to create recommendations that could be implemented at the field level. The CF was of particular interest to the Security pillar, which could then use this information to adjust on-the-ground strategies for response staff deployment:

"Regarding the threats, we share this information with the Security Committee. We go to that Committee to tell them, "Look, this is what we received." And we pay a lot of attention to incidents, because the threats become almost constant. The interesting thing is that this system allows us to see the intensity of the threats. For example, if we get more threats this week, we get concerned and look into what's happening, and raise an alert…. We can't say it's 100% reliable... But we think that sharing that information and taking action is always better than doing nothing and facing problems later." (Community engagement specialist, Goma).

Actions developed as a result of CF could then be developed in concert with the other pillars of the response. Where possible, the co-creation of recommendations between CF actors and pillar leadership was felt to be helpful in getting findings taken up and used, as opposed to simply presenting findings and asking the pillars to develop their own recommendations, as this MoH respondent explained:

"We set up these community feedback groups and asked the networks to have everyone, especially the [pillar] president, participate in this group. Because once they participated, together we could view the feedback from the community. We could analyse it together and, on the basis of this analysis, everyone could see there is this or that problem, question, concern regarding specific pillars. …And that would get them to take action, to get involved and think of options, make decisions and ask all the actors on the ground to figure out how to respect the concerns and desires of the population. And that's how, over the course of the meeting, we could formulate recommendations. For example, regarding the…collection of elements that need to be burnt in [infection prevention and control activities]… We make recommendations to the IPC [pillar]: 'This method is not well-received by the community… And instead of getting the community involved, it makes people withdraw. So you have to change things in order to get the population involved in our measures'" (RCCE specialist, Goma).

The success of some IPC recommendation changes was felt by respondents to be linked to the engagement of the pillar lead in the process of generation of recommendations, demonstrating the importance of modelling good leadership. Good leadership was also seen in the relative speed of changes in response to CF in the SDB pillar. Respondents attributed this success to the fact that that pillar was co-led by the Red Cross, so they were able to push for change based on the feedback they were collecting more effectively than in other pillars where their influence was more distal. There were several examples of the rapid integration of CF into SDB protocols, such as this one, described by a community engagement staff member and Beni local, around the local importance of burial rites:

"Despite the fact that there's an epidemic, the community wishes to preserve the way they honour the dead. To us, honouring the dead means being able to see them…The important thing is that the response, through the SDB teams, was able to let a family member participate in all of the process. That is to say, how the body is wrapped, how it is dressed, how it is cleaned, how it is placed in the body bag. Furthermore, the response has changed the kind of body bag used, by adding a window through which one can see the deceased person's face, which makes it possible to continue honouring funeral rites here in North-Kivu." (programme coordinator, Beni).

Another example of success in changing protocols based on CF in the SDB pillar was explained by an SDB team lead in Beni, when asked about burial of the dead in coffins:

"…[provision of a coffin] depends on whether the family asks for it. Because a family may say, "We have our own coffin." Or "We have our own family grave." So we go with the family to where they want to bury the dead…it was very hard at the start, because it was hard for the family to have the body. The teams would arrive with coffins, the teams carried the bodies and buried them, and all the family could do was watch. Today, the positive change is that we give back the body after we have rendered it safe. Once the body is [confirmed] negative, we can give it to the family for the burial. We may not be sure where they bury the coffin, but we give the family gloves, so the family can bury it. And we send someone to observe the whole burial process. Because, since the family doesn't have instructions on how to take off the gloves and all that, or where to put them after the burial, that person will be in charge of collecting all the gloves and [ensuring safe disposal]. We made that change to earn the families' trust within the community. It was a community suggestion once they too wanted to participate in the burials." (SDB coordinator, Beni).

This respondent felt that it was possible to make these changes quickly because they were hearing from CF as well as from the SDB teams on the ground that these changes were being asked for by the community. Hearing similar messages from different sources added weight to the discussions with Pillar leadership to change operational protocols for SDB.

DISCUSSION

This analysis of the Red Cross CF system has allowed for broader lessons to be drawn out relating to evidence production, its value, use, and operationalization in the 2018-2020 North-Kivu and Ituri DRC Ebola outbreak. The scale of this CF system is dramatically different to previous and other similar systems that have been documented in the past, with more data points allowing for improved analyses of trends in feedback as well as granular analyses ("deep dives") of issues of particular importance to the response leadership. However, given that the Red Cross' system was both novel and produced such a large volume of data, the way in which the feedback was considered for decision-making and operationalized into policy change was still being improved in the latter days of the Ebola outbreak in Eastern DRC. There were two broad areas which led to challenges in getting CF from production to utilization: (i) production and presentation of evidence, and (ii) policy-maker decision-making and then operationalization of the evidence.

Overall, the Red Cross CF system adapted well to local response needs and changes, by ensuring that analysis was conducted and shared at the local level (through health zone coordination structures) to make local level response changes while ensuring that contextual knowledge was not lost, and by developing wider thematic briefs in response to strategic coordination requests. However, challenges arose as a result of the "branding" or positionality of the CF data as being owned and produced by the Red Cross, and likely contributed to delays in adoption of the feedback data as meaningful evidence in the early days of the Ebola response. As the Red Cross' reputation as a data-generating organisation grew (with the support of the US CDC), and CF data were integrated with other social science data, the respect for the information also grew. This was also likely linked to strategic changes made at the response coordination level, when the Red Cross and NGOs were brought into strategic coordination in a formalized way (following the establishment of the UN Ebola Mission in May

2019) (World Health Organization 2019, Crawford, Holloway et al. 2021). IFRC’s strong background in community engagement in outbreaks also likely contributed to the Red Cross CF initially only being considered as relevant for the RCCE pillar of the Ebola response, as opposed to being able to feed actionable insights into different pillars’ activities and decision-making. This is unsurprising: operational social science data (such as CF) is often siloed into the RCCE pillar during outbreaks, which has been substantially critiqued (Leach and McGregor 2020). Efforts to merge the Red Cross’ system with other systems of CF were perceived to be time-consuming and inappropriate given different approaches to data collection, and given the uptake and advocacy efforts required to influence decision making with this novel dataset, merging multiple feedback datasets would have presented a substantial opportunity cost.

Making qualitative CF data more palatable to the Ebola response leadership, who often came from highly quantitative backgrounds, was an additional learning process for those advocating for improved use of the data. Tensions existed between wanting to make the data easy to digest, essentially by “quantifying” it and losing much of the nuance, and the desire to present the data in all its complexity. These tensions reflect longstanding debates in quantitative and qualitative research about the appropriateness of the quantification of qualitative work (Viljoen 2018).

Qualitative “complaint” data in the securitized North-Kivu and Ituri environment (where complaints could forewarn violence) had additional weight in the response, but, according to respondents, only when there were quantifiably enough complaints to reach above a certain threshold. The potential consequences of this, where there must be a substantial number of complaints to spur action, could lead to response workers and civilians being put at risk. This links to further debates in the field of outbreak response, where social scientists and anthropologists who focus on listening to CF are only considered to be of use by the response when their work relates to the prevention or lifting of community resistance (Lees, Palmer et al. 2020).

The fact that the leadership of the security pillar did find the CF so useful is a boon for this novel system, especially given the potentially dire consequences for response staff of not listening to community concerns. This also appears to have been the case among some of the other pillar leads, who saw that their field teams were unable to accomplish their tasks and goals without being accepted by the local community, leading the CF data to become a highly valued source of information. However, this research has suggested that this was not true for all pillars, with some pillar leads failing to participate in feedback meetings, despite encouragement from Coordination leadership.

The challenge of transforming evidence into policy and operational action has been extensively documented in humanitarian contexts (Salajan, Tsolova et al. 2020), and it's therefore not surprising that a new data source like CF was not easy to integrate into decision-making in the early days of the Ebola response. However, as the evidence became more trusted and used to develop recommendations, the slow pace of change in the response even in the face of evidence suggesting a change was necessary, belied the concept of an evidence-based response. Some Infection Prevention and Control activities like the burning of people's goods during Ebola home decontaminations, were long known to be a flashpoint for community anger anecdotally and through community-based research, and yet it still took many months for policy changes to take place to stop this action (Rohan and McKay 2020). Policy change required engagement and buy-in from a vast number of actors, processes and validation steps. Operationalizing any policy change in turn required substantial communication, coordination, and training of field staff. Taken together, these processes could take so long to accomplish that communities and response workers often felt that protocols were entirely inflexible, despite all the evidence that a given policy change needed to be made. This "evidentiary inertia", whereby even credible and voluminous evidence is insufficient to drive changes in policy or operations, emanates from the size, structure, and complexity of an epidemic response such as that deployed in the North-Kivu and Ituri outbreak.

Recommendations

Our foremost recommendation is that CF systems should be considered for deployment in future outbreaks, whether large or small. However setting up a CF system like the one referenced here can be time-consuming as well as being logistically and financially burdensome if implemented on such a large scale, and may not be suitable for smaller outbreaks or in some contexts. The scope and scale of the CF system should be aligned with the severity of the outbreak and the resources available, with a global discussion of thresholds that would trigger the deployment of a basic system, or scale up of a more complex system as an outbreak progresses. By capacitating countries with a basic package of tools to set up a CF system in "peacetime", the potential time lag to roll-out in the event of an emergency would be reduced.

By normalizing CF systems in outbreaks, there is likely to be an increased uptake and use of such data to make strategic and operational decision-making. These CF systems should be linked to wider social science efforts, from rapid qualitative work and anthropology, to other sources of community perceptions data (including knowledge, attitude and practices surveys) that are widely used in outbreak settings (Bardosh, Gercama et al. 2019). These varied sources of data can be used to triangulate against CF data and to create evidence briefs and other knowledge products.

A recommendation both for the Red Cross and for other CF systems in general, is that while the Red Cross CF system did not take a sampling approach for logistical and operational reasons, moving in that direction could facilitate more trust in the data, especially by response staff who are less familiar with qualitative methods and approaches. Partially separating the CF system from standard community engagement activities would allow organisations to rapidly scale up or down their CF work, independent of their other activities. The Red Cross or any other organisation that is engaged in CF must have the capacity to conduct robust and rapid analyses of social science data, through partnership or by developing this skill in-house.

To address challenges and issues identified in future outbreaks this research offers the following recommendations where CF systems are used:

1. Engage humanitarian organisations that are collecting CF (eg. DRC Red Cross) in strategic and operational coordination structures from early on in outbreak response.
2. Response leaders should be trained in the use of multiple data types. Integrating qualitative data training in epidemiological training programmes (eg. Field Epidemiology Training Programmes) as well as in outbreak response training programmes (eg. WHO's Incident Management System) would be a first step in this direction.
3. CF collection, analysis and interpretation should be seen as a particular technical skillset and should have clear SOPs so that any actors engaged in this space in outbreaks are able to feed their data into a centralized system.
4. Test different approaches to the presentation of CF data in future outbreaks to create templates that can be easily interpreted by different audiences including response leadership and quantitatively trained (as well as qualitatively trained) staff.
5. Establish CF as a key source of intelligence across outbreak response pillars (not just in RCCE) and ensure tracking systems for recommendations are used and acted upon both at the strategic and operational levels. This would therefore likely sit under the broader monitoring, evaluation and accountability function of the overall response.

The Red Cross CFS benefited from an end-to-end learning system, where adjustments in the approach were made based on ongoing (though informal) process evaluation, and where data were used weekly to shape messages and train staff. This willingness to adapt and grow an approach over time as new evidence and learning is uncovered is to be lauded, and should be a part of outbreak response culture.

Limitations

The primary research for this piece took place over two weeks in two locations of the North-Kivu Ebola response: Goma and Beni. Despite sincere efforts, the extreme workload of much of the response leadership in managing multiple flare-ups of Ebola in different geographies meant that it was not always possible to interview staff involved in higher levels of responsibility for strategic decision-making.

This research focused on the use of CF data by formal coordination structures, and therefore did not specifically look to document the small, day to day changes in response actions made at the field level based on feedback.

As a result of insecurity, it was not possible to include interviews with those providing CF (e.g. community members), and this was not within the scope of the study. Due to the Covid-19 pandemic in 2020-2021, planned validation workshops to share the results of this research did not take place.

The research team conducting this study were well positioned due to their previous experience in the DRC and West African Ebola outbreaks. Possible potential biases may be related to their previous interactions and affiliations with responding NGOs and UN Agencies. While the IFRC were the hosting agency for this research, the lead researchers worked to maintain distance from the IFRC through reflexive journaling and through frequent discussions of potential bias arising from the relationship with the organisation being studied. Staff conducting the research had previously been involved directly in the response, and therefore may have, due to a sense of responsibility for the response’s performance, have been positively biased towards it.

CONCLUSIONS

When CF is given to the right decision-makers in an outbreak, in a format that they can understand and use to develop clear recommendations, it can be a highly valuable tool for outbreak response. CF data have both instrumental value insofar as they can be used to improve outbreak response operations, and intrinsic value in respecting and being accountable to communities (Reynolds and Sariola 2018). However, challenges of absorptive capacity for new evidence, the loss of contextual information when qualitative data are quantified and the reputation presenting the data can make it difficult to get such evidence considered in policy decisions. Furthermore, once feedback evidence is considered and policy is made, the challenges of slow operationalization of policy change can lead to frustration on the part of communities and response staff that there is a functional accountability mechanism and that change is coming.

AUTHORS' CONTRIBUTIONS

Concept and Design	FC, HR, GM, OB
Data Collection & Acquisition	GM, OB, CC, EE, LR
Data Analysis & Interpretation	GM, HR
Drafting Manuscript	GM, HR
Securing Funding	FC, HR, GM, OB
Overall Guarantor	GM

All authors contributed critical revisions, approved the final draft and are accountable for the work.

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DISCLAIMER

The views expressed in this publication are those of the authors and not necessarily those of the UK Department of Health and Social Care.

COMPETING INTERESTS SUMMARY STATEMENT

The authors have no conflicts of interest to declare.

8.0 Discussion

This thesis aimed to understand how communities engaged in outbreaks of Ebola in the DRC and in Sierra Leone, and how the responses integrated community knowledge and experience. The two case studies presented each addressed a particular objective, as laid out in the introductory chapter. Objective 1, presented in chapters 4 & 5, sought to understand how women navigated family planning, a gendered health care service in the Sierra Leone Ebola outbreak; and objective 2, presented in chapters 6 & 7, sought to understand how communities were heard and how their feedback was taken up by the DRC North-Kivu Ebola response. This chapter brings together the learning from these two case studies in fulfillment of the overarching research aim, identifies the contributions that this thesis makes to public health knowledge and practice, and responds to objective 3, the presentation of recommendations for action in future outbreaks of infectious disease.

8.1 Learning on community engagement in Ebola outbreaks

The case studies that make up this research sought to understand how, in Ebola outbreaks, communities engage with the response, and how those responses integrate community knowledge and experience. The literature review in Chapter 2 began by referencing Morgan's description of the two different models of community participation, the utilitarian model (participation can reduce cost and effort of health services through community resource investment) and the empowerment model (participation creates space for communities to build their own solutions to health concerns) (Morgan 2001), with the WHO's current approach to community engagement aligned with the empowerment model (World Health Organization 2020). The findings from the case studies demonstrated that how community engagement was operationalized in the two outbreaks aligned, in part, with both models of participation. On the utilitarian side, women had to use their own resources to seek FP in Sierra Leone when additional barriers were enacted due to the response, and some decision-makers in DRC identified that by engaging with community feedback the Ebola field teams were better able to conduct their tasks. Both case studies also found evidence of the empowerment model at work, with women analysing and carefully weighing up risks and benefits of seeking out health care in the changed Ebola context, and communities advocating for themselves by essential feedback that was used to make response policy changes, especially in the IPC and safe and dignified burials pillars. Whether empowerment or utilitarian in intention, community engagement was acknowledged in both case studies to be important to good outcomes for the response and the population, though the challenges and failures on the part of the response to truly engage community knowledge and experience did hinder efforts to reduce the impact of the outbreaks.

The debates raised in the literature review spoke to how the actions of Ebola responses can either support or hinder the engagement of communities, with subsequent impacts on the ending of the outbreak and on health care seeking. Community feedback systems such as that of the Red Cross supported this engagement, by bringing the response activities close to the homes of those most affected, localizing the response so that communities were able to raise their concerns and questions in an environment where they felt safe. This benefit of bringing the response closer to communities was also shown in the community care centres in Sierra Leone, where these smaller centres were felt to be more responsive to local community needs and were often staffed by people from the local area (Oosterhoff, Mokuwa et al. 2015). The women's health case study also echoed the importance of local availability of services, ideally by health care providers who were known, and therefore trusted, by the women. However both case studies also add to concerns raised in the literature about how poor actions by Ebola responses can obstruct the engagement of communities.

The two case studies both identified that there were mismatches between the expressed needs of communities (for FP in Sierra Leone, or for non-Ebola needs like security in DRC) and the priorities of the Ebola response itself. This mismatch was highly linked to the Ebola emergency imperative that drove the response structures, whereby the stopping of transmission was paramount, with the result that community engagement, knowledge and experiences were not placed at the forefront of response actions. This has also been found by other researchers, attributed to limited community engagement by responses and the lack of funding allocated to local organisations who would be better placed to know the needs of their geography and the communities that they serve (DuBois, Wake et al. 2015, Colombo and Pavignani 2017, Lees, Palmer et al. 2020). Barriers to responsive community engagement identified in both case studies include the prioritization of ending transmission of the virus above all else, the technocratic approach of the response, and the inertia of Ebola responses.

8.1.1 Stopping the spread

Stopping transmission of Ebola was the overarching priority of the Ebola responses in both countries during their respective outbreaks, and this tunnel-vision tended to exclude other, longer term humanitarian and development needs. In an Ebola response ending transmission does need to be the aim, however as my research, and the research of others, has shown, the lack of engagement with the holistic needs of communities in affected areas can result in negative impacts both on the communities and the response itself (DuBois, Wake et al. 2015, Nuriddin, Jalloh et al. 2018, Crawford, Holloway et al. 2021, Nyenyezi Bisoka, Vlassenroot et al. 2021).

In both case studies the focus on stopping Ebola to the exclusion of other health or social issues was identified as a key problem for communities and decision makers. In the case of Sierra Leone, women self-censored going to the clinic to seek FP care not only to not burden the health care system or to avoid being infected with Ebola, but also to avoid the clinic because they were concerned that with the focus on Ebola they would not be treated well while attending services, as was also found in other research examining maternal health services in Ebola (Jones and Ameh 2015, Jones, Gopalakrishnan et al. 2016, Yerger, Jalloh et al. 2020). In the DRC, community feedback relating to issues most important to the communities themselves, especially concerns about violence by armed groups, were not part of the Ebola calculus in the early stages of the outbreak, and thus these concerns were felt to be beyond the scope of the response, despite being a key issue and concern for people, and likely contributing to increased violence against the response itself (Nyenyezi Bisoka, Vlassenroot et al. 2021). As was found in my research, when communities had their concerns responded to, and thus had more trust in the response, the response itself was better able to conduct their transmission-prevention activities. This is a key lesson for future outbreaks, that stopping transmission is less likely to succeed when the holistic needs of communities are not heard.

The ongoing conversation about localization of humanitarian aid so that it is through the actions of geographically local organisations (who are more likely to be known and thus trusted by the affected population) is a positive step towards faster, less costly and more nuanced responses to public health emergencies. However, as we have seen in Covid-19, the secondary impacts of the virus on the economies, health services and social structures of affected populations have been severe, with mitigating measures limited by the sheer scale of the pandemic (Borkowska and Laurence 2020, Kotlar, Gerson et al. 2021). The emergency imperative to "stop transmission" so that life can return to "normal" is a difficult one to push back against, when the emergency is causing so much disruption in the lives of people and in the functioning of societies.

8.1.2 Mismatches between technocracy and community knowledge

Some of the narrow focus on stopping spread was related to the highly technocratic approach[12] of the responses, largely run by epidemiologists or other medically trained individuals, often parachuted in from outside the area, country or region (Wilkinson, Parker et al. 2017, Bylund and Packard 2021, Crawford, Holloway et al. 2021, Nyenyezi Bisoka, Vlassenroot et al. 2021). This meant that these individuals had little to no understanding of the local factors, nuances, geographies and behaviours which contributed to spreading the disease. Ebola is often thought of as a disease of love (Lancaster 2019), because it is through day to day caring activities that it spreads: caring for sick children, holding the hand and washing the body of a dying family member, attending the funeral of an honoured community member who has passed away (World Health Organization 2021). Highly medicalized approaches to stopping transmission such as "do not touch others", "hold no funerals", "only medical burials are safe", "do not care

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[12] Technocrats are people with scientific or technical knowledge with important positions in government or industry. A technocratic approach in development or health is thus one where complex social issues (like outbreaks) are led by "experts" with who see the problem as one to be solved through technical solutions in a top-down way, often with limited or no engagement with those most affected by the problem itself.

for sick people at home", are so divorced from context and day to day practice of people living in the affected geography. Inadvertent and intended breaches of guidance should not be unexpected in such situations, and indeed have been widely reported (Lipton 2017, Wilkinson, Parker et al. 2017).

The two case studies in this thesis both revealed the mismatches between the technocratic approaches of the response and the lack of engagement with community knowledge and experiences. In case study 1, technocratic efforts were made to reduce the impacts of the Ebola outbreak on women's health care, largely through infection prevention and control measures at the health facility level, including personal protective equipment and training of health staff. While these efforts were appreciated by some women, key factors influencing their choices about taking or not take FP were not considered by the response, including issues of trust in the health workers providing the care, and the more distal concerns related to the impacts of the reduction in economic opportunities making the cost of FP prohibitive. In case study 2, community feedback relating to community priorities for increased security and changes in response policies (eg. The burning of people's goods during decontamination procedures) were not initially heard or responded to by the response leadership, in part due to the problem of hierarchy of knowledge, where particular forms of evidence (such as qualitative data from communities) were not valued as significantly as other, more "epidemiological" forms of data, such as quantitative case counts.

Trying to run a response and manage or stop an outbreak requires deep and comprehensive understanding of the geography, community dynamics and power structures that are contributing to the epidemic. This is difficult, as response leadership is generally from outside the affected community, region or even country, with those placed in charge of responses tending to have formal outbreak experience and technical knowledge (Ross 2017). As critiqued by Wilkinson and colleagues, the contested concept of community complicates efforts to understand local dynamics. If there is no "one community", then it is critical to engage in research to parse the social and political nuances of people in the affected area that may be driving (or at least not helping to stop) transmission (Wilkinson, Parker et al. 2017). By engaging explicitly with a diversity of community members from affected areas (including women and men), who are more likely to have nuanced knowledge, then it may be possible to develop understanding of who can be trusted to share information, who should be heard, how people make decisions and other issues relevant to response operations and strategy (DuBois and Wake 2015, Enria, Lees et al. 2016, Wilkinson, Parker et al. 2017, Crawford, Holloway et al. 2021). Findings from the two case studies in this thesis revealed how these nuances were not often considered, leading to frustration on the part of communities and responders when there continue to be challenges in stopping the outbreak, and further evidencing how localization efforts can be supportive of improved outbreak response in future.

8.1.3 The inertia of Ebola responses

Stopping transmission of a virus requires nimbleness and a willingness to make changes to processes, strategies and approaches. However, Ebola responses are “big ships”, in that once the actors, policies and systems are set on the path to stopping transmission it can be very difficult to make rapid changes in response to changing needs (Ross 2017, Crawford, Holloway et al. 2021). The limited agility of response has been highlighted in both case studies, with women seeking FP feeling that their needs for FP were being subsumed by the focus on Ebola, and other authors finding that women seeking maternity care struggled to access services, or when they did, that the quality was very poor (Jones and Ameh 2015, Jones, Gopalakrishnan et al. 2016, Elston, Cartwright et al. 2017, Jones, Sam et al. 2017). Even when there were efforts by the response to improve maternal health services, this still took time to be enacted at the health service level, given shortages of staff, personal protective equipment and training (Yerger, Jalloh et al. 2020). In the North-Kivu response, community feedback was often not translated into policy change, frustrating communities and making them feel that their feedback was not valued, possibly contributing to increases in violence against the response (Nyenyezi Bisoka, Vlassenroot et al. 2021). This ”evidentiary inertia” of the response, the theory developed in the DRC case study, states that despite masses of evidence that a particular policy or action needs changing it may be the case that a response is just too large and unwieldy to make needed adaptations in a reasonable timescale.

8.2 Contributions to public health knowledge and practice

This thesis contributes to the advancement of public health knowledge and practice in the field of outbreak response, by advancing theory and understanding of how communities engage and are engaged in outbreaks, and how community experiences are taken on board by Ebola responses. This section will outline how this thesis makes specific contributions to public health knowledge, including by proposing recommendations for future practice in outbreaks to improve community engagement.

8.2.1 Seeking out health care in Ebola is a complex calculus

The first case study, on FP in Ebola, contributes to ongoing debates about how epidemics differently impact on women versus men, and gives further justification to why it is critical not to see “communities” as a homogeneous group when conducting community engagement activities. This case study provided the first qualitative analysis of women’s perspectives of seeking (or not seeking) FP in an Ebola outbreak, finding that their decisions and approaches to accessing health care were dependent on their own personal circumstances, the societal barriers inherent in seeking women’s gendered health care, and that reasons to seek FP could be amplified by an Ebola outbreak. Employing the framing of distal and proximal reasoning for seeking health services in an outbreak setting is a novel expansion of Shrum et al’s concept of “locative fear” (2020). By taking a holistic view of women’s risk analysis, this research revealed that it is the combination of Ebola-risks and broader structural issues that come together as women engage (or do not engage) with women’s gendered health care in outbreaks. While there are myriad reasons why it is of vital importance to listen to and engage with women in Ebola outbreaks, the research in Sierra Leone identified that normal physiological events, like menstruation, can become a threat in times of viral hemorrhagic fevers. In such times, when women’s bleeding (from regular menstruation or as a side effect of FP) can be interpreted as a danger sign and thus of death and disease, women found themselves afraid to admit to bleeding, as they feared being taken away to an Ebola centre, possibly to catch the disease and die. The disruption of unexplained (or even explained) bleeding can betray women and their families, by putting them at risk of disease. Menstruation as a pollutant was initially conceptualized by Mary Douglas, and this finding about bleeding during Ebola provides empirical evidence of how menstrual blood can be perceived as a risk or pollutant (Douglas 1966).

8.2.2 Evidence-based responses are not necessarily responsive to evidence

Case study 2 evaluated the innovative Red Cross community feedback system in the Ebola response in North-Kivu, a system that had not been previously implemented nor researched, and used this system to shine a light on the challenges of bringing in a new qualitative data stream into outbreak policy making. The case study identified that the challenges of integrating a new stream of data into the response were difficult to overcome, with issues of epistemological hierarchy and evidentiary inertia hampering the use of this data to make policy. The findings from the study demonstrated that the North-Kivu Ebola outbreak was highly numerically driven, with the new qualitative community feedback not easily absorbed by the response, partly due to the quantitatively trained response leadership preferring epidemiological data. Furthermore, responder study participants spoke about how the large apparatus and cumbersome validation processes of the response obstructed the ability to respond and shift policies and approaches, even when there was significant evidence (from a variety of sources) that change was needed. These findings contribute to the literature about how policy change does or does not happen in emergency settings, and back-up Salajan et al's work that found that policy makers in outbreaks were besieged by data and thus had trouble sifting through the varying interpretations of information to set a new course (Salajan, Tsolova et al. 2020).

8.2.3 Practice implications of this research

As this is a DrPH thesis, the research contribution to public health practice is integral. The research conducted presents an alternative view of the emergency imperative of Ebola response, by demonstrating that the focus on stopping transmission of the virus in an environment where community needs were not always heard or responded to, resulted in harms to the very populations that the response existed to serve, and to the response itself. The findings of this research present a clear recommendation that involving communities in epidemic response is essential, not only to end the outbreak and to promote health care seeking, but also to promote trust between communities and institutions, including outbreak response agencies and health ministries. Involving communities in responses is a complex, complicated process, and requires that responding institutions reflexively consider how their technocratic approaches and hierarchical structures can be a barrier to community engagement.

The lack of community engagement and community understanding has been well documented in Ebola outbreaks (DuBois and Wake 2015, Gillespie, Obregon et al. 2016, Laverack and Manoncourt 2016), and there has been admirable progress in bringing communities and their needs closer to the forefront, as was seen in the later stages of the North-Kivu response when community demands for improved security were somewhat addressed by the new UN led multi-sectoral response approach (Crawford, Holloway et al. 2021). However this needs to go further, by prioritizing community feedback and closing feedback loops so that people feel that their voices are not just heard, but also responded to, by understanding the agency of community members to adapt to crisis scenarios, and by ensuring that health services for all types of health needs, including women's services like FP, are maintained in times of crisis.

There must be more agility in Ebola responses, to take into account community needs and perspectives. Ebola responses need to consider their impact beyond the Ebola sphere, to challenge the emergency imperative, to think about how they can minimize the impacts on non-Ebola health care, and to reflect on how responses may be perpetuating or reinforcing inequities (such as harmful gender norms). Outbreak preparedness efforts need to consider and mitigate how outbreaks place additional barriers to day to day life on all those in the affected area, and pay particular attention to how those with additional vulnerability may be further affected. Women's priorities and needs are generally insufficiently considered in outbreak response, with consequences ranging from reductions in health care access to economic losses

(Takemoto, McKay et al. 2021). Gender considerations must be about more than just providing training to humanitarian workers on the prevention of sexual exploitation and abuse, there must be a concerted effort to undertake gender analyses and plan gender responsive strategies into outbreak preparedness efforts.

Finally, more work needs to be done on how to integrate Ebola responses (and other outbreak responses) within the broader health, humanitarian and development needs of the countries in which they occur. This has started with the IASC Humanitarian System-Wide Scale-up Activation Protocol for the Control of Infectious Disease Events, which proposes that coordination structures will be set up in a way so that there will be consideration of "*access and security constraints, population movements and displacements, conflict and gender dynamics, protection challenges, and on how IASC and other partners can best support the response. This will include implications for any wider humanitarian response in the area.*" (Inter-Agency Standing Committee 2019, p.3) However this needs to be reassessed in light of the challenges encountered in the DRC North-Kivu Ebola response, including the delayed and not-to-protocol implementation of the IASC Scale Up (Crawford, Holloway et al. 2021).

8.2.4 Recommendations for practice – community engagement in outbreaks

1) Strategies for community engagement in outbreaks must be grounded in a robust contextual analysis, including formative research with affected communities on their perceptions of the outbreak, the outbreak response, and community needs and priorities. These analyses must be conducted at regular intervals as outbreak responses continue, to ensure that response strategies are adapted and respectful of the changing context and the dynamism of communities.
2) Institutions and staff in responses must be receptive to hearing community priorities, which may or may not relate to the infectious disease outbreak, and make strides to address these issues as part of a holistic response. This requires targeted research with vulnerable groups whose experiences may not be identified through standard community perception research approaches.

8.2.5 Recommendations for practice – women's health care in outbreaks

1) Family planning remains an essential service in outbreaks of infectious disease, and may increase in demand given economic, educational and maternal health care disruptions. Such services must remain open, accessible, and ideally free or very low-cost, through inclusion in essential service continuity plans, and resources (FP methods & staff) must be maintained. Some services may be able to be conducted in community settings (i.e. pharmacies) to reduce fears about contamination at health facilities, or could be provided through self-care approaches (i.e. self-injected contraceptives)
2) Working to maintain confidence in non-Ebola health care in outbreaks must remain a priority to reduce the risks of loss of service uptake. Women strongly value familiar health care staff, and these health workers must be trained in screening and safe care provision, equipped with appropriate PPE, and the facilities they work in must be made as safe as possible through infection prevention and control measures to reduce the risk of nosocomial transmission.
3) Efforts to maintain non-Ebola women's health services require an understanding of pre-outbreak gender norms related to health care seeking, as any barriers are likely to have been exacerbated by the outbreak itself. Gender-focused strategies to drive demand, minimize access barriers, and ensure women have decision making power in seeking health care must be considered in outbreak plans, and regularly reviewed and updated in outbreak settings, including into the recovery period.

8.2.6 Recommendations for practice – community feedback systems in outbreaks

Recommendations specific to case study 2 have already been presented in the published paper, but I have also summarized them here:

1) Community feedback systems should be rolled out from the outset in future outbreaks, but the size and scale of the system must be carefully considered, with smaller

outbreaks (and thus smaller responses) able to implement the basics of such a system rapidly and without undue financial hardship.

2) Community feedback must be linked to other social science efforts in the outbreak response, and when there are multiple forms of CF system, data collection approaches should be aligned so that triangulation and joint recommendation-generation is possible.
3) The organisations engaged in CF data collection should be engaged in decision making efforts at all levels of the response, to maximize the likelihood that recommendations will be prioritized and tracked through to implementation.
4) To ensure that qualitative data streams like CF are understood by often-quantitatively trained response leadership, different approaches to presentation of this type of data should be tested. Furthermore response leadership would benefit from training in qualitative data.

8.3 Future research

Future research opportunities identified from this thesis include that a health systems perspective on FP in outbreaks would be beneficial, with perspectives from health policy makers, government health care providers and NGOs providing FP. Another area for future research would be to assess community perspectives of community feedback systems and processes, and how these types of innovation should be adjusted or changed in future outbreaks. This could include perspectives from community feedback collectors to better understand how the system runs and what could be improved. Finally, additional research into how communities engage with responses to outbreaks of infectious disease and broader humanitarian crises is always needed. This research can be conducted for formative or implementation purposes during the crises themselves to ensure that responses are engaging in ways that are acceptable and appropriate for the communities that they are serving, but such research can also be conducted for broader theory-development purposes, to continue to develop ideal models of community engagement for future crises.

8.4 Conclusion

Outbreaks of Ebola (and other infectious diseases) are often disordered, complex and dynamic spaces, where communities and response structures interact on a multitude of levels. This thesis used a social science approach to research how communities engaged in the Sierra Leone and North-Kivu outbreaks of Ebola, and how their knowledge and experiences were integrated into response actions. This work revealed that the priorities of outbreak responses and the priorities of affected communities are often misaligned, and recommends that community engagement efforts need to be improved in future outbreaks, and that responses need to be made more adaptable and agile if community knowledge is to form the basis of evidence-based responses.

9.0 Integrating Statement

Since starting my DrPH in September 2015, I have grown as a researcher, policy-influencer, and public health professional. On starting the DrPH I had experience in the implementation of public health programmes in low-income countries with an NGO, but did not have the theoretical or practical knowledge or skills conducting high-quality, robust research, or how to use research to influence policy. Coming out of the degree nearly 7 years later, I can confidently say that I have developed into a public health leader in the secondary impacts of outbreaks of infectious disease on communities, with a specialty in impacts on women, and have worked to build a network of colleagues and partners who will support me in my next steps in the professional public health world.

I began the programme with the two required courses, Understanding Leadership and Management in Organisations (ULMO) and Evidence-Based Policy and Practice (EBPHP). In ULMO I learned how to conduct a strategic analysis of an problem in an organisation, using a variety of tools. I have had the opportunity to put these tools into practice not only in the assignment for that course (which I conducted on my own organisation, and was able to use to help direct the next steps in its expansion), but also in several consultancy projects I have undertaken with NGOs and UN agencies over the course of my degree. From the EBPHP course I learned how to critically evaluate studies, conduct a systematic review, and how to write policy briefs based on evidence. I have used these skills time and again in my professional career and academic programme over the last 7 years. I was able to use the skills of critically analysing evidence and creating a policy strategy to take the learning from case study 1, about family planning in Sierra Leone's Ebola outbreak, to the DRC, where I advocated with WHO and the IRC to include sexual and reproductive health in their Ebola programmes as a critical function. While I have not conducted additional systematic reviews since completing the modules, the skills I learned in how to conduct a systematic search, organise and extract data and critically evaluate papers has been helpful in all the research I have conducted since, both within and outside my DrPH programme.

The courses also gave me the knowledge I needed to complete my DrPH Organisational Policy Analysis (OPA), which I conducted at my former organisation. The OPA was entitled: Knowledge management and organisational learning in GOAL Global for health emergency preparedness. The analysis aimed to identify how GOAL learned internally, shared that learning and adapted programming, by conducting a case study of the barriers and facilitators to learning from the West Africa Ebola outbreak and a measles outbreak in South Sudan. The organisation was involved in both of these outbreaks, and I sought to understand how learning from those outbreaks had been shared across countries through documentary means, as well as through other knowledge management approaches including conferences, meetings and technical team supports. The work involved qualitative interviews with purposively selected staff of GOAL from South Sudan and Sierra Leone, as well as Headquarters, and a survey that was sent out widely to the staff of both country teams. I also conducted workshops with GOAL staff in Sierra Leone to validate findings and develop recommendations in a participatory fashion. I utilised a series of tools from the ULMO module to design the data collection tools, and to analyse the data, particularly McKinsey's 7S model and Leavitt's Diamond (Leavitt 1965, Mindtools 2016).

The thesis for my DrPH drew on both my coursework and my OPA. In my coursework for EBPHP one assignment was to develop a knowledge transfer and influencing strategy for a hypothetical organisation on a topic of our choosing. I chose to focus my assignment on youth reproductive health in Sierra Leone, as this would give the opportunity to dive into the Sierra Leone reproductive health policy landscape in the post-Ebola environment. Furthermore I used the assignment to conduct a stakeholder analysis of reproductive health in Sierra Leone to identify key potential health stakeholders who would be of value to speak with during my thesis. I also took advantage of my time in Sierra Leone conducting data collection for my OPA to engage with family planning organisations in country, including Marie Stopes Sierra Leone, and the Ministry of Health and Sanitation to ascertain their interest in my potential case study 1 topic. For case study 2, on decision-making in the North-Kivu Ebola outbreak, I drew again on my coursework, with the learning from EBPHP especially valuable. As I sought to understand why there was "evidentiary inertia" in the Ebola response, for example when there was ample evidence of the need to stop actions like the burning of people’s goods during decontamination procedures, I found support in Kingdon’s framework (Kingdon 1984). Kingdon’s model posits that in order for there to be a policy window, the problem, policy (solution) and politics (environment) streams must all come together for the issue to be prioritized for action. The Ebola response in North-Kivu had many problems to solve, often with multiple possible solutions, in an environment with dozens of actors and complicated power dynamics and processes for policy change.

This thesis therefore is the culmination of my DrPH journey, not only of the thesis research itself, but of the whole of my last 7 years of learning and growth at the LSHTM. By always looking back on what I’ve learned in previous components of the programme and building on this, I believe I’ve created a body of work that successfully integrates research, policy and management, three components that are essential in any professional Public Health practitioner.

10.0 References

Abdullah, I. and A. Kamara (2017). "Confronting Ebola with Bare hands: Sierra Leone's health sector on the eve of the Ebola epidemic." Understanding West Africa's Ebola Epidemic: 112-136.

Abramowitz, S. (2014). "Ten things that anthropologists can do to fight the West African Ebola epidemic." LSE Blogs https://blogs.lse.ac.uk/africaatlse/2014/11/18/ten-things-that-anthropologists-can-do-to-fight-the-west-african-ebola-epidemic/.

Aembe, B. and D. Dijkzeul (2019). "Humanitarian governance and the consequences of the state-fragility discourse in the Democratic Republic of Congo's health sector." Disasters **43 Suppl 2**: S187-S209.

African Development Bank. (2016). "Women's resilience: Integrating gender in the response to Ebola." Retrieved March 20, 2018, from https://gsdrc.org/document-library/womens-resilience-integrating-gender-in-the-response-to-ebola/

Agadjanian, V. and N. Prata (2002). "War, peace, and fertility in Angola." Demography **39**(2): 215-231.

Baggio, O. (2020). "Real-time Ebola community feedback mechanism. ." SSHAP Case Studies Retrieved Jan 28, 2020, from https://opendocs.ids.ac.uk/opendocs/handle/20.500.12413/15423.

Baggio, O., C. Camara and C. Prue (2019). "Bringing Community Perspectives to Decision-Making in the Ebola Response in the Democratic Republic of Congo." Social Science for Humanitarian Action.

Bardosh, K., I. Gercama and J. Bedford (2019). "Social science and behavioural data compilation, DRC Ebola outbreak, November 2018-February 2019."

BBC (2014). Profile: Leading Ebola doctor Sheik Umar Khan. BBC, BBC.

Benton, A. and K. Y. Dionne (2015). "International Political Economy and the 2014 West African Ebola Outbreak." African Studies Review **58**(01): 223-236.

Bietsch, K., J. Williamson and M. Reeves (2020). "Family planning during and after the West African Ebola crisis." Studies in Family Planning **51**(1): 71-86.

Black, B. O. (2015). "Obstetrics in the time of Ebola: challenges and dilemmas in providing lifesaving care during a deadly epidemic." BJOG **122**(3): 284-286.

Black, B. O., S. Caluwaerts and J. Achar (2015). "Ebola viral disease and pregnancy." Obstet Med **8**(3): 108-113.

Blanchet, K., A. Alwan, C. Antoine, M. J. Cros, F. Feroz, T. Amsalu Guracha, O. Haaland, A. Hailu, P. Hangoma, D. Jamison, S. T. Memirie, I. Miljeteig, A. Jan Naeem, S. L. Nam, O. F. Norheim, S. Verguet, D. Watkins and K. A. Johansson (2020). "Protecting essential health services in low-income and middle-income countries and humanitarian settings while responding to the COVID-19 pandemic." BMJ Global Health **5**(10): e003675.

Bonino, F., I. Jean, P. K. Clarke and T. P. Curmi (2014). "Humanitarian Feedback Mechanisms: Research, evidence, and guidance."

Borkowska, M. and J. Laurence (2020). "Coming together or coming apart? Changes in social cohesion during the Covid-19 pandemic in England." European Societies **23**(sup1): S618-S636.

Braun, V. and V. Clarke (2006). "Using thematic analysis in psychology." Qualitative Research in Psychology **3**(2): 77-101.

Bylund, P. L. and M. D. Packard (2021). "Separation of power and expertise: evidence of the tyranny of experts in Sweden's COVID-19 responses." Southern Economic Journal **87**(4): 1300-1319.

Calman, L., L. Brunton and A. Molassiotis (2013). "Developing longitudinal qualitative designs: lessons learned and recommendations for health services research." BMC medical research methodology **13**(1): 1-10.

Camara, B. S., A. Delamou, E. Diro, A. H. Beavogui, A. M. El Ayadi, S. Sidibe, F. M. Grovogui, K. C. Takarinda, P. Bouedouno, S. D. Sandouno, J. Okumura, M. D. Balde, J. Van Griensven and R. Zachariah (2017). "Effect of the 2014/2015 Ebola outbreak on reproductive health services in a rural district of Guinea: an ecological study." Trans R Soc Trop Med Hyg: 1-8.

Carter, S. E., S. Ahuka-Mundeke, J. Pfaffmann Zambruni, C. Navarro Colorado, E. van Kleef, P. Lissouba, S. Meakin, O. le Polain de Waroux, T. Jombart, M. Mossoko, D. Bulemfu Nkakirande, M. Esmail, G. Earle-Richardson, M. A. Degail, C. Umutoni, J. N. Anoko and N. Gobat (2021). "How to improve outbreak response: a case study of integrated outbreak analytics from Ebola in Eastern Democratic Republic of the Congo." BMJ Glob Health **6**(8).

CHS Alliance, Groupe URD and The Sphere Project. (2014). "Core humanitarian standard on quality and accountability." Retrieved Sept 1, 2020, from https://corehumanitarianstandard.org/files/files/Core%20Humanitarian%20Standard%20-%20English.pdf.

Colombo, S. and E. Pavignani (2017). "Recurrent failings of medical humanitarianism: intractable, ignored, or just exaggerated?" The Lancet **390**(10109): 2314-2324.

Council of Delegates of the International Red Cross and Red Crescent Movement. (2019). "Movement-wide Committments for Community Engagement and Accountability." Retrieved Oct 20, 2021, 2021, from https://communityengagementhub.org/wp-content/uploads/sites/2/2020/04/R1-Movement-wide-commitments-for-CEA.pdf.

Cousins, S. (2020). "COVID-19 has “devastating” effect on women and girls." The Lancet **396**(10247): 301-302.

Crawford, N., K. Holloway, J. Baker, A. Dewulf, P. Kaboy Mupenda, E. Kandate Musema, A. Mushagalusa Ciza and R. Southgate. (2021). "The Democratic Republic of Congo's 10th Ebola response: Lessons on international leadership and coordination." Retrieved Oct 10, 2021, 2021, from https://odi.org/en/publications/the-democratic-republic-of-congos-10th-ebola-response-lessons-on-international-leadership-and-coordination/.

Dewulf, A., A. Ciza and L. Irenge (2020). "Collective approaches to risk communication and community engagement in the Ebola response in North Kivu, Democratic Republic of Congo." London: ODI.

Diaz-Quijano, F. A., D. M. Pelissari and A. D. P. Chiavegatto Filho (2018). "Zika-Associated Microcephaly Epidemic and Birth Rate Reduction in Brazilian Cities." American Journal of Public Health **108**(4): 514-516.

Donnelly, C. A., I. Dorigatti, P. Nouvellet and A. Forna (2020). "Case Fatality Ratio Estimates for the 2013–2016 West African Ebola Epidemic: Application of Boosted Regression Trees for Imputation." Clinical Infectious Diseases **70**(12): 2476-2483.

Douglas, M. (1966). Purity and danger: An analysis of concepts of pollution and taboo, Routledge.

DuBois, M. and C. Wake (2015). The Ebola Response in West Africa: exposing the politics and culture of international aid. London, Humanitarian Policy Group: Overseas Development Institute.
DuBois, M., C. Wake, S. Sturridge and C. Bennett (2015). The Ebola response in West Africa: Exposing the politics and culture of international aid. London, Humanitarian Policy Group,.
Dynes, M., L. Miller, T. Sam, M. Vandi and B. Tomczyk (2015). "Perceptions of the risk for Ebola and health facility use among health care workers and pregnant and lactating women - Kenema district, Sierra Leone, September 2014." Morbidity and Mortality weekly report **63**(51&52): 1226-1227.
Earle-Richardson, G., E. Erlach, V. Walz, O. Baggio, M. Kurnit, C. A. Camara, C. Craig, L. R. Dios, D. Yee and G. N. Soke (2021). "New Mixed Methods Approach for Monitoring Community Perceptions of Ebola and Response Efforts in the Democratic Republic of the Congo." Global Health: Science and Practice **9**(2): 332-343.
Elston, J. W., C. Cartwright, P. Ndumbi and J. Wright (2017). "The health impact of the 2014-15 Ebola outbreak." Public Health **143**: 60-70.
Enria, L. and S. Lees (2018). "Citizens, dependents, sons of the soil: Defining political subjectivities through encounters with biomedicine during the Ebola epidemic in Sierra Leone." Medical Anthropology Theory **5**(4).
Enria, L., S. Lees, E. Smout, T. Mooney, A. F. Tengbeh, B. Leigh, B. Greenwood, D. Watson-Jones and H. Larson (2016). "Power, fairness and trust: understanding and engaging with vaccine trial participants and communities in the setting up the EBOVAC-Salone vaccine trial in Sierra Leone." BMC Public Health **16**(1): 1140.
Erlach, E., B. Nichol, S. Reader and O. Baggio (2021). "Using Community Feedback to Guide the COVID-19 Response in Sub-Saharan Africa: Red Cross and Red Crescent Approach and Lessons Learned from Ebola." Health Secur **19**(1): 13-20.
Everly, G. S., Jr., O. Lee McCabe, N. L. Semon, C. B. Thompson and J. M. Links (2014). "The development of a model of psychological first aid for non-mental health trained public health personnel: the Johns Hopkins RAPID-PFA." J Public Health Manag Pract **20 Suppl 5**: S24-29.
Fofana Ibrahim, A. (2017). "I am a woman. How can I not help?": Gender performance and the spread of Ebola in Sierra Leone. Understanding West Africa's Ebola Epidemic: Towards a political economy. I. Abullah and I. Rashid. London, Zed Books: 161-186.
Freudenthal, E. (2020). How “Ebola business” threatens aid operations in Congo. The New Humanitarian.
Gale, N. K., G. Heath, E. Cameron, S. Rashid and S. Redwood (2013). "Using the framework method for the analysis of qualitative data in multi-disciplinary health research." BMC medical research methodology **13**(1): 117.
Gatiso, T. T., I. Ordaz-Nemeth, T. Grimes, M. Lormie, C. Tweh, H. S. Kuhl and J. Junker (2018). "The impact of the Ebola virus disease (EVD) epidemic on agricultural production and livelihoods in Liberia." PLoS Negl Trop Dis **12**(8): e0006580.
GAVI. (2020). "5 reasons why pandemics like Covid-19 are becoming more likely." Retrieved Apr 14 2022, from https://www.gavi.org/vaccineswork/5-reasons-why-pandemics-like-covid-19-are-becoming-more-likely.
Gillespie, A. M., R. Obregon, R. El Asawi, C. Richey, E. Manoncourt, K. Joshi, S. Naqvi, A. Pouye, N. Safi and K. Chitnis (2016). "Social mobilization and community engagement central to the

Ebola response in West Africa: lessons for future public health emergencies." Global Health: Science and Practice **4**(4): 626-646.

Glennerster, R., T. Suri and S. Bhogale (2016). "The implications of the Ebola outbreak on markets, traders, and food security in Sierra Leone." Bulletin: The economic impacts of Ebola.

Grand Bargain Secretariat. (2022). "About the Grand Bargain." Retrieved Apr 6, 2022, from https://interagencystandingcommittee.org/about-the-grand-bargain.

Gray, N., B. Stringer, G. Bark, A. Heller Perache, F. Jephcott, R. Broeder, R. Kremer, A. S. Jimissa and T. T. Samba (2018). "'When Ebola enters a home, a family, a community': A qualitative study of population perspectives on Ebola control measures in rural and urban areas of Sierra Leone." PLoS Negl Trop Dis **12**(6): e0006461.

Hoskins, J. (2002). "Introduction: blood mysteries: beyond menstruation as pollution." Ethnology: 299-301.

Inter-Agency Standing Committee. (2019). "Humanitarian System-Wide Scale-Up Activation Protocol for the Control of Infectious Disease Events." Retrieved January 14, 2022, from https://interagencystandingcommittee.org/system/files/2021-03/IASC%2C%20Humanitarian%20System-wide%20Scale-Up%20Activation%20Protocol%20for%20the%20Control%20of%20Infectious%20Disease%20Events%2C%202019.pdf.

Inter-Agency Standing Committee reference group for gender in humanitarian action. (2015). "Humanitarian crisis in West Africa (Ebola) Gender Alert." Retrieved Sept 18, 2018, from https://interagencystandingcommittee.org/system/files/iasc_gender_reference_group_-_gender_alert_west_africa_ebola_2_-_february_2015_0.pdf.

Inter-Agency Working Group on Reproductive Health in Crisis. (2010). "Inter-agency field manual on reproductive health in humanitarian settings." from http://iawg.net/wp-content/uploads/2016/07/IAFM-2010.pdf.

International HIV/AIDS Alliance and Frontiers Prevention Project. (2006). "Tools together now! 100 participatory tools to mobilise communities for HIV/AIDS." Retrieved Aug 10, 2013, from https://www.aidsalliance.org/assets/000/000/370/229-Tools-together-now_original.pdf?1405520036.

James, M., J. G. Kasereka and S. Lees (2021). "The Politics of the Second Vaccine: Debates Surrounding Ebola Vaccine Trials in Eastern Democratic Republic of the Congo." Journal of Humanitarian Affairs **3**(3): 4-13.

Jones, S. and C. Ameh. (2015). "Exploring the impact of the Ebola outbreak on routine maternal health services in Sierra Leone." Retrieved Sept 19, 2018, from https://www.vsointernational.org/sites/default/files/VSO%20Sierroa%20Leone%20-%20Impact%20of%20Ebola.pdf.

Jones, S., B. Sam, F. Bull, S. B. Pieh, J. Lambert, F. Mgawadere, S. Gopalakrishnan, C. A. Ameh and N. van den Broek (2017). "'Even when you are afraid, you stay': Provision of maternity care during the Ebola virus epidemic: A qualitative study." Midwifery **52**: 19-26.

Jones, S. A., S. Gopalakrishnan, C. A. Ameh, S. White and N. R. van den Broek (2016). "'Women and babies are dying but not of Ebola': the effect of the Ebola virus epidemic on the availability, uptake and outcomes of maternal and newborn health services in Sierra Leone." BMJ Glob Health **1**(3): e000065.

Kaldor, M. and J. Vincent (2006). "Evaluation of UNDP assistance to conflict-affected countries: Case study Sierra Leone." Human Security. United Nations Development Programme Evaluation Office, New York.
Kapiriri, L. and L. Be LaRose (2018). "Priority setting for disease outbreaks in Uganda: A case study evaluating the process." Global Public Health **14**(2): 241-253.
Kentikelenis, A., L. King, M. McKee and D. Stuckler (2015). "The International Monetary Fund and the Ebola outbreak." The Lancet Global Health **3**(2): e69-e70.
Kingdon, J. (1984). Agendas, Alternatives and Public Policies. Boston, USA and Toronto, Canada, Little Brown and Company.
Koroma, M. and S. Lv (2015). "Ebola wreaks havoc in Sierra Leone." Infectious diseases of poverty **4**(1): 1-4.
Kotlar, B., E. Gerson, S. Petrillo, A. Langer and H. Tiemeier (2021). "The impact of the COVID-19 pandemic on maternal and perinatal health: a scoping review." Reprod Health **18**(1): 10.
Labat, A., M. Medina, M. Elhassein, A. Karim, M. B. Jalloh, M. Dramaix, W. H. Zhang, S. Alexander and K. E. Dickson (2018). "Contraception determinants in youths of Sierra Leone are largely behavioral." Reprod Health **15**(1): 66.
Lancaster, R. (2019). "When love spreads disease: the 2014-2016 Ebola epidemic." Retrieved June 6, 2022, from https://storymaps.arcgis.com/stories/0ceb74e64f0442ab95ec7570f623947a.
Laverack, G. and E. Manoncourt (2016). "Key experiences of community engagement and social mobilization in the Ebola response." Glob Health Promot **23**(1): 79-82.
Leach, M. and H. McGregor (2020). "Pandemics – social sciences are vital, but we must take the next steps." https://www.ids.ac.uk/opinions/pandemics-social-sciences-are-vital-but-we-must-take-the-next-steps/ 2020.
Leavitt, H. J. (1965). "Applied organizational change in industry: Structural, technological and humanistic approaches." Handbook of organizations **1144**: 1170.
Lees, S., J. Palmer, F. Procureur and K. Blanchet (2020). "Contested legitimacy for anthropologists involved in medical humanitarian action: experiences from the 2014-2016 West Africa Ebola epidemic." Anthropology & Medicine: 1-19.
Leight, J., C. Hensly, M. Chissano and L. Ali (2021). "Short-term effects of the COVID-19 state of emergency on contraceptive access and utilization in Mozambique." PLoS One **16**(3): e0249195.
Lewis, C., A. Banga, G. Cimanuka, J. De Dieu Hategekimana, M. Lake and R. Pierotti (2019). "Walking the Line: Brokering Humanitarian Identities in Conflict Research." Civil Wars **21**(2): 200-227.
Lie, J. H. S. (2020). "The humanitarian-development nexus: humanitarian principles, practice, and pragmatics." Journal of International Humanitarian Action **5**(1).
Lipton, J. (2014). "Care and burial practice in Urban Sierra Leone."
Lipton, J. (2017). "'Black'and 'white'death: burials in a time of Ebola in Freetown, Sierra Leone." Journal of the Royal Anthropological Institute **23**(4): 801-819.
Lipton, J. (2019). Taking Life 'Off Hold': Pregnancy and Family Formation During the Ebola Crisis in Freetown, Sierra Leone. Pregnant in the Time of Ebola, Springer: 329-337.
Loewen, S., J. Pinchoff, T. D. Ngo and M. J. Hindin (2021). "The impact of natural disasters and epidemics on sexual and reproductive health in low- and middle-income countries: A narrative synthesis." Int J Gynaecol Obstet.

Macrotrends. (2021). "Goma, Republic of Congo Metro Area Population 1950-2022." Retrieved Jan 10, 2022, from https://www.macrotrends.net/cities/205453/goma/population#:~:text=The%20metro%20area%20population%20of,a%206.19%25%20increase%20from%202017.

Madianou, M., J. C. Ong, L. Longboan and J. S. Cornelio (2016). "The Appearance of Accountability: Communication Technologies and Power Asymmetries in Humanitarian Aid and Disaster Recovery." Journal of Communication **66**(6): 960-981.

Manguvo, A. and B. Mafuvadze (2015). "The impact of traditional and religious practices on the spread of Ebola in West Africa: time for a strategic shift." The Pan African Medical Journal **22**(Suppl 1).

McKay, G., B. Black, S. Mbambu Kahamba, E. Wheeler, S. Mearns and A. Janvrin (2019). Not All That Bleeds Is Ebola: How has the DRC Ebola outbreak impacted Sexual and Reproductive Health in North-Kivu? New York, USA, The International Rescue Committee

McPake, B., S. Witter, S. Ssali, H. Wurie, J. Namakula and F. Ssengooba (2015). "Ebola in the context of conflict affected states and health systems: case studies of Northern Uganda and Sierra Leone." Confl Health **9**: 23.

Mendenhall, E. (2017). "Syndemics: a new path for global health research." The Lancet **389**(10072): 889-891.

Mindtools. (2016). "The McKinsey 7S Framework 2016." Retrieved June 12, 2022, from https://www.mindtools.com/pages/article/newSTR_91.htm.

Minor, O. M. (2017). "Ebola and Accusation." Anthropology in Action **24**(2): 25-35.

Moran, B. (2018). "Fighting Ebola in conflict in the DR Congo." The Lancet **392**(10155): 1295-1296.

Morgan, L. M. (2001). "Community participation in health: perpetual allure, persistent challenge." Health policy and planning **16**(3): 221-230.

Mosse, D. (2006). "Anti-social anthropology? Objectivity, objection, and the ethnography of public policy and professional communities." Journal of the royal anthropological institute **12**(4): 935-956.

MSF. (2019). "Medical activities suspended after Ebola treatment centre attack." Retrieved Feb 25, 2022, from https://www.msf.org/medical-activities-suspended-after-ebola-treatment-centre-attack.

Nam, S. L., C. Thomas, F. Yumkella, R. Le Voir, A. Karim, M. Yilla and S. Kamara. (2016). "Health system resilience: Addressing mistrust in Sierra Leone." Retrieved June 30, 2017, from https://options.co.uk/sites/default/files/research_brief_health_systems_resilience_addressing_mistrust_in_sierra_leone.pdf.

Nejad, S. B., B. Allegranzi, S. B. Syed, B. Ellis and D. Pittet (2011). "Health-care-associated infection in Africa: a systematic review." Bulletin of the World Health Organization **89**: 757-765.

Nobles, J., E. Frankenberg and D. Thomas (2015). "The effects of mortality on fertility: population dynamics after a natural disaster." Demography **52**(1): 15-38.

Nqeketo, S., W. Mapanga, B. Mihretu, T. Adelekan, L. Chauke, Z. Dwane and L. Baldwin-Ragaven (2020). "Early Effects of the COVID-19 Pandemic on Family Planning Utilisation and Termination of Pregnancy Services in Gauteng, South Africa: March–April 2020." Wits Journal of Clinical Medicine **2**(2).

Nuriddin, A., M. F. Jalloh, E. Meyer, R. Bunnell, F. A. Bio, M. B. Jalloh, P. Sengeh, K. M. Hageman, D. D. Carroll and L. Conteh (2018). "Trust, fear, stigma and disruptions: community perceptions and experiences during periods of low but ongoing transmission of Ebola virus disease in Sierra Leone, 2015." BMJ global health **3**(2): e000410.
Nyenyezi Bisoka, A., K. Vlassenroot and L. Ramazani (2021). From Biolegitimacy to Antihumanitarianism: Understanding People's Resistance to Ebola Responses in the Democratic Republic of the Congo. Congo Research Briefs. SSRC. **Issue 8**.
Oosterhoff, P., E. Mokuwa and A. Wilkinson (2015). Community-based Ebola Care Centres: a formative evaluation, Ebola Response Anthropology Platform.
Pathmanathan, I., K. A. O'Connor, M. L. Adams, C. Y. Rao, P. H. Kilmarx, B. J. Park, J. Mermin, B. Kargbo, A. H. Wurie and K. R. Clarke (2014). "Rapid assessment of Ebola infection prevention and control needs—six districts, Sierra Leone, October 2014." MMWR. Morbidity and mortality weekly report **63**(49): 1172.
Pieterse, P. and T. Lodge (2015). "When free healthcare is not free. Corruption and mistrust in Sierra Leone's primary healthcare system immediately prior to the Ebola outbreak." Int Health **7**(6): 400-404.
Piot, P., J.-J. Muyembe and W. J. Edmunds (2014). "Ebola in west Africa: from disease outbreak to humanitarian crisis." The Lancet Infectious Diseases **14**(11): 1034-1035.
Reynolds, L. and S. Sariola (2018). "The ethics and politics of community engagement in global health research." Critical Public Health **28**(3): 257-268.
Richards, P., J. Amara, E. Mokuwa, A. Mokuwa and R. Suluku (2015). Village responses to Ebola virus disease and it's prevention: Gbo Chiefdom, Bo District, Sierra Leone. 8th interim Report to the SMAC programme, DfID. Freetown, Sierra Leone, Njala University.
Richardson, E., M. Barrie, D. Kelly, Y. Dibba, S. Koedoyoma and P. Farmer (2015). "Biosocial approaches to the 2013-2016 Ebola pandemic." Health and Human Rights Journal **18**(1).
Riley, T., E. Sully, Z. Ahmed and A. Biddlecom (2020). "Estimates of the potential impact of the COVID-19 pandemic on sexual and reproductive health in low-and middle-income countries." Int Perspect Sex Reprod Health **46**: 46.
Roepstorff, K. (2019). "A call for critical reflection on the localisation agenda in humanitarian action." Third World Quarterly **41**(2): 284-301.
Rohan, H. and G. McKay (2020). "The Ebola outbreak in the Democratic Republic of the Congo: why there is no 'silver bullet'." Nat Immunol **21**(6): 591-594.
Ronse, M., A. M. Sáez, C. Gryseels, M. Bannister-Tyrrell, A. Delamou, A. Guillard, M. Briki, F. Bigey, N. Haba and J. van Griensven (2018). "What motivates Ebola survivors to donate plasma during an emergency clinical trial? The case of Ebola-Tx in Guinea." PLoS neglected tropical diseases **12**(10): e0006885.
Ross, E. (2017). "Command and control of Sierra Leone's Ebola outbreak response: evolution of the response architecture." Philos Trans R Soc Lond B Biol Sci **372**(1721).
Rull, M., I. Kickbusch and H. Lauer (2015). "Policy Debate | International Responses to Global Epidemics: Ebola and Beyond." Revue internationale de politique de développement **6**(2).
Rycroft-Malone, J., K. Seers, A. Titchen, G. Harvey, A. Kitson and B. McCormack (2004). "What counts as evidence in evidence-based practice?" Journal of advanced nursing **47**(1): 81-90.

Salajan, A., S. Tsolova, M. Ciotti and J. E. Suk (2020). "To what extent does evidence support decision making during infectious disease outbreaks? A scoping literature review." Evidence & Policy: A Journal of Research, Debate and Practice.
Sandi, C., O. Barrie, H. Kanu and F. Sesay (2017). "Notes from the Field: Impact of Increasing the Number of Ebola Surveillance Officers—Kambia District, Sierra Leone, September 2014–September 2015." MMWR. Morbidity and mortality weekly report **66**(3): 90.
Schindell, B. G., A. L. Webb and J. Kindrachuk (2018). "Persistence and Sexual Transmission of Filoviruses." Viruses **10**(12): 683.
Shepler, S. (2017). ""We Know Who is Eating the Ebola Money!": Corruption, the State, and the Ebola Response." Anthropological Quarterly **90**(2): 451-473.
Shirley, A., S. Lilley, L. Stark, K. Muldoon, D. King, D. Lamin and M. Wessells (2014). Preventing Teenage Pregnancy in Sierra Leone. Impact Evaluation Baseline Report. London, Interagency Learning Initiative on Community-Based Child Protection Mechanisms and Child Protection Systems.
Shoman, H., E. Karafillakis and S. Rawaf (2017). "The link between the West African Ebola outbreak and health systems in Guinea, Liberia and Sierra Leone: a systematic review." Global Health **13**(1): 1.
Shrum, W., J. Aggrey, A. Campos, J. Pamplona da Costa, J. Joseph, P. Kreimer, R. Kroeger, L. Rodriguez Medina, P. Miller and A. Palackal (2020). "Who's afraid of Ebola? Epidemic fires and locative fears in the Information Age." Social Studies of Science: 0306312720927781.
Siekmans, K., S. Sohani, T. Boima, F. Koffa, L. Basil and S. Laaziz (2017). "Community-based health care is an essential component of a resilient health system: evidence from Ebola outbreak in Liberia." BMC Public Health **17**(1): 84.
Sikakulya, F. K., M. K. Ilumbulumbu, S. F. Djuma, G. K. Bunduki, A. K. Sivulyamwenge and M. K. Jones (2021). "Safe and dignified burial of a deceased from a highly contagious infectious disease ebolavirus: Socio-cultural and anthropological implications in the Eastern DR Congo." One Health **13**: 100309.
Sochas, L., A. A. Channon and S. Nam (2017). "Counting indirect crisis-related deaths in the context of a low-resilience health system: the case of maternal and neonatal health during the Ebola epidemic in Sierra Leone." Health Policy Plan **32**(suppl_3): iii32-iii39.
Sofaer, S. (1999). "Qualitative methods: what are they and why use them?" Health services research **34**(5 Pt 2): 1101.
Statistics Sierra Leone and ICF Macro (2009). Sierra Leone Demographic and Health Survey 2008. Freetown, Sierra Leone, Calverton, Maryland, USA, Statistics Sierra Leone (SSL) and ICF Macro.
Statistics Sierra Leone (SSL) and ICF International (2014). Sierra Leone demographic and health survey 2013. Freetown, Sierra Leone
Rockville, Maryland, SSL and ICF International.
Strong, A. and D. A. Schwartz (2016). "Sociocultural aspects of risk to pregnant women during the 2013-2015 multinational Ebola virus outbreak in West Africa." Health Care Women Int **37**(8): 922-942.
Takemoto, M. L. S., G. McKay, M. Amorim, C. N. Gbomosa, A. F. Tengbeh and C. Wenham (2021). "How can countries create outbreak response policies that are sensitive to maternal health?" BMJ **373**: n1271.

Tan, D. A., R. Haththotuwa and I. S. Fraser (2017). "Cultural aspects and mythologies surrounding menstruation and abnormal uterine bleeding." Best Practice & Research Clinical Obstetrics & Gynaecology **40**: 121-133.
The International Rescue Committee (2019). Everything on her shoulders: rapid assessment on gender and violence against women and girls in the Ebola outbreak in Beni, DRC.
US Centers for Disease Control and Prevention. (2022). "History of Ebola Virus Disease (EVD) outbreaks." Retrieved Feb 24, 2022, from https://www.cdc.gov/vhf/ebola/history/chronology.html.
Van Bortel, T., A. Basnayake, F. Wurie, M. Jambai, A. S. Koroma, A. T. Muana, K. Hann, J. Eaton, S. Martin and L. B. Nellums (2016). "Psychosocial effects of an Ebola outbreak at individual, community and international levels." Bull World Health Organ **94**(3): 210-214.
Vigh, H. (2008). "Crisis and chronicity: Anthropological perspectives on continuous conflict and decline." Ethnos **73**(1): 5-24.
Viljoen, L. (2018). "Beyond the Numbers: Why Qualitative Data Should Not Be Used to Make Quantifying Claims--Understanding the Real Value of Qualitative Research." DSBS Fieldnotes http://www.dsbsfieldnotes.uct.ac.za/news/beyond-numbers-why-qualitative-data-should-not-be-used-make-quantifying-claims-understanding.
Wilkinson, A., M. Parker, F. Martineau and M. Leach (2017). "Engaging 'communities': anthropological insights from the West African Ebola epidemic." Philos Trans R Soc Lond B Biol Sci **372**(1721).
Witter, S., N. Brikci, T. Harris, R. Williams, S. Keen, A. Mujica, A. Jones, A. Murray-Zmijewski, B. Bale and B. Leigh (2016). "The Sierra Leone free health care initiative (FHCI): process and effectiveness review."
Witter, S., H. Wurie and M. P. Bertone (2016). "The free health care initiative: how has it affected health workers in Sierra Leone?" Health Policy Plan **31**(1): 1-9.
Wong, P. N. (2012). "Discerning an African Post-colonial Governance Imbroglio: Colonialism, Underdevelopment and Violent Conflicts in the Democratic Republic of Congo (DRC), Liberia and Sierra Leone." African and Asian Studies **11**(1-2): 66-94.
Wood, S. N., C. Karp, F. OlaOlorun, A. Z. Pierre, G. Guiella, P. Gichangi, L. A. Zimmerman, P. Anglewicz, E. Larson and C. Moreau (2021). "Need for and use of contraception by women before and during COVID-19 in four sub-Saharan African geographies: results from population-based national or regional cohort surveys." The Lancet Global Health **9**(6): e793-e801.
World Health Organization (1978). Declaration of Alma-Ata, World Health Organization. Regional Office for Europe.
World Health Organization (2015). World health statistics 2015, World Health Organization.
World Health Organization. (2016). "Ebola data and statistics: Countries with intense transmission: Sierra Leone." Retrieved Aug 15, 2017, from http://apps.who.int/gho/data/node.ebola-sitrep.ebola-country-SLE?lang=en.
World Health Organization. (2016). "Ebola situation report - 30 March 2016." Retrieved Aug 16, 2017, from http://apps.who.int/ebola/current-situation/ebola-situation-report-30-march-2016.
World Health Organization (2017). "Emergency response framework (ERF)."

World Health Organization (2018). "Risk communication and community engagement preparedness and readiness framework: Ebola response in the Democratic Republic of Congo in North Kivu."

World Health Organization. (2019). "United Nations strengthens Ebola response in Democratic Republic of the Congo."   Retrieved Sept 9 2020, from https://www.who.int/news-room/detail/23-05-2019-united-nations-strengthens-ebola-response-in-democratic-republic-of-the-congo.

World Health Organization (2020). "Community engagement: a health promotion guide for universal health coverage in the hands of the people."

World Health Organization (2020). Ebola Virus Disease Democratic Republic of the Congo External Situation Report 98.

World Health Organization (2020). Pulse survey on continuity of essential health services during the COVID-19 pandemic: interim report, 27 August 2020, World Health Organization.

World Health Organization. (2021). "COVID-19 continues to disrupt essential health services in 90% of countries." from https://www.who.int/news/item/23-04-2021-covid-19-continues-to-disrupt-essential-health-services-in-90-of-countries.

World Health Organization. (2021). "Ebola Virus Disease."   Retrieved Sept 25, 2021, 2021, from https://www.who.int/news-room/fact-sheets/detail/ebola-virus-disease.

Wurie, H. R., M. Samai and S. Witter (2016). "Retention of health workers in rural Sierra Leone: findings from life histories." Hum Resour Health **14**: 3.

Yerger, P., M. Jalloh, C. E. M. Coltart and C. King (2020). "Barriers to maternal health services during the Ebola outbreak in three West African countries: a literature review." BMJ Global Health **5**(9): e002974.

Appendix A: Sierra Leone Topic Guides

Interviews: Women who took FP

1) Please introduce yourself. (ethnicity, location, religion, age, #children, married, occupation)
2) Tell me about your Ebola story.
3) Tell me about your FP experience. What do you think about FP?
4) Before Ebola, did you get FP services? If yes, tell me about getting such services.
5) What happened during Ebola for you? (very open ended question, just to get people talking). Ask about experiences with health services generally.
6) Why did you want FP during the Ebola outbreak? What it like to get FP during the Ebola outbreak? What made it easier or harder to get FP? Where did you go to get it? (Prompt for specific examples and locations)
7) How did religion impact on your decision to seek family planning?
8) How did your husband or partner impact on your decision? What about your mother or sisters or mother in law?
9) How did you make the decision to seek out FP during Ebola? Who was involved in the decision? Why were they involved in your decision?
10) Do you want more children post ebola? Did your ebola experience change this for you in any way?
11) Were there barriers to overcome to get FP during Ebola? If so, how did you overcome them? Why did you want to? Why was it important to you to get the FP?
12) Tell me about the consultation you had with your FP service-provider during Ebola. How did they treat you? Did they wear gear/PPE? If yes, how did the PPE make you feel? What contraceptive options did they offer you? Why did you choose a particular contraceptive option?
13) Tell me about the method you chose to take. Why that one? Would you ever change?
14) What was the communication like between you and the provider?

15) Do you remember the “*no-touch*” policy? What did this policy mean to you? How did it impact your life? (Prompt re. child care, care of the sick, day to day life). How did it impact on your access to FP services? How did the “*no-touch*” change the FP service consultation?
16) Did sexual relations change during the time of Ebola? If yes, why? If no, why not?
17) Did you discuss FP with others? Tell me about any conversations you had with other women (friends, family) about getting FP during Ebola. (Prompt re. encouragement to go to clinic, reasons for discussions, fears about childbirth risks etc.)
18) Tell me about any conversations you had with husbands, boyfriends, uncles about getting FP during Ebola.
19) Did you or anyone you know get pregnant during Ebola? What did they do? What do “others” do if they get pregnant by accident? (Trying to ask about abortion services)
20) What if you wanted FP but it wasn’t available then what would you do? If you were impregnated by mistake what would you do?
21) If you had the option of getting a method that you could take yourself, would you have liked that?
22) Do you feel that the outbreak impacted your experiences of FP? Your relationships with providers of FP? Your attitudes towards healthcare services? If yes or no, why?
23) What do you think that health care workers, or the government, or other people could do to make this service more accessible in future outbreaks?
24) What behaviour change messages do you remember from Ebola? How did these impact on FP / reproduction / sex?
25) What suggestions do you have to improve FP if there was another similar outbreak in future?

Interviews: Women who did not take FP

1) Please introduce yourself. (ethnicity, location, religion, age, #children, married, occupation)
2) Tell me about your FP experience. What do you think about FP?
3) Tell me about your Ebola story.

4) Before Ebola, did you get FP services? If yes, tell me about getting such services. What did you take? Why did you stop taking this? Why did you never start taking any method?
5) What happened during Ebola for you? (very open ended question, just to get people talking). Ask about experiences with health services generally.
6) Did you want FP during the Ebola outbreak? Why did you not want it? What was it like to try to get FP during the Ebola outbreak? (Prompt for specific examples and locations)
7) Who was involved in the decision not to take FP? Why were they involved in your decision?
8) Was religion at all important in your decision?
9) Was you husband/partner/other family member important in your decision?
10) Do you remember the "*no-touch*" policy? What did this policy mean to you? How did it impact your life? (Prompt re. child care, care of the sick, day to day life). How did it impact on your access to FP services?
11) We know that during Ebola so things changed. Did sexual relations change during the time of Ebola? If yes, why? If no, why not?
12) Did your thoughts around reproduction change at all? Do you want more/less children post ebola?
13) How were young women thought of differently to married women who got pregnant during Ebola?
14) Did you discuss FP with others? Tell me about any conversations you had with other women (friends, family) about getting FP during Ebola. (Prompt re. encouragement to go to clinic, reasons for discussions, fears about childbirth risks etc)
15) Tell me about any conversations you had with men about getting FP during Ebola.
16) Did anyone you know get pregnant during Ebola? What did they do? What do "*others*" do if they get pregnant by accident? (Trying to ask about abortion services)
17) Do you feel that the outbreak impacted your experiences of FP? Your relationships with providers of FP? Your attitudes towards healthcare services? If yes or no, why?
18) What do you think that health care workers, or the government, or other people could do to make this service more accessible in future outbreaks?

19) What behaviour change messages do you remember from Ebola? How did these impact on FP / reproduction / sex?
20) What suggestions do you have to improve FP if there was another similar outbreak in future?

Interviews: Health Care Workers

1) Tell me about yourself: age, level of training, years of experience and position during the outbreak.
2) Tell me about your Ebola story.
3) Tell me about providing FP services before Ebola.
4) What was providing FP like during the Ebola outbreak? How did you feel? How did your family feel about you providing care? What was it like after?
5) What made it easier or harder to provide FP? (Prompt for specific examples)
6) Why did you keep providing care? Did you feel afraid?
7) Did any policies impact on FP care during the Ebola response?
8) Delving into the "*no-touch*" policy, can you tell me what providing care was like with this policy in place? Did it change the relationship with your client? How so? Can you give an example?
9) Did you provide any care to patients outside the clinic setting? Did clients ever ask you to do this? Do you know anyone who did?
10) Tell me about the PPE that was used when providing care during Ebola? (Prompt re. availability, training etc.). How did this change the relationship with your client?
11) Tell me about how different methods of contraception (i.e. IUDs, pills, injectables) are offered now. And how were they offered in Ebola? Were there stockouts?
12) Thinking about how IUDs and pills are different in terms of how they are provided (invasiveness), did this change decision making around providing or receiving this type of contraception? Can you give me examples?
13) How did your family feel about your providing care during Ebola?

14) What suggestions do you have to improve FP services if there was another similar outbreak in future? (Sayana Press?)

Interviews: Stakeholders

1) Tell me about yourself: age, level of training, years of experience and position during and after the outbreak.
2) Tell me about FP services in your District/Country/Region. How are they delivered? Who delivers them? (Only clinics? Or also pharmacies?) Who is prioritized for FP services? What are the opportunities and challenges?
3) Ask about experience during Ebola as a policy-maker/implementer and about FP policy-making and implementation experiences
4) Tell me about FP services back during the Ebola outbreak. Did the services change? What were the opportunities and challenges? How were FP services prioritized during the Ebola response?
5) How was record keeping for FP services during the outbreak?
6) If an outbreak similar to Ebola was to happen again, how would you like the FP services to be implemented? What would be different to last time? (Prompt re. scale up, prioritization, quality)
7) Who else would you recommend that I should talk to about this issue?
8) Are there particular documents that you think I should know about and read? Ie. Strategies etc?
9) How did other messaging around behaviour change impact on family planning messaging?

Focus Group Discussions: Women who did/did not receive FP services

Using FlipChart: What are the main fears and concerns you had during Ebola? Then rank them in order.

We’re going to talk about FP. Although pregnancy wasn’t a major concern now I want to talk about your access to FP. What experiences do you have with FP? Before Ebola? After Ebola? Why do women want FP?

Using FlipChart: What barriers are there between a woman wanting and getting FP during Ebola? Draw. How can we minimize those barriers? What would you suggest?

1) What made it hard to get FP during Ebola? Were there barriers?
2) What made it easy to get FP during Ebola? Were there facilitators?
3) Some women have said that it was pretty easy to get FP during Ebola, but often through “unconventional means” (i.e. going to the HCP after hours and paying). What do you think about this?
4) If you were to get FP during Ebola, where would you go? How would you negotiate this decision with your family?
5) How did your family feel about you going to get HC during Ebola? Was it dangerous? Or safe?
6) How did you feel about HCP during Ebola? Has this changed post-Ebola? Is there any change in the relationship?
7) Was the clinic the place of infection? Or was the HCP the source? Would you have sought HC from a HCP outside the clinic?

Intimacy

1) The “no-touch” or “avoid body contact” policy made a difference for some people in the home. Can you tell me about this?
2) The “no-touch” or “avoid body contact” policy made a difference for some people outside the home. Can you tell me about this?
3) How did the policy differ between insiders/close contacts (family and people in the home) and others/outsiders (people in market, neighbours)?

4) In the household, how about mummy-daddy business (sex) during Ebola? How did this change or not change?

Quarantine

1) How did quarantine change pregnancy?
2) How did quarantine change FP?
3) How did quarantine change sexual behaviour?

If in 2020 there was a similar outbreak, what would you do differently? How would you deliver services? How would you want the services to be organized? If you were able to provide FP care privately (with PPE) during Ebola, would you? How could it be made safer? What about pharmacies, how can they be places for women to get FP during outbreak times when clinics are closed?

Appendix B: North-Kivu Topic Guides

*Note that this guide iterated over time.

Question	Probe
For all respondents	
Please can you start by telling us a little about your role within the North-Kivu Ebola response	What does your organisation do? Which response pillars does your organization support? In what ways? With what activities?
What is your role within that organisation/those activities?	Has your role changed over time? In what ways?
Please can you tell us a little about strategic/policy decision making processes within the N. Kivu response? (please feel free to provide an example from a specific pillar or initiative)	Who/which organisations are involved in decisions relating to changes of protocols or other policy guidance? At which level of the response are those decisions taken? At which level of the response are those decisions implemented? What factors play into the way that decisions are made in this response? (political/social/economic/coordination structures etc) Are changes in policy or protocol communicated to other decision makers or organisations involved in coordination and decision-making? How?
What is considered 'evidence' in this response?	Where does the evidence for strategic or policy decision making come from? Who produces it?

	Are some forms of evidence used or valued more than others and why? What factors play into the decision to use some evidence vs. others? Is the quality of the evidence used or considered assessed; if so, how?
How does evidence – epidemiological or otherwise – inform decision making?	Who is responsible for ensuring that new information or analytical work is communicated to decision-makers? Are there routine channels for communicating new evidence from the response to decision-makers? Are these effective? Why/why not? How does that process work in practice? What's the information flow? Is uptake of evidence affected by who produced it? How? In what ways?
What challenges exist to improving response decision-making processes?	How fast are decisions made? How long between making a decision and changing a policy/approach/strategy? Speed of decision-making? Location of decision-making (e.g. different coordination levels)? Information management/flow of evidence to inform decisions?

	Institutional/information management/political/complexity of response – probe as to what exactly and how those challenges play out.
What are the processes for cascading decisions down to the implementation level?	How are policy changes communicated to implementing organisations or staff? How well does this process work? What are the specific challenges with reducing that policy/practice gap?
What do you know about IFRC's CF mechanism?	How does it work? How does it compare to other feedback mechanisms? What are its strengths and weaknesses?
How is the information from the CF system integrated into response decision-making/strategy development?	Is it similar or different to the other evidence uptake processes we discussed earlier? In what ways? *(If different)* Why do you think this is?
What are the barriers for improving the integration of the CF mechanism (into Ebola coordination/decision-making)?	What opportunities are there to improve that integration?
Can you give me an example of how the CF has successfully been used to change a policy/protocol/strategy/approach?	How did that work? Why was it successful?
Can you give me an example of a time where CF was available but it was **not**	Why was it not considered?

incorporated into strategy development/decision-making?	What are the challenges with making that policy/practice change? What could be done differently?
How would decisions relating to this example/event have differed if the CF information had been available/been known about?	Use negative event example/timeline to prompt respondents
What recommendations would you give to ensure that CF is better integrated into response strategy and decision-making?	Different ways of presenting the information/wider reach for the feedback data/clearer recommendations/different engagement with decision-makers? How? In what ways? Why?
For respondents associated with the SDB or RCCE pillars	
Tell us about the SDB or comms pillar. How does it work?	What is its role/remit within the wider response? Who are the organisations or critical individuals involved? Who typically makes decisions within/for the SDB/RCCE pillar?
What are the processes for changing SDB or risk comms SOPs?	What information is used to make changes? Who produces that information? How does it communicated to the SDB pillar/pillar leads?
In your opinion, does the SDB pillar have information needs that have been/are currently unmet?	What are these?

	Are there ways you can see that could resolve these information needs? Who would need to be involved in resolving this?
How is the information from the IFRC's CF mechanism (or other feedback mechanisms) integrated into SDB strategies and protocols?	What are the barriers/challenges in this process? What are the opportunities?
Tell me about the linkages between CF and SDB strategy and approaches.	How has CF data fed into SDB decision making? What specific changes have you seen in SDB approaches/strategy relating to CF information? What hasn't changed yet based on this information? What may be blocking these changes?

FOCUS GROUP TOPIC GUIDES

*Note that this guide iterated over time.

Question	Probes
(Around the table) Tell us about your role in the Ebola Response	
How does the CF information collection system work?	Can you draw it out for us? Tell us how you record CF – count number of times etc. How do you decide what to record?

	How do you decide who to talk to for the feedback? Are there particular groups that are more/less likely to talk to you? Which ones? What changes to the system have taken place since you started working in this area? Why were these changes made? Are they positive or negative and why?
Do you get information about what other communities have told your colleagues through the CF system?	(if yes) how do you use this information? (if no) would you like to receive this information? How would it help you? What would you do with it?
Tell us about the challenges that you encounter collecting this information?	Prompt re. people's willingness to talk, security issues, language etc
After the information is collected, what happens?	If there is a clear recommendation for change (from the community) as regards the Ebola Response strategy or approach does the change take place? If yes, how? If no, why not?
If a change based on CF has been recommended and no change is made what happens?	How does the community feel about this? How does this affect you and your work?
How could the feedback mechanism work better?	For you?

	For the community? For other Ebola response workers? What recommendations would you make?

For respondents associated with the SDB or RCCE pillars	
Tell us about the SDB or comms pillar. How does it work?	What is its role/remit within the wider response? Who are the organisations or critical individuals involved? Who typically makes decisions within/for the SDB/RCCE pillar?
What are the processes for changing SDB or risk comms SOPs?	What information is used to make changes? Who produces that information? How does it communicated to the SDB pillar/pillar leads?
In your opinion, does the SDB pillar have information needs that have been/are currently unmet?	What are these? Are there ways you can see that could resolve these information needs? Who would need to be involved in resolving this?
How is the information from the IFRC's CF mechanism (or other feedback mechanisms) integrated into SDB strategies and protocols?	What are the barriers/challenges in this process? What are the opportunities?
Tell me about the linkages between CF and SDB strategy and approaches.	How has CF data fed into SDB decision making?

	What specific changes have you seen in SDB approaches/strategy relating to CF information? What hasn't changed yet based on this information? What may be blocking these changes?

Appendix C: North-Kivu Coordination Meetings, Documents and Interviewee Profiles

COORDINATION MEETINGS ATTENDED AND DOCUMENTS REVIEWED

Coordination Meeting	Coordination Level
Community Feedback	Sub-Coordination Level – Beni
Risk Communications & Community Engagement Partners	Operational Level – Beni
Risk Communications & Community Engagement Partners	Strategic Level – Goma
General Coordination	Strategic Level – Goma
UN Communications Coordination	Strategic Level – Goma
Community Feedback	Operational Level – Goma
Internal Red Cross Community Feedback	Sub-Coordination Level – Goma

Document	Author	Version or Date
Strategic Response Plan 3: February – July 2019 For the Ebola Virus Disease Outbreak in the Provinces of North-Kivu and Ituri	DRC MOH	13 Feb 2019
Strategic Response Plan 4: July – December 2019 For the Ebola Virus Disease Outbreak in the Provinces of North-Kivu and Ituri	DRC MOH	9 August 2019

Safe and Dignified Burial: An Implementation Guide for Field Managers	International Federation of the Red Cross	Version 4
Risk Communication and Community Engagement Preparedness and Readiness Framework: Ebola Response in the Democratic Republic of Congo in North-Kivu	Risk Communications & Community Engagement Incident Management Team for the DRC Ebola outbreak response (WHO, UNICEF, IFRC, GOARN Research, US CDC, SSHAP, Anthrologica)	September 2018
Red Cross CF Mechanism in DRC: Guidance on how to collect and use Community Feedback during an Ebola operation	IFRC	29 May 2019
Community Feedback Infographic	IFRC	2019
Annexe des 25 Questions: Questions & Réponses Sur Les Vaccins Contre Ebola	IFRC & RCCE Pillar	November 2019
Enterrements Communautaires d'Urgence a Moindre Risque (ECUMR)	IFRC & DRC Red Cross	November 2018

KEY INFORMANT INTERVIEWS

*Note that organisations and profiles of interviewees have been left deliberately vague to ensure anonymity of research participants

Type of Organisation	**Profile of Interviewee**	**Number of Interviewees**
Response Technical Commission	Risk Communications & Community Engagement Specialist	4
Response Technical Commission	Case Management Specialist	1
Response Technical Commission	Social Science Specialist	1
Response Technical Commission	Monitoring and Evaluation Specialist	1
Response Technical Commission	Infection Prevention and Control Specialist	3
Response Technical Commission	Epidemiologist	1
UN Agency	Area Coordinator	1
UN Agency	Programme Coordinator	1
UN Agency	Communications Specialist	2
National Humanitarian Agency	Risk Communications & Community Engagement Coordinator	1
National Humanitarian Agency	Safe and Dignified Burials Manager	1
National Humanitarian Agency	Programme Coordinator	1
National Humanitarian Agency	Information Management Manager	1
International Humanitarian Agency	Community Engagement Specialist	2
International Humanitarian Agency	Safe and Dignified Burials Coordinator	1
International Humanitarian Agency	Infection Prevention and Control Coordinator	1
Technical Assistance Body	Technical Advisor	2
Funding Body	Technical Advisor	1
International NGO	Communications Expert	1
International NGO	Public Health Coordinator	1
International NGO	Programme Manager	1
International NGO	Risk Communications & Community Engagement Coordinator	1

Focus Group Discussions with Red Cross staff

Technical Area of Interviewees	**Location**	**Number of Participants**
Community Engagement and Accountability	Goma	18
Safe and Dignified Burial	Beni	7 (over two FGDs)