A Partnership Approach to Improving Humanitarian Assistance: Patient and Community Narratives of Cholera in Haiti

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November, 2021

A thesis submitted to McGill University, in partial fulfilment of the requirements of the degree of Doctor of Philosophy (PhD) at the Department of Family Medicine

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Abstract

There remains a certain level of hesitancy, not only on an operational level but also on an academic level to implement participatory research (PR) approaches in humanitarian settings with real barriers such as the required investment in time, access and priorities to respond to urgent needs. In this thesis I explore 'if and how' PR, that involves the collection of individual and community experiences with illness and health, might contribute to improving the humanitarian hygiene promotion (HP) response. Understanding and integrating the experiences and perceptions of the affected population is important as the success of HP depends mostly on human behaviour. I explore the implementation of a PR approach that aims to improve peoples' experiences with HP services in the cholera outbreak in Haiti. Cholera was inadvertently introduced in Haiti after the earthquake in 2010 by United Nations peacekeepers and caused almost 10.000 related deaths. A large national and international response followed which included HP efforts to motivate the population to adopt safe hygiene practices.

In this thesis I first examine the literature on PR approaches in humanitarian settings. Second, I consider previous research investigating the HP response of the cholera outbreak in Haiti. Third, I report on the implementation and findings of an Experience-Based Co-Design (EBCD) study in the HP response in Haiti. The scoping review found that the use of PR approaches in humanitarian settings is an emerging field. PR was described to be particularly valuable to establish trust between different stakeholders and it provided much needed contextual understanding. Previous research investigating HP efforts in the cholera response in Haiti rarely collected data on local knowledge, experiences and trust and none applied a PR approach. Thus, studies to date have contributed to addressing mechanisms related to biomedical knowledge, but have missed addressing mechanisms related to perceptions and experiences. The pilot EBCD created a process where both the humanitarian staff and the affected community members had the opportunity to discuss complex issues and potential changes or solutions. Building upon the different findings I demonstrate how listening to and collaborating with affected populations, through participatory methods, can contribute to improved HP and humanitarian programs. The research presented in this thesis contributes to the continued efforts and intentions of humanitarian organizations to implement participatory approaches in the field.

Résumé

Il existe toujours un certain niveau d'hésitation, non seulement au niveau opérationnel mais aussi au niveau académique, à mettre en œuvre des approches de recherche participative dans des contextes humanitaires avec de véritables obstacles tels que l'investissement de temps nécessaire, l'accès et les priorités pour répondre aux besoins urgents. Dans cette thèse, j'explore " si et comment " la recherche participative, mettant en vedette l'engagement des patients, des membres de la communauté et du personnel de l'AAH comme partenaires, leurs perceptions individuelles et communautaires de la maladie, pourraient contribuer à améliorer la réponse humanitaire en matière de promotion de l'hygiène.

Il est important de comprendre et d'intégrer les expériences et la perception de la population touchée, car le succès de la promotion de l'hygiène dépend essentiellement du comportement humain. J'étudie la mise en œuvre d'une approche de recherche participative visant à améliorer les expériences des gens avec les services de promotion de l'hygiène lors de l'épidémie de choléra en Haïti. Le choléra a été introduit par inadvertance après le tremblement de terre en Haïti en 2010 par des soldats de la paix des Nations Unies et a causé près de 10 000 décès. Une réponse nationale et internationale de grande envergure a suivi, impliquant des efforts de promotion de l'hygiène pour motiver la population à adopter des pratiques d'hygiène sécuritaires.

Dans cette thèse, j'analyse d'abord la documentation sur les approches de recherche participative dans les contextes humanitaires. Ensuite, j'étudie les recherches précédentes sur la réponse de promotion de l'hygiène à l'épidémie de choléra en Haïti. Enfin, je présente la mise en œuvre et les résultats d'une étude de « co-conception fondée sur l'expérience » (Experience-Based Co-Design - EBCD) dans le cadre de la réponse de promotion de l'hygiène en Haïti. L'examen exploratoire a révélé que l'utilisation des approches de RP dans les contextes humanitaires est un domaine émergent. La recherche participative a été décrite comme étant particulièrement utile pour établir la confiance entre les différentes parties prenantes et elle a apporté une compréhension contextuelle indispensable. Les recherches antérieures sur les efforts de promotion de l'hygiène dans le cadre de la réponse au choléra en Haïti ont rarement recueilli des données sur les connaissances, les expériences et la confiance au niveau local et aucune n'a appliqué une approche de recherche participative. Ainsi, les données recueillies ont contribué à aborder les mécanismes liés aux connaissances biomédicales, mais ont omis d'aborder les mécanismes liés aux perceptions et aux expériences. L'EBCD pilote a créé un processus par lequel le personnel humanitaire et les membres des communautés affectées ont eu l'occasion de discuter de questions complexes et de changements ou solutions potentiels. En me basant sur les différents résultats, je démontre comment l'écoute et la collaboration des populations affectées, par le biais de méthodes participatives, peuvent contribuer à améliorer les stratégies de promotion de l'hygiène et d'aide humanitaire. La recherche présentée dans cette thèse contribue aux efforts continus et aux intentions des organisations humanitaires de mettre en œuvre des approches participatives sur le terrain.

Dedication

To Joel for seeing what I do not see

To Jonan for giving truth a new meaning

To Kyara who knows that words do not always mean what they say

Acknowledgements

The people who led Haiti to liberty, have been characterized by ‘he who opened the way’ (Toussaint Louverture) and “he who was able to finish tasks” (Jean-Jacques Dessalines); one could not have succeeded without the other. The strength of participatory research, to me, is that it acknowledges the strength and skills of many different people. The research in this thesis was possible because of the contribution of many different people and especially because of two inspiring supervisors: Drs. Susan Law and Ann C. Macaulay. These women have been a source of encouragement, generosity and motivation. It is sometimes said that people fear the unknown, the contrary is true for Susan Law who has the impressive skill to see the solutions rather than the problems. Ann C. Macaulay’s continuous efforts to add another layer of participation have changed the orientation of this research in a profound way.

The nervousness I felt when hosting the first PhD committee meeting rapidly changed to feeling excited to be able to share my research with these intelligent, wise and humble people. These meetings became the highlight of my study and allowed me to learn in profound ways. Dr. Jon Salsberg was a source of new ideas and insights while at the same time not losing an eye on the practical aspects. Dr. Matthew Hunt has continuously showed me new perspectives and areas of knowledge to explore. Plato said that wise (wo)men speak because they have something to say, it could not be truer for Dr. Alison Doucet who has moved my perspective and ideas in thoughtful ways when sharing her thoughts. Dr. Lisa Hinton was a source of inspiration always adding new ideas, vision and initiatives.

Even from a distance, the staff and students at the Department of Family Medicine have continued to inspire and support this research – especially Shinjini Mondal, who has been a true friend with whom I shared victories and challenges on a daily basis. Katya Loban and Svetlana Puzhko, thank you for reaching this final stage together and I would also thank Nadia O’Brien and David Loutfi, whose work has been an inspiration for how a thesis could look like.

Arriving in a new country to set-up a project is always a special moment, and when I think of the hygiene promotion team in Haiti, I still feel the enthusiasm, persistence and creativity of people who were always ready to engage in a serious conversation to tell me more about their work, country and people. A deep thank you to this special team in the Gonaives. I cannot close this session without specifically mentioning Action Against Hunger’s staff

members involved in the research: Kendy Massena, Guerby Dervil, Mazard Trazillio, Armelle Sacher, Bram Riems and Nicolas Villeminot, thank you for making this research possible.

In the Allegory of the cave, Plato describes a group of people, chained to a wall all their lives and whose reality exists of the shadows they see on the walls rather than the real world. My gratitude goes out to the participants' efforts and willingness to open a door to their lived reality which has profoundly changed how I perceive 'the shadows on the wall'. I wish to share an experience on my last day in the field in Haiti: we visited the cholera treatment centre and the hygienist, a kind man, opened the gate for us. His tasks were diverse; he cleaned the cholera treatment centre, cared for patients in the absence of nurses at night or when they had not been paid. He patiently showed us around and shared his experiences in an interview. Only this last day, he shared that he had done this work for seven years and never got paid. He is one of so many people I have encountered during my humanitarian work and research from whom I strive to learn how much can be done with so little.

What I will not be able to express in words is the gratitude I feel towards my family who provided their unfaltering support and presence at the good and bad times. My partner, Joel Montanez, has helped me in so many different dimensions and has been on my side while I struggled to find the right balance between work, family life and studies. This thesis has been written while I was in Canada, Bangladesh, the Democratic Republic of Congo, Haiti and of course the Netherlands where my roots are; my family's continuous love, confidence and perseverance have made this work so much lighter and enjoyable.

Acknowledgement of financial support

This thesis research has been made possible with financial support from Dr. Ian Graham's CIHR Foundation grant: *Moving knowledge into action for more effective practice, programs and policy: A research program focusing on integrated knowledge,* Fonds de Recherche Quebec – Santé (FRQS), doctoral award (2018-2021) Family Medicine Academic Excellence Research Award (2016) and the Graduate Mobility Award, McGill University (2017, 2020) from the McGill University, Department of Family Medicine. In addition, Action Against Hunger has provided financial and material support for the conduct of the research (including salary of the research assistant, accommodation, transport, and per diems)

Preface

This thesis follows the requirements and structure of a manuscript-based thesis. One manuscript has been published, two are under review and one will be submitted.

Contribution of authors

The overall scope and focus of the thesis (two reviews and field research) was originally determined in collaboration with Dr. Susan Law and with Dr. Ann Macaulay when she became a joint supervisor in 2017. This was a PR project that included and valued the contributions of everyone involved in this research including the community members and key stakeholders. The contents and direction of the scoping review and the review of research investigating the HP response in Haiti was determined in collaboration with the PhD thesis committee – Drs. Matthew Hunt, Lisa Hinton, Jon Salsberg and Alison Doucet. The pilot of the EBCD has been made possible thanks to a collaboration with the humanitarian organization Action Against Hunger (AAH). This research was part of the hygiene promotion (HP) response in the cholera outbreak in Haiti. The design of the EBCD approach was initially developed in collaboration with the thesis supervisor Dr. Susan Law, the members of the PhD committee, and Nicolas Villeminot, Trazillio Mazard and Francis Alerte who all worked for AAH. Dr. Ann C. Macaulay (supervisor), Kendy Massena, Armelle Sacher provided contributions since the start of the study. Even though I perceive this project as a collaborative approach, I as a PhD candidate and first-author on all the manuscripts included in this dissertation had the final responsibility for the identification of the field research opportunity, the establishment of a research team in Haiti, the data analysis, interpretation of findings, design and writing of the manuscripts and the introduction, literature review and discussion in this thesis.

Manuscript 1:

Ormel I, Salsberg J, Hunt M, Doucet A, Hinton L, Macaulay A, Law S. (2020). "Key issues for participatory research in the design and implementation of humanitarian assistance: a scoping review." *Global Health Action* 13(1): 1826730. DOI: 10.1080/16549716.2020.1826730

IO designed the scoping review, screened the manuscripts, extracted the data, conducted the analysis and interpretation and wrote the manuscript. SL contributed to the design, manuscript screening, data extraction, interpretation and writing. JS, MH, AD, LH, AM each contributed to the design, interpretation and writing. All authors read and approved the final manuscript.

Manuscript 2:

Ormel I, Hunt M, Hinton L, Salsberg J, Doucet A, Massena K, Macaulay AC, Law S. Hygiene promotion research in disease outbreaks in humanitarian settings: the case of cholera in Haiti*. Submitted to BMC Public Health, May 2021*

IO designed the review, screened the manuscripts, extracted the data, conducted the analysis and interpretation and wrote the manuscript. SL contributed to the design, manuscript screening, data extraction, interpretation and writing. MH, LH, JS, AD, KM and AM each contributed to the design, interpretation and writing. All authors read and approved the submitted manuscript.

Manuscript 3:

Ormel I, Massena K, Doucet A, Hinton L, Salsberg J, Hunt M, Macaulay A, Sacher A, Law S. The role of trust in the hygiene promotion response in the cholera outbreak in Haiti: results from an Experience-Based Co-Design study. *Submitted to BMJ Open, May 2021*

IO designed the EBCD, collected the data, conducted the analysis and wrote the manuscript. KM contribute to the data collection and interpretation. AD, LH, JS MH, AM, AS and SL each contributed to the design, interpretation and writing. All authors read and approved the submitted manuscript.

Manuscript 4:

Ormel I, Massena K, Doucet A, Hinton L, Salsberg J, Hunt M, Macaulay A, Law S. The Cholera Outbreak in Haiti: Lessons Learned of Applying an Experience-Based Co-Design to improve the Hygiene Promotion Response. *Will be submitted to BMJ Health Care Services Research, July 2021*

IO extracted data from study notes and wrote the manuscript. KM, AD, LH, JS, MH, AM and SL each contributed to the design, interpretation and writing. All authors read and approved the manuscript.

Contribution to original knowledge

This thesis reported on the current practices of PR in humanitarian settings and the feasibility of adopting a particular PR approach to determine improvements in the HP response to the cholera outbreak in Haiti. Methodological contributions were identified through the implementation and reflections on the impact and challenges of conducting a pilot EBCD in a humanitarian setting. It demonstrated that it is possible to make adaptations to the traditional EBCD process, to make it culturally more appropriate and feasible within HP settings. The findings from this research also contributed to greater insight into how an improved understanding of affected communities' experiences and perspectives can contribute to improving the HP response in three different ways (improved understanding of the individual experience, as a mechanism of change and as an outcome measure). This research finds that an EBCD approach facilitates the generation of new knowledge based on experiential data, the application of the learning from affected communities' experiences and perspectives on improvements to the HP approach, and the implementation of collaborative approaches.

List of abbreviations

AAH	Action Against Hunger
CATI	Case-Area Targeted Interventions
CHS	Core Humanitarian Standard in Quality and Accountability
EBCD	Experience-Based Co-Design
HP	Hygiene promotion
IKT	Integrated Knowledge Translation
KAP	Knowledge, Attitudes and Practices
KTA	Knowledge to Action
LMIC	Low- and Middle-Income Countries
(i)NGO	(International) Non-Governmental Organization
ORS	Oral Rehydration Solution
PEER	Participatory Ethnographic Evaluation and Research
PR	Participatory Research
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
UNICEF	United Nations International Children’s Emergency Fund
WHO	World Health Organization

1 INTRODUCTION

Humanitarian medicine is not a marginal practice on the fringes of biomedicine and public health; it is an attempt to respond to the expectations of those people who are deprived of access to health care, in spite of their sometimes considerable demographic weight. Its specific and most important contribution to public health consists in developing medical practices that are better adapted to the living conditions and priorities of patients who are generally ignored (Magone, Neuman, & Weissman, 2012).

1.1 Introduction to the thesis

The focus of this thesis to explore 'if and how' PR, featuring engagement with patients, community members and AAH staff as partners, while also integrating individual and community perceptions of illness, might contribute to improving humanitarian responses. The last decades of humanitarian assistance have seen an increased attention to listening to the voices of affected communities. There remain, however, challenges to translate findings into changes in practice (Brown & Donini, 2014; Nouvet, Abu-Sada, de Laat, Wang, & Schwartz, 2016). In this thesis, a particular participatory or integrated Knowledge Translation (IKT) approach was adopted, known as Experience-Based Co-Design (EBCD), that combines research, patients' and staff's experiences and quality improvement components. To date, this approach has been mostly implemented in high income countries and in health care service settings (T. Green et al., 2020). In this thesis I pilot the implementation of this approach in the cholera outbreak in Haiti where the aim was to improve the HP services through learning from the affected populations' experiences.

The term 'hygiene promotion' (HP) can refer to a range of actions and practices and used indifferent ways. In this thesis, hygiene promotion concerns helping "people to understand and develop good hygienic practices, so as to prevent disease and promote positive attitudes towards cleanliness". While hygiene promotion is more narrowly defined than health promotion, HP is not simply the provision of information but also includes activities such as education, social mobilization, community engagement and encouraging community management (Howard & Bogh, 2002).

Figure 1-1 presents the three domains or bodies of knowledge that inform this thesis. The research for this thesis is situated in the centre of this figure where these domains converge; this conceptual orientation is also the starting point for framing the observations, interview questions and analysis (Morse, Hupcey, Penrod, & Mitcham, 2002).

*EBCD: Experience-Based Co-Design

***Figure 1- 1**: Conceptual domains for thesis research*

1.1.1 Participation[1] and humanitarian assistance (yellow and green domain):

A common understanding of 'participation' as an umbrella term includes 'different means for a group or the public to take part in all aspects of an activity, including the decision process' (Pouligny, 2009). In this thesis I apply the notion of participation that is 'about building a two-way relationship, a sharing of know-how and experiences' (CDA Collaborative Learning Projects, 2008), formerly known as the Collaborative for Development Action (CDA). Here, participation is regarded as a 'partnership' relationship. This thesis is guided by the body of literature that considers how collaboration with affected populations can contribute to improved humanitarian assistance. Anderson et al. (2012) has described this approach in such a context as the basis for a theory of change (2012):

> *"The role of international assistance in promoting positive social, political, and economic change in the countries where it is offered is to expand the range of options*

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[1] Participation as a concept is used in two different contexts in this proposal: participation of affected populations in the design, implementation and evaluation of humanitarian **interventions** and the use of participatory **research** approaches in humanitarian settings.

> *that people in that society can consider, to engage with them in weighing the costs and benefits of each option and, from this, to co-develop and co-implement a joint strategy for pursuing the changes they seek."*

The authors describe this as a paradigm shift from an externally driven delivery system to that of a collaborative system.

Literature that addresses the importance of participation identifies there is a need to report on how practice can be informed by the affected population's perceptions (Elmusharaf, Byrne, Manandhar, Hemmings, & O'Donovan, 2017; Nouvet et al., 2016). In the research conducted for this thesis, I collaborated with health promotion staff, humanitarian professionals and decision makers to jointly contribute to knowledge generation; we then worked together to apply this learning to improve the HP responses. I followed an IKT model which is a PR approach that aims to enhance the relevance and uptake of new knowledge (Kothari & Wathen, 2017) by ensuring engagement with decision makers in all aspects of knowledge creation (Graham, Tetroe, & Pearson, 2014) − the aim is to support the more timely application of new knowledge in mobilising research results into practice through the engagement of knowledge users. The learning from the experiences of former cholera patients, the perceptions of cholera in the community, and the perspectives of staff involved in cholera prevention efforts are central in this research.

1.1.2 Experiences of health and illness (pink domain):

Personal experiences of health and illness are "contextualized in terms of social history, social relations, socially-transmitted understandings and attitudes (e.g. stigma), economic structures and inequalities, power relations, and moral orientations" (Calabrese, 2013). The value of gathering and using health experiences has been well-documented (Hurwitz, Greenhalgh, & Skultans, 2008; Lucius-Hoene, Holmberg, & Meyer, 2018; Ziebland, Coulter, Calabrese, & Locock, 2013). In the health domain, there is a rapidly growing interest and appreciation for the value of narratives in changing health (Drewniak, Glässel, Hodel, & Biller-Andorno, 2020; Ziebland & Wyke, 2012) and health care (Locock et al., 2019). A recent evidence review of research on health programs in humanitarian crises highlighted priorities for further research, including the need to better understand the end-users perception of humanitarian health care delivery; and the need to better understand the ‘role and methods of behavioural change of end-users’ (Blanchet et al., 2015). In many situations, humanitarian agencies and government decision makers have some knowledge or perception regarding the population’s perspective on *what* should be done to improve practice, but it remains challenging to specify *how* change might be brought (Brown & Donini, 2014; Eyben, 2008; Nouvet et al., 2016). In the book *Understanding and Using Health Experiences: Improving Patient Care* (Ziebland et al., 2013), the authors demonstrate how understanding peoples’ experiences can contribute to a better understanding of what is working well in health care, what needs to change and how improvements might be made. This ‘narratives approach to change’ notion, as depicted in the conceptual framework, is captured in the statement “collecting data on patients experiences is not enough they must be used to improve care” (Coulter, Locock, Ziebland, & Calabrese, 2014).

1.1.3 Experience-Based Co-Design and scoping review (middle domain)

EBCD, as a form of IKT, involves patients, community members, staff, and decision makers from the beginning of the project – they participate as partners in a two-phase process, first to generate new knowledge about experiences of illness and care, and second to identify and implement recommended improvements. As described in more detail in the methods section and in the manuscripts, for this research, the creation of knowledge was based largely on the learning from the experiences of people who had or had not had cholera and key professionals involved in cholera response and prevention efforts; data was collected through focused observations and video or audio recorded interviews. In the classic application of EBCD, all project partners and participants are then invited to jointly identify recommendations for change that could improve the patients experience, followed by an implementation phase. In the case for this thesis, as described in the sections below, this second phase was not feasible for the reasons explained.

1.2 Overall aim

The general aim of this thesis was to explore ‘if and how’ PR, featuring engagement with patients, community members and AAH staff as partners, while also integrating individual and community perceptions of illness, might contribute to improving humanitarian responses. The specific research questions were articulated in each individual phase.

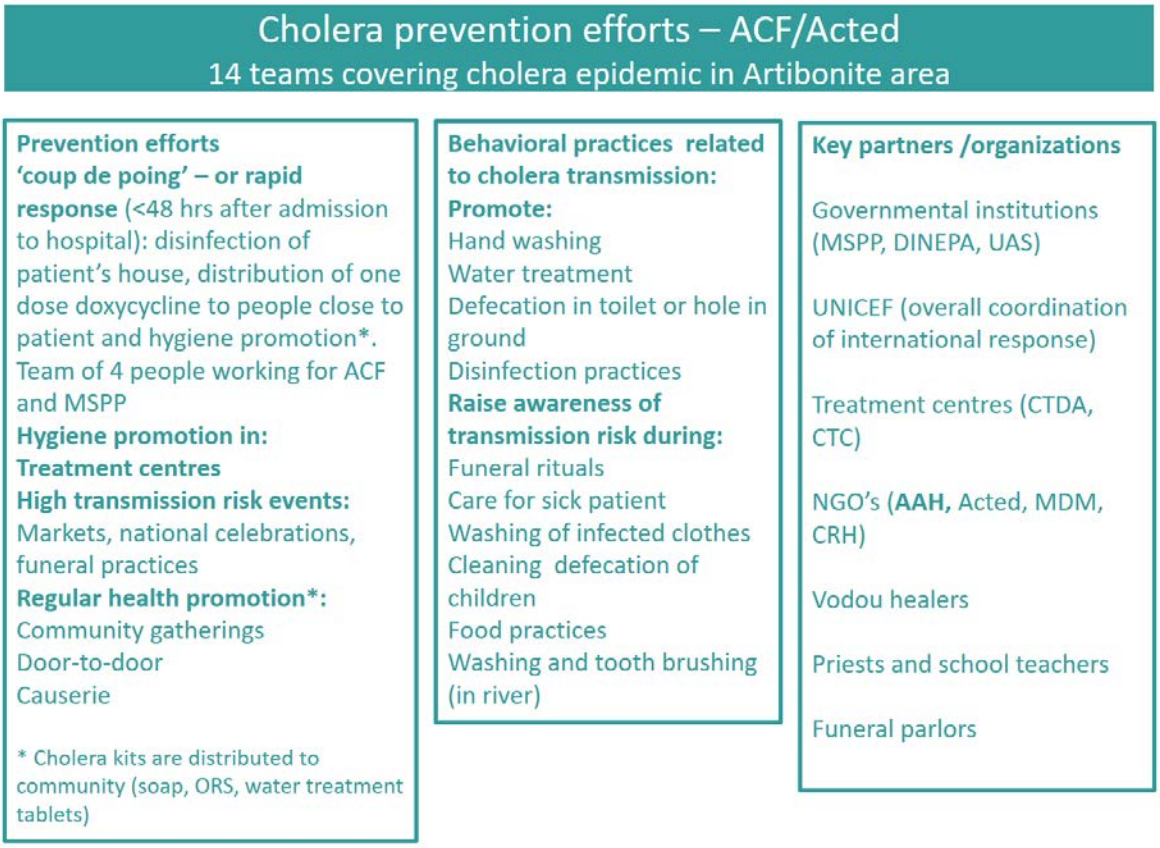
Addressing this aim was accomplished in three phases;

- In **Phase one**, I conducted a scoping review to identify current PR approaches and initiatives in all humanitarian research activities;
- In **Phase two**, I consider the specific case and context of the cholera outbreak in Haiti and conducted an evidence review of published manuscripts and grey literature of research studies investigating the HP response in Haiti;
- and in **Phase three,** I undertook an EBCD study, that engaged community members and humanitarian staff, to explore how the experiences and perceptions of cholera in Haiti can contribute to improvements in the HP efforts and activities as provided by AAH.

1.3 Partnership with Action Against Hunger (AAH) and content

In 2017, I established a partnership with AAH who invited me to collaborate with key stakeholders in the field to explore how an EBCD approach might contribute to improvements in the current cholera prevention efforts in the Artibonite Department of Haiti; this fell within a much larger overall effort by government, organizations, and others to eradicate cholera, including, for example, programs to promote preventive practices and behaviours of the population, improve access to community resources (e.g. access safe water, sanitation, and access to products such as soap and oral rehydration solution (ORS), ensure the treatment of people with cholera and to monitor cholera prevalence.

AAH’s prevention activities had focused on the dissemination of HP messages, desinfection of the houses of cholera patients and the distribution of a single dose doxycycline treatment for people in close contact with patients. The latter two responses were executed within 48hrs after the admission of a patient to the treatment centre with Case-Area Targeted Interventions (CATIs) (Rebaudet et al., 2019). See Appendix A for a detailed description of the cholera response activities and the key stakeholders in Haiti and Figure 1-2 for a schematic overview.



Cholera prevention efforts – ACF/Acted
14 teams covering cholera epidemic in Artibonite area

Prevention efforts
'coup de poing' – or rapid response (<48 hrs after admission to hospital): disinfection of patient's house, distribution of one dose doxycycline to people close to patient and hygiene promotion*.
Team of 4 people working for ACF and MSPP
Hygiene promotion in:
Treatment centres
High transmission risk events:
Markets, national celebrations, funeral practices
Regular health promotion*:
Community gatherings
Door-to-door
Causerie

* Cholera kits are distributed to community (soap, ORS, water treatment tablets)

Behavioral practices related to cholera transmission:
Promote:
Hand washing
Water treatment
Defecation in toilet or hole in ground
Disinfection practices
Raise awareness of transmission risk during:
Funeral rituals
Care for sick patient
Washing of infected clothes
Cleaning defecation of children
Food practices
Washing and tooth brushing (in river)

Key partners /organizations

Governmental institutions (MSPP, DINEPA, UAS)

UNICEF (overall coordination of international response)

Treatment centres (CTDA, CTC)

NGO's (**AAH,** Acted, MDM, CRH)

Vodou healers

Priests and school teachers

Funeral parlors

Figure 1- 2: *Schematic overview of the prevention efforts, behavioural practices related to cholera transmission and key partners and organizations.*

This overview helped to inform the identification of key partners in this study design, the focus for the observations, and the sampling strategy for the interviews of people implicated in the cholera prevention efforts.

AAH is a global humanitarian organization that has worked in Haiti for over 30 years and has been part of the cholera eradication efforts since the start of the outbreak. The cholera outbreak was inadvertently introduced in the Artibonite area in Haiti in 2010, nine months after a powerful earthquake, by United Nations peacekeepers (Frerichs, 2016; Morris Jr, 2016) through a poorly installed sanitation system in the camp of UN peacekeepers (Eppinger et al., 2014; Payton, 2017). In 2016, the UN officially finally apologized for its role in the cholera epidemic (Bartels, Fraulin, & Lee, 2020; Wilson, 2018). An estimated USD 16 billion was pledged to the response effort (Hsu & Schuller, 2020). Cholera spread rapidly, with over 820,000 people infected and almost 10,000 related deaths (Centers for Disease Control and Prevention (CDC), 2019). Like smallpox brought by Europeans to the Americas, Haiti was exposed to an unknown, devastating illness (see figure 1-3 for the cholera persistent zones at the time of the start of this research in 2017; setting for the field work is near St. Michel). Seven years after the outbreak, AAH's reliance on traditional cholera prevention activities had reached the limit of effectiveness; they wanted to better understand peoples' perception of cholera to help improve their cholera prevention efforts.

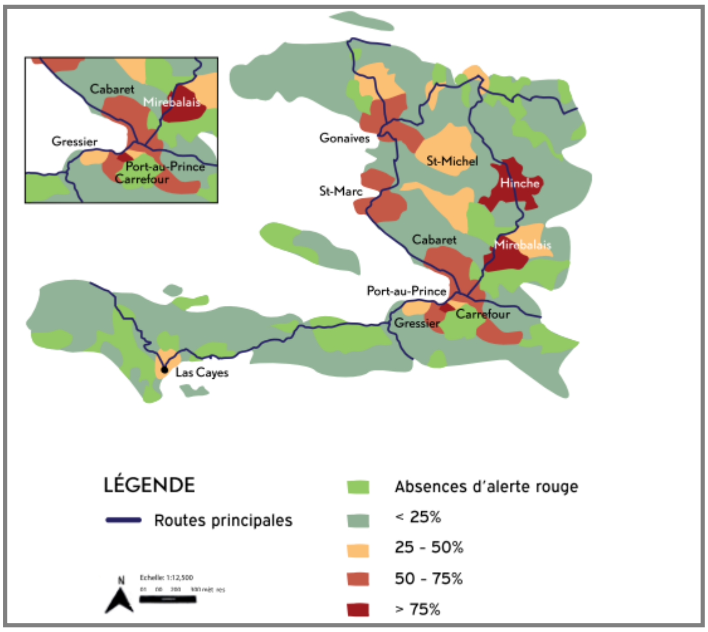


Figure 1- 3: *Map of Haiti and the cholera persistent zones in 2017 (Biscan B, 2017)*

This goal, as articulated by AAH, aligned well with my research interests for this thesis, and provided a unique opportunity to jointly explore how local experiences and perceptions of cholera in this setting might contribute to insights how improvements might be made. AAH staff (water and sanitation specialist, behaviour change specialist, cholera response coordinator and the field manager) and I established a research agreement for this work.

1.4 Research position

The following is a personal reflection on my position and significance of this work in my life and experiences as a professional and early career researcher.

Many times, my fingers have created the words that are caught in my mind; they describe my past humanitarian experiences that remain in my memory. As soon as the words form into sentences, I start missing the smells, sounds and generous smiles of people. Life is sucked out of the stories while my unease is growing. I delete the words but not my memories.

Some experiences have remained with me only as I never felt I could do justice to the resilience people need when experiencing disaster. In this paragraph I try to share some of these experiences as I want to illustrate how and why some of the assistance offered never worked. In South-Sudan, for example, I was responsible for the construction of toilets when we rebuilt a hospital, but did not, at that time, realize how important it was to involve the community in the design. In this sentence I could have also said *a hospital destroyed by war*. Only three more words but with so many implications. My memories then take me back to the two different kinds of children's drawings on the hospital walls; beautiful strong cows (important animals in South-Sudan) and destructive planes with bullets or bombs falling from the sky (as a memory of the war). How can we develop sufficient understanding of these complex processes? For example, what could we have done differently to stop a family in South Sudan trying to save their pregnant daughters' life by conducting an abortion with local means while our hospital and services were directly available to them? Why did a desperate Congolese community decide to burn down an Ebola treatment centre that was there to help stop the Ebola outbreak? While words don't seem enough to describe the experiences, I struggle even more to give the surviving enough credit when describing these events.

After working in humanitarian settings, I completed a MSc in public health and worked for many years on research that put peoples' experiences with illness at the centre of the process. During this time, I also learned about and used the EBCD approach. This work has brought my attention to experiential knowledge, the diverse insights that can be gained learning from the patient's perspective and by patient engagement. My deep desire and interest was to pilot some of these methods with the aim of improving humanitarian assistance.

Long before the advent of the internet, poet T.S. Eliot, 1934, reflected on wisdom, knowledge and information: 'Where is the wisdom we have lost in knowledge? Where is the knowledge we have lost in information?'. There is, however, also a link to experience as stated in this quote "wisdom is the reward of experience and should be shared" or that "by three methods we may learn wisdom: First, by reflection, which is noblest; second, by imitation, which is easiest; and third by experience, which is the bitterest" (Confucius).

This thesis is about better understanding how shared illness experiences can contribute to improved humanitarian assistance but also about piloting and contributing to improved participatory approaches such as EBCD and IKT in these settings. It aims to look beyond the stories of suffering, atrocities and unimaginable truth but to do justice to every day lived experience of people, their strengths, knowledge and ideas.

With this thesis I hope to contribute to finding methods and approaches that can help people understand that it is possible to collect experiential knowledge and partnering with those affected by disasters to integrate the learning in improved humanitarian responses. In addition, I feel committed to helping new humanitarian workers learn to value the experiences and knowledge of the affected populations by giving them access to their voices. As the reality is that in emergencies workers will not have sufficient time to overcome barriers such as the time, to make the opportunity to talk to people and to integrate the learning in their practice. I see it as a task of researchers or other professionals to set-up research project in humanitarian settings to make these voices more easily accessible to humanitarians and to bridge these barriers through new and innovative methods.

1.5 Organization of the thesis

The basic structure of this thesis consists of three chapters that present an introduction, literature review, then a set of four manuscripts (with brief preambles) followed by a discussion chapter and appendices.
Three bodies of published literature were considered for the literature review in Chapter 2: 1) humanitarian assistance and participation as ‘good’ practice; 2) illness experiences and the potential value of narrative approaches to change; and 3) Haiti and the cholera prevention efforts. Chapter 3 provides an overview of the three research phases and the methods applied in each phase. A detailed description of the methods can be found in the manuscripts.

Chapter four is a manuscript entitled “*Key issues for participatory research in the design and implementation of humanitarian assistance: a scoping review*”. This manuscript describes a scoping review exploring PR practices in humanitarian settings. This paper finds that while participation and collaboration are gaining prominence in humanitarian recommendations, PR in these settings continues to be rarely applied. From the included manuscripts in the scoping review, it is found that PR can contribute to an improved localized response, increased trust and sustainability.

Chapter five is a manuscript entitled "*Hygiene promotion research in disease outbreaks in humanitarian settings".* This manuscript presents the results of a review of research studies investigating the HP response in Haiti. None of the selected studies applied PR methods and rarely collected data on local knowledge or perceptions. The predominant focus on biomedical considerations overshadows the value and importance of experiential and local knowledge in determining effective strategies.

Chapter six is a manuscript entitled "*The role of trust in the hygiene promotion response in the cholera outbreak in Haiti".* This manuscript illustrates, with the collected data from the EBCD study, the importance of trust in HP strategies. Concluding that applying participatory approaches can contribute to improving trust and therefore strengthen HP strategies.

In the last chapter I discuss three main contributions of this research. First, I discuss how this research contributed to our understanding of the current PR practices in humanitarian health settings. Second, I examine how a better understanding of affected populations' experiences can contribute to an improved hygiene promotion response. Third, I describe the feasibility of EBCD as a quality improvement approach in a manuscript entitled *"The Hygiene Promotion Response to the Cholera Outbreak in Haiti: Applying an* Experience-Based Co-Design to Improve *the Experience of Affected Communities*". This manuscript reflects on the adaptations made to the EBCD while implementing it for the first time in a humanitarian setting. Although the complexity of the context (e.g. lack of access to resources and the uncertainty of the continuation of the cholera response) challenged the team to identify actionable changes, the EBCD approach did lead to a process where humanitarian staff and affected populations discussed complex issues and potential solutions.

2 LITERATURE REVIEW

Participation of patients and community members in research within humanitarian settings remains challenging. The humanitarian literature is dominated by descriptions of participation of affected populations in the design and implementation of humanitarian programs on an operational level, whereas much less is reported on the value of **PR** approaches in humanitarian settings. I describe the literature in these domains as well as the humanitarian literature reporting on experiential data and perception studies. This is then continued with a section of literature describing how a better understanding of illness experiences can contribute to improved health care services. In the final section I describe the pertinent literature on the experiences and perceptions of cholera in Haiti.

2.1 Humanitarian assistance and participation as 'good' practice

The following focuses on participation of affected populations in the design, implementation and evaluation of humanitarian **operations** as well as PR in humanitarian settings. Participation is perceived to have long been embedded into the humanitarian standards and guiding principles (Bloom & Betts, 2013). Engaging in collaborative practices and integrating an understanding of population needs and perspectives in humanitarian health practices is considered part of the move away from the more traditional top-down assistance models (Nouvet et al., 2016). Bottom-up movements and participatory approaches have been on the rise since the 1970s and promote a more egalitarian form of knowledge production. More recently, the International Rescue Committee called for a radical change in humanitarian assistance where affected women and girls should not 'fit into' existing programming but where their voices should drive the design of programs that meet their needs (International Rescue Comittee, 2014). It is argued that participation should enhance the design and implementation of locally sustainable response that increase ownership and accountability (Abu-Sada, 2012; Anderson et al., 2012; Bonino, Jean, & Knox, 2014; Darcy, Alexander, & Kiani, 2013; Magone et al., 2012) but should also increase the likelihood of successful outcomes (Ferguson & Gupta, 2002). In addition, it ensures the inclusion of those who have been most affected by the crisis (Afifi et al., 2020). Effective response to public health crises requires humanitarian resources as well as localized efforts with communities affected by crisis (Christensen, Dube, Haushofer, Siddiqi, & Voors, 2020). Participation in humanitarian settings brings its own specific challenges such as: restricted time to consult in life-threatening situations, incoherent social structures within displaced populations with the increased danger of putting people at risk with engagement activities, security constraints, and the asymmetrical relationships between affected people and humanitarian organizations (Dufour, Grünewald, & Levy, 2003; Nouvet et al., 2016). In addition, it is argued that humanitarian operations rarely have participation and accountability as a goal in itself but that these objectives or intentions are is more often implemented as add-ons to planned interventions (International Committee of the Red Cross (ICRC) and Harvard Humanitarian Initiative (HHI), 2018). It should also be kept in mind that there is a wide application and interpretation of different concepts related to participatory approaches (Tembo et al., 2021). For example, focusing on accountability towards affected populations in humanitarian settings alone already brings up four main themes: "empowering assistance recipients, being in an optimal position to do the greatest good, meeting expectations and being liable" (Tan & von Schreeb, 2015).

Humanitarian organizations do not always explicitly state why engagement is important for them (Bonino et al., 2014; Brown & Donini, 2014) but three main rationales for participation and engagement have been identified in the literature; value based or normative rationales (it is the right thing to do), instrumental rationales (increase effectiveness) and emancipatory rationales (to address underlying vulnerabilities and inequalities and to strengthen society) (Brown & Donini, 2014).

The Core Humanitarian Standard in Quality and Accountability (CHS) reports that some initiatives explicitly acknowledge affected populations as primary stakeholders, but also state that more should be done to integrate people affected by crises as partners (CHS Alliance, 2020). Research on the perspectives of people affected by crisis in relation to this subject reports that people often desire to be independent from external assistance (Anderson et al., 2012). Enhanced independence, as seen from the perspectives of these humanitarian care recipients, can be promoted by increasing the focus on existing resources and capacities, to adopt approaches that foster creativity in problem-solving, and to promote respect and meaningful communication with local partners that in turn improves the impact of humanitarian assistance (Anderson et al., 2012). A system that supports increased participation contributes to enhanced design and implementation of humanitarian assistance that are locally sustainable as well as to increased ownership and accountability (Anderson et al., 2012) and increased likelihood of successful outcomes (Ferguson & Gupta, 2002).

Knowledge generation – a shift towards co-production

Indigenous and local knowledge are given particular prominence in the recently launched Intergovernmental Science---Policy Platform on Biodiversity and Ecosystem Services (IPBES) of the United Nations acknowledging that 'indigenous, local and scientific knowledge systems are viewed to generate different manifestations of valid and useful knowledge ' (Tengö, Malmer, Brondizio, Elmqvist, & Spierenburg, 2013). Likewise in humanitarian settings, indigenous, local, humanitarian and scientific knowledge systems can contribute to improved humanitarian assistance, 'through complementarities as well as new ideas and innovation from cross-fertilization across knowledge systems' (Tengö et al., 2013). In the 1990s there was a strong interest in an emerging movement known as 'knowledge for development', particularly by the World Bank, which was, in part, due to the new possibilities offered by the availability of the Internet. The central idea was that humanitarian 'agencies could and should be employing their knowledge to transform development' (Ramalingam, 2013). Now, however, it is understood that existing knowledge cannot simply be implemented in different settings as the 'knowledge' needs to fit within local structures, context and culture. This insight contributed to more recent interest in co-producing knowledge in order to integrate local and indigenous knowledge into humanitarian approaches and science. This builds on the notion that '*what* the researcher finds out is inherently connected with *how* she finds it out' (Emerson, Fretz, and Shaw, 1995 cited in Kovats-Bernat, 2002, p. 217). Or in other words knowledge generation is influenced by the way you interact with the people that are the focus for your study (van der Haar, Heijmans, & Hilhorst, 2013). Van der Haar (2013) considers collaboration between the host organization, host population, local research assistants and others to be research encounters that influence the construction of knowledge and therefore also the nature of the knowledge that will be generated.

Humanitarian and participatory research

While research in humanitarian settings has increased steadily in the last decade (Blanchet et al., 2015), there continues to remain a significant limitation of the quantity and quality of evidence used to inform the humanitarian response (Kohrt, Mistry, Anand, Beecroft, & Nuwayhid, 2019). More specifically, there remains a clear lack of evidence on the effectiveness of water, sanitation and hygiene (WASH) strategies to control outbreaks in humanitarian situations (Ramesh, Blanchet, Ensink, & Roberts, 2015; Taylor, Kahawita, Cairncross, & Ensink, 2015), with the impact of HP to be severely under-researched (Ramesh et al., 2015; Yates, Vujcic, Joseph, Gallandat, & Lantagne, 2018).

In addition, research conducted in humanitarian settings, is frequently published in grey reports only due to a lack of capacity or incentive to publicly share data (Ager et al., 2014). The lack of research evidence for this specific context can lead to the reliance on evidence from other settings. It is, however, not possible to simply 'import' health programs from these settings in humanitarian response. Interestingly though is that many of the studies, assessing the research status in humanitarian settings, do mention the importance of collaboration and participation of the affected population on the operational level but hardly consider PR as a recommended approach.

PR, defined as a "systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting change" (L. W. Green et al., 1995) is considered as one of the approaches that might contribute to improved accountability to communities in humanitarian settings (Darcy et al., 2013). PR combines research with co-learning as well as a collaborative action to democratize the knowledge production process (Cargo & Mercer, 2008; L. W. Green et al., 1995). Knowledge is produced through a collaborative effort and with the potential to offer practical solutions (Cargo & Mercer, 2008). In addition, Non-Governmental Organization (NGO) and researcher partnerships are associated with opportunities for mutual learning, improved knowledge translation, and improved access for researchers to communities (Olivier, Hunt, & Ridde, 2016). It has been recognized as well suited for research with oppressed and marginalized populations who have historically been left out of the research process (Corburn, 2005; Hall, 1981). This approach is favourable to promoting health by improving capacity building, sustainability and unanticipated new activities (Jagosh et al., 2012) in a mutual learning process (Macaulay & Nutting, 2006). In addition, engaging people as partners in the co-construction of research (Jagosh et al., 2012) increases the commitment of these stakeholders to use the research findings and take action (Cargo & Mercer, 2008). One approach that draws on PR is the EBCD approach (Bate & Robert, 2007; Donetto, Tsianakas, & Robert, 2014) where patients and service providers work together to jointly identify and implement service improvements, with as a central tool a catalyst film, that features key moments of patient experiences, to support the co-design process. Studies that collect data on the experiences and perceptions of affected populations have grown in popularity (Nouvet et al., 2016).

Improving the understanding of the affected populations perspectives

The image of suffering people in distant countries has shaped our perception of humanitarian conflicts and crises (Höijer, 2004). This has led to distorted perceptions and stereotypes related to single stories, as well as less informed notions about asymmetrical power relationships (Calain, 2013). Or as writer Chimamanda Ngozi Adichie stated in a TED talk: '*The single story creates stereotypes, and the problem with stereotypes is not that they are untrue, but that they are incomplete. They make one story become the only story.*' (Adichie, 2009). But this is changing. A growing number of high quality research studies and reports published by and for humanitarian practitioners provide further evidence of the value in listening to affected populations and integrating this in the project design, evaluation and monitoring (Nouvet et al., 2016). They are referred to as perceptions studies: 'qualitative studies that gather and analyse local population accounts, expectations and assessments of humanitarian organisations, projects and practices' (Nouvet et al., 2016). These studies have for example elicited affected populations' perspectives on humanitarian assistance and provide insight into the diversity of local views, deepens the understanding of the population's needs and preferences, and offers understanding on how humanitarian response can be improved by providing insights into 'priorities, expectations and social dynamics, program gaps and program strengths' (Abu-Sada, 2012; Anderson et al., 2012; Nouvet et al., 2016). Even the act of dedicating time and resources to these activities can provide a strong message across all levels of an organisation of the value of the experiences and insights of the affected populations (Nouvet et al., 2016). This approach falls under the broader category of feedback-gathering mechanisms that 'allow humanitarian aid recipients to provide information on their experience of a humanitarian agency or of the wider humanitarian system' (Bonino et al., 2014).

Several manuscripts exist on the importance and value of understanding the populations' perspectives and reactions as a response to disease outbreaks. A large group of scientists, for example, published a manuscript in May 2020, providing evidence how social and behavioural sciences can provide valuable insights for managing the COVID-19 pandemic and its impact (Van Bavel et al., 2020). And the Ebola outbreak in West-Africa brought insight in how anthropologists can function in public health emergencies by providing insight in the social dynamics of health, illness and disease transmission (Stellmach, Beshar, Bedford, du Cros, & Stringer, 2018). Yet, disease outbreak responses continue to be described as top-down (Contzen & Mosler, 2013; Laverack & Manoncourt, 2016) despite genuine efforts to improve communities' perspectives and understanding. With this increasing attention for understanding and collecting the perceptions and experiences of affected populations comes a need to understand how this data can be best applied to improve the humanitarian response. The following sections looks into approaches that aim to understand the experiences and perceptions of illness to improve humanitarian response.

2.1.1 Illness experience and the potential value of narrative approaches to change

An often-cited quote when speaking about illness experiences is from William Osler stating that 'the study of phenomenon of diseases without books is to sail an uncharted sea, while to study books without the patient is not to go to sea at all' (William Osler 1849-1919). William Osler, sometimes also referred to as the father of modern medicine, emphasized the importance of listening to patients' experiences and learning from them over 100 years ago. More recently Mulley et al (2012) highlighted the mismatch between what patients want and what doctors think they want, e.g. one of the studies cited found that doctors believed that 71% of breast cancer patients have as a top priority the preference of keeping their breast while only 7% of the patients prioritized this (Abelson et al., 2015). This difference may be partly explained by Kleinman's (1988) distinction between a disease understood as what 'the healer creates in the recasting of illness in terms of theories and disorder' and illness seen as embedded in 'local cultural orientations' (the patterned ways that we have learned to think about and act in our life worlds and that replicate the social structure of those worlds)'. Kleinman states further that these perceptions of illness then organize 'our conventional common sense about how to understand and treat illness; thus, we can say of illness experience that it is always culturally shaped.'

In humanitarian settings it is found that even though certain illnesses are preventable and can be managed with low-cost programs, this is not sufficient to stop these illnesses. There remain challenges to translate this knowledge into effective humanitarian programs (Isanaka et al., 2012). It is argued therefore that the learning from illness experiences can be used to improve the quality of health care. The book 'Understanding and Using Health

Experiences: Improving Patient Care' describes a wide range of methods and types of data that are applied to the recording and analysis of people's experience of health and healthcare and how this data is used to improve crucial aspects in health care (Ziebland et al., 2013). In this book, the authors present examples of how a better understanding of personal health experiences: is a crucial element in quality assurance (Coulter, 2013); has provided insight on how decisions are made and why action is taken (Stevenson, 2013); or, how they are used to prompt improvements to services through EBCD (Robert, 2013). Some of the identified barriers include available time and resources, clear structural plans for use in quality improvement and staff freedom to set directions for quality improvement (Gleeson et al., 2016; Locock, Graham, et al., 2020). Narratives can also be applied to create a change in perspective or behaviour amongst health care professionals (T. Green et al., 2020; Papoulias, 2018; Ramos, Bowen, Wright, Ferreira, & Forcellini, 2020). In these initiatives many individual experiences create an insight in the collective experiences within a health system (Papoulias, 2018; Ziebland, Grob, & Schlesinger, 2020). In health care systems where patient experiences are actively collected there is concern that this data is not used to improve care (Locock, Graham, et al., 2020). Similar concerns have been expressed for humanitarian settings where it is argued that rich qualitative data has little value in "information graveyards" (Nouvet et al., 2016) as good evidence doesn't automatically lead to learning and change (Brown & Donini, 2014).

Given the socio-cultural and political contexts, it might be assumed that in humanitarian settings the gap between what health care professionals understand about patients' perceptions, needs and illness experience, and the patients' own preferences, will also be present. Applying the learning of people's illness experience to improve humanitarian programs may therefore provide a valuable contribution to the efforts to improve disease-oriented response in such a way that it optimises the quality and effectiveness of the care provided. In relation to the cholera prevention activities in Haiti, there is value in learning from former cholera patients and to use this learning to improve the HP response.

2.2 Haiti and the cholera prevention efforts

The following section provides background knowledge on cholera as an illness, and a summary of the existing literature on the experiences and perceptions of cholera among the Haitian population. This is followed by an overview of what is published on the effectiveness of cholera prevention and how these hygiene promotion messages have effectively changed practice and behaviour in Haiti.

2.2.1 Cholera treatment, transmission and prevention

Vibrio cholerae, the causative agent of cholera was first described by Filippo Pacini more than 150 years ago; its water borne transmission was later demonstrated by John Snow (Nair & Takeda, 2008). People can get cholera through fecal contamination of water and food (Orata, Keim, & Boucher, 2014), and the disease is not likely to spread directly from person to person (CDC, 2016a). Cholera is a virulent disease that causes mild to moderate symptoms amongst the majority of the population. Nonetheless the bacteria remain present in the feces of people who do not develop symptoms and can therefore still infect others. People who do develop acute, watery diarrhea with severe dehydration can die within hours of the onset of the symptoms (World Health Organization, 2017). The strain identified in Haiti, serogroup O1, serotype Ogawa, biotype El Tor, particularly causes severe symptoms (Piarroux et al., 2011). Yet, cholera is an easily treatable disease, and the majority of people can be treated successfully with the administration of oral rehydration solution. Severely dehydrated patients receive intravenous fluids and may be given antibiotics. Rapid access to treatment is key in cholera outbreaks. In order to control cholera transmission and reduce deaths, a multifaceted approach is required and includes a combination of surveillance, clean water, good sanitation and hygiene, social mobilization, as well as access to treatment and oral cholera vaccines (World Health Organization, 2017). The absence of cholera outbreaks in high income countries has proven that it is possible to prevent transmission when individual cases are detected in these settings. Low- and middle-income countries (LMICs), however, continue to face the threat of cholera outbreaks that now drag over longer periods compared to the past (Nair & Takeda, 2008). Researchers estimate that between 21,000 to 143,000 die globally every year due to cholera (World Health Organization, 2017). The challenge today is to reduce cholera transmission in impoverished settings (Nair & Takeda, 2008) such as in Haiti where the known risk factors for the transmission of cholera such as low socio economic status, poor water and sanitation infrastructure, population displacement and population density have contributed to the spread of cholera (Williams et al., 2015).

The lack of a proper sanitation infrastructure can be traced back to the cycle of debt and foreign interference (Saini, 2017) since Haiti's enslaved people rose against colonial powers and liberated Haiti in 1804 form its oppressors (Payton, 2017). This liberation was followed by political turmoil, foreign interference and decades of paying off the debt to French colonizers for loss of property (Payton, 2017), making Haiti one of the poorest countries of the western hemisphere (United Nations Development Programme (UNDP), 2019).

In 2017, the efforts to eliminate cholera in Haiti comprised an estimated 140 operation cholera treatment centres and 88 emergency rapid response teams. The cholera response is led by the Ministry of Health and supported by NGOs who investigate suspected cholera cases and respond to these cases within 48 hours (Zarocostas, 2017). See appendix A for a more detailed description of AAH's current cholera prevention efforts in collaboration with local Haitian partners.

2.2.2 "Mikob pa touye ayisyen" – Microbes don't kill Haitians

In the early days of the cholera outbreak, health care workers and the population had to rapidly adjust to a little understood and new life-threatening reality. The Haitian Red Cross conducted nine discussion and awareness-raising groups with community members on cholera in order to better understand peoples' perception of cholera (Haitian Red Cross, 2010). The Haitian Creole saying "Mikrob pa touye ayisyn" (microbes don't kill Haitians) was often used by community members to explain two different ways of looking at the perceived risk of infection and the explanations of the cause of the sudden outbreak of cholera in Haiti. Primarily, people did not perceive any increased risk of infection from microbes as this disease had never manifested itself before, and living conditions had remained the same in years, so why would microbes all of the sudden pose a threat to kill Haitians? It was also discovered that many participants suspected that the illness had been introduced by foreigners in a deliberate attempt to kill people, to divide the populations, or for NGOs to get more money. These suspicions relate back to the 'decades of foreign interference in Haiti' as well as to the disappointment and mistrust between the population and international organizations following the international earthquake response (Haitian Red Cross, 2010).

Secondarily, people made a distinction between 'cholera mystique' caused by a magic 'kolera powder' prepared by vodou priests and 'cholera naturelle'. In Haiti certain illnesses, such as cholera mystique, are considered to be the result of the possession of an evil spirit (Saini, 2017). Healing from cholera mystique can only take place by seeing a vodou healing master such as the houngan and mambo (Haitian Red Cross, 2010). With regards to the cholera response it is important to consider that “those who believed foreigners were responsible (for the cholera outbreak) were less likely to use western medications and those who considered cholera to be a spiritual illness were more likely to access spiritual care”(Saini, 2017). Even though the majority of Haitians are Catholic, 85% of the population also believe in and practice Vodou (Desrosiers & St Fleurose, 2002). Based on the findings as reported by the Haitian Red Cross, Grimaud (2011) emphasized the importance of psychosocial support to address certain emotions (e.g. stigma), beliefs (e.g. seeing ORS as a vaccine) and perceptions (e.g. that foreigners are involved in the spread of the disease) to improve trust and confidence between the population and humanitarian actors.

2.2.3 Knowledge, attitudes and practices to reduce cholera transmission

The KAP (Knowledge, Attitudes and Practices) survey is a standardized survey instrument that is commonly used within populations in southern countries to inform health programs. The KAP survey was initially designed in the 1950s to understand the knowledge, attitudes, and practices in family planning so that it could be used for program purposes (Cleland, 1973). Since then the survey has been used in many different settings and contexts and is now an established method to investigate health behaviour (Launiala, 2009). One of the first conducted KAP studies took place in December 2010 in resource limited settings in the region of Port-au-Prince, three months after the start of the cholera outbreak (Beau De Rochars et al., 2011). This study found that overall, the knowledge related to cholera with regards to symptoms, prevention, treatment, and modes of transmission had been effectively transmitted by public health information efforts. In addition, these efforts had successfully promoted behaviour change in terms of increasing acceptance of drinking only treated water (Beau De Rochars et al., 2011). Another study published the results of a KAP survey before (August 2013) and after a cholera vaccination campaign (July 2014) in Petit Anse and Cerca carvajal (Childs et al., 2016). Childs et al. (2016) also report an overall good level of knowledge during the 2013/2014 cholera vaccination campaign study. Nevertheless, in the post campaign survey, a decrease in drinking water treatment was measured. Childs et al. (2016) concludes that the decrease in prevention practices as compared to the former

KAP study (Beau De Rochars et al., 2011) may be due to a reduced perceived risk of cholera infection. A later study, conducted in September 2015 in the Artibonite area (Oxfam, 2014), shows a less optimistic picture with regards to cholera preventive behaviour: 50% of people collected water from non-protected sources and 48% of people drank untreated water. In addition, people perceived a low cholera transmission risk (16.6%) from contact with fecal matter. People mentioned that washing fruits and vegetables before eating (93.1%) and covering food to protect it from flies (80%) were good practices to reduce the transmission of diarrhea or cholera. But at the same time people perceived that praying every night (26.5%) and eating twice a day (19.9%) were also good protective measures. The report also concluded that sanitation practices continued to contribute to the transmission risk for cholera: a limited number of people used a latrine (46.5%), and others practiced open defecation (43.2%) or used a shallow dug hole (10.4%). It should be kept in mind that this is most likely due to the limited number of people who possess a toilet and not because of individual choice. While most people washed their hands before eating (75.6%), when leaving the toilet (68.7%) and after touching something dirty (36.8%,) people rarely washed their hands before feeding a child and after cleaning a dirty diaper (<25.0%). This study shows that, after 5 years of intensive cholera eradication efforts, many cholera prevention behaviours and practices had not been strongly established. Only a few qualitative studies have investigated how peoples' perception of cholera affected their knowledge, attitudes and behaviour. A 2012 qualitative study involving 17 focus groups with the Artibonite population and one with community health workers provides some valuable insight as to why people were not changing their behaviour (Williams et al., 2015). The study found that the HP messages were understood and perceived as beneficial and were not confusing. Reasons for not changing behaviour in rural areas were due to not having easy access to safe water, not having latrines in the area and lack of funds to construct them, and difficulties finding water treatment products in the market. However, this study also reports that women in the focus groups stated that the reason for not people not to treat their water was being lazy or careless or that they did not believe that untreated water was a threat.

Access to safe water

A survey conducted to test the water quality in the Artibonite area in 2012 demonstrated that only 42.3% of households used an improved drinking water source such as a borehole, protected spring or vended water, and that half of these sources (50.9%) tested positive for Escherichia coli which can potentially carry cholera. Only 12.7 % of the stored water in households was treated appropriately (Patrick et al., 2013). A 2016 follow-up draft confidential survey report provided proof that the situation had not significantly changed (CDC, 2016b). Overall, it can be concluded that although people are aware of the importance of collecting safe water and/or treating unsafe water with disinfection products, there continues to be a mismatch between people's knowledge and their practices.

Future efforts to contribute to stop cholera transmission in Haiti

Most published reports have been conducted in the initial two years of the cholera outbreak, yet it is a reasonable assumption that practices, perspectives and motivations for behaviour change alter over time given distance and time since the original crisis; the threat for cholera infection is now reduced and certain behavioural practices have become more familiar. The presence of extreme poverty in combination with recent natural disasters such as the 2010 earthquake and the 2008 flooding have brought a large flow of donations of products, services and resources in the past six years. And even though all of this international assistance is well intentioned, it may have contributed to a culture of dependency (Williams et al., 2015). Haiti has been the home to more NGOs per capita than any other place in earth (Muggah, 2010). The Haitian context has contributed significantly to the current discussions on the dichotomy in humanitarian assistance: are NGOs good or bad for Haiti's development? Or in other words is their presence an invasion – where NGOs are seen as part of Haitian's problems , or infusion - in the sense that NGOs are closer to the people and less corrupt than the government (Schuller, 2007)? It might be that the belief that others are responsible for fixing one's own social situations is "an extremely complex situation that often reflects historical repression, unstable political situations, corruption and other social factors that cut across sectors" (Williams et al., 2015). These authors argue that "public health interventions will need to allow time for communities and individuals to shift gradually from dependency to enhanced individual determination." Others argue that addressing the needs of the Haitian people via public health responses should therefore incorporate participatory approaches in their conception and development (Arvai & Post, 2012) to enhance local capacity and ownership.

2.3 Summary of key points and gaps in research

The following provides an overview of some of the key points and gaps in research that are relevant for this research:

- Important reasons exist to improve and increase the use of participatory approaches in humanitarian settings but challenges remain to put these approaches in practice. Within the scant literature of PR in humanitarian settings, there is a clear lack of evidence on the effectiveness of WASH strategies with the impact of HP severely under-researched.
- Perceptions and experiences from affected populations are increasingly collected and analysed, it is however also important to not create ‘information graveyards’ – where evidence repositories are created but not used. Gaps remain in our understanding how the collected evidence can by applied for learning and change.
- It has been observed that the population in Haiti has a good knowledge of cholera in Haiti but also that the population is not always adapting the recommended protective practices. While many studies measured the existing knowledge and practices, limited research exists that contributes to our understanding why people do not change their practices and how they can be best supported to make changes.

3 METHODS

The research for this thesis had 3 phases: scoping review, evidence review and field work. Field work included data collection, analysis, report writing for AAH, and round tables to discuss the findings with the HP team followed with a final analysis and writing manuscripts. A detailed description of the methods can be found in the four manuscripts. The objectives and research questions for each phase are described below.

Phase one – scoping review

The objective of the scoping review was to explore the extent of application and reported value of PR approaches within humanitarian research efforts. The research question for this review was: *What kind of research approaches and methods have been used to investigate the HP response in Haiti? What lessons can be drawn from these efforts, and what are the implications for future research?*

Phase two – review of research investigating the HP response in Haiti

The objective of the review was to learn from past HP research in disease outbreaks to inform improvements in future responses. I posed the following questions: *What kind of research approaches and methods have been used to investigate the HP response in Haiti? What lessons can be drawn from these efforts, and what are the implications for future research?*

Phase three – Experience-Based Co-Design

The research question for the phase three study is: How can the voices and perspectives of individuals and communities in Artibonite contribute to improving humanitarian efforts to prevent cholera and support eradication in this region?

In collaboration with the AAH team and supervisors I defined the following questions for participants in this initiative:

- How do individuals and communities perceive cholera as a disease?
- What are individual, community and professional perspectives on the barriers, issues, priorities and solutions in the cholera prevention efforts to reduce the risks and improve access to health care?

- In what way do individuals, communities, humanitarian professionals and other key informants value narratives or health experiences in contributing to improved prevention?
- Is the adoption of an EBCD approach acceptable in this context and environment?
- Is EBCD an appropriate vehicle for bringing individual and community voices to the fore?

The EBCD work was planned in two parts in sequence: the qualitative research component, which then informed the quality improvement application. The objectives of the qualitative research were to:

- Observe and document the culture and processes of the cholera prevention efforts in the Artibonite area.
- Collect a variation sample (including diversity in terms of age, experience with cholera, gender) of peoples' experiences with the cholera prevention efforts through in-depth qualitative video interviews (or focus groups as deemed culturally appropriate in this setting) with community members and former cholera patients of the Artibonite area.
- Document key aspects and issues related to the existing prevention process from the perspectives of experienced professionals (e.g. doctors, nurses, coordinators and alternative health practitioners) working on the cholera response (prevention and treatment) through in-depth qualitative interviews.
- Identify topics important to the patients/caregivers and staff participants through the analysis of the interview material.

The objectives of the quality improvement application:

- Develop a catalyst film (or series of very short films) that reflects themes identified by participants in the interviews
- Provide an opportunity for professionals and communities to interpret the results and implications together to determine related quality improvements initiatives
- Provide an opportunity where professionals, individuals and communities are empowered in a collaborative process to recommend and implement changes through co-design working groups.

3.1 Knowledge to action framework

It is well acknowledged that failing to translate research knowledge into action in health care contributes to health inequities and wastes costly and time-consuming research (Ward, House, & Hamer, 2009). In reality, the process is typically slow and requires effort as well as dedicated resources. Knowledge translation typically takes place at the end of research initiatives and broadly falls within three categories: diffusion (let it happen), dissemination (help it happen) and application (make it happen) (Canadian Institutes of Health Research, 2012). One published estimate indicates that it takes, for example, an estimated 17 years for 14% of researcher-driven scientific discoveries to be translated into day-to-day practice (Balas & Boren, 2000).Knowledge Translation (KT) approaches are emerging in public health policy and practice to facilitate the closure of the know-do gap. KT can be defined as: “a dynamic and iterative process that includes the synthesis, dissemination, exchange and ethically sound application of knowledge to improve health, provide more effective health services and products and strengthen the health care system” (Straus, Tetroe, & Graham, 2009).

This approach acknowledges the typically inefficient adoption of knowledge created through research into practice, resulting in the ineffective use of research and resources and reducing optimal health outcomes (Graham et al., 2006). In contrast, this thesis is guided by the Knowledge To Action (KTA) framework which was developed to improve faster uptake of research results (Graham et al., 2006), see Figure 3-1. This framework presents two dimensions. The first is a central *knowledge generation* process, portrayed as a ‘funnel’, where primary research is conducted and results are synthesised and refined into products to support evidence-based decision-making through knowledge inquiry and synthesis. Therefore, in this study, I focussed on partnering with AAH to generate new knowledge through better understanding the perspectives and experiences of former cholera patients, the community and key professionals engaged in cholera response efforts.

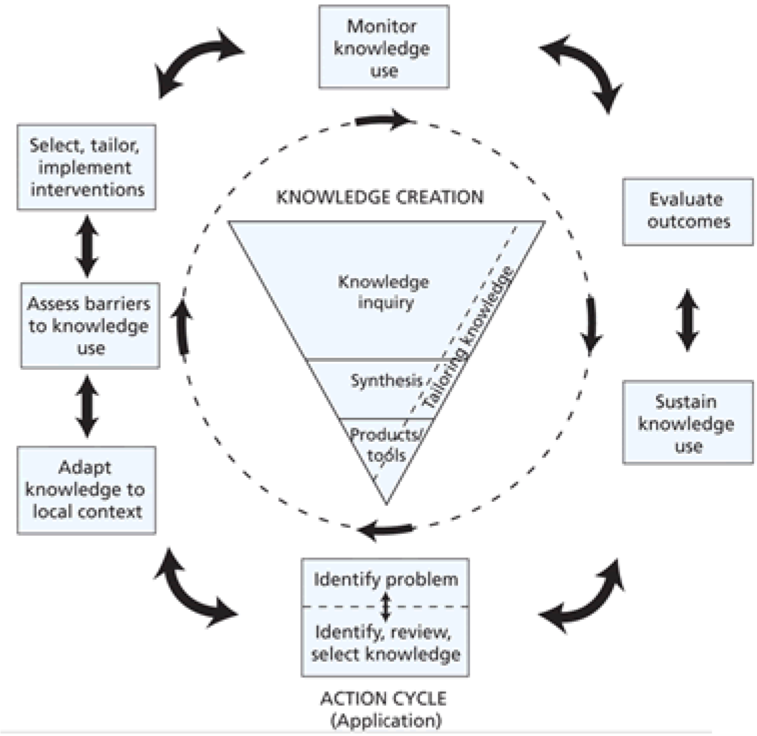


Figure 3- 1: *Knowledge to action framework (Graham et al., 2006)*

The KTA framework then presents a *knowledge to action* dimension or cycle where knowledge producers, brokers and end-users work together to identify, tailor, apply and implement these knowledge products in their local contexts. In addition, knowledge to action works best when all stakeholders are involved in generating the research; this is at the core of IKT. IKT aims to optimize the applicability of the results to the population under study, focusing on engagement with end users and their context. “Integrated KT requires a collaborative approach to the research process that is action oriented and focused on solutions and impact” (Graham et al., 2014). This has similarities to- for example - PR (Macaulay et al., 1999; Nguyen et al., 2020) and EBCD (Bate & Robert, 2006). PR, IKT and EBCD share core values and similarities. Similarities among IKT and PR “included (1) true partnerships rather than simple engagement, (2) focus on essential components and processes rather than labels, (3) collaborative research orientations rather than research methods, (4) core values and principles, and (5) extensive time and financial investment” (Nguyen et al., 2020). Some of the principles and core values included trust, fostering relationships, reciprocity, co-creation and shared decision-making in the research process (Nguyen et al., 2020).

3.2 Ethical considerations

This research received ethics approval from St. Mary's Hospital Research Ethics Committee in Montreal, Canada (July 2017) and the 'Comité National de Bioéthique en Haïti' (September 2017). See appendix B and C for ethics approval notices and appendix D for all forms used in this research (e.g. consent forms, demographic data form, interview and focus groups guidelines).

4 KEY ISSUES FOR PARTICIPATORY RESEARCH IN THE DESIGN AND IMPLEMENTATION OF HUMANITARIAN ASSISTANCE; A SCOPING REVIEW – MANUSCRIPT 1

4.1 Preamble

This manuscript reports on a scoping review that explored to what extend PR values and practices have been adopted in humanitarian health settings and the key issues in applying PR in this context. The results demonstrate that PR is seen as a valued approach for contexts where there is mistrust and where there is a need for contextualized understanding. This manuscript contributes to the literature on participation and accountability towards affected populations in humanitarian settings. To our knowledge, this is the first scoping review of PR in humanitarian contexts. These findings informed the EBCD pilot (manuscript 3 and 4) and also contributed to my interest to review the participatory level of research studies investigating the HP response in Haiti (manuscript 2).
This manuscript was published in Global Health Action in December 2020.

Reference: Ormel I, Salsberg J, Hunt M, Doucet A, Hinton L, Macaulay A, Law S. (2020). "Key issues for participatory research in the design and implementation of humanitarian assistance: a scoping review." *Global Health Action* 13(1): 1826730. DOI: 10.1080/16549716.2020.1826730

Key issues for participatory research in the design and implementation of humanitarian assistance: a scoping review

Short running title: Participatory research in humanitarian settings

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4.2 Abstract

Background: Participatory approaches that engage affected populations are increasingly applied in humanitarian health programs in concert with emerging accountability frameworks and the rapid growth of research in these settings. Participatory initiatives within this domain appear to be largely adopted at an operational level and are infrequently reported as a component of research efforts. Yet the evidence of the benefits of research involving community members is growing worldwide. This is the first review of participatory research (PR) in humanitarian settings.

Objectives: This study sought to understand the extent to which PR values and practices have been adopted in humanitarian health programs and to explore key issues in applying PR in this context.

Methods: This scoping review was based on the approach developed by Arksey and O'Malley. The search for relevant peer-reviewed articles included scientific databases, a humanitarian database, targeted journals and online resources published since 2009. Eleven articles were retrieved and reviewed to identify practices and key issues related to conducting PR in humanitarian settings.

Results: Four key themes were identified: building trust with local research stakeholders and participants; the importance of contextual understanding; implications of collaborating with affected populations in PR; and neutrality of researchers and Non-Governmental Organizations (NGOs). Study teams considered PR as a valued approach where there was mistrust or a need for contextualized understanding. The studies described how adaptations made during the study optimized collaboration with affected populations and how the presence of NGOs influenced the approach and results of PR.

Conclusions: One of the most important contributions of humanitarian health programs is to develop 'medical practices that are better adapted to the living conditions and priorities of patients who are generally ignored'. Participatory approaches, such as PR, support the development of health-related practices that are more relevant and sustainable for affected populations.

4.3 Background

The use of participatory research (PR) methods in humanitarian health programs remains limited despite the increasing application of participatory approaches at an operational level, emergent accountability frameworks and the rapid growth of research in humanitarian settings. Yet evidence of the benefits of research involving community members is growing world-wide.

Participation of affected population in humanitarian response

Humanitarian health programs – where organizations and individuals respond to the health needs of populations affected by humanitarian crises such as armed conflicts, natural disasters or epidemics – are facing challenges that are growing in scale, scope and complexity [1]. The average duration of such crises has increased from four to 7 years between 2005 and 2017 [2]. Major crises in the past (for example the 1994 Goma refugee crisis, 2004 South Asian Tsunami, 2010 Haiti earthquake and 2014/2015 Ebola epidemic in West Africa [3] have generated new insights and concerns about the effectiveness and value of humanitarian assistance [4-6]. Aid organizations have more recently focused on the notion of 'accountability' of their work with respect to local populations [7,8], with initiatives such as the Core Humanitarian Standard (CHS) and the Active Learning Network for Accountability and Performance (ALNAP) who have promoted greater participation of affected populations. There is, however, not yet a single-accepted definition for 'accountability' in the humanitarian sector [3]. Accountability can now be assessed in consideration, for instance, of how donor money was spent, but also how humanitarian programs respond to the needs of affected populations. Accountability towards affected populations alone can mean different things: empowering aid recipients; being in an optimal position to do the greatest good; meeting expectations; and, being liable [3].

Research in humanitarian settings

Another factor that plays an important role in the design and implementation of humanitarian health programs is state of evidence underpinning current humanitarian practice [9,10]. While research in humanitarian settings has significantly increased in the last decade [10] there is still a high need to identify and address current evidence gaps even in settings with limited funding and high immediate survival needs [11]. Health research in these settings typically aims to contribute to more effective humanitarian health programs, optimization of the delivery of care in crisis settings and the production of knowledge that is appropriate for these specific settings [11]. Knowledge created through research informs and influences humanitarian health programming, but it must be kept in mind that 'what a researcher finds out is inherently connected with how she finds it out' [12]. The nature of the design, implementation and analysis will influence the process of knowledge generation. Humanitarian health programs are typically implemented in complex settings, often assisting vulnerable and marginalized population groups. Health researchers conducting research with marginalized or vulnerable population groups stress the importance of using PR approaches with populations who have historically been left out of the research process [13,14].

Participatory research (PR)

PR covers a wide range of different terms including, among others, community-based participatory-research (CBPR), participatory action research (PAR), IKT (where decision-makers collaborate in the research process with the aim to enhance the relevance and use of research [15]) as well as co-design or co-production initiatives [16]. Community engagement (where collaboration is established between researchers and communities) is one of the approaches that falls under a participatory approach [16]. PR requires meaningful involvement of end users that can occur across the range of research activities throughout the life cycle of a project or initiative, including engagement in defining the research question, collecting and interpreting data, and reporting and applying the findings [17,18]. Recent reviews of PR approaches argue that engaging people as partners in the co-construction of research [17] increases the commitment of these stakeholders to use the research findings and take action [19] and improves the relevance of research findings [16].

Participatory research in humanitarian settings

While participation, accountability and research are now an integral part of humanitarian programming and implementation, there remains a lack of insight and evidence regarding the extent of PR approaches applied in humanitarian health programs. Critical reviews of PR approaches in predominantly Western health-care settings sought to distil the key challenges and added value of PR [19], mechanisms 'by which PR adds value to the research process' [17], and 'successful strategies to engage research partners for translating evidence into action in community health' [20]. Previous reviews of PR approaches have predominantly focused on research conducted in Western settings whereas this review focuses on PR in humanitarian settings. As this is a novel undertaking, for this paper an adopted a scoping review methodology was conducted. Our research question is broad and exploratory in nature, aiming to ascertain the range of different study designs that have been deployed in this setting and associated findings, in contrast to the approach adopted in systematic reviews that typically focus on a well-defined question where appropriate study designs can be identified in advance [21].

4.4 Methods

Scoping reviews are typically conducted to map key concepts in a research area or summarize the main sources and types of available evidence [22,23]. This approach can be particularly useful in an area that is complex, has not been reviewed comprehensively before [23] or in areas with emerging evidence [24]. In the case of PR in humanitarian settings, where there is inherent complexity related to context as well as novelty in the adoption of participatory approaches within research, we believed that a scoping review could provide insight into the state and scope of existing evidence. We adopted the specific approach advanced by Arksey and O'Malley [21] that involves five key steps: identifying the research question; identifying relevant studies; study selection; charting the data; and, collating, summarizing and reporting the results. We worked closely with a qualified health sciences librarian who has extensive experience in conducting scoping reviews. We used the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) criteria to guide the conduct and reporting of the review [25].

1. Identifying the research question

The research question was developed iteratively with the research team and librarian in the preliminary phase of scanning the literature and establishing the search strategy: *How, and to what extent, have PR values and practices been described in published articles of humanitarian health research studies?* Our secondary question was: *What are key issues related to applying PR in humanitarian settings as reported in these studies.*

We considered the literature in relation to three concepts: 'PR' and 'humanitarian settings' and 'low- and middle-income countries (LMICs)'. The search terms for these three concepts have been adapted from earlier published reviews: a scoping review of IKT in evaluations in health care [16]; a realist review of studies describing PR partnerships [17]; an evidence review of research on health interventions in humanitarian crises [10] and, the LMIC search filter developed by the Cochrane Collaboration in 2012 [26] and the LMIC country list published by the World Health Organization (WHO) [27]. Please see Appendix A for a detailed overview of all the search terms.

2. Search strategy

A preliminary search was undertaken with the help of a qualified librarian. The results of this search were discussed with team members and used to establish a more comprehensive search strategy with explicit inclusion and exclusion criteria (see Appendix B) and multiple information sources (see Appendix C). First author (IO) conducted all searches in close collaboration with author SL and a qualified librarian. The search was conducted from May through to September 2017 and the search was updated again for articles up to 1 February 2019. This phase yielded 3729 titles.

3. Identification of relevant studies

The initial search yielded a large number of irrelevant articles, for example including articles on health emergencies in high-income countries, emergency prepared- ness and disaster prevention. This reflected the challenge in defining the terms and concepts related to humanitarian settings and PR. In collaboration with the librarian, more precise and selective search criteria were developed (e.g. war$.mp was replaced with war1$.mp). In addition, it was decided to add search terms for LMICs and to limit the search to studies published after 2008, covering a period of 10 years which was deemed to be likely to capture most relevant literature given that PR approaches in humanitarian settings are a relatively new practice.

In the next phase, we selected relevant studies and refined the inclusion and exclusion criteria through initial screening of titles, abstracts and then review of full articles. See Appendix C for a more detailed description of the exclusion and inclusion criteria as well as the scanning process.

4. Charting the data

We reviewed each article to extract relevant data [including bibliometric data (e.g. title, publication year, authors), reasons for PR, challenges and limitation, out- comes] and identify themes in response to the primary and secondary research questions using a qualitative descriptive analysis [28].

5. Collating, summarising and reporting the results of identified data

IO and SL first coded all relevant texts independently and we then examined patterns and linkages within and across articles to identify themes which reflected key issues addressed in the data. This process was iterative where we constantly returned to the articles to read certain sections again while coding and selecting text abstracts.

4.5 Results

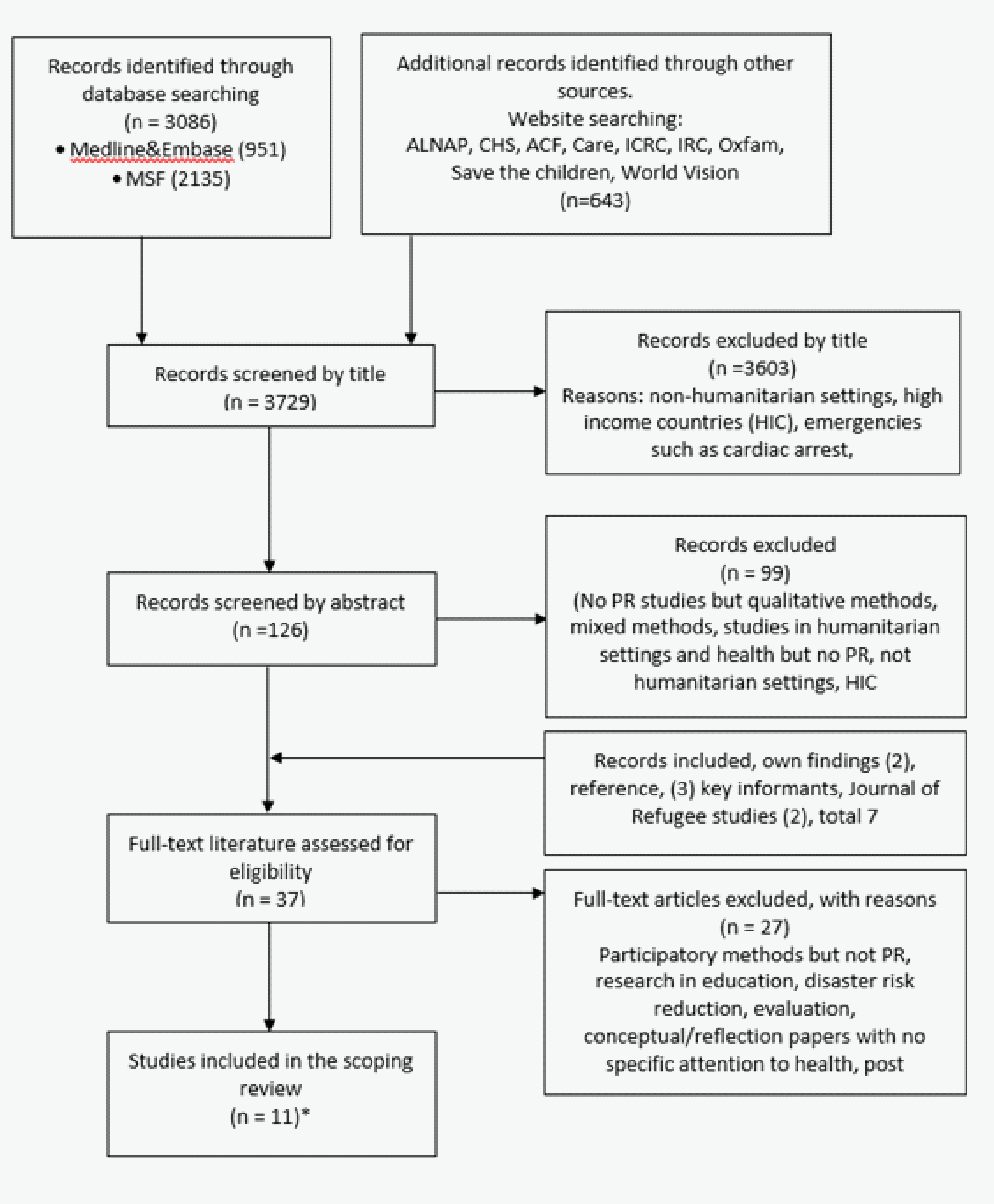
The outcome of the review is twofold: firstly, the scanning of relevant literature resulted in eleven articles. This finding reflects the relatively limited extent where PR values and practices have been adopted in research within humanitarian health settings. Secondly, after close reading of the eleven articles based on eight studies, we identified four themes representing important key issues while applying PR in humanitarian settings: building trust with local research stakeholders and participants, importance of contextual understanding implications of collaboration with affect populations in PR and, interdependence between PR and the role of NGOs (see Table 4-2 for a detailed description of the findings).

Search results

After the removal of duplicates (n = 191), the academic databases produced 951 articles. These were screened together with 2135 articles identified in the MSF database and 643 titles extracted from the humanitarian organizations' websites. The 3729 records were screened by title by one reviewer (rejection of 3603 articles) and abstract (rejection of another 99 articles). The abstract and original text of 37 articles were then independently assessed by IO and SL to select the final sample. Discrepancies between the researchers were resolved by discussion. In total, we selected 11 articles for inclusion in the review. See Flowchart 4-1 and Table 4-1.

***Table 4- 1**: General information of identified studies*

1. Author (year) 2. Study location and context	1. Title 2. Type of PR (type of framework)	1. Study objectives 2. Health Focus
1. Abdulrahim et al. (2010) [35] 2. Palestinian refugee camp in Lebanon (Beirut)	1. The potentials and challenges of an academic–community partnership in a low-trust urban context. 2. CBPR	1. Designing and implementing an intervention to improve the mental health and enhance school attachment. 2. Mental health
1. Afifi et al. (2011) [36] 2. Same as in Abdulrahim (2010)	1. Developing a logic model for youth mental health: participatory research with a refugee community in Beirut. 2. Same as in Abdulrahim (2010)	1. Planning, implementing and evaluating a logic model and intervention 2. Same as in Abdulrahim (2010)
1. Makhoul et al. (2014) [39] 2. Same as in Abdulrahim (2010)	1. Community-based participatory research in complex settings: clean mind-dirty hands. 2. Same as in Abdulrahim (2010)	1. Same as in Afifi (2011) 2. Same as in Abdulrahim (2010)
1. Jones et al. (2018) [37] 2. Post Ebola response in Liberia	1. Rebuilding people-centred maternal health services in post-Ebola Liberia through participatory action research. 2. PAR	1. Build communication between stakeholder groups and identify impacts of Ebola epidemic and shared actions to improve the system. 2. Maternal health
1. Tanabe et al. (2017) [32] 2. Refugee settings in Kenya, Nepal, Uganda	1. “Nothing about us, without us”: Conducting participatory action research among and with persons with disabilities in humanitarian settings 2. PAR	1. Identify specific risks, needs, and barriers to access sexual and reproductive health (SRH) services, and the capacities and practical ways in which these challenges can be addressed. 2. Sexual and reproductive health
1. Elmusharaf et al. (2017a) [40] 2. Post war, South Sudan (Renk County)	1. Participatory Ethnographic Evaluation and Research: Reflections on the Research Approach Used to Understand the Complexity of Maternal Health Issues in South Sudan. 2. PEER (interpretivist approach)	1. Provide a contextualized understanding of maternal health issues in South Sudan and provide recommendations for programmatic health interventions. 2. Maternal health
1. Elmusharaf et al. (2017b) [33] 2. – Same as in Elmusharaf (2017a)	1. Social and traditional practices and their implications for family planning: a participatory ethnographic study in Renk, South Sudan. 2. Same as in Elmusharaf (2017a)	3. Gain in-depth understanding of the social determinants of family size to inform local policy and practice. 1. Same as in Elmusharaf (2017a)
1. Glass et al. (2012) [34] 2. Post conflict, Democratic Republic of Congo (DRC)	1. A Congolese-US participatory action research partnership to rebuild the lives of rape survivors and their families in eastern DRC. 2. PAR	1. Understanding the health, social, cultural and economic factors that influence reintegration to families and communities. 2. Rape
1. Edstrom (2018) [38] 2. Refugees from Great lakes area, Uganda.	1. Breaking the Spell of Silence: Collective Healing as Activism amongst Refugee Male Survivors of Sexual Violence in Uganda 2. Collaborative and grounded approach	1. Explore how male refugee survivors of sexual violence have been able to organize, heal and become activists. 2. Healing from sexual violence against men
Not all inclusion criteria but relevant		
1. Nelems and Curie (2012) [30] 2. Refugee camp, Jordan	1. Listening to Iraqi refugee children in Jordan, but then what? Exploring the impact of participatory research with children. 2. PAR	1. Understand lived experiences and explore the potential for PR to transform programming and the obstacles to institutionalising change. 2. General protection
1. Shanks et al. (2015) [29] 2. Violence, Chechnya and conflict, DRC	1. Losing the tombola”: a case study describing the use of community consultation in designing the study protocol for a randomised controlled trial of a mental health intervention in two conflict-affected regions. 2. Co-design	1. Consultation with community prior to finalising RCT study protocol 2. Mental health



*The published article indicates a total of 10, the correct number, however, is 11

Flowchart 4- 1: *The process of article selection for the scoping review.*

The 11 identified articles were based on the results of eight research projects. The search yielded two studies that we initially considered excluding. One study consulted and engaged with the community to inform the design of a Randomized-Controlled Trial (RCT) [29] which we identified as one of the first stages of participation. A second study did not have a precise health focus but related to health in that it focused on child protection where there were mental health implications for the participants [30]. We decided that these articles contained relevant information and could contribute to a better understanding of the value of PR in humanitarian settings. Half (50%) of the studies were published in the last three years, which is consistent with the growth of research studies in humanitarian settings [31] and may indicate an increase as well in PR in humanitarian settings. The studies covered a wide variety of countries, different humanitarian crises, a range of participatory approaches and different health foci. The majority of studies aimed to better understand risks, needs, and barriers in relation to health, social, economic and cultural factors, as well as lived experiences. These studies provided practical ways or recommendations in which these kinds of issues could be addressed [30,32,34,38]. Two studies aimed to design and implement a program to improve current health services available in the humanitarian setting [35–37]. A study in Uganda analyzed data, obtained through collaborative approaches, to improve the understanding of how a local group for male rape victims became organized [38], and lastly a study conducted in the Democratic Republic of Congo (DRC) and Chechnya aimed to consult with the community prior to finalizing an RCT [29].

Building trust with local research stakeholders and participants

Trust was the primary reason as expressed by authors why several studies adopted a PR approach, while for other studies improved trust was described as an outcome in contexts with existing mistrust between communities and humanitarian organizations or amongst local actors. One study described how participation helped to adapt the study in such a way that it would not create mistrust [29].

A number of studies identified the motivation for their choice to apply PR as a way to build up trust amongst the community members and actors in the health system. The IRC, for example, partnered with a local hospital in Liberia when Ebola incidence started to decrease in late 2014. The slow rate of service use uptake post-Ebola was anticipated to be caused by fear of infection and mistrust of health-care professionals [37]. Through a PAR approach, IRC was able to engage with local-trusted health personnel that contributed to more meaningful forms of community and health worker participation. Jones et al. have argued that this can support the development of more resilient, responsive and trusted health systems [37]. While trust itself was not specifically measured it is noted in the article that the PAR approach resulted in strengthened relationships and improved communication. Similarly, in South Sudan collaborating with locally trained data collectors enabled the team to reduce the time required for data collection and trust-building and helped overcome trust issues between the North Sudanese researcher and South Sudanese study participants.

And in Lebanon, the PR process contributed to reduced mistrust amongst NGOs and United Nations (UN) agencies due to strengthened relationships [35,36]. These authors noted the importance of contextualizing mistrust 'within the broader structural conditions that create conflict and competition between partners' and the importance of building on community strengths. For the authors of this study, it was evident that 'respect and trust are as, if not more, important, than participation at all stages of the research [39]. Even though the PR process had improved trust slowly, in this study, it had not completely dissipated mistrust [35]. The participatory process in a community consultation study to inform the design of an RCT study revealed that affected populations distrusted research conducted by NGOs as they feared a hidden purpose. In addition, this community suggested that all questions in the survey should relate to the illness otherwise it would be seen as spying [29]. Shanks [29] reported that splitting up existing community groups (e.g. religious leaders, healthcare staff members) for focus groups would have led to distrust, contrary to finding from Abdulrahim et al. [35] where trust in their collaborative meetings was enhanced by forming smaller youth groups.

Table 4- 2: *Findings with regards to the four themes; building trust with local research stakeholders and participants, importance of contextual understanding, implications of collaborating with affected populations, neutrality of researchers and NGOs*

Reported findings – Building trust with local research stakeholders and participants	
Reasons for mistrust	Competing for funding, little return from research, research approach, overall mistrust towards the health care system, organisations and NGOs
Value of PR	Contributed to improved trust, was seen as a way to support trusted health systems and could help reduce the required time for trust building
Helpful approaches	Smaller and more confidential meetings, funding to include requirement for collaboration, transparency, allowing time to build trust, include community in decision making
Considerations	Pay attention to mistrust between collaborators, contextualize mistrust within broader structural conditions, allow sufficient time for trust building, community trust is as important as participation
Reported findings – Importance of contextual understanding	
Impact context	The complexity of the settings impacted the level of participation and application of research methods, population prioritised immediate benefits over longer term benefits, context challenged implementation of project recommendations, presence of research fatigue,
Importance context	A contextualized understanding can help tailor interventions that are more likely to be accepted and utilised, collaborators need to be able to respond to changing contexts, important to consider health issues as situated in and linked to social contexts – this requires the use of multi-methods to understand reality
Value of PR	Increased understanding of complex issues and hard-to-reach communities, complexity requires interdisciplinary teams, local experience and knowledge can help overcome cultural barriers
Helpful approaches	PR approaches require time, commitment, and top-down complimentary support to be of maximum benefit, funding that supports assessing the complexity,
Considerations	Have attention to and address context specific challenges and community forces that influence participation, important to take time to understand community perceptions to help localize the study, participatory approaches can support more resilient, responsive, and trusted health systems.
Reported findings – Implications of collaborating with affected populations	
Challenges	Engaging of male participants was difficult, camp settings interfered with participation, limited participation because of camp conditions,
Value of PR	Allowed for direct local consultation, minority groups were heard, member commitment sustained partnerships, community gained confidence to act in their health system and changed perception on actions women could take, possibility for new learning and development of new approaches
Helpful approaches	Flexibility in applying research methods (e.g. consent process, methods, recruitment or objectives, allow informal participation, use of symbols and short interviews for illiterate data collectors, adaptations to language use and translations, sufficient time at start, broad community representation
Considerations	Assess feasibility of participation at start-up, assess forces that affect participation, identify priorities of stakeholders, promote ownership over findings, identify local networks, evaluate (ethical) risks of study designs, don't expect participation in all phases, need for further research on how to include hard-to-reach populations, attention to capacity building, reflective practices and genuine dialogue
Reported findings – Neutrality of researchers and NGOs	
Role NGOs	NGOs facilitation of research may have influenced discussions, biased project trajectories or marginalised certain stakeholder groups, PR efforts needed to run parallel with NGOs actions, researchers perceived competition with NGO, stressful early meetings due to competition for funds amongst NGOs, people, affiliated with NGOs, felt compelled to take part
Value of PR	PR inspired community to be part of research, outcomes helped other NGOs to prioritise projects based on children's perspectives, organisations became convinced of value of participatory engagement, approach was feasible despite the context and provided valuable information
Helpful approaches	NGOs working alongside co-facilitators from stakeholder groups to minimise impact of presence NGO workers, NGO leading research sessions helped to clarify any misperceptions, funding to support collaborative approaches and not only fund evaluations of outcomes,
Considerations	NGOs need to find new ways of working better to respect local knowledge and experiences, be more flexible in programming based on children's priorities, need for longer-term staff positions, NGOs wanted to be engaged but found various aspects difficult,

Importance of contextual understanding

The articles described how the complexity of the humanitarian settings (e.g. political restrictions and displacement) and/or of the particular health issues (e.g. rape victims and Ebola outbreak) negatively affected the level of participation, required adaptations to PR methods or created obstacles for participation.

In the study in Lebanese refugee camps, the level of participation was affected for men who had limited time to participate given they were often working more than one job, but also because of the outbreak of a war and difficulties in setting up participatory approaches due to the United Nations Relief and Works Agency's (UNRWA) bureaucracy [39]. Populations also expressed a lack of interest in participating, as the data collected by international NGOs were not going to be used to implement and sustain programs [34,39].

On the other hand, it was also noted that PR approaches, in these complex settings, contributed to a better contextualized understanding which helped to address health issues and develop more effective, acceptable and tailored humanitarian services. PR contributed to a better understanding of the complex context in South Sudan where a maternal health program was being implemented. Addressing barriers to maternal health involves changing complex behaviours; a good understanding of the context of (hard-to-reach) communities and the complexity in which different behaviours occur [40] enables the tailoring of services so that they are more likely to be accepted and used [39,40]. A study of an approach to rebuild the lives of rape survivors and their families in eastern DRC demonstrated that different factors (e.g. security, social norms, and economic impact) have negative impacts on health and human rights of the local population. Addressing health therefore requires an interdisciplinary collaboration with diverse sets of expertise, including health care and gender specialists, human right lawyers and military advisors [34].

Furthermore, in certain studies, the authors noted the link between contextual factors and the level of impact or outcomes of the initiative or program. It was, for example, reported that the complexity of the context (factors such as the lack of staff continuity in organizations and the institutionalized power relationships between the Jordanian government and the donor community members) hindered the implementation of the PR results [30]. On the other hand, however, the PR results helped organizations form a better understanding of the context and influenced how one NGO related to their staff and volunteers in more egalitarian ways ‘based on a greater understanding of the complexity of their lives’ [30].

Implications of collaborating with affected populations in participatory research

In most studies, collaborating with affected populations as part of the participatory process involved engagement by researchers in training local partners, and further, that collaboration led to changes to the PR question, the methods or the co-development of methods with the affected population.

Several studies described substantial training efforts for local partners over 3–4 days [32,35,37,40]. It was noted that collaborating partners appreciated the certificate awarded at the end of the training as well as the opportunity to learn [40]. In Nepal, the importance of participatory and co-production processes were highlighted when data collectors invited family members to join a debriefing session as it was seen as an important personal achievement to have a critical role in a research process [32]. The attention to capacity building enhanced participation, reflective practices, and created conditions for genuine dialogue [40].

Participation of local data collectors was sometimes made possible through adaptations of the approach, which brought certain benefits. In South Sudan, interview guidelines were developed with the use of symbols and drawings (developed with the collaborating partners) so that illiterate data collectors were able to conduct the interviews [40]. In another study, data collectors who had disabilities experienced difficulties with the limited accessibility infrastructure of the camp yet had the ability to engage and relate to participants with disabilities while ‘creating a safe and open environment for dialogue’. In addition, their presence served as a powerful icebreaker [32]. Engaging local women as researchers in South Sudan helped to identify women who were willing to participate and enhanced their willingness to trust the researcher [40]. It also helped gain more in-depth understanding and insightful information [40]. It was also noted that partners were keen and able to take active roles in research [38] and their high level of commitment to enhancing youth welfare served as a driving force to sustain the partnerships [35].

Some studies described making changes to the design, data collection and recommendations such as allowing short conversations with vulnerable individuals who otherwise would not have been included

[32] or by allowing multiple participants rather than individual participation so that people were more confident to participate [37]. PR also opened up new learning and the development of new approaches [38] as well as the application of a rights-based approach which fostered increasing levels of participation [32]. In Lebanon, the study group felt at times challenged as the impoverishment and the difficult living conditions in the camp influenced the participants' interests in the direction of research that offered immediate benefits (e.g. providing English lessons) over scientific health research that offered no immediate benefits. These authors advised that it is important to assess the feasibility and level of interest to participate when starting a participatory research project to understand barriers and possible strategies to mitigate them [39]. Finally, it was suggested that there is a need for further research to look at how to best include the perspectives of hard-to-reach communities [40].

One study reported that none in the collaborating community received compensation due to a lack of available funds [35]. Two studies described providing a small token of appreciation for the *participants* such as monetary or non-monetary gifts/contributions (small food items or money) as well as the provision of refreshments and reimbursement of transportation costs [29,37]. Another study assessed what the community felt should be the compensation for participation and participants advised that a small amount of food or money would be appropriate, but felt that should not be too much in order to prevent participation solely for the incentive [29]. The other studies did not mention whether or not partners were paid or compensated in any way. Difficulties with participation were also noted due to the challenging working conditions and the need to prioritize paid work over volunteer participation [39].

While most studies mentioned the specific collaborating partners (e.g. international and local NGOs, universities, representatives of UN, health-care workers) it was not always clear in the published reports exactly which collaborators took part in each of the various phases of research, such as in the analysis, interpretation and reporting of the data. In addition, only two articles included local partners as authors [34,37].

Neutrality of researchers and NGOs

To enable PR in humanitarian settings, researchers are often dependent or reliant on the structures and processes of NGOs to enable certain research processes due to security issues, access [12] and the capacity of staff members to conduct research in these kinds of settings. How the research is going to be conducted, and how the research and researcher are perceived in the field are therefore also influenced by the work and reputation of the NGO. Several authors reflected on how collaboration with the NGOs influenced research studies. In some cases, the research in the selected articles was led by a representative of an NGO, in other cases, external researchers depended to some extent on the collaboration with NGOs to be able to conduct their research. This interaction had both potentially positive and negative impacts on the research.

Some collaborating NGOs also provided the services that were subject of the research and this dynamic potentially had an impact on the data collection and results [29,37,39,40]. In Lebanon, participants felt compelled to take part as their families were affiliated with the NGOs [39]. In Congo and Chechnya, it was anticipated that this situation biased responses to be more positive in an attempt to please or not offend the NGO staff, but at the same time, it was also identified as a strength as they had the opportunity to address more directly any misconceptions about the program and the NGOs' objectives [29]. In Liberia the authors describe that this may have influenced 'the discussions, biased project trajectories or unintentionally marginalized certain stakeholder groups' and PR efforts needed to run parallel with the institutional actions and resources [37]; in order to minimize these effects, the NGO worked alongside co-facilitators from across the stakeholders groups [37]. The presence of NGOs, not related to the study, also influenced the PR approach. In South Sudan, the team was only able to offer participation in the research project and therefore anticipated difficulties recruiting partners whereas other NGOs were offering food and services for participation in a variety of activities. PR was identified as an approach that could inspire and motivate the community to be part of the research [40]. In Lebanon, the funding structure in the camps created an atmosphere of competition and mistrust amongst the NGOs, rather than a culture of collaboration. The researchers recommend that funding agencies need to improve community participation and collaboration by setting up funding structures that promote collaborative processes [39].

The collaboration and results of PR also had a positive impact on other NGOs. One study specifically focused on exploring ‘the potential for PR to transform programming and the obstacles to institutionalizing change’. One of the most profound and unexpected outcomes was that participating NGOs became convinced of the value of participatory engagement to better understand the local context. These NGOs developed a greater commitment to participatory approaches, felt better equipped to publicly discuss the findings based on the availability of ‘sound evidence’ and changed their advocacy approach [30].

4.6 Discussion

This scoping review was conducted to better understand key issues in relation to PR as designed and implemented in humanitarian settings. We have demonstrated that the use of PR approaches in humanitarian settings positively contributed to improved trust, a better understanding of complex issues, and engagement with vulnerable and marginalized populations. While participation, accountability and engagement gain prominence in the policy and strategy documents of humanitarian organizations, this review demonstrates that participation needs more than just the rhetoric. The results of the scoping review indicate that PR requires a considerate approach, interdisciplinary teams, time, and flexibility to adapt the methods and tools to the local context. In addition, it is important to continuously consider and address issues such as tense relationships, neutrality, complexity and trust.
The included studies in this review contained only sparse information related to compensation provided to collaborating stakeholders. At the moment, there is no clear guidance on whether collaborators should be paid (and if so, how much and when), with proponents arguing that participation costs time and should therefore be compensated while others argue that payment may negatively impact natural collaborative systems and reduce the willingness to volunteer to support local initiatives [41]. In addition, the level of collaboration with key stakeholders is frequently not clearly described in the identified studies. This is a common critique of published PR studies and approaches [42,43]. This lack of recognition for the contributions of local partners in research may be indicative of the continued challenges with existing inequity and asymmetrical power relations within such collaborations or partnerships [44].

There are countless publications, books and reports urging for change in the way humanitarian assistance is provided. These approaches to change and the paradigms underpinning such approaches are likely ‘bound to be partial and incomplete and shaped by the author positionality’ [45]. Within the humanitarian innovation field, it is noted that there is ‘a longstanding and unjustifiable lack of engagement with recipients of aid’ [1]. In the book entitled ‘*Time to listen: hearing people on the receiving end of international aid*’, Anderson reports on the insights, ideas, and analysis of almost 6000 people who received humanitarian assistance. Affected populations indicated that they want a system ‘that integrates the resources and experiences of outsiders with the assets and capacities of insiders to develop contextually appropriate strategies for pursuing positive change’. This suggests a need to move away from the current approach with a dominant focus on the delivery of resources (and knowledge) towards a system that supports a more collaborative approach to the analysis of the context, design and decisions about the best strategy [41]. While the need to move away from top-down systems is now broadly acknowledged, it remains challenging to transform humanitarian health programs.

The four themes discussed in the results are not about what could be described as the ‘hardware’ of humanitarian assistance – or the delivery of resources. We describe in our findings what is ‘in between’ humanitarian structures and systems, such as the interpersonal relationships, trust, collaboration and the intersections between components of what are characteristically complex contexts – the ‘software’. It is argued that the ‘software’ has a major influence on the success and effectiveness of humanitarian programs [46,47]. If humanitarian organizations truly want to build trusting relationships with affected populations and move beyond a top-down approach of the implementation of evidence-based knowledge then there is a need to engage affected populations at all levels of humanitarian assistance, including research in this field. PR is one of the approaches that contributes to a better understanding of complex systems while generating new knowledge in a mutual learning process.

Implications

Research conducted in humanitarian settings is often limited in the types of studies that can take place [48] given the context and constraints in humanitarian settings. This is not unique to PR, engaging vulnerable or hard to reach populations remains an issue in many different areas of PR but much can be learned about effective engagement practices by comparing the literature, for example, from PR research experiences in the fields of HIV [49], women discharged from prison [50] and mental health research [51] among others. The studies included in this scoping review provided some insight into how PR was applied, the challenges, and indications of the value of such approaches in humanitarian settings. See Table 4-3 for implications and recommendations.

Table 4- 3*: Implications and recommendations for future research derived in this scoping review*

Type and source of recommendation	Suggested areas for further work
Author recommendations for others involved in assessments of HP programs	- explore for the availability of guidelines and training resources with regards to PR in humanitarian settings - consider standard ways of reporting on incentives, honorariums, role of the collaborating partners in the data collection and analysis, and reporting on the continuation of research studies - Include local partners on articles, presentations and reports.
Suggestions for future research	- explore timing and conditions for when it may be appropriate and meaningful to apply PR approaches in emergency responses - further testing and adaptation of PR approaches in humanitarian settings - improve methods or approach to understanding the context and complexity of humanitarian health programs (better descriptions of context and setting for programs and studies) - Engage with affected populations as well as with key decision makers such as health care professionals, policy makers, government agency leaders to help identify problems (and shared understanding of the problems), and improve implementation of results into practice, using for example an integrated knowledge translation approach.
Recommendations drawn from included articles	- increase funding opportunities that encourage participatory approaches or support research on the processes of PR rather than on evaluation and outcomes [31] - address the scarcity of bottom-up health system research approaches [34] - increase commitment to learning across the humanitarian community [38] - document more of the PR experiences in humanitarian crises settings [31].

Strengths and limitations

This scoping review was based on a search of various types of resources (academic databases, NGO websites, journal searches). The selection process for the articles was conducted in close collaboration with a second researcher and reviewed in discussion with an expert advisory committee. There were important limitations in this review. Our search was limited to two academic databases given the likely yield based on our preliminary exploratory searches; we also reviewed references within documents, as well as reports and publications on NGO websites. We did not, however, include a full review of unpublished or ‘grey’ literature, nor did we search in languages other than English. Future reviews could consider the inclusion of other databases or grey literature to increase the number of identified articles, provide additional information and lessons [52] from PR research and to include consultations with community members and key stakeholders to validate the scoping review findings [24]. The search terms PARTICIPATORY RESEARCH and HUMANITARIAN CRISES are difficult to define but we optimized our search strategy as guided by other published strategies [10,16,17] and by adding search terms for 'LMIC'. Future searches could consider checking whether the terms community engagement, pandemic and endemic provide an additional yield of relevant papers. Further development of effective search strategies and common definitions to support such work in the future would strengthen the methods and findings for such a review with further lessons for PR and humanitarian programs.

4.7 Conclusions

One of the most important contributions of humanitarian health programs is to develop 'medical practices that are better adapted to the living conditions and priorities of patients who are generally ignored' [53]. Learning how to optimize and improve humanitarian health programs for those that are deprived of access to health care, requires the inclusion of these populations throughout the processes related to the production and application of new knowledge. PR approaches offer potentially effective mechanisms for identifying priorities for change, adapting medical practices to the local context, improving trust and engaging vulnerable and marginalized populations or community groups in sustainable solutions.

Acknowledgments

The authors would like to thank the librarian at McGill University who has provided invaluable feedback and suggestions for adjustments in the search terms. This scoping review has been made possible with financial support from Dr. Ian Graham's CIHR Foundation grant: *Moving knowledge into action for more effective practice, programs and policy: A research program focusing on integrated knowledge translation* as well as a Fonds de Recherche Quebec Santé (FRQS) doctoral training scholarship for IO.

Author contributions

All authors have contributed with:

(1) Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND
(2) Drafting the work or revising it critically for important intellectual content; AND
(3) Final approval of the version to be published; AND

(4) Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Disclosure statement

No potential conflict of interest was reported by the authors.

Ethics and consent

Not applicable.

Paper context

In the provision of humanitarian aid, engagement with local communities and affected individuals is largely reported an operational level, and infrequently within research. This is the first review of participatory research (PR) in humanitarian contexts, which aims to contribute to the growing evidence regarding the benefits of research involving end-users. Those involved in humanitarian aid should consider PR approaches that involve the co-production of new knowledge in collaboration with affected populations for relevant, sustainable solutions.

Funding information

This paper was supported by Dr. Ian Graham's CIHR Foundation grant: Moving knowledge into action for more effective practice, programs and policy: A research program focusing on integrated knowledge translation (FDN # 143237) and Fonds de Recherche Quebec Santé (FRQS) doctorate grant (dossier # 254903).

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4.8 References

[1] Ramalingam B, Rush H, Bessant J, et al. Strengthening the humanitarian innovation ecosystem. Brighton, Eastbourne: University of Brighton; 2015.

[2] United Nations. Office for the coordination of humanitarian affairs. In: Policy analysis and innovation section world humanitarian data and trends 2018. Geneva, Switzerland: United Nations Office for the Coordination of Humanitarian Affairs (OCHA); 2019.

[3] Tan YA, von Schreeb J. Humanitarian assistance and accountability: what are we really talking about? Prehosp Disaster Med. 2015;30:264–270.
[4] Ramalingam B. Aid on the edge of chaos: rethinking international cooperation in a complex world. Oxford, England: Oxford University Press; 2013.
[5] Moyo D. Dead Aid: why aid is not working and how there is a better way for Africa. New York, United States: Macmillan; 2009.
[6] Redfield P. Life in crisis: the ethical journey of doctors without borders. Berkeley, California: Univ of California Press; 2013.
[7] Darcy J, Alexander J, Kiani M. Humanitarian account- ability report. London, United Kingdom: Active Learning Network for Accountability and Performance (ALNAP); 2013.
[8] Foran MP, Williams AR. Global uptake of the humanitarian accountability partnership over its first ten years. Prehosp Disaster Med. 2014;29:413–416.
[9] Ager A, Burnham G, Checchi F, et al. Strengthening the evidence base for health programming in humanitarian crises. Science. 2014;345:1290–1292.
[10] Blanchet K, Roberts B, Sistenich V, et al. An evidence review of research on health interventions in humanitarian crises. London: London School of Hygiene & Tropical Medicine; 2013.
[11] Kohrt BA, Mistry AS, Anand N, et al. Health research in humanitarian crises: an urgent global imperative. BMJ Glob Health. 2019;4:e001870.
[12] van der Haar G, Heijmans A, Hilhorst D. Interactive research and the construction of knowledge in conflict-affected settings. Disasters. 2013;37:S20–35.
[13] Corburn J. Street science: community knowledge and environmental health justice. Cambridge, Massachusetts: MIT Press; 2005.
[14] Hall BL. Participatory research, popular knowledge and power: A personal reflection. Convergence. 1981;14:6.
[15] Kothari AMC, Graham ID. Defining integrated knowledge translation and moving forward: a response to recent commentaries. Int J Heal Policy Manag. 2017;6:299.
[16] Gagliardi AR, Berta W, Kothari A, et al. Integrated knowledge translation (IKT) in health care: a scoping review. Implement Sci. 2016;11:38.
[17] Jagosh J, Macaulay AC, Pluye P, et al. Uncovering the benefits of participatory research: implications of a realist review for health research and practice. Milbank Q. 2012;90:311–346.
[18] Straus S, Tetroe J, Graham ID. Knowledge translation in health care: moving from evidence to practice. Hoboken, New Jersey: John Wiley & Sons; 2013.
[19] Cargo M, Mercer SL. The value and challenges of participatory research: strengthening its practice. Annu Rev Public Health. 2008;29:325–350.
[20] Salsberg J, Parry D, Pluye P, et al. Successful strategies to engage research partners for translating evidence into action in community health: a critical review. J Environ Public Health. 2015;2015:1–15.
[21] Arksey H, O'Malley L. Scoping studies: towards a methodological framework. Int J Soc Res Methodol. 2005;8:19–32.
[22] Anåker A, Heylighen A, Nordin S, et al. Design quality in the context of healthcare environments: a scoping review. HERD Health Env Res Des J. 2017;10:136–150.
[23] Mays N, Pope C. Qualitative research in health care: assessing quality in qualitative research. BMJ. 2000;320:50–52.
[24] Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. Implement Sci. 2010;5:69.Moher D, Liberati A, Tetzlaff J, et al. Preferred reporting items for systematic

reviews and meta-analyses: the PRISMA statement. PLoS Med. 2009;6:e1000097.

[25] Cochrane. LMIC filters 2012. 2012. Available from: https://epoc.cochrane.org/lmic-filters

[26] The World Bank. LMIC country list. 2018; [cited 2020 Mar 17] Available from: https://datahelpdesk.world bank.org/knowledgebase/articles/906519

[27] Sandelowski M. Sample size in qualitative research. Res Nurs Health. 1995;18:179–183.

[28] Shanks L, Moroni C, Rivera IC, et al. "Losing the tombola": a case study describing the use of community consultation in designing the study protocol for a randomised controlled trial of a mental health intervention in two conflict-affected regions. BMC Med Ethics. 2015;16:31–39.

[29] Nelems M, Currie V. Listening to Iraqi refugee children in Jordan, but then what? Exploring the impact of participatory research with children. Dev Pract. 2012;22:600–612.

[30] Tansey CM, Pringle J, Davé A, et al. Earthquakes to floods: A scoping review of health-related disaster research in low-and middle-income countries. PLoS Curr Disasters. 2018 Aug 30;10:10.

[31] Tanabe M, Pearce E, Krause SK. "Nothing about us, without us": conducting participatory action research among and with persons with disabilities in humanitarian settings. Action Res. 2018;16:280–29834.

[32] Elmusharaf K, Byrne E, O'Donovan D. Social and traditional practices and their implications for family planning: a participatory ethnographic study in Renk, South Sudan. Reprod Health. 2017 Jan 17;14:10.

[33] Glass N, Ramazani P, Tosha M, et al. A congolese-US participatory action research partnership to rebuild the lives of rape survivors and their families in eastern Democratic Republic of Congo. Glob Public Health. 2012;7:184–195.

[34] Abdulrahim S, El Shareef M, Alameddine M, et al. The potentials and challenges of an academic–community partnership in a low-trust urban context. J Urban Health. 2010;87:1017–1020.

[35] Afifi RA, Makhoul J, El Hajj T, et al. Developing a logic model for youth mental health: participatory research with a refugee community in Beirut. Health Policy Plan. 2011;26:508–517.

[36] Jones T, Ho L, Kun KK, et al. Rebuilding people-centred maternal health services in post-Ebola Liberia through participatory action research. Glob Public Health. 2018;13(11):1–20.

[37] Edström J, Dolan C. Breaking the spell of silence: collective healing as activism amongst refugee male survivors of sexual violence in Uganda. J Refugee Stud. 2018;32:175–196.

[38] Makhoul J, Nakkash R, Harpham T, et al. Community-based participatory research in complex settings: clean mind-dirty hands. Health Promot Int. 2014 Sep;29:510–517.

[39] Elmusharaf K, Byrne E, Manandhar M, et al. Participatory ethnographic evaluation and research: reflections on the research approach used to understand the complexity of maternal health issues in South Sudan. Qual Health Res. 2017 Jul;27:1345–1358.

[40] Anderson MB, Brown D, Jean I. Time to listen: hearing people on the receiving end of international aid. Cambridge, UK: CDA Collaborative Learning Projects; 2012.

[41] Hearod JB, Wetherill MS, Salvatore AL, et al. Community-based participatory intervention research with American Indian communities: what is the state of the science? Curr Dev Nutr. 2019;3:39–52.

[42] O'toole TP, Aaron KF, Chin MH, et al. Community- based participatory research: opportunities, challenges, and the need for a common language. J Gen Intern Med. 2003;18:592.

[43] Olivier C, Hunt MR, Ridde V. NGO–researcher partnerships in global health research: benefits,

challenges, and approaches that promote success. Dev Pract. 2016;26:444–455.

[44] Sandvik KB. Now is the time to deliver: looking for humanitarian innovation's theory of change. J Int Humanitarian Action. 2017;2:8.

[45] Eyben R. Power, mutual accountability and responsibility in the practice of international aid: A relational approach. Brighton, UK: IDS; 2008.

[46] Hilhorst D. Classical humanitarianism and resilience humanitarianism: making sense of two brands of humanitarian action. J Int Humanitarian Action. 2018;3:1–12.Krystalli R, Ott E. Evidence synthesis in the humanitarian sector: a guidance note. Boston, United States: Oxfam–Feinstein International Center; 2015.

[47] Karris MY, Dubé K, Moore AA. What lessons it might teach us? Community engagement in HIV research. Curr Opin HIV AIDS. 2020;15:142–149.

[48] McLeod KE, Korchinski M, Young P, et al. Supporting women leaving prison through peer health mentoring: A participatory health research study. CMAJ Open. 2020;8:E1.

[49] Raanaas RK, Bjøntegaard HØ, Shaw L. A scoping review of participatory action research to promote mental health and resilience in youth and adolescents. Adolesc Res Rev. 2018 Oct 1;5:1–6.

[50] Taylor DL, Kahawita TM, Cairncross S, et al. The impact of water, sanitation and hygiene interventions to control cholera: a systematic review. PLoS One. 2015;10:e0135676.

[51] Magone C, Neuman M, Weissman F. Humanitarian negotiations revealed: the MSF experience. Hurst. 2012. p. 216.

4.9 Appendices

Appendix 1: Search terms for scoping review in databases MEDLINE and Embase

Concept 1 – PR or IKT	**2 – Humanitarian crises**	**3 – LMIC**
Patient Participation/	Humanitarian$.mp.	Developing Countries**.sh,kf.**
Engag* adj3 patient*.mp	Relief work/	(Africa or Asia or Caribbean or West Indies or South America or Latin America or Central America)**.hw,kf,ti,ab,cp.**
Participatory research.mp.	relief work.mp.	
Interactive research.mp	Disaster$.mp.	
Action research.mp.	Disaster medicine/	((developing or less* developed or under developed or underdeveloped or middle income or low* income or underserved or under served or deprived or poor*) adj (countr* or nation? or population? or world))**.ti,ab.**
Social responsibility/	Disasters/ or	
Accountability.mp.	Disaster planning/	
Participative research.mp	Disaster victims/	
Participatory rural.mp	(Emergency health care or emergency healthcare).mp.	
Participatory appraisal.mp	Armed conflicts/	((developing or less* developed or under developed or underdeveloped or middle income or low* income) adj (economy or economies))**.ti,ab.**
Emancipatory research.mp	Conflict$1.ti	
Empowerment evaluation.mp	Armed conflict$.mp	
cbpr.mp	Refugees/	
Collaborative inquiry.mp	(refugee$ or evacuee$ or evacuated).mp	(low* adj (gdp or gnp or gross domestic or gross national))**.ti,ab.**
Social reconnaissance.mp	“Displacement (Psychology)”/	
Community-Based Participatory Research/	(displace$ adj2 (force$ or population or human or internal$)).mp	(lmic or lmics or third world or lami countr*)**.ti,ab.**
IKT	Medical Missions, Official/	(low adj3 middle adj3 countr*)**.ti,ab.**
Knowledge/	((relief or aid) adj2 work$).mp	transitional countr*.ti,ab.
(knowledge adj2 synthes*).mp.	exp war/	**
(knowledge adj2 translat*).mp.	War$1.mp	
(integrat* adj2 knowledg* adj2 translat*).mp.	(conflict affected adj3 (population$ or person$ or communit$ or state$)).mp	
(knowledge adj2 disseminat*).mp.	Avalanches/	
(knowledge adj2 exchang*).mp.	Earthquakes/	
Information Dissemination/	Floods/	
(information adj2 disseminat*).mp.	(avalanche$ or earthquake$ or flood or floods or flooding or flooded or landslide$ or tsunami$).mp	
engaged scholarship.mp.	Tidal Waves/	
stakeholder	Tsumanis/	
Translational Medical Research/	Cyclonic storms/	
Comparative Effectiveness Research/	(typhoon$ or hurricane$ or cyclone$).mp	
	Landslides/	
	Droughts/	
	drought$.tw.	
	Starvation/	
	(starvation or famine$).mp	
	(armed or zone) adj2 conflict$)).mp	
	Emergencies/	
	Emergency shelter/	
	Rescue work/	

(Afghanistan or Albania or Algeria or Angola or Armenia or Armenian or Azerbaijan or Bangladesh or Benin or Byelarus or Byelorussian or Belarus or Belorussian or Belorussia or Belize or Bhutan or Bolivia or Bosnia or Herzegovina or Hercegovina or Botswana or Brasil or Brazil or Bulgaria or Burkina Faso or Burkina Fasso or Burundi or Urundi or Cambodia or Khmer Republic or Cameroon or Cameroons or Cameron or Camerons or Cape Verde or Central African Republic or Chad or China or Colombia or Comoros or Comoro Islands or Comores or Congo or Zaire or Costa Rica or Cote d'Ivoire or Ivory Coast or Cuba or Djibouti or Dominica or Dominican Republic or East Timor or East Timur or Timor Leste or Ecuador or Egypt or United Arab Republic or El Salvador or Eritrea or Ethiopia or Fiji or Gabon or Gabonese Republic or Gambia or Gaza or Georgia Republic or Georgian Republic or Ghana or Grenada or Guatemala or Guinea or Guiana or Guyana or Haiti or Honduras or India or Maldives or Indonesia or Iran or Iraq or Jamaica or Jordan or Kazakhstan or Kazakh or Kenya or Kiribati or Korea or Kosovo or Kyrgyzstan or Kirghizia or Kyrgyz Republic or Kirghiz or Kirgizstan or Lao PDR or Laos or Lebanon or Lesotho or Liberia or Libya or Macedonia or Madagascar or Malagasy Republic or Malaysia or Malaya Sabah or Sarawak or Malawi or Nyasaland or Mali or Marshall Islands or Mauritania or Mauritius or Agalega Islands or Mexico or Micronesia or Moldova or Moldovia or Moldovian or Mongolia or Montenegro or Morocco or Mozambique or Myanmar or Myanma or Burma or Namibia or Nepal or Nicaragua or Niger or Nigeria or Pakistan or Paraguay or Peru or Philippines or Philipines or Phillipines or Phillippines or Romania or Rumania or Roumania or Russia or Russian or Rwanda or Ruanda or Saint Lucia or St Lucia or Saint Vincent or St Vincent or Grenadines or Samoa or Samoan Islands or Sao Tome or Senegal or Serbia or Montenegro or Sierra Leone or Sri Lanka or Ceylon or Solomon Islands or Somalia or South Africa or Sudan or Suriname or Surinam or Swaziland or Syria or Tajikistan or Tadzhikistan or Tadjikistan or Tadzhik or Tanzania or Thailand or Togo or Togolese Republic or Tonga or Tunisia or Turkey or Turkmenistan or Turkmen or Uganda or Ukraine or USSR or Soviet Union or Union of Soviet Socialist Republics or Uzbekistan or Uzbek or Vanuatu or New Hebrides or Venezuela or Vietnam or Viet Nam or West Bank or Yemen or Zambia or Zimbabwe or Rhodesia).hw,kf,ti,ab,cp.**

Appendix 2 Inclusion and exclusion criteria

Selection criteria	**Yes/No**
1. Does the full-text paper indicate health related research?	
2. Does the full-text paper indicate that participation occurred in one or more of the following three areas:	
a. partners were involved in identifying or setting the research questions?	
b. partners were involved in setting the methodology or collecting data or analysing the data?	
c. partners were involved in uptake or dissemination of the research findings?	
3. Does the full-text paper describe the research setting? (indicate community-based, organizational, or other (describe))	
a. humanitarian crises / humanitarian context / post-disaster context	
4. Does the full-text paper indicate empirical research (i.e., that there is some description of methods, data collection and analysis)? (Specify the methodology)	
5. Does the full-text paper describe PR-related outcomes?	
6. Does the full-text paper describe PR processes or contexts (or is there a reference to the process/context in a cited companion paper)?	

Appendix 3: Detailed description of scoping review steps

Data sources: The final search strategy included the following sources with publications since 2009: (1) electronic peer-reviewed health science databases (Medline and Embase), (2) an online database of published grey and peer reviewed papers hosted by the humanitarian aid agency Médecins Sans Frontières (MSF), 3) databases from two humanitarian umbrella organisations ALNAP) and CHS, and 4) website resources or databases from seven of the bigger humanitarian organizations who had some kind of database with resources or academic publications (Action Contre la Faim (AAH), Care, International Rescue Committee (IRC), International Committee of the Red Cross (ICRC), Oxfam, Save the Children and World Vision).

Inclusion and exclusion critera: Exclusion criteria included: non-health related humanitarian assistance, disaster preparedness, and studies that described a participative evaluation of humanitarian assistance. At the same time, we applied broad inclusion criteria for health-related assistance, meaning that all empirical studies related to the determinants of health (nutrition, poverty, etc.) or for example general needs assessments and water and sanitation studies were included. Nonetheless, studies on education and agriculture were excluded.

Scanning process: IO and SL met regularly throughout this phase to discuss the findings, adjust the selection criteria, and made decisions regarding the eligible studies for full review. We followed an adapted approach to the scoping review methodology as only one reviewer (IO) screened titles and abstracts, while all uncertainties were discussed with another team member (SL) (1). IO and SL independently assessed the full text of all (2) selected articles and together refined and agreed on the final inclusion and exclusion criteria. In this phase it was for example decided to include studies conducted in upper middle-income countries, and to include studies conducted in humanitarian crisis settings (e.g. country in war) that were not directly related to humanitarian assistance. See appendix 3 for the PRISMA flow-chart.

1. Pal NE, Eckenwiler L, Hyppolite S-R, et al. Ethical considerations for closing humanitarian projects: a scoping review. Journal of International Humanitarian Action. 2019;4(1):17.
2. Moher D, Liberati A, Tetzlaff J, et al. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS medicine. 2009;6(7):e1000097.

5 HYGIENE PROMOTION RESEARCH IN DISEASE OUTBREAKS IN HUMANITARIAN SETTINGS – MANUSCRIPT 2[2]

5.1 Preamble

In the scoping review I found that participatory research was rarely applied in humanitarian settings. I decided to further explore the level of engagement and interest in the perspectives of the people affected by the cholera outbreak in Haiti. In this manuscript I considered the published and grey literature of research investigating the HP response of the cholera outbreak in Haiti. During my field work, I noticed that most studies investigating the HP activities conducted a KAP survey. I wanted to better understand to what extent local experiences were part of research and to what extent the studies applied participatory methods. Learning from research conducted in the cholera response in Haiti can provide important lessons for HP responses in future outbreaks. In this manuscript, we conclude that the predominant focus on biomedical or scientific information in these studies overshadowed the potential value and importance of the human or behavioural components in HP as emphasized in participatory approaches in other contexts.

This manuscript aims to offers explanation and practical guidance for setting up research studies to professionals working in disease outbreaks settings. This manuscript contributed to demonstrating the lack of application of participatory approaches in research investigating the HP response in Haiti, to date. It also provided evidence why it was important to pilot an EBCD, even if data collection took place six years after the start of the cholera outbreak. This manuscript has been submitted to Critical Public Health in March 2021 and is currently under review.

Reference: Ormel I, Hunt M, Hinton L, Salsberg J, Doucet A, Massena K, Macaulay AC, Law S. Hygiene promotion research in disease outbreaks in humanitarian settings: the case of cholera in Haiti. Submitted to Critical Public Health

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[2] This thesis has the version of the paper as submitted in March 2021. Since the publication of this thesis, an updated version has been submitted.

Hygiene promotion research in disease outbreaks in humanitarian settings: the case of cholera in Haiti

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5.2 Abstract

Hygiene promotion (HP) response to humanitarian emergencies is challenging for many reasons. An important limitation is the scant research evidence available regarding the effectiveness of HP practices in these contexts. Learning from past HP research in disease outbreaks can inform improvements in the design, conduct and implementation of future responses. In this study, we consider the published and grey literature of research conducted over the past 8 years that investigated the HP response of the cholera outbreak in Haiti. We identified three operational reports in the grey literature (reference checking and online searches and repositories) and nine published research studies, all based on a total of seven distinct research studies. Six research studies have a predominant focus on measuring the population's cholera-related knowledge and practices, using surveys (n=5) and focus groups (n=1). The last study reported on local knowledge and perceptions. None reported on alternative health practitioners' perspectives or health care seeking behaviour, nor did any describe using a participatory approach.

The predominant focus on biomedical or scientific information in these studies overshadowed the potential value and importance of the human or behavioural components in HP. The impact and success of HP, however, depends on human behaviour which is influenced by many different factors. A deeper understanding of the range and combination of factors that contribute to the reduction of cholera transmissions are

therefore a prerequisite to change. Consideration of adopting participatory approaches in future research and evaluation efforts would further ensure that interventions are not addressing the wrong mechanisms.

5.3 Introduction and Purpose

Measuring and evaluating hygiene promotion (HP) disease response in humanitarian assistance remains challenging. Learning from research investigated the HP response the cholera outbreak in Haiti, one of the largest cholera outbreaks following a disaster, can contribute to advancing best practice in humanitarian HP in future disease outbreaks. We present an overview of HP responses in humanitarian settings, the current literature related to HP responses in disease outbreaks and the cholera epidemic in Haiti. We reflect on the state of evidence and approaches and draw upon the results of this review to offer guidance to researchers and humanitarian actors about important factors to consider when designing a humanitarian HP response in disease outbreak settings.

Research and hygiene promotion in humanitarian settings

In a large review of research in humanitarian settings only 6 studies focused on water, sanitation and hygiene (Blanchet et al., 2015). The majority of these studies investigate choices for efficacious delivery models for clean water and sanitation (Blanchet et al., 2015). Within research studies focusing on interventions to control cholera, a minority of studies investigate promotional activities and behaviour change. These studies tend to focus on how to improve knowledge and the uptake of messages, rather than focusing on the targeted behaviour changes (Taylor, Kahawita, Cairncross, & Ensink, 2015) despite long-existing evidence that HP response should move beyond knowledge dissemination (Hausmann-Muela, Ribera, & Nyamongo, 2003). As a result, HP strategies are currently limited to a blind trial-and-error process (Mosler, 2012).

Current best research practices

A recent review on handwashing and sanitation behaviour change approaches in low- and middle-income countries found that a combination of different promotional elements such as community-based approaches and the application of elements of psychosocial theory are likely to be the most effective strategies (De Buck et al., 2017). Evidence also suggests that formative research and/or market research are particularly important for programs that require behaviour change (especially sanitation and handwashing with soap) (DFID UK, 2013). While there is a wide range of availability of research approaches and outcome measures, it is important to also understand what kind of research is conducted in practice and how the research contributed to the optimization of HP strategies. The 2010 cholera outbreak in Haiti has lasted for over eight years and humanitarian assistance included a large HP response. Learning from the research studies investigating the HP response in Haiti can therefore provide insight in what happened in practice and how future research can be optimized.

The Haitian cholera outbreak

A poorly maintained sanitation system within a United Nations peacekeepers camp in Haiti led to the introduction of cholera (Peyton, Gercama, & Bedford, 2019) in the Artibonite area in October 2010, nine months after the massive 2010 earthquake. No new cases have been reported since February 2019 (Pan American Health Organization, 2020), but the cholera outbreak infected close to 800,000 people and has caused almost 10,000 deaths since the outbreak began in 2010 (Childs et al., 2016). Cholera continued to persist for more than eight years despite the launch of an extensive response of surveillance, case detection, treatment with rehydration, establishment of cholera treatment centres (CTC), community health education, and efforts to improve water and sanitation (Miller & Birnbaum, 2018). The large scale of the outbreak and the response has led to a variety of research studies investigating different elements of the HP response. We posed the following research questions in this context: What kind of research approaches and methods have been used to investigate the HP response in Haiti? What lessons can be drawn from these efforts, and what are the implications for future research?

5.4 Methods

Identified research studies

We conducted a review of published studies supplemented by general searches for grey literature on specific web sites known to produce reports that might be relevant, given the likelihood that relevant studies and reports may not have been published in mainstream academic journals.

The search strategy for scientific studies included the databases Medline and Embase, using keywords Haiti AND cholera (up to January 19, 2020), consistent with an earlier search strategy conducted to characterize interventional studies of the cholera outbreak in Haiti, where these keywords were also used (Miller & Birnbaum, 2018). The search for grey literature included general Google and Google Scholar searches using the same keywords, in addition to checking reference lists within retrieved studies, and online repositories of documents published by two key humanitarian organizations (Action Against Hunger and Doctors Without Borders). The search was unlimited in terms of dates, English or French and qualitative or quantitative studies. Any/all studies and reports that investigated the HP efforts in the cholera outbreak in Haiti were targeted in the search and considered in the selection process. Articles discussing other aspects of the cholera strategy such as the installation of water sources, CTCs or the cause of the cholera outbreak were excluded if they were not covering HP aspects. Potential studies were assessed by two researchers, in case of discrepancies with regards to the selection of the studies were discussed until agreement was reached.

5.5 Results

A total of nine published research studies and three operational reports were identified (see table 5-1) reporting a total of seven distinct research studies. One draft and one confidential operational report, not publicly available, were excluded. Six of the research studies applied surveys (Aibana et al., 2013; Beau De Rochars et al., 2011; Childs et al., 2016; Contzen & Mosler, 2013; Contzen & Mosler, 2012; Patrick et al., 2013). With two studies combing surveys with focus groups (Williams et al., 2015) and observations (Contzen & Mosler, 2013). The remaining research study, reported in a ‘series’ of three studies (Grimaud & Legagneur, 2011), described the beliefs and perceptions of the Haitian population in relation to the cholera outbreak and response and was published rapidly after the cholera outbreak in Haiti. Five studies were conducted in the first two years of the outbreak and the remaining two in 2014 and 2015. Some of the aspects that were most frequently highlighted in the background were the description of cholera and its’ prevalence (n=6), the earthquake (n=4), Haiti being the poorest country in the Western hemisphere (n=2) and the cholera strategy (n=2). But other aspects such as the, at the time, suspicions of the UN’s role in the introduction of cholera in Haiti, role of alternative health practitioners, local knowledge and

Haiti being the first country to liberate itself from slavery were not mentioned by any study even though these factors may also play a role in the effectiveness of the HP efforts. None of the studies adopted community-based, participatory or formative approaches. In the following section we describe how HP activities were described and defined, which outcomes were measured and how impact was reported.

***Table 5- 1**: Overview of selected research manuscripts and reports which report on studies investigating the HP efforts in the cholera response in Haiti (manuscripts and reports of the same study have been grouped together).*

Author and year	Date data collection	Methods	Description
Beau De Rochars, 2010	Dec 2010	KAP*/household survey	Conduct of a survey to assess the effectiveness of hygiene promotion interventions (knowledge cholera).
Haitian Red Cross, 2010, Grimaud, 2011, International Organization of Migration, 2011	Nov-Dec 2010	Informal FGDs*	1 academic paper and 2 reports on an informal data collection initiative investigating local beliefs and perceptions.
Contzen, 2012, 2013, 2015	May-Jun 2011	Survey and observations	Association of specific promotion activities with perceptions and beliefs about handwashing with soap and therefore capable of changing handwashing behaviour at key times.
Aibana, 2013	Pre: Feb 2012 Post: Sep 2012	Knowledge and practice survey	Changes in knowledge of cholera prevention and transmission and hygiene practices after the vaccine campaign
Patrick, 2013	May 2012	Household survey	Describe the type and quality of water sources used by rural households in Artibonite and determine knowledge, access, and use of household water treatment products. Quantitative study conducted in conjunction with a qualitative study (Williams, 2015).
Williams, 2015	Mar-Apr 2012	17 FGD with community, 1FGD with health workers	Population's response to WASH messages, use and acceptability of water treatment products, and water treatment and sanitation knowledge, attitudes and practices at the household level. Qualitative study conducted in conjunction with quantitative study (Patrick, 2013).
Childs, 2016	Jul 2014	Knowledge and practices survey	Evaluate any changes in knowledge and practices regarding cholera, WASH practices before and a year after the 2013 OCV campaign in Haiti.
Oxfam, 2016	Aug-Sep 2015	KAP survey	Measure knowledge, attitudes and practices in relation to children

*KAP – Knowledge, attitude and practices, FGD – Focus group discussion

Hygiene promotion activities

HP messages were quickly spread through a plethora of activities such as radio, megaphone, pamphlets, theatre and group discussions. At the same time the HP teams also engaged in door-to-door activities to respond to specific questions, deepen understanding, educate, distribute and demonstrate use of products, solve problems, foster self-help and demonstrate good and bad behaviour (e.g. group discussions, home visit, theatre).

There was consistency across studies regarding the overall aim for activities – to prevent new cholera cases (Beau De Rochars et al., 2011) or reduce transmission (Patrick et al., 2013) in order to eliminate cholera in Haiti (Aibana et al., 2013; Beau De Rochars et al., 2011). We identified three kinds of specific aims: 1) improve knowledge through education (Aibana et al., 2013); 2) stimulate/reinforce good practices through knowledge (Aibana et al., 2013; Childs et al., 2016), through changing perceptions and beliefs about healthy behaviours (Contzen & Mosler, 2012) or through the distribution of goods and demonstration of good practices (Williams et al., 2015); 3) gain trust and acceptance from the communities by listening to their perspectives and beliefs (Grimaud & Legagneur, 2011). Different terms, including hygiene education, social mobilization and emergency public health response, were used to refer to similar activities. In this article we use HP activities to refer to these different kinds of activities. In addition, there was also variety of different kind of 'domains' in HP such as water, sanitation, vaccination and hygiene as well as a diverse focus within each domain (e.g. water source, water storage and water treatment). Overall, it is important to note that there was a variety in activities across different kinds of domains and with a different focus in each domain as well as different aims for the HP efforts and different terms used to describe a set of activities.

Outcomes

Here we describe how studies measured outcomes related to 1) knowledge and practice; 2) behavioural factors; 3) perception, beliefs, and attitudes; and, 4) access. Table 5-2 provides details of outcome measures. Most studies focused on measuring outcomes in line with existing biomedical or scientific knowledge.

***Table 5- 2**: Description of the different sort of collected data and how this data was collected, illustrated with examples from the studies*

Sort of outcome	Examples of data collected related to outcome
Knowledge	**Correct response (% of good answers or e.g. No. of correct answers):** questions related to knowledge of cholera (knowledge if preventable symptoms, origin) and knowledge related to handwashing (when, what alternative), cause of diarrhoea, transmission and prevention mechanisms, duration of protection after vaccination, health risk if people do not use their toilets. **Binominal questions:** knowledge whether water is treated, knowledge about oral cholera vaccines
Practice	**Self-reported frequency of:** handwashing**,** use handwashing station, water treatment, daily water quantity collected. **Observation of presence products:** No. of water container(s), lid on container, kind of container opening, handwashing station, water treatment products, soap, specifics container, tap, toilet and type of toilet. **Description of practice:** purchase of water, who collects water, method and location of defecation, No. of people sharing toilet, indicated presence of toilets in community, faeces in community, materials used after defecation, faeces removal from children. **Testing of quality water** **Questions providing indications:** source of water treatment, water for drinking and other use. reasons for not treating water, how to assure water is safe, options when no products are available, barriers for use of water treatment product, reasons for specific drinking water source, who decides to construct toilet, reasons for not having a toilet
Access	**Response to open and closed questions:** Availability of water treatment products and soap, access to cholera communication, exposure to cholera prevention messages or HP activities, most frequent messages heard, contact and meetings with community health worker (CHW), home visit received by CHW, items received, options for health care seeking pathway, distance to CTC, hospital or water source, whether people pay for water and price, reasons for not paying for water, alternative sources when not using paid services, how to improve access to water
Preferences	**Open questions:** Preferred place to buy water treatment products, best product, most trusted vendor, preferred forms of communication, best way to reach communities
Perception (attitudes)	**Open questions:** Safety of drinking water, taste of purified water, if water quality is sufficient, attitudes towards HP activities (liking, trustworthiness, convincingness), appreciation for access to water or services received, characteristics of a good water, perceived impact of good water on health, advantages of clean environment and of using a toilet, willingness to get oral cholera vaccines, clarity of message, perception oral rehydration solution (ORS), beliefs of causes and transmission
Behavioural factors	**Survey questions:** behavioural factors influencing handwashing with soap (risk factors, attitude factors, norm factors, ability factors and self-regulation factors)
Experiences	**Focus group discussions:** Experiences around cholera treatment centres and how people felt about the treatment

Knowledge and practice

Knowledge and practice were mostly measured with knowledge, attitudes and practices (KAP)- oriented surveys. Studies described objectives such as 1) to understand how a cholera vaccination campaign impacted knowledge and health practice (Aibana et al., 2013; Childs et al., 2016), 2) measure water treatment and sanitation knowledge, attitudes and practices at the household level (Williams et al., 2015), 3) determine the knowledge and use of household water treatment products (Patrick et al., 2013), and 4) measure the use and acceptability of water treatment products (Williams et al., 2015).

Measuring knowledge

Knowledge was commonly reported in relation to cholera symptoms, prevention, and transmission mechanisms. Other aspects were also measured such as if people knew how to treat water or knew of the origin of cholera, see table 5-2. All reported data was in line with biomedical or scientific knowledge (e.g. washing hands as preventive methods), with the exception of one study which included some statements that were based on beliefs such as, for example, ‘praying before eating helps to protect against cholera’ (Oxfam, 2014). While the majority of studies focused on measuring knowledge, and one recommended continued focus on improving knowledge alone with the help of additional campaigns (Beau De Rochars et al., 2011) it was also highlighted that in future research other behaviour change factors (besides the factor knowledge) such as ability factors, perceived impediments and self-regulation factors (Aibana et al., 2013) or social, cultural and behavioural factors (Patrick et al., 2013) should be measured. These studies acknowledged, however, that this would require additional research to determine which factors play a role in choosing to adapt a certain behaviour (Williams et al., 2015) or it may require transitioning from an emergency to a developmental response to be able to better study the impact of other factors (Patrick et al., 2013).

Measuring individual practices

The research studies used different indicators for practice. Most studies reported on self-reported practice (e.g. frequency of hand washing, or treatment of water and/or kind of toilet used) as well as observations related to practice (e.g. presence of soap and toilet). Examples of other indicators can be found in table 5-2.

Several studies identified challenges in being able to verify if reported practice is a correct representation of actual practice (Aibana et al., 2013). One study reported that social desirability bias may lead to over reporting of certain practices (Childs et al., 2016). In other words, the more the population learns that they should wash their hands to prevent cholera and the more people feel that this is the right thing to do; the more likely they will report an overestimation of their frequency of handwashing. It might therefore be possible that increased knowledge of the importance of handwashing may be positively related to higher reported practice. It should be noted that even though self-reports are prone to social desirability bias '*they have been found to be associated with child diarrhea and child diarrhea mortality'* (Contzen & Mosler, 2015), suggesting observational data may be preferable (Contzen & Mosler, 2013). This approach, however, can be more time consuming or challenging in certain contexts (Contzen & Mosler, 2015). While studies conducted in the field focused on measuring biomedical knowledge they did, at the same time, highlight the importance of measuring other factors. In addition, limitations were identified to measure practice such that it is a correct representation of actual practice.

Factors influencing behaviour change

Only one study, conducted by Oxfam in Haiti (Contzen & Mosler, 2013) examined which specific promotion activities (e.g. radio emission, house visits), were most effective in changing hand washing with soap (HWWS) behaviour. The premise of this study was that promotion activities either directly influenced HWWS or directly influenced behaviour change factors which in turn influenced HWWS behaviour. These factors, derived from the Risk, Attitudes, Norms, Ability, and Self-regulation of behavioural change model (RANAS) are categorized as risk factors (including knowledge), attitude factors (including beliefs about cost and benefit, and affective belief), norm factors, ability factors, and self-regulation factors. See for a more detailed description Mosler (Mosler, 2012). Data was collected with the help of a tailored survey, with a focus on collecting biomedical oriented data, and included questions to measure exposure to different cholera programs and behavioural factors in relation to HWWS. Authors concluded that promotional activities in 2011 continued to focus on the behaviour change factor risk (which includes knowledge) and argue that promotional activities can be made more effective when they are carefully selected according to how they can potentially change the behaviour or the factors of behaviour change. Compared to the studies that focused on measuring knowledge and practice, this study added knowledge on how different factors influence behaviour change.

Perceptions and beliefs (local knowledge)

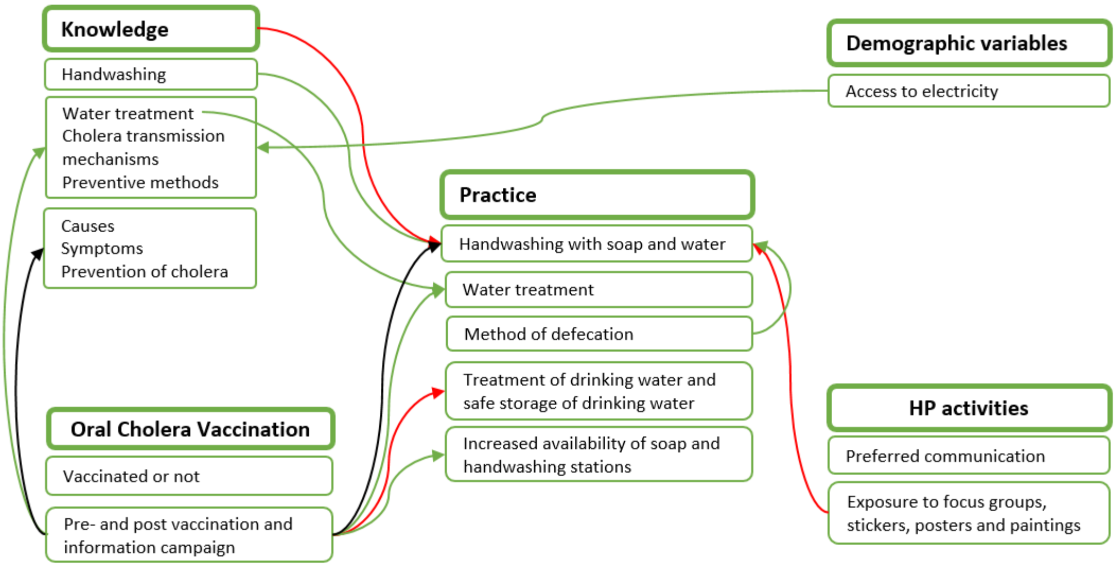
Overall, perceptions, beliefs, and attitudes were rarely measured by research studies. One study collected perceptions and beliefs of affected communities during informal focus groups (Grimaud & Legagneur, 2011) and the authors demonstrated that certain perceptions of cholera were in sharp contrast with the nature of cholera as presented through HP messages. People also expressed a strong mistrust towards the intention of foreign organizations and felt that the establishment of CTCs posed a risk for infection in the community. It was argued that local perceptions and beliefs could negatively impact the ability of the humanitarian response to carry out effective programs and should therefore be integrated in subsequent HP efforts (Grimaud & Legagneur, 2011). While this local knowledge, described as beliefs and perceptions, was reported early in the outbreak, none of these kind of outcomes were reported in subsequent studies, except for the factor 'trust' which was measured by one other study (Contzen & Mosler, 2013). In this study the participants were asked to rate the HP activities for perceived appreciation, trustworthiness, and convincingness (Contzen & Mosler, 2013).

Outcomes (access)

Access outcomes were measured with regards to water treatment products and soap, access to cholera communication, health care services and contact with community health workers (CHWs). See table 5-2.

Associations (types of impact and measuring impact)

While some studies limited reporting to measured outcomes, other studies analyzed associations between different factors, see table 5-3. Most frequently, associations were drawn between the level of knowledge and measured performance of the desired practice and, less frequently, differences in characteristics of people practicing a certain behaviour and those not, and the impact of HP activities on practice.



*Red arrows demonstrate a negative association, green a positive and black no association.

Figure 5- 1: *Representation of different associations and links made in the selected studies.*

Associating knowledge to practice: There are contradicting findings regarding whether improved cholera knowledge was positively associated with improved preventive practices (see table 5-3 for a description of the findings). These findings overall suggest ongoing uncertainty regarding the pathway between knowledge and practices in common HP interventions as well as a lack in knowledge of other factors that may influence practice.

Do-er, non do-er analysis: two studies measured how the characteristics of those who practice a certain behaviour (do-ers) and those who don't (non do-ers) are associated to behavioural factors or HP activities (Aibana et al., 2013; Contzen & Mosler, 2013). This approach allowed to identify behaviour change factors that are positively associated with a certain behaviour (Contzen & Mosler, 2013).

Hygiene promotion activities: one study (Contzen & Mosler, 2013)) looked at the positive or negative effect of different HP activities on desired behaviour change. This helped to identify which activities should be seriously revised or optimized (Contzen & Mosler, 2012). Two other studies investigating two different oral cholera vaccination (OCV) campaigns collected pre- and post-campaign and were able to measure how the campaign impacted the level of knowledge and practice (Aibana et al., 2013; Childs et al., 2016).

Finally, it was noted by one study that no data exists on how improved knowledge and hygiene practices, measured by KAP surveys, result in improved outcomes (e.g. decreased incident cases and mortality rates) in areas experiencing a cholera epidemic (Aibana et al., 2013). Likewise, in the selected studies for this article, these outcomes were not measured as an indicator of impact.

5.6 Discussion

We presented the results from studies and reports investigating the HP activities that supported the cholera response in Haiti. These documents covered a wide range of different aspects of HP, contributing information about a wide variety of outcomes and impacts measures.

Knowledge gaps

The studies investigated a selection of certain outcomes mostly related to handwashing or water treatment practices. None of the studies, however, provided an insight of which practices are most urgent to address or most effective in stopping cholera transmission. Some examples of practices that were not reported but that appeared to play a role in the transmission of cholera, based on IO's observations of the HP activities in Haiti, include practices related to food handling in hospitals and on markets, funeral practices, breast feeding while sick and whether people know how to prepare oral rehydration solution(ORS). In addition, knowledge and practices with regards to alternative health practitioners and health care seeking behaviour were not part of the data collection; the perception of CTCs was only mentioned by two studies (Childs et al., 2016; Grimaud & Legagneur, 2011).

The heterogeneity of the HP aims, data and research methods described in this article, underline the challenges of comparing the outcomes, impact and best practices. It also highlights the importance of collecting a wider variety of information, which includes local knowledge and perceptions. It should also be noted that peoples' information and behaviour needs are likely to change during the development of a disease outbreak which may require adaptation of different methods. For example, health education, in disease outbreaks, may be a good primary response to peoples' immediate information needs but additional secondary responses are needed to establish and maintain good preventive practices (Contzen, De Pasquale, & Mosler, 2015; Curtis et al., 2011). There is also a need to understand structural obstacles which may influence peoples' ability to change behaviour as there is a risk that HP strategies may feed into a 'blame the victim' approach making the assumption that people with health information have the real option to influence the behaviour of the population (Hausmann-Muela et al., 2003), or other harmful effects caused through the HP activities such as aid dependency and decreased self reliance (Gugglberger, 2018). Most of these factors were not highlighted by the studies. The sample of included studies is relatively small, and it is therefore difficult to state whether the focus or research methods adapted over time. There may have been a tendency that earlier KAP surveys focused on general knowledge whereas later KAP surveys focused on a specific aspect in the response (e.g. knowledge of children or influences of the vaccination campaign). KAP surveys continued to be applied throughout the cholera outbreak and while results from former KAP studies were cited in subsequent studies, the study on perceptions and beliefs was rarely cited and integrated.

Best research practice

The variety of approaches applied in the Haiti response have great richness in their data collection and these diverse approaches have different strengths, weaknesses, and objectives with regards to the type of data they aim to generate. There is, however, no 'cookbook' for the right approach to choose. It seems that researchers are more hesitant to, for example, explore other methods such as observations as they are perceived as time consuming and costly. When selecting an appropriate approach, insight and critical reflection are key to deciding what the purpose is of the study and how can this inform the HP strategy (Hausmann-Muela et al., 2003). KAP oriented surveys were most frequently applied in the selected studies but even though KAP surveys are well established and able to provide rich information rapidly they are also contested for their appropriateness to meet the objectives of the research needs (Launiala, 2009) as well as for their tendency to include biomedical oriented knowledge and exclude local knowledge that may deviate from biomedical concepts (Hausmann-Muela et al., 2003). Inquiry about these other types of knowledge, sometimes also described as 'beliefs' tend to be highly neglected in KAP studies (Hausmann-Muela et al., 2003). Local perceptions can describe other knowledge systems that are in contradiction with biomedical knowledge. Integrating these other knowledge systems will, consequently, influence how HP strategies and research studies are designed, implemented and ultimately received. Or, in other words, the objectives, focus of study and knowledge generation will change if we integrate local knowledge and perceptions (van der Haar, Heijmans, & Hilhorst, 2013). This builds on the notion that '*what* the researcher finds out is inherently connected with *how* she finds it out' (van der Haar et al., 2013) and this related to the question whether knowledge is power or whether power is knowledge (Ramalingam, 2013) and whose knowledge or results count (Eyben, 2008).

Nor did the research studies report how the produced knowledge has been applied or impacted the ongoing HP efforts. The predominant focus in Haiti on the dissemination of biomedical or scientific information overshadowed the value and importance of the human component in HP. The impact and success of HP though depends on human behaviour and this is influenced by many different factors such the determinants of behaviour change (Contzen & Mosler, 2013), trust (Grimaud & Legagneur, 2011), perceptions, and the experiences with cholera and care received. Better understanding the combination of factors is therefore a prerequisite to change.

Participation and engagement concepts have gained importance in the humanitarian sector where we find an increasing emphasis on bottom-up approaches even when this may be challenging in emergency situations. For example, only in in 2015, during the Ebola outbreak in West Africa, social mobilization and community engagement were, for the first time, included as a 'cluster system' in the humanitarian response (Gillespie et al., 2016). Also in this context it was argued that biomedical oriented approaches can miss improving cultural and social acceptability of the HP response (Marais et al., 2015). None of the included studies in this review, however, discussed nor mentioned participatory research approaches as an option for future studies. This may be related to the fact that participatory research in humanitarian settings appears to be an emerging practice but have not yet been fully integrated in these settings (Ormel et al., 2020).

Some recent epidemics were characterized by violent attacks on health care workers brought forth by high levels of mistrust and suspicion (Cohn & Kutalek, 2016). Public compliance to restrictive policies are seen to require high levels of trust (Van Bavel et al., 2020), public trust, however, doesn't seem to be associated with knowledge (Blair, Morse, & Tsai, 2017; Deurenberg-Yap et al., 2005). Participatory approaches in humanitarian settings have been described to be useful in complex settings as it can contribute to building trust (Ormel et al., 2020). It remains, nevertheless, challenging to put engagement in place in humanitarian settings (Cohn & Kutalek, 2016). Lessons learned from the Ebola outbreak in West-Africa (2013-2016) demonstrate that community engagement is still somewhat new to the global health emergency context and that there is a need to ‘formally place these approaches within the global humanitarian response architecture’. There is also a need to strengthen guidelines, capacity, training and ongoing support (Gillespie et al., 2016). It is also necessary to apply research approaches that imply the collaboration of key stakeholders and affected populations. There are certainly research approaches, currently mostly applied in non-humanitarian settings, that not only collect data but also facilitate and guide the process of adaptation and change in practice. For example, integrated knowledge translation is a participatory health research approach where researchers work with knowledge users are meaningfully and equitably involved in *all appropriate stages of the research* and have the ability to implement research recommendations. There are indications that this way of working will ‘contribute to better science, more relevant and actionable research findings, increased use of the findings in policy or practice, and mutual learning’ (Kothari A, 2017). Another participatory research approach, experience-based co-design aims to learn from the experiences of patients with health care services and to then implement improvements by guiding a collaborative co-design process (Bate & Robert, 2006). In addition, there the DEPICT model supports collaborative and inclusive analysis of qualitative data (Flicker & Nixon, 2015). Application and implementation of these kind of methods in humanitarian settings can contribute to new learning and, importantly, facilitates to implement the new knowledge into practice. Participatory research approaches can support insight into local attitudes and perceptions and support behaviour change more effectively. Interdisciplinary and use of a diversity of approaches and perspectives can also contribute to improved awareness of unintended effects of HP (Gugglberger, 2018). The predominant focus on biomedical knowledge and top-down approaches has as a consequence that only certain behaviour mechanisms are targeted while others remain excluded. Not acknowledging and learning from local knowledge can lead to the exclusion and marginalization of those that are supposed to be helped through humanitarian aid programming.

Limitations

We used a robust strategy to search for studies published in scientific databases, but we adopted a more selective approach to gathering relevant studies from the grey literature, given limited resources for this study. It is possible that a more exhaustive search of the grey literature, or contacting other humanitarian organizations for relevant reports, would have yielded more grey reports of this nature. The results and discussion are therefore limited to what we found in these studies. We do feel, however, that we found most, if not all published studies, using this search strategy. The selected studies provided an overview of key challenges and recommendations for conducting research in support of the HP response in the cholera outbreak in Haiti.

5.7 Implications for practice and research

Research studies looking at the HP response in disease outbreaks should not be limited to one approach as the application of multiple approaches have the potential to contribute across a wider range of the complexity of HP aims, activities and outcomes. There is an overall agreement within the literature that other approaches such as formative research and participatory approaches are required to further inform HP strategies (De Buck et al., 2017). There are existing formal participatory frameworks that are theory-based and use a variety of research methods to inform HP strategies that could be adopted, such as the PRECEDE-PROCEED model (Green & Kreuter, 2005) (see the book health behaviour and health education for detailed description of other participatory models (Glanz, Rimer, & Viswanath, 2008) and the eight-step approach as proposed by Marais (Marais et al., 2015). In the context of Haiti, however, these approaches have not been applied in published research studies, to our knowledge. Researchers and humanitarian practitioners should consider the adoption of such frameworks and approaches in the design of future studies that would help to guide engagement efforts, the collection of data relevant to all stakeholders, and interpretation of results so that there is better alignment with local priorities and capacity for change.

5.8 Conclusions

In this review, we found that studies to date have focused predominantly on measuring the knowledge and practices of the community using surveys that were administered by humanitarian actors and researchers. The use of multiple approaches and outcomes made it challenging to compare best practice. Most of the data collection focused on participants' biomedical knowledge about cholera and actions to reduce the risk of infection. This predominant biomedical focus overshadowed the value and importance of the human component in the success of HP interventions/programs. The impact and success of HP, however, depends on human behaviour and this is influenced by many different factors. A better understanding of the individual and inter-related factors is therefore a prerequisite to change; the application of a research tools and approaches more suited the collection and analysis of human factors at play should contribute to more sustainable, community-oriented solutions. Humanitarian organizations are encouraged to critically reflect on what they wish to achieve (both process and content) with a research endeavour and how the selected approach will contribute to their objectives. The absence of participatory approaches results in HP actions targeting the wrong mechanisms. Given the persistence of non-participatory approaches and methods with limited engagement of local communities over the past decade with little yield in terms of securing effective behavioural change, perhaps it is time for new methods to contribute evidence and experience-based approaches to assessing HP responses to outbreaks. Future research efforts should consider the potential value of adopting participatory approaches that align with current initiatives amongst humanitarian and aid organizations to engage more directly with local communities and members of affected populations to promote participation and accountability (CDA Collaborative Learning Projects, 2008; Darcy, Alexander, & Kiani, 2013; Ramalingam et al., 2015). Participatory research can support insight into local attitudes and support behaviour change mechanisms more effectively.

5.9 References

Aibana, O., Franke, M., Teng, J., Hilaire, J., Raymond, M., & Ivers, L. C. (2013). Cholera vaccination campaign contributes to improved knowledge regarding cholera and improved practice relevant to waterborne disease in rural Haiti. *PLoS neglected tropical diseases, 7*(11), e2576.

Bate, P., & Robert, G. (2006). Experience-based design: from redesigning the system around the patient to co-designing services with the patient. *BMJ quality & safety, 15*(5), 307-310.

Beau De Rochars, V. E., Tipret, J., Patrick, M., Jacobson, L., Barbour, K. E., Berendes, D., . . . Handzel, T. (2011). Knowledge, attitudes, and practices related to treatment and prevention of cholera, Haiti, 2010. *Emerging Infectious Diseases, 17*(11), 2158-2161.

Blair, R. A., Morse, B. S., & Tsai, L. L. (2017). Public health and public trust: Survey evidence from the Ebola Virus Disease epidemic in Liberia. *Social science & medicine, 172*, 89-97.

Blanchet, K., Roberts, B., Sistenich, V., Ramesh, A., Frison, S., & Warren, E. (2015). *An evidence review of research on health interventions in humanitarian crises*. Retrieved from https://www.elrha.org/wp-content/uploads/2015/01/Evidence-Review-22.10.15.pdf

CDA Collaborative Learning Projects. (2008). *The Listening Project. Discuss Together, Decide Together, Work Together*. Retrieved from http://cdacollaborative.org/wordpress/wp-content/uploads/2016/02/Discuss-Together-Decide-Together-Work-Together.pdf

Childs, L., Francois, J., Choudhury, A., Wannemuehler, K., Dismer, A., Hyde, T. B., . . . Tohme, R. A. (2016). Evaluation of Knowledge and Practices Regarding Cholera, Water Treatment, Hygiene, and Sanitation Before and After an Oral Cholera Vaccination Campaign-Haiti, 2013-2014. *American Journal of Tropical Medicine & Hygiene, 95*(6), 1305-1313. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=prem&AN=27799642

Cohn, S., & Kutalek, R. (2016). Historical parallels, Ebola virus disease and cholera: understanding community distrust and social violence with epidemics. *PLoS currents, 8*.

Contzen, N., De Pasquale, S., & Mosler, H.-J. (2015). Over-reporting in handwashing self-reports: Potential explanatory factors and alternative measurements. *PloS one, 10*(8), e0136445.

Contzen, N., & Mosler, H.-J. (2013). Impact of different promotional channels on handwashing behaviour in an emergency context: Haiti post-earthquake public health promotions and cholera response. *Journal of Public Health, 21*(6), 559-573.

Contzen, N., & Mosler, H.-J. (2015). Identifying the psychological determinants of handwashing: results from two cross-sectional questionnaire studies in Haiti and Ethiopia. *American journal of infection control, 43*(8), 826-832. Retrieved from https://www.ajicjournal.org/article/S0196-6553(15)00429-0/fulltext

Contzen, N., & Mosler, H. (2012). Factors determining the effectiveness of Oxfam's public health promotion approach in Haiti. *J Public Health (Bangkok), 21*, 559-573.

Curtis, V., Schmidt, W., Luby, S., Florez, R., Touré, O., & Biran, A. (2011). Hygiene: new hopes, new horizons. *The Lancet Infectious Diseases, 11*(4), 312-321.

Darcy, J., Alexander, J., & Kiani, M. (2013). *Humanitarian Accountability Report*. Retrieved from London, United Kingdom: https://www.alnap.org/help-library/the-2013-humanitarian-accountability-report

De Buck, E., Van Remoortel, H., Hannes, K., Govender, T., Naidoo, S., Avau, B., . . . Mosler, H.-J. (2017). Approaches to promote handwashing and sanitation behaviour change in low-and middle income countries: a mixed method systematic review. *Campbell Systematic Reviews, 7*, 1-447.

Deurenberg-Yap, M., Foo, L., Low, Y., Chan, S., Vijaya, K., & Lee, M. (2005). The Singaporean response to the SARS outbreak: knowledge sufficiency versus public trust. *Health Promotion International, 20*(4), 320-326.

DFID UK. (2013). *Water, Sanitation and Hygiene, Evidence Paper*. Retrieved from https://www.gov.uk/government/publications/water-sanitation-and-hygiene-evidence-paper

Eyben, R. (2008). *Power, mutual accountability and responsibility in the practice of international aid: A relational approach*. Retrieved from Brighton, UK: https://www.ids.ac.uk/publications/power-mutual-accountability-and-responsibility-in-the-practice-of-international-aid-a-relational-approach/

Flicker, S., & Nixon, S. A. (2015). The DEPICT model for participatory qualitative health promotion research analysis piloted in Canada, Zambia and South Africa. *Health Promotion International, 30*(3), 616-624.

Gillespie, A. M., Obregon, R., El Asawi, R., Richey, C., Manoncourt, E., Joshi, K., . . . Quereshi, S. (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. doi:10.9745/GHSP-D-16-00226

Glanz, K., Rimer, B. K., & Viswanath, K. (2008). *Health behavior and health education: theory, research, and practice*: John Wiley & Sons.

Green, L., & Kreuter, M. (2005). *Health promotion planning: an educational and ecological approach.*

Grimaud, J., & Legagneur, F. (2011). Community beliefs and fears during a cholera outbreak in Haiti. *Intervention, 9*(1), 26-34.

Gugglberger, L. (2018). Can health promotion also do harm? *Health Promotion International, 33*(4), 557-560. doi:10.1093/heapro/day060

Hausmann-Muela, S., Ribera, J. M., & Nyamongo, I. (2003). *Health-seeking behaviour and the health system response*. Retrieved from https://pdfs.semanticscholar.org/3511/6a3c0a88898a531ce214e4448861ae00e320.pdf

Kothari A, M. C., Graham ID. (2017). Defining Integrated Knowledge Translation and Moving Forward: A Response to Recent Commentaries. *Int J Heal Policy Manag, 6*(5), 299.

Launiala, A. (2009). How much can a KAP survey tell us about people's knowledge, attitudes and practices? Some observations from medical anthropology research on malaria in pregnancy in Malawi. *Anthropology Matters, 11*(1).

Marais, F., Minkler, M., Gibson, N., Mwau, B., Mehtar, S., Ogunsola, F., . . . Corburn, J. (2015). A community-engaged infection prevention and control approach to Ebola. *Health Promotion International, 31*(2), 440-449. doi:10.1093/heapro/dav003

Miller, J., & Birnbaum, M. L. (2018). Characterization of interventional studies of the cholera epidemic in Haiti. *Prehospital and disaster medicine, 33*(2), 176-181.

Mosler, H.-J. (2012). A systematic approach to behavior change interventions for the water and sanitation sector in developing countries: a conceptual model, a review, and a guideline. *International journal of environmental health research, 22*(5), 431-449.

Ormel, I., Salsberg, J., Hunt, M., Doucet, A., Hinton, L., Macaulay, A. C., & Law, S. (2020). Key issues for participatory research in the design and implementation of humanitarian assistance: a scoping review. *Global Health Action, 13*(1), 1826730. doi:10.1080/16549716.2020.1826730

Oxfam. (2014). *Projet: eau, assinissement et hygiene au benefice des enfant du departement de l'Artibonite*. Retrieved from Haiti: https://www.ungm.org/Public/Notice/102873

Pan American Health Organization. (2020). Haiti reaches one-year free of Cholera. Retrieved from https://reliefweb.int/report/haiti/haiti-reaches-one-year-free-cholera

Patrick, M., Berendes, D., Murphy, J., Bertrand, F., Husain, F., & Handzel, T. (2013). Access to safe water in rural Artibonite, Haiti 16 months after the onset of the cholera epidemic. *The American journal of tropical medicine and hygiene, 89*(4), 647-653.

Peyton, D., Gercama, I., & Bedford, J. (2019). Key considerations: Ebola preparedness and readiness in Goma, DRC.

Ramalingam, B. (2013). *Aid on the Edge of Chaos: Rethinking International Cooperation in a Complex World*. Oxford, England: Oxford University Press.

Ramalingam, B., Rush, H., Bessant, J., Marshall, N., Gray, B., Hoffman, K., . . . Warren, K. (2015). *Strengthening the Humanitarian Innovation Ecosystem*. Retrieved from Brighton, Eastbourne, England: https://assets.publishing.service.gov.uk/media/57a08977e5274a31e00000c6/Humanitarian_Innovation_Ecosystem_Research_Project_FINAL_report_with_recommendations.pdf

Taylor, D. L., Kahawita, T. M., Cairncross, S., & Ensink, J. H. (2015). The impact of water, sanitation and hygiene interventions to control cholera: a systematic review. *PloS one, 10*(8), e0135676.

Van Bavel, J. J., Baicker, K., Boggio, P. S., Capraro, V., Cichocka, A., Cikara, M., . . . Druckman, J. N. (2020). Using social and behavioural science to support COVID-19 pandemic response. *Nature Human Behaviour*, 1-12.

van der Haar, G., Heijmans, A., & Hilhorst, D. (2013). Interactive research and the construction of knowledge in conflict-affected settings. *Disasters, 37 Suppl 1*, S20-35. doi:https://dx.doi.org/10.1111/disa.12010

Williams, H. A., Gaines, J., Patrick, M., Berendes, D., Fitter, D., & Handzel, T. (2015). Perceptions of Health Communication, Water Treatment and Sanitation in Artibonite Department, Haiti, March-April 2012. *PLoS ONE [Electronic Resource], 10*(11), e0142778. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=medl&AN=26562658

6 THE ROLE OF TRUST IN THE HYGIENE PROMOTION RESPONSE IN THE CHOLERA OUTBREAK IN HAITI – MANUSCRIPT 3

6.1 Preamble

This is the first of two manuscripts reporting on the EBCD study. Manuscript 1 demonstrated that participatory research is rarely applied in humanitarian settings and in manuscript 2 it was found that only two studies, investigating the HP response in Haiti, mention trust as a contextual or outcome measure. This study looked at the qualitative data collected during the EBCD approach and reports on the role of trust in the HP response. We looked at what people said about the HP efforts and how their behaviour to protect themselves was affected. Overall we found similarity across the data gathered in the individual interviews and in the focus groups. Divergence was observed in differences of opinion where some highlighted that the HP strategy was good but that 'negligent' people did not change their behaviour, and others felt that people did not change their behaviour because the HP strategy did not match their reality. This difference was noticed between those interviewed and those in focus groups. We reflect that HP strategies could be greatly strengthened by incorporating approaches that address a deficit of trustworthiness through collaboration with the affected population. In addition, we argue that data collection alone does not automatically lead to change of health programmes and that EBCD is one participatory approach that is able to guide a process of change. The second manuscript reports on the feasibility of the implementation of EBCD as a quality improvement approach of the HP response in the cholera outbreak in Haiti.

Ormel I, Massena K, Hinton L, Salsberg J, Hunt M, Doucet A, Macaulay A, Law S. The Hygiene Promotion Response to the Cholera Outbreak in *Haiti*: Lessons Learned of Applying an *Experience-Based Co-Design to Improve* the Experience of Affected Communities. *Submission to BMJ Open*

6.2 Abstract

Objectives: This study aimed to better understand communities' perceptions of cholera and to involve them in the design of the HP response.

Design: A quality improvement approach, with the user experience at the centre (Experience-Based Co-Design - EBCD) was applied and data was collected through community-based observations, stakeholder interviews and focus groups with people who had or had not had cholera. The analysis we undertook for this paper explored the following questions: What did participants say in relation to trust? How does trust influence how people speak about behaviour change?

Settings: The hygiene promotion response to the cholera outbreak in two villages (Dessalines and St. Michel D'Attalaye) in Haiti.

Participants: A participatory research study with 68 men and women who had or had not had cholera, 10 Houngan and assistants, 7 key professionals working in the cholera response.

Results: In the analysis we noted that trust was a key aspect in three major themes; (1) mistrust of foreign assistance (2) lack of congruence between personal experiences, beliefs and HP guidance (3) blame as a consequence of perceived individual responsibility. Both trust and mistrust influenced the effectiveness of the HP efforts.

Conclusions: The trustworthiness of the HP response in Haiti was undermined by historical and recent actions of international entities making the HP response less effective. HP strategies would be greatly strengthened by incorporating approaches that address this deficit of trustworthiness through collaboration with the affected population. Collecting data on peoples' experiences can uncover complex issues and requirements with no simple or 'one-size-fits-all' type solution. Data collecting and improved understanding, however, does not automatically lead to change. EBCD can provide useful guidance for stakeholders seeking to engage in a process of change.

The role of trust in the health promotion response in the cholera outbreak in Haiti: results from an Experience-Based Co-Design study.

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6.3 Background

The Haitian cholera outbreak

After the massive earthquake in 2010, Haiti was confronted with a cholera outbreak that lasted over eight years and resulted in over 820,000 reported cholera cases and almost 10,000 related deaths (Centers for Disease Control and Prevention (CDC), 2014). Cholera, an infectious disease, can cause severe diarrhoea resulting in dehydration and ultimately death within a few hours from the appearance of the first symptoms (World Health Organization, 2017). The Ministry of Public Health and Population (MSPP), the national water and sanitation agency and supported by the United Nations Children's Fund (UNICEF) and other international partners launched an unprecedented case-area targeted interventions (CATIs) (Pan American Health Organization, 2020) which contributed to the last case of cholera in January 2019 (Pan American Health Organization, 2020). For cholera outbreaks during humanitarian crises, the World Health Organization (WHO) recommends a response to reduce mortality (Nair & Takeda, 2008; Taylor, Kahawita, Cairncross, & Ensink, 2015), that involves both prompt individual case management combined with hygiene promotion (HP) actions to provide safe water, adequate sanitation, improved hygiene, and safe food handling practices for the affected community. In Haiti, rumours of the United Nation's (UN) role in the outbreak started within days after the first case of cholera, 20 Oct 2010, but it took six years before the UN acknowledged that a poorly maintained sanitation system in the camp, housing UN peacekeepers in the Artibonite area, inadvertently led to contamination of the nearby river (Payton, 2017). The response involved surveillance, case detection and investigation, treatment with rehydration, establishment of cholera treatment centres (CTCs), community health education, targeted distribution of hygiene material (e.g. soap, water treatment produces) and water and sanitation efforts (Miller & Birnbaum, 2018). The hygiene promotion (HP) efforts were characterized by top-down health educational approaches (radio spots, posters, leaflets) with some bottom-up community-based work (such as community mobilization) that foster mutual learning and self-help (Contzen & Mosler, 2013) intending to motivate the population to adopt safe hygiene practices such as handwashing and the use of toilets. HP, is a relatively recent term that attempts to capture the variety of drivers that optimize behaviour change within a population, whereas more traditional health education initiatives are based on the notion that knowledge will be sufficient to change people's behaviour (DFID UK, 2013). Studies in recent decades have shown that knowledge on its own is a far less effective driver for change than behavioural drivers (e.g. self-efficacy and desire for prestige). The concept of **hygiene education** has therefore been superseded by **hygiene promotion** (DFID UK, 2013) which includes hygiene education activities. In Haiti, HP teams, working for the humanitarian organization Action Against Hunger (AAH), noted that people did not change their behaviour despite increased knowledge of the disseminated cholera messages and that the traditional health education response was reaching its' limits of effectiveness. They wished to better understand peoples' perception of cholera to help improve their cholera prevention efforts.

Illness narratives to improve the quality of care

Worldwide, there is a growing interest and appreciation for the value of using patient narratives to contribute to a better understanding of what is working well in health care, what needs to change and how improvements might be implemented (Contzen & Mosler, 2013). This concept is central component in the participatory hybrid research/quality improvement approach developed in the United Kingdom known as Experience-Based Co-Design (EBCD) (Robert, 2013) and this approach was therefore selected for this study. Understanding people's experience with the HP services may be critical to optimize the quality and effectiveness of the care provided. Published research investigating HP efforts in Haiti rarely collected data to understand and evaluate local knowledge, perceptions, experiences, and none applied participatory research approaches (Ormel, Hunt, et al.). In a scoping review of participatory research in humanitarian settings, we found that despite the principles of community engagement, participatory research (PR) is rarely applied in practice (Ormel et al., 2020). The review found that PR is valuable in contexts where there is a need to build trust or address mistrust and a need for contextual understanding.

Trust as a critical factor in effective humanitarian response strategies

Cholera, new to the Haitian population, emerged in a complex setting, with a population deprived of health care resources and an ambiguous foreign assistance history. Researchers rapidly reported how reactions such as fear, suspicion and disbelief had resulted in incidents such as the burning of international non-governmental organizations (iNGO) treatment centres (Grimaud & Legagneur, 2011). Mistrust towards the contents of the disseminated messages was also identified as a factor that negatively influenced the willingness of some people to adopt preventive measures, such as handwashing or water treatment (Grimaud & Legagneur, 2011).

Trust is defined as “a psychological state comprising the intention to accept vulnerability based upon positive expectations of the intentions or behaviour of another” (Rousseau, Sitkin, Burt, & Camerer, 1998). Trust is closely linked to how an individual assesses the trustworthiness of someone since “the condition of risk is a critical component of trust because an individual evaluates the vulnerability and uncertainty of whether the trusted party intends to and will act appropriately (Kim, 2016).”

The cholera outbreak also gave rise to conspiracy theories such as the idea that cholera was introduced by foreigners to exterminate Haitians (Grimaud & Legagneur, 2011). Conspiracy theories and rumours are associated with deeper layers of mistrust which can contribute to the spread of the disease due to delayed health care seeking and resistance to public health measures (Cohn & Kutalek, 2016). While there remain gaps in understanding the role of trust in disease outbreak settings, several insights can be drawn from other settings. First, there is evidence that greater trust in government has led to increased compliance with restrictive policies in the Ebola outbreak in Liberia (Van Bavel et al., 2020). Engagement with trusted community members contributed to increased reporting of Ebola cases in Sierra Leone (Christensen, Dube, Haushofer, Siddiqi, & Voors, 2020). Public trust in government, however, does not seem to be associated with high knowledge levels of Ebola in Liberia or with SARS and control measures in Singapore (Blair, Morse, & Tsai, 2017; Deurenberg-Yap et al., 2005). In a realist review of participatory research, trust was identified as a context, mechanism and outcome at different points in a participatory partnership (Jagosh et al., 2015; Jagosh et al., 2012). For example, in a context with no pre-existing trust, structural interventions need to be applied to create an (intermediate) *outcome* of trust. Then in the next iteration of the project's trajectory, a context will exist where trust is now available as a mechanism to create further desired outcomes (Jagosh et al., 2015).

Only two studies that investigated the HP response in Haiti mention trust as a contextual or outcome measure (Ormel, Hunt, et al.). Yet, the lack of trust may have been an important factor in the effectiveness of HP activities in Haiti. In this paper, we report the findings of a qualitative study, answering the following questions: What did participants say in relation to trust? How does trust influence how people speak about behaviour change?

6.4 Methods

This study collected data from qualitative interviews and observations of the HP team and members of the local community as part of an adapted Experienced Based Co-Design (EBCD) approach (Bate & Robert, 2007; The Point of Care Foundation (The King's Fund)). This study reports on the findings in the qualitative data not on the conduct of the EBCD itself which is described elsewhere (Ormel, Massena, et al.). EBCD typically incorporates patient and staff experiences with a health care services, using qualitative data collection. A short-edited film, a catalyst film, is produced from key moments in the patients' care as identified in the patient interviews. Finally, staff and patients are brought together to co-design actions to improve the health care service. See figure 6-1 for a presentation of the different stages and table 6-1 for the timeline and total number of participants. EBCD has typically been applied in healthcare settings to improve services within high income countries (HICs) but was judged appropriate to answer the research questions. To our knowledge this is the first time this approach has been applied in these kinds of settings. This research received ethics approval from the 'Comité National de Bioéthique en Haïti' and from St. Mary's Hospital Research Ethics Committee in Montreal, Canada.

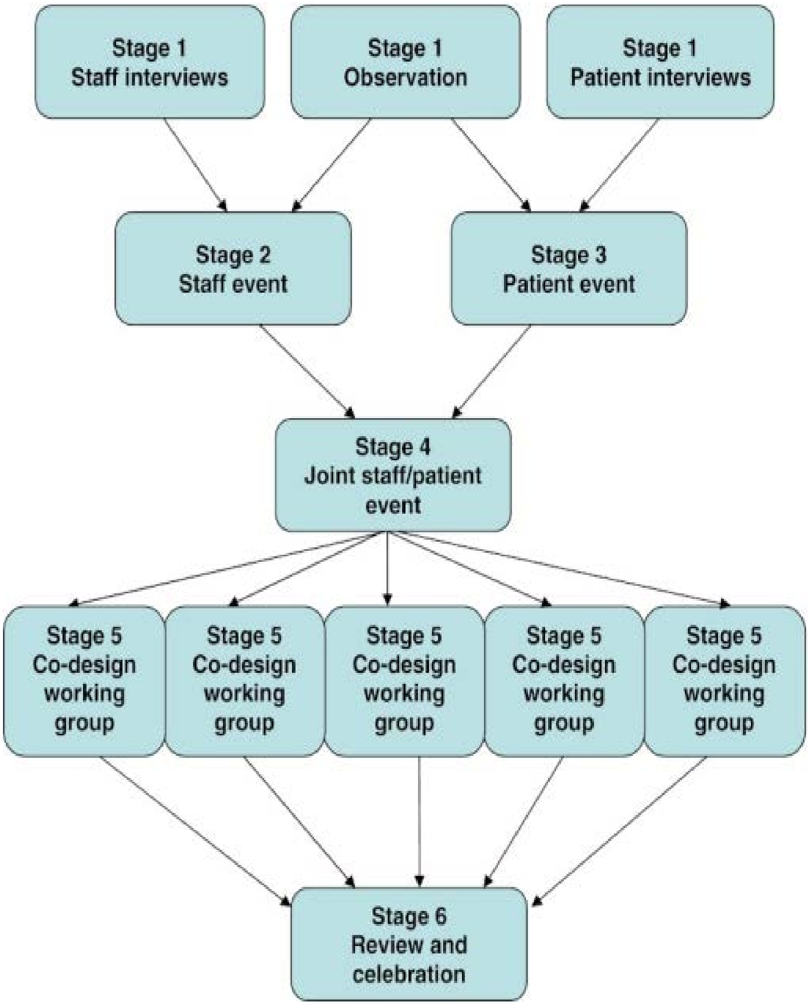

***Figure 6- 1**: Different stages of the Experience-Based Co-Design approach*

Patient and public involvement

This participatory research approach aimed to improve the user experience of the HP activities. We therefore collected the communities' experiences and intended to include them in the co-design sessions (due to reduced funding this phase could not be completed (see table 6-1). The HP staff was involved in the design and implementation of the study through workshops and by continuously seeking their feedback.

***Table 6- 1**: Timeline of all data collection activities, including the number of participants*

Data collection method	Who	Date	Number of participants
Observations (16 days)	HP activities	30 Oct/24 Nov 2017	NA
Workshop to discuss issues in field and ideas	HP team leads	11 Nov 2017	8
Interview doctor (UAS, MSPP, Nurse NGO, coordinators NGOs (2), assistant CTDA)	Health care professionals	10 Nov-2 Dec 2017	7
Focus group	People who had or had not had cholera	10 Nov-2 Dec 2017	68
Focus group	Houngan and assistants	24 Nov 2017	10
Community group	Reporting data back to community members (participant event)	1-10 May 2018	20
Staff feedback event combined with training	HP team members	11 May 2018	12
Interviews	People who have a toilet	25 Apr-5 Jun 2018	7
Workshop for article development		5 Dec 2020	4

Collaboration with a humanitarian organization

A research agreement, developed jointly with AAH, and lead author IO, was signed in 2017 and we met on a regular basis. Key stakeholders included: a) the head office in New York (USA); b) the country office senior management level in Port-au-Prince (Haiti); and, c) the field level in the local Artibonite region (Haiti). Other key stakeholders such representatives of governmental agencies, alternative health practitioners and collaborating NGOs were invited to participate in key stakeholder interviews.

Data collection

Observations

Observations of the HP teams' activities, conducted by authors KM (research assistant) and IO (PhD student) included handwashing promotion activities during national celebrations, door-to-door and community information sessions, and HP activities in the CTCs. KM and IO took detailed field notes following each observation.

Staff interviews

Recruitment: Seven key professionals, see table 6-2, participated in individual interviews. As per their request, alternative health practitioners and their assistants participated in a focus group. A hygienist, working at a CTC, helped recruit participants for the focus group, and others were invited by KM and IO, who visited several alternative health practitioners. No compensation was provided.

Interviews were conducted at the place of work or in AAHs office. Six interviews were conducted in French by IO and one was conducted in Creole by KM. The audio recorded interviews lasted between 30-100 minutes. Questions related to existing protocols, patient and family engagement, care structure and existing HP activities (see supplementary files for the interview guideline).

Interviews with community members

Recruitment: Four focus groups were conducted in the communities Dessalines and St. Michel with females or males and with people who had or had not had cholera (see table 6-2). The communities were selected due to the high prevalence of cholera and lower reported levels of practice change. The team applied different methods to invite appropriate participants (e.g. people attending HP sessions, during home visits) while paying attention to different demographic characteristics (e.g. age, gender and living conditions – urban or rural). Focus groups dates and spaces were determined before people were invited to participate (e.g. in churches, community or health care centres), spaces opened up for this particular occasion and close to the communities to facilitate participation of those who may otherwise be excluded (Cornwall, 2002). People were informed that no financial compensation would be provided for their participation.

***Table 6- 2**: Total number of participants in each focus group*

Dessalines	Participant had cholera	Participant had not had cholera	Total
Women	10	10	**20**
Men	6	9	**15**
St. Michel D'Attalaye			
Women	10	7	**17**
Men	8	8	**16**
Total	**34**	**34**	**68**

Focus group discussions were conducted in Creole by the RA and supported by IO. After obtaining consent (which sometimes required 60 minutes) and a general explanation of the project, the groups discussed the questions for 120-150 minutes. These sessions were video or audio recorded, depending on the consent. Data were stored on a password protected hard disc and computer. Minor adaptations were made after the first focus group to adjust the order of questions to improve the flow. In line with AAH's policies, all participants received a meal after the session.

Informed consent

Written or oral consent for participation in the focus group as well as for video and/or audio recording was obtained before the start of the interviews and focus groups.

Analysis

The qualitative data from the interviews and focus groups was analysed following Gale's 7 step framework: 1) transcription; 2) familiarization with the data; 3) coding; 4) developing a working analytical framework; 5) applying the analytical framework; 6) charting data into the framework matrix and 7) interpreting the data (Gale, Heath, Cameron, Rashid, & Redwood, 2013). All audio recording (French and Creole) was transcribed directly into French by KM. IO and KM both coded several focus group transcripts independently, using inductive as well as deductive coding, drawing from the conception of trust from the literature. Coding was discussed until agreement was found in the identified themes. A coding framework was developed which represented the themes as identified in the interviews, focus groups and field notes. This framework was presented to members of the AAH team and PhD committee members. Data management and analysis were supported using NVivo10 and Transana (for video data). Results were member checked through community focus groups. Results were summarized in a report, written in collaboration with AAH staff, shared with the funder of the HP response (UNICEF) and interested research participants. In the analysis we noted that trust was a key aspect that crosses over different themes. For this paper we further analysed the themes to explore the role of trust. A wide selection of quotes for this paper were shared [December 5, 2020] in a workshop with four HP staff facilitated by KM and IO. In this workshop they defined trust, reviewed the quotes and discussed whether this data related to trust or not. The results of this workshop were summarized in a report and are integrated in this article.

6.5 Results

Data collected through various activities (focus groups, interviews and workshops) is presented in this section, see Tables 6-3 and 6-4 for more details. Most participants finished high school (37%) or primary school (17%). Most common occupations were farmer (32%) or merchant (22%).

The concept of trust featured strongly across the three major themes: (1) Mistrust of foreign assistance; (2) lack of congruence between personal experiences, beliefs and HP guidance; (3) blame as a consequence of perceived individual responsibility.

***Table 6- 3**: Sociodemographic characteristics participants*

Marital status (n=68)	**N**	**Dwelling (n=68)**	
Married	32 (47.1%)	Private	45 (66.2%)
Single	17 (25.0%)	Rental	12 (17.6%)
Partner	17 (25.0%)	Shared house	9 (13.2%)
Widow	1 (1.5%)	Unknown	2 (2.9%)
Unknown	1 (1.5%)		
		Roofing house (n=68)	
Age (n=68)		Metal sheets	61 (89.7%)
18-29	19 (27.9%)	Concrete	7 (10.3%)
30-44	22 (32.4%)		
>45	25 (36.8%)	**Materials dwelling (n=68)**	
Unknown	2 (2.9%)	Rock / soil	42 (61.8%)
		Cement / wall	17 (25.0%)
Children (n=68)		Rocks / soil and cement	9 (13.2%)
0	9 (13.2%)		
1-2	25 (36.8%)	**Employment (n=68)**	**N**
3-4	26 (38.2%)	Farmer	23 (33.8%)
5-6	7 (10.3%)	Merchant (commerce)	16 (23.5%)
Unknown	1 (1.5%)	Merchant and school	4 (5.9%)
		Teacher	3 (4.4%)
School education (n=68)		Professor	2 (2.9%)
Never attended	4 (5.9%)	Community agent	2 (2.9%)
Alphabetization	4 (5.9%)	Unknown	5 (7.4%)
Primary	17 (25.0%)	**Each once mentioned:** unemployed, builder/electrician, professional, hygienist auxiliary, instructor, dentist/businessman, iron worker, seamstress, nurse, security agent, student, agricultural technician	1 (1.5%)
Secondary	38 (55.9%)		
University	4 (5.9%)		
Unknown	1 (1.5%)		

***Table 6- 4**: Types of material possessions participants*

	Running water [%]	Toilet [%]	Handwashing station [%]	Shower [%]	Electricity [%]	Radio [%]	TV [%]	Tel [%]	Other [%]
Participants who had had cholera									
St. Michel, women	10	60	20	50	0	30	10	60	NA
St Michel, men	13	75	25	38	63	63	25	88	NA
Dessalines, women	0	0	9	0	0	0	0	36	Well
Dessalines, men	0	83	0	0	17	17	17	67	Fridge
Average	**6**	**55**	**14**	**22**	**20**	**28**	**13**	**63**	
Participants who had not had cholera									
St. Michel, women	29	57	57	29	43	14	29	86	NA
St. Michel, men	25	75	25	38	75	75	75	88	NA
Bois Marie (village in the area of Dessalines), women	0	70	70	50	20	60	10	80	NA
Coup-a-Linde (village in the area of Dessalines), men	0	50	0	0	0	30	20	70	NA
Average	**14**	**63**	**38**	**29**	**35**	**45**	**34**	**81**	**NA**

Mistrust of foreign assistance

Several participants in different focus groups spoke spontaneously about the origin of cholera and the role of the UN, even when there were no questions related to this subject. They, however, also expressed mistrust towards other NGOs and the Haitian government. It should be noted that the data collection took place after the announcement (Dec 1, 2016) of the UN’s role in the outbreak (Bartels, Fraulin, & Lee, 2020; Wilson, 2018). Participants expressed suspicions about how cholera was introduced and uncertainty about the true cause.

> *It is also said that cholera exists in Haiti because of certain foreigners. They brought cholera on our land. But we do not really know the cause of this problem. (FG4)*

A reaction from another participant in the same focus group illustrates how past experiences with foreign intervention shapes the context for the current situation.

> *It's like something real, it's really a germ that they spilled that is causing it. Just as they introduced something that caused the death of the Creole pigs, it is in the same way that they want to exterminate us too”.* (FG8)

This participant makes reference to Haitian creole pigs, well adapted to the local circumstances and low maintenance, which were deliberately ‘killed as part of a swine disease control efforts required to integrate Haiti into the hemisphere economy' in 1982/83 (Ehrenfeld, 2005). They were replaced by pigs from Iowa that required clean water and imported food to survive. Haitians lost an estimated $600 million resulting in drop of 30% in rural school enrolments (Ehrenfeld, 2005) as tuition could not be paid. Linking cholera to the Creole Pigs illustrates how past events play a role in the interpretation of current events. Some participants shared how the perceived malicious intent of the Minustah *(UN stabilisation mission in Haiti)* provoked a refusal to adopt the promoted cholera prevention measures:

> *They (members of our community) simply say that it is Minustah who leaves something to kill the Haitians, that is why they will not take precautions. ... That's why they don't want these hygiene rules. (FG5)*

This was also explained by participants who indicated that the UN, responsible for the introduction of cholera in Haiti, should assume the responsibility of the construction of toilets for the population and not community members (data from observations). Participants not only expressed a mistrust towards UN agencies but also to NGOs:

> *We must be in poverty for these institutions to exist. I think we have to have cholera to be able to give work to certain agents. For me they are not for the eradication of cholera, but they are trying to diminish it. (FG6)*

Both the UN (UNICEF) and foreign NGOs (iNGOs) were involved in the HP strategy and dissemination of the public health guidance. In the next session we describe how the contents of these messages was questioned.

Lack of congruence between personal experiences, beliefs and HP guidance

Participants expressed doubt about the effectiveness of some of the advised behaviours; they did not understand how cholera was transmitted, doubted whether the measures were protecting them for real and questioned the value of putting behaviours into practice if they still got sick:

> *But when you do that (follow the principles of hygiene) it does not guarantee that you are protected from the disease. There are people who take precautions, but they still get cholera. (FG5)*

With one participant suggesting that it is worse when you take precautions: *I've noticed that when you take precautions, that's when you catch it the fastest (FG3).*

Others doubted the validity of the messages as certain behaviours safely practiced in the past could now make them sick:

> *If germs used to kill Haitians, there would be no more Haitians on this earth [monchè, si mikròb te konn tiye Ayisyen, pa gen Ayisyen ki tap sou tè an toujou]. The majority of Haitians would be dead (FG2)*

The most frequently heard explanation was that people indicated that there were these little moments where you risk infecting yourself (e.g. when you bathe in the river and water enters your mouth). Others described transmission mechanisms that were in contradiction to the HP messages. Regularly people spoke of transmission through dust or air and through a trap *[pèlen]*. At times people indicated that nobody would escape from infection, that infection took place through divine will, by eating too much or because of cold weather.

> *Sometimes a person gets cholera, she goes to the centre and she dies. Others say it was not cholera, but it was a trap [pèlen]. (FG2)*
> *Also, I am informed that cholera is in the air. That's why the disease is not stopped, it is still there. (FG1)*

Having failed to protect himself from infection of cholera while following all precautions, one participant describes how it changed his behaviour:

> *I thought if I took all these precautions and I'm still affected by cholera, so I made another resolution. I started to drink water from the spring. And sometimes you feel like eating sugar cane, while there is no water to wash hands and cane. So, I changed my behaviour, I eat sugar cane like this. (FG4)*

Participants used arguments to explain why they mistrusted the contents of the public health messages. The content of the messages also seemed to influence how people who had or hadn’t had cholera were perceived by their community.

Blame as a consequence of perceived individual responsibility

In every focus group, but most frequently in focus groups where participants had had cholera, participants indicated how the behaviour of others in the community, the lack of required resources and poor infrastructure limited their ability to put the public health guidance into practice. Participants described lacking public and private toilets to stop defecation in the field, access to water treatment products or safe water as well as an inability to buy soap or water treatment products but also a shortage and sometimes even absence of health care staff in the CTCs.

> *No matter how careful you are, you will still catch it because you don't have a latrine, you live in a field of germs. Not the latrine, you don't have a place to get water. You have to go to the spring to get water. There is no well. (FG1)*

These participants also explained that the required hygiene measures were unrealistic and that most people would risk getting infected even if they did their best.

> *For me, the preparation is that we can tell a person that he or she must take precautions. But financially you can't help the person. For me it's a mess. Let's take the case at Platana (locality in Haiti). The pipe comes with untreated water. These people don't have a latrine at home. So how are you going to tell this person not to defecate on the ground? (FG6)*

In addition, people indicated that even when they respected the hygiene rules, they were still exposed to transmission risk as the people surrounding them did not respect the HP guidance.

> *Even if you make efforts but you know that everyone goes to the hills to relieve themselves and you live in the valley… the fly can come back from the cholera infected faeces and land on it. (FG1)*

The above explanations could be seen as an attempt of people who had cholera to explain that it was not that they were just negligent or unhygienic, but that there were other causes that made them sick despite their efforts. Summarized by this participant as *'I see that cholera catches clean people and dirty people'* (FG2). In addition, these kind of quotes demonstrate that these participants had a good understanding of the risk of transmission. Whereas participants who did not have cholera, 'accused' community members who had been sick of being negligent or unhygienic and putting themselves and others at risk with this behaviour. *Neglect is when you .. tell someone not to touch something, he doesn't touch it at that time. But he touches it after.* (FG3)

> *We ourselves do not catch this disease, we take precautions, but there are people who are not careful; they defecate in the open air, they do not wash their hands. ... The careless people are responsible for the persistence of cholera until today.* (FG8)

Participants speak about how individual behaviour affects the safety of other community members. With participants divided whether individuals who had cholera can be 'blamed' of improper behaviour or whether the cause of infection lies in surrounding circumstances. Besides this strong focus on individual responsibility some participants also spoke about the importance of community efforts and solidarity:

> *But we all feel concerned by this, which means that we should have a sense of responsibility to reach out to others, to get them interested in applying the hygiene rules. For example, close to home, if I see a child defecating in the open air, I run after him. I reach his parents to educate them about not having this behaviour. (FG9)*

While participants did not speak directly of trust, it can be noted that cholera led to shame, blame and accusations.

6.6 Discussion

The HP activities were part of successful cholera response strategy. The three themes in this paper (mistrust of foreign assistance, lack of congruence between personal experiences, beliefs and HP guidance; challenges to solidarity, personal responsibility and negligence) summarize the frequently heard concerns and issues expressed by community members in the HP field in Haiti. However, these perspectives, experiences and needs rarely factor into the design, data collection or results of research investigating HP responses. We provided examples of how mistrust and disbelief led to reactions that impacted the HP effectiveness. The broad concerns might be replicated across settings, but the particular ways they are manifested will of course be distinct – here the issue around the role of the UN in causing the cholera outbreak, and, for example, the preceding history of imperialism (e.g. creole pigs) help to explain how this manifested in this particular context as well as many other factors that have not been further researched.

Association between mistrust and morbidity and mortality

Before attempting to shift behaviour it is essential to build trust, engage with communities, understand their context, motivations and beliefs that shape their existing behaviour. In Haiti it was found that those who believed foreigners were responsible for introducing cholera were less likely to seek western treatment (Saini, 2017) and that mistrust in the HP guidance interfered with the prevention messages and awareness raising (Grimaud & Legagneur, 2011). Yet, only one (Contzen & Mosler, 2013) of the subsequent seven research studies investigating the HP response attempted to measure trust as an outcome (Ormel, Hunt, et al.). In complex contexts, with a low perceived trustworthiness of foreign and governmental assistance, information coming from these sources is not necessarily perceived as trustworthy (Bangerter, 2014). In the USA members of racial and ethnic minority communities who experience a higher level of distrust are more likely to be suspicious towards public health information, less willing to adopt new behaviours and more sensitive to misinformation (Van Bavel et al., 2020). For example, the Tuskegee Study in 1972 (research where black men were denied effective syphilis treatment for 40 years) led to increased medical mistrust and mortality and decreased physician interactions for older black men (Alsan & Wanamaker, 2018). It was also found that amongst Black Americans a greater COVID-19 mistrust is related to greater vaccine and treatment hesitancy (Bogart et al., 2021). Research shows that non-compliance cannot only be reduced to ignorance or deficient knowledge but should also be seen as a form of active resistance (Bangerter, 2014). Research in the cholera outbreak in the 90's in Brazil demonstrated how the presence of conspiracy theories could be seen as a form of resistance to address a history of social and economic inequity and domination (Nations & Monte, 1996). Haiti has a rich history of resistance starting perhaps when enslaved people rose against colonial powers and succeeded in liberating Haiti in 1804 from its oppressors (Payton, 2017). The UN officially apologized in 2016 for its role in Haiti's cholera outbreak after a long process involving scientific investigations and debates around legal aspects (Payton, 2017). Also the COVID-19 response has been negatively impacted by rumours and violence against health care workers and the national organization GHESKIO reports how they try to overcome mistrust and stigma by engaging local leaders (Rouzier, Liautaud, & Deschamps, 2020).

Individualization of behaviour change responsibilities

It is argued that prevention campaigns in Haiti placed the burden of controlling the disease with the affected populations through the emphasis on individual-level actions (Guillaume, Jerome, Ternier, Ivers, & Raymond, 2019). Perhaps similar tendencies can be observed in other prevention campaigns. Placing this burden with the population contributed to overlooking the responsibility of institutions to address structural issues (Guillaume et al., 2019). This individualisation of behaviour change responsibilities can cause shame, stigma and self-blame and even more so when cholera becomes seen as 'the dirty hands' disease which can contribute to a 'blame the victim' culture (Guillaume et al., 2019). It is argued that stigma should never be used as a tool for behaviour change as it damages those already vulnerable, reinforcing health disparities (Brewis & Wutich, 2019). In addition, targeting fear in HP interventions, can lead to defensive reactions if and when people feel helpless to act (Witte & Allen, 2000). Several participants insisted that reducing cholera transmission should also be a community effort. Indeed, also in the Ottawa Charter for Health Promotion (World Health Organization, 1986) it is emphasized that “Health promotion strategies and programmes should be adapted to the local needs and possibilities of individual countries and regions to take into account differing social, cultural and economic systems”, and this requires more than developing locally appropriate information material.

The need to consider, assess/measure and integrate trust as an important component for successful HP promotion strategies

It is important to note that this article is part of a sparse body of literature on the lived experiences related to the cholera outbreak in Haiti; the voices of the people who suffered the consequences have rarely been brought forward in research (Guillaume et al., 2019). Even though trust was identified as an important factor in the adaptation of the HP guidance, these factors were hardly integrated in subsequent studies investigating the HP response in Haiti (Ormel, Hunt, et al.). Former studies informed biomedical interventions or mechanisms but failed to reinforce other mechanisms that are also essential for an effective response from the population (e.g. role of trust, experiential and local knowledge or health care seeking behaviour). Community-based participatory research studies have measured trust as related to the context, relational aspects or the complexity of the concept (Gilfoyle, MacFarlane, & Salsberg, 2020). It is, however, also argued that collecting data is not enough, this data should also be used to improve health care (Coulter, Locock, Ziebland, & Calabrese, 2014) guidance in the process of change can be provided by approaches such as EBCD.

Limitations

The primary limitations were related to the relatively small sample size for such a complex context, the challenges associated with local language and reliance on local interpretation and translation, the changing dynamic of the disease during the life of the project. For these reasons, replicating this study may require adaptations to the design and implementation of an EBCD project. It is not known to what extent results can be generalized but it can be expected that trust is an important factor in research investigating HP response in disease outbreaks and could therefore be a focus in data collection as well as in analysis of the data. An in-depth understanding of the role and influence of the local medical male (houngan) and female (Mambo) practitioners would have required more time and additional funding.

Yet, this study did include a focus group with houngans to gather their perspectives and experiences as well as one individual interview with a houngan. In addition, several participants shared their perspectives of the role of alternative health practitioners and for example about the cholera ‘magique’.

6.7 Conclusions

The findings of the qualitative research suggest that trust played a role in relation to the HP response actors, in the acceptance of the HP messages and that it may have played a role in the relationship amongst community members. It also looks at how the deficit of trust may have impacted the effectiveness of the HP response. HP strategies may be greatly strengthened by incorporating approaches that address this deficit of trustworthiness through collaboration with the affected population. A recent scoping review on trust in community-based participatory research (Gilfoyle et al., 2020), illustrates the complexities of trust. Further investigation of how HP responses are impacted by trust or the lack of it is required. This article reflects on how the HP response in Haiti could have been further optimized. However, some of the findings can also be applied in other HP strategies in other settings responding to cholera, Ebola, COVID or nutrition and hygiene. Collecting data on peoples’ experiences can uncover complex issues and requirements and with no simple or ‘one-size-fits-all’ type solution. Data collecting and improved understanding, however, doesn’t automatically lead to change (Brown & Donini, 2014), guidance in the process of change can be provided by approaches such as EBCD.

6.8 Acknowledgements

This research was made possible by generous contributions and time from patients, community members and professionals who shared their experiences and perceptions which were inspiring and insightful.

We thank the AAH teams in Gonaïves, Port-au-Prince and New York, who took time to understand our goals and provided support and resources. A special thanks to the participants, Lesly Succes, Evenin Oreste, Wisline Michel and Gabriel Junior Bien-Aimé Gabriel Junior who contributed to the analysis by sharing their ideas, insights and experiences from the field.

We thank AAH's national and international partners who contributed expertise and knowledge; UNICEF, MSPP, USA, DINEPA, CRH, MDM and Acted.

This research was made possible with the financial support from Dr. Graham's CIHR Foundation grant: *Moving knowledge into action for more effective practice, programs and policy: A research program focusing on integrated knowledge translation,* Fonds de Recherche Quebec Santé (FRQS) doctoral training scholarship, and travel awards from McGill University.

6.9 References

Alsan, M., & Wanamaker, M. (2018). Tuskegee and the health of black men. *The quarterly journal of economics, 133*(1), 407-455.

Bangerter, A. (2014). Investigating and rebuilding public trust in preparation for the next pandemic. In: Hogrefe Publishing.

Bartels, S., Fraulin, G., & Lee, S. (2020). Cholera in the Time of MINUSTAH: Experiences of Community Members Affected by Cholera in Haiti. *Research Square*.

Bate, P., & Robert, G. (2007). *Bringing user experience to healthcare improvement: The concepts, methods and practices of experience-based design*: Radcliffe Publishing.

Blair, R. A., Morse, B. S., & Tsai, L. L. (2017). Public health and public trust: Survey evidence from the Ebola Virus Disease epidemic in Liberia. *Social science & medicine, 172*, 89-97.

Bogart, L. M., Ojikutu, B. O., Tyagi, K., Klein, D. J., Mutchler, M. G., Dong, L., . . . Kellman, S. (2021). COVID-19 related medical mistrust, health impacts, and potential vaccine hesitancy among Black Americans living with HIV. *Journal of Acquired Immune Deficiency Syndromes (1999), 86*(2), 200.

Brewis, A., & Wutich, A. (2019). Why we should never do it: stigma as a behaviour change tool in global health. *BMJ Global Health, 4*(5), e001911. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6830281/pdf/bmjgh-2019-001911.pdf

Brown, D., & Donini, A. (2014). *Rhetoric or reality? Putting affected people at the centre of humanitarian action*. Retrieved from https://www.alnap.org/help-library/rhetoric-or-reality-putting-affected-people-at-the-centre-of-humanitarian-action-0

Centers for Disease Control and Prevention (CDC). (2014). Cholera - vibrio cholerea infection. Retrieved from https://www.cdc.gov/cholera/illness.html

Christensen, D., Dube, O., Haushofer, J., Siddiqi, B., & Voors, M. (2020). *Community-Based Crisis Response: Evidence from Sierra Leone's Ebola Outbreak.* Paper presented at the AEA Papers and Proceedings.

Cohn, S., & Kutalek, R. (2016). Historical parallels, Ebola virus disease and cholera: understanding community distrust and social violence with epidemics. *PLoS currents, 8*.

Contzen, N., & Mosler, H.-J. (2013). Impact of different promotional channels on handwashing behaviour in an emergency context: Haiti post-earthquake public health promotions and cholera response. *Journal of Public Health, 21*(6), 559-573.

Cornwall, A. (2002). Making spaces, changing places: situating participation in development.

Coulter, A., Locock, L., Ziebland, S., & Calabrese, J. (2014). Collecting data on patient experience is not enough: they must be used to improve care. *BMJ: British Medical Journal (Online), 348*.

DFID UK. (2013). *Water, Sanitation and Hygiene, Evidence Paper*. Retrieved from https://www.gov.uk/government/publications/water-sanitation-and-hygiene-evidence-paper

Deurenberg-Yap, M., Foo, L., Low, Y., Chan, S., Vijaya, K., & Lee, M. (2005). The Singaporean response to the SARS outbreak: knowledge sufficiency versus public trust. *Health Promotion International, 20*(4), 320-326.

Ehrenfeld, D. (2005). The environmental limits to globalization. *Conservation Biology, 19*(2), 318-326.

Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC medical research methodology, 13*(1), 117.

Gilfoyle, M., MacFarlane, A., & Salsberg, J. (2020). Conceptualising, Operationalising, and Measuring Trust in Participatory Health Research Networks: a Scoping Review. *Research Square*.

Grimaud, J., & Legagneur, F. (2011). Community beliefs and fears during a cholera outbreak in Haiti. *Intervention, 9*(1), 26-34.

Guillaume, Y., Jerome, G. J., Ternier, R., Ivers, L. C., & Raymond, M. (2019). ‘It was a ravage!’: lived experiences of epidemic cholera in rural Haiti. *BMJ Global Health, 4*(6).

Jagosh, J., Bush, P. L., Salsberg, J., Macaulay, A. C., Greenhalgh, T., Wong, G., . . . Pluye, P. (2015). A realist evaluation of community-based participatory research: partnership synergy, trust building and related ripple effects. *BMC Public Health, 15*(1), 1-11.

Jagosh, J., Macaulay, A. C., Pluye, P., Salsberg, J., Bush, P. L., Henderson, J., . . . Herbert, C. P. (2012). Uncovering the benefits of participatory research: implications of a realist review for health research and practice. *Milbank Quarterly, 90*(2), 311-346.

Kim, Y. (2016). Trust in health information websites: A systematic literature review on the antecedents of trust. *Health Informatics Journal, 22*(2), 355-369. doi:10.1177/1460458214559432

Miller, J., & Birnbaum, M. L. (2018). Characterization of interventional studies of the cholera epidemic in Haiti. *Prehospital and disaster medicine, 33*(2), 176-181.

Nair, G. B., & Takeda, Y. (2008). Cholera: the need to translate research knowledge into effective preventive and control measures. *Future Medecine*.

Nations, M. K., & Monte, C. M. (1996). “I'm not dog, no!”: Cries of resistance against cholera control campaigns. *Social science & medicine, 43*(6), 1007-1024.

Ormel, I., Hunt, M., Hinton, L., Salsberg, J., Doucet, A., Macaulay, A. C., & Law, S. Hygiene promotion research in disease outbreaks in humanitarian settings: the case of cholera in Haiti. *Submitted to BMC Public Health*.

Ormel, I., Massena, K., Doucet, A., Hinton, L., Salsberg, J., Hunt, M., . . . Law, S. The Hygiene Promotion Response to the Cholera Outbreak in Haiti: Lessons L earned of Applying an Experience-Based Co-Design to Improve the Experience of Affected Communities – To be submitted to *BMJ Health Care Services Research in July 2021*

Ormel, I., Salsberg, J., Hunt, M., Doucet, A., Hinton, L., Macaulay, A. C., & Law, S. (2020). Key issues for participatory research in the design and implementation of humanitarian assistance: a scoping review. *Global Health Action, 13*(1), 1826730. doi:10.1080/16549716.2020.1826730

Pan American Health Organization. (2020). Haiti reaches one-year free of Cholera. Retrieved from https://reliefweb.int/report/haiti/haiti-reaches-one-year-free-cholera

Payton, C. A. (2017). In Moral Debt to Haiti: In the world’s first independent Black Republic, cholera victims and their international allies continue to fight the UN for their basic right to clean water and monetary reparation. *NACLA Report on the Americas, 49*(1), 64-70.

Robert, G. (2013). Participatory action research: using experience-based co-design to improve the quality of healthcare services. In *Understanding and Using Health Experiences–improving patient care* (pp. 138-149): OUP Oxford.

Rousseau, D. M., Sitkin, S. B., Burt, R. S., & Camerer, C. (1998). Not so different after all: A cross-discipline view of trust. *Academy of management review, 23*(3), 393-404.

Rouzier, V., Liautaud, B., & Deschamps, M. M. (2020). Covid-19 Notes: Facing the Monster in Haiti. *The New England Journal of Medicine*.

Saini, G. (2017). Humanitarian aid policy changes following the 2010 cholera outbreak in Haiti. *NEXUS: The Canadian Student Journal of Anthropology, 25,* 2-12.

Taylor, D. L., Kahawita, T. M., Cairncross, S., & Ensink, J. H. (2015). The impact of water, sanitation and hygiene interventions to control cholera: a systematic review. *PloS one, 10*(8), e0135676.

The Point of Care Foundation (The King's Fund). Experience-based co-design toolkit.

Van Bavel, J. J., Baicker, K., Boggio, P. S., Capraro, V., Cichocka, A., Cikara, M., . . . Druckman, J. N. (2020). Using social and behavioural science to support COVID-19 pandemic response. *Nature Human Behaviour*, 1-12.

Wilson, J. M. (2018). The use of intelligence to determine attribution of the 2010 Haiti cholera disaster. *Intelligence and National Security, 33*(6), 866-874.

Witte, K., & Allen, M. (2000). A meta-analysis of fear appeals: Implications for effective public health campaigns. *Health Education & Behavior, 27*(5), 591-615.

World Health Organization. (1986). The Ottawa Charter for Health Promotion. Retrieved from https://www.who.int/publications/i/item/ottawa-charter-for-health-promotion

World Health Organization. (2017). Cholera. Retrieved from http://www.who.int/mediacenter/factsheets/fs107/en/

7 THE HYGIENE PROMOTION RESPONSE TO THE CHOLERA OUTBREAK IN HAITI*:* APPLYING AN EXPERIENCE-BASED CO-DESIGN TO IMPROVE THE EXPERIENCE OF AFFECTED COMMUNITIES – MANUSCRIPT 4

7.1 Preamble

Learning from manuscript 1 and 2 that participatory approaches are not yet frequently applied, I reflect in this manuscript on the feasibility of implementing an EBCD in humanitarian settings. This setting was distinctly different in comparison to the settings were most EBCDs have been applied. These differences helped to identify five factors (service, space, staff, clients and context) that influenced the EBCD process. This pilot EBCD provides the opportunity to better understand how different factors influence the mechanisms which in turn result in specific outcomes for individual EBCDs.

Reference: Ormel I, Massena K, Doucet A, Hinton L, Salsberg J, Hunt M, Sacher H, Macaulay AC, Law S. The Hygiene Promotion Response to the Cholera Outbreak in Haiti*:* Applying an *Experience-Based Co-Design to Improve* the Experience of Affected Communities. This paper will be submitted to *BMJ Health Care Services Research*

The Hygiene Promotion Response to the Cholera Outbreak in Haiti: Applying an Experience-Based Co-Design to Improve the Experience of Affected Communities

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7.2 Abstract

Background: Hygiene promotion strategies in the response conducted by humanitarian organizations to disease outbreaks such as cholera and Ebola remain top-down, despite acknowledgement in the sector of the value of participatory approaches. A key challenge for participation is gathering and integrating the perspectives of affected populations into humanitarian operations. One promising approach in this direction is Experience-Based Co-Design (EBCD). In the first application of EBCD in a hygiene promotion setting, we explored the feasibility of this approach as a quality improvement intervention in the humanitarian response to the cholera outbreak in Haiti.

Methods: EBCD draws on participatory action research, user-centred design, learning theory and narrative-based approaches to change. This approach supports the design and implementation of changes to improve the experience of service users. In this article, we are guided by the three aspects of the Donabedian model (structure, process and outcome) to draw lessons and highlight considerations regarding the adaptations required to implement an EBCD in humanitarian settings.

Results: The collaboration with key stakeholders resulted in the adaptation of the data collection and analysis in the EBCD. We describe five factors (service, space, staff, clients and context) that were different in this setting and that impact the EBCD process. Adaptations were made to the consent and data collection process. It was possible to

discuss the acceptability of video recording in the focus groups. The EBCD process facilitated a process where staff and community members were able to discuss the complexity of the context and priorities for change.

Conclusion: While there are still important limitations and challenges with the adoption of an EBCD approach in these settings, we argue that it is exactly the processes embedded in this approach to gather and integrate local experience, in collaboration with a multidisciplinary team, that make it valuable.

7.3 Introduction and Purpose

Background

The humanitarian responses to recent disease outbreaks, such as Ebola in West Africa in 2014 and in the Democratic Republic in Congo (DRC) in 2018, as well as the cholera outbreak in Haiti in 2010, have received criticism for: the use of top-down approaches (Contzen & Mosler, 2013; Laverack & Manoncourt, 2016; Marais et al., 2015); a predominant focus on viral transmissions (Marais et al., 2015); the late engagement of key stakeholders (Marais et al., 2015; Masumbuko Claude & Hawkes, 2020); and, limited support for local leaders and health professionals (Masumbuko Claude & Hawkes, 2020). Or in the words of Kickbusch (2015): *"Health promotion knowledge needs to be fully integrated into infectious disease control, especially in the context of outbreaks. This has been the key lesson of the HIV/ AIDS epidemic, yet it is forgotten again and again, as the focus is on the virus rather than the people."* There remain key barriers (e.g. the required investment in time and resources) not only on an operational level but also on an academic level to implement participatory research approaches in these settings (Bruno & Haar, 2020). Despite this conflict it is argued that there is an ethical obligation to conduct research in these settings (Bruno & Haar, 2020) and increasingly there is an emphasis on the use of participatory research, for example from funding agencies. This article discusses the feasibility of an EBCD approach to identify and implement changes to improve the experience of members of affected communities with the hygiene promotion (HP) response in the cholera outbreak in Haiti and can be seen as an extension of the approach which typically focuses on improving the patient experience of a certain health care service.

Experiential data as a mechanism for change

Marginalizing the knowledge, perceptions and experiences of affected populations risks further traumatize populations (Afifi et al., 2020) and may unintentionally reinforce existing inequities and oppression (Afifi et al., 2020; G. Mulvale et al., 2019) therefore negatively impacting those that humanitarian programs aim to serve. Research underscores the need for meaningful engagement of vulnerable populations through participatory approaches and supportive institutional contexts (G. Mulvale et al., 2019). Even though these concepts are not new in HP, there is limited evidence of uptake on operational (Kickbusch & Reddy, 2015) as well as humanitarian research levels (Ormel et al., 2020); it remains challenging to implement the learning of this kind of data into humanitarian operations (Brown & Donini, 2014; Eyben, 2008).

Populations affected by crisis also ask for improved participation in humanitarian programs. The authors of *Time to Listen,* argue that the cumulative evidence of 6,000 diverse people on the receiving end of aid in diverse settings, all produce a similar message, in that it is time to listen to the affected populations experiences and use this information to improve humanitarian assistance (Anderson, Brown, & Jean, 2012). In addition, there is a need to find approaches that can contribute to learning and change: there is a need to report on how perception studies contribute to change in practice (Nouvet, Abu-Sada, de Laat, Wang, & Schwartz, 2016).

EBCD is a novel approach that draws on narrative-based approaches to change, user-centred design, participatory action research and learning theory (Larkin, Boden, & Newton, 2015). *It supports the design and implementation of changes to improve the user experience.* EBCD has been predominantly used in health care services and high-income countries. Little is yet know how EBCD can support efforts to address challenges faced by vulnerable populations (A. Mulvale, Miatello, Hackett, & Mulvale, 2016). EBCD might be a useful approach in settings where power imbalance among health care professionals and people experiencing the services is high (A. Mulvale et al., 2016). The research undertaken for this study piloted if this approach could also be successfully applied in the humanitarian HP response to the cholera outbreak in Haiti.

The Haitian cholera outbreak and opportunity for a different approach

In January 2019 Haiti reported its last cholera case, successfully ending a period with over 820,000 reported cholera cases and close to 10,000 cholera related deaths (Centers for Disease Control and Prevention (CDC), 2019). Cholera was inadvertently introduced to Haiti in 2010 through a poorly maintained sanitation system within a UN peacekeeping camp (Payton, 2017). People infected with vibrio cholera can develop severe diarrhoea resulting in dehydration and ultimately death if not treated rapidly (World Health Organization, 2017). An extensive governmental and humanitarian response followed the outbreak and included surveillance and detection of cholera cases, establishment of cholera treatment centres (CTC), rehydration treatment, water and sanitation efforts and community health education (Miller & Birnbaum, 2018).

Six years into the cholera outbreak response, humanitarian health promotors, working for the humanitarian organization Action Against Hunger (AAH), were interested in surveying peoples' perspectives of cholera and the cholera response to inform and improve their HP response. When we joined the team, however, the NGO agreed with our proposal to pilot an EBCD approach, given that it offered the potential to understand peoples' experiences with cholera, as well as with the HP services, and involved co-designing changes to improve the user experience. The detailed methods and findings of the pilot EBCD study are being published elsewhere (Ormel et al., Submitted May 2021). Given that there were several factors contributing to a novel application of EBCD in circumstances that were substantively different from the existing tradition of EBCD studies – i.e. public health domain vs. health services, humanitarian setting in a lower/middle income country, and involving HP workers and community members vs hospital staff and patients, and in a context with many different stakeholders from community, NGOs and foreign academics, and governmental services – we felt it was important to reflect on the implications for future work of this nature. In this context and f*or the purposes of this article, we are addressing the* following questions: what were the considerations and adaptations undertaken by the project team, as per the usual steps to implement an EBCD approach, for this setting and for HP-related practices and behaviour? What is the potential value and contribution of an EBCD approach in a humanitarian HP response?

7.4 Methods

This study followed the established EBCD, first piloted in the UK National Health Service in 2005, and now also published as online toolkit and training hosted at The Point of Care Foundation (The Point of Care Foundation (The King's Fund)). EBCD engages patients and health care staff to share their experiences and identify service improvements for a particular program of care, with the aim of improving patient and professional experience. At the core of this approach are narratives accounts of individual experiences. Key moments of the patient experiences are highlighted in a short edited film to stimulate reflection, discussion amongst patients and practitioners, and identification of potential improvements in care delivery. EBCD is usually implemented in a health care department (the service) that provides care to sick people (the users). In Haiti, however, our interest was in how community members (the ‘users’) who had or hadn’t had cholera experienced the HP activities (the service).

The intention of the study was to assess the applicability, appropriateness and feasibility of conducting an EBCD in a humanitarian response and in HP settings. We present the results, following the eight stages of EBCD in its original form as described in the EBCD online toolkit and a systematic review on the use and reporting of EBCD (T. Green et al., 2020; The Point of Care Foundation (The King's Fund)), see Table 7-1 below. The third column describes each stage as was implemented in Haiti. This study obtained ethics approval in 2017 from the ‘Comité National de Bioéthique en Haïti’ and the St. Mary’s Hospital Research Ethics Committee in Montreal, Canada. Data for this study was collected between October 2017 and July 2018.

Table 7- 1*: Overview of EBCD stages and associated activities based in comparison to the project stages as conducted in Haiti*

EBCD stages	EBCD stages	EBCD in Haiti
Stage 1: Site Observations	Observations in the health care service setting, average of 5-20 hrs	16 days of observations (KM and IO) of activities of HP team in the community,
Stage 2: Gathering service provider experiences	Predominant data collection through interviews, sometimes focus groups with nurses, doctors and allied health, some including managers, clerical staff, receptionist and other staff. With an range off 4-54 participants.	HP team invited 7 professionals for an interview, everyone accepted. Sample included two doctors (UAS and MSPP), a nurse (NGO), two cholera HP coordinators NGO, one assistant CTDA, interviews took place in their local office or AAH's office and one focus group with houngans and assistants (n=10) in the community
Gathering service-user experience	Predominant data collection through interviews, sometimes focus groups with patients, family caregivers, family members and or service user advocates. (participants n=6-38)	Focus group discussions conducted in the communities Dessalines and St. Michel, with people who had or had not had cholera**.** Conducted in Creole and audio or video recorded, dependent on the preference of the group.
Analysing experience data	Different analysis methods including framework analysis	Framework analysis (Gale, Heath, Cameron, Rashid, & Redwood, 2013) conducted by IO and KM, to identify 'touchpoints', key moments or events from the affected populations' experiences with the HP activities. Data was registered in Transana and Nvivo. Framework was discussed with PhD supervisors, PhD committee members and AAH staff members
Stage 3: Edit interviews into catalyst film	Watching all unedited film with someone else or alone and create a video of about 30 minutes	Analysis for video conducted by IO, KM and AS. A selection of video and audio clips was made by team and KM created a 21 minute catalyst film for **stage 3.**
Stage 4: Service provider feedback event	Facilitated meeting with service provider participants. (n=4-39)	Event with 10 HP members where the catalyst film was presented, combined with a 2 hour behaviour change training and a feedback form for the EBCD approach
Stage 5: Service-user feedback event	Facilitated meeting with patient participants (n=3-64)	Team discussed results of analysis and potential changes or improvements with former participants and others present in communities in 4 focus groups with about 10 participants each
Stage 6: Joint workshop	Facilitated meeting with patients and staff where catalyst film is shown followed with identification of priority areas for work. (2-15 service user participants and 2-16 service provider participants)	Following stage 5, a report was submitted to obtain further funding for the continuation of the research. Following this proposal, cholera prevalence rapidly decreased and no further funding was available for stage 6,7 and 8. All AAH's training documents were reviewed to assess potential improvements of these documents.
Stage 7: Small co-design teams	Working groups that implement proposed changes	NA
Stage 8: Celebration event	Celebration event	NA

Additional steps: Adaptations were made to fit the context and to emphasize participatory research (PR) defined as a “systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting change” (L. W. Green et al., 1995) and Integrated Knowledge Translation (IKT) (Graham et al., 2006). IKT is the movement of knowledge into action through the meaningful involvement of end-users in the knowledge creation process. As such, it shares a heritage with co-design. A jointly developed research agreement was signed in 2017 with AAH. The researcher invited several different stakeholders for meetings and workshops to collaboratively design the research design, data collection tools (e.g. interview guidelines) and implementation. This preparation phase included a workshop with the HP team (n=8) in October 2017 to discuss the research question. The AAH team, and specifically the HP staff members, went through great efforts to facilitate this research; they recruited participants, brought us along during their work activities and provided relevant and important feedback with regards to conducting this EBCD. The research assistant conducted an additional 7 interviews with people who had a toilet (Apr-Jun 2018), at the request of AAH, to better understand the motivation for people to build a toilet. The researchers also conducted an additional analysis to describe differences between men and women, and across villages and age groups, and to describe the perception of the taste of water, and air, dust and wind. In addition, a report was written summarizing the data for AAH and UNICEF. Finally, we included an online workshop, with health promotors from the field, to collaboratively analyse data for a paper describing the results (Ormel et al., under review - May 2021).

Iterative discussions with the NGO staff, local providers and the advisory group for IO’s thesis created opportunities to develop a deeper understanding of the similarities and differences of this pilot EBCD in HP settings as compared to the majority of EBCD projects implemented in health care service settings. In this paper, we applied an adapted version of the three elements of the Donabedian model, used originally to assess the quality of care, (Donabedian, 1988, 2002) as the three elements helped to assess the conduct of the pilot EBCD and structure the results of this paper: structure (environment where the study was conducted), process (research activities involved in implementing the EBCD) and outcomes (effects of the EBCD study). Even though this model was originally designed as a conceptual model for quality assessment in health care, it also provides a good structure for the results of this paper.

7.5 Analysis

In this section we discuss the considerations and adaptations to the EBCD following the three elements of the Donabedian model.

Structure: Implementing EBCD in different settings

In this EBCD our interest was in how community members (the 'users') who had or hadn't had cholera experienced the HP activities (the service). The focus on HP activities changed the nature of certain factors such as the context, space, staff, clients and co-design event (see table 7-2 for a detailed description).

***Table 7- 2**: Differences between the context of the majority of published EBCD studies (based on Green's review) and this pilot study*

	EBCD in health care services	**HP in humanitarian settings**
Services	Relative certainty of continuity of services and health care needs. Services offer a minimum of resources required to treat the client	Unpredictability of continuity of services, resources and development of cholera outbreak. Essential resources and living conditions could not be met by HP services
Space	Existing space usually in a building with less or no focus on other healing practices outside of the defined space	HP 'space' was defined as the mobile teams who provide their services
Staff	1 employer with a well-established health care team and management team (nurses, doctors, allied health and some including managers, clerical staff, receptionists and other staff	Approach a combined effort of Ministry of Health, Ministry of Sanitation, UNICEF and (i)NGOs. Local HP teams were composed of three staff members from NGOs and one staff member from the Ministry of Health. HP activities were coordinated by a field management team and supported by staff based in the capital and in New York.
Clients	Patients, caregivers, family and/or service user advocates	People living in affected or at risk areas
Context	Relatively stable context	The researchers joined the HP teams (n=30 people) to collect data in the field, researchers lived in the at risk area during this period, and were accompanied by an AAH car at all times in the field, in line with the security guidelines.

Process: Adaptations made to the data collection process

In general, communities were willing to host the focus groups in local places such as the church or school. Hosting the focus groups in the community helped optimize attendance and the ability to reach out to the most vulnerable people. Local public spaces were made available for the occasion such as a churches, schools or community treatment centres. Being in community places also meant that there was a certain level of fluidity with participants leaving and others asking if they could join after the focus groups were already underway. At times the focus groups were observed by other community members.

To collect demographic data, we either handed out forms at the end of the focus group or we sat with the participants and filled in the forms together. Going through these forms could take up to 60 minutes and therefore limited our time for data collection (focus groups were planned for two hours). Both these activities were more time consuming than originally planned. Participants showed an interest in the process of consent and data collection and some participants read the forms. Participants in one focus group, however, also commented on the use of paper and forms:

> *The majority of people who are based in Port-au-Prince can read. But when you get to this commune you will find that the majority of people cannot read. And when you get further down it will be worse. So can you give a sheet like this to this person. You are going to say to this person in this case here is this and that but when you give a sheet like this to someone it is disrespectful. The person will tell you that it is a gift. And the person will use it to wipe their butt, they don't understand what it is.*
> (Participant in focus group 6)

Acceptability of the use of video in focus groups

One main pre-occupation for the research team was whether video recording would be acceptable or not. Before the start of each focus group, we explained the reasons why we wanted to video record and provided people with the choice to be audio or video recorded. In most focus groups, the participants reached a shared agreement whether or not they would accept video recording (see table 7-3), except for two focus groups: in both groups one person was placed in such a way that they would not be included in the recording. The most frequently heard reason for not wanting to be video recorded related to participants feeling unsure how the material would be used – '*it can end up anywhere in Canada*'. All four focus groups from the commune Dessalines accepted to be video recorded, while three of the four group community members from St. Michel did not wish to be video recorded while this kind of differences was not noted between people who had or had not had cholera or between men and women. While this sample is too small to draw any conclusions, it might be possible that there are local differences of acceptance towards video recording. The HP team, for example, perceived differences between these two communities such as different levels of access to resources, resistance to change and levels of trust towards NGOs.

***Table 7- 3**: Focus groups video or audio recorded.*

Village, participants, (No.)	**Participants who had had cholera**	**Participants who had not had cholera**
St. Michel, women (10) / (7)	Audio	Audio
St Michel, men (8) / (8)	**Video**	Audio
Dessalines, women (11) / Bois Marie, village in the area of Dessalines, women (10)	**Video**	**Video**
Dessalines, men (6) / Coup-a-Linde, village in the area of Dessalines, men (9)	**Video**	**Video**

Those who were video recorded were also asked whether they accepted that the video would be published on the www.healthexperiences.ca website. We, nevertheless, only used the developed 'catalyst film' for local purposes as we did not feel confident that all participants had the level of agency needed to refuse the suggested video recording and/or were able to estimate the implications of having their video published on internet.

Finding the right questions to collect the required data

After the first focus group we decided to change our approach as we noticed that participants' responses reflected the messages they heard during HP activities (e.g. wash your hands, don't defecate in the field). Our interest though was to hear about participants' experiences with cholera and with the provided services. In subsequent focus groups we first asked people to share what they knew about cholera, thanked them for sharing this, and then explained that we wanted to put this information aside as we were interested to hear about their experiences, perspectives and knowledge.

Another example related to the topic 'cholera mystique' which is explained by the houngans, (male priest in Haitian Vodou):

> *There is 'natural' cholera and 'mystical' cholera. … When a zombie cholera is sent on the person, you will think that he has cholera and that is not true. This is where the houngans are strong; as soon as it is a case of zombie cholera, they quickly recognize it. In the case of zombie cholera, the houngan already knows that he should not send that person to a centre. That's why the brother told you that if you give an injection to this person, he will die (alternative health practitioners FGD)*

It appeared that participants were a bit reluctant to speak about this subject; only two participants referred to cholera mystique during the focus groups and in some occasions, during the observations, participants seemed to dismiss this subject if someone brought it up. Interestingly though, in one of the last group discussions we framed our question differently and we asked the participants the difference in symptoms between the two different illnesses and suddenly participants became really engaged and started explaining the differences without hesitation. With these examples we illustrate the importance of remaining flexible and reflective about how research is conducted, the implications of an approach and the required adaptations as well as to pay attention to the participants' engagement and reactions.

Process: Increasing inclusiveness and uptake with PR and IKT aspects

This research was a collaboration between a PhD student (IO) living in Canada, an RA (KM), from Port-au-Prince and with a past experience in qualitative research and hired for this project by AAH, NGO staff members based at AAHs head office in the USA and NGO staff members based in Haiti. The design of the study was mostly discussed through email and online meetings; the researcher visited the site twice for 7 weeks, each trip for data collection and workshops to search for feedback on the research from the HP team.

Participatory research

There was an overall support and enthusiasm for participatory approaches, key professionals who were interviewed spoke about the importance of designing and implementing interventions, such as the following quote:

> *We can accept that they do it for us because we don't know. But immediately, we have to do things together so that we can be left to do them alone. This is the true path of development. If we don't get to that point, we will be dependent forever. So when someone comes to help us, we must always look for the sustainability side of the action. It's not a half-done job [kole pyese]. You really have to go deep, even if you lose a little bit of time.* (Interview 2 with a doctor)

Participants also mentioned that that participatory processes are often initiated at the end of projects rather than at the beginning and emphasize the importance of improved participation with the community. Community participants suggested that increasing participation might contribute to improving the HP response. In addition, participants requested that the researchers communicate results back to them (see quote) but when we organized feedback sessions it was challenging to get all former participants to attend again.

> *I would say one thing, if there is a research that is done on cholera, I wish there would be advice, structures to be put in place to help the department or the country. I would like to see something coming out of this investigation because if there is an investigation on cholera, I expect something in return (Participant focus group nr 8).*

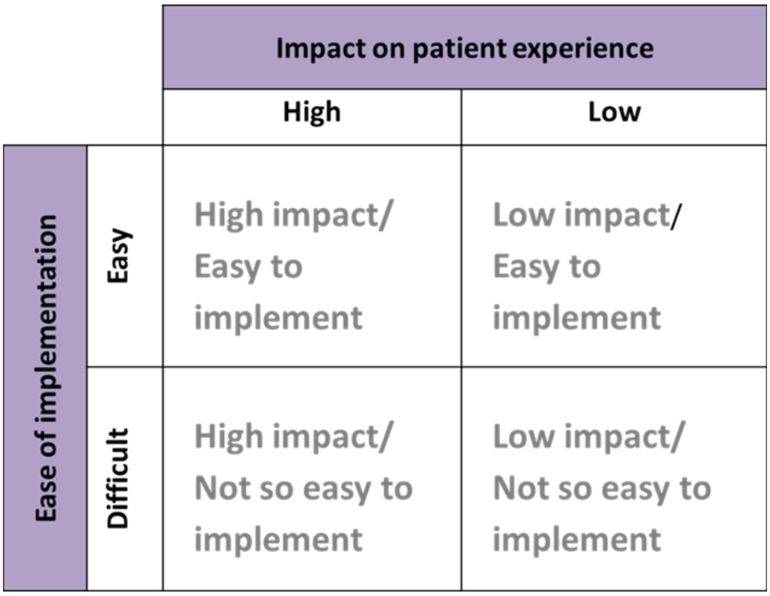
While we highlight some quotes here that relate to participation, further research is required to develop tailored approaches to ensure that results are communicated to communities. In addition, the level of participation, the timing and best approaches should also be further explored.

Stakeholder engagement

Humanitarian response usually involves a wide variety of different actors, which was also the case in the cholera outbreak response. Key stakeholders included NGOs, governmental agencies, UN and alternative health practitioners. As part of the IKT approach we aimed to include key stakeholders who would be able to contribute to operational change and therefore decided to limit these stakeholders to AAH's staff members. We did however invite professionals, working for other NGOs and governmental agencies, for interviews to gather a broad range of perspectives and experiences. We also shared the results with those professionals who expressed an interest to remain informed in the results of the study.

Outcomes: Co-design in complex settings

At the start of this research, AAH shared some anticipated challenges of organizing the co-design event with staff and community members due to the distance of the field sites. While the project was still well funded at the start of the research, at the stage of the feedback event AAH had to drastically scale down their team and activities due to reduced funding. As a response to this situation we did not organize a co-design session (phase 6/8) but sought feedback for suggestions for improvements in focus groups with the communities and in a workshop with AAH staff separately. During the focus group, which included former participants as well as new participants, we summarized our findings and asked participants to provide us feedback if this reflected their own experiences. In addition, we asked how they felt we could improve the HP services to the community. During the feedback event we showed the 21-minute catalyst film to the staff, followed by feedback session of what the staff felt could be improved. This discussion was organized in such a way that two groups were asked to fill in the opportunities/ideas matrix (see figure 7-1). We encouraged the staff to think on a ‘micro’ level – defined as the operational level where the organization itself had the capacity and power to make changes rather than on a meso or macro level, which relates to changes on a managerial, governmental or policy level. This event was combined with a behaviour change training, hosted by an AAH staff member.



		Impact on patient experience	
		High	**Low**
Ease of implementation	**Easy**	High impact/ Easy to implement	Low impact/ Easy to implement
	Difficult	High impact/ Not so easy to implement	Low impact/ Not so easy to implement

***Figure 7- 1**: Opportunities/ideas matrix*

Perceptions of reasons for limited behaviour change: why a training was included in the co-design event

During the conduct of this research it became clear that the HP staff as well as the participants from the communities were divided between two perspectives. The first is the idea that the HP response was good but that the populations was not willing or too negligent to change their behaviour

> *“We use terms that the population should understand but unfortunately they (the population) don’t want to (change their behaviour). It is true that there is an education problem but they don’t have the will…if they had done what we asked them to do then we can guarantee them that they can protect themselves.” (Interview 3 with a nurse working for a NGO)*

The contrasting perspective came from individuals who expressed that it was necessary to adapt the HP response to the context of the population and to improve collaboration in order to have better results.

> *"we want to impose our perception. We say 'these people are farmers; we will educate them'. This is often not true because normally, the message will not pass. You have to allow people to bear witness to their way of living, their problems, their aspirations and after that, try to see how we can involve people in our activity. Trying to understand the population and bring solutions." (Interview 4 with a HP coordinator working for an NGO)*

It has been long established that behaviour does not automatically change by providing people information alone (see for example Labonte (1986)) there are many different factors that influence behaviour change. The fact that staff members expressed that the dissemination of information alone was sufficient to evoke behaviour change led to the conclusion that the training guidelines as well as the current HP strategy were not up-to-date. The researcher reviewed the training guidelines and together with AAH staff we identified a need for a workshop to support personal reflection on the behaviour change process, needed to, for example, create empathy with users and audience and build active listening skills. This workshop was therefore perceived to support the co-design process.

The impact of the catalyst film on the HP staff members

The catalyst film contained a selection of clips highlighting issues around behaviour change, communication and how the HP activities were perceived. The catalyst film was played on a computer during the workshop with the HP staff, we observed that the film gripped peoples' attention; participants were engaged, laughed and responded to what was said in the film. We had anticipated that the film would evoke a discussion on the barriers and facilitators to behaviour change (e.g. the lack of resources, beliefs in contradiction with the messages etc.) but did not observe this reaction from the viewers. If we could have done this a second time, we could use a more guided approach where we would show the film in shorter fragments and take more time to discuss the viewers' observations and thoughts on how this related to their own work. It could however also be that HP staff is already more attuned with the users' perspective through their work and their own personal experiences to the risk of being infected with cholera. Another option in future projects could be to create a catalyst film that triggers reflections on other barriers such as the needs of specific vulnerable population groups or incoherencies between the lived reality and the HP messages.

How the complexity of the context influenced the outcome of the EBCD process

Participants in the focus groups overall appreciated the HP teams' dynamics, messages, and presence in the community indicated challenges to behaviour change were mostly related to their living conditions with a lack of access to clean water, lack of sanitation facilities and lack of access to basic products such as soap and water treatment products. Participants (community members as well as professionals) reflected whether the HP strategy was addressing the right mechanisms and issues. They brought up issues such as the fairness of the distribution of goods (such as soap, water treatment products and oral rehydration salt (ORS)), the value of the distribution of goods while basic services, associated with these products, were not in place (such as access to water, health care services and good sanitation, see quote), but at the same time the necessity to distribute products in order to enable the adaptation of the promoted behaviour.

> *The advice we would give them, I would tell them that even if you give us aqua Tabs, even if you give us the serum, but ''Nothing+Nothing=Nothing'' because it doesn't matter what you do ... I myself don't have a latrine, the neighbor doesn't have a latrine. Where do we relieve ourselves? One place. And when the feces come down, it goes down to everyone's house. Even if we do what we should do, you give us the serum it's good, when we have the disease we can drink some oral serum by the time we get to the hospital, even if the people who arrive give us everything, it can't stop the disease. (Participant in focus group 1)*

While the complexity of the context made it challenging to identify actionable changes, we did observe a process where staff and community members had the opportunity to reflect on the current challenges and how improvements could be made. Even in these difficult circumstances we saw value in facilitating this process through EBCD.

7.6 Discussion

We summarized some of the key challenges and considerations experienced during the implementation of a pilot EBCD in the HP response to the cholera outbreak in Haiti, structured with the three elements of the Donabedian model for thinking about quality in healthcare: structure, process and outcome. While we prepared for certain differences at the start of the EBCD project (e.g. implementing EBCD in humanitarian settings vs regular health care settings) others appeared while we were conducting the research as they were

‘naturally’ changed (we had to, for example, join the HP teams in their activities to be able to conduct the observations). It was during these kinds of adaptations that we gained more insight into the considerations and differences of conducting EBCD in these settings. We felt that the participatory approach was well received by community and staff members; participants were reflexive in our encounters and brought up important ideas for the conduct of the EBCD. This led, for example, to the decision to collect data from community members through focus groups, rather than individual interviews, as this was seen as culturally more appropriate. It also provided the opportunity to actively engage with alternative health practitioners (known locally as ‘houngans’) and led to additional activities, not planned for in the EBCD approach, such as the writing of a report for donors, a review of internal training procedures, a workshop on behaviour change and additional analysis.
Here we will elaborate on the question: What is the potential value and contribution of an EBCD approach in a humanitarian HP response? Table 7-4 summarizes key considerations and lessons learned.

***Table 7- 4**: Key considerations and lessons learned of this pilot EBCD in humanitarian settings*

Key considerations and lessons learned	
Rapid EBCD	Development and piloting of a rapid version of EBCD, which can be applied within a period of 2-3 months that can be implemented with limited resources.
Develop a theoretical model of how and why EBCD works	This paper highlights five factors (services, staff, clients, space and context) that were distinctly different compared to previous conducted EBCDs. In addition, it highlights factors such as existing relationships or trust that should be further explored. These factors may contribute to better understanding the mechanisms of change that produce outcomes in an EBCD. Better understanding how and why EBCD works can contribute to effective implementation of EBCD in different contexts.
Catalyst film	For HP response in humanitarian settings, other versions of the EBCD could be tested, perhaps even combine this with other approaches such as theatre or role play. Future research could explore how the contents and types of clip impact the EBCD process.
Stakeholder engagement	Future research can look at how the involvement of different key stakeholders can impact the outcomes of EBCD (e.g. from NGO’s or governmental agencies, national and international actors)
Vulnerable and marginalized populations	Explore best practices and approaches to engage populations affected by crises. Define key principles that should be respected when working in these kinds of settings.

Structure –barriers to the implementation of improvements: In Haiti, the proposed solutions were often related to long-standing, complex issues (e.g. efforts to ensure access to safe water and/or improve sanitation facilities) rather than solutions that could be implemented on a project level. One of the reported barriers in other EBCD studies in complex settings (such as long-term care) is that identified improvements cannot be implemented in the timeframe allotted, as they often require more time to resolve and implement (Ramos, Bowen, Wright, Ferreira, & Forcellini, 2020). Future EBCD in humanitarian settings could assess whether there is also a need to include key stakeholders that have the capacity to make changes on different levels. Such an approach was implemented in a study looking at the emergency department staff experience to improve service design (Gager, Keating, Mossop, & Wiltshire, 2020). Listening to and understanding their experiences resulted in process changes as well as a cultural change where staff feel valued. In addition, in a review of EBCD studies it was noted that those that engaged with a health care systems perspective tended to maintain a service-centred orientation, with managers focusing on quantitative indicators and achieving imposed goals rather than making changes in the directions proposed by patients and staff (Ramos et al., 2020). This might have been a barrier in the HP response as well where outcome measures were quantitative and focused on service delivery itself (such as the number of people reached, number of sessions provided, etc.) rather than on assessing local experiences with the service, or on outcomes related to the aims of HP (such as reduction in morbidity and mortality, changed behaviours, etc.).

In the results we describe that we did not publish the catalyst film as participants may not have had the agency to consent to this process. A review article published on the insights from an international collaboration on co-designing health and other public services with vulnerable and disadvantaged populations found that participants recommended following core principles such as taking time to engage, only move forward when participants are ready, finding ways to share power etc. These principles can be adopted when working with vulnerable populations (G. Mulvale et al., 2019). Even though participatory processes should be led by local stakeholders, they are often enabled by strong ‘outsider’ facilitation (Salsberg, Macridis, Garcia Bengoechea, Macaulay, & Moore, 2017) and setting principles to optimize the participation of vulnerable populations is one important aspect.

Demonstrating the benefits in response to experiential evidence related to service improvements as well as demonstrating the cost-effectiveness of EBCD remains a future research priority (Donetto, Tsianakas, & Robert, 2014; Ramos et al., 2020).

Process – reflecting on communities' experiences of health portrayed on video as a mechanism of change: In the results we described that it might have been better to use a more guided approach and play shorter fragments. There is a need for a better understanding of how the selected data for catalyst films influences the co-design process and whether film is required to create this process. There is an emerging body of literature on the different ways narratives can positively impact health (de Graaf, Sanders, & Hoeken, 2016; Shaffer, Focella, Hathaway, Scherer, & Zikmund-Fisher, 2018; Ziebland & Wyke, 2012) and health care (L Locock et al., 2020). A recent study on the value of narratives proposes that a specific type of narrative (e.g. a narrative describing a process, outcome or experience) may each have a different impact on the recipient. Catalyst films are typically a central feature of the EBCD approach to stimulate joint discussions between patients and staff (Raynor et al., 2020), but other means to communicate the users' experience have also been used such as a touchpoint lists and experience maps (T. Green et al., 2020). Future research could further explore the impact of different kind of clips.

During the conduct of the study certain staff members shared that they perceived the community as negligent as they did not adapt the public health guidance, whereas other staff members argued that the HP strategy should be adapted as people did not in fact change their behaviour in response to information. In a study that considered what motivates students to learn about local knowledge in Colombia, it was found that the focus on community voices provoked a positive attitude towards traditional medicine and co-designing helped the students address the disconnect between the sociocultural context they would work in and their medical training (Pimentel, Sarmiento, Zuluaga, & Andersson, 2020). In the context of Haiti, allowing space for local voices, perspectives and experiences through for example an EBCD may contribute to reducing the disconnect between the local context and the current HP strategy as well as contribute to more effective HP strategies.

Dual imperative – tensions in meeting expectations for both academic research and for practice

Research in humanitarian emergencies requires academically sound approaches but should at the same time be practically relevant (Bruno & Haar, 2020). The tension between these two factors is also described as the 'dual imperative' (Bruno & Haar, 2020). In Haiti, we also experienced challenges between the required time to collect and analyse the data involved in the EBCD processes and AAH's need to rapidly produce results so that they could inform their HP strategies with the findings from the research. Developing less intensive or 'rapid' versions of the EBCD approach may resolve this issue. Several studies have piloted the implementation of an accelerated EBCD approach in high income settings, whereby the process was accelerated through the use of existing video recorded data from a national database to develop a catalyst film (Louise Locock et al., 2014). A limitation of this accelerated approach is that it reduces the time spent with the collaborators and affected communities. Time, however, is an important aspect of engagement in PR, build trust and set-up meaningful collaborations with the research partners.

Another way of accelerating the approach is by using a catalyst film, developed for one local context, in other settings with similar services, as tested in the United Kingdom (Clarke et al., 2021). In addition, the EBCD can be applied in a more targeted and efficient manner through the development of a better understanding of the underlying mechanisms that influence how EBCD works. For example, quality improvement approaches such as EBCD, work because they enact strategies that are intended to trigger mechanisms that lead to changed outcomes. The link between mechanism-to-outcome is context specific and outcomes will therefore vary in different contexts, even if a similar approach is used. Better understanding the context-mechanism-outcome process would generate an underlying theoretical model of how EBCD works (Pawson, 2003). Future research, looking into these kinds of processes, can contribute to a better understanding how EBCD works.

Outcomes – the conclusions of shared experiences as an indicator of change mechanisms and future research:

We describe that we observed a process where staff and community members had the opportunity to reflect on the current challenges and how improvements could be made. Even in these difficult circumstances we saw value in facilitating this process through EBCD. In table 7-1 we describe some of the evident differences of an EBCD in settings such as in Haiti. Other underlying factors have not been described such as the role of existing relationships and trust amongst different stakeholders and clients. A realist evaluation of community-based participatory research describes the importance of developing and strengthening partnership synergy through trust (Jagosh et al., 2015). Community members tend to have only one or occasional encounters with HP staff as these teams cover entire populations at risk whereas in other EBCD studies clients have an existing relationship with the health care staff. On the other hand, an ethnographic study of front-line quality improvement in the UK found that quality improvement activities to improve the patient experience was greater in teams with a broad range of disciplines and levels of seniority. These teams were more confidently engaged and implemented a more ambitious set of projects (Montgomery, Parkin, Chisholm, & Locock, 2020). HP teams in disease outbreak settings may therefore profit from their wide variety of skills, knowledge and networks but at the same these teams are facing a high turnover of staff due to insecurity about the continuation of their work in these settings. We have not fully explored the impact of relationships and future research could explore this.

7.7 Conclusions

The implementation of the EBCD process in a different setting contributed to a better understanding of how factors such as services, space, staff, clients and context influence the EBCD. There are however also other factors such as the level of relationships and trust that could be further explored. The EBCD produced insight in how the development of a rapid EBCD may be a better fit in humanitarian settings and that it is possible to discuss the option of using video recording during the data collection. While there are still many limitations and challenges with the adoption of an EBCD approach in these settings, we argue that it is exactly the processes embedded in this approach to gather and integrate local experience, in collaboration with a multidisciplinary team, that make it valuable.

7.8 References

Afifi, R. A., Abdulrahim, S., Betancourt, T., Btedinni, D., Berent, J., Dellos, L., . . . Saravanan, M. (2020). Implementing Community-Based Participatory Research with Communities Affected by Humanitarian Crises: The Potential to Recalibrate Equity and Power in Vulnerable Contexts. *American Journal of Community Psychology, 66*(3-4), 381-391. Retrieved from https://onlinelibrary.wiley.com/doi/10.1002/ajcp.12453

Anderson, M. B., Brown, D., & Jean, I. (2012). *Time to listen: hearing people on the receiving end of international aid*. Cambridge, UK: CDA Collaborative Learning Projects Cambridge, MA.

Brown, D., & Donini, A. (2014). *Rhetoric or reality? Putting affected people at the centre of humanitarian action*. Retrieved from

Bruno, W., & Haar, R. J. (2020). A systematic literature review of the ethics of conducting research in the humanitarian setting. *Conflict and health, 14*(1), 27. doi:10.1186/s13031-020-00282-0

Centers for Disease Control and Prevention (CDC). (2019). Global Health - Haiti. Retrieved from https://www.cdc.gov/globalhealth/countries/haiti/default.htm

Clarke, D., Gombert-Waldron, K., Honey, S., Cloud, G., Harris, R., Macdonald, A., . . . Jones, F. (2021). Co-designing organisational improvements and interventions to increase inpatient activity in four stroke units in England: a mixed-methods process evaluation using normalisation process theory. *BMJ Open, 11*(1), e042723. doi:10.1136/bmjopen-2020-042723

Contzen, N., & Mosler, H.-J. (2013). Impact of different promotional channels on handwashing behaviour in an emergency context: Haiti post-earthquake public health promotions and cholera response. *Journal of Public Health, 21*(6), 559-573.

de Graaf, A., Sanders, J., & Hoeken, H. (2016). Characteristics of narrative interventions and health effects: A review of the content, form, and context of narratives in health-related narrative persuasion research. *Review of Communication Research, 4*, 88-131.

Donabedian, A. (1988). The quality of care: how can it be assessed? *Jama, 260*(12), 1743-1748.

Donabedian, A. (2002). *An introduction to quality assurance in health care*: Oxford University Press.

Donetto, S., Tsianakas, V., & Robert, G. (2014). Using Experience-based Co-design (EBCD) to improve the quality of healthcare: mapping where we are now and establishing future directions. *London: King's College London*.

Eyben, R. (2008). *Power, mutual accountability and responsibility in the practice of international aid: A relational approach*. Retrieved from Brighton, UK: https://www.ids.ac.uk/publications/power-mutual-accountability-and-responsibility-in-the-practice-of-international-aid-a-relational-approach/

Gager, M., Keating, L., Mossop, D., & Wiltshire, M. (2020). Quality Time: Using experience-based co-design to capture emergency department staff experience. *The Journal of Health Design, 5*(1).

Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC medical research methodology, 13*(1), 117.

Graham, I. D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in knowledge translation: time for a map? *Journal of continuing education in the health professions, 26*(1), 13-24. Retrieved from http://ssr-eus-go-csi.cloudapp.net/v1/assets?wkmrid=JOURNAL%2Fjcehp%2Fbeta%2F00005141-200626010-00003%2Froot%2Fv%2F2017-05-31T223607Z%2Fr%2Fapplication-pdf

Green, L. W., George, M. A., Daniel, M., Frankish, C. J., Herbert, C. J., Bowie, W. R., & O'Neill, M. (1995). Study of participatory research in health promotion. *Review and recommendations for development of participatory research in health promotion in Canada. Ottowa, Ontario: The Royal Society of Canada*.

Green, T., Bonner, A., Teleni, L., Bradford, N., Purtell, L., Douglas, C., . . . Chan, R. J. (2020). Use and reporting of experience-based codesign studies in the healthcare setting: a systematic review. *BMJ quality & safety, 29*(1), 64-76.

Jagosh, J., Bush, P. L., Salsberg, J., Macaulay, A. C., Greenhalgh, T., Wong, G., . . . Pluye, P. (2015). A realist evaluation of community-based participatory research: partnership synergy, trust building and related ripple effects. *BMC Public Health, 15*(1), 1-11.

Kickbusch, I., & Reddy, K. S. (2015). Community matters – why outbreak responses need to integrate health promotion. *Global Health Promotion, 23*(1), 75-78. doi:10.1177/1757975915606833

Labonte, R. (1986). Social inequality and healthy public policy. *Health Promotion International, 1*(3), 341-351.

Larkin, M., Boden, Z. V., & Newton, E. (2015). On the brink of genuinely collaborative care experience-based co-design in mental health. *Qualitative Health Research,* 1049732315576494.

Laverack, G., & Manoncourt, E. (2016). Key experiences of community engagement and social mobilization in the Ebola response. *Global Health Promotion, 23*(1), 79-82. doi:10.1177/1757975915606674

Locock, L., Graham, C., King, J., Parkin, S., Montgomery, C., Gibbons, E., . . . Gager, M. (2020). Understanding how front-line staff use patient experience data for service improvement: an exploratory case study evaluation. *Health Services and Delivery Research, 8*(13).

Locock, L., Robert, G., Boaz, A., Vougioukalou, S., Shuldham, C., Fielden, J., . . . Pearcey, J. (2014). Testing accelerated experience-based co-design: a qualitative study of using a national archive of patient experience narrative interviews to promote rapid patient-centred service improvement.

Marais, F., Minkler, M., Gibson, N., Mwau, B., Mehtar, S., Ogunsola, F., . . . Corburn, J. (2015). A community-engaged infection prevention and control approach to Ebola. *Health Promotion International, 31*(2), 440-449. doi:10.1093/heapro/dav003

Masumbuko Claude, K., & Hawkes, M. T. (2020). Ebola crisis in Eastern Democratic Republic of Congo: student-led community engagement. *Pathogens and Global Health, 114*(4), 218-223. doi:10.1080/20477724.2020.1754654

Miller, J., & Birnbaum, M. L. (2018). Characterization of interventional studies of the cholera epidemic in Haiti. *Prehospital and disaster medicine, 33*(2), 176-181.

Montgomery, C., Parkin, S., Chisholm, A., & Locock, L. (2020). 'Team capital'in quality improvement teams: findings from an ethnographic study of front-line quality improvement in the NHS. *BMJ Open Quality, 9*(2), e000948. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7259840/pdf/bmjoq-2020-000948.pdf

Mulvale, A., Miatello, A., Hackett, C., & Mulvale, G. (2016). Applying experience-based co-design with vulnerable populations: Lessons from a systematic review of methods to involve patients, families and service providers in child and youth mental health service improvement. *Patient Experience Journal, 3*(1), 117-129.

Mulvale, G., Moll, S., Miatello, A., Robert, G., Larkin, M., Palmer, V. J., . . . Girling, M. (2019). Codesigning health and other public services with vulnerable and disadvantaged populations: Insights from an international collaboration. *Health Expectations, 22*(3), 284-297. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6543156/pdf/HEX-22-284.pdf

Nouvet, E., Abu-Sada, C., de Laat, S., Wang, C., & Schwartz, L. (2016). Opportunities, limits and challenges of perceptions studies for humanitarian contexts. *Canadian Journal of Development Studies/Revue canadienne d'études du développement, 37*(3), 358-377.

Ormel, I., Salsberg, J., Hunt, M., Doucet, A., Hinton, L., Macaulay, A. C., & Law, S. (2020). Key issues for participatory research in the design and implementation of humanitarian assistance: a scoping review. *Global Health Action, 13*(1), 1826730. doi:10.1080/16549716.2020.1826730

Pawson, R. (2003). Nothing as practical as a good theory. *Evaluation, 9*(4), 471-490.

Payton, C. A. (2017). In Moral Debt to Haiti: In the world's first independent Black Republic, cholera victims and their international allies continue to fight the UN for their basic right to clean water and monetary reparation. *NACLA Report on the Americas, 49*(1), 64-70.

Pimentel, J., Sarmiento, I., Zuluaga, G., & Andersson, N. (2020). What motivates medical students to learn about traditional medicine? A qualitative study of cultural safety in Colombia. *Int J Med Educ, 11,* 120-126. Retrieved from https://www.ijme.net/archive/11/cultural-safety-training-in-colombia.pdf

Ramos, M., Bowen, S., Wright, P. C., Ferreira, M. G. G., & Forcellini, F. A. (2020). Experience based co-design in healthcare services: an analysis of projects barriers and enablers. *Design for Health*, 1-20.

Raynor, D. K., Ismail, H., Blenkinsopp, A., Fylan, B., Armitage, G., & Silcock, J. (2020). Experience-based co-design—Adapting the method for a researcher-initiated study in a multi-site setting. *Health Expectations*.

Salsberg, J., Macridis, S., Garcia Bengoechea, E., Macaulay, A. C., & Moore, S. (2017). Engagement strategies that foster community self-determination in participatory research: Insider ownership through outsider championship. *Family practice, 34*(3), 336-340. Retrieved from https://watermark.silverchair.com/cmx001.pdf

Shaffer, V. A., Focella, E. S., Hathaway, A., Scherer, L. D., & Zikmund-Fisher, B. J. (2018). On the Usefulness of Narratives: An Interdisciplinary Review and Theoretical Model. *Annals of Behavioral Medicine, 52*(5), 429-442. doi:10.1093/abm/kax008

The Point of Care Foundation (The King's Fund). Experience-based co-design toolkit.

World Health Organization. (2017). Cholera. Retrieved from http://www.who.int/mediacentre/factsheets/fs107/en/

Ziebland, S., & Wyke, S. (2012). Health and illness in a connected world: how might sharing experiences on the internet affect people's health? *Milbank Quarterly, 90*(2), 219-249. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3460203/pdf/milq0090-0219.pdf

8 GENERAL DISCUSSION

The overall question I posed for this thesis was ‘if and how’ participatory research, featuring engagement with patients, community members and AAH staff as partners, while also integrating individual and community perceptions of illness, might contribute to improving the humanitarian hygiene promotion (HP) response. In this section I discuss three main contributions of this research in light of the pre-existing knowledge in this field, and implications for future research and practice. First, I discuss how this research contributed to our understanding of the current **PR practices in humanitarian health settings**, through the findings of the scoping review of PR in humanitarian settings (Manuscript 1) and the investigation of HP research conducted in the cholera outbreak in Haiti (Manuscript 2). Second, I examine how a **better understanding of affected populations’ experiences can contribute to an improved HP response.** Here, I draw upon the results of the scoping review (Manuscript 1) as well as the implications of the pattern in Haiti where populations’ experiences were not assessed over time, as determined in the review of research investigating the HP response in Haiti (Manuscript 2). The potential to improve the effectiveness of an HP response through improved understanding of the populations perspective is the focus for Manuscript 3. Third, I report on **the feasibility of EBCD as a quality improvement approach of the HP response in the cholera outbreak in Haiti.** This is summarized in Manuscript 4. This chapter concludes with a statement of limitations, suggestions for future research and a summary of the contributions of this research. Together, the results of this research contribute to the continuous efforts and intentions of humanitarian organizations to respond in a humane and effective way to the affected populations’ needs.

8.1 CONTRIBUTION #1 – Understanding of the current participatory research practices in humanitarian health settings

In this section I discuss how this thesis research contributed to our understanding of the current PR practices in humanitarian health settings. The scoping review, conducted for this thesis, found that PR is rarely applied in humanitarian settings, based on the identification of only eight studies and 11 published manuscripts over a period of 10 years (2009 up to 2019) in this review. Despite the paucity of evidence, however, this review highlights that it is feasible to conduct PR in these settings and that this approach can make important contributions to humanitarian assistance (Ormel et al., 2020). Research for this thesis also found that none of the research studies, investigating the HP response in Haiti, had applied a PR approach (Ormel et al., Submitted May 2021). In this section I further examine the meaning of these findings within two sub-sections entitled: *As local as possible, as international as necessary*, and *The dual imperative of academic research in humanitarian settings.*

8.1.1 As local as possible, as international as necessary

During the World Humanitarian Summit (UN, 2016) the Secretary-General stated that humanitarian action should be 'as local as possible, as international as necessary' (UN General Assembly, 2016). Local, national and international NGOs have come together under the Charter for Change, committing to principles that support more local humanitarian action, usually referred to as localisation or local humanitarian action (Barbelet, 2018). Research on local humanitarian capacity in the Democratic Republic of Congo shows that humanitarian action remains 'as international as possible and where local capacity is only considered when international limits are reached' (Barbelet et al., 2019). Further, a recent systematic literature review of the ethics of conducting research in humanitarian settings found that the majority of the included manuscripts were from high-income and Western countries, concluding that local involvement of researchers remains limited (Bruno & Haar, 2020). This may be, in part, due to a shortage of local capacity in research (Bruno & Haar, 2020). These results are in line with the findings from work conducted for this thesis; in the scoping review and the review of research investigating the HP response in Haiti, where the majority of the selected manuscripts were authored by researchers from Western institutions (Ormel et al., Submitted May 2021; Ormel et al., 2020).

The Core Humanitarian Standard in Quality and Accountability found that despite efforts to improve communication and participation in humanitarian action, this commitment remains further from achievement than many others such as ensuring that humanitarian assistance is appropriate, relevant, effective and timely. This report further points out that the focus of the current COVID-19 pandemic has to remain local when looking at the impact of control measures (CHS Alliance, 2020). It emphasizes the importance of understanding how communities perceive both the disease and respond to it, this way NGOs can act accordingly. But if the sector remains static then it will fail to remain trusted and relevant by the people who need help most (CHS Alliance, 2020). It is argued that decentralisation efforts of NGOs missed collectivism, discussion, and negotiation with communities at the grassroots level, arguing that there is a dire need to focus on the marginalized and excluded (Hsu & Schuller, 2020). In addition, ccommunity engagement, knowledge and respect for cultures and beliefs are seen as essential to reduce resistance and violent outbreaks (Cohn & Kutalek, 2016). Recent disease outbreaks have led to resistance and violent outbreaks such as in West Africa (2014-2016) (Cohn & Kutalek, 2016), in the Democratic Republic of Congo (2018-2020) (Masumbuko Claude, Underschultz, & Hawkes, 2019) as well as in the cholera outbreak in Haiti (Grimaud & Legagneur, 2011). And most recently, reactions to the COVID-19 outbreak led to for example to the destruction of telecommunication masts in Europe, North America, and Australasia caused by the spread of misinformation (Jolley & Paterson, 2020). Resistance and violence can lead to a reduced ability to offer essential services such as health care or telecommunication services. In addition, mistrust, fear and rumors can lead to people disregarding public health guidance such as hiding family members with Ebola symptoms (Marais et al., 2015). In Manuscript 3 I look at the role of trust in the HP response, here I find that mistrust helped explain why people did not change their behaviour or visit a treatment centre when experiencing cholera symptom, yet mistrust was rarely a focus of research investigating the HP response (Ormel et al., Submitted May 2021). Addressing and measuring factors related to trust and resistance, often requiring participatory oriented strategies, were less frequently applied in HP strategies in Haiti. Recent major disease outbreaks are now rapidly followed with calls for the importance of the application of approaches and methods that can contribute to inclusion and collaboration in the humanitarian response. For example, the recent COVID-19 outbreak was quickly followed with calls for the application of participatory approaches (Dahab et al., 2020) or social and behavioural science (Van Bavel et al., 2020). Shortly after the Ebola outbreak in West-Africa an eight step model was published that can contribute to community-engaged infection prevention and control approaches to Ebola (Marais et al., 2015). Yet, there are not yet many academic manuscripts published on the conduct of PR studies in the humanitarian settings (Ormel et al., 2020). With the current lack of evidence it is important to identify the factors that support more complementary ways of working (Barbelet, 2018). PR is one of the approaches that can contribute to a more diverse authorship and to strengthening local institution as it involves the creation of equitable partnerships between those affected by the issue under study and researchers (Andersson, 2018) and aims to produce knowledge through a mutual learning process to benefit the community (Macaulay et al., 1999). This approach can contribute to collaborating with local researchers and ensuring relevance of the research question (Bruno & Haar, 2020).

8.1.2 The dual imperative of academic research in humanitarian settings

Research in humanitarian emergencies requires academically sound approaches but should at the same time be practically relevant (Bruno & Haar, 2020). The tension between these two factors is also described as the 'dual imperative' (Bruno & Haar, 2020). It is argued that research is justifiable when it is needs-driven, relevant for affected populations and not at the expense of humanitarian action (Pringle & Cole, 2009). In addition, rich research data is of little value when it does not contribute to learning and change (Brown & Donini, 2014; CHS Alliance, 2020; Nouvet et al., 2016). Partnerships across the humanitarian-academic divide reveal the different cultures, time frames and missions (Kohrt et al., 2019). A review on NGO-researcher partnerships in global health research suggests that 'collaborations characterised by trust, transparency, respect, solidarity, and mutuality contribute to the development of successful and sustainable' NGO–researcher partnerships (Olivier et al., 2016). The most frequently cited principles, identified in a review of 'good' global health research partnerships, were mutual benefits between partners and equity (Monette et al., 2021).

PR approaches assume an interesting place within humanitarian settings as they have the potential to contribute to many of the above cited principles. Yet, research in humanitarian settings often involves unstable and unpredictable environments (Kohrt et al., 2019) as well as rapidly changing needs and response. Conducting research in these settings requires a certain flexibility and ability to adapt methodologies. In addition, research questions should not be answered in these settings if they can be answered elsewhere (Kohrt et al., 2019) due to the constraints in these settings. Existing PR approaches may not be in line with the humanitarian pace which usually requires rapid outcomes. I facilitated a training while working for Doctors Without Borders as a HP manager in the Ebola response in the Democratic Republic of Congo (2020). This training, entitled 'the stories of change approach', includes the collection of narratives of the affected population and can be carried out within one-week (Jong, date not indicated). With regards to the conduct of EBCD in humanitarian settings a solution may be to develop a rapid or ‘light’ EBCD version. Several studies have already piloted the implementation of an accelerated EBCD approach, whereby existing video recorded data from a national database was used to develop a catalyst film that can be used in local settings (Locock et al., 2014a). Another study tested whether a catalyst film, developed for one local context, could be used in other settings with similar services (Clarke et al., 2021). Both adaptations aimed to reduce the required time and costs associated with this approach (Clarke et al., 2021; Locock et al., 2014a). There are also existing studies that tested PR approaches adapted to humanitarian settings such as the application of Participatory Ethnographic Evaluation and Research (PEER), using local data collectors, reducing the time required to develop trusting relationships with the community (Elmusharaf et al., 2017). Using local data collectors also contributes to overcoming issues related to the time it takes to properly engage in PR, especially with the support of individuals external to the context. Another interesting initiative is WHO’s recently launched online social listening platform supported with artificial intelligence to provide real time information about how people talk about COVID-19 online, available on their website (World Health Organization, 2020). Also, on an operational level, it might be possible to collect data rapidly by including a data collection team within the HP response; this team could operate in collaboration with the existing primary and secondary teams in United Nations International Children’s Emergency Fund’s (UNICEF’s) case-area targeted rapid response (Rebaudet et al., 2019). These initiatives show that existing PR and data collection approaches can be adapted so that they respond to the population’s need and produce relevant data that contributes to an improved humanitarian response.

8.1.3 Final comment

The scoping review found that PR approaches are rarely applied in humanitarian settings and that certain approaches continue to be heavily weighted to international interests and goals (Barbelet, 2018). Researchers can make important contributions by developing methods and approaches that optimize the rapid collection of data and production of knowledge appropriate for humanitarian settings and through efficient knowledge translation mechanisms. In addition, it is important to allow for mutual adaptive learning processes and to thus allow for flexibility and change in the research plan (Tembo et al., 2021).

8.2 CONTRIBUTION #2: How a better understanding of affected populations' experiences can contribute to an improved hygiene promotion response

In this section I examine how a better understanding of affected populations' experiences can contribute to an improved HP response**.** Research reporting on the results of an EBCD approach discuss different aspects relating to the collected data on peoples' experiences. Studies can, for example, report on the **lived individual experiences** with a certain illness and/or service (Coy, Brock, Pomeroy, Cadogan, & Beckett, 2019) but also on the data selection process and functioning of the catalyst film **as a mechanism for change** (Papoulias, 2018) as well as on tangible changes in services and impact on experiences, where experience functions as an **outcome** measure (Goodrich, 2018). Similarly, the manuscripts in this thesis report on the **lived experiences** of the community in relation to the HP messages and activities, but also reflect on **the impact of the catalyst film** on the HP staff as well as on the implications of the HP design when there is a focus on the collection of **biomedical oriented outcomes** only. In this section I reflect on how improved understanding of the affected communities' experiences can contribute to the design of effective strategies for containment and prevention looking at these three different aspects: individual lived experiences, narratives as a mechanism for change and experience as an outcome measure.

8.2.1 Individual lived experiences

In this section I reflect on the implications of the different types of individual experiences that are collected in an EBCD but start with describing why individual experiences can contribute to improved care. 'Narratives and stories, oral or written, are far and away the most powerful and natural way of accessing human experiences, and it is, therefore no surprise to find them in rapidly growing professional use in contemporary medicine and medical research'(Locock et al., 2014b). It is argued that patient experience is positively associated with clinical effectiveness and safety and should therefore be included as one of the pillars of quality of healthcare (Doyle, Lennox, & Bell, 2013). Peoples' illness experiences cover a wide variety of topics such as their experience with the illness, health care service, received treatment and interactions with health care professionals (The Point of Care Foundation (The King's Fund)). The aim of the data collection in EBCD is to help patients, carers and staff identify and explore ‘touch points’ in their care or treatment journey with the aim to ‘design’ better experiences around these touch points (Bate & Robert, 2007). EBCD projects report on, for example, improving the provision of consistent information (Brady, Goodrich, & Roe, 2020), ensuring that early reassurance is provided during admittance(Coy et al., 2019) and explaining the importance of the model of therapy to patients (Cooper, Gillmore, & Hogg, 2016). One of the distinct differences with the EBCD in this thesis research is the focus on HP services rather than on health care services for patients. The provided HP services focused on informing people and motivating them to adapt certain behaviours rather than providing a treatment. Participants in this study therefore included people who had cholera and who had not had cholera. Data in this study included ‘touch points’ that influenced behaviour change. Looking at the collected data I wondered which kind of ‘touch points’ could have contributed to ‘design’ better services. Being confronted with complex issues (lack of water and sanitation services) I wondered whether it was possible that improving patients’ experiences is more of a ‘luxury’ problem for settings where health care services are well established.

I do, however, think that understanding and optimizing experiences remains valid in urgent and complex situation as individual experiences in this study related to the participants’ efforts and ability to protect themselves and others as well as to their experiences with the illness itself, their health care decision making and treatments that they received. In the symptom and decision phase, participants described a process of decision making that involves reaching out to others, listening to other peoples’ experiences as well as referring back to personal past illness experiences. Participants expressed, in their own words, that they felt mistrust and disbelief towards the contents of the messages, they described behaviours that were in contradiction with the HP guidance and described how they were unable to follow the HP guidance due to limited access to basic resources including clean water and latrines. These latter findings are described in manuscript 3 (Ormel et al., under review - May 2021). While there were many other complex issues that limited the effectiveness of the HP response, the EBCD approach brought attention to the importance of understanding people’s experiences from their perspective as well as finding ways to integrate this into the design of effective HP strategies. This leads to the next section which discusses the potential as narratives as a mechanism of change.

8.2.2 Narratives as a mechanism for change

EBCD is based on the premise that listening to patients' experiences of the services will be a powerful approach to motivate staff to rethink how care (Locock et al., 2014b) or, in this case HP, is provided. Patient narratives describe recalled experiences that are not objective, based on facts or verifiable but because they are subjective and human they help us access the human experience and enable us to perceive things through the eyes of others (Locock et al., 2014a). Narratives can provide new perspectives to health care providers and open new reflections of how care can be improved (Greenhalgh, Russell, & Swinglehurst, 2005; Piper et al., 2012). At the centre of the EBCD is the catalyst film (Raynor et al., 2020), there is, however, limited understanding of how these narratives in video format function as a mechanism for change. The impact of the use of narratives has been mostly examined at the individual level, for example, how narrative information as a mechanisms of change impacts decision making (Shaffer & Zikmund-Fisher, 2013; Winterbottom, Bekker, Conner, & Mooney, 2008), how it impacts health behaviour change (Shaffer, Focella, Hathaway, Scherer, & Zikmund-Fisher, 2018) or how sharing experiences on the internet affect people's health (Ziebland & Wyke, 2012). Within the domain of behaviour change it is argued that there remain major gaps in our theoretical understanding of how narratives work and how they influence behaviour (Shaffer et al., 2018). Research found that certain characteristics in narratives, such as a high emotional content, showing the healthy behaviour and narratives in the first person perspectives are associated with impact on behaviour change (de Graaf, Sanders, & Hoeken, 2016). In addition, research points out that narratives are not 'homogeneous in either content or effect and hence should not be considered as a single construct in research' (Shaffer & Zikmund-Fisher, 2013). Shaffer classifies narratives in process, outcome and experience narrative which each have their own purpose in dimensions such as to inform, engage, model behaviour, persuade or provide comfort (Shaffer & Zikmund-Fisher, 2013). It is not yet known to what extend the choice of the content and type of clip influences the co-design process. In addition, adaptions to the EBCD have been reported which also may influence the mechanisms of change such as the inclusion of participants in the analysis of the narratives (Locock et al., 2019) or the use of other formats than the catalyst film (e.g. a touchpoint lists an experience map of user experiences, interview quotes and lists of improvement areas) (T. Green et al., 2020). The catalyst film and workshop in this study touched upon themes related to mechanisms of behaviour change and perceptions of AAH's work. Despite the focus of the catalyst film on behaviour change, the participants came forward with solutions relating to structural issues such as the lack of water and sanitation resources. A manuscript discussing the barriers and enablers of EBCD found that contexts that require more complex changes, for example in long-term care settings, brought into an EBCD project may require changes that take too long or cannot be implemented, in addition, they require more investigation (Ramos et al., 2020). In manuscript 4 (Ormel et al., To be submitted in July 2021) I suggest that in the context of this research it might have been better to demonstrate single clips during the adapted 'co-design' session followed with a discussion of the implications of these clips; the clips were demonstrating complex mechanisms of behaviour change and therefore would have required some additional discussion and perhaps more training for the staff on behaviour change mechanisms and techniques. During the implementation of this project AAH also asked me to review their internal training procedures as it was noted that health promotors, trained in this environment, learned about the value and importance of knowledge dissemination based on biomedical and scientific knowledge with less attention to existing behaviour change approaches and the importance of local knowledge and experiences. While the feedback was appreciated, no further changes were made due to the ending of the cholera outbreak response. Variations of the catalyst film length and context could be tested to optimize the impact of the quality improvement process.

8.2.3 Experiences as an outcome measure

The two preceding sections looked at the required data collected during an EBCD and how this data can contribute to mechanisms of change. The aim of EBCD is to improve the patient experience and to measure the impact of the changes implemented in the EBCD process, the patient experience functions as an outcome measure. A recent systematic review on quality improvement approaches in hospital settings and patient experiences found that studies either focused on improving the interaction of staff with patients or on improving processes such as waiting time or noise disturbance (Bastemeijer et al., 2019). It was also noted that studies that 'in advance targeted the improvement of one outcome measure such as improving waiting experience or overall patient experience were most successful (Bastemeijer et al., 2019). Looking at how frontline staff use patient experience data for service improvement it was found that staff with the least power in the organization may have rich tacit and embodied intelligence but are more likely to be able to mobilize this knowledge if they have a wider team capital behind them (Locock, Montgomery, et al., 2020). This highlights the importance of a shift from top-down measurement to an approach which involves the inclusion of frontline wisdom (Locock, Montgomery, et al., 2020).

Research of this thesis found that research investigating the HP response in Haiti rarely included measuring the affected communities' experiences (Ormel et al., Submitted May 2021). One research study, nevertheless, stood out in this review as the survey included attitudes such as liking, convincingness, and trustworthiness of the experienced HP activities (Contzen & Mosler, 2013). This study shows that certain HP activities such as focus groups, stickers, posters, and paintings were less liked, perceived as less convincing and less trustworthy than other promotional activities. These less favourable activities were also associated with decreased faeces- and food-related handwashing. This study demonstrated that HP should not follow standard approaches relying solely on the personal experience of relief workers; some activities may even have behaviour-impairing effects (Contzen & Mosler, 2013). Measuring experiential outcomes can help maximise HP effectiveness and eliminate unwanted effects (Contzen & Mosler, 2013). Other factors such as how people think of the contents of the messages, of the behaviour of the team and how they perceive the NGOs delivering the messages could also be interesting to integrate in data collection efforts.

8.2.4 Final comments

This section looked at how experiential data can contribute to deepen the understanding of the individual experiences but also as a mechanism of change and as an outcome measure. Patient experiences, or in this case the experiences of affected communities, are a part of the evidence base (Ziebland & Herxheimer, 2008) and not including this kind of data risks limiting the effectiveness of the humanitarian response. Or in other words: 'Clinicians should resist side-lining patient experience as too subjective or mood-oriented, divorced from the 'real' clinical work of measuring safety and effectiveness' (Doyle, 2013). This is also true for researchers and professionals working in HP.

8.3 CONTRIBUTION #3: The feasibility of EBCD as a quality improvement approach of the hygiene promotion response in the cholera outbreak in Haiti.

Use of PR approaches are increasingly recognized as crucial to respectful, contextually appropriate, locally acceptable, and effective humanitarian health programmes. While valued, PR approaches continue to be seen as difficult to implement and optional in rapid response scenarios. This section is represented in manuscript 4, while limitations are described in section 8.4.

In summary, in this manuscript, I describe the following methodological contributions:

- Insights and lessons learned from implementing EBCD in a novel context (humanitarian and hygiene promotion settings)
- Development of a better understanding of how and why EBCD works, for example, by describing the importance of five different factors (services, space, staff, clients and context) that influence the conduct of an EBCD.
- Description of the adaptations made in the data collection process, such as the conduct of focus groups rather than interviews, the testing of the acceptability to video record focus groups and the importance of asking the questions in the right way.

8.4 Strengths and limitations of this thesis

This thesis research piloted EBCD for the first time in a humanitarian and HP setting and at this point it is not possible to know whether this approach, if applied in comparable settings, would obtain a similar result. Nevertheless, this approach has brought quality improvements in a diverse range of health care settings and in different high-income countries such as the UK, Canada and Australia. This approach has also been tested in family planning settings in Nigeria (Oguntunde, Nyenwa, Kilani-Ahmadu, Salihu, & Yusuf, 2019) as well as in hospital services for malnourished children in South Africa (Deventer van, Robert, & Wright, 2016). Based on the research conducted in this thesis and other EBCD studies it can be expected that EBCD would offer promise as a potentially useful approach to support a process of change in other humanitarian or HP settings. It may, however, require some adaptations such as the development of a rapid EBCD approach or local adaptations such as we did in Haiti where we conducted, for example, focus groups with the affected communities rather then individual interviews.

This research was conducted with limited funding provided by minimal support from AAH, my PhD student stipend, and McGill travel awards. In addition, AAH's funding significantly reduced as cholera prevalence dwindled and ended with the last reported cholera case in January 2019 (Pan American Health Organization, 2020). This led to the decision to adapt the EBCD and combine the staff feedback session with a co-design session to reduce further spending. Continuation of the study would have required AAHs ability to host the study as well as further funding. Despite these challenges, AAH saw a benefit in this research design and was willing to host the study, the collaborators continued to be supportive of the initiative and this led to, for example, additional activities such as a workshop with the research assistant and health promotors, two years after the last data collection, a review of their internal training procedures and the development of a report as part of a request for more funding. This highlights the importance of engagement of the whole team, including affected communities, to affect change. As part of the PR approach, I continuously supported the RA to take a leading role for example in leading the focus groups, presenting the results to NGOs and in conducting the analysis and writing the reports for AAH. After this research he was hired by AAH in a monitoring and evaluation position. This research led to the development of a post-doctoral research proposal where we aim to develop a rapid EBCD for humanitarian settings in collaboration with the Canadian Red Cross.

This research approach included several PR and IKT elements which are not included in the 'traditional' EBCD process. For example, in order to support capacity building, I created opportunities for the RA to lead data collection initiatives, to present this research on several occasions and for HP staff and the RA to suggest how the research approach could be improved; this was followed by changes to the design of the study (e.g. we did not conduct individual interviews with focus groups with the affected community members). Since the end of this research project, the RA has continued working as a valued staff member with AAH in the monitoring and evaluation department where he continues to collect feedback from affected communities, reflect on AAH's practice and conducts other studies. The RA and I also returned to the communities where we conducted the focus groups to summarize the analysis for the affected community members and asked for their feedback on the results. As it was challenging to reconnect with all participants to invite them for these events, we made these sessions open to the whole communities and had over 10 participants in each of the four sessions. Participants engaged in the discussion following the presentation and were in general agreement with our summary. They emphasized and advocated for the need to support for the construction of toilets and clean water sources. I also organized an online workshop with four HP staff members to co-analyze the data from the research. The behaviour change specialist working for AAH identified this approach as an opportunity to reflect on practice and grow in their positions. AAH has continued to shift their practices towards a participatory approach, not directly related to this study, and staff have indicated a general aspiration and interest for more dialogue and horizontal collaboration with local stakeholders. Nevertheless, time and funding restrictions limited the level of integration of PR and IKT elements, for example, while we sought feedback from community members for the results of the analysis, we did not include them during the analysis and not all key stakeholders were included in the research design which is always the goal of a full PR and IKT approach (though not always acted upon) (Cargo & Mercer, 2008; Locock et al., 2019).

An in-depth understanding of the role and influence of the local medical male (houngan) and female (manbo) practitioners would have required more time and additional funding. Yet, this study was one of the first to include a focus group with houngans to gather their perspectives and experiences as well as one individual interview with a houngan. These participants provided examples how they could help in the cholera response (e.g. if they indicated that they could help people trying to reach the cholera treatment centres by giving them oral rehydration solutions). AAH requested additional interviews to better understand the perspectives of the houngan. In addition, several participants shared their perspectives of the role of alternative health practitioners and for example about the cholera ‘magique’. Finally, the Haitian Creole and French speaking research assistant was from the capital (Port-au-Prince) and not from the regions where the data was collected, in addition, I am originally Dutch and white. It is possible that researchers with similar characteristics as the communities would have collected different kind of data. In addition, it is possible that we were identified as one of the AAH staff members rather than independent researchers. Partly because we needed to respect AAHs security rules, which for example included that we had to always be accompanied by a car and driver from AAH in case of security issues. Due to limited resources this meant that we mostly accompanied HP teams to the field. This may have influenced what people decided to share with us during the focus groups. Nevertheless, participants of the focus groups did demonstrate a very critical attitude and were not shy to provide criticism towards our research process or the HP activities.

8.5 Future directions for research

There are currently many major research gaps acknowledged in humanitarian research (Blanchet et al., 2015), but I have highlighted here some future directions that are most relevant to the domain of this research: 1) support for further exploration of using EBCD in humanitarian settings, 2) investigating the role of video containing narratives related to health care improvements, 3) addressing other factors associated with improving HP strategies in humanitarian programs and 4) development of innovative PR approaches in humanitarian settings, that include alternative health practitioners

8.5.1 Support for further exploration of using EBCD in humanitarian settings

As stated before in this thesis there is currently an overall effort to collect data on peoples' experiences and perceptions but it remains challenging to find ways to implement the learning from this data into humanitarian programs (Eyben, 2008). Research can make important contributions to develop effective approaches that support the process of change to improve participation as well as finding ways to apply the learning from patients' experiences, such as an EBCD. In the settings for this research approach, it could be valuable to test whether EBCD can contribute to addressing structural and/or complex issues. Research could, for example explore whether it is possible to implement EBCD at different levels in the humanitarian response (e.g. organizations, coordination or governmental levels) to improve the understanding of the importance of integrating the affected populations' perspectives in humanitarian programs. This was, for example, tested in a study looking at how EBCD can contribute to improving the staff experience in an emergency department in the UK (Gager, Keating, Mossop, & Wiltshire, 2020). But research could also focus on developing a better understanding of how humanitarian staff uses patient experiences to improve humanitarian programs, similar to a study looking at how front-line staff uses patient experiences data for service improvement (Locock, Montgomery, et al., 2020).

Finally, one EBCD study, conducted in Nigeria, looked at improving family planning services – an application within the context of population health, rather than services that treat patients. This study found that EBCD provided a platform that made clients active contributors to family planning service improvement plans thereby ensuring quality services that meet the need of women (Oguntunde et al., 2019). Further testing is required to better understand the value of EBCD in HP settings, where the services are delivered in the community to healthy people rather than where community members visit the health care service such as in the majority of the EBCD settings (T. Green et al., 2020).

8.5.2 Investigating the role of video containing narratives in health care improvements

Video is increasingly used as a means for health care service improvement, such as in video reflexive ethnography (Iedema et al., 2018), EBCD (Robert, 2013) and Visual Intervention/Prevention Assessment (Chalfen & Rich, 2004). The role of video in health care services improvement is not yet well explored; in this thesis research it was found that in this context it might have been better to show shorter sections of the catalyst film and provide more guidance and reflection on why participants were saying certain things (Ormel et al., To be submitted in July 2021). The catalyst film for EBCD is created from selected fragments of the overall patient experience with the health care service. Further research on how experiential information contributes to change can enhance the use of qualitative data in such a way that it optimizes opportunities for change. This research could draw from current findings of the value of narratives in decision aids (Shaffer & Zikmund-Fisher, 2013), the health effects impact in narrative interventions (de Graaf et al., 2016), how patient experiences contribute to decision making (Ziebland & Herxheimer, 2008) or research on the risk and benefits of patient narratives (Drewniak et al., 2020).

8.5.3 Addressing other factors associated with improving hygiene promotion strategies in humanitarian response

This thesis considered, from different perspectives, how the experiences of communities affected by cholera can contribute to improvements in the HP response. It discussed and discovered some gaps in our current knowledge. Further research could contribute to developing outcome measures that look at how the HP services are experienced and how this impact the effectiveness of these programs. Research can also look into the value and importance of including houngan and mambos in the program response. Including trusted key community leaders in the response may help improve the impact of HP programs. Another field of research is to investigate the impact of individualized messages and how messages could better fit the lived realities of the communities. Researchers and humanitarian organizations could contribute with research to develop a better understanding of individual as well as inter-related factors that influence the effectiveness of HP strategies and behaviour change.

8.5.4 Development of innovative participatory research approaches in humanitarian settings

Research in humanitarian settings is not always a priority, therefore innovative approaches are necessary to conduct meaningful and contextual appropriate research in these settings (Guha-Sapir & Scales, 2020). Further research could, for example, explore if rapid versions of PR approaches are a better fit for these settings such as participatory rapid appraisal (The SAGE Encyclopedia of Action Research, 2014).

8.6 Summary of contributions

This thesis reported on the current practices of PR in humanitarian settings and the feasibility of adopting a particular PR approach to determine improvements in the HP response to the cholera outbreak in Haiti. Methodological contributions were identified through the implementation and reflections on the impact and challenges of conducting a pilot EBCD in a humanitarian setting. It demonstrated that it is possible to make adaptations to the traditional EBCD process, to make it culturally more appropriate and feasible within HP settings. The findings from this research also contributed to greater insight into how an improved understanding of affected communities' experiences and perspectives can contribute to improving the HP response in three different ways (improved understanding of the individual experience, as a mechanism of change and as an outcome measure). This research finds that an EBCD approach facilitates the generation of new knowledge based on experiential data, the application of the learning from affected communities' experiences and perspectives on improvements to the HP approach, and the implementation of collaborative approaches.

9 REFERENCES

Abelson, J., Li, K., Wilson, G., Shields, K., Schneider, C., & Boesveld, S. (2015). Supporting quality public and patient engagement in health system organizations: development and usability testing of the Public and Patient Engagement Evaluation Tool. *Health Expectations*.

Abu-Sada, C. (2012). In the eyes of others: how people in crises perceive humanitarian aid. *Médecins Sans Frontières*.

Adichie, C. N. (2009). The danger of a single story. In: TED Talk.

Afifi, R. A., Abdulrahim, S., Betancourt, T., Btedinni, D., Berent, J., Dellos, L., . . . Saravanan, M. (2020). Implementing Community-Based Participatory Research with Communities Affected by Humanitarian Crises: The Potential to Recalibrate Equity and Power in Vulnerable Contexts. *American Journal of Community Psychology, 66*(3-4), 381-391. Retrieved from https://onlinelibrary.wiley.com/doi/10.1002/ajcp.12453

Ager, A., Burnham, G., Checchi, F., Gayer, M., Grais, R. F., Henkens, M., . . . Spiegel, P. (2014). Strengthening the evidence base for health programming in humanitarian crises. In (Vol. 345, pp. 1290-1292): High Wire Press.

Anderson, M. B., Brown, D., & Jean, I. (2012). *Time to listen: hearing people on the receiving end of international aid*. Cambridge, UK: CDA Collaborative Learning Projects Cambridge, MA.

Andersson, N. (2018). Participatory research—A modernizing science for primary health care. *Journal of general and family medicine, 19*(5), 154-159. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6119794/pdf/JGF2-19-154.pdf

Arvai, J., & Post, K. (2012). Risk Management in a Developing Country Context: Improving Decisions About Point-of-Use Water Treatment Among the Rural Poor in Africa. *Risk Analysis, 32*(1), 67-80.

Balas, E. A., & Boren, S. A. (2000). Managing clinical knowledge for health care improvement. *Yearbook of medical informatics 2000: Patient-centered systems*.

Barbelet, V. (2018). As local as possible, as international as necessary: Understanding capacity and complementarity in humanitarian action. *Report*.

Barbelet, V., Kokere, P. B., Kandate, E., Mwambusa, P. M., Ciza, A. M., & Namahira, S. N. (2019). *Local humanitarian action in the Democratic Republic of Congo: capacity and complementarity*. Retrieved from https://odi.org/en/publications/local-humanitarian-action-in-the-democratic-republic-of-congo-capacity-and-complementarity/

Bartels, S., Fraulin, G., & Lee, S. (2020). Cholera in the Time of MINUSTAH: Experiences of Community Members Affected by Cholera in Haiti. *Research Square*.

Bastemeijer, C. M., Boosman, H., van Ewijk, H., Verweij, L. M., Voogt, L., & Hazelzet, J. A. (2019). Patient experiences: a systematic review of quality improvement interventions in a hospital setting. *Patient related outcome measures, 10*, 157-169. doi:10.2147/PROM.S201737

Bate, P., & Robert, G. (2006). Experience-based design: from redesigning the system around the patient to co-designing services with the patient. *BMJ quality & safety, 15*(5), 307-310.

Bate, P., & Robert, G. (2007). *Bringing user experience to healthcare improvement: The concepts, methods and practices of experience-based design*: Radcliffe Publishing.

Beau De Rochars, V. E., Tipret, J., Patrick, M., Jacobson, L., Barbour, K. E., Berendes, D., . . . Handzel, T. (2011). Knowledge, attitudes, and practices related to treatment and prevention of cholera, Haiti, 2010. *Emerging Infectious Diseases, 17*(11), 2158-2161.

Biscan B. (2017). Analyse des facteur de persistance du choléra et élaboration d'un plan d'intervention - Pour la ville de Gonaives.

Blanchet, K., Roberts, B., Sistenich, V., Ramesh, A., Frison, S., & Warren, E. (2015). *An evidence review of research on health interventions in humanitarian crises*. Retrieved from https://www.elrha.org/wp-content/uploads/2015/01/Evidence-Review-22.10.15.pdf

Bloom, L., & Betts, A. (2013). The two worlds of humanitarian innovation. *Refugee Studies Centre*.

Bonino, F., Jean, I., & Knox, C. (2014). Humanitarian Feedback Mechanisms; research, evidence and guidance. *ALNAP Study. London: ALNAP/ODI*.

Brady, G. C., Goodrich, J., & Roe, J. W. G. (2020). Using experience-based co-design to improve the pre-treatment care pathway for people diagnosed with head and neck cancer. *Supportive care in cancer, 28*(2), 739-745. doi:10.1007/s00520-019-04877-z

Brown, D., & Donini, A. (2014). *Rhetoric or reality? Putting affected people at the centre of humanitarian action*. Retrieved from https://www.alnap.org/help-library/rhetoric-or-reality-putting-affected-people-at-the-centre-of-humanitarian-action-0

Bruno, W., & Haar, R. J. (2020). A systematic literature review of the ethics of conducting research in the humanitarian setting. *Conflict and health, 14*(1), 27. doi:10.1186/s13031-020-00282-0

Calabrese, J. (2013). Ethnographic approaches to health experiences research. *Understanding and using health experiences: Improving patient care*, 28-38.

Calain, P. (2013). Ethics and images of suffering bodies in humanitarian medicine. *Social science & medicine, 98*, 278-285.

Canadian Institutes of Health Research. (2012). *Guide to Knowledge Translation Planning at CIHR: Integrated and End-of-grant Approaches*: Canadian Institutes of Health Research.

Cargo, M., & Mercer, S. L. (2008). The value and challenges of participatory research: Strengthening its practice. *Annu. Rev. Public Health, 29*, 325-350.

CDA Collaborative Learning Projects. (2008). *The Listening Project. Discuss Together, Decide Together, Work Together*. Retrieved from http://cdacollaborative.org/wordpress/wp-content/uploads/2016/02/Discuss-Together-Decide-Together-Work-Together.pdf

CDC. (2016a). Cholera - Vibrio cholerae infection Retrieved from https://www.cdc.gov/cholera/general/index.html

CDC. (2016b). A Follow-up Assessment of Household Water Treatment Products and Water Use in Artibonite Department, Haiti.

Centers for Disease Control and Prevention (CDC). (2019). Global Health - Haiti. Retrieved from https://www.cdc.gov/globalhealth/countries/haiti/default.htm

Chalfen, R., & Rich, M. (2004). Applying visual research patients teaching physicians through visual illness narratives. *Visual Anthropology Review, 20*(1), 17-30.

Childs, L., Francois, J., Choudhury, A., Wannemuehler, K., Dismer, A., Hyde, T. B., . . . Tohme, R. A. (2016). Evaluation of Knowledge and Practices Regarding Cholera, Water Treatment, Hygiene, and Sanitation Before and After an Oral Cholera Vaccination Campaign-Haiti, 2013-2014. *American Journal of Tropical Medicine & Hygiene, 95*(6), 1305-1313. Retrieved from https://doi.org/10.4269/ajtmh.16-0555

Christensen, D., Dube, O., Haushofer, J., Siddiqi, B., & Voors, M. (2020). *Community-Based Crisis Response: Evidence from Sierra Leone's Ebola Outbreak.* Paper presented at the AEA Papers and Proceedings.

CHS Alliance. (2020). *Humanitarian Accountability Report. Are We Making Aid Work Better for People*. Retrieved from Geneva:

Clarke, D., Gombert-Waldron, K., Honey, S., Cloud, G., Harris, R., Macdonald, A., . . . Jones, F. (2021). Co-designing organisational improvements and interventions to increase inpatient activity in four stroke units in England: a mixed-methods process evaluation using normalisation process theory. *BMJ Open, 11*(1), e042723. doi:10.1136/bmjopen-2020-042723

Cleland, J. (1973). A critique of KAP studies and some suggestions for their improvement. *Studies in Family Planning, 4*(2), 42-47.

Cohn, S., & Kutalek, R. (2016). Historical parallels, Ebola virus disease and cholera: understanding community distrust and social violence with epidemics. *PLoS currents, 8*.

Contzen, N., & Mosler, H.-J. (2013). Impact of different promotional channels on handwashing behaviour in an emergency context: Haiti post-earthquake public health promotions and cholera response. *Journal of Public Health, 21*(6), 559-573.

Cooper, K., Gillmore, C., & Hogg, L. (2016). Experience-based co-design in an adult psychological therapies service. *Journal of Mental Health, 25*(1), 36-40. Retrieved from https://www.tandfonline.com/doi/full/10.3109/09638237.2015.1101423

Corburn, J. (2005). *Street Science: Community Knowledge and Environmental Health Justice* Cambridge, Massachusetts, United States: MIT Press.

Coulter, A. (2013). Understanding the experience of illness and treatment. In *Understanding and Using Health Experiences–improving patient care* (pp. 6-15): OUP Oxford

Coulter, A., Locock, L., Ziebland, S., & Calabrese, J. (2014). Collecting data on patient experience is not enough: they must be used to improve care. *BMJ: British Medical Journal (Online), 348*.

Coy, K., Brock, P., Pomeroy, S., Cadogan, J., & Beckett, K. (2019). A Road Less Travelled: using Experience Based Co-Design to map children’s and families’ emotional journey following burn injury and identify service improvements. *Burns, 45*(8), 1848-1855.

Dahab, M., van Zandvoort, K., Flasche, S., Warsame, A., Ratnayake, R., Favas, C., . . . Checchi, F. (2020). COVID-19 control in low-income settings and displaced populations: what can realistically be done? *Conflict and health, 14*(1), 54. doi:10.1186/s13031-020-00296-8

Darcy, J., Alexander, J., & Kiani, M. (2013). *Humanitarian Accountability Report*. Retrieved from London, United Kingdom: https://www.alnap.org/help-library/the-2013-humanitarian-accountability-report

de Graaf, A., Sanders, J., & Hoeken, H. (2016). Characteristics of narrative interventions and health effects: A review of the content, form, and context of narratives in health-related narrative persuasion research. *Review of Communication Research, 4*, 88-131.

Desrosiers, A., & St Fleurose, S. (2002). Treating Haitian patients: key cultural aspects. *American journal of Psychotherapy, 56*(4).

Deventer van, C., Robert, G., & Wright, A. (2016). Improving childhood nutrition and wellness in South Africa: involving mothers/caregivers of malnourished or HIV positive children and health care workers as co-designers to enhance a local quality improvement intervention. *BMC health services research, 16*(1), 358.

Donetto, S., Tsianakas, V., & Robert, G. (2014). Using Experience-based Co-design (EBCD) to improve the quality of healthcare: mapping where we are now and establishing future directions. *London: King’s College London*.

Doyle, C., Lennox, L., & Bell, D. (2013). A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open, 3*(1), e001570. doi:10.1136/bmjopen-2012-001570

Drewniak, D., Glässel, A., Hodel, M., & Biller-Andorno, N. (2020). Risks and benefits of web-based patient narratives: systematic review. *Journal of Medical Internet Research, 22*(3), e15772.

Dufour, C., Grünewald, F., & Levy, C. (2003). Participation by Crisis-Affected Populations in Humanitarian Action: A Handbook for Practitioners. *London, ALNAP*.

Elmusharaf, K., Byrne, E., Manandhar, M., Hemmings, J., & O'Donovan, D. (2017). Participatory Ethnographic Evaluation and Research: Reflections on the Research

Approach Used to Understand the Complexity of Maternal Health Issues in South Sudan. *Qualitative Health Research, 27*(9), 1345-1358. doi:https://dx.doi.org/10.1177/1049732316673975

Emerson, R. M., Fretz, R. I., & Shaw, L. L. (2011). *Writing ethnographic fieldnotes*: University of Chicago Press.

Eppinger, M., Pearson, T., Koenig, S. S., Pearson, O., Hicks, N., Agrawal, S., . . . Crabtree, J. (2014). Genomic epidemiology of the Haitian cholera outbreak: a single introduction followed by rapid, extensive, and continued spread characterized the onset of the epidemic. *MBio, 5*(6).

Eyben, R. (2008). *Power, mutual accountability and responsibility in the practice of international aid: A relational approach*. Retrieved from Brighton, UK: https://www.ids.ac.uk/publications/power-mutual-accountability-and-responsibility-in-the-practice-of-international-aid-a-relational-approach/

Ferguson, J., & Gupta, A. (2002). Spatializing states: toward an ethnography of neoliberal governmentality. *American ethnologist, 29*(4), 981-1002.

Frerichs, R. R. (2016). *Deadly River: Cholera and Cover-up in Post-earthquake Haiti*: Cornell University Press.

Gager, M., Keating, L., Mossop, D., & Wiltshire, M. (2020). Quality Time: Using experience-based co-design to capture emergency department staff experience. *The Journal of Health Design, 5*(1).

Gleeson, H., Calderon, A., Swami, V., Deighton, J., Wolpert, M., & Edbrooke-Childs, J. (2016). Systematic review of approaches to using patient experience data for quality improvement in healthcare settings. *BMJ Open, 6*(8).

Goodrich, J. (2018). Why experience-based co-design improves the patient experience. *The Journal of Health Design, 3*(1).

Graham, I. D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in knowledge translation: time for a map? *Journal of continuing education in the health professions, 26*(1), 13-24. Retrieved from http://ssr-eus-go-csi.cloudapp.net/v1/assets?wkmrid=JOURNAL%2Fjcehp%2Fbeta%2F00005141-200626010-00003%2Froot%2Fv%2F2017-05-31T223607Z%2Fr%2Fapplication-pdf

Graham, I. D., Tetroe, J., & Pearson, A. (2014). *Turning knowledge into action: practical guidance on how to do integrated knowledge translation research*: Lippincott Williams & Wilkins.

Green, L. W., George, M. A., Daniel, M., Frankish, C. J., Herbert, C. J., Bowie, W. R., & O'Neill, M. (1995). Study of participatory research in health promotion. *Review and recommendations for development of participatory research in health promotion in Canada. Ottowa, Ontario: The Royal Society of Canada*.

Green, T., Bonner, A., Teleni, L., Bradford, N., Purtell, L., Douglas, C., . . . Chan, R. J. (2020). Use and reporting of experience-based codesign studies in the healthcare setting: a systematic review. *BMJ quality & safety, 29*(1), 64-76.

Greenhalgh, T., Russell, J., & Swinglehurst, D. (2005). Narrative methods in quality improvement research. *BMJ quality & safety, 14*(6), 443-449.

Grimaud, J., & Legagneur, F. (2011). Community beliefs and fears during a cholera outbreak in Haiti. *Intervention, 9*(1), 26-34.

Guha-Sapir, D., & Scales, S. E. (2020). Challenges in public health and epidemiology research in humanitarian settings: experiences from the field. *BMC Public Health, 20*(1), 1-6.

Haitian Red Cross. (2010). *Case study: HRC and perceptions of cholera*. Retrieved from https://www.alnap.org/help-library/case-study-hrc-and-perceptions-of-cholera

Hall, B. L. (1981). Participatory research, popular knowledge and power: A personal reflection. *Convergence, 14*(3), 6.

Höijer, B. (2004). The discourse of global compassion: The audience and media reporting of human suffering. *Media, Culture & Society, 26*(4), 513-531.

Howard, G., & Bogh, C. (2002). *Healthy villages: a guide for communities and community health workers*: World Health Organization.

Hsu, K. J., & Schuller, M. (2020). Humanitarian aid and local power structures: lessons from Haiti's 'shadow disaster'. *Disasters, 44*(4), 641-665. doi:10.1111/disa.12380

Hurwitz, B., Greenhalgh, T., & Skultans, V. (2008). *Narrative research in health and illness*: John Wiley & Sons.

Iedema, R., Carroll, K., Collier, A., Hor, S.-Y., Mesman, J., & Wyer, M. (2018). *Video-reflexive ethnography in health research and healthcare improvement: theory and application*: CRC Press.

International Committee of the Red Cross (ICRC) and Harvard Humanitarian Initiative (HHI). (2018). *Engaging with people affected by armed conflicts and otehr situations of violence – Taking stock. Mapping trends. Looking ahead. Recommendations for humanitarian organizations and donors in the digital era.* Retrieved from

International Rescue Comittee. (2014). Are we listening? Acting on Our Commitments to Women and Girls Affected by the Syrian Conflict.

Isanaka, S., Elder, G., Schaefer, M., Vasset, B., Baron, E., & Grais, R. (2012). Bridging the gap from knowledge to delivery in the control of Childhood Diarrhoea. In (Vol. 90, pp. 635-635).

Jagosh, J., Macaulay, A. C., Pluye, P., Salsberg, J., Bush, P. L., Henderson, J., . . . Herbert, C. P. (2012). Uncovering the benefits of participatory research: implications of a realist review for health research and practice. *Milbank Quarterly, 90*(2), 311-346.

Jolley, D., & Paterson, J. L. (2020). Pylons ablaze: Examining the role of 5G COVID-19 conspiracy beliefs and support for violence. *British Journal of Social Psychology, 59*(3), 628-640. doi:https://doi.org/10.1111/bjso.12394

Jong, A. d. (date not indicated). Story of Change: when your story becomes our story. Retrieved from http://msfmakes.com/story/

Kleinman, A. (1988). The illness narrative. *New York: Basic Book*, 49.

Kohrt, B. A., Mistry, A. S., Anand, N., Beecroft, B., & Nuwayhid, I. (2019). Health research in humanitarian crises: an urgent global imperative. *BMJ Global Health, 4*(6).

Kothari, A., & Wathen, C. N. (2017). Integrated knowledge translation: digging deeper, moving forward. *J Epidemiol Community Health*, jech-2016-208490.

Kovats-Bernat, J. C. (2002). Negotiating dangerous fields: Pragmatic strategies for fieldwork amid violence and terror. *American Anthropologist, 104*(1), 208-222.

Launiala, A. (2009). How much can a KAP survey tell us about people's knowledge, attitudes and practices? Some observations from medical anthropology research on malaria in pregnancy in Malawi. *Anthropology Matters, 11*(1).

Laverack, G., & Manoncourt, E. (2016). Key experiences of community engagement and social mobilization in the Ebola response. *Global Health Promotion, 23*(1), 79-82. doi:10.1177/1757975915606674

Locock, L., Graham, C., King, J., Parkin, S., Montgomery, C., Gibbons, E., . . . Gager, M. (2020). Understanding how front-line staff use patient experience data for service improvement: an exploratory case study evaluation. *Health Services and Delivery Research, 8*(13).

Locock, L., Kirkpatrick, S., Brading, L., Sturmey, G., Cornwell, J., Churchill, N., & Robert, G. (2019). Involving service users in the qualitative analysis of patient narratives to support healthcare quality improvement. *Research involvement and engagement, 5*(1), 1.

Locock, L., Montgomery, C., Parkin, S., Chisholm, A., Bostock, J., Dopson, S., . . . Ziebland, S. (2020). How do frontline staff use patient experience data for service improvement? Findings from an ethnographic case study evaluation. *Journal of health services research & policy, 25*(3), 151-161. doi:10.1177/1355819619888675

Locock, L., Robert, G., Boaz, A., Vougioukalou, S., Shuldham, C., Fielden, J., . . . Pearcey, J. (2014a). Testing accelerated experience-based co-design: a qualitative study of using a national archive of patient experience narrative interviews to promote rapid patient-centred service improvement. *Health Services and Delivery Research*.

Locock, L., Robert, G., Boaz, A., Vougioukalou, S., Shuldham, C., Fielden, J., . . . Pearcey, J. (2014b). Using a national archive of patient experience narratives to promote local patient-centered quality improvement: an ethnographic process evaluation of ‘accelerated’experience-based co-design. *Journal of health services research & policy*, 1355819614531565.

Lucius-Hoene, G., Holmberg, C., & Meyer, T. (2018). *Illness narratives in practice: Potentials and challenges of using narratives in health-related contexts*: Oxford University Press, USA.

Macaulay, A. C., Commanda, L. E., Freeman, W. L., Gibson, N., McCabe, M. L., Robbins, C. M., & Twohig, P. L. (1999). Participatory research maximises community and lay involvement. *Bmj, 319*(7212), 774-778. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1116604/pdf/774.pdf

Macaulay, A. C., & Nutting, P. A. (2006). Moving the frontiers forward: incorporating community-based participatory research into practice-based research networks. *The Annals of Family Medicine, 4*(1), 4-7. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1466984/pdf/0040004.pdf

Magone, C., Neuman, M., & Weissman, F. (2012). *Humanitarian Negotiations Revealed: The MSF Experience*: Hurst.

Marais, F., Minkler, M., Gibson, N., Mwau, B., Mehtar, S., Ogunsola, F., . . . Corburn, J. (2015). A community-engaged infection prevention and control approach to Ebola. *Health Promotion International, 31*(2), 440-449. doi:10.1093/heapro/dav003

Masumbuko Claude, K., Underschultz, J., & Hawkes, M. T. (2019). Social resistance drives persistent transmission of Ebola virus disease in Eastern Democratic Republic of Congo: A mixed-methods study. *PloS one, 14*(9), e0223104. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6762146/pdf/pone.0223104.pdf

Monette, E. M., McHugh, D., Smith, M. J., Canas, E., Jabo, N., Henley, P., & Nouvet, E. (2021). Informing ‘good’global health research partnerships: A scoping review of guiding principles. *Global Health Action, 14*(1), 1892308. Retrieved from https://www.tandfonline.com/doi/pdf/10.1080/16549716.2021.1892308?needAccess=true

Morris Jr, J. G. (2016). Deadly River: Cholera and Cover-Up in Post-Earthquake Haiti. *Emerging Infectious Diseases, 22*(11), 2029.

Morse, J. M., Hupcey, J. E., Penrod, J., & Mitcham, C. (2002). Integrating concepts for the development of qualitatively-derived theory. *Research and theory for nursing practice, 16*(1), 5.

Muggah, R. (2010). Is anyone listening to the Haitians? . Retrieved from https://www.idrc.ca/en/node/7277

Mulley, A. G., Trimble, C., & Elwyn, G. (2012). Stop the silent misdiagnosis Patients’ preferences matter. *Bmj, 345*, 23.

Nair, G. B., & Takeda, Y. (2008). Cholera: the need to translate research knowledge into effective preventive and control measures. *Future Medecine*.

Nguyen, T., Graham, I. D., Mrklas, K. J., Bowen, S., Cargo, M., Estabrooks, C. A., . . . MacLeod, M. (2020). How does integrated knowledge translation (IKT) compare to other collaborative research approaches to generating and translating knowledge? Learning from experts in the field. *Health research policy and systems, 18,* 1-20.

Nouvet, E., Abu-Sada, C., de Laat, S., Wang, C., & Schwartz, L. (2016). Opportunities, limits and challenges of perceptions studies for humanitarian contexts. *Canadian Journal of Development Studies/Revue canadienne d'études du développement, 37*(3), 358-377.

Oguntunde, O., Nyenwa, J., Kilani-Ahmadu, S., Salihu, A., & Yusuf, I. (2019). Addressing socio-cultural barriers to family planning and co-designing services to improve utilization: evidence from northern Nigeria.

Olivier, C., Hunt, M. R., & Ridde, V. (2016). NGO–researcher partnerships in global health research: benefits, challenges, and approaches that promote success. *Development in Practice, 26*(4), 444-455.

Orata, F. D., Keim, P. S., & Boucher, Y. (2014). The 2010 cholera outbreak in Haiti: how science solved a controversy. *PLoS pathogens, 10*(4), e1003967. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3974815/pdf/ppat.1003967.pdf

Ormel, I., Hunt, M., Hinton, L., Salsberg, J., Doucet, A., Massena, K., . . . Law, S. (Submitted May 2021). Hygiene promotion research in disease outbreaks in humanitarian settings: the case of cholera in Haiti. . *BMC Public Health*.

Ormel, I., Massena, K., Doucet, A., Hinton, L., Salsberg, J., Hunt, M., . . . Law, S. (To be submitted in July 2021). The Hygiene Promotion Response to the Cholera Outbreak in Haiti: Applying an Experience-Based Co-Design to Improve the Experience of Affected Communities - Forthcoming. *BMJ Health Care Services Research*.

Ormel, I., Massena, K., Doucet, A., Salsberg, J., Hunt, M., Hinton, L., . . . Law, S. (under review - May 2021). The role of trust in the health promotion response in the cholera outbreak in Haiti: results from an Experience-Based Co-Design study. *BMJ Open*.

Ormel, I., Salsberg, J., Hunt, M., Doucet, A., Hinton, L., Macaulay, A. C., & Law, S. (2020). Key issues for participatory research in the design and implementation of humanitarian assistance: a scoping review. *Global Health Action, 13*(1), 1826730. doi:10.1080/16549716.2020.1826730

Oxfam. (2014). *Projet: eau, assinissement et hygiene au benefice des enfant du departement de l'Artibonite*. Retrieved from Haiti: https://www.ungm.org/Public/Notice/102873

Pan American Health Organization. (2020). Haiti reaches one-year free of Cholera. Retrieved from https://reliefweb.int/report/haiti/haiti-reaches-one-year-free-cholera

Papoulias, C. (2018). Showing the Unsayable: Participatory Visual Approaches and the Constitution of ‘Patient Experience’ in Healthcare Quality Improvement. *Health Care Analysis, 26*(2), 171-188. doi:10.1007/s10728-017-0349-3

Patrick, M., Berendes, D., Murphy, J., Bertrand, F., Husain, F., & Handzel, T. (2013). Access to safe water in rural Artibonite, Haiti 16 months after the onset of the cholera epidemic. *The American journal of tropical medicine and hygiene, 89*(4), 647-653.

Payton, C. A. (2017). In Moral Debt to Haiti: In the world’s first independent Black Republic, cholera victims and their international allies continue to fight the UN for their basic right to clean water and monetary reparation. *NACLA Report on the Americas, 49*(1), 64-70.

Piarroux, R., Barrais, R., Faucher, B., Haus, R., Piarroux, M., Gaudart, J., . . . Raoult, D. (2011). Understanding the cholera epidemic, Haiti. *Emerging Infectious Diseases, 17*(7), 1161. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3381400/pdf/11-0059_finalS.pdf

Piper, D., Iedema, R., Gray, J., Verma, R., Holmes, L., & Manning, N. (2012). Utilizing experience-based co-design to improve the experience of patients accessing emergency departments in New South Wales public hospitals: an evaluation study. *Health services management research, 25*(4), 162-172. Retrieved from https://journals.sagepub.com/doi/10.1177/0951484812474247?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%3dpubmed

Pouligny, B. (2009). Supporting local ownership in humanitarian action. *Global Public Policy Institute-Humanitarian Policy Paper Series*.

Pringle, J. D., & Cole, D. C. (2009). Health Research in Complex Emergencies: A Humanitarian Imperative. *Journal of Academic Ethics, 7*(1), 115-123. doi:10.1007/s10805-009-9095-y

Ramalingam, B. (2013). *Aid on the Edge of Chaos: Rethinking International Cooperation in a Complex World*. Oxford, England: Oxford University Press.

Ramesh, A., Blanchet, K., Ensink, J. H., & Roberts, B. (2015). Evidence on the effectiveness of water, sanitation, and hygiene (WASH) interventions on health outcomes in humanitarian crises: a systematic review. *PloS one, 10*(9), e0124688. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4580573/pdf/pone.0124688.pdf

Ramos, M., Bowen, S., Wright, P. C., Ferreira, M. G. G., & Forcellini, F. A. (2020). Experience based co-design in healthcare services: an analysis of projects barriers and enablers. *Design for Health*, 1-20.

Raynor, D. K., Ismail, H., Blenkinsopp, A., Fylan, B., Armitage, G., & Silcock, J. (2020). Experience-based co-design—Adapting the method for a researcher-initiated study in a multi-site setting. *Health Expectations*.

Rebaudet, S., Bulit, G., Gaudart, J., Michel, E., Gazin, P., Evers, C., . . . Barrais, R. (2019). The case-area targeted rapid response strategy to control cholera in Haiti: a four-year implementation study. *PLoS neglected tropical diseases, 13*(4), e0007263.

Robert, G. (2013). Participatory action research: using experience-based co-design to improve the quality of healthcare services. In *Understanding and Using Health Experiences–improving patient care* (pp. 138-149): OUP Oxford.

Saini, G. (2017). Humanitarian aid policy changes following the 2010 cholera outbreak in Haiti. *NEXUS: The Canadian Student Journal of Anthropology, 25,* 2-12.

Schuller, M. (2007). Invasion or infusion? Understanding the role of NGOs in contemporary Haiti. *Journal of Haitian Studies,* 96-119.

Shaffer, V. A., Focella, E. S., Hathaway, A., Scherer, L. D., & Zikmund-Fisher, B. J. (2018). On the Usefulness of Narratives: An Interdisciplinary Review and Theoretical Model. *Annals of Behavioral Medicine, 52*(5), 429-442. doi:10.1093/abm/kax008

Shaffer, V. A., & Zikmund-Fisher, B. J. (2013). All stories are not alike: a purpose-, content-, and valence-based taxonomy of patient narratives in decision aids. *Medical Decision Making, 33*(1), 4-13.

Stellmach, D., Beshar, I., Bedford, J., du Cros, P., & Stringer, B. (2018). Anthropology in public health emergencies: what is anthropology good for? *BMJ Global Health, 3*(2), e000534.

Stevenson, F. (2013). Observing interactions as an approach to understanding patients' experiences. *Understanding and using health experiences: Improving patient care,* 27.

Straus, S. E., Tetroe, J., & Graham, I. D. (2009). Defining knowledge translation. *CMAJ, 181*. doi:10.1503/cmaj.081229

Tan, Y. A., & von Schreeb, J. (2015). Humanitarian assistance and accountability: what are we really talking about? *Prehospital and disaster medicine, 30*(03), 264-270.

Taylor, D. L., Kahawita, T. M., Cairncross, S., & Ensink, J. H. (2015). The impact of water, sanitation and hygiene interventions to control cholera: a systematic review. *PloS one, 10*(8), e0135676.

Tembo, D., Hickey, G., Montenegro, C., Chandler, D., Nelson, E., Porter, K., . . . Mumba, N. (2021). Effective engagement and involvement with community stakeholders in the co-production of global health research. *Bmj, 372*.

Tengö, M., Malmer, P., Brondizio, E., Elmqvist, T., & Spierenburg, M. (2013). The Multiple Evidence Base as a framework for connecting diverse knowledge systems in the IPBES. In *Discussion Paper 2012-06-04*: Stockholm Resilience Centre (SRC), Stockholm University Sweden.

The Point of Care Foundation (The King's Fund). Experience-based co-design toolkit.

The SAGE Encyclopedia of Action Research. (2014, 2021/05/31). Participatory Rapid Appraisal. Retrieved from https://methods.sagepub.com/reference/encyclopedia-of-action-research

UN General Assembly. (2016). One humanity: Shared responsibility. Report of the Secretary-General for the World Humanitarian Summit. *70th session, 2*.

United Nations Development Programme (UNDP). (2019). Inequalities in Human Development in the 21st Century. Retrieved from http://hdr.undp.org/en/data

Van Bavel, J. J., Baicker, K., Boggio, P. S., Capraro, V., Cichocka, A., Cikara, M., . . . Druckman, J. N. (2020). Using social and behavioural science to support COVID-19 pandemic response. *Nature Human Behaviour*, 1-12.

van der Haar, G., Heijmans, A., & Hilhorst, D. (2013). Interactive research and the construction of knowledge in conflict-affected settings. *Disasters, 37 Suppl 1*, S20-35. doi:https://dx.doi.org/10.1111/disa.12010

Ward, V., House, A., & Hamer, S. (2009). Developing a framework for transferring knowledge into action: a thematic analysis of the literature. *Journal of health services research & policy, 14*(3), 156-164.

Williams, H. A., Gaines, J., Patrick, M., Berendes, D., Fitter, D., & Handzel, T. (2015). Perceptions of Health Communication, Water Treatment and Sanitation in Artibonite Department, Haiti, March-April 2012. *PLoS ONE [Electronic Resource], 10*(11), e0142778. Retrieved from https://doi.org/10.1371/journal.pone.0142778

Wilson, J. M. (2018). The use of intelligence to determine attribution of the 2010 Haiti cholera disaster. *Intelligence and National Security, 33*(6), 866-874.

Winterbottom, A., Bekker, H. L., Conner, M., & Mooney, A. (2008). Does narrative information bias individual's decision making? A systematic review. *Social science & medicine, 67*(12), 2079-2088.

World Health Organization. (2017). Cholera. Retrieved from http://www.who.int/mediacentre/factsheets/fs107/en/

World Health Organization. (2020). Early AI-supported Response with Social Listening. Retrieved from https://whoinfodemic.citibeats.com/?cat=fYJ1oBNEUQtfbExrkGvsyr

Yates, T., Vujcic, J. A., Joseph, M. L., Gallandat, K., & Lantagne, D. (2018). Water, sanitation, and hygiene interventions in outbreak response: a synthesis of evidence. *Waterlines, 37*(1), 5-30.

Zarocostas, J. (2017). Cholera outbreak in Haiti—from 2010 to today. *Lancet, 389*(10086), 2274-2275. doi:https://dx.doi.org/10.1016/S0140-6736(17)31581-7

Ziebland, S., Coulter, A., Calabrese, J. D., & Locock, L. (2013). *Understanding and using health experiences: improving patient care*: OUP Oxford.

Ziebland, S., Grob, R., & Schlesinger, M. (2020). Polyphonic perspectives on health and care: Reflections from two decades of the DIPEx project. *Journal of health services research & policy*, 1355819620948909.

Ziebland, S., & Herxheimer, A. (2008). How patients’ experiences contribute to decision making: illustrations from DIPEx (personal experiences of health and illness). *Journal of nursing management*, *16*(4), 433-439. Retrieved from http://onlinelibrary.wiley.com/store/10.1111/j.1365-2834.2008.00863.x/asset/j.1365-2834.2008.00863.x.pdf?v=1&t=iz053ztg&s=f8027ac7346ff11ef35f7e5ec9a7c7915b825aea

Ziebland, S., & Wyke, S. (2012). Health and illness in a connected world: how might sharing experiences on the internet affect people's health? *Milbank Quarterly*, *90*(2), 219-249. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3460203/pdf/milq0090-0219.pdf

APPENDICES

Appendix A: The current cholera intervention activities and the key stakeholders in Haiti

This appendix provides an overview of the main actors and populations involved in the cholera intervention efforts in the Artibonite area in Haiti.

Haïtien actors

MSPP	Ministère de Sante Public et de la Populations / Ministry of Public Health and Population
DINEPA	Direction National de l'Eau Potable et de l'Assainissement / National Directorate of Drinking Water and Sanitation
DSA	Departement sanitaire de Artibonite / Atribonite Health Department
CTDA	Centre de Traitement de Diarrhée Aigue (treatment centre for people with acute diarrhoea)
CTC	Cholera treatment centre
UAS	Unités d'arrondissement (Arrondissement unit)
HRC	Haitien Red Cross

International actors

UNICEF	United Nations International Children's Emergency Fund
(i)NGO	(international) Non Governmental Organization
AAH	Action Against Hunger
MDM	Médecins du Monde / Doctors of the world

The cholera prevention effort in Haiti was a combined intervention approach with different national and international key agencies involved; MSPP, DINEPA, UNICEF and (i)NGO's. These agencies are responsible for the treatment of patients, public health programs, latrine construction and drinking water provision.

Treatment of people with cholera: people with symptoms of cholera will be treated in a CTC which is located on the same location as the CTDA. The CTDA and CTC fall under the direction of the DSA, which in turn is directed by the MSPP.

Drinking water and sanitation: The DINEPA, is responsible for drinking water and sanitation. The DINEPA directs five UAS in the Artibonite region that are under the supervision of medical doctors.

iNGOs: UNICEF funds and coordinators the response of NGOs such as AAH, HRC, MDM. These are all NGOs that respond that support the HP efforts (AAH, Acted and CRH) and treatment of cholera patients (MDM and HRC).

Activities AAH: At the time of the data collection AAH had 14 cholera prevention teams who were working mostly in St. Michel d'Attalaye and Dessalines. Every morning the teams passed by the CTDA in the community to send the information of the new cases to the cholera coordinator and to plan their day. The 'rapid response' teams aimed to meet the family of the cholera patients within the first 48 hours after the patients' admission at the treatment centre (following UNICEFs case-area targeted interventions). Teams existed out of 3-4 people; 1 nurse from the MSPP who provided a single dose treatment of doxycycline to household contacts of cholera cases and 2-3 members of the AAH team members with one member responsible for the disinfection of the patient's and surrounding houses and the other members responsible for the dissemination of the hygiene promotion messages and the distribution of cholera prevention kits (this could be soap, aqua tabs and ORS serums – dependent on the availability to products). There were also sensitization teams engaged in different activities with the community such as community meetings, dissemination of HP messages, demonstration of certain handwashing and water treatment practices, door to door visits, focus groups etc. These teams generally spent more time with the community and therefore had more time to respond to questions, concerns and to motivate people to make changes. These teams also revisited the houses of former patients to report changes made by the family and to check if the water in the house has been treated.

One technical team repaired water pumps and engaged in certain reconstruction projects such as the construction of toilets and water taps in a market place. Most of these activities however were directed by DINEPA.

AAH did not engage in the construction of toilets except in some rare cases to support good sanitation facilities in public places such as a market or school.

Appendix B : Ethics approval Comité National de Bioéthique

REPUBLIQUE D'HAITI
MINISTERE DE LA SANTE PUBLIQUE
ET DE LA POPULATION
Comité National de Bioéthique

Approbation initiale

13 septembre 2017

Susan Law
Ilja Ormel
Trazillio Mazard
Francis Alerte

Réf: 1617-56
Perspectives des communautés sur l'épidémie de cholera en Haïti, six ans après : quelles sont les perceptions des patients et des communautés de l'Artibonite et comment leur voix peut-elle influencer l'amélioration de la prévention et des soins pour éradiquer la maladie

Mesdames et Messieurs,

Le Comité National de Bioéthique a analysé le dossier soumis et donne un avis favorable pour sa conduite du 13 septembre 2017 au 12 septembre 2018 et approuve le protocole, la forme de consentement et le guide d'interview.

Prière de soumettre pour approbation avant implémentation une copie de toute modification apportée au protocole, une copie des différents rapports, publications et présentations qui seront élaborés à partir de cette évaluation.

Le Comité souhaite que les résultats de cette étude soient présentés en Haïti.

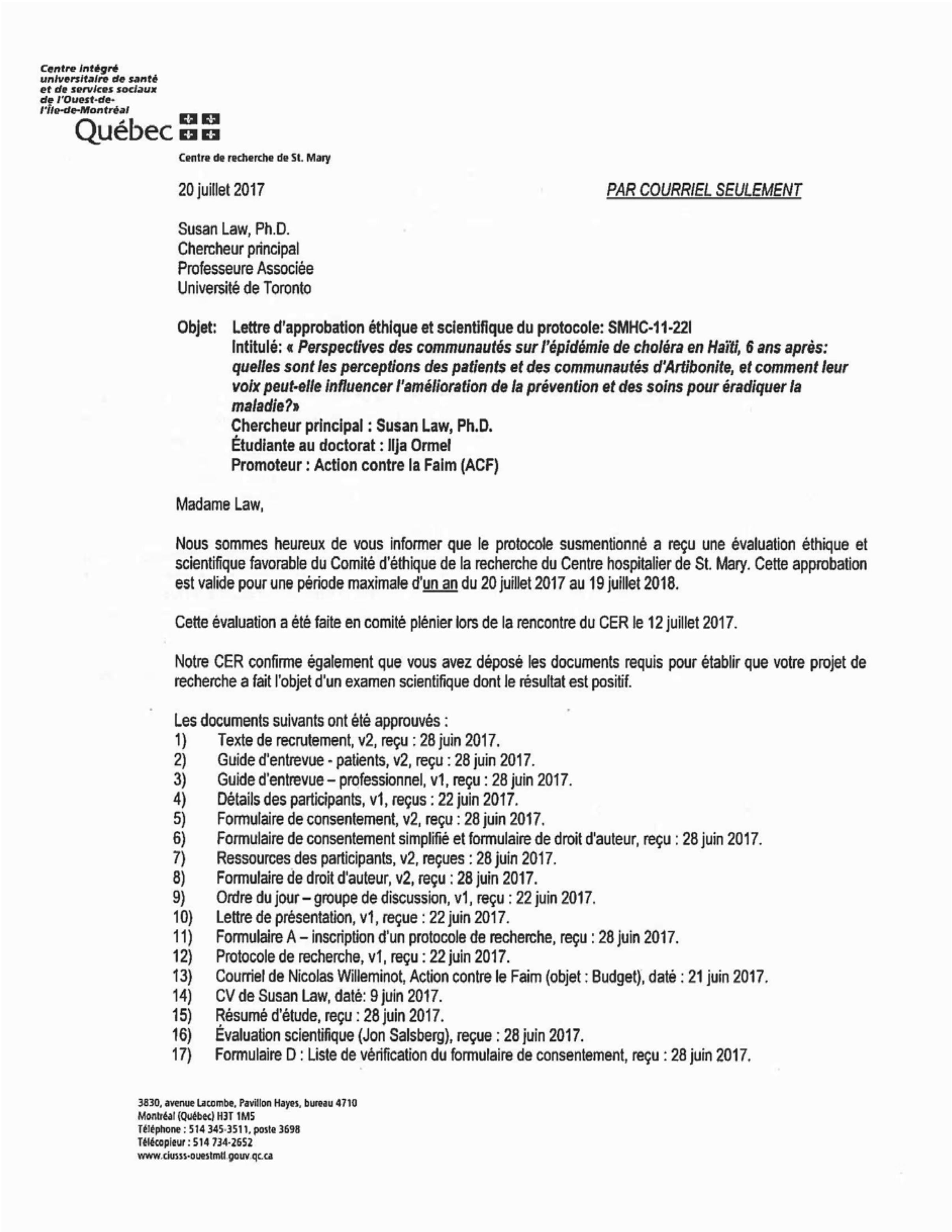
Le Comité vous souhaite du succès dans la conduite de cette étude.

Pour le Comité

Gerald Lerebours
Président

Comité National de Bioéthique
c/o Association Médicale Haitienne (AMH
29, 1^{e} avenue du Travail, Port-a-au-Prince

Appendix C: Ethics approval St. Mary's Research Centre



Centre intégré
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Québec
Centre de recherche de St. Mary

20 juillet 2017

<u>*PAR COURRIEL SEULEMENT*</u>

Susan Law, Ph.D.
Chercheur principal
Professeure Associée
Université de Toronto

Objet: Lettre d'approbation éthique et scientifique du protocole: SMHC-11-22I
Intitulé: « *Perspectives des communautés sur l'épidémie de choléra en Haïti, 6 ans après: quelles sont les perceptions des patients et des communautés d'Artibonite, et comment leur voix peut-elle influencer l'amélioration de la prévention et des soins pour éradiquer la maladie?*»
Chercheur principal : Susan Law, Ph.D.
Étudiante au doctorat : Ilja Ormel
Promoteur : Action contre la Faim (ACF)

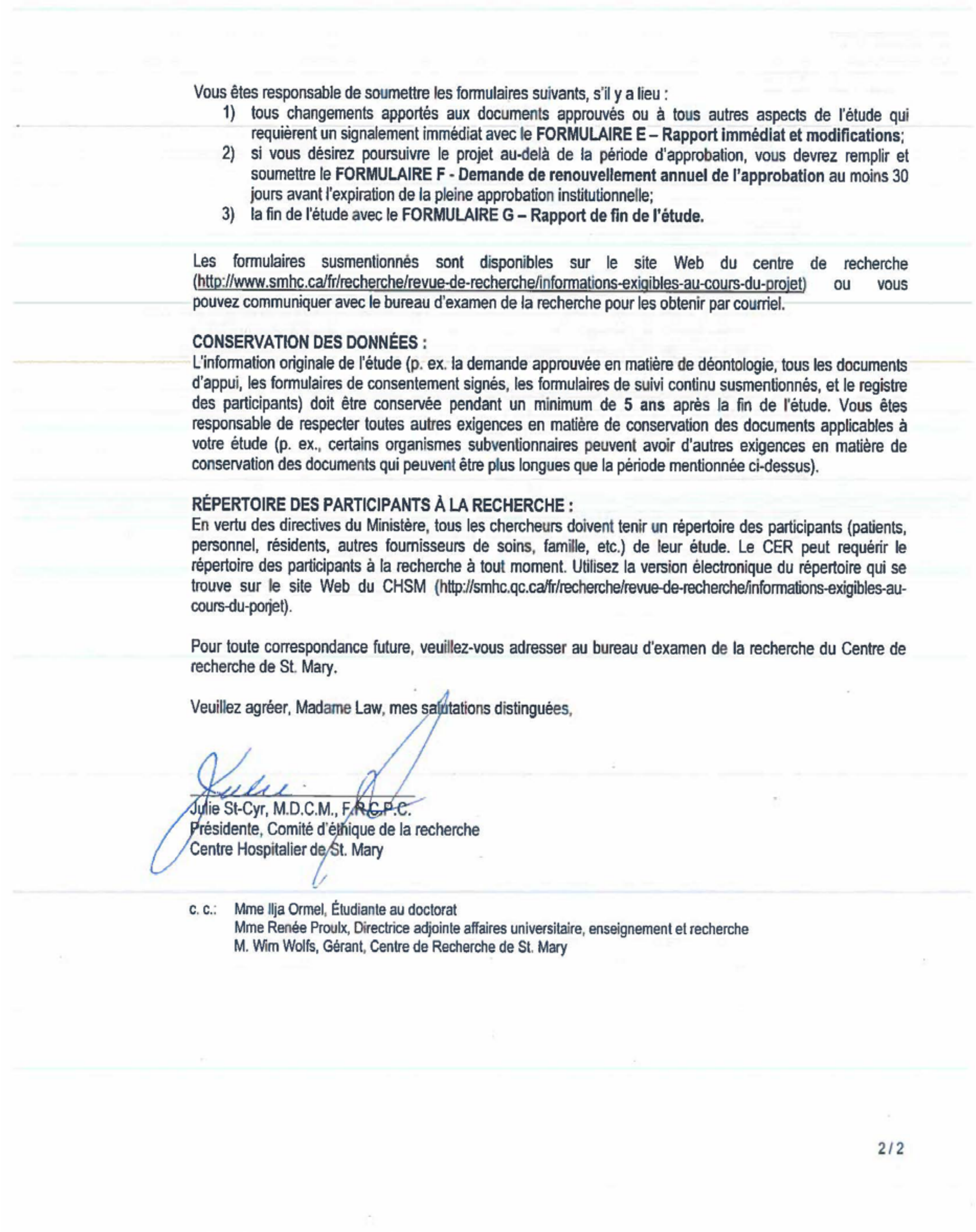
Madame Law,

Nous sommes heureux de vous informer que le protocole susmentionné a reçu une évaluation éthique et scientifique favorable du Comité d'éthique de la recherche du Centre hospitalier de St. Mary. Cette approbation est valide pour une période maximale d'<u>un an</u> du 20 juillet 2017 au 19 juillet 2018.

Cette évaluation a été faite en comité plénier lors de la rencontre du CER le 12 juillet 2017.

Notre CER confirme également que vous avez déposé les documents requis pour établir que votre projet de recherche a fait l'objet d'un examen scientifique dont le résultat est positif.

Les documents suivants ont été approuvés :
1) Texte de recrutement, v2, reçu : 28 juin 2017.
2) Guide d'entrevue - patients, v2, reçu : 28 juin 2017.
3) Guide d'entrevue – professionnel, v1, reçu : 28 juin 2017.
4) Détails des participants, v1, reçus : 22 juin 2017.
5) Formulaire de consentement, v2, reçu : 28 juin 2017.
6) Formulaire de consentement simplifié et formulaire de droit d'auteur, reçu : 28 juin 2017.
7) Ressources des participants, v2, reçues : 28 juin 2017.
8) Formulaire de droit d'auteur, v2, reçu : 28 juin 2017.
9) Ordre du jour – groupe de discussion, v1, reçu : 22 juin 2017.
10) Lettre de présentation, v1, reçue : 22 juin 2017.
11) Formulaire A – inscription d'un protocole de recherche, reçu : 28 juin 2017.
12) Protocole de recherche, v1, reçu : 22 juin 2017.
13) Courriel de Nicolas Willeminot, Action contre le Faim (objet : Budget), daté : 21 juin 2017.
14) CV de Susan Law, daté: 9 juin 2017.
15) Résumé d'étude, reçu : 28 juin 2017.
16) Évaluation scientifique (Jon Salsberg), reçue : 28 juin 2017.
17) Formulaire D : Liste de vérification du formulaire de consentement, reçu : 28 juin 2017.



Vous êtes responsable de soumettre les formulaires suivants, s'il y a lieu :

1) tous changements apportés aux documents approuvés ou à tous autres aspects de l'étude qui requièrent un signalement immédiat avec le **FORMULAIRE E – Rapport immédiat et modifications**;
2) si vous désirez poursuivre le projet au-delà de la période d'approbation, vous devrez remplir et soumettre le **FORMULAIRE F - Demande de renouvellement annuel de l'approbation** au moins 30 jours avant l'expiration de la pleine approbation institutionnelle;
3) la fin de l'étude avec le **FORMULAIRE G – Rapport de fin de l'étude.**

Les formulaires susmentionnés sont disponibles sur le site Web du centre de recherche (http://www.smhc.ca/fr/recherche/revue-de-recherche/informations-exigibles-au-cours-du-projet) ou vous pouvez communiquer avec le bureau d'examen de la recherche pour les obtenir par courriel.

CONSERVATION DES DONNÉES :
L'information originale de l'étude (p. ex. la demande approuvée en matière de déontologie, tous les documents d'appui, les formulaires de consentement signés, les formulaires de suivi continu susmentionnés, et le registre des participants) doit être conservée pendant un minimum de **5 ans** après la fin de l'étude. Vous êtes responsable de respecter toutes autres exigences en matière de conservation des documents applicables à votre étude (p. ex., certains organismes subventionnaires peuvent avoir d'autres exigences en matière de conservation des documents qui peuvent être plus longues que la période mentionnée ci-dessus).

RÉPERTOIRE DES PARTICIPANTS À LA RECHERCHE :
En vertu des directives du Ministère, tous les chercheurs doivent tenir un répertoire des participants (patients, personnel, résidents, autres fournisseurs de soins, famille, etc.) de leur étude. Le CER peut requérir le répertoire des participants à la recherche à tout moment. Utilisez la version électronique du répertoire qui se trouve sur le site Web du CHSM (http://smhc.qc.ca/fr/recherche/revue-de-recherche/informations-exigibles-au-cours-du-porjet).

Pour toute correspondance future, veuillez-vous adresser au bureau d'examen de la recherche du Centre de recherche de St. Mary.

Veuillez agréer, Madame Law, mes salutations distinguées,

Julie St-Cyr, M.D.C.M., F.R.C.P.C.
Présidente, Comité d'éthique de la recherche
Centre Hospitalier de St. Mary

c. c.: Mme Ilja Ormel, Étudiante au doctorat
Mme Renée Proulx, Directrice adjointe affaires universitaire, enseignement et recherche
M. Wim Wolfs, Gérant, Centre de Recherche de St. Mary

Appendix D: Official forms to be used for research study

Contents

D1 Consent Form Professionals

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Information form for participant and consent form

Project: Community Perspectives on the Cholera Epidemic in Haiti, 6 Years Later: What are the perceptions of patients and communities in Artibonite, and how can their voices influence improved prevention and care to eradicate the disease?

Hello,

We invite you to participate in a research project conducted by Action Against Hunger (AAH) and McGill University. My name is Ilja Ormel and I am a student conducting research in collaboration with AAH. This project is designed to better understand how interventions against cholera can be improved. As part of the project, we will be interviewing community members and professionals working in the cholera response. Please read this information sheet carefully before deciding whether or not you would like to participate in this study. If you are interested, please talk to your friends, family, or family doctor. You can contact me if you have any further questions. You will receive a copy of this informed consent form for your records. Please take as much time as you need to make your decision.

Thank you for your attention.

What is the purpose of this study?

Our research project aims to better understand how we can improve our cholera interventions from the perspective of community members. This is part of a larger program of the Canadian Health Experiences research group based at McGill University in Montreal.

What is Health Experience Research Canada?

Health Experience Research Canada brings together a group of researchers who are working to improve our understanding of people's experiences of health and illness and to provide resources to support people with a variety of health conditions. We do this by collecting personal stories about what matters to people facing health challenges. Participants share their experiences, knowledge, coping strategies and suggestions for improving health care.

Who can participate in this study?

For this study, we are looking for people who have been infected with cholera or who live in areas at risk of cholera infection and professionals who work with cholera. If you would like to participate, we will explain our activities or arrange a telephone interview and answer any questions you may have. We will also check if your experience is relevant to our study

What do you do with the collected data?

This study will allow us to identify issues for patients, caregivers and professionals involved in cholera, thus contributing to the understanding of their experiences with a health problem or illness. The ultimate goal of this study is to increase public awareness of the experience of people at risk of cholera infection and how we can better meet the needs of their families, friends and professionals involved in cholera. We collect information on video and audio tapes and then the interviews are transcribed and can be used in different ways:

- to learn what is important to people at risk of cholera infection and their families who are facing different health problems;
- to develop other sources of support and information for people
- to train health professionals;
- to write research reports.

The data will be used in strict accordance with the standards of the National Bioethics Committee in Haiti and also with the laws of Canada and Quebec. The study data may be reviewed by McGill University personnel for verification and control purposes.

Do I have to participate?

No. It is entirely up to you to decide whether or not you wish to participate. If you decide to participate you will receive an information sheet for your records. You are always free to stop participating at any time without giving a reason. If you decide to stop, we will not ask any questions. Your decision to participate in the study or not will not affect the quality of medical care you or your family member receives.

What will happen if I participate?

Your participation in this research project is completely voluntary. I will contact you either in person or by phone to schedule an interview. Most interviews take place at the participant's home. If you wish to have this interview at another location that we will arrange this.

Giving your consent

I will ask you if you agree to have the interview videotaped or audiotaped. You will receive the "consent form". You only sign this form if you agree to participate in the interview. You will receive a copy of the consent form to keep.

The researcher, sponsor, St. Mary's Hospital Research Ethics Board do not routinely offer compensation but you do not waive your rights to compensation by signing this consent form. You are not waiving your rights and the sponsor, the research ethics board and the researcher are not absolved of their professional responsibility.

How will the interview be conducted?

The interview will be conducted as a conversation in which I will ask you to talk about yourself in your own words. I will ask you about your experience with cholera, what your thoughts and feelings were about cholera, how you got information about cholera, and what were the good and bad parts of that experience.

How long will the interview take?
The length of the interview varies depending on what you have to say, but most interviews last about an hour. A few extra minutes are also needed for preparation, answering your questions and completing the consent process.

What if I decide to withdraw from the study after the interview?
You are free to withdraw at any time. If you decide to withdraw after the interview, all videos, audiotapes, transcripts, and recordings of your interview will be destroyed. If you decide to withdraw after the website or other audio-visual sources are completed, we would remove your contribution from all subsequent versions, but we would be unable to destroy existing material already viewed by others.

What happens after the interview?
I will identify the tape with a code number to keep your anonymity and give it to a typist who will transcribe everything you said in the interview. The typist has signed a confidentiality agreement. The tape and transcript identified only by the code number will be kept in a locked cabinet at St. Mary's Research Centre for five years. After this period, they will be destroyed unless the principal investigator wishes to keep them for a longer period of time for further analysis. All digital data will be kept on Susan Law's or Ilja Ormel's password-protected computers at the St. Mary's Research Centre or at AAH's offices.

Reviewing your interview

After the interview you will have one week to notify us if you do not want your interview or certain sections of your interview to be used. We will remove the sections you do not want us to use.

You can also choose the format in which you want your interview to appear on the resources we produce (see below). You will have a choice of video, audio, and/or handwritten versions of your interview. If you value anonymity, we will invite you to use an alias for yourself and others, and you may remove any part of the interview that might identify you.

How will the researcher use the tape and transcript of the interview?

If you sign this form, you are assigning the copyright associated with the interview to St. Mary's Hospital Centre. It is very important that you take the time to think about and discuss the copyright form before you sign it. A copy of the form will be given to you for your records.

If you decide to allow your interview to be used for the study, it will be used with the interviews of 8-10 other community members. The interview will be used to create a "trigger film" and in interviews about the co-design process. The data will be used strictly in accordance with the standards of the National Bioethics Committee of the MSPP in Haiti and the laws of Canada and Quebec. Individuals from the St. Mary's Hospital Research Centre and the donor will be able to access the study data for verification and monitoring purposes.

What will the patient feedback meetings look like?

Following the development of the trigger film, we will invite community members to participate in a reflection session on the content of the trigger film lasting approximately two hours. Participants will help shape the next phase of this project and develop ideas to fuel the process of change and improvement. The second session, lasting approximately three hours, will be a joint patient-staff meeting where you will have the opportunity to identify common priorities for improving services to your community.

Are there any risks to participate in this study?

During the interview all questions will be about your experience. Some people find it helpful to share their experiences with the researchers and other participants, others may feel sad, emotional or overwhelmed when talking about their experiences in the hospital. This research is not a health care service. When you choose to post your own video on the Internet, you may be identified by others. If you are recognized on a website or DVD, this could be compared to a television appearance.

You may discuss this with your family members if you wish as they may be related to your appearance on the screen.

The material on the website is under copyright and may not be copied or recorded, but it is possible that it may be. If you are unsure about how you would like your interview included (either video, text only, or with an alias), please talk to me or I could, if you prefer, find you an independent consultant to talk to.

Who reviewed this study?

This study was approved by the National Bioethics Committee in Haiti and the Research Ethics Committee of St. Mary's Hospital.

Who is organizing and funding this research?
The project entitled "Community Perspectives on the Cholera Epidemic in Haiti, 6 Years Later" is partially funded by Action Against Hunger and a stipend from CIHR for student work.

For more information
If you have any concerns about the project or wish to discuss anything, please call Ilja Ormel at [+509 4893 4912].
If you wish to speak with someone not related to the study about your rights as a participant, or if you have any complaints about the research, you may call the Complaints and Quality Services Commissioner at the National Bioethics Committee in Haiti, Dr. Lerebours Gerald, President: 29, avenue de la Ligue Féminine ci-devant 1e avenue du Travail, Port-au-Prince.

Note:
- I am a professional researcher and I am paid for my work.
- The project has received approval from the National Bioethics Committee of the MSPP in Haiti.
- The project has received approval from the St. Mary's Research Ethics Committee for Health Research.

Thank you for reading this information sheet.

Ilja Ormel

PARTICIPANT CONSENT FORM

Database reference number: ____________

Please initial in the square.

1. I confirm that I have read the participant information sheet for the study "Community Perspectives on the Cholera Epidemic in Haiti, 6 Years Later", had the opportunity to ask questions, and believe that I have received satisfactory answers. ☐
2. My participation is voluntary and I am free to withdraw at any time without giving any reason and without repercussion on my medical care or rights. ☐
3. I acknowledge that individuals from St. Mary's Research Centre (Research Ethics Board and an independent monitor) may view relevant data collected during this study for audit and control purposes, and when relevant to my participation in this research. I authorize these individuals to view the record of my participation in this research. ☐
4. I agree to participate in the project entitled "Community Perspectives on the Cholera Epidemic in Haiti, 6 years later". ☐
5. If you decide to participate in this research project, you will be given a copy of this consent form. ☐
6. May we contact you for participation in future research project? Oui/Non

Name (Capital letters) : ________________________________
Signature : ____
Date : ____
Name of the researcher: ______________________________
Signature: ____
Date : ____

D2 Simplified Consent Form Community Members

Reference number of the database: _______________

CONSENT FORM

Community Perspectives on the Cholera Epidemic in Haiti, 6 Years Later: What are the perceptions of patients and communities in Artibonite, and how can their voices influence improved prevention and care to eradicate the disease?

This is a consent form. Consent means to agree. You can check the box if you agree. ☐

I want to be part of this project. ☐

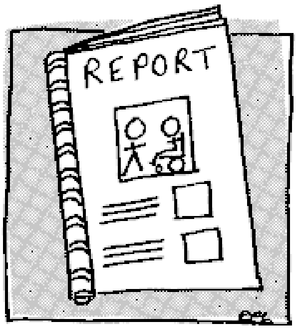
I know that Kendy Massena and Ilja Ormel want to talk to me about my cholera experiences. ☐

I understand the information form and Kendy or Ilja answered my questions. ☐

I know I can say 'no' and change my mind at any time. ☐

Je sais que Kendy et Ilja vont garder mon information en sécurité. ☐

I know that Kendy and Ilja will keep my information safe. ☐



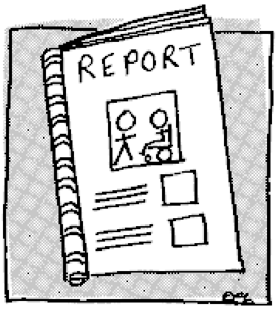
I know that Kendy and Ilja want to write a report but nobody will know my name. ☐

How my interview will be used

This form explains how my interview will be used in the future. This is up to me; I don't have to say yes.

I know that Kendy and Ilja want to create a film that can be put on the Health Experiences' or ACF's website. This means that anyone can see it. ☐

I know Kendy and Ilja want to write a report but they won't use my name. ☐



I know that the Health Experiences research group and others, approved, by Susan Law may use my interview in various ways for teaching or reporting purposes. ☐

I agree that my interview should be used as:

- ☐ video
- ☐ audio recording
- ☐ in writing only

I am happy that St. Mary's Research Centre is using my interview in this way. I know that if I change my mind at any time, I can ask Kendy Massena or Ilja Ormel not to use my interview.
My name: ____

Signature: ____
Date: ________________________

Name of the researcher: ILJA ORMEL
Signature: _______________________________________
Date: ___________________

Interviewer: ____
Registration available as: ☐ Video ☐ Audio
Number of interviews with this person: _______________
Database ID: _____________
Title of series: ______________________

D3 Copyright consent form

Projet manager at McGill:
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(+509) 3170 7351

Project: Community Perspectives on the Cholera Epidemic in Haiti, 6 Years Later: What are the perceptions of patients and communities in Artibonite, and how can their voices influence improved prevention and care to eradicate the disease?

Future use of my interview

I agree that members of the St. Mary's Research Centre (SMRC) research team and other researchers authorized by SMRC may have access to my interview for teaching, dissemination, research, and the production of audio-visual resources and other publications. I consent to all such uses, including any translation of the material into other languages.

I also agree that my interview may be used to contribute to the "Experiences of Health and Illness" collection on the www.healthexperiences.ca website. Summaries on the websites will be publicly available and excerpts from my interview may appear on other sites approved by the organization.

I understand that for these purposes, the materials may be shared and used by academics, presenters, training course writers, web designers, information disseminators and others. They will not be used for advertising or purely commercial purposes.

I understand that by agreeing to have my interview and related materials posted on the Internet, they will be accessible to Internet users around the world, including countries with less stringent data protection laws than Canada. I also understand that the research group may at times wish to collaborate with reputable partners in these countries and I consent for my interview and related materials being shared and used by these partners.

I agree that my interview may be made available in the following format(s) (check all that apply):

☐ Video recording ☐ Audio recording ☐ Written transcript

To allow full use of my interview, I assign copyright of my contribution to St. Mary's Research Centre. In return, my interview will only be used as described above. If I decide that I no longer want my interview to be used on the website (or otherwise), it will be immediately removed at my request, although I recognize that it may not be possible to remove all existing copies from circulation

Title of the series: Community Perspectives on the Cholera Epidemic in Haiti, 6 Years Later: What are the perceptions of patients and communities in Artibonite, and how can their voices influence improved prevention and care to eradicate the disease

Registration in : ☐ Vidéo ☐ Audio	Number of interviews with this respondent: ________________	Database ID : _________________________
__________________________ Name of participant (**Capital letters**)	__________________________ Date	__________________________ Signature
__________________________ Interviewer	__________________________ Date	__________________________ Signature

D4 Focus Group Guide: Community, Nov 2017 (translated from French)

Day, Date, Time, Location:

Goals of this session:

- Review and receive feedback on current cholera interventions.
- To identify participants' preferences for cholera interventions

Agenda

Facilitator: name and position
1. [5 MIN] Welcome, overview of the project and purpose of this session
2. [15 MIN] Consent form - explanation and signature
3. [10 MIN] Introductions - participants, team members and background

Questions for discussion:

4. 4. [5 MIN] What do you know about cholera?

5. [10 MIN] People often describe a negligent attitude of the populations towards cholera prevention measures.
- How does it make you feel when people say the population is negligent?
- Could you give an example of what is currently, for you, another more important concern then cholera?

6. Do you think you continue to be at risk of cholera infection?
- Do you think you are able to prevent cholera infection for yourself and your family?

7. Is there anything new you have learned recently about cholera?
   - What kind of effect (change) has this new knowledge had?
   - In your opinion, do you think the hygiene promotion messages provide good information?
   - Messages that did not make sense or did not adequately inform your community?

9. 15 MIN] What are your hopes for cholera awareness in your community?
   - What kind of things can you do to help stop the cholera epidemic?

10. 10. [5 MIN] Summary of key points and priorities, next steps

Thank you and end the meeting

D5 Focus Group Guide: Cholera Patients

Day, Date, Time, Location:

Goals of this session:

- Better understand what it was like to be sick with cholera.
- Review and receive feedback on current cholera interventions.
- Identify participants' preferences for cholera interventions.

Agenda

Facilitator: Kendy Massena, Research Assistant

1. [5 MIN] Welcome, overview of the project and purpose of this session
2. [15 MIN] Consent form - explanation and signature
3. [10 MIN] Introductions - participants (describe something you like and dislike)

Questions for discussion

4. 10 MIN] What do you know about cholera?

Thank you for giving us all this very important information, and we are sure you are well informed. And now we want to put this aside and we would like to talk about your experiences with cholera.

5. [10 MIN] We invite you to think about the time when you were sick and tell us an experience/story that illustrates an important or significant moment in the experience.
   - What do people say when someone has cholera?

6. [10 MIN] Did your experience with the disease change your behaviour?
   - What are you doing differently to protect yourself?
   - How were you able to make this change in behaviour?
   - Are there any changes you would like to make?
   - Why did you decide to make this behaviour change?

7. [10 MIN] Brainstorm on ideas for improving cholera interventions
   - Is there anything you wish professionals who respond to cholera knew or would consider differently?
   - What kinds of things could be done to help stop the cholera epidemic?
   - If I gave you a magic wand, is there anything you would change about the care/services you received?

8. [5 MIN] Summary of main points and priorities, next steps

Thank you and end the meeting

D6 Focus Group Guide: Alternative health Practitioners, Nov 2017 (translated from French)

Day, Date, Time, Location:

Goals of this session:

- Examine and gather feedback on the current interventions on cholera
- Identify what participants appreciate most of the cholera interventions

Agenda

Facilitator: Kendy Masséna, Research Assistant

1. [5 MIN] Welcome, take a look at the project and the purpose of the session
2. [15 MIN] Consent Form - Explanation and Signature
3. [10 MIN] Presentation of participants, team members and background

Questions for discussion

4. [5 MIN] What do we know about cholera? (we're going to put this aside)
5. [10 MIN] People often describe a negligent attitude in the population in relation to cholera prevention.
   - How do you feel when people are said to be negligent?
   - Could you give an example at the moment, for you, of another more important concern than cholera?

6. [10 MIN] When do people who think they have cholera come to you?
   - What are their fears and anxieties about cholera?

7. [10 MIN] When is it a case of ‘cholera naturelle’ or a case of ‘cholera mystique’?
   - Can you give us an example of how you treat ‘cholera mystique’?
   - Do you manage to heal people with cholera?

8. [10 MIN] How do you see your role with regards to the professionals who intervene in cholera?

9. [10 MIN] What is our hope for raising awareness about cholera in the community. How should ‘cholera mystique’ be addressed?
   - At what point do you think would community members have the skills to protect themselves from cholera infection?
   - What do you think we can do to help stop the cholera outbreak?

10. [5 MIN] What are the priorities for the next step?

Thank you and end the meeting

D7 Interview Guide: Professionals, Nov 2017

Introduction
Hello - My name is [NAME]. I am part of the team for this study and I work for Action Against Hunger (AAH). Thank you for agreeing to participate in this project. The goal is to improve the experiences of both those providing and receiving AAH's cholera interventions. This pilot project is part of a larger goal to improve the way services are delivered. We are using an approach called Experience-Based Co-Design. This approach provides a unique opportunity for staff and community members to work together to redesign services to improve community and staff experiences.
Today we would like to speak with you in order to better understand your experience with cholera in relation to the perspective, experiences and needs regarding cholera prevention. With your consent, we will make an audio recording of this interview. Part of this project involves the development of a short film (called a "catalyst film") about key issues related to improving cholera interventions - to share with other patients and families, as well as with the clinical team. This will inform the meeting we will have together to plan changes that will improve people's experiences with the cholera prevention efforts. The interview data we will use will be anonymized and you will also have the opportunity to review the film before it is released.
For the purposes of this interview, it will focus on the following themes

1. The issues response professionals face with respect to cholera.
2. Your experiences and vision for the communities that are part of the cholera response.
3. What do you think could improve the response process?

Information

- Let's start with your role in the cholera response
    - o What are your responsibilities, including your primary responsibilities? (disinfection, public health, data collection, prevention etc.)
    - o How would you describe your team, i.e. the team you work with most often?

Interventions

Decision-making and interdisciplinary team (involvement of different disciplines)

- How would you describe teamwork around cholera interventions?
    - o How are decisions about interventions made?
    - o What happens when there are differences of opinion around the context of cholera interventions? How are these differences managed? Who usually mediates in such situations?
- How much autonomy does your team have to make decisions about cholera interventions?
- Do you work with other health facilities and/or organizations when you work?
    - o How would you describe this process?
    - o What organizations do you need to contact or interact with?
    - o What obstacles or barriers emerge? How is this managed?

    - To what extent would you say that information sharing improves or worsens interventions?

- What do you think are the roles of alternative health practitioners in the cholera response?
- Have you had any collaboration with alternative health practitioners? If so, what kind of collaborations do you have with alternative health practitioners?
- How would you describe the role of the intervention team in the cholera response? What are your impressions of this? Do you think the intervention team could play a bigger role in this? How would you describe this?
- What are your impressions of the experience of community members following the response?
    - What gives you that impression?
    - Can you think of situations that led you to have this impression?

Existence of a structured protocol or plan

- Is there a structured protocol or plan in place? How useful is it? Why or why not? What do you think could improve such a protocol or plan?
    - What does such a protocol or plan include?
- What are the barriers to this? How are they managed?

Patient and family engagement

- What kind of discussions or conversations are taking place with the community regarding cholera?
- What do community members say most often? What do they talk about? What are their fears and anxieties about cholera? To what extent would you say these fears and anxieties are being addressed?

Behaviour of the population

- It is said that the population is well informed about the cholera messages, but that they have not yet changed their practice? What do you think of this?
- What changes have you observed since the beginning of cholera until now?
- What are the means you are using to convey awareness messages? In your opinion, is this way of doing things really adapted to the expectations of people in the community?
- Does the population feel that they can protect themselves?
- In your opinion, after being sick, are patients more motivated to change?

Improving services

- What do you think communities would identify as things that would improve their experiences?
- What do you think would be the major elements or critical moments in the cholera prevention trajectory (and that help shape their overall experience)
- With respect to staff. What would be the priorities for process improvement?
- How should things be done?
- What other things do you think would need attention to improve your experience and that of the staff responsible for the response?

- What do you think your team or institution can do better in raising awareness?
- What are the strengths and weaknesses of the (outreach) team?

Orientation-Discharge/Exit Strategy

- How involved are you in interventions to train community members so that they know how to protect themselves from cholera infection? How useful do you think these interventions are for community members?
- How do you develop interventions to teach community members to protect themselves from cholera infection?
- When do you try to engage community members in this process? How are you doing this? How are you successful in making such efforts?

Coping and Care Management

- How do you think community members feel about the services you provide?
- How well would you say communities have the skills to protect themselves from cholera infection? What makes you say this?
- What do you think are the main issues that communities face in protecting themselves?
    - What do you think is happening right now to address these issues?

End of interview:
Is there anything else you would like to share with me about your experiences and what could be done to make things better in the future?

- ➢ Please ensure that the participant has the contact information.

Thank you for your participation!

D8 Participant details – community members

Reserved section - to be completed by the researcher:
Name: No. Reference:

General Profile:

Age groups: ☐ 18-29 ☐ 30-44 ☐ 45 and above

Marital status:
☐ Single
☐ Married
☐ Divorced or separated
☐ Common law
☐ Widowed

Gender: ☐ Woman ☐ Man ☐ Other_____________

Number of people in your household: ____________
Children: ☐ yes ☐ no
Age children: _____________________
Address:
____

____

Education level: ☐ never attended school ☐ literate ☐ elementary school ☐ high school, college

Employment status :
Main occupation of the interviewee: __________
Primary occupation of head of household: __________

Additional community responsibilities (e.g., health worker, water point management committee, pastor, religious leader, etc.):

Residence:
Do you live in a:
☐ Private house
☐ Rented house
☐ Shared house
☐ Other __________

Do you live:
☐ In the city (urban/suburban setting)
☐ In the country (rural setting)
☐ Other :_____________

Roofing of the house: ☐ stain/straw ☐ concrete ☐ sheet metal ☐ other

Partition materials: ☐ wood ☐ earth/clay/mud ☐ rock/wood/earth ☐ cement/block ☐ brick/rock ☐ other
Equipment: ☐ Water facility ☐ latrine ☐ hand washing device ☐ shower ☐ electricity ☐ radio ☐ TV ☐ cell phone ☐ other, specify:
Health status:
Did you have cholera? ☐ Yes ☐ No

How many times did you have cholera: ___________________

Dates when you had cholera: ___________________________

D9 Participant details – professionals involved in the cholera response

Reserved section - to be completed by the researcher:	
Name:	No. Reference:

Personal information:

Age groups: ☐ 18-29 ☐ 30-44 ☐ 45 and above **Marital status:** ☐ Single ☐ Married ☐ Divorced or separated ☐ Common law ☐ Widowed	**Gender:** ☐ Woman ☐ Man ☐ Other_____________ **Address:** ____ ____ ____

Education level: ☐ Primary school ☐ Secondary school ☐ University ☐ Professional

Qualification : __________________________

Employment status:

Position :

____

______

Job description :

____

____

____

Experience

Number of years of experience in cholera (relevant to your position):

____

D10 Guide for Brainstorm Session with Team Leaders

Focus Group with Rapid Response Team Leaders
Date: Friday, November 11, 2017
Time: 3:00 - 4:30
Duration: 90 minutes
Location : Gonaïves, Haïti (ACF Office)

Purpose Session

- Better understand how the hygiene promotion activities are perceived and the behaviour change.
- To identify opportunities and ideas for improving cholera interventions.

Agenda for the session

Facilitator:
1. 5 MIN] Welcome, overview of the project and purpose of this session
2. 10 MIN] Consent form - explanation and signature
3. 10 MIN] Introductions - participants, team members and background

Questions for discussion:

4. [60 MIN] Brainstorming (with small group of 4 people)

A. [20 MN] Community members' perceptions during cholera interventions [INTERVENTIONS]	Q1: What are your impressions of the outreach received by community members? a. What gives you that impression? b. Can you think of any situations that led you to have this impression?
B. [20 MN] Identification of barriers to behaviour change in communities [OBSTACLES]	Q2: What are the main issues communities face? a. What do you think of these issues as a barrier in the process of behaviour change in communities? b. What kind of discussions or conversations are taking place and what do people say most often?
C. [20 MN] Identification of opportunities/improvement in the service offered by Action Against Hunger in the fight against cholera in the communities [CHANGES]	Q3: In your experience, what should be changed in the interventions to achieve behaviour change in the community? a. Are there specific opportunities? b. Suggestions for improvement?

5 [MIN] Summary of main points and priorities, next steps
Thank you for your participation!