



**THE ROLE OF COMMUNITY ENGAGEMENT AND INVOLVEMENT FOR  
COMMUNITY EMPOWERMENT IN HEALTH SETTINGS: THE CASE OF  
INGWAVUMA COMMUNITY, KWAZULU-NATAL, SOUTH AFRICA**

**By**

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A Thesis by Manuscripts Submitted in Fulfilment of the Requirement of the Degree of Doctor of  
Philosophy (PhD) in the Department of Public Health Medicine

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College of Health Sciences

**University of KwaZulu-Natal, Durban, South Africa**

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2023


## **PREFACE**

The study described in this thesis was carried out in the Department of Public Health Medicine in the School of Nursing and Public Health, College of Health Science, University of KwaZulu-Natal (UKZN), Durban in South Africa between June 2019 and January 2023. The work was supervised by Professor M J Chimbari. The study described in this thesis is original work done and reported by the PhD candidate. The study has not been used in any form, by any person or submitted to any tertiary institution for the award of a degree or diploma. Some of the work has been published in accredited journals in line with the thesis guidelines of UKZN. Due acknowledgments have been accorded where other people's work has been used in the text. This study is on community engagement and involvement for community empowerment and was conducted under the KwaZulu-Natal Ecohealth Program (KEP) projects. The findings reported are based on the MABISA (Malaria and Bilharzia in Southern Africa) and TIBA-SA (Tackling Infections to Benefit Africa-South Africa) studies.

## **Declaration 1: Plagiarism**

I, **Zinhle Mthembu** declare that:

- (i) The research reported in this thesis, except where otherwise indicated, is my original work.
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## Declaration 2: Publications

The publication (published, in print and/or submitted) that constitute this thesis and the contribution I made to each of the manuscripts are presented below:

### Publication 1

Mthembu, Z., Mogaka, J.J.O and Chimbari, M.J. Community Engagement Processes in Low-and Middle-Income Countries Health Research Settings: A Systematic Review of the Literature. *BMC Health Services Research* (2023) 23:457 <https://doi.org/10.1186/s12913-023-09466-9>.

#### *Authors contributions*

The PhD candidate led the entire process of developing the paper, from conceptualizing and designing the study to finding relevant studies using databases and registries, data extraction, and finalization with guidance from the supervisor (MJC). The other authors (MJC and JOM) contributed to the conceptualization of the work and edited and critically examined each draft. The submission was approved by both authors.

### Publication 2

Mthembu, Z., Chimbari, M.J., and Macherera, M., 2023. Facilitating community engagement: Researchers' lived experiences in rural communities in the KwaZulu-Natal Ecohealth Program, South Africa. *Cogent Social Sciences*, 9(1), p.2225833.

#### *Author contributions*

Together with my supervisor (Prof. Chimbari) who is the second author of this paper, I conceptualized the study, and I also collected the data and wrote the manuscript. The manuscript was evaluated critically by my supervisor and the third author.

### Publication 3

Mthembu, Z. and Chimbari, M., Community Engagement: Health Research through Informing, Consultation, Involving and Empowerment in Ingwavuma Community. *Frontiers in Public Health* (2023), 11:1933 <https://doi.org/10.3389/fpubh.2023.1050589>

#### *Author contributions*

The PhD candidate led the entire process of developing the paper, from conceptualizing and designing the study to finding relevant studies using databases and registries, data extraction, and finalization with

guidance from the supervisor (MJC). All drafts of the manuscript were critically evaluated and revised by the supervisor.

#### **Publication 4**

Mthembu, Z., Chimbari M.J. 2023. Community engagement and collaboration between researchers and community stakeholders for schistosomiasis and malaria projects in Ingwavuma, uMkhanyakude District, KwaZulu-Natal. Submitted to *Humanities & Social Sciences Communications*. Status: Manuscript Under Consideration: 18 January 2024.

#### **Author contributions**

The PhD candidate led the entire process of developing the paper, from conceptualizing and designing the study to finding relevant studies using databases and registries, data extraction, and finalization with guidance from the supervisor (MJC)

Signed

A black rectangular box redacting the signature of the author.

Date: 25 September 2023

**Zinhle Mthembu**

## **Dedications**

This work is a fruit of countless and arduous sacrifices.

This thesis is wholeheartedly and proudly dedicated to my mother, *Pinky Priscilla Mdanda* and my late father, *Thulani Gabriel Mthembu* and his twin sister *Nokuthula Cecilia Mthembu*, whose love for me knew no bounds and, who has taught me to work hard for the things that I aspire to achieve.

To my son, *Phumelela*, who has been affected in every way possible by this quest.

Last but certainly not least, I dedicate this work to *God Almighty*, my creator, my strong pillar, my source of inspiration, wisdom and knowledge.

## Acknowledgements

I thank those who have helped and supported me personally and professionally during the thesis process. Words cannot express my gratitude to my supervisor, Professor Moses J Chimbari for his enthusiasm for research and his invaluable patience and feedback. He generously provided support, guidance and knowledge throughout this study. I have learned so much from him, indeed, "*Nothing is impossible with Moses.*" The vast wisdom and wealth of experience of Prof Chimbari have inspired me throughout my doctoral studies and academic journey. A special thanks go to Dr Tafadzwa Mindu for his unreserved input into the study. I would like to thank the KwaZulu-Natal (KEP) research team, community research assistants (CRAs), community advisory board (CAB) members, community health workers, primary school principals, the traditional leaders (Izinduna) and the community of Ingwavuma for availing themselves during the data collection process. Their input in this study is highly appreciated. I also appreciate CRAs who assisted me with data collection. I acknowledge the Department of Public Health Medicine, in the School of Nursing and Public Health at the University of KwaZulu-Natal for providing me with the resources to pursue this study. In addition, I thank Ms Nokwanda Majola and Mrs Sambulo Ntombela for the administrative and technical support provided throughout my research. Lastly, I would be remiss in not mentioning my family, especially my son and my mom. Their belief in me has kept my spirits and motivation high during this process.

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## **List of acronyms**

<b>CAB</b>	Community Advisory Board
<b>CBPR</b>	Community-Based Participatory Research
<b>CCG</b>	Community Care Giver
<b>CE</b>	Community Engagement
<b>CEI</b>	Community Engagement and Involvement
<b>CHW</b>	Community Health Worker
<b>CLO</b>	Community Liaison Officer
<b>CRA</b>	Community Research Assistant
<b>KEP</b>	KwaZulu-Natal Ecohealth Program
<b>MABISA</b>	Malaria and Bilharzia in Southern Africa
<b>PAR</b>	Participatory Action Research
<b>PI</b>	Principal Investigator
<b>PRA</b>	Participatory Research Appraisal
<b>TIBA</b>	Tackling Infections to Benefit Africa
<b>UKZN</b>	University of KwaZulu-Natal
<b>VBDs</b>	Vector-Borne Diseases
<b>WHO</b>	World Health Organisation

## Abstract

Community Engagement (CE) in health research can improve a community's ability to address its own health needs and health inequalities, while ensuring that researchers understand community priorities. However, if effective CE processes are not used, communities will not be empowered to make effective decisions about their own health and wellbeing. This study is based on community-based health research projects; the Malaria and Bilharzia in South Africa (MABISA) and Tackling Infections Disease Burden in Africa-South Africa (TIBA-SA) implemented by the KwaZulu-Natal Ecohealth Program (KEP). I evaluated CE processes and outcomes, with a focus on schistosomiasis and malaria in a rural community of Ingwavuma, uMkhanyakude district in KwaZulu-Natal. The research approach was both qualitative and quantitative (mixed methods) with data collected through 34 in-depth interviews, 4 focus group discussions and 338 household questionnaires. Data was collected from heads of households, community advisory board members, community research assistants, primary school principal and KEP research team (including the project principal investigator and administrators). Data was collected in line with the five-stages of Community Engagement Vancouver Coastal Health framework. Data was analysed using QSR International Pty Ltd, NVivo 12 Pro and Chi-square tests were performed to assess associations between demographic variables and respondents' knowledge and information of projects. The Principal Investigators informed the community about the project through community leaders (headmen) before the project commencement. As community members were involved at every stage of the process, from conceptualisation to dissemination, the study provided empirical evidence that collaborative partnerships lead to win-win outcomes. Involving headmen (indunas), CAB members, and CRAs in the project ensured shared goals, reciprocity, and mutual benefit, demonstrating the project's intention to help the community. Nearly half (48%) of the surveyed community members had never heard of MABISA. Ninety-four percent (94%) and ninety-seven percent (97%) of respondents had heard of bilharzia and malaria. Nearly the same proportions knew how both diseases are transmitted, thus demonstrating empowerment of community members on schistosomiasis and malaria issues. This study contributed to the understanding of best practices for community empowerment. The study provided information on how communities can positively influence their lives and manage their health problems. Such information can be extracted from the thesis and presented in vernacular language from the area. Furthermore, the thesis provided information of empowering researchers on how they can empower communities through effective engagement. Policy briefs that can be generated from the thesis provided useful information on community empowerment to policymakers and other stakeholders.

**Keywords:** Community engagement, empowerment, community-based research, schistosomiasis, TIBA-SA, malaria.

**CHAPTER 1**  
**INTRODUCTION AND LITERATURE REVIEW**

## 1.1 Introduction

Based on experiences from the case of the epidemic of the Ebola virus disease (EVD), the World Health Organization (WHO) now places a strong emphasis on the significance of Community Engagement and Involvement (CEI) in dealing with health issues. In 2014, the EVD outbreak provided an opportunity to learn more about CEI in terms of what did and did not work as the CEI was employed to strengthen health systems and communities (World Health Organization, 2015). CEI is one of the requirements for public health research that plays a crucial role in the recruitment process and informed consent (Allotey, Reidpath, Devarajan, Rajagopal, Yasin, Arunachalam, Debora Imelda, Soyiri, Davey, and Jahan, 2014). CEI is an ongoing process that is the meaningful, respectful, and fit-for-purpose involvement of a range of community members in one or more aspects of the research project (“Resource guide for community engagement and involvement in global health research,” n.d.). Allotey et al. (2014) reported that because of CEI processes a response rate of 85% in the research of the communities was achieved, thus indicating the importance of CEI in mobilizing study communities. Nelson (2019) states that all CEI work requires a deeper understanding of the intersecting experiences of marginalisation and exclusion of those most affected to achieve a transformative impact. ‘Community engagement’ and ‘involvement’ in global health research are not new concepts. Since the late 1950s, debates over public health planning, health systems development, and horizontal versus vertical approaches to international public health interventions have centred on community engagement and its potential to improve the health and well-being of poor and marginalized populations (“Resource guide for community engagement and involvement in global health research,” n.d.). In recent years, Community Engagement (CE) as an umbrella term has been used more often, therefore, the term CE was used in this thesis consistently.

WHO defines Community Engagement (CE) as “a process of developing relationships that enable stakeholders to work together to address health-related issues and promote well-being to achieve positive health impact and outcomes” (World Health Organisation, 2017). CE in research is also defined by Ahmed, Nelson, Kissack, Franco, Whittle, Kotchen, Meurer, Morzinski, Brandenburg, 2015:161) as “a process of inclusive participation that supports mutual respect of values, strategies, and actions for the authentic partnership of people affiliated with or self-identified by geographic proximity, special interest, or similar situations to address issues affecting the well-being of the community or focus.” United Nations International Children's Emergency Fund (UNICEF) (2019h) perceived CE as a foundational action for working with a wide range of communities including vulnerable groups, civil society, community leaders and collective social groups to address the issues that affect their lives. The term CE is not a relatively new terminology for WHO commonly referred to it as the practice of moving communities towards a better change through empowerment. Overall, there are several definitions of CE provided by the above-mentioned authors (World Health Organization, 2017; Ahmed et al., 2015; and UNICEF, 2019h), and in most of these definitions, there seems to be some evidence to indicate that CE is about community participation and empowerment working with a wide range of stakeholders.

Therefore, the current study describes CE as a co-owned, continuous, sustainable, participatory interaction between community members, stakeholders and researchers or implementers who share equitable power and decision-making roles to protect the health and well-being of the entire ecosystem.

Engaging communities, empowers social groups, leaders and the community at large and improves development as well as a wide range of organisations, agencies and networks in the community. However, many studies have reported that there is little guidance on how to assess the CE effectiveness, the outcomes and the impact on communities, which should lead to community empowerment (Allotey et al., 2014; Chen, Mullins, Novak, Thomas, 2016; and World Health Organization, 2017). Engaging communities in research initiatives can be a messy process and lead to unfair health outcomes and inequalities especially if there is no guidebook or model to follow. This can also create tensions when dealing with the complexity of communities, actors and researchers with different levels of power. There is still a challenge of power sharing in setting research agendas initiated and led by researchers, community organisations and key informants that encourage community participation and voices of marginalised groups (“Resource guide for community engagement and involvement in global health research,” n.d.). Community engagement turns out to be less inclusive and effective when involving top-down approaches in all processes of project implementation and dissemination of information to communities leading to disempowered communities (Baybay and Hindmarsh, 2019). Community engagement and community empowerment are two interdependent concepts. Community empowerment is, therefore, more than engaging; nonetheless, it is the community’s capability to make informed decisions about their health care (Chen et al., 2016). Throughout this thesis, the term community participation will be used to refer to “both individuals and communities involved in active participation in community health activities by building capacity and confidence to address and tackle power and control over their lives” (McCollum, 2016:2).

The core element of any research effort is the involvement of communities in the conceptualisation, planning and implementation of the project. This requires the researchers to become part of the community and the community members to become part of the research team, thereby working together in collaboration and creating a learning environment before, during, and after the research (Ahmed et al., 2015). With careful consideration of the distinctions between community engagement and community empowerment, in health literacy, these two prevailing concepts can be used to complement and improve compliance to empower individuals and communities (Batterham, Hawkins, Collins, Buchbinder, Osborne, 2016). Therefore, the clearest roadmap for researchers to accomplish community empowerment is through genuine community engagement. However, the gap still exists in ensuring that communities are empowered in healthcare. Hence, empowerment is the ultimate goal in the proposed study, which aims at outlining the process of community empowerment through community engagement using the Ecohealth approach (Charron, 2012; Chimbari, 2016).

## 1.2 Literature Review

This section is comprised of a published manuscript supplemented by a narrative review. Emphasis of the literature review on identifying and discussing stages of the community engagement process. Community engagement process involves five distinct stages (**Fig 1**) in line with the Community Engagement Vancouver Coastal Health framework ([www.vch.ca/ce](http://www.vch.ca/ce)). The stages include 1) Informing the community, 2) Consulting the community, 3) Involving the community, 4) Collaborating with the community and 5) Empowering the community. These stages are not fully explained in the published paper and hence are discussed in detail in the supplementing narrative review that precedes the published article.



**Figure 1:** *Community Engagement Vancouver Coastal Health Framework* (source: [www.vch.ca/ce](http://www.vch.ca/ce))

### ***Informing the community***

Informing communities is the process of providing information to people about research taking place in their area; this is done to ensure that the communities are included in decision-making and to ensure they understand the problem, alternatives, opportunities and possible solutions. Sharing or providing community with accurate, relevant and timely information prior to the initiation of a research project is a necessary requirement and the cornerstone of successful community engagement (Tindana, de Vries, Campbell, Littler, Seeley, Marshall, Troyer, Ogundipe, Alibu, Yakubu, Parker, 2015). Informing communities helps in getting people to participate in the study. Informing communities means that human rights of participants are respected; in this case, participants (or communities) are given enough information about the study so that they can decide if they want to participate (Palaganas, Sanchez, Molintas and Caricativo, 2017). An organisation's decision on a project might benefit from community input in the form of information, which can include facts, context, relevance, or stance (Johnston, 2010). Community engagement provides opportunity for co-creation/co-designing of studies/programmes. The key premise is that a community's knowledge and reality are produced by its members. As a result, communities can identify their problems and needs, as well as develop appropriate solutions to tackle these concerns. In this way, all projects should emerge from the realities of communities that are constantly (re)created by their members (Peralta, 2017). There are different ways in which communities can be engaged and informed about research that is conducted in their area. The means of communication can include one on one interviews, town meetings (or public forums), workshops, focus group discussion, media, surveys and can be through community advisory boards (Committee on Clinical Trials During the 2014-2015 Ebola Outbreak, Board on Global Health, Board on Health Sciences Policy, Health and Medicine Division, National Academies of Sciences, Engineering, and Medicine, 2017). Another platform for community engagement is during a community meeting where

information about the research study and research institution is provided. However, researchers ought to consider the fact that some people may not attend community meetings or public forums. Different methods, therefore, need to be employed to reach a wider audience especially those who are reluctant to attend public meetings.

Informing communities is important in ensuring that the history of unethical research that took place in the past where communities were included in research without informed consent is not repeated. When communities are provided with concise and objective information, they are more likely to make an informed decision about their participation (Committee on Clinical Trials During the 2014-2015 Ebola Outbreak et al., 2017). Informing communities eliminates the misconceptions about research. In the Ebola outbreak study, communities in Liberia were convinced that the participants were used as guinea pigs because they were not properly informed about the research (Committee on Clinical Trials During the 2014-2015 Ebola Outbreak et al., 2017). In recent years, literature has emerged that offers contradictory findings on informing communities. Researchers have investigated a variety of approaches to informing communities and the findings make several noteworthy contributions to the importance of fully engaging communities and stakeholders and promoting citizen science in research (Chimbari, 2016; Nelson, 2019; Charron, 2012; Musesengwa, Chimbari and Mukaratirwa, 2017). Recent evidence on coronavirus disease (COVID-19) also suggests that public health measures to stop the spread of COVID-19 must be implemented with full engagement of all members of society, including communities and professional groups (WHO, 2020; Ebrahim, Ahmed, Gozzer, Schlagenhaut, Memish, 2020; Bartoszko, Farooqi, Alhazzani, Loeb, 2020). The WHO declared COVID-19 on March 11, 2020, as a global pandemic, after the identification of > 118,000 cases in 114 countries (Bartoszko et al., 2020).

Furthermore, 229 countries and territories around the world were faced with the COVID-19 crisis originated from Wuhan, China (“Countries where Coronavirus has spread - Worldometer,” n.d.), where people were in confusion, and responses were incomplete and unreliable. However, it was important to keep the communities well informed. Though, decisions on what needed to be done were not made in a democratic manner and resulting in exclusion of poor communities in the decision-making process. All measures were to be accompanied by clear, accessible and regular communication to explain the response strategy, which encourages community engagement, enables people to make informed decisions to protect themselves, and helps achieve the public health goal of ending the outbreak (WHO, 2020). Therefore, if communities are not informed from the onset, they are more likely to feel like objects rather than partners. For effectiveness the informing process, communities must be informed in their language (Committee on Clinical Trials During the 2014-2015 Ebola Outbreak et al., 2017). This is beneficial in developing a meaningful partnership and building trust. In the process of informing

communities, it is important to give all the information about the research or programme, how it is beneficial to the community and what risks may be associated with their involvement.

When conducting research or implementing a programme that involves communities it is important to engage them, and consent should be sought to ensure that social value is maximized thereby conducting the research or implementing the programme respectfully. However, there are challenges experienced worldwide in ensuring that informed consent regulatory and practical requirements are met (Boga, Davies, Kamuya, Kinyanjui, Kivaya, Kombe, Lang, Marsh, Mbeti, Mlamba, Molyneux, Mulupi, Mwalukore, 2011). A study by Marsh, Kamuya, Mlamba, Williams and Molyneux (2010) on experiences with community engagement and informed consent during a genetic cohort study in Kenya found that field workers experienced some challenges in explaining the study to the community caused by issues of communication and misunderstanding about the research. In response to issues of the informing process, Strauss, Sengupta, Quinn, Goeppinger, Spaulding, Kegeles, and Millett, (2001) proposed that informed consent be conducted by community advisory boards (CABs) as they are composed of community members who share a common identity, history, symbols and language, and culture. Therefore, CAB can convey to participants their right to refuse or their right to full disclosure of information about the benefits and risks of the study and previous relevant research (Strauss et al., 2001).

A challenge that has been identified in most research initiatives is ensuring that consent to participate in research is voluntary, that there is freedom of choice that is not controlled by external factors and that people are participating in the study with genuine intention (Molyneux and Bull, 2013). Amongst other things, voluntarism can be impacted by social constructs and gender norms. These factors are problematic in the sense that autonomy of decision may not exist in certain settings, for instance, a wife might hand over the decision-making responsibility to their spouse because culture dictates that. In addition, there are some concerns if senior members of the communities or authoritarians purport to consent to research on behalf of the community rather than to view their role as approving recruitment amongst community members. The concept of consent has both legal and ethical aspects and when the two are compared the ethical concept is most empowering as it views consent as a shared decision-making process, in this case, people can freely make decisions that they are not likely to regret later. Economic constraints are also a major concern as they can lead to people participating in research so that they can gain access to research-related benefits even though their understanding of the study is limited or have reservations about the study.

### ***Consulting the community***

Community consultation is a process that facilitates genuine community development. Community consultation is defined as the process of soliciting opinions and perspectives from individuals and interested community members regarding a specific issue defined by an organisation (Johnston, 2010).

In essence, the goal of community consultation is not to collect the ideas of each and every community member, but rather to collect a wide variety of perspectives from members of the community who are engaged in a particular topic. If well conducted it can empower communities to articulate their concerns and enable them to identify solutions to their problems. It gives communities autonomy where decision-making is concerned. Consulting to obtain community feedback on various aspects of a research project (Tindana et al., 2015) and building a partnership between the community and researchers (James and Pitterway, n.d.). Consulting the community as part of a process to develop government policy or build community awareness. Community consultation is very important in conducting high-quality, ethically sound research (H3Africa, 2014). In order to achieve this, recent evidence suggests a community consultation flow that encourage openness regarding advantages of research as well as the community's role in research (Mutero and Chimbari, 2021).

Community consultation and consent are not mutually exclusive; however, community consultation should not be mistaken for community consent (Dickert and Sugarman, 2005). The purpose of community engagement is to inform, consult, involve, collaborate and empower the study community. In community consultation, people are given objective information so that they understand better the problem and possible solutions. According to Dickert and Sugarman (2005:1123), community consultation does not include asking for approval or permission, however, includes eliciting feedback, criticism, and suggestions and "seeking advice or information." In accordance with the present argument, the previous study (Burgess, 2004) has demonstrated that consultation is an attempt to describe the various perspectives of the interested parties (e.g., health professionals, patients and families) in sufficient depth to enable a shared understanding and clear ethical analysis. Together these studies (Dickert and Sugarman, 2005; Burgess, 2004) provide important insight into the community consultation process. One study that described the processes from consultation to collaboration showed the importance of community consultation for social acceptance of a wind project development (Jami and Walsh, 2017).

As noted in the study by Marsh et al. (2010), the consultation was initiated by the Community Liaison group which first explained and discussed the research with the chiefs of the study area, to assess chiefs' perceptions and attitudes towards the study and seek their recommendations. This consultation was conducted during a one-day workshop, which was part of a wider community engagement agenda (Marsh et al., 2010). According to the community consultation policy (2018), community consultations should not be a once-off exercise, rather it should continue throughout the project to improve the outcomes of the project. However, community consultation can be challenging, as it can be difficult to identify communities, stakeholders and representatives that have legitimate and relevant interests to the research study (Dickert and Sugarman, 2005). Extensive research that has been carried out on community engagement noted that consultation requires fair, balanced and accurate representation of diverse constituencies (such as political and religious leaders, community advisory boards or respected

individuals) within the community (Tindana et al., 2015; Marsh et al., 2010; Morin, Maiorana, Koester, Sheon, and Richards, 2003). It is important to consult with community leaders and seek permission before approaching members of the community.

Community consultation is an empowering tool that places decision-making in the hands of the study community. It speaks to the direct involvement or participation of the community in the research, enabling a meaningful partnership between researchers and community members and empowering researchers to better understand the study community (Nyirenda, Gooding, Lora, Kumwenda, McMorrow, Everett, 2018). Community consultation also enables meaningful dialogue between researchers and the community to identify more areas of concern with regard to the acceptability of medical research in general (Samuel and Tisherman, 2018). According to Breen and O'Connor (2014) having stakeholders playing a role in decisions that directly affect them tends to be tokenism as stakeholders are only involved to achieve a certain research goal rather than to empower them. Perhaps because of this fact researchers should be more careful in community-based participatory research as participation can be used paradoxically. The benefits of including communities in research and engagements are having good understanding of real-life experiences, and to determine methods of communication that accommodate different groups. Analysis of most studies on community engagement indicates that there are still gaps that need to be addressed to ensure that there is full participation of communities in research or development programmes. In this thesis an attempt to fill this gap has been made.

### ***Involving the community***

Community involvement refers to the active participation of communities in the design, implementation, and monitoring of healthcare programs. It is a fundamental component of primary healthcare and is often used interchangeably with terms like community engagement and participation (Arriola-Vigo et al., 2019). The call to "Leave No One Behind" within the Sustainable Development Goals, as articulated in a resource guide for community engagement and involvement in global health research, makes it imperative that all projects must include community engagement and involvement as a core component of the research strategy, planning, implementation, and evaluation process (Nelson, 2019). Tora, Mengiste, Davey and Semrau (2018:4) emphasise the "importance of involving and gaining buy-in from community members and leaders and health-system leaders from the start (for example, through forming of a stakeholder committee); linking raising awareness to the available services; and using 'Training of Trainers' approaches to achieve scale-up."

Gaining measurable project outcomes requires a dedication to community involvement and engagement, which involves actual power-sharing, bidirectional learning, and needs assessment, as well as incorporating the voice and agency of indigenous and ethnic communities in the study protocol (Nelson, 2019). Investment of time, human resources investment and an interdisciplinary team with the

necessary 'soft skills' to undertake relationship-building work and navigate complex relationships of power are important for community involvement in a project. However, most projects fail due to poor conception as well as the exclusion of communities during ideation and initiation phases. It has been proven that when communities participate in health programmes sustainability and affordability of the programme improve (Makaula, Bloch, Banda, Mbera, Mangan, de Sousa, Nkono, Jemu and Muula, 2012).

Community engagement interventions include a range of approaches to involve communities in the improvement of their health and wellbeing. Community-directed interventions (CDI) and community-based strategies are one of the CE approaches, which are used interchangeably. However, these two concepts are different. Community-based strategy can be described as a variety of strategies including planning, community-based prioritization, implementation and running of intervention that has no direct community involvement (Katararwa, Habomugisha, Richards and Hopkins, 2005). Community-directed intervention, on the other hand, speaks to a more focused process, where communities are directly involved in making sure that their health system functions better (Sapri, Richards, Kokho and Theobald, 2015). CDI is a method whereby community members organize themselves as a collective to come up with ways of dealing with their health and developmental challenges using the information they would have received from internal or external experts (Katararwa et al., 2005). Communities select their community health care workers and supervisors who provide service in kinship zones (areas/zone in which social relations amongst people is based on origin or characteristics). In Uganda some rural communities selected both male and female community healthcare workers which ensured that there was equitable and quality healthcare delivery for all community members (Katararwa et al., 2005). This strategy was endorsed by the health sector since it promoted the gender strategy for deepening women's involvement (Katararwa et al., 2005).

### ***Collaborating with the community***

Collaborating with the community is generally described as “the process of working together by sharing resources and expertise to achieve a jointly agreed-upon, common goal that cannot be reached by one party alone” (Dotterweich, 2006:855). Collaboration can take different forms, from organisations working together to develop a grant proposal to community groups coming together to achieve a common objective by sharing resources and skills. Stampfer, Mittelstaedt, Vásquez, Karr (2019:4) identified four important elements of genuine collaboration: “(1) funding for relationship building and partnership sustainability, (2) community representation in the partnership, (3) recognition of community strengths (including relying on community partner knowledge and skills), and (4) community partner capacity building.”

Community collaboration is achieved through engaged research. It is a collaboration effort between researchers or people outside academia and the community to carry out a study or research that is of

benefit to them. According to Holliman (2017) researchers from different disciplines do not have consensus on the definition of engaged research. He provided a rational definition of engaged research that refers to various methods in which researchers connect meaningfully with multiple stakeholders at any or all phases of a research process, from conceptualization of an issue to the production or co-creation of new information, to knowledge evaluation and dissemination (Holliman, 2017). Through engaged research initiatives, communities and institutions of higher education often work collaboratively together to identify the problem to be studied, investigate that problem through data collection, analyse and interpret the collected information, and decide how to implement an intervention based on the findings. According to Bassler, Brasier, Fogle, and Taverno (2008), the collaboration between universities and local communities may help in developing more efficient solutions; enhancing residents' understanding of and aptitude for addressing problems; enabling and integrating individuals from various backgrounds; establishing local networks of community members; creating multiple opportunities for community members to voice their concerns, which may help to prevent unrest; and creating trust in community organisation and local government. However, there are also limitations when it comes to engaged research. These include the language barrier which might affect the partnership between communities and academics, especially during the formative phase of the partnership, because there might not be a clear shared language or a way of working together.

Community initiatives often operate as partnerships of coalitions. If all groups such as community sectors, organizations, or constituencies are represented, they create a partnership to work toward a common goal. The multiparty partnership facilitates the transition between people and the environment to influence systems and organize resources. Collaborative partnership transforms relationships amongst parties and communities serve as change agents, which enables them to exercise urgency in issues that concern them. The collaboration method may be more effective in solving public health issues since all partners share responsibility and contribute to community empowerment. A method that has been studied looks at collaborative partnership as an empowering tool. The model investigates 4 strategies that facilitate empowerment. The first strategy includes enhancing experience and competence, where community leaders or the board of directors initiates collaboration to understand more about the issues. More work is done to understand more about potential barriers to intervention as well as available resources and specific community-based solutions (Fawcett, Paine-Andrews, Francisco, Schultz, Richter, Lewis, Williams, Harris, Berkly, Fisher and Lopez, 1995). The second strategy enhances group structure and capacity where different organizations became collaborative partners to effect change in varied community sectors. The third strategy of removing social and environmental barriers enables all partners to work in coalition in coming up with strategies to reduce environmental barriers; and the fourth strategy is about enhancing environmental support and resources to foster community empowerment (Fawcett et al., 1995).

In the inter-organizational field of public health, there is both functional and structural distinction of an organization that is dealing with public health issues. Although they fall under the health sector, they also fall under other governmental sectors such as education and social services. Inter-organizational collaboration, therefore, allows different sectors to explore their differences to find solutions that will not be limited by their individual visions. The collaboration partnership related to differentiation and fragmentation enables them to pursue objectives that will result in a larger impact which is not possible if they act independently. Success in inter-organizational collaboration in public health appears to be found in multidisciplinary teams that have been working with each other for a long time. This is achievable because, in such teams, members build trust amongst each other, and they have similar values and shared goals. Decision-making in such teams is mostly a shared responsibility and the teams usually share a similar culture (Axelsson and Axelsson, 2006).

Some challenges arise because of integration and collaboration and managing collaboration is even more difficult compared to integration. These are due to structural barriers because of differences in administration, laws, budget, rules and regulations that exist in the different collaborating organizations. Other barriers are not necessarily structural; they are more related to the culture of organizations, the differences in values and interests and individual/ organizational commitment. Researchers have indicated that differences in structures are easy to integrate as opposed to values and culture (Axelsson and Axelsson, 2006). MacQueen et al, (2001:1936) have also mentioned, “community collaboration in public health programs and research presents many challenges, in part because the community has been defined in ambiguous and contradictory ways.” However, collaborating with the community is vital for developing partnerships to formulate options, find solutions and provide recommendations.

### ***Empowering the community***

Community empowerment refers to the process of enabling communities to increase control over their lives. It has been defined by various authors (Assefa, Hill, Gilks, Admassu, Tesfaye, Van Damme, 2020; Douglas, Grills, Villanueva, Subica, 2016; Wallerstein and Bernstein, 1994) as the process by which members of a community collaborate to strengthen their power or control over the provision of health care and the implementation of policies and psychosocial changes to reduce the underlying social, economic, political and environmental factors that lead to health inequalities. According to Kruahong, Tankumpuan, Kelly, Davidson and Kuntajak (2023) a key concept in health promotion is community empowerment, which can help communities set priorities, make decisions, design strategies, and put those strategies into action in order to enhance health and reduce health inequities. While there are many definitions of the term community empowerment, in this thesis the definition by Melo and Alves (2019) that refers to community empowerment as the combination of community engagement, processes and leadership that enables the community to identify and solve problems and mobilize community resources will be used.

Community empowerment can be a shared leadership empowering the community to make decisions and to implement and manage change. In other words, decision-making is placed in the hands of the community. There is an unambiguous relationship between community empowerment and health promotion. Avery, Sjogren Forss and Ramgard (2022) found that the lack of community control over their health has a dual impact on health by limiting access to resources and affecting social determinants of health, such as education, occupation, poverty and social capital, which results to poor housing, dangerous jobs or exposure to pollution. Power imbalances often cause underrepresented groups to be silenced in the planning, management and implementation of research aimed to improve their own health (Avery et al., 2022). According to Beckham, Stockton, Galai, Davis, Mwambo, Likindikoki, and Kerrigan (2021) community empowerment models have potential to increase family planning uptake among the at-risk population, as suggested in their study that examined the relationship between participation in an HIV prevention programme and the use of contraceptive. This reveals that community empowerment should be as combination of community participation and ownership. Another study (Khalid, Ahmed, Ramavah, Hwang and Kim, 2019) examines the relationship between community empowerment and sustainable tourism development, along with the mediating role played by community support for tourism. The findings of that study imply that high community empowerment enables the community to establish successful sustainable tourism development through local people's support for tourism (Khalid et al., 2019).

Although empowerment can be a useful tool to improve the capabilities and assets of local communities, both individually and collectively, community empowerment requires the engagement of community members and the collective action of community members rather than the individual action of community members (Khalid et al., 2019). There are methods and tools perceived as a vehicle for community empowerment. Literacy is seen as an empowerment tool as it enables one to exercise urgency over lifestyle choices (Estacio, 2013). It also allows people to be involved in decision-making and gives them responsibility regarding their health. Although literacy has long been recognized as an empowerment tool, the concept is relatively new in health promotion. Literacy was understood as the capacity to obtain, understand and use information to promote and maintain good health (Institute of Medicine, 2004). However, in the literature, the term literacy tends to be used to refer to a range of skills including social and communication skills (Nutbeam, 2009); the ability to apply these skills in a healthcare context and across the lifespan (Kirsch, Jungleblut, Jenkins, and Kolstad, 1993; Rootman and Gordon-El-Bihbety, 2008). Literacy also benefits people as people acquire more knowledge that improves their potential thereby increasing their quality of life, and enhancing their participation in society, socially and economically (Estacio, 2013).

According to Wallerstein and Bernstein (1994), participatory education as a method of empowerment can be empowering if people are actors in history and not objects of political and educational projects. The authors advocate for conditions where people can identify their problems and come up with their

own solutions. Community empowerment is also possible through dialogue where people engage and listen to each other so that they can identify their mutual support and come up with strategies to change their trajectory. Through dialogue, people can learn from each other, get a new perspective and eventually see new ways of dealing with a problem. If there are, no dialogues and communities do not participate in decision-making where a problem is defined and solved, community empowerment cannot be achieved. If policies are made without involving the community whether they are socio-economic or risk factor reduction, they cannot contribute to community empowerment. Ultimately, the strategies for community empowerment must be linked to a larger society to ensure policies and political solutions that will reduce socioeconomic inequalities and improve the quality of life where healthier living conditions are promoted. These tools are processes of empowering communities and community empowerment is the ultimate goal of community engagement and is therefore a result of all the other processes, informing, consulting, involving and collaboration.

Power dynamics whether from culture, class, ethnicity, and gender, among other obstacles to community empowerment, raise the question: Can privileged groups empower others? Or do people need to take power and empower themselves? It is widely recognised that powerlessness is a high-risk factor for diseases. The question then may arise as to what role the privileged groups should play in marginalized communities. Wallerstein and Bernstein (1994), assert that health practitioners, who are relatively privileged compared to the communities in which they operate, must fulfill two crucial tasks. First and foremost, health practitioners need to create an environment and opportunities for people to participate in community dialogue as partners, dipping themselves into the learning process. Second, the transformation of the healthcare system could create favourable conditions for collaboration, public advocacy, political action, and community empowerment.

### **Literature review (Article)**


The following article authored by Ms Mthembu (PhD candidate), Dr Mogaka and Professor Chimbari is an extension of the literature review. This article is published in the journal of *BMC Health Services Research* (May 08, 2023). This systematic review focuses on community engagement processes in low- and middle-income countries in health research settings.

RESEARCH

Open Access



# Community engagement processes in low- and middle-income countries health research settings: a systematic review of the literature

Zinhle Mthembu<sup>1,2\*</sup> , John J. O. Mogaka<sup>1</sup> and Moses J. Chimbari<sup>1,3</sup>

## Abstract

**Background** Community Engagement is an important ethical imperative in research. Although substantial research emphasizes its real value and strategic importance, much of the available literature focuses primarily on the success of community participation, with little emphasis given to specific community engagement processes, mechanisms and strategies in relation to intended outcomes in research environments. The systematic literature review's objective was to explore the nature of community engagement processes, strategies and approaches in health research settings in low- and middle-income countries.

**Methods** The systematic literature review design was informed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines. We searched for peer-reviewed, English-language literature published between January 2011 and December 2021 through three databases on the internet (PubMed, Web of Science and Google Scholar). The terms "community engagement," "community involvement," "participation," "research settings," and "low- and middle-income countries" were merged in the search.

**Results** The majority of publications [8/10] were led by authors from low- and middle-income countries, with many of them, [9/10] failing to continuously include important aspects of study quality. Even though consultation and information sessions were less participatory, articles were most likely to describe community engagement in these types of events. The articles covered a wide range of health issues, but the majority were concerned with infectious diseases such as malaria, human immunodeficiency virus, and tuberculosis, followed by studies on the environment and broader health factors. Articles were largely under-theorized.

**Conclusions** Despite the lack of theoretical underpinnings for various community engagement processes, strategies and approaches, community engagement in research settings was variable. Future studies should go deeper into community engagement theory, acknowledge the power dynamics underpin community engagement, and be more practical about the extent to which communities may participate.

**Keywords** Community engagement, Participation, Empowerment, Research settings, Low-and middle-income countries

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## Background

Bridging the gap between researchers and the researched and linking communities to valuable resources is key to community empowerment. Community Engagement (CE) or Empowerment is increasingly becoming critical across contexts and an integral part of most research endeavours [1]. Broadly, World Health Organisation (WHO) defines CE as a process that allows people to be actively and genuinely involved in defining matters that concern them, to make decisions about factors that affect their lives, in addition to formulating and implementing policies, planning, developing and delivering services, and to take measures to improve desired change [2]. Similarly, CE has been described as a process of working with and through groups of people affected by geographical proximity, special interests, or similar situations to address issues affecting their well-being or to identify priorities, resources, needs and solutions in the community in such a way that representative participation, good governance, accountability, and peaceful change are encouraged [3]. CE, particularly in research settings, is a dynamic research strategy that evaluates what role communities impacted by the issue under investigation should have in the research process itself. Therefore, CE in research may be viewed as a continuum, since it fits within a range of study designs and should not be viewed as a singular method. It is also a participatory research technique, in which communities participate equally in all research decision-making, at one end of the spectrum. However, even when a completely participatory design is not suitable or practical, there are several additional considerations for communities to be involved or engaged in research (e.g., in some basic science or biomedical research). The criteria for including CE in research can be employed with any research methodological approaches, including qualitative methods, quantitative methods, and the analysis of secondary data. In the same manner, the concepts of CE in research can be applied to all areas of health research, such as clinical research, laboratory science, and epidemiological studies. Community engagement in research occurs on a continuum. This continuum includes initiatives that are totally academic led with little community engagement, as well as those that are wholly created and executed by community members and/or groups. The most truly community-integrated and involved research on this continuum is classified as participatory research, community-based participatory research (CBPR), or participatory action research (PAR). In this paper, community-based health research approaches are described as those that strive to integrate scientifically sound principles with community-centred theories of change and efforts by communities to address pressing community health concerns.

There have been many studies on community engagement and empowerment in dealing with health issues [4-8]; however, these studies have not been rigorous. A study by Chen, Mullins, Novak, and Thomas [9] shows the importance of patient activation and empowerment as a cyclical process through a patient's accumulation of knowledge, confidence, and self-determination for their health. These authors suggested an empowerment framework (from individual to a health care professional to community and health care delivery system-level), intended to inform the development of culturally informed personalized patient activation and empowerment (P-PAE) interventions to improve population health and reduce racial and ethnic disparities [9]. Another study found peer navigators useful for addressing health problems through community-based participatory research (CBPR) in ensuring that communities are empowered on health issues [10]. Core concepts and principles of CBPR were also found to be effective in the management of health issues at the community level [11]. CBPR is the oldest and best-known approach under the umbrella term of community-engaged research (CEnR) used to represent a variety of activities and methodologies (e.g., stakeholder engagement, patient engagement, public involvement, and participatory action research). Nevertheless, all CEnR approaches draw from CBPR's emphasis on including community members as equal partners in many aspects of the research process, from the identification and selection of priority topics and research questions to the development of data collection materials and analytical strategies to the drafting and dissemination of the publication of findings [5].

CE in research has been proven to increase the impact of health studies on communities on several occasions. This way, research demonstrates greater sensitivity to the perception, needs and unique circumstances of researched communities. Many studies have pointed out the need to better apply research, disseminate research results more effectively, and synthesize research into evidence-based guidelines and "best practices" for more immediate use by practitioners and community members [12-15]. In line with these observations, CE has been considered crucial and pivotal, as involving communities in research settings can make findings and recommended interventions more relevant to local needs, informed by local knowledge and priorities, and thus more effective [16, 17]. An empowered community is one that can identify its own needs and have the capability to raise questions and issues with others; has opportunities to make choices or influence decisions being made by others on its behalf; as well as can stimulate and monitor actions in pursuit of the decisions that were made or influenced by the community. Existing literature underlines the need

for improved practice, coordination, integration, and measurement of community engagement [18]. These are essential components of community systems strengthening, with multifaceted implications and demonstration of intervention effectiveness, responsiveness, and accountability across sectors.

From the definitions of CE, it is evident that the concept of “community” is central. However, there are many types of communities [19]. Communities are typically described as geographical, as in settlements or parts of town, but they are not always territorial. They can also include groups of people who share common practices or goals (such as investment or advocacy groups) and can exist in a variety of settings (e.g., virtual or physical spaces) [17]. In this sense, a community has been defined as a social unit that is locally relevant just above the level of the household (i.e., neighbourhood, town, parish). A community may also include non-geographically focused social networks of interaction, exchange, and interdependence. Such networks could contribute to the transfer of health, education, social, information, economic, cultural, and political resources [18]. Depending on the socio-economic and political circumstances at the time, CE can be transformative, supporting marginalized groups in empowering and emancipating themselves. Community mobilization that ignores suitable CE tactics and their intended consequences, on the other hand, might detract from community participation’s goals, aggravate exclusionary practices, and further entrench disparity.

While CE remains an important aspect of research it is one of the most less understood and less funded aspects of the research process [19]. When grant writers seek funding for research the critical steps which require community engagement have already been surpassed. The funder requires to see a complete proposal with the problem already identified, funders also anticipate that the researchers have done the necessary consultations with the researched communities to identify problems together. This initial step is important; however, researchers intentionally skip this step as it requires more resources such as time and funding. The CE process is unique in the sense that it happens prior to the research, then it comes in during the research process and continues after the research has ended. Most funding can only support CE during the research process because the funding will be available by then, otherwise prior to the release of funds and post the reporting stage funding is not available. This unavailability of funding is one of the key barriers which limit the implementation of CE by many researchers. Another limitation is that most researchers are not

trained or oriented systematically to the process of CE. Quite often researchers miss the key step because they are not aware of it, or they simply do not have the expertise to go about it. Therefore, training in community engagement is just as important as training in any other field and it has the potential to shape the future conceptualisation, implementation and impact of CE research [20]. This is further coupled by the fact that some funders are reluctant to release funds to support the development of skills and awareness around CE. The bulk of researchers only focus on dissemination skipping all so important process of CE.

Studies on approaches to community engagement and empowerment have mostly focused on aspects of community consultation (decision-making processes) but less on the other crucial, equally important elements: assessing how the community’s capacity is developed; and, ensuring that implementation follows and is in accord with the consultation and decision-making process. The growth in interest and utilization of CE in research, therefore, raises the more compelling question of the actual outcomes of community participation and involvement. What kinds of evidence are there to support the CE’s substantive outcomes? What have been social-ecological impacts on local communities where CE has been implemented? These general questions, however, are linked to a more significant question: what are the various CE processes, strategies and approaches that have been adopted in research settings? The purpose of this systematic literature review was to review the literature on the processes, strategies and approaches of community engagement and empowerment that have been adopted by researchers in low-income countries to determine the best practice for community engagement and empowerment. It is noticeable that most CE definitions refers to CE as a process/strategy/approach, and these three concepts are considered to be synonymous; these focus on single specific hypothesised processes drawn from the community engagement framework to identify how one phenomenon influences another. Hence, these concepts were used in this systematic literature review interchangeably as they were also part of the search terms. In line with these pertinent questions, this systematic literature review sought to understand the nature of CE processes in health research environments in Lower Middle-Income Countries (LMICs). LMICs refer to those countries defined by the World Bank based on the countries’ Gross National Income as having “low-income economies,” “lower middle-income economies” or “upper middle-income economies” as may be amended from time to time [21].

## Methods

This systematic literature review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. Since this was primarily a qualitative systematic review, no specific comparator interventions or demographics were sought, and a wide range of study approaches, whether experimental, descriptive, or exploratory/explanatory, were considered. We predominantly considered qualitative, quantitative, and mixed-methods studies. All of the articles ultimately included in this systematic literature review were based on empirical research. In accordance with our objectives and problem statement, we employed thematic data analysis which is qualitative in its nature. The nature, scale, and intended effects of CE processes, strategies and approaches in research environments were among the domains reviewed. The systematic literature review did not explore all the models that are available in the literature, we limited our scope to certain criteria to achieve the systematic literature review purpose. Due to the limited amount of time that was available to conduct the review and the limited scope of the review, we avoided exploring other existing models. An extensive search of the models was conducted, but we were restricted in what we could access. We only included records that were publicly available. Some of the records in the databases where we were searching for our records were not available for free, limiting our record selection.

## Information sources

A literature search was carried out in three electronic databases: PubMed, Web of Science and Google Scholar in December 2021. Each database was searched from January 2011 to December 2021 for articles containing

concepts related to community, engagement, research settings and LMICs as shown in Table 1. We searched for the latest findings and latest evidence in literature within the past 10 years to track trends of the studied phenomenon. Studies reviewing the same topic have been conducted and we needed latest findings on this topic area. Beyond that, the evidence would become obsolete. Recent studies are, therefore, highly relevant to the research question. Apart from searching databases, we have also looked for references that were included in the citation we have found.

## Data collection process and data items

In Google Forms, a data extraction form was constructed to help extract information from each article on essential components of community engagement processes, strategies, and approaches in research settings, as listed under the research objectives. The study quality was assessed using the Critical Appraisal Skills Program (CASP) and elements of rigour in doing research [22]. Critical appraisal skills program is a central process to evidence-based practice and is used in reviewing scientific papers to determine good research from bad research. Critical appraisal has two main roles which are, first to eliminate studies of low quality which have results that may compromise the validity of the research; secondly, to identify the strengths and limitations of included studies [23]. The manner in which critical appraisal is done is important in determining the quality of a systematic review, CASP is usually done at the stage of full text assessment. For qualitative papers its aim is to call out the rigor of research papers and determine levels of transferability, while for quantitative papers its purpose is to reduce the risk of bias or misleading readers [23]. From CASP, four

**Table 1** Concepts and associated terms used as search terms in the literature search

Concept	Search Terms
Community Engagement	"Community Networks"[Mesh] OR "Community "[text word] OR "Communities"[text word] OR "Community Research Planning"[Mesh] OR "Community-Institutional Relations"[Mesh]
Process	Process OR Strategies OR Approaches
Community Engagement Outcomes	"Research Partnerships", Accountability, "Project Ownership", "Community Empowerment", Sustainability
Research Settings	"Health Services Research" [Mesh] OR "Community-Based Participatory Research" [Mesh] OR "Operations Research" [Mesh] OR "Qualitative Research" [Mesh] OR "Evaluation Studies as Topic" [Mesh] OR "Evaluation Studies" [Publication Type] OR "Health Care Evaluation Mechanisms" [Mesh] OR "Program Evaluation" [Mesh]
LMICs	"Lower-middle-income economies"[tiab] OR "low income economies"[tiab] OR "Developing countries"[mh] OR "developing countries"[tiab] OR "developing country"[tiab] OR "under-developed countries"[tiab] OR "under-developed country"[tiab] OR "third-world countries"[tiab] OR "third-world country"[tiab] OR "developing nations"[tiab] OR "developing nation"[tiab] OR "underdeveloped nations"[tiab] OR "third-world nations"[tiab] OR "third-world nation"[tiab] OR "less-developed countries"[tiab] OR "lessdeveloped country"[tiab] OR "less-developed nations"[tiab] OR low and middle income countries[tiab] OR lmic[tiab] OR low income country[tiab] OR low income countries[tiab] OR lower income countries[tiab] OR middle income country[tiab] OR middle income countries[tiab] OR lower middle income country[tiab] OR lower middle income countries[tiab] OR "Afghanistan" ... Zimbabwe[tiab]

broad categories were derived for study quality assessment, these were: sampling, data collection, analysis, and trustworthiness—reliability (or dependability) and validity (or credibility) of the research. Reliability refers to the extent to which results are repeatable under different conditions, validity refers to the extent to which the measures or mirrors the concept being researched on [23]. Mthembu and Mogaka from the review team independently piloted the form by abstracting two sample articles. The form was revised and further improved after a collective review and discussion. We refined the google form based on the objectives, inclusion and exclusion criteria. Once we had the inclusion and exclusion criteria, we tested it by searching the databases. Then we looked at the results whether they were of satisfaction, if not, we refined the form again. This was an iterative process that involved going back and forth trying to find what works best. Therefore, the form was changed to adjust it to what was going to produce the results in terms of outcomes of the review. The reviewers came to an agreement on how to abstract the remaining articles. The remaining articles were abstracted, and the researchers had regular online sessions to discuss new findings, issues encountered throughout the abstraction process, and a consensus approach to resolving them.

#### Analysis

Findings were synthesized using a thematic approach, commonly used in systematic reviews to summarize qualitative and quantitative studies [24]. This systematic literature review applied the Vancouver Coastal Health Community Engagement Framework ([www.vch.ca/ce](http://www.vch.ca/ce)) which involves five CE distinct stages (see Fig. 1). The stages include informing the community, consulting the community, involving the community, collaborating with the community and empowering the community. In this systematic literature review, these stages were interpreted as whether communities were (a) informed about the problems and solutions proposed in the research; (b) consulted in identifying and defining the problems and interventions designed to address those problems; (c) involved through participating in the implementation of research projects; (d) collaborated with in managing research project resources e.g. monitoring and evaluation; and/or (e) Empowered in taking ownership of the research process. Abstracted findings were synthesized

into detailed outputs after articles were revisited multiple times. Following a process of constant comparison, two reviewers (Mthembu and Mogaka) reviewed and amended them in consultation with the supervisor (Chimbari). The design and analysis of the systematic literature review were also evaluated and reported on for quality using CASP.

## Results

### Article selection

As shown in the PRISMA flow diagram in Fig. 2, the result of our search yielded 1,389 articles, which after 303 duplicates were removed, left a total number of 1,086 articles. 1022 were excluded at title/abstract stage. This meant that 64 articles were sought for retrieval. However, of these, 51 were assessed for eligibility because 13 could not be retrieved. Some articles were simple not available as the authors did not post them online or posted a citation not the actual paper and we did not have access to authors. At this stage, this had a minimal impact to understand the studied phenomenon, however we did miss the chance to find papers which could possibly qualify for the main review. Of the 51 records assessed for eligibility 42 were further excluded as a result of low levels of CE throughout the study cycle, non-health research settings. This left 9 articles that were finally admitted for data extraction. A further six articles were identified through the references section of the admitted articles. However, four of these could not be retrieved and one was excluded after applying the inclusion/exclusion criteria. This left one article admitted for data extraction. In total, therefore, ten articles were finally examined, and data extracted on CE processes. Research settings and CE outcomes of intent.

### Article characteristics

The geographic location where the CE processes/strategies/approaches were studied/implemented were assessed. We also assessed where and who publishes health research in LMIC that involves community engagement. When two different affiliations were mentioned, only the first affiliation mentioned was categorized. Locations were divided into 3: Low-Income, Lower/Upper Middle-Income, and High-Income countries. Regions, where CE strategies were implemented/



**Fig. 1** Community engagement vancouver coastal health framework (source: [www.vch.ca/ce](http://www.vch.ca/ce))

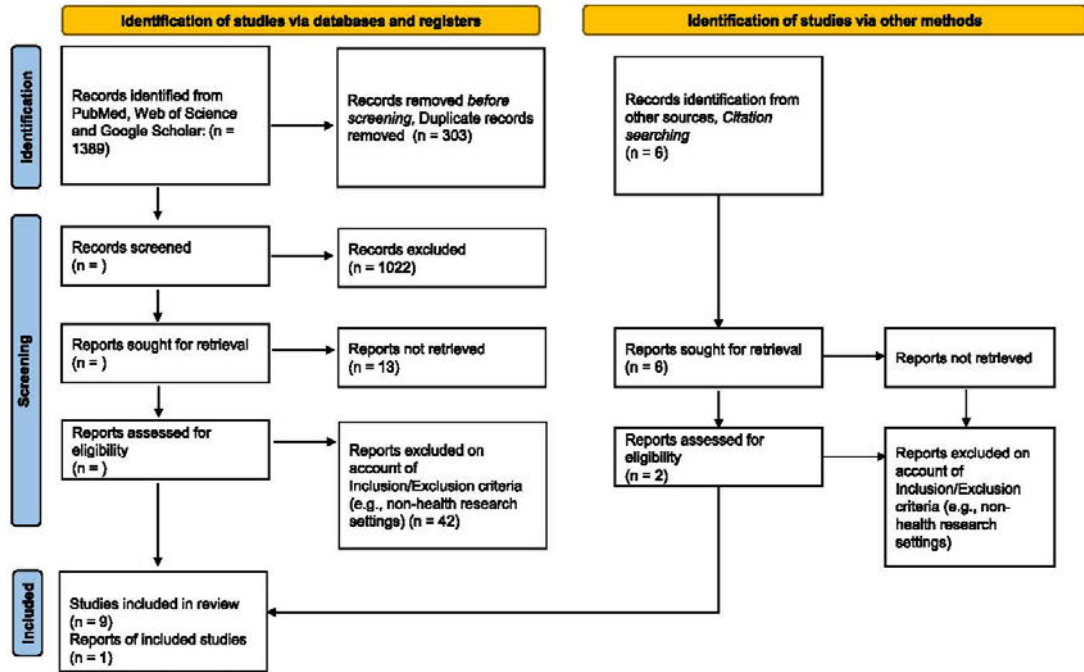


Fig. 2 PRISMA flow diagram for the systematic literature review

studied according to surveyed literature, were divided into 4: Sub-Saharan Africa, Latin America and the Caribbean, South Asia or simply Multiple regions if the focus of the reviewed paper was global in nature. The results are illustrated in Fig. 3.

Despite the emphasis on LMICs, some of the first/ corresponding authors were from high-income nations. Among those articles whose first/ corresponding author was based in an LMIC region, [70%] which is 7/10 focused on either multiple regions or Sub-Saharan Africa. Moreover, it was noted that half of

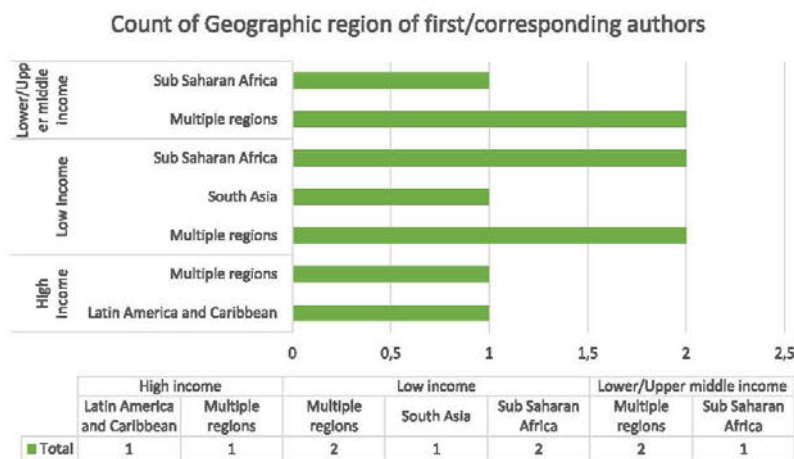


Fig. 3 Study characteristics of geographic regions of first/ corresponding authors and study location

these articles were authored by those in Low-Income countries.

**Health research domains**

The assessment was based on which health research domains had strategies that involved community engagement and identified only three major research fields: Basic Biomedical research, Health Promotion research and Information Systems research (Fig. 4). As shown in Fig. 4 and Table 2, engaging communities in health promotion was most prevalent in Sub-Saharan Africa, with over 50% of the research that took place in Sub-Saharan Africa and/or whose focus was also on multiple regions mainly featuring this type of research. However, Sub-Saharan Africa also featured Basic Biomedical and Information Systems research. The majority of the health-related promotion articles in this review included community participation in research activities mainly in community involvement in the research process and empowerment but were less likely to have communities defining the problem that needed to be addressed, defining the intervention to be recommended, managing resources for it or monitoring/evaluating the research project. Information Systems was the health research domain with the fewest articles [10%] which is 1/10 and the least participatory with regard to community empowerment and ownership of research processes, among other CE outcomes of interest at [20%] which is 2/10.

**Types of health conditions**

The assessment was based on which types of health conditions were most likely to be addressed through research that involved community engagement. Community participation was most frequently observed in research concerned with infectious diseases, including Vector-Borne Diseases (VBDs) e.g., Malaria, human immunodeficiency virus (HIV) and tuberculosis (TB) [40%], which is 4/10, followed by articles presenting studies on the environment [20%] which is, 2/10 as well as those pertaining to other broader health determinants, broader health issues and primary care [20%], which is 2/10. The least health conditions that were investigated and at least involved some degree of CE were found in studies concerned with reproductive and child health (Maternal, Under Five/Newborn, Family planning) [10%] as well as those concerned with non-communicable disease and other similar conditions [10%].

**Process or stage of CE described in the article**

The findings on type of CE strategy used were classified and presented following the Vancouver Coastal College CE framework. The classifications helped us to determine whether each study was able to articulate the 5 stages of the community engagement cycle. Here we state each part of the cycle and the articles that applied each stage/process in their study: (a) community informed about the problems and solutions proposed in the research [28, 29, 31-33]; (b) community consulted in identifying and defining the problems and interventions designed to address those problems [25-28, 30-32,

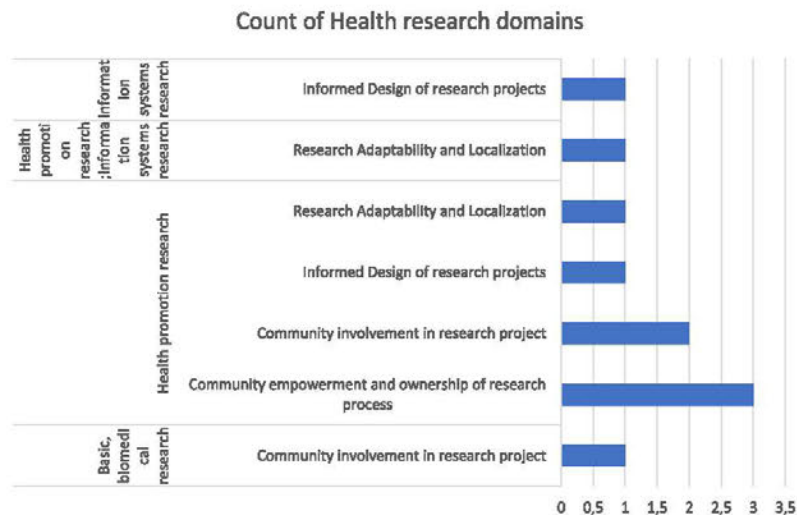


Fig. 4 Study characteristics of geographic regions and health research domains

**Table 2** Summary of systematic literature review findings

First/Corresponding Author (Surname and Name) and Year of Publication	Geographic region of First/Corresponding authors	Geographic region of CE process/strategy/ approach	Health research domains	Type of health condition researched	Process or stage of CE described in the article?	CE approach/method used
Chaka Chirozva, 2016 [25]	Low income	Sub-Saharan Africa	Basic, biomedical research	Environment	1. Consultation in identifying or defining problems & interventions 2. Involvement in a research project	Focus group discussions
Chiao-Wen Lan, 2017 [26]	Low income	Multiple regions	Health promotion research	Reproductive and child health (Maternal, Under-five/Newborn, Family planning)	1. Consultation in identifying or defining problems & interventions 2. Empowerment and ownership of research process	
Irene Jac, 2015 [27]	Low income	Sub-Saharan Africa	Health promotion research	Other broader health determinants, Broader health issues, primary care	1. Informing communities about problems & solutions proposed 2. Consultation in identifying or defining problems & interventions 3. Collaboration with community in monitoring, evaluating research projects 4. Empowerment and ownership of research process	Community research project oversight groups; Community awareness campaigns
Greer Hainz, 2019 [28]	Lower/Upper middle income	Multiple regions	Health promotion research	HIV and Other sexual and reproductive health	1. Informing communities about problems & solutions proposed 2. Consultation in identifying or defining problems & interventions 3. Empowerment and ownership of research process	Education, information-education-communication (IEC) campaigns, behavior change, peer-led, participatory, empowerment-based, communication campaigns, social and behavioral communication campaigns, and mass-media campaigns
Sheri A. Lippman, 2017 [29]	Lower/Upper middle income	Multiple regions	Health promotion research	HIV and Other sexual and reproductive health	1. Informing communities about problems & solutions proposed 2. Involvement in research project 3. Empowerment and ownership of research process	Partnership building, groups/networks engagement (community action teams); workshops, print material dissemination, Short films (Digital stories); Door to door outreach screening

**Table 2** (continued)

First/Corresponding Author (Surname and Name) and Year of Publication	Geographic region of First/Corresponding authors	Geographic region of CE process/strategy/ approach	Health research domains	Type of health condition researched	Process or stage of CE described in the article?	CE approach/method used
Jose A. Arriola-Vigo, 2019 [30]	High income	Latin America and Caribbean	Health promotion research	Non-communicable disease/other conditions	<ol style="list-style-type: none"> <li>1. Consultation in identifying or defining problems &amp; interventions</li> <li>2. Collaboration with community in monitoring, evaluating research projects</li> <li>3. Empowerment and ownership of research process</li> </ol>	Employing community mental health workers; home visits; psychosocial clubs; mental health workshops and campaigns; peer support groups
Irene Jao, 2015 [31]	Lower/Upper middle income	Sub-Saharan Africa	Health promotion research, Information systems research	Broader health issues, primary care	<ol style="list-style-type: none"> <li>1. Consultation in identifying or defining problems &amp; interventions</li> <li>2. Collaboration with community in monitoring, evaluating research projects</li> </ol>	
Osama Ahmed Hassan, 2017 [32]	Low income	Multiple regions	Health promotion research	TB and Other infectious diseases	<ol style="list-style-type: none"> <li>1. Informing communities about problems &amp; solutions proposed</li> <li>2. Consultation in identifying or defining problems &amp; interventions</li> <li>3. Empowerment and ownership of research process</li> </ol>	Community consultation through Community Surveys; Face-to-face interviews with household heads
Kimberly Baltzell, 2019 [33]	High income	Multiple regions	Health promotion research	Malaria	<ol style="list-style-type: none"> <li>1. Informing communities about problems &amp; solutions proposed</li> <li>2. Involvement in research project</li> <li>3. Empowerment and ownership of research process</li> </ol>	Thought leaders (defined as those with expertise or leadership positions in sectors included in the study); Focus group discussions (FGDs); Community meetings; Drama and music performances; art, shows; and school-based activities; Door-to-door engagement; Community motivation
Abhay Gaidhan, 2020 [34]	Low income	South Asia	Information systems research	Environment	<ol style="list-style-type: none"> <li>1. Consultation in identifying or defining problems &amp; interventions</li> </ol>	Photographs and stories

34]; (c) community involved through participating in the implementation of research projects [25, 29, 33] (d) community collaborated with in managing research project resources e.g. monitoring and evaluation [27, 30, 31]; (e) community empowered in taking ownership of the research process [27-30, 32, 33].

#### Type of CE method or approach

The broad range of methods and approaches for CE were assessed and outlined as mentioned/discussed in surveyed literature. These techniques varied based on whether communities were informed, consulted, involved, collaborated with or empowered. Table 2 summarizes the major techniques for CE included. 4 main categories were identified and are explained below:

##### 1) CE through Artwork and Creativity

- a) **Photography:** Photography was seen as an essential and successful technique for integrating people into health-related research activities [34]. Images integrate living experiences with scientific knowledge, allowing individuals to relate to health messaging. Photographs can also be used to represent health-related demands and opinions without the use of complicated language or scientific understanding.
- b) **Short films and digital story screening:** these were also seen as effective means of engaging the community [13].
- c) **Communities were also engaged through festivities that involved songs, poems and similar artworks [33].** These artworks described the area of the community, changes members would like to see, and their ideal environment.

##### 2) CE through Workshops and Focus Groups

Workshops [13, 35] and focus groups [6, 33] were seen as avenues that allow people to discuss their ideas in an open and relaxed atmosphere. There were a variety of workshop formats described in the surveyed literature. Some workshops were meant for the exchange of information; others to discuss the strengths, weaknesses, opportunities and threats of an idea or project, while others were for obtaining ideas and innovative thinking for a way forward for a project. Focus groups by contrast are designed to specifically concentrate on a single issue. Both workshops and FGDs were avenues for education, information-education-communication (IEC) campaigns, behaviour change, peer-led, participatory,

empowerment-based, communication campaigns, social and behavioural communication campaigns, and mass-media campaigns [28].

##### 3) CE through forums

A forum was seen as a regular meeting of people who represent a group of organizations and were issue or area based. Those involved typically comprised members of civic, political, professional, economic or social groups from a local area. A number of articles [13, 27, 35] referred to community leader forums as key influencer forums, and that research programs are likely to fail if local leadership does not support the program's goals.

##### 4) CE through community surveys

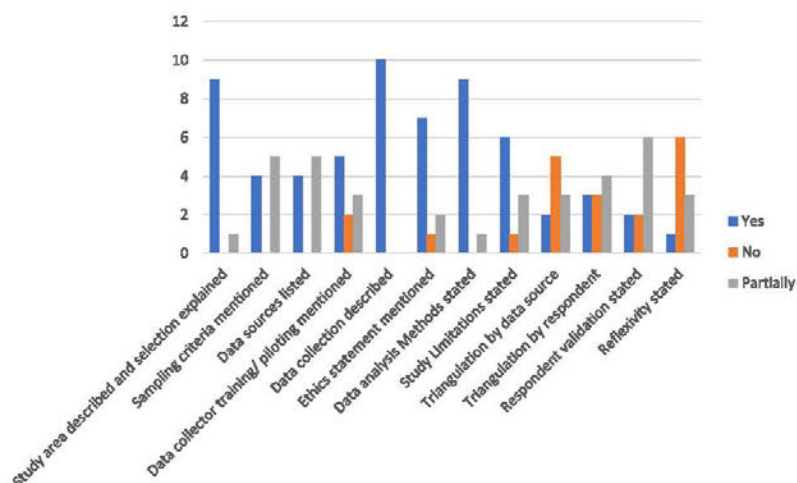
Questionnaire surveys were seen as means of identifying the needs and views of a large number of people in a standard format [32].

#### Quality of study design and analysis

Several components of the study quality-examined were clearly unsatisfactory when it came to the interpretation of responses to the quality of study designs and data analysis. Independent of the data collection description, no article fulfilled every requirement for a research article. At least 60% of studies provided basic aspects related to describing study area and selection, data sources and collection, and triangulation across data sources. Despite this, 30 percent of articles did not have declaration of ethical approval from review boards, while 60% of the papers acknowledged limitations (Fig. 5). The quality of studies varied depending on their study designs. No study could possibly list all of the characteristics of good quality design that we discussed, some studies did not adequately list their sample criteria [25, 27, 31, 32, 34], study participation rates [28-31, 33, 34], ethics statements [6, 26, 31], only two studies adequately mentioned respondent validation [29, 34], and only one study mentioned researcher reflexivity [28]. (See supplementary table 1 in the supplementary material showing how each study rated in the study quality assessment).

#### Discussion

A distinguishing mark of the CE research literature in health research settings is that more needs to be done at a variety of levels. For community engagement in LMICs as previously de-fined, we have found very few published studies of empirically collected CE processes data [26, 27, 29], and in fact, few published CE processes studies of any kind, in professional journals. Some related evidence comes from



**Fig. 5** Systematic literature review Quality assessment results

studies of non-research settings of community engagement projects and initiatives [28, 34].

Although our analysis included studies that are simply qualitative, quantitative, or mixed methods, the majority of studies were exploratory in origin, with only a few using probability or experimental designs to evaluate or describe health research in relation to community engagement. Some reviews on community participation have also noted the scarcity of experimental designs that examine the effectiveness of community participation [36, 37], others have called to attention the lack of process evaluations [7] and qualitative research [38] to investigate more thoroughly how community participation contributed to the health outcomes linked to it. The challenge in noticing such an effect has previously been ascribed to insufficient distinction between CE as a continuous social process, not as a once-off or now-and-again community intervention, a process that requires alternative evaluation models [19, 39]. Given the variable study quality of many of the publications in this systematic literature review, as well as the challenge of assessing community engagement, due to its multi-faced, context-specific, and contentious nature, more high-quality research is needed to better understand the CE processes or strategies.

#### CE approaches

Several CE approaches were presented in the surveyed literature. However, a deeper discussion on the appropriate contexts where each can be used was lacking across all articles. For instance, the utility of Arts and Creative approaches for CE are very appropriate where local people are involved in expressing their views and

generating ideas in a participative approach. They are a useful technique for engaging with people of all ages through education or school programs, local community forums and resident or interest groups. However, they are specifically beneficial at the beginning of a community research project in the planning process to generate interest and raise awareness of the projects. Moreover, this technique often depends on the availability of a large space to exhibit or display results. It may also be difficult to interpret participants' ideas in this mode of CE. It is significant to understand cultural dynamics in the community engagement discourse as culture provides a sense of belonging in the community, shapes identities, and affects how people interact with one another, define power, and generate meaning [40]. Culture also affects perceptions of collaboration, trust, and negotiation. As a result, culture influences how communities are engaged, and cultural knowledge is necessary for successful community engagement [41]. Therefore, researchers and practitioners need to understand the cultural dynamics of specific groups and institutions in order to build relationships, identify ways to effectively collaborate, and build respect and trust. Workshops and focus group discussions are useful approaches for encouraging discussion among those who may feel less confident in larger group meetings, with the benefit of targeting participants or certain interest groups. However, even though this has the advantage of identifying and inviting those often excluded from a wider engagement exercise, with such small groups, it is often difficult to be sure all stakeholders or interests are represented. Workshops can also be dominated by articulate and confident individuals if not

carefully facilitated, unless experienced facilitators are present.

Many of the assessed articles presented creative and socially based approaches to showcase CE. However, utilizing multiple channels of communication is important. Examples of other techniques and channels for CE include the use of soccer clubs, films, community drama, television, songs, Facebook, social events such as weddings, music festivals, and community fairs with prizes. Children were repeatedly mentioned as important change agents and it was recommended that youth groups be mobilized to assist with messaging. This is one way of ensuring that a part of the community actually participates in the role of the research. Mobilizing groups of young people to become citizen scientist or assistant researchers can significantly improve the involvement of young people, it also brings in the element of collaborations especially when young people bring in their ideas and expertise in solving some of the problems as they work with the researchers. CE borders mainly informing, consulting, involving, collaborating and empowering, hence it is important to have an approach that can accommodate all or most of these stages. Drama and creative art facilitate the process of informing, involving but lacks consultation, collaboration and empowerment. Workshops and FGDs bring on the aspect consultation but still lack in collaboration and empowerment unless the workshops take the form of trainings. Peer educators, community forums (such as community advisory boards) and other forms of collaboration including working with community health workers and community research assistants enable the implementation of all the five stages of the CE process framed by the Vancouver Coastal College CE framework (informing, consulting, involving, collaborating and empowering).

#### **Implications of CE in lower-and middle-income countries**

The review shows that the understanding of implementing principles of CE in researching health-related issues is still in its developmental phase, which poses threats to recognising communities from LMICs as knowledge experts. This review demonstrated that there is limited literature on empirical research published on CE processes in relation to health issues in LMICs. Furthermore, the dearth of empirical research in this study subject calls for more measures to conduct empirical studies to close the gaps between a theoretical perspective and its application in the real world to determine the relevance of CE strategies and approaches to address social issues. Some scholars raised great concern by describing CE as less participative and lacking theoretical components that are responsive to the needs of the researched communities in LMICs [6, 13, 27, 35, 42]. However, this is

debatable because LMICs have different characteristics that researchers need to consider. Sometimes researchers in LMICs dominate the research processes, without full or direct participation from researched communities. Another realisation is that some of the CE approaches are not applicable and responsive to the needs of people in LMICs when dealing with health issues in a research context. This suggests the reorganization or reconsideration of the assets that exist not only as regards the content or principles and the methods, but a rethinking of various phases and processes of CE [43, 44]. Moreover, these gaps pose a threat to the need to envision CE as a participatory approach in which all components, including understanding the concepts, theories and processes are considered when conducting engaged research on health-related issues in LMIC.

This review highlights how crucial it is for researchers conducting community engagement health studies in LMICs to take into consideration the level and the nature of community participation. There is a need for high-quality study designs to better understand the CE processes and approaches in achieving successful community engagement. A key area that emerged from the systematic literature review is that most CE techniques are creative in nature and socially based but the appropriateness, feasibility and value of these techniques are not considered when dealing with health issues in LMICs. Therefore, participatory approaches and strategies, such as community based participatory research (CBPR) being the most established and well-known in the health field should be recognised and adopted in CE. This could provide more in-depth insights into community engagement in health interventions as well as the connections between variables such as power dynamics and their impact on community participation outcomes. Previous studies that adopted CBPR in dealing with health initiatives found CBPR to be one of the most successful strategies for improving community participation in rural settings [5, 45, 46]. These findings suggest that researchers should identify the best CE processes, strategies and approaches that are most appropriate to community settings when dealing with health interventions in LMICs.

#### **Limitations**

We faced limitations during the literature search where some studies that qualified for abstract screening were not available or accessible for free (were available on purchase) and we did not have funding to buy the articles, our institutional library also did not have access to these papers. Because of the unavailability of funds to pay to access these articles, we could not access them or use them in the next stages of the review. The institutional access which our university offered was not

covering these journals. Other reasons for not accessing papers included the fact that some papers were listed as citations, but no full papers were available to view them, this could be a problem with wrong referencing or broken links to the source of the articles. In total we failed to access at least 13 papers which impacted the possible outcomes of our review. Another limitation of the review is that grey literature was not looked for. We only focused on peer reviewed and published articles. These limitations slightly reduced the scope of papers included the review and they may have affected the analysis and outcomes in general. Another limitation of the systematic literature review was the use of only the first institutional affiliation, given that two separate affiliations for the first and/or corresponding author were mentioned. This might have resulted in a measurement inaccuracy in terms of determining which economic region to adopt in classifying the study. However, the first author of a publication is typically the student/researcher who conducted the research, while the corresponding author is typically the senior author who gives intellectual input and prepares and approves the procedures to be used in the systematic literature review. We suggest the attribution as provided in this work is fair because it is based on the first or corresponding author of the selected publication.

## Conclusions

Even though reviewed works were relatively rigorous and appeared balanced, the findings on CE approaches and strategies were inconclusive. While desired change does sometimes occur, overall, the documented research evidence for positive coalition or partnership outcomes is weak. The reviewed publications contain some great examples of CE approaches and strategies, they also contain key cautionary components. Despite the importance of community participation and its history, there is still a lack of general understanding of the concepts, motivations, and social processes that drive it. Many publications are undertheorized and uncritical, with few citations to definitions or frameworks. While this may not appear to be relevant to the social transformation or utilitarian goals that motivate community engagement initiatives, it can help to explain the assumptions that underpin the type of community participation project that is supported, as well as clarify expectations about the scope of change that is expected, and the techniques required to achieve it on multiple levels.

## Abbreviations

CASP	Critical Appraisal Skills Program
CBPR	Community-Based Participatory Research
CE	Community Engagement
CEnR	Community-Engaged Research
IEC	Information-Education-Communication

LMICs	Low- and Middle-Income Countries
PAR	Participatory Action Research
P-PAE	Patient Activation and Empowerment
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
VBDs	Vector-Borne Diseases
WHO	World Health Organisation

## Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12913-023-09466-9>.

**Additional file 1: Supplementary Table 1.** Study quality assessment and appraisal table.

## Acknowledgements

I acknowledge the contribution of my supervisor Prof Chimbari and Dr Mindu for his support. It is with gratitude that I thank Prof Masuku for his encouragement. Special thanks go to my colleagues from KwaZulu-Natal Ecohealth Program (KEP) for their unreserved input into the review. I also acknowledge my family and friends for all the support during the course of writing this paper.

## Authors' contributions

ZM led all aspects of the paper's development from conceptualization and designing the study, identification of studies via databases and registers, data extraction to finalization. MJC and JOM were also involved in the conceptualization of the paper and critically reviewed and edited all drafts of the paper. Both authors approved the submission.

## Funding

This work was supported by National Research Foundation (NRF) (grant number: 116263) through my supervisor (Prof Chimbari) and by a PhD Scholarship from the University of KwaZulu-Natal, College of Health Sciences.

## Availability of data and materials

The datasets used and/or analysed during the current systematic literature review available from the corresponding author on reasonable request.

## Declarations

### Ethics approval and consent to participate

Not applicable.

### Consent for publication

Not applicable.

### Competing interests

The authors declare no competing interests.

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Received: 21 December 2022 Accepted: 27 April 2023

Published online: 08 May 2023

## References

- Ahmed SM, Palermo AGS. Community engagement in research: frameworks for education and peer review. *Am J Public Health*. 2010;100(8):1380–7.
- Organization WH. Twenty steps for developing a healthy cities project. Copenhagen: WHO Regional Office for Europe; 1997.

3. McCloskey DJ, Akintobi TH, Bonham A, Cook J, Coyne-Beasley T. Principles of Community Engagement (Second Edition). *COMMUNITY Engagem.* :197.
4. Irish E, Burke K, Geyer E, Allard I. Patient Empowerment: A Partnership for Community Engagement in Three Phases. *J Consum Health Internet.* 2022;26(1):109–18.
5. Luger TM, Hamilton AB, True G. Measuring community-engaged research contexts, processes, and outcomes: a mapping review. *Milbank Q.* 2020;98(2):493–553.
6. Chirozva C. Community engagement in the governance of Transfrontier Conservation Areas: An analysis of the implementation of Sengwe Tshipise Wilderness Corridor, Zimbabwe [Doctoral Thesis]. Australia: Charles Sturt University; 2016.
7. Farnsworth SK, Böse K, Fajobi O, Souza PP, Peniston A, Davidson LL, et al. Community engagement to enhance child survival and early development in low- and middle-income countries: an evidence review. *J Health Commun.* 2014;19 Suppl 1(sup1):67–88.
8. Estacio EV. Health literacy and community empowerment: it is more than just reading, writing and counting. *J Health Psychol.* 2013;18(8):1056–68.
9. Chen J, Mullins CD, Novak P, Thomas SB. Personalized strategies to activate and empower patients in health care and reduce health disparities. *Health Educ Behav Off Publ Soc Public Health Educ.* 2016;43(1):25–34.
10. Corrigan P, Pickett S, Kraus D, Burks R, Schmidt A. Community-based participatory research examining the health care needs of African Americans who are homeless with mental illness. *J Health Care Poor Underserved.* 2015;26(1):119–33.
11. R X, Jr S, Je H, Sg K. Promoting Community Health and Eliminating Health Disparities Through Community-Based Participatory Research. *Phys Ther.* 2016;96(3). Available from: <https://pubmed.ncbi.nlm.nih.gov/26251479/>. [Cited 2022 Dec 15].
12. MacQueen KM, McLellan E, Metzger DS, Kegeles S, Strauss RP, Scotti R, et al. What is community? An evidence-based definition for participatory public health. *Am J Public Health.* 2001;91(12):1929–38.
13. Lippman SA, Pettifor A, Rebombo D, Julien A, Wagner RG, Kang Dufour MS, et al. Evaluation of the Tsima community mobilization intervention to improve engagement in HIV testing and care in South Africa: study protocol for a cluster randomized trial. *Implement Sci IS.* 2017;12(1):9.
14. Matthews AK, Anderson EE, Willis M, Castillo A, Choure W. A community engagement advisory board as a strategy to improve research engagement and build institutional capacity for community-engaged research. *J Clin Transl Sci.* 2018;2(2):66–72.
15. Evans E, Funes M, Hong H, Reuter K, Ahmed S, Calhoun K, et al. Defining and measuring community engagement and community-engaged research: clinical and translational science institutional practices. *Prog Community Health Partners Res Educ Action.* 2018;12(2):145–56.
16. Nutbeam D. Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. *Health Promot Int.* 2000;15(3):259–67.
17. Patrick DL, Wickizer TM. Community and Health. In B. C. Amick, S. Levine, A.R. Tarlov & D. C. Walsh (Eds.), *Society and Health*. New York: Oxford University Press; 1995. pp. 46–92.
18. Bedson J, Skrip LA, Pedi D, Abramowitz S, Carter S, Jalloh MF, et al. A review and agenda for integrated disease models including social and behavioural factors. *Nat Hum Behav.* 2021;5(7):834–46.
19. George AS, Mehra V, Scott K, Sriram V. Community participation in health systems research: a systematic review assessing the state of research, the nature of interventions involved and the features of engagement with communities. *PLoS One.* 2015;10(10):e0141091.
20. Dudley L, Gamble C, Allam A, Bell P, Buck D, Goodare H, et al. A little more conversation please? Qualitative study of researchers' and patients' interview accounts of training for patient and public involvement in clinical trials. *Trials.* 2015;16(1):190.
21. Lencucha R, Neupane S. The use, misuse and overuse of the 'low-income and middle-income countries' category. *BMJ Glob Health.* 2022;7(6):e009067.
22. Long HA, French DP, Brooks JM. Optimising the value of the critical appraisal skills programme (CASP) tool for quality appraisal in qualitative evidence synthesis. *Res Methods Med Health Sci.* 2020;1(1):31–42.
23. Porritt K, Gomersall J, Lockwood C. JBI's systematic reviews: study selection and critical appraisal. *AJN Am J Nurs.* 2014;114(6):47–52.
24. Lucas PJ, Baird J, Arai L, Law C, Roberts HM. Worked examples of alternative methods for the synthesis of qualitative and quantitative research in systematic reviews. *BMC Med Res Methodol.* 2007;7(1):4.
25. Chirozva C. Community engagement in the governance of Transfrontier Conservation Areas: An analysis of the implementation of Sengwe Tshipise Wilderness Corridor, Zimbabwe. [Doctoral Thesis, Charles Sturt University]. Australia Charles Sturt University. 2016;1-326.
26. Lan CW, Tavrow P. Composite measures of women's empowerment and their association with maternal mortality in low-income countries. *BMC Pregnancy Childbirth.* 2017;17:1–11.
27. Jao I, Kombe F, Mwalukore S, Bull S, Parker M, Kamuya D, et al. Involving research stakeholders in developing policy on sharing public health research data in Kenya: views on fair process for informed consent, access oversight, and community engagement. *J Empir Res Hum Res Ethics.* 2015;10(3):264–77.
28. Lamaro Haintz G. "Theorising community engagement in sexual and reproductive health promotion in South Africa." PhD dissertation, Deakin University. 2019;1-322.
29. Lippman SA, Neillands TB, MacPhail C, Peacock D, Maman S, Rebombo D, et al. Community mobilization for HIV testing uptake: results from a community randomized trial of a theory-based intervention in rural South Africa. *J Acquir Immune Defic Syndr.* 2017;74(Suppl 1):S44.
30. Arriola-Vigo JA, Stovall JG, Moon TD, Audet CM, Diez-Canseco F. Perceptions of community involvement in the Peruvian mental health reform process among clinicians and policy-makers: a qualitative study. *Int J Health Policy Manag.* 2019;8(12):711.
31. Jao I, Kombe F, Mwalukore S, Bull S, Parker M, Kamuya D, et al. Research stakeholders' views on benefits and challenges for public health research data sharing in Kenya: the importance of trust and social relations. *PLoS ONE.* 2015;10(9):e0135545.
32. Hassan OA, Affognon H, Rocklöv J, Mburu P, Sang R, Ahim C, et al. The One Health approach to identify knowledge, attitudes and practices that affect community involvement in the control of Rift Valley fever outbreaks. *PLoS Negl Trop Dis.* 2017;11(2):e0005383.
33. Baltzell K, Harvard K, Hanley M, Gosling R, Chen L. What is community engagement and how can it drive malaria elimination? Case studies and stakeholder interviews. *Malar J.* 2019;18:1–11.
34. Gaidhane A, Holding P, Shah M, Patil M, Telrandhe S, Jadhav N, et al. Photostory—A "Stepping Stone" approach to community engagement in early child development. *Front Public Health.* 2020;8:578814.
35. Arriola-Vigo JA, Stovall JG, Moon TD, Audet CM, Diez-Canseco F. Perceptions of community involvement in the Peruvian mental health reform process among clinicians and policy-makers: a qualitative study. *Int J Health Policy Manag.* 2019;8(12):711–22.
36. Preston R, Waugh H, Larkins S, Taylor J. Community participation in rural primary health care: intervention or approach? *Aust J Prim Health.* 2010;16(1):4–16.
37. Atkinson JA, Valley A, Fitzgerald L, Whittaker M, Tanner M. The architecture and effect of participation: a systematic review of community participation for communicable disease control and elimination. Implications for malaria elimination. *Malar J.* 2011;10(1):225.
38. Marston C, Renedo A, McGowan CR, Portela A. Effects of community participation on improving uptake of skilled care for maternal and newborn health: a systematic review. *PLoS One.* 2013;8(2):e55012.
39. Marston C, Hinton R, Kean S, Baral S, Ahuja A, Costello A, et al. Community participation for transformative action on women's, children's and adolescents' health. *Bull World Health Organ.* 2016;94(5):376–82.
40. Chapter 1: Useful Concepts | Principles of Community Engagement | ATSDR. 2018. Available from: [https://www.atsdr.cdc.gov/communityengagement/pce\\_useful.html](https://www.atsdr.cdc.gov/communityengagement/pce_useful.html). [Cited 2023 Apr 21].
41. Chapter 2: Before Starting a Community Engagement Effort | Principles of Community Engagement | ATSDR. 2018. Available from: [https://www.atsdr.cdc.gov/communityengagement/pce\\_principles\\_starting.html](https://www.atsdr.cdc.gov/communityengagement/pce_principles_starting.html). [Cited 2022 Jul 26].
42. Lan CW, Tavrow P. Composite measures of women's empowerment and their association with maternal mortality in low-income countries. *BMC Pregnancy Childbirth.* 2017;17(2):337.
43. Adhikari B, Vincent R, Wong G, Duddy C, Richardson E, Lavery JV, et al. A realist review of community engagement with health research. *Wellcome Open Res.* 2019;2(4):87.

44. Nimdet K, Chaiyakunapruk N, Vichansavakul K, Ngorsuraches S. A systematic review of studies eliciting willingness-to-pay per quality-adjusted life year: does it justify CE threshold? *PLoS One*. 2015;10(4):e0122760.
45. Salimi Y, Shahandeh K, Malekafzali H, Loori N, Kheiltash A, Jamshidi E, et al. Is Community-based Participatory Research (CBPR) Useful? a systematic review on papers in a decade. *Int J Prev Med*. 2012;3(6):386–93.
46. HoonChuah FL, Srivastava A, Singh SR, Haldane V, HuatKoh GC, Seng CK, et al. Community participation in general health initiatives in high and upper-middle income countries: a systematic review exploring the nature of participation, use of theories, contextual drivers and power relations in community participation. *Soc Sci Med*. 2018;1(213):106–22.

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### **1.3 Research problem and significance**

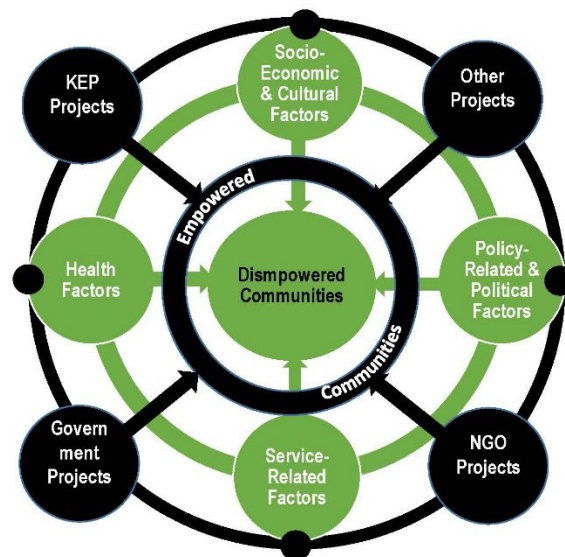
Community empowerment is about supporting people to increase control of their own health needs and having the ability to self-manage their own illnesses and changes in living environments (World Health Organization, 2015). Therefore, community empowerment is more than participation, involvement or engagement. It entails ownership and action of a community aiming at social, political and health change. KwaZulu-Natal Ecohealth Program (KEP) has been conducting research projects in uMkhanyakude aimed at reducing the burden of infectious diseases. One of the projects previously implemented in the same area was MABISA (Malaria and Bilharzia in South Africa) which began in 2014 and ended in April 2017. MABISA assessed the impacts of climate change on malaria and bilharzia in semi-arid dry areas in Botswana, Zimbabwe and South Africa with the ultimate aim of reducing the vulnerability of communities to the diseases and general climate change effects (Musesengwa, Chimbari and Mukaratirwa, 2017).

Through the MABISA project, a Community Advisory Board (CAB) was established and Community Research Assistants (CRAs) were recruited. CABs play the watchdog role of ensuring that ethical conduct is observed in the communities and that the community needs and interests are captured, addressed and not sidestepped. CRAs on the other hand, work side by side with researchers on data collection and assist with mobilizing the community. The MABISA project produced results, which give an understanding of the way stakeholders can help manage or monitor diseases through environmental and people centred measures. TIBA-SA (Tackling Infections Disease Burden in Africa) a new initiative continued to work with stakeholders recruited by MABISA project. TIBA-SA focused, but not limited to, on schistosomiasis and malaria diseases and applied the Ecohealth approach. One of the six pillars of Ecohealth is community participation through which the project aimed to empower communities to manage their health issues.

The TIBA-SA projects operated in an environment where there were already health challenges as well as economic, political, service-related and socio-cultural challenges. These challenges compromised empowerment of the community. There have been several projects (including TIBA-SA, NGOs, government and other projects) operating in the same environment and most of them had similar goals. There was a tendency for unhealthy competition among the projects. Notwithstanding the competitive nature of the environment, TIBA-SA projects intended to capture the diverse challenges of healthcare systems in the area and addressed the health delivery gap resulting in either non-deployment of diagnostics or interventions or a lack of operational knowledge to improve the health of affected populations.

People are engaged and empowered when they are given the opportunities, skills, and resources they need to become empowered users of health services (World Health Organization, 2015). Therefore, community empowerment is critical, and communities should be empowered to make effective decisions about their own health and well-being. As discussed in the literature review above, this is self-

empowerment, which has a ‘two-sides equation’ that involves a balance of power rather than a one-way dynamic. It is important to emphasise specific characteristics on both sides including leadership and participation in a collective team spirit. As a result, CE is associated with development, sustainability and ownership. However, communities are disempowered because of many reasons. Ocloo and Matthews (2016) found that communities are disempowered because of failure to adequately involve patients and the public in implementation of healthcare programmes. Poor access to information and limited interaction of people with environment, resources and support disempowers communities in decision making (World Health Organization, 2015). Poor collaboration, lack of co-production, and poor utilization of knowledge in healthcare limits the empowerment of communities (Rycroft-Malone, Burton, Bucknall, Graham, Hutchinson, Stacey, 2016). Poverty and non-recognition of community assets (such as skills and knowledge, social networks and community organisations) are also limitation blocks for good health and community empowerment (South, 2015).

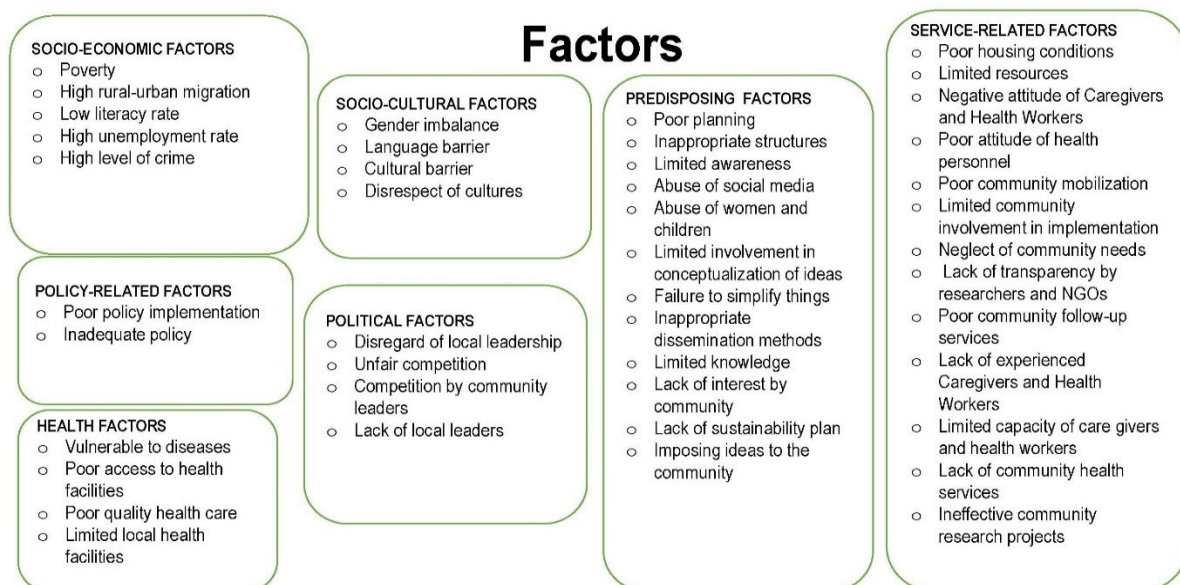


**Figure 2:** *The conceptual framework illustrating disempowerment of the Ingwavuma communities, Jozini Municipality, KwaZulu-Natal, South Africa; by the author (2023)*

The community of Ingwavuma is constituted of individuals living in households. Around individuals, there is a big environment with biophysical, social, economic and political factors. All these factors influence what happens in a community (see **Figure 2** above). Generally, the Ingwavuma community is a very poor area and poverty makes its local people less empowered. Eaton, Flisher and Aaro (2002) speak about the proximal context which focuses on interpersonal relationships and how individuals are affected by both the physical and organisational environments. In this proximal context, individuals and their environment are influenced by wide-ranging social conditions. According to Eaton et al., (2002), these may include gender-based violence and imbalance of power; poor communication, supervision

and guidance from community leaders; poor access to information; lack of recreational facilities and poor living environment.

The proximity of Ingwavuma community to the borders of the Republics of Mozambique and Swaziland exposes the community to the risk of socio-cultural factors such as gender imbalance (where women experiencing oppression in their patriarchal relationships) which is considered the norm in a larger society. Eaton et al. (2002) states that culture involves norms and beliefs of a society and culturally entrenched gender discrimination increases the risk of diseases for African women. Therefore, cultural barrier and disrespect of cultures also hinder community empowerment. Socio-economic factors including poverty as a major risk factor for poor health outcomes. Poverty is associated with lower total household income triggered by a high unemployment rate and low literacy rate. The relative scarcity of health resources in the poorest rural areas and limited access to them is a problem that continues to affect the health of the communities. Service-related factors (poor housing conditions, limited resources, negative attitude and lack of experienced Caregivers and Health Workers, poor attitude of health personnel, lack of community health services, and poor community follow-up services) also contribute to the disempowerment of communities. In Ingwavuma community, there is a political environment characterised by unfair competition by community leaders, where Inkatha Freedom Party (IFP) and African National Congress (ANC) are considered almost equally powerful political parties. This has concentrated power at political level leaving the communities disempowered. However, there are organisation institutions such as KEP, NGOs, government and political parties, which claim that they are working closely with the community of Ingwavuma to empower them to address health related challenges. Notwithstanding the community of Ingwavuma seems to be not yet empowered. Multiple factors that contribute to the dis-empowerment of communities are presented in **Figure 3** below.



**Figure 3:** Multiple factors contribute to the dis-empowerment of communities; by the author (2023)

This thesis has analysed the factors that negatively affect community well-being using the Community Engagement Vancouver Coastal Health framework illustrated above in **Figure 1** and in the literature review.

Most studies on community engagement and empowerment on health challenges have not been rigorous enough. A study by Chen, Mullins, Novak, and Thomas (2016) shows the importance of patient activation and empowerment as a cyclical process through a patient accumulation of knowledge, confidence, and self-determination for their health. These authors suggested an empowerment framework (from individual to a health care professional to community and health care delivery system-level), intended to inform the development of culturally informed personalized patient activation and empowerment (P-PAE) interventions to improve population health and reduce racial and ethnic disparities. Another study found peer navigators useful for addressing health problems through community-based participatory research (CBPR) in ensuring that communities are empowered on health issues (Corrigan, Pickett, Kraus, Burks and Schmidt, 2015). Core concepts and principles of CBPR were also found to be effective in the management of health issues at the community level (Xia, Stone, Hoffman and Klappa, 2016). Musesengwa, Chimbari, and Mukaratirwa (2018) developed a framework that shows how the community can be engaged in health projects. Consequently, a considerable amount of literature has been published on community engagement practices. These studies explored how communities are engaged, how to enter into the community and the experiences of community members and researchers in community engagement (Musesengwa and Chimbari, 2017; Musesengwa, Chimbari and Mukaratirwa, 2017; Musesengwa and Chimbari, 2017). Although many projects claiming to empower communities have been conducted in Ingwavuma no systematic assessment of the level at which the community has been empowered has been done. Hence, the purpose of this study was to determine the level of research empowerment of the Ingwavuma community in the uMkhanyakude District regarding schistosomiasis and malaria.

As TIBA-SA projects aimed to have impact on the society affected by health challenges, the projects adopted an Ecohealth approach with an emphasis on community engagement. TIBA-SA believed that through their projects, the community of Ingwavuma would be empowered through working with the community on preventative health measures, knowledge uptake as well as understanding infectious diseases such as schistosomiasis and malaria. People from the community can take action on their own and sustain it. However, there was also greater concern about whether the communities got empowered or disempowered because according to the literature, the gap still exists. Therefore, this study explored community engagement and involvement in empowering communities regarding schistosomiasis and malaria. The study determined the extent of the level of empowerment that resulted from the 7 years of community engagement under the MABISA and TIBA-SA projects. It shows where the Ingwavuma community is in terms of being empowered on health issues. The role of the Community Advisory Board (CAB), as well as that of Community Research Assistants (CRAs), was studied to assess the

capacity of the community in dealing with malaria and schistosomiasis issues. CAB and CRAs worked together with the TIBA research team.

#### **1.4 Research questions, objectives and hypothesis**

This study addressed the question, “what is the level of research empowerment of the Ingwavuma community in the uMkhanyakude District on schistosomiasis and malaria?” In order to answer the broad question, the following specific questions were investigated:

##### ***1.4.1 Specific research questions***

1. How informed is the Ingwavuma community about research projects on schistosomiasis and malaria that are implemented in their area?
2. To what extent have researchers consulted communities before they conceptualise and implement their research projects?
3. How involved is the Ingwavuma community in schistosomiasis and malaria projects implemented in their area?
4. What is the nature of the collaborative arrangements between researchers working on schistosomiasis and malaria; and the community?
5. What is the level of empowerment of the Ingwavuma community on aspects of schistosomiasis and malaria?

##### ***1.4.2 General objective***

The main objective of this study was to assess the level of research empowerment at which the Ingwavuma community in the uMkhanyakude District is pertaining to schistosomiasis and malaria. This assessment was conducted in order to evaluate and scale up community empowerment activities of MABISA/TIBA projects aimed at reducing community vulnerability to schistosomiasis and malaria in the community of Ingwavuma.

##### ***1.4.2.1 Specific objectives***

1. To determine the extent to which the community of Ingwavuma understands the schistosomiasis and malaria projects that have been implemented in their area.
2. To determine the level of community consultation that has been done by researchers working on malaria and schistosomiasis in the Ingwavuma community.
3. To investigate how the community is involved in schistosomiasis and malaria research projects implemented in Ingwavuma.
4. To explore the nature of collaboration between the community and researchers that have and are currently working in Ingwavuma.

5. To explore the level of empowerment of the Ingwavuma community on schistosomiasis and malaria-related issues.

### ***1.4.3 Hypothesis***

1. The community of Ingwavuma is not well informed about the schistosomiasis and malaria research projects implemented in their area.

2. Researchers working in the Ingwavuma community do not adequately consult the community about their projects before implementation.

3. The community of Ingwavuma has not been genuinely involved in the implementation of schistosomiasis and malaria research projects in their area.

4. The collaborative arrangements between the researchers and the Ingwavuma community are weak.

5. The level of empowerment of the Ingwavuma community on schistosomiasis and malaria-related issues is low.

## **1.5 Methodology**

### ***1.5.1 Research paradigm***

For the purpose of this study, a pragmatism paradigm was utilised. This is a mixed-method approach that is predicated on the idea that there is not just one way to learn but rather various ways to comprehend due to the existence of multiple realities. The philosophy of pragmatism is based on the idea that researchers ought to employ the philosophical and methodological strategy that proves to be the most successful in addressing the specific research topic that is being addressed (Tashakkori Teddlie and Teddlie 1998). Therefore, this study adopted both a constructivist (interested in in-depth meaning as constructed by the community, which calls for a qualitative approach) and a positivist (generalizing realities and experiences of communities) which allowed for measurement of extent and level which was quantitative. The goal of the integration of two paradigm was to gain a better understanding of community engagement and empowerment of the Ingwavuma community.

#### ***1.5.1.1 Constructivism***

Constructivist perspectives was adopted to address qualitative research questions, respectively (Creswell and Tashakkori, 2007). A social constructivist paradigm was adopted in this study to explore how schistosomiasis and malaria projects have empowered the community of Ingwavuma. The social constructivist paradigm aims to understand and explore the deeper meaning of the issue of a phenomenon. This study was located in the social constructivist because knowledge is not only constructed by observation but constructed by people's intervention, beliefs and decision-making (agency). The discourse is constructed in social meanings and plays a key role in this paradigm (system knowledge) that was interrogated to understand how people make meaning of their lives. Social

constructivism was employed to explore and understand the empowerment of a community and individual experiences, their behaviour and their perceptions of schistosomiasis and malaria.

#### *1.5.1.2 Positivist paradigm*

The positivism paradigm was used to understand and generate realities and experiences of local people of Ingwavuma communities, which allowed for measurement of extent and level to which the community of Ingwavuma was involved on schistosomiasis and malaria projects. The philosophy of positivism is founded on the quantifiable and quantitative observations that are then statistically analysed. These statistical investigations have as their primary goal the determination of any "correlations" that may exist between three or more variables (De Villiers, Dumay, and Maroun, 2019). In the positivist paradigm, knowledge is discovered through direct observation or measurements of phenomena, and facts are determined by analysing or scrutinising parts of a phenomenon to determine what they are or how they manifest in reality (Krauss, 2012).

#### *1.5.2 Study design*

This study adopted a cross-sectional design embedded with a mixed-methods approach. The study followed the Ecohealth approach adopting community-based participatory research. KEP projects, particularly MABISA and TIBA were used as a case studies and the overall study used mixed methods involving qualitative and quantitative aspects to assess the level of community empowerment in rural areas through health research. A case study refers to the investigation of an individual, group or phenomenon (Crowe, Cresswell, Robertson, Huby, Avery, Sheikh, 2011), that is partly ethnographic (interpretive) entailing doing a thorough study of an individual or a group as an entity through interviews, observations and document reviews (Cohen, Manion and Morisson, 2002). Regardless of the study being a mixed-method design, qualitative methods dominated this study. Three specific objectives (2, 3 & 4) were achieved through qualitative methods. The remaining two specific objectives (1 and 5) were achieved by the use of quantitative methods. Key informant interviews, focus group discussions and direct observations were conducted to answer the qualitative aspects of the study. Household questionnaires were used to analyse the level of involvement of the community in schistosomiasis and malaria projects implemented in the study area and also to determine the knowledge the community has on schistosomiasis and malaria and the extent to which the community is empowered.

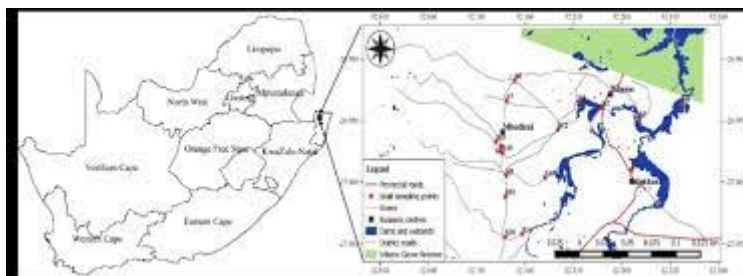
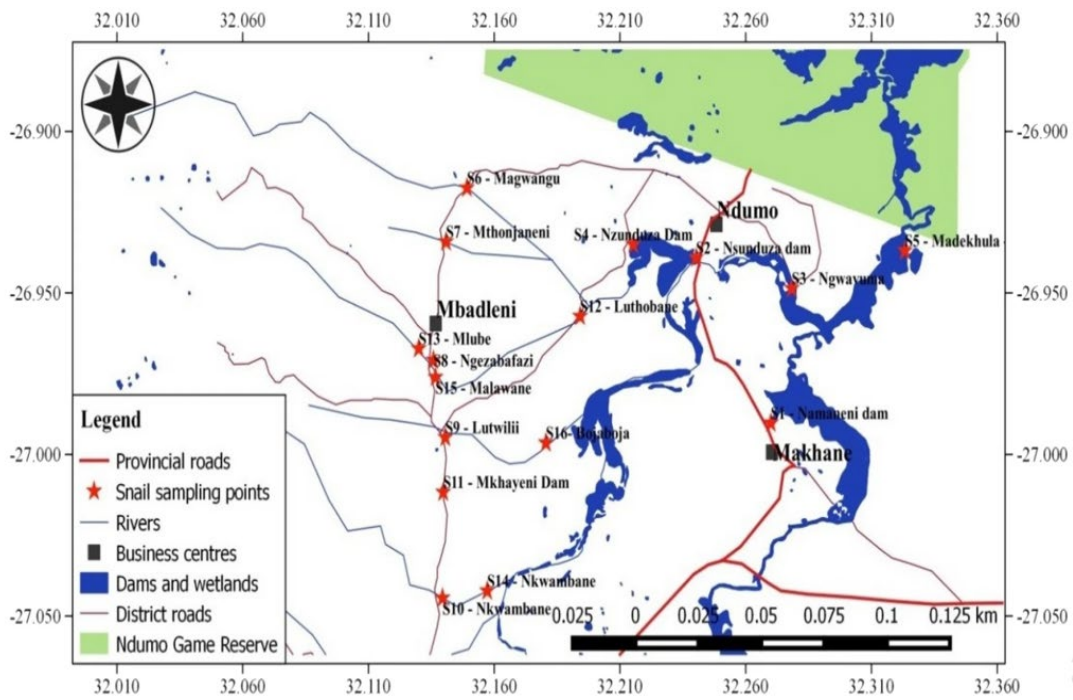
#### *1.5.3 Sampling procedure*

Two sampling procedures were adopted to achieve the outlined objectives. First purposive or judgmental sampling and snowballing sampling methods which argue that it is appropriate to select a sample based on the researcher's own knowledge of the population (Blanche and Durreim, 1999) was adopted. The purposive sampling technique was used to identify participants such as KEP project team members, village headmen, CAB members, CRAs, CHWs, and school principals to shed insight into

community engagement as well as empowerment of Ingwavuma community. Purposive sampling was used to identify important people or experts in the field instead of selecting a random sample of the population. Therefore, the participants mentioned above were purposefully sampled as potential key informants, based on their involvement in the CE activities and their knowledge about the MABISA/TIBA projects implementation. Snowball sampling was also adopted for this study because it allows the researcher to gain access to a population that may be hard to reach. This sampling criterion was also relevant to this study since the participants interviewed also referred the researcher to participants who were part of the MABISA project in 2014 but who had left the project during the time of the data collection of the current study. The researcher took a leading role in the data collection by conducting interviews and facilitating focus group discussions with the assistance of a colleague, who was also a researcher. Meetings with project stakeholders were organised to request permission to conduct the study.

#### ***1.5.4 Study area***

This study was conducted in the Ingwavuma community located in the uMkhanyakude District Municipality of KwaZulu-Natal Province under Jozini Local Municipality. Ingwavuma is over 700 metres above sea level in the Lebombo Mountains. The area is three kilometres from the country's border with Swaziland and overlooks the plains of Maputaland to the East. It falls within the Mngomezulu Tribal Authority. This area is underdeveloped with limited infrastructure; the roads are still being constructed and most villages are only accessible through gravel roads. The schools in the communities are dispersed and provide the bare minimum, with the majority lacking access to running water. Ingwavuma is situated in a low-lying area characterised by unexpectedly warm temperatures, quiet and slow-moving water bodies, and low humidity (Africa, n.d.). The area is susceptible to vector-borne illnesses (VBD), particularly schistosomiasis (bilharzia) and malaria, due to its geographic location. The area, which is plagued by several diseases and low levels of education, is also impoverished (Africa, n.d.). These factors indicate that a comprehensive and inclusive approach to community health education is necessary. The villages that were included in this study are Ndumo, Makhane, Mgedula, Mbadleni and Madeya (**Figure 4**).



**Figure 4:** Map showing the study area in uMkhanyakude: Adapted from (Manyangadze, Chimbari et al., 2016)

### 1.5.5 Data Collection Tools

Thirty-four in-depth semi-structured interviews and 4 Focus Group Discussions (FDGs) were conducted with participants to gather information on the level of community consultation that had been done by researchers working on malaria and schistosomiasis in Ingwavuma community; to determine

the extent to which the community is involved in schistosomiasis and malaria research projects implemented in Ingwavuma, and to determine the nature of collaboration between the community and researchers that had and were at the time of the study working in Ingwavuma. Three hundred and thirty-nine household questionnaires were administered to determine the extent to which the community of Ingwavuma understands the schistosomiasis and malaria projects that was implemented in their area. As well as to determine the level of empowerment of Ingwavuma community on schistosomiasis and malaria-related issues. In addition, secondary data was sourced from previously published studies (journal articles and books) conducted in the study area. Also, relevant information was extracted and used to supplement primary data. Below is a summary of how data for objectives was acquired:

#### *1.5.5.1 In-depth semi-structured interviews*

Participants that were interviewed face-to-face during fieldwork, which constitute a principal investigator (1), 9 KEP researchers, 2 projects administrative staff, 7 CRAs, 6 CABs, 3 Headmen, 2 CHWs and 4 primary school principals who had been part of the MABISA and TIBA-SA projects. The 9 researchers were all part of KEP and had been involved in MABISA and TIBA-SA projects, they were also researchers conducting studies in the same study area of Ingwavuma. The permission to interview KEP researchers was granted by the project investigators of the TIBA-SA projects. The community participants were invited through the gatekeepers (traditional authorities) of the area and purposively recruited as they had been working with the researcher in the study area for the past 9 years. Questions were asked using an interview guide (see **Appendices 5a, 5b, 5c, 5d, 6, 7 and 8**) and an audio recorder was used to capture the responses with the participants' permission. The interviews lasted one hour per participant.

#### *1.5.5.2 Focus group discussions*

Focus group discussions (FGDs) were held with 4 groups consisting of a minimum of 8 and/or a maximum of 10 community members from each group. Gender equity was maintained through participation of both males and females in the study. FGDs give a social context for research, and an opportunity to investigate how people think and talk about a topic, and how their thoughts are shaped and generated through communication with others (Ritchie and Lewis, 2003). This method has made it possible to effectively collect a large amount of information over a relatively short period of time (Mack et al., 2005). The FGDs were conducted at the Mosvold hospital hall, which is a district hospital that oversees Mbandleni and Ndumo clinics, which are part of Jozini Municipality. The FGDs were also recorded using an audio recorder. Consent to audio record the discussions was verbally requested. There were 2 research assistants assisting during the group discussions. One researcher assisted in recording the responses and the other assisted by taking notes of the attitudes, expressions and answers of the participants to the questions asked by the facilitator. Questions were asked using the same interview guide used for in-depth semi-structured interviews (see **Appendices 5a, 5b, and 5c**). Focus groups were also used during questionnaire development to identify issues that could come up during data collection.

#### *1.5.5.3 Questionnaires*

The study used a modified random-route procedure to administer a standardized questionnaire to 339 household heads selected randomly from Ndumo, Mgedula, Makhane and Mbadleni villages and the researcher with the assistance of CRAs administered the questionnaires face-to-face. This method was preferred because it is relatively quick, cheaper and easy to conduct, and it makes it possible to reach many people within a short period. An informed consent form was signed by participants (see **Appendix 3a**). The questionnaire was made short by only addressing relevant questions to avoid challenges associated with low responses rate associated with long questionnaires. General health questions and questions on health projects conducted in the area were asked. Questions on knowledge tests about schistosomiasis and malaria were also asked to understand the projects that had been implemented in the area (see **Appendix 4a**). KoboCollect a free open-source tool for mobile data collection using phones and tablets, was used to administer the questionnaires in this study.

#### *1.5.5.4 Direct observation*

The researcher also used an observational protocol for documenting practices and daily routines of the projects implemented. Participants' information (such as portraits, a description of physical settings, and accounts of particular events, or activities) was recorded while observing. In this method, it is not necessary for the researcher to ask questions of the participants; instead, he or she should simply listen to what the participants have to say and observe what they do (Immy, 2005; Ritchie and Lewis, 2003). Therefore, the researcher's personal thoughts, including "speculation, feelings, issues, ideas, hunches, impressions, and prejudices," were recorded through reflective notes (Creswell, 2014). There were also events (such as school drama competitions; community feedback meetings and cultural activities) that the researcher attended and participated in to capture key attributes, processes, relations and outcomes related to the study. One major disadvantage of observation is that it takes time, but as stated by Robson (2002) observation provides a researcher with real life in the real world.

#### *1.5.6 Data analysis*

The recorded interviews of focus group discussions and in-depth semi-structured interviews were transferred from the audio recordings into a computer for transcribing. The transcripts were written in English, and a computer-based software program (QSR International Pty Ltd, NVivo 12 Pro) was used to organise, analyse, and find insights from the convergence of information gathered. Observational field notes were typed and organised, carefully read (getting a sense of the information and an opportunity to reflect on its overall meaning), and then coded into nodes for analysis using the same computer software program. Codes were created and then sorted into common themes. The codes were matched with the quotes associated with each theme based on similarities, differences, and meanings. This was adopted in order to draw conclusions from the combination of data acquired from focus group discussions and in-depth interviews. The data were then analysed through qualitative thematic analysis to capture the experiences of the participants on community engagement processes in schistosomiasis and malaria projects implemented by KEP.

Data from the household questionnaires were analysed using descriptive statistics specifically frequencies and percentages. Chi-square tests of associations were done to assess associations between demographic variables (age, gender, education, village) and respondents' knowledge and information of the MABISA/TIBA projects as well as their participation. Further Chi-square tests were done to assess the association between participating in the study and knowledge about its aims, activities, researchers, and sites as well as whether respondents believed they had benefitted from the projects. Cramer's V tests were applied to all statistically significant Chi-square tests to measure the strengths of associations while descriptive contingency tables were used to identify relationships within the associations with a V of 0 indicating no relationship and a V of 1 showing the strongest possible association between tested variables (Akoglu, 2018). A probability value of 0.05 was used in both the Chi-square and Cramer's V tests. The general view behind the tests was that an informed and the consulted audience would exhibit statistically significant results that showed strong associations between project participation and knowledge of the projects' aims, activities, researchers and research sites. Also, they would show a strong association between project participation and benefits.

#### ***1.5.7 Ethical considerations***

In conducting this research, it was important to fulfil several obligations to meet ethical considerations. There are many ethical considerations that were considered. For this research, ethical approval was obtained from the Humanities and Social Sciences Research Ethics Committee (HSSREC) at the University of KwaZulu-Natal (UKZN) (see **Appendix 1**). A letter of informed consent was signed by each participant interviewed and participated in focus group discussions (see **Appendix 2a**). This study was conducted in a way that honours the participants. The type and nature of the questions asked during group discussions were taken into consideration. Participants were fully informed about the goals of the focus group discussion before the consent form was signed. Also, clear and sufficient information about the research which includes the risks, the benefits, and the expected outcomes was articulated to participants before they signed the consent form. Therefore, participants exercised their right to participate in the study voluntarily and the right to withdraw from participating in the study at any point in time.

The study received a gatekeeper permission letter from the Inkosi (traditional leader) of Ingwavuma communities also used by MABISA and TIBA researchers for whom this study was following up on. The same gatekeeper approval letter (see **Appendix 9**) obtained for the MABISA study was used for this investigation because it was an integral part of that larger study or inquiry into the effects of climate change on the infection and disease morbidity of schistosomiasis. Permission to conduct the study with community members was sought from the Izinduna (headmen) in each village selected for the study. These headmen are the elected gatekeepers with authority over villages and are accountable to the traditional leader, the tribal council and their community.

In ensuring anonymity, a participant's data was not associated with his/ her name or any other identifier. The researcher assigned a fabricated name to a participant's data to ensure they remain anonymous. Fabrication and falsification of data was avoided in ensuring the trustworthiness of the study.

## **1.6 Overview of thesis**

This thesis starts with some background information and then moves on to Chapter 1, which has an introduction and a review of studies that have been done on community engagement in rural areas of sub-Saharan Africa. The results of the study are shown in Chapters 2, 3, and 4. These chapters are presented as manuscripts submitted to journals for publication. The conclusions of the thesis are in Chapter 5, which also serves as a synthesis of the numerous parts that make up the thesis. It gives an overview of the thesis and explains how the various chapters are connected to one another. Below is a description of a detailed summary of the thesis's overall structure:

### ***Chapter 1: Introduction and literature review***

This is the first chapter of the thesis and provides a background, a review of the relevant literature, and a statement of the research problem. This chapter also provides a literature review of the 5 stages on the community engagement process (informing the community, consulting the community, involving the community, collaborating with the community and empowering the community). The systematic review paper titled: *Community Engagement Processes in Low- and Middle-Income Countries Health Research Settings: A Systematic Review of the Literature* is published under the BMC Health Services Research (Quartile: Q1).

### ***Chapter 2: Facilitating community engagement: researchers' lived experiences in rural communities in the KwaZulu-Natal Ecohealth Program, South Africa***

This chapter focuses on the experiences of KEP researchers during the first stage of community engagement, which is informing phase. A phenomenological qualitative approach was adopted to document the KEP research team's lived experiences. The manuscript titled: *Facilitating community engagement: researchers' lived experiences in rural communities in the KwaZulu-Natal Ecohealth Program, South Africa* is published under Cogent Social Sciences (Quartile: Q2).

### ***Chapter 3: Community Engagement: Health Research through Informing, Consultation, Involvement and Empowerment in Ingwavuma Community***

While community-based health research has potential to improve people's lives, recent findings reveal that some factors continue to be a barrier in informing and involving communities, as well as consulting with and empowering communities in research projects beneficial to them. Therefore, this chapter presents the extent to which the Ingwavuma community in the KwaZulu-Natal province was informed, involved and consulted about two Ecohealth research projects conducted between 2014 and 2021 in uMkhanyakude district. The manuscript titled: *Community Engagement: Health Research through*

*Informing, Involvement, Consultation and Empowerment in Ingwavuma Community* is published under Frontiers in Public Health (Quartile: Q1).

***Chapter 4: Community engagement and collaboration between researchers and community stakeholders for schistosomiasis and malaria projects in Ingwavuma, uMkhanyakude District, KwaZulu-Natal***

The process of engaging the community is broken down into five stages: informing, consulting, participating, collaborating, and empowering. The purpose of this manuscript was to investigate the experiences of community stakeholders throughout the collaboration phase of the CE process, which was co-developed by researchers and community members for the purpose of putting projects into action. The manuscript titled: *Collaboration between researchers and community stakeholders for research projects on schistosomiasis and malaria in Ingwavuma, uMkhanyakude District, KwaZulu-Natal* is under peer review with Humanities and Social Sciences Communications (Quartile: Q1). Status: Manuscript Under Consideration: 18 January 2024.

***Chapter 5: Synthesis of findings***

The final chapter of the thesis, Chapter 5, presents a synthesis of all chapters and an overview of the study, including the general discussion, summary of findings and general conclusion for all the chapters. This chapter also discusses the study's implications and potential application and areas of research that could be pursued in the future.

**1.7 References**

- Africa, S.S., n.d. Main Place | Statistics South Africa. URL [https://www.statssa.gov.za/?page\\_id=4286](https://www.statssa.gov.za/?page_id=4286) (accessed 10.20.22).
- Ahmed, S.M., Nelson, D., Kissack, A., Franco, Z., Whittle, J., Kotchen, T., Meurer, J.R., Morzinski, J., Brandenburg, T., 2015. Towards Building a Bridge between Community Engagement in Research (CEnR) and Comparative Effectiveness Research (CER). *Clin Transl Sci* 8, 160–165. <https://doi.org/10.1111/cts.12236>
- Akoglu H. User's guide to correlation coefficients. *Turk J Emerg Med.* 2018;18(3):91–3.
- Allotey, P., Reidpath, D.D., Devarajan, N., Rajagopal, K., Yasin, S., Arunachalam, D., Debora Imelda, J., Soyiri, I., Davey, T., Jahan, N., 2014. Cohorts and community: a case study of community engagement in the establishment of a health and demographic surveillance site in Malaysia. *Global Health Action* 7, 23176.
- Arriola-Vigo, J.A., Stovall, J.G., Moon, T.D., Audet, C.M., Diez-Canseco, F., 2019. Perceptions of Community Involvement in the Peruvian Mental Health Reform Process Among Clinicians and Policy-Makers: A Qualitative Study. *International Journal of Health Policy and Management* 8, 711–722. <https://doi.org/10.15171/ijhpm.2019.68>
- Assefa, Y., Hill, P.S., Gilks, C.F., Admassu, M., Tesfaye, D., Van Damme, W., 2020. Primary health care contributions to universal health coverage, Ethiopia. *Bulletin of the World Health Organization*, 98(12), 894-905A. <https://doi.org/10.2471/BLT.19.248328>.

- Avery, H., Sjögren Forss, K., Rämgård, M., 2022. Empowering communities with health promotion labs: Result from a CBPR programme in Malmö, Sweden. *Health Promotion International*, 37(1), daab069.
- Bassler, A., Brasier, K., Fogle, N., Taverno, R., 2008. Developing effective citizen engagement: A how-to guide for community leaders. Centre for Rural Pennsylvania, Pennsylvania State University Cooperative Extension.
- Batterham, R.W., Hawkins, M., Collins, P.A., Buchbinder, R., Osborne, R.H., 2016. Health literacy: applying current concepts to improve health services and reduce health inequalities. *Public Health* 132, 3–12. <https://doi.org/10.1016/j.puhe.2016.01.001>
- Baybay, C.S., Hindmarsh, R., 2019. Resilience in the Philippines through effective community engagement. *Australian Journal of Emergency Management*, The 34, 65–70.
- Beckham, S. W., Stockton, M., Galai, N., Davis, W., Mwambo, J., Likindikoki, S., Kerrigan, D., 2021. Family planning use and correlates among female sex workers in a community empowerment HIV prevention intervention in Iringa, Tanzania: A case for tailored programming. *BMC Public Health*, 21(1), 1377.
- Charron, D.F., 2012. *Ecohealth Research in Practice: Innovative Applications of an Ecosystem Approach to Health*. Springer, International Development Research Centre, New York, pp. 1–282.
- Chen, J., Mullins, C.D., Novak, P., Thomas, S.B., 2016. Personalized Strategies to Activate and Empower Patients in Health Care and Reduce Health Disparities. *Health Educ Behav* 43, 25–34. <https://doi.org/10.1177/1090198115579415>
- Chimbari 2016. Lessons from implementation of ecohealth projects in Southern Africa: A principal investigator's perspective. *Acta Tropica* 2016
- Cohen, L., Manion, L., Morisson, K., 2002. *Research Methods in Education*. Routledge.
- Committee on Clinical Trials During the 2014-2015 Ebola Outbreak, Board on Global Health, Board on Health Sciences Policy, Health and Medicine Division, National Academies of Sciences, Engineering, and Medicine, 2017. *Integrating Clinical Research into Epidemic Response: The Ebola Experience*. National Academies Press, Washington, D.C. <https://doi.org/10.17226/24739>
- Community Consultation Framework, June 2019, Macedon Ranges Shire Council.
- Corrigan, P., Pickett, S., Kraus, D., Burks, R., Schmidt, A., 2015. Community-based participatory research examining the health care needs of African Americans who are homeless with mental illness. *Journal of health care for the poor and underserved* 26, 119.
- Countries where Coronavirus has spread - Worldometer [WWW Document], n.d. URL <https://www.worldometers.info/coronavirus/countries-where-coronavirus-has-spread/> (accessed 4.28.23).
- Crowe, S., Cresswell, K., Robertson, A., Huby, G., Avery, A., Sheikh, A., 2011. The case study approach. *BMC Med Res Methodol* 11, 100. <https://doi.org/10.1186/1471-2288-11-100>
- De Villiers, C., Dumay, J., Maroun, W., 2019. Qualitative accounting research: dispelling myths and developing a new research agenda. *Accounting & Finance*, 59 (3), pp. 1459-1487.
- Douglas, J.A., Grills, C.T., Villanueva, S., Subica, A.M., 2016. Empowerment praxis: Community organizing to redress systemic health disparities. *American Journal of Community Psychology*, 58(3-4), 488-498. <https://doi.org/10.1002/ajcp.12101>.
- Eaton, L., Flisher, A.J., Aaro, L.E., 2002. 'Unsafe sexual behaviour in South African youth'. *Social Science & Medicine*, 56(1), pp.149-165.

- Holliman, R., 2017. Supporting excellence in engaged research. *JCOM* 16, C04. <https://doi.org/10.22323/2.16050304>
- Immy, H., 2005. *Qualitative Research in Health Care*. McGraw-Hill Education (UK).
- Jami, A.A., Walsh, P.R., 2017. From consultation to collaboration: A participatory framework for positive community engagement with wind energy projects in Ontario, Canada. *Energy research & social science* 27, 14–24.
- Khalid, S., Ahmad, M.S., Ramayah, T., Hwang, J., Kim, I., 2019. Community Empowerment and Sustainable Tourism Development: The Mediating Role of Community Support for Tourism. *Sustainability* 11, 6248. <https://doi.org/10.3390/su11226248> 32.
- Krauss, J., 2012. "Infographics: More than words can say." *Learning & leading with Technology* 39(5): 10-14.
- Kruahong, S., Tankumpuan, T., Kelly, K., Davidson, P.M., Kuntajak, P., 2023. Community empowerment: A concept analysis. *Journal of Advanced Nursing* n/a. <https://doi.org/10.1111/jan.15613>
- Manyangadze, T., Chimbari, M.J., Gebreslasie, M., Mukaratirwa, S., 2016. "Risk factors and micro-geographical heterogeneity of *Schistosoma haematobium* in Ndumo area, uMkhanyakude district, KwaZulu-Natal, South Africa." *Acta Tropica* 159: 176-184.
- McCollum, R., Gomez, W., Theobald, S., Taegtmeier, M., 2016. How equitable are community health worker programmes and which programmes features influence equity of community health worker services? A systematic review. *BMC Public Health* 16, 419. <https://doi.org/10.1186/s12889-016-3043-8>
- Melo, P., Alves, O., 2019. Community empowerment and community partnerships in nursing decision-making. *Healthcare (Switzerland)*, 7(2), 76. <https://doi.org/10.3390/healthcare7020076>.
- Musesengwa, R., Chimbari, M.J., 2017. Community engagement practices in Southern Africa: Review and thematic synthesis of studies done in Botswana, Zimbabwe and South Africa. *Acta Tropica* 175, 20–30.
- Musesengwa, R., Chimbari, M.J., 2017. Experiences of community members and researchers on community engagement in an Ecohealth project in South Africa and Zimbabwe. *BMC medical ethics* 18, 76.
- Musesengwa, R., Chimbari, M.J., Mukaratirwa, S., 2017. Initiating community engagement in an ecohealth research project in Southern Africa. *Infectious diseases of poverty* 6, 22.
- Musesengwa, R., Chimbari, M.J., Mukaratirwa, S., 2018. A framework for community and stakeholder engagement: Experiences from a multicenter study in Southern Africa. *Journal of Empirical Research on Human Research Ethics* 13, 323–332.
- Mutero, T., Chimbari, M., 2021. Consulting the Community on Strategies to Strengthen Social Capital for Community Disease Control. *International Quarterly of Community Health Education* 42, 0272684X2110049. <https://doi.org/10.1177/0272684X211004939>
- Nelson, E., 2019. *A Resource Guide for Community Engagement and Involvement in Global Health Research*.
- Palaganas, E. C., Sanchez, M. C., Molintas, M. P., Caricativo, R. D., 2017. Reflexivity in Qualitative Research: A Journey of Learning. *The Qualitative Report*, 22(2), 426-438.
- Resource guide for community engagement and involvement in global health research [WWW Document], n.d. URL <https://www.nihr.ac.uk/documents/resource-guide-for-community-engagement-and-involvement-in-global-health-research/27077> (accessed 12.2.22).

- Ritchie, J., Lewis, J., 2003. *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. SAGE.
- Rycroft-Malone, J., Burton, C.R., Bucknall, T., Graham, I.D., Hutchinson, A.M., Stacey, D., 2016. Collaboration and co-production of knowledge in healthcare: opportunities and challenges. *International journal of health policy and management* 5, 221.
- South, J., 2015. *A guide to community-centred approaches for health and wellbeing*. WHO community engagement framework for quality, people-centred and resilient.
- Stampfer, O., Mittelstaedt, G., Vásquez, V.B., Karr, C.J., 2019. Guidance for Genuine Collaboration: Insights from Academic, Tribal, and Community Partner Interviews on a New Research Partnership. *International Journal of Environmental Research and Public Health* 16, 5132. <https://doi.org/10.3390/ijerph16245132>
- Tashakkori, A., Teddlie, C., Teddlie, C.B., 1998. *Mixed methodology: Combining qualitative and quantitative approaches*, 46, Sage.
- Tindana, P., de Vries, J., Campbell, M., Littler, K., Seeley, J., Marshall, P., Troyer, J., Ogunipe, M., Alibu, V.P., Yakubu, A., Parker, M., 2015. Community engagement strategies for genomic studies in Africa: a review of the literature. *BMC Med Ethics* 16, 24. <https://doi.org/10.1186/s12910-015-0014-z>
- Tora, A., Mengiste, A., Davey, G., Semrau, M., 2018. Community Involvement in the Care of Persons Affected by Podoconiosis—A Lesson for Other Skin NTDs. *Tropical Medicine and Infectious Disease* 3, 87. <https://doi.org/10.3390/tropicalmed3030087>
- UNICEF., 2019h, *Minimum Quality Standards and Indicators for Community Engagement: DRAFT*. Draft prepared by consultants: Jamie Bedson and Sharon Abramowitz. UNICEF C4D, New York, NY, July 2019.
- Wallerstein, N., Bernstein, E., 1994. Introduction to Community Empowerment, Participatory Education, and Health. *Health education quarterly* 21, 141–8. <https://doi.org/10.1177/109019819402100202>
- World Health Organization, 2015. *WHO global strategy on people-centred and integrated health services: interim report* (No. WHO/HIS/SDS/2015.6). World Health Organization.
- World Health Organization., 2015. *Health literacy toolkit for low-and middle-income countries: A series of information sheets to empower communities and strengthen health systems*. WHO Regional Office for South-East Asia.
- World Health Organization., 2017. *WHO community engagement framework for quality, people-centred and resilient health services*. World Health Organization.
- Xia, R., Stone, J.R., Hoffman, J.E., Klappa, S.G., 2016. Promoting community health and eliminating health disparities through community-based participatory research. *Physical therapy* 96, 410–417.

The introduction and literature review presented in Chapter 1 showed the importance of the stages of the community engagement process. It begins by discussing the process of informing the community when conducting health research. The literature demonstrated the importance of informing the community and seeking community consent to avoid misconceptions about the research. Having identified the relevance of community engagement and identified and discussed stages of the community engagement process, Chapter 2 documented the lived experiences including the processes, challenges and lessons learned by KwaZulu-Natal Ecohealth Program researchers in engaging with the Ingwavuma community when conducting health research in rural communities of uMkhanyakude district.

**CHAPTER 2**  
**FACILITATING COMMUNITY ENEGAGEMENT: RESEARCHERS' LIVED**  
**EXPERIENCES IN RURAL COMMUNITIES IN THE KWAZULU-NATAL**  
**ECOHEALTH PROGRAM, SOUTH AFRICA**

*Published: Cogent Social Sciences*



Received: 25 December 2022  
Accepted: 12 June 2023

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## SOCIOLOGY | RESEARCH ARTICLE

# Facilitating community engagement: Researchers' lived experiences in rural communities in the KwaZulu-Natal Ecohealth Program, South Africa

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**Abstract:** Community engagement approaches are case-specific, enabling communities to address health and well-being challenges. The stages of community engagement are progressive, and particularly, the early stage of community engagement ensures researchers have access to potential participants and research sites. This study aimed to document the processes, challenges and lessons learned by KwaZulu-Natal Ecohealth Program researchers in engaging with the Ingwavuma community. We used a phenomenological qualitative approach to document the KwaZulu-Natal Ecohealth Program research team's



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lived experiences during community engagement process. In-depth, semi-structured interviews with researchers, staff, and the project investigator were conducted and thematically analysed. The findings revealed that the issue of language and cross-cultural interactions, which resulted in misunderstanding and incorrect interpretation of the data being communicated with communities, appeared to be a recurring issue that caused dissatisfaction in the community engagement process. Therefore, informing the community about the research study is a subjective experience that necessitates mindfulness when interacting and engaging with communities. We recommend an inclusive framework for a higher level of engagement that would give guidance to both researchers and communities to ensure active participation and a collaborative decision-making process.

**Subjects:** Culture & Development; Rural Development; Health & Development; Health & Society

**Keywords:** Community engagement; informing phase; community empowerment; KZN Ecohealth; KEP researchers

## 1. Introduction

Community engagement (CE) is a useful strategy to improve a community's ability to address its own health needs and health disparities with the facilitation of researchers who understand the community's priorities (Ahmed & Palermo, 2010). Globally, CE is considered as a tool that empowers research participants and improves the quality of research and its relevance. However, notwithstanding an increase in CE activities related to health research in recent years, this term still has a wide range of meanings and practices in the fields of international development, health promotion, and health-related research and programs (Adhikari et al., 2019). Essentially, when communities are engaged in research projects, they should ultimately be empowered. Despite the growing scholarship on the practice of CE in global health research, there is still debate on how effective various CE methods, approaches and models are in empowering communities. CE has been described as the process of consultation and negotiating with local authorities (community leaders) to seek guidance, interaction with various stakeholders, collaboration in decision-making, healthcare information promotion and delivery and partnership, as well as empowering action in informal and formal groups (Musesengwa et al., 2017). It is a term that describes a group's shared interests, goals and aspirations positioned as a networked series of communicative interactions and involvement (Johnston & Lane, 2018).

There have been debates and inconsistencies regarding the objectives of various forms of engagement, the implementation processes and their impact, and important contextual factors (Richardson et al., 2021). This may be due to the unpreparedness of the leaders for engaging partners and the public in CE, meaning that elected officials and community advisors may not have embraced it, which resulted in unsuccessful applications of CE (Schoch-Spana et al., 2007). Researchers frequently misinterpret how engaging community in research is characterised across different disciplines (Holliman, 2017). The key premise is that a community's knowledge and reality are produced by its members. As a result, communities can identify their problems and needs, as well as develop appropriate solutions to tackle these concerns. In this way, all projects should emerge from the realities of communities that are constantly (re)created by their members (Peralta, 2017). However, there is still a concern about how communities are engaged in research projects that will be of benefit to them. Some genomic studies conducted in Africa have applied CE prior to data collection, while others used CE throughout the duration of the study (Musesengwa et al., 2017).

Community engagement facilitates both the identification of research needs and goals as well as the recognition of ethical difficulties associated with a study (Matthews et al., 2018). Unfortunately, the reality and the results are frequently very different. In the early stages of CE (informing phase) or tokenistic engagement from Arnstein's theory of Ladder of Citizen Participation (Arnstein, 2019), the public generally view engagement as tokenistic since they believe that decisions have already been made because of existing inequalities (Curtis et al., 2014). Tokenism is defined as the practice of making perfunctory or symbolic efforts to engage communities or patients in research projects (Hahn et al., 2017). Conversely, non-tokenism necessitates a collaborative arena, that is conducive in building positive relationships with communities, active participation and possibility for collaborators to express their opinion and critiques (Romsland et al., 2019).

The World Health Organization (WHO) emphasises the importance of CE in dealing with health issues, as illustrated in the case of the outbreak of the Ebola virus disease (EVD) in 2014. The EVD outbreak provided an opportunity to learn more about what CE strategies worked and what did not work to strengthen health systems and communities (National Academies of Sciences, 2017). Nelson (2019) states that CE work requires a deeper understanding of the intersecting experiences of marginalisation and inclusion of those most affected in order to achieve transformative impact (Nelson, 2019). However, the possible impact of community engagement and other community-engaged research on population health outcomes have received little attention in the literature (Luger et al., 2020). A systematic literature review conducted on community engagement for disaster preparedness indicated that not all community engagement approaches are helpful in creating at least some level of increased preparedness (Ryan et al., 2020). This is because those who are privileged, and with greater networks are more likely to participate, meaning that the CE process is unlikely to be entirely representative when those attempting to participate have no idea of how to do so effectively (Curtis et al., 2014). A systematic literature review conducted has shown that due to a lack of any benchmarking study, context, and skill levels of those implementing the engagement, other factors were presumed to be at fault rather than structural or conceptual issues with the technique itself (Ryan et al., 2020).

In essence, there are different forms of engaging community members in research, but they are conceptualised from different disciplinary perspectives. Community Engaged Research (CEnR) is an umbrella term or a variety of activities and methodologies (e.g., stakeholder engagement, patient engagement, public involvement, participatory action research), with Community-based participatory research (CBPR) being the most established and well-known of these in the health field (Luger et al., 2020). The popularity of CBPR indicates that researchers are becoming more involved in the communities they are researching and are dedicated to upholding social justice and preventing harm, and are committed to establishing caring relationships while conducting their research (Akondeng et al., 2022). CBPR, as a CEnR approach, refers to a collaborative research approach that equitably involves community members, researchers and other stakeholders in the research process and recognises the unique strengths that each brings (DeJonckheere et al., 2019). Collaboration with community members, community-based organisations, community leaders, and practitioners enables the research design to be grounded in diverse perspectives and knowledge while also being more responsive to community needs. However, the expectations of engagement can become too much for people to handle. According to research on participation in environmental issues, community engagement has been most successful in raising community awareness, enhancing decision quality, and educating the local community members. However, it has been much less successful in incorporating community values into decisions, resolving conflicts between competing interests, and fostering institutional trust (Curtis et al., 2014). Although all CEnR approaches draw on CBPR's emphasis on including community members as equal participants in many areas of the research process, from research questions identification and selection of priority themes, the development of data collecting materials and analytical strategies to the drafting and dissemination of findings (Gilmore et al., 2020), all CEnR approaches, including CE,

**Figure 1. The vancouver community engagement framework.**

(Source:Author).



share a common critique which is power relations, existing inequality and the inadequacy of accountability by community members for the expenditure of public funds (Curtis et al., 2014).

Although there are different models for community engagement, very few studies have documented the process of how researchers truly engage communities. Previous studies have indicated that there is limited contribution of the community to the engagement process (Chantler, 2012; Ryan et al., 2020). The Community Engagement Vancouver Coastal Health framework ([www.vch.ca/ce](http://www.vch.ca/ce)), often quoted in many studies involves five distinct stages: 1) Informing the community, 2) Consulting the community, 3) Involving the community, 4) Collaborating with the community, and 5) Empowering the community (Figure 1). This framework was modified from Sherry Arnstein's theory of the Ladder of Citizen Participation and is one of the significant models and the most extensively referenced in the area of democratic public involvement (Arnstein, 2019).

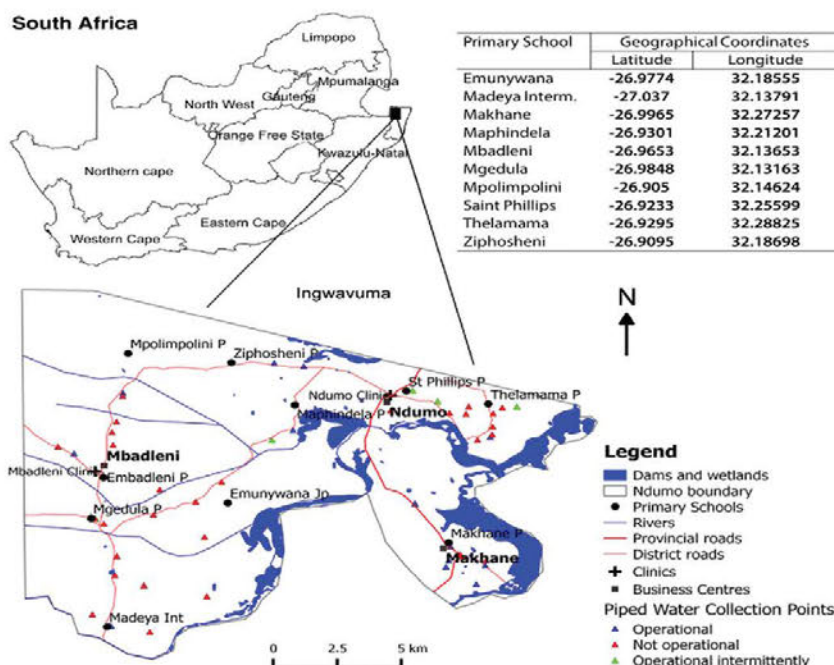
Informing communities entails informing residents about local research projects. It is done to ensure that the communities are included in decision-making. Providing information prior to the initiation of a research project is a necessary requirement in the community engagement process (P. Tindana et al., 2015). Some studies have suggested that many of the researchers working with rural communities have limited understanding of the CE process and experience in engaging communities (Ahmed & Palermo, 2010). The KwaZulu-Natal Ecohealth Program (KEP) researchers claim to have applied the Vancouver Coastal Health framework in their CE processes. However, no assessment of the effectiveness of the strategy had been done before our study. We, therefore, engaged with the researchers of KEP to document the processes, the challenges and the lessons learnt in engaging with the Ingwavuma community in South Africa.

## 2. Materials and methods

### 2.1. Study design and setting

A phenomenological qualitative approach was adopted to document the process of community engagement from the researchers' perspectives. Phenomenology provides complex contextual descriptions of people's experiences in a research issue (). This approach was used to gain more

Figure 2. Map of Ingwavuma areas, uMkhanyakude District, Jozini Municipality, KwaZulu-Natal, South Africa, adapted from Kabuyaya et al. (2017).



understanding of the lived experiences of researchers and what they had in common during the initial phases of CE. The paper is based on work in a larger project which uses a participatory action research methodology. This study was conducted in the Ingwavuma community under Jozini Local Municipality in the uMkhanyakude District in the province of KwaZulu-Natal, South Africa. uMkhanyakude has traditional structures and falls within the Mngomezulu Tribal Authority (see Figure 2). The headmen (*izinduna*) are the elected gatekeepers with authority over villages and are accountable to the chiefs, the tribal council and their community (Musengwa et al., 2017). The area is a predominately an underdeveloped, isiZulu-speaking rural community, and community members have limited access to basic services. UMkhanyakude District is the third poorest in the KwaZulu-Natal province. About 14% of the unemployed have no formal education, while only 17% have completed primary school. The majority of unemployed individuals have completed high school, and around 30% have secondary education. The district has a high rate of adult illiteracy. More than 27% of adult women and 22% of adult men have not completed any type of formal education (Mthembu & Hlophe, 2020). UMkhanyakude District was the relevant area for this particular research as it is characterised by being dry and having water systems (lakes, rivers, rain-fed systems, irrigation schemes) within dry land and endemic to malaria and schistosomiasis. The fact that uMkhanyakude shares a border with Mozambique, where malaria is still a serious issue, this district has not experienced the same success as the rest of South Africa in its efforts to control the disease. As a result, the prevalence of schistosomiasis in the district is also among the highest in the country.

### 3. KwaZulu-Natal Ecohealth Program (KEP)

KwaZulu-Natal Ecohealth Program (KEP) research in uMkhanyakude aims to reduce the burden of infectious diseases. Projects previously implemented by KEP in the same area include the MABISA (Malaria and Bilharzia in Southern Africa) which began in 2014 and ended in April 2017. The MABISA project produced results which gave an understanding of the way stakeholders can help control malaria and bilharzia. Through the MABISA project, a community advisory board (CAB) was established, and community research assistants (CRAs) were recruited. The CAB plays the

watchdog role of ensuring that ethical conduct is observed in the communities and that the community's needs and interests are fully considered and addressed, and not sidestepped. CRAs, on the other hand, work with researchers on data collection and assist in identifying transmission sites in the study area as well as mobilising the community. MABISA was succeeded by TIBA-SA (Tackling Infections to Benefit Africa-South Africa), which was a new project but also adopted Ecohealth approaches. Stakeholders who had been involved in the MABISA project continued to work with TIBA-SA researchers and updating the community about the progress of the TIBA-SA projects, ensuring that the community played their expected roles in project implementation. TIBA-SA, just like MABISA mainly focused on bilharzia and malaria.

#### 4. Sampling and data collection

The KEP research team comprises researchers from different African countries, namely South Africa, Zimbabwe, Lesotho, Botswana, Nigeria and the Democratic Republic of the Congo. A total of 12 participants, comprising 9 KEP researchers, 2 administrative staff, and 1 principal investigator were purposely selected and interviewed based on the criteria that they are part of the KEP research team and have been involved in projects conducted at uMkhanyakude District. In terms of age, one participant was in the "50 and above" category. The other participants ranged between 32 and 45 years of age with 5–14 years of experience in research. Regarding qualifications, two participants had a bachelor's degree, while the remaining 10 had postgraduate qualifications. This information is summarised in Table 1. The selection of the sampling strategies was premised on the need to assess the researchers' first-hand lived experiences of CE (Smith et al., 2013). The main inclusion criteria of this study were being part of KEP and being involved in ongoing projects at the time of the study. The experiences of community-level participants such as CAB members and traditional authority are addressed in other journal papers that are part of this project, hence only the KEP research team was chosen for this study to document their lived experiences in CE. All

**Table 1. Demographic characteristics of the participants**

	Pseudonyms	Gender	Age (years)	Highest qualification	Nationality	Native language	Years of experience
1	Principal investigator	Male	61	PhD in Public Health	Zimbabwean	Shona	24
2	Project coordinator	Female	32	Bachelor of Arts	South African	IsiZulu	5
3	Finance officer	Female	43	Bachelor of Arts	South African	IsiZulu	7
4	Researcher 1	Male	42	PhD in Development Studies	Basotho	Sesotho	6
5	Researcher 2	Male	35	PhD in Public Administration	Zimbabwean	Shona	14
6	Researcher 3	Female	33	PhD in Public Health	South Korean	French	8
7	Researcher 4	Female	32	MSc in Biostatistics	Nigerian	Yoruba	7
8	Researcher 5	Male	32	PhD in Public Health	Zimbabwean	IsiNdebele	5
9	Researcher 6	Male	38	PhD in Public Health	Zimbabwean	IsiNdebele	10
10	Researcher 7	Male	38	PhD in Public Health	Kenyan	Swahili	8
11	Researcher 8	Male	34	MA in Economics	Zimbabwean	Shona	8
12	Researcher 9	Female	45	Masters in Psychology	South African	IsiXhosa	4

participants were assured of confidentiality and anonymity, as stipulated and carefully outlined in the informed consent they willingly signed before the interviews began. Participants were not compensated for their time during the interviews.

Data on the involvement and experiences of the participants in projects pertaining to malaria and schistosomiasis in the Ingwavuma community were collected through in-depth interviews. In this regard, questions posed to participants were on their experiences of CE and the role they played in informing the community about the various KEP projects. Participants shared their experiences of engagement activities during implementation of projects and indicated the challenges they faced. A total of four face-to-face in-depth interviews were conducted during fieldwork, and five interviews were conducted online via the Microsoft Teams platform since there was a COVID-19-induced lockdown which restricted traveling and research fieldwork activities. The interviews lasted 1 h per participant and all interviews were recorded with the participants' permission. Face-to-face interviews took place in November 2019 and the online interviews were conducted in May 2020.

### **5. Data analysis**

The recorded interviews were transcribed precisely, and a computer-based software program (QSR International Pty Ltd, NVivo 12 Pro) was used to organise, analyse, and find insights from the convergence of information gathered through the in-depth interviews. The data were then analysed through qualitative thematic analysis to capture the experiences of the KEP research team in the CE informing process. Interview transcripts from study participants and other writings that reflect experientially on the subject of the study were used to record qualitative data, and the participants' responses to questions were coded into nodes for analysis. Recurring themes were also generated. The similarities, differences, and links among themes were identified and grouped. Then, thematic content analysis was adopted for data interpretation after the themes were captured from the in-depth interviews.

### **6. Trustworthiness**

We did member checking to ensure appropriate trustworthiness of the study. That is a quality control process whereby the research participants were given an opportunity to look through their interview transcripts to see if they were accurate and valid, and that the written translation of their experiences was correct. At the end of each interview, the researcher summarised the points from the interview to ensure that the participants' responses had been captured accurately.

### **7. Ethical considerations**

Ethical approval was obtained from the Humanities and Social Sciences Research Ethics Committee (HSSREC) (Protocol reference number: HSSREC/0001650/2020) of the University of KwaZulu-Natal (UKZN) before the study commenced. An informed consent form containing a detailed explanation of the various ways of ensuring anonymity and confidentiality of the study participants was developed and signed by each recruited participant. The participants who were interviewed online gave verbal consent. The participants were granted the right to participate in the study voluntarily and were allowed to withdraw from participating in the study at any time. To ensure anonymity, the participants' data were not associated with their name or any other identifier.

### **8. Results**

KEP researchers adopted the Ecohealth research approach emphasising CE. The CE process involves five distinct stages, or phases, that are progressive as mentioned in the introduction. Three broad themes emerged from thematic analysis, namely the processes of engaging, the significance of relationships in CE, and the challenges encountered during the CE process. The experiences of the researchers are described in the following section.

### 9. Processes of engaging the community

Informing communities is a method of telling local people about research that is planned to take place in their area; this is done to ensure that the communities are involved in decision-making. The principal investigator (PI) shared the information that the KEP principal investigators visited the community with a prepared detailed study document before they engaged with community:

... we already had a proposal that we had been developing to submit to the World Health Organisation so that the project will potentially be funded ... (KEP Principal Investigator, aged 61)

In this methodology, it should be noted that it is the researchers who decided on the project and found a way to get the community involved by informing them about the project and engaged community members to have input on the design, methodology, and execution of the project. This engagement technique provides a community with fair and unbiased information that will aid in their understanding of the project proposed and the potential solutions.

The community liaison officer (CLO), who had previously worked for other NGO projects in the same area, was referred to the MABISA project team by the Provincial Health District, to assist during the initial phase of CE. The CLO then linked the principal investigators with the leaders of the community to introduce the ideas of the project:

... we were able to link up with a guy who was already working in that area as a malaria liaison officer, so we recruited him as our liaison officer so that he could link us with the leadership ... we introduced the ideas that we had and then we agreed on a meeting with the rest of the community for us to identify what their challenges were so that we could incorporate them into our project ... (KEP Principal Investigator, aged 61)

This shows how the principal investigators were introduced to the leaders of the community and indicates that the community was informed about the MABISA project from the first phase of the project. The interactions with community leaders were through several meetings (three- or four-times per month), 3 h, over a span of a year. Each meeting was summarised in meeting minutes and memoranda that contained one or two words to remind the leaders of their practical responsibilities and provided direction for future collaboration and the research process. The project team were able to meet with the rest of the community through the headman (*induna*) of the area to inform the community about the project. The community meeting was organised by the *induna* and activities for participatory rural appraisal (PRA) were conducted to identify issues that were to be researched. The inclusion of *induna* in the initial process instilled trust in the community members while also ensuring the validity of the project and the obtaining of permission prior to project commencement. Having an *induna* who is well respected chairing the community meeting creates boundary partnership and increases the likelihood of the project being fully accepted. The project investigator also revealed that most of the KEP researchers were not part of the informing phase during the MABISA project as they had joined the project team during the implementation stage when the proposal had already been developed.

The KEP researchers were involved in the informing phase when the project transitioned into TIBA-SA. One of the KEP researchers mentioned that the informing was previously completed during the MABISA project, but, before TIBA-SA project commenced the research team engaged with the community through focus group discussions (FGDs) to re-inform, introduce, and discuss the TIBA-SA project initiatives:

... given that the MABISA project has been in existence for three years before TIBA-SA was introduced, the informing was already being done and partnership were established with communities. Following that, we had focus group discussions with members of the community to inform them about TIBA-SA project and to discuss how they will participate in the

dissemination of research findings and how the information given to them will be managed. (KEP Researcher 7, aged 38)

This implies that most of the KEP researchers at the time this study was conducted were not part of the conceptualisation and implementation of MABISA. However, since they were working with different communities in Ingwavuma during fieldwork, they had built cordial relationships with those communities. The community engagement process necessitates the sharing or provision of information prior to the start of a research study. There are numerous ways that communities can be informed and participate in a research project being conducted in their area. Individual interviews, meetings, workshops, focus group discussions, and community advisory boards can all be used to accomplish this. When communities are provided with concise and objective information, they are more likely to make an informed decision about their participation. Informing communities eliminates the misconceptions about the proposed research.

However, one of the participants noted that before they could carry out any research activities, they had to learn from the community during the informing phase as they had no prior experience working in the specific areas of those communities. She further mentioned that, at times, the researchers would go to some areas of the community without informing the leaders, which created problems for the team as they would be perceived as strangers in the area:

... We were somewhere around Mkhuze, and we just went to start scooping snail species for my project and one man came to us and told us we were under arrest. We asked why? So, he took us to Inkosi's house. We had to prove ourselves, gave the letter and all that, and so since then they accepted us and I also think that maybe that should have been part of the procedure to, first, see the Inkosi of the area ... (KEP Researcher 4, aged 32)

Researchers emphasised the significance of notifying the traditional leaders (gatekeepers) of the village before they begin the project, even after informing the communities at a district level about the activity occurring in the areas. Working in rural areas necessitates being aware of one's objectives and behaviours when immersed in a community. The study that is given local legitimacy ensures adequate participation and efficient data collecting, and allows entry into remote communities through the acknowledgment and involvement of reliable leaders and accessible individuals of rural communities.

#### **10. The significance of relationships in CE**

The participants reported that the amicable relationships already in place with communities helped to make the initial stages of community engagement seamless as communities were updated about the information found in their surroundings. The community embraced the subsequent project since they had been informed at project conclusion about the potential for a new initiative, TIBA-SA:

... I would say the people have been welcoming to the best of my knowledge, and I think it's also because of the background work and the relationships that have been built over the years, and the trust that people have for us as researchers. And the respect we give back to them in terms of giving them feedback on what we found in the environment. (KEP Researcher 4, aged 32)

The researchers felt welcomed by the community, which allowed them to easily obtain community entry. This was expressed by one of the researchers:

... But because of the turnout in our first community meeting when we were launching TIBA and the fact that almost 80% of izinduna (headmen) in that area attended that meeting including iNkosi (a Chief). iNkosi put in a good word about the project, involvement changed from that day. (KEP Project Coordinator, aged 32)

Traditional leaders are particularly crucial in getting the community involved in projects due to the respect they command. However, the transition from the MABISA to the TIBA-SA project created some confusion for the community as people were initially not sure of what value the new project TIBA-SA would add to their communities. The MABISA project yielded findings which gave an understanding of the way stakeholders can help manage and keep track of the presence of the disease in their areas. Hence, TIBA-SA, a new initiative, was launched, and the stakeholders who had been recruited continued to collaborate with TIBA-SA researchers, inform the community of the project's progress, and make sure that the community played their expected roles in the project's implementation.

... I joined toward the end of MABISA when the project's principal investigators were informing the community about the MABISA coming to an end ... the community was really not happy about the ending of MABISA ... the community was somewhat confused by the change from the MABISA to the TIBA-SA projects since no one was initially sure what value the new project TIBA-SA would offer. (KEP Researcher 3, aged 33)

It was determined that failing to provide valuable clear information during project closure causes confusion in the community, discouraging them from participating in future research and jeopardising any future rural research opportunities in the same area. As a result, informing the community was critical at this stage and resulted in community buy-in.

Through the MABISA project, the CAB was formulated during community meetings without interference from the project team. Allowing community members to choose and appoint their representatives during community meetings delegates some authority within the research process in recognition of community knowledge; it creates multiple opportunities for community members to voice their concerns, which may help to prevent unrest; and it fosters trust in researchers and community organisations. The CAB members are the eyes of the study; they serve as a community telecommunications base station, taking community messages to the project and from the project to the community. CRAs work with the research team facilitating access to households and assisting with data collection. Participants were asked about the role of CAB members and CRAs in the informing stage and the impact of their working relationship. One had this to say:

... I think CAB members help in mobilising the community to keep on welcoming us in the community to do research work ... guess it will be a bit challenging to sort of establishing relationships in the community. So, they sort of make it easier for us to be able to get into the villages to do the work which is similar to the work of the CRAs. (KEP Researcher 5, aged 32)

Participants reported that CAB members played a crucial role in mobilising the community, which helped to build relationships between the researchers and the community. Furthermore, unlike CRAs, CAB members were more useful during the informing phase. This was affirmed by one of the participants who reported that

The CAB was a very valuable resource in that they were able to open doors that we as a research team would have struggled to open... they were helpful in advocating for us... So, we went to an area without informing the Nduna of the location, and we ended up in his space. However, our association with CAB members provided him with information about who we are and what we were doing. (KEP Researchers 6, aged 38)

This demonstrates how CAB members were helpful in containing the damage done and the mistakes made by researchers that would have otherwise jeopardised the study. The importance of CABs in the informing phase cannot be overstated. The way the researchers establish connections to acquire access to the community has a significant impact on the efforts and how well the project turns out.

## 11. Challenges in CE

Participants reported challenges encountered during the informing stage, such as cultural and language barriers, as well as miscommunication and misinterpretation. One of the aspects that caused dissatisfaction in the community engagement process was cultural differences. Since the KEP research team comprised researchers from different African countries, language was sometimes a barrier that created communication problems. A participant expressed their experience of working with the team leader, who at the time of the project being implemented did not speak the local language: "... at times the contingent of people who did not speak the local language was large including in my case where the team leader did not speak the local language ..." (KEP Researcher 9, aged 45). A participant who did not speak the local language also attested to this: "... the language barrier was also a challenge ... personally, I am not speaking isiZulu ... so the language barrier is sort of a challenge because our research sites are in the rural areas" (KEP Researcher 2, aged 36).

The fact that the language barrier was one of the difficulties researchers faced throughout the community engagement process had a detrimental impact on the informing process because the community did not understand what was being communicated to them. As a result, the research team had to be in contact with the CRAs for assistance in terms of passing messages to the community. The presence of those research team members who knew the culture and language provided an assurance that the study did not have malicious intent. One of the participants mentioned the importance of understanding and speaking the local language when working with local people from rural areas:

... I think what is also important when conducting research in a rural setting should be the value of being able to speak and understand the local language ... as activities of doing community work involves stakeholder engagement. (KEP Researcher 8, aged 34)

Another participant stated that they had to consider cultural differences and that knowledge of the local language was found to be an important skill: "... one of the main attributes was being culturally sensitive. I think by far that's one attribute that stood out" (KEP Researcher 1, aged 38). This is important because the work was in rural areas where knowledge of the local language was imperative. Participants also shared the view that involving local people in their studies, and being in an environment where people think differently, assisted them in seeing problems in different ways. In order to employ a CE strategy that stresses cultural distinctiveness and competency, the study team must include research scientists and important stakeholders from that particular culture. Another important factor to consider is the suitability of the study questions or language used in a culturally particular CE.

When engaging with community leaders in rural settings, the appropriate attire was a crucial issue. One of the researchers said: "... we had to make sure that we dressed appropriately when talking with the *induna*. During fieldwork, our everyday clothing code was long skirts and dresses ... ." (KEP Researcher 7, aged 38). It was also reported that respect was shown by adhering to cultural norms, such as dress code, procedure, and utilising clan names, when interacting with the community.

Misinterpretation of what had been communicated with the local community members regarding the potential research project to be conducted in the area was also found to be a challenge during the informing dialogue. As one of the participants expressed: "... it was observed in some of the instances that the community failed to understand what was communicated to them during the informing community meeting ..." (KEP Researcher 3, aged 33). This issue becomes more difficult when it comes to gaining trust from the community and inaccurate information is presented; misinformation could lead to incorrect interpretation of data and this problem becomes more difficult to solve.

## 12. Discussion

The findings revealed the significance of understanding how the researchers engage with the community prior to initiating a study and what entails community entry. Sharing and providing information before the initiation of a research project is a requirement in the community engagement process (P. Tindana et al., 2015). The initial stage of community engagement, particularly, the informing phase emphasises the value of collaborative effort where researchers become part of the community and the community members become part of the research team with the purpose of learning from each other to address the identified phenomenon.

In the context of this study, both community and researchers had a common shared vision to address the burden of infectious diseases and better the current situation. The Ecohealth approach, which is participatory in nature, was adopted during the CE process as the core element of engaging the community to ensure the active participation and adoption of the project by ensuring full ownership of both parties. The MABISA project started with Rapid Rural Appraisals (RRA) where communities were given information on the project using participatory methods of problem identification, stakeholder analysis and community mapping among others. This gave the communities information on research and the need to have gatekeepers since they were also given information on research ethics. After being equipped with the knowledge they were left to make informed decisions on whom they wanted to be CAB members. The selection of the CAB members was left to the community and the research team did not facilitate the selection process. The RRA meetings were meant to allow the communities to make informed decisions and therefore select people who would be beneficial to the project according to their own expectations. Then, KEP researchers were offered opportunities to work with different communities and, as a result, positive working relationships were built with those communities to address infectious diseases through collaborative effort. Through these relationships, the communities were involved in all project decision-making and subsequently enhanced their research understanding, built rapport, and empowered all parties. The established relationships built trust with the formal and informal leadership, and sought the commitment of community leaders in mobilising the community (McCloskey et al., 2011).

In this study, the community was represented in all CE stages by their leaders, namely *izinduna* and CAB members because of their inherent influence in the community. The CAB members for the MABISA project were also members of the WARD Health Team. The criteria used for selection was the same as that for the KEP which was based on the influence of the CAB members in the society. The authors emphasise that community leaders are considered as an important structure and as gatekeepers in rural settings (Ramsbottom et al., 2018). Gatekeepers can ensure researchers gain access to research sites and potential participants, as well as influence the research progress through facilitating the running of research activities to completion (McFadyen & Rankin, 2016). The informing phase in this context is the foundation of collaborative conceptualisation and the planning of the identified research project to reach consensus and attain the desired sets goals that are beneficial to all parties involved. The emphasis is that informing phase sees communication as a two-way process and mechanism to acknowledge the needs of communities without underestimating their capacities to provide possible solutions to the success of the project (Ramsbottom et al., 2018).

The study revealed that researchers are perceived by community members as solely experts in the research project, which creates one-way information flow from the research that hinders communities to be part of the decision-making process. This leads to non-active participation and less ownership of the project. Evidence from the literature suggests that the first phase of engagement should lead to a genuine collaborative partnership, reciprocal relationships, mutual respect and acceptance of differences and shared power, vision, and decision-making, contributing to greater community acceptance of research (Anderson et al., 2012).

The researchers in the field of CE and CBPR perceive communities or participants as source of data without being mindful that communities can generate knowledge based on their lived experiences. The study portrays that researchers habitually engage communities with pre-

empting ideas and answers, which undermines the insights and lived experiences of communities. The findings echo existing literature indicating that researchers frequently lack community engagement from the perspective of service users (communities), and interventions may not fully reflect community priorities and lived experiences (Baptiste et al., 2020). This suggests that researchers are expected to create an environment where the community will provide their thoughts from the conceptual phase and be able to reflect on the initial stage of CE before moving to the next stage of the project. Furthermore, this enhances the value of local and indigenous knowledge that could be used by researchers to provide remedies to problems of the community. This further allows researchers and community members to become equal partners in the process, as a result of proactively, cautiously and conscientiously seeking the community's opinion in the research project initiated (Musesengwa et al., 2017).

The study confirms that most researchers acknowledged their limitation on how to engage communities during the informing phase. Previous studies have demonstrated that early interaction with community leaders can give important context for later interviews with community members and unanticipated challenges can be avoided (Bergen & Labonte, 2020). However, the main challenges encountered by the KEP researchers were not being familiar with the cultural practices and not fluent in isiZulu as the local language. However, CRAs understood the local language as they were part of the communities and were always available to assist the researchers with data collection in all the villages. Some scholars argue that engaging communities in the research context requires an understanding of indigenous or local language and cultural practices as it yield positive results of the research project and contribute to mutual benefit (Bracic, 2018; Ramachandra et al., 2014; P. O. Tindana et al., 2020). A lack of cultural and language sensitivity may have a negative effect on the quality and equity of the research project on the delivery of healthcare in monolingual communities (Peled, 2018). Previous research also observed that researchers working in the rural areas need to understand the cultural dynamics of specific groups and institutions in order to build relationships, identify ways to effectively collaborate, and build respect and trust (Mthembu & Hlophe, 2020).

### 13. Conclusion

The study confirms that researchers overlook the significance of the initial phase of CE (informing phase), as evidently shown that many research engaged projects fail due to poor communication, inadequate consultation, and poor design and implementation, which systematically demonstrate passive participation towards the researched communities. Therefore, we conclude that in engaging researched communities, a higher level of engagement in the initial stage of CE is essential and is a crucial stage that should not be neglected during research procedures. Overall, the study acknowledged that the informing phase as the initial stage of CE is a significant process of engagement which creates meaningful long-term relationships with the researched communities and stakeholders who have interest and influence in the engaged research-based projects. The understanding of cultural and language differences in the process of community engagement is crucial to ensure meaningful communication and active participation to have a balanced collaboration that is beneficial to all parties who have an interest in the project.

Apart from extensive literature in CE, there is a dearth of empirical research on the initial stage of CE and its role to effectively execute CE without overlooking any of the phases. Therefore, the study recommends the formulation guidelines specifically for the informing phase for both researchers and communities to ensure that no one is disregarded during the conceptualisation stage.

#### Acknowledgments

The authors would like to acknowledge the KEP research team for allowing them to collect data during their field-work and those who also availed themselves during online interviews. We are also indebted to uMkhanyakude communities for allowing us to work with them. IREX funding through the UASP alumni small grants program is acknowledged for providing a platform for the development of this publication.

#### Funding

This work was supported by National Research Foundation (NRF) (grant number: 116263) through my PhD supervisor (MC) from the University of KwaZulu-Natal, College of Health Sciences.

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#### Disclosure statement

No potential conflict of interest was reported by the author(s).

#### Citation information

Cite this article as: Facilitating community engagement: Researchers' lived experiences in rural communities in the KwaZulu-Natal Ecohealth Program, South Africa, Zinhe Mthembu, Moses Chimbari & Margaret Macherera, *Cogent Social Sciences* (2023), 9: 2225833.

#### References

- Adhikari, B., Vincent, R., Wong, G., Duddy, C., Richardson, F., Lavery, J. V., & Molyneux, S. (2019, August 2). A realist review of community engagement with health research. *Wellcome Open Research*, 4, 87. <https://doi.org/10.12688/wellcomeopenres.15298.1>
- Ahmed, S. M., & Palermo, A. G. S. (2010, August). Community engagement in research: Frameworks for education and peer review. *American Journal of Public Health*, 100(8), 1380–1387. <https://doi.org/10.2105/AJPH.2009.178137>
- Akondeng, C., Njamnshi, W. Y., Mandi, H. E., Agbor, V. N., Bala, L. E., & Njamnshi, A. K. (2022, May). Community engagement in research in sub-Saharan Africa: Approaches, barriers, facilitators, ethical considerations and the role of gender – a systematic review protocol. *British Medical Journal Open*, 12(5), e057922. <https://doi.org/10.1136/bmjopen-2021-057922>
- Anderson, E. E., Solomon, S., Heltman, E., DuBols, J. M., Fisher, C. B., Kost, R. G., Lawless, M. E., Ramsey, C., Jones, B., Ammerman, A., & Ross, L. F. (2012, April 1). Research ethics education for community-engaged research: A review and research agenda. *Journal of Empirical Research on Human Research Ethics: JERHRE*, 7(2), 3–19. <https://doi.org/10.1525/jer.2012.7.2.3>
- Arnstein, S. R. (2019). A ladder of citizen participation. *Journal of the American Planning Association*, 85(1), 24–34. <https://doi.org/10.1080/01944363.2018.1559388>
- Baptiste, S., Manouan, A., Garcia, P., Etya'ale, H., Swan, T., & Jallow, W. (2020, October 1). Community-led monitoring: When community data drives implementation strategies. *Current HIV/AIDS Reports*, 17(5), 415–421. <https://doi.org/10.1007/s11904-020-00521-2>
- Bergen, N., & Labonté, R. (2020). "Everything is perfect, and we have no problems": Detecting and limiting social desirability bias in qualitative research. *Qualitative Health Research*, 30(5), 783–792. <https://doi.org/10.1177/1049732319889354>
- Bracic, A. (2018). For better science: The benefits of community engagement in research. *PS, Political Science & Politics*, 51(3), 550–553. <https://doi.org/10.1017/S1049096518000446>

- Chantler, T. (2012). Community engagement & ethical practice in vaccine research
- Curtis, A., Ross, H., Marshall, G. R., Baldwin, C., Cavaye, J., Freeman, C., Carr, A., & Syme, G. J. (2014, April 3). The great experiment with devolved NRM governance: Lessons from community engagement in Australia and New Zealand since the 1980s. *Australasian Journal of Environmental Management*, 21(2), 175–199. <https://doi.org/10.1080/14486563.2014.935747>
- DeJonckheere, M., Lindquist-Grantz, R., Toraman, S., Haddad, K., & Vaughn, L. M. (2019, October 1). Intersection of mixed methods and community-based participatory research: A methodological review. *Journal of Mixed Methods Research*, 13(4), 481–502. <https://doi.org/10.1177/1558689818778469>
- Gilmore, B., Ndejjo, R., Tchetchia, A., de Claro, V., Mago, E., Diallo, A. A., Lopes, C., & Bhattacharyya, S. (2020, October). Community engagement for COVID-19 prevention and control: A rapid evidence synthesis. *BMJ Global Health*, 5(10), e003188. <https://doi.org/10.1136/bmjgh-2020-003188>
- Hahn, D. L., Hoffmann, A. E., Felzien, M., LeMaster, J. W., Xu, J., & Fagnan, L. J. (2017). Tokenism in patient engagement. *Family Practice*, 34(3), 290–295. <https://doi.org/10.1093/fampra/cmw097>
- Holliman, R. (2017, December 13). Supporting excellence in engaged research. *Journal of Science Communication*, 16(5), C04. <https://doi.org/10.22323/2.16050304>
- Johnston, K. A., & Lane, A. B. (2018). Building relational capital: The contribution of episodic and relational community engagement. *Public Relations Review*, 44(5), 633–644. <https://doi.org/10.1016/j.pubrev.2018.10.006>
- Kabuyaya, M., Chimbari, M. J., Manyangadze, T., & Mukaratirwa, S. (2017, April 7). Efficacy of praziquantel on Schistosoma haematobium and re-infection rates among school-going children in the Nduma area of uMkhanyokude district, KwaZulu-Natal, South Africa. *Infectious Diseases of Poverty*, 6(1), 83. <https://doi.org/10.1186/s40249-017-0293-3>
- Luger, T. M., Hamilton, A. B., & True, G. (2020). Measuring community-engaged research contexts, processes, and outcomes: A mapping review. *The Milbank Quarterly*, 98(2), 493–553. <https://doi.org/10.1111/1468-0009.12458>
- Matthews, A. K., Anderson, E. E., Willis, M., Castillo, A., & Choure, W. (2018). A community engagement advisory board as a strategy to improve research engagement and build institutional capacity for community-engaged research. *Journal of Clinical and Translational Science*, 2(2), 66–72. <https://doi.org/10.1017/cts.2018.14>
- McCloskey, D. J., Akintobi, T. H., Bonham, A., Cook, J., & Coyne-Besley, T. (2011). Principles of community engagement (second edition). *Community Engagement*, 11, 197. [https://www.atsdr.cdc.gov/communityengagement/pdf/PCE\\_Report\\_508\\_FINAL.pdf](https://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf)
- McFadyen, J., & Rankin, J. (2016). The role of gatekeepers in research: Learning from reflexivity and reflection. *GSTF Journal of Nursing and Health Care (JNHCC)*, 4(1), <https://doi.org/10.1080/1745-0495/177114>
- Mthembu, A., & Hlopho, S. (2020). Building resilience to climate change in vulnerable communities: A case study of uMkhanyokude district municipality. *Town Reg Plan*, 77, 42–56. <https://doi.org/10.1882/02415-0495/177114>
- Musesengwa, R., Chimbari, M. J., & Mukaratirwa, S. (2017, December). Initiating community engagement in an

- ecohealth research project in Southern Africa. *Infectious Diseases of Poverty*, 6(1), 22. <https://doi.org/10.1186/s40249-016-0231-9>
- National Academies of Sciences, Engineering, and medicine. (2017). *Integrating clinical research into epidemic response: The Ebola experience* [Internet]. Keusch, G., McAdam, K., Cuff, P. A., Mancher, M., Busta, E. R., Eds., The National Academies Press, Retrieved August 20, 2021, from <https://www.nap.edu/catalog/24739/integrating-clinical-research-into-epidemic-response-the-ebola-experience>
- Nelson, E. (2019). A resource guide for community engagement and involvement in Global Health Research. <https://media.tghn.org/articles/NIHR-Community-Engagement-Involvement-Resource-Guide-2019.pdf>
- Peled, Y. (2018). Language barriers and epistemic injustice in healthcare settings. *Bioethics*, 32(6), 360–367. <https://doi.org/10.1111/bioe.12435>
- Peralta, K. (2017, December 4). Toward a deeper appreciation of participatory epistemology in community-based participatory research. *PRISM: A Journal of Regional Engagement*, 6(1) <https://encompass.eku.edu/prism/vol6/iss1/4>
- Ramachandra, A., Mansor, N. N. A., Vicky Duckworth & Jonathan Tummons, D. (2014). Sustainability of community engagement—in the hands of stakeholders? *Education + Training*, 56(7), 588–598. <https://doi.org/10.1108/ET-07-2014-0084>
- Ramsbottom, A., O'Brien, E., Ciotti, L., & Takacs, J. (2018). Enablers and barriers to community engagement in public health emergency preparedness: A literature review. *Journal of Community Health*, 43(2), 412–420. <https://doi.org/10.1007/s10900-017-0415-7>
- Richardson, E. Z. L., Bandewar, S. V. S., Boulanger, R. F., Mehta, R., Lin, T., Vincent, R., Molyneux, S., Goldstone, A., Lavery, J. V. (2021, March 29). Addressing diversity and complexity in the community engagement literature: The rationale for a realist review. *Wellcome Open Research*, 5, 1. <https://doi.org/10.12688/wellcomeopenres.15525.2>
- Ramsland, G. I., Milosavljevic, K. L., & Andreassen, T. A. (2019, June 4). Facilitating non-tokenistic user involvement in research. *Research Involvement and Engagement*, 5(1), 18. <https://doi.org/10.1186/s40900-019-0153-3>
- Ryan, B., Johnston, K. A., Taylor, M., & McAndrew, R. (2020, October). Community engagement for disaster preparedness: A systematic literature review. *International Journal of Disaster Risk Reduction*, 49, 101655. <https://doi.org/10.1016/j.ijdrr.2020.101655>
- Schoch-Spano, M., Franco, C., Nuzzo, J. B., & Usenza, C. (2007, March). Community engagement: Leadership tool for catastrophic health events. *Biosecurity Bioterrorism Biodefense Strategy Practice Science*, 5(1), 8–25 <https://doi.org/10.1089/bsp.2006.0036>
- Smith, A. R., Colombi, J. M., & Wirthlin, J. R. (2013). Rapid development: A content analysis comparison of literature and purposive sampling of rapid reaction projects. *Procedia computer science*, 16, 475–482. <https://doi.org/10.1016/j.procs.2013.01.050>
- Tindana, P., de Vries, J., Campbell, M., Littler, K., Seeley, J., Marshall, P., Troyer, J., Ogundipe, M., Alibu, V. P., Yakubu, A., & Parker, M. (2015, April 12). Community engagement strategies for genomic studies in Africa: A review of the literature. *BMC Medical Ethics*, 16(1) 24. <https://doi.org/10.1186/s12910-015-0014-z>
- Tindana, P. O., De Vries, J., & Kamuya, D. (2020). Ethical challenges in community engagement practices in research during the COVID-19 pandemic in Africa. *AAS Open Research*, 3, 23. <https://doi.org/10.12688/aasopenres.13084.1>

Chapter 2 discussed the lived experiences of KEP researchers at the during community engagement process of projects life cycles. The nature of engagement of researchers with the community representatives (izinduna, CAB members, and CRAs) prior to initiating schistosomiasis and malaria projects was also described and discussed. Thus, Chapter 3 presents the perceptions of communities on the extent to which they were informed, involved, consulted and empowered on Ecohealth research projects conducted in their area.

### **CHAPTER 3**

## **COMMUNITY ENGAGEMENT: HEALTH RESEARCH THROUGH INFORMING, CONSULTATION, INVOLVING AND EMPOWERMENT IN INGWAVUMA COMMUNITY**

*Published: Frontiers in Public Health*



## OPEN ACCESS

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RECEIVED 21 September 2022  
ACCEPTED 16 May 2023  
PUBLISHED 02 June 2023

CITATION  
Mthembu Z and Chimbari M (2023) Community  
engagement: health research through  
informing, consultation, involving and  
empowerment in Ingwavuma community.  
*Front. Public Health* 11:1050589.  
doi: 10.3389/fpubh.2023.1050589

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# Community engagement: health research through informing, consultation, involving and empowerment in Ingwavuma community

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**Introduction:** The goal of community involvement in health research is to improve a community's ability to address its own health needs while ensuring that researchers understand and consider the community's priorities. Recent data show that socio-economic and environmental challenges continue to be a barrier to informing, consulting, involving and empowering communities in community-based health research beneficial to them. The aim of this study was to assess the extent to which the Ingwavuma community in KwaZulu-Natal Province, in rural South Africa, was informed, consulted, involved and empowered about two research projects conducted between 2014 and 2021.

**Methods:** The study used the modified random-route procedure to administer a standardized questionnaire to 339 household heads selected randomly. The questionnaires were administered face-to-face. The sample size was estimated using the Yamane sample size generating formula. Chi-square tests were performed to assess associations between demographic variables (age, gender, education, village) and respondents' knowledge and information of the projects, Malaria and Bilharzia in Southern Africa and Tackling Infections to Benefit Africa as well as their participation.

**Results:** The communities were generally well-informed about the health projects that were being carried out. Fewer than half of those who had heard about the projects had directly participated in them. The majority had been tested for one or more diseases and conditions, mostly high blood pressure, diabetes, and schistosomiasis, and had participated in a community feedback group; many had given their children's permission to be tested for schistosomiasis or to participate in project research activities. Others participated in public awareness campaigns and surveys. There was some evidence of a consultation process in the form of public consultation discussed in the projects, and not much discussion on empowerment.

**Discussion:** The findings demonstrate that researchers' CE approach was adaptable as communities were largely educated, involved, and subsequently empowered though without much consultation and that researchers had provided a space for sharing responsibilities in all engagement process decision-making. For the empowerment of the community, projects should take into account the intrapersonal and personal aspects affecting the community's capacity to effectively benefit from the information, consultation, involvement, and empowerment procedures.

## KEYWORDS

ecohealth, involvement, communities, community engagement, health research

## 1. Introduction

Community engagement (CE) in health research aims to strengthen a community's ability to tackle its own health problems while drawing the attention of researchers to known health challenges in the community. Communities in which community health research is conducted must perceive the research process as authentic and credible (1). However, power imbalances between researchers and the participants (communities) that result in community members not always having a voice in the decision-making process (2) sometimes lead to the withdrawal of communities from studies due to mistrust and suspicion (3). Community trust is significantly associated with community engagement and if a community lacks trust, it may decide to disengage (4). Strong evidence found poverty and unemployment in remote rural communities influence how research participants misinterpret outside researchers as potential sources of various material benefits. Many studies have reported that there is little guidance on how to assess the CE processes, the outcomes and the impact on communities, which should lead to community empowerment (5–7). CE in community health research refers to efforts that promote the exchange of information, ideas and resources between community members and researchers. It is a collaborative co-governance of research including researchers and people affected by issues under investigation or in positions to act on research findings, such as end-users including intervention participants, health managers, and policymakers (8). Researchers can acquire knowledge and trust, but they may not fully appreciate the true community health status to adequately address pertinent research questions. On the other hand, some communities may not always trust the intentions of researchers, or the methods used in the research (9, 10). Similarly, ordinary community members may have limited research skills, knowledge and training, and may not fully appreciate the complexities of research methodology and theories (11). Therefore, while health researchers share their health expertise, services, and other resources with the community as part of community engagement in the research process, the community may provide crucial local knowledge and experience that can greatly help direct the efforts of health research projects/programs. It is important to engage communities in all research processes so that they fully benefit from the research. This implies that the concept of CE is critical in community research and the inclusion of communities in the research process from inception can improve the way research is planned, carried out and used (12).

CE improves health outcomes by increasing the cultural and logistical adaptation of community-based research projects to their settings, promoting community empowerment, and facilitating the translation of research-generated health knowledge into practice (13). In addition, CE can help to uncover the social, political, and economic contexts that underpin both facilitators and barriers to knowledge and resources needed for health (14), especially when the research process is co-governed with end users. Although community engagement is considered important in health research, its implementation is still understudied (15). CE can be challenging as it requires effort, capacity, investment of time as well as money (16) and the researched community may be indispensable regarding the methods and execution of the project (17). Therefore, dialogues between community members and researchers with different levels of involvement, decision-making and control between community and health researchers can overcome these challenges (18). Consequently,

researchers must approach communities as research partners, with community members and leaders' participation viewed as critical for acceptability and success of a research project/program. The challenges are amplified when a particular health issue or research question is not prominent in the consciousness of the targeted community.

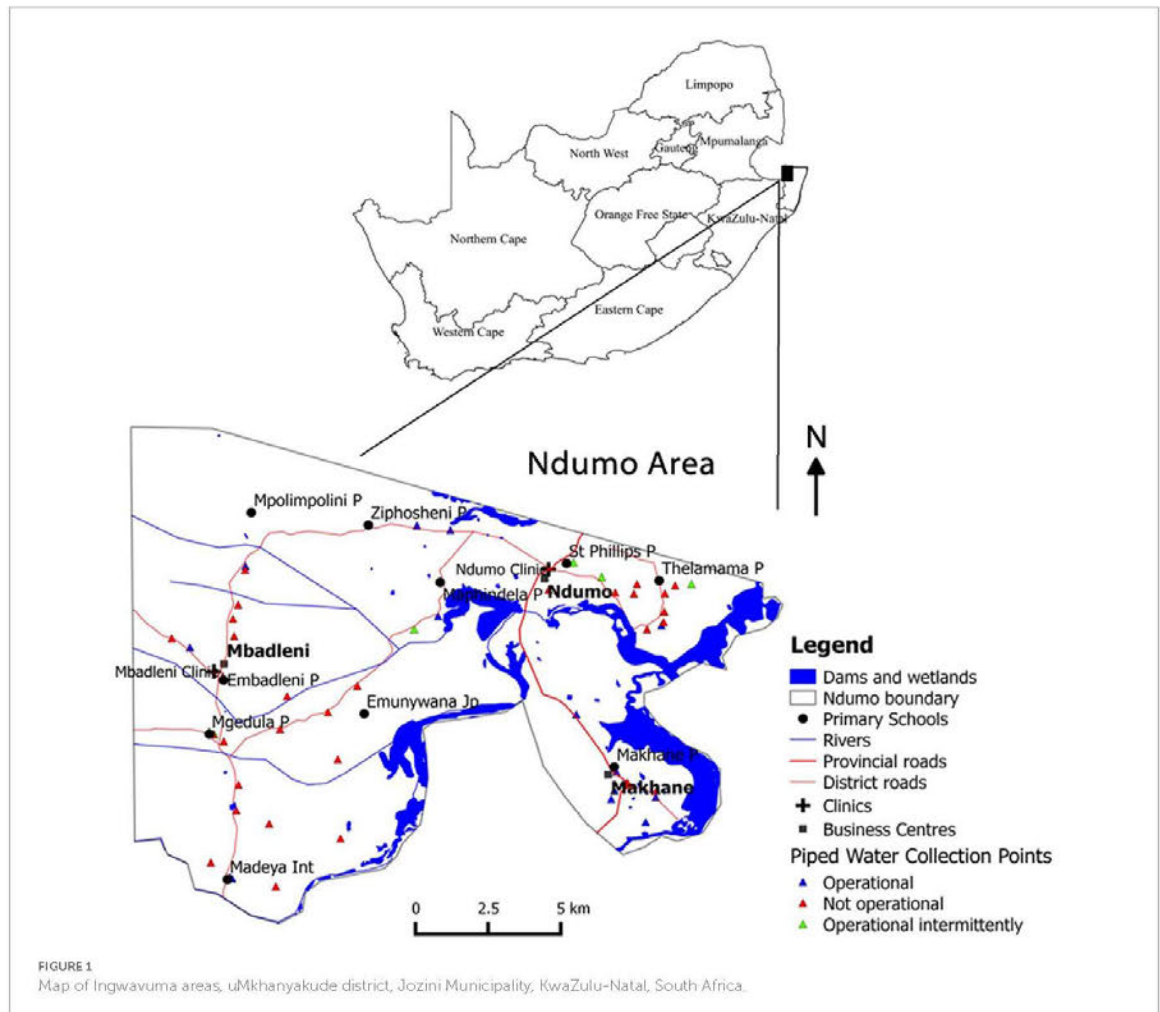
In community health research settings, investigators and their teams must inform, consult, involve and empower the community about the objectives, rationale and benefits of research projects for the community. However, little is often known about the extent to which they are informed and/or educated about health research projects in their localities/communities. Without a clear assessment and understanding of the extent of information and communication communities received from research project teams, researchers are likely to fail in their attempts to involve community members in research collaborations. Establishing a research partnership without effective communication and information can lead to decisions and actions that further violate the trust of the community. Distrust not only affects the immediate research relationship, and, in turn, the validity of the data collected, but also has a profound impact on the future willingness of the affected populations to engage in the research enterprise. In this article, we present findings on the extent to which a local community was informed, consulted, involved and empowered about research projects and related activities in their locality. It is based on two community based projects; Malaria and Bilharzia in Southern Africa (MABISA) and Tackling Infections to Benefit Africa-South Africa (TIBA-SA) (19), carried out between 2014 and 2021 in the Ingwavuma area of KwaZulu-Natal Province in rural South Africa.

## 2. Materials and methods

### 2.1. Study setting and MABISA/TIBA-SA project overview

This study was conducted in Ingwavuma, an underdeveloped area in the uMkhanyakude district, KwaZulu-Natal province, South Africa (20). The area lies on the north-east border with Mozambique and Swaziland and is adjacent to the Ndumo game reserve (Figure 1). A permanent river, the Pongola River, flows through it. The Pongola has distributaries that start from within the mountains that border Swaziland, one of which is the Ingwavuma River. There is very little infrastructure in this area; the road network is still being developed and much of the area is accessible through gravel roads. Schools are sparsely distributed throughout the villages and offer minimum utilities with most of them having no tap water. Due to the dry weather conditions in the region, agricultural activities and other related economic activities are limited. Apart from an irrigation system that draws water from the Pongola Dam, which is more than 35km away, there is no other irrigation system. The town of Ingwavuma is located in a low-lying area, characterised by hot temperatures, stagnant and slowly moving water bodies. These geographical conditions make the region a hotspot for schistosomiasis and malaria. Individuals in these areas experience extreme poverty and low levels of education. These factors indicate the need to involve the community in health education in a robust and inclusive way.

The MABISA (Malaria and Bilharzia in southern Africa) and TIBA-SA (Tackling Infections to Benefit Africa-South Africa) research projects were initiated in 2013 and 2017 respectively, upon realization



that social and environmental determinants of health have a major influence on the epidemiology of vector-borne diseases (VBDs) and that the influence is exacerbated by climate change (19). The Ingwavuma area faces different socio-economic and environmental challenges, which offer opportunities to investigate the impact of these factors on VBDs. These community-based health research projects were designed to address the impact of social-environmental determinants and climate change on two VBDs, malaria and schistosomiasis. The projects focused on the ecologies and water systems of dry land (rivers, lakes, rain-fed systems, irrigation systems) within dry land in order to develop adaptation strategies to reduce vulnerability to these diseases in population health. TIBA-SA had components of BP and Diabetes project. Throughout the projects, the study team relied on the input of members of the community to guide the nature and structure of interventions.

The paper is based on work in a larger project, the KwaZulu-Natal Ecohealth Program (KEP) which uses a participatory action research methodology. A governance structure and an operational strategy that involves the community to ensure that the community fully

participated in MABISA/TIBA-SA projects was established during the first phase (Informing) of CE. A 12-member Community Advisory Board (CAB) comprising of one headman (induna), two community leaders, three school board members, three community care givers and three ordinary community members was established at the inception of the MABISA project and is functional to date. The headmen (izinduna) are the elected gatekeepers with authority over villages and are accountable to the chiefs, the tribal council and their community (21). The informing of the community in the MABISA project was through the community liaison officer (CLO), who was referred to the MABISA project by the Provincial Health District, as he had previously worked for other NGO projects in the area. The CLO then linked the principal investigators with the leaders of the community to introduce the ideas of the project. The project principal investigators visited the community with a prepared detailed study document to engage with the community. In this methodology, it is important to note that the researchers were the ones who came up with the idea for the project, found a way to get the community involved by informing them about the project, and engaged

community members to have input on the design, methodology, and execution of the project. The community meeting was organized by the induna and activities for participatory rural appraisal (PRA) (origins of PRA) were conducted to identify issues that were to be researched. This method of engagement gives a community access to accurate and objective information that will assist them in better understanding the project proposed as well as the potential solutions.

The project field operations were carried out by researchers and CRAs as they were trained to attain the required skills for the fieldwork. The presence of the CAB and CRAs has been instrumental in promoting the concept of community change makers for prevention and control of vector borne diseases including zoonosis. Decisions concerning survey design and implementation, as well as techniques to collecting anthropometric and biochemical data, were influenced by community leaders and community members employed as staff (CRAs). The initiatives in the TIBA-SA projects are designed to have an influence on the society that is affected by health issues; they take an Ecohealth approach with a focus on community participation. The projects were founded on the idea that academics working with the Ingwavuma community would be able to change health behaviour, collect information, and increase understanding of infectious illnesses including schistosomiasis and malaria. The project produced good results which were largely disseminated through various means, workshops, local radio station and journal publications (much less for communities and government agencies). As part of the uptake activities, we had school children drama competitions focusing on malaria and schistosomiasis. We have realized that edutainment is an effective way of disseminating information to communities and that uptake is likely when the information is naturally assimilated through music, dance, poetry and drama. We used a group called Ubuciko, the Art to provide edutainment. During MABISA project they performed during PRA meetings and the response from the community was overwhelming in terms of information dissemination. This method of information dissemination resonates well with the culture of communities we worked in. In addition, a community feedback meeting was used as a platform to disseminate findings of the project to all stakeholders. Because of the capacitation of CRAs we made and involvement of Department of Health personnel we believe that the project ideas will be sustained in the community and relevant government departments.

### 2.1.1. The community engagement Vancouver coastal health framework

The study applied the Community Engagement Vancouver Coastal Health framework<sup>1</sup> which involves five CE components. The stages include (1) informing the community, (2) consulting the community, (3) involving the community, (4) collaborating with the community, and (5) empowering the community and are summarized in Table 1. This paper focuses on the Informing, Consultation, Involving and Empowerment phases. Although there are different methods and frameworks for community engagement, this framework, often quoted in many studies (22–26) was suitable for this study. We wanted to engage the community across the full spectrum of participation levels ranging from informing, consulting and

involving to collaborating and empowering. The Vancouver framework outlines community engagement as public participation and is based on the principle that people have the right to participate in the decision-making processes that affect them and that everyone has a say when it comes to their health care (27). This framework was adapted from Sherry Arnstein's theory of Ladder of Citizen Participation which is one of the most widely referenced and influential models in the field of democratic public participation (28). Arnstein's theory discusses about eight levels of participation arranged in a ladder pattern with each rung corresponding to the extent of citizens' power in determining the end product. The bottom rungs of the ladder are, first (*Manipulation*), and second (*Therapy*), which describes "non-participation" real purpose here is not to give individuals a voice in planning or executing initiatives, but rather to provide those in positions of authority the opportunity to "educate" or "cure" the people who are involved (28). In the third (*Informing*) and fourth (*Consultation*) rungs, "tokenism" increases to the point that the have-nots can finally be heard and their voices heard. Rung fifth (*Placation*) is simply a higher-level tokenism because the ground rules allow have-nots to advise, but retain for the powerholders the continued right to decide. Rung six (*Partnership*) enables them to negotiate and engage in trade-offs with traditional powerholders. At the top most rungs, seven (*Delegated Power*) and eight (*Citizen Control*) have-not citizens obtain the majority of decision-making seats, or full managerial power (28). For local leaders, organizers, and facilitators who want to understand foundational theories of public engagement and participation, and the ways in which empowered public institutions and officials deny power to citizens, Arnstein's theory was also essential for this particular study aimed to assess the extent to which the community, in rural South Africa, was informed, consulted, involved and empowered about two research projects (MABISA and TIBA-SA).

## 2.2. Study participants and data collection

The study was carried out between November 2019 and November 2021. The study used the modified random-route procedure (29) to administer a standardized questionnaire to 339 household heads selected randomly. The sample size was estimated using the Yamane sample size generating formula (30). The modified random route procedure involved dropping interviewers at different locations within the designated geographical area and allowing them to choose a starting point and direction for the selection of households. Since this method is employed when there is not a complete list of households, it aims to produce equal selection probabilities so that each household has an equal chance of being included in the sample (31). Questions were arranged in a logical sequence and uploaded to KoboCollect (32), an online open source platform for data collection and analysis. Questionnaires were administered face-to-face.

The questionnaire was designed in English and translated into the study area local language, isiZulu. Community Research Assistants (CRAs) who administered the questionnaire received intensive training over 2 days. In order to ensure uniform understanding and evaluation of data collection, the instrument was pre-tested in one of the villages in the area, with similar socio-demographic and cultural characteristics to the study area. The village where pre-testing was done was excluded from the main study. Additional modifications to

<sup>1</sup> [www.vch.ca/ce](http://www.vch.ca/ce)

TABLE 1 Five components of community engagement.

Inform	Consult	Involve	Collaborate	Empower
<b>Objective</b>	<b>Objective</b>	<b>Objective</b>	<b>Objective</b>	<b>Objective</b>
To provide community with balanced and objective information to assist them in understanding the problem, alternatives, or solutions.	To obtain community feedback on analysis, alternatives, or decisions.	To work directly with the community throughout the entire process to ensure that community and organizational concerns are consistently understood and considered.	To partner with the community in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision-making in the hands of the community
<b>Promise to the community</b>	<b>Promise to the community</b>	<b>Promise to the community</b>	<b>Promise to the community</b>	<b>Promise to the community</b>
We will keep you informed.	We will keep you informed, listen to and acknowledge your concerns, and provide feedback on how community input influenced the decision.	We will work with you to ensure your concerns and issues are directly reflected in alternatives developed and provide feedback on how community input influenced the decision.	We will look to you for direct advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	To place final decision making in the hands of the community.

the tool were done based on the results from the pre-testing. The questionnaire included questions on demographics, such as age, gender, and the level of education of the household heads. In order to determine how informed the community was about research projects in their locality, respondents were asked to name any health research project they remembered to have been conducted in their community in the past 7 years during which the two projects were undertaken in the community. Those who had lived in the research area for over 10 years may have had rich information. They were also asked whether they had ever heard of MABISA/TIBA-SA research projects, among other questions. Items were designed to be closed ended, but an option for additional open-ended responses was included for most of the questions.

### 2.3. Data analysis

Data were analysed using descriptive statistics specifically frequencies and percentages. Chi-square tests of associations were done to assess associations between demographic variables (age, gender, education, village) and respondents' knowledge and information of the MABISA/TIBA-SA projects, their involvement as well as empowerment. Further Chi-square tests were done to assess the association between participating in the study and knowledge about its aims, activities, researchers, sites as well as whether respondents believed they had benefitted from the projects. Cramer's V tests were applied to all statistically significant Chi-square tests to measure the strengths of associations while descriptive contingency tables were used to identify relationships within the associations with a V of 0 indicating no relationship and a V of 1 showing the strongest possible association between tested variables (33). A probability value of 0.05 was used in both the Chi-square and Cramer's V tests. The general view behind the tests was that an informed, consulted, involved and empowered audience would exhibit statistically significant results that showed strong associations between project participation and knowledge of the projects' aims, activities, researchers and research sites. Also, they would show a strong association between project participation and benefits.

### 2.4. Ethical considerations

Ethical approval was obtained from the University of KwaZulu-Natal (UKZN) Institutional Ethics Board, Humanities and Social Sciences Research Ethics Committee (HSSREC), Protocol reference number: (HSSREC/0001650/2020). All participants gave informed consent to participate in the study.

## 3. Results

### 3.1. Participants demographics

Table 2 below shows that respondents' demographic information. The study used a sample of 339 respondents from five villages in the Ingwavuma Community.

Of the five villages, 107 (31%) respondents came from Ndumo followed by 85 (25%) from Makhane (see Table 2). The majority of respondents (88%) had stayed in the study area for more than 10 years which could mean that they had rich information about the community projects and what happens in their community. More than 26.9% of respondents were aged 35 years and below, while those above 66 to 75 of age were 3.3%. Further, the results show that more than two-thirds (72%) of the households surveyed are female-headed and that most (over 90%) have secondary education and less as their highest level of education.

As indicated in Table 3, out of 338 respondents, 177 (52.4%) had heard about the MABISA/TIBA projects while 161 (47.6%) had not. Of the 177, 41.8% participated in the projects. Less than half of the respondents who had heard about the projects were involved as participants. Of the 177 respondents who said they had heard about the MABISA/TIBA projects, 64.4% stated that they were familiar with the projects on Schistosomiasis, 20.3% with the Malaria project while 18.6% said they had forgotten about the project they had heard about. Respectively, 10.7, 7.3 and 4.5% of the respondents who knew about and who had heard about the MABISA/TIBA projects knew about the BP, Diabetes and infectious diseases/diseases projects. The participants were therefore exposed to information about different projects with

TABLE 2 Study participant demographics.

Description	Participants	Frequency	Percent
Gender	Males	92	27.3
	Females	245	72.7
Age (Years)	<25	89	26.3
	26–35	91	26.9
	36–45	57	16.9
	46–55	45	13.3
	56–65	35	10.4
	66–75	11	3.3
	>75	10	3.0
Village	Ndumo	107	31.7
	Mbadleni	73	21.6
	Mgedula	49	14.5
	Madeya	23	6.8
	Makhane	86	25.4
Highest Education level	No formal education	60	17.8
	Primary	83	24.6
	Secondary	164	48.5
	College level	9	2.7
	Above college level	3	0.9
	Other	19	5.6

some having no information about running projects. A considerable number reported to be uninformed or having forgotten about some projects. Among the 177 respondents who had heard about the projects, 43.5% had heard about these from CCGs, 28.2% from schools, 15.3% from family/neighbours and 13.6% from community meetings. Also, 2.8% had heard about these from their traditional leadership and another 2.8% from television/radio. CCGs and schools were therefore the commonest sources of MABISA/TIBA projects information.

### 3.2. Participation and benefits

The respondents were asked if they took part in any of the projects and what they had learnt from them. Table 4 summarises their responses.

Out of 76 respondents, 46.1% had been tested for one or more diseases and conditions, mostly BP, Diabetes and Schistosomiasis. Also, 25.7% had participated as part of a community feedback group and 11.8% had participated by consenting for their children to be tested or to take part in the projects' research activities. 10.5% participated in awareness campaigns and 6.6% participated as survey respondents.

The above Table 4 focuses on 76 respondents who responded "Yes" to the question *What did you learn or understand from the projects that are being done in your community?* Out of the 77, most of the respondents (68.8) learnt about Schistosomiasis, 44.2% about personal health and hygiene, 29.9% about Malaria and 20.1% about infectious

TABLE 3 Information on health research projects and involvement.

	Responses	Frequency	Percent
C2 Have you ever heard of MABISA/TIBA projects?	No	161	47.6%
	Yes	177	52.4%
	Total	338	100.0%
Did you participate in the project?	No	103	58.2%
	Yes	74	41.8%
	Total	177	100.0%
C3 Mention MABISA/TIBA projects that you know about:	Schistosomiasis	114	64.4%
	Malaria	36	20.3%
	Do not know/have forgotten	33	18.6%
	BP	19	10.7%
	Diabetes	13	7.3%
	Infectious diseases/diseases	8	4.5%
	HIV	1	0.6%
Where did you hear about these projects?	CCG	77	43.5%
	School	50	28.2%
	Family/neighbours	27	15.3%
	Community meeting	24	13.6%
	Other	16	9.0%
	Traditional leadership	5	2.8%
	Television/radio	5	2.8%

diseases in general. Of these, 13% reported to have forgotten what they learnt while 6.5% said they learnt nothing from the projects. The majority had therefore benefitted through learning about Schistosomiasis. A minority had also learnt about Malaria and infectious diseases.

### 3.3. Associations between informing, involvement and participation

Table 5 analyses data from the 177 respondents who had participated in the projects' activities focusing on associations between participation, informing and consultation.

Out of 74 respondents who participated in the projects 52 (70.3%) of the respondents knew about the research activities conducted by MABISA/TIBA projects. The remaining 22 (29.7%), despite taking part, were not aware of the organisation's projects. Also out of the 74, only 20 (27%) were familiar with the projects' research sites. The remaining respondents had no idea about these projects. In the same group, 19 out of 74 (25.7%) participants knew about the projects' research aims while the rest did not. The majority of the respondents (69 out of 74) or 93.2% had, however, met directly with the MABISA/TIBA researchers while only 5 had not. Also, 33 out of 74 (44.6%) knew the researchers' names while the rest did not suggest that despite this contact, some respondents remained poorly informed about the

TABLE 4 Participation and benefits.

	Question/Statement	Frequency	Percent
Did you participate in the projects? if yes how?	Tested for diseases and conditions	35	46.1%
	Survey respondent	5	6.6%
	Consented for children to participate	9	11.8%
	Community feedback group	19	25.7%
	Training and awareness recipient	8	10.5%
What did you learn or understand from the projects that are being done in your community?	Schistosomiasis	53	68.8%
	Personal health and hygiene	34	44.2%
	Malaria	23	29.9%
	Infectious diseases in general	16	20.1%
	I have forgotten	10	13.0%
	Diabetes	8	10.4%
	Importance of visiting healthcare facilities	6	7.8%
	BP	6	7.8%
	Nothing	5	6.5%
	HIV/STDs	5	6.5%
	Importance of taking medication	4	5.2%
	Cancer	4	5.2%

research projects' aims and sites. Almost all the respondents who had participated in the MABISA/TIBA projects stated that they had signed a consent form, and the same number also affirmed that these consent forms had enough background information about the project. Finally, only 26 out of 74 (35.1%) respondents said they had benefitted from the projects while 48 (64.9%) said they had not.

In the above crosstabulations, statistically significant  $X^2$  confirms the association between participating in the projects and knowing about them specifically the activities conducted in them ( $X^2(1) = 15$ ,  $p = 0.00$ ); participation and knowledge of research sites ( $X^2(1) = 19.68$ ,  $p = 0.00$ ), aims ( $X^2(1) = 23.2$ ,  $p = 0.00$ ) and researchers involved ( $X^2(1) = 16.8$ ,  $p = 0.00$ ). In all these associations, Cramer's  $V$  ranged from 0.15 on the benefits to 0.97 on consent. Besides the low size effect (low Cramer's  $V$ ) on the benefits of participation, moderately strong to very strong associations were recorded these being highest on consent (Cramer's  $V = 0.97$ ,  $p = 0.00$ ).

However, the results point to a weak association between participation and benefitting from the projects ( $X^2(1) = 4.11$ ,  $p = 0.00$ ) further supported by a Cramer's  $V$  of 0.15. Ironically, more respondents (50.5% or 52 out of 103) reported to have benefited from

the projects without participating compared to 35.1% (26 out of 74) who benefitted from direct participation. The project, therefore, had an impact beyond those who were directly reached out to as information about projects also filtered to those who did not directly participate. The data above also highlights some inconsistencies that suggest limited information on the part of the respondents. Specifically, 71 out of 74 reported that they had received and signed consent forms that provided them with research projects' adequate background. This is despite 19 out of 74 stating that they did not know of the projects' research aims. The above data highlights the following patterns: Involvement without critical full information (aims, activities, identities, sites of the projects); Poor understanding of the research consent process among the participants and consequentially low benefits from involvement/participation.

### 3.4. The association between information and demographic groups

There were no statistically significant associations between the question – *Can you list the aims of the research project?* and the variables gender, age, level of education, village and the number of years one had stayed in the surveyed community. The same applied to the association between the question *Did you participate in the projects?* And the above variables.

There was also no statistically significant association between benefitting from the projects and the variables age, level of education, village and the number of years one had stayed in the surveyed community. Persons of different genders however benefitted differently from the projects as shown by statistically significant  $X^2$  (see Table 6).

Females benefitted less (53 out of 133 or 39.8%) than males (56.8%). A Cramer's  $V$  of 0.148, however, indicates that this association was not very strong. The data in this subsection demonstrates an inclusive approach to community engagement by indicating that information and involvement in the projects were not centred towards specific demographic groups.

## 4. Discussion

The findings from this study show varying dynamics in the respondent's levels of information and involvement in MABISA/TIBA projects. From the sample, 52.4% of the 339 respondents indicated that they were informed of the projects, 21.9% participated in them and 6% were consulted for feedback as illustrated in Figure 2.

More respondents benefitted from the projects than those who participated. Nonetheless, the data showed an inverted pyramid pattern where fewer respondents progress to the next advanced participation phases. A 52.4% project awareness rate, however, could be justifiable considering the rural nature of the communities involved. The conversion from being an informed person to a participant highlights potential challenges in getting communities involved in the projects. Such limited interest to participate highlights engagement challenges that include, among other things, feeling marginalized, and failure to identify with research and project purposes and methods among others (34).

TABLE 5 Informing and involvement and participation.

Statement/ Question	Response	C16 Did you participate in the project?			X <sup>2</sup>		Cramer's V	
		No	Yes	Total	Stat	Sig.	Stat	Sig.
C5 Do you know the research activities conducted by MABISA/TIBA projects?	No	61	22	81				
	Yes	42	52	94				
	Total	103	74	177				
C7 Do you know the project's research sites?	No	99	54	153	19.68	0.00	0.33	0.00
	Yes	4	20	24				
	Total	103	74	177				
C8 Can you list the aims of the research project?	No	101	55	156	23.2	0.00	3.62	0.00
	Yes	2	19	21				
	Total	103	74	177				
C12 Have you met the MABISA/TIBA researchers?	No	74	5	79	73.8	0.00	0.65	0.00
	Yes	29	69	98				
	Total	103	74	177				
C14 Can you list the names of the research team?	No	86	41	127	16.8	0.00	0.31	0.00
	Yes	17	33	50				
	Total	103	74	177				
C18 Did you sign the consent form before you participated in the research project?	No	103	3	106	165.02	0.00	0.97	0.00
	Yes	0	71	71				
	Total	103	74	177				
C20 Did you get enough background information about the project from the consent form?	No	103	3	106	165.02	0.00	0.97	0.00
	Yes	0	71	71				
	Total	103	74	177				
Benefitted	No	51	48	99	4.11	0.04	0.15	0.04
	Yes	52	26	78				
	Total	103	74	177				

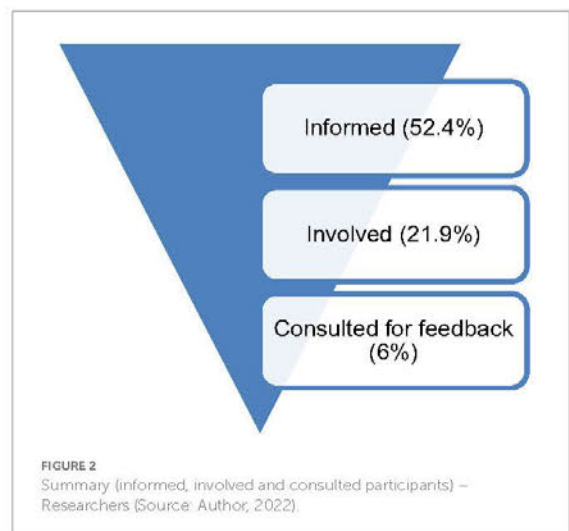
The bold values are the total of respondents who participated in the projects.

TABLE 6 Association between gender and benefits from the projects.

		X <sup>2</sup>		Cramer's V			
		Stat	Sig.	Stat	Sig.		
	Benefitted						
	No	Yes	Total				
Female	80	53	133				
Male	19	25	44				
Total	99	78	177				

### 4.1. Informing

The study identified two major levels of public information involved in the projects. The first was to inform whole communities of the projects' existence. The second level involved informing part of the communities that chose to participate in the research. The data shows that the five communities that took part in the research



exhibited poor levels of information about the projects on both levels. Approximately half of the respondents had never heard of the projects.

Among those who had heard about the projects and chose to participate, there were critical information asymmetries between the researchers and the participants on what the project was about, where it was based, who their researcher was and what activities it involved (35). These are considered key aspects that define research, yet they remain unknown to respondents. One of the major activities and tools used to inform communities about research is the consenting process, regularly done through the handing over and signing of a consent form. Almost all participants went through this. While that process provided all the required project background it failed to have the desired impact on the researched communities. Lack of knowledge cannot be blamed for the poor understanding of the projects' aims, as there were no statistically significant differences in this regard.

The consent issues raised above highlight possibilities of poor understanding of the consenting process among research respondents (36). The University of California, San Diego Brief Assessment of Capacity to Consent Questionnaire (UBACC) is one of the reliable and validated tool that can be used routinely to assess individuals' capacity to consent to a research protocol and improve understanding of research study through iterative learning (37). The UBACC is designed to assist researchers in identifying study participants who require a more comprehensive decisional capacity assessment and/or remedial efforts prior to enrolment (37). If individuals are assessed using the UBACC, it provides more certainty that they are informed about what they are enrolling for. This is particularly important given some risks of health research. Research respondents may agree to participate in a study without knowing or rigorously looking at its pertinent details. Procedural weaknesses particularly the handing over of a consent form together with the questionnaire for immediate filling can also deny respondents the chance to fully grasp what they are consenting to Ref. (36). Relatable findings were also made in the study on how rural community respondents fail to recall the contents of consent forms (38). In the study that was conducted in rural KwaZulu-Natal, some respondents had participated in projects under the belief that they would materially benefit from them. The process of getting meaningful consent to clinical research participation may be hampered by therapeutic misconception, which occurs when research subjects fail to appreciate the distinction between the imperatives of clinical research and ordinary treatment, and therefore inaccurately attributes therapeutic intent to research procedures (39). A study demonstrated that therapeutic misconception occurs in the South African oncology research setting and has the potential to lead to underestimating of the risks of a Phase 3 clinical trial. Therefore, it is vital to emphasise the experimental nature of a clinical trial throughout the consent process in order to overcome therapeutic misconceptions in oncology research (40). Another South African study on the ethical challenges in obtaining informed consent for genomic research in general and the implications of recruiting healthy controls for genomic research in particular discovered that diagnostic and therapeutic misconceptions were the main challenges (41). In terms of informed participation, this creates a risk of a sample that is not fully involved in a study due to information asymmetries between the researcher and the research targets (42). Such targets, reveal vulnerabilities that the researchers must consider during the research process (43).

The linkage of consent challenges to the quality of participation has previously been explored (44). Passive participation occurs when respondents consent to research they may not fully understand, either lack of knowledge or out of being poorly oriented by the researcher. Passive participation is also common when passive consent approaches are applied in research (45). In this study, the enigma is that the respondents asserted that they participated voluntarily and were fully informed of the research background, yet they were unable to identify the researchers, the research aims and sites. Therefore, before consenting to research studies, potential participants should be informed about research objectives, procedures, and benefits and risks to minimise diagnostic and therapeutic misconceptions (41). Before enrolling participants in research studies, researchers must assess their familiarity of scientific jargon and concepts. Research team recruiting potential study participants must be innovative and ethical during the process. Researchers must be able to adapt consent processes to the recruitment setting to help potential study participants make informed decisions (39–41).

## 4.2. Consultation

We found some evidence of consultative processes. Twenty-five-point seven percent (25.7%) of the respondents who participated in the projects were consulted for feedback relating to the projects. Further to that, the largest percentage of respondents had heard about the projects from community caregivers. Community meetings were also another form of public consultation discussed in the projects. However, the overall data suggests that such consultative practices, despite being procedural might not have resulted in quality information output as the consulted groups mostly indicated lack of knowledge about the projects (aims, identity, activities, researchers and sites). Furthermore, the respondents did not list consultative processes as an ongoing research activity like the surveys they listed. This also suggests that the consultation processes were for post-evaluation processes (46) posit that community consultations in research projects were a basis for the creation of mutually beneficial and more productive engagements between researchers and communities. Such consultations span include methodological and content processes that can enhance the attainment of project goals (46). Consultation is a form of involvement that supports the co-creation of projects and wider participation of marginal and disadvantaged groups and communities that may otherwise be excluded from research institutions (34). This view applies to the five remote communities studied. Consultative processes help to clear up such misconceptions, thereby improving the quality of health research interventions. Poverty and unemployment in remote rural communities have been found to have a strong influence on how research participants misinterpret outside researchers as potential sources of various material benefits (38). Consultative processes iron out such misconceptions enhancing the quality of health research interventions.

## 4.3. Involvement

Defining involvement from the Community Engagement Vancouver Coastal Health framework there is evidence of limited

public involvement from the results. This is highlighted in the majority of the respondents' failure to identify the project, specifically, its project sites and researchers. As expected, community engagement efforts generally result in the availing of such information to the research subjects. While the majority of the respondents who participated in the study acknowledged meeting the researchers, the failure to identify them suggests limited engagement. Limited engagement disempowers communities and limits their contribution, as well as benefits, from health projects (46).

#### 4.4. Collaboration and empowerment

In the study, there is not much discussion on research collaboration between the researchers and the communities. As highlighted, community members were primarily the participants for surveys, beneficiaries of awareness programmes, and test subjects for medical examinations and screenings. A small fraction did give its feedback to the researchers as discussed earlier. Thus, according to the Community Engagement Vancouver Coastal Health framework, the research projects may be discussed as reaching the informed and involved stages. The advantages of community empowerment in research include more active and wider participation that supports desired behavioural change (47). Such benefits might have been missed by the research.

Tests of associations attempted to find relationships between information and involvement (participation) and demographic data. As indicated in Figure 3, the first dimension affecting participation consists of intrapersonal factors (48).

From the projects, the pattern of being poorly informed and less keen on participation was common among respondents of different ages, genders and levels of education. This points to the limited dominance of intrapersonal factors in the participation processes (48). This suggests that interpersonal and institutional factors may be more responsible for low information and low participation in the projects. At the same time, however, some respondents did signify that despite being engaged and informed, they had forgotten what the projects

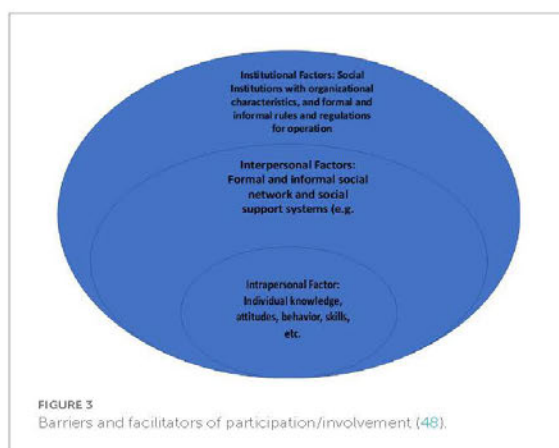
were all about, pointing to some intrapersonal limitations affecting information and involvement as well. In the conceptual model presented above in Figure 3, this could indicate knowledge retention and cognitive issues or even attitudinal issues that affect participation levels (48).

The same study by Bay et al. (48) also points to the importance of formal and informal social networks in research participation – similar to this study. Participation through social networks was mostly evident in the number of respondents who benefitted from the research projects without directly being part of them – mainly through information flows. Parents indicated benefiting from the projects through their schoolchildren whom they consented to participate. Other respondents noted that they only knew about the projects from neighbours and family. This shows a strong interpersonal component in participation.

#### 4.5. The study's proposed framework

We propose using a hybrid framework the Community Engagement Vancouver Coastal Health framework and Bay et al.'s (48) conceptual framework on factors that affected individual and community participation in health projects (see Table 7) below.

The framework highlights a need to engage communities more meaningfully in research through effectively informing, consulting, involving and empowering processes. Our study found that the communities were mostly informed and involved but were not fully consulted and not empowered. To empower communities, projects should consider the intrapersonal and personal factors affecting community capacity to fully benefit from the information, consultation, involvement, and empowerment processes. In our study, poor understanding of the project was suggested to be a result of both intrapersonal issues – for example, respondents stated that they were involved in the project but did not understand or had forgotten what it was about. Intrapersonal factors came out as important in the dissemination of information about the project. Health research institutions had the role to develop research methods and processes that took into consideration the intrapersonal and interpersonal characteristics of the communities involved.



#### 5. Limitations

A CE strategy that fully engages the community is limited by community research literacy levels, time, and resources, but creates an environment conducive for research. The time lapse between when participants participated in the MABISA and TIBA-SA research projects have impacted their collection of details such as researcher's names and particulars about the study. This paper currently does not address how the community was "empowered," because measuring community empowerment may be difficult. The CE framework that forms the foundation for the study is Canadian. Apart from extensive literature in CE, there is a dearth of empirical research conducted using the Community Engagement Vancouver Coastal Health framework in a South African context. Therefore, this framework may not be generalised to apply to all studies conducted in South Africa, but it can be transferrable to communities in similar contexts seeking to strengthen the process of how researchers truly engage communities. Factors that contributed to limited dissemination of

TABLE 7 The engagement-empowerment framework (Researchers).

		Levels of engagement		
		Intrapersonal	Interpersonal	Institutional
Levels of participation and decision-making	Inform	Individual characteristics and understanding	Group characteristics and understanding	Institutional systems and processes to support intrapersonal and interpersonal information
	Consult	Consult individuals based on their nature and understanding of the project	Consult unique groups and niches based on their nature and understanding of the project	Institutional systems and processes to support individual and group consultation
	Involve	Involve individuals based on their nature and understanding of the project and consultation outcomes	Involve groups based on their nature and understanding of the project and consultation outcomes	Institutional systems and processes to support individual and group consultation
	Empower	Empower individuals to effectively make decisions about the project processes based on their personal capacities	Empower groups to effectively make decisions about the project processes based on identified group characteristics	Develop institutional systems and processes to support individual and group decision-making and control of projects

findings to the community are varied including but not limited to inadequate funding to produce materials in vernacular languages, incomplete data sets for developing adaptation strategies, limited engagement with other partners like NGOs and in adequate knowledge on communities' preferred channels for dissemination. It is important that the findings of the study are adequately and effectively disseminated within the community and are applied to reduce vulnerability of the communities to diseases.

## 6. Conclusion

Overall, the findings indicate that participants had limited knowledge of the two projects in which they had participated in, as well as an approach to the projects that was researcher-driven and community-responsive. While the researchers endeavoured to inform almost all the participants, critical information asymmetries exist in

the community's understanding of research project activities, aims, sites and identities. This is despite some respondents being asked to provide feedback on the projects. The findings also show evidence of the interaction of multi-level factors affecting effective participation (information, consultation and involvement) in community research projects. Individual-level factors affected knowledge retention while interpersonal factors played a role in information dissemination creating risks that poorly connected respondents might be left out. The institutional level – consisting of the researchers, their systems and processes exhibit challenges in informing the wider communities about the projects (noting the rural nature of the communities), weaknesses in converting community members with project knowledge into active participants, enhancing consultative processes beyond feedback mechanism systems and most importantly a questionably managed consent process where respondents appeared to consent to something they did not fully understand. Nonetheless, the communities recorded benefits that included learning and being tested for Schistosomiasis and Malaria among other things. Such benefits were also appreciated by community members who had not directly participated in the projects highlighting the project's potential in disseminating information deeper into communities.

In addition to the framework discussed in Table 7, we recommend the following approaches: First, the projects needed to streamline consent processes to ensure that community members know the projects' aims, identities and activities. Second, the projects needed to widen their outreach by utilising informal communication systems and social networks as information and involvement drivers. Third, the projects' participation systems needed to consider cognitive challenges among participants through information aids that enhanced both the understanding and remembering of information disseminated to participants. Finally, the projects needed to follow more community-engaging approaches. Community empowerment through consulting participants on the methods, processes and activities to include for improving the projects has the potential to improve participant interest, knowledge and understanding of the projects.

## Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## Ethics statement

The studies involving human participants were reviewed and approved by Humanities and Social Sciences Research Ethics Committee. The patients/participants provided their written informed consent to participate in this study.

## Author contributions

ZM led all aspects of the paper's development from conceptualization and designing the study, data collection, analysis, and reporting. MC guided the process of manuscript writing and critically reviewed and edited all drafts of the manuscript. All authors contributed to the article and approved the submitted version.

## Funding

This study was supported by the National Research Foundation (NRF) (grant number: 116263) through my supervisor (MC) from the University of KwaZulu-Natal, College of Health Sciences.

## Acknowledgments

The authors acknowledged all respondents, KEP researchers, CRAs, uMkhanyakude district health office, Ingwavuma area community leaders and uMkhanyakude communities who contributed to this study. Without their support this project would not have been possible.

## References

- Eisinger A, Senturia K. Doing community-driven research: a description of Seattle Partners for Healthy Communities. *J Urban Health*. (2001) 78:519–34. doi: 10.1093/urban/78.3.519
- Firestone J, Hoen B, Rand J, Elliott D, Hübner G, Pohl J. Reconsidering barriers to wind power projects: community engagement, developer transparency and place. *J Environ Policy Plan*. (2018) 20:370–86. doi: 10.1080/1523908X.2017.1418656
- Adhikari B, Pell C, Cheah PY. Community engagement and ethical global health research. *Glob Bioeth*. (2020) 31:1–12. doi: 10.1080/11287462.2019.1703504
- Di Napoli I, Dolce P, Arcidiacono C. Community trust: a social indicator related to community engagement. *Soc Indic Res*. (2019) 145:551–79. doi: 10.1007/s11205-019-02114-y
- Organization WH. *WHO community engagement framework for quality, people-centred and resilient health services*. Geneva: World Health Organization (2017). (WHO/HIS/SDS/2017.15). Licence: CC BY-NC-SA 3.0 IGO.
- Chen J, Mullins CD, Novak P, Thomas SB. Personalized strategies to activate and empower patients in health care and reduce health disparities. *Health Educ Behav*. (2016) 43:25–34. doi: 10.1177/1090198115579415
- Dodson S, Good S, Osborne R. Health literacy toolkit for low and middle-income countries: a series of information sheets to empower communities and strengthen health systems. (2015).
- Jagosh J, Pluye P, Macaulay AC, Salsberg J, Henderson J, Sirett E, et al. Assessing the outcomes of participatory research: protocol for identifying, selecting, appraising and synthesizing the literature for realist review. *Implement Sci*. (2011) 6:1–8. doi: 10.1186/1748-5908-6-24
- Burnette CE, Sanders S. Trust development in research with indigenous communities in the United States. *Qual Rep*. (2014) 19:1–19. doi: 10.46743/2160-3715/2014.1223
- Corbie-Smith G, Thomas SB, Williams MV, Moody-Ayers S. Attitudes and beliefs of African Americans toward participation in medical research. *J Gen Intern Med*. (1999) 14:537–46. doi: 10.1046/j.1525-1497.1999.07048.x
- Onyumba T, Wilson K, Derrick CJ, Mukherjee N. The use of focus group discussion methodology: insights from two decades of application in conservation. *Methods Ecol Evol*. (2018) 9:20–32. doi: 10.1111/2041-210X.12860
- Tembo D, Hickey G, Montenegro C, Chandler D, Nelson E, Porter K, et al. Effective engagement and involvement with community stakeholders in the co-production of global health research. *BMJ*. (2021):372. doi: 10.1136/bmj.n178
- George MA, Daniel M, Green LW. Appraising and funding participatory research in health promotion. *Int Q Community Health Educ*. (1998) 18:181–97. doi: 10.2190/C1B5-7PPE-7TYL-7YN8
- O'Fallon LR, Deary A. Community-based participatory research as a tool to advance environmental health sciences. *Environ Health Perspect*. (2002) 110:155–9. doi: 10.1289/ehp.02110s2155
- Molyneux S, Bull S. Consent and community engagement in diverse research contexts: reviewing and developing research and practice: participants in the community engagement and consent workshop, Kilifi, Kenya. *J Empir Res Hum Res Ethics*. (2013) 8:1–18. Consent and Community Engagement in Diverse Research Contexts: Reviewing and Developing Research and Practice. doi: 10.1525/jer.2013.8.4.1
- Grumbach K, Cottler LB, Brown J, LeSarre M, Gonzalez-Fisher RE, Williams CD, et al. It should not require a pandemic to make community engagement in research leadership essential, not optional. *J Clin Transl Sci*. (2021) 5:e95. doi: 10.1017/cts.2021.8
- Bracic A. For better science: the benefits of community engagement in research. *PS Polit Sci Polit*. (2018) 51:550–3. doi: 10.1017/S1049096518000446

## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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- Head BW. Community engagement: participation on whose terms? *Aust J Polit Sci*. (2007) 42:441–54. doi: 10.1080/10361140701513570
- Chimbari MJ. Lessons from implementation of ecohealth projects in southern Africa: a principal investigator's perspective. *Acta Trop*. (2017) 175:9–19. doi: 10.1016/j.actatropica.2016.09.028
- Stats SA. *Statistics South Africa. Form Census*. (2011). Available at: [https://www.statssa.gov.za/?page\\_id=3839](https://www.statssa.gov.za/?page_id=3839) (Accessed May 2023).
- Museengwa R, Chimbari MJ, Mukaratirwa S. Initiating community engagement in an ecohealth research project in southern Africa. *Infect Dis Poverty*. (2017) 6:22. doi: 10.1186/s40249-016-0231-9
- Is KLAI. *Developing community-based primary health Care for Complex and Vulnerable Populations in the Vancouver coastal health region: Health Connection Clinic*. *Perm J*. (2018) 22:18–010. doi: 10.7812/TPP/18-010
- Lillies B. *A model for practice change: seniors fall & injury prevention initiative Vancouver coastal health authority*. Ph.D. Thesis, Royal Roads University. (2008).
- Phipps GA. *Developing mentorship programs within Vancouver coastal health*. Ph.D. Thesis, Royal Roads University. (2008).
- Jorgensen V, Ritson M, Tam G. Cantonese-style barbecue meat food safety in Vancouver coastal health. *Environ Health Rev*. (2019) 62:112–20. doi: 10.5864/d2019-025
- Shukor AR, Edelman S, Brown D, Rivard C. *Developing community-based primary health care for complex and vulnerable populations in the Vancouver coastal health region: HealthConnection clinic*. *Perm J*. (2018) 22:22. doi: 10.7812/TPP/18-010
- Engage Vancouver Coastal Health [Internet]. Engage Vancouver coastal health. Available at: <https://engagevch.ca/engagementhq.com/projects> (Accessed Feb 19, 2023).
- Arnstein SR. A ladder of citizen participation. *J Am Plan Assoc*. (2019) 85:24–34. doi: 10.1080/01944363.2018.1559388
- Hoffmeyer-Zlotnik JH. New sampling designs and the quality of data. *Dev Appl Stat*. (2003) 19:205–17.
- Morse JM. *Determining sample size In: Qualitative health research*, vol. 10. Thousand Oaks, CA: Sage Publications Sage CA (2000). 3–5.
- Bauer JJ. Selection errors of random route samples. *Sociol Methods Res*. (2014) 43:519–44. doi: 10.1177/0049124114521150
- Palla F, Le Bel S, Chavernac D, Cornéls D. New technologies: mobile data collection system implication for wildlife management in Central Africa. (2016).
- Akogh H. User's guide to correlation coefficients. *Turk J Emerg Med*. (2018) 18:91–3. doi: 10.1016/j.tjem.2018.08.001
- Pratt B, de Vries J. Community engagement in global health research that advances health equity. *Bioethics*. (2018) 32:454–63. doi: 10.1111/bioe.12465
- Kumar R. *Research methodology: a step-by-step guide for beginners*. Sage. (2018). 1–528.
- Nayak M, Narayan KA. Strengths and weaknesses of online surveys. *Technology*. (2019) 6:0837–2405053138. doi: 10.9790/0837-2405053138
- Jeste DV, Palmer BW, Appelbaum PS, Golshan S, Glorioso D, Dunn LB, et al. A new brief instrument for assessing decisional capacity for clinical research. *Arch Gen Psychiatry*. (2007) 64:966–74. doi: 10.1001/archpsyc.64.8.966
- Ngwenya N, Luthuli M, Gunda R, Gumede NA, Adeagbo O, Nkosi B, et al. Participant understanding of informed consent in a multidisease community-based

- health screening and biobank platform in rural South Africa. *Int Health*. (2020) 12:560–6. doi: 10.1093/inthealth/ihaa072
39. Appelbaum PS, Anatchkova M, Albert K, Dunn LB, Lidz CW. Therapeutic misconception in research subjects: development and validation of a measure. *Clin Trials Lond Engl*. (2012) 9:748–61. doi: 10.1177/1740774512456455
40. Malan T, Moodley K. Phase 3 oncology clinical trials in South Africa: experimentation or therapeutic misconception? *J Empir Res Hum Res Ethics*. (2016) 11:47–56. doi: 10.1177/1556264616637736
41. Mashe E, Mayosi B, de Vries J. "I passed the test?" evidence of diagnostic misconception in the recruitment of population controls for an H3Africa genomic study in Cape Town, south Africa. *BMC Med Ethics*. (2017) 18:12. doi: 10.1186/s12910-017-0175-z
42. Dekking SA, van der Graaf R, van Delden JJ. Strengths and weaknesses of guideline approaches to safeguard voluntary informed consent of patients within a dependent relationship. *BMC Med*. (2014) 12:1–11. doi: 10.1186/1741-7015-12-52
43. Adhikari B, Vincent R, Wong G, Duddy C, Richardson E, Lavery JV, et al. A realist review of community engagement with health research. *Wellcome Open Res*. (2019) 4:87. doi: 10.12688/wellcomeopenres.15298.2
44. Steinsbekk KS, Kåre Myskja B, Solberg B. Broad consent versus dynamic consent in biobank research: is passive participation an ethical problem? *Eur J Hum Genet*. (2013) 21:897–902. doi: 10.1038/ejhg.2012.282
45. Solberg B, Eikemo H. Passive consent for passive participation? *Tidsskr Den nor Legeforening*. (2021).
46. Reynolds L, Sariola S. *The ethics and politics of community engagement in global health research*. Vol. 28, London, UK: Critical Public Health. Taylor & Francis. (2018). p. 257–268.
47. Egan M, Abba K, Barnes A, Collins M, McGowan V, Ponsford R, et al. Building collective control and improving health through a place-based community empowerment initiative: qualitative evidence from communities seeking agency over their built environment. *Crit Public Health*. (2021) 31:268–79. doi: 10.1080/09581596.2020.1851654
48. Bay AA, Prizer L, Orusa A, Hart AR, Perkins MM, Hackney ME. Effects of a health education and research participation enhancement program on participation and autonomy in diverse older adults. *Gerontol Geriatr Med*. (2020) 6:2333721420924952. doi: 10.1177/2333721420924952

Through the lenses of researchers and that of communities Chapters 2 and 3 demonstrated how researchers involved community stakeholders in health research-based projects on schistosomiasis and malaria during the informing, involving, and consulting stages of CE. The findings detailed the level of consultation, the extent to which the community was involved and empowered in schistosomiasis and malaria research projects implemented in Ingwavuma as well as nature and level of empowerment. These two chapters did not discuss the extent of collaboration between the community and researchers that had and were ongoing at the time of the study in Ingwavuma. Chapter 4 describes and discusses how researchers and community stakeholders collaborated on research initiatives on malaria and schistosomiasis in Ingwavuma, uMkhanyakude District, KwaZulu-Natal.

## **CHAPTER 4**

### **COLLABORATION BETWEEN RESEARCHERS AND COMMUNITY STAKEHOLDERS FOR RESEARCH PROJECTS ON SCHISTOSOMIASIS AND MALARIA IN INGWAVUMA UMKHANYAKUDE DISTRICT, KWAZULU-NATAL**

*Under review: Humanities & Social Sciences Communications*

# **Community engagement and collaboration between researchers and community stakeholders for schistosomiasis and malaria projects in Ingwavuma, uMkhanyakude District, KwaZulu-Natal**

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## **Abstract**

Community engagement involves five phases: informing, consulting, involvement, collaboration, and empowerment. This study explored the experiences of community stakeholders during the collaborative phase of community engagement co-developed by researchers and community members for the implementation of projects. The study was carried out in uMkhanyakude District, South Africa. A qualitative case study approach was used to explore the collaboration phase. Data was collected from key community stakeholders through key informant interviews, focus group discussions, and direct observations. The findings indicated that village headmen, community advisory board members and community research assistants can collaborate as trustworthy partners to address community health challenges. Community research assistants complement the role of participatory-based research appropriately, as they get to be involved hands-on together with the researchers. However, despite the significant role community research assistants played in the projects implemented by the KwaZulu-Natal Ecohealth Program, maintaining collaborative relationships was marred with unforeseen difficulties due to many barriers which included stretched work hours, lack of breaks, miscommunication around compensation, inappropriate behavior from the research team, and humiliation/oppression over language. Initiatives for community-based participatory research have proven to be effective as a collaborative approach that combines methodical research, involvement, and action to address health-related problems. However, it is necessary to consider the local socio-cultural aspects that could lead to barriers and misunderstandings between the locals and the researchers. Collaborative partnerships should ultimately result in community empowerment.

**Keywords:** community engagement; collaboration; KEP researchers; headmen; community advisory boards

## Introduction

Community engagement (CE) on health issues is more than community participation. It is a process of developing relationships that enable stakeholders to work together to address health-related issues and promote well-being to achieve positive health impact and outcomes (World Health Organisation, 2020; World Health Organization, 2017). CE is also defined as a process of working collaboratively with groups of people who are affiliated by geographic proximity, special interests, or similar situations, with respect to issues affecting their well-being (McCloskey et al., n.d). Therefore, successful community engagement requires goals that are based on community needs, beliefs, and values; external financial and technical resources; women's involvement; and positive relationships between the community and professionals/researchers (Putranto et al., 2022).

However, quite often some community partners rely on researchers to address their problems. This may present challenges related to ethics, trust, and cultural sensitivity. Many projects fail due to the non-involvement of community stakeholders which causes a lack of basic knowledge about the project and communities become a bit more docile and apathetic (Ashade & Mutereko, 2021). Engagement and collaboration between researchers and community stakeholders is crucial for the success of projects as researchers can gain valuable insights, local knowledge and support that can enhance the effectiveness and impact of their interventions (Rakhra et al., 2022). Hence a critical engagement method is preferred to improve collaboration in engagement projects (Sathorar & Geduld, 2021). This critical engagement method resides in a critical theory paradigm that enables the researcher to examine a social phenomenon and establish what is wrong and who can solve it in bringing about change in society (Flick, 2022). This concept advocates for social justice and equality.

Building formal partnerships for frequent collaborative work between rural communities and researchers can be difficult. On the other hand, engaging the community to participate in projects is particularly challenging due to the nature of projects with complex methodologies such as conservation which is a type of work that requires specific skills, a lengthy experience, particular infrastructures, and arguably extensive time and money (Putranto et al., 2022). The collaborative arrangements therefore require the pooling of various resources, knowledge and expertise (Ashade & Mutereko, 2022). In this context, the term 'collaboration' is an active relationship between the community and academic investigators on funded research. WHO (2020) defines collaboration as partnering with the community in each aspect of the decision-making process, including the development of alternatives and the identification and delivery of the preferred solution. These definitions are close to those of Ansell and Gash (2007, cited in Ashade & Mutereko, 2022:236) who define collaboration in relation to governance *“as a governing arrangement where one or more public agencies directly engage non-state stakeholders in a collective decision-making process that is formal, consensus-oriented, and*

*deliberative and that aims to make or implement public policy or management public programs or assets.”*

In collaborative partnerships, challenges are mostly observed in the academic research process as well as in fulfilling research roles and issues of rurality and culture (Cramer et al., 2018). However, a collaboration between researchers and community members, many of whom benefit from the research, and involving community partners in every stage of the study is essential for the success of community-based participatory research (CBPR) (Musesengwa & Chimbari, 2017). Ashade and Mutereko (2021) study revealed that communities that are not actively involved in the initial stage of the project can create a high rate of resentment, suspicion and conflict during implementation. This means that community stakeholders may lack trust and be skeptical of the project initiatives and outcomes, and this may also hinder effective collaboration and community engagement. It is well recognised that CBPR is a part of the ongoing social research initiative to move beyond disciplinary borders and towards interdisciplinary collaborations (Mosavel et al., 2005). Health researchers and practitioners have used CBPR to address health inequities and community empowerment for health promotion (Salimi et al., 2012). Various limitations such as budget, deliverables, and milestones set with funders and project investigators can affect how and to what extent these collaborations can be implemented in practice (Polidano et al., 2022). There are concerns regarding top-down methodologies used by researchers while conducting research projects in rural settings, as well as the lack of community collaboration and involvement in studies intended to improve their circumstances (Gilmore et al., 2020).

In community collaboration, many things are taken for granted such as knowledge, know-how and methods to use. This is likely to occur in terms of social status and power relations between researchers and community members, which could also potentially harm these relationships (Polidano et al., 2022). For instance, it should not be assumed that power structures might not impede community engagement and collaborative relationships. Although hierarchies between researchers and communities can be broken down, research project decisions can be democratic, and community expectations can be fulfilled (Polidano et al., 2022). There is limited empirical evidence regarding the factors that contribute to the success of CE in biomedical research (Tindana et al., 2011). Little is known about how communities in rural settings collaborate on research projects. Previous research has suggested in order to establish effective policies concerning vector-borne diseases, there must be a collaboration between multiple agencies and communities at risk (Naserrudin et al., 2022). Furthermore, these authors argued that further evidence through research is needed in the form of reflections from researchers and community members engaging in participatory approaches (Naserrudin et al., 2022). Therefore, this article presents the experiences of community stakeholders who partnered with KwaZulu-Natal Ecohealth Program (KEP) researchers to plan and execute research projects intended to reduce the burden of schistosomiasis and malaria. The article may be useful to researchers and

community members who are interested in forming, sustaining, and enhancing collaborative partnerships with community members for the purpose of research to address priority community concerns through community-based participatory research.

## Methods

### *Theoretical framework*

As shown in **Table 1**, this paper is based on a CE framework comprised of 1) a community-oriented approach 2) a community-based approach 3) a community-managed approach 4) a community-owned approach in line with the Community Engagement Vancouver Coastal Health framework ([www.vch.ca/ce](http://www.vch.ca/ce)). The stages include 1) Informing the community, 2) Consulting the community, 3) Involving the community, 4) Collaborating with the community and 5) Empowering the community.

**Table 1.** Approaches to community engagement. Adapted from World Health Organization (2020).

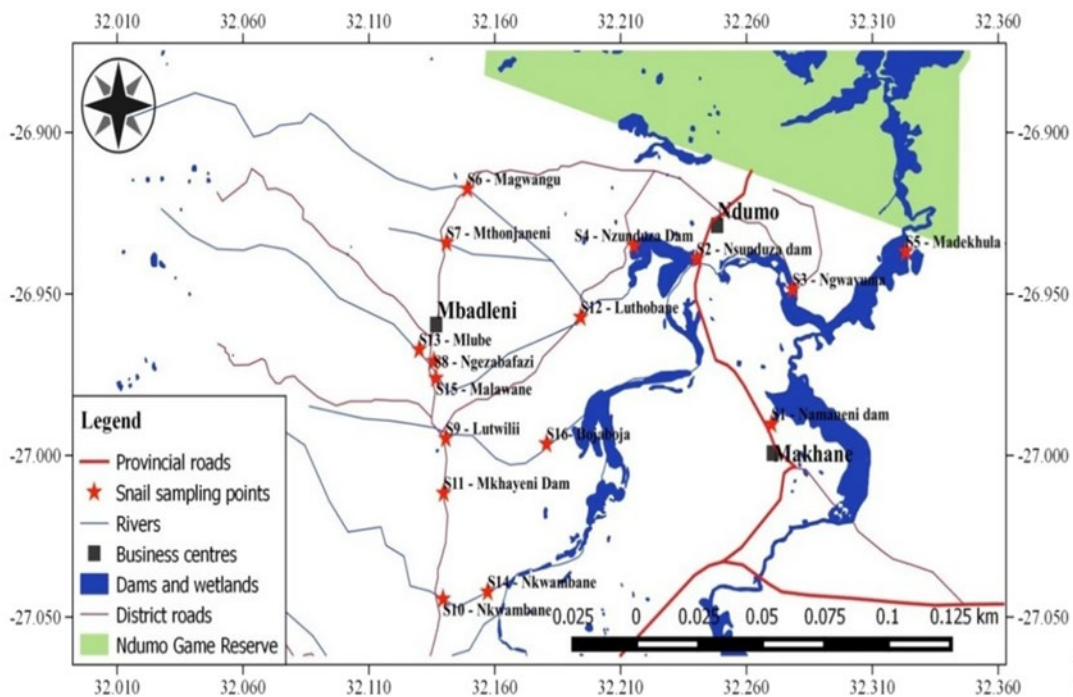
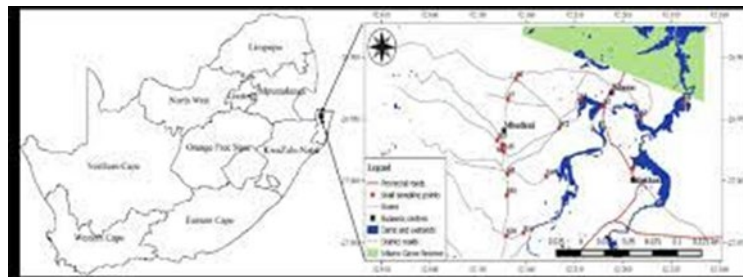
<b>Level 1</b>	<b>Level 2</b>	<b>Level 3</b>	<b>Level 4</b>
<b>Community-oriented approach</b>	<b>Community-based approach</b>	<b>Community-managed approach</b>	<b>Community-owned approach</b>
The community is <i>informed</i> and mobilized to participate in addressing immediate short-term concerns with external support.	The community is <i>consulted</i> and <i>involved</i> to improve access to health services and programmes by locating interventions inside the community with external support.	There is a <i>collaboration</i> with leaders of the community to enable priority settings and decisions from the people themselves with or without external support.	Community assets are fully mobilised, and the community is <i>empowered</i> to develop systems for self-governance, establish and set priorities, implement interventions and develop a sustainable mechanism for health promotion with partners and external support groups as part of a network.

Using this framework, we actively engaged the community at various levels of participation, ranging from informing, consulting and involving to collaborating and empowering, ensuring that everyone had a voice and a role to play in the project. The Vancouver framework emphasizes the importance of community engagement, highlighting the value of public participation and the right for everyone to have a voice in decisions that impact their healthcare (Mthembu & Chimbari, 2023).

### *Study setting*

The study was conducted in five villages (Ndumo, Mbadleni, Mgedula, Madeya and Makhane) in the Ingwavuma area of uMkhanyakude District, the second largest District in the KwaZulu-Natal province, South Africa. This underdeveloped area is near the Ndumo game reserve and shares a border with

Mozambique and Swaziland. This area has relatively little infrastructure; the road system is currently being developed, and most of the area is only accessible by gravel roads. Schools in the villages are widely spaced and provide the barest necessities, with the majority lacking access to running water. The town of Ingwavuma is located in a low-lying area that is characterized by hot temperatures, still and slowly moving water bodies, and low humidity (Africa, n.d.). Due to its geographic location, the area is vulnerable to vector-borne diseases (VBD), particularly schistosomiasis (bilharzia) and malaria. The area, which is endemic to many diseases and has poor levels of education is plagued by poverty (Africa, n.d.). These issues suggest that a broad and inclusive approach to community health education is required in this area. The study area is served by Mosvold, a district hospital, which also oversees two clinics (Mbandleni and Ndumo) that are part of Jozini Municipality. The five villages involved in MABISA research are depicted on the map (**Figure 1**) as having numerous primary schools nearby.





**Figure 1.** Map showing the MABISA study area in Ndumo, uMkhanyakude: Adapted from (Manyangadze et al., 2016).

### *The KwaZulu-Natal Ecohealth Program (KEP) overview*

The KwaZulu-Natal Ecohealth Program (KEP) has been working in Ingwavuma since 2014 when the MABISA (Malaria and Bilharzia in Southern Africa) project was initiated. The KEP conducted research projects, in uMkhanyakude, intended to lessen the impact of these VBDs. Previously KEP initiatives in the area included MABISA and TIBA-SA (Tackling Infections to Benefit Africa-South Africa) projects, which started in 2014. These two projects focused on bilharzia and malaria and adopted Ecohealth approaches. Key to KEP's success has been the establishment of a governance structure and operations strategy that involves the community to ensure that the community fully participates in MABISA/TIBA-SA projects. This was established during the first phase of CE, which is Informing phase (Mthembu and Chimbari, 2023). A 12-member Community Advisory Board (CAB) comprising one headman (induna), two community leaders, three school board members, three community caregivers and three ordinary community members was established at the inception of the MABISA project and is functional to date. The headmen (izinduna) are the elected gatekeepers with authority over villages and are accountable to the chiefs, the tribal council and their community (Musesengwa, Chimbari and Mukaratirwa, 2017). Throughout this paper, the term Ecohealth will be used, which commonly involves promoting the health of humans, animals and ecosystems, including environmental sustainability and socioeconomic stability and conducting research that acknowledges the inextricable connections between the health of all species and their environments (Lerner and Berg, 2017).

### *Design and sample*

A cross-sectional design embedded with a mixed-methods approach was employed using In-depth Interviews (IDIs), Focus Group Discussions (FGD) and Direct Observations (DO) to critically analyse the experiences of community stakeholders in collaborative partnerships on CE processes during the implementation of KEP projects. These three approaches are common methods used and are

appropriate, particularly in healthcare research (Cohen et al., 2002). It is advantageous to combine two or more qualitative methods for data collection as that allows complementarity and increases the trustworthiness of the study (Lambert & Loisel, 2008). A total of 4 FGDs and 34 participants for IDIs, comprising Community Research Assistants (CRAs), Community Advisory Board (CAB), headmen (who are members of the tribal council), Community Caregivers (CCGs) which are currently known as Community Health Workers (CHWs) and school principals, as indicated in (**Table 2**) were purposively selected and interviewed based on their involvement in CE activities and their knowledge about Ecohealth projects implemented in the study area. The existing relationship between the KEP and the community of Ingwavuma was used to select study participants. The authors identified possible important stakeholders using the stakeholder analysis matrix (SAM) method and categorised them into different segments according to their level of interest and influence to achieve the study objectives (Henjewe et al., 2013) (also see **Table 3**). FGDs consisted of 9 to 12 participants per group with a mix of genders and different age groups. There were no incentives or tokens (compensation) given to participants. FGDs and IDIs were conducted at Mosvold Hospital in Ingwavuma. The CAB and CRAs played a crucial role in promoting the concept of community change agents for the prevention and control of vector-borne diseases.

**Table 2.** Distribution of key informants and number of interviews conducted.

<b>Key Informants</b>	<b>In-depth Interviews (IDIs)</b>	<b>Focus Group Discussions (FGDs)</b>	<b>Total Number of Participants (IDIs and FGDs)</b>
Community Research Assistants (CRAs)	7	1 FGD = 8 participants (1 man, 7 women)	15
Community Advisory Boards (CABs)	6	1 FGD = 8 participants (3 men, 5 women)	14
Headmen	3	0	3
Community Health Workers (CHWs)	2	2 FGDs = 20 participants (6 men, 14 women)	22
School Principals	4	0	4
<b>TOTAL</b>	22	4	58

The researcher also used an observational protocol for recording participants' information (such as portraits, a description of physical settings, and accounts of particular events, or activities) while observing. The researcher's personal thoughts, including "speculation, feelings, issues, ideas, hunches, impressions, and prejudices," were also recorded through reflective notes (Creswell, 2014). Author 1 was an independent researcher who collected the data with the assistance of CRAs. The two authors (Author 1 & Author 2) led the CE evaluation of this paper, Author 1 was the second author's PhD student; Author 2 is the principal investigator of the KEP. Participants shared their experiences of

engagement activities during the implementation of projects and indicated the opportunities and challenges they encountered. Ethical clearance was granted for this study prior to data collection. Data collection took place between May and December 2021. Written consent was obtained from each individual who participated in this study. Interviews were conducted in isiZulu and later translated into English by Author 1. For IDIs that lasted between 40-60 minutes, a semi-structured interview guide was developed. With the participant's consent, the interviews were digitally recorded and/or notes written on paper.

Data analysis The Stakeholder Analysis Matrix was used to determine the best course of action for each key stakeholder who took part in the study (see **Table 3**). The recorded interviews were transcribed, and observational field notes were typed and organised, carefully read (getting a sense of the information and an opportunity to reflect on its overall meaning), and then coded into nodes for analysis using a computer-based software program (QSR International Pty Ltd, NVivo 12 Pro). Codes were created and then sorted into common themes. The codes were matched with the quotes associated with each theme based on similarities, differences, and meanings. Data interpretation was done through thematic analysis. This method was adopted in order to draw conclusions from the combination of data acquired from focus group discussions and in-depth interviews. Four broad themes derived from the thematic analysis are presented in detail in the results section.

## **Results**

The role of stakeholders in the collaboration phase of the project is given in Appendix 1. This includes details about each stakeholder and what role they played in the project since its inception. The following themes emerged from the thematic analysis. Theme 1: *Formation of community advisory boards (CAB) and recruitment of community research assistants (CRAs)*; Theme 2: *role of Indunas in collaboration phase*; Theme 3: *opportunities of collaboration*; Theme 4: *challenges of collaboration*).

### **Formation of community advisory boards (CAB) and recruitment of community research assistants (CRAs)**

During the consultation phase, community advisory boards (CABs) were established, and community research assistants (CRAs) were recruited in order to ensure that the ideas and inputs of the community are prioritised in decision-making. Therefore, the collaboration began by constituting a committee and joint (CAB and project management) recruitment of a group of fieldworkers that worked together with the research team. The KEP research team emphasized to the community during the introduction of MABISA (informing phase) in 2014 that they wanted to collaborate with a committee that would represent the community from all the villages. The committee served as a boundary partner between the researchers and the community and helped researchers periodically evaluate community perceptions of

the project. The CAB is comprised of 12 members: one headman (known as *induna* in traditional Zulu society), two community leaders, three school board members, three community health workers and five community members who are representatives from each village. The community advisory board was formed during the first community meeting, as illustrated in the following quotes:

*“...when MABISA people arrived, they wished that there could be a committee, so I formed the committee and selected people to serve on it. We initially had four people, but as the projects expanded to other villages, we ended up with two members in Mbandleni, four in Ndumo, four in Makhane, and four here in Mgedula. We have been working ever since as we move forward...” (induna #3, IDI).*

Prior to the community meeting, the headman appointed additional community members. This implies that some community members attended the first community meeting hoping to be selected for a committee position. The Community Advisory Board (CAB) functions as a watchdog to ensure that ethical conduct is maintained within the communities and that the concerns and interests of the community are properly considered, addressed, and not ignored. One of the committee members stated that he joined the group in order to ensure that the local community was given the opportunity to provide input, gain expertise, and obtain information regarding the initiatives that were carried out in their area.

*“...I wanted to see our community, getting assisted and impacted with knowledge, especially on malaria and bilharzia. It happens sometimes that people come with the goal of empowering the community, but the information gets distorted along the way due to poor communication. Now that CAB members exist, they can transfer the knowledge from the research team to the community...” (CAB member #6, FGD).*

During an FGD a member stressed the necessity of having community research assistants working collaboratively with the research team in order to engage fully with the community and ensure that the community is empowered as they develop research skills. The presence of the CAB and CRAs has been instrumental in promoting the concept of community change-makers for the prevention and control of vector-borne diseases. In addition, CRAs collaborate with researchers to gather data, identify transmission sites in the study area, and mobilize the local community. Traditional leaders and the community at large generally supported the notion of CRAs working together and joining the research team. However, there was some misunderstanding that this would result in full-time employment for the CRAs, which was not the case. One of the CRAs had the following to say:

*“...we were led to believe that the study team was from the Department of Health, that this would be long-term work with decent compensation, and we'd foreseen ourselves becoming*

*millionaires, only to discover that it was not exactly what we had been told. Even people thought we are working well, and this job is paying us a lot... ” (CRA #5, IDI).*

This collaboration began with the village chief and headmen as community leaders who were informed about the study before the entire community was informed.

### **The role of indunas (headmen/local traditional leadership) in the collaboration phase**

When the research team arrived at the research sites during the MABISA project, mistakes were made. Although the study was accepted by the tribal council of the Mgedula village some villages did not fully embrace the project as indicated by the statement of one of the indunas:

*“...I saw people in the river called Umagwanga and I stop them and ask what they were doing here...they said they were doing research about bilharzia. I then asked them who gave them permission, and do they know the king, they said no. I asked them if they know me, and they said no. I told them I am a tribal council, and that they shouldn't just show up and head to the river without first consulting us... ” (induna #2, IDI).*

This implies that the research team may not have followed all expected protocols of the community as it is implicit that this particular induna was not aware of the project. Despite the fact that community entry had already been completed at the community level and approval had been acquired, the research team still needed to be aware of the uniqueness of villages and made sure that the proper entry procedures were followed when they visited each village. The traditional authority has a significant role in paving pathways for researchers. The Induna further mentioned that after he had interacted with the researchers, they made appointments with all the tribal councils, which led to a collaborative partnership. According to protocol, the study team was supposed to inform the village headmen in advance of their visit. Researchers came to a consensus after realizing how crucial the tribal councils were to the study projects. This study revealed that a person who is a leader in an area participates in every meeting organized by the research team. It is the responsibility of leaders to notify the community in advance if a research team plans to work in a certain village so that the leader can prepare the community.

The CAB's objectives, responsibilities, and duties were specified during the formation of the committee. The CAB members were not paid in terms of salary but were provided with meeting allowances and a limited budget to cover travel expenses and other necessary expenses. Their contribution to the study, however, is clear and well-documented: as induna #2, IDI stated, “...since the study team does not reside permanently in our community, it is our responsibility to mediate between the research team and community members... ”. Other roles were mentioned such as ensuring that rules and regulations made by the project are observed by the community members. Another role was indicated below:

*“...the committee’s role is to gather all the project-related information and disseminate it to the community. Also, to ensure people’s well-being, explain to them what has taken place. Inform the community when the research team will be visiting their homes and give them assurance that there will be no harm by participating in the projects. We always remind them to cooperate...” (induna #3, IDI).*

Some CAB members stated that whether the community accepts or rejects the research team depends on them, though they had benefited from their collaboration in research projects by acquiring certain research skills and learning from the project. This is what they expressed:

*“...how we as CAB members present the research team to the community determines whether or not community people would accept or reject them. Even though they do not speak the local language, it is part of our responsibility to ensure they’re acceptable in the community, by motivating and giving clarity on the humanity of the team...” (CAB member #3, FGD).*

The CAB members have also acquired more knowledge of research and the purpose that it serves in the community. On behalf of the community, they discuss the pros and cons of the project with the research team. The local traditional leaders are often invited to participate in meetings and workshops conducted to map out strategies and plan for research activities. The presence of the village headmen and CAB members in the meetings created an opportunity to involve them in the planning and preparation for the projects currently running in the study area. This collaboration between the research team and the village headmen and CAB members was genuine and transparent because they are well-informed about the project and involved at every stage of planning. The CAB and Indunas also got an opportunity to understand the research activities and how they had an impact on their communities. One of the CAB members stated that the purpose of a committee is to protect young females from being exploited during the implementation of research projects, as has previously occurred, as well as to ensure that the interests of community members are not misled.

*“...CAB members are also given the prerogative to investigate the project if there are underlying factors pertaining to the researcher’s behaviour. For example, we have young girls in our community, if the researchers divert from what they came here for but decide to have love affairs with them, we should investigate such behaviours and report them to the headmen. We have observed some projects we once had in our area, whereby individuals come but end-up impregnating girls in the community...” (CAB member #6, IDI).*

## **Opportunities of collaboration**

The collaboration of the research team and the community enabled other CAB members to travel to attend workshops in other countries, which was their first-time experience. They had the opportunity to create new networks with a diverse set of people from various communities, which was highly valued by the respondent:

*“...being in collaboration with the research team, I have gained a lot. I have been given an opportunity to go to Zimbabwe. Everything covered passport, flight tickets and accommodation. We trained every day from 7 am to 4 pm. There were presentations and I also had a chance to present my village, which is something I have never done before. I learned to communicate with other people who do not speak my language. I made connections in Zimbabwe. It was a wonderful and enlightening experience...” (CAB member #8, FGD).*

Since the KEP objectives are not only to reduce infections and transmission of diseases but also to identify and address non-communicable diseases, malnutrition, and water, sanitation and hygiene (WASH) challenges through knowledge and learning. Therefore, vast community training and workshops were also provided in order to strengthen collaborations and help the community to understand the research information that the study intended to share with them. Community Health Workers (CHWs) acknowledged the acquisition of new knowledge and skills in the field of health-related research which for others enhanced their own professional practices. This was expressed as follows:

*“...during the MABISA project, we have also taken to Jozini for training, and the research managers booked us in a beautiful hotel. They taught us about stakeholders, malaria and schistosomiasis transmission and other research skills. Through KEP projects, I have been exposed to so many things...” (CHW #4, FGD).*

*“...In other meetings, the research team would teach us about stroke, diabetes, and blood pressure; this provided the community with a wealth of knowledge. We can apply the knowledge we learned in our daily work as caregivers...” (CHW #2, IDI).*

The participants acknowledged that there were learning aspects for them throughout the projects. The KEP organized twice-yearly community feedback meetings to share study updates and project findings. This is typically accomplished through edutainment techniques including drama performances and poetry by CRAs, schoolchildren, and community youth members. These meetings also provide a platform for all villages to unite. The community change makers project of KEP was supported by CRAs, teachers, and learners in primary schools. Through their respective schools, teachers and learners were involved in edutainment activities that supported the community health education program for the

area. Schools took part in an annual performance art competition where students actively contributed to the performance-based dissemination of study findings. Participating schools incorporated indigenous theatre practices and everyday activities, offering a rich source of relatable metaphors that aided in the formation of meaning, enhancing understanding and potential research uptake.

The KEP team invested over the years in capacitating CRAs through training on research. They were introduced to aspects of research ethics, the epidemiology of malaria and schistosomiasis, fundamental research techniques, quality assurance, and technical data-gathering skills. They became knowledgeable about parasitology and were actively

involved in specimen collection and screening. Such experience was acknowledged by one of the CRAs:

*“...I have benefited a lot since it was MABISA until it changed to TIBA, I am not going to lie. Now I have a lot of experience, which will be useful if I apply for another job. With the knowledge I have learned, I can succeed in various fields of work. I received this information for free, and the experience I have obtained is valuable to me because I may not have had the funds to pay for it otherwise. Also, receiving a certificate was a bonus...” (CRA #6, IDI).*

The community initially viewed the research team with suspicion and mistrust. However, the KEP project had a significant impact on the community and altered the perception of males, who were often viewed as being obstinate when it comes to going to clinics for their health.

*“...we always see the research team moving around with scales, weighing children and the elderly, so the community easily notices them when they are not present in the area. Men used to prefer not to visit clinics, but since the team began working in our community, this has changed. This shows that the door-to-door visits that they do make a positive impact on the community...” (CAB member #8, FGD).*

### **Challenges of collaboration**

The community indicated some challenges associated with their collaboration with researchers. Although CRAs were appreciative of the learning opportunity and skills they acquired through the project including collecting both qualitative and quantitative data, collecting stool and urine specimens, processing samples, and mapping vectors and geospatial basic techniques, they were not entirely satisfied with the way they worked with the research team. Specifically, they were not very happy with the working hours, and the limited cooperation and communication within the research team. The CRAs were much more grateful for the exposure they were receiving from collaborating and working together with the research team, participating in research activities, and all the training they were given.

However, they were not pleased that the certificates of participation they were given did not have their ID numbers and that could compromise authenticity. Below we present some of the challenges stated by the CRAs.

#### *Poor working conditions*

The CRAs cited poor working relations as one of the major barriers to their collaboration with the researchers. According to the CRAs researchers were not very organized in the way they managed time and allocation of working days. The CRAs complained that it was hard to work with the researchers since they did not get a chance to take lunch breaks or at least provide them with lunch. They also complained about the irregularities in the number of working days.

*“...working relationships are bad, there is no cooperation at all. There is no job where you can't have a lunch break. I'm saying this because, if there was cooperation, they would take into account that some people don't eat in the morning, and there should be teatime and lunchtime in the workplace. Some of us can't eat in the early hours of the day. We receive none of these, and we end up conducting research at someone's home while hungry...” (CRA #1, IDI).*

*“...the only thing I have observed is that the team is not well organized. Our working days are not consistent. They would tell us in the morning that you are needed in the field. There are always disagreements among researchers. It is like the researchers do not plan their work on time and it is not right...” (CRA #4, IDI).*

The issue with irregular working days was due to the fact the type of research which researchers were doing varied and, on some occasions, there was no need for many research assistants while on some days there was a need for more hands. During field trips that required a few people, the researchers would make the CRAs take turns so that all of them would get a chance to experience the type of work which was being done. Instead of just picking two CRAs to come throughout the week they would give each person at least two days and make them work in pairs or groups of three until everyone has had the chance to do that particular work. This was not viewed as appropriate by the CRAs, since this meant less stipend in total on that particular field visit.

This misunderstanding also extended to the issues of lunch breaks, which were caused by travelling long distances. The areas where the studies were being done were too far from the main shopping centre, hence the research team could not access shops where they could buy food. This resulted in the team having to go for the whole day without buying food. In addition to this challenge, the long distance travelled to get to study sites meant that the team had to depart early in the morning before the shops in the main centre opened, this resulted in CRAs having to spend the rest of the day without eating since

they did not pack lunch and relied on money to buy food. Another issue was the nature of the work which was being done, it was so intense that the team could not afford to take breaks. For example, during stool collection, the team had to move from school to school collecting samples, this would stretch up to lunch hour and then the team had to travel from the last school and head towards the processing centre. The team could either have their lunch break during the time of driving to the centre. Once at the centre there was no time to delay since the urine samples had to be processed before the eggs expire. Such complications in the nature of the work led to complaints by the CRAs.

Certainly, these are not conducive working conditions, however, there were limited options for the team since the distance and the poor infrastructure in the community led to these poor conditions. We recognize that these issues were not pleasant for the CRAs and that there was a need to come up with solutions such as sending extra people to the processing centre to prepare food in advance. We also consider that it would have been worthwhile to enable all CRAs to work for more days, or to create a consistent roster of duties and working days, but the reasons for the irregularity were due to the irregular nature of the research work as well as the working conditions in the area. Consulting the CRAs on the best possible solution would have been a solution, but beyond this, there was no way around the problem.

#### *Poor time management*

The issue of time management created hardship for many community research assistants, which made it more difficult to sustain collaborative relationships. The CRAs had this to say during the focus group discussion:

*“...there is a problem with not keeping up with the times. The timing for pick-up varies. The team leader will tell you that they will pick you up at 7 a.m., and you will wait for an hour or longer for them to arrive. Sometimes you go to bed not knowing what you're going to work on the next day. They would phone us in the morning and say, "You are working today; any plans you had for that day must be cancelled." (CRA #2, FGD).*

*“...as CRAs we stick to the time of resuming our duties, but the knock-off time is not always kept. Sometimes the research team releases us late at night, whereas I left home very early in the morning. The number of hours we will be working each day should be specified, and we should adhere to those hours...” (CRA#1, FGD).*

Poor time management led to many difficulties in the work done by the researchers and the CRAs. Time management was not easy to handle mostly because of the distance travelled to data collection sites and the unavailability of transport in the area. For a long time, the team relied on one car to move around, picking up the CRAs at different points, then travelling to the data collection sites. After the work was

complete one car had to drop everyone in their respective places, which led to some people being dropped off as late as 8 pm. This challenge was later resolved by availing two cars that would go in different directions to manage the transportation challenges. Despite the use of two cars, there was still a challenge with distance, and team members had to wake up very early to start the pick-ups.

The other misunderstanding with working days and being notified in the morning to come to work was a result of a lack of organization from the team leader's end. There is a need to ensure that field plans are prepared and communicated with the CRAs in advance so that everyone has a clear idea of what they have to do and when they are expected to be at work. Another thing that the team should have considered was planning all field trips together with the CRAs, this would enable them to understand why certain decisions are made and why the work often stretches. The greatest challenge was not that CRAs had to be dropped off late, but that they were not aware of the reasons for such problems. This raises another point which is the need to involve the CRAs in planning the field trips. Planning together may help the team resolve some of the issues that may hinder the productivity of the team.

#### *Misbehaving of the research team leader*

The CRAs also reported about bad behavior demonstrated by some researchers which made their work relations tough. Owing to drunkenness one of the researchers (team leader) failed to address the CRAs appropriately or resolve simple issues such as payment of stipends. This particular team leader would forget how much he had paid CRAs and this would lead to misunderstandings. This raises serious behavioral concerns on the part of the research team and it certainly affected the collaboration with the CRAs.

*“...the project's team leader used to drink a lot and would pay us our stipend when he is drunk as we were getting paid daily. The next day, there would be a misunderstanding over whether or not he had given us extra money or whatsoever...” (CRA #5, IDI).*

The issue of the team leader being drunk during working hours is not good at all, however, this particular team leader was released from the job as soon as the PI found out about his behavior. This information highlights the typical challenges that often go unspoken about in research projects. This behavior is often swept under the carpet and no one brings out such issues concerning community engagement projects. These findings showcase how team behavior plays an important role in ensuring that the communities are engaged in the most appropriate way. If team members are not disciplined and monitored, their behavior may paint the whole project bad. One action from a researcher, especially the one in leadership may raise a lot of scrutiny from the community.

### *Insufficient allowance*

There were also concerns regarding the insufficient allowance CRAs were receiving. This was a controversial issue owing to the rising cost of living in the country and the failure of the project to increase the payment as requested by the CRAs. The problem of the insufficient allowances came from the misunderstanding that the CRAs were employed by the project yet in fact they were involved on a voluntary basis, the stipend was a token of appreciation for the voluntary work. However, the communication on the stipend was not done properly at the onset of the project and the community worked on the assumption that the CRAs were employed.

*“...the R170 allowance we are receiving is too little. The community has this perception that this is a full-time job (as we did when we joined the project), and we are getting decent salaries as we are dropped off by fancy cars. But this money is not even enough to buy cosmetics...”*  
(CRA #3, IDI).

The amount that was paid initially was R150, this later increased to R170 after some years when the CRAs complained. The total number of days that the CRAs would be engaged with the researchers was usually 3-5 days. The best solution would have been to consider increasing the stipend; however, the project was limited by the budget that was available for such costs. This challenge emanates from the fact that research projects must submit budgets at the onset of projects that stipulate how the money will be used. These budgets are audited against the actual expenditures made by the project personnel. This type of monitoring makes it unlikely for stipends and salaries to be reviewed during the consequent years after the programs have started. This was the major hurdle faced by the PI in trying to review the amount. The increase from R150-170 was made possible by the introduction of new projects which enabled money to be shared towards the CRAs. These projects were aligned with work that the PI was already doing in the area.

### *Undermining CRAs due to English incompetence*

Since the CRAs do not speak English well, language was a problem when they wanted to voice their opinions about the project. This may explain some of the negative impressions of community research assistants. The research assistants felt oppressed by the researchers who failed to accommodate their inability to speak in English, as a result, they did not voice their opinions because of fear of being ridiculed or the assumption that their voices would be ignored. This challenge presented a bigger issue than the language barrier, it showed the level of inequality experienced by the CRAs.

*“...we struggle to communicate in English (our home language, is IsiZulu) during meetings with the research team, especially with the principal investigator (PI). We end up keeping our mouths shut and not bringing up the difficulties we have because we are afraid to speak English.*

*Since most people can't pronounce it correctly, they tend to believe everything they are told. Some project administrators make fun of us when we try to speak English...” (CRA #8, FGD).*

*“...we feel oppressed when they expect us to express ourselves in English because we are not native English speakers, we already feel defeated...” (CRA #1, FGD).*

Apart from the undermining and feeling oppressed we also note the issue of misrepresentation. The statement given by the respondents that they tend to believe everything they are told poses a risk of failure to understand what the project is all about. The inability of the research assistants to ask questions and also raise concerns creates a danger of ethical violations. This speaks to the researcher's inability to sympathize with the CRAs. It would have been appropriate to have the researchers try to understand and speak the local language. This would have placed the CRAs in a better position to communicate and express their concerns and also to understand what was being spoken about during stakeholder meetings. In future projects, there needs to strive to have good representation of people who speak the local language among the researchers. The team of researchers should be comprised of people who are able to speak the local language fluently. These people could play the role of interpreters between the team members and the research assistants. Also, the researchers should ensure that they try to learn the local language so that they may be able to hear on their own what the issues on the ground are. Sometimes relying on a middleman to interpret may lead to misconceptions and loss of context. The Project leader may think things are going well yet, there are major grievances that subordinates are hiding.

## **DISCUSSION**

This study sought to investigate the experiences of the community during the CE collaborative phase of KEP projects. The findings revealed the value of establishing and sustaining collaborative partnerships with stakeholders. It is important for the collaboration to be strong particularly because of the length of the project timelines (particularly in this study which spanned from 2014 – to 2022). These findings are consistent with Chiam et al. (2022) which suggest that the engagement process must be long-term and must allow time and space for diverse and divergent views while attempting to reach a consensus. The study demonstrated that the research team has been collaborating with community stakeholders for a long time and that working groups such as CAB and CRAs, who were part of the decision-making in activities of the KEP projects had been established.

The study demonstrates a correlation between collaborative partnerships and mutual benefits as the community members were involved in designing the projects and data collection and disseminating the results. The involvement of village headmen (Indunas), together with CAB members and CRAs in the projects meant that goals were shared, and reciprocity and mutual benefit were

achieved as evidence of deliberate intent and efforts of the project to benefit the community. These findings are consistent with those of Mutero and Govender (2019) who argue that community collaboration and partnerships should emphasize mutuality and reciprocity. Therefore, when researchers and communities collaborate, they should have a shared vision and it should be mutually beneficial. Our findings agree with other research findings (Strier, 2014) that distinguish between “transactional” partnerships and “transformational partnerships.” The author claims that individual or institutional interests are met through the exchange in transactional partnerships where both parties benefit from the interchange (Strier, 2014). Transformational partnerships on the other hand are distinguished by their comprehensiveness, collaborative planning, management, evaluation, mutuality, long-term commitment, strong leadership support, and university involvement in the process of community capacity building (Strier, 2014).

The duties of the traditional authority normally cover a variety of functions, all of which centred around the fundamental principle of guiding, protecting, defending, and providing for the needs of the society they serve (Mboh, 2021). The results of the current study also revealed, in addition, a progression on the part of community leadership toward health education through these collaborative partnerships. The impact of these relationships can easily be demonstrated through community knowledge uptake of vector-borne diseases, particularly schistosomiasis and malaria, research skills and numerous learnings from KEP projects. A comparable study by Musesengwa and Chimbari (2017) showed that the community of Ingwavuma had minimal research experience, but collaborations enabled co-learning and engagement opportunities.

The stakeholders’ contributions to projects became increasingly obvious from the first interactions we had with them. The study confirms that traditional leaders are very strategic in successfully navigating the negotiating process for study approvals and successful implementation. These results are in accordance with the findings of Tindana et al. (2011), which found that collaborating with traditional leaders can bring the entire community together in a “well-structured and serial manner,” which may increase the likelihood of the community embracing the research projects. Our study indicates that community research assistants as well as headmen and members of community advisory boards are perceived as community change-makers for the prevention and control of vector-borne diseases, particularly schistosomiasis and malaria. Traditional leaders play a key role in ensuring that initiatives are carried out without any problems and have the community's full acceptance and support. These results build on existing evidence for promoting community engagement through the establishment of a neutral place and leadership that encourages collaboration among varied participants to develop common goals that stimulate action and bring about social transformation (Sathorar & Geduld, 2021).

The findings showed that CRAs and CAB members can be credible resources and partners in addressing community health issues. Providing workshops and training to both CRAs and CAB members using communication tools adapted to the local context assisted in strengthening collaborations and opened opportunities for them to build partnerships abroad. Capacitation of community members in data collection and in promoting the concept of community change for prevention and control of vector-borne diseases was also achieved through capacity development initiatives offered to community members through numerous trainings. It was evident that community members were fully equipped with both health knowledge and research skills through collaborative working with multidisciplinary teams. The main partners in this project were community leadership, with whom the research team worked closely to achieve all the objectives of KEP projects. The role of traditional leadership made it possible for the project activities to be recognized and accepted by the community. Local-level structures were enhanced to facilitate the co-designing of community-based projects by researchers and communities through genuine collaboration. Community-based participatory research projects have proven to be a potential collaborative approach that combines systematic investigation, participation and action in addressing health problems (Minkler, 2023).

Community trust was also achieved through CAB members and CRAs. Their support allowed KEP to stay informed about the community's perception of the project and to remain socially and culturally relevant. This finding is in agreement with Camara et al. (2020) findings which showed that collaborating with community leaders and CBOs was helpful in reducing community reluctance and mistrust. This implied that CRAs maintain the visibility of KEP and are boundary partners between the research team and the community. This strengthened the community research project implementation capacity.

Notwithstanding this, there were challenges to sustaining collaborative relationships, some of which were poor cooperation and communication among the researchers and the CRAs. Language issues hindered community members from fully voicing their opinions to the research team about the project. These findings are consistent with those of Peled (2018) who argued that language barriers are one of the many challenges of healthcare provision and initiatives in a multilingual and multicultural society. Apart from just the inability to communicate, our respondents alleged that the actions of researchers towards their inability to speak English were similar to mistreatment or misdemeanor. While it is evident that speaking in English was a challenge for the CRAs, it was also inappropriate for the researchers to ridicule or fail to sympathize with them over their inability. Ultimately, we noted that CRAs felt mistreated and undervalued by the fact that researchers could not bother themselves to try and understand them in their own language.

Another notable challenge included the issue of inconsistent work hours and lack of breaks during the data collection. These issues required that both parties come up with a resolution to the

manner in which work was conducted. It seems it was inevitable for the researchers to want to stretch the hours for as long as possible so that they could achieve all the objectives of their work in the duration of the field visits. This was beneficial to the researcher but not so good for the CRAs whose concerns were beyond the completion of the work. They wanted to assist but they were worried more about working normal hours and were not very happy being pushed so much. In fact, they were worried about being abused and made to work for too long. In addition to this, there was a report about a team leader who came to work drunk and would mistreat the CRAs causing misunderstandings over payment of stipends. These are very pertinent issues that could have potentially made the collaborations sour if they had gone on unresolved.

Still, on the point of stipends, we found issues around compensation that also arose from the interviews. The compensation received by CRAs was not much compared to what they were expecting. The amount was meant to be a token of appreciation, it was also meant to cushion them when they were in the field (buying food, paying for transport to get to pick-up points, etc.). But from what we gathered the CRAs and the community saw this work as actual work which was meant to pay the standard wage amount for a day's work. While the CRAs were fully made aware of the nature of their work and the reasons for the stipend, they still expected their concerns for a normal wage to be met. This was more of an issue of negotiation since the CRAs understood that the project had no obligation to pay salaries, but they had issues in their household that required them to have enough money. If the project expected them to avail themselves for the work, then it should have been able to acknowledge the needs of the CRAs and support them. Their point was simply that, they had to forgo other opportunities in the village because they were trying to serve the needs of the project, moreover, the community views them as employed people. Their only hope was to get something substantial from the project.

## **Conclusion**

For community engagement to be successful, it is essential to collaborate with community stakeholders at all stages of the project. This study found that the formation the CAB and recruitment of CRAs created a conduit between researchers and the community, ensuring an avenue for transparent, democratic and equitable decision-making which resulted in the completion of projects. The KEP research team made a great effort to ensure that community members were involved in most aspects of the project, which led to community members developing new networks and gaining new skills. The study also ensured that local-level leaders were consulted and the right channels for community entry followed. The traditional authority which was consulted by KEP played an important role in laying the road for the researchers making the implementation of projects run smoothly. In addition to approvals and buy-in from local leadership, positive collaborative relationships among the members of the research team and the community were made possible by embracing partners such as CRAs and CABs. However, there were some noteworthy challenges to these working collaborations emanating from the

researchers mostly. These challenges included extended working hours, low stipends, language barriers, researchers misbehaving and undervaluing the CRA's opinions. These challenges posed a great threat to the collaborative efforts and could potentially erase all gains achieved from the initiatives taken to involve the community in citizen science activities. This study points out the importance of respecting and valuing community members in collaborative partnerships and demonstrates how such values can transform relationships between researchers and communities.

## **Recommendations**

More empirical research projects in collaboration with the local communities are required to keep growing the number of engagement efforts and to make certain that everyone who participates in them is empowered. Stronger collaboration between communities and researchers is needed in order to successfully address health-related issues in rural settings. We discovered a variety of health challenges in the study research site through community engagement and collaboration. These health challenges prevent communities from realizing their full potential for empowerment. Therefore, our study recommends using traditional strategies for knowledge sharing in order to ensure that communities are empowered. Also, when designing and carrying out research studies in rural settings, it is important to take into consideration the local sociocultural aspects. Future efforts to strengthen the health system should focus on community empowerment, local leadership development, and establishing relationships between local communities and the health system, rather than only educating and capacitating health workers.

## ***Acknowledgments***

The authors would like to acknowledge all the Ingwavuma community members (including Headmen, CAB members, CRAs, CHW, and school principals) who were actively involved in this study. Without their support, this project would not have been possible. We also acknowledge the non-author contributions from all KEP research team members.

## **References**

Africa SS, n.d. Main Place | Statistics South Africa. URL [https://www.statssa.gov.za/?page\\_id=4286](https://www.statssa.gov.za/?page_id=4286). Accessed 20 October 2022

Ashade, O., Mutereko (2021) Building Trust and Support for Partnership Agendas through the Requisites of Early Community Involvement. *African Journal of Inter/Multidisciplinary Studies* 3, 270–281. <https://doi.org/10.51415/ajims.v3i1.874>

Awasthi KR, Jancey J, Clements AC, Leavy JE (2021) Community engagement approaches for malaria prevention, control and elimination: a scoping review protocol. *BMJ open* 11, e049812.

- Camara S, Delamou A, Millimouno TM, Kourouma K, Ndiaye B, Thiam S (2020) Community response to the Ebola outbreak: Contribution of community-based organisations and community leaders in four health districts in Guinea. *Global Public Health* 15, 1767–1777. <https://doi.org/10.1080/17441692.2020.1789194>.
- Chiam AL, Cheng NWI, Larson H (2022) Community engagement for outbreak preparedness and response in high-income settings: A systematic review. *Global Public Health* 17, 1113–1135. <https://doi.org/10.1080/17441692.2021.1919734>.
- Cohen, L., Manion, L., Morisson, K., 2002. *Research Methods in Education*. Routledge.
- Cramer ME, Lazoritz S, Shaffer K, Palm D, Ford AL (2018) Community Advisory Board Members' Perspectives Regarding Opportunities and Challenges of Research Collaboration. *West J Nurs Res* 40, 1032–1048. <https://doi.org/10.1177/0193945917697229>.
- Creswell JW (2014) *Qualitative, quantitative and mixed methods approach*.
- Engage Vancouver Coastal Health [Internet]. Engage Vancouver coastal health. Available at: <https://engagevch.ca/engagementhq.com/projects> (Accessed Feb 19, 2023).
- Flick U (2022) An introduction to qualitative research. *An introduction to qualitative research*, pp.1-100.
- Gilmore B, Ndejjo R, Tchetchia A, De Claro V, Mago E, Lopes C, Bhattacharyya S (2020) Community engagement for COVID-19 prevention and control: a rapid evidence synthesis. *BMJ global health* 5, e003188.
- Henjewe C, Fewings P, Rwelamila PD (2013) De-marginalising the public in PPP projects through multi-stakeholders management. *Journal of Financial Management of Property and Construction*, 18, 210– 231. <https://link.springer.com/article/10.1007/s10734-013-9698-5>. Accessed 14
- Journal of Urban Health* 82223. <https://doi.org/10.1093/jurban/jti034>.
- Lerner H. Berg C (2017) A Comparison of Three Holistic Approaches to Health: One Health, EcoHealth, and Planetary Health. *Frontiers in Veterinary Science* 4.
- MacQueen KM, McLellan DS, Metzger DS, Kegeles S, Strauss RP, Scotti R, Blanchard L, Trotter RT (2001) What Is Community? An Evidence-Based Definition for Participatory Public Health, *American Journal of Public Health*, Vol 91, No. 12, pp 1929-1937.

- Manyangadze T, Chimbari MJ, Gebreslasie M, Mukaratirwa S (2016) "Risk factors and micro-geographical heterogeneity of *Schistosoma haematobium* in Ndumo area, uMkhanyakude district, KwaZulu-Natal, South Africa." *Acta Tropica* 159: 176- 184.
- Mboh L (2021) An investigation into the role of traditional leaders in conflict resolution: The case of communities in the Mahikeng Local Municipality, Northwest Province, South Africa. *African Journal on Conflict Resolution* 21, 33–57.
- McCloskey DJ, Akintobi TH, Bonham A, Cook J, Coyne-Beasley T, et al n.d. *Principles of Community Engagement (Second Edition)*. Community Engagement 197.
- Minkler M (2023) Community-based research partnerships: challenges and opportunities.
- Mosavel M, Simon C, van Stade D, Buchbinder M (2005) Community-based participatory research (CBPR) in South Africa: Engaging multiple constituents to shape the research question. *Social Science & Medicine* 61, 2577–2587. <https://doi.org/10.1016/j.socscimed.2005.04.041>
- Mthembu, Z, Chimbari MJ (2023) Community engagement: health research through informing, consultation, involving and empowerment in Ingwavuma community. *Frontiers in Public Health*, 11, 1050589.
- Musesengwa R, Chimbari MJ (2017) Experiences of community members and researchers on community engagement in an Ecohealth project in South Africa and Zimbabwe. *BMC Medical Ethics* 18, 76. <https://doi.org/10.1186/s12910-017- 0236-3>.
- Musesengwa R, Chimbari MJ, Mukaratirwa S (2017) Initiating community engagement in an ecohealth research project in southern Africa. *Infect Dis Poverty*, pp. 6:22. doi: 10.1186/s40249-016-0231-9.
- Mutero IT, Govender IG (2019) Moving from Transactional Partnerships to Collaborative University Community Engagement: A Case Study Evaluating Creative Placemaking in KwaZulu-Natal Province. *South African Review of Sociology* 50, 3–17. <https://doi.org/10.1080/21528586.2019.1632578>.
- Naserrudin NA, Culleton R, Pau Lin PY, Baumann SE, Hod R, Jeffree MS, Ahmed K, Hassan MR (2022) Generating Trust in Participatory Research on *Plasmodium knowlesi* Malaria: A Study with Rural Community Gatekeepers during the COVID-19 Pandemic. *Int J Environ Res Public Health* 19, 15764. <https://doi.org/10.3390/ijerph192315764> November 2022

- Peled Y (2018) Language barriers and epistemic injustice in healthcare settings. *Bioethics* 32, 360–367.
- Polidano K, Parton L, Agampodi SB, Agampodi TC, Haileselassie BH, Lalani JM, Mota C, Price HP, Rodrigues S, Tafere GR (2022) Community engagement in cutaneous leishmaniasis research in Brazil, Ethiopia, and Sri Lanka: a Decolonial approach for global health. *Frontiers in Public Health* 10.
- Putranto WA, Sari IN, Mayzana RDS (2022) An Isolated and Behind-the-Scenes Work Called Conservation: Developing Collaboration and Community Engagement of Conservation Practice in Indonesia, in: *Handbook of Research on the Role of Libraries, Archives, and Museums in Achieving Civic Engagement and Social Justice in Smart Cities*. IGI Global, pp. 1–15.
- Rakhra, A., Mishra, S., Aifah, A., Colvin, C L., Gyamfi, J., Ogedegbe, G., & Iwelunmor, J. (2022). Sustaining capacity building and evidence-based NCD intervention implementation: Perspectives from the GRIT consortium. <https://scite.ai/reports/10.3389/frhs.2022.891522>
- Salimi Y, Shahandeh K, Malekafzali H, Loori N, Kheiltash A, Jamshidi E, Frouzan AS, Majdzadeh R (2012) Is Community-based Participatory Research (CBPR) Useful? A Systematic Review on Papers in a Decade. *Int J Prev Med* 3, 386–393.
- Sathorar H, Geduld D (2021) A Critical Approach to University-Community Partnerships: Reflecting on the Diverse Realities. *Educational Research for Social Change* 10, 88–104. <https://doi.org/10.17159/2221-4070/2021/v10i2a6>.
- Strier R (2014) Fields of paradox: University–community partnerships.” *Higher Education* 68(2): 155–165. URL
- Tindan PO, Rozmovits L, Boulanger RF, Bandewar SVS, Aborigo RA, Hodgson AVO, Kolopack P, Lavery JV (2011) Aligning community engagement with traditional authority structures in global health research: a case study from northern Ghana. *Am J Public Health* 101, 1857–1867. <https://doi.org/10.2105/AJPH.2011.300203>.
- World Health Organization (2017) WHO community engagement framework for quality, people-centred and resilient health services. World Health Organization.
- World Health Organization (2020) Community engagement: a health promotion guide for universal health coverage in the hands of the people. World Health Organization.

### ***Competing interests***

The authors report there are no competing interests to declare.

**Data availability**

The data that support the findings of this study are available from the corresponding author, upon reasonable request.

**Ethical approval**

Ethical clearance was granted for this study prior to data collection.

**Informed consent**

Written informed consent was obtained from each individual who participated in this study.

**Appendix 1:** Table 3: Summary of stakeholders and their roles in collaboration.

<b>Stakeholder Name</b>	<b>Impact</b> <i>How much does the project impact them? (Low, Medium, High)</i>	<b>Influence</b> <i>How much influence do they have over the project? (Low, Medium, High)</i>	<b>What is important to the stakeholder?</b>	<b>How could the stakeholder contribute to the project?</b>	<b>How could the stakeholder block the project?</b>	<b>Role/function in collaboration</b>
Village Headmen	High	High	Maintaining and sustaining collaborative partnerships that have been established with the KEP research team.	Organise community meetings and activities in villages to disseminate schistosomiasis research findings.	Rejecting the study and denying gatekeeper approval.	Village headmen are the main points of contact for the entire community. They are in charge of all traditional matters pertaining health and safety of local people. The headman (Induna), who in turn reports to the great King

						(Isilo), provides reports to the Chief (Inkosi).
Community Advisory Boards (CABs)	High	High	Gather the community members for meetings and grant researchers' permission to enter their villages and conduct research.	Informs community members about new health trends and issues in their area by coordinating the dissemination of information to community members through the village headmen.	Discouraging the community from taking part in the KEP research projects.	CRAs are used to mobilize the community members on behalf of the researchers to come and participate in learning activities that can promote health and reduce the burden of the disease among the community members.
Community Research Assistants (CRAs)	High	High	Mobilising community members to participate in the KEP projects.	Assist researchers in collecting data.	Withdrawing from the study.	Collecting data with researchers. Assisting in transferring knowledge on health diseases in the local language.
Community Health Workers (CHWs)	Medium	High	Make the link between the community and the health system. Maximising quality of care for patients. Supplying equipment and drugs for treating schoolchildren found with infections in the schools.	Conduct door-to-door visits in the community to educate the community about health-related infections occurring in the area.	Withdrawing from the study.	CHWs visit patients in their homes to provide support with health difficulties and help home-based patients with medicine. They engaged community members through home visits. Distributing pamphlets to the community on behalf of KEP.
School Principals	Medium	Medium	Educate schoolchildren and make sure that they are recruited for parasitology	Mobilizing schoolchildren and making sure that the knowledge is transferred to	Rejecting the study and denying access to schoolchildren.	School principals are used to helping schoolchildren to learn about schistosomiasis in the

			research by the KEP.	school learners.		classroom. Encourages learners to do screening and treatment for schistosomiasis on a regular basis. Make sure learners utilise books, booklets, and posters provided by researchers. Schools are great place to host meetings with parents to educate them about schistosomiasis.
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The previous chapters determined how the Ingwavuma community and community stakeholders were informed, consulted and involved in research activities that were carried out in their area by the KEP research team. Collaboration between KEP researchers and community working on schistosomiasis and malaria were analysed as well as the obstacles and factors influencing the success and efficacy of community engagement. The nature of the Ingwavuma community's empowerment in relation to schistosomiasis and malaria was also assessed as part of the study. This chapter synthesises the findings reported in the thesis showing the connectivity between the various chapters. The recommendations are also discussed in this chapter.

**CHAPTER 5**  
**SYNTHESIS, CONCLUSIONS AND RECOMMENDATIONS**

## **5.1 Synthesis**

This study aimed to explore community engagement and involvement for empowering communities on health issues (specifically schistosomiasis and malaria) in Ingwavuma, uMkhanyakude District in KwaZulu-Natal. An analysis was conducted on community stakeholders who were impacted by schistosomiasis and malaria to identify how they were informed, consulted, and involved in research initiatives carried out in their area by the KEP research team. The nature of the collaboration arrangements between the researchers working on schistosomiasis and malaria and the community, as well as the challenges and factors determining the success and efficacy of community engagement was analysed. The nature of the empowerment of the Ingwavuma community with regard to issues of schistosomiasis and malaria was also evaluated as part of the study.

The study adopted the Community Engagement Vancouver Coastal Health framework ([www.vch.ca/ce](http://www.vch.ca/ce)). Emphasis was placed on identifying, analysing and discussing stages of the community engagement process. Community engagement process involves five distinct stages; 1) Informing the community, 2) Consulting the community, 3) Involving the community, 4) Collaborating with the community and 5) Empowering the community. In the following sections the key findings of this thesis are discussed in the context of summarised below and contextualised in relation to other studies.

### **5.1.1 Researchers' experiences during the informing phase of community engagement**

In Chapter 2, the researchers' experiences during the implementation of schistosomiasis and malaria projects were established to determine the informing phase of community engagement as the first stage of the CE process. For the purpose of documenting the lived experiences of the KEP research team during the CE informing stage, a phenomenological qualitative technique was adopted. In-depth, semi-structured interviews with researchers, staff, and the project investigator were carried out, and the results were analysed thematically. It was crucial to start by discussing the procedures for informing the community while carrying out health research. Therefore, Chapter 2 provides details on the processes, challenges and lessons learned by KEP researchers as a result of such engagement with the community of Ingwavuma. The findings highlighted the significance of informing the community and obtaining consent from the community so that misconceptions regarding the research might be avoided. Previous studies have reported that there are researchers with limited understanding of and experience with effective methods of engaging communities (Ahmed and Palermo, 2010; Hoon Chuah et al., 2018; Arriola-Vigo et al., 2019). The findings of this study also revealed that the issue of language and cross-cultural interactions, which may have resulted in misunderstanding and incorrect interpretation of the data being communicated with communities, appeared to be a recurring issue that caused dissatisfaction in the process of informing. Some researchers' limited proficiency on language and cross-cultural interactions could have led to inaccurate interpretation of the data. Most of the MABISA and TIBA researchers were not fluent with local language (IsiZulu) and this was an impediment to fully achieving

community engagement as most community members could not fully understand and contextualise the research questions as presented. The KEP research team relied on CRAs and some KEP researchers who were fluent in local language for data collection and cross-language in dissemination of findings. Language is one of the most important factors in getting specific response on objectives and questions when implementing projects in rural settings (Cheema, Mehmood, Khan, 2018). Squires (2008) found that when cross-language in research is methodologically addressed systematically, findings become accurate and reflect the experiences of the participants without losing meaning during translation. Therefore, informing the community about the research study is a subjective experience that requires attentive interaction and engagement with the community while cross-language is considered in order to be successful.

### **5.1.2 Enhancing community engagement in health research through informing, consulting, involving and empowering communities**

Recent findings indicate that due to the prevailing socioeconomic and environmental issues in South Africa, it is difficult to engage, involve, and empower communities in community-based health research (Gupta, Nishi, Gasparatos, 2022; Dolezal and Novelli 2022). Chapter 3 discussed in greater detail the process of informing, involvement and consultation with the communities but that should not be mistaken with community consent as the two are not mutually exclusive. Despite the significance of this distinction, it is not uncommon for the terms; engagement, consultation, and participation to be used interchangeably, with the assumption that a community has been consulted and included in a decision-making process (Johnston, 2010). It is important to consult with the representation of diverse constituencies (such as political and religious leaders, community advisory boards or respected individuals) within the community and seek permission before approaching members of the community. According to Schiavo (2021) it is not enough to simply inform or survey communities or ask for their advice on initiatives that are otherwise planned and run by individuals who are not members of the community. Rather, communities need to be empowered and collaborated with. Therefore, it is important to pay attention to the perspectives of the local communities and to acknowledge the expertise that exists inside each individual member of the community as well as each leader who represents the community. Community involvement can be done through a range of mechanisms to ensure that issues and concerns are understood and considered as part of the decision-making process. Involvement goes beyond information giving and consultation.

Chapter 3 was quantitative in nature and examined the extent to which the Ingwavuma community was informed about research projects on schistosomiasis and malaria implemented in their area. The research interrogated the involvement processes during implementation of the schistosomiasis and malaria projects and determined the nature of empowerment resulting from the process. The modified random-route approach was utilised in the study to administer a standardised questionnaire to randomly

selected household heads. The findings demonstrated that the researchers' approach to community engagement was adaptable, as communities were largely informed, consulted and involved, and subsequently empowered. This is probably because researchers had created a space for responsibility sharing in all the engagement processes including decision-making. The capacity of the community to effectively benefit from the information, consultation, involvement, and empowerment methods should be considered in projects aimed at empowering the community. In a similar study, where five projects were examined, and the results indicated that community engagement in the development of the various wind projects was limited to the "inform," "consult," and rarely "involve" areas of the participation ladder (Jami and Walsh, 2017). While community engagement is considered to be an extension of an organization's boundary-spanning duty of connecting with its community, literature provides little direction on the inform process (Johnston, 2010) despite the availability of appropriate CE frameworks that may be adopted in research projects. The conceptual framework developed by Bay, Prizer, Orusa, Hart, Perkins and Hackney (2020) argue that there are intrapersonal, interpersonal and institutional barriers that prevent racial minorities from engaging socially in various contexts. Intrapersonal barriers include lack of individual knowledge skills and distrust of authoritative professionals (medical, research, law enforcement, etc.), which may hinder an individual's participation in all domains. Interpersonal barriers consist of overt racism, smaller formal and informal social networks, and social support systems, all of which result in diminished social capital. Disparities in wealth, income, housing, healthcare, and work possibilities are examples of institutional impediments to participation (Bay et al, 2020). In reflection of the literature on the subject matter Chapter 3, presented a conceptual framework that integrates features of both the Vancouver Community Engagement Framework and Bay et al. (2020) conceptual framework on factors that affected individuals' and communities' engagement and empowerment in health projects.

### **5.1.3 Collaboration between researchers and community stakeholders for research projects on schistosomiasis and malaria**

The data presented in Chapter 2 and Chapter 3 showed how CE stages (Informing, Involving, Consultation and Empowerment) was achieved in the health research projects implemented in Ingwavuma community. Chapter 4, investigated the perspectives of community stakeholders throughout the collaborative phase of the CE process, co-developed by researchers and community members for the purpose of project implementation. The results showed that CAB members and CRAs could work together as reliable partners on community health issues. Collaborating with advisory committees and developing community partnerships and interventions are two of the most important aspects of community-based participatory research, as demonstrated in a systematic review paper by McFarlane, Occa, Peng, Awonuga, and Morgan (2022).

Although traditional leaders played a vital role in the KEP projects, poor cooperation and communication presented some challenges. Community members could not eloquently express their reservations on some aspects of the project to the research team due to language problems. According to the findings of McFarlane et al. (2022) in order to contribute to the existing body of scholarly work on community-engaged methodologies, researchers need to be more forthright about the level of community participation and should thoroughly and accurately describe the nature of the collaboration they have with community members. Health-related issues are best tackled in a team effort through community-based participatory research initiatives.

Local socio-cultural factors must be taken into account during planning and implementation of research in rural locations. Community empowerment should be the ultimate goal of collaborations. Work reported in this thesis suggests that collaborative approaches can be effective only when the context knowledge (such as values, beliefs and opinions) held by the community are acknowledged (Johnston, 2010). This acknowledgement results from an investment made by all parties in the form of activity to find a mutually accepted solution. Having discussed the collaboration processes, collaborating with the community is vital for developing partnerships to formulate options, find solutions and provide recommendations. Power dynamics were amongst other challenges in community empowerment. It is widely recognised that those who are powerless are a high-risk factor for diseases.

## **5.2 General conclusions**

The following general conclusions were drawn from the chapters of this thesis that were informed by the objectives and research questions of the overall study.

- Despite the fact that the reviewed articles were fairly rigorous and appeared to be biased, the findings on CE approaches and strategies were inconsistent. In contrast to the vast body of written material on CE, there is a lack of empirical study on the first stage of CE and the role it plays in the successful execution of CE while ensuring that none of the phases are skipped over. Even though the desired change does not always take place, there is not a lot of data that supports the idea that positive outcomes can be achieved through coalitions or partnerships. The articles that were studied not only have excellent instances of CE approaches and strategies, but they also include essential components of cautionary language. There is still a dearth of general awareness of the concepts, motivations, and social processes that drive community involvement, although the importance of community participation and its history are well known. Several articles lack adequate levels of theory and critical analysis, and often provide inadequate citations to definitions and frameworks. Even though this may not appear to be relevant to the social transformation or utilitarian goals that motivate community engagement initiatives, it can be helpful in explaining the assumptions that underpin the type of community participation project that is supported, as well as clarifying expectations regarding the scope of change that is expected, and the techniques required to achieve it on multiple levels.

- The study provided evidence that researchers failed to recognise the significance of the first phase of CE, which is known as the informing phase. It is evident that many engaged research projects fail due to poor communication, inadequate consultation, and poor design and implementation, all of which demonstrate passive participation towards the communities that are being researched. As a result, this study concluded that in order to involve studied communities, a higher level of engagement in the early stage of CE is required. This stage is a critical one that ought not to be disregarded while conducting research methods. The first phase of “informing” is an important step in the engagement process because it establishes meaningful, long-term relationships with researched communities and stakeholders who have interest and influence in the engaged research-based projects. This conclusion was reached after the study acknowledged that the informing phase is the initial stage of CE. Also, in order to have a balanced collaboration that is beneficial to all parties who have an interest in the project, it is essential to have an understanding of the cultural and linguistic differences that exist within the community during the process of community engagement. This is necessary to guarantee meaningful communication and active participation.
- This study has shown that communities understand the projects implemented in their area as they were directly and indirectly involved and participated in these projects. Despite the fact that they had a limited knowledge, specifically of the two projects in which they had engaged, as well as an approach to the projects that was researcher-driven and community-responsive, they were able to contribute. The study discovered that the majority of the community members were involved or participated in the projects in different stages and activities through: (i) consenting for their children who undertook schistosomiasis testing. (ii) participating in public awareness campaigns and surveys conducted by KEP research team. (iii) being screened for at least one disease or condition, the most common of which were high blood pressure, diabetes and schistosomiasis. In addition, many of these participants had attended community feedback meetings. CAB members and CRAs were directly involved in the projects as they worked part and parcel with the research team.
- The study also revealed that CAB members and CRAs can work together as reliable partners to address community health issues. The traditional authority plays a vital part in creating the groundwork for researchers, which facilitated the efficient execution of projects. When carrying out research in rural areas, it is absolutely necessary to make certain that the appropriate entry procedures for gaining approval at the local level are adhered to. Nonetheless, despite the important part that traditional leaders played in the KEP initiatives, the study found that it was difficult to maintain collaborative ties due to a lack of cooperation and communication. Also, because of the language barrier, it was difficult for people of the community to express their concerns to the research team about the project. According to the findings of the study, utilising

educational entertainment methods while also disseminating project results through community feedback sessions is both powerful and effective. Because they took into account their collaborators' requirements, the members of the research team were able to maintain fruitful working relationships with one another (such as CRAs). When researchers and communities work together to develop collaborative partnerships, the resulting relationships are transformed, and the researchers take on the role of change agents. This enables the communities to prioritise the problems that are important to them.

- There were consultative processes between KEP research team and stakeholders, which served as a foundation for the establishment of relationships that are mutually beneficial between researchers and communities. These partnerships led to increased levels of effective engagements. We also found that through collaborative arrangements, engagements and meaningful long-term relationships were created with the researched communities, researchers and stakeholders who had interest and influence in the engaged research-based projects.
- The findings also provide evidence that the interaction of several factors at different levels has an effect on the effectiveness of participation (information, consultation, and involvement) in community research initiatives. Knowledge retention was influenced by elements at the individual level, whereas information transmission was influenced by characteristics at the interpersonal level, which created the possibility that respondents with fewer connections could be left out. The institutional level, which consists of the researchers, their systems, and their processes, demonstrates difficulties in informing the wider communities about the projects (taking into account the rural nature of the communities), deficiencies in converting community members who have knowledge of the project into active participants, enhancements to consultative processes that go beyond feedback mechanism systems, and, most importantly, a questionably managed consent process in which respondents appeared to consent to something that they did not fully understand. Despite this, the communities that participated reported a number of benefits, some of which included education and screening for schistosomiasis and malaria, among other things. These benefits were also recognised by people of the community who had not directly participated in the projects, which highlights the project's potential in terms of disseminating information farther into communities.

### **5.3 Recommendations**

Based on the general conclusions reached in this thesis the following 5 recommendations are presented.

5.3.1 More empirical engaged research projects with local communities are recommended. Such studies should ensure that meaningful CE is done following the 5 stages of the engagement process and emphasis should be placed on determining ultimate empowerment of communities.

5.3.2 A Participation system that considers the cognitive challenges that may be experienced by participants is recommended. This may be done by providing information aids that improve the ability of participants to absorb and recall information.

5.3.3 Utilisation of informal communication systems and social networks for collection and dissemination of information are recommended for enhancement of community participation.

5.3.4 Stronger collaboration between communities and researchers is vital for successfully addressing health related challenges in rural areas. This should begin during ideation leading to co-designing of studies and maintained throughout the lifespan of the projects.

5.3.5 Fully understanding of CE and its application to rural settings is strongly recommended for all researchers working in rural communities. This is important as generally communities are not empowered enough to make meaningful contribution on aspects affecting their livelihoods and wellbeing, yet they are the ones best positioned to provide sustainable solutions for communal challenges.

#### **5.4 Implications for further research**

This research investigated community engagement processes for empowering communities on schistosomiasis and malaria in the area of Ingwavuma. Based on the experiences of community members, stakeholders and researchers on schistosomiasis and malaria the following potential future studies are indicated:

5.4.1 Further studies not limited to health issues to push the boundaries of the field of community engagement.

5.4.2 Development and validation of a local community engagement framework for rural communities in southern Africa.

#### **5.5 Study limitations**

Full physical participation of some community stakeholders and researchers was impeded by the COVID-19 pandemic and hence may have compromised quality of the outcomes. It was not possible to collect supplementary data as originally planned. However, this experience inculcated a new culture of virtual engagement in the team, and hence it was possible to fulfil all objectives of the study.

#### **5.6 References**

Ahmed, S.M., Palermo, A.-G.S., 2010. Community engagement in research: frameworks for education and peer review. *American journal of public health* 100, 1380–1387.

Arriola-Vigo, J.A., Stovall, J.G., Moon, T.D., Audet, C.M., Diez-Canseco, F., 2019. Perceptions of Community Involvement in the Peruvian Mental Health Reform Process Among Clinicians and Policy-Makers: A Qualitative Study. *International Journal of Health Policy and Management* 8, 711–722. <https://doi.org/10.15171/ijhpm.2019.68>

- Bay, A.A., Prizer, L., Orusa, A., Hart, A.R., Perkins, M.M., Hackney, M.E., 2020. Effects of a Health Education and Research Participation Enhancement Program on Participation and Autonomy in Diverse Older Adults. *Gerontol Geriatr Med* 6, 2333721420924952. <https://doi.org/10.1177/2333721420924952>
- Cheema, A.R., Mehmood, A., Khan, F.A., 2018. Challenges of research in rural poverty: lessons from large field surveys. *Development in Practice* 28, 714–719. <https://doi.org/10.1080/09614524.2018.1467881>
- Dolezal, C. and Novelli, M., 2022. Power in community-based tourism: empowerment and partnership in Bali. *Journal of Sustainable Tourism*, 30(10), pp.2352-2370.
- Gupta, H., Nishi, M., Gasparatos, A., 2022. Community-based responses for tackling environmental and socio-economic change and impacts in mountain social–ecological systems. *Ambio* 51, 1123–1142.
- Hoon Chuah, F.L., Srivastava, A., Singh, S.R., Haldane, V., Huat Koh, G.C., Seng, C.K., McCoy, D., Legido-Quigley, H., 2018. Community participation in general health initiatives in high and upper-middle income countries: A systematic review exploring the nature of participation, use of theories, contextual drivers and power relations in community participation. *Social Science & Medicine* 213, 106–122. <https://doi.org/10.1016/j.socscimed.2018.07.019>
- Jami, A.A., Walsh, P.R., 2017. From consultation to collaboration: A participatory framework for positive community engagement with wind energy projects in Ontario, Canada. *Energy research & social science* 27, 14–24.
- Johnston, K.A., 2010. Community engagement: Exploring a relational approach to consultation and collaborative practice in Australia. *Journal of Promotion Management* 16, 217–234.
- McFarlane, S., Occa, A., Peng, W., Awonuga, O. and Morgan, S.E., 2022. Community-Based Participatory Research (CBPR) to enhance participation of racial/ethnic minorities in clinical trials: a 10-year systematic review. *Health communication*, 37(9), pp.1075-1092.
- Schiavo, R., 2021. What is true community engagement and why it matters (now more than ever). *Journal of Communication in Healthcare*, 14(2), pp.91-92.
- Squires, A., 2008. Language barriers and qualitative nursing research: methodological considerations. *International nursing review* 55, 265–273.

## **List of Appendices**

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Appendix 5a: Key Informant Interview Guide for CCGs

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Appendix 6: Interview Schedule for TIBA-SA Researchers

Appendix 7: Interview Schedule for Project Administrators

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Appendix 9: Gatekeeper permission letter

## Appendix 1: Approval letter



24 April 2021

Miss Zinhle Mthembu (210538969)  
School of Nurs & Public Health  
Howard College

Dear Miss Mthembu,

Protocol reference number: HSSREC/00001650/2020  
Project title: Community Engagement and Involvement for Empowering Communities: A Case of MABISA/TIBA-SA, UMkhanyakude District, KwaZulu-Natal.  
Degree: PhD

### Approval Notification – Full Committee Reviewed Protocol

This letter serves to notify you that your response received on 20 April 2021 to our letter of 15 September 2020 in connection with the above, was reviewed by the Humanities and Social Sciences Research Ethics Committee (HSSREC) and the protocol has been granted **FULL APPROVAL**.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number. **PLEASE NOTE:** Research data should be securely stored in the discipline/department for a period of 5 years.

**This approval is valid for one year until 24 April 2022**

To ensure uninterrupted approval of this study beyond the approval expiry date, a progress report must be submitted to the Research Office on the appropriate form 2 - 3 months before the expiry date. A close-out report to be submitted when study is finished.

All research conducted during the COVID-19 period must adhere to the national and UKZN guidelines.

HSSREC is registered with the South African National Research Ethics Council (REC-040414-040).

Yours faithfully

.....  
Professor Dipane Hlalele (Chair)

/dd

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Humanities & Social Sciences Research Ethics Committee  
UKZN Research Ethics Office Westville Campus, Govan Mbeki Building  
Postal Address: Private Bag X54001, Durban 4000  
Tel: +27 31 260 8350 / 4557 / 3587  
Website: <http://research.ukzn.ac.za/Research-Ethics/>

Founding Campuses: ■ Edgewood ■ Howard College ■ Medical School ■ Pietermaritzburg ■ Westville

**INSPIRING GREATNESS**

## Appendix 2a: Consent form (interview - English)

CONSENT (Edit as required)

I ..... (Name) have been informed about the study entitled **COMMUNITY ENGAGEMENT AND THE LEVEL OF COMMUNITY EMPOWERMENT PERTAINING TO SCHISTOSOMIASIS AND MALARIA: A CASE OF INGWAVUMA COMMUNITIES, KWAZULU-NATAL.**

I understand the purpose and procedures of the study.

I have been given an opportunity to answer questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any of the benefits that I usually am entitled to.

I have been informed about any available compensation or medical treatment if injury occurs to me as a result of study-related procedures.

If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher at Mobile - 071 795 7839 and email - [mthembuz3@ukzn.ac.za](mailto:mthembuz3@ukzn.ac.za).

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

**HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION**  
Research Office, Westville Campus  
Govan Mbeki Building  
Private Bag X 54001  
Durban  
4000  
KwaZulu-Natal, SOUTH AFRICA  
Tel: 27 31 2604557 - Fax: 27 31 2604609  
Email: [HSSREC@ukzn.ac.za](mailto:HSSREC@ukzn.ac.za)

Additional consent, where applicable

I hereby provide consent to:

Audio-record my interview / focus group discussion	YES / NO
Video-record my interview / focus group discussion	YES / NO
Use of my photographs for research purposes	YES / NO

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Witness  
(Where applicable)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Translator  
(Where applicable)

\_\_\_\_\_  
Date

## Appendix 2b: Consent form (interview - IsiZulu)

### IMVUME

Mina ..... (Igama) nginikiwe ulwazi mayelana nocwaningo lolu isihloko salo sithi: UKUHLANGANISWA KOMPHAKATHI NEZINGA LOKUTHUTHUKISWA KOMPHAKATHI OKUPHATHELENE NEZINHLELO ZOKUSEBENZA NGESICHENENE KANYE NOMALALEVEVA KWIMIPHAKATHI YASENGWAVUMA, KWAZULU NATALI olwenziwa ngu Zinhle Mthembu.

Ngियाqonda inhloso kanye nendlela yalolucwaningo

Nginikwe ithuba lokuzibuzela imibuzo ngocwaningo, ngaphendulwa futhi nganeliseka

Ngiyazibophezela ekutheni ngibe yigxanye yalolucwaningo, angiphoqiwe futhi ngingahoxa noma nini ngaphandle kwempi

Nginikiwe ulwazi mayelana nokuba khona kwenxephezelo noma ukulashwa uma ngabe ukulimala kuba khona kumina okudalwe izinqubo ezihlobene nokwenziwa kocwaningo.

Uma nginemibuzo noma ukudideka mayelana nocwaningo ngiyaqonda ukuthi kufane ngixhumane nomcwaningi keleminingwane: Inombolo yocingo: 071 795 7839, Imeyeli: [mthembuz3@ukzn.ac.za](mailto:mthembuz3@ukzn.ac.za)

Uma nginemibuzo noma nenkinga mayelana namalungelo ami njengombambiqhaza kulolucwaningo noma uma ngiba nokukhathazeka mayelana nokunye okuphathelele nocwaningo noma umcwaningo ngingaxhumana ne:

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Tel: 27 31 2604557 - Fax: 27 31 2604609

Email: [HSSREC@ukzn.ac.za](mailto:HSSREC@ukzn.ac.za)

Imvume eyengeziwe, lapho kufanele khona

Ngiyavuma ukuthi:

Ukuqoshwa komsindo yenxoxo yami/ ingxoxo yeqembu lokugxila  
Ukuqoswa kwevidiyo yenxoxo yami/ ingxoxo yeqembu lokugxila  
Ukusebenzisa izithombe zami ngezinhloso zocwaningo

YEBO / CHA  
YEBO / CHA  
YEBO / CHA

\_\_\_\_\_  
Isignesha yalocwaningayo

\_\_\_\_\_  
Usuku

\_\_\_\_\_  
Isignesha yomfakazi  
(lapho kufanele khona)

\_\_\_\_\_  
Usuku

\_\_\_\_\_  
Isignesha yomtoliki  
(lapho kufanele khona)

\_\_\_\_\_  
Usuku

## Appendix 3a: Consent form (questionnaire - English)

### UKZN HUMANITIES AND SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE (HSSREC)

APPLICATION FOR ETHICS APPROVAL  
For research with human participants

#### INFORMED CONSENT RESOURCE TEMPLATE

Note to researchers: Notwithstanding the need for scientific and legal accuracy, every effort should be made to produce a consent document that is as linguistically clear and simple as possible, without omitting important details as outlined below. Certified translated versions will be required once the original version is approved.

There are specific circumstances where witnessed verbal consent might be acceptable, and circumstances where individual informed consent may be waived by HSSREC.

#### Information Sheet and Consent to Participate in Research

Date: / /2020

Greeting: Thank you for allowing me this opportunity to speak with you on an important topic.

My name is **Zinhle Mthembu** from the University of KwaZulu-Natal (UKZN), Howard College Campus. I am a PhD student in the School of Nursing and Public Health. My contact details are: Mobile Number - 071 795 7839, Email - [mthembuz3@ukzn.ac.za](mailto:mthembuz3@ukzn.ac.za)

You are being invited to consider participating in a study that involves research on community engagement and the level of community empowerment on Schistosomiasis and malaria. The aim and purpose of this research is to determine the extent of the level of empowerment that resulted from the 7 years of community engagement under the MABISA and TIBA projects; to determine the extent to which the community of Ingwavuma understands the schistosomiasis and malaria projects that have been implemented in their area; to determine the level of community consultation that has been done by researchers working on malaria and schistosomiasis in Ingwavuma community; to determine the extent to which the community is involved in schistosomiasis and malaria research projects implemented in Ingwavuma; to determine the nature and extent of collaboration between the community and researchers that have and are currently working in Ingwavuma; to determine the nature and level of empowerment of Ingwavuma community on schistosomiasis and malaria-related issues, and based on the experiences on schistosomiasis and malaria; to develop a framework for empowering communities on health-related research. The study is expected to enrol a total of 39 participants for in-depth interviews including 10 Community Research Assistants (CRAs), 9 Community Advisory Boards (CABs), 4 village heads, 4 School principals and 9 TIBA-SA researchers, 1 Project Investigator, 1 Research Coordinator, and 1 Financial Administrator. A total of 160 Self-administered structured questionnaires will be conducted with households within the affected villages including Ndumo, Mgedula, Makhane and eMbadleni. There will be 40 questionnaires administered to parents and schoolchildren in each village. Focus group discussions will be held with 4 groups which consisting of a minimum of 8 and/or maximum of 10 community members for each group. The participants will be invited through the gatekeepers of the area, purposively recruited as they have been working with the researcher in the study area for the past 7 years. The permission to interview the researchers will be granted from the project investigators of the TIBA-SA projects. The duration of your participation, if you

choose to enroll and remain in the study, is expected to be 30 to 45 minutes. The study is funded by National Research Foundation (NRF)

This study does not have activities that cause any harm and/or discomforts. There are no direct benefits from the study to you. However, by participating in this study you will contribute to the knowledge that will be useful for documenting best practices for community empowerment and the information provided will also assist in developing a framework for empowering communities on health issues. The university will also be able to learn how true engagement with communities can be done and what values bring to the entire university.

This study has been ethically reviewed and approved by the UKZN Humanities and Social Sciences Research Ethics Committee (approval number\_\_\_\_\_).

In the event of any problems or concerns/questions you may contact the researcher at 071 795 7839 or 0312601189, email: [mthembuz3@ukzn.ac.za](mailto:mthembuz3@ukzn.ac.za) or the UKZN Humanities & Social Sciences Research Ethics Committee, contact details as follows:

**HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION**

Research Office, Westville Campus  
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Tel: 27 31 2604557- Fax: 27 31 2604609  
Email: [HSSREC@ukzn.ac.za](mailto:HSSREC@ukzn.ac.za)

Participation in this research is voluntary and you may withdraw your consent and discontinue the study at any time without penalty. If you choose to withdraw from the study, all the information collected from you will be removed from the study consistent with the provisions on consent.

You can indicate your willingness to participate in this study by signing in the space provided in this form. The electronic signatures collected as a sign of consent are recognized as signatures on paper and have equal rights of consent for participants. The researchers will maintain the confidentiality of any elicited information pertaining to you and as such, the participant will only know the information. No other information related to you will be passed on to anyone else without your knowledge and permission. Data collected in this study will be kept on a secure server managed by the study supervisor (Professor Chimbari, School of Nursing and Public Health, UKZN) for 5 years after the study to allow for any further analysis and research publication.

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## Appendix 3b: Consent form (questionnaire - IsiZulu)

### UKZN HUMANITIES AND SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE (HSSREC)

APPLICATION FOR ETHICS APPROVAL  
For research with human participants

#### INFORMED CONSENT RESOURCE TEMPLATE

**Kubacwaningi:** kufanele besebenze ngozikhandla ekuqikileleni uma benza umbhalo wesivumelwano, futhi kufane beqinisekise ukuthi ubhalwe ngolimi olucacile kanye nolufandeka kalula, ngaphandle kokushiya imininingwane ebhalwe ngaphansi. Ucwangingo olutolikiwe luzofuneka uma lolu lokuqala seluphasisiwe.

Kunezimo lapho isivumelwano esinobufakazi esenziwe ngenkulumo singavumeleka. Nakanjalo zikhona futhi izimo lapho isivumelwano esenziwe umuntu ngamunye zingachithwa yiHSSREC (Humanities and Social Sciences Research Ethics Committee)

#### Isigaba semininingwane kanye nemvume yokuba yingxenywe yolucwaningo.

Usuku: / /2020

**Isibingelelo:** Ngibonga ithuba eningiphe lona lokuba ngikhulume nani ngesihloko esibalulekile.

Igama lami ngingu **Zinhle Mthembu** oqhamuka kwiNyuvesi yakwaZulu-Natali (UKZN), Howard College Campus. Ngingumfundi owenza iPhD (isiqu sobudokotela) esikoleni sobunesi kanye nempilo yomphakathi. Imininingwane yami yokuxhumana ile: Inombolo yocingo - 071 795 7839, Imeyeli - [mthembuz3@ukzn.ac.za](mailto:mthembuz3@ukzn.ac.za)

Uyamenywa ukuba ubambe iqhaza kucwaningo oluhlangukisa ukuhlangukiswa komphakathi nezinga lokuthuthukiswa komphakathi okuphathelene nezinhlelo zokusebenza ngesichenene Kanye nomalaleveva kwimiphakathi yaseNgwavuma, KwaZulu Natali. Inhloso nenjongo yalolucwaningo ukuthola nokunquma ukuthi ukuzibandakanya komphakathi kucwaningo lweMABISA noma lweTIBA kuyithuthukise kangakanani imiphakathi yaseNgwavuma. Lolucwaningo luphinde lifune ukubonisa uhambo locwaningo lweMABISA noma lweTIBA ngokwemigomo yokuveza ukuthi imiphakathi isikephi mayelana nokuthuthukiswa. Luphinde lifuna ukuthola nokunquma ukuthi imiphakathi kaseNgwavuma inolwazi olungakanani ekuqondeni imicwaningo ngesifo sesichenene nomalaleveva ezenziwe ezindaweni zabo. Luphinde lufune ukuthola nokunquma ukuthi ukubonisana nobudlelwana komphakathi nabacwaningi okuke kwenziwa ezindaweni zabo zaseNgwavuma besebenza bonke ngocwaningo lomalaleveva nesichenene belunjani. Luphinde lufune ukuthola nokunquma ukuthi umphakathi ubuzibandakanya kanjani kucwaningo lwesichenene nomalaleveva obulwenziwe kwimiphakathi yaseNgwavuma. Luphinde lufune ukuthola nokunquma ukuthi ukusebenzisana komphakathi nosonocwaningo eNgwavuma bekunjani. Liphinde lifune ukuthola nokunquma ukuthi kungakanani ukunikezwa amandla komphakathi waseNgwavuma ekudileni nezinkinga zesifo sesichenene nomalaleveva. Okokugcina ukuthuthukisa nokukhipha uhlaka lokuthuthukisa imiphakathi kwimicwaningo ehlobene nezempilo. Kulolucwaningo kulindeleke ukuthi kube abantu abayishumi amathathu nesishiyagalolunye (39) abazobamba iqhaza kulo lolucwaningo.

Kufaka phakathi ama Community Research Assistants (CRAs) ayishumi (10), amaCommunity Advisory Boards (CABs) ayisishagalolunye (9), Izinhloko zomphakathi ezine (4), abaphathi bezikole abane (4) kanye nosonocwaningo beTIBA-SA abayisishagalolunye (9), umsunguli wocwaningo oyedwa (1), umxhumanisi wocwaningo oyedwa (1) kanye nomphathi wezimali oyedwa (1). Inani eliyikhulu namashumi ayisithupha (160) elizogcwalisa aphendule uhlu lwemibuzo (questionnaire) kumakhaya ethintekile kufaka phakathi iNdumo, Mgedula, Makhane kanye neMbadleni. Amashumi amane (40) lwehlu lwemibuzo oluzobuzwa abazali kanye namantwana besikole endaweni ngayinye. ingxoxo yeqembu lokugxila (FGDs) luzobanjwa amaqembu amane (4) oluzokuketha abantu bomphakathi abayisishagalolombili (8) noma abayishumi (10) kwiqembu ngalinye. Ababambiqhaza bazocelwa kubaphathi bomphakathi bakwindawo ngayinye, baqashwe ngokolwazi lomcwaningo njengoba sebeke babamba iqhaza kolunye locwaningo olwaluqoshwe kwizindawo zaseNgwavuma eminyakeni eyisikhombisa edlule. Umuntu eyedwa uzothatha imizuzu engu 30 kuya ku40. Lolucwaningo luxhaswe iNational Research Foundation (NRF)

Lolucwaningo luzobe lungenabungozi. Akukho lutho ezohlunyulwa ngabantu, kepha ukubayingxenye kwakho kulolucwaningo kuzosiza ekunikeleni ulwazi oluzoba usizo kubacwaningo mayelana nokwazwi imikhuba evumelekile ekuthuthukiseni imiphakathi. Ulwazi ozosinika lona luzolekelela ekuhloleni uhlaka olusetshenziswe ucwaningo lweMABISA noma lweTIBA ekuthuthukiseni imiphakathi. Abacwaningi kanye neNyuvesi yonkana bazokwazi ukufunda ukuthi imiphakathi ithuthukiswa kanjani ngokweqiniso nangendlela evumelekile.

Lolucwaningo lubuyekwezwe yikomodi (HSSREC) lokuziphatha kwabacwaningi eNyuvesi yaKwaZulu Natali (inombolo yevume:.....).

Uma unemibuzo noma nenkinga mayelana nalolucwaningo xhumana nomphathi wocwaningo ku: 071 795 7839 noma 031 260 1189, imeyili: [mthembuz3@ukzn.ac.za](mailto:mthembuz3@ukzn.ac.za) noma uxhumane nekomidi laseNyuvesi yaKwaZulu Natali lokuziphatha kwabacwaningi kuleminingwane elandelayo:

#### **HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION**

Research Office, Westville Campus

Govan Mbeki Building

Private Bag X 54001

Durban

4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604557- Fax: 27 31 2604609

Email: [HSSREC@ukzn.ac.za](mailto:HSSREC@ukzn.ac.za)

Ukuba yingxenye yalolucwaningo akuphoqelekile unghoxa nanoma yinini uma usuzwa ngathi usufuna ukuyeka. Uma ukhetha ukuhoxa yonke iminingwane ebitholakala kuwena izosuswa nayo ingabasabi ingxenye yololucwaningo.

Ungakhombisa ukuba ufuna ukuba yingxenye yalo ngokusayina ebhokisini elikulelifomu. Nokusayina kungqonomushini kuthathwa njengekusayina ephepheni. Iminingwane yakho izobe yaziwa umcwaningi kuphela ayikho ezodluliswa ngaphandle kwemvumo yakho. Yonke iminingwane yalolucwaningwaningo izogcinwa iminyaka emihlanu, ukugcinwa kwayo kwenzelwa izidingo zayo kusasa umakukhona okushicilelwayo emphakathini mayelana nalo. Iminingwane eqoqwe kulolucwaningo izogcinwa kwiseva ephephile ephethwe umphathi wocwaningo (uSolwazi Chimbari, eSikoleni Sobuhle ngakazi kanye Nezempilo Yomphakathi, e-UKZN) iminyaka emi-5 ngemuva kocwaningo ukuze kuvunyelwe noma yikuphi ukucubungula okwengeziwe nokushicilelwa kocwaningo.

## Appendix 4a: English version Questionnaire tool

**STUDY TITLE:** THE ROLE OF COMMUNITY ENGAGEMENT AND INVOLVEMENT FOR COMMUNITY EMPOWERMENT IN HEALTH SETTINGS: THE CASE OF INGWAVUMA COMMUNITY, KWAZULU-NATAL, SOUTH AFRICA.

Interviewer's name .....

Interview date (device date).....

Interview starting time (device time).....

My name is Zinhle Mthembu. I am part of the research team that is interviewing people in this area of Ingwavuma to:

1. Determine the extent to which the community of Ingwavuma understands the schistosomiasis and malaria projects that have been implemented in their area.
2. Determine the level of community consultation that has been done by researchers working on malaria and schistosomiasis in the Ingwavuma community.
3. Investigate how the community is involved in schistosomiasis and malaria research projects implemented in Ingwavuma.
4. Explore the nature of collaboration between the community and researchers that have and are currently working in Ingwavuma.
5. Explore the level of empowerment of the Ingwavuma community on schistosomiasis and malaria-related issues.

This is a research project being conducted by Zinhle Mthembu under the supervision of Prof Moses Chimbari at University of KwaZulu-Natal, Durban You are invited to participate in this research project because you are one of the potential participants for this study.

Your participation in this research study is voluntary. You may choose not to participate. If you decide to participate in this research survey, you may withdraw at any time. If you decide not to participate in this study or if you withdraw from participating at any time, you will not be penalized.

The procedure involves responding to questions an interviewer will pose orally that will take between 30 to 45 mins. Your responses will be confidential, and we do not collect identifying information such as your name, email address or IP address. Data from this study will be stored on a secure server managed by the study Supervisor, Professor Chimbari. You do not have to answer any questions that you do not want to answer, and you may end this interview anytime you want to. The results of this study will be used for scholarly purposes only. Your honest answers will help us to understand how knowledgeable the Ingwavuma community is about schistosomiasis and malaria and the research projects that are implemented in their area. Your participation will also help us to understand how the community of Ingwavuma is empowered on schistosomiasis and malaria. We would greatly appreciate your help in responding to this survey.

If you have any questions about the research study, please contact 0717957839.

This research has been reviewed according to University of KwaZulu-Natal’s HSSREC procedures for research involving human subjects.

Would you be willing to participate?”

Yes

No

(Signature of respondent on KoBoCollect certifying informed consent)

.....

**SECTION A: INTERVIEW DETAILS AND BACKGROUND CHARACTERISTICS**

No	Questions	Responses and coding categories
A1	Name	
A2	Gender	
A3	Age	
A4	Name of area	
A5	Name of village	
A6	Mobile number	
A7	What is the highest level of school you completed?  <b>select one</b>	No formal education 0 Primary 1 Secondary 2 College level 3 Above college level 4 Other _____ 5
A8	How long have you lived in this area?	Less than 6 months 1 Less than 1 year 2 Less than 3 years 3 Less than 6 years 4 Less than 10 years 5 More than 10 years 6

**SECTION B. GENERAL HEALTH QUESTIONS**

No	Questions	Responses and coding categories
B1	Where do you generally get healthcare services?	Public clinic/hospital 0 Private clinic/hospital 1 Private pharmacy 2 Traditional healer 3 Faith healer 4

		Other _____	5
B2	Do you sometime fail to seek health care when ill?	No	0
		Yes	1
		Sometimes	2
B3	List the reasons that make you not to seek health care when ill	<i>List the factors</i>	
B4	What are the most dominant health diseases in your family or in this area?	<i>List the diseases</i>	
B5	Which health diseases contribute to the most deaths in this area?	<i>List the diseases</i>	

### SECTION C. HEALTH PROJECTS

No	Questions	Responses and coding categories	
C1	What community health projects have you heard about in the past 7 years in your areas?	<i>List at least 5 projects</i>	
C2	Have you ever heard of MABISA/TIBA projects?	No	0
		Yes	1
		<b>If No skip to C12</b>	
C3	Mention MABISA/TIBA projects that you know about.	<i>List at least 3 projects</i>	
C4	Where did you hear about these projects?	<i>(Tick all that apply)</i>	
		Radio	0
		Television	1
		School	2
		Posters	3
		Neighbor	4
		Family member	5
		Induna	6
		Health worker (Nurse)	7
		Community Caregiver	8
		Community meeting	9
		Others (specify)	10
		_____	
C5	Do you know the research activities conducted by MABISA/TIBA projects?	No	0
		Yes	1
		<b>If No skip to C7</b>	
C6	Can you list the research activities?	<i>List the research activities</i>	
C7	Do you know the project's research sites?	No	0
		Yes	1
		<b>If No skip to C9</b>	
C8	Can you list the aims of the research project?	<i>List the aims</i>	
C9	Do you know the areas of the research sites?	No	0

		Yes	1
		<b>If No skip to C11</b>	
C10	Can you list the research sites?	<i>List the areas</i>	
C11	What is the target population researched by the research team?	Below 18 years	0
		18 – 30 years	1
		30 – 40 years	2
		40 – 50 years	3
		Above 50 years	4
		All age groups	5
		Do not know	6
C12	Have you met the MABISA/TIBA researchers?	No	0
		Yes	1
		<b>If No skip to C14</b>	
C13	Do you know their names?	No	0
		Yes	1
		<b>If No skip to C15</b>	
C14	Can you list the names of the research team?	<i>List the names</i>	
C15	Do you know the principal investigator for the project?	No	0
		Yes	1
		<b>If Yes. Provide the name below:</b>	
		_____	
C16	Did you participate in the project?	No	0
		Yes	1
		<b>If No skip to C22</b>	
C17	If yes, how did you participate?	<i>List all responses</i>	
C18	Did you sign the consent form before you participated in the research project?	No	0
		Yes	1
		<b>If No skip to C22</b>	
C19	Did the consent form have enough information about what your rights were?	No	0
		Yes	1
		<b>If No skip to C22</b>	
C20	Did you get enough background information about the project from the consent form?	No	0
		Yes	1
C21	If it was your child, what was your response on the consent form?	No	0
		Yes	1
C22	Did any member of your family participate in any project conducted by MABISA/TIBA?	No	0
		Yes	1
		<b>If No skip to C24</b>	
C23	If yes, how did he/she participate?	<i>List all responses</i>	
C24	What did you learn or understand from the projects that are being done in your community?	<i>List the learnings</i>	

## SECTION D. KNOWLEDGE TEST

Now I am going to ask you some questions about bilharzia and malaria		
Serial	Questions	Responses and coding categories
D1	Have you ever heard about bilharzia before?	No 0 Yes 1 <b>If No skip to</b>
D2	Where did you hear about bilharzia?	<i>(Tick all that apply)</i> Radio 0 Television 1 School 2 Posters 3 Newspaper 4 Neighbour 5 Family member 6 Health worker (Nurse) 7 Community Caregiver 8 Community meeting 9 Others (specify) _____ 10
D3	What are the causes of bilharzia?	<i>(Tick all that apply)</i> Parasitic flat worms 0 Schistosomes 1 Mosquito 2 Bedbug 3 Cockroach 4 Rat 5 Others (specify) _____ 6 Do not know 7
D4	Bilharzia can be transmitted to human by...?	<i>(Tick all that apply)</i> Drinking contaminated water 0 Swimming in dirty rivers 1 Washing clothes in rivers 2 Bathing in a dirty river 3 Coming into close contact with a bilharzia patient 4 Fishing and farming 5 Other (specify) _____ 6 Do not know 7
D5	Do you think bilharzia can kill you if it is untreated?	No 0 Yes 1 Do not know 2
D6	What do you think are the most common signs and symptoms of bilharzia infection?	<i>(Tick all that apply)</i> High temperature/Fever 1 Loss of energy 2 Vomiting 3 Diarrhoea 4 Headache 5 Abdominal pain 6 Blood in stool 7

		Blood in urine	8
		Dizziness	9
		Chills	10
		Other (specify) _____	11
		Do not know	12
D7	Which of these are ways to prevent and control bilharzia?	<i>(Tick all that apply)</i>	
		Avoid swimming in dirty rivers	1
		Avoid washing clothes in river	2
		Cleaning dark corners in the house	3
		Wearing long sleeved clothes	4
		Avoid bathing in dirty rivers	5
		Covering stagnant water with oil	6
		Draining stagnant water	7
		Other (specify) _____	8
		Do not know	9
D8	Do you think you know enough about bilharzia?	No	0
		Yes	1
		Do not know	2
		<b>If Yes or Do not know, skip to D10</b>	
D9	If No, what information would you like to get about bilharzia?	Information on treatment	1
		Information on control	2
		Information on prevention	3
		Signs and symptoms	4
		Nature of the disease	5
		Any information	6
		Other (specify) _____	7
		Do not know	8
D10	Have you ever heard about malaria before?	No	0
		Yes	1
		<b>If No skip to...</b>	
D11	Where did you hear about malaria?	Radio	0
		Television	1
		School	2
		Posters	3
		Newspaper	4
		Neighbour	5
		Family member	6
		Health worker (Nurse)	7
		Community Caregiver	8
		Community meeting	9
		Others (specify) _____	10
D12	Which vector can transmit malaria to humans?	Rat	0
		Tick	1
		Cockroach	2
		Fly	3
		Mosquito	4
		Bedbug	5

		Other (specify) _____	6
		Do not know	7
D13	Malaria can be transmitted to human by...?	<i>(Tick all that apply)</i> Drinking contaminated water	0
		Eating contaminated food	1
		Eating a lot of mangoes or corn	2
		Bite of mosquito infected with Malaria	3
		Coming into close contact with a malaria patient	4
		Bite of fly, bedbug, cockroach or tick	5
		Other (specify) _____	6
		Do not know	7
D14	Do you think Malaria can kill you if it is untreated?	No	0
		Yes	1
		Do not know	2
D15	What do you think are the most common signs and symptoms of Malaria infection?	<i>(Tick all that apply)</i> High temperature/Fever	1
		Loss of energy	2
		Vomiting	3
		Sweating	4
		Headache	5
		Body pains	6
		Itching	7
		Loss of appetite	8
		Dizziness	9
		Chills	10
		Other (specify) _____	11
		Do not know	12
D16	Which of these are ways to prevent and control Malaria?	<i>(Tick all that apply)</i> Sleeping in bed nets	1
		Making fire and smoke	2
		Cleaning dark corners in the house	3
		Wearing long sleeved clothes	4
		Spraying insecticide	5
		Covering stagnant water with oil	6
		Draining stagnant water	7
		Other (specify) _____	8
		Do not know	9
D17	22. Do you think you know enough about Malaria?	No	0
		Yes	1
		Do not know	2
		<b>If Yes or Do not know, skip to end of the questionnaire.</b>	
D18	If No, what information would you like to get about Malaria?	Information on treatment	1
		Information on control	2
		Information on prevention	3
		Signs and symptoms	4
		Nature of the disease	5

		Any information	6
		Other (specify) _____	7
		Do not know	8

Thank you so much for your time

Interview end time ..... (Device time)

**END**

**STUDY TITLE: UKUHLANGANISWA KOMPHAKATHI NEZINGA LOKUTHUTHUKISWA KOMPHAKATHI OKUPHATHELENE NEZINHLELO ZOKUSEBENZA NGESICHENENE KANYE NOMALALEVEVA KWIMIPHAKATHI YASENGWAVUMA, KWAZULU NATALI.**

Igama lalocwaningayo .....

Usuku lokucwaninga (device date) .....

Isikhathi sokuqala ucwaningo (device time) .....

Igama lami nginguZinhle Mthembu, ngiyinxenye yeqembu labacwaningi abavashelele indawo yaseNgwavuma ukuze:

1. Sithole ukuthi umphakathi waseNgwavuma unolwazi olungakanani ekuqondeni imicwaningo emayelana nesifo nesichenene kanye nomalaleveva ezenziwe ezindaweni zabo.
2. Sithole nokunquma ukuthi ukubonisana nobudlelwana komphakathi nabacwaningi okuke kwenziwa ezindaweni zabo zaseNgwavuma besebenza bonke ngocwaningo lomalaleveva nesichenene belunjani.
3. Sithole ukuthi umphakathi ubambe iqhaza elingakanani kumaphrojekthi ocwaningo lwesichenene kanye nomalaleveva anziwe eNgwavuma.
4. Sithole ukuthi kunjani futhi kukhulu kangakanani ukusebenzisana komphakathi nosonocwaningo abasebenza eNgwavuma.
5. Sithole ubunjalo nezinga lokufukulwa komphakathi waseNgwavuma kwizinkinga ezihlobene nesichenene kanye nomalaleveva, futhi

Lena iphrojekthi yocwaningo olusungulwe uZinhle Mthembu ngaphanzi kokusekelwa uSolwazi Moses Chimbari eNyuvesi yaKwaZulu Natali, eThekwini. Uyamenywa ukube ubambe iqhaza kulolucwaningo ngoba ungomunye abaqokwe ukuthi babe inxenye yalolucwaningo.

Ukuba yingxenye yalolucwaningo akuphoqelekile unghoxa nanoma yini uma usuzwa ngathi usufuna ukuyeka. Uma ukhetha ukuhoxa yonke imininingwane ebitholakala kuwena izosuswa nayo ingabasabi ingxenye yololucwaningo.

Umuntu eyedwa uzothatha imizuzu engu 30 kuya ku45. Yonke imininingwane yalolucwaningwaningo izogcinwa iminyaka emihlanu, ukugcinwa kwayo kwenzelwa izidingo zayo kusasa umakukhona okushicilelwayo emphakathini mayelalana nalo. Imininingwane eqoqwe kulolucwaningo izogcinwa kwiseva ephaphile ephethwe umphathi wocwaningo (uSolwazi Chimbari, eSikoleni Sobuhlengikazi kanye Nezempilo Yomphakathi, e-UKZN) iminyaka emi-5 ngemuva kocwaningo ukuze kuvunyelwe noma yikuphi ukucubungula okwengeziwe nokushicilelwa kocwaningo. Awuphoqelekile uthi uphendulo imibuzo ongafuni ukuyiphendula, unyahoxa kulolucwaningo ngesikhathi othanda ngaso. Imiphumela yalolucwaningo izosetshenziswa ngenhloso yemfundo kuphela. Izimpendulo zakho eziqotho zizosiza ekuqondeni ukuthi imiphakathi yaseNgwavuma inolwazi olungakanani mayelana nesichenene nomalaleveva kanye neminye imicwaningo eke yenziwa kwizindawo zaseNgwavuma. Ukubamba iqhaza kwakho kulolucwaningo kuzosisiza ukuqonda ukuthi umphakathi waseNgwavuma unamandla amangakanani ekulweni nesifo sesichenene kanye nomalaleveva. Singakuthokozela kakhulu ukusisiza uphendulo imibuzo kulolucwaningo.

Uma unanoma iyiphi imibuzo ngalolucwaningo, siyacela uxhumane 071 795 7839.

Lolucwaningo lubuyekwezwe yikomodi (HSSREC) lokuziphatha kwabacwaningi eNyuvesi yaKwaZulu Natali

Ngabe uzimisele ukubamba iqhaza?

Yebo

Cha

(Isignesha yopendulayo kwiKoBoCollect Signature of respondent on KoBoCollect eqinisekisa invume enolwazi)

.....

**SECTION A: INTERVIEW DETAILS AND BACKGROUND CHARACTERISTICS**

Inombolo	Imibuzo	Izimpendulo												
A1	Igama lalobuzwayo													
A2	Ubulili balobuzwayo													
A3	Iminyaka yobuzwayo													
A4	Igama lendawo													
A5	Igama lesigodi													
A6	Inombolo yocingo													
A7	Wagcine kuliphi ibanga kwezemfundo  <b>(khethe okukudwa)</b>	<table border="0"> <tr><td>Ayikho imfundo ehlelekile</td><td>0</td></tr> <tr><td>Emabangeni aphantsi</td><td>1</td></tr> <tr><td>Ebangeni eliphezulu</td><td>2</td></tr> <tr><td>Ekolishi</td><td>3</td></tr> <tr><td>Ngaphezukwekolishi</td><td>4</td></tr> <tr><td>Okunye_____</td><td>5</td></tr> </table>	Ayikho imfundo ehlelekile	0	Emabangeni aphantsi	1	Ebangeni eliphezulu	2	Ekolishi	3	Ngaphezukwekolishi	4	Okunye_____	5
Ayikho imfundo ehlelekile	0													
Emabangeni aphantsi	1													
Ebangeni eliphezulu	2													
Ekolishi	3													
Ngaphezukwekolishi	4													
Okunye_____	5													
A8	Usuhlale isikhathi esingakanani kulendawo?	<table border="0"> <tr><td>Ngaphansi kwezinyanga eziyisithupha</td><td>0</td></tr> <tr><td>Ngaphansi konyaka owodwa</td><td>1</td></tr> <tr><td>Ngaphansi kweminyaka emithathu</td><td>2</td></tr> <tr><td>Ngaphansi kweminyaka eyisithupha</td><td>3</td></tr> <tr><td>Ngaphansi kweminyaka eyishumi</td><td>4</td></tr> <tr><td>Iminyaka engaphezu kweyishumi</td><td>5</td></tr> </table>	Ngaphansi kwezinyanga eziyisithupha	0	Ngaphansi konyaka owodwa	1	Ngaphansi kweminyaka emithathu	2	Ngaphansi kweminyaka eyisithupha	3	Ngaphansi kweminyaka eyishumi	4	Iminyaka engaphezu kweyishumi	5
Ngaphansi kwezinyanga eziyisithupha	0													
Ngaphansi konyaka owodwa	1													
Ngaphansi kweminyaka emithathu	2													
Ngaphansi kweminyaka eyisithupha	3													
Ngaphansi kweminyaka eyishumi	4													
Iminyaka engaphezu kweyishumi	5													

**SECTION B. IMBUZO NGEZEMPILO**

Inombolo	Imibuzo	Izimpendulo												
B1	Ujwayele ukulutholaphi usizo lwezempilo?	<table border="0"> <tr><td>Umtholampilo womphakathi</td><td>0</td></tr> <tr><td>Umtholampilo ozimele</td><td>1</td></tr> <tr><td>Ikhemisi elizimele</td><td>2</td></tr> <tr><td>Umthandazi</td><td>3</td></tr> <tr><td>Inyanga</td><td>4</td></tr> <tr><td>Okunye_____</td><td>5</td></tr> </table>	Umtholampilo womphakathi	0	Umtholampilo ozimele	1	Ikhemisi elizimele	2	Umthandazi	3	Inyanga	4	Okunye_____	5
Umtholampilo womphakathi	0													
Umtholampilo ozimele	1													
Ikhemisi elizimele	2													
Umthandazi	3													
Inyanga	4													
Okunye_____	5													

B2	Uke uhluleke ukufuna usizo lwezokuphepha uma uzizwa ugula?	Cha Yebo Kwesinye isikhathi	0 1 2
B3	Uma kunguYebo, bhala izizathu ezenza ungayi esibhendlela/ emtholampilo uma ugula	<b>Bhala izizathu</b>	
B4	Iziphi izifo ezihlasela umndeni wakho okanye kulendawo?	<b>Bhala izifo</b>	
B5	Iziphi izifo ezibulala kakhulu abantu bakulendawo?	<b>Bhala izifo</b>	

### SECTION C. IMICWANINGO YEZEMPILO

Inombolo	Imibuzo	Izimpendulo	
C1	Iyiphi imicwaningo yezempilo yomphakathi oke wezwa ngayo eminyakeni eyisikhombisa edlule kulendawo?	<b>Bhala okungenani emihlanu imicwaningo</b>	
C2	Useke wezwa ngocwaningo lweMABISA noma ngeTIBA phambilini?	Cha Yebo	0 1
		<b>Uma kunguCha, welela kuC12</b>	
C3	Bhala imicwaningo yeMABISA noma yeTIBA oyaziyo.	<b>Bhala okungenani emithathu imicwaningo</b>	
C4	Ngabe wezwa kephi ngalemicwaningo?	<b>(Thikha konke okuyikona)</b>	
		Umsakazo	0
		Ithelevishini	1
		Esikoleni	2
		Amaphosta	3
		Umakhelwane	4
		Ilungu lomndeni	5
		Induna	6
		Umsebenzi wezempilo	7
		Unompilo	8
		Umhlangano womphakathi	9
		Okunye (cacisa) _____	10
C5	Uyayazi imisebenzi yocwaningo lweMABISA noma lweTIBA?	Cha Yebo	0 1
		<b>Uma kunguCha, welela kuC7</b>	
C6	Ungayibala yini imisebenzi yocwaningo?	<b>Bhala imisebenzi yocwaningo</b>	
C7	Uyawazi ama sayithi ocwaningo lweMABISA noma lweTIBA?	Cha Yebo	0 1
		<b>Uma kunguCha, welela kuC9</b>	
C8	Ungazibala izinhloso zocwaningo lweMABISA noma lweTIBA?	<b>Bhala izinhloso</b>	
C9	Uyazazi izindawo zocwaningo lweMABISA noma lweTIBA?	Cha Yebo	0 1
		<b>Uma kunguCha, welela kuC11</b>	
C10	Ungawafaka ohlwini amasayithi ocwaningo?	<b>Bhala izindawo</b>	
C11	Yisiphi isibalo sabantu okubhekiswe kubo esicwaningwe yithimba locwaningo?	Ngaphansi kweminyaka eyishumi nesishiyagalombili	0

		Iminyaka eyishumi nesishiyagalombili kuya kwengamashumi amathathu 1 Iminyaka engamashumi amathathu kuya kwamashumi amane 2 Iminyaka engamashumi amane kuya kumashumi amahlanu 3 Ngaphezu kweminyaka engamashumi amahlanu 4 Yonke iminyaka yobudala 5 Angazi 6
C12	Uke wahlangana nosonocwaningo beMABISA noma beTIBA?	Cha 0 Yebo 1 <b>Uma kunguCha, welela kuC14</b>
C13	Uyawazi amagama abo?	Cha 0 Yebo 1 <b>Uma kunguCha, welela kuC15</b>
C14	Ungawabala amagama ethimba locwaningo?	<b>Bhala amagama</b>
C15	Uyamazi umphenyi oyinhloko yocwaningo lweMABISA noma lweTIBA?	Cha 0 Yebo 1 <b>Uma kunguYebo. Bhala igama ngezansi:</b>
C16	Uke walibamba iqhaza kucwaningo lweTIBA?	Cha 0 Yebo 1 <b>Uma kunguCha, welela kuC22</b>
C17	Uma kunguYebo, ubuzibandakanye kanjani kucwaningo?	<b>Bhala zonke izimpendulo</b>
C18	Ngabe usayine ifomu lokuvuma ngaphambi kokuthi ubambe iqhaza kuphrojekthi yocwaningo?	Cha 0 Yebo 1 <b>Uma kunguCha, welela kuC22</b>
C19	Ngabe ifomu lokuvuma belinolwazi olwanele mayelana nokuthi ayini amalungelo akho?	Cha 0 Yebo 1 <b>Uma kunguCha, welela kuC22</b>
C20	Ngabe uthole imininingwane eyanele engemuva mayelana nephrojekthi kwifomu lokuvuma?	Cha 0 Yebo 1
C21	Uma bekuyingane yakho, ibithini impendulo yakho kwifomu lokuvuma?	Cha 0 Yebo 1
C22	Ngabe kukhona ilunga lomndeni wakho elike labamba iqhaza kunoma iluphi ucwaningo olenziwe yi-MABISA noma iTIBA?	Cha 0 Yebo 1 <b>Uma kunguCha, welela kuC24</b>
C23	Uma kunjalo, wabamba iqhaza kanjani?	<b>Bhala zonke izimpendulo</b>
C24	Yini oyifundile noma waqonda kucwaningo oluke lenziwa emphakathini wakho?	<b>Bhala konke okufundile</b>

#### SECTION D. ISIVIVINYO SOLWAZI

Manje ngizokubuzisa imibuzo mayelana nesichenene kanye nomalaleveva		
Inombolo	Imibuzo	Izimpendulo

D1	Ngabe sewake wezwa ngeSichenene phambilini?	Cha Yebo <b>Uma kunguCha, welela kuD10</b>	0 1
D2	Ngabe wezwa kuphi ngeSichenene?	<i>(Thikha konke okuyikona)</i> Umsakazo Ithelevishini Esikoleni Amaphosta Umakhelwane Ilungu lomndeni Induna Umsebenzi wezempilo Unompilo Umhlangano womphakathi Okunye (cacisa) _____	0 1 2 3 4 5 6 7 8 9 10
D3	Kungabe sidalwa yini iSichenene?	<i>(Thikha konke okuyikona)</i> Izikelemu eziyizimbuzane AmaSchistosomes Umiyane Izimbungulu Iphela Igundane Okunye (cacisa) _____ Angazi	0 1 2 3 4 5 6 7
D4	ISichenene sidluliseleka kubantu kanjani?	<i>(Thikha konke okuyikona)</i> Ukuphuza amanzi angcolile Ukubhukuda emifuleni engcolile Ukuwasha izingubo emifuleni Ukugeza emfuleni ongcolile Ukuthintana kakhulu nesiguli esineSichenene Ukudoba nokulima Okunye (cacisa) _____ Angazi	0 1 2 3 4 5 6 7
D5	Ngabe ucabanga ukuthi iSichenene singakubulala uma ungasilaphanga?	Cha Yebo Angazi	0 1 2
D6	Iziphi izimpawu ocabanga ukuthi zijwayelekile ezibonakalisa iSichenene?	<i>(Thikha konke okuyikona)</i> Ukushisa okuphezulu noma umkhuhlane Ukulahlekelwa amandla Ukuhlanza Uhudo Ubuhlungu bekhanda Ubuhlungu besisu Igazi kumakaka Igazi emchameni Isiyezi	0 1 2 3 4 5 6 7 8

		Amakhaza 9 Okunye (cacisa) _____ 10 Angazi 11
D7	Yiziphi kulezi izindlela zokuvimbela nokulawula neSichenene?	<i>(Tick all that apply)</i> Gwema ukubhukuda emifuleni engcolile 0 Gwema ukuwasha izingubo emifuleni 1 Ukhlamba amakhona amnyama endlini 2 Ukugqoka izingubo ezinemikhono emide 3 Gwema ukugeza emifuleni ongcolile 4 Ukumboza amanzi amile ngamafutha 5 Ukukhipha amanzi amile 6 Okunye (cacisa) _____ 7 Angazi 8
D8	Ucabanga ukuthi ulwazi onalo ngeSichenene lwanele?	Cha 0 Yebo 1 Angazi 2 <b>Uma kunguYebo noma Angazi, welela kuD10</b>
D9	Uma impendulo yakho ithi 'Cha' iluphi ulwazi ongathanda ukulithola ngeSichenene?	Imininingwane yokwelashwa 0 Imininingwane ekulawuleni 1 Imininingwane yokuvikela 2 Izimpawu 3 Isimo sesifo 4 Noma yiluphi ulwazi 5 Okunye (cacisa) _____ 6 Angazi 7
D10	Ngabe sewake wezwa ngoMalaleveva phambilini?	Cha 0 Yebo 1 <b>Uma kunguCha, welela kuD</b>
D11	Ngabe wezwa kephi ngoMalaleveva?	<i>(Thikha konke okuyikona)</i> Umsakazo 0 Ithelevishini 1 Esikoleni 2 Amaphosta 3 Umakhelwane 4 Ilungu lomndeni 5 Induna 6 Umsebenzi wezempilo 7 Unompilo 8 Umhlangano womphakathi 9 Okunye (cacisa) _____ 10
D12	Ngabe isiphi isinambuzane esidlulisela uMalaleveva kubantu?	Igundane 0 Umkhaza 1 Iphela 2 Izindiza 3 Umiyane 4 Izimbungulu 5

		Okunye (cacisa) _____ 6 Angazi 7
D13	UMalaleveva udluliseleka kubantu kanjani?	<i>(Tick all that apply)</i> Ukuphuza amanzi angcolile 0 Ukudla ukudla okungcolile 1 Ukudla umango omningi noma ummbila 2 Ukulunywa umiyane otheleleke ngoMalaleveva 3 Ukuthintana kakhulu nesiguli esinoMalaleveva 4 Ukulunywa impukane, izimbungulu, iphela noma umkhaza 5 Okunye (cacisa) _____ 6 Angazi 7
D14	Ngabe bonke omaskito basabalisa uMalaleveva?	Cha 0 Yebo 1 Angazi 2
D15	Ucabanga ukuthi ungakubulala uMalaleveva uma ungalashwanga?	Cha 0 Yebo 1 Angazi 2
D16	Iziphi izindlela okuyizona ekuvikeleni futhi zilawule uMalaleveva?	<i>(Thikha konke okuyikona)</i> Ukushisa okuphezulu noma umkhuhlane 0 Ukulahlekelwa amandla 1 Ukhlansa 2 Uhudo 3 Ubuhlungu bekhanda 4 Ubuhlungu besisu 5 Igazi kumakaka 6 Igazi emchameni 7 Isiyezi 8 Amakhaza 9 Okunye (cacisa) _____ 10 Angazi 11
D17	Iyiphi kulezizindlela okuyiyona evikela futhi ilawule uMalaleveva?	<i>(Tick all that apply)</i> Ukulala ngezinehi zombhede 0 Ukwenza umlilo nentuthu 1 Ukhlansa amakhona amnyama endlini 2 Ukugqoka izingubo ezinemikhono emide 3 Ukufafaza isibulali zinambuzane 4 Ukumboza amanzi amile ngamafutha 5 Ukukhipha amanzi amile 6 Okunye (cacisa) _____ 7 Angazi 8
D18	Ngabe ucabanga ukuthi ulwazi onalo ngoMalaleveva lwanele?	Cha 0 Yebo 1 Angazi 2

		<b>Uma kunguYebo noma Angazi, welela ekugcineni kwemibuzo.</b>
D19	Uma impendulo yakho ithi 'Cha' iluphi ulwazi ongathanda ukulithola ngoMalaleveva?	Imininingwane yokwelashwa 0 Imininingwane ekulawuleni 1 Imininingwane yokuvikela 2 Izimpawu 3 Isimo sesifo 4 Noma yiluphi ulwazi 5 Okunye (cacisa) _____ 6 Angazi 7

Ngiyabonga kakhulu ngesikhathi sakho

Isikhathi sokuphela kocwaningo .....(Device time)

**END**

**COMMUNITY ENGAGEMENT AND INVOLVEMENT FOR EMPOWERING COMMUNITIES:  
A CASE OF MABISA/TIBA, UMKHANYAKUDE, KWAZULU-NATAL.**

**UKUZIBANDAKANYA KOMPHEKATHI KUCWANINGO LWEMABISA NOMA LWETIBA  
EKUTHUTHUKISENI IMIPHEKATHI YASEMKHANYAKUDE KWAZULU NATALI.**

**KEY INFORMANT INTERVIEW GUIDE FOR  
COMMUNITY CARE GIVERS (CCGs)**

1. Do you have any collaborations with MABISA/TIBA researchers? If yes, how were these collaborations formed?  
**Unakho yini ukusebenzisana nosocwaningo bakwaMABISA noma TIBA? Uma kunjalo, ukusebenzisana kwaqala kanjani?**
2. Who initiated and facilitated these collaborations?  
**Ubani owaqalisa noma wenza lokusebenzisana?**
3. When did this collaboration begin?  
**Naqala nini ukusebenzisana?**
4. What was the purpose of these collaborations?  
**Isiphi isizathu esenza nisebenzisane?**
5. How long have the collaborations been going on?  
**Sekuyisikhathi esingakanani nisebenzisana?**
6. What is your role as a Community Care Giver within the research team?  
**Iyiphi indima oyidlalayo kwiqembu locwaningo njengonompilo?**
7. What are your perceptions of the collaboration with the MABISA/TIBA researchers?  
**Ithini imibono yakho mayelana nokusebenzisana nosocwaningo beMABISA noma beTIBA?**
8. How have you benefited from working with the MABISA/TIBA researchers in terms of your personal growth and team goals?

**Ikuphi okuzuzile ngokusebenzisana nosonocwangi beMABISA noma beTIBA mayelana nokukhula kwakho kanye nokuzuza izifiso zeqembu losonocwaningo?**

9. What has been the impact of these collaborations to the community?

**Imuphi umphumela emphakathini obe khona njengosebenzisana kwakho nosonocwaningo?**

10. Do you think working with MABISA/TIBA researchers has improved or worsen community support for the research? Probe; In what ways.

**Ukusebenzisana kwakho nosonocwaningo beMABISA noma beTIBA kulinyusile noma kulehlisile uxhaso lomphakathi kulolucwaningo?**

11. If worsen community support, how can these collaborations be improved for future projects?

**Uma lwehlile uxhaso lomphakathi, kungathuthukiswa kanjani ukusebenzisana nosonocwaningo kweminye imicwaningo esazoba khona?**

12. What challenges do you encounter working with the research team as a CCG?

**Iziphi izinqinamba ohlangabezane nazo njengonompilo ngenkathi usebenzisana neqembu losonocwaningo?**

13. What challenges do the research team face on daily running of the MABISA/TIBA project?

**Iziphi izinqinamba osonocwaningo abahlangabezana nazo nsuku zonke kucwaningo lweMABISA noma lweTIBA?**

14. Are there any trainings or workshops you have attended which were organised by TIBA? If yes, explain what were the training/s or workshop/s about?

**Kukhona ukuqeqesheka owake wakuthola okuhlelwe iMABISA noma iTIBA? Uma uvuma, chaza ukuthi ikuphi.**

15. Do the CCGs have meetings? If yes, explain how often do the group meet monthly? The day and time of the meetings and what, do you discuss in those meetings?

**Ikhona imihlangana yonompilo? Uma uvuma, chaza ukuthi onompilo bahlangana kangakanani enyangeni? Usuku nesikhathi somhlangano futhi nezingxoxo eniba nazo kuleyomihlangano?**

16. What is the quality of the relationship with the MABISA/TIBA researchers that you have collaborated with? Do conflicts exist within the groups? If yes, what kind of conflicts?

**Bunjani ubuhlobo bakho nosonocwaningo beMABISA/TIBA osebenzisana nabo? Iyaba khona ingxabano kwiqembu losonocwaningo? Uma uvuma, iziphi lezo zingxabano?**

17. What do you think are the causes of the conflicts within the research team?

**Ucabanga ukuthi iziphi izimbangela ezidala ingxabano kwiqembu losonocwaningo?**

18. What are the consequences of the conflicts, if they exist?

**Imiphi imiphumela yalezo zingxabano, uma zikhona?**

19. What is the procedure of handling incidents of conflicts?

**Iyi inqubo yokuphatha izigameko zengxabano?**

20. What do you think can be done to reduce conflicts within your team?

**Ikuphi ocabanga ukuthi kungenziwa ekwehliseni ingxabano kwiqembu losonocwaningo?**

21. What qualities do you expect in a leader of your choice?

**Ibuphi ubuhlobo obulindele kumholi uzikhethela?**

22. What more you can tell us regarding MABISA/TIBA project.

**Iyikuphi okunye ongathanda ukusho ngochwano leMABISA noma leTIBA?**

***COMMUNITY ENGAGEMENT AND INVOLVEMENT FOR EMPOWERING COMMUNITIES:  
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***UKUZIBANDAKANYA KOMPHEKATHI KUCWANINGO LWEMABISA NOMA LWETIBA  
EKUTHUTHUKISENI IMIPHAKATHI YASEMKHANYAKUDE KWAZULU NATALI.***

**KEY INFORMANT INTERVIEW GUIDE FOR  
COMMUNITY RESEARCH ASSISTANCES (CRAs)**

1. Do you have any collaborations with MABISA/TIBA researchers? If yes, how were these collaborations formed?  
**Unakho yini ukusebenzisana nosocwaningo bakwaMABISA noma TIBA? Uma kunjalo, ukusebenzisana kwaqala kanjani?**
2. Who initiated and facilitated these collaborations?  
**Ubani owaqalisa noma wenza lokusebenzisana?**
3. When did this collaboration begin?  
**Naqala nini ukusebenzisana?**
4. What was the purpose of these collaborations?  
**Isiphi isizathu esenza nisebenzisane?**
5. How long have they been going on?  
**Sekuyisikhathi esingakanani nisebenzisana?**
6. What is your role as a CRA within the research team?  
**Iyiphi indima oyidlalayo kwiqembu locwaningo njengelunga leCRA?**
7. What are your perceptions of the collaboration with the MABISA/TIBA researchers?  
**Ithini imibono yakho mayelana nokusebenzisana nosocwaningo beMABISA noma beTIBA?**
8. How have you benefited from working with the MABISA/TIBA researchers in terms of your personal growth and team goals?

**Ikuphi okuzuzile ngokusebenzisana nosonocwangi beMABISA noma beTIBA mayelana nokukhula kwakho kanye nokuzuza izifiso zeqembu losonocwaningo?**

9. What has been the impact of these collaborations to the community?

**Imuphi umphumela emphakathini obe khona njengosebenzisana kwakho nosonocwaningo?**

10. Do you think working with MABISA/TIBA researchers has improved or worsen community support for the research? Probe; In what ways.

**Ukusebenzisana kwakho nosonocwaningo beMABISA noma beTIBA kulinyusile noma kulehlisile uxhaso lomphakathi kulolucwaningo?**

11. If worsen community support, how can these collaborations be improved for future projects?

**Uma lwehlile uxhaso lomphakathi, kungathuthukiswa kanjani ukusebenzisana nosonocwaningo kweminye imicwaningo esazoba khona?**

12. What challenges do you encounter working with the research team as a CRA?

**Iziphi izinqinamba ohlangabezane nazo njengeCRA ngenkathi usebenzisana neqembu losonocwaningo?**

13. What challenges do the research team face on daily running of the MABISA/TIBA project?

**Iziphi izinqinamba osonocwaningo abahlangabezana nazo nsuku zonke kucwaningo lweMABISA noma lweTIBA?**

14. Are there any trainings or workshops you have attended which were organised by TIBA? If yes, explain what were the training/s or workshop/s about?

**Kukhona ukuqeqesheka owake wakuthola okuhlelwe iMABISA noma iTIBA? Uma uvuma, chaza ukuthi ikuphi.**

15. Do the CRAs have meetings? If yes, explain how often do the group meet monthly? The day and time of the meetings and what, do you discuss in those meetings?

**Ikhona imihlangana yama CRAs? Uma uvuma, chaza ukuthi iqembu lama CRAs lihlangana kangakanani enyangeni? Usuku nesikhathi somhlangano futhi nezingxoxo eniba nazo kuleyomihlangano?**

16. What is the quality of the relationship with the MABISA/TIBA researchers that you have collaborated with? Do conflicts exist within the groups? If yes, what kind of conflicts?

**Bunjani ubuhlobo bakho nosonocwaningo beMABISA/TIBA osebenzisana nabo? Iyaba khona ingxabano kwiqembu losonocwaningo? Uma uvuma, iziphi lezo zingxabano?**

17. What do you think are the causes of the conflicts within the research team?

**Ucabanga ukuthi iziphi izimbangela ezidala ingxabano kwiqembu losonocwaningo?**

18. What are the consequences of the conflicts, if they exist?

**Imiphi imiphumela yalezo zingxabano, uma zikhona?**

19. What is the procedure of handling incidents of conflicts?

**Iyi inqubo yokuphatha izigameko zengxabano?**

20. What do you think can be done to reduce conflicts within your team?

**Ikuphi ocabanga ukuthi kungenziwa ekwehliseni ingxabano kwiqembu losonocwaningo?**

21. What qualities do you expect in a leader of your choice?

**Ibuphi ubuhlobo obulindele kumholi uzikhethela?**

22. What more you can tell us regarding MABISA/TIBA project.

**Iyikuphi okunye ongathanda ukusho ngochwano leMABISA noma leTIBA?**

***COMMUNITY ENGAGEMENT AND INVOLVEMENT FOR EMPOWERING COMMUNITIES:  
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***UKUZIBANDAKANYA KOMPHEKATHI KUCWANINGO LWEMABISA NOMA LWETIBA  
EKUTHUTHUKISENI IMIPHAKATHI YASEMKHANYAKUDE KWAZULU NATALI.***

**KEY INFORMANT INTERVIEW GUIDE FOR  
COMMUNITY ADVISORY BOARDS (CABs)**

1. Please share with me your experiences regarding your involvement in the MABISA or TIBA project/s from the time that you joined.

**Ngicela usichazele kabanzi ngolwazi onalo mayelana nokuzibandakanya kwakho ngenkathi uqala ukuba inxenye kucwaningo leMABISA noma leTIBA.**

1.1 When did you start living in your area?

**Uqale nini ukuhlala kelendawo.**

1.2 How did you join MABISA or TIBA project/s?

**Ngabe wangena kanjani kucwaningo leMABISA noma leTIBA?**

1.3 What CABs do and when did you join?

**Yini umsebenzi weCABs futhi uqale nini ukuba ilungu leCABs?**

1.4 Why did you join the CAB?

**Iziphi izizathu ezakwenze ujoyine iCAB?**

1.5 What is your role in the TIBA project as a CAB member?

**Iyiphi indima oyidlalayo kucwaningo njengelunga leCAB?**

1.6 What attributes were you taught as a CAB member?

**Iziphi izimfanelo owafundiswa zona mayelana nokuba yilungu leCAB?**

2. Are there any trainings or workshops you have attended which were organised by MABISA/TIBA? If yes, explain what was the training/workshop about?

**Kukhona ukuqeqesheka owake wakuthola okuhlelwe iMABISA noma iTIBA? Uma uvuma, chaza ukuthi ikuphi.**

3. In your opinion, since 2014 the time MABISA project started, how were you consulted about the health problems in this area before the implementation of MABISA?

**Ngombono wakho, kusukela ku2014 ngenkathi luqala ucwaningo lweMABISA, kwaba khona ukuboniswana ngezinkinga zezempilo ezikhona kuyo lendawo ngaphambi kokuqala ucwaningo lweMABISA?**

4. How did you feel about the consultation? Was the consultation appropriate?

**Wazizwa kanjani emva kokubonisana? Ngabe ibikahle yini?**

5. If it was inappropriate, what do you think could have been done differently?

**Uma yayingekahle, yini okungenziwa ngokuhlukile?**

6. Were you part of the conceptualisation of the project? If yes, how were you involved in the conceptualisation of the project?

**Ngabe ubuyinxenye ngenkathi kusungulwa ucwaningo lweMABISA noma lweTIBA? Uma kunjalo, ubuzibandakanye kanjani?**

7. Were you involved in the planning of the project? If yes, how were you involved in the planning of the project?

**Ubuyinxenye yokuhlelela ucwaningo? Uma kunjalo, ubuzibandakanye kanjani kulolucwaningo?**

8. How was the project implemented? By whom?

**Lwenziwa kanjani lolucwaningo? Lwenziwa ngubani?**

9. Were you part of the implementation of the MABISA or TIBA project/s?

**Ubuyinxenye ngenkathi kwenziwa ucwaningo leMABISA noma leTIBA?**

10. If yes, what was your role in the implementation of the project?

**Uma kunguyebo, iyiphi indima obukade uyidlala kucwaningo leMABISA noma leTIBA?**

11. What more you can tell us regarding MABISA/TIBA project.

**Iyikuphi okunye ongathanda ukusho ngochwano leMABISA noma leTIBA?**

**Appendix 5d: Key Informant Interview Guide for School Principals**

***COMMUNITY ENGAGEMENT AND INVOLVEMENT FOR EMPOWERING COMMUNITIES:  
A CASE OF MABISA/TIBA, UMKHANYAKUDE, KWAZULU-NATAL.***

**KEY INFORMANT INTERVIEW GUIDE FOR  
SCHOOL PRINCIPALS**

1. Do you have any collaborations with MABISA/TIBA researchers? If yes, how were these collaborations formed?
2. Who initiated and facilitated these collaborations?
3. When and how did this collaboration begin?
4. What was the purpose of these collaborations?
5. What role played by the school in the TIBA projects?
6. What are your observations, based on your working relationship with TIBA/MABISA projects? Is there any misunderstanding or conflict with the team? What are your perceptions of the collaboration with the MABISA/TIBA researchers? Is it good or bad?
7. Was the school representatives' part of the project during the initial planning?
8. How have the learners or the school in general, benefited from this project through working with the research team or taking part in the project?
9. According to your knowledge, how has the community benefited from the project?
10. What challenges a school encountered working with the research team?
11. What are communication channels/procedures did the research team follow to engage with the school?
12. Are there any trainings or workshops you or teachers have attended which were organised by TIBA? If yes, explain what were the training/s or workshop/s about?
13. According to your observation, do you see a need for the teacher's training by TIBA?
14. What qualities do you expect in a leader of your choice?

**Appendix 6: Interview Schedule for TIBA-SA Researchers**

***COMMUNITY ENGAGEMENT AND INVOLVEMENT FOR EMPOWERING COMMUNITIES:  
A CASE OF MABISA/TIBA, UMKHANYAKUDE, KWAZULU-NATAL.***

**INTERVIEW SCHEDULE FOR TIBA-SA RESEARCHERS**

1. Please share with me your experiences regarding your involvement in the MABISA or TIBA project/s from the time that you joined.
2. What is your role within the TIBA projects research team as a researcher?
3. What attributes were you taught as a TIBA researcher?
4. How have you benefited from working with the MABISA/TIBA researchers in terms of your personal growth and team goals?
5. What challenges do you encounter working with the research team as a TIBA-SA researcher?
6. What challenges does the research team face on the daily running of the MABISA/TIBA project?
7. Are there any trainings or workshops you have attended which were organised by TIBA-SA? If yes, explain what the trainings/s or workshop/s were about.
8. Do the TIBA-SA researchers have meetings? If yes, explain how often the group meets monthly. The day and time of the meetings and what do you discuss in those meetings?
9. What is the quality of the relationship with the MABISA/TIBA CAB members or CRAs that you have collaborated with? Do conflicts exist within the group? If yes, what kind of conflicts?
10. What do you think are the causes of the conflicts within the research team?
11. What procedure for handling incidents of conflicts?
12. What do you think can be done to reduce conflicts within your team?
13. What is your view of the administrative support staff (Sam and Nokwanda)? Does their presence improve or restrict the project's progress and in what ways?
14. What is your view of the Community Advisory Board? Does their presence improve or restrict the project's progress and in what ways?
15. What is your view of the team leader? Does his or her presence improve or restrict the project's progress and in what ways?
16. What do you think needs to be improved by the above-mentioned offices and the research team?

**Appendix 7: Interview Schedule for Project Administrators**



***COMMUNITY ENGAGEMENT AND INVOLVEMENT FOR EMPOWERING COMMUNITIES:  
A CASE OF MABISA/TIBA, UMKHANYAKUDE, KWAZULU-NATAL.***

**INTERVIEW SCHEDULE FOR TIBA-SA PROJECT  
ADMINISTRATORS**

1. Please share with me your experiences regarding your involvement in the MABISA or TIBA project/s from the time that you joined.
2. What is your role within the TIBA projects research team as a project administrator?
3. Were you part of the conceptualisation of the project? If yes, how were you involved in the conceptualisation of the project?
4. Were you involved in the planning of the project? If yes, how were you involved in the planning of the project?
5. Were you part of the implementation of the MABISA or TIBA project/s? if yes, how was the project implemented? By whom? And what was your role in the implementation of the project?
6. How have you benefited from working with the MABISA/TIBA researchers in terms of your personal growth and team goals?
7. What challenges do you encounter working with the research team as a project administrator?
8. Are there any trainings or workshops you have attended which were organised by TIBA-SA? If yes, explain what the trainings/s or workshop/s were about.
9. Do the TIBA-SA project administrators have meetings? If yes, explain how often the group meets monthly. The day and time of the meetings and what do you discuss in those meetings?
10. In what ways has your life changed (benefits) since joining this group in terms of personal growth and working with the team?

***COMMUNITY ENGAGEMENT AND INVOLVEMENT FOR EMPOWERING COMMUNITIES:  
A CASE OF MABISA/TIBA-SA, UMKHANYAKUDE DISTRICT, KWAZULU-NATAL.***

INTERVIEW SCHEDULE FOR TIBA-SA PRINCIPAL INVESTIGATOR

1. I would like to understand how the community was involved in the proposal development.
2. What are collaborative arrangements that are in place between the researchers and the community of Ingwavuma. Tell me how the collaborations with the KEP Community Advisory Boards (CABs) or Community Research Assistants (CRAs) were formed? Who initiated and facilitated these collaborations? When did this collaboration begin? What was the purpose of these collaborations? How long have they been going on?
3. What is your role as a Project Investigator within the KEP projects research team?
4. How do you operate within the research team?
5. How many members were in your research team when you started? Probe
6. How has your interaction with team members from different socio-disciplinary backgrounds affected your ways of thinking about how you could achieve your personal and team goals?
7. Has the partnership between CAB members, CRAs and researchers facilitated or blocked community-wide support for the research? Probe; In what ways?
8. What constraints do you as a group face in the daily running of your project/s in relation to; Group functioning? Group project (s)? Lack of information/training, group disputes, and lack of trust.
9. How often do the group meet in a month?
10. What time of the day do you schedule your meetings? What do you discuss in these meetings? What is the quality of these meetings?
11. Any special meetings within the month? If Yes, which ones?
12. Do you take minutes in your meetings? If Yes: what kind of records do you keep? Who keeps them? If not, why don't you keep records?
13. What are capacity development workshops/training held to prepare community/stakeholders to continue with activities after project termination.
14. Do you think the community is empowered? How the empowered community able to sustain certain key activities for improving the situation of malaria and bilharzia in the area.
15. What is your view of the administrative support staff (Sam and Nokwanda)? Does their presence improve or restrict the project's progress and in what ways?
16. What is your view of the Community Advisory Board? Does their presence improve or restrict the project's progress and in what ways?
17. What is your view of the team leader? Does his or her presence improve or restrict the project's progress and in what ways?
18. What do you think needs to be improved by the above-mentioned offices and the research team?

13 October 2020

Inkosi Yesizwe SaseManyiseni  
Manyiseni Tribal Authority  
Manyiseni Area  
Ingwavuma

Request for permission to conduct research in Ingwavuma

Dear Nkosi Matherijwa,

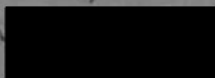
Tackling Infections to Benefit Africa (TIBA) is an Africa-led, wide-ranging, multi-disciplinary research programme that explores and draws lessons from the ways that different African health systems tackle infectious diseases. In the context of TIBA we have a PhD fellow who is studying the Community Engagement and the level of community empowerment pertaining to schistosomiasis and malaria – A Case of Ingwavuma Communities, KwaZulu-Natal

The mother project has been approved provincially. The fellow has submitted her protocol to the University of KwaZulu-Natal's (BREC) Biomedical Research Ethics Committee and they have provisionally approved the project pending gatekeeper permission from the community leadership.

In view of the above, we are kindly requesting for permission to conduct research. We will submit the letter to BREC for final approval and when we get full approval we will send it to you for your records. For now, we have attached to this letter the Proposal that was submitted to BREC.

Thank you for your continued support.

Yours sincerely,



Professor MJ Chimbari  
tibaSA Project Leader  
TIBA Co-Deputy Director



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