



**Stakeholder Engagement in the context of a Community Advisory Board within
a university research setting (in South Africa)**

by

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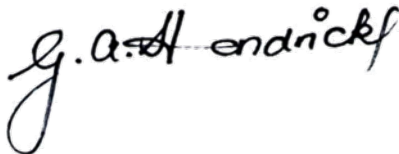
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ABSTRACT

This dissertation is a qualitative study undertaken to explore stakeholder engagement principles and practises applied in the management of a Community Advisory Board (CAB) within a university research setting. This was effected against the framework of the stakeholder theory, and the two way symmetrical communication model of the Excellence Theory in Public Relations Management.

The in-depth interview process was didactic and complex with the emergence of several related themes developing. The data was collected and analysed using the Braun and Clarke's (2006) thematic analysis. Emergent themes may seek to inform operational improvement in the general management of Community Advisory Boards both locally and internationally.

The key findings revealed compliance to the Public Relations principles and guidelines and alignment to South African and international guidelines as set forth in the GPP (Good Participatory Practice) Guidelines (2011), the Stockholm Accord (2010) and the King IV Report (2016).

Key words: Community Advisory Board, community stakeholder, community engagement, research, public relations, participatory

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GLOSSARY

CAB/CAG	Community Advisory Board/Community Advisory Group
CLO/CEO/CE	Community Liaison Officer / Community Engagement Officer / Community Educator
CRS	Clinical Research Site
CTU	Clinical Trials Unit
CWG	Community Working Group
DAIDS	Division of AIDS, NIAID
DR-TB	Drug-Resistant Tuberculosis
DS-TB	Drug-Susceptible Tuberculosis/Drug-Sensitive Tuberculosis
DTTC	Desmond Tutu TB Centre
EXCO	Executive Committee
FHI 360	Family Health International and Academy for Educational Development
FMHS	Faculty of Medicines and Health Science
GPP	Good Participatory Practice (Guidelines for biomedical HIV prevention trials)
HIV/AIDS	Human Immunodeficiency Virus/ Acquired Immunodeficiency Syndrome
ICF	Informed Consent Form
IRB/HREC/REC	Institutional Review Board/Human Research Ethics Committee
MCC	Medicines Control Council
MDR-TB	Multidrug-Resistant Tuberculosis
NIAID	National Institute of Allergy and Infectious Diseases
NIH	National Institutes of Health
PI	Principal Investigator
SAHPRA	South African Health Products Regulatory Authority
SOP	Standard Operating Procedure
TASK	TASK Applied Science

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CHAPTER 1: INTRODUCTION AND BACKGROUND TO THE STUDY

1.1. INTRODUCTION

In 1990 a community-stakeholder structure or Community Advisory Board (CAB) model was formally initiated in the USA at the National Institute of Aids (NIAID) after a group of AIDS activists were invited to participate in an annual meeting of the AIDS Clinical Trials Group (ACTG) in response to community demands. By 1996, Community Advisory Boards were also a requirement for funding for the individual clinical research sites (CRSs) and clinical trials units (CTUs) sites as well. Today community engagement is a pre-requisite for funding by all National Institute of Health (NIH) HIV/AIDS clinical trials networks and sites (HIV AIDS Network Coordination (HANC) and Community Partners in collaboration with USA NIH and NIAID, 2014). Where are we in terms of successful engagement thirty-two years after the CAB model was initiated and what are the views of current CAB members who serve on such a committee?

The organisation, The Desmond Tutu Tuberculosis (TB) Centre (DTTC) is an academic research centre located in the Department of Paediatrics and Child Health, Faculty of Medicine and Health Sciences, Stellenbosch University, Cape Town, South Africa. It was officially named after Archbishop Emeritus Desmond Tutu in 2004, who himself is a TB survivor. The goals of the Centre are built on basic and applied research, as well as on the training of students and communities in all aspects of tuberculosis (TB) and HIV/AIDS. The majority of the Centre's financial support is sourced from research grant funding, obtained through international and national grant funding agencies including networks affiliated to the USA's National Institute of Health. (Desmond Tutu TB Centre Communications, 2019). As a recipient of NIH/NIAID funding the Desmond Tutu TB Centre established its own Community Advisory Board (CAB) in 2015, for the purpose of community consultation in the biomedical health research process. The CAB is appointed as a representative body of the larger community and research participant stakeholder-base in the Cape Metro region.

This case study will delve in to explore stakeholder engagement principles and practises applied in the establishment of the Desmond Tutu TB Centre Community Advisory Board (DTTC CAB) within this university research setting, against the two-way symmetrical communication model and stakeholder theory. It will explore the communication channels adopted in the health research context in which the Desmond Tutu TB Centre (DTTC), engages with the Community Advisory Board and the overall extent of the organisation's

performance in terms of its corporate social investment and its contribution toward the triple bottom line (TBL) of people, profit and planet. The DTTC CAB comprises of a diverse group of individuals, who are a reflection of the community stakeholder and the board acts as an intermediary between the organisation and the community.

Professor Jimmy Volmink, former Dean of the Faculty of Medicine and Health Sciences, Stellenbosch University in Cape Town, South Africa, recently said that he realised that successes and social impact were best achieved when all the stakeholders worked together for the same purpose. (Meehan, S, Yang, B, Van Niekerk, M, Boffa, J, Dunbar, R, Felix, R, James, A, Makola, N, Mandla, N, Molaolwa, J, Naidoo, V, Ndiki, Z, Nel, K, Scheepers, M, Theart, M, Viljoen, L, 2017). This statement acknowledges the stakeholders' power in an organisation and its importance to be aligned towards achieving a common goal. This ideal state of a collaborative partnership can only be achieved through a consultative process between an organisation and its stakeholders wherein mutual respect is a reality and is nurtured.

The state of “stakeholder engagement” and the Community Advisory Board (CAB) as a mechanism

According to Kujala *et al*, 2022, the first murmurs about stakeholder engagement started in the 1990s, but only began to gain prominence in the 2000s. While there is often a fragmented understanding of its construct, the most common understanding relates to the relationship between an organization and its stakeholders through dialogue (Kujala, Sachs, Leinonen, Heikinnen, Laude, 2022).

The King Report (2009) pointed to stakeholder inclusiveness and the Triple Bottom Line (TBL), corporate governance and strategic management. The report describes stakeholder engagement as a fundamental accountability mechanism, in which the organisation is fully accountable and answerable to the stakeholders for their decisions, actions and performance (Steyn, De Beer, 2012).

Rensburg and De Beer (2011) posit that the organisation should conduct research and environmental scanning to collect information on the legitimate expectation of stakeholders and incorporate the findings in the organisational strategy (Rensburg, De Beer 2011).

In 2019, approximately twenty years after the concept was first discussed, we see that researchers have accepted the appointment of Community Advisory Boards (CABs) for achieving participation, collaboration, and community-academic research partnerships with stakeholders (Mlambo, Vernooij, Geut, Vrolings, Shongwe, Jiwan, Flemming, Khumalo 2019).

However, several challenges exist in relation to ethical accountability and power differentials, educational disparity between researchers and the community, role clarification and the motivation for participation. The researcher hopes to highlight and discuss these challenges in relations to the scholarly literature and findings.

1.2. THE THEORETICAL FRAMEWORK

For this study's purposes, the Community Advisory Board (CAB) structure has been identified as a significant representative of the community-stakeholder in health research, as it provides the gateway for researchers to reach the vulnerable stakeholder-communities from which research participants are recruited. The relationship is reciprocal. Communities need new health intervention strategies by the research studies, and the organisation needs the guidance and advice of community representatives serving on the Community Advisory Board (CAB) in terms of raising awareness, approach, messaging, cultural sensitivities and vernacular language use and interpretation. This study will therefore be premised on the framework of the "stakeholder theory" and its approach to an organisation (Freeman, 2010). This theory endorses the corporate environment as an ecosystem of related groups, all of whom need to be considered and satisfied to keep the company healthy and successful in the long term (Freeman, 2010).

From the 1960s through to the 1990s business underwent a paradigm shift when the approach changed to view the organisation as a part of its environment with theories such as corporate social responsibility, corporate social responsiveness and corporate social performance becoming the norm. This shift highlighted the importance of the Triple Bottom Line (TBL) approach, emphasising people, profits, and the planet. The stakeholder approach basically parallels this evolution in the business sphere and required managers to undergo a huge conceptual shift (Steyn, 2002). There was now a need for organisations to recognise multilateral relationships with stakeholder groups to include individuals or groups who themselves felt they had a stake in the organisation and its business (Freeman, 2010). Furthermore, in 1988, Harrison and St John stated that the strategic management process

would include stakeholder consultation to learn from, establish a direction, achieve, and execute goals to satisfy key stakeholders (Steyn, 2002).

The “stakeholder theory” is concerned with the ethical and moral issues involved in the running of an organisation (Freeman, 1984). It is a management process to which this responsibility is assigned. It is based on the assumption that any organisation cannot operate independently of its environment (Freeman, 1984). As such, an organisation and its stakeholders are interconnected (Freeman, 1984). The principles are loosely based on rules of engagement such as transparency, consultation, fairness and longevity (Bhasin, 2020). It is of interest to weigh up these standards of the business organisation and how it may or may not apply to a funded research organisation. It is hoped that this study is able to share the lessons learnt from the stakeholder theory in the context of funded research organisations.

To support the stakeholder theory, the study will explore the findings against the two-way symmetrical communication model. Two-way symmetrical communication points to a dialogue rather than a monologue, which according to Grunig induces “symbiotic changes in the ideas, attitudes and behaviours of both the organisation and its publics” (J. E. Grunig, 1989. P.29). It is based on the premise of equality between the parties, in which both parties are likely to influence each other’s decisions. This is accomplished through bargaining and negotiation to overcome conflict to reach a “win, win” solution, and benefit both parties. (Grunig, Hunt, 1984).

The Stockholm Accord, Good Participatory Practice (GPP) guideline and the King IV Report are existing international and local guidelines which speak to stakeholder relationships that recognise optimisation of stakeholder engagement as being a key to the success and sustainability of every organisation. These guidelines may be instrumental for use as a benchmark in exploring a framework for global and local strategies to value and build stakeholder relations and two-way symmetrical communication.

Philosophical assumptions

Ontological assumption:

In research the philosophy of ontology relates to the nature of being. In this study, we will assume the stakeholder theory from an ontological perspective, based on human social interaction. From a social perspective the world is understood based on the interaction

undertaken with others in a group culture wherein the truth depends on many things as experienced in a group setting (Littlejohn, Foss, Oetzel, 2017).

Epistemological assumption:

Epistemology is the philosophical phenomenon which deals with how knowledge or truth is created and applied. In the context of the stakeholder theory as applies to the Community Advisory Board, the process determining the knowledge is referred to as social construction, wherein the reality is socially constructed within the framework of group and cultural life (Littlejohn, Foss, Oetzel, 2017).

The Paradigm:

This study aims to apply the reflective paradigm of public relations (PR) as suggested by Holstrom, alongside the stakeholder theory. The reflective paradigm of PR does not take a normative or critical stand on PR but acknowledges it as a necessary and neutral function to maintain an organisation as a social system through communication with its environment (Holstrom, 2002).

Furthermore, Burger in a 2009 article, refers to the reflective public relations framework which was first described in a European Body of Knowledge (EBOK) study. In this framework the emphasis is on social development, whereby, public relations is utilised fully as the intervention for both the internal and external environments. In reflective public relations, business is seen as part of society, and the aim is to benefit all of society, which then stands to reason, includes the business. This is in opposition to the market-orientated and social investment public relations frameworks (Burger, 2009).

An organisation's enterprise level strategies should reflect a responsibility to stakeholders, which is an approach that includes non-financial goals which would benefit the society (Steyn, Puth, 2000). This approach is in line with the triple bottom line (TBL) approach which emphasises the equal relevance of people (social), profit (financial) and planet (the environment) (Kenton, 2019). Public Relations and corporate communications' strategic role in the enterprise strategy is notably focussed predominantly on the people and the planet aspects of the triple bottom line approach (Steyn, Niemann, 2010). Implementation of the enterprise strategy incorporating an organisation's values, reputation, governance principles and societal responsibility ultimately leads to organisational sustainability as it will thus be

trusted and accepted as a legitimate and sustainable entity by its stakeholders (Steyn, Niemann, 2010).

In a reflective approach an organisation will evaluate itself against the societal expectations, values and norms; and the interdependence between the organisation and the society is exposed. The strategic role of PR or the corporate communications practitioner will be to view the organisation from the societal perspective with its specific implication of the impact of the organisation towards the society or public sphere. The reflective paradigm has a reflective task managed through PR/corporate communication which involves gathering and analysing information from the environment and feeding this back to the organisation, (inward communication), with suitable recommendations for the benefit of both the organisation and the society. It is important to note that this reflective situation is not static, but constantly changing, requiring adjusted recommendations and approaches (Steyn, Niemann, 2010).

1.3. THE CONTEXT

A Definition of the Desmond Tutu TB Centre Community Advisory Board (DTTC CAB)

The Community Advisory Board (CAB) is a representative body of the larger community-stakeholder group. The organisation, namely, The Desmond Tutu TB Centre is a research-funded department at Stellenbosch University as opposed to a corporate profit-generating business organisation. By definition, a Community Advisory Board can provide the mechanism to harness key community stakeholders expertise and offset those possible power differentials between the health researchers and the participating communities (Simwinga, Porter, Bond, 2018).

Relational Diagram: Desmond Tutu TB Centre Community Advisory Board, the funder and the community-stakeholder.

Stakeholder Map

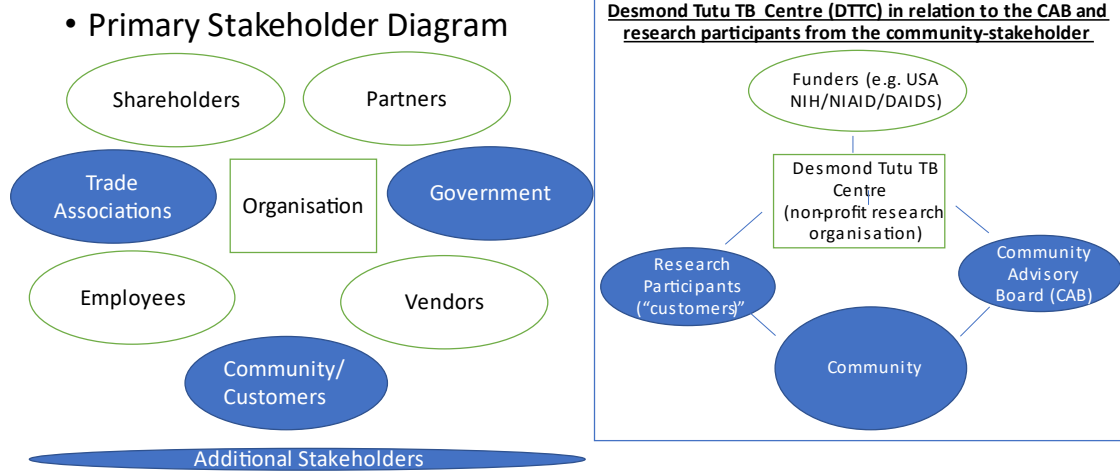


Figure 1. Stakeholder Map (own conceptualisation)

In Figure 1, above, the USA Funder represents the “partner” and The Desmond Tutu TB Centre (DTTC), Stellenbosch University, is the “organisation”. As a research funded organisation, the DTTC’s “customers” are the research participants who are recruited from the high burden TB and HIV-infected and affected communities of the Cape Metro. This vulnerable population is represented by an intermediary body linking the DTTC and the community, namely, the Community Advisory Board (CAB). The CAB is a group of volunteers who have grassroots knowledge about their community and are a diverse group made up of community leaders, clergy, members of non-governmental structures, members of community-based structures, housewives and activists and anyone with a vested interest in the community’s TB/HIV health and wellness. Many DTTC CAB members are themselves TB and HIV/AIDs survivors and have a good understanding of the diseases and the impact health and well-being have on the broader community.

Stakeholders may be internal or external to the organisation, with a vested interest in the business. The primary stakeholders of an organisation are employees, shareholders, vendors, partners and customers (Fernando, 2021). This is typical of the corporate business structure. Since there has been an increased focus on corporate social responsibility, the stakeholder map has been broadened to include communities, governments and trade associations (See Figure 1, pg 7.)

Why does Stakeholder Engagement Matter?

Global trends in all sectors in this century have seen a strong focus on the needs and wants of stakeholders, showing an outside-in approach. An integrated communication approach is needed to maximise stakeholder centrality (Rensburg, Cant, 2009). Integrated communication may be defined as, “the strategic management process of organisationally controlling or influencing all messages and encouraging purposeful, data-driven dialogue to create and nourish long-term profitable relationships with stakeholders” (Rensburg *et al*, 2009, pg 5). The theoretical components of integrated communication are, two-way symmetrical communication and the management of stakeholder relationships, brand relationship management and brand equity and cross-functional processes and planning (Rensburg *et al*, 2009). The case study will explore the organisation’s stakeholder relationships within the dynamic process of two-way symmetrical communication with the Community Advisory Board. The study aims to identify the communication channels used, and to observe how the engagement process is supported and promoted through these channels.

There is a need for managers and academics to restore civil society’s trust by adopting more collaborative partnerships with their environmental stakeholders (Steyn, Niemann, 2014). A company’s stakeholders are those without whose support the organisation would cease to exist (Freeman, 2010). These groups would include customers, employees, suppliers, political action groups, environmental groups, local communities, the media, financial institutions, governmental groups, and more. Therefore, the corporate and academic environment is an ecosystem of related groups, all of whom need to be considered and satisfied to keep the organisation healthy and successful in the long term (Freeman, 2010).

1.4. THE PROBLEM STATEMENT

Community engagement and the use of the Community Advisory Boards (CABs) in public health research has become common practice in recent decades but challenges remain (Reynolds, Sariola, 2018). Questions on independence and autonomy including the control of resources exist. (Reddy, Buchanan, Sifunda, James, Naidoo 2010). Certain scholars highlight power-struggles and window-dressing (Nyirenda, Sariola, Gooding, Phiri, Sambakunsi, Moyo, Bandawe, 2018). Other authors question full participation in the research process (Green, Mercer, 2001), (Strauss, Sengupta, Crouse, Goepfinger, Spauding, Kegele, Millett, 2001). (Green, LW, Mercer, SL, 2001). Scholars are calling for the Community Advisory Board’s scope to be clarified (Mlambo, Vernooij, Geut, Vernooij, Geut, Vrolings, Shongwe,

Jiwan, Flemming, Khumalo, 2019), (Walsh, River, Pinzon, Entriken, Hite, Baldwin, 2015). Problems exist with consultation versus consent (MacQueen, McLellan, Metzger, Kegeles, Strauss, Scotti, Blanchard, Trotter, 2001). The educational disparity between the researchers and the community is viewed as a serious disadvantage (Mwinga, Moodley, 2005), (Musesengwa, Chimbari, 2017). Issues with accountability and community representation and selection are reported (Kafuruki, Juma, Sharifu, Burgess, Abdulla, 2009), (Simwinda et al, 2018). These challenges noted above could potentially affect perceptions and consensus regarding the Community Advisory Board's role in the stakeholder engagement process.

While several journals explore the role of the Community Advisory Board (CAB) in public health research, the researcher was unable to identify many articles which specifically explored the establishment of a Community Advisory Board against the business model of stakeholder engagement. One such study of interest, is an article looking at how to engage stakeholders in health research. Herein the authors address the issue of closing the gap between research production and research use (Boaz, Hanney, Borst, O'Shea, Kok, 2018). There appears to be a gap in identifying a study on stakeholder engagement management in the context of a Community Advisory Board against a public relations approach to the stakeholder engagement theory.

1.5. THE RESEARCH OBJECTIVE

The research objective is to explore how stakeholder engagement principles and practises were perceived by the Community Advisory Board (CAB) members within the university research setting, against the two-way symmetrical communication model and the stakeholder theory.

1.6. THE RESEARCH QUESTIONS

Primary Question:

What processes and practises were implemented to establish a platform for stakeholder engagement with a Community Advisory Board (CAB) in a university research setting.

Sub-questions:

1. What are the channels of symmetrical two-way communication channels and how are these managed to represent the best interest of the community and the research objectives of the Desmond Tutu TB Centre?

2. What do Community Advisory Board (CAB) members perceive their “stake” to be, if any, in the Desmond Tutu TB Centre in the context of its research mandate?

1.7. SIGNIFICANCE OF THE STUDY

This study aims to build on the body of scholarly knowledge related to the establishment of a Community Advisory Board (CAB) for community-stakeholder engagement, focusing on the role of the CAB in a university research setting. The findings are intended to identify principles and practises in setting up the Desmond Tutu TB Centre Community Advisory Board (DTTC-CAB) against the broader backdrop of collaborative and partnership strategies embedded in the stakeholder engagement framework. This (Steyn *et al*, 2010) would be based on taking into account the varying dimensions of working within a funded research setting which is non-profit driven. It will explore the perceived stake of members in the Desmond Tutu TB Centre and to health research in general and their aspirations. Furthermore it will identify which communication channels were applied for meaningful community-stakeholder engagement and how these were managed based on Community Advisory Board members’ perceptions. It will also explore the challenges experienced by the Community Advisory Board members to represent the best interest of the community and the research organisation simultaneously.

Furthermore, the study hopes to contribute to the body of knowledge by exploring communication channels to achieve two-way symmetrical communication between an organisation and its community-stakeholders at the highest level. In so doing, it hopes to highlight the importance of striving to achieve the model of excellence in public relations and corporate communication as cited by scholars such as Grunig and Dozier (Toth, 2007). Thereby, it would contribute towards the broad-based enterprise strategy of an organisation. This is an overarching business strategy which aligns an organisation with the values, norms and standards of the society in which it operates. It gives an organisation its political and social legitimacy, by emphasising the importance of people (social) and the planet (environmental) issues over and above profit (financial) only.

CHAPTER 2: LITERATURE REVIEW

2.1. INTRODUCTION: “The State of Stakeholder Engagement”

2.1.1. The business environment and Public Relations strategies

According to Kujala *et al*, 2022, the first notions about stakeholder engagement started in the 1990s, but only began to gain prominence in the 2000s. While there is often a fragmented understanding of its construct, the most common understanding relates to the relationship between an organization and its stakeholders and scholars generally base their interpretation on Freeman's (2010) theory. However, the article does point to a dark side in which differing goals and expectations, or the clashing of cultural norms can lead to conflict between the organisation and its stakeholders. (Kujala, J, Sachs, S, Leinonen H, Heikkinen A, Laude D, 2022).

Writing from a South African perspective, Steyn and De Beer (2012) cite the financial collapse and the global economic crisis of 2009 as a wake-up call to the world. The authors refer to the King Code of Governance (2009), as introducing the requirement for paradigm shift. It allowed for a platform by which businesses could re-build trust through cultivating relationships with stakeholders. The King Report pointed to stakeholder inclusiveness and the Triple Bottom Line (TBL), corporate governance and strategic management. These strategies encompassed care and consideration for the employees, the customers and the environment and was not only about gaining profit. The report describes stakeholder engagement as a fundamental accountability mechanism, in which the organisation is fully accountable and answerable to the stakeholders for their decisions, actions and performance (Steyn, De Beer, 2012).

To further expand on the above, an article by Rensburg and De Beer (2011) discusses practical methods of engaging with stakeholders. They posit that the organisation should conduct research and environmental scanning to collect information on the legitimate expectation of stakeholders and incorporate the findings in the organisational strategy. Channels of communication such as the web, brochures, events and the integrated report should explain how these expectations were addressed by the organisation. Quoting Foster and Joker (2005:52) the article states that messages should not be passively received and understood by stakeholders. Instead the stakeholder should actively develop meaning in terms of their world perspective. This method of engagement demonstrates a strong reflexive quality (Rensburg, De Beer, 2011). In referencing Muzi-Falconi (2009), these authors deduce that a responsible organization will be effective when it manages to balance the objectives of the organization with its stakeholder groups and the general public (Rensburg, De Beer 2011).

Furthermore, Burger in a 2009 article, refers to the reflective public relations framework which was first described in a European Body of Knowledge (EBOK) study. In this framework the emphasis is on social development, whereby, public relations is utilised fully as the intervention for both the internal and external environments. In reflective public relations, business is seen as part of society, and the aim is to benefit all of society, which then stands to reason, includes the business. This is in opposition to the market-orientated and social investment public relations frameworks (Burger, 2009).

An organisation's enterprise level strategies should reflect a responsibility to stakeholders, which is an approach that includes non-financial goals which would benefit the society (Steyn, Puth, 2000). This approach is in line with the triple bottom line (TBL) approach which emphasises the equal relevance of people (social), profit (financial) and planet (the environment) (Kenton, 2019). Public Relations and corporate communications' strategic role in the enterprise strategy is notably focussed predominantly on the people and the planet aspects of the triple bottom line approach (Steyn, Niemann, 2010). Implementation of the enterprise strategy incorporating an organisation's values, reputation, governance principles and societal responsibility ultimately leads to organisational sustainability as it will thus be trusted and accepted as a legitimate and sustainable entity by its stakeholders (Steyn, Niemann, 2010).

In a reflective approach and organisation will evaluate itself against the societal expectations, values and norms and the interdependence between the organisation and the society is exposed. The strategic role of PR or the corporate communications practitioner will be to view the organisation from the societal perspective with its specific implication of the impact of the organisation towards the society or public sphere. The reflective paradigm has a reflective task managed through PR/corporate communication which involves gathering and analysing information from the environment and feeding this back to the organisation, (inward communication), with suitable recommendations for the benefit of both the organisation and the society. It is important to note that this reflective situation is not static, but constantly changing, requiring adjusted recommendations and approaches (Steyn, Niemann, 2010).

The above Public Relations strategies are embodied in Grunig's Excellence Theory which is leveraged around the two-way symmetrical model of communication. Two-way symmetrical communication points to a dialogue rather than a monologue, which according to Grunig induces "symbiotic changes in the ideas, attitudes and behaviours of both the organisation and its publics" (Grunig, 1989, pg 29). This is accomplished through bargaining and negotiation to overcome conflict to reach a "win, win" solution. To succeed it requires an environment of mutual trust and respect in which parties are equal and communication is used to influence

and adjust each other's ideas (<https://excellencetheory.wordpress.com/2013/09/27/the-two-way-symmetrical-model-of-communication/#:~:text=The%20two-way%20model%20provides,and%20developing%20issues%20or%20problems>)

2.1.2. In the research environment

In biomedical research, the point of departure would be the Good Participatory Practise (GPP) Guidelines for biomedical HIV prevention trials which states that the starting point of any clinical trial is the identification (or “mapping”) of key stakeholders. The guideline defines stakeholders as, “groups, individuals, organisations, government bodies or any other individuals or collection of individuals who can influence, or are affected by the conduct or outcome of a biomedical HIV prevention trial” (Global Advocacy For HIV Prevention (AVAC), 2011). It is known that the term, “community” may be interpreted differently by different people. The GPP Guideline prefers the term, “community stakeholder”, which includes the largest diaspora of stakeholders linked to a biomedical research trial. See the diagram below for examples.



Figure 2.1.2. The Stakeholder Map: Layers of Biomedical Prevention Research Trial Stakeholders. (Global Advocacy For HIV Prevention (AVAC), 2011), page 15.

The GPP Guideline further defines stakeholder engagement as, “a process through which trial funders, sponsors and implementers build transparent, meaningful and collaborative and

mutually beneficial relationships with interested or affected individuals or groups of individuals or organisations with the ultimate goal of shaping research collectively". (Global Advocacy For HIV Prevention (AVAC), 2011).

2.1.3. Conclusion: The State of Stakeholder Engagement

This researcher is in agreement with the findings and deductions in both the business and biomedical research spectrums. Based on the scholarly literature, it can be determined that business and research are very well aligned in their definitions of what a stakeholder is and what stakeholder engagement means. Literature for both business and biomedical research is leaning strongly towards stakeholder engagement being a mutually beneficial relationship, achieved through dialogue. This would refer to the two-way symmetrical communication model and the excellence theory which underpin the overarching theory of stakeholder engagement as the ultimate and desired "state" of care for not only profit, but equally for "people" and the "planet" in the triple bottom line of the stakeholder theory model.

2.2. "THE WAY FORWARD"

The literature on participation and collaboration examines various strategies to address the challenges to varying degrees of success. The literature did not produce any significant identifiable contradictions or disputes, just a plethora of diverse findings and experiences. However, in studying the role, purpose and functions of the Community Advisory Board, several cross-cutting issues emerged. All authors who conducted studies in the USA and several African countries agree that participatory and collaborative research is the only acceptable way forward. This researcher firmly aligns with the position of participatory and collaborative research as the future of stakeholder engagement principles and practises. Still, there is a vast framework of varying findings and experiences, dependent on the context. The literature landscape regarding the role of the research organisation, the Community Advisory Board (CAB) and the ethics committees (IRB/HREC) in community-stakeholder engagement highlights the following main issues and guidelines as discussed below:

2.3. FINDINGS IN THE LITERATURE LANDSCAPE

The findings reported between 1998 and 2019 centred mainly around matters concerning participation, collaboration, ethics, motivation to participate in, and the role of the Community Advisory Board (CAB).

2.4. PARTICIPATION AND COLLABORATION

As far back as 1998, Cox determined that Community Advisory Boards (CABs) are valuable because they help design and promote AIDS research; and Morin (2003) found that Community Advisory Boards can improve the quality of HIV prevention trials through improving recruitment, retention, and the protection of research participants. He further found that Community Advisory Boards can both identify and help resolve ethical issues in HIV prevention research.

In 2001 authors were seeking ways to make public health research more sensitive and participatory by suggesting that any research uptake should be determined by the community involved (Green, Mercer, 2001). According to MacQueen (2001), once a real partnership is established between the researchers and the community, and there is on-going dialogue which allows the community to participate in the design and the implementation of the research, true impact is attained (MacQueen et al, 2001). In the process of seeking to implement more participatory and collaborative styled research with the community-stakeholders over the years, various challenges were experienced.

Approximately twenty years later, by 2019, we see that researchers have accepted the appointment of Community Advisory Boards (CABs) for achieving participation, collaboration, and community-academic research partnerships with stakeholders. Notably by 2019 there is a shift in focus from the authors to during the early stages of setting up a CAB, towards defining the scope, addressing the independence, determining the budget, providing emotional and psychosocial support and continuous training and capacity building, as their recommendations (Mlambo *et al*, 2019).

2.5. ETHICS: ACCOUNTABILITY AND POWER DIFFERENTIALS

One of the most critical factors in the research and community engagement process is the question of ethical conduct. In 2005 Dickert and Sugarman proposed four goals to ensure ethical conduct in community engagement which they recommend should be universal, namely, enhanced protection, enhanced benefits, community legitimacy and shared responsibility (Dickert, Sugarman, 2005). In a study conducted in South Africa, Community Advisory Board (CAB) members expressed their frustration at being fully dependent on the

research teams for their financial support, resources to work in the community and their training; and expressed a need to find alternative financing from a different entity (for example, the Dept. of Health), to operate independently (Reddy *et al*, 2010). As a result, the question to the Community Advisory Board's independence and autonomy to advocate their views independently is raised.

More recently Nyirenda (2018) examined the role of the Community Advisory Board in relation to ethics to determine how to avoid tokenism and address the contentious issue of compensation and democratic representation, which in the studied scenario failed as it became viewed as a form of employment opportunity by Community Advisory Board members. The study concludes that meeting the ethical requirement for true engagement requires Community Advisory Board members to be equipped to provide critical input (Nyirenda *et al*, 2018). Another 2018 article by Simwanga, Porter and Bond, entitled, "Who is Accountable to Whom?", the authors address the accountability relationship between the Community Advisory Board and the researchers, alluding to an imbalance of power existing in favour of the research organisation which held the monopoly of scientific knowledge, research literacy and financial resources (Simwanga *et al*, 2018)

According to Kafuruki (2009) the roles of the Community Advisory Board and the Institutional Review Board (IRB)/Human Research Ethics Committee (HREC) differ. The Community Advisory Board has a purely advisory role, while the Institutional Review Board/Human Research Ethics Committee has a legal mandate to approve or withhold approval of research on either scientific or ethical grounds, something the Community Advisory Board has no mandate to do. The Community Advisory Board may, however, suggest changes in a protocol to the IRB/HREC. The issues dealt with by the Community Advisory Board usually relate to issues of social and cultural ramifications, whereas the IRB/HREC must consider both national and international norms in all discussions (Kafuruki *et al*, 2009).

2.6. THE ROLE AND MOTIVATION OF COMMUNITY ADVISORY BOARDS

Elements regarding the role of the Community Advisory Board (CAB) is cross-cutting through all the literature and is experienced differently in every given context, covering studies undertaken in the USA, Far East and Africa. It does appear that one of the first identified and agreed roles of the Community Advisory Board was to assist with the informed consent requirements in public health research as guided by the Nuremberg Code of 1947 (Mlambo *et al*, 2019), and various other international guidelines.

In the 2001 article, “The Role of Community Advisory Boards: Involving Communities in the Informed Consent Process”, called for improved strategies to ensure that the Community Advisory Board (CAB) is developed to serve the interests of the target community as well as drive the research agenda of the investigators Strauss (2001) argues that while some attention is given to the Community Advisory Board’s role in improving recruitment and participation in clinical trials, no studies evaluated the lessons learned from the Community Advisory Board’s impact on effecting change in the way research should be conducted (Strauss *et al*, 2001).

Walsh (2015) conducted interviews with Community Advisory Board (CAB) members in a National Institute of Health (NIH) research centre to assess what they perceived their role to be. The article, “Assessment of the Perceived Role and Function of a Community Advisory Board in a NIH Centre of Excellence: Lessons Learned” found that every respondent considered the Community Advisory Board’s role to be the liaison between the Centre for Equal Health and the community. Interestingly, in addition, respondents expressed a need for the Centre to tap into and use the skill set present within the memberships and listed either their own skills or skills of other members which was overlooked by the research study team (Walsh *et al*, 2015).

In a South African based study, Reddy (2010) found that the dual functions of advancing the research and protecting the community appear to be filled with tension, thereby requiring careful reconsideration (Reddy *et al*, 2010). It is important therefore to gauge whether there has been a shift in the perceptions of the Community Advisory Board (CAB) and the investigators as to the perceived role of the CAB. In the article, “The Role of Community Advisory Boards in health research: Divergent views in the South African experience”, Reddy critically analyses whether the role of the CAB is to be accountable to the community or to accomplish the research objectives of the research institution. The study highlights four emergent themes namely, purpose, membership and representation, power and authority, sources of support and independence (Reddy *et al*, 2010). This researcher would like to argue that the role of the CAB is to be accountable to both the community and the research organisation.

In their article, “Engaging with Community Advisory Boards (CABs) in Lusaka, Zambia: perspectives from the research team and CAB members”, Mwinga and Moodley (2015) state that a lack of commitment and low research literacy levels of members posed a threat to the role of the Community Advisory Board. Therefore, training for members was vitally important (Miwnga, Moodley, 2015).

2.7. CONCLUSION: THE CASE “AGAINST” AND “IN FAVOUR”

The conclusion was drawn from two opposing points of view in articles published in 1997. One article by Argenti presented a case against stakeholder engagement. The second article by Campbell argued the case in favour of the stakeholder approach theory.

2.7.1. The Case Against – Argenti

In conclusion we need to explore opposing views within literature, either favouring a stakeholder approach or not. In the article, *Long Range Planning*, Vol. 30, No.3 pp. 442-449, 1997, the authors, Argenti and Campbell argue their respective views regarding stakeholders. John Argenti's article "Stakeholders: The Case Against", adopts the basic capitalist argument and framework proposed by, economist, Milton Friedman, that the only stakeholders a company should care about are its shareholders - and thus, its single bottom line (Argenti, 2007). Friedman's view is that companies are compelled to make a profit, to satisfy their shareholders, and to continue positive growth.

2.7.2. The Case in Favour – Campbell

In the opposing camp, Andrew Campbell in his article, "Stakeholders: The Case in Favour", supports the framework proposed by Edward Freeman's stakeholder theory which states that a company's stakeholders include just about anyone affected by the company and its workings (Campbell, 1997). The Case in Favour, furthermore, echoes the sentiment of John Elkington, the famous British management consultant and sustainability guru who in 1994 coined the phrase "triple bottom line" or "TBL" as his way of measuring performance. The idea being that we can manage a company in a way that earns financial profits, and improves the livelihood of society and the environment, in other words, "profit, people and planet" (Kenton, 2019).

2.7.3. Deduction

Scholars who have studied the Community Advisory Board as a representative of the community-stakeholder have found more benefit in the "case for" as it satisfies the ethical requirement of participatory and collaborative engagement, although some ambivalence was also reported depending on the context.

CHAPTER 3: RESEARCH METHODS

3.1. DESIGN

This was an exploratory study using interviews with in-depth qualitative data. A qualitative method, such as an interview is best for interpreting, contextualising, and gaining in-depth insight into specific concepts or phenomenon (McCombes, n.d.). This qualitative approach served the purpose of being descriptive in that it could reveal the multifaceted nature of the setting, the processes, the people, and the relationships. The researcher was also able to draw from policies and guidelines to make recommendations to support and strengthen stakeholder-relationships.

The research design selected to achieve the research objective is a case study with in-depth qualitative data. Case Study Research: Design and Methods, Yin defined a case study as “an empirical inquiry that investigates a contemporary phenomenon (the. 'case') in depth and within its real-world context” (Yin, 2014, pg16).

3.2. ETHICAL CONSIDERATIONS

The main ethical considerations include anonymity, confidentiality, respect, right to comment, provide the reason and background for the research, feedback regarding research outcomes, and adherence to the most recent Data Protection Act SA, 12 September 2019. It should be noted that interviews conducted with the Community Advisory Board (CAB) members entail dealing with vulnerable populations. Specific Human Research Ethics Committee (HREC) guidelines relating to vulnerable populations have been considered. -Reasonable ethical consideration needs to be given to the protection of identities of all research participants. Coding will be used in all cases to ensure anonymity.

-An undertaking to report the findings through data analysis honestly and accurately and adherence to the latest Data Protection Act was applied.

-Power relationships, coercion between the researcher and the participants was considered and explained in the informed consent form. The participation was on a strictly voluntary basis. Participants were informed of their right to withdraw from the interview at any time should they not feel comfortable or if they had any concerns.

-Confidentiality was exercised using an alphabetic and numeric coding method. Documents will be stored for the required period in a secure cabinet in the DTTC offices.

-Any form of bias will be considered unethical. Participants will be ensured of a safe platform to respond honestly and candidly to achieve an accurate outcome.

3.3. PERMISSIONS

Stellenbosch University (SU) & Stellenbosch University Health Research Ethics Committee (SU-HREC)

-In order to pursue a full-scale Research Proposal and Report, formal written permission was sought from the organisations where the research was conducted, namely, Stellenbosch University (SU); and Stellenbosch University Health Research Ethics Committee (SU-HREC) for ethics approval prior to implementation of the research.

Ethics application to the Cape Peninsula University of Technology Faculty of Informatics and Design (CPUT FID)

-The proposal was submitted to the CPUT FID and the CPUT Ethics Committee.

3.4. INFORMED CONSENT

All participants were 18 years and older. To participate as adults, each participant signed an informed consent document regarding their participation and publishing their opinions. Records of the dates of birth of the Community Advisory Board (CAB) members from their SA identity documents are held in the CAB Regulatory file on site. All Community Advisory Board members were given an equal opportunity to participate, however, everyone was not expected or pressurised to participate. This was expressed in the Informed Consent Form (ICF). The Informed Consent Form included the terms and conditions of complete voluntary participation and participants were advised about their right to withdraw at any stage of the interview process if they chose to do so.

Research outcomes will be fed back to participants using their preferred method of face to face or via digital platform such as MS Teams and/or all participants.

3.5. SAMPLE AND SAMPLING LOGIC

The case study design was therefore applied to study the establishment of a Community Advisory Board (CAB) structure in the Faculty of Medicine and Health Sciences at Stellenbosch University.

It explored what principles and processes were implemented in setting up the Community Advisory Board (CAB) and how the members experienced the structure as stakeholders in the context of two way symmetrical communication. It was anticipated that similar results would be produced from any of the current Community Advisory Boards within the South African setting in some respects but could differ widely in other respects as is determined by the context. It is unknown how this will compare to other findings and experiences from the literature which stems from the USA, the Far East, other African countries, and other South African studies. The case study is suitable to learn more about the perceived stake of the Community Advisory Board members in their participation of research undertaken by the Desmond Tutu TB Centre, which is a research unit within the Faculty of Medicine and Sciences at Stellenbosch University.

The interviews reached a sample size of 12 Community Advisory Board (CAB) members. The members reside in various areas of the Cape Metropole. All 25 currently serving Community Advisory Board (CAB) members were invited to participate and the sample of 12 were those who within the 60 day deadline returned their signed Informed Consent forms as requested. These CAB members were then scheduled for interviews which were conducted by an appointment via the Microsoft "MS Teams" platform and email with a backup communication via WhatsApp. The researcher issued the invitation request for an interview and allowed the CAB member to advise their preferred date and time, which was then booked and communicated in writing.

No exception criteria (other than CAB membership and submission of the Informed Consent Form within 60 days) was applied to participate in the interviews. All the Community Advisory Board (CAB) members serving at the time of the interviews were invited to participate, but their participation was emphasised as not being compulsory and that participation or non-participation will not benefit nor prejudice their membership in any way. The participation therefore was conducted on a strictly voluntary basis. Participants were also given the right to leave the discussion at any time should they not have felt comfortable with the process or if they may have had any objections to the process or to the questions asked. This option was also communicated clearly in the Informed Consent Form (ICF) and repeated verbally at the beginning of each interview.

Table 1: Participants demographics and interview record

Participant code	Recording reference	Date/Time	Years of experience in the CAB
A-001	0232	04/10/2022 [16H30-18H00]	7
B-001	*0233; 0242	04/10/2022 [20H00-21H30]	4
C-001	0234	07/10/2022 [10H10 – 11H10]	6
D-001	0235	07/10/2022 [11h30 – 12H55]	4
E-001	0236	08/10/2022 [09H30 – 10H30]	6
F-001	0237	08/20/2022 [15H00 – 16H00]	5
G-001	*0238	10/10/2022 [18H00 – 19H50]	7
H-001	0239	10/10/2022 [20H00 -21H30]	7
I-001	0240	26/10/2022 [19H00- 20H30]	6
J-001	0243	31/10/2022 [10H10 – 11h00]	6
K-001	0244	01/11/2022 [18H00 – 19H00]	4
L-001	0245	03/11/2022 [19H00 – 20H30]	7

**Loadshedding interruption / experienced connectivity issues due to loadshedding.*

(“load shedding” refers to scheduled power interruptions in South Africa)

3.6. DATA COLLECTION PROCESSES

Interviews were conducted with Community Advisory Board (CAB) members on their agreed and appointed times via the MS Teams platform. Individual electronic appointments were emailed to participants. All the invitations were duplicated in WhatsApp via direct messaging (DM) as some CAB members do not have laptops and requested to use their smartphones, as they do for online CAB meetings as well.

Semi-structured interview guides or questionnaires were used for the interviews. All interviews were recorded with the permission of the participants. In this way, it was possible to be replayed and analysed in-depth. In addition, the researcher transcribed from MS Teams as well as hand-written notes of every interview for analysis. In addition a back-up voice recording was also made to circumvent any technical glitches. In the case of participant D-001 the Teams recording was not activated – however, the voice recorder and the handwritten notes were used.

The researcher at every occasion, introduced the topic, putting the respondent at ease and asked specific questions as per the provided interview guide. At times it was indeed necessary to explore the response more deeply and at times it was necessary to re-phrase questions for a better understanding. Responses were also often repeated to enquire if the response was

correctly interpreted. The discussion was recorded with care taken that the equipment did not cause a distraction, (Dawson, 2002), as well as written notes. However, there were two instances where the national loadshedding caused poor connectivity requiring the researcher to repeat part of the interviews with participants B-001 and G-001 respectively. The interviews in most cases lasted the anticipated 60 minutes with 2 stretching to 80 minutes and 3 continuing for between 81 - 90 minutes including those affected by loadshedding. Care was taken by removing the areas of residence from the sample of 12 so as not to compromise identity and confidentiality in this small sample.

Data recordings are being stored in a secure platform under the management of the Desmond Tutu TB Centre (DTTC) Data Department for 5 years. The original informed consent forms and copies of the handwritten notes are stored in a locked CAB Regulatory Filing cabinet on the DTTC office premises at the Faculty of Medicine and Health Sciences in Tygerberg, Western Cape.

3.7. DATA ANALYSIS PROCESS

The interviews have been transcribed. In addition:- (i) details were organised and arranged in a logical order; (ii) data was categorised into themes or meaningful groups; (iii) single instances were examined to find relevant information; (iv) themes and patterns which characterise the cases were identified; (v) a synthesis of the case/s will be constructed (Leedy, Ormrod, 2013). The output resulted in a thematic analysis. To help the researcher with the analysis of qualitative data, the researcher produced an interview summary. This included practical details about the time and place, the respondent codes, the duration of the interview and details about the content and emerging themes (Dawson, 2002). According to Dawson (2002), when data is analysed by theme, it is called a thematic analysis.

The thematic analysis is suggested as a process of identifying themes and patterns from within the data based on the Braun & Clarke 2006 method which allows for flexibility since it is not tied to a particular epistemological or theoretical perspective (Maguire, Delahunt, 2017).

Table 2: based on Braun & Clarke's Framework (Maguire, Delahunt, 2017).

Phase	Action	Description of the activity
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1	Become familiar with the data	Transcribing, reading and re-reading, make notes and jot down early impressions
2	Generate initial codes	Organise the data in a systematic way. Coding reduces data into smaller meaningful chunks of information – codes
3	Search for themes	Translate the codes into themes that capture a pattern
4	Review themes	Review, modify and develop the preliminary themes
5	Define themes	Define what the theme is saying. Identify the crux of the theme. Explore if there are any sub-themes. How do the themes relate.
6	Write-up	Produce a report wherein compelling evidence is listed and discussed.

This 6-phase guide provided the framework determining the lessons learned and challenges in setting up a community advisory board to achieve stakeholder engagement using the two-way symmetrical communication model for the community advisory board at the Desmond Tutu TB Centre.

3.8. TABLE 3: GENERATION OF INITIAL CODES

Interview extracts	Initial codes
<p>Participant background and involvement in CAB and community for context:</p> <ul style="list-style-type: none"> • <i>I live in a community of semi-formal and informal settlements</i> • <i>My community has a high poverty and unemployment rate.</i> • <i>TB/HIV burden is very high in my area.</i> • <i>Some challenges in my community are crime, teenage pregnancy, substance abuse and school drop-outs</i> • <i>My friend told be about the CAB and so I became interested.</i> • <i>My mom was saying that they were honouring a young person from the CAB so I was very interested and joined in 2018.</i> 	<ul style="list-style-type: none"> • Impoverished communities • Social challenges • High disease burden • Word of mouth referrals • Cross-NGO contacts • Health-driven interest • Role clarification required

- *My friend was a member of the P-ART-Y CAB and they were doing interesting things in HIV, so I joined.*
- *I was referred to CAB by a DTTC field worker*
- *I ran an NGO in Gugulethu and so I first became involved in setting up the first CAB structures in SA in 2004 and DTTC CAB in 2015 after training the members.*
- *I was a research participant, then I heard about the FAMCRU CAB. I joined DTTC CAB when it started in 2015.*
- *I responded to a mainline newspaper advert and joined the CAB in 2015.*
- *I am also an executive member of Sisonke, a health focussed NGO in Gugulethu.*
- *I am an executive member of NACOSA, an NGO, a networking HIV and AIDS Committee of Southern Africa.*

- *Seek community contact*
- *Good learning platform*
- *Yearning to share information (with community)*

Expectations when joining the CAB:

- *Well I thought the CAB would interact with the community more so my expectations were not 100% fulfilled*
- *The meetings were very beneficial and I really learned a lot about health*
- *I thought it was just a social club but I was pleasantly surprised and I learnt a lot – I did not know how high the TB and HIV burden was*
- *My expectations were not really met. I want to share more with my community especially youth.*
- *Initially I was very lost and confused but the CAB events on World TB Day were very interesting and insightful.*
- *For the first 3 years I struggled to understand what the CAB was about and why there was a CAB but I now I have learned a lot.*
- *Initially I thought the CAB would be more community outreach work but now I understand we are an institutional CAB*
- *Yes I knew the CAB was about TB and HIV therefore I was interested, but it didn't do work like I thought it would in the community.*

<ul style="list-style-type: none"> • <i>I imagined the CAB would function more in the communities but then I found out the CAB does much background work like the protocol reviews</i> 	
<p>Communication channels between the CAB and the organisation:</p> <ul style="list-style-type: none"> • <i>Communication is conducted via the CAB Liaison Officer (CLO) and the monthly meetings. Yes it is effective because the CLO reports to the organisation's executive.</i> • <i>There is a link between the CAB and the research team through the monthly meetings. Would be good to meet the PI (Director) more often.</i> • <i>There is an opportunity at events like World TB Day to showcase what we learnt but the Dissemination Meeting is not so easy to follow – it is very scientific. [Researcher's comment – The Dissemination Meeting is targeting research staff and services staff from the Department of Health to showcase an overview of the Centre's research studies].</i> • <i>Monthly meetings between CAB and organisation are good, perhaps need twice monthly as one hour is short for a discussion.</i> • <i>The monthly guest speaker is effective but I would like more practical activity and see the doctors and nurses in the work area to see how this research is done.</i> • <i>We have a big group but sometimes I feel like our CAB members do not participate enough. Probably because they do not understand the terminology and research process.</i> • <i>CAB is not initiating discussion as we do not have an idea of the full scope of the DTTC's work, so only reactive.</i> • <i>The Annual Dissemination is good but we need to be up to speed on the work throughout the year. And all CAB members cannot participate during working hours.</i> • <i>It is good to hear from the doctors monthly but sometimes the terminology is very confusing.</i> 	<ul style="list-style-type: none"> • Monthly Meetings are a good channel • Improve participation at monthly meeting • Improve follow-up and feedback • Dissemination meetings are challenging to understand • Meetings at high theoretical and scientific level • Improve direct access and communication • Reactive communication vs pro-active communication • Link communication to feedback and action • Explore alternative communication channels including social media

<ul style="list-style-type: none"> • <i>The monthly communication between the DTTC and CAB is “closed” in that things always come through the CLO. We need to open up communication whereby a CAB member also has access to the DTTC Executive - like slot on the EXCO.</i> • <i>I’m really happy with the monthly doctors’ talks. They inspire us.</i> • <i>The feedback to the doctors from the CAB is always well received. We learn a lot.</i> • <i>At the Dissemination Meetings and the World TB Day the CAB is there to listen. There is no opportunity for feedback. We need an opportunity to ask “where to from now”. How can we meet each other half-way. CAB would like to be more involved.</i> • <i>The follow-up on monthly discussions isn’t working so well. Sometimes we are put on a spot. We say we will re-group to discuss further but never really do. There was only one example when I was invited to join the staff meeting to discuss more. That was good exposure. I felt I could contribute.</i> • <i>Annual Dissemination and World TB Day are always held during working hours so I am not always able to attend.</i> • <i>No, I did not even know DTTC has a website.</i> • <i>No. I am unaware that DTTC has a website.</i> • <i>Why isn’t social media used?</i> • <i>I visited the SU website but never knew DTTC has a website.</i> • <i>Yes. I visited the SU and DTTC websites although not recently. It would be great to post a CAB newsletter then I would visit it regularly.</i> 	
<p>CAB set-up and structure to support stakeholder engagement:</p> <ul style="list-style-type: none"> • <i>We need to explore reaching out to more diverse communities to recruit members.</i> • <i>We need capacity building for CAB members especially the newer members.</i> • <i>We need to address the youth participation.</i> 	<ul style="list-style-type: none"> • Improve member diversity • Member capacity building

<ul style="list-style-type: none"> • <i>The executive structure is working well.</i> • <i>There are lots of opportunities in the CAB and a lot of exposure. When I started 7 years ago I knew nothing. Now I serve internationally.</i> • <i>We must recruit more TB survivors, TB caregivers, TB healthcare workers and TB advocates.</i> • <i>Use social media to recruit more diverse members e.g. the LGBTIQ</i> • <i>Use social media like a FB for CAB members to interact on</i> • <i>Half of the members are young people and we use social media to communicate</i> • <i>I saw how effective Influencers are to raise awareness these days</i> • <i>We need to improve working with local NGOs – it was a good start to send members to the Durban SA TB Conference.</i> • <i>We need the senior members to mentor the youth.</i> • <i>The site needs to involve the CAB more end from the beginning through to the end of a study. There is a big gap between the site and the CAB.</i> • <i>The way we recruit members is not sustainable. We must establish a guiding document and define whom we want to target.</i> • <i>More training is needed for the CAB to work in the communities properly.</i> • <i>Our CAB is constantly improving, but we need to support each other on a personal level as well by taking a personal interest. Then the CAB will be even stronger.</i> • <i>The DTTC must involve the CAB more if there are problems to track down a participant. As CAB we feel we are limited to the office.</i> • <i>CAB members are linked to other structures and we want to be consulted more and contribute and use these connections</i> 	<ul style="list-style-type: none"> • Promote participation of youth • Targetted recruitment • Consider social media • Strengthen local collaborations • Explore extended CAB contributions • Invest in training • Transparency • Raise profile • Structured training • Influencers
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<ul style="list-style-type: none"> • <i>The DTTC CAB manages a good mix across age and gender and respectfully work together (I have seen very different situations in other CABs.</i> <p>The CAB and the community engagement:</p> <ul style="list-style-type: none"> • <i>I would like to emphasize that there must be transparency between the DTTC and the CAB and the community and we need to hear the recommendations coming from the community</i> • <i>We need to raise the profile of the CAB on the DTTC website and raise the profile of the CAB in the community</i> • <i>The CAB can do more community interventions but in a structured manner with proper training otherwise more damage can be done.</i> 	
<p>CAB members’ perceived “stake” in the organisation and in the research process:</p> <ul style="list-style-type: none"> • <i>This is tricky because the CAB does not have real influence because it is not technically neutral. The CAB is dependent on SU to survive.</i> • <i>The CAB needs to drive the research Agenda from the beginning and organisations are exploring to reach this ideal – but at present the CAB just rubber-stamps</i> • <i>Yes absolutely – I see myself having a big stake in the DTTC and in research as a CAB member. It offers me a platform to influence, contribute and to advocate to people in authority.</i> • <i>Yes, in my role as an international rep I interact with high level role players in the political and medical spectrum</i> • <i>Yes I have a personal stake because I have a voice. It is not always immediate but long-term my ideas are implemented and executed so I feel that I am making a difference.</i> • <i>I have grown so much in my knowledge and understanding and as part of the SU-HREC I learnt to understand things I never thought about. I am even considering a career change to work in the community not in corporate.</i> 	<ul style="list-style-type: none"> • Autonomy/power differentials and struggles • Drive the research agenda • Personal stake and community stake • Influence • Voice • Platform • Benefits • Opportunities • Personal growth and development • Career-changing • Life-changing • On-going research is needed

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| <ul style="list-style-type: none"> • <i>I first joined the CAB for personal reasons but I learnt so much I would like to see the CAB working more in the community</i> • <i>I don't feel I am making a difference by attending one meeting a month and I have no platform to share the information I get there. But I attend because I always learn something new. I do agree the CAB is influencing the researchers and we all come from different communities and we can give them good feedback.</i> • <i>I am impressed with the CAB's achievements and how they can rise above the situation. Also friendships develop.</i> • <i>I am given an opportunity to give my opinion but I am shy so I don't. But I volunteer because it benefits me – I learn so much at the CAB and I can teach and help my family. The community can benefit more – we need to have talks in the community.</i> • <i>The CAB is vibrant and members are getting amazing opportunities like travelling overseas to share their stories</i> • <i>Yes I have a stake and my feedback is received positively by the PIs so I feel I am contributing. I volunteer because health and education is my passion and I want to be part of people making a change so I can go to bed feeling good.</i> • <i>I believe I have a platform to influence research. We need more community engagement. I am the voice for the community so I need to engage with the community.</i> • <i>Yes I have a stake in the DTTC and the research. More TB and HIV research is required. I am not aware of any research happening in my community in Phillipi. The CAB needs to work more with the community and visit the clinics.</i> • <i>The CAB has a huge stake and is definitely making a difference and we are being consulted. Many opportunities exist for CAB members – it is not stagnant.</i> • <i>The DTTC-CAB is still developing but definitely moving strongly and in the right direction with good leadership.</i> | <ul style="list-style-type: none"> • NSP targets for 2030 • CAB and community – role • Raise CAB visibility • Raise organisational visibility • Access to new drugs and treatments • Research uptake and implementation |
|---|---|

The Community's stake:

- *The communities greatly benefit from DTTC's on-going research*
- *DTTC has an important role to play in raising community awareness and education in TB and HIV.*
- *There is a big challenge to achieve the National Strategic Plan (NSP) guidelines for 2030 to eliminate TB/HIV/STIs and DTTCs work is making a major contribution.*
- *The CAB also needs to build partnerships with SANAC etc*
- *The community would stand to lose too much if the DTTC stops its work.*
- *The CAB would need to consider an immediate response to work in the community*
- *The CAB could support community such as drug addicts that do not want to go to government health facilities for treatment*
- *The CAB and the DTTC must be more visible in the communities. DTTC is doing very important research but the people do not know what the CAB is and what DTTC is doing. They do not recognize my uniform. I have never seen DTTC working in Delft. So the people do not know what DTTC is doing for TB and HIV. We must do community awareness programmes.*
- *There is a big stake for communities to benefit from research and we need to support research to find a vaccine for HIV and a new TB vaccine.*
- *Communities need access to drugs used in the research*
- *The community must benefit from the research – we don't see much awareness like the mobile trucks anymore in the community to speak about HIV like a few years ago so the young people are losing out.*

3.9. TABLE 4: IDENTIFYING THEMES AND SUB-THEMES

Codes	Themes
<ul style="list-style-type: none"> • Impoverished communities • Social challenges • High disease burden • Word of mouth referrals • Cross-NGO contacts • Health-driven interest • Good learning platform 	<p>Conextual lessons learned</p>
<ul style="list-style-type: none"> • Monthly Meetings are a good channel • Improve participation at monthly meeting • Improve follow-up and feedback • Dissemination meetings are challenging to understand • Meetings at high theoretical and scientific level • Improve direct access and communication • Reactive communication vs proactive communication • Link communication to feedback and action • Explore alternative communication channels including social media 	<p>Communication channels used</p>
<ul style="list-style-type: none"> • Autonomy/power differentials and struggles • Drive the research agenda • Personal stake and community stake • Have influence • Have voice • Platform provided • Benefits gained • Opportunities offered 	<p>CAB member perceptions and aspirations</p>

<ul style="list-style-type: none"> • Personal growth and development • Career-changing • Life-changing • On-going research is needed • CAB and community – role • Raise CAB visibility • Raise organisational visibility 	
Codes	Sub-themes
<ul style="list-style-type: none"> • Autonomy • Power • Independence • Transparency • Scientific knowledge 	Imbalance: power and knowledge differentials
<ul style="list-style-type: none"> • Want to work in the community • Feel like office-based • Feel out of touch and Disconnected 	Role clarification and determination
<ul style="list-style-type: none"> • Yearning to share information • Seek community contact • Word of mouth communication • Scientific knowledge • Seek psycho-social support 	Culture and societal norms
<ul style="list-style-type: none"> • Young members use social Media • Influencers are effective to raise awareness 	Using social media
<ul style="list-style-type: none"> • NSP Targets for 2030 • Research uptake: rollout and implementation • Vaccines for TB/HIV • Access to study drugs 	Lobbying: Linking engagement with government policy/plans

3.10. REVIEWING THEMES AND SUB-THEMES

Theme 1: Lessons learned

Data collected on the theme of lessons learned provided information for an understanding of who the individuals are who serve on the Community Advisory Board and their backgrounds. It provided the researcher with insight to what drives and motivates members of civil society to serve as volunteers on formal structures in a university setting.

Theme 2: Communication channels used

This theme provided an understanding of how the communication between the Community Advisory Board happened and how the efficacy of this communication was perceived by the members. A sub-theme to explore additional channels such as social media emerged.

Theme 3: Member perceptions and aspirations

This theme on members' perceptions and aspirations introduced a varied but consistent framework envisioned by the members to take themselves and the Community Advisory Board into a greater level of expertise and influence with a wider reach directly into the communities. This did raise the question prompting an emergent sub-theme of role clarification and determination.

Sub-theme 1: Imbalance: power and knowledge differentials

This sub-theme initially emerged from the question of the "stake" and the extent of the Community Advisory Board's influence neutrality. It was felt that the power was held by the research organisation who basically determines the budget and thus the neutrality is impacted.

Sub-theme 2: Role clarification / determination

This sub-theme emerged throughout the data collection process where participants at various stages expressed a personal desire to work directly in their respective communities to make a positive change where it was most needed. From the outset the role of an institutional Community Advisory Board does not include direct community engagement and consultation as in the case of a study-specific or ad-hoc community advisory board serving within a specific setting and having a specific purpose.

Sub-theme 3: Culture and societal norms

Sub-theme 3 arose from a sense of cultural norms in which consultation is key. There emerged a sense of hesitance to represent a community without any direct consultation whatsoever. Furthermore a sense of Ubuntu was expressed by members of the identifying a need to connect directly more with both the organisation and the communities which they represent.

Sub-theme 4: Using social media

Sub-theme 4 was an expression from largely the younger contingent who feel that social media is a communication norm and as such should be part of the Community Advisory Board and the organisational engagement.

3.11. TABLE 5: DEFINING AND NAMING THEMES AND SUB-THEMES

Themes and sub-themes	Definition
The lessons learned	Providing a contextual framework to understand the background and personalities of civil society members who volunteer their services in the research setting
Communication channels used	Identifying the medium through which information flows between the organisation, the Community Advisory Board and the community stakeholders and what works and what does not work
CAB member perceptions and aspirations	Taking a deep dive into the perceptions and aspirations of Community Advisory Board Members as to their stake in the organisation and in the research process
Imbalance: power and knowledge differentials	Addressing the imbalance of power between the organisation in terms of the financial control and scientific knowledge and bridging the gap
Role clarification and determination	Clarification and determination of the understanding of the role of the Community Advisory Board and its responsibility towards the organisation and the community stakeholder
Culture and societal norms	Understanding where culture and societal norms meet science and research goals and obligations
Using social media	Using social media responsibly as a positive advantage in a complex and didactic stratosphere
Lobbying government	Linking engagement with government to positive outcomes in research uptake, implementation and access

Defining and naming themes represents the final activity in Braun and Clarke’s (2006) thematic analysis which enabled the researcher to identify the emergent themes and sub-themes presented in the thematic map below.

3.12. THEMATIC MAP OF EMERGENT AND SUB-THEMES

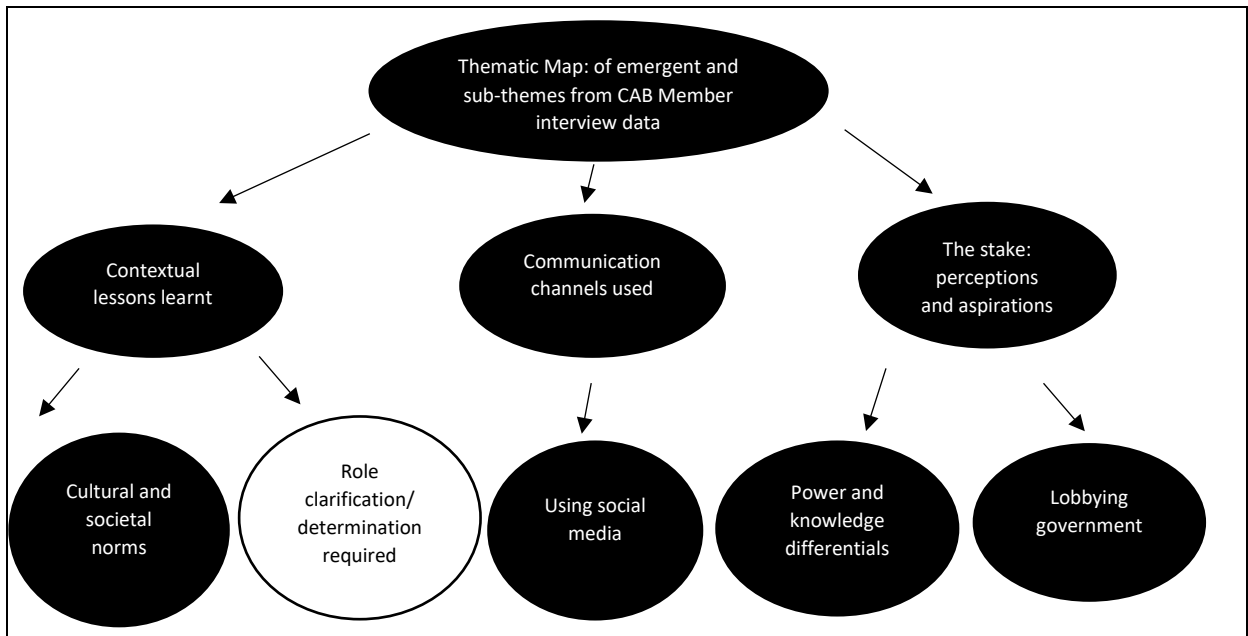


Figure 3.14 Thematic Map of emergent and sub-themes (own conceptualisation)

3.13. CHAPTER SUMMARY

In this chapter the researcher details the method applied for collecting data for the study. A qualitative method was used to learn lessons about stakeholder engagement in the context of a Community Advisory Board in a university research setting.

In-depth interviews were conducted with 12 participants using a semi-structured interview guide and purposive sampling. The data was analysed using the Braun and Clarkes (2006) method by identifying codes and themes relevant to the research objective (Maguire, M;

Delahunt, B, 2017). This required transcribing and reading through the data several times to familiarise herself with the data. Following the step of organising the data into meaningful smaller chunks it was found that much of the data was cross-cutting and relevant to more than one theme identified as listed above. The themes were then grouped and reviewed the themes and sub-themes accordingly, which will be used as the basis for the discussion and findings in the next chapter.

CHAPTER 4: FINDINGS & DISCUSSION

4.1. INTRODUCTION

This chapter will provide an outline of the findings derived from the thematic analysis which were extrapolated from the emergent theme and sub-themes of data collected during this study. Direct participant quotations will be used to support the narrative and illustrate the themes as relate to the study objectives. It should be noted, however, that the quotations from participants are their opinions and perceptions and may not necessarily reflect the true organisational operation and intention; or it may simply show communication gaps around the purpose and function of the CAB and the organisation. *(To be addressed under “Limitations” in the next chapter – suggested further research should be conducted from the organisational perspective where Desmond Tutu TB Centre executives are interviewed to reflect a balanced investigation.)*

4.2. FINDINGS AND DISCUSSION

The themes and sub-themes from Chapter 3 serve as the basis of the findings below and are in response to the aims and objectives of this study. The themes were identified from data collected from participants through an in-depth interview process using the MS Teams electronic meeting platform. The aim of the study is to explore stakeholder engagement principles and practises applied in the establishment of a Community Advisory Board (CAB). In the next chapter these findings will be considered against the two-way symmetrical communication model and the stakeholder theory.

4.2.1. Understanding the context – lessons learnt:

Valuable lessons were learnt by getting to understanding the context in which the volunteer Community Advisory Board (CAB) members and the community stakeholders whom they represent, live, engage and operate. Also referred to as

community psychology, there is a leaning towards including research in the ecology of lives wherein the assessment of social settings and their impact on behaviour, culture and diversity is considered (Trickett, 2009).

Participant G-001 said, *“I live in a community of semi-formal and informal housing structures. One of the challenges is health and in particular TB and HIV and stigma is a huge challenge. We have a high population of young adults living here aged between 17 – 25 years, many of whom were born HIV+ and most are unaware of their status, compounding the spread of the disease.”*

Participant C-001 said, *“Our challenges in the community include crime, teenage pregnancies and school drop-outs.”*

Participant B-001 included the following, *“There is high unemployment especially amongst the youth. Participation in sport and extra-curricular activities is impossible because infra-structure has been damaged or stolen.”*

Participant D-001 added, *“The challenges are drug and alcohol abuse and people are living under unsanitary-conditions.”*

Participant F-001 stated, that *“There is a lack of knowledge and awareness especially amongst the youth. They know about the high burden of diseases [TB/HIV], but they don’t care about living healthy lifestyles and they do not exercise either.”*

The responses to the community lifestyle and challenges were reportedly very similar across all the participants. It lent a deeper understanding and insight into why the CAB members possibly are so committed to serving as volunteers on a Community Advisory Board to support research to relieve the high burden of TB and HIV in their respective communities. Some participants are concerned by the decline in governmental awareness programmes which were present in their communities for HIV education in previous years. Several information sessions were conducted at schools but type of campaign this has largely dwindled to nothing more recently.

This situation may very well be giving rise to the feeling of at least 83% (n=10) of participants wanting to engage directly within their various communities to raise awareness and education by sharing information. This emergent theme will be discussed more under the sub-theme, “cultural and societal norms”.

Cultural and societal norms:

There is an overwhelming level of feedback from all participants stating that they believe that direct community-stakeholder interaction is desired and a much needed role for both self and community-stakeholder validation for the role which they perform as community-stakeholder representatives, serving on the DTTC-CAB. Most participants said that they joined the CAB with the expectation to be directly involved in education and awareness about TB in their respective communities and areas of influence. Some feel strongly enough about this in what could be described as the African cultural ethos as contained in the spirit of Ubuntu which states, “*Umuntu Ngumuntu Ngabantu*” or literally translates to “A person is /becomes a person through other people”. It essentially means that all people are connected and that one person can only grow and progress through the development and progress of other people. “Ubuntu” has thus been used as a reminder for society on how we should be treating other members of society. (Bolden, 2014). The need for direct community interaction is expressed in examples below from participant interviews.

“The community should be better informed about the CAB. There is also still a big separation between CABs and researchers, and this is a problem. The community needs to be more informed about research and the CAB needs the trust of the community. The community needs to understand the CAB’s function and this is the case even for an institutional CAB. Once this link is strengthened, the research process will be positively impacted, recruitment of research participants will improve, myths will be removed, there will be collaboration and the community can help to find quick solutions.” (Participant H-001)

“We [CAB] need to interact more with the community and maybe go to the clinics to introduce ourselves and share what we do. This could build good relationships. Health is my concern and I have a love for my community. By being in the CAB I am helping the whole community without them even knowing it. I don’t need respect but the whole community must benefit. Being in the CAB gives me a sense of purpose and I do not need anything in return” (Participant G-001)

“We need more direct community interaction. We need more time with the people whom we advocate for so the community knows us. We need that visibility. We can adopt

quite a casual approach so that we can relate to everyone. We need to speak the peoples' language and speak at their level. And, the community must be able to relay their own issues back to the CAB as the CAB is in the middle. This will also be valuable to the CAB so that we can make an impact.” (Participant K-001)

“I would like to see us setting up community meetings with the youth. The youth will be very interested if we have activities that draw them like games and competitions.” (Participant E-001)

“The CAB can do more direct community interaction if like our community engagement initiative via the TB Advocacy Group (TAG) and the Community Research Advisory Group (CRAG) who are sponsoring it because it can get quite involved and we will need extra financial support and resources” (Participant A-001)

4.2.2 Communication channels used:

CAB members were largely satisfied with the regular monthly meetings as a channel of communication whereby a Principal Investigator (PI) would review a protocol; provided study updates; or requested feedback for a new study or grant application or discussed the Informed Consent Form (ICF) and community sensitisation strategies. However, there were some varied opinions which are also included below. The researcher simultaneously wished to explore evidence of two-way symmetrical communication and the stakeholder theory.

“The monthly meetings are effective. There are regular monthly speakers and the CLO is present at all the monthly meetings. The CLO also reports to the Centre’s Executive which is very important.” (Participant A-001)

However, in contradiction, 1 member felt that he considered communication between the CAB and the organisation to be too controlled and that there ought to be more spontaneity and flexibility.

“The CLO always gives good feedback when there is a question posed to the organisation, but at times this engagement should extend to the full CAB executive or the CAB chairperson should be invited to attend and speak at the organisation’s executive meeting as well. However, I am really happy with the monthly meetings and

the doctors' presentations to the CAB. This really drives and inspires us." (Participant K-001)

A third CAB member stated that he had years of experience with community structures and in his opinion the DTTC-CAB's expectations are met in terms of managing communication channels effectively.

"Monthly DTTC-CAB CAB meetings have an open channel of communication which is largely dependent on the Community Liaison Officer (CLO). In my past experience there seemed to be fear to put community concerns to the organisation. This is not my experience in the DTTC-CAB at present. When questions are asked by the community these are all addressed. There is good communication and we get a response. The role of the CLO is vital to ensure that this happens." (Participant H-001)

A fourth CAB member stated that the monthly meetings were effective and improved his understanding and experienced the meetings as an opportunity to link to the clinical research team.

"The monthly meetings are effective. It improved my understanding of clinical research and it provided communication link between the CAB members and the research team." (Participant B-001)

Another participant agreed that the monthly meetings were beneficial and that she learnt a lot. Interestingly, she found the online meetings during lockdown advantageous as there was more time to study presentations and interact without interrupting the speaker by using the "chat" option on MS Teams and so she built her confidence levels engaging in this manner.

"The Meetings were very beneficial and I learnt a lot for health from the guest speakers. During lockdown there was more time to participate. I felt very comfortable with the online meeting as I could easily type statements and questions in the "chat". This was a good opportunity. I became more confident. Online was positive!" (Participant C-001)

Another participant suggested that the allocation of one hour during the monthly meetings to listen to a presentation and provide feedback was too short.

"Sometimes we, [the CAB] are put on a spot when we are trying to understand [and deliberate]. Then we say will re-group and provide feedback, but we never do so there

is no follow-through and the opportunity is lost. Sometimes there are long periods of silence between study updates. We need a list of all the DTTC studies with the intended timeframes to initiate specific follow-up. I quite enjoyed one Principal Investigator's approach to invite me to join the staff meetings in formulating a grant proposal. It was good exposure for me to be involved in the protocol development." (Participant I-001)

When exploring the Stellenbosch University and Desmond Tutu TB Centre websites as a possible channel of communication between the CAB and the organisation there was one participant who suggested that it may be good to add the CAB's Weekly Report to the website to share the CAB's activities in a more public space. However, only 6 participants have visited one of the websites and of the remaining 6 participants, some were unaware that there was a website at all. Hence there was not an emerging sense of much interest in the website, with several of these participants requesting some form of interactive social media platform instead. Some quotations to support the above finding are listed below and the social media will be addressed as an emergent sub-theme.

"Yes, I visited the DTTC website. SU website is good, but I did not find much interaction with communities. There were more reports on academia, nothing extra." (Participant B-001)

"I was unaware that SU and DTTC have websites. A Facebook page may be better for sharing information." (Participant D-001)

"I have visited the SU and DTTC websites. There was no drawcard for me personally. Why isn't social media used? Facebook, Instagram, Twitter and You-tube will be more effective." (Participant I-001)

"Yes I have visited SU and DTTC websites, although not lately. I would like to see the CAB newsletter of the website because that is community engagement, and we can raise the profile of the CAB. And also would be good to include socio-behavioural research so CAB members can also read about the challenges because we are not out there in the field." (Participant H-001)

4.2.3. Exploring the "stake" of members through perceptions and aspirations:

The general response of the participants leaned towards the perception that they considered themselves to have a "stake" in the organisation and the research process.

They were also very forthcoming in what some of their additional aspirations were. Here we would also include some of the responses which CAB members shared during the interview process.

In response to the question as to whether the participant feels that her or she has a personal stake in the research process or feels that they have an influence on the research, some responses recorded were as follows:

“Oh yes, absolutely. It is even exciting to be in the CAB. I see a huge gap [of opportunity]. The CAB is a very important platform to develop personally and influence and contribute and advocate to people in authority. In our international role we interact with high level role players the medical and political spectrum” (Participant B-001)

“Yes, I have a voice. It is not always an immediate [to see results], but long-term I see my ideas being implemented and executed. So I believe that I am making a difference.” (Participant C-001)

“The achievements reported in some of the on-going studies give hope. And knowledge on what is happening in the TB landscape. In the CAB we are at the receiving end of knowledge, action and opportunity and I have a platform to add my voice.” (Participant I-001)

“Yes, I believe that I am contributing towards research because the research is presented to us to provide feedback and the Principal Investigators (PIs) respond positively to the feedback.” (Participant K-001)

“Yes, I have a platform in the CAB to influence research, to tackle challenges and influence the language in the protocols.” (Participant L-001)

“Yes, [we have a stake and influence] because when the doctors come to explain the studies the CAB is asked to give feedback. So yes, the CAB plays a huge role.” (Participant G-001)

“The CAB is definitely making a difference in research, and we are being consulted. Many opportunities are afforded to CAB members for exposure nationally and internationally.” (Participant H-001)

There were 3 participants who responded that they do not feel they have a stake in the research process, however, when rephrasing the question and delving deeper the

participants did express the belief that being part of the CAB allowed them to influence and contribute to the research process and that it was beneficial to them:

“No I don’t feel that meeting once a month for a few hours that I can make a difference. I am getting information but it is only for me and not the community. But I do believe the CAB is influencing the researchers. And we are from different communities and can give very good information.” (Participant E-001)

“No, I have not put in the effort. I think I lack confidence. Maybe if I need to present. I will feel different [if given the responsibility]. It is better in small group discussions. I volunteer because I always learn something new in health and its good to know about health especially in young people and children.” (Participant F-001)

“No, I am given the chance to ask but I struggle to talk in public although no-one is judging. I volunteer because it benefits me and I can inform and share this knowledge with my family.” (Participant J-001)

Power and knowledge differentials:

When asked about having a stake the research process 1 participant raised the scenario discussed in the literature review regarding the issue of power and knowledge differentials between the CAB and the organisation (Simwinga *et al*, 2018).

“With regard to having a stake, I believe that we [the CAB] do not have that level of influence. In our role we need to be neutral and independent. But the CAB is dependent on SU to survive. So on paper we are independent – but not really. Furthermore the CAB is not involved in the study design. We are merely rubber-stamping. The CAB needs to drive the research agenda more.” (Participant A-001)

Another participant shared part of this view, wanting to see increased CAB involvement in the entire research process, noting that the CAB is more responsive as opposed to being pro-active. Some of her views are shared below.

“The CAB is not initiating contact with the DTTC study team. We tend to get “lost” in the whole process of all the studies. We need a list with DTTC’s full scope of studies and overview on a spreadsheet with relevant information such as the timelines

involved/the target population/the area for recruitment. Because we don't have this it is difficult for the CAB to initiate contact and we remain on the receiving end [of what the organisation chooses to present and when]. Such a document will empower the CAB to request updates and improve the two-way communication between the CAB and the DTTC.

Also the CAB plays a big role in the research process and there are cases where research was stopped from being done in communities. However, the CAB needs to be involved from the very beginning of the entire research process. There is a big gap between the CAB and the [DTTC] site." (Participant I-001)

Aspirations – why volunteer to be a CAB member:

Civil society or community-stakeholders voluntarily offer their time to serve on structures such as the Community Advisory Board to engage with clinical staff in various academic research and other similar institutions. When asked why they volunteer, they responded as mentioned below:

"I have a passion to improve the situation in my community and I can contribute to improve community health issues by volunteering my time." (Participant A-001)

"I always served as a volunteer – even in college I served on the SRC. I feel there is an absence [sic] for health improvement. I would like to do a CAB Newsletter which is accessible to more at anytime." (Participant B-001)

"At first I joined the CAB for social reasons, but now that I understand that it is about taking a stand to make a difference to this side of health I am very invested, and I have been grabbing opportunities. I joined the SU Ethics Committee as a community advisor." (Participant C-001)

"The reason why I volunteered is for personal family reasons as my cousin contracted TB. I wanted to gain some education and self-learning." (Participant D-001)

“I personally volunteer to be more involved and in my mind I have committed this time to do this work.” (Participant E-001)

“I volunteer because I always learn something good and new in health especially about young children.” (Participant F-001)

“I volunteer because health is my concern and I have a love for my community. With the CAB I can help the whole community and I do not need anything in return.” (Participant G-001)

“Personally my passion is to find solutions to help people. I was able to develop self and I have recently joined the SU Ethic Committee. There are great opportunities in this work – it is never stagnant. There is reward and upward mobility and it provides one with a good experience.” (Participant H-001)

“I volunteer my personal time because TB is a huge burden in SA and I we need to eradicate TB. I also benefitted from working in the CAB by learning new skills such as Minute taking. I am also exposed to interesting seminars and I am representing the CAB on a global level and receiving international exposure” (Participant I-001)

“I volunteer because it benefits me and I gain a lot of knowledge so I can inform and educate my family. The CAB members are vibrant and I like to see members are getting great opportunities even sharing their stories internationally.” (Participant J-001)

“I volunteer because community health and education are my passion. So I want to be a part of people bringing change.” (Participant K-001)

“I want to ensure that the community is represented correctly. I am a voice for the community to say what is acceptable or not because I am the one who understands. I am also there to get more experience.” (Participant L-001)

Lobbying government and aligning government policies and plans and external collaborations:

There is a burden amongst CAB members to link in with the government policies and plans and lobby government to implement research findings and roll-out tested diagnostics and treatments promptly and provide on-going access to care for research participants. The interviewed participants also shared a keen interest in strengthening local collaborations with SA-based civil society structures.

“We will be facing a big challenge to contribute towards reaching the 2030 target to eradicate TB and HIV according to the National Strategic Plan which will be launched next year. It may be good to consider forming collaborations with organisations such as SANAC to strengthen our relevance in the TB/HIV landscape.” (Participant A-001)

“Locally we are weak and not yet on the right level of of collaborations. There is a gap, but sending representatives to the 7th SA TB Conference in 2022 was a good start. In the past we also made good contacts through the TB/HIV Care network and could be considered.” (Participant I-001)

“We could consider networking locally through high customer yielding service outlets such as barber shops and hair salons in the townships.” (Participant B-001)

“I can speak to TB Proof colleagues to build collaborations with them for community outreach and community engagement.” (Participant L-001)

4.3. SUMMARY OF FINDINGS

In conclusion, the data from interviews conducted and discussed in chapter 4 provide valuable lessons to understand the context in which the participants live and respond to the social environment and what their perceptions are. Participants were candid and forthcoming about their experiences in the structure and the functioning of the Community Advisory Board to continue strengthening community engagement principles and practices in the future. This exercise provided an opportunity to explore recommendations in the next chapter in which the Community Advisory Board and the organisation may consider the way forward in a manner

which further enhances the stakeholder theory and incorporates a framework to achieve common goals by applying the principles to strengthen two-way symmetrical communication. The researcher invited participants to share experiences from their community to establish the context and provide the researcher with an understanding of their world view.

Stakeholder needs and expectations: Rensburg and De Beer (2011) posit that the organisation should conduct research and environmental scanning to collect information on the legitimate expectation of stakeholders and incorporate the findings in the organisational strategy. On this basis it is important to be cognisant of the fact that this Community Advisory Board is an institutional CAB and was not established to link actively and directly with the rest of the stakeholder community. However this need was expressed by the majority of the participants as lacking in their perspective. This expectation will be threaded through the recommendations section. The intended role and function of an institutional CAB is based on a long-term ongoing appointment and does not involve direct community interaction. A study-specific CAB on the other hand is appointed for a short-term for the duration for the study and members are directly involved with the community and usually hail from that community as well. A challenge for the organisation would be to support the CAB to creatively extend their communication to be that link between the organisation and the community. In this extended function the two-way symmetrical model of communication would need to be extended to include CAB and community interaction. (Refer to the Stakeholder Map, figure 1 page 7).

Channels of communication: Channels of communication such as the web, brochures, events and the integrated report should explain how these expectations of stakeholders were addressed by the organisation according to Rensburg and De Beer (2011). While the CAB members experienced the monthly meeting interaction with the organisation in a positive light and identified value in the communication between themselves and the researchers, the other existing channels of communication in the organisation were not reaching and extending to the CAB members. CAB members were largely unaware of the organisation's website and the printed materials. These channels if adapted and shared more actively and if used to address more stakeholder community expectations and experiences, could become a valuable channel for enhanced communication. The organisation has demonstrated an interest in promoting an environment of respect and trust by including the community members in their organisational events such as the annual dissemination meetings and event such as World TB Day commemoration. Although the meetings a predominantly scientific in nature the gap in scientific knowledge can be addressed by continued training and capacity building efforts. (Mwinga, Moodley, 2005)

Having a personal stake in the organisation and the research process: Scholarly articles and literature refer to the collaborative partnerships and mutually beneficial relationships as a key element of stakeholder engagement (MacQueen *et al* 2001). The general consensus from CAB members was that they were given a platform to voice their opinions and contribute to the overall research agenda of the organisation. CAB members felt that their ideas were considered and implemented by the research teams. Some CAB members felt that they wanted to make an even greater contribution by sharing their personal and collective skills in advancing the research goals of the organisations. They would like to be consulted more broadly when issues such as strike action and security matters arise in the communities and other strategic educational interventions are considered beyond the scientific research platform.

In the GPP Guideline (2011) AVAC goes a step further by adding that these collaborative partnerships ought to achieve have the ultimate goal of shaping research collectively (Global Advocacy For HIV Prevention (AVAC), 2011). While an instance did emerge whereby a participant experienced involvement at the project design stage (when she was invited to participate in the staff brainstorming sessions until the project came to fruition), others raised concern that they were mere rubber-stamping new research studies and not being involved at the design stages.

One participant also alluded to the sentiments from the study in South Africa conducted by Reddy (2010), echoing some frustration at being fully dependent on the research teams for their financial support, resources to work in the community and their training (Reddy *et al*, 2010). There is therefore a challenge to the organisation to support the CAB to find alternative financing from a different entity, to operate more independently in the future. The organisation would need to address ways and means of supporting the CAB structure with the resources and financial management systems to manage external funding options.

According to Grunig (1989), two-way symmetrical communication in the excellence model induces “symbiotic changes” in the ideas, attitudes, and behaviours of both the organisation and its publics (Grunig, 1989). There is some evidence to support the basis of this theory from the participants’ views which state that their questions put to the organisations have been addressed with the appropriate responses received and actions taken. This is in reference to responses from participant H-001 in particular, when sharing his experience.

5. CHAPTER FIVE: CONCLUSIONS AND RECOMMENDATIONS

5.1. INTRODUCTION

Today researchers realise that stakeholder relationships are important, and the power, legitimacy and urgency of every stakeholder needs to be determined. Relationship building needs to be a key action item in the organisational strategy (Myllykangas, Kujala, Lehtimäki, 2010). The importance of stakeholder relationships and salience has been addressed in the literature (Mitchell, Agle, Wood, 1997). The stakeholder's role, however, is what determines the dialogue required to build the relationship. This dialogue becomes the lifeblood of the organisation and needs nurturing. The foundations of participatory stakeholder engagement in public health research are embodied within the guideline document, "Good Participatory Practice" (GPP), which highlights the importance of building strong collaborative partnerships between an academic research team and the community stakeholders. The authors posit that stakeholder engagement is an investment in the biomedical research process and should be mutually beneficial. (Global Advocacy for HIV Prevention (AVAC), 2011).

Other international and local guidelines that speak to good corporate governance and stakeholder relations are, for example, the Stockholm Accord (2010) and the King III Report (2010). The King Report became internationally acclaimed as the most comprehensive approach to corporate governance. The Report was updated to version II in 2002, followed by King III in 2009 and King IV in 2016 (www.iodsa.co.za). Chapter 8 of the King III Report and Part 5.5 of the King IV Report is dedicated to governing stakeholder relationships (www.iodsa.co.za).

The Stockholm Accords were published on 15 June 2010 as a call to action for Public Relations and Communication in a global society by industry leaders representing every continent. The Report captures the essence of stakeholder management under the broad framework of: i) sustainability; ii) governance; iii) management; iv) internal communication; v) external communication, and vi) the co-ordination of internal and external communication (The Editorial Board of the Global Alliance, 2010).

This chapter will conclude by discussing the key findings of the study based on the research questions and will be discussed to evaluate how these findings speak to the theoretical framework which points to the stakeholder theory and the two way symmetrical communication model. The key findings will also be discussed of topical themes identified within the literature review. The findings will also be addressed in relation to the above mentioned guidelines.

5.2. THE RESEARCH QUESTIONS

The research questions posed to participants, comprised of 4 categories, namely:

- (i) The participant's background: the community challenges, how they were informed about the Community Advisory Board (CAB), length of service, other civil society affiliations.
- (ii) Communications channels between the CAB and the organisation: what are the platforms, organisational awareness; participation in DTTC events, describe current/desired engagement with the community stakeholders.
- (iii) How CAB is set-up, structured and supported to achieve community engagement: how are members recruited and selected; how to target diversity and promote inclusivity; opportunities for partnerships and collaboration
- (iv) What is the CAB member's stake in the organisation and in research: personal stake; community stake; why do you volunteer; is TB/HIV research still relevant to you/your community

5.3. KEY FINDINGS

5.3.1. The Stakeholder Theory as guiding a principle

The "stakeholder theory" basically highlights the importance of the interconnected relationships which exist between an organisation and its publics and a stakeholder is defined as any group or individual who can affect or is affected by the achievement of the organisation's objectives (Freeman, 2010). In the Good Participatory Guidelines document (GPP), stakeholder engagement is defined as a process through which researchers build transparent, meaningful, collaborative and mutually beneficial relationships with stakeholders with the aim of shaping research collectively (Global Advocacy For HIV Prevention (AVAC), 2011).

In this case study we selected to explore the achievement of the stakeholder theory in the relationship between, the Desmond Tutu TB Centre (DTTC), a research centre affiliated to Stellenbosch University as the "organisation" and the Community Advisory Board (CAB), appointed by the DTTC as a representative body of stakeholders of the community stakeholders. These Community Advisory Board members are invited from the various sub-districts of the Cape Metropole from which the research participants are recruited.

The researcher conducted in-depth interviews from a sample of 12 CAB members as participants to establish what processes and practises were implemented to establish a platform for stakeholder engagement through the establishment of a Community Advisory

Board (CAB) in this university research setting to achieve stakeholder engagement and the communication channels applied to achieve this.

It was found that members were initially recruited by means of advertisements and in local news media and local clinics and thereafter mainly by word of mouth to form a group of 25 active members since its inception in 2015. The primary means of engagement is by a regularly scheduled monthly meetings. These monthly meetings are hosted by the organisation's CAB Liaison Officer (CLO) at which all CAB members were invited to engage with any one of the Principal Investigators (clinician) and other members of the research study team to discuss various research related matters ranging from protocol reviews, informed consent language and translation, study updates, results dissemination. The same monthly meeting platform was also used to inform and consult CAB members regarding new research grant applications or any study related matters.

The general response from the participants indicated that these meetings were well received and an excellent opportunity to discuss and provide feedback which was well received by the study teams. The participants agreed that the meetings were effective and a good opportunity to engage in the research process of the organisation. The level of knowledge participant felt they gained from these meetings was immeasurable and many have used this knowledge gained to inform neighbours, family and friends. CAB membership elevated members to a higher status within their local communities as they were knowledgeable about diseases such as TB, HIV and research (especially regarding new diagnosis, treatments shortening regimens, novel drug formulations and child-friendly formulations). Detailed responses from the participants is detailed in chapter 4 above.

Furthermore the organisation extended invitations to CAB members to join in the various scientific events hosted by the DTTC for its staff such as the "Annual World TB Day" event and the "Annual Dissemination Meeting" as well as the regular international scientific webinars and virtual meetings hosted by its funders internationally. This level of interaction for the CAB and the staff to meet in person or virtually has promoted stronger relationships in which the CAB members benefit and experience the attribute of inclusivity from the organisation. Participants also expressed pride in having the opportunity to represent the site as international representative on the global platform as this was very empowering.

Some recommendations which emerged include (i) structuring the monthly discussions in the form of a workshop to allow small group discussion. In so doing it would facilitate and encourage the less vocal and newer members to participate in the process. (ii) It was also suggested that providing the CAB members with a spreadsheet detailing a portfolio of all studies would enable the members to be more proactive in engaging about specific studies and areas of interest as needed. (iii) CAB members would like to explore opportunities of

working more directly in the communities to provide education and raise awareness in the fight against TB and HIV. It is felt that this area of more formal engagement in the communities would help to raise the profile of the organisation and help to reduce the high burden of TB and HIV in their communities. (iv) more training and capacity building for CAB members in areas such as research competency would greatly enhance the dialogue at monthly meetings and overall provide greater empowerment to members when engaging with researchers.

5.3.2. The two-way symmetrical model of communication as a guiding principle

The stakeholder theory may be underpinned by the “two-way symmetrical model” from Grunig’s Excellence Theory. This model may be defined as a dialogue between two entities – in this case the Community Advisory Board and the Desmond Tutu TB Centre – in which both are equally likely to influence one another to change their opinions (Grunig, Hunt, 1984). The underlying factor according to Grunig is that symmetrical communication is built on trust. When there is trust, transparency, honesty, integrity and respect become the common denominator which allows for equal communication between an organisation and its public at this level (Grunig, 2013). This principle includes negotiations and bargaining.

The researcher would like to refer to a participant’s feedback as discussed in chapter 4 during the in-depth interview process to argue that the organisation has endeavoured to build that environment which is conducive to mutual trust and developed a channel for two-way symmetrical communication to exist. More can be done by the organisation in terms of capacity building and skills training initiatives to equalise the playing field for community members.

“Monthly DTTC-CAB CAB meetings have an open channel of communication which is largely dependent on the Community Liaison Officer (CLO). In my past experience there seemed to be fear to put community concerns to the organisation. This is not my experience in the DTTC-CAB at present. When questions are asked by the community these are all addressed. There is good communication and we get a response. The role of the CLO is vital to ensure that this happens.” (Participant H-001)

If a PR practitioner is able to share the voice of the external public at strategic management level it means that the external public has a voice at the executive table and demonstrates an

environment conducive to two way symmetrical communication. This model creates a level playing field for negotiation and mutual understanding (Grunig, 2013).

The researcher would like to argue that the organisation has demonstrated its openness to engage with the CAB at executive level by supporting the statement from another in-depth interview discussed in chapter 4.

“The monthly meetings are effective. There are regular monthly speakers and the Community Liaison Officer (CLO) is present at all the monthly meetings. The CLO also reports to the Centre’s Executive which is very important.” (Participant A-001)

5.3.3. International guidelines

The Stockholm Report captures the essence of stakeholder management under the broad framework of: i) sustainability; ii) governance; iii) management; iv) internal communication; v) external communication, and vi) the co-ordination of internal and external communication (The Editorial Board of the Global Alliance, 2010). The researcher would like to posit that a positive sense of the above mentioned components are upheld within the Desmond Tutu TB Centre organisation and the Community Advisory Board which has long-term serving members, with both structures managed by an actively engaged executive structure, both operating effectively at a an international level seem to have a solid foundation to achieve strong stakeholder engagement principles and practises.

Both the DTTC and the CAB seem well placed to comply with the King III (2009) and King IV in (2016) which was drafted in South Africa and has international acclaim. Chapter 8 of the King III Report and Part 5.5 of the King IV Report is dedicated to governing stakeholder relationships (www.iodsa.co.za). Principle 16 of King IV reads, “In the execution of its governance role and responsibilities, the governing body should adopt a stake-holder inclusive approach that balances the needs, interests and expectations of material stakeholders in the best interest of the organisation over time” (Institute of Directors Southern Africa, 2016).

5.4. LIMITATIONS OF THE STUDY

Face to face interviews were not recommended during the global Covid-19 pandemic lockdown restrictions. This caution was extended during 2022 in the light of the Department of Health reporting increased cases and the expectation of the 6th Wave of Covid-19 in South Africa. The electronic meeting platforms have gained popularity and are widely used. However, the technology was in certain cases negatively impacted by the national load shedding, namely, scheduled electricity outages. However, these outages are scheduled and rotational therefore interviews could be re-scheduled if a participant was affected.

A nominal data allowance of R100 per hour interview has been agreed with the Stellenbosch University Health Research Ethic Committee (SU-HREC) as reasonable compensation to participants for their time and their data re-imburement. The amount was furthermore applied to allow an equal opportunity for all Community Advisory Board (CAB) members to participate unreservedly on the electronic media platforms irrespective of their financial various financial situations. This platform may limit the interviewer from picking up on nuances and delving deeper into a discussion based on such observations. Agreement was reached with the participants not to activate the video in order that no participant felt marginalised by their surroundings and participated feeling equally empowered.

It is further noted that although the Community Advisory Board (CAB) membership requires language proficiency in English, since this is a long-term appointed group who need to communicate regularly at an international level, 90% of the members speak English as a second language. It is considered that the majority of the membership have an average to above average command of English. Of the twelve study participants only two use English as a first language.

It needs to be noted that the participants are volunteers and not staff. Responses from the participants are their opinions and perceptions and may not necessarily reflect accurately, the true organisational structure operation and intention. Community Advisory Board members may not have complete access to knowledge about the organisational structure and the roles of personnel. Alternatively, it may simply show communication gaps around the purpose and function of the CAB and the organisation. Further suggested research should be conducted from the organisational perspective where Desmond Tutu TB Centre executives are interviewed to reflect a balanced investigation.

5.5. CONCLUSION OF THE STUDY

The overall outcome of this study points to compliance by the Desmond Tutu TB Centre at Stellenbosch University, as relates to the principles and practises put forth in the stakeholder theory and the two-way communication model of the Excellence in Public Relations Theory.

Feedback emerging from in-depth interviews place the principles and practices of stakeholder engagement in the context a Community Advisory Board in a university research setting in South Africa in alignment with local and international guidelines as upheld in the King IV Report (2016) and the Stockholm Accord (2010).

This proves that the Public Relations principles and guidelines are multi-faceted and can be adapted across various industries and disciplines. As Grunig stated, the oldest Public Relations theories still hold strong in the modern communications era (Grunig, 2013)

Several themes emerging from the in-depth interviews as discussed above may be further explored through regular operational functioning channels of the Community Advisory Board under the guidance of the Community Liaison Officer (CLO) and the Executive Committee of the Desmond Tutu TB Centre, Stellenbosch University.

5.6. RECOMMENDATIONS FOR FUTURE RESEARCH

While this study provided an in-depth view from the perspectives of the members of the Community Advisory Board within a research setting, the researcher would like to propose that a study is conducted from the perspective of the research organisation and study team to identify gaps they may identify in stakeholder engagement principles and practices.

From the perspective of both the organisation and community stakeholder structures, the researcher would like to explore the possibility of involving the community stakeholder and the Community Advisory Board from the research design phase through to dissemination of results and research uptake.

Although this study may only be scraping the tip of the iceberg, the researcher is hopeful that other organisations will find the findings insightful and that organisations starting out will feel confident in applying the Public Relations principles and practices for Community Advisory Boards in research settings in South Africa and elsewhere.

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