

**Conceptions of research and attitudes towards research and research collaboration: A  
community perspective**

**Nondumiso Zukelwa**

**2009**

**Thesis submitted in partial fulfilment of requirements for the degree of Master of Social  
Science in Counselling Psychology in the School of Psychology, University of KwaZulu-  
Natal, Pietermaritzburg**

**Supervisor: Professor Nhlanhla Mkhize**

## Table of contents

### Contents

Table of contents.....	ii
Declaration.....	vi
Acknowledgement.....	vii
Abstract.....	viii
CHAPTER 1 .....	1
INTRODUCTION .....	1
1.1 Background to research.....	1
1.2 Broad problems and issues to be investigated .....	4
1.2.1. Research problems and objectives .....	5
1.2.2 Objectives of the study.....	5
1.3 Justification for the research .....	5
1.4 Methodology .....	6
1.5 Working definitions .....	6
1.6 Outline of the dissertation.....	8
CHAPTER 2 .....	9
LITERATURE REVIEW .....	9
2.1 Community .....	9
2.1.1 Defining the term ‘community’ .....	9
2.1.2 Implications for research.....	10
2.2 Community engagement: Conventional and collaborative research approaches.....	11
2.2.1 Conventional research approaches to community participation .....	11
2.2.1.1 Critique of conventional research .....	12
2.2.1.2 Power dynamics: Intellectual property rights and indigenous knowledge.....	12
2.2.1.3 Interpretation of results: Imposition of inappropriate conceptual categories.....	16
2.2.2 Community participation: Collaborative research .....	17

2.2.2.1 Active collaboration.....	18
2.2.2.2 Co-learning .....	19
2.2.2.3 Community-driven projects .....	19
2.2.2.4 Culturally-appropriate intervention strategies.....	20
2.2.2.5 Dissemination of research findings.....	22
2.2.2.6 Balancing research and action.....	23
2.2.2.7 Collaborative research in practice: A critique.....	23
2.2.3 Community conceptions of research and their attitudes and perceptions towards research collaboration .....	25
2.2.3.1 Community perceptions of and attitudes towards research: A review.....	26
2.2.3.2 Distrust between communities and researchers .....	26
2.2.3.3 Appropriation of indigenous knowledge.....	27
2.2.3.4 Benefits and distributive justice.....	29
2.2.3.5 Distributive justice and indigenous knowledge .....	31
2.2.3.6 Scientific enquiry .....	33
2.2.3.7 Confidentiality .....	34
2.2.3.8 Informed consent .....	35
2.4 Concluding comments .....	38
CHAPTER 3 .....	40
METHODOLOGY .....	40
3.1 Research setting .....	40
3.2 Research participants .....	40
3.3 Sampling.....	41
3.4 Justification for the qualitative research paradigm .....	41
3.5 Piloting.....	42
3.6 The research process .....	43
3.6.1 Community entry .....	43
3.6.2 Formal introduction .....	44
3.6.3 Appointments.....	44
3.7 Introduction to each informant.....	45
3.7.1 Informed consent .....	45
3.7.2 The research instrument.....	46

3.8 Procedure for the main study .....	46
3.9 Analysis.....	47
3.10 Issues of validity and reliability .....	48
3.10.1 Reliability.....	48
3.10.2 Validity .....	48
3.11 Summary .....	49
CHAPTER 4 .....	50
RESULTS AND DISCUSSIONS .....	50
Introduction.....	50
4.1 Conceptions of research.....	50
4.1.1 Research as service delivery .....	50
4.1.2 Research as community development.....	52
4.1.3 Research as an inquiry into knowledge.....	55
4.1.3.1 Incorporating local knowledge.....	56
4.1.4 Research as researcher-centred .....	60
4.2 Factors affecting research understanding.....	62
4.2.1.1 Lack of consultation.....	63
4.2.2 Uninformed consent / community involvement.....	66
4.3 Attitudes towards research.....	69
4.3.1 Research serves researchers' self-interest.....	69
4.3.2 Misinterpretation of results .....	71
4.4 Conceptions of research collaboration.....	73
4.4.1 Research collaboration as exchange of ideas/co-learning.....	73
4.4.2 Research collaboration as community openness and cooperation .....	76
4.5 Factors affecting research collaboration .....	79
4.5.1 Lack of respect.....	79
4.5.1.1 Local language .....	82
4.5.2 Lack of capacity building.....	83
4.5.3 Lack of involvement in decision-making and planning .....	87
CHAPTER 5 .....	93
CONCLUSIONS AND RECOMMENDATIONS .....	93
5.1 Overview of the study and its background.....	93

5.2 Conclusions about research questions.....	93
5.3 Implications for theory.....	95
5.4 Implications for policy and practice.....	96
5.5 Implications for future research.....	96
5.6 Conclusion .....	97
6.0 References.....	98
Appendix A: Interview Schedule.....	115
Inkonyane B: Iminingwane yocwaningo ne khasi lokuvuma, ngeSiZulu.....	117
Ikhasi elingubufakazi bokuvuma ukubamba iqhaza ngokukhululekile nokungenampoqo (Informed Consent Form) .....	119
Appendix C: Project Information and Consent Form, English Version .....	121

## Declaration

I, Nondumiso Zukelwa, hereby declare that this thesis entitled Conceptions of research and attitudes towards research and research collaboration: A community perspective, is my own work and all the sources I have used or quoted have been indicated and acknowledged by means of complete referencing.

Signature

.....

## Acknowledgements

I would like to extend my sincere gratitude to all the people who supported me in the completion of this study. In particular I would like to thank the following:

- Professor Nhlanhla Mkhize, my supervisor, for his generous support and guidance throughout the process of undertaking this study.
- All the participants who availed themselves for the interviews.
- The staff at HEARD.
- My darling daughter, Mihle Zukelwa, for giving me the strength to carry on.
- My mother for her unfailing love and support.
- Ndaba Gaolathe for his support and encouragement.
- My dear friend Richard Mukuka for his support and encouragement throughout my studies.
- My wonderful aunts Kholeka Ndulula, Pumla Tafa, and Zoleka Mbanga for their love and support.
- My late grandparents Charles Danisa Tafa and Nomathemba Tafa, whose spirits live through.
- My siblings Vuyisile and Mbuyekezo Zukelwa.
- This study was partially sponsored by NRF grant GUN 2063961.

## **Abstract**

This study investigated community members' understanding of research and research collaboration. Their attitudes towards research, as well as their perceptions of research, were explored as were factors that affected their understanding of research and research collaboration. The study used maximum variation sampling to select 12 participants who occupy different influential positions in the community. The current study was conducted in the eastern part of KwaZulu-Natal. An interview guide was used to collect data, aimed at acquiring in-depth understanding of community conceptions of research and research collaboration. The attitudes and perceptions of the research were examined. Lastly, factors that affect research and research collaboration were explored.

The results suggest that the participants have a limited understanding of Western research. Community training and education is thus warranted. Participants indicated that community members would appreciate the establishment of relationships characterised by mutual respect for different world views held by researchers and participants. This was viewed as a vehicle towards a more consultative approach to research which does not overlook the interface of world views for research outcomes to be useful. This was also perceived as likely to facilitate adequate participation in decision making in the research process. The involvement of key community members was emphasised.

# CHAPTER 1

## INTRODUCTION

### 1.1 Background to research

The so-called “developing nations” have attracted a lot of research in recent years (Costello & Zumla, 2000; Khalil, Silverman, Rafaat, El-Kamary & El-Setouhy, 2007; Starling, Kimunya, Gikonyo, Molyneux & Marsh, 2007). This is motivated by the need to address the high burden of disease which gives birth to many social ills in the so-called “developing nations”, child-headed households arising from the HIV/AIDS pandemic being a prime example. According to statistical reports, infectious diseases cause half of all deaths in “developing nations” (Postnote, 2008). The consequences of diseases are going to be felt for a long time as it is the case with negative consequences of colonialism in Africa. “Developing nations” have a long history of oppression and exploitation dating back to the days of slavery and colonialism. It is shown below that research does not take place independently of this history.

According to Battiste (2004), Eurocentric education and political systems and their assimilation processes have severely eroded and damaged indigenous knowledge. Battiste (2004) writes:

Today the indigenous people throughout the world are feeling the tensions created by a modern conventional education system that has taught them not only to mistrust their own indigenous knowledge and elders’ wisdom but also their own instincts, creativity and inspiration (p.498).

Research in “developing nations” is viewed by some as a simulation of colonialism. According to Costello and Zumla (2000), the research model supported by many funding agencies conducting research in “developing nations” remains semi-colonial in nature; he further suggests that foreign domination in setting research priorities and agenda is evident in research and has negative consequences which outweigh the apparent benefits of research findings. To address

this problem, efforts have been put in place to develop systems that will protect these “developing nations” from exploitation and harm due to unethical conduct by some researchers. A report by Postnote (2008) indicates that since year 2000 there have been efforts to improve research ethics in “developing nations”. This is also confirmed by Khalil et al. (2007), who suggest that ethical conduct of research specific to “developing nations” has become subject to recent discussions and it is addressed in several research ethical guidelines (for example, the CIOMS, 2002; Good Clinical Practise of World Health Organisations, 1995; UNAIDS, 2000).

Starling et al. (2007) state that low understanding of research is common throughout the world and this poses a challenge in achieving ethical ideals in any setting. They argue that in “developing nations” the understanding of research is even lower due research literacy and lack of systems to carry out ethical reviews. Postnote (2008) highlights some problems encountered by research ethics committees in developing countries: a) heavy workloads, where there are too few research ethics committees to deal with growing numbers of research projects; b) recruiting sufficiently diverse memberships (research ethics committees are generally expected to include scientists, ethicists and lay persons from different backgrounds and genders); c) ensuring that decisions are made independently of governmental, institutional and financial interests; d) making decisions on new and complex research that poses ethical dilemmas, for example genetic research; and e) lack of mechanisms for quality assurance and avenues of redress for researchers.

The above-mentioned problems and gaps in ethical guidelines increase the risk of and vulnerability to exploitation. Studies done in some African-American communities indicate that African-Americans tend to have a negative view towards research. The Tuskegee Syphilis study is cited as one of the major causes of African-Americans’ distrust and negative perceptions towards research (Lanae, Muktar & Lyons, 2006; Smith, 1997; Smith & Taylor, 2002). Smith and Taylor (2002) argue that such distrust stems from the history of racial discrimination and exploitation in the United States. For example, in the case of the Tuskegee syphilis study black rural men were used to study the untreated course of syphilis, the subjects were deprived of demonstrably effective treatment in order not to interrupt the project long after such treatment became readily available. Smith and Taylor (2002) maintain that “the US study of Public Health Service has come to symbolize ethical misconduct in the context of clinical research” (p.1).

It is a common feeling among some African communities that HIV/AIDS is a white man's invention for getting rid of Africans. As such white-led HIV/AIDS research would attract mistrust in the minds of these communities. With reference to the African context, Mfuso-Bengo (2003) notes that the perceptions and attitudes of research subjects have not been widely documented, nor has the notion of meaningful community participation been systematically explored from the perspective of research participants and communities (Molyneux, Wassenaar, Peshu & Marsh, 2005). This despite the fact that Emmanuel, Wendler, Killen and Grady (2004) list community participation/partnerships as one of the essential components in deciding on the ethicality of clinical research in developing countries. This is echoed by Starling et al. (2007) who suggest that

meaningful community participation has been advocated for many types of research for some time, forms and mechanisms are debated but there is a broad agreement on the potential for increased participation to afford greater protection, respect and empowerment to communities while facilitating research (p.21).

The notion of community participation is more relevant and urgent in "developing nations" due to the nature of problems and lack of research capacity. The control of research conducted in "developing nations" still rests in the hands of investigators who generally apply a one-size-fits-all approach with little consideration for the unique problems of "developing nations". Gonsalves (2002 in Sinclair 2004) views this as an establishment of new colonialism that is as unilateral as the administration of new policy. The Eurocentric approach to research is reductionist; it often ignores people's lived experiences. There are moves advocating for multiple sources of guidance to enable researchers to draw from different perspectives when conducting research as research is carried out in different social, cultural and economic contexts. This is echoed by Kilama (2009), who notes that researchers have been bringing readymade solutions to the communities without involving them at all in the investigations of their problems.

Kilama (2009) suggests that the remedy lies in involving communities in setting research agendas. This will build a sense of ownership and promote community participation in solving the health problems which affect them directly and which they have identified. This move can

contribute to the development of ethical principles that are sensitive to the local context. Currently, this has not been achieved because ethical principles are a form of take-it-or-leave-it, pre-packaged with research funding that advances Western agendas, failing to take into account differences in cultural and social norms and technological development. This raises concerns about the perspectives of local participants when research is carried out (Starling et al., 2007).

The current study aims to explore what community members understand by the terms ‘research’ and ‘research collaboration’. Given the proliferation of biomedical and other forms of research (Madsen, 1999; Roger, 2005; Smith, 1997; Smith & Taylor, 2002) it is imperative that people’s perceptions of and attitudes towards research be investigated. It is plausible that respondents’ perceptions and attitudes towards research can impact on their responses and hence affect the outcomes of the research study.

## **1.2 Broad problems and issues to be investigated**

Due to the unequal distribution of knowledge and other historical factors outlined above, it is possible that researchers and community members do not have a common understanding of research and research collaboration. The current study seeks to investigate these groups’ understanding of research and research collaboration and the practical implications of differences, if any. Particularly, the study’s main focus is on community understanding of and attitudes towards research and research collaboration. Due to different positions occupied by researchers and community members, different conceptions of research are expected. The community may have different expectations regarding research and research collaboration and without an understanding of these expectations the researchers are likely to fail in their attempt to engage community members in research collaboration. Ammerman, Smith and Marie (2003) suggest that initiating a research partnership without a full understanding of expectations may result in decisions and actions that further violate trust of the community.

### **1.2.1. Research problems and objectives**

The current study addresses the following questions:

- What do community members understand by the term research? (What does research mean to them or how do they define research?)
- What are the factors affecting research understanding?
- What are the attitudes, beliefs and perceptions of the communities towards research?
- What do community members understand by the term research collaboration? (What does research collaboration entail in the minds of community members?)
- What are the factors that affecting research collaboration?

### **1.2.2 Objectives of the study**

- To explore the conceptualisation of research collaboration by community members;
- To identify and contextualise barriers and facilitators to research collaboration;
- To understand attitudes and perceptions of community members towards research;
- To establish the community's general understanding of research and the research process;
- To explore the understandings and definitions of research collaboration in order to develop a community-based model of research collaboration.

### **1.3 Justification for the research**

Studies indicate a gap in the way researchers and communities understand research (Fitzgerald et al., 2002; Lindegger & Richter, 2000; Mfuso-Bengo, 2003). From the perspective of communities, especially in less developed and poor nations, understandings of research and research collaboration has not been well documented. According to Postnote (2008), any attempt to bridge the gap in “developing nations” using the research models developed by developed nations is met with challenges as these models assume universality at the level of concepts and practices.

These practices are met with challenges as most “developing nations” experience problems with research capacity and structures on the ground which are often overlooked (Postnote, 2008). We have a moral obligation to understand the perceptions and attitudes of communities towards research with the purpose of developing research models that will meet their needs. Research initiatives in communities are often met with suspicion: Community partnerships and research collaboration are seen as methods that can possibly address these problems (Ammerman, Smith & Marie 2003; Costello & Zumla, 2000; Kilama, 2009).

#### **1.4 Methodology**

This research study utilised a qualitative research design. Purposive sampling, which is characterised by use of judgment, was used to obtain information-rich cases by including informants who were most likely to yield relevant information characterised by use of judgment (Miles & Huberman, 1994; Pasha, 1979). The logic of purposive sampling lies in selecting information-rich cases, those from which one can learn a great deal about issues of central importance to the purpose of the research, for in-depth study (Pasha, 1979). This method made it possible for the researcher to select a sample on the basis of her knowledge of the population.

#### **1.5 Working definitions**

Key and contentious terms are defined below in an attempt to establish positions taken in this study. While working definitions are given, the implication of these terms cannot be understood in isolation from the entire work. The meaning of these terms will then surface or emerge as they are used throughout the study.

a) *Community*: is Defining the term ‘community’ is a challenge because of its many socially constructed dimensions (O’Fallon & Dearry, 2006). Akbar, Saaffir and Granberry (1996) argue that the term ‘community’ is an elusive concept; they also argue that this concept has been oversimplified by experts in their efforts to adhere to something concrete. For the purposes of this study, Green, Daniel, and Novick’s (2001) definition of community will be assumed. In line with this definition community is understood as referring generally to localities but also groups

that have a common interest or cause even if they do not share a common location. This definition is also similar to McQueen's (2001), who defines community as a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings.

*b) Community participation:* In recent years the concept of community participation has become increasingly important in the literature. The meaning of participation is ambiguous in many contexts where the term is often used. For the basis of this study 'community participation' will be defined as the involvement of the community in planning, organisation, operation, administration, financing and control of a project or enterprise (McKieran, del Barrio & Texas, 2004).

*c) Indigenous:* The very term 'indigenous person' is confusing because most people in the world are 'indigenous' to their countries in the sense of having been born in them and being descended from people who were born in them (Mfuso-Bengo, 2003, p.9). Indigenous peoples are clearly native to their countries in this sense too, but they also make another claim, namely that they were there first and are still there and so have rights of prior occupancy to their lands. This criterion works well in other parts of the world that have been colonised. For the purpose of this study we have used the definition by Betancourt, Green and Carrillo (2002):

Indigenous peoples are the people who claim their lands because they were the first or have occupied them since time immemorial. They are also groups that have been conquered by peoples racially, ethnically or culturally different from themselves. They have thus been subordinated by or incorporated in alien states which treat them as outsiders and, usually, as inferiors (p.31).

*d) Developing Nations:* The term 'developing nations' is used to refer to nation states whose economic and political structures are not well developed, in relation to the wealthier, industrialised world. Developing nations have low income levels and agricultural or resource-based economies, but are making efforts to industrialise and boost income. Developing nations have something in common; they are emerging from a history of colonisation by European

nations, followed by several decades of economic colonisation by the West. Most of these countries are in Africa, the Middle East, Asia and Latin America. The use of this term is sometimes controversial since it implies that western industrialism is the standard for judging development.

*e) Eurocentrism:* Eurocentrism is the practice of viewing the world from a European perspective, with a belief, either consciously or subconsciously, in the pre-eminence of European (and, more generally, of Western) culture. This practice places an emphasis on European western theories and ideas at the expense of those of other cultures (Brown, 2003). Implicit in this definition is the assumption that Western concepts are fundamentally different from those in other cultures or civilisations. They imply that Western concepts have a universal cultural currency into which elements of other cultures can relatively easily convert (Smith, 1999).

## **1.6 Outline of the dissertation**

This dissertation consists of five chapters. The first chapter serves as an introduction to the study. The second chapter reviews literature on research methodologies and critiques theory and practice of these research methodologies. Chapter Three describes the qualitative methodological strategy employed. Chapter Four deals with the analysis of data, and discussion of findings while Chapter Five presents the study's conclusions and recommendations.

## **CHAPTER 2**

### **LITERATURE REVIEW**

This chapter presents the review of literature. It engages critically with the literature on community understandings of research and community members' attitudes and perceptions thereof. Various definitions of 'community' are considered in an effort to highlight the implications of research. The chapter also gives a critical overview of assumptions and general practices underpinning conventional and collaborative approaches to research, in an effort to determine research models that are best located to respond to community needs. The chapter concludes with a discussion of the literature on community perceptions of and attitudes towards research.

#### **2.1 Community**

There has been widespread discussion by social scientists about the meaning of the term 'community'. Social scientists agree that there is a need for consensus regarding the definition of 'community' within research especially since there is growing emphasis on community collaboration (McQueen, 2001). The way the term is defined has implications for intervention programmes informed by research as well as programme evaluation.

##### **2.1.1 Defining the term 'community'**

Akbar et al. (1996) define a 'community' as a network of interconnecting processes which form the physical, mental and spiritual environments for effective human development. The term 'community' can also be seen as a definition of who the person is; what his or her allegiance and responsibilities are. In this sense 'community' is viewed as an important source of one's self-concept, which is nourished by one's identifications from the various places of the community (Akbar et al., 1996). On the other hand, 'community' could be conceived as a set of resources or

environments in which various components of the self receive nourishment for growth (Akbar et al., 1996). Similarly, Ermine, Sinclair, and Browne (2005) define ‘community’ as a system of relationships within indigenous societies in which the nature of personhood is identified. According to Ermine et al. (2005) community is a structure of support mechanisms that include the personal responsibility for the collective and reciprocally, the collective concern for individual existence.

Green, Daniel and Novick (2001) use the term ‘community’ to refer generally to localities but also groups that have a common interest or cause even if they do not share a common location. They argue that communities form mutual trust based on openness and equal opportunity for all their members. McQueen (2001) defines ‘community’ as a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings. In South Africa, it is not uncommon to use the term ‘community’ when referring to the under-served black communities. In the context of this study, the term ‘community’ is to be understood in terms of a group of people who share a common identity, interest or risk. These people may or may not be living in the same geographic area, but they must live in areas where research is conducted or has been conducted in the past (McQueen, 2001).

### **2.1.2 Implications for research**

Studies conducted by McQueen (2001) indicate that community context has been identified as an important determinant of health outcomes. Recognition of these facts has led to increased calls for community collaboration as an important strategy for successful research. According to McQueen (2001), the lack of an accepted definition of the term ‘community’ can result in different collaborators forming contradictory or incompatible assumptions about the community and this can undermine the researcher’s ability to evaluate the contribution of community collaborators in the achievement of public health research objectives. McQueen (2001) further proposed that the likelihood to validate effectiveness or ineffectiveness of collaborative models can be possible if core dimensions of community that have external validity across communities

are consistent with measures that have internal validity within diverse communities and have predictive value of community-level health outcomes.

## **2.2 Community engagement: Conventional and collaborative research approaches**

There is little local literature investigating community understandings of research and research collaboration. Gasa (1999) investigated cultural conceptions of research and informed consent and she found that consent is not limited to the researcher-participant relationship but is enhanced by an acknowledgement of participants' social embeddedness. To put the current study into context, a critical overview of conventional and collaborative research is conducted, given that most research is undertaken within these two approaches. The two approaches are compared and contrasted to determine which one is best located to engage with the community as partners to the research process.

### **2.2.1 Conventional research approaches to community participation**

Conventional (traditional) research is characterised by a limited interaction between the researchers and the participants. Biomedical research, designed to obtain new information about the efficacy of a drug, or other therapeutic, diagnostic or preventive modality, generally follows the conventional research paradigm (CIOMS, 2002). The primary distinguishing feature of conventional research is its objective approach to the research process: it generally treats people as passive objects; power rests primarily with the researchers (Pergamon, Conwall & Jewkes, 1995). As Freeman (1998) notes, this tends to alienate study participants, creating a possibility for distrust between the communities and researchers.

Conventional research methods also focus on generating knowledge for understanding, which may be completely independent of its use and implementation. There are other problems that arise from conventional methods: There is the problem of power dynamics between communities and researchers; language differences and knowledge about the research process and imbalances in terms of access to resources (as such, one party might be entirely dependent on the other,

especially due to differences in scientific or research literacy and hence understanding of the research process). Each of these problems and challenges is discussed in detail below.

### **2.2.1.1 Critique of conventional research**

Literature indicates that it is not always possible to achieve the goals of research because of the power dynamics between the researchers and the communities. Kelly, and Van der Riet (1999) argue that the community may have been alienated from the resources that are needed in order for it to develop. They argue that “the nature of such alienation invariably involves marginalization of the community from means of exercising power in political, economic, technical, and intellectual arenas” (Kelly & Van der Riet, 1999, p.164). This poses a lot of questions in the sense that if there are power dynamics between the two parties, the other party (i.e. the community) is bound to be dominated in terms of the research; the party that has more power is more likely to define the rules and further its own interests ahead of the interests of the community. This view is supported by Ermine et al. (2005) when they suggest that the western values and motivations are entrenched in research, while the values and interests of indigenous people are misrepresented.

Health departments usually employ conventional methods of research; it is rare that study communities get consulted in advance about the research questions, research design and the research process. The history of inequality has also had an immense impact on the way that research in the health care sector is conducted. For example, Ibrahim (2003) argues that the research that evolved was more focused on shedding light on what causes health disparities between communities. It did not focus on or target factors to eliminate or reduce health disparities, nor did it get the community involved in the process.

### **2.2.1.2 Power dynamics: Intellectual property rights and indigenous knowledge**

The problem of power dynamics between researchers and communities often manifests itself in relation to the question of intellectual property rights (Mashelkar, 2005). Participating communities are often not aware of their rights as far as ownership of knowledge is concerned.

Indigenous communities have been marginalised for too long and their ways of knowing have been disrespected and looked down upon. Communities may be at risk of exploitation and of being robbed of their indigenous knowledge because the language of the researchers dominates over that of the community.

Gadzirayi, Mutwandwa, Chihiya, and Chikosa (2006) locate the Africa-West battle over resources and control back to the days of slavery and industrial revolutions when Blacks were a hot labour resource and the West battled with African kingdoms for labour. They inform us that the pre-colonial era was dominated by traditional leadership (chiefs and elders) that enforced good management of indigenous knowledge through customary law, taboos and other forms. Colonial powers introduced laws which alienated Africans from indigenous resource management and knowledge (Gadzirayi et al., 2006).

In recent years there has been a move toward establishment of laws and systems that protect intellectual property rights. Statutory bodies have since been established. These include the International Patent Classification System (IPC), the World Intellectual Property Organization and the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS, 1994). These bodies are dedicated at regulating, protecting and promoting use of intellectual property in a manner that clearly identifies and acknowledges the source of knowledge. These laws have many flaws and they are seen by many as inadequate and furthering the agendas of the researchers. Research indicates that the nature of indigenous peoples' intellectual property is often inseparable from spiritual, cultural, social and economic aspects of indigenous life. The notion of collective ownership of such property is not adequately addressed in existing international intellectual property law (Ermine et al., 2005; Gadzirayi et al., 2006; Tauli-Copurs, 1999). Ermine et al. (2005) warn that what may appear as a move towards the protection of indigenous communities from further exploitation through the introduction of intellectual property rights and patent laws is a continuation of cultural imperialism. Young (1990) in Ermine et al. (2005) describes cultural imperialism as a form of oppression by a dominant society. Apart from assimilating or securing the subordinated status of cultures, cultural imperialism is usually characterised by economic profitability. Tauli-Copurs (1999) echoes the very same concern when he states that there are problems with the

essence of the law that underlie intellectual property rights. According to Tauli-Copurs (1999), these laws are an embodiment of western legal philosophy, norms, values and mindset which are contrary to many indigenous people's cosmologies and values.

Tauli-Copurs (1999) suggests that intellectual property rights are monopoly rights given to individuals or legal persons (such as transactional corporations) who can prove that the inventions or innovations they made are novel, innovative and capable of industrial application. However, indigenous knowledge and cultural heritage are usually collectively evolved and owned; no individual has a right to give out knowledge for selfish reasons. Tauli -Copurs (1999) warns against the flaws and dangers of intellectual property rights:

If indigenous peoples have to use western Intellectual property rights to protect their own knowledge and innovations, they will have to identify individual inventors. This will push scrupulous indigenous individuals to claim ownership over potentially profitable indigenous knowledge which will cause the further disintegration of communal values and practices. It can also cause infighting within and among indigenous communities over who has ownership over a particular knowledge or innovation (p.2).

Gadzirayi et al. (2006) take this argument further by suggesting that post-colonial era has not remedied the situation. Instead, it has transferred the ownership and control of resources to government ministries which turn indigenous knowledge into open access. This view is also supported by Peterson (1982) in Sinclair who argues that in some indigenous societies collective ownership meant no ownership. Sinclair et al (2004) write: "Unfortunately this has led to the rationale that since there is 'no ownership' doors are open to state ownership (p.29). This rationale has translated into the concept of public domain in the academic arena and has led to the disregard of indigenous claims to intellectual, cultural and property right.

It is argued that intellectual property rights are not bad in themselves. They emerge out of a world view that individuals or legal entities should get credit (financially or just recognition) for their creative products. This becomes problematic when this world view meets the other world views. For example, in the Afrocentric world view the community takes the credit for an

individual's brilliance because they are the ones who groomed him and what that individual produced belongs to the community. What is problematic is that when these world views meet in one research project the Western world view dominates in determining issues of ownership. Similarly, Brown (2003) informs us that the creation of knowledge is a collective effort in some indigenous communities. The individual can not claim personal ownership even though technically he created it.

In the South African context the case of the San clan and the Hoodia plant is a typical example of misconduct against indigenous people. According to Dawson (2004) the San had used the Hoodia plant as an appetite suppressant for many centuries especially during the hunting expeditions where little food was available for many days. The Council for Scientific and Industrial Research in South Africa (CSIR) first became aware of the plant in 1937 through a Dutch scientist. The plant was patented by the CSIR in 1995 and licensed in 1997 to Phytopharm (a British Biotech Company) which conducted trials relationships within indigenous societies in which the nature of personhood is identified, which trials confirmed the plants' chemical appetite suppressing qualities. According to Ster (1994), the San clan gave information to researchers that led to a direct patent and the group only heard about their product in the news without prior consultation with them. According to Dawson (2004) Phytopharm believed that the San had disappeared. The San are one of the most marginalised groups in South Africa, weighed down by high rates of unemployment and little formal education. Taking the knowledge from them without compensation left them feeling exploited. This brings about critical questions such as who owns indigenous (commonly available) knowledge. To answer this question it is important to consider Hazelrigg's (1999) distinction between 'discovery' and to 'discover'.

According to Hazelrigg (1989), to 'discover' means to disclose and bring to sight or acknowledge for the first time that which already exists but which had not been known: "Discovery means bringing to light from its concealment something previously unknown" (p.7). Using this definition, one can suggest that the San made a discovery of the Hoodia plant and they passed this information on to scientists who failed to acknowledge the former's contribution. Pelkon and Kohl (2005) suggest that supplementing scientific data with local knowledge can

broaden the information base needed for better decision-making regarding research.

Conventional research approaches rarely supplement scientific knowledge with local knowledge and this has implications for the interpretation of results and findings.

### **2.2.1.3 Interpretation of results: Imposition of inappropriate conceptual categories**

Macaulay (1996) argues that classical and traditional methods in health and social science research have been slow to address cultural and ethical factors in research. Such factors could have implications for the interpretation of research findings. The net result could be the imposition of inappropriate categories of experience and ways of knowing on the communities that are studied (Brown, 2003).

This also finds support in Riley and Wakely (2005), who argue that communities are often given little scope for decision-making, owing to the belief that communities have little to contribute. As a result, the research imposes the outcomes and findings on the communities. These incidents, being less dramatic than the Tuskegee syphilis study, receive less attention from the media and hence go unnoticed. For example, some research initiatives have revealed the ignorance of the researchers in matters that are of concern to communities (Riley & Wakely, 2005). Pergamon et al. (1995) stipulate that in many cases people have participated in a process which lies outside their ultimate control. Likewise, Macaulay (1993, 1996) argues that research agendas and responsibility for analysis and representation generally remain the preserve of the researchers.

In recent years, we have witnessed a dramatic move toward research collaboration (Kelly & Van der Riet, 2001; Macaulay, 1996; Myrick, 2005). It is appropriate at this stage to introduce collaborative research methodologies as a possible mechanism by which power dynamics between researchers and communities can be addressed and community participation enhanced.

### **2.2.2 Community participation: Collaborative research**

Collaborative research methods can be helpful in actively addressing some of the problems of conventional research. O’Fallon and Dearry (2002) define community-based participatory research as a methodology that promotes active community involvement in the processes that shape research as well as in conduct of research and intervention strategies. There is evidence which suggests that working collectively with the community leads to better results and addresses a host of important issues that arise in a community (Kretzman & McKnight, 2001). Reports indicate that collaborative research methods, such as participatory research, are gaining respectability in developing countries (Akbar et al., 1996; Ashworth, 2000; Macaulay, 1996; Riley & Wakely, 2005).

Green, Daniel, and Novick (2001) argue that “partnerships and coalitions are necessary in developing prevention and health promotion programs or research today because no one agency has the resources, access, and trust relationships to address the wide range of community determinants of public health” (p.14). Partnerships are also needed for community-based research as a result of limited perspectives that any one profession, discipline, or organisation has on people’s actual experiences in dealing with life issues (Green et al., 2001). To qualify this argument, Green et al. (ibid) state that researchers are skilled in measuring the objective aspects in research but they need the help of other role players, for example lay persons or community members who have the adequate understanding about subjective aspects of the issues.

Collaborative research, as opposed to conventional research, is more inclusive of the community. Local knowledge and perspectives are not only acknowledged but form the basis for research and planning (Pergamon et al., 1995). Power is decentralised in that decision-making also involves the community. Emphasis is on a “bottom-up” approach with a focus on locally defined priorities and local perspectives. Communities are acknowledged as active participants in knowledge generation. Local knowledge and perceptions are explored in depth (Hacking, 1999; Pelkon & Kohl, 2005).

Collaborative research stresses the relationship between the researcher and the community as well as direct benefits to the community as a potential outcome of the research. The community's involvement is itself beneficial (Macaulay, 1999). The goal is that research subjects should own the research process and use its results to improve their quality of life. Collaborative research can also be viewed as a partnership among equals with complementary knowledge. Collaborative research, as suggested by Macaulay (1999), "attempts to negotiate a balance between developing valid generalizable knowledge and benefiting the community that is being researched and to improve research protocols by incorporating the knowledge and expertise of community members" (p.11).

It is appropriate at this stage to introduce the principles of community based participation research, namely: (a) active collaboration, (b) co-learning, (c) community-driven projects, (d) culturally-appropriate intervention strategies, (e) dissemination of research findings, and (f) balancing research and action (O'Fallon & Dearry, 2002).

### **2.2.2.1 Active collaboration**

Collaborative research promotes active collaboration and participation at every stage of the research process. It is assumed that this method provides participants with an equal sense of ownership over the research and the outcomes (O'Fallon & Dearry, 2002). In practice, the researchers have to be cautious and recognise the fact that partnership with community-based organisations does not always lead to community participation. O'Fallon and Dearry (2002) suggest that there are often different levels of participation within the community. They suggest the use of different modes of interaction to ensure that different voices in a community are heard. For example, some studies indicate that internal divisions exist within communities, due to the fact that multiple communities will have different needs, expectations and claims on the partnership. This is particularly true if there are little or no strong ties between people (Brown & Ashman, 1996; O'Fallon & Dearry, 2002). Therefore, it is important for the researchers not to fall into the trap of communicating with a few individuals while sidelining the already-excluded members of the community, such as criminals and drug/alcohol addicts (Ashworth, 2000; Borowiak, 2004; Riley & Wakely, 2005). Ensuring community involvement at all levels by

conducting public presentations for less active members of the community is crucial (Riley & Wakely, 2005).

#### **2.2.2.2 Co-learning**

The second principle, co-learning, entails that both community residents and researchers contribute their expertise as partners learning from each other (O'Fallon & Dearry, 2002). The communities learn research skills and researchers learn about community networks. In practice, this process of co-learning can be problematic due to historical legacies. The communities may be scared due to their previous dealings with the research community: they may not be totally wrong to distrust researchers because some researchers have been schooled in a particular way and the partnership may also be new to them. Trust building is very critical for both. Riley and Wakely (2005) suggest that building trust, respect and mutualism demands changes in the ways in which people and institutions have traditionally communicated and perceived each other. Further, research indicates that a higher level of communication and understanding in a partnership, results in the achievement of improved collaboration. It is argued that trust not only enables communication but it also has the potential to transform social relationships (Westfall, 2006).

#### **2.2.2.3 Community-driven projects**

Collaborative research ensures projects are community driven. This means that local issues or concerns guide research questions to the community. There is a danger when researchers do not place communities at the core of the project. The danger in such cases is that tensions and conflict erupt, undermining the research project because the community does not take ownership of the project. For example, providing services to the community, with little consideration of the cultural factors and overt Eurocentrism, can result in poor uptake of the service because the diversity within the community is not catered for. These are the types of services that are criticised for not considering the opinions and preferences of communities so that special circumstances can be catered for (Johnson & Carroll, 1995; Subhra, 2002). Early

research may be criticised for treating communities as ‘passive recipients’ of service provision (Subhra, 2002).

According to Gadzirayi et al. (2005) in order “to understand the current issues facing indigenous communities, it is important to understand the history of colonisation. The past resonates into the present” (p.43). This is echoed by Brown (2003) who suggests that the trauma inflicted by the upheaval of the post-colonial era has removed the close cultural kinship ties that existed previously within the indigenous communities. As a result communities are often disintegrated and distrustful of the outsiders. According to Brown (2003) the communities are still vulnerable and fractured from the past and these factors have to be taken into account when conducting community development projects.

Cadd (2002) suggests that an approach is required to firmly develop the bonds of trust for a stable foundation towards community development from an indigenous perspective. Community development programmes should be based on the conviction that people are capable of finding solutions to their problems. This suggests that the role of the researcher should be to support initiatives decided collectively by the people who have joined together to address their needs (Sinclair, 2004). This idea is supported by Burchill & Higgins (2004) in his suggestion for a positive indigenous community research model, yarning up not down. He writes: “yarning up relates to yarning for outcomes rather than speaking down to the indigenous people. Yarning down is an indication that the outsider knows best or takes control of the outcomes for indigenous people” (p.48).

#### **2.2.2.4 Culturally-appropriate intervention strategies**

The fourth principle is that collaborative research ensures that research and intervention strategies are culturally appropriate. With active participation of community residents from inception, research and intervention strategies are more likely to be based on the cultural context of the community intended to benefit them from. McKieran et al. (2006) suggest that for this to be achieved researchers have to be culturally competent. According to Betancourt et al. (2002) cultural competence describes the ability of systems to provide care to people with diverse

values, beliefs and behaviours including tailoring of delivery to meet people's social, cultural and linguistic needs. Betancourt et al. (2002) describe cultural competence as both the vehicle to increase quality research as well as a strategy to attract new subjects. McKieran et al (2006) recommend that cultural competence of the researchers should be intended to improve public health professionals' recognition and understanding of the role of culture in health-related activities which are often subject to research. A study conducted by Betancourt et al. (2002) made a direct link between cultural competence and the elimination of racial and ethnic disparities. This study also suggests congruence between cultural competence and quality improvement of health services.

Language barriers between health researchers and the community where research is conducted is one of the factors that affects research understanding. Betancourt et al. (2002) suggest that more often than not researchers and the researched are most likely have different perspectives on health, medical care and expectations about diagnosis and treatment. This is particularly true in indigenous communities. For example, certain beliefs and perceptual distortions which are considered to be normal in one culture can be considered abnormal in another culture. For example, amongst Africans psychotic symptoms which form part of the diagnosis of schizophrenia may be attributed to *intwaso*, which is a calling to become a traditional healer. Cultural sensitivity and awareness is important when making a diagnosis. This indicates that psychopathology can be misdiagnosed and sometimes is usually examined without reference to normal behaviour. In this regard Betancourt et al. (2002) write: "achieving cultural competence in health care would help remove these barriers and supplanting the current one-size fits-all approach with a system more responsive to the needs of an increasingly diverse population" (p.3). When researchers fail to understand socio-cultural differences between themselves and participants, the communication and trust between them may suffer; in the context of health research this may lead to patient dissatisfaction, poor adherence to medication and health outcomes. Betancourt et al. (2002) point out that when providers fail to take socio-cultural factors into account, they may resort to stereotyping, which can affect their behaviour and clinical decision-making. McKieran et al. (2006) suggest that facilitating communication and improved mutual understanding, language assistance and cultural competency programmes

should foster public health professionals' engagement of the diverse communities they serve and improve their ability to recognise changing community needs.

#### **2.2.2.5 Dissemination of research findings**

The fifth principle is that collaborative research disseminates results in useful ways (O'Fallon & Dearry, 2002). Upon completion of the collaborative project, results are communicated to all partners in culturally-appropriate, respectful and understandable terms. It is argued that often research findings are not presented to the indigenous communities in an accessible form. For example, it is considered inappropriate and disrespectful to disseminate results to the community in the form of research papers prepared for journal publication. According to Henry, Dunbar, Arnott, Scrimgeour, and Murakami-Gold (2004), delays in feedback of research findings reduce their potential usefulness. This is echoed by the Center for Aids Prevention Studies (CAPS) (2006); they suggest that HIV research, no matter how innovative, will never make a difference in the epidemic unless it is disseminated in an appropriate and timely manner to the people and organisations providing HIV services.

The CAPS Community Advisory Board suggests the creation of dissemination plan for studies. For this to be achieved the following suggestions have to be adhered to: a) develop a budget that supports dissemination efforts, including translation, printing, mailing and community forums' costs, b) develop a timeline for dissemination efforts, c) obtain input from study participants and community representatives on the best methods to disseminate research findings, d) ask participants how they would like to be informed of findings, e) use multiple methods to disseminate findings to study participants, and f) make dissemination accessible paying particular attention to language and literacy needs of the audience as was done during the outreach/recruitment study phase. The dissemination plan and timeline have to be established in partnership with the CABS from the onset; it must clearly state who will receive the research findings, when they will receive them, what they will receive and how they will receive them.

### **2.2.2.6 Balancing research and action**

Lastly, collaborative research is a way to balance research and action. Research indicates the increasing use of collaborative research in health departments. This state of affairs is fostered by the realisation that the single sector programmes previously employed by health departments could not adequately address the needs of communities. Recent literature indicates that the use of collaborative research methods is very useful; there are reports of sustainability of interventions that came about through community participatory methods of research. In particular, health care systems can benefit from making use of participatory research methods. There is evidence that community involvement in research produces positive outcomes for both the community and the researchers (Ammerman et al., 2003; Minkler, 2002; Westfall, 2006). For example, Costello, and Zumla (2000) suggest that local partners in research are highly influential and respected within the medical, academic and policy-making fraternity and they have greater opportunities to achieve budgetary discipline through local economic knowledge and influence policy-making better than if the expatriate academic were managing the research programme. The local researchers also have a deeper understanding of the cultural fine decision-making processes and health-seeking behaviour.

### **2.2.2.7 Collaborative research in practice: A critique**

It is clear that collaborative research methods are better options to community intervention because their approach is different from traditional expert planning approaches. However, research indicates that collaborative research approaches can be used not only to enable local people to seek their own solutions, according to their priorities, but also to secure funding that will have little benefit to the community that is studied. Instead, such funding could further the agendas of others or justify short-cut research within a top-down process (Pergamon et al., 1995). Pergamon et al. (ibid) argue that much of what passes as collaborative research goes no further than contracting people into projects which are entirely scientist-led, designed and managed. McKieran et al. (2006) highlight that the meaning of participation is ambiguous in many contexts where the term is often used.

According to McKieran et al. (2006), community participation is commonly understood as the involvement of the community in planning, organisation, operation, administration, financing, and control of the project enterprise. They further stipulate that the

goal of participation at grass roots participation is not simply involvement but rather distribution of power that deliberately includes traditional 'have-nots' in the sharing of information, setting of priorities and policies, allocation of resources and distribution of benefits and service (McKieran et al., 2006, p.107).

Often, researchers recognise the need to integrate local knowledge and experience into research planning and aim for a more collaborative process during field research. In many cases, people are 'participated' in a process, which lies outside their ultimate control. Researchers continue to set the agendas and take responsibility for analysis and representation of outcomes (Pergamon et al., 1995).

Due to the lack of capacity on the side of community members, initiatives that are meant to engage communities into partnerships become one sided with more power residing with the researcher. This situation is made worse by some of the challenges that were mentioned in conventional research. The communities are usually unfamiliar with the research process and there is often a language barrier; these factors inhibit capacity building in communities (Macaulay, 1996). McKieran et al (2006) conducted a study on community-based practice, research collaboration and power sharing. The findings suggested that efforts to engage community participation in government-funded projects were criticised by people as mere tokenism that did not get the public very far up the ladder of citizen participation and were also viewed as permitting maximum feasible manipulation of lay people rather than promoting partnership and citizen control. McKieran et al (ibid) argue that the fundamental ethical challenge of authentic partnerships and true sharing of authority with community members lies in overcoming the significant disparity in power between community members and research professionals who have specialised knowledge, technical skills, and institutional support or governmental support. They further suggest that establishing a partnership requires mutual trust, which is built over time and after visible results have been achieved. According to McKieran et

al. (ibid), sustaining a partnership in which collaborators have significantly different degrees of access to power typically requires ongoing financial, political, and community support, reinforced by positive outcomes from the collaborative project. It is possible that researchers and community members do not have the same understanding of the research process, incorporating research collaboration. In all likelihood, each of these communities has a different conception of these terms and may be acting on different assumptions and premises during the conduct of research. There may be differences in perceptions of who generates, analyses and owns the results.

### **2.2.3 Community conceptions of research and their attitudes and perceptions towards research collaboration**

Cohen and Uphoff (in Kelly & Van der Riet, 1999) describe participation as people's involvement in decision-making about what should be done and how, in the implementation of the project, in sharing in the benefits of a project and in evaluating the project. In reality, not all members of the community become involved in the project. During the conduct of research, communities are often represented by bodies such as community advisory boards (CABs). Senaratna (2002) notes, researchers are more likely to get carried away communicating with a few people who are active members in the community who may not be representing the entire community. Thus, some voices remain unheard. Some individuals may be looking at individual or personal benefits, like prospects of employment as opposed to something that will benefit the community at large. McKieran et al (ibid) also recognise the problem; they state that effectiveness and ethical quality of community participation in any public health activity are dependent upon the authenticity of the individuals and groups representing the community of interest.

According to McKieran et al. (ibid),

in theory community representatives are able to provide insight into the norms, values and experiences, questions, objections and appreciation of the community they represent, expanding, correcting, and ideally validating the approach taken by public health professionals in practise and research (p.108).

It can also happen that the researchers involve or select the community representatives for their own purposes and lose sight of the needs of the community. Consultation with the community is very critical in order to get proper community representative as this will give insight to the community's organisational and power structure. McKiernan et al. (2006) warn that research or public health activities could result in tokenism if the primary purpose of inclusion is simply to satisfy an external requirement for community participation or to secure approval of proposed projects. They suggest that for an authentic partnership to be formed it must be grounded on what he calls the six 'R's of participation which include recognition, respect, role, relationship, reward, and results. They further suggest that without these components the community is likely to discount the professionals' sincerity and disengage from the project.

#### **2.2.3.1 Community perceptions of and attitudes towards research: A review**

Generally, there is lack of knowledge about the general attitudes and perceptions of communities towards research in South Africa. How communities actually experience research and how they actually decline or accept participation is not well documented, particularly among the African population. Fear of the unknown, lack of information and the desire to maintain personal influence are often cited as the causes of negative attitude towards research in international studies (Madsen, 1999), while positive attitudes usually stem from the presence of public research ethics committees.

#### **2.2.3.2 Distrust between communities and researchers**

South Africa's history of human rights abuse and the legacy of apartheid have left communities vulnerable to and suspicious of outsiders (Riley & Wakely, 2005). Kelly and Van der Riet (1999) note that "the history of South Africa and the legacy of the past may cause some degree of suspicion and mistrust and will arguably do so for some time to come" (p.23). Distrust of the research community is frequently cited as the source of negative perceptions of communities towards research. According to Smith and Taylor (2002), "Negative events such as violations of

public trust and unethical behavior are widely distributed, because these instances have become more visible and they may carry greater psychological weight and adversely affect the ability to overcome trust” (p.22).

Smith’s (1997) study on African-Americans’ attitudes toward participation in medical research showed that communities tend to mistrust scientists; many participants described concerns about the ethical conduct of clinicians and investigators. One of the key issues was the fear of exploitation which was linked to participants’ low socioeconomic status. They were also concerned that research would be more beneficial to the investigators than the communities. Some felt that they were being used as guinea pigs for something that will not be of benefit to them. Concern was also raised about the consent process, seen by participants as a legal mechanism to protect researchers.

### **2.2.3.3 Appropriation of indigenous knowledge**

Misuse of local knowledge is one of the reasons the research community is viewed in a negative light by communities in which research is conducted. Ermine et al. (2005) argue that research lends itself to the appropriation of indigenous knowledge for purposes of Western gain, power exploitation, and domination. This idea is supported by Smith (1999), who suggests that

the language of imperialism and colonialism may have changed over time but the unavoidable perception is that these realities, borne of domination in history, have never been effectively discounted and still exist in their various modern forms and contexts that continue to affect indigenous people (p.27).

Greaves (1994) warns that

the very cultural heritage that gives indigenous people their identity now more than before is under real or potential assault from those who gather it up, strip away its honoured meaning, convert it to products and sell it (p.ix).

The research institutions are viewed with suspicion that they do everything for financial benefit with little regard for the wide range of indigenous claims (Ermine et al., 2005). Usher (1994, in Brown, 2005) echoes this when he suggests that research that gains access in indigenous communities and their artistic designs is often used as part of a broader process to turn indigenous creations to be consumed by Western society.

According to Briza (1997), the community of traditional healers in South Africa would be familiar with this statement after they were coerced into participating in research by pharmaceutical companies; this community was deceived into compiling their indigenous knowledge of plants and herbs. These plants were to be tested for toxins to make them safer for public consumption. The traditional healers were approached to be partners in research and promised full access to the database. Following this the Traditional Medicines Project (TRAMED) and Traditional Medicine Research Group (TMRG) were established.

These groups declared that researchers intend to collect information on Southern African plants and use this to set safety standards regarding herbal remedies. They championed the interests of traditional healers stating that traditional healers seek recognition and scientific verification of their remedies. MRC Press Release (1997) writes:

What we will not do is use their intellectual property to make profits which do not benefit them; an important objective will be to create a comprehensive traditional medicines database for use by traditional healers, policy makers, drug regulatory authorities, the pharmaceutical industry and the public, we are committed to making the database universally accessible.

Traditional healers naïvely collaborated with TRAMED for years handing over indigenous knowledge in the hope of recognition (Briza, 1997). Instead, the researchers and doctors who were part of the consortium benefited only themselves as the ancestral knowledge of the nation was raped by commercial interests, whilst scientific feedback to the traditional healers as a whole has been negligible (Hughson, 1995, in Briza, 1997). It is important to note that indigenous knowledge is not controlled by one person. As Sinclair (2004) puts it no one person has the

right to decide what happens to indigenous knowledge. He warns that the danger in passing this knowledge on to an outsider is that once it is published the community loses control of how it is used and who receives it because it now falls into public domain. This is supported by Posey (1994, in Ermine et al.), who notes that another outcome of publication is that even though the research report resulted from information provided freely by the traditional communities, the researcher, writer, publishing company, or sponsor of research claims copyright. He further argues that government or university sponsors often justify holding copyright because public funds were used to support the projects. This was the case with the traditional healers in South Africa; a few doctors developed own ranges of enthopirated medicines and also published books on medicinal plants of South Africa (Briza, 1997). According to Stillitoe (1998) failure to acknowledge indigenous sources is an issue some indigenous people are unaware of. This deposits the moral and ethical responsibility on researchers and/or academics to respect the sources of information and to share any benefits, economic and otherwise (Stillitoe, 1998).

#### **2.2.3.4 Benefits and distributive justice**

Justice is one of the most debated concepts in the literature; this section tries to engage with the literature in this area and also attempts to locate the origins and meaning of distributive justice in the context of research. According to Lamont (1941), justice is the use of authority to define what is right. It can be assumed that mankind has basic ethics which distinguish right from wrong; in reality there are varying ideologies which advocate differently as far as the definition of justice is concerned. The ideas found in the literature about justice are linked to the positivistic philosophy which situates itself in the world of objectivity. This ideology subscribes to the view of fixed narrative points of view and clear-cut moral positions (Klages, 2007). This ideology equates knowledge with science and contrasts with good knowledge and discards narratives as bad, irrational and primitive. This is also the ideology that claims or advocates for the existence of universal ethical principles. This therefore dictates that particular cultural practices be discarded due to their primitive nature while others are adopted because they provide all socially 'useful' forms of knowledge (Klages, 2007). This ideology holds a view that science knowledge is neutral and objective and that those who produce scientific knowledge through their unbiased rational capacities, must be free to follow the laws of reason and not be

motivated by other concerns (Klages, 2007). Aristotle, among others, states that any man made justice will still seem like injustice to some party; therefore there is no one way of seeing things. The source of these differences is attributed to a number of factors which include different socio-cultural, political and social backgrounds. Kincheloe and Steinberg (2008) argue that different frames of reference inform people's realities. This is supported by Mosha (2000), who argues that knowledge produced by a particular culture can both be true and just to that particular culture, therefore its criteria for truth cannot lay claim to universality nor can it claim power via its ability to negate or validate knowledge produced in other cultures.

Kincheloe and Steinberg (2008) assert that analysts must consider the process of knowledge production and truth claims in relation to historical setting, cultural situatedness and the moral needs of the reality they confront. Harding (1998) notes that the context from which one observes an entity shapes what he or she sees; consequently different frames of reference produce multiple interpretations and multiple realities. The literature highlights decades of European cultural dominance accompanied by its positivistic and reductionism principles which are obsessed with universal principles of human existence. These principles adopted a simplistic approach in their dealings with other cultures, particularly the indigenous groups, which also included exploitation and maltreatment of research subjects from this population. This then led to the development of some ethical guidelines to protect people from such.

In a positive light, in recent years we have observed the shift and appreciation of differences and good input to the knowledge development that can be brought about by the dialogue between cultures. The value of this dialogue as highlighted by Kincheloe and Steinberg (2008) suggest that forms of knowing that have been excluded by Western positivism can move us to new vantage points and unexplored planetary perspectives (Kincheloe and Steinberg, 2008). They further argue that

understandings derived from the perspectives of the excluded or culturally different allow for an appreciation of the nature of justice, the invisibility of the process of oppression, the power of difference, and the insight to be gained from a recognition of divergent cultural

uses of long hidden knowledge that highlight both social construction as individuals and the limitations of monocultural ways of meaning making (p.140).

Indigenous peoples still face the risk of exploitation, being used as subjects in research that does not benefit them and in some cases participate in research and impart indigenous knowledge to scientist sharing no benefits in the profits. Ermine et al. (2005) allege that research on indigenous people often results in innumerable benefits to the outsiders with little compensation to the communities.

Concerning the exploitation of indigenous knowledge, Posey (1996) writes:

by estimate the market value of plant based medicines alone which were first used by indigenous people sold in developed countries more that 43 billion dollars in 1985; however it is less than 1 percent that has ever been returned to the source communities (p .9).

In support of this Smith (1999) argues that indigenous peoples are often treated as client populations rather than as contributors to research. As a result any benefits accruing from researcher activities go the researchers. Ermine et al. (2005) argue that this issue is manifested in multiple processes including advantages to institutions in terms of funding under the name of indigenous research with little or no benefit to the communities in terms of programmes or problem solving (Ermine et al., 2005). Distributive justice is meant to play a corrective role to the problems highlighted above. The ethical guidelines as stipulated by the Belmont Report (1979) call for the risks and benefits of research to be distributed fairly.

#### **2.2.3.5 Distributive justice and indigenous knowledge**

Documented literature reflects some consensus with regards to the definition of distributive justice. Literature suggests that the principle of distributive justice is concerned with fairness and appropriate treatment according to what is due or owed to the person (Faden & Beauchamp, 1986; Sullivan & Decker, 1988). Lamont (1941) defines distributive justice as a creation of a

system of rights according to the principle of equality of consideration for all; and rights are protected fields for activity within which individuals or groups may pursue their interests. Klages (2007) views distributive justice as concerned with the distribution of money, honour, or other resources that are divided among all who have a share in some public organisation. Faden and Beauchamp (1986), and Sullivan and Decker (1988) state that distributive justice concerns not only the distribution of income and wealth but also the division of opportunities, economic powers, and positions of responsibility amongst those who take part in and contribute to production and cooperative output. In recent times there has been an interest in indigenous knowledge which attracts research in different areas of traditional knowledge (Kincheloe & Steinberg, 2008; Mashelkar, 2005).

Western education is calling for a move towards an intercultural and interracial effort for justice and self-direction of indigenous people (Kincheloe & Steinberg, 2008). They argue that the purpose of indigenous education will allow for indigenous self-sufficiency “while learning from the vast storehouse of indigenous knowledge that provide compelling insights into all domains of human endeavors” (p.135). Mashelkar (2005) suggests that indigenous people have nurtured and refined their knowledge systems and have therefore generated a rich store of traditional knowledge. Therefore, these calls for intercultural methods may lead to globalisation and this raises concerns to “developing nations” because the process of globalisation is threatening the appropriation of elements of collective knowledge of society into proprietary knowledge for the commercial profit of a few.

Studies conducted by Mensah (2004) reveal that often researchers obtain knowledge by deception by sending employees, sometimes people from the communities, who do not admit that their purpose is to search for knowledge that will be of financial benefit to their company. The pharmaceutical industry continues to investigate and confirm the efficacy of many medicines and toxins used by indigenous people. Indigenous people often feel exploited and mistreated because in many cases the land gets converted to produce more raw materials for the companies. In the process traditional knowledge and resources disappear. Jackson (1993) notes that traditional knowledge produces more commercial benefits for others than for the people who own it. It is argued that academics and scientists rarely become rich by recording traditional

knowledge, yet their academic careers may be enhanced considerably by doing such research in terms of improvements in both their status and their salaries. It is argued that the local communities or individuals do not have the knowledge or the means to safeguard their property in a system which has its origin in very different cultural values and attitudes. There is a concern that intellectual property rights systems encourage the appropriation of traditional knowledge without the fair sharing of benefits of the holders of this knowledge. When this happens, distributive justice is infringed and therefore reparation has to take place. The aim of reparation is to restore the enjoyment of the infringed right to the injured party (Lamont, 1941).

#### **2.2.3.6 Scientific enquiry**

The scientific distance that is adopted by most research to understand African phenomena created resentment and suspicion from African communities (Mkabela, 2005). The objective stance taken by Western scientists leads to conclusions that depict indigenous peoples in a negative light due to lack of understanding. Ermine et al. (2005) argue that the claims to objectivity freedom from bias and misrepresentation only yield and harbour the ideological and value-laden perspectives of the researcher. They further argue that, researchers are simply able to discard phenomena and data that do not fit in with their specialist area and still receive the stamp of scientific approval because it is rational. Mkabela (2005) supports this; she informs us that research on indigenous African culture has typically addressed the concerns of the researcher (both Western research and African researchers trained in Western methodologies) and ignores the African view point. She further argues that the findings of researchers reflect the way they approach and assess African indigenous knowledge and know-how. This resulted in development of policies and objectives that are not consistent with the views, wishes and interests of indigenous communities (Mkabela, 2005). Mkabela argues that policies have had a negative impact on indigenous communities' lives, including culture loss and alienation of learners from their community.

Mkabela (2005) stipulates that exclusion of indigenous communities from research processes has led researchers to take cultural information out of context resulting in the creation of published documents that were factually incorrect. Consequently indigenous communities have felt

excluded from policy making. The same concerns are expressed by Aboriginal communities. Sinclair (2004) stipulates that within these intolerant discourses indigenous people may find themselves described in derogatory terms regardless of the progress they have made. He states that negative images and attitudes about indigenous peoples perpetuated and recreated through the scholarship of established Eurocentric consciousness, continue to have an influence well beyond their special and temporal origins. Ermine et al. (2005) point out that

after the commotion has subsided the book remains in the library where naïve and uninformed people will read it for decades to come so they take the content of the book as the truth and derive their knowledge of Indians from it (p.459).

Mkabela (2005) informs us that for most of South African research initiatives the nature of participation of indigenous communities has not been satisfactory. Their participation appears in some cases to be limited to being consulted on research priorities, design and assisting in the execution and evaluation of research results. She further argues that they have been treated as informants rather than colleagues and equals. She stipulated that researchers come from their universities, do their research over a number of months, get to know people in the community, get local help and go back to write and publish their findings. The researchers are the ones policy-makers listen to when making decisions about delivery in indigenous communities.

### **2.2.3.7 Confidentiality**

Confidentiality is important in academic research. It needs to be incorporated into the design and guaranteed in writing by the researcher and the participants (Ermine et al., 2005). The NHRPAC (2002) specify that researchers in biomedical, social and behavioural fields have to be proactive in designing research, ensuring that the dignity, welfare and privacy of research participants is protected and that the information about the individual remains confidential as expressed in the ethical codes of conduct of professionals. This is also consistent with ethical responsibilities stipulated in the Belmont Report on ethical principles and guidelines for the protection of human subjects of research. NHRPAC specifies that the primary responsibility of researchers is to

ensure that data collected from and about individuals is protected and this element is viewed as the key in minimising risks such as identification of participants.

The NHRPAC (2002) stipulates that confidentiality minimises subjects' concerns over use and misuse of data. The major benefit of confidentiality is that it allows researchers to conduct difficult research on important societal problems such as HIV; because under the confidentiality clause subjects are likely to provide accurate information thereby improving data used in the analysis; consequently improving the quality of research. Ermine et al. (2005) highlight a different perspective; they argue that confidentiality can have the effect of featuring the researcher's voice in instances where acknowledging the views of the participants and the knowledge system as the source of the information is appropriate. "From the indigenous perspective smuggling of knowledge happens through the confidentiality clause in ways that highlight the researcher and the researcher's interpretation of knowledge but hides the source of information" (p.33).

#### **2.2.3.8 Informed consent**

Informed consent is a process whereby prospective participants are informed about the general nature of the investigation and about their expected roles in terms of time and effort (Locke, Spirduso, & Silverman, 1993). Guarino, Lamping, Elbourne, Carpenter, and Peduzzi (2005) declare that informed consent is considered one of the most important components for ethical research involving human investigators, government, and the general public. Informed consent is also the foundation of clinical trials, as it is the fundamental requirement for participation in studies to test HIV and AIDS vaccines (Lindegger & Richter, 2000). According to Lindegger and Richter (2000) informed consent as implemented in human research incorporates four essential components: i) disclosure of all the relevant information about the research study; ii) comprehension by prospective participant of this information in order to make an informed decision; iii) freedom from all coercion of the prospective participant; iv) explicit and formal consent by the participant usually in written form. There is widespread agreement about the necessity of informed consent; however, there are also some uncertainties about the adequacy of current informed consent practices and procedures.

It could be argued that informed consent as the ethical principle is based on culturally relative notions of personhood. Western conceptions of personhood are essentially founded on assumptions of individualism as the core of personhood. It is the notion of individualism that gives rise to the core elements of informed consent, for example autonomy, the individual's right to decide one's best interests, and freedom from coercion. Ermine et al. (2005) argue that informed consent rests on the presumption that competent adults generally have the capacity and the right to decide whether they want to participate in a study. They warn that "no single individual can ever be aware of all the cultural concerns that may exist in the community" (Ermine et al., 2005, p.25).

The complexity of informed consent in different cultural contexts is also captured by Smith (1999); she argues that the Western paradigm of individualism that recognises the right of the individual to give knowledge through 'informed consent' is contradictory to the concept of collective ownership understood by indigenous people. This would also be typical of most African cultures which regard the core notion of persons as persons by reason of their participation in a community, or by reason of their relationship with other people. This is echoed by Sinclair (2004) who writes: "informed consent rests on the conditions of Western sensibilities of the legal individual and individuality. This binding agreement overlooks other cultures forms of social organisation where individuality is less pronounced" (p.12). Sinclair (ibid) suggests that communities which emphasise less individuality tend to regard informed consent with great suspicion, as opportunistic and exploitative. Krosin, Klitzman, Levin, Cheng, & Ranney (2005) suggest that culturally diverse notions of personhood might hypothetically give rise to conflicts and controversies regarding the issue of consenting to participation, and especially who should consent to participation. For example, the principle of Western medicine, reflected in the notion of informed consent, would assume the absolute right of each person to make the decision to participate in vaccine trials themselves. On the other hand representatives of other cultural contexts may stress the need for the consent of partners, local leaders or community leaders. In some cases it may even be suggested that the latter consent may function as a proxy or substitute for the consent of the person.

Comprehension of informed consent is another concern; available data suggests that research participants may frequently not understand disclosed information (Lindegger & Richter, 2000; Krosin et al., 2005). The Helsinki Accord requires that participants in any medical research project have a full understanding of the various aspects of the study, including the aims and methods of the study as well as advantages and risks of participation. A number of studies are conducted in the area of comprehension; so far the literature indicates that often than not research participants do not have adequate understanding of what they are signing up for. For example, Flory and Emanuel (2004) investigated understandings of informed consent in a clinical trial; they found that approximately 30% of participants in a cross-section of oncology clinical trials believed that their treatment had already been proven to be the best treatment for their cancer.

Fitzgerald, Marotte, Verdier, Johnson and Pape (2002) investigated comprehension of informed consent in less developed nations. They found that misunderstanding and low levels of comprehension are frequent in “developing nations”. Fitzgerald et al. (2002) highlight an added consideration for populations typically involved in HIV vaccine trials; they warn that in these communities there is a risk of autonomy erosion through inducements and through the conflagration of service and research. They also cautioned that people in these nations, particularly indigenous people, usually have different views on the causality of disease.

Lindegger and Richter (2000) argue that understanding is an indescribable concept; they further state that the understanding that someone has of a concept, an event or a process is difficult to gauge. They state that expressed understanding on the part of research participants is no guarantee of true understanding and may well be a manifestation of compliance and social desirability (Lindegger & Richter, 2000). This is echoed by Fitzgerald et al. (2002) when they suggest that research participants may not fully understand the study in which they are enrolled nor their rights as participants, despite having signed the consent form.

Lindegger and Richter (2000) suggest that implementation of informed consent in medical research focuses on the understanding of technical, product and methodological information. They further suggest that the adequacy of these forms is checked using an information test or

review of the participants after the transmission of information at different stages of research. Lindegger and Richter (2000) argue that these tests are a test of verbal memory rather than an assessment of comprehension, as there is no guarantee that adequate recall involves understanding. According to Lindegger and Richter (2000) the current informed consent process satisfies legal indemnity and does not meet ethical requirements. As a result the informed consent process is less likely to provide the psychosocial information that potential participants need in order to make personally informed decisions. It is apparent that a number of factors have to be taken into account in “developing nations”, especially the cultural norms and values of the locals, even though some of these factors are taken into account in some ethical guidelines, where it is suggested that the research community should consider drafting culturally sensitive guidelines for implementing informed consent procedures in developing countries (UNAIDS, 2000).

## **2.4 Concluding comments**

The review of literature presented in this chapter suggests the existence of a gap in research understanding within communities. This gap appears to be even bigger in the indigenous communities due to the history of marginalisation which is still evident today. Marginalisation resulted in researchers being illiterate in traditional or indigenous world views and the indigenous communities being scientifically or research illiterate. This chapter has shown that no world view possesses universal principles and when research is conducted there is an interface of world views which should not be overlooked for research outcomes to be useful. The chapter also highlighted collaborative methodologies as the appropriate methods that should be employed to overcome existing problems with the understandings of research.

The current study intends to establish community members’ understandings of research and research collaboration. Their attitudes towards research, as well as their perceptions of research, will be investigated. An understanding of how research collaboration is constituted and defined among these parties will help in developing a community-based model for research collaboration. According to Vitiello (2005), community understandings of research have not been well documented. Macaulay (1996) has done extensive work in community research and

partnership. His focus was to better understand under-served communities; their understanding of research. Research indicates that researchers had higher perceptions of the degree of mutual work than members of the communities. There can be many areas of disagreement between the communities and the researchers that researchers may not be aware of, with researchers being of the view that the community fully understands and accepts the conditions of research. This has become apparent in the work by Macaulay and colleagues (e.g. Macaulay, 1993, 1996; Macaulay et al., 1999), which shows that communities often do not view themselves as equal partners in research, whereas researchers see communities as such.

## **CHAPTER 3**

### **METHODOLOGY**

This chapter presents the methodological procedure of the study. The research participants are introduced first. The justification for the qualitative research paradigm is then outlined. The interview guide used for the semi-structured interviews is presented. The data collection procedures are outlined, including the challenges encountered during this process. This is followed by a discussion on the data analysis method. The ethical issues and limitations of the method are considered last.

#### **3.1 Research setting**

Participants of the study were drawn from a community in the eastern part of KwaZulu-Natal. This area is at the heart of the HIV/AIDS pandemic, and it is plagued by a high rate of unemployment and poverty. This area used to be one of the economically active places in South Africa, focusing on mining and agriculture. Most mines have since closed down leaving thousands of people in extreme poverty. This community was an ideal choice because it has become an important area for research and research participants were previously selected from it. Another advantage for the researcher was the presence of a research-based organisation affiliated to the local university within this community. The district has four municipalities falling under it consisting of rural, urban and semi-urban communities. The study focus was taken from the semi-urban area of the region. The selection of the participants in the area was based on easy accessibility.

#### **3.2 Research participants**

Twelve participants enrolled for the study; five men and seven women. They were all Zulu-speaking Africans. Their ages ranged between 26 and 58. They occupied different positions in the community; two were local councillors, one a traditional healer, one a traditional leadership

spokesperson, three from women's groups, two from faith-based organisations and three from a youth group member organisation.

### **3.3 Sampling**

Sampling was purposive; the logic of purposive sampling is to select information-rich cases (Miles & Huberman, 1994; Pasha, 1979). A decision was made to approach people who were perceived as occupying influential positions within the community, because it was thought that the influential positions held by the participants make it possible for them to maintain direct contact with the community. They would therefore be more informed about issues of importance within their community such as community beliefs, opinions, attitudes, perceptions and norms. This knowledge would enable them to express these beliefs and ideas.

The informants were also selected to mirror differences as influenced by age, gender, tradition and religion. Maximum various variation sampling made it possible for participants who occupied different influential positions to share their perceptions and understanding of research and research collaboration (Patton, 2002). This type of sampling facilitated an exploration of individuals' understanding of research with regards to their social context, whilst yielding important shared patterns. The researcher looked for information that shed light on differences and frequent patterns across participants.

Attempts were made to ensure that the sample was representative of people in leadership positions in the community and existing community-based organisations. It became difficult to obtain the same number of community leaders as it proved difficult to access some traditional leaders (*inkosi*). Some community-based organisations were not represented. It can be argued that some sectors were less represented than others. This may have resulted in information bias.

### **3.4 Justification for the qualitative research paradigm**

Qualitative research is more exploratory in nature and is more likely to take place in natural settings. Qualitative research seemed to be more suitable as it is directly concerned with

experience as it is lived; this is useful because it allows the researcher to gain more insight into phenomena (Roshan, 2009). Qualitative research provides depth into and quality of people's experiences instead of being concerned about who responds in a particular way (Miles & Huberman, 1994). Qualitative methods aim at understanding experience in the same way as the person who experienced it (Miles & Huberman, 1994). Qualitative research places emphasis on the identification of the meanings that people place on their lives such as their perceptions, assumptions, prejudgments and presuppositions (Miles & Huberman, 1994). This seemed to be the best paradigm to enable the researcher to explore understandings and attitudes toward research.

Roshan (2009) cautions about the shortcomings of qualitative research as sometimes the researcher may have to deal with unexpected circumstances where one's own behaviours and perceptions can affect research. Equally, Fish (1990, in Gasa, 1999) argues that an interpreter's personal, relational and social context as well as ethical and political values shape and influence his or her interpretation of a text. Therefore, it might prove difficult for researchers to distance themselves from research interviews as they bring their values, bias to the research situation. This makes it inevitable for the researcher to reflect on her own social and cultural positionality and how this affects her approach to the study.

### **3.5 Piloting**

A pilot study was conducted in order to assess how the interview schedule for the main study could be tailored to obtain better results. The researcher needed to test the appropriateness of the research questions. Secondly, it was of interest to establish whether or not questions in the schedule were comprehensible (Van Teijlingen & Hundley, 2001). It was hoped that the pilot would give an indication as to questions that needed revision, and also give clues and ideas not foreseen prior to the pilot. As such clues and ideas could greatly increase the chances of obtaining clear-cut findings in the main study. The researcher wanted to explore how some probes could be used in order to get in-depth information about the subject.

A focus group was conducted in one of the CBOs. The participants were from different community-based organisations. Because of the difficulties experienced when getting the group together, e.g. different commitments at different times, it was decided that focus groups would not be utilised; people would be approached individually. However, the exercise was rewarding as it gave practice in conducting an interview and highlighted the necessity to probe for quality. This process also proved useful in familiarising the researcher with the interview schedule and enabled her to refine her interview skills. As part of the pilot study three individual interviews were conducted. The participants were asked main questions and probed in cases where they gave brief answers. The pilot study proved informative with regards to the preparation of the main study. The participants described the questions as appropriate and thought provoking. The data obtained from the pilot study was not included in the main study, and none of the pilot study participants participated in the main study.

### **3.6 The research process**

#### **3.6.1 Community entry**

The researcher had an opportunity to become a research intern at an organisation that was active in the area where research was conducted. At the time of the internship, the researcher did some field work on a separate project and this process afforded the researcher an opportunity to actively to learn about the community of the study through participation in some community activities and ceremonies. Prior to data collection, the researcher spent a period of three months in the community. The period spent afforded the researcher an opportunity to become integrated in the community by participating in some of the community initiatives and wedding ceremonies. This was also a time when the research organisation was surveying the existing registered and non-registered community-based organisations and non-profit organisations within the community. The researcher used this opportunity to engage informally with the community members who were part of the women's groups, youth group members, traditional healers and the house of traditional leaders. The researcher had an opportunity to attend a community meeting organised by the department of social development. This meeting was very fruitful as the community expressed dissatisfaction with the lack of consultation by the government on

service delivery issues. It also gave an indication of community members who represented the community and this is how some were chosen to be part of the study.

Being part of the research organisation may have posed some disadvantages related to the power dynamics. It was evident that the research organisation had formed solid relationships with the community of interest and many of them were assisted by the research assistant who was taking the researcher around to initiate and register their CBOs. His commitment in community development initiatives earned him a lot of respect from the community and he was always well received by the CBOs. The community members also displayed high regard for the researcher from the first day of our encounter. There appeared to be some level of interest in the researcher because of the home language, people responded enthusiastically and showed a keen interest on in the researcher's background and some participants were inclined to give the researcher a positive experience of the Zulu culture which is similar to the Xhosa culture.

### **3.6.2 Formal introduction**

Specific sectors were approached to introduce the researcher. Local traditional leadership was approached first as a sign of respect for the cultural norms of the area such as the importance of informing traditional leaders about any project to be conducted in their area of command. The traditional leadership knew about the presence of the research organisation in the area it was necessary to obtain specific permission to conduct the study. The field worker, who is effectively a community liaison officer, was the key person in all the introductions, as mentioned above. The community gave both a warm welcome; it was mentioned in the introductions that the researcher had come to conduct research into community's conceptions, perceptions and attitudes toward research. All the relevant information pertaining to the study was disclosed and dialogue permitted for people to gain understanding about the study.

### **3.6.3 Appointments**

Decisions regarding who should be interviewed as a 'representative' were based on recommendations by the field worker and also some members of the CBOs based on their

knowledge of the community and the key role players. These decisions were made in consultation with the research organisation. The decisions were also made subject to the availability of the participants. Following the negotiations with the field worker and the senior researcher from the research organisation, visits were made to the respective CBOs and key members of the community who were part of the sample. The researcher made appointments to meet the participants. Appointment times were determined by the availability of the participants. The selected list was a mix of people who had participated in research before and those who had never participated before. This was driven by the need to understand different conceptions of research and research collaboration by various members of the community. Hence the researcher worked in consultation with people who helped select a sample on the basis of their knowledge of the population. Viewed from another angle, of course, this could have its own drawbacks, seeing that the research organisation was indirectly part of the subject of this study.

### **3.7 Introduction to each informant**

Informants were greeted formally and respectfully, despite the fact that they already knew the researcher from the initial meetings as mentioned above. In order to build rapport and to facilitate communication during the interview, the researcher reintroduced herself to the participants.

#### **3.7.1 Informed consent**

Before the interviews were conducted consent was sought from the participants clarifying all the necessary information pertaining to the research. The participants were made aware of the purpose of the study, the format in which the data will be published; it was also explained that there would be no harm involved in the study and it was stressed that they were under no obligation to participate. The researcher saw the respondents twice; the first visit was to introduce the study to the recruits and to clarify whatever questions they may have, and then leave them with the consent form including the details of the study. The respondents then set the time for the next visit, during which the interview was conducted. All participants appreciated

the space they were given to make the decision about participating or not participating and it is something they made reference to in the interview process.

### **3.7.2 The research interviews**

The interview schedule was used to collect data through open-ended questions. This aimed at getting an in-depth understanding of the community's conceptions of research. The interviews were conducted on site employing a semi-structured interview protocol. The interviews were appropriate because of their ability to elicit open-ended responses. The interview schedule covered areas such as the meaning of research to the participants, collaboration and partnership as well as their attitudes and perceptions toward research. This tool was developed from the literature for this purpose (Ermine et al., 2005; Henry et al., 2002; Henry et al., 2004; Sinclair, 2004). (See Appendix A.)

These comprehensive individual interviews were conducted, as a stand alone method to explore and probe deeper into the participants' perceptions and attitudes toward research and research collaboration.

### **3.8 Procedure for the main study**

Necessary arrangements were made with all the study participants and appointments were made with the councillors; a difficult exercise as they were not easy to get hold of due to their busy schedules. The councillors and traditional healers opted to be interviewed in my office as it would have been difficult to carry it out in their offices due to anticipated disruptions, whereas other participants were interviewed in their places of work as the CBOs were able to provide office space to conduct interviews on site. All the interviews were conducted in isiZulu and they were audio-recorded (with the participants' permission) and then transcribed for further analysis. Each interview took approximately 45 minutes. All interviews were later transcribed, a procedure which lasted approximately 5–6 hours per interview on average.

### **3.9 Analysis**

Thematic analysis was used to analyse the data. Thematic analysis involves the identification and analysis of themes and patterns of similarity within qualitative research (Braun & Clark, 2006). It is not grounded in any particular theoretical and epistemological framework and can therefore be applied across a wide range of qualitative research approaches (Braun & Clark, 2006). The analysis began during data collection as the researcher began noting and recording emerging themes during the interview process. It was not fixed to a particular time and the researcher also took separate notes observing the varied emotional reactions to some questions. It was noted that some participants wanted to say some things of the record and therefore the researcher had to switch the recorder off in those instances. The overall analysis approach that was used followed the conventions of template analysis where the researcher produces a list of codes (template) representing themes identified in textual data (King, 2004). The researcher organised the data first and the transcripts were coded into broad themes based on research objectives and interview questions to create an initial template.

Braun & Clark (2006) states that in seeking to analyse data, thematic analysis can either identify the themes pertaining to a particular research question (deductive analysis) or it can identify themes that are observed across the entire data range (inductive analysis). Inductive thematic analysis occurs when the researcher observes themes from the data without having had a particular preconception of the various themes that would emerge. Deductive thematic analysis on the other hand, is guided by the researcher's particular thematic interest and seeks to analyse a specific area of the data. I used an inductive means of analysis as I went into the research with the intention of merely exploring the attitudes and perceptions of the participants. However, as the research process continued, I began to observe certain themes of particular interest.

### **3.10 Issues of validity and reliability**

#### **3.10.1 Reliability**

According to Miles and Huberman (1994), reliability is concerned with the extent to which the research process is consistent and stable over time across researchers and methods. Marshall and Roseman (1999) argue that the universe is not static; it continuously changes and therefore people change and develop and also their points of view will evolve with time. Thus, attaining absolute reliability can be problematic. In order to strengthen reliability, the researcher kept a record of observations and different accounts occurring during the interview process, (Miles & Huberman, 1994; Mkhize, 2003; Patton, 2002). Data were transcribed as soon as possible after it had been collected; this enabled the researcher to complete contact summary sheets and to do follow-up interviews where deemed necessary (Marshall & Roseman, 1989; Silverman, 2001). The researcher conducted all the interviews to ensure consistency. The researcher asked for assistance with coding; it was also necessary to check understanding of terms with a Zulu-speaking person as the researcher is Xhosa speaking and even though the languages are quite similar, the meaning of certain terms does differ. The researcher and a colleague coded a few interviews separately and thereafter compared notes to determine the reliability of the coded themes.

#### **3.10.2 Validity**

The validity of qualitative research has been questioned (Denzil & Lincoln, 2000). Miles and Huberman (1994) note that traditional notions of validity emphasise external validity, which is the generalisability of the findings in other contexts. However, generalisation from sample to population is not a major purpose in qualitative research (Miles & Huberman, 1994; Kvalle, 1996). Qualitative research is an appropriate method for this study because its interest is in the attitude and perceptions of people. Kvale (ibid) explains how the validity of qualitative research depends on the researcher's ability to act as her/his own 'research tool', namely her/his ability to

reflect critically and reflexively on the process, including the possible influences she/he might bring to bear on the study by virtue of her/his values and prior assumptions, throughout the conduct of the study.

Due to language differences between the researcher and participants, the researcher was alert in the interview process and she paused and asked for clarity on certain terms asking for specific examples to clarify the implications of concepts used. This is consistent with the concept communicative validation (Kvale, 1995) which involves a verification of interpretation by means of a dialogue between the researcher and the participants. Likewise, Miles and Huberman (1994) recognise the importance of using different sources and testing the evidence of each source. Emerging findings were also discussed with a peer researcher and the site supervisor to get alternative opinions; member validation was also be used to test the meaningfulness of the findings from the perspectives of the participants (Miles & Huberman, 1994). The field research assistant proved a useful tool in clarifying and edifying the researcher's understanding of results.

### **3.11 Summary**

The purpose of this study was to explore community conceptions of research and research collaboration, highlighting perceptions and attitudes toward research. This chapter discussed the methodology adopted in the study. Characteristics of the research setting and participants were presented. Approaches and techniques used in the collection and analysis of data were mentioned. Finally, validity, reliability and ethical issues were addressed. The discussion and results of the study are discussed in the following chapter.

## **CHAPTER 4**

### **RESULTS AND DISCUSSIONS**

#### **Introduction**

The results and discussions are presented in this chapter. The emerged themes are the wide-ranging conceptions of research. The results indicate a link between social context and individual conceptions of research. Through the research findings the participants mentioned lack of training and poor community consultations and community involvement as the factors that contribute to a poor understanding of research.

#### **4.1 Conceptions of research**

The following emerged as conceptions of research in the current study: research as service delivery, research as an inquiry into knowledge, research as community development, and research as researcher-centred.

##### **4.1.1 Research as service delivery**

The participants understood research as service delivery; this is an indication of the social context in which the study was conducted where councillors play a major role in people's lives. In extract 1 the councillor is viewed as a guardian, displaying a fatherly role/relationship to the community. This shows that local needs are determined by the key political leaders and these leaders are viewed as advocates within the communities. These findings highlight the complexities of doing research in politicised and underprivileged communities.

*Interviewer:* Can you tell me what you understand by the term research? What comes to your mind when you hear the word research?

*Extract 1*

*Respondent:* Youth group member

*The councillor has the ability to know what the needs of the community are, we as his people who are deprived of things such as proper shelter, the researcher can then be able to do something about satisfying the needs perceived with the help of his or her authorities.*

*Extract 2*

*Respondent: Youth group member*

*To help the government develop certain places, the government sends people and when he sends these people they are able to say in this place there are no roads, clinics and in certain places there is no water. Then the government is able to bring closer those needs to the people so that they can have a better life.*

*Extract 3*

*Respondent: Faith-based organisation member*

*For me research depends on the services that need to be rendered in the community. Anybody in the government who wants to render services in the community has to look and decide if the service he wants to render are relevant to the community, so the government departments as the service providers should be the ones who conduct research.*

*Extract 4*

*Respondent: Women's group member*

*I think it has to do with service delivery especially within the community, a way of investigating development of the people or maybe when the government wants to deliver a certain service he has to investigate how people will accept that service.*

The research findings indicate the importance of taking into consideration the context in which the study is conducted. In the current study the political context was considered to find meaning in the participants' conceptions of research. This idea is supported by Nielsen & Gould's (2007) assertion that research should take cognisance of socio-historical context so that there is an understanding of factors leading to the issues under investigation. The context in which research is viewed has an important influence on people's perceptions of research and its significance (Huntington, Trainor, Natcher, & Chapin, 2006).

It appears that the participants cannot distinguish between government service delivery and research. These findings support Smith's (1999) submission that research cannot be separated from politics as the two are connected. In the context of the current study, past research contributed to the marginalisation of the local people as its methods advanced the apartheid policies within the communities, robbing people of own identity and self-determination (Mkabela, 2005; Nielsen & Gould, 2007; Smith, 1999). Indigenous people were deprived of the opportunity to participate meaningfully in decisions that affected their lives (Huntington et al., 2006).

Politics played a major role in the liberation struggle and hence the leaders are viewed as guardians of the community. The findings confirm Stark's (1998, in Gasa, 1999) assertion that research is a social endeavour, and it is conducted among people who are embedded in a number of social contexts each of which has social norms and cultural expectations.

It appears that cooperation of the political and traditional leaders is essential for they are the ones who speak on behalf of the official community structure and they could conceivably block any research about which they have doubts (Nielsen & Gould, 2007). Due to the presence of corruption in every society, Deloria (2002) warns that politics can be a minefield for the unwary researcher; as has happened, academics may face pressure from community leaders, funding agencies to further their political agendas.

#### **4.1.2 Research as community development**

The participants understood research as a method that serves multiple functions, and the gist of their understanding was that after research is conducted something useful must come out of it for the benefit of the community. The participants emphasised that when knowledge is generated it must come back to be of service to the communities from which this knowledge was generated.

The following extracts reflect this theme.

*Extract 5*

*Respondent:* Women's group member

*I think research is about whether something can be of help or not. This is because the aim is for the community to gain or benefit something when there has been research.*

*Extract 6*

*Respondent: Faith-based organisation member*

*I think research is about gathering the views and perceptions of people about certain issues in the community.*

*Extract 7*

*Respondent: Local councillor*

*Research is significant because we are living in a continuously changing world so with research we can keep track of what is going on around us.*

*Extract 8*

*Respondent: Youth group member*

*I think it is important because it brings much more validity of the circumstances in question since it is inappropriate and misleading to inform people, for example about a certain disease affecting the community at large without any form of proof and the degree to of validity of that disease or crisis is after all. The main aim of the research is to bring light to the community and to help the people know what to do to help themselves and be helped.*

*Extract 9*

*Respondent: Women's group member*

*To me it is important because you can't just want to start up something without information on it, it is essential that you have necessary information required for you to do it. I think research is about asking if something is of help or not. This is because the aim is for the community to gain and benefit when there has been research.*

*Extract 10*

*Respondent: Local councillor*

*Anybody who wants to develop a community has to conduct research first to get to know whether his idea will be successful or not and getting a way forward.*

Most participants put forth the consideration of community benefits and development in any research conducted within their community. There is an indication of positive regard for research as long as it adheres to the above. Nielsen et al. (2007) recommend that the negotiations should occur as to what the community derives from research. These findings parallel Nielsen et al.'s (2007) remark that on a larger scale research in indigenous communities should result in some tangible good to the community.

It appears that if research is organised appropriately by considering the community benefits, the community is likely to conceive it as an appropriate tool for development (Anderson, 1996). Similar views are held by Porsanger (2004). He states that it is essential to ensure that research conducted on local community issues is conducted in a respectful, ethical, correct, sympathetic, useful and beneficial fashion seen from the point of view of the local community. There is a large body of documented literature suggesting that the primary focus of traditional research for centuries has been on serving the interests of the researchers (Deloria, 2002; Ermine et al., 2005; Henry et al., 2004; Smith, 1999; Sinclair, 2004). The findings of the study suggest that research should be community based because community-based research “involves a process of systematic enquiry aimed at generating information or understanding which contributes to community development” (Nielsen & Gould, 2007, p.8). This research as required by the community can meet the criteria of benefit, relevance and utility (Sinclair, 2004).

The traditional methods of research focus more on producing quality research whilst neglecting social benefit (Mkabela, 2005; Smith, 1999). This has to change particularly with researchers working or intending to work in disenfranchised communities like the one in the current study. The recommended methodologies are aimed at both social benefit and quality research.

### 4.1.3 Research as an inquiry into knowledge

Most of the participants understood research as an inquiry into knowledge, or in-depth investigation. This in-depth investigation produces information from local knowledge which all the participants felt is important to include in research. What emerged in the themes was that whatever the researchers are enquiring about within the community, the input of the community is valuable and it needs to be included in research to benefit the community under study. This challenges traditional research which is conducted for publications and career advancement of the researchers with little or no benefits for the community in which the study is conducted (Mkabela, 2005; Sinclair, 2004).

#### *Extract 11*

*Respondent:* Local councillor

*From its own definition, I understand research to be in-depth understanding of that particular question especially if one wants to know how to go about tackling the research question.*

#### *Extract 12*

*Respondent:* Women's group member

*Research is when you want to get an in-depth understanding about something that one is facing, when you want to know how it started.*

#### *Extract 13*

*Respondent:* Traditional healer

*Research is a way of getting the deep views of the community on something.*

#### *Extract 14*

*Respondent:* Women's group member

*Research affects us all from community organisations, projects and government departments. Before they start anything research must be conducted, we are all human*

*beings; researchers are also humans living with us; they affect our lives just like we affect theirs; we have to live together for things to be alright.*

#### **4.1.3.1 Incorporating local knowledge**

Participants were also of the view that the research process should take cognisance of local knowledge and this is expressed in the interview extracts below.

*Interviewer:* Do you think it is important to include local knowledge in research?

*Extract 15*

*Respondent:* Traditional healer

*Most of the time the researcher relies on the community for information and most of the time the community gives the right information. Local knowledge is important because if you do not know how I think or what I think as the local person you wouldn't know how to approach me. But if you start getting to know how I do things even if you get that from me it's still important, to know how to deal with me. The researcher comes to the community because they want a way forward. The person interviewed at the time will give useful information which will help the community.*

*Extract 16*

*Respondent:* Traditional leadership

*Yes, it is right because we are different people with different ideas so doing research without the inclusion of the community's knowledge is of no use because the success of the research is dependent on our knowledge. So the researcher's role is only to compile these ideas after comparing and constructing just the way he/she learned how to.*

The above extract displays the value of different perspectives and exchange of ideas which exists between the researcher and the community; the solution to this problem lies in these putting these perspectives together. The participant takes the view that as members of the community they are the experts in their own right. It also highlights the importance of engagement with the

community which is deeper than involvement because, as the participant clearly states, it's only when you have an in-depth understanding about someone or something in its context that you are qualified to say something about it. They emphasise that knowledge lies within the community.

*Extract 17*

*Respondent:* Youth group member

*Within the community there are those who have in-depth knowledge which they have never shared with anyone but when people are put together they can share this knowledge with other people. This sharing gives an opportunity for the researchers to listen independently; they can see if they have same ideas or not.*

In this extract the participant makes a distinction about levels of knowledge which is highly significant because in indigenous communities, like this one, the depth of knowledge differs and is not based on formal education; on the basis of traditional knowledge, some people will be more knowledgeable about certain things; knowledge is also based on wisdom that comes with age.

*Extract 18*

*Respondent:* Women's group member

*It is probably the researcher's knowledge that is more important but we as the community are equally important because we have a different perspective, which in itself is important. The researcher depends on the participation of the community. But it seems that the researcher is the one because he has higher education, yes the community needs to have a lot input but as I have just explained the researcher is more important.*

In the above extract the participant seems to be caught in-between; partly she feels she has to choose one or the other. The current research practices communicate to her that the researcher's knowledge is more important especially because it is a formal type of the knowledge.

Most of the participants indicated that the current order of research does not take indigenous knowledge into account. There is also an indication that the participants acknowledge that a

space can be created for two world views to exist and draw from each other instead of working in opposition. As suggested by Ermine et al. (2005), confrontation of world views sets up the conditions by which an extended engagement of dialogue is necessary for the pursuit of ethical interaction.

Sinclair (2004) suggests that the models of new knowledge from different world views are what is required to bring about cooperative spirit between institutions and indigenous people in a manner that brings honour to all. The values of both participant and researcher would be accommodated through in-depth exploration of both world views. The participants in their understanding or conception of research as an inquiry into knowledge are not fixed on the researcher or investigator as an expert with preconceived ideas about the researched phenomenon.

The in-depth enquiry into knowledge, referred to by participants, is based on indigenous ways of knowing. According to Nathani (2005) in indigenous knowledge the self exists within a world subject to flux; he suggests that the purpose of indigenous knowledge such as the one under current study, is to reunify the world or at least reconcile the world with itself. Inquiry or investigation facilitates learning about the other without changing the other's world view. This was reflected during the research process. The participants posed enquiring questions about the researcher's life experiences. The participants' reception and openness highlighted observations from literature that, in the African context, knowledge is seen as cumulative and is formed from everyday experiences; this was an observation made throughout (Arewa, 1998; Sheurich & Young, 1997).

Most informants recommended both researchers and the community should share own perspectives about the phenomenon under study. These findings are consistent with suggestions from literature that the indigenous and Western community can learn from each other through dialogue that respects the integrity of both cultures (Hughes, 2000; Porsanger, 2004; Parra, 2009). According to Hughes (2000) the benefit of dialogue will be the development of underlying patterns of interdependence and balance between complementary opposites. This calls for respect and understanding of each others ways of knowing and doing. When parties

come together they will develop a deep understanding and appreciation of each other's difference without seeking to dominate the other as has been the trend since the colonial times.

Brown (2003) cautions that a shift from the status quo is not easy due to power dynamics in research, stating that the cultural element between the politically weak and the politically strong is not equivalent to exchange among equals. In societies as the one under current study social embeddedness of the individual is emphasised. The researcher should not start from a theoretical departure point but rather from indigenous ethical protocols, in order to develop methods that will suit the local culture, thereby initiating projects which consider indigenous interests and needs (Porsanger, 2004). As observed the way the two world views come to know is very different and therefore there is a need for a reciprocal relationship. Mkabela (2005) cautions that researchers need to be aware of the fact that the local community does not need validation from the researcher about what they know nor should it be assumed that Western conventions of knowledge production should take precedence in African cultural context.

This is echoed by Sinclair (2004) who suggests that it is good to follow the local community protocol also ensuring inclusion of all stake holders he suggests that this will help people to support each other in recounting and articulating knowledge as it relates to cross-cultural protocol. For example, the participants highlight the importance of putting across their own perspectives on research subject matter; therefore it is important that the interests of the researchers are aligned with the interests of the community (Pillota et al., 2004). Nathani (2005) writes: "Indigenous world views hold at their teaching source a caring and feeling that survives the tensions of listening for the way of living within the context of flux, paradox and tension; they respect the pull of dualism" (p.1).

Pillota et al. (2004) suggest that the dialogical character of interpretation is not looking at the other; rather it is looking with the other at something which the other seeks to communicate. In this method, as Pillota (ibid) points out, it is only on the basis of one's own belief that the point of view of another person can be understood. In this engagement the point of critical self-reflection is to determine which of one's beliefs are appropriate and which are inappropriate given a particular situation (Pillota et al., 2004).

There are indications that people are interested to know the spirit that exists in every relationship. According to Nathani (2005) in the African systems of thought the ontological position emphasises that to understand reality is to weave a holistic view of society which accepts the need for harmonious co-existence between nature, culture and humans.

It has been suggested that although it might prove difficult to respect cultural differences in cross-cultural settings, it is nonetheless achievable.

Porsanger (2004) suggests that important issues for indigenous methodologies be itemised. As Smith suggests the research agenda should take into account survival, recovery, and development, which are conditions and states of being, through which indigenous communities are moving.

#### **4.1.4 Research as researcher-centred**

##### *Extract 19*

*Respondent:* Faith-based organisation member

*What comes to my mind when I think about research is that it all depends on the person who is doing the research and the actual research question, what it is all about. At the end of the day the researcher aims to compare the wrong with the right (with regard to the research) in order to get an idea of how to approach the research itself.*

##### *Extract 20*

*Respondent:* Women's group member

*I have to respect the views, perspectives and ideas of the researcher because he/she has more knowledge on the topic than us the participants.*

*Extract 21*

*Respondent: Women's group member*

*In my view when the researcher gets into the community he comes with the knowledge and he shares his knowledge with the community so the community becomes more enlightened, the community begins to see, before you came we did not see and we did not know. You are coming with the great knowledge and you shared with us as the people, now all of this knowledge has to spread throughout the community.*

*(lo mcwaningi uyena oseyenza ukuthi umphakathi ubone kakhulu phela besikade singaboni lokho ufike wena wasifundisa nento ebesingayazi. Wena ufika nolwazi olukhulu wasithelela nathi njengomphakathi.)*

*Extract 22*

*Respondent: Faith-based organisation member*

*I think the researcher understands the concept that is being researched to some degree. This is taken to help the community learn something from the researcher and so the knowledge/ understanding that the community has on that particular issue improve which is good because after this people are bound to have in-depth information about issues that affect them.*

*Extract 23*

*Respondent: Local councillor*

*I would say research is conducted to be used by the researchers, or intellectuals, I suppose these are the people who can look and analyse things in a way. Some people are trained to be researchers while other members in the community are born intellectuals; they end up working as consultants for group of researchers helping them so that they have proper planning, that's how I see it.*

In the above extracts the participants are of the view that the researchers are more knowledgeable, and superior to them, a view which has resulted from the way the researchers have always come across to the communities. This is supported in documented literature making

reference to the history of cultural imperialism, cultural dominance and colonialism (Costello & Zumla, 2000; Smith, 1999; Young, 1994). In the context of this study apartheid and racism have led to the view that local knowledge is inferior and insignificant. The participants are assuming a submissive role according more power to the researchers based on their educational qualifications. The themes highlight Porsanger's (1999) assertion that Western academic research aimed at solving "indigenous problems" has given power and control to the non-indigenous world because in the past research has been affiliated to the interests of people who have been exclusively non-indigenous. The feelings of inadequacy and powerlessness equally display Smith's (1999) declaration that research has disempowered indigenous people who have long been used as sources of information. In the current study there appears to be a need for connection between individuals and their settings, for them to have control over representation of local issues (Henry et al., 2004).

This is also consistent with Ermine et al.'s (2005) assertion that indigenous communities like the one under current study had a way of handling local knowledge, until Western elitist knowledge devalued and mystified their knowledge resulting in some people disconnecting with their values, while others became reluctant to share their thoughts with outsiders because through this process their indigenous knowledge was disrespected by the Western world and religious institutions.

This conception captures Stringer's (1996) assertion that research operates at a distance from everyday lives of the people and largely fails to penetrate the experienced reality of their day-to-day work. Similarly Parra (2009) argues that there is a disconnection between what counts as social research and what serves society's needs and interests. He further suggests that social research theory is embodied in the real lives of the people. There is an indication that research does not help non-academic people understand their context and practices.

#### **4.2 Factors affecting research understanding**

The understanding of research is a concern throughout the world; this concern is even more evident in "developing nations" because of the extent to which communities have been

marginalised from research. Several authors argue that research scholarship has largely taken the form of propositional knowledge, that is, facts and information about phenomena and experience generated by rigorously controlled experimentation; statistical analysis of observed variables and disinterested speculation (Mcniff, 2000, in Parra, 2009). The factors that were highlighted by the participants confirm what is discussed in literature about research capacity in developing societies like the current one (Costello & Zumla, 2000; Ermine et al., 2005; Parra, 2009). Consistent with existing literature the majority of participants cited lack of consultation, power dynamics, lack of training and uninformed consent as the factors that hamper understanding of research.

#### **4.2.1.1 Lack of consultation**

The participant highlighted the possible dangers that are posed by the research community when they fail to consult. The community feels left out in research that is being conducted within their community.

##### *Extract 24*

*Respondent:* Youth group member

*The community is never well informed and I am saying this because I think it is vital for it causes unnecessary conflict, the community complains that there are things that some researchers tend to overlook. Things such as telling us about the research at short notice can really be inconvenient.*

##### *Extract 25*

*Respondent:* Traditional healer

*I heard somebody say that a researcher from Durban was coming to our town to conduct a research but that person did not really say what the research was all about. So as a person who likes learning and who is a very active member of the community I went there. In other words I heard by chance but there should be a way which can allow the community time to prepare for the research before participating. Otherwise the community will not participate in numbers if they are not informed or properly consulted.*

*Extract 26*

*Respondent: Women's group member*

*I understand research but not very well, because there are many issues that should be researched but they are not. Some of these issues are researched and some are not. You just hear in the community that something has been implemented when no research was done, for that reason I would say I think I understand research at the same time I do not understand the way it is done in practice.*

*Extract 27*

*Respondent: Traditional leadership*

*I think everything depends on the community involvement. You see as the Zulu people we have a tendency to say if someone does not involve me in his things I will not bother but we still get offended, people would like to be in the picture from the beginning to the end.*

*Extract 28*

*Respondent: Local councillor*

*The communities are not treated fairly; people have to be informed about research, all the stakeholders should be involved. The community needs to play an oversight role like I said earlier; there should be a community structure that will outline a protocol in which the researchers will follow.*

*Extract 29*

*Respondent: Traditional leadership*

*I think for research to be fair the researcher needs to involve the community, consultation with all the community leaders, including traditional leaders, it must not only end with the Councillors.*

The statement that there are things researchers overlook, seems to emphasise the importance of dialogue which has been dealt with the previous section. Extract 24 acknowledges the social

harm that can arise resulting from absence of consultation in community research. Ermine et al. (2005) also caution about other potential risks that result from lack of consultation. They state that the danger of not involving local communities is that researchers miss the opportunity of allowing the localities to utilise their knowledge as the researchers are not fully aware of them. This statement is supported by Stringer's (1999) assertion that very often validity of knowledge held by academics is threatened by their reluctance to process indigenous information from locals. Stringer suggests that cooperation and consensus should be the primary orientation of research activity. He further suggests that this method seeks to link groups that are in conflict so that they may attain viable, sustainable, and effective solutions to their problems through dialogue and negotiations.

Most of the participants felt that research is not introduced to the entire community to enable community members to make informed choices about participating or not participating in research. This perceived marginalisation may make it difficult to set up open relationships with the participants in future community involvement which is necessary for research. There are indications that researchers may benefit from establishing ethical relationships with the community of interest.

The NHMRC (2003) recognises community as a complex notion that can be invoked in relation to different cultural groups. Consequently, the construction of ethical relationships between researchers and participants and/or the community must take into account the principles and values of community cultures (NHMRC, 2003). In this regard it would be recommended that researchers draw from the past in order to understand the present and to determine the future. This is so because values held by people underpin their perceptions and beliefs.

The NHMRC (2003) writes: "To misrecognise or fail to recognise cultural difference can inflict harm, can be a form of oppression, imprisoning someone or a group in a false, distorted and reduced model of being" (p.3). This is supported by Gasa's (1999) submission that participants from predominantly collectivist societies tend to emphasise the importance of relationships. This is due to being socialised to view the world in terms of relationships. This suggests that there needs to be community engagement with the purpose of selecting community advisory boards

which will help to direct the research community on what is culturally appropriate or inappropriate in the community. In theory, community representatives are able to provide insight into the norms, values, experiences, questions, objections and appreciation for the community they represent, expanding, correcting and ideally validating the approach taken by professionals in practice and research (McKieran, 2004). They are meant to create dialogue and also serve as a bridge between their respective communities and researchers.

Researchers and prospective participants might benefit from mutual exploration of expectations with regards to researcher-participant relationships. CABs could provide constructive criticism and feedback to help improve the quality of research protocol (Morin, Maiorana, Koester, Sheon & Richards, 2003). It might however prove challenging to encourage participants to be forthright about their expectations and motivation for participation (Gasa, 1999). The primary barrier to this can be a knowledge gap between researchers and members of the community as well as power dynamics (Gasa, 1999; Morin et al., 2003). It would be appropriate for researchers to engage community representatives not only for the purpose of meeting external requirement for community participation, but also to respond to disparities in knowledge. Researchers can be trained in methods that will help them communicate and work effectively with communities. Research participants can be encouraged to participate in CAB meetings to share their experiences in research and to offer feedback.

#### **4.2.2 Uninformed consent / community involvement**

What emerged in this theme is the lack of informed consent or community involvement in research. This was because the researchers usually explain to the participants afterwards that they were participating in research. This is what Maddock (1992, in Sinclair, 2004) warns about, that researchers need to refrain from taking advantage of gullible or uncomprehending individuals for opportunistic study

*Extract 30*

*Respondent:* Youth group member

*In many research projects we never really understand what is expected of us. It seems the researcher briefs the participant about the research question which brings very little clarity and participants end up answering to questions they would not have answered to if they had known that those questions are the actual research, or what the research is all about.*

*Extract 31*

*Respondent: Faith-based organisation member*

*It is just that people have to be informed about research, explaining to the participants what the research is all about and getting them to agree or decline to participate in the research after having clearly understood the impact and or the benefit that results from their participation.*

*Extract 32*

*Respondent: Youth group member.*

*In most cases you find that the word spreads that some researchers will be coming to do research and then people go in numbers to participate in the research without being informed and therefore agreeing to participate.*

*Extract 33*

*Respondent: Women's group member*

*There is never a time where it is explained or declared that people are doing research. You just see unknown people present in the community saying we are doing such and such a thing, we are not properly informed or given an opportunity to decide to be part of research.*

Ethical guidelines in research strongly emphasise the importance of informed consent in research (Belmont Report, 1979; South African MRC, 2003). It is clearly stipulated that participants should understand information disclosed. The theme of informed consent indicates an existence of discrepancy in the way in which the informed consent is sought. Existing literature suggests that many research participants may not fully understand the study in which they are enrolled nor

their rights, despite having signed the consent form. This problem is pertinent all over the world but it is pervasive in vulnerable and poor communities. It is in these communities that researchers are often accused of ethical misconduct for setting research priorities and project management practices which have negative consequences which outweigh the benefits of research (Costello et al., 2000). There is an indication that in some instances researchers still afford little or no attention to the thoughts and values of the participants; therefore research bears more negative consequences than positive, whether in the form of appropriation of local knowledge or misrepresentation of the people or community in which research is conducted (Costello et al., 2000; Henry et al., 2004; Hughes, 2000; McKieran, 2004; Parra, 2004; Posey, 1994).

It appears that there is a need for the understanding of informed consent to be improved (Lavori et al., 1999, in Flory & Emanuel, 2004). Due to people's unfamiliarity with research, understanding of informed consent can be a big challenge. This challenge can be overcome by treating informed consent as a process rather than a document that needs to be signed (Ermine et al., 2005). It is evident that community education is important. Ermine et al. (ibid) suggest that the notion of informed consent must be adapted for researchers to establish relationships and trust with the community and participants. He further asserts that it is important that the nature and the significance of the study is explained to the whole community before seeking individual participation.

While Fitzgerald et al. (2002) suggest that person-to-person interactions, especially the extended interventions, can be more effective in improving understanding of informed consent, particularly because extended one-on-one interaction with another person has more potential for active engagement and responsiveness to the individual needs of the research participants (Flory & Emanuel, 2004). However there can be variations in terms of people's preferences; some people may possibly appreciate the one-on-one attention which explains to them about research and the consent process. Others on the other hand may have strong communal values therefore it would be useful if the manner in which the participants are approached facilitates good relationship building both individually and communally (Gasa, 1999). This can be achieved through community consultation. In this process all the leaders in the community would need to

be involved in a manner that is respectful. In this case community entry strategies would need to be followed; appointments can be made to meet with the leaders to inform them about the general nature of the study.

As Stark (1998, in Gasa, 1999) suggests, research involves not only the individuals whose consent is sought, but also the identifiable groups to which they belong. He adds that it is a matter of courtesy and ethical interest to request consent from the leaders of target communities prior to conducting research with members of the community, as failure to consult may contribute to the perception that research is conducted by “experts” *on* people rather than *with* them, and may further disadvantage people who are already disadvantaged. There is an indication that researchers have to spend a reasonable amount of time in community involvement because everything depends on informed consent. If an unjust action is performed against a particular community it always filters through to affect people individually.

### **4.3 Attitudes towards research**

Most participants expressed concerns about current practices of research and distinguished some factors as negative consequences of research. Participants identified researchers’ self-interest and misinterpretation of results as problems with the current practices of research.

#### **4.3.1 Research serves researchers’ self-interest**

One of the participants mentioned that research fails to follow the right protocol when they enter the community. This participant felt that this raises questions about researchers’ interests.

#### *Extract 34*

*Respondent:* Local councillor

*What is not right about research is that proper procedures are not followed, no they are not followed. They only care about what they want; Researchers do not sit with us and give us time to understand what they are talking about. Instead people just come in a*

*hurry and do whatever they need to do and they barely give you time to even think and understand what research is about.*

This participant questions the motives of the researchers as self-centred with no interests or concern for the community and subjects of the study

*Extract 35*

*Respondent:* Youth group member

*Researchers use the community to further their interests, and when they need information or knowledge they do not involve the community. That's what affects community participation. Nobody likes to be used, and then when you don't need anything from me I am of no value to you. I would also say, most researchers use the community to further their interests and they leave the community behind.*

Participants expressed concerns about the researchers who communicate with a few individuals within the community whilst ignoring the majority. This is viewed as one of the problems that cause social disharmony within the community.

*Extract 36*

*Respondent:* Traditional leadership

*Research can cause conflicts in the community; this can lead to instability even when there are big problems affecting everyone. People fail to see eye to eye because the researchers caused a rift by getting together with a certain group while sidelining others because they know they will get what they want. Another thing is when researchers make empty promises about helping people resolve problems they are facing.*

Many of the ethical issues raised by participants in the current study require partnership between researchers and potential participants or their representatives. One approach to community-based research has been the establishment of community advisory boards to provide consultation and to articulate community needs (Morin et al., 2003). The findings of the current study

indicate that the CABs are minimally involved or sometimes not involved in research operations. They are viewed as having no capacity to challenge the researchers. There are indications that the people who are elected to become CABs are not properly screened to ensure that their motives will serve the best interest of the community and the election process usually involves little community participation. This is nothing short of window dressing and those elected carrying out their personal interests ahead of the community. It appears that proper community consultation needs to be done when research is to be conducted. Several authors recommended working with individuals who represent the local community that is being researched. The formation of community advisory boards can be used as a model for promoting active involvement of community representatives in all stages of research (Morin et al., 2003).

#### **4.3.2 Misinterpretation of results**

Few participants were concerned about the way in which the results are sometimes interpreted. These concerns were influenced by their past experiences with research

*Extract 37*

*Respondent:* Traditional leadership

*When research is conducted and inappropriate or inaccurate results are disseminated; it has detrimental effects on the community. When I say inaccurate I mean when the researcher misinterprets the information given by the community.*

*Extract 38*

*Respondent:* Youth group member

*When the researcher conduct research about something that does not affect the community, and they carry on entering the community without consultation and then portray the community badly when they interpret the results, that results in bad consequences because the community was not informed about research in the first place.*

*Extract 39*

*Respondent: Traditional healer*

*There are many things that happen within the communities which are not right. Some researchers and community members share with the media, newspapers particularly, things such as the way we as traditional healers use our traditional medicine, it is due to their lack of understanding and too much focus on their respective religions in a rather narrow manner.*

The findings of the study correspond with empirical studies which suggest that the researchers often fail to either respect or be sensitive to cultures under examination (Deloria, 2002; Ermine et al., 2005; Henry et al., 2004; Sinclaire, 2004). These results support Deloria's (2002) suggestion that researchers need to stop publishing information about indigenous people without asking the research subjects to interpret, analyse or review the manuscripts. There are indications that extra care needs to be taken to ensure that private and sacred rituals of indigenous people like the one under current study are not publicised without permission (Deloria, 2002; Wilson, 1998). It appears that research partnership would be the appropriate methodology for research conducted among indigenous communities.

Huntington, Trainor, Natcher, and Chapin (2006) warn that the most challenging aspect of partnering with indigenous communities is accounting for the diverse ways in which people see the world and the accompanying diverse beliefs about how people gain knowledge about the world. They state that true partnership requires mutual respect and the ability to create bridges between these differing world views. The findings suggest that this diversity is not only situated between researchers and the community; intracommunity diversity exists, and this is influenced by different religious beliefs and the existence of minority groups within indigenous communities (Nielsen & Gould, 2007).

Smith (1999) cautions researchers against blindness to these differences within the communities. Similarly Jones (1995) notes that, "within the same geographical area different communities can exist and it is not uncommon for their interests to clash" (p.4). To resolve this concern Henry et al. (2004) recommend respectful research relationships which acknowledge and affirm the right

for people to have different values, norms and belief systems. There are indications that researchers' failure to address issues of diversity can cause harm to the community in the form of negative depiction, misrepresentation, distortion of religious practices. Literature suggests that the misrepresentation of results is caused by conflicting understanding between researchers and the community (Navarro, 2008). It appears that community advisory boards composed of people who are knowledgeable about what happens in the local community should be involved in the research process. This indicates that researchers ought to make room for culture-based differences within the community (Ermine et al., 2005).

#### **4.4 Conceptions of research collaboration**

The participants provided various conceptions of collaborative research and these seemed to be informed by their desire to transform the current research practices. Overall the participants had a positive regard toward collaborative research as the only hope towards capacity building and community development. The following emerged as the main conceptions of research collaboration: 1) research collaboration as co-learning or exchange of ideas; 2), research collaboration as community openness and cooperation.

##### **4.4.1 Research collaboration as exchange of ideas/co-learning**

Most of the participants described research as co-learning or an exchange of ideas. It appears that the participants understand that the researcher is not an expert in community life. This assertion from the participants acknowledges the significant role the community plays in research. The following extract highlights the existence of two world views in research: that of the researcher and that of the community. These world views are also embedded in different beliefs and values. The view is that the two world views can play a complementary role rather than a contradictory one. One of the participants said that:

*Extract 40*

*Respondent: Local councillor 1*

*Research is of no value without the community, the researchers on their own can not do anything. The whole truth can only be discovered by the members of the community, researchers only have half of it. If they do not use the members of the community, they can end up making conclusions on their research based on mere assumptions and their beliefs. So if they involve the community they can get a lot of information because the community members play a vital role in the success of the research.*

Similarly another participant emphasised the diversity in terms of people's understanding within the same context.

*Extract 41*

*Respondent: Women's group member 1*

*We are allowed to have different understandings of similar issues that differ but at the end of the day there must be common ground where all the understandings can be combined to form a single idea that both parties understand equally and similarly.*

*(Mina ngingakujabulela kakhulu if kubanjiswana ocwaningweni, kuchaza nje ukuthi... lokho kuyasho nje ukuthi nathi sinemqondo yethu, kufanele sithelelane imiqondo, imiqondo yethu ihlanganiswe ukuze kuphume into eright.)*

*Extract 42*

*Respondent: Women's group member 2*

*I would really appreciate research collaboration because it means that we have a brain and we have to share ideas to come up with a right thing.*

*Extract 43*

She added that:

*When research is conducted it is important to understand each other, each person may want things to be done their way so that if there is misunderstanding people can weigh different ideas and come up with a reasonable idea at the end.*

Research usually places a lot of power in the hands of researchers or project leaders to the entire community. There is an indication that researchers may need to adopt approaches that include all the stakeholders in the investigation. This, according to Stringer (1999), creates a context that enables diverse groups to negotiate the various agendas in an atmosphere of mutual trust. This shift will ensure involvement of everyone in the community, including the antagonist. It also ensures that the most powerless voices are heard and social cultural imperatives that dominate people's lives are met. The obtained data affirms Sinclair's (2004) suggestion that "following local values and norms is integral in respecting human dignity of a people who have governed themselves and their lands for a millennia" (p.31). Therefore the researchers must establish what the traditions and protocols of the local community are and follow them.

Gasa (1999) suggests that the researcher is seldom presented as someone who might benefit from understanding the participants' life circumstances. This results in researchers having limited understanding of research participants and thus being more likely to conduct research in a manner that is guided by their own beliefs. This is echoed by McTaggart's (1994) suggestion that researchers often express commitment to certain values in order to serve particular sets of interests ahead of others. Broudy (1981) advocates that such an act devalues and demoralises the beliefs of others by diminishing and denying their relevance. In the current study there is an indication that the participants are advocating for an approach that is willing to engage and learn from them as much as they too will learn from researchers. This process will be embracing the cooption of action research which acknowledges that there are different ways of knowing in the world; people who have the same facts or information will interpret them differently according to their world views (McTaggart, 1994). The researchers can benefit from engagement of the participants or community as this brings to light the community's social construction or created realities from which peoples social lives are built. This is important but not limited to a cross-cultural research because the aim of the enquiry is not to establish the truth or what is really happening but to reveal the truth and realities held by different individuals (Stringer, 1999).

As Ermine et al. (2005) suggest the way to go about this requires the levelling of playing fields to ensure that a mutually beneficial relationship is built. In order to achieve this, it is imperative that researchers earn the trust and goodwill in the community and it should be made clear that the community will share under the complexities of the subject under inquiry (Sinclair, 2004). Similarly Ermine et al. (2005) warn that if the researcher's relationship with the local people is merely seen as means to an end for producing a report to meet some personal academic, commercial or professional goal the community members might perceive the research negatively and they can deliberately be untruthful in the process, skewing the research data and any analysis based on it.

Ermine et al. (2005) introduce the concept of ethical space to counter this problem; they suggest that ethical space provides an avenue within which to articulate the possibilities and challenges of bringing together different ways of gaining knowledge and applying the theory to the practice of research. The current study suggests that researchers can increase their effectiveness if they acknowledge the input of the community and immerse themselves in the richness of group life through the development of empathic understanding that develops through close involvement with the people.

#### **4.4.2 Research collaboration as community openness and cooperation**

It appeared that the participants value the role of co-operation and openness between stake holders in research. They were also specific about the kind of openness they want, one that allows them to express their views about different issues. They even go as far as acknowledging that people can have conflicting views and that it is through the exchange of ideas that the resolution of a particular issue can be reached. It was thought that the participants had been able to identify the gaps in the research process and also their limitations toward research participation. It appeared that the participants used the current study to express their dissatisfaction and to make suggestions with the current practices and their responses were indicative of this.

*Extract 44*

*Respondent:* Traditional healer

*If we want to work together we have to communicate every time something happens. The community shouldn't have to wait for the researcher to keep them updated, the community has to be free to make follow up with the researcher.*

*Extract 45*

*Respondent:* Local councillor 1

*We can have different understandings of similar issues with the researchers but at the end of the day there must be common ground where all understandings can be combined to form a single idea that both parties understand similarly or equally.*

*Extract 46*

*Respondent:* Youth group member

*That's why communication is important, communication of various where researchers and people can make their views known.*

The current study indicates that researchers need to pay attention to community involvement particularly communication strategies. These findings support Mkabela's (2005) view that current research does not take into account the interests of the indigenous communities like the community under current study. She clearly points out that often indigenous participation is neither sought nor considered relevant and the consequence of this is the production of results that have no impact on indigenous communities. It appears that participants feel that research is conducted without proper consultation or without taking into account the interests of people who live in the communities.

Mkabela's (2005) view is that research often informs national development objectives and policies and this therefore results in objectives and policies that are not consistent with the views, wishes, and interests of indigenous communities affected by them. This idea is supported by Stringer (1996); he advocates for community involvement; his view is that communication is key because it has direct effects on feelings of well-being and these feelings can enhance or detract

from the efficacy of individual work where it would be beneficial to use forms of communication that facilitate harmonious relationships and attainment of objectives agreed upon by all parties involved in research. Stringer (1996) declares that often researchers fast pace their projects, in their efforts to meet deadlines leading to complete isolation of the local community in research activities (Stringer, 1999). It appears that researchers need to ensure community involvement. It is also understandable that the community seeks to be empowered to effect decisions that have an impact on their community.

Corrective steps towards filling the gaps in research is what Guba and Lincoln (1989) call careful management of research activities so that stakeholders can formulate jointly constructed definitions of the situation. The researchers can achieve positive results through open action communication, which Habermas (1979) defines as the capacity for people to work through disagreements to achieve effective solutions to problems. Starting with basics, Habermas stipulates that four fundamental conditions have to be met for community involvement to work. He suggests communication in its basic form taking into account the following elements:

a) *Understanding*: This ensures that the receiver can understand what is being communicated to him; frequently researchers use jargon or complex language that the lay man or local community cannot understand. This can lead to people saying they were not informed of research conducted in their community. Another factor that can cause problems is if researchers distort or misrepresent information in an effort to deceive or persuade people.

b) *Sincerity*: Researchers have to be sincere because it is lack of sincerity that breaks down communication and it may be difficult for that relationship to develop or recover.

c) *Appropriate*: Researchers have to ensure that they speak with appropriate people within the community as it is likely that researchers communicate with someone they consider to be popular in the community but that person might not be the right person because the particular subject is not of interest to him or her, and therefore fail to advocate of the people concerned. The only way to ensure that appropriate people are addressed is through community consultation.

## 4.5 Factors affecting research collaboration

The following emerged as factors inhibiting research collaboration: a) lack of respect; b) lack of capacity building; and c) lack of involvement in planning and decision making.

### 4.5.1 Lack of respect

It appears that the concept of ethics in African communities goes beyond confidentiality and consent. As pointed out by Smith (1999), “ethics in indigenous communities are underpinned by the concept of ‘respect’ both in terms of relationships and also in relation to the environment” (p.120). Respect for the elders and humility are one of the values that are esteemed in the African Culture. In the African tradition the elders are the proprietors of knowledge and wisdom for the young generation. The elders are the people who maintained order in the communities before colonisation. In this context the term elderly (*abadala*) can also be used when referring to the ancestors. The following participant could have been referring to both.

*Extract 47*

*Respondent: Traditional leadership*

*... Disrespect and the researchers who are not doing their job properly. Some of the researchers misbehave and disrespect the elders. But I hope that the researchers are learned people, they will not lie and they will also keep their promises. Another thing is that the researchers should stick to their words just like you; you said you'd come and interview me today and you did, after all I had to cancel things I had to do. It would have been very disrespectful of you if you had not showed up. Again it is important for the researcher to have the humility that you have Nondumiso, this is exactly what makes the community even willing to participate.*

The following extract highlights the importance of following a local protocol when one is entering the community, one that is open and without any preconceived ideas about the community. It is an open invitation to good ethical practices, acknowledges that the views of the people matter and is an indication of the need for ethical space as suggested by Ermine et al.

(2005) that it will be in the ethical space where all assumptions, biases and misrepresentation about the other are brought to bear in the interest of identifying ethical and moral principles in cross-cultural interaction.

*Extract 48*

*Respondent: Traditional healer*

*... If the researcher just shows up in the community and does not have the appropriate way of communicating with the community, the mentality of knowing it all is not good because it will make the community hesitant to be part of the research. When the community sees that its views are not protected. The law has to protect everyone, we can't just see a researcher conducting research without issuing the details of the study authorising him and indicating that he knows what he is doing, because we cannot just accept things at face value no matter who says it. We have to welcome a person who really is a researcher and who can teach and most importantly a person who will work with the community in unity and be patient with us no matter what problems may arise.*

*Extract 49*

*Respondent: Traditional leadership*

*Using a language that the person you are talking to does not understand is being rude and disrespectful from all angles. It is only when the two people understand each other where a flow of communication can be found. There would be no problem if the researcher and the participants speak the same language, then they can understand each other.*

The findings of the study indicate that recognition of, and respect for the indigenous way of life is fundamental to good research practice (Ermine et al., 2005; Mkabela, 2005). There are subtle indications of lack of trust towards the research community and the need to protect community values and norms. These findings highlight indications of documented literature about the indigenous people throughout the world. For example, empirical evidence suggests that indigenous people view research with hostility and suspicion because researchers often employ unethical practices which include intrusion, inaccurate representation of findings, disrespect for

indigenous ways of life and a disregard for values and beliefs (Henry et al., 2004; Ermine et al., 2005; Sinclair, 2004). “The consequence is that a combination of inaccurate research, inadequate education, slanted media coverage, and dehumanizing stereotypes make even the most ‘educated’ professional grossly uninformed about indigenous life and culture” (Ermine et al., 2005, p.13).

In the South African context Mkabela (2005) echoes the same concern suggesting that exclusion of indigenous communities from research processes has led researchers to take cultural information out of context and have resulting in the creation of published documents that were factually incorrect. It appears that researchers should ensure that they utilise research methods that give a voice to the oppressed and marginalised and the methods should also promote empowerment, inclusivity and respect (Dickson (2000, in Ermine et al., 2005). The possible way to achieve this would be the development of guidelines by researchers in consultation with indigenous communities; this will ensure respect for indigenous cultural philosophies and adherence to indigenous cultural protocols in research practice (Ermine et al., 2005).

It appears that the researchers might have to approach the elders in the community or people who specific knowledge of traditional laws, ensuring that the people who are identified by the community as the elders and knowledge keepers are properly consulted and given authority and control over research that relates to them (Ermine et al., 2005; Mkabela, 2005; Stringer, 1996; Stringer, 1999). The researcher might need to take a lead from the community and abide by the local procedures. Sinclair et al. (2004) suggest that in cases where the elders are silent the researcher ought to find out the traditional protocols people have in place. There are indications that local norms and values are to be observed and respected.

Ermine et al. (2005) highlight the importance of adhering to local norms when they suggest that in indigenous cultures a researcher cannot ask an indigenous person to answer any question that the researcher thinks of. Even the mere act of asking can be disrespectful and inappropriate; protocols must be followed to gain access to certain information. In African tradition children learn by observation and there are practices that are observed and internalised without engaging in a dialogue or conversation. Whereas in Western tradition which includes academic

institutions as Ermine et al. (2005, p.13) put it “a researcher can ask anything without concern that: a) the mere asking was inappropriate, b) the researcher is not entitled to the information for procedural, spiritual or cultural reasons”. As Denzin and Lincoln (2000) suggest the more inclusive and respectful research becomes of other ways of knowing the more applicable Western qualitative research will be to indigenous people, and indigenous issues. Sinclair et al. (2004) write that:

Research institutions should explicitly recognise the right and privileges of alternate knowledge systems represented by indigenous people. This recognition should include support and development of educational, research and training centres that are controlled by indigenous communities and strengthen these communities’ capacity to document, protect, teach and apply all aspects of their heritage (p.33).

#### **4.5.1.1 Local language**

For some participants, lack of respect manifests itself in the researchers’ unwillingness or inability to converse with the locals in their language, addressing them in a language that they do not understand. Grills, Bass, Brown and Akers (1996) observed that some researchers sometimes use own language and scientific skill as a form of power that they hold over the communities they work with. As proven by the findings this is likely to have negative implications on the community under study.

Gxilishe (2009) writes:

It is said that of all the elements which best characterize an individual, language is the most obvious. It is through language that we convey our ideas. All the accumulated knowledge, value systems, aspirations, beliefs, history and identity find expression through language. Language constitutes an important piece of person’s multiple identities and is accessible to a whole culture, a cultural experience; a way of looking at the world hence losing a language will core out a nation and reduce it to a nation without a heart and soul (p.1).

The findings of the current study resonate with this expression. It is also supported by Sinclair (2004); an indigenous community's language is more than a spoken word or a tool for conversation; it is linked to one's identity and a sense of personhood. In essence these are the things that Africans were stripped of. Language, because of its cultural embeddedness, is important for maintaining the indigenous knowledge system.

Sinclair (2004) argues that people cannot be removed from their language because the terms in a language derive their full meaning from the rest of the language, from the context they are typically used in, from the cultural values and practices and from the world view of which it forms part. There is an indication that conversation between radically different world views can become difficult because different languages possess different cultural assumptions. Translation in an attempt to capture meaning is difficult. It can therefore not be assumed that languages can be perfectly transferred to another without losing meaning. This assumption is what facilitated the domination of one culture by another. The use of local language when conducting research ensures that there is no oversimplification of views on important matters in the community.

#### **4.5.2 Lack of capacity building**

All of the participants felt that the community lacks training and development in the area of research; they defined lack of training and skills as factors that influence inadequate participation in research.

*Extract 50*

*Respondent: Traditional leadership*

*When the community has learnt more about research and understands what research is, I think they can participate in research management; they will want to know how research works and the research results. Right now they do not know about research and they do not even bother asking for feedback about research. Even the CABs don't seem to know.*

In the above extract the participant also viewed the research as an already established system that the community does not know much about; for the community any participation would feel like an intrusion into territory of the researchers.

*Extract 51*

*Respondent:* Local councillor

*The community can only play an oversight role; they can't play a big role, because if they manage research generally there would be some negative implications. Reason being that of lack of training. The CABs are the people who might understand and they can represent the community in research when they are trained.*

*Extract 52*

*Respondent:* Traditional healer

*The role played by the Community advisory board currently is not satisfactory. Like I said earlier you find that the community is not trained or taught about research. Some people are elected to represent and advise the community but they do not put an effort and they are not taking pride in this work. I believe for some people it's a real calling and they are feeling it inside. While others have hidden agendas, just like now people are more involved in politics and they use these positions to further their own interests and not following proper procedures. Eventually the community loses interest in community activities.*

It appears that the community feels incapacitated to participate in a research process and the main reason that is articulated through the data is the lack of skills and empowerment. The above extracts indicate a dire need for training and empowerment of the local community under current study. These findings bring to light Kemmis's (1992, in Jones, 1995) argument that researchers need to work practically and theoretically to help people to analyse their suffering, to articulate the conditions that disfigure their lives and to use these processes of enlightenment to help develop social movements which can change the community's unsatisfying forms of existence.

Grills et al. (1996) suggest that researchers should not approach the community as the guru with skills and expertise to be bestowed on its residents but rather on the same level as the community and as people that possess no greater level of power; in this process the researcher engages in a collaboration in which all parties bring equal albeit different expertise to the table. The current study indicates that the community places more power in the hands of the researcher; this is particularly so because historically the position of power has been placed outside the community.

According to Grills et al. (1996), this does not mean that the community does not recognise its power or that it assumes a helpless role; rather it means that the community judges the reality of the extenuating conditions levied against it in the past. Grills et al. (ibid) further suggest that the community recognises that the process of change is small; as a result they do not make unrealistic expectations in the process of empowerment. It is however critical that researchers treat everyone with respect and not use their skills and education in an elitist fashion.

Andrews (1996) suggests that research ethics should be closely monitored with particular sensitivity to the situation that, historically, low income populations like the one under current study have been denied personal power and treated unfairly. In the current study it appears this is evident as it is clear that some participants feel certain responsibilities are suited for the researchers by virtue of their educational status. That being the role of data analysis, it has been proven that when data is analysed collectively by the researchers and community it brings forth enlightenment about issues that affect the community. Often there are differences in analysis which are due to different contextual and cultural backgrounds and if the researchers work independently it results in negative bias about the community under study. Andrews (1996) argues that communities that have a history of marginalisation like the community under study are susceptible to feelings of powerlessness in the face of overwhelming challenges. There is consensus about the need to reform support systems for the marginalised groups (Ermine et al., 2005; Grills et al., 1996; Henry et al., 2004; Mkabela, 2005). Broudy (1981) suggests confidence building through active participation is one of the ways to address this problem.

It appears that for training to have some positive contribution researchers have to follow similar guidelines to those that were suggested by McTaggart (1994). He suggests that researchers have to ensure that learning and training entails collective responsibility; he suggests that this will ensure that the people contribute to the development of their community. According to McTaggart (1994) researchers have to ensure that they establish a cooperative working community that has ownership and control of the work. He further suggests that it has to be ensured that training is conducted with an understanding that the fundamentally important role that negotiation plays in the research process is not for the benefit of individuals but for the entire community. According to McTaggart (1994) the participants have to be given recognition as learners in their community to develop further skills and knowledge in research. He further suggests that researchers should respect the participants as teachers because the spirit of reciprocity prevails in each interaction, meaning that while the researchers are giving something they are getting something back from the community and they must not undervalue that. This is echoed by Andrews' (1996) suggestion that the training and empowerment programmes must be highly participative at all cost; they must avoid interactions that might be perceived as authoritative and controlling.

Equally, Shapiro (1988) suggests that traditional methods that rely solely on quantified measures or objectives should be regarded as inappropriate for these purposes. Instead mutual exchange or reciprocity must be emphasised, rather than a charitable model where one person is perceived as more powerful than another (Andrews, 1996; McTaggart, 1994; Shapiro, 1988). McTaggart also suggests the establishment of common objectives as this process would provide a platform to share ideas and an opportunity for the community and researchers to critically analyse each other's suggestions and agree to the plan.

Barry (1992, in Gasa, 1999) suggests that Community Advisory Boards should involve people who are uninfluenced by the prospects of money, prestige, or personal gain from the project, whose role would be to provide ongoing evaluation of the project in order to contribute towards its success. Morin et al. (2003) suggest that in poverty-stricken societies like the one under current study people are often motivated by personal gain such as reimbursement, lunch, tokens, travel and stipends. Such things are likely to affect sustainability and retention of members.

Morin et al. (2003) suggest that researchers need to look at what motivates the people to become CABs; those who join because they have something meaningful to give the community are often likely to stay longer.

Morin et al. (2003) suggest that researchers should look for ways to best promote the capacity of CABs to improve the welfare of the community. The current study indicates that there is a knowledge gap between researchers and the members of CABs. Researchers might want to look for ways to best empower the CABs for the success of the project. Morin et al. (ibid) suggest that researchers can debate issues with the CABs and also structure the debates in ways that produce useful results. Community advisory boards would also provide a forum for the discussion of issues that arise from the research investigation (Gasa, 1999). It can however take a long time for the CABs to establish themselves and for a clear understanding of roles and responsibilities to evolve (Morin et al., 2003). The struggles are attributed to the development of mutual trust between CABs and the research team and issues that affect the development of trust are covered in the previous section.

#### **4.5.3 Lack of involvement in decision-making and planning**

Almost all the participants felt that the community does not participate in the research process and all of them felt that the community should be involved in research from beginning to the end i.e. decision making, planning, monitoring to dissemination of results. Most of the participants felt that research illiteracy prevents adequate participation in research. Some participants also expressed concerns about the way CABs are exploited.

*Interviewer:* Does the community participate in the planning of research?

*Extract 53*

*Respondent:* Women's group member

*Decisions are taken without community involvement, you hear through hearsay that such and such a thing is happening and this all happens without communicating with us, or sharing and getting the views of the community, because it is important for us to be heard.*

*(Savulwa, sonke sikwidemocracy, ukuthi sikwiSouth Africa ekhululekile kufanele sikhulume nathi izimvo zethu.) Democracy applies to all of us.*

The participant expressed frustrations that even during this new political dispensation their rights are still being violated, and voices unheard. This highlights once more that research is not viewed independently from politics. The following extract highlights participants' observations that some social policies have changed regarding the social position of local communities, while the tendency of the research process to sideline the community remains unaltered.

*Extract 54*

*Respondent: Youth group member*

*I think the community should be involved in the planning of the research because they are the ones who have information on the research question and the researcher has to analyse the data. But the problem is that the community is not educated.*

*(Ngibona kumele ukuthi umphakathi ubambe iqhaza eliphelele ekuhlelweni kocwaningo ngoba usuke usazi isihloko ekufanele sicwaningwe bese ubuyisa amaphuzu okumele acwaningwe kusomqulu ongumcwaningi bese umphakathi futhi ubuyise umbono namasu ukuthi ucwaningo kumele luhambe kanjani. Manje inkinga umphakathi awufundisekile.)*

In the above extract the participant acknowledges that the community has more knowledge about the problems that affect them and it is on that basis that they should be involved in the research process.

*Extract 55*

*Respondent: Youth group member*

*No, the community does not participate because they do not know anything, just like me; I wouldn't participate in research because I don't know. I am not educated about this thing.*

*(Cha umphakathi awulibambi iqhaza ngoba awazi lutho njengami nje, bengingeke ngilibambe iqhaza ngako ukuthi angazi, ngingathi kunento okuthi njengoba phela angifundisekile ngaleyo nto.)*

*Extract 56*

*Respondent: Women's group member*

*Our community needs to participate in research planning, but the problem is that our community is not educated properly. I would say our community is not educated, I could tell a person that the researchers are coming in this house (referring to women's group centre), they wouldn't know what that means. Our community needs to be educated about research.*

*Extract 57*

*Respondent: Local councillor 1*

*Not in the majority, officially researchers have to get facts from the community, the community should get an opportunity to express its views and then the researchers can look and see what the majority of the community says and then go with the majority view.*

*(Cha hayi ngobuningi bawo. Ngokomthetho kumele abasebenza ngalo bathathe amaphuzu athile emphakathini umphakathi uthole isikhathi sokukhuluma bese bona beyabheka baprioritize babone ukuthi umphakathi omningi utheni bese bephasisa lokho bese kuba ukuthi cishe uma kwenziwa kanjalo sizobe siyalibamba iqhaza Kodwa konke kuzohamba ngentando yeningi.)*

*Extract 58*

*Respondent: Local councillor*

*No there we would be making a fool of the community (cha lapho ngabe siganga ngawo). Isn't it that you do everything because you have been trained for it? As an example you can not be expected to make a judgment when you are not a judge. You need to be trained and as a judge you are given an opportunity to compare the facts. You see, if you are not*

*trained for such things how can you make decisions? Really the community has to be trained to take decisions.*

*Extract 59*

*Respondent: Women's group member*

*I personally think it means that we as the community are the ones who have little education. This is because you can't say you know something just because someone briefly gave you an idea about it. I think people need to communicate further away from the time of the research.*

This extract highlights the importance of investing time on the community so that people can be educated about the research. It appears that the participants feel that researchers need to engage them in a way that leaves them with some level of education about research.

*Extract 60*

*Respondent: Women's group member*

*I think it is important for the researcher to go out into the community and teach the members of the community so that they will have some information, as I have said that I only heard people talk about the researcher who was coming ... as you are talking right now, I am slowly understanding the fact that you went to study for this and I have very little information about it but I'm learning from you.*

The extract above captures the dire need for community members to be trained and empowered to be part of the research through training and development. The participant felt that there is a distance between them and the researchers and they hear about research through hearsay. The importance of dialogue is highlighted; as some participants stated, through dialogue between participants and researchers, learning is taking place.

*Extract 61*

*Respondent: Faith-based organisation member*

*I think it is for the researcher and the participants to work together because the researcher has formal training of that which is being researched. Since they have their higher*

*education as a reference, they should share this with the community, and knowledge should be transferred equally to all the members of the community.*

*(Umsusa kwenye indawo umbeka kwenye ngokuthi ikhona lento enje vele phela umuntu ongazi lutho angithi kumele azi.)*

It appears that the participants feel that researchers need to engage the community in a way that leaves them with a good understanding of research. This view supports Pillota (2001) notion that research tends to maintain a false impression of authority in the community, through centralisation of power, while limiting the local community's access to information with the intention of retaining private ownership of research and also limits the possibility of allowing people access in resolving their own problems. It appears that there is a perceived distance between researchers and local communities. This is partly created by the theoretical conception of research which appears to have little to do with people's realities (Jones, 1995).

Some participants state that researchers have a moral obligation to train them; this view is supported by Pillota (2001), who argues that the community has to be enabled to develop knowledge, skills, methods and strategies necessary to formulate social action plans. Repo (1977, in Jones, 1995) observed that individuals actively participate in research and development initiatives only if they have basic knowledge necessary to participate in the development of the community. He further suggests that strategy for involving people in social change must include education which involves them dealing with the situation in its totality, providing a scientific analysis that makes meaningful short-term action and long-term total transformation possible. This view is echoed by Jones's (1995) suggestion that people at local level need to be trained through non-formal education to analyse their socio-political positions in order to plan ways of improving social situations in order to bring about changes in their lives at community level. Similarly Pillota (2001) states that

increasingly citizens are seeking to take control of circumstances generating social stress due to the inability of service organisations to provide equitable effective solutions. In the

search of self sufficiency a lack of necessary knowledge and skills often stands as a barrier to community action (p.10).

## CHAPTER 5

### CONCLUSIONS AND RECOMMENDATIONS

#### 5.1 Overview of the study and its background

The purpose of the study was to explore community understanding, attitudes and perceptions towards research. The study also investigated factors that affect research understanding, and research collaboration. Using an in-depth semi-structured interview schedule, interviews were held with participants drawn from various community groups; these were guided by available literature.

#### 5.2 Conclusions about research questions

The current study highlights the influence of socio-political context in research, thereby confirming Smith's (1999) assertion that politics and research cannot be separated as the two are inextricably linked. This is an important consideration, especially in poor communities which may be particularly vulnerable to power dynamics (Gasa, 1999). The results also confirm Stark's (1998) assertion that research is a social endeavour conducted among people who are embedded in a number of social contexts, each of which has social norms and cultural expectations.

The current study highlights the importance of consideration of benefits to be accrued by the community before any research is conducted. The findings suggest that research is considered an important tool for community development if it is conducted ethically. The current findings also indicate the importance of conducting research on topics that are relevant to the community as opposed to researchers' self-interests.

The importance of relationship building has been highlighted in the findings of this study. This will provide a forum for dialogue on local protocol, giving insight into cultural norms and beliefs.

The current study highlights a gap in training and capacity building. This gap is perceived as a hindrance to meaningful contribution towards research. The current study also highlights the importance of community involvement at all levels of research and adequate community involvement in research planning and decision-making.

There is an indication that inadequate community involvement is likely to lead to social harms caused by misinterpretation of results. A researcher may not always get the desired information from research participants and consultation with community members is important and indicative of a culturally sensitive approach (Gasa, 1999). It can be rather challenging for researchers working independently of the community to determine the social benefit of research. Particularly because researchers and communities come from different worlds and contexts and they also have different value systems.

A researcher's view of benefits can be different from that of the local community. To counter this problem several authors recommend that the two value systems be reconciled; this can be done through the involvement of the local community in the design, execution and evaluation of research. This is critical as participants often engage with the research establishment from a position of marginalisation and disadvantage (Anderson, 1996; Barry, 1992; Gostin, 1995; Levine & Murray, 1984).

Community consultation needs to be maximised. This could be achieved by closing the gap between researchers and community members. To counter the discrepancy in knowledge continuous training for researchers and the CABs is required. The community indifference towards the outcome of research can be addressed by both researchers and community advisory boards alike, by adopting a hands-on approach and creating a sense of ownership of the project.

An approach that perceives the Western world views as universal is likely to be counter-productive as there are major differences between the local world view and researchers. Communities being researched have a world view specific to them; imposition of the researchers' world view on them would not be in anyone's interest. When research is to be

conducted in the community, the participants have to be approached with respect bearing in mind that their knowledge is particular to them and they have a particular way of dealing with their own issues (Ermine et al., 2005; Mkabela, 2005; Sinclair, 2004).

There are indications that research has to be cautious about interviewing the same individuals within the community. The findings indicate that a considerable amount of time has to be spent ensuring community involvement. The same view is held by Schaffer (2009). He suggests that it can take time to discover issues of interest to the community. Schaffer (2009) recommends a cultural guide who will ensure that proper procedures are followed and sidelined members of the community are included when research is conducted (Henry et al., 2004; Jones, 1996; Stringer, 1999). The findings indicate that communities are not homogenous; therefore they may not share the same perspectives on the solutions to their problems (Henry et al., 2004). Schaffer suggests that researchers should take into account these factors; failure to do so might lead to a disruption of existing social relationships in the community (Schaffer, 2009).

The current study indicates that the community has to be empowered in order to have a better understanding of research and to take a more proactive role in research in order to protect and promote their local knowledge.

### **5.3 Implications for theory**

The probing nature of the study provided some insightful information and ideas about the development of faltering theories on conceptions of research and research collaboration. The results of the study indicate that participants need to have more input in research projects conducted in their community. The ethical protocol that is currently employed in research needs to be revised to meet the local needs. There is also an indication that the participants have their own local ethical protocol which needs to be respected. It is apparent that seeking informed consent from the community needs to be a long and educational process from both sides. In other words, researchers have to allow the community to educate them about the acceptable cultural practices when entering the community.

The community views reflect the ongoing debates about Eurocentric ideologies and Afrocentric ideologies. It appears that each world view has to be given equal status and that there can be no justice as long as the other is more dominant and imposing on the other.

#### **5.4 Implications for policy and practice**

There is an indication that researchers have to shift to a more consultative research approach which ensures community involvement. This move requires researchers to investigate local community's interpretation of consultation, community involvement and community control within the context of indigenous research activity (Anderson, 1996). The findings suggest that giving a voice to the community in the research process, including the decision-making process, would be an effective strategy for decreasing ethical problems as articulated in the current study (Schaffer, 2009). Mkabela (2005) proposed an African centered research,

“research where indigenous African people are significant participants, and are typically senior members of research teams. She further suggests that often in this method the teams are made up of all indigenous African people and primarily meet expectations and quality standards set by indigenous communities. There are indications that for research to achieve this they will have to set educational research goals in terms of improving the quality of life and life opportunities by injecting cultural values into them and promoting development in a more caring manner (p.184).

#### **5.5 Implications for future research**

African indigenous culture needs to be kept in the forefront of any research and recommendations affecting indigenous communities and their culture. The participants of the current study have a strong orientation towards collective values, particularly a sense of collective responsibility. Methodologically speaking such research is translated into collaborative and co-operative research on behalf of the community and individuals within the community (Mkabela, 2005). This means the promotion of increased community involvement in

all phases of the research process, including powers to guide research towards enhancing community and cultural activity (Mkabela, 2005).

## **5.6 Conclusion**

The findings of the study highlight gaps in current research practices. The study provides results that can be useful in developing a culturally appropriate research model.

## 6. References

- Akbar, N., Saaffir, A.C., & Granberry, D. (1996). *Community psychology and systems intervention*. Trenton: Africa World Press.
- Ammerman, J.A., Smith, M.F., & Marie, P. (2003). The practice of participatory research and gender analysis in natural resource management. *Natural Resource Forum*, 28(3) 189-200.
- Anderson, I., & Saunders, W. (1996). Aboriginal health and institutional reform within Australian federalism. Centre for Aboriginal Economic Policy Research. The Australian National University. Discussion paper no 17.
- Anderson, I., Young, H., Markovic, M., & Mandersoon, L. (2001). 'Aboriginal primary health care in Victoria: Issues for policy and planning.' Vic Health Koori Health unit, Discussion paper no 1.
- Arewa, W. (1998). African women, cultural knowledge and environmental education with a focus on Kenya's indigenous women. *Canadian Journal of Environmental Education*, 7, 16-21.
- Ashworth, C. (2000). Changing cultures and building shared ownership. *Local Economy*, 15(3), 256-260.
- Barry, M. (1992). Ethical considerations of human investigation in developing countries. *The New England Journal of Medicine*, 319, 1083-1085.
- Battiste, M. (2008). *Research ethics for protecting indigenous knowledge and heritage: Institutional and researcher responsibility*: In N.K. Denzin, Y.S. Lincoln, & L.T. Smith (Eds.), *The Critical and Indigenous Methodology* (pp.498-508) New Zealand: University of Auckland.

- Belmont Report (1979). Ethical principles and guidelines for the protection of humans subjects of biomedical and behavioural research.  
[www.hunger.brown.edu/Administration/ResearchAdministration/Belmont/Belmont.html](http://www.hunger.brown.edu/Administration/ResearchAdministration/Belmont/Belmont.html)
- Betancourt, J.R., Green, A.R., & Carrillo., J.E. (2002). *Cultural Competence in Health Care: Emerging Frameworks and Practical Approaches*.
- Bishop, R. (1998). Freeing ourselves from neo-colonial domination in research: A Maori approach to creating knowledge. *Qualitative Studies in Education*, 11(2), 199-219.
- Borowiak, C. (2004). Farmers' Rights: Intellectual Property Regimes and the Struggle over Seeds. *Politics and Society*, 32(4), 511-543.
- Boyatzis, R.E. (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA: Sage.
- Braun, V., & Clark, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- Briza, A.P. (1997). *Median plants of South Africa*. Cape Town: Oxford University Press.
- Broudy, H.S. (1981). *Truth and credibility*. New York: Longman.
- Brown, L., & Ashman, D. (1996). Participation, social capital and intersectoral problem solving: African and Asian cases. *World Development*, 24(9), 1467-1479.
- Brown, L.D. (2004). Ideology and political economy in inquiry: Action research and participatory research, Participatory Research and Health. *Proceedings of the International Symposium on Participatory Research*, 19, 277-294.
- Brown, M.F. (2003). *Who owns native culture?* London: Havard University Press.

- Burchill.M (2004) Indigenous community development. *Aboriginal and Islander Health Worker Journal*, 23,7-8.
- Cadd, J.R. (2002). Intellectual property and collaborative research: Joint ventures. *Technovation*, 24, 433-422.
- Center for AIDS Prevention Studies (2006). Recommendation for research dissemination. University of California: San Francisco.
- CIOMS. (2002). *International Ethical Guidelines for Biomedical Research Involving Human Subjects*. CIOMS: Geneva.
- Clark, J., & Murdoch, J. (1997). Local knowledge and the precarious extension of scientific networks: A reflection of three case studies. *Sociologia Ruralis*, 37, 38-60.
- Costello, A., & Zumla, A. (2000). Moving to research partnerships in developing countries. *BMJ*, 321, 827-829.
- Dawson, L. (2004). *Case study: The San and the Hoodia plant*. Open democracy website article Hugh Brody.
- Deloria, J.R. (1999). *For this land: Writings of religion in America*. Routledge: New York.
- Deloria, V. (2002). *Reforming the future, where is academy going?*, Key note address at the annual meeting of western social science.
- Deloria, V. (2005). Continuity and vitality of world views toward organisational culture. *Journal of Anthropology*, 20, 330-335.
- Denzil, K.L., & Lincoln, M.A. (2000). Psychosocial intervention for rural women with breast cancer. *J Gen Intern Med*, 18(7), 499-507.

- Duran, B., & Duran, E. (2000). Applied postcolonial clinical and research strategies. In M. Battiste (Ed.), *Reclaiming indigenous voice and vision* (pp. 86-100). Vancouver, UBC Press.
- Emmanuel. E, Wendler. R, Killen.,& Grady C. (2004) Ethical and Regulatory Aspects Of Clinical Research: Readings and Commentary. Baltimore and London: The Johns Hopkins University Press.
- Ermine, E., Sinclair, R., & Browne, L. (2005). The ethics of research involving indigenous people. Report of the Indigenous Peoples' Health Research Centre to the Interagency advisory Panel on Research Ethics.
- Fitzgerald, D.W., Marotte, C., Verdier, R.I., Warren D.J., & Pape, J.W. (2002). Comprehension during informed consent in a less developed country. *Lancet*, 360, 1301-1302.
- Flory, J., & Emanuel, E. (2004). Interventions to improve research participants understanding: A systematic review, *JAMA*, 292, pp.593-1601.
- Folke, C., Colding, J., & Berkes, F. (2003). Synthesis: building resilience and adaptive capacity in social-ecological systems. In F. Berkes, J. Colding, & C. Folke (Eds.), *Navigating social-ecological systems: Building resilience for complexity and change*. (pp.352-387). Cambridge: Cambridge University Press.
- Freeman, W.L. (1998). The role of community in research with stored tissue samples. *Community Organisation and Rural Development*, 45, 25-38.
- Gadzirayi, C.T., Mutandwa, E., Chihya, J., & Chikosa, M.(1991). Indigenous knowledge systems in sustainable utilization of wetlands in communal areas of Zimbabwe case of Hwedza district. *African Journal of Agricultural Research*, 4, 131-137.

- Gamble, V.N. (1993). A legacy of distrust: African-Americans and medical research. *Journal of Preventive Medicine*, 9(6), 35-38.
- Gasa, N.B.K. (1999). *Cultural conceptions of research and informed consent*. A thesis submitted in partial fulfilment of the requirements for the degree of Master of Art (Clinical Psychology) in the Department of Psychology, University of Natal, Pietermaritzburg.
- Gibbs, M. (2001). Toward a strategy for undertaking cross-cultural collaborative research. *Society and Natural Resources*, 14, 673-687.
- Gibson, N., & Gibson, G. (1999). Articulating the agendas: Negotiating a collaborative model for public health. In D. Wall, M.M.R. Freeman, P.A. McCormack, M. Payne, E.E. Wein, & R.W. Wein (Eds.), *Securing northern future: developing research partnerships* (pp.109-114). Edmonton, AB: The Canadian Circumpolar Institute.
- Gibson, N., Gibson, G., & Macauley, A.C. (2001). Community-based research: Negotiating research agendas and evaluating outcomes. In J. Morse, J. Swanson, & J. Kuzel (Eds.), *The nature of qualitative evidence* (pp.161-181). California: Thousand Oaks.
- Gostin, I. (1995). *Self determination: Aborigines and the state in Australia*. School of Community Health. Sydney. The University of Sydney.
- Greaves, G. (1994). *Scrambe for Africa*. The complete HIV/AIDS resource, *Politics and Society*, 32, 203.
- Green, L., Daniel, L., & Novick, L. (2001). Partnerships and Coalitions for community based research, *Journal of Community Development*, 116, 1-14.
- Grills, C.N., Bass, K., Brown, D.L., & Akers, A. (1996). Empowerment evaluation: Building upon a tradition of activism in the African American community. *Journal of development studies*, 62, 3060-3071.

- Guarino, P., Lamping, D.L., Elbourne, D., Carpenter, J., & Peduzzi, P. (2005). A brief measure of perceived understanding of informed consent in a trial was validated, *Journal of Clinical Epidemiology*, 59, 608-614.
- Guba, E.G., & Lincoln, Y.S. (1989). *Fourth generation evaluation* Newburg Park, CA: Sage.
- Gxilishe, S. (2009). *Afrikaans, African languages and indigenous knowledge systems - The connection paper presented at the roots conference at the University of the Western Cape, 22-23 September 2009.*
- Habermas, J. (1979). *Communication and evolution of society*. Boston: Beacon.
- Hacking, I. (1999). *The social construction of what?* Cambridge: Harvard University Press.
- Harding, S. (1998). *Is science multicultural? Post colonialisms, feminisms, and epistemologies*. Bloomington: Indiana University Press.
- Hayes, N. (2000). *Doing psychological research: Gathering and analysing data*. Buckingham: Open University Press.
- Hazelrigg, L. (1989). *Claims of knowledge*. Florida: Florida State University Press.
- Henry, J., Dunbar, T., Arnott, A., Scrimgeour, M., Mattheus, S., Murakami-Gold, L., & Chamberlain, A. (2002). *Indigenous research reform agenda: Positioning the cooperative research centre for aboriginal and tropical health* (Series 1). Australia: CRCATH.
- Henry, J., Dunbar, T., Arnott, A., Scrimgeour, M., & Murakami-Gold, L. (2004). *Indigenous research reform agenda: A review of the literature* (Series 5). Australia: CRCATH.

- Holmes, W., Stewart, P., Garrow, A., Anderson, I., & Thorpe, L. (2002). Researching Aboriginal health: Experience from a study of urban young people's health and well-being. *Social Science and Medicine*, 54(8), 1267-1279.
- Hook, D., Mkhize, N., Kiguwa, P., & Collins, A. (2004). (Eds.). *Critical psychology*. Cape Town: UCT Press.
- Hughes, I. (2000). Ganma: Indigenous knowledge for reconciliation and community action. Presented to the participatory action research world congress.
- Humphrey, K. (2001). Dirty questions: Indigenous health and Western research. *Australian and New Zealand Journal of Public Health*, 20, 476-482.
- Huntington, H.P., Trainor, S.F., Natcher, D.C., Huntington, O.H., DeWilde, L., & Chapin, F.S. (2006). The significance of context in community-based research: understanding discussions about wild fire in Huslia, Alaska, *Ecology and Society*, 11, 40.
- Ibrahim, M.D. (2003). Achieving health equity: An incremental journey. *American Journal of Public Health*, 93, 1619-1621.
- Jackson, T. (1993). A way of knowing: Participatory research and the Aboriginal movement in Canada. In P. park, M. Brydon-Miller, B. Hall, & T. Jackson (Eds.), *Voices of change: Participatory research in the United States and Canada* (pp.47-64). Toronto, ON: The Ontario Institute for Studies in Education.
- Johnson, M.R.D., & Carroll, M. (1995). *Dealing with diversity: Good practice in drug prevention work with racially and culturally diverse communities*. Centre for Research in Ethnic Relations, University of Warwick, Warwick.
- Jones, A.M.E. (1995). *Community, Control and Change*. Ashgate: Brookfield.

- Kelly, K., & Van der Riet, M. (2001). Participatory research in community settings: processes, methods and challenges. In M. Seedat, N. Duncan, & S. Lazarus (Eds.), *Community psychology: Theory, method and practice - South African and other perspectives* (pp.159-188). Cape Town: Oxford University Press
- Kemmis, B. (1992) The Emerging Culture of Educational Administration and What We Can Do about It. Paper presented at the National Conference of the Australian Council for Educational Administration Darwin, Northern Territory, Australia.
- Khalil, S.S., Silverman, H.J., Rifaat, M., El-Kamary, M., & El-Setouhy, M. (2007). Attitude, understanding and concerns regarding medical research amongst Egyptians: A qualitative pilot study. *Bio Medical Ethics*, 8, 131-140.
- Kilama, W. (2009). From research to control: Translating research finding into health policies. Operational guidelines and health products. *Health Research in Africa*, 112, 91-101.
- Kincheloe, J.L., & Steinberg, S.R. (2008). Indigenous knowledges in education: In N.K. Denzin, Y.S. Lincoln, & L.T. Smith (Eds.), *The Critical and Indigenous Methodology* (pp.498-508).
- King, N. (2004). *Using interviews in qualitative research*: New Zealand: University of Aukland.
- Klages, M. (2007). *Literary theory: A guide for the perplexed: Postmodernism*. Continuum Press: Sage.
- Krosin, M.T., Klitzman, R., Levin, B., Cheng, J., & Ranney, M.L. (2006). Problems in comprehension of informed consent in rural and peri-urban Mali, West Africa. *Society for Clinical Trials*, 3, 306-313.
- Kvale, S. (1996). *Methods of analysis in interviews*. Thousand Oaks, CA: Sage.

- Kylama, B.S. (1999). Culturally competent research: an ethical perspective. *Clin Psychol Rev.*, *19*, 45-55.
- Lamont, M.A. (1941). Justice: Distributive and corrective. *Journal of Philosophy*, *61*, 225-228.
- Lannae, A., Muktar, H., & Lyons, P.D. (2006). African-American community attitudes and perceptions toward schizophrenia and medical research: An exploratory study. *Journal of the National Medical Association*, *98*, 18-27.
- Leininger, M.M. (1985). Ethnography and ethnonursing: Models and modes of qualitative data analysis. In M.M. Leininger (Ed.), *Qualitative research methods in nursing* (pp.33-72). Orlando, FL: Grune & Stratton.
- Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Lindegger, G., & Richter, L. (2000). HIV vaccine trials: Critical issues in informed consent. *South African Journal of Science*, *96*, 313-317.
- Lockhart, A., & McCaskill, D. (1986). Toward an integrated, community based partnership model of Native development and training: A case study in process. *Canadian Journal of Native Studies*, *6*(1), 159-172.
- Macauley, A.C. (1993). Community collaboration in primary care research. In M.K. Bass, E.V. Dunn, P.G. Norton, M. Stewart, & F. Tudiver (Eds.), *Conducting research in the practice setting* (pp.152-163). Newbury Park, Sage Publications.
- Macauley, A.C. (1996). Participatory research with native community of Kahnawake creates innovative code of research ethics: Breaking the Monopoly with Participatory Action Research. *J Consult Clin Psych*, *9*, 105-108.

- Macauley, A.C., Commanda, L.E., Freeman, W.L., Gibson, N., McCabe, M.L., Robbins, C.M., et al. (1999). Participatory research maximizes community and lay involvement. *British Medical Journal*, 319, 774-778.
- Madsen, S.M. (1999). Ethical aspects of clinical trials: the attitude of participants in two non-cancer trials, *Journal of Internal Medicine*, 248, 463-474.
- Manderson, L. (1998). The politics of community: Negotiation and consultation in research on women's health. *Journal of Human Organization*, 57, 317-322.
- Markus, H.Z., & Kitayama, S.A. (1994). A collective fear of the collective: Implications for selves and theories of selves. *Personality and Social Psychology Bulletin*, 20, 568-577.
- Marshall, H.W., & Roseman, E.E. (1999). Public conceptions of mental illness: labels, causes, dangerousness, and social distance. *Am J Public Health*, 89, 1328-1333.
- Mashelkar, R.A. (2005). Intellectual property rights and the third world: Science in the third world. *Current Science*, 81, 955-965.
- Maxwell, J.A. (1992). Understanding validity in qualitative research. *Harvard Educational Review*, 62, 279-300.
- Maxwell, J.A. (1998). Designing a qualitative study: In L. Bickman, & D.J. Rog (Eds.), *Handbook of applied social science research methods* (pp.69-100). Thousand Oaks, CA: Sage.
- McKieran, L.C., del Barrio, E.C., & Texas, SA. (2006). Community-Based Practise and Research: Collaboration and Sharing Power.
- McKnight, J., & Kretzman, J. (2001). *Building communities from the inside out*. Chicago: ACTA Publications.

- McQueen, M.K. (2001). What is community? An evidence-based definition for participatory public health. *American Journal of Public Health, 91*, 12-24.
- McTaggart, R. (1994). Participatory Action Research: Issues in theory and practice. *Educational Action Research, 39*, 331-337.
- Medical Research Council MRC Press Release (1997). Report-back regarding the legal working group of the national reference center for traditional national policy. Hallmark Building, department of health, Pretoria.
- Meisel, A. & Roth, L.H (1983). Toward an Informed Discussion of Informed Consent: A Review of the Empirical. *Studies. Arizona Law Review, 25*, 265-345.
- Mensah, R.I. (2004). *African philosophy: Foundation for black psychology*. In R. Jones (Eds.), *Black Psychology* (pp.23-35).
- Mfuso-Bengo, J. (2003). *A gateway to biomedical research in Africa*. New Jersey: Nova Publishers.
- Miles, M.B., & Huberman, A.M. (1994). *Qualitative data analysis* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage.
- Minkler, M. (2002). *Community organizing and community building for health*. New Brunswick, NJ: Rutgers.
- Mkabela, Q. (2005). Using the Afrocentric method in researching the indigenous African Miles, culture: The qualitative report, *10*, 178-189 retrieved from [http://www.nova.edu/ssss/QR/QR\\_10-Mkabela\\_PDF](http://www.nova.edu/ssss/QR/QR_10-Mkabela_PDF)
- Mkhize, N.J. (2003). *Culture and the self in moral and ethical decision-making: A dialogical approach*. A thesis submitted in fulfilment of the requirements for the degree of Doctor of

Philosophy (Psychology) in the School of Psychology, University of Natal,  
Pietermaritzburg.

- Moewaka Barnes, H. (2000). Collaboration in community action: A successful partnership between indigenous communities and researchers. *Health Promotion International*, 15(1), 17-25.
- Molyneux, C.S., Wassenaar, D.R., Peshu, N., & Marsh, K. (2005). Even if they ask you to stand by a tree all day, you will have to do it (laughter): Community voices on the notion of informed consent for biomedical research in developing countries. *Social Science and Medicine*, 61(2), 443-454.
- Morgan, L.N. (2003). Focus groups: A new tool for qualitative research. *Human Organisation*, 48, 39-58.
- Morin, F.M., Maiorana, N., Koester, A.K., Sheon, M.N., & Richards, T.A. (2003). Community consultation in HIV prevention research: A study of community advisory boards at 6 research sites. *Journal of Acquired Immune Deficiency Syndromes*, 33, 513-520.
- Morrow, B.H. (1999). *Identifying and mapping community vulnerability*. *Disasters*, 23, 1-18.
- Mosha, R. (2000). *The heartbeat of indigenous Africa: A study of Chagga educational system*. New York: Garland.
- Myrick, J. (2005). Production, consumption and world summit on sustainable development. *Environment, Development and Sustainability*, 5, 63-93.
- Nabudere, D. (2004). Development theories, knowledge production, and emancipatory practice. Address presented at the 50th Anniversary Conference reviewing the first Decade of development and democracy in South Africa. University of KwaZulu-Natal: South Africa.

- Nathani, W.N. (2005). African knowledge: Claiming, writing, storing, and sharing the discourse. *Journal of Thought*, 2, 40-42.
- Navarro, B. (2008). *Singing the land, signing the land*. Geelong, Deakin University.
- Nielsen, O.M. (2007). Non-Native scholars doing research in Native American communities: A matter of respect. *Journal of Social Sciences*, 2, 22-25.
- O'Fallon, H.C., & Dearry, J. (2006). Participatory studies for Agro ecosystem evaluation. *Agriculture, Ecosystems and Environment*, 87, 179-190.
- O'Fallon, L.R., & Dearry, A. (2002). Community-based participatory research as a tool to advance environmental health sciences. *Environ Health Perspectives*, 110(2), 155–159.
- Parra, Y.J.F. (2009). Action Research and Collaboration: A new paradigm in Social Research and Language education. *International Journal for Developmental Research*, 36, 216-222. <http://www.thefreelibrary.com> retrieved 5 September 2009.
- Pasha, R.A. (1979). *Why sociology does not apply: A study of use of sociology in public planning*. New York: Blackwell.
- Patton, M.Q. (2002). *Qualitative evaluation and research methods* (3<sup>rd</sup> ed.). Thousand Oaks, CA: Sage.
- Pelkon, V.Y., & Kohl, J. (2005). The role of local ecological knowledge in sustainable urban planning: Perspectives from Finland. *Science, Practice and Policy*, 1(1), 1-12.
- Pergamon, E.K., Conwall, A., & Jewkes, R. (1995). What is participatory research? *American Journal of Anthropology*, 12, 65-81.
- Pillota, J.J. (2001). *Communication and Social Action Research*. Hampton Press: New Jersey.

- Porsanger, J. (2004). An essay about indigenous methodology. Seminar presentation.
- Posey, D.A. (1990). Intellectual property right: Just compensation for indigenous knowledge. *Anthropology Today*, 6, 13-16.
- Posey, D.A. (1994). *Working with indigenous knowledge: A guide for researchers*. International Development Research Center. Canada.
- Posey, D.A. (1996). *Beyond intellectual property: Toward traditional resource rights for indigenous peoples and local communities*. Ottawa: International Development Research Center.
- Postnote (2008). *Research Ethics in Developing Countries: Guidance Document*. Geneva.
- Ranney, M.L. (2006). Problems in comprehension of informed consent in rural and peri-urban Mali, West Africa. *Society for Clinical Trials*, 3, 306-313.
- Rigney, L. (1999). Internalization of an indigenous anticolonialist cultural critique of research methodologies: *A guide to indigenous research methodology and its principles*, 14, 109-113.
- Riley, E., & Wakely, P. (2005). *Communities and Communication: Building partnership*. North Yorkshire, ITDG Publishers.
- Roger, S.A. (2005). *Biodiversity and traditional knowledge: Equitable partnerships in practice*. London: Earthscan.
- Roshan, B. (2009). Justifications for qualitative research in organisations: *A step forward*, 17, 413-423.

- Schaffer, A.M. (2009). Progress in community health partnership: *Research, Education and Action*, 3, 80-90.
- Senaratna (2002). Community Participation in Research: Community participation as myth or reality. *American Journal of Developmental Studies*, 48, 1-16.
- Shapiro, J.P. (1988). Participatory evaluation: Towards a transformation of assessment for women's studies, programs and projects. *Educational Evaluation and Policy Analysis*, 10, 191-199.
- Sheurich, J.J., & Young, M.D. (1997). Coloring epistemologies: are our research epistemologies racially biased? *American Education Research Journal*, 32, 465-491.
- Silverman, D. (2001). *Interpreting qualitative data: Methods for analysing talk, text and interaction: 2nd edition*, London: Sage.
- Sinclair, I. (2004). Aboriginal health research and the national aboriginal health strategy: *An Australian Journal of Public Health*, 16, 144-115.
- Smith, C.G. (1997). Attitudes and beliefs of African-Americans toward participation in medical research. *Journal of General Internal Medicine*, 14, 537-546.
- Smith, C.G., & Taylor, K. (2002). Distrust, race, and research. *American Medical Association*, 48, 1-8.
- Smith, T.L. (1999). *Decolonizing Methodologies, Research and Indigenous peoples*. Zed Books Ltd. London & New York.
- Stark, C. (1998). Ethics in the research context: Misplaced misgiving. *Canadian Psychology*, 39, 202-211.

- Starling, B., Kamuya, D., Gikonyo, C., Molyneux, C., & Marsh, V. (2007). Reveal challenges of communicating research in Coastal Kenya. *Science & Public Affairs*, 1-32.
- Ster, M.F. (1994). *Who owns native culture?* London: Harvard University Press.
- Stillitoe, P. (1998). The development of indigenous knowledge: *A New Applied Anthropology*, 39, 223-30.
- Strauss, J.C. (1990). *Basics of Qualitative Research: Grounded theory procedures and techniques*: London, Zed Books.
- Stringer, T.E. (1996). *Action Research: Second Edition*. Sage: London.
- Stringer, T.E. (1999). *Action Research: A handbook for practitioners*. Sage: London.
- Subhra, G. (2002) *Drinking in Black and Minority Ethnic Communities. 100% Proof: research for action on alcohol*. London: Sage.
- Tauli-Copurs, V. (1999). Indigenous Peoples and Intellectual Property rights .Trips and its potential impacts on indigenous peoples. *Journal of Science and Healing*, 2, 256-259.
- Thompson, E.E. (1989). Recruitment and retention of African American patients for clinical research: An exploration of response rates in urban psychiatric settings. *International Health Foundation for Developed Countries*, 48, 12-48.
- Terre Blanche, M., & Kelly, N .(2002). Interpretive methods. In K. Durheim, K.Taylor, & A Cornwall (Eds.), *Research in practice: Applied methods for social sciences* (pp.146-169). Cape Town: University of Cape Town Press.
- UNAIDS. (2000). *Guidance Document Ethical considerations in HIV Preventive Vaccine Research*. UNAIDS, Geneva, CIOMS.

Van Teijlingen, E.R., & Hundley, V. (2001). The importance of pilot studies. *Social Research Update*, 35, 7-14.

Van Vlaenderen, H., & Neves, D. (2004). Participatory action research and local knowledge in community contexts. In D. Hook et al., N. Mkhize, P. Kiguwa, & C. Collins (Eds.), *Critical Psychology* (pp.445-464). Cape Town: UCT Press.

Vitiello, A. (2005). Recruitment and retention of African-American patients for clinical research: an exploration of response rates in an urban psychiatric hospital. *J Consult Clin Psych.* 64, 861-867.

Westfall, D.L. (2006). Implementing community-based participatory research centres in diverse urban settings. *Journal of Urban Health*, 78, 488-494.

## Appendix A: Interview Schedule

- Are you familiar with a research that is conducted in your community?  
Kungabe uyazi ngocwaningo olwenziwa endaweni yangakini?
- Can you tell me what you understand about research? What comes to your mind when you hear the word research?  
Ungangitshela ukuthi uqondani ngalolu cwaningo? Kufikani emqondweni wakho uma uzwa igama cwaningo?
- Can you tell me if you have participated in research or do you know of anyone who has participated?  
Usuke waba yini ingxenye yalolucwaningo? noma ukhona yini omaziyo oseke waba?
- What were the reasons for participating or not participating?  
Yiziphi izizathu ezenza ube noma ungabi inxenye yalo?
- Why is the research conducted?  
Kungani kukhona lolucwaningo
- Who is the research for?  
Lwenzelwa bani lolucwaningo?
- How is the community informed about the research?  
Indawo yangakini yaziswe kanjani ngalolucwaningo?
- What were the goals of the research in the beginning?  
Kwakuyiziphi izinjongo- senzo zocwaningo ekuqaleni?
- Who initiates the research project?  
Ubani umqali walolucwaningo?
- Who takes part in the stages of research process?  
Ubani oba yingxenye ezigabeni zalolucwaningo ngenkathi liqhubeka?
- What do you understand about collaborative research?  
Uqondani ngocwaningo oluhlanganiselwe?
- Whose knowledge counts in the research?  
Olwabani ulwazi olubalulekile kulolucwaningo?
- Does the community become involved in the planning of the research?  
Kungabe izakhamuzi ziyaba yini ingxenye ekwakhiweni/ekusungulweni kwalolucwaningo?

- Do you participate in the decision-making process?  
Uyazibandakanya wena ekuthathweni kwezinqumo?
- Who makes the decisions in the research?  
Ubani othatha izinqumo kulolucwaningo?
- Are there any advantages and disadvantages of research that you can think of?  
Bukhona yini ubuhle nobubi bocwaningo?
- Do you ever find that there is conflict or disagreement between the members of the community and researchers?  
Kukhona yini ukungaboni ngasolinye phakathi kwabacwaningi nomphakathi?
- How is research results interpreted?  
Icutshungulwa ngani imiphumela yalolucwaningo?
- Who owns the results of the project?  
Ubani uphakathi wemiphumela yalolucwaningo?
- Do you feel that the research system that is used when conducting research is fair?  
Ucaba/ Uzwa ukuthi indlela esetyenziswayo uma kwenziwa ucwaningo iyiyo?
- What do you think needs to be done if you don't think it's fair?  
Kungayini engenziwa uma ubona ukuthi indlela ayinabo ubulungiswa?
- Do you have the capacity to challenge researchers?  
Uzibona ungaba nawo yini amandla okuphosa inselelo kubacwaningi?

## Inkonyane B: Iminingwane yocwaningo ne khasi lokuvuma, ngeSiZulu

<b>Iminingwane ngocwaningo</b>	
Isihloko:	
<p>Imiqondo, izimvo nemizwa yomphakathi mayelana nocwaningo kanye nokubambisana ngokulinganayo phakathi kwabacwaningi nomphakathi uma kwenziwa ucwaningo</p> <p><b><i>English translation: Conceptions of research and attitudes toward research and research collaboration: A community perspective</i></b></p>	<b>Inombolo yocwaningo:</b>
<b>Umcwaningi:</b> Nondumiso Zukelwa	<b>Isizinda:</b> University Of KwaZulu-Natal
<b>Indawo:</b> Umgungundlovu	<b>Ucingo:</b> 078134364
<b>Umpathi:</b> Solwazi N.J. Mkhize	<b>Isizinda:</b> University Of KwaZulu-Natal
<b>Indawo:</b> Umgungundlovu	<b>Ucingo:</b> 033-260 5963

Ngiyakubingelela,

Lapha senza uphando mayelana nendlela abantu abaqonda ngayo ucwaningo, ukuthi luyini; sibheka futhi nemizwa nezimvo zabo mayelana nocwaningo, kubandakanya ukubambisana phakathi kwabacwaningi nomphakathi. Inhloso ukuthola ulwazi ukuthi ngabe ucwaningo luqonda ukuthini kubantu jikelele, ukuzwa imizwa yabo ngocwaningo, nokuqonda kabanzi ngezindlela ezahluka-hlukene zokubambisana phakathi kwabacwaningi nomphakathi.

Uyamenywa ukuba ubambe iqhaza kulolucwaningo. Uma ubamba iqhaza, umcwaningi uzokubuza imibuzo ehleliwe, esizoxoxela phezu kwayo. Umbuzo ngamunye uzolandelwa eminye imibuzo ukucacisa izimpendulo zakho. Umbuzo ngamunye awunayo impendulo eyodwa kodwa okubalulekile ukuveza imibono yakho. Kunokwenzeka abantu babe nemibono

eyahlukene; kungakho nje senza lolucwaningo. Imibuzo cishe izothatha isikhathi esingaba yihora elilodwa sekuhlanganisiwe.

Ukubamba iqhaza kwakho kulolucwaningo ngeke kube nangozi kuwe. Uma ungene ezindlekweni zokuhamba ngenxa yokubamba iqhaza kulolucwaningo, uzobuyiselwa izindleko zakho. Loluphando ngeke lube namthelela kumuntu ngamunye kodwa umthelela walo uzokuba ekusimamiseni ulwazi olusafufusa mayelana nokuthi imiphakathi icabangani ngocwaningo nokubambisana ngokulinganayo phakathi kwabacwaningi nomphakathi.

Ukubamba iqhaza akuyona impoqo futhi ngeke kuze kube nemiphumela emibi kuwe uma ungathandi ukuzibandakanya kulolucwaningo. Ukuzibandakanya kwakho kulolucwaningo kuzogcinwa kuyimfihlo ngokungavezi imininingwane engadalula wena siqu sakho. Imininingwane ezoqoqwa izogcinwa ekhabethezi lensimbi elikhuywayo, ehhovisi lomphathi wocwaningo. Ngumcwaningi nomphathi wakhe kuphela abazobheka lemininingwane. Futhi unelungelo lokuhoxa noma inini ngisho noma usuluqalile ucwaningo, futhi ukuhoxa ngeke kube nomphumela omubi kuwe.

Uma unemibuzo ngalolucwaningo, uyakhuthazwa ukuba uthintane nami noma no Solwazi Mkhize okunguye osingethe ucwaningo. Imininingwane uzoyithola ekuqaleni kwalelikhasi (ngasenhla). Uma uneminye imibuzo ngalolucwaningo, noma unemibuzo mayelana nendlela oluqhubeka ngayo kodwa ongazimisele ukuxoxisana ngakho nabacwaningi, ungathintana no Nkosazane P. Ximba emahhovisi e Nyuvesi aphaathelene nobulungiwa ocwaningweni. Nansi i Nombolo: 033- 260 3587

Yimi ozithobayo,

Nondumiso Zukelwa

**Ikhasi elingubufakazi bokuvuma ukubamba iqhaza ngokukhululekile nokungenampoqo**

**(Informed Consent Form)**

University of KwaZulu-Natal  
School of Psychology  
Private Bag X01  
Scottsville  
3209

Mnumzane/Nkosazana/Nkosikazi ehloniphekileyo

Ngingumfundi esizindeni sezemfundo ephakeme saKwaZulu-Natali. Njengengxenywe yezifundo zami, kumele ngenze ucwaningo ngizwe izimvo mayelana nesihloko esithile. Mina-ke isihloko sami simayelana nokuthola ulwazi ukuthi ngabe umphakathi uqonda ukuthini ngocwaningo jikelele, ukuzwa imizwa yomphakathi ngocwaningo, nokuqonda kabanzi ngezindlela ezahluka-hlukene zokubambisana phakathi kwabacwaningi nomphakathi

Ukuqoqa imininingwane ngocwaningo, ngizobuza imibuzo ehleliwe bese siba nengxoxo ehlobene nemibuzo nezimpendulo zakho. Lengxoxo izothatha cishe imizuzu engu -60. Ingxoxo yonke izoqoshwa ngesi-qophamazwi (tape-recorder), bese ibuye ibhalwe njengoba injalo ukuze ihlaziywe.

Ukuzibandakanya kulolucwaningo kungokukhululekile, akunampoqo. Inkulumo-ngxoxo iyohlelwa ngesikhathi esihambisana nawe. Ngaso sonke isikhathi umcwaningi uyokuhlonipha ukuba yimfihlo kwayo yonke imininingwane ecoshelwe kule-nculomo-ngxoxo.

Uma kwenzeka ushintsha umqondo wakho mayelana nokuzibandakanya, unelungelo lokuhoxa noma inini, ngisho noma ucwaningo seluqalile. Umcwaningi uyolihlonipha lelungelo ngaso sonke isikhathi: Ukuhoxa kwakho angeke kube nomthelela omubi kuwe.

Imiphumela yalolucwaningo iyobhalwa ngokufingqiwe. Yize kunokwenzeka ukuthi kucashunwe engxoxweni yakho njengoba injalo ukucacisa amaphuzu athile, imininingwane ebalula umuntu ngamunye iyogodlwa.

Uma ufisa ukubamba iqhaza kulolucwaningo, uyacelwa ukuba ulobe igama lakho uphinde usayinde emgqeni ngezansi.

Mina .....(igama) ngiyavuma ngokukhululekile ukubamba iqhaza kulolucwaningo oluchazwe ngasenhla. Ngichazeliwe inhloso yocwaningo nokuthi lubandakanya ini. Ngiyaqonda ukuthi ngingahoxa noma inini uma ngifisa.

.....  
Sayinda

.....  
Indawo

.....  
Usuku



## Appendix C: Project Information and Consent Form, English Version

Project Information	
Project Title: <i>Conceptions of research and attitudes towards research and research collaboration: A community perspective</i>	Project Number:
Researcher: Nondumiso Zukelwa	Organization: University Of KwaZulu-Natal
Location: Pietermaritzburg	Phone: 078-134 364
Project Supervisor: Professor N.J. Mkhize	Organization: University Of KwaZulu-Natal
Location: Pietermaritzburg	Phone: 033-260 5963

### Greetings

We are doing research in order to gain knowledge about community members' understandings of the terms 'research' and 'research collaboration'. We also intend to find out how community members perceive research in general, including the conduct of research in their communities; their attitudes towards the research in general. Our primary objective is to find out about conceptions of research in the community, as well as the various understandings of what collaboration between researchers and community members might entail.

You are invited to participate in this research. If you participate, the researcher will engage you in a conversation around a set of prepared questions. Each question will be followed up with additional probes or sub-questions in order to clarify your answers. It is important to realise that there is no single correct answer: we are interested in your opinions bearing in mind that different people might see the situation differently. It is envisaged that each interview will take approximately one hour.

Your participation will not expose you to any dangerous risks. You will not incur any expense as a result of participating in this research. If you happen to have travelled to a common site in order to participate in the research, your travelling expenses will be re-imbursed. This research will not have any benefits for each individual, but it will contribute to the growing body of knowledge concerning community participation in research.

Your participation is voluntary; there will be no penalties if you do not wish to participate in this research. Your participation in this study will be kept confidential: personal/identifying information will not be given out in the process of reporting about the study, nor for any other purpose. Information collected during the study will be kept in a locked cabinet in the supervisor's office: only the researcher and the supervisor will have access to it. You are also entitled to withdraw at any stage during the conduct of the study, even if the research has started. You will not incur any penalties whatsoever by withdrawing.

If you have any questions about this study you are urged to contact me or Professor Mkhize, the project supervisor. Phone details are indicated above. Should you have questions about the conduct or ethics of this study that you would rather not raise with the researchers at any stage during the conduct of the study, please feel free to contact Ms P. Ximba at the University's Research Office. The phone number is 033 260 3587

Thank you for your time.

Yours truly,

Ms. Nondumiso Zukelwa.