# PERCEPTIONS OF RISK OF NON-COMMUNICABLE DISEASES ASSOCIATED WITH OVERWEIGHT AND OBESITY AMONG INDIVIDUALS LIVING IN DIEPSLOOT INFORMAL SETTLEMENT, JOHANNESBURG, SOUTH AFRICA

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# ABSTRACT

Chronic non-communicable diseases are a major contributor to the burden of disease in developed countries, and are increasing rapidly in developing countries. The purpose of the study was to explain and predict health behavior by focusing on the attitudes and beliefs of informal settlement dwellers.

# **KEYWORDS**

Non Communicable Diseases, Overweight, Chronic, Global health challenge, Diepsloot, Unhealthy.

# **METHODS**

The cross sectional study collect quantitative data using closed ended questionnaires. Systematic sampling was done, selecting every 7<sup>th</sup> person who participated in the BMI assessment. Data were collected using self-administered questionnaire loaded onto an electronic data collection system and analyzed using SPSS software. Bivariate logistic regression analysis was performed to assess association between selected covariates and being overweight. Variables with p-value  $\leq 0.05$  on bivariate analysis were included into the multivariate logistic regression model. All factors with p $\leq 0.05$  were considered significant.

# RESULTS

A total of 2277 (47.7% male and 54.3% female) individuals were interviewed. Participants who indicated that Being Obese/ overweight will lead me to getting chronic diseases were 1.26 times (OR: 1.26 95% CI: 0.98-1.62) more likely to be overweight. Participants with a perception that their family medical history makes it likely to get chronic diseases were less likely to be overweight: (OR: 0.66 95% CI: 0.52-0.84)

### CONCLUSIONS

There is a need to initiative service excellence in informal settlement settings throughout South Africa to trial, assess, and implement integrated care interventions for chronic infectious and non-communicable diseases so as to dispel misinformation.

### INTRODUCTION

Non-communicable diseases (NCDs) are a major global health challenge in developed countries and are increasing rapidly in the developing countries such as South Africa due to urbanization (World Health Organization 2008)(World Health Organization 2004).This is mainly due to demographic transitions and changing lifestyles of populations associated with urbanization (Puoanei et al. 2008). Chronic non-communicable diseases are largely due to preventable and modifiable risk factors such as, high blood cholesterol, high blood pressure, obesity, physical inactivity, unhealthy diet, tobacco use and inappropriate use of alcohol(Surjadi et al. 2012). These factors result in various long-term disease processes, culminating in high mortality rates attributable to stroke, heart attack, tobacco- and nutrition-induced cancers, obstructive lung diseases and many others(Puoanei et al. 2008). Omission of NCDs from the 2015 United Nations Millennium Development Goals (MDGs) will impact attaining the MDG objectives, as their effect which causes premature deaths, exacerbate poverty and threaten national economies, are the fundamentals of MDG(Beaglehole et al. 2011)(World Health Organization 2013).

#### PURPOSE OF THE STUDY

The purpose of the study was to explain and predict health behaviour by focusing on the attitudes and beliefs of informal settlement residents. The study sought to increase the understanding of perceived risk and severity of non-communicable diseases among informal settlement dwellers so as to designed informed intervention programs in the lower resource settings. The study also delves into the cues to action and self-efficacy on preventing non-communicable disease.

### **OBJECTIVES OF THE STUDY**

- To assess the perceived susceptibility to non-communicable diseases
- To assess the perceived severity of non-communicable diseases
- To determine barriers to preventing non communicable diseases
- To establish practices for prevention of non-communicable diseases
- To make recommendations on strategies to prevent non communicable diseases

# CONTEXT OF THE STUDY

In developing countries, an estimated 863 million people live in slums, areas characterized by poor quality or informal housing, unhealthy living conditions, poverty, and marginalization from the formal health sector (UN-Habitat 2013). Because slum dwellers represent a third of the urban population of low- and middle-income countries, addressing intra-urban health inequities is an important challenge facing cities in the developing world (Bourne et al. 2002; Heitzinger et al. 2014).

The city of Johannesburg has adopted an innovative governance model to rebuild local government and improve service delivery (UN-Habitat 2013). Health inequalities between slums and adjacent urban areas may be masked by their inclusion in a single surveillance catchment area, which has led to repeated calls for more robust intra-urban morbidity and mortality data (Bourne et al. 2002; Heitzinger et al. 2014). Inadequate water and sanitation facilities lead to deterioration of the urban environment, adding to the burden of disease for the urban poor, particularly in slums and squatter settlements (UN-Habitat 2013).

# PROBLEM STATEMENT

Non-communicable diseases are a major contributor to the burden of diseases in the low and middle-income countries. This is mainly due to demographic transition and changing lifestyle. The rapid urbanization, in the context of globalization, has been accompanied by a large shift in health patterns of South Africans, thus increasing the prevalence of non-communicable diseases. Little is known about the burden of disease in slums and low-income informal settlements because, due to their unofficial status and lack of resources, they are more frequently excluded from governmental epidemiologic surveillance and research studies (Bourne et al. 2002; Heitzinger et al. 2014).

The increasing urbanization of cities and demand for better opportunities such as employment, better life and working opportunities has been largely driven by migrants from the rural areas to the urban areas(World Health Organization 2013)–[7]. However an inability to find employment and places to stay, forces migrants to stay in the informal settlements, whereby they adopt unhealthy lifestyles of urbanization. With the lack of nutritional knowledge, healthy foods become less important and migrants settle for cheap unhealthy food at a lower price, consuming large food portions without any accompanying physical exercise, and engage in excessive smoking and binge drinking(World Health Organization 2008). Their challenges are further compounded by the fact that informal settlements are a marginalized population who face

exclusion from urban social services to access health information and care, thereby increasing the prevalence of non-communicable diseases such as diabetes, hypertension, chronic respiratory diseases, and some cancer.

The aim of this study was to increase the understanding of the burden of NCDs among the Diepsloot informal settlement residents using a health belief model. This will assist policy makers develop policies towards reversing the rising burden of NCDs in South Africa as shown by an increasing number of deaths from diabetes, hypertension, asthma and cancer and increasing proportion of disability-adjusted life years, which is the number of years lost due to a disability or death (DALYs)(Mayosi et al. 2009).

## SIGNIFICANCE OF THE STUDY

The study provides guidance to increase the understanding of perceptions of risk of NCD associated with overweight and obesity among individuals living in Diepsloot informal settlement, Johannesburg, South Africa.

## DELIMITATIONS OF THE STUDY

• This study was restricted to volunteer subjects identified during a health services campaign.

# DEFINITION OF TERMS

- Health Belief Model (HBM) A theory focused on the degree of fear of an illness related to the potential benefits of taking health action. Perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self- efficacy are the components of the HBM
- Health Behavior: refers to the actions of individuals, groups and organizations as well as their determinants, correlates, and consequences, including social change, policy development and implementation, improved coping skills, and enhanced quality of life (Frankenfield 2009).
- Perceived Barriers: one's opinion of the tangible and psychological costs of the advised (Matsuda 2002)
- Perceived Benefits: one's belief in the efficacy of the advised action to reduce risk or Seriousness of impact (Anderson 2006).
- Perceived Severity: one's opinion of how serious a condition and its consequences are. Perceived Susceptibility: one's opinion of chances of getting a condition(Matsuda 2002).

# LITERATURE REVIEW

### **INTRODUCTION**

Non-communicable diseases (NCDs) are a major global health challenge in developed countries and are increasing rapidly in the developing countries such as South Africa due to urbanization (World Health Organization 2008)(World Health Organization 2004). Omission of NCDs from the 2015 United Nations Millennium Development Goals (MDGs) will impact attaining the MDG objectives, as their effect which causes premature deaths, exacerbate poverty and threaten national economies, are the fundamentals of MDG(Beaglehole et al. 2011)(World Health Organization 2013). Shifts in dietary intake, to a less prudent pattern, are occurring with apparent increasing momentum, particularly among blacks, who constitute three-quarters of the population (Bourne et al. 2002).

### NON-COMMUNICABLE DISEASES IN SOUTH AFRICA

South Africa constitutes one of the 23 countries globally that are responsible for 80% of the burden of chronic diseases in all middle-income and low-income countries combined(Beaglehole et al. 2011). In the context South Africa alone, NCDs in 2004 were estimated to contribute to 12% of the overall disease burden and caused 28% of the total burden of disease measured by disability-adjusted life years(Mayosi et al. 2009).

In 2008 study, a total of 190,500 people died of NCDs. Of all the NCD deaths 39.7% were males and 28.7% females died under the age of 60. The total number of NCD deaths was higher amongst women (98,100) than men (92,400)(Mayosi et al. 2009; Beaglehole et al. 2011).

### CARDIOVASCULAR DISEASES

Hypertension is a prevalent cardiovascular disease among the South African black population. In South Africa, the percentages of men and women who are measured as being hypertensive are 12.5% and 17.9% respectively. However, the percentages are higher in White men (35.8%) and Indian women (29.1%). Hypertension can be controlled with diet and physical activity and prescribed medication, which may need to be taken for life. In 2003, national data showed that only 18% of men and 22% of women had controlled hypertension (Puoanei et al. 2008). This was proven by a Transition and Health during Urbanization of South Africans (THUSA) study which found an association between blood pressure and high fat diets(United Nations 2000).

### DIABETES

The burden of diabetes mellitus in South Africa is unacceptably high with rates higher than the African average. The death rate for CVDs and diabetes was reported to be 327.9 for males and 315.2 for females.

### CHRONIC RESPIRATORY DISEASES

The prevalent chronic respiratory diseases in the context of South Africa are pulmonary disease (COPD), asthma, and lung cancer. In 2008, the death rate due to chronic respiratory diseases was 86.6 (male) and 44.5 (female).

### CANCER

In 2008, the death rate due to cancer was 207.2 (male) and 123.9 (female).

# THEORETICAL BASIS

# HEALTH BELIEF MODEL

The Health Belief Model (HBM) is one of the first health education theories, developed in the 1950s by social psychologists Hochbaum, Rosenstock and Rosenstock, and Kegels to understand how a health behavior can prevent and detect a disease(Rosenstock et al. 1988a). It is mostly used to study people's behavioral responses to health-related conditions that are determined by seven personal beliefs or perceptions constructs about a disease. These seven constructs namely perceived susceptibility, perceived seriousness/severity, perceived benefits, perceived barriers; cues to action and self-efficacy are the bases of the HBM which can be used to develop health education strategies as shown on Figure 1 below (Rosenstock et al. 1988b).





Unplanned urbanization such as in the development of informal settlements has made settlers susceptible to NCD risk factors through adoption of unhealthy lifestyles, such as an increase in the intake of fat and sugar, inadequate consumption fruit & vegetable, binge drinking, excessive smoking, and lack of physical activity(Puoanei et al. 2008; World Health Organizattion 2008). The resultant ill-health from the unplanned urbanization or development of informal settlements is further fuelled by exclusion from urban services like education, health, welfare, public transportation and child care thereby increasing the population's risk for non-communicable diseases(Puoanei et al. 2008; World Health Organizattion 2008). In relation to the burden of preventable NCDs such as type 2 diabetes, cardiovascular diseases, respiratory diseases, and cancer at the Diepsloot informal settlements, the HBM's constructs can be used as the framework for motivating people to take positive health actions to avoid or reduce negative health-related effects of NCD on risks that individuals perceive are modifiable, such as healthy eating habits and engaging in physical activity(Glanz et al. 2002).

### PERCEIVED SUSCEPTIBILITY TO A NCD

This is a person's belief or perception about getting a disease or condition and putting measures to prevent the disease(Glanz et al. 2002; Resource Center for Adolescent Pregnancy Pregnancy Prevention n.d.; Rosenstock et al. 1988b; Glanz, K; Rimer, B; Viswanath 2002; NursingTheories n.d.; Redding et al. 2000). In the case of an informal settler in Diepsloot, the settlers can perceive developing an NCD illness if they perceive the health determinants such as an increase in the intake of fat and sugar, inadequate consumption fruit & vegetable, binge drinking, excessive smoking, and lack of physical activity) as risks that they are susceptible to(Glanz et al. 2002). Thus the greater the NCD health-related risks that informal settlers perceive, the greater are the like hood to engage in actions that will decrease the risks. However if an informal settlement dweller(s) do not perceive their unhealthy lifestyles as NCD risks, then they are unlikely to change their behaviours and thus continue with unhealthy behaviours towards developing an NCD illness(Resource Center for Adolescent Pregnancy Pregnancy Prevention n.d.).

### PERCEIVED SERIOUSNESS OF NCD

This is defined as one's belief about how serious an illness or condition and its negative effects are(Glanz et al. 2002; Resource Center for Adolescent Pregnancy Pregnancy Prevention n.d.; Rosenstock et al. 1988b; NursingTheories n.d.; Redding et al. 2000; Glanz, K; Rimer, B; Viswanath 2002). The informal settlement dwellers will likely be motivated to prevent any NCD related illness if he/she believes certain actions will lead to developing a disease, or pose a serious outcome such as death, disability or suffering(Redding et al. 2000). However if an individual perceives the risks as minimal, then it's unlikely that they will be motivated to change.

### PERCEIVED BENEFITS TO PREVENTING A NCD

This is about engaging in behaviours or actions toward prevention of a disease that an individual perceives as a threat(Glanz et al. 2002; Resource Center for Adolescent Pregnancy Pregnancy Prevention n.d.; Rosenstock et al. 1988b; NursingTheories n.d.; Redding et al. 2000; Glanz, K; Rimer, B; Viswanath 2002). Therefore, an informal settler who believes that a particular action will reduce his/her susceptibility to an NCD health-related illness or decrease its seriousness, then he or she is likely to engage in healthy behaviors.

#### PERCEIVED THREATS TO PREVENTING A NCD

This refers to an individual's assessment of the hindrances to behavior change, which is the combination ofperceived severity and perceived susceptibility (Glanz et al., 2002; Glanz, K; Rimer, B; Viswanath, 2002; Redding et al., 2000; Rosenstock et al., 1988b).Even if an individual perceives a health condition as threatening and believes that a particular action will effectively reduce the threat, barriers may hinder engagement in the health-promoting behavior. The individual will have to perceive the benefits outweighing the perceived barriers in order for

behavior change to occur(Glanz et al. 2002; Resource Center for Adolescent Pregnancy Pregnancy Prevention n.d.; Rosenstock et al. 1988b; Nursing Theories n.d.; Redding et al. 2000; Glanz, K; Rimer, B; Viswanath 2002). In the case of a Diepsloot, an individual will have to belief the benefits of taking corrective action to prevent and reduce an NCD-related illness far outweighs the other barriers such as the time it takes to prepare healthy foods than face the threat of dying in the future.

### CUES TO ACTING TOWARDS REDUCING AN NCD ILLNESS

Cues to action are internal or external triggers that are necessary for prompting engagement in health-promoting behaviors(Glanz et al., 2002; Glanz, K; Rimer, B; Viswanath, 2002; Redding et al., 2000; Rosenstock et al., 1988b). The motivation to heed to cues varies between individuals due to difference in perceived susceptibility, seriousness, benefits, and barriers, as for example one individual will be motivated to change unhealthy eating behaviours if they feel more susceptible to being diabetic, where as another individual does not perceive diabetes as being severe

### SELF-EFFICACY

Self-efficacy is the extent to which people believe they are capable of performing specific behaviors in order to prevent acquiring an illness(Maibach et al. 1991). The importance of perceived self-efficacy is it can motivate people on how they feel and behave(Maibach et al. 1991). The more an individual believes that a particular behavior can result in reducing an NCD illness, the greater the likelihood an increased perceived self-efficacy for that behavior results in its acceptance and adherence(Corr 1990).

# **RESEARCH METHODOLOGY**

This chapter elaborates on the research methodology that wasapplied during the execution research. This section is divided into study design, study settings, study population

### STUDY DESIGN

A cross-sectional survey was conducted. The interviews were conducted with informal settlements residents over a period of 6 days with 2 days allocated for data collection from each of the Extension 2 Blocks (Block I, J and K).

### STUDY SETTING

Diepsloot is a densely populated settlement of black people located in Region A, the North of Johannesburg, South Africa. The area was established in 1993, primarily to relocate few informal settlement emigrants from Zevenfontein on a temporary basis until land became available (Johanesburg Development Agency 2013a). However, land did not come available and thus Diepsloot became a permanent home to 360 000 people, in which 45.51% are females and 54.49% are males (Johanesburg Development Agency 2013b). The language that is mostly spoken in Diepsloot is isiZulu (35%), followed by Sesotho (11%), isiXhosa (10%) and other languages (Thea De Wet, Leila Patel, Marcel Korth 2008a; Johanesburg Development Agency 2013b).

The Diepsloot's economic active force available is estimated to be 73.7% of the population, comprising of the age group 20 to 59 years old (Thea De Wet, Leila Patel, Marcel Korth 2008b). However, low education levels at 34% has led to high unemployment rate and overall low-incomes (Anon n.d.). 76% of the population in Diepsloot, lives in overcrowded shacks commonly referred to as informal settlements (Anon n.d.). The rapid establishment of informal settlements due to unplanned urbanization is made up of low quality informal housing in unpaved roads, use of communal sanitation and toilets, and inadequate sewage system (Johanesburg Development Agency 2013b). The informal settlements are overcrowded by inhabitants and the residents of Diepsloot is characterised by numerous local shops called spaza shops which sell low-priced unhealthy foods, which lead to unhealthy lifestyle and ultimately to an increase in chronic diseases such diabetes, cancer, chronic respiratory diseases and obesity (Anon n.d.). The rapidly increasing population of Diepsloot from the informal settlements has led to numerous service delivery protests due to inadequate basic infrastructure. This is evidenced by the presence of only four primary schools, one clinic, a hospital 25km away, a police station 10km away, and the fire brigade and a post office which are 20km away.

# STUDY POPULATION

Diepsloot is divided into 2 wards (ward 95 and ward 113). Within each ward there are extension and within the extensions there are blocks. The focus of the study will be on the informal settlements that are in Extension 2. There are an estimated number of 18,247 people living in Block I, Block J and Block K informal settlements with a total number of 2699, 1008 and 1660 shacks.

### SAMPLE SIZE

Sample-size determination is often an important step in planning an epidemiological study. There are several approaches to determining sample size however, for purposes of this study the simplified sample size calculation will be used as shown below. (Kasiulevičius et al. 2006)

# EQUATION 1: FORMULA FOR SAMPLE SIZE CALCULATION

 $n = \frac{N}{1 + N e^2}$ 

(Kasiulevičius et al. 2006)

The total population (N) is 18,247. The parameters for the sample size will at a confidence interval of 95%, significance of 0.5 and a precision level of  $\pm 5\%$ .

## SAMPLING METHOD

A cross-sectional survey was conducted. The interviews were conducted with informal settlements residents over a period of 6 days with 2 days allocated for data collection from each of the Extension 2 Blocks (Block I, J and K).

The study targeted people that voluntarily participated in the health services. The health services provided included HIV testing, Body Mass index assessments, blood pressure checks and health education. Only those that participated in the BMI assessments were requested to participate in the survey. Systematic sampling was done; every 7<sup>th</sup> person who participated in the BMI assessment was requested to participate in the study. Field workers at the Health services campaign were approached as potential participants then they were asked f they were willing to participate in the study. Those who voluntarily accepted to take part were recruited to complete a closed ended questionnaire.



### FIGURE 4 : SYSTEMATIC SAMPLING IN SELECTION OF RESPONDENTS

# THE RESEARCH INSTRUMENT

The research questions inquired about the existence of a relationship between the HBM constructs and the risk of NCDs. Since correlation tests measure relationships, the goal of the research questions was to assess the relationship between participants' perceived risk and their association with 1) perceived susceptibility and 2) perceived severity of pregnancy, 3) the benefits and 4) barriers to behavior modification, and 5) the self-efficacy to perform desired behaviors. The questionnaire was closely aligned to the aims of the survey. The instrument was sub-divided into the following sections:

- Demographic information
- Perceived susceptibility to NCDs
- Perceived severity of NCDs
- Barriers to behavior modification, and
- Self-efficacy to perform desired behaviours

# DATA COLLECTION

Data were collected using self-administered closed ended questionnaire loaded onto an electronic data collection system using personal tablet computers. The fieldwork was conducted by ten well-trained fieldworkers who were recruited fromDiepsloot community and they have been involved in various survey conducted in the areas.

Fieldworkers were provided with a detailed training manual highlighting, inter alia, the following:

- aim and background of the study
- how to conduct the interview
- sampling procedure
- sample size
- probing guidelines
- quality control measures
- interviewing do's and don'ts

The Principal Investigator reviewed completed questionnaires in the TouchPoll electronic data collection system. Incomplete questionnaires were removed from survey data.

Interviewing is an art and one learns it by experience. However, the following points were kept in view by an interviewer for eliciting the desired information:

• Interviewer planned in advance and knew the problem under consideration. They selected the suitable time and place so that the interviewee were at ease during the interview period. For this purpose some knowledge of the daily routine of the interviewee was

essential, they were also requested to indicate if they had time to respond to the questionnaire.

- Interviewer's approach was friendly and informal. Initially friendly greetings in accordance with the cultural pattern of the interviewee were exchanged and then the purpose of the interview was explained to the participant.
- Efforts were made to establish proper rapport with the interviewee; people are motivated to communicate when the atmosphere was favourable.

### LIMITATIONS OF THE STUDY

A major problem was that a large proportion of the research was on perceptions. Another limitation was the use of a cross sectional survey design. In this type of survey design, information is gathered on a population at a single point in time. This type of survey design is used throughout social science literature; however, it does not show a cause and effect relationship between variables.

The refusal rates with recruitment of respondents post service provision were also not captured. Interviewing the respondents that had refused might have given a different picture of the study population.

The study was conducted in one day, conducting it over a longer period might have given varied findings. The use of personal tablets as data collection tools might have prevented potential technophobic or elderly participants from answering the survey. However, support was provided to those that needed any assistance from the field staff. It is from these limitations that caution should be exercised before generalising the study results to other areas and population groups of similar characteristics.

# VALIDITY AND RELIABILITY

### VALIDITY OF RESULTS

Any sample survey is subject to error, and as such, yields useful estimates but no precise values. The most common errors, namely sample errors, interviewer errors, and reporting errors are discussed below.

### SAMPLING ERRORS

Sampling error occurs when the sample selected is not perfectly representative of the population. The population size (18 247) was an estimate of the total population based on the numbers of shacks (5 367) and the estimated household size (3.4) per shack. This estimation was due to the fact that there is no available data on the selected informal settlement.

### INTERVIEWER ERRORS

Three types of errors can occur as a result of an interviewer's behaviour, namely errors when asking questions, errors when recording answers and errors due to cheating. The level of experience of fieldworkers eliminated the first two types of errors. Checkbacks by the Principal Investigators was used to establish if the fieldworkers did cheat, and none was found to have cheated.

### REPORTING ERRORS

Reporting errors usually stem from memory errors, misunderstanding of questions or reluctance to answer them. The need to minimise reporting errors was factored in during the construction of the questionnaire and with the selection and training of field workers.

# STATISTICAL ANALYSIS

# ETHICAL APPROVAL

Ethical clearance was sought from the Monash University School of Public Healthas part of a bigger study. The research team members adhered to strict ethical standards in all research performed. During data collection, processing and storage, strict ethical standards were followed. All participants were briefed on their participation in the research and requested to provide written informed consent prior to data collection. Confidentiality of responses was also assured. Participants had the right to choose if they want to participate and they were not discriminated against if they refuse to participate. All participants were asked if they have any questions or concerns about the study.

As ethical issues come to the fore where human participants are involved, efforts were made to ensure that the following principles are taken into consideration:

### INFORMED CONSENT AND VOLUNTARY PARTICIPATION

Informed consent was obtained from research participants before the commencement of the research. Either written or verbal informed consent will be obtained from each of the participants. Verbal consent (where the participant is illiterate) was obtained in the presence of a literate witness who will verify in writing and duly sign that informed verbal consent had been obtained.

Participants were free at any time to withdraw their participation from the research project without having to face any negative consequences or disadvantages. Means were in place to ensure informed consent and privacy on behalf of all respondents to prevent respondents from being persuaded or coerced to participate and to safeguard the interests of minors. Furthermore, a concerted effort was made to ensure that no unrealistic expectations resulting from participation in the study are developed on behalf of the respondents. Researchers also respect participants' rights to change their decision or withdraw their prior informed consent at any stage of the research without incurring any penalty whatsoever. It is an ethical imperative that the fieldworker/interviewer recognise and respect each person's choice to participate or not participate. To ensure the respect of the participant, the process of securing consent was a gradual and emerging process where the respondent is capable of making an informed decision based on experience and information.

### DISCLOSURE

The participants involved in the study were informed in advance that the researchers have a mandatory reporting obligation that is not dependent on their consent if issues of rape, assault and exploitative sex arise. These cases were to be reported to the relevant authorities.

## **COERCION AND PERVERSE INCENTIVES**

Any kind of coercion or issuing of perverse incentives is seen as a breach of ethical conduct and is deemed to be unethical research. For this reason, researchers will ensure that no undue incentives are provided to those who consent to take part in the study. Prospective participants will neither be intimidated nor compelled to take part in the research.

### PRIVACY AND CONFIDENTIALITY

The research teamkept the personal information gathered from the participants private and confidential by keeping the names of participants anonymous in the reports and publications.

### **AVOIDANCE OF HARM OR NON-MALEFICENCE**

In this research, the team carried the onus of ensuring the dignity and the physical and emotional safety of all participants during the research process and evaluation. The evaluation will not evoke any emotional distress requiring counselling.

# INCLUSION AND EXCLUSION CRITERIA

No person was inappropriately or unjustly excluded on the basis of race, age, sex, sexual orientation, disability, education, religious beliefs, marital status, ethnic or social origin, conscience, belief or language.

The research methodology applied to collect primary data from households residing in the Deipsloot informal settlement is explained below.

# STATEMENT OF RESULTS, DISCUSSION AND INTERPRETATION

## **INTRODUCTION**

This chapter focuses on reporting the results that were obtained from the data collected through the research process.

# DEMOGRAPHIC CHARACTERISTICS

*Table 7: Demographic characteristics of the sample (N=2277)* 

Factor	n	%
Gender	J	
Female	1236	54.3
Male	1041	45.7
Ethnicity		
Black	2250	98.8
Coloured	27	1.2
Total	2277	100.0
Employment status	J	
Employed	291	12.8
Unemployed	1986	87.2
Nationality		
non-South African	294	12.9
South African	1983	87.1
Age group	11	

20-39 years	1854	81.4
40-49 years	300	13.2
50-59 years	57	2.5
60-69 years	54	2.4
70-79 years	9	.4
80-89 years	3	.1
Marital Status	I	
Cohabitating	6	.3
Divorced	27	1.2
Married	543	23.8
Single	1692	74.3
Widowed	9	.4
People in household	I	
Alone	84	3.7
2-5 people	1203	52.8
6-10 people	990	43.5

#### N=2277

*Table 1* above shows the breakdown of demographic characteristics. A total of1, 1286 (54.3%) of the respondents who took part in the study were women. The majority (98.8%) of the respondents were black while the rest were coloured (1.2%). At the time of the study, 12.8% of the respondents were employed and the remaining 87.2% were unemployed. Most (87.1%) of the respondents were South African. The age range for majority of respondents (81.4%) was 20-39 years followed by 13.2% for the range 40-49 years. The majority (74.3%) of the respondents are single, followed by married (23.8%), divorced (1.2%), widowed (0.4%) then cohabitating (0.3%). A total of 52.8% of the respondents live in a household of 2-5 people while 43.5% live in a household of 6-10 people and only 3.7% stay alone.



*Figure 5: Number of years staying in the community* 

*Figure 3* above shows that, half of the respondents (50%) have for the past 6 to 10 years stayed in Diepsloot informal settlement community for, while 46% had stayed for 1 to 5 years. This was followed by the group of those living there for 11 to 15 years representing 3% of the respondents and those who were there for more than 15 years representing 1%.





*Figure 4* above shows the types of dwelling the respondents reside in. A total of 1854 and 423 respondents reside in shacks and houses respectively. Most of the respondents (81.4%) stay in shacks as the study was conducted in an informal settlement.



*Figure 7: Distribution of Educational Qualification among respondents* 

Large proportions (56%) of the respondents have no matric qualification as shown in figure 4 above. A total of 35% of the respondents had a matric while only 4% has a diploma as their highest qualification.

Figure 8: Distribution of the Individual income of respondents



Figure 5 above shows the distribution of individual income per respondent. The majority (87%) of the respondents live on less than a R1000 a month. While 11% earn between R1000 and R5000 per month.

# PERCEIVED SUSCEPTIBILITY

Table 8: Frequency distribution of perceived susceptibility of the respondents

Factors		Normal	Overweight	Total	p value
Being Obese/ overweight will lead me to getting chronic diseases	Disagree	153 (17.7%)	384 (28.1%)	537 (24.1%)	.000
	Agree	711 (82.3%)	984 (71.9%)	1695 (75.9%)	
My family medical history makes it likely to get chronic diseases	Disagree	207 (24.0%)	402 (29.4%)	609 (27.3%)	.005
	Agree	657 (76.0%)	966 (70.6%)	1623 (72.7%)	
Smoking make it likely to get chronic diseases	Disagree	96 (11.1%)	387 (28.3%)	483 (21.6%)	.000
	Agree	768 (88.9%)	981(71.7%)	1749 (78.4%)	
Unhealthy eating habits can make me get chronic diseases	Disagree	135 (15.6%)	405 (29.6%)	540 (24.2%)	.000
	Agree	729 (84.4%)	963 (70.4%)	1692 (75.8%)	
Physical inactivity can make me get chronic diseases	Disagree	102 (11.8%)	378 (27.6%)	480 (21.5%)	.000
	Agree	762 (88.2%)	990 (72.4%)	1752 (78.5%)	

The questionnaire assessed the perceived susceptibility among the populations of getting chronic diseases. Four factors were found to be statistically significant and these were being obese, smoking, unhealthy eating habits and physical inactivity all at p<.001. This implies that the respondents were most likely to identify these factors as significant to them having chronic diseases. Family medical history was however non-significant implying that respondents did not identify it as a significant factor to them having chronic diseases (p=.005).

# PERCEIVED SEVERITY

 Table 9: Frequency distribution of perceived severity of non-communicable diseases

Factor		Normal	Overweight	Total	p value
Having a Chronic diseases will	Disagree	120 (13.9%)	384 (28.1%)	504 (22.6%)	.000
have major effects on my life &					
family	Agree	744 (86.1%)	984 (71.9%)	1728 (77.7%)	
Having a chronic disease will have	Disagree	123 (14.2%)	399 (29.2%)	522 (23.4%)	.000
major effects on my work and					
income	Agree	741(85.8%)	969 (70.8%)	1710 (76.6%)	
Having a chronic disease will	Disagree	135 (15.6%)	375 (27.4%)	510 (22.8%)	.000
_					

cripple me	Agree	729 (84.4%)	993 (72.6%)	1722 (77.2%)	
Having a chronic disease will change my outlook	Disagree	126 (14.6%)	402 (29.4%)	528 (23.7%)	.000
	Agree	738 (85.4%)	966 (70.6%)	1704 (76.3%)	
Thought of having chronic diseases scares me	Disagree	81(9.4%)	330 (24.1%)	411 (18.4%)	.000
-	Agree	783 (90.6%)	1038 (75.9%)	1821(81.6%)	

The questionnaire assessed the population perceived severity of non-communicable diseases. Chronic diseases were found to statistically significantly contribute to major effects on family, major effects on work and income, crippling of individual, changing of outlook as well as scaring o individual all at p<.001. This implies that chronic diseases were identified by respondents to have significant effects on all factors.

# PERCEIVED BENEFITS

*Table 10: Frequency distribution of perceived benefits of behaviour change in preventing non-communicable diseases* 

		Normal	Overweight	Total	p value
Not having a chronic disease is	Disagree	78 (9.0%)	414 (30.3%)	492 (22.0%)	.000
	Agree	786 (91.0%)	954 (69.7%)	1740 (78.0%)	
Physical activities prevent chronic diseases	Disagree	102 (11.8%)	300 (21.9%)	402 (18.0%)	.000
	Agree	762 (88.2%)	1068 (78.1%)	1830 (82.0%)	
Heathy lifestyle prevents chronic diseases	Disagree	93 (10.8%)	294 (21.5%)	387 (17.3%)	.000
	Agree	771 (89.2%)	1074 (78.5%)	1845 (82.7%)	
Managing weight prevents chronic diseases	Disagree	81(9.4%)	276 (20.2%)	357 (16.0%)	.000
	Agree	783 (90.6%)	1092 (79.8)	1875 (84.0%)	
Not smoking prevents chronic diseases	Disagree	99 (11.5%)	321 (23.5%)	420 (18.8%)	.000
	Agree	765 (88.5%)	1047 (76.5%)	1812 (81.2%)	
Regular health checks will detect	Disagree	120 (13.9%)	312 (22.8%)	432 (19.4%)	.000
chionic diseases early	Agree	744 (86.1%)	1056 (77.2%)	1800 (80.6%)	
Regular health checks are beneficial	Disagree	129 (14.9%)	390 (28.5%)	519 (23.3%)	.000
	Agree	735 (85.1%)	978 (71.5%)	1713 (76.7)	

The questionnaire assessed the population perceived benefits or behaviour change in preventing non-communicable diseases. Majority of the respondents viewed that not having a chronic disease is beneficial. Majority of the respondents viewed that a healthy lifestyle, weight management, non-smoking, regular health checks can prevent chronic diseases. This was statistically significant p < 0.001.

### PERCEIVED BARRIERS

*Table 11: Frequency distribution of perceived barriers to behavior change in preventing non-communicable diseases* 

		Normal	Overweight	Total	p value
Very little that can be done to prevent chronic diseases	Disagree	291 (33.7%)	576 (42.1%)	867 (38.8%)	.000
	Agree	573 (66.3%)	792 (57.9%)	1365 (61.2%)	
No treatment will be effective in curing chronic diseases	Disagree	402 (46.5%)	615 (45.0%)	1017 (45.6%)	.468
	Agree	462 (53.5%)	753 (55.0%)	1215 (54.4%)	
Healthy foods are expensive	Disagree	270 (31.3%)	534 (39.0%)	804 (36.0%)	.000
	Agree	594 (68.8%)	834 (61.0%)	1428 (64.0%)	
Healthy check-ups are expensive	Disagree	336 (38.9%)	624 (45.6%)	960 (43.0%)	.002
	Agree	528(61.1%)	744 (54.4%)	1272 (57.0%)	
Preparing healthy foods is time	Disagree	315 (36.5%)	624 (45.6%)	939 (42.1%)	.000
consuming	Agree	549 (63.5%)	744 (54.4%)	1293 (57.9%)	
Health check-ups are time consuming	Disagree	282 (32.6%)	648 (47.4%)	930 (41.7%)	.000
	Agree	582 (67.4%)	720 (52.6%)	1302 (58.3%)	
It is embarrassing to go for health checks	Disagree	378 (43.8%)	645 (47.1%)	1023 (45.8%)	.116
	Agree	486 (56.3%)	723 (52.9%)	1209 (54.2%)	

The questionnaire assessed the population perceived barriers to behaviour change in preventing non-communicable diseases. Respondents in both the normal and overweight category perceive that there is little that can be done to prevent NCD's, this is statistically significant p < .001. The respondents report that no treatment would be effective in curing NCD's, however this was proven to be not statistically significant p = .468. Majority of the respondents reported that healthy foods and health check-ups are expensive, preparation of healthy foods is time

consuming and going for health check-ups are time consuming, this was statistically significant, p<.001. The majority of the participants said that going for health check-ups were embarrassing, however this was statistically insignificant.

## CUES TO ACTION

1 dete 12: 1 requerte, distribution of ettes to detten on benditter enditiges	<i>Table 12:</i>	Frequency	distribution	of Cues to	action on	behavior	changes
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		Normal	Overweight	Total	p value
I eat a well-balanced diet	Disagree	192 (22.2%)	504 (36.8%)	696 (31.2%)	.000
	Agree	672 (77.8%)	864 (63.2%)	1536 (68.8%)	
I always follow medical orders to benefit my health	Disagree	180 (20.8%)	420 (30.7%)	600 (26.9%)	.000
	Agree	684 (79.2%)	948 (69.3%)	1632 (73.1%)	
I frequently make efforts to improve my health	Disagree	147 (17.0%)	462 (33.8%)	609 (27.3%)	.000
	Agree	717 (83.0%)	906 (66.2%)	1623 (72.7%)	
I exercise regularly at least 3 times per week	Disagree	156 (18.1%)	402 (29.4%)	558 (25.0%)	.000
	Agree	708 (81.9%)	966 (70.6%)	1674 (75.0%)	
I avoid fatty foods	Disagree	135 (15.6%)	447 (32.7%)	582 (26.1%)	.000
	Agree	729 (84.4%)	921 (67.3%)	1650 (73.9%)	
I eat small portion meals	Disagree	138 (16.0%)	417 (30.5%)	555 (24.9%)	.000
	Agree	726 (84.0%)	951(69.5%)	1677 (75.1%)	

The questionnaire assessed the population cues to action on behaviour changes in preventing non-communicable diseases. Respondents in both the normal and overweight category reported that they eat a well-balanced diet, follow medical orders and frequently make efforts to improve their health, this was statistically significant p <.001. Respondents in both the normal and obese categories reported that they exercise regularly, avoid fatty foods and eat small meal proportions, this was statistically significant p <.001. This can indicate that either the participants did not know what a balanced diet was and what foods were fatty and thus reported that they avoid it or it can indicate they generally lead a healthy lifestyle.

# SELF-EFFICACY

# TABLE 13: FREQUENCY DISTRIBUTION OF SELF-EFFICACY IN INDIVIDUALBEHAVIOUR CHANGES

		Normal	Overweight	Total	p value
I am confident about how to prevent chronic diseases	Disagree	111 (12.8%)	408 (29.8%)	519 (23.3%)	.000
	Agree	753 (87.2%)	960 (70.2%)	1713 (76.7%)	
I am actively working on a healthy lifestyle to prevent	Disagree	90 (10.4%)	423 (30.9%)	513 (23.0%)	.000
chronic diseases	Agree	774 (89.6%)	945 (69.1%)	1719 (77.0%)	
I attend health assessments to prevent chronic diseases	Disagree	81 (9.4%)	447 (32.7%)	528 (23.7%)	.000
	Agree	783 (90.6%)	921 (67.3%)	1704 (76.3%)	
I have information on how to prevent chronic diseases	Disagree	27 (3.1%)	429 (31.4%)	456 (20.4%)	.000
	Agree	837 (96.9%)	939 (68.6%)	1776 (79.6%)	
There is lot I can do to reduce my chances of getting a chronic	Disagree	192 (22.2%)	504 (36.8%)	696 (31.2%)	.000
related illness	Agree	672 (77.8%)	864 (63.2%)	1536 (68.8%)	

The questionnaire assessed the population self-efficacy on behaviour change. Respondents in both the normal and overweight category reported that they were comfortable in preventing non communicable diseases, this was statistically significant p < .001. Respondents in the normal category were prone to attend health assessments to prevent chronic diseases, had information on how to prevent the chronic disease compared to the overweight category, this was statistically significant p < .001.

# UNIVARIATE ANALYSIS

Tuble 14. Onivariale analysis of factors associated with being over weight	Table	14:	Univariate	analysis	of factors	associated	with being	overweight
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Factors	OR (95% CI)		
Being Obese/ overweight will lead me to getting chronic diseases	Disagree	1	
	Agree	1.26 (0.98-1.62)	0.076
My family medical history makes it likely to get chronic diseases	Disagree	1	

	Agree	0.66 (0.52-0.84)	0.001
Smoking make it likely to get chronic diseases	Disagree	1	
	Agree	2.47 (1.84-3.32)	0.000
Unhealthy eating habits can make me get chronic diseases	Disagree	1	
	Agree	1.21 (0.91-1.61)	0.200
Physical inactivity can make me get chronic diseases	Disagree	1	
	Agree	1.84 (1.37-2.48)	0.000

Participants who indicated that Being Obese/ overweight will lead me to getting chronic diseases were 1.26 times (OR: 1.26 95% CI: 0.98-1.62) more likely to be overweight. Participants with a perception that their family medical history makes it likely to get chronic diseases were less likely to be overweight: (OR: 0.66 95% CI: 0.52-0.84). Participants who indicated that being obese/overweight will lead me to getting chronic diseases were 1.26 times more likely to be overweight than those who indicated that being obese/overweight would not lead them into getting chronic diseases but the relationship was not statistically significant.

Participants with a perception that their family medical history makes it likely to get chronic diseases were 0.34 times less likely to be overweight than those with a perception that medical history does not make it likely for them to get chronic diseases and the relationship was statistically significant. Participants who indicated that smoking made it more likely for them to get chronic diseases were 2.47 times more likely to be overweight than those who indicated that smoking did not make it likely for them to get chronic diseases and the relationship was statistically significant.

There was a statistically insignificant relationship that participants who indicated that unhealthy eating habits made them get chronic diseases were 1.21 times more likely to be overweight than those who indicated that unhealthy eating habit did not lead them to getting chronic diseases. Participants who indicated that physical inactivity led them into getting chronic diseases were 1.84 times more likely to be overweight than those who indicated that physical inactivity did not lead them into getting chronic diseases and the relationship was statistically insignificant.

# CONCLUSION AND RECOMMENDATIONS

The burden of these diseases will probably increase as the roll-out of antiretroviral therapy takes effect and reduces mortality from other chronic diseases (De Maio 2011). The scale of the

challenge posed by the combined and growing burden of HIV/AIDS and non-communicable diseases demands an extraordinary response that South Africa is well able to provide.

Concerted action is needed to strengthen the district-based primary health-care system, to integrate the care of chronic diseases and management of risk factors, to develop a national surveillance system, and to apply interventions of proven cost-effectiveness in the primary and secondary prevention of such diseases within populations and health services. I urge the launching of a community initiative to establish sites of service excellence in informal settlement settings throughout South Africa to trial, assess, and implement integrated care interventions for chronic infectious and non-communicable diseases.

# APPENDIX

# APPENDIX 1: QUESTIONNAIRE

Questionnaire Number Non-communicable Disease Questionnaire											
Section 1: Demographic Measures											
District		Ward		1	Extension		7	Block		1	
Ethnicity	Black	White	Asian	Coloured	1						
Type of dweling	House	Shack	Other		Employmen	t status	Unemployed	Employed	1		
Nationality	South African	Non South Africa	n	1	Monthly Income			1	1		
Gender	Male	Female	1	1	Age			]			
Marital Status	Single	Married	Divorced	Cobabitating	, ngo	Widowod		]			
Highest Education	No motrio	Matria	Cortificato	Diploma	Degree	Othor					
Fighest Education	No matric	Watric	Certificate	Dipioma	Degree	Other					
Section 2: Antropomet	ric measuremen	ts		7					7		
Height (cm)				]	Weight (kg)						
Waist (cm)				]	Hip (cm)				]		
Blood Pressure		Systolic	Diastolic	]	Systolic	Diastolic		Systolic	Diastoli	0	]
Section 3: NCD Suscep	otibility Measure	S							1		
Health Problems you kno	ow about ?			Diabetes	Cancer	Obesity	Health diseases	Respiratory Diseases	HIV	Other	
Health problems YOU su	mer from ?	a from 2		Diabetes	Cancer	Obesity	Health diseases	Respiratory Diseases	HIV	Other	
Health problems your far	nilv members sut	ffer from ?		Diabetes	Cancer	Obesity	Health diseases	Respiratory Diseases	HIV	Other	
Which of the following as	sessments have	you done in the	oast year	Blood sugar	Cancer	BMI	Waist/ Hip Ratio	,	HIV	Other	1
Have you ever heard abo	out Non Commur	nicable Diseases	chronic diseases		•	Yes	No				
I perceive myself as				underweight	normal	overweight	obese	severely over weight			
Obese/ overweight peop	le are likely to ha	ive the following h	iealth problem (s)	Diabataa	Canaar	Diabetes	Cancer	Health diseases	Respiratory Diseases	HIV	Other
Indicate the extent to which you agree or disagree to the following statements where 1= Strongly Disagree, 2= Disagree, 3= Neutral, 4= Agree, 5= Strongly Agree Perceived Susceptibility 1 2 3 4 5											
Being Obese/ overweigh	t will lead me to g	getting chronic dis	seases								
My family medical history	y makes it likely t	o get chronic dise	ases								
Unhealthy eating habits	get chronic dise	ases chronic diseases	2				+				
Physical inactivity can m	ake me get chror	nic diseases	,								
Perceived Severity:	· · ·										
Having a Chronic diseas	es will have majo	or effects on my li	fe & family								
Having a chronic disease	e will have major	effects on my wo	rk and income								
Having a chronic disease will chapte me Having a chronic disease will chapte my outlook											
Thought of having chron	ic diseases scare	es me									
Perceived Benefits :											
Not having a chronic dise	ease is beneficial										
Heathy lifestyle prevents	chronic disease	85					+				
Managing weight prevents chronic diseases											
Not smoking prevents ch	nronic diseases										
Regular health checks will detect chronic diseases early											
rregular inearu circus ate certellicial Perrejuda Rariers -											
Very little that can be do	ne to prevent chr	onic diseases									
No treatment will be effe	ctive in curing ch	ronic diseases									
Healthy foods are expen	sive										
Healthy checkups are expensive Preparing healthy foods is time consuming									-		
Health check ups are time consuming						-					
It is embarrassing to go for health checks											
Cues to Action:											
I eat a well-balanced die	t										
I always tollow medical orders to benefit my health							+		-		
I trequently make efforts to improve my health							-				
I avoid fatty foods											
Leat small portion meals											
Self-Efficacy:											
1 and connectination row to prevent critoring classases											
I attend health assessments to prevent chronic diseases							+				$\vdash$
I have information on how to prevent chronic diseases							1				
There is lot I can do to reduce my chances of getting a chronic related illness											

### APPENDIX 2: EXPLANATORY STATEMENT

Project: perceptions of risk to non-communicable diseases among overweight and obesity individuals living in informal settlements in johannesburg, south africa.

### **Prof Peter Nyasulu**

Department: School of Public Health Phone: +27 11 950 4287 Email : peter.nyasulu@monash.edu

You are invited to take part in this study. Please read this Explanatory Statement in full before deciding whether or not to participate in this research. If you would like further information regarding any aspect of this project, you are encouraged to contact the researchers via the phone numbers or email addresses listed above.

### WHAT DOES THE RESEARCH INVOLVE?

The purpose of the study is to provide guidance to increase the understanding of perceptions of risk of NCDs associated with being overweight and obesity among individuals living in informal settlements in Johannesburg. Overall data will be collected using a structured interview administered questionnaire, which will be loaded into an electronic data collection personal computer tablet. Since participation is voluntary, feel free to stop participating at any given point. Data will be collected through administering a questionnaire and anthropometric measurements.

### QUESTIONNAIRE ADMINISTRATION

The research questions will have questions on the following: 1) perceived susceptibility and 2) perceived severity of non-communicable diseases, 3) the benefits and 4) barriers to behavior modification, and 5) the self-efficacy to perform desired behaviors.

# ANTHROPOMETRY AND BLOOD PRESSURE MEASUREMENT

### **BLOOD PRESSURE**

Anthropometry and blood pressure measurements will be done at the campaign sites in the mobile van using standardized methods. Blood pressure will be measured using a digital sphygmomanometer (Omron Digital Blood Pressure Monitor HEM-712C), with participants seated in a quiet location in a chair with back support. Three readings will be taken with a 5-

minute interval between each. If the difference between the 2nd and 3rd readings is more than 10mmHg, a fourth reading will be taken. The mean value between the two closer measurements will be used as the final value.

### HEIGHT

To measure height, a tape measure will be secured to a smooth surface at a  $90^{\circ}$  angle to the floor, using a plumb line to ensure the tape is exactly vertical. A drafting triangle will be used to identify  $90^{\circ}$  surfaces. Study participants will be asked to remove their shoes and ensure their hair is flat. They will then be measured standing with their back against the tape measure, their knees touching with heels together and feet a  $60^{\circ}$  angle apart, their palms in, and their chin slightly up. Measurements will be taken taking twice. If the difference between readings is more than 0.5 cm a third measurement will be taken. The mean value between the two closer measurements will be used as the final value. All measurements will be taken at the campaign sites.

### HIP AND WAIST

To measure hip circumference, participants will be asked to remove their shoes and stand with their arms at the sides, palms facing inward, their feet together with heels touching and the external third of the feet at a  $60^{\circ}$  angle. The hip measurement will be taken around the most prominent lateral part of the hip, which is identified by asking the participant to flex the hip joint. To measure waist circumference, participants will be asked to stand in the same position with arms held out. Waist measurements will be taken around the most prominent part of the abdominal wall (usually, at the level of the navel). Both measurements will be taken twice. If the difference between the readings was more than 0.5cm, a third measurement was taken. The mean value between the two closer measurements will be used as the final value. All measurements will be taken at the campaign sites.

### WEIGHT

Weight will be measured in kilograms using a digital scale (Tanita: Glass Bathroom Scale HD-380) with a maximum capacity of 150 kg. The scale will be placed on the floor on a smooth horizontal surface, and subjects will be asked to remove their shoes before stepping on the scale. Two readings will be taken. If there is greater than a 0.5kg difference between the two, a third reading will be taken. The mean value between the two closer measurements will be used as the final value. All measurements will be taken at the campaign sites.

Participation in the Questionnaire is expected to take 15 minutes, while participation in the Anthropometry and Blood Pressure Measurement is expected to take 45 minutes.

Why are you chosen to participate in this research?

# ETHICAL CONSIDERATION

Research team members adhere to strict ethical standards in all research performed. During data collection, processing and storage, strict ethical standards will be followed. All participants will be briefed on their participation in the research and requested to provide written informed consent prior to data collection. Confidentiality of responses will be assured. Only the research team will have access to identifying information. Participants have the right to choose if they want to participate and they will not be discriminated against if they refuse to participate. All participants will be asked if they have any questions or concerns about the study.

As ethical issues come to the fore where human participants are involved, efforts will be made to ensure that the following principles are taken into consideration:

### INFORMED CONSENT AND VOLUNTARY PARTICIPATION

Informed consent will be obtained from research participants before the commencement of the research. Either written or verbal informed consent will be obtained from each of the participants. Verbal consent (where the participant is illiterate) will be obtained in the presence of a literate witness who will verify in writing and duly sign that informed verbal consent had been obtained.

Participants will be free at any time to withdraw their participation from the research project without having to face any negative consequences or disadvantages. Means will be in place to ensure informed consent and privacy on behalf of all respondents to prevent respondents from being persuaded or coerced to participate and to safeguard the interests of minors. Furthermore, a concerted effort will be made to ensure that no unrealistic expectations resulting from participation in the study are developed on behalf of the respondents. Researchers will also respect participants' rights to change their decision or withdraw their prior informed consent at any stage of the research without incurring any penalty whatsoever. It is an ethical imperative that the fieldworker/interviewer recognise and respect each person's choice to participate or not participate. To ensure the respect of the participant, the process of securing consent will be a gradual and emerging process where the respondent is capable of making an informed decision based on experience and information.

### DISCLOSURE

The participants involved in the study will be informed in advance that the researchers have a mandatory reporting obligation that is not dependent on their consent if issues of rape, assault and exploitative sex arise. These cases will be reported to the relevant authorities.

### COERCION AND PERVERSE INCENTIVES

Any kind of coercion or issuing of perverse incentives is seen as a breach of ethical conduct and is deemed to be unethical research. For this reason, researchers will ensure that no undue incentives are provided to those who consent to take part in the study. Prospective participants will neither be intimidated nor compelled to take part in the research.

### PRIVACY AND CONFIDENTIALITY

The research team will keep the personal information gathered from the participants private and confidential by keeping the names of participants anonymous in the reports and publications.

### AVOIDANCE OF HARM OR NON-MALEFICENCE

In this research, the team will carry the onus of ensuring the dignity and the physical and emotional safety of all participants during the research process and evaluation. The evaluation will not evoke any emotional distress requiring counselling.

### STORAGE OF DATA

All identifying information will be kept in a locked file cabinet on the premises of a secure facility and will not be available to others. Only research team members will have access to the data and the data must be checked out and checked back in through the principal investigator anytime the data is accessed. All records relating to the participants will be shredded after 5 years.

# RESULTS

If you would like to receive feedback on our study, we will record your phone number on a separate sheet of paper so we may send you the results of the study when it is completed in approximately six months. Otherwise, study results will be distributed to the district and presented to the community in an oral presentation and the conclusion of the study.

# COMPLAINTS

Should you have any concerns or complaints about the conduct of the project, you are welcome to contact the Prof Peter Nyasulu.

## **Appendix 3: Consent Form**

#### Who we are

Hello, I am .....and I am working on a study by Monash University School of Public Health and Community AIDS Response

#### What we are doing

We are conducting a research study on the perceptions of risk to non-communicable diseases among overweight and obesity individuals living in informal settlements in Johannesburg, South Africa. The study will involve residents in informal settlements.

### YOUR PARTICIPATION

Prior to reviewing this consent form, you should have read an explanatory statement that outlines the details fo the study. We are asking you to give consent to voluntarily participate in a focus group discussion or questionnaire where you will be requested to share your knowledge and opinions about non communicable diseases. A focus group is when people sit together and discuss their general opinions on a topic and a researcher records or keeps notes about the points made during the discussion. If you agree, this discussion will last for approximately one hour. We are also asking you to give us permission to tape record the discussion. We tape record interviews so that we can accurately record what is said. If you are asked to participate in the questionnaire you should be prepared to spend about 30 minutes filling out 53 multiple choice questions regarding menstrual hygiene.

Please understand that **your participation is voluntary** and you are not being forced to take part in this study. The choice to participate or not participate in the study **lies with you**. If you choose not to take part, this will not affect you in any way whatsoever. If you agree to participate, you may stop participating in the research at any time and inform the facilitator you do not want to continue. If you do this, there will be no penalties for you in ANY way.

### CONFIDENTIALITY

Although the research team will adhere to confidentiality and ensure anonymity of the data and reports, the team cannot guarantee that other participants will regard the information as confidential, but they will be urged to do so. You are therefore advised to not give information on any personally sensitive topics. Any study records that identify you will be kept confidential to the extent possible by law. The records from your participation may be reviewed by people responsible for making sure that the research was done properly, including members of the research ethics committee (All of these people are required to keep your identity confidential).

Otherwise, records that identify you will be available only to people working on the study, unless you give permission for other people to see the records.

The information you provide will not be published unless you give your specific permission in writing at the end of this consent form. All identifying information will be kept in a locked file cabinet and will not be available to others. All records relating to your participation will be destroyed after 5 years. We will refer to you by a code number or pseudonym (another name) in any publication.

### DISCLOSURE

Researchers have a mandatory reporting obligation which is not dependent on your consent if issues of rape, assault and exploitative sex arise. These cases will be reported to the relevant authorities.

### RISKS/DISCOMFORTS

At the present time, we do not see any risks in your participation. The risks associated with participation in this study are no greater than those encountered in daily life.

### BENEFITS

There are no immediate benefits to your participation in this study. However, this study will be extremely helpful in promoting an understanding of the practices associated with non-communicable diseases and hence influence policies and programmes in favour of girls in this country.

If you would like to receive feedback on our study or, if applicable, review the interview transcript, we will record your phone number on a separate sheet of paper so we may send you the results of the study when it is completed in approximately six months.

If you have concerns or questions about the research you may call the project leaders at CARe by dialing 011 728 0218.

### CONSENT

I have read the explanatory statement and I hereby agree to participate in the research study concerning factors affecting non-communicable diseases in South Africa. I understand that I am participating freely and not being forced to participate in any way. I also understand that I can stop participating at any point should I not want to continue and that this decision will not have any negative consequences.

I understand that this research project is not intended to benefit me personally in the immediate or long term future.

I understand that my participation will remain confidential.

••••••

Signature

Date: .....

I hereby agree to the tape-recording of my participation in the study if I participate in the focus group or key informant interview.

APPENDIX 4: TIME-TABLE

#### Table 15: Time-plan for completion of research report by 26 September 2014

	20/07/2014	27/07/2014	03/08/2014	10/08/2014	17/08/2014	24/08/2019	31/08/2020
Finalise proposal							
Gain approval							
Training Field Staff							
Data Collection							
Data Analysis							
Write Report							
Finalise report							

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