

# **The emotional experiences of participants in a cardiovascular research study**

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It all starts here <sup>TM</sup>



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## Summary

In recent times, the World Health Organisation (WHO) has recommended health programmes and interventions for the management and control of various risk factors of cardiovascular disease. This gave rise to an increasing amount of health research being conducted globally and in South Africa, but the psychological impact of the health research programmes has hardly been explored.

Globally, there is a wealth of research being conducted on the psychological effects, including the emotional experience of participants attending medical screening or health screening, as the experience at screening may influence future health behaviour. However, there is a lack of research being performed on the emotional experiences associated with taking part in health research. While the aim of medical screening is the clinical diagnosis of disease, the aim of health research is often not to diagnose a disease, but rather to find the best way of disease prevention or management. However, the possibility that an overlap exists between the emotional experiences of medical screening and health research should be investigated.

Emotional experience refers to the emotions or emotional reactions the participants go through before, during and after a health research process. The importance of a person's emotional experience of a health research process cannot be overlooked, as it has the potential of posing an ethical dilemma when people who perceive themselves as healthy, may be told they are potentially ill. This can occur in health research, although the aim in this study is not to include any clinical diagnosis or reference thereof, but participants might still be expectant of obtaining such information when going through a health research process.

What individuals perceive as emotional experiences, are seen as valid reflections of their subjective understanding of their emotions. Contradicting evidence exists regarding the psychological impact that screening and health research has on participants; where some research indicate that participants experienced adverse consequences, such as anxiety and depression, other studies do not report any adverse consequences and rather highlight the benefits of health screening. Additionally, a great number of research studies indicate short-term adverse consequences, whilst others report no long-

term impact of health screening. Much less literature, especially in the South African context, could be found regarding the emotional impact of participating in medical screening and in particular in health research screening programmes.

Thus the aim of the study was to explore the emotional experiences of participants who took part in the African-PREDICT health research process. A qualitative research method with a descriptive approach was used. Sixteen participants (n=16) were recruited and took part in the study. Data were collected through semi-structured interviews, which were transcribed and analysed by means of inductive thematic analysis using Grounded Theory.

Four main themes were identified: 1) Primary emotional experience; 2) Secondary emotional experience; 3) Emotion linked to the research process; and 4) Impact of emotional experience on perception. The findings firstly indicate that the most prominent primary emotion describing participants' overall experience of the health research process was happiness. Secondly, participants experienced specific emotions, of which comfortability (level of emotional comfort) and irritability were mostly expressed. The third theme reflected emotions experienced by the participants before, during and directly after the health research process. Lastly, there were various aspects which had an impact on the participants' perception of the health research process, including past screening experiences, previous health scares, adverse consequences of the use of various instruments, and the experience of good service during the health research process. This study has therefore provided additional information on how participants experience cardiovascular research and could inform ways to improve emotional support of participants during the health research process to meet ethical and moral obligations and to promote the participant returning for follow-up visits.

**Keywords:** Cardiovascular research, emotional experience, health research, psychological impact

## Opsomming

Die Wêreldgesondheidsorganisasie (WGO) het in die afgelope tyd gesondheidsprogramme en -intervensies vir die bestuur en beheer van verskeie risikofaktore van kardiovaskulêre siekte aanbeveel. Met die gevolglike toename in gesondheidsnavorsing wat wêreldwyd en in Suid-Afrika gedoen word, is die psigologiese impak van gesondheidsnavorsingsprogramme nog skaars ondersoek.

’n Rykdom van navorsing is wêreldwyd uitgevoer op die psigologiese effekte, wat die emosionele ervaring van deelnemers wat mediese sifting of gesondheidssifting bywoon insluit, aangesien die ervaring by sifting toekomstige gesondheidsgedrag mag beïnvloed. Aan die ander kant is daar ’n tekort aan navorsing wat op die emosionele ervarings wat met die deelname aan gesondheidsnavorsing geassosieer word, gedoen is. Terwyl die doel met mediese sifting die kliniese diagnose van siekte is, is die doel van gesondheidsnavorsing dikwels nie om siekte te diagnoseer nie, maar eerder om die beste manier vir siektevoorkoming of -bestuur te vind. Tog moet die moontlikheid dat daar oorvleueling bestaan tussen die emosionele ervarings van mediese sifting en gesondheidsnavorsing ondersoek word.

Emosionele ervaring verwys na die emosies of emosionele reaksies wat die deelnemers ervaar voor, gedurende en na ’n gesondheidsnavorsingsproses. Die belangrikheid van ’n persoon se emosionele ervaring van ’n gesondheidsnavorsingsproses kan nie misgekyk word nie, aangesien dit die potensiaal het om ’n etiese dilemma te skep wanneer mense wat hulself as gesond beskou, meegedeel kan word dat hulle potensieel siek is. Dit kan in gesondheidsnavorsing gebeur, alhoewel die doel van hierdie studie nie is om enige kliniese diagnose of verwysing daarna in te sluit nie, alhoewel deelnemers steeds die verkryging van sulke inligting mag verwag wanneer hulle deur ’n gesondheidsnavorsingsproses gaan.

Wat individue as emosionele ervarings beskou, word gesien as geldige refleksies van hulle subjektiewe begrip van hulle emosies. Daar bestaan teenstrydige bewyse met betrekking tot die psigologiese impak wat sifting en gesondheidsnavorsing op deelnemers het; terwyl sommige navorsing aandui dat deelnemers ongunstige gevolge soos angs en depressie ervaar, ander studies rapporteer nie enige ongunstige gevolge nie en fokus eerder op die voordele van gesondheids-sifting. Bykomend daartoe, toon ’n groot aantal navorsingstudies korttermyn ongunstige gevolge, terwyl ander geen langtermyn

impak van gesondheidsifting kan bewys nie. Veel minder literatuur, veral in die Suid-Afrikaanse konteks, kon gevind word met betrekking tot die emosionele impak van deelname aan mediese sifting en spesifiek in gesondheidsnavorsingsiftingsprogramme.

Daarom was die doel van die studie om die emosionele ervarings van deelnemers wat deelgeneem het aan die “African-PREDICT” gesondheidsnavorsingsproses te verken. ’n Kwalitatiewe navorsingsmetode met ’n beskrywende benadering is gebruik. Sestien deelnemers (n=16) is gewerf en het deelgeneem aan die studie. Data is versamel met behulp van semi-gestruktureerde onderhoude, wat getranskribeer en geanaliseer is aan die hand van inductiewe tematiese analise deur gebruik te maak van Gegronde Teorie.

Vier hoofemas is geïdentifiseer: 1) Primêre emosionele ervaring; 2) Sekondêre emosionele ervaring; 3) Emosie gekoppel aan die navorsingsproses; en 4) Impak van emosionele ervaring op persepsie. Die bevindings dui in die eerste plek aan dat die mees prominente primêre emosie wat die deelnemers se algehele ervaring van die gesondheidsnavorsingsproses gekenmerk het, geluk was. Tweedens het deelnemers spesifieke emosies ervaar, waarvan gemaklikheid (vlak van emosionele gemak) en geïrriteerdheid die meeste aangetoon is. Die derde tema het op ervaarde emosies deur die deelnemers voor, tydens en direk na die gesondheidsnavorsingsproses gereflekteer. Laastens was daar verskeie aspekte wat ’n impak op die deelnemers se persepsie van die gesondheidsnavorsingsproses gehad het, wat vorige siftingservarings, vorige gesondheidskrikmaakervarings, ongunstige gevolge van die gebruik van verskeie instrumente en die ervaring van goeie diens tydens die gesondheidsnavorsingsproses insluit. Hierdie studie het dus addisionele inligting produseer aangaande die wyse waarop deelnemers kardiovaskulêre navorsing ervaar en kan inligting verskaf op wyses waarop die emosionele ondersteuning van deelnemers tydens die gesondheidsnavorsingsproses verbeter kan word om etiese en morele verpligtinge na te kom en om die deelnemers se terugkeer vir opvolgbesoeke te bevorder.

**Sleutelwoorde:** Kardiovaskulêre navorsing, emosionele ervaring, gesondheidsnavorsing, psigologiese impak

## **Preface**

This mini-dissertation is presented in article format as described in the Manual for Postgraduate studies and in the rules A 5.4.2.7 as prescribed by the North-West University.

The article will be submitted for possible publication to the Journal of Health Psychology.

This mini-dissertation is presented in accordance with the American Psychological Association (APA) Publication Manual (6th edition) referencing and editorial style for examination purposes. However, the article is presented in accordance with Harvard referencing style, as indicated by the Journal of Health Psychology.

Dr. A. Bonthuys and Dr. L. Ware, co-authors of the article in this dissertation, have provided consent for the submission of this article for examination purposes in partial fulfilment of the MA Counselling Psychology degree.

The mini-dissertation was sent to Turn-it-in and the report was within the norms of acceptability.

### Letter of permission

The student is hereby granted permission to submit her mini-dissertation for the purpose of obtaining a MA degree in Counselling Psychology. The student's work has been submitted to Turn-it-in and a satisfactory report has been obtained.

Supervisor:

A handwritten signature in black ink, appearing to read 'Annelize Bonthuys', written in a cursive style.

Dr Annelize Bonthuys

Co-supervisor:

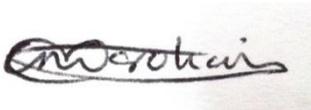
A handwritten signature in black ink, appearing to read 'Lisa Ware', written in a cursive style.

Dr Lisa Ware

### Solemn Declaration

I, Caroline Marokane, declare herewith that the mini-dissertation entitled, The emotional experiences of participants in a cardiovascular research study, which I herewith submit to the North-West University, Potchefstroom Campus, in compliance with the requirements set for the MA in Counselling Psychology degree, is my own work, has been language edited and has not already been submitted to any other university. I understand and accept that the copies that are submitted for examination are the property of the University.

Signature of student:



.....

Caroline M Marokane

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## **Section 1: Introduction, Problem Statement and Aims**

### **Introduction**

It has been well-established that the prevalence of cardiovascular disease in sub-Saharan Africa is on the rise (Nkosi & Wright, 2010). Risk factors such as smoking, obesity, diabetes and hypertension all contribute to cardiovascular disease. According to Hendriks et al. (2012), hypertension in particular is the most frequently observed risk factor for cardiovascular disease in both urban and rural communities in sub-Saharan Africa. This condition is a non-communicable chronic disease that is found globally (Gaziano, Bertram, Tollman, & Hofman, 2014). With a 77,9 % prevalence rate in people above the age of fifty, hypertension is continually contributing to the increasing cardiovascular mortality and stroke rate in South Africa (Lloyd-Sherlock, Beard, Minicuci, Ebrahim & Chatterji, 2014). In the year 2000, non-communicable diseases (NCD) caused 37% of all deaths and 21% of the premature mortalities in South Africa (Nkosi & Wright, 2010). More recently, the mortality rate caused by NCD in South Africa has increased to 43% (World Health Organisation [WHO], 2014).

Consequently, the World Health Organisation (WHO) has recommended health programmes and interventions for the management and control of the various risk factors for cardiovascular disease. Risk factors include tobacco use, physical inactivity, an unhealthy diet and harmful alcohol use (World Economic Forum, 2011). These recommendations are to be introduced in Sub-Saharan countries like South Africa in order to help people manage their illness, and to adopt lifestyle practices to prevent the community from having cardiovascular diseases such as strokes and heart attacks, particularly in populations where economic resources are limited (Schutte, 2012). Thus, in order to determine the most effective and locally acceptable non-communicable disease prevention programmes, health research has been employed. With the increasing amount of health research being conducted in South Africa and globally, the psychological impact of these health research programmes has hardly been explored.

Globally, there is a wealth of research being conducted on the psychological effects, including the emotional experiences of patients attending medical screenings, and how these different emotional experiences could impact future health behaviour (Brett & Austoker, 2001; Scaf-Klomp, Sanderman, Van

de Wiel, Otter, & Van den Heuvel, 1997). However, there is a lack of research on the emotions experienced when taking part in health research and the impact this could have on future health behaviour, as compared to medical screening. The possible overlap of emotional experiences found in medical screening with that of health research screening processes, should therefore be investigated, especially since similar events are said to trigger similar emotions (Weiten, 2014).

### **Emotional experience**

Emotional experience refers to the emotions or emotional reaction the participants experience before, during and after a health research process. The importance of emotional experience cannot be overlooked in a health research process, as it has the potential of posing an ethical dilemma when people who perceive themselves as healthy, may be told they are potentially ill. This aspect is explored in more detail in section two of this study.

Subjective experience is central when defining the emotions of participants and how they feel (Ekman, 1992). Emotions are what affect one's every day experiences, and can be defined as an adaptive form of information-processing, which promotes a person's well-being (Greenberg, 2004). Emotions seem to have a motivational component for mental operations and manifest behaviour (Izard, 2009). Hence, it is evident that emotions involve coordinated changes across behavioural, experiential and physiological response systems (Mauss, Levenson, McCarter, Wilhelm & Gross, 2005). What individuals perceive as emotional experiences, are therefore valid reflections of their subjective understanding of these emotions.

Although there are numerous explanations of what emotions are, Weiten's (2014) definition of emotion is highlighted in this study. According to Weiten (2014), emotion is a subjective, conscious and personal experience accompanied by bodily arousal, followed by a behavioural component (Weiten, 2014). This definition is grounded in two theories. The conscious experience of emotion can be explained by the Cannon-Bard theory (Cannon, 1927), which argues that an emotion occurs when the thalamus sends signals to the cortex and autonomic nervous system simultaneously, and then the cortex creates the conscious experience of emotion (Weiten, 2014). Furthermore, bodily arousal can be illustrated through

the James-Lange theory (James, 1884; Lange & Kurella, 1887), which proposes that feelings of arousal cause emotions (Weiten, 2014). Although emotional feelings are consequences of neurobiology, it is also evident that it can be influenced by other factors, such as appraisals and non-cognitive processes (Izard, 2009).

Cognitive theories of emotion state that people's cognitive appraisals of the events in their lives are key determinants of the emotions that they experience (Izard, 1992; Weiten, 2014). For example, in this study the way people view and experience the health research process, will ultimately determine the emotions that they experience. Depending on previous health testing experiences, observing disease in family or friends and according to their own perceptions of risk, different people could view the health research process differently. There may also be mixed emotions, as the participants could perceive some aspects of the process as pleasant, whilst viewing other aspects as unpleasant. This may be as a result of one's cognitive schemas and/or affective feelings. According to Izard (2009), cognitive schemas are dynamic emotion-cognition interactions that consist of situational responding that emerges over developmental time. Affective feelings on the other hand, are said to be the pleasant or unpleasant experiential cues characterising moods and emotions (Gohm & Clore, 2000).

Ekman and Cordaro (2011) further separate and highlight basic emotions from other affective states, since these emotions are discrete, which means that it can definitely be distinguished from other emotions. Furthermore, basic emotions are said to be continuous across time and place (Levenson, 2011). There are six emotions termed as basic emotions, based on their universal applicability and innate neural substrates (Izard, 1992). These emotions are happiness, fear, sadness, disgust, anger and surprise and these emotions have been shown to be the most prevalent in studies conducted on emotion and its relatedness to health screening (Burger et al., 2014; Bynum, Davis, Green & Katz, 2012; Peckham & Dezateux, 1998). These basic emotions are mostly experienced as first line emotions, followed by other affective states (Ekman & Cordaro, 2011).

Weiten (2014) further found that similar types of events are said to trigger similar emotions across cultures. On the other hand, one cannot presume that every social context which calls for emotion

will be the same for all cultures (Ekman, 1992). Therefore, given the high level of NCD research taking place on the African continent, the researcher is interested in specifically investigating the emotional experiences of participants in cardiovascular health research within the South African context.

### **African-PREDICT, health research and screening**

This study investigated the emotional experiences of participants who were participating in the African Prospective research study on the Early Detection and Identification of Cardiovascular disease and hypertension (African- PREDICT) at the North-West University, Potchefstroom. African-PREDICT is a longitudinal cohort research study, in which hypertension screening is conducted every four years as part of an in-depth series of cardiovascular measures in participants aged 20-30 years, who are apparently healthy at baseline. The aim of the study is to identify predictors or early markers for the development of cardiovascular disease and hypertension in black and white South Africans (Schutte, 2012).

The African-PREDICT research process allows one to have a detailed feedback on the participants' cardiovascular health profiles, enabling them to make the necessary lifestyle changes, thus focusing on the medical and physical factors that are related to hypertension (Schutte, 2012). Although the African-PREDICT research process includes a battery of psychological questionnaires to determine the psychological functioning of the participants in terms of identifying psychological wellbeing and psychopathology, there is currently no investigation into the emotional experience of the participants while taking part in the research process itself.

While the African-PREDICT study is mainly focused on health research, a medical screening component forms part of the baseline visit, initial recruitment and stage one of the study. Research found that medical screening and health research are similar, as they conduct tests on apparently healthy people to identify those at an increased risk of a disease (Grimes & Schulz, 2002). Different emotional experiences have been shown to arise during such screenings, including fear when the various tests are conducted more frequently, which may in turn lead to possible adverse consequences such as anxiety (Considine, Morgenstern, Kudadjie-Gyamfi, Magai & Neugut, 2006). Knowledge of these emotional experiences may also be important for participants undertaking health research studies that require more

than one visit, as is often the case with longitudinal health research. This was illustrated in a study conducted in the Limpopo province of South Africa, in which newly diagnosed hypertensive patients experienced psychological and emotional stress coupled with anxiety (Mothiba, Malema, & Lekhuleni, 2013).

Literature in the medical environment is available, but in the research setting it is scant. Therefore, while there is a difference between testing employed in healthy people in research studies, such as African-PREDICT, and testing employed in clinical practice to investigate, diagnose or manage conditions, it is important to understand the emotional impact of testing on the individual in general.

### **Problem Statement**

It is evident that there are many factors which influence the emotional experience of participants before, during and after health research processes. Despite the growing number of screening programmes and health research in South Africa, as yet limited research has been undertaken to look at the emotional impact of those programmes on the participants (Mothiba et al., 2013). Furthermore, the contribution of psychological aspects and emotional reactions to screening behaviour seem to be unclear (Absetz, Aro, & Sutton, 2003; Consedine, Magai, & Neugut, 2004).

One study showed that people who were found to be hypertensive in a workplace screening programme, had increased anxiety, increased sickness absence and a reduced self-perceived health status (Peckham & Dezateux, 1998). Also, a systematic review of 54 studies examining the psychological impact of predicting an individuals' risk of illness, concluded that 'adverse psychological effects are a common immediate consequence of positive test results' (Goyder, Barratt & Irwig, 2000, p.124). In contrast, there are various studies that also concluded that screening does not lead to adverse psychological effects. A study, which was conducted in America, suggested that many participants experienced psychological benefits from hypertension screening, with no increase in anxiety (Fravel, Ernst, & Bergus, 2010).

Despite contradictory evidence on how emotion affects a person's screening behaviour, these psychological factors are surely present when an individual participates in a screening programme or in

health research. Studies in relation to medical screening have been conducted in several parts of the world, but evidence regarding the effects of health research is lacking (Daniels et al., 1999; Kagee, 2010). Based on the literature review, it appears that a study of this nature has not previously been conducted within South Africa, especially in relation to cardiovascular health research. This study is therefore one of the first to investigate from a qualitative perspective South African participants' emotional experiences when participating in a cardiovascular health research study.

### **Aim of the Study**

The aim of this study is to investigate and explore the emotional experiences of participants who participated in the baseline measurement of the longitudinal African-PREDICT cardiovascular research study. It is anticipated that the findings may generate new knowledge of emotional factors, thus contributing to perceptions of health research. Furthermore, this may inform the way in which future screening and health research programmes could be conducted in order to also provide psychological (emotional) support to participants, before, during and after the said screening and research processes. This should be done to promote the ongoing engagement of participants with health services, screening and research.

### **Outline of the Manuscript**

Section 1 provides an overview of the literature review and theoretical framework that forms the basis and background of the study. Section 2 presents the manuscript, written in article format, addressing the aims of the study through discussion of methodology, findings and conclusion, as well as the author guidelines for submission to the Journal of Health Psychology for possible publication. Section 3 provides a critical reflection on the study and a discussion of the study's research contributions towards academic literature.

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## Section 2: Article

### Guideline for authors: Journal of Health Psychology

#### Instructions to authors

##### *Article length and house style*

Articles should be as short as is consistent with clear presentation of subject matter. There is no absolute limit on length but 6,000 words, including footnotes and reference list, is a useful maximum. Longer articles will be considered at the discretion of the Editor. Harvard referencing is used as the house style.

##### *Article format*

*Authors and affiliations.* List authors in the order that they appear on the manuscript. Authors' first name should be in full, middle names should be initials *without* full stops (e.g. Simon PS Sharma) and no spaces between multiple initials. No series comma before the 'and' before the final author name. Affiliations should contain only the following: department *or* faculty, institution, country.

*Title.* The title should indicate exactly, but as briefly as possible, the subject of the article. Please format with an initial capital only and remaining words lower case, unless proper names. Italics can be included where necessary (e.g. genus name). Run on subtitle after colon, with initial capital after colon. It is essential that your literature review is completely up to date. Please check recent issues of the Journal of Health Psychology and other key journals to ensure that any relevant papers are cited. Papers that fail to do this will be rejected.

*Abstract.* An Abstract should be at the start of the manuscript and not exceed 100 words (in spite of what is stated on the ScholarOne website) accompanied by five keywords should be selected from the list provided on the JHP ScholarOne website. The abstract should appear in bold without a colon, text should start on the next line, with no indent.

*Keywords.* (All one word) should appear in bold without a colon. The keywords should start on the next line, separated by commas only, not semi-colons. The first keyword should have an initial cap.

*Headings.* 1. Headings should have an initial capital with everything else lowercase, unless proper names. 2. Italics can be included in A heads (H1) if needed, e.g. mathematical symbol or genus name. 3. Headings are unnumbered and formatted. 4. Where headings are referred to in the text use section names, as headings are not numbered.

*Tables.* Tables and figures count as 500 words each which should be attached as separate pages at the end. "INSERT HERE" signs should be noted within the text. All tables should be numbered consecutively and cited in the text as Table 1, Table 2 etc. (Table should be spelled out in full, not abbreviated). Spellings and punctuation in quoted texts should not be altered. If they are obviously incorrect, query with author or insert [sic]. Tables should only have minimal horizontal rules for clarity, and no vertical rules. Tables do not need to be a full column width or page width, but should be the appropriate width for the content.

*References.* References are not numbered but appear in alphabetical order by first author surname.

*Appendices.* Numbering of figures/tables/equations in Appendices should follow on from the numbering in the text. All tables/figures should have captions. All appendices should be cited in the text, e.g. (see Appendix 1). If they are not cited, authors need to be queried for a citation position.

*Acknowledgements.* Any acknowledgements should appear first at the end of your article prior to your Declaration of Conflicting Interests (if applicable), any notes and your References.

Article

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## The emotional experiences of participants in a cardiovascular research study

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### Abstract

There is a growing burden of hypertension and subsequently hypertension research on the African continent. To determine participants' emotional experience of health research, a qualitative study, including a purposeful sample (n=16 adults; North West province, South Africa), was conducted. Thematic analysis of semi-structured interviews revealed four main themes: primary and secondary emotional experiences; emotional experiences linked to the research process; and finally, impact on perception based on the interaction between emotional experience and cognitive schemas. This study highlights the importance of emotional support for participants during interaction with health research in order to support their ongoing engagement with health services.

### Keywords

Cardiovascular research, emotional experience, health research, psychological impact

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## The emotional experiences of participants in a cardiovascular research study

Non-communicable disease (NCD) and consequent NCD interventions and screening programmes are becoming ever more prevalent in sub-Saharan Africa (Mayosi et al., 2009; Nkosi & Wright, 2010; WHO, 2014). According to the World Health Organisation (WHO), screening is implemented to discover those who have a disease, even if they seemingly appear well (Wilson & Jungner, 1968). While a multitude of health screening programmes are conducted globally, the psychological and emotional impact of these on participants has largely remained unquestioned.

Medical screening programmes and health research are similar in the respect that both may include testing on apparently healthy people to identify those at an increased risk of a disease (Grimes & Schulz, 2002). In South Africa, screening programmes indicating the prevalence of NCDs such as diabetes and hypertension, showed a relatively high incidence of these NCDs among people with psychological distress (Sorsdahl et al., 2016). This indicates a greater need to understand the impact of screening or research on the participant, through investigating how participants experience these situations or events. The focus of the current study is not on one single reality of the experiences of participants during a health research study, but rather on multiple realities punctuated from the possible emotional experience of the participants going through a health research process (Edwards, Duff & Walker, 2014).

Emotional experience refers to the emotions or emotional reactions participants experience before, during and after the health research process. Happiness, fear, sadness, disgust, anger and surprise are basic emotions evident in most of the studies conducted on emotional experience and its relatedness to international health interventions (Burger et al., 2014; Bynum et al., 2012; Peckham & Dezateux, 1998). However, evidence from the African continent relating to the emotional experiences of participants during health research and interventions are scant (Mothiba et al., 2013). Emotional experience could be ascribed to the cognitive appraisals of events in people's lives, which are key determinants of the emotions they experience during these events (Izard, 1992; Weiten, 2014). Experiences may stem from the understanding that hypertension is said to be a chronic disease that can only be controlled, but not healed (Mothiba et al., 2013). Cognitive appraisals are also influenced by individual differences, as people in the same situation can have different emotional experiences of that situation, due to the evaluation of what that experience implies for their personal wellbeing (Smith & Lazarus, 1990).

There appears to be conflicting evidence regarding the emotional experience of people when participating in various forms of health and medical screening. The most prevalent experience seems to be either an increase or reduction in anxiety (Ginty, Carroll, Roseboom, Phillips & De Rooij, 2013; Wu, Prosser & Taylor, 2010). However, several studies found that screening does not necessarily lead to adverse psychological effects, for example a study of breast cancer screening did not show any changes in

participants' anxiety levels (Bickler, Hunter, Saidi & Sutton, 1995). Furthermore, a recent study conducted in America suggested that many patients experienced psychological benefit following hypertension screening, for example motivation to adopt lifestyle changes, again with no increase in anxiety (Fravel et al., 2010).

In contrast, other studies have found that health and medical screening do have short-term adverse effects, although long-term effects on emotional functioning of participants have not been indicated (Broadstock, Marteau & Michie, 2000; Collins, Lopez & Marteau, 2011; Ebrooll et al., 2007; Shaw, Abrams & Marteau, 1999). It therefore appears that health and medical screening may have adverse effects on a person's emotional experience, but it is often not a lasting effect.

The perceptual view of participants also plays an important role. Izard (2009) stated that this is due to the way in which emotions can be influenced by cognitive appraisals and non-cognitive processes. Absetz, Aro and Sutton (2003) proposed that having a family history of a disease may influence the impact of screening on a participant's emotional experience. A further study on participants undergoing pre-screening of breast cancer indicated that the experience of a screening process can also create health-awareness, therefore participants are inclined to take part in further screening tests (Absetz et al., 2003). It was however found that although the intention of participating in further screening processes may be high, the subsequent attendance is much lower (Brett, Bankhead, Henderson, Watson & Austocker, 2005).

The frequency of screening and health research is increasing and alongside it, the possible ethical dilemmas that can arise (Delatycki, 2012). These include issues related to consent for screening (such as when people cannot make informed decisions about their participation due to not receiving or understanding the detailed information about the process), receiving a false negative or false positive result (which can lead to further unnecessary tests or inappropriate medication use), and the impact that the screening has on the individual (such as anxiety) (Delatycki, 2012). Thus, the emotional impact of medical screening and health research requires investigation, especially considering the growing number of screening programmes and health research studies being conducted in Sub-Saharan countries such as South Africa. The cardiovascular health research programme being studied incorporates both health screening (to identify healthy research participants) and subsequent longitudinal cardiovascular health research, which presents a unique opportunity to evaluate the effects of these processes on participants' emotional experiences within South Africa. Therefore, our core research question is: What are the emotional experiences of participants who participated in a multiphasic health screening and cardiovascular health research process?

According to the WHO (2014), multiphasic screening occurs when two or more screening tests have been administered to a large group of people. This cardiovascular screening and subsequent research process is conducted in an apparently healthy community, raising an ethical responsibility for researchers

to ensure that the psychological impact of screening is not potentially harmful to the participants involved. As the medical screening literature has identified both positive and negative psychological effects of screening, this study will focus on exploring the potential psychological impact in terms of the emotions participants experience throughout the health screening and research process.

The aim of this study is therefore to gain new knowledge on how participants emotionally experience screening and health research in the South African context. The rationale is to explore and expand on the little research undertaken, that look at the psychological impact of the growing amount of screening programs and health research, which aim to prevent the onset of numerous diseases in South Africa (Mothiba, Malema, Lekhuleni, 2013). The gained insights could provide guidance for future screening and health research programmes with regards to emotional support of participants before, during and after the process and could promote continued participant engagement in health services and research.

## **Methods**

### *Design*

A descriptive, qualitative research design was used to identify, analyse and report patterns within the data (Dawson, 2009; Terre Blanche, Durrheim & Kelly, 2006; Elliot & Timulak, 2005; Vaismoradi, Turunen & Bondas, 2013). The design will be descriptive as it is found to be most appropriate for identifying, analysing and reporting patterns within the data for the current study (Vaismoradi, Turunen & Bondas, 2013). Data were collected by means of semi-structured interviews. Different aspects, patterns, ideas and themes of participants' emotional experiences of the health research process were identified, decoded and described (Cooper & Schindler, 2006; Elliot & Timulak, 2005). The researcher adopted a Grounded Theory Lite perspective, through linking results to cognitive theories of emotion for the purpose of gaining new knowledge (Weiten, 2014).

### *Theoretical framework*

Cognitive theories of emotion state that people's cognitive appraisals of the events in their lives are key determinants of the emotions that they experience (Weiten, 2014). Although participants in this study experienced a similar process, the cognitive appraisal of the process varied due to unique individual circumstances. In other words, if a person in this study appraises his or her relationship to the health research process in a certain way, whether positively or negatively, then a specific emotion associated with the appraisal pattern will follow (So, Kuang & Cho, 2016).

### *Participants and context*

A purposive sample (Marshall, 1996; Small, 2009) of sixteen (N=16) participants, who completed the baseline visit and were screened and found to be eligible for inclusion in the cardiovascular research, took

part in this study. Data saturation was reached at sixteen participants as no new themes emerged (Charmaz, 2006). The sample consisted of both male (n=6) and female (n=10) participants.

#### *Procedure and ethical issues*

Ethical approval was obtained from the Health Research Ethics committee (HREC) of the North-West University (Potchefstroom Campus) (Reference: NWU-00190-15-S1), which conformed to the ethical guidelines of the Declaration of Helsinki. The study furthermore adhered to the ethical guidelines and rules of conduct stipulated by the Health Professions Council of South Africa (HPCSA, 2006). All participants were assigned with a research number, which ensured confidentiality, anonymity and privacy (Cooper & Schindler, 2006). Further protection of participant privacy and anonymity were achieved by conducting interviews in a separate and private room.

All participants gave written informed consent prior to taking part in the study. Due to the nature of the research, namely exploring the emotional experiences of participants, referral to a psychologist was available if required. Trustworthiness for this research was accomplished by using the eight strategies suggested by Tracy (2010). The first strategy included how the researcher made use of a worthy topic by choosing a relevant topic within the South African context. Second, rich rigour was sought through the use of a monitoring plan to evaluate the data collection process and through the use of multiple data sources, such as semi-structured interviews and timelines. The third strategy included how rich rigour was achieved through ensuring that themes produced were a reflection of questions asked during the interview (transferability) and also through illustrating that if the study is repeated, in the same context, with the same methods and same participants, similar results would arise (dependability) (Vaismoradi, Turunen & Bondas, 2013). The fourth strategy ensured rich rigour (validity and reliability) was achieved through having research findings that are congruent with reality (credibility) (Shenton, 2004).

The fifth strategy was transparency. Transparency was illustrated by showing confirmability, which is the ability to show that the findings emerge from the data and not the researchers own predispositions (McGloin, 2008; Shenton, 2004). Sincerity was the sixth strategy which was obtained through triangulation to ensure further transparency and honesty in the findings (McGloin, 2008; Shenton, 2004). Continuous reflection was conducted with the supervisors of this study to reduce researcher bias.

Resonance was the seventh strategy and it is the way in which the research can meaningfully influence an audience (Tracy, 2010). The researcher will publish the study so that the study has a greater audience as the study does contribute to the understanding of participants' emotional experiences throughout a research process. Lastly meaningful coherence is another strategy identified by Tracy (2010). The researcher produced a meaningfully coherent study in which the study achieves its purpose and there is interconnectedness between the literature review and methods used.

### *Data Collection*

Data were gathered during individual, semi-structured interviews (Elliot & Timulak, 2005), which included a timeline (Berends, 2011; Deacon & Piercy, 2001). Participants were asked to complete the timeline of the health research process by writing down any thoughts or feelings about their experience in each phase of the process (Timm & Blow, 1999). One of the participants was illiterate, thus the researcher explained the timeline to the participant in detail and wrote down the participant's responses on the timeline. The researcher further checked that the information was correct by reading the information back to the participant.

After completion of the timeline, a list of basic emotions, found to be most frequently experienced as immediate adaptive reactions to events (Ekman & Cordaro, 2011), was given to the participants. The participants were then asked to answer seven questions with reference to the list of emotions (See Appendix 1). The questions were drawn up in an interview guide to assist the interviewer with sustaining focus on the aims of the study, whilst still providing enough room for the natural development and flow of the interview (Elliot & Timurak, 2005; Wilson & MacLean, 2011). The interviews were completed within 30 to 45 minutes and conducted in English and SeTswana. All interviews were recorded with the participant's consent and transcribed verbatim. The transcriptions included a detailed written account of the interaction between the researcher and the participants (Wilson & MacLean, 2011). The participants' completion of the timeline was not audio recorded, but the information was discussed during the interviews.

### *Data Analysis*

Data were analysed through thematic analysis using ATLAS.ti (ATLAS.ti, 2016). The researcher, together with the additional reviewers A and B, adhered to the six phases of data analysis, as stipulated by Braun and Clark (2006). Firstly, the researcher familiarised herself with the transcribed data and the data written on the timelines (by reading and re-reading the data for initial analytical observations). The data were then coded by the researcher, using grounded theory techniques to inform the coding (Charmaz, 2006). The approach can be termed Grounded Theory Lite, as the aim was to investigate the emotional experiences of participants and not to develop a theory (Braun & Clarke, 2006).

There seems to be no consensus regarding whether emotions and feelings are the same or different (Bosse, Jonker & Treur, 2008; Madell & Ridley, 1997; Perkins, 1966). The researcher therefore regarded both terms as relevant in addressing the aims of the study during thematic analysis and grounded theory application of using participants' own words to generate themes.

Lastly, the researcher searched for themes (in order to review similarities within the data). Reviewer A then checked the coding and themes. Thereafter, the researcher, reviewer A and B further reviewed, defined and named the themes. After this, the final report was produced (Braun & Clarke,

2006). Theoretical and narrative constructs were formulated (Auerbach & Silverstein, 2003; Braun & Clarke, 2006), and where appropriate, data were also analysed and presented as frequency distributions.

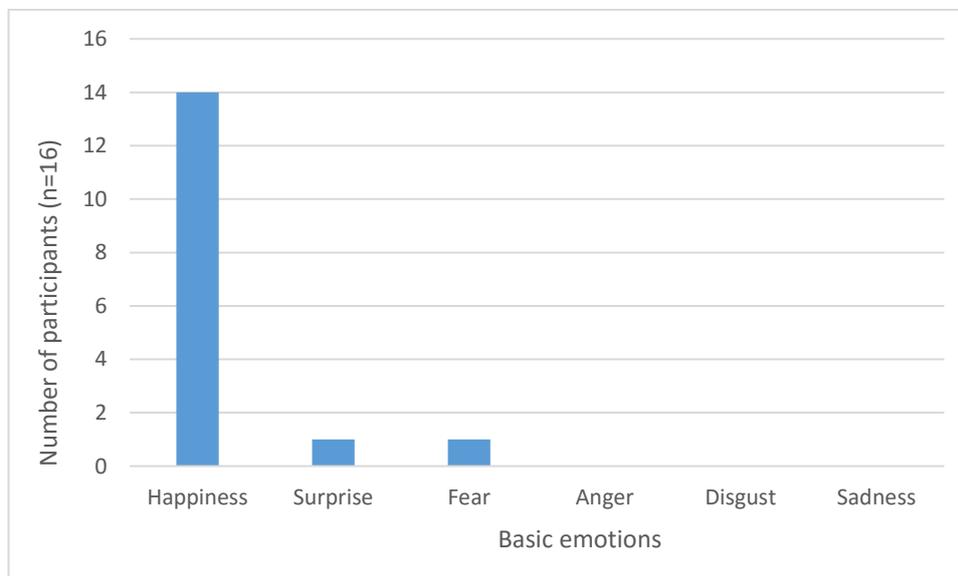
## Results

Four main themes, namely ‘primary emotional experiences’, ‘secondary emotional experiences’, ‘emotional experience linked to process’ and ‘impact on perception’ as well as subthemes emerged from the narratives (See Appendix 2) and data analysis. Each theme will be addressed separately and illustrated with supporting quotations from the participants.

“INSERT TABLE 1 HERE”

### *Theme 1: Primary emotional experience*

Participants’ initial thoughts about their emotional experience of the cardiovascular research process emerged from the list of basic emotions (See Figure 1):



*Figure 1: A bar chart of the frequency of the primary emotion experienced by each participant*

**Happiness:** The majority of participants (n=14) indicated that they experienced some form of happiness as primary emotion, when describing their overall emotional experience of the African-PREDICT research process. Participant 5 explained:

“I would say first of all happy. I think happiness because emm you know you don’t really get much time to go for check-up and stuff like that.”

Some of the participants related their happiness with health outcomes and excitement, by stating:

“I was happy because the screening was for my whole body”. (Participant 3); “Happiness is also part of the fact that it is like an adventure and it makes you happy”. (Participant 4).

Surprise: A feeling of surprise reportedly came from procedural aspects which Participant 7 discussed:

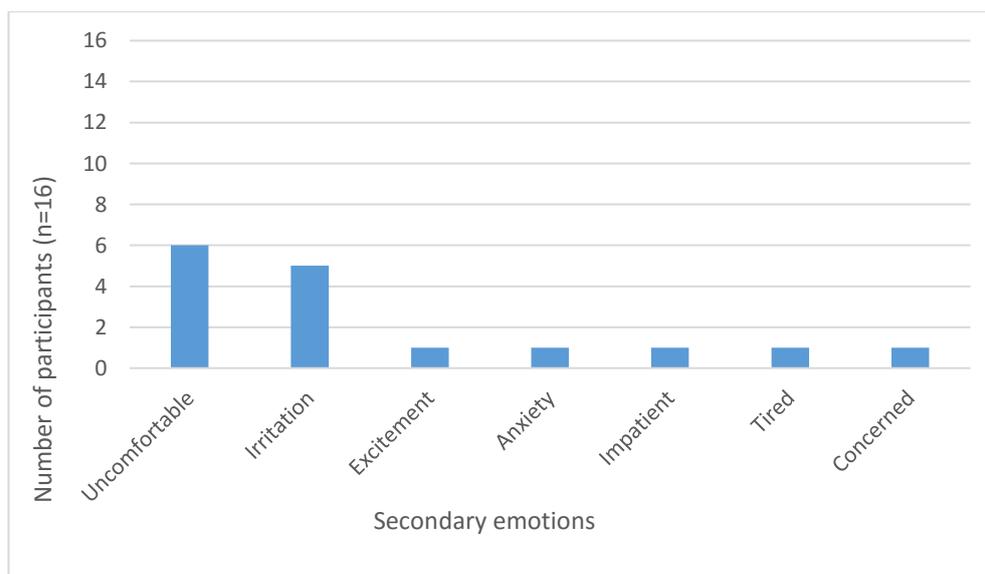
“I was surprised that the eye drops hurt as much as they did. So that was the only time. That and the hand in the ice bucket”.

Fear: The feeling of fear was reflected as:

“Emm a little bit of fear but that doesn’t come from the study just that needle just that prick. I’m not scared of needles but you know there’s just that thought of ag needles again”. (Participant 5).

### *Theme 2: Secondary emotional experience*

Participants elaborated on their primary emotional experiences throughout the research process and secondary emotional experiences emerged (See Figure 2):



*Figure 2: A bar chart of all secondary emotions experienced by all participants*

Uncomfortable: The most frequent secondary emotion expressed by six participants (n=6) was the feeling of being *uncomfortable* with various parts and/or the complete research process. To this regard, Participant 10 stated:

“...so you had to remove your top and your bra. It was just a bit uncomfortable but it is just because I am a shy person. I’m not very, like I don’t walk around for instance in my bra at home even, so I was just a bit uncomfortable”.

Another participant shared the experience of not feeling comfortable with the cardiovascular research process:

“Like I am not comfortable with my blood going out. It just I feel like I am more sensitive so I could feel it”. (Participant 7).

Irritation: Five participants (n=5) mentioned feeling *irritated*:

“The heart thing that I had to go home with, I didn’t like. It was itchy, it was just irritating, so I didn’t like that but other than that everything was okay”. (Participant 15); “Irritable because of that one of putting your hand in the ice and when they tested your eyes”. (Participant 11).

Various other emotional, psychological and physical effects of the process were expressed: *excitement* (n=1), *impatient* (n=1), *anxiety* (n=1), *concern* (n=1) and *being tired* (n=1).

### Theme 3: Emotional experience linked to process

Participants experienced similar emotions during the different stages of the cardiovascular research process, which they indicated on the timelines. These were grouped into emotional experiences before (See Figure 3.1), during (See Figure 3.2) and after the process (See Figure 3.3).

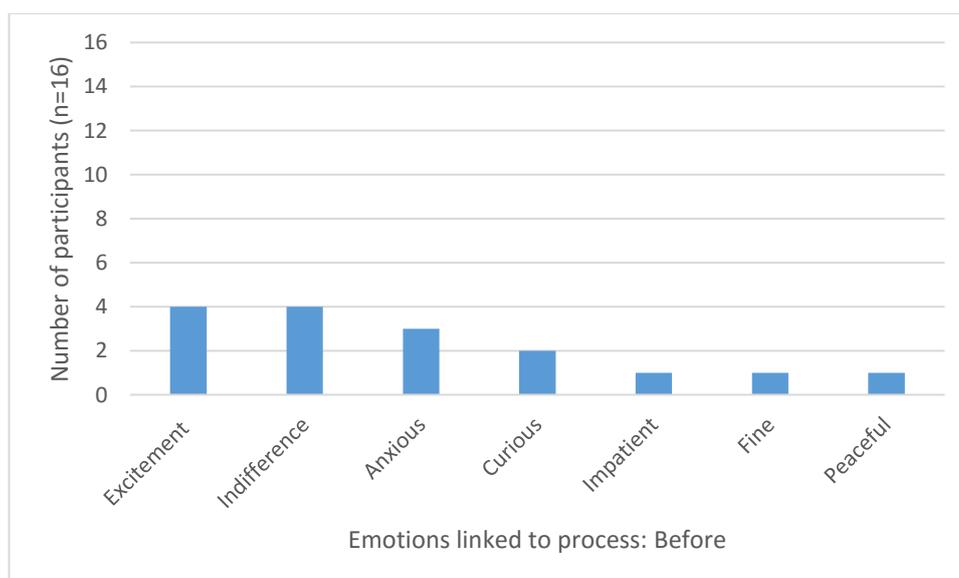


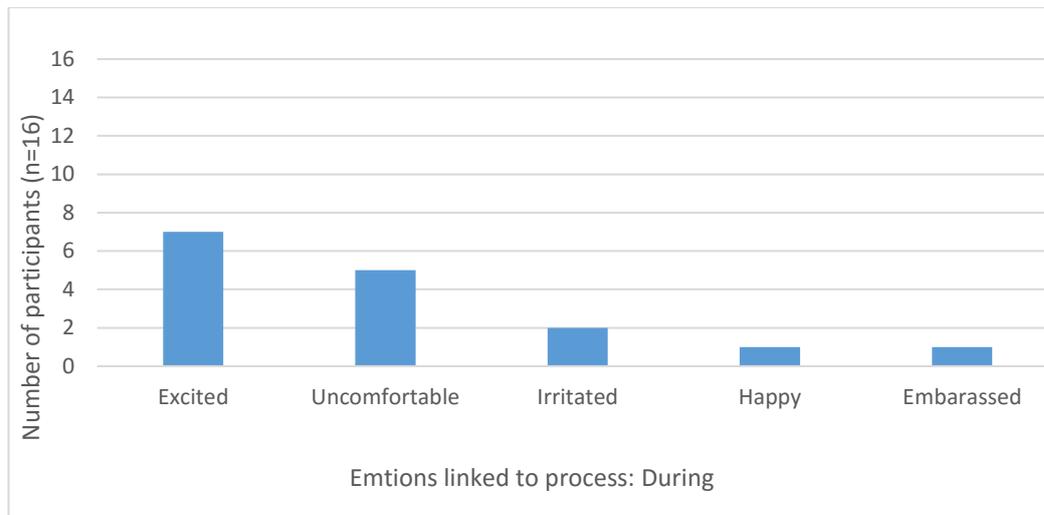
Figure 3.1: A bar chart of the emotional experience linked to process: Before (as the participants arrived at the venue, before orientation to the study)

**Excited:** Many participants were excited upon arrival for participation in the cardiovascular research. Four participants (n=4) in particular indicated being *excited*, which Participant 2 linked with feeling welcomed and appreciated by the friendliness of the research team.

**Indifference:** Four of the participants (n=4) felt indifferent towards the process and experienced it as nothing new (Participant 5).

**Curious:** Another two participants (n=2) reported that they were curious. Participant 7 wanted to know more about the research process itself; what would be expected and how would it be done.

**Anxious:** Three of the participants (n=3) were anxious. Participant 8 was particularly anxious about the possible pain that may be experienced.



*Figure 3.2: A bar chart of the emotional experience linked to process: During (as participants underwent various assessments such as blood and urine sample collection and anthropometric measurements)*

After commencement of the cardiovascular research process, the following emotions were reportedly experienced:

**Excited:** Seven participants (n=7) experienced excitement during the process. According to Participant 7 excitement was felt whilst viewing the participant's heart on the heart sonar for the first time.

**Uncomfortable:** Five participants (n=5) were more uncomfortable due to procedural aspects. Participant 2 elaborated on feeling uncomfortable with the burning sensation of the eye drops and the machinery cables.

**Embarrassed:** Participant 1 indicated a feeling of embarrassment about the comments of other people in the community about the various wearable devices they were expected to take home.

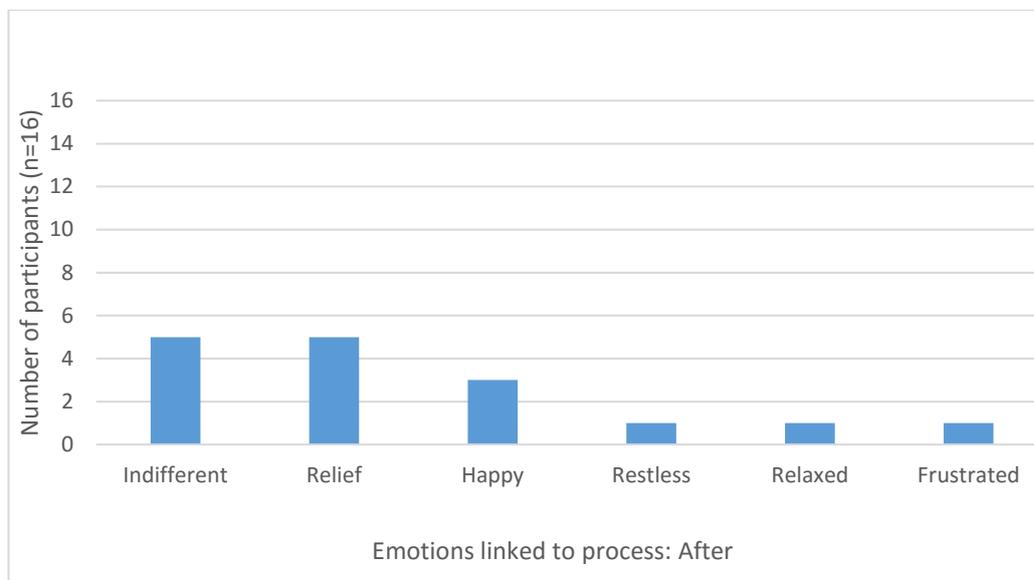


Figure 3.3: A bar chart of the impact on emotional experience linked to process: After (seven days after the participants had completed the process and had returned their wearable devices)

Participants had mixed emotions at the end of the baseline visit once all the measurements were done and the wearable devices collected:

Relief: (n=5). This emotion was felt by Participant 6, who seemed to have had some concerns during the study, which were addressed throughout the research process.

Indifference: (n=5). This was experienced by some participants, like Participant 12, who seemed to enjoy certain aspects, whilst having apprehensions about other aspects of the process.

Happy: Three participants (n=3) experienced happiness. Participant 10 in particular was happy to be part of the research process and for confirmation of a good health status. Participants were also happy about being able to return all the wearable devices, as indicated by Participant 7 with: “*I felt free*” (n=1).

#### Theme 4: Impact on perception

The following subthemes were generated according to code frequency (n=85) and were identified as contributing to participants’ perceptions and therefore, emotional appraisal of the health research process (See Figure 4):

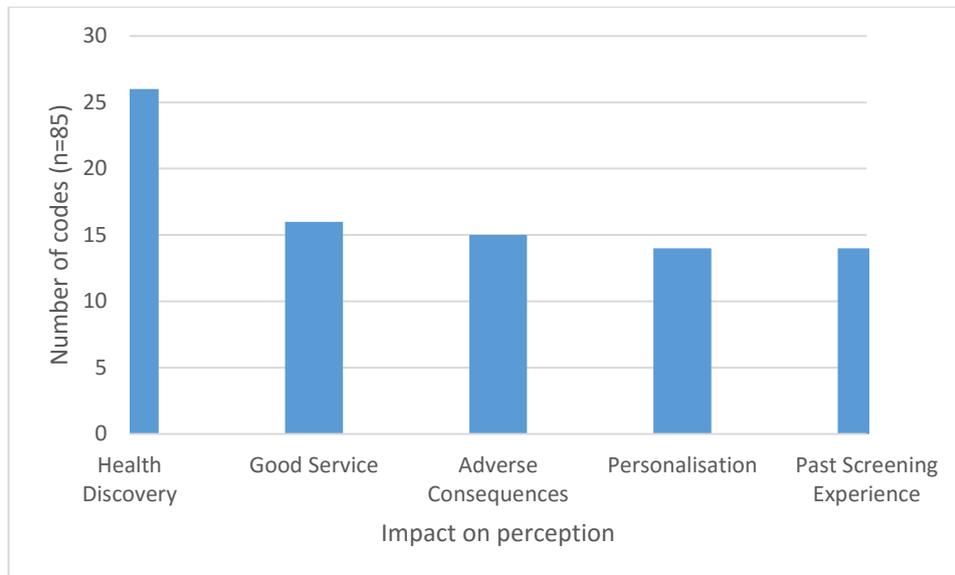


Figure 4: A bar graph illustrating the impact on perception

Health discovery: Expressions of health discovery emerged (n=26) and was based on participants experience or expected experience of some form of health discovery, as indicated:

“I will finally find out whether I am sick or not”. (Participant 1).

Another participant experienced relief through gaining knowledge of a healthy heart:

“My dad had a heart attack more than ten years ago and he told me what to look for when you see the sonar on the heart attack and which parts of the heart didn’t work. So that explained it a lot better for me because I didn’t, emm I couldn’t get my head around because I know he had a heart attack but then when I saw how the heart actually works, it was like okay cool, I get this now. So it was the most that was the biggest thing for me”. (Participant 2).

Participant 5 also reported:

“Even though they said that there was a bit of leakage on my heart but that’s normally on this valve where there is a bit of leakage but he said that it is normal and everybody or most of people go through that whereby there is a little bit of blood that comes from that ventricle into the atrium. So when he explained that this is actually normal, it’s not really one of the alarming things that I have to check.”

Participant 6 discovered:

“yet finding out that my heart is actually fine was a relief and yes it made me happy to find out that. It means I do not have to worry about that part of my life”.

Good service: The frequency of responses (n=16) indicated that participants experienced good service and it included the professional nature of the research team within the cardiovascular research process, as well as receiving information about the purpose of the research process. Participant 2 illustrates:

“...Everyone was really friendly with me and I asked them a lot of questions and they emm answered everything for me and when they did have the sonars and stuff, they explained everything to me that happened on the screen and they went into detail from the different tests that they did and I appreciate that they did. I appreciate that quite a lot because I was involved in the whole process, they kept me emm in the loop emm for lack of a better word, on everything they did and why they were doing it and how they could use this for other research and how it could help in the future and how, emm, ya, the different stuff that they did about it and all the different aspects that connect in the whole study”.

Participant 8 stated: “If the team is the same as this one then I would do it again because they were good”.

Another participant experienced a sense of purpose towards the process, when provided with more information by the research team, and concluded:

“It does give you the feeling that you are contributing to something bigger and you know that this can possibly help someone in the future, even myself. So that gave it a little bit of a purpose and not just playing around with some instruments”. (Participant 4).

Adverse consequences: A high frequency of responses was also found with regards to the experience of adverse consequences (n=15), which were mainly due to procedural aspects of the health research process that had an influence on the participants’ perceptions, like the unwillingness to participate in health research again:

“I had said that I won’t because anger arose on the last day when they had to come take the machines. Here at work they put pressure on me, I had to give back the machine, that time its knockoff time and they don’t want to come take their machine. I called them and never got a hold of them so there I was irritated and told myself that I do not want anything that associates myself with those people because they do not keep their promises. That day I was very irritated”. (Participant 3).

The negative affective feelings which were experienced by most of the participants were:

“The only problem I had was the every 30minutes BP process (blood pressure) and the other thing was that I felt some pain every time I got irritated or angry”. (Participant 1).

In addition, another participant became impatient with the process:

“Ya like the machine didn’t work on me for almost an entire hour and because it wasn’t working, I was not allowed to eat until late. So I was like o my word, I’m hungry. So impatience was how I felt at that time. Emm ya that’s about it”. (Participant 12).

Participant 1 felt scared at some point during the process:

“I just asked myself why they ran so many tests on me and I was scared of all those machines”.

Another participant explained not taking home the wearable devices as instructed, as it would have caused discomfort:

“Having not to bath the next day, it was just ya. I was on my period and that’s why I didn’t take the apparatus, so I literally refused to take the apparatus. They told me that I wouldn’t have to bath and for me that was a lot to ask”. (Participant 6).

Health scare: There were participants who joined the research process due to perceived ill health. This was expressed numerous times (n=14), as participants mentioned health scares:

“When they did heart sonar, I didn’t know what they were going to find because I tend to get chest pains so I was expecting something to come out there”. (Participant 16).

Another participant mentioned worrying that the heart was not functioning well:

“Because you know what, I don’t know because I saw that two weeks before I went there I was coming from a funeral of my brother who killed herself. So during that time I had a heart beat which seemed not right. It’s like I was depressed or something so I felt as if my heart is not functioning well. So since I was there and they explained that it’s okay and I explained the feeling that I had and they said maybe it’s because of the hurt that I went through but the heart is okay”. (Participant 3).

In addition, another participant had eye problems, and mentioned:

“Emm I struggle a bit with my eyes and my vision is not always good and when they took all the photos, emm they let me have a look at it and I could see, okay no everything is fine because in was wondering about the cholesterol and everything that I know can go wrong with the eye and they said okay no you’re fine”. (Participant 2).

Past screening experience: Most of the participants have been involved in medical screening before. Sixteen percent (16%; n=14) of the code frequency indicated a description of the participants’ past screening experience. Participant 14 indicated that the only past screening experience was visiting a doctor:

“Ya I have. It was a doctor check-up because we have diabetes in the family so I have to go check now and then”.

Other participants gave examples of how these previous experiences influenced the current health research experience. Participant 3 said:

“Yes normally I check blood pressure, diabetes, HIV, and then pap smear. So the eye tests I do them at work when they say the people have come to test eyes but not in the way that the people did there. We do the number tests. So that’s why I felt that I should do something different, maybe they will find something because you know women have lots of illnesses”.

Another participant pointed out that because of positive past screening experiences, this process was expected to have a similar effect:

“We had to do it on ourselves so I have done it and I have done it for medical reasons as well. So nothing surprised me or was uncomfortable or unknown to me. The only thing that was unknown because I haven’t done it was an HIV test but that as of itself was not a very painful procedure”. (Participant 9).

According to another participant, the screening process was not as quick as previous experienced processes:

“The thing is emm, yes I have done a lot of blood donations...But that’s really quick. Screening in terms of what we did there, emm not really”. (Participant 4).

## Discussion

A wealth of knowledge exists regarding the impact of medical screening processes on the emotional and psychological experiences of participants, but it is very limited in health research. The aim of this study was therefore to gain new knowledge regarding participants' emotional experiences of a health research process and the possible psychological impact of going through such a process. In this study, people's perceptions and experiences of the health research process ultimately determined the emotions which they experienced (Gross, 1999; Izard, 1992; Weiten, 2014).

To enable vocalisation of their emotional experience, participants were provided with a list of basic emotions which research found to be the most prominent during screening processes (Ekman & Cordaro, 2011). When given the opportunity to express further emotional experiences, participants in this study had limited ability to express how they were feeling about and during the health research. This could be due to limited emotion-related vocabulary, despite conducting interviews in a local language. This finding supports literature in that people find it difficult to differentiate between emotional experiences, but with the development of insight into their feelings, they are better able to vocalise them. Thus, providing the participants with the list of basic emotions enabled them to gain insight into their emotional experiences (Erbaş, Ceulemans, Lee Pe, Koval & Kuppens, 2014).

The researcher's findings agree with previous research indicating that participants experience mixed emotions during screening processes (Brain et al., 2013; Hershfield, Scheibe, Sims & Carstensen, 2013; Ebrooll et al., 2007). This study showed that different stages of the screening process elicited different emotions in the participants.

Findings indicate that participants' emotional experiences were mostly due to their cognitive appraisals of the cardiovascular research process (Izard, 1992; Weiten, 2014). The interaction between perception and emotion, which cognitive theorists refer to as cognitive schemas (Izard, 2009), was very prominent as participants were willing to endure and tolerate some unpleasant emotional experiences, such as discomfort, to be able to contribute to health research. In other words, the pattern of appraisal followed by the participants in terms of their relationship to the health research process, formed the basis of their emotional experience (So, Kuang & Cho, 2016).

Most participants indicated a willingness to participate in cardiovascular research again, despite not feeling comfortable during various stages of the process. This supports the assumption that people may feel obliged to tolerate unpleasant medical procedures for the sake of their health, or that the personal sacrifice is worthwhile for the greater common good (Ent & Gerend, 2015). This cost/benefit approach seems to include various aspects such as weighing some discomfort against the prospect of contributing to cardiovascular research for the greater community, as well as the incentive of finding out about one's own health status. This finding is in line with other studies in which participants felt that the

benefit of contributing to research was greater than any negative emotions experienced (Brain, Clements, Fraser, Lancaster & Lifford, 2013).

The link between emotions and perceptions was also related to how participants thought and felt about their health status. Some had anxiety, and uncertainty was evident, therefore they explained experiencing relief when insight gained through the health research, changed their perceptions of their health status. This illustrates that finding meaning during the health research process also impacted on the emotional and psychological experience of the participants (Gross, 1998).

The findings further revealed that, although the basic emotional experiences of participants were expressed in different ways, they attributed these experiences to different aspects of the cardiovascular research process, and they appraised their overall experience as mostly a positive emotional experience, which is consistent with previous studies (Ent & Gerend, 2015; Marteau, Kinmonth, Thompson & Pyke., 1996).

This study therefore supports previous findings that additional emotions are induced by procedural aspects (Bynum et al., 2012). Several studies indicate short-term negative psychological impacts as experienced by the participants as a result of medical and health research screening (Heshka et al., 2007; Ogden, 2016). This study had similar findings and further found that the negative emotions experienced were mainly due to specific occurrences, such as medical devices not working or communication gaps with the health research team. Considering that affective feelings are the pleasant or unpleasant experiential cues that characterize a person's moods and emotions (Gohm & Clore, 2000), these incidents were therefore likely to influence the affective feelings of some participants. This was observed in the data, with participants reporting anxiety, anger and irritation. Even though participants indicated these emotional experiences during the process, there was not a definite indication from them that it had a negative impact on subsequent attendance. The importance of that finding is particularly relevant for longitudinal health research studies such as this cardiovascular study, with a follow-up every four years. Other studies have shown that attitudes towards unpleasant medical screening may cause people to have reservations of participating in further medical procedures (Borrayo & Jenkins, 2001; Ent & Gerend, 2015). However, the true effect of the experiences reported in this study on future participation will not be clear until the follow-up visit.

There were a few participants whose experiential and behavioural responses were influenced by their presenting emotional state. Again, there was some indication of possible influence on their willingness to participate in further health research and screening. This supports the assumption that emotions seem to have a motivational component of mental operations and manifest behaviour (Izard, 2009). It also highlights the notion that the participants' positive emotional states during the process were indicated through their willingness to further participate in the screening process.

The participants also viewed the health research process differently, according to previous health testing experiences. Although the majority of participants have experienced health research or medical screening before, they all mentioned that their previous screening experiences had not been as extensive as the cardiovascular research study process. This had an effect on the expectations that participants entered the process with. Some participants' experience of previous screenings was in line with the African-PREDICT process and they described it as being painless. Others, however, did not feel their expectations were met, since participants expected the process to be as "quick" as previously experienced, which was not the case with this process. According to Rimé (2009), expectations, either being met or not, have a direct influence on the emotional experience of participants, which was also observed in this study.

Although testing was conducted on seemingly healthy individuals, the data indicated that the participants own perceptions of their perceived health played a role in their perceptions of possible ill health and consequently impacted their emotional experience.

## **Strengths and Limitations**

The strength of this study lies in the participants own descriptions of their emotional experiences and perceptions of taking part in health research. However, this study had some limitations, which need to be considered when taking the results into account. The data were self-reported and analysed using primarily qualitative research methods (with the exception of frequency graphs to support the results). A mixed methods approach by adding the use of standardised psychological assessments could enhance the empirical evidence of such studies and allow the investigation of negative or positive psychological impacts of such experiences. Furthermore, due to the scant literature on emotional experiences of participants taking part in health research in Africa, there is little pre-existing data to compare these results with, although these results do appear to support the need for such studies. Furthermore, the list of basic emotions given to the participants was not developed in a South African context. However, in this perspective, the list appeared to translate well for the study population, allowing the exploration of emotions. Further research to validate such techniques within the population and to elicit vocalisation of emotions or equip participants with an emotion-related vocabulary, would also be useful to empower participants' expression of emotional experience.

The data collection in this study took place within two weeks of the participants' participation in the cardiovascular health research process, which meant that the researcher could not comment on the long-term emotional impact past two weeks. Even though there seems to be no consensus regarding the length of time defining short-term versus long-term psychological effects, future studies would benefit from a follow-up, to determine the length of time the emotional experience is held and whether it influences behaviour, particularly behaviour relating to participants' ongoing engagement with health

services, screening and research. A further limitation may be the small sample size, although this is not unusual in qualitative research and rigorous methods were employed to ensure that saturation was met.

The findings from this present study were also limited to participants who participated in one cardiovascular research study, therefore the results may not be generalizable to all cardiovascular health research studies and could well be influenced by different processes present in different research studies. However, to our knowledge, this is the first study within South Africa to examine this important topic.

## **Conclusion and recommendations**

This study found that participants experienced various emotions throughout a cardiovascular research process in the North West region of South Africa. The findings in this study illustrated how different emotional experiences take importance in a health research context. Emotional experiences were not only influenced by procedural aspects of the health research process, but also by the participants' own perceptions, cognitive appraisals of the experience and cognitive schemas related to various factors of their health. In some respects, this study shows similar results to previous research however, it has also generated new knowledge regarding the emotions people experience when participating in cardiovascular research.

Based on the findings it is recommended that health research teams provide comprehensive orientation sessions prior to the research study, which can include asking participants about their perceptions of health and health difficulties previously or presently experienced. The importance of monitoring emotional experiences during a health research process could provide additional emotional support to participants, who in the current study, would have benefitted from such support. Debriefing, following a health research process that is focused on their emotional experiences, could further support participants. In resource poor environments, health researchers could implement a debriefing group at the end of the process to provide a platform for participants to gain insight into their emotional experiences. More research is needed to understand if and how emotional experiences impact subsequent attendance of health research and screening.

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## Appendix 1

1. Which of these words would best describe your emotional experience of the African-PREDICT health research process?
2. Can you explain why you chose these word/words?
3. Think about the process that you have gone through, each stage (Refer to the timeline). How did these stages influence your emotions the most? ..... What aspects of the process brought about this emotion/s the most?
4. Please tell us about what are the other emotions that you experienced?
5. What aspects of the process brought about that emotion/s the most?
6. Is this an experience that you would be willing to go through again? Can you tell us more about your answer?
7. Have you had any previous experience with health research and/or clinical screening? If yes, can you tell us more about your answer?

## Appendix 2

*Table 1: Coding Frame showing the Themes and Subthemes of the Participants' Emotional Experiences of Cardiovascular Health Research*

Topic area	Code	Description of code	Example of quote
<b>Primary emotional experience</b>	Happiness	The overall feeling of enjoyment experienced by the participants	<i>I would say first of all happy. I think happiness because emm you know you don't really get much time to go for check-up and stuff like that.</i>
	Fear	The overall feeling experienced as a threat of harm.	<i>Emm a little bit of fear but that doesn't come from the study just that needle just that prick. I'm not scared of needles but you know there's just that thought of ag needles again.</i>
	Surprise	The overall emotion experienced as a sudden, unexpected event.	<i>And then surprise is the reaction. I was surprised that I didn't know that some of the things that we were going to take them home.</i>
<b>Secondary emotional experience</b>	Uncomfortable	The emotion described due to procedural aspects of the research process.	<i>It was quite uncomfortable with the whole eye thing.</i>
	Irritated	The emotion described due to procedural aspects of the research process.	<i>The heart thing that I had to go home with, I didn't like. It was itchy, it was just irritating, so I didn't like that but other than that everything was okay.</i>

	Excitement, impatient, anxiety, concern and tired	Other secondary emotions which exist in interpersonal situations.	<i>But I think overall it would be worried because what if they put that thing in my eye but they haven't referred me to an optometrist first. They are just going to spray chemicals into my eye, what if I go blind? Those were the concerns I had.</i>
<b>Emotional experiences linked to process</b>	Excited	The emotion experienced upon arrival at the African-PREDICT research process.	<i>Timeline: The participant felt welcomed as everyone she encountered was friendly.</i>
	Indifference	The emotion experienced upon arrival at the African-PREDICT research process.	<i>Timeline: The experience was nothing new to the participant</i>
	Curious	The emotion experienced upon arrival at the African-PREDICT research process.	<i>Timeline: The participants were curious to know more information about the process</i>
	Anxious	The emotion experienced upon arrival at the African-PREDICT research process.	<i>Timeline: This was the anxiety felt about the possible painful experience</i>
	Embarrassed	The emotion experienced during the different stages of the African-PREDICT research process.	<i>Timeline: The embarrassment about what other people in the community would comment about when the participants were seen with various machines.</i>
	Uncomfortable	The emotion experienced during the different stages of the African-PREDICT research process.	<i>Timeline: The eye drop produced burning sensation.</i>

	Excited	The emotion experienced during the different stages of the African-PREDICT research process.	<i>Timeline: Excited to see the heart through the heart sonar.</i>
	Relief	The emotion experienced upon completion of the African-PREDICT research process.	<i>Timeline: Relieved to be finished with the process.</i>
	Indifference	The emotion experienced upon completion of the African-PREDICT research process.	<i>Timeline: Felt nothing in particular at the end of the process.</i>
	Happy	The emotion experienced upon completion of the African-PREDICT research process.	<i>Timeline: Happy to have been part of the research.</i>
<b>Impact on perception</b>	Health discovery	This theme is related to the participants finding out that they are healthy.	<i>O and sorry the eye test. Emm I struggle a bit with my eyes and my vision is ya not always good and when they took all the photos, emm they let me have a look at it and I could see, okay no everything is fine ...</i>
	Good service	This theme emerged due to the professional nature of the examiners within the African-PREDICT team.	<i>Everyone was really friendly with me and I asked them a lot of questions and they emm answered everything for me and when they did have the sonars and stuff, they explained everything to me that happened on the screen and they</i>

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		<p><i>went into detail from the different tests that they did and I appreciate that they did. I appreciate that quite a lot because I was involved in the whole process, they kept me emm in the loop emm for lack of a better word, on everything they did and why they were doing it and how they could use this for other research and how it could help in the future and how, emm, ya, the different stuff that they did about it and all the different aspects that connect in the whole study”.</i></p>
Adverse consequences	<p>Some procedural aspects of the process influenced the emotions which people experienced.</p>	<p><i>I had said that I won't because anger arose on the last day when they had to come take the machines. Here at work they put pressure on me, I had to give back the machine, that time its knockoff time and they don't want to come take their machine. I called them and never got a hold of them so there I was irritated and told myself that I do not want anything that associates myself with those people because they do not keep their promises.</i></p>
Health scare	<p>This theme related to the participants' perceived ill health.</p>	<p><i>When they did heart sonar, I didn't know what they were going to find because I tend to get chest pains so I was expecting something to come out there.</i></p>

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Past screening experience	Most of the participants have a history of past screening, but not as extensively as in the African-PREDICT.	<i>Yes normally I check blood pressure, diabetes, HIV, and then pap smear. So the eye tests I do them at work when they say the people have come to test eyes but not in the way that the people did there.</i>
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### Section 3: Critical Reflection

#### Critical reflection

My previous perceptions of a research process were that research can only be viewed as an educational tool. However, conducting this study, I experienced that research is far more than that, it changed my thoughts and feelings, which made it both enriching as well as challenging.

The challenge began the moment I decided on a research topic. Sometimes one thinks that the process should be smooth after that, however, that was not the case. I faced five challenges in particular. Firstly, I did not have as much academic knowledge as I thought I had about the topic at hand. This frustrated me at first, as I thought that my knowledge base was lacking, specifically regarding emotions and their impact on people. I found that this increased my curiosity, which led to the literature review process being more interesting for me. What I found most interesting, were the emotion theories and how there is no clear consensus on the psychological impact and its relation to emotions experienced. The second challenge was the recruitment of participants, since it seemed as if people were not eager to participate in my study. It seems as if people do not make time for studies in which they do not see a direct benefit. Adding incentives could potentially increase participation, but it would depend on the nature of the study. The third challenge came when the semi-structured interviews were taking place. No matter how much one probes, sometimes people do not have much to say about the research topic at hand. This left me feeling frustrated, as I felt a little bit disheartened because I wanted to understand their experience. It was also important for me to separate the semi-structured questions from the narrative which followed in order to attain a better understanding of the participants' experiences. This was done through consulting literature in order to inform the process. However, on the other hand, I was also able to interview other participants who had numerous thoughts and opinions which they wanted to share about their experience of the African-PREDICT programme. Those participants may have been more expressive due to their own unique style of interacting during the interview. The next challenge was transcribing the audio-taped interviews and conducting the data analysis. This was a long process. Transcribing the data was time-consuming, but it was informative, since I was able to reflect on the

interviews. Conducting the data analysis was equally time-consuming and I had doubts about my competence in this regard. Thus, I sought support and received training in the software that I used. Lastly, time became an immense challenge on its own, mainly due to times of procrastination. Nonetheless, I have learned to be more productive, even under pressure.

This research process has also been enriching, due to three aspects in particular. Firstly, I was able to learn so much, not only about the research process in its entirety, but also about the psychological impact of health screening. Reading up on previous research increased my curiosity about the gaps in literature and I was more motivated once I became aware of the relevance my study has. In the second place, I was able to increase my research abilities and communication skills. This was through practically going through the various phases of the research process as well as coming into contact and communicating with not only the participants, but also all the other stakeholders (such as staff members from the African-PREDICT team and my supervisors). What I would do differently in further research, is to communicate the urgency of calling back potential participants if they do not answer on a particular day. The third aspect is that I am inspired by the health research and screening work being conducted throughout the world. This is mainly due to the realisation of a need in the health field that is gradually being met, as well as the mental health needs that still have to be addressed extensively. I am grateful for the opportunity not only to gain a richer understanding of peoples emotional experiences throughout a health research process, but also for the opportunity of personal and academic growth.

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