Knowledge, attitudes and perceptions of Genomic Medicine among medical students, private medical practitioners and the general public in eThekwini, KwaZulu-Natal

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By

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DECLARATION

The author hereby declares the content of this research project is the author's own unaided original work, except where specific indication is given to the contrary (by reference). This work has not been previously submitted to the Durban University of Technology (DUT) or any other University.

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DEDICATION

Dedicated to my Lord and Saviour Jesus Christ

to my loving parents Nathan and Gonum Naidoo and my beautiful sister Presanthi Naidoo

“You saw me before I was born. Every day of my life was recorded in your book. Every moment was laid out before a single day had passed.”

Psalm 139:16 (NLT)

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ABSTRACT

The use of genomics in public health has the potential to contribute towards the diagnoses of diseases, ensuring the efficiency of health promotion interventions and assist in developing more effective pharmaceuticals. Research conducted abroad has documented the discourse of public and medical perceptions towards genetic testing, however, there is a lack of information to inform the health sector within South Africa with respect to the knowledge and attitudes of the general public and medical sector towards genetic testing. Therefore, the aim of this study was to document and evaluate the knowledge, attitudes and perceptions surrounding the use of public health genomic (PHG) medicine.

This was a quantitative cross sectional study and our convenient sample included representatives from the general public, medical students and medical practitioners within the eThekwini region in KwaZulu-Natal (n=170). Participants were required to fill out administered questionnaires which included likert scale questions. Medical practitioners from both private and public health sector in the KZN region were sampled (n=45). Medical students comprised of second year students from the UKZN Nelson R Mandela medical school who had not yet been exposed to the genetic module in their medical curriculum (n=79). Representatives of the general public included educators from private and public primary schools in Durban and surrounding areas (n=46). Descriptive and frequency analysis using mean, standard deviation and range was used for quantitative variables. Knowledge and attitude responses were stratified by gender, race and for medical practitioners by practice type. Bivariate correlations using Spearman's rho test and principle component analysis was conducted. Scoring scales were used to determine the level of knowledge and type of attitude among participants towards predictive genetic testing.

Results revealed that the knowledge of the general public, medical practitioners and medical students towards the use of public health genomics were adequate. Medical students displayed a negative attitude towards the uptake of predictive genetic testing which was contrary to the positive attitudes of the general public and medical practitioners. Stratification by gender indicated that women from the general public were more accepting of PHG despite the increased costs associated with genetic testing. We found that females were knowledgeable on the primary use of predictive genetic testing, and more Africans (77%) than Indians (46.2%) and Whites (50%) were aware that genetic testing is being offered in South Africa. Results of bivariate correlations revealed that current medical practitioners would still use predictive

genetic testing despite the possible ethical, legal, and social implications for the end user. PCA (Principle Component Analysis) confirmed a strong factor loading for a willingness to use predictive genetic testing among the general public. PCA yielded a high factor loading on an awareness for the need for a proper legislative framework for PHG among medical students. Medical students articulated a need for additional training in public health genomics.

In order to improve knowledge among the medical fraternity, institutions should adapt undergraduate and post-graduate curriculum to make provision for relevant PHG training that would be extended not only to medical and health care students but offered to qualified practitioners for continuous professional development training. In addition, awareness should be created on various media platforms to inform the public about the availability and costs associated with predictive genetic testing services in South Africa. Relevant stakeholders from both the public and private health sector in South Africa should be aware of the challenges that could impact on the uptake of public health genomics in South Africa, given its potential for use in the NHI (National Health Insurance) structure.

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CHAPTER 1: INTRODUCTION

1.1 Background to the study

Public health genomics (PHG) is a multidisciplinary field concerned with the effective and responsible translation of genome-based knowledge and technologies for the improvement of health in a population (Lanuale et al. 2014). Hahn et al. (2010) define genomic medicine as the use of genetic information for the improvement of health outcomes which involves incorporating an individuals' genotype, family medical history or expression analysis into disease risk assessment (Hahn et al. 2010). Diaz et al. (2014) add that it also includes the use of genetic information to improve medical treatment (Diaz et al. 2014). Therefore, it is important to prepare the health care fraternity to engage in the use of genetics and genomic information in the public health sector and to guide patients in prevention of diseases or decisions that are needed in relation to their health (Lanuale et al. 2014).

Introducing PHG to students in the medical fraternity is essential given the significant advancement of medical genomics. A cross-sectional survey conducted among Italian public health post-graduates revealed that medical doctors practicing in the field needed to be educated on PHG in order to ensure the sustainability of the National Health System and contribute towards the improvement of policies relating to PHG (Lanuale et al. 2014). In the United States, perceptions, motivations and intentions of "adopters" of personal genomics has been identified among the general public. The majority of respondents were personally motivated to know their disease risk to improve their health, while others had a misconstrued interpretation of personal genomic testing (Gollust et al. 2015). Significantly, a longitudinal study carried out in the Netherlands regarding public attitudes towards genetic testing revealed that the expectations of benefits and potential use of genetic testing were higher than the ethical and social concerns associated with genetic testing, and younger people showed a more positive attitude towards genomics (Henneman et al. 2013).

A random sample of medical practitioners and students in Cameroon found a poor level of knowledge of genetics among participants, although there was an acceptance of the principles of medical genetics among the cohort (Wonkam, Njamnshi and Angwafo 2006). It would

appear that developed countries and developing countries contrast in knowledge and perceptions towards public health genomics among the public and medical fraternity.

A qualitative study in Nigeria confirmed that the knowledge of policy makers, health care professionals, religious leaders, healthy civilians and those with complex diseases was limited with respect to genomic testing. When provided with an explanation, their understanding improved. The study also found that religious beliefs influenced participants' perceptions regarding genomic testing with the majority of participants disclosing their fear of direct to consumer personal genomic testing and disclosing of results to third parties (Fagbemiro and Adebamowo 2014). The results of a qualitative study conducted among advanced midwifery learners in South Africa revealed that advanced midwifery learners lack the foundational genetic knowledge required for practice (Phaladi-Digamela, Mulaudzi and Maja 2014). This was attributed to the absence of adequate genetics education in the advanced midwifery course.

In South Africa a study conducted on the uptake of genetic counselling for cystic fibrosis patients showed that the majority of patients who attended genetic counselling, were in fact parents of patients who were minors, who sought additional support. However, when genetic counselling was incorporated into clinical care, patients attended genetic counselling without parents. The researcher concluded that medical practitioners do not refer their patients to attend genetic counselling as they themselves do not understand the vital significance of genetic counselling (Macaulay, Gregerson and Krause 2012). There is thus an urgent need for medical practitioners to be trained at a grassroots level on public health genomics so that they can direct patients accordingly.

Disease prevention is directly proportional to the education, experience and exposure of healthcare professionals (Wonkam, Njamnshi and Angwafo 2006). The abovementioned studies conducted globally and locally reveal a common trend of misinterpretation or inadequate knowledge pertaining to genomic medicine where difference in perceptions of genomic medicine are based on the level of knowledge that one has regarding genomic medicine. Henneman et al. (2013) state that attitudes are equally important and vary with age and gender. An individual who has more knowledge about genetic testing may not necessarily be more supportive as increased knowledge may cause a reduced perceived benefit.

There is limited research in the South African context to evaluate knowledge and perceptions of the public towards PHG. It is essential to obtain the opinions of the public regarding predictive testing in relation to non-communicable diseases as they are end users of the services

of PHG. There may be various factors that influence ones' knowledge, attitudes and perceptions regarding genomic medicine. It is also important that one identifies and establishes the knowledge and perceptions of PHG in context since each country varies in their level of knowledge and understanding of genomic medicine. This study aims to identify the level of knowledge and perceptions regarding PHG among South Africans in medical practice, medical students and the general public.

1.2 Problem statement

A number of South African insurers have introduced support for the use of predictive genetic testing which can offer individualised risk assessment to mitigate chronic diseases among individuals. The medical fraternity also is tasked with providing correct interpretation of genetic testing and advice so as to properly manage the future healthcare and wellbeing of patients. Research results of knowledge and perceptions of public health genomics in the medical fraternity and the general public in different parts of the world are similar in having a positive attitude towards the use of PHG despite a lack of knowledge. However, it can be ascertained that limited research has been published pertaining to the knowledge and attitudes of the general public towards predictive genetic testing for chronic diseases, as much focus has been on neonatal genetic testing. In studies pertaining to genetic testing for chronic diseases, the level of knowledge and perceptions are based on personal opinions and attitudes of individuals. To this end, perceptions, attitudes and knowledge regarding PHG, specifically predictive genetic testing for chronic diseases within the medical fraternity and the general public, has not been investigated in South Africa.

This current study aimed to evaluate and document the current knowledge, attitudes and practices of three study populations namely:

- The general public, to evaluate what their knowledge, attitudes and practices are on the uptake of predictive genetic testing as patients;
- Medical practitioners, to ascertain if they have introduced patients to predictive genetic testing or if they are keen on recommending it; and
- Medical students, to determine their views on the use of predictive genetic testing and whether they will adopt predictive genetic testing in future practice.

This study may inform the health sector in South Africa, inclusive of all relevant stakeholders from policy makers to educators, on the gaps that exist regarding public health genomics within the health system of South Africa.

1.3 Study location

Due to the nature of this study, several sites were used in KwaZulu-Natal (KZN), ranging from central Durban to north of Verulam. These study sites consisted of five schools within central Durban and the North Coast, a university based in central Durban and a consortium of private and public medical practitioners located in central Durban.

1.4 Aims and objectives

The aim of this study was to determine and document the knowledge, attitudes and perceptions of medical students, private medical practitioners and the general public in eThekwini towards public health genomic medicine.

The objectives of this study were to determine the knowledge attitudes and perceptions of:

- The general public and their knowledge of services available for predictive testing of non-communicable diseases.
- Medical practitioners towards the use of genomic medicine.
- Second and fifth year medical students toward genomic medicine.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

Genomics is the study of genes and their functions, including related techniques (Zusevics et al. 2014). Public Health Genomics (PHG) has the potential to contribute towards diagnosis of diseases to make health promotion interventions more efficient and to assist in developing more effective pharmaceuticals. The use of genomics in the public health sector is intended to benefit the health of people particularly at grassroots level, and its application in diagnosis, treatment of diseases and behavioural change in humans has advanced (Zusevics et al. 2014). Research pertaining to PHG is advancing rapidly and it is important that end users are prepared and informed accordingly. It is thus important to identify the knowledge, attitudes and perceptions of individuals regarding the use of PHG so that the educational structure is strengthened so that PHG can benefit patients.

The introduction of mandatory health insurance in South Africa aims to address the challenges of the current health system in South Africa. The main objective of the National Health Insurance (NHI) plan (South Africa, Department of Health 2015) is to provide equitable health care to all citizens of South Africa, to decrease the burden of communicable and non-communicable diseases, and to decrease the morbidity and mortality rates. Currently, clinical genetic services are an integral part of antenatal care among women. This involves the cradle to grave process of prenatal to postnatal health care. The NHI also makes provision for early identification of illnesses that may adversely affect foetal development. According to Genetic Counselling South Africa (GC-SA) (2016), the White Paper on the NHI found that clinical genetic services have a role to play in the "comprehensive package" of health services of the NHI and are not bound to a specific tier of the NHI structure. The inclusion of genetic services within the NHI system is a strategy using a preventative rather than curative approach. Knowledge of risk of lifestyle/chronic diseases, obtained by predictive genetic testing, may lead to interventions such as behavioural modification to avoid entirely, or prolong the onset of such diseases. Some public health advocates contend that interventions based on environmental changes will be more effective than those focused entirely on individual behaviour change. This means that when a person identifies their increased risk for contracting a non-communicable disease with the use of predictive genetic testing, they will be motivated

or driven to change their lifestyle or behaviour based on their results. Behavioural modification is not limited to the lifestyle of the individual, but is inclusive of environmental, social and physical modification (McBride et al. 2010).

For over a decade genetic testing has been made available to the public outside the standard clinical environment in countries such as the United States and the United Kingdom. It has been established that most companies operate on an online basis, where clients can order a test online, and, without the mediation of health professionals, receive their results. Vayena et al. (2014) refers to this as the direct-to-consumer (DTC) model. The DTC model has risks related to the interpretation of results (Vayena et al. 2014).

Those supportive of public health genomics argue that increasing knowledge of genomics and molecular pathology could unlock effective diagnostic techniques and treatments, as well as better target public health interventions. Predictive genetics have currently few applications in clinical practice, but the scenario is likely to change in the future. In some developed countries, predictive testing has raised interest, particularly in the case of high-penetrance genetic variants associated with common types of cancer (breast/ovarian/colon cancer) and hypercholesterolemia. These predictive genetic tests have been demonstrated to be both efficacious and cost-effective (McBride et al. 2014).

Should the NHI support the use of PHG in healthcare in South Africa, it may prove to be cost-effective, achieving the main objectives of reducing the burden of disease while providing equitable health care. Morbidity, mortality and incidence of non-communicable diseases may be reduced. However, it is important to ascertain and evaluate the current knowledge, attitude and perceptions of potential end users of PHG and those who will support the use of PHG in the future. The GCSA has stated that one of the barriers to the delivery of medical genetic services is the lack of knowledge of the value of these services and the support available to utilise them, particularly as the advance of genetics from research to public health care delivery poses various challenges (Genetic Counselling South Africa 2016).

2.2 Current health situation in South Africa

A country's history can be traced through the evolution of its health system by analysing the epidemics of communicable and non-communicable diseases. This is invariably linked with policies pertaining to that country. The history of South Africa is infused with discrimination which has shaped the current infrastructure and appropriation of resources. In spite of being 25

years into democracy, South Africa is still faced with challenges in the public health sector which are interwoven with other factors such as unemployment and poverty leading to inadequate access to health care. South Africa is currently engaged with establishing an equitable form of healthcare service delivery which is encapsulated in the NHI. The proposed NHI seeks to address challenges faced in the current health system (McIntyre et al. 2009). The Health Systems Trust (HST) (2014) highlighted that 82% of the population depends on the provision of public health care (Barron and Padarath 2017). McIntyre et al. (2009) observe that there is a significant difference in resource availability between the public and private sectors. This is due to private specialists locating their consulting rooms within private hospitals, so that their patients have access to on site facilities (McIntyre et al. 2009). Nearly 46% of all health-care expenditure is ascribed to less than 15% of the population in South Africa who are members of private sector medical schemes (McIntyre et al. 2009). The white paper of the NHI is aimed at addressing this disparity by advocating the use of taxes to fund the majority who cannot afford to have an equitable health service. This is aligned with the three dimensions of universal health coverage as suggested by the World Health Organisation (as cited in South Africa. Department of Health 2015):

- Population coverage: where access to health care services will be extended throughout South Africa regardless of the socio-economic status of South Africans with prioritisation being given to those who need health care services the most.
- Service coverage: this is where individuals will be able to access health care services with an NHI card from a primary health care level to other specialist multidisciplinary medical practitioners when referred from primary health care. Listed as a comprehensive package, but not limited to the categories listed in to NHI White Paper, the prospective application of the NHI aims to respond and act upon the medical needs of those who are disadvantaged.
- Cost coverage: refers to the extent to which the populace is protected from direct costs and refers to those who are legally entitled to benefit from the NHI which includes not being responsible for any medical costs and out of pocket fees at the point of service delivery.

However, the roll out of the NHI revealed a possible discrepancy between the day to day lived reality of public health care consumers and the intended policy transformation (Weimann and Stuttaford 2014). Not all individuals are keen on this new perspective of health care

transformation as it may result in a burden for both the public health care consumer and the delivery of health care services by medical practitioners. The ratio of patients without access to primary health care to medical practitioners is very high, making health care service delivery less efficient. This may result in compromised quality of health care service delivery which is contrary to the NHI goal of higher quality service delivery.

Weimann and Stuttaford (2014) reported that consumers were concerned about whether there would be an improvement of treatment efficiency, specifically of non-communicable and communicable diseases within the NHI system. They were also concerned about the improvement of service delivery and medication availability. The NHI is focused on the prevention of non-communicable diseases by introducing strategic health promotion and prevention programmes. Within this context, genetic screening can be pivotal as DNA screening provides valuable information about disease susceptibility particularly regarding non-communicable diseases such as diabetes, cancer, and hypertension. Education on behaviour and lifestyle modification following these genetic tests can contribute to a healthier nation with a lower incidence of health problems.

2.3 Definition of public health genomics

Public health genomics (PHG) is a multidisciplinary field concerned with the effective and responsible translation of genome-based knowledge and technologies for the improvement of health in a population (Lanuale et al. 2014). Hahn et al. (2010) define genomic medicine as the use of genetic information for the improvement of health outcomes and is inclusive of incorporating an individual's genotype, family medical history or expression analysis into disease risk assessment (Hahn et al. 2010). South African insurers have introduced medical reporting of genes to patients by providing genomic information which offers individualised risk assessment to those interested in their future health status.

2.4 Perceived benefits of public health genomics

Urban (2015) states that genomics is a complex field which interacts with many aspects of health care. There is an anticipation that PHG will transition into a broader prototype of precision medicine which requires in depth training of future medical practitioners (Urban 2015). PHG or predictive genetic testing has the ability to diagnose diseases and provide therapeutic measures that are tailored according to the patient, also assisting in preventing adverse drug reactions (Tiffin 2014).

In the global context, the advent of such technology may be used for the reduction of communicable diseases and in the prevention of birth defects and common chronic diseases (Zimmern and Khoury 2012). Akinyemi et al. (2015) state that the diversity of African populations provides a unique opportunity to discover genes that may lead to new and improved prevention and treatment options particularly for stroke patients of African ancestry (Akinyemi et al. 2015). In his review of the genomics of stroke he confirms that Africa is currently in an epidemiological transition where there is an increase in non-communicable diseases, including hypertension, diabetes mellitus and dyslipidaemia which may lead to stroke. Genomics research also includes population interactions between environmental factors and cultural behaviours in relation to disease outcomes (Akinyemi et al. 2015).

Reflections on the advent of public health genomics in South Africa has been positive, as the objective of a good genetic service is to assist individuals with a genetic disadvantage to live and reproduce normally and responsibly. This however is restricted to neonatal genetic testing to ensure that babies are not born with genetic diseases as a result of mutations. Predictive genetic testing for non-communicable diseases does not have the same extent of support, but it can be advocated for in future. Beighton et al. (2012) suggest that offering of genetic services should include diagnosis, counselling and comprehensive care to those whose lives could be afflicted by a genetic condition. This would imply resource allocation within the NHI system particularly for post-test counselling and care.

2.5 Concerns regarding the use of public health genomics

There are many concerns pertaining to the use of predictive genetic testing in South Africa. Various concerns raised in reviews, editorials and comments in literature are discussed below.

2.5.1 Education and training of health professionals in public health genomics

There is a lack of literature to identify the status of health professionals in terms of knowledge levels in applying public health genomics in medical practice. Most academic institutions do not make provision for training of health professionals in the use of predictive genetic testing. For example, once a patient has been notified of their predisposed factor for a disease, there is no structure in place for the next step, which should include a genetic counsellor. This is due to the paucity of resources and absence of guidelines. The shortage of trained professionals to offer these services is of concern in the implementation of PHG (Beighton et al. 2012). Additionally, South Africa consists of a multicultural and multilingual society, which creates

a demand for native language speakers to convey multifaceted genetic concepts to those who undergo predictive genetic testing. Presently there is no training for the profession of genetic counselling in South Africa (Beighton et al. 2012).

Research conducted in developed countries such as the United Kingdom and United States has shown that medical practitioners do not understand the importance of predictive genetic testing (Villari et al. 2013; Teng and Spigelman 2014; Avard et al. 2009). It is still unclear if general medical practitioners are able to interpret and communicate genetic test results to patients. This indicates the need for educational approaches to help medical practitioners comprehend the concepts of interpreting genetic risks effectively (Avard et al. 2009). Medical practitioners attending a Coalition for Health Professional Education in Genetics meeting in Bethesda participated in an exercise where they received a name tag with a risk estimate of obtaining a disease. Medical practitioners were requested to identify the level of risk and the groups they would fall into based on the information on the tag. Results revealed that most professionals failed to identify that they all fell into the same category of risk based on the name tag (Avard et al. 2009).

2.5.2 Users/consumers understanding of public health genomics and predictive genetic testing:

In Africa, cultural and religious beliefs have an impact on ones' knowledge and understanding of the health impact of genomics. A study conducted in Nigeria showed that participants believed that the use of genomics could be beneficial and even assist in promotion of healthier lifestyle, but the practice of genomics introduced critical ethical issues. The use of PHG could directly contradict religious beliefs or lead to actions that contradict religious beliefs. In order to achieve success and popularise the use of personalised genomic medicine to aid in health and lifestyle amendments, it is important for people to have relevant knowledge on PHG (Akinyemi et al. 2015). Despite limited public information and restricted access to direct to consumer genetic testing, the general public have a positive attitude towards PHG. Even though people have misunderstandings about predictive genetic testing, it does not prevent them from acknowledging health related benefits. Evidence is provided in a study of British adults, where the majority of participants did not agree with the possibility of fatalism relating to public health genomics even though they did not have a proper understanding of the subject. Individuals who recognised the influence of genetics regarding chronic diseases were more likely to recognise that the symptoms of these diseases arise from ones' lifestyle (Hahn et al.

2010). A review of studies conducted in the US and Australia also revealed positive attitudes of individuals towards genetic testing despite lack of knowledge of genetic testing (Hahn et al. 2010). The appreciation individuals have for predictive genetic testing creates the possibility of future research being carried out on their psychosocial health in relation to predictive genetic testing.

2.5.3 Ethical legal and social implications regarding the use of predictive genetic testing in society

When viewed from a legal perspective in most countries, DTC genomics prohibits genetic testing that is not approved by a physician. However, it does not prohibit individuals from purchasing such services abroad. In Switzerland, the Ministry of Health does not support online genetic tests due to concerns about quality and data privacy. However, 59% of Swiss university students were positive regarding DTC genomic testing and genomic research, whereas the remaining 41% were not keen due to the possibility of receiving unpleasant results (Vayena et al. 2014). It is important to note that there also was a positive correlation between males studying natural sciences and support for genetic testing.

The advent of predictive genetic testing may result in an overload of patients with limited available professional resources as patients begin to exercise their right to access their personal health information. However, policies relating to the regulation of access to public health genomic information are scarce (Roberts, Dolinoy and Tarini 2014). Reviews carried out globally have confirmed that policies conform to the medical model with clinical experts being gatekeepers of such information. However, most medical genomic information would be regarded as unsuitable for disclosure, as there are limitations in the predictive value among other aspects linked to the information such as interpretation and possible treatment.

In South Wales, Australia, Wilde et al. (2010) evaluated public interest with regards to genetic testing for psychiatric illnesses and aimed to identify public concerns about genetic testing within context. This was carried out in the form of focus groups, with the majority of participants indicating an interest in having a genetic test done for susceptibility towards major depression. However, they also voiced concerns about genetic discrimination and privacy (Wilde et al. 2010). Psychological and social harm is also seen as a possible contributing factor as the individual must deal with the reality of the prediction of a disease. This can also lead to discrimination in the life of an individual (Geller et al. 2014; Robert et al. 2015). For example, if a person carries out a predictive genetic test to identify their predisposition for any disease,

in this case, it can be cancer or heart disease, there is a high risk of the individual being discriminated against. If he or she were to seek employment, medical surveillance would be carried out, and since there is no legislation that protects the interests of an individual who has had a genetic test carried out, they would be obligated to disclose their potential future risk for non-communicable diseases such as cancer and heart disease. This can result in discrimination and hinder the individuals' chances of being employed. Zusevics et al. (2014) agreed that ethical, legal and social implications should be considered by health professionals, scholars, researchers and policy makers. These concerns involve the disclosure of genetic test results, which can have a discriminatory impact on the employment and insurance, as well as social stigmatisation.

Robert et al. (2015) from the United States stated that leading professional organisations in clinical genetics have issued policy statements advocating that genetic testing should be deferred until adulthood unless the implementation of genetic testing can result in medical benefit in childhood (Roberts, Dolinoy and Tarini2014). They maintain that the clinical benefits do not outweigh the potential harm of disturbing information which can cause stigmatisation for a child. Therefore, the accuracy of information being delivered to the public regarding public health genomics is essential. This social context includes close families and friends who play a role in the understanding of public health genomics (McBride et al. 2010). Furthermore, because family members share genetic profiles, the social context becomes relevant for understanding the effects of communicating genomic information, with emphasis on the emotional and mental strain when an individual receives negative results pertaining to their genetic risk profile (McBride et al. 2010).

Sporadic evidence of research being carried out in the field of genomics is a sign of interest and participation of individuals in wanting to know more about this technology for the improvement of health outcomes. To recognise the positive impact and potential of this technology, capacity building among researchers, academic institutions, and creation of partnerships with developed and developing countries is advised. Most importantly, a national framework for South Africa would be required for the consideration for the ethical implications of public health genomics together with its' application in various contexts (Wonkam and Mayosi 2014).

Therefore, those who administrate the use of DNA sequence must give careful thought to who may access genetic data. Another concern is one of exploitation, where genetic data is used for

research purposes without consent. The main objective of carrying out local research with genetic data must be for the advancement in health outcomes and not only for commercialisation. It has been suggested by some authors that the main purpose for the development of genetic research in South Africa is for the acquiring data sets and medical records of patients to advance commercialisation of companies abroad, without the consideration of the needs of South Africans. This should raise concerns about patient exploitation (Lombard et al. 2016). Currently, in South Africa, there are a few institutions that offer personalised genetic testing. Kromberg, Sizer and Christianson (2013) report that these services are nestled in academic institutions, provincial health departments and the National Health Laboratory Services. There are trained geneticists, genetic counsellors and medical scientists that are able to deliver these services. However, there is a limitation in funding allocated towards the development of this fraternity in South Africa (Kromberg, Sizer and Christianson 2013). In the private sector, there are a number of genetic testing laboratories which offer DNA testing for disease susceptibility. A few private laboratories and medical aid schemes have also introduced the same. These services are inclusive of diagnosis, counselling and comprehensive care for those who receive a positive diagnosis for a predisposing genetic condition (Beighton et al. 2012).

2.5.4 Information systems within the context of public health genomics

The advancement of PHG may contribute towards the phenomenal growth of information pertaining to health and disease (Zimmern and Khoury 2012). However, one of the anticipated challenges is that practitioners are likely to be inundated with genomic data (Karczewski and Montgomery 2013). Making genomic information available to the public and medical practitioners in a transparent, ethical and understandable format is vital to the success of the PHG rollout (Zimmern and Khoury 2012).

Raghavan and Vassy (2014) reported that barriers against the implementation of public health genomics may include health systems, patients, interpretation and communication between medical/health care practitioners and patients. Zimmern and Khoury (2012) believe there is a need for the establishment of sound, accessible databases and information systems which can summarise evidence for the efficient diagnosis and predictive tests including therapeutic interventions. They further elaborate that public health departments must be the main stakeholder in the development, dissemination and implementation of these information systems and academic institutions should be included in this process (Zimmern and Khoury

2012; Karczewski and Montgomery 2012). Not only will this promote the use of public health genomics, it will allow for only authorised personnel to access such information ensuring respect of patients' confidentiality and privacy. However, Phimister, Feero and Guttmacher (2012) are of the belief that the acceleration for such a system does not equal the pace at which advances in public health genomics are being made. In contrast, Beighton et al. (2012) raise a concern that the commercialisation and development of PHG will broaden the gap between the developed and the developing world, as the main focus is still on communicable and non-communicable diseases that are not genetically inherited. Ninety percent of the 7.6 million children that are diagnosed with non-communicable conditions are from middle- and low-income countries (Beighton et al. 2012).

A cross-sectional study conducted in Japan examined the attitudes of the public towards the use of genetic information for medical purposes (Ikeda 2008). This information was captured in the form of a self-administered questionnaire, where a stratified random sample of 500 individuals aged between the ages of 20 and 69 years of age were analysed. The results of this study established that both young and old participants supported the use of their genetic information for medical research, as it would be useful to determine future susceptibility to disease (Ikeda 2008).

2.6 Significance of knowledge attitude and practice surveys

The use of a knowledge attitude and practice (KAP) model is vital when one wants to give an educational diagnosis to a society (Kelly 2006). This is done by measuring the knowledge, attitude and practice of a community. The United States Agency for International Development (2011) confirms this by stating that the a KAP survey is a quantitative method that is applied to provide access to quantitative and qualitative information (USAID 2011). KAP surveys make provision for the researcher to unravel any misunderstandings and misconceptions that may exist as obstacles to the activity or practice being implemented and identify potential barriers to behaviour change.

Kelly (2006) advises that prior to creating awareness in any community regarding a topic, it is important to assess the environment in which formation of awareness regarding the topic will take place (Kelly 2006). She goes on to elaborate on the three topics that a KAP survey aims to measure, namely:

- Knowledge: knowledge possessed by a community or an individual is related to their understanding of any given topic.

- Attitude: this refers to the emotions of the community towards the topic including predetermined ideologies that the community may have towards the topic.
- Practice: this is defined as the manner in which the community will demonstrate their knowledge and attitude. In this study, it will be in the form of the uptake of predictive genetic testing or DTC testing.

A KAP survey has the following uses:

- The ability to measure the intricacy of a known situation, provide new perspectives on a situations' reality and confirm or disapprove a hypothesis.
- Enhance the knowledge, attitudes and practices of specific themes. Identification of what is known and what is practised with respect to health-related subjects.
- Establishment of a baseline for use of future assessments pertaining to the subject being surveyed and aids in the effective measurement of health education activities with the intention of changing or modifying health-related behaviours.
- The ability to introduce a suggestive intervention strategy that reflects specific local and cultural factors so that the suggested strategies are tailor made according to the population being targeted and is efficacious (USAID 2011).

According to Launiala (2009), KAP surveys offer an easy design and quantification of data, ease of interpretation and representation of results. Results may be generalised if the sampling is planned appropriately (Launiala 2009). In contrast, some researchers argue that the data generated by KAP surveys are inaccurate and cannot be utilised for programme planning processes (Launiala 2009). The consensus is that the results merely provide researchers with an idea of the current trends pertaining to the study of a subject.

In this study, the use of the KAP model will be used to identify the viewpoints and position of the medical fraternity along with the public who have access to medical aid schemes with respect to the uptake of predictive genetic testing (USAID 2011).

2.7 Factors affecting knowledge attitudes and practices of public health genomics

2.7.1 Positive attitudes with limited understanding in society

Many surveys have been conducted to assess knowledge, attitudes and professional behaviour of physicians toward predictive genetic testing for chronic diseases. In Italy results showed that the medical fraternity has the necessary attitudinal background to contribute to the proper use

of predictive genetic testing for chronic diseases, but additional training to increase methodological knowledge was required (Marzuillo et al. 2013). Despite this, public health physicians have more gaps in their knowledge than other public health professionals, reflecting possible deficiencies in the genetics components of current medical curricula in Italy (Marzuillo et al. 2013). A web-based survey was carried out in the United States assessing the knowledge and attitudes of health educators which revealed a deficiency in knowledge towards public health genomics along with negative attitudes towards the efficiency of public health genomics (Chen and Goodson 2007). In Cameroon, a random sample of pre-clinical medical students, clinical medical students and physicians found a poor level of knowledge of genetics, although there was an acceptance for the principles of medical genetics among the cohort (Wonkam, Njamnshi and Angwafo 2006). Most the respondents were unaware of what a DNA diagnosis entailed, however, they viewed genetic counselling as obligatory. Despite having a lack of knowledge, the cohort accepted the principles of medical genetics (Wonkam, Njamnshi and Angwafo 2006).

2.7.2 Financial impact on genetic testing

A self-administered questionnaire completed by 4050 voluntary participants in the United Kingdom to assess public awareness and motivational reasons for undertaking predictive genetic testing revealed a positive attitude towards the uptake of testing (Cherkas et al. 2010). Initially, only one in twenty participants were interested in the uptake of predictive genetic testing when a cost was attached to the services rendered. However, half of the study population became interested and were willing to undergo predictive genetic testing if it was offered free. Research also established that the majority of participants would be willing to let their families know of their test result and would allow their physician to interpret their results (Cherkas et al. 2010).

In a mixed method study, patient attitudes towards the uptake of genomics testing for prostate cancer susceptibility in Utah showed differences between patients and providers (Birmingham et al. 2013). Almost 52% of patients expressed interest in genetic testing together with an expectation that providers should interpret results and utilise them to assist in personalised administration of treatment. However, most providers revealed that they would not advise predictive genetic testing for their patients as they felt the information received would not be useful in patient care (Birmingham et al. 2013). Other studies, from the US evaluated attitudes of the public on the validity of the genetic test results and utility in personal health care.

Concerns were raised about costs, the need to be educated about the nature of the predisposed disease and the control of access to personal genomic information (Nicol and Liddicoat 2013).

2.7.3 Misinterpretations of genetic test results among patients and providers of genetic testing

Hall et al. (2015) attempted to understand both patient and provider perceptions towards genomic medicine where experiences of genetic counsellors and their patients were used to frame a discussion. While patients were confident and keen in the uptake of predictive genetic testing, genetic counsellors had difficulty in communicating and interpreting genetic results for their patients particularly in the context for predisposition for cancer. This exposes the lack of knowledge among providers with respect to the interpretation and dissemination of results (Hall et al. 2015). Research undertaken to identify attitudes among primary health care physicians in the United States who incorporated genetic testing into their practices (offering of personalised medicine to the public) revealed that the odds of public health physicians ordering personalised predictive genetic testing for themselves was higher than those who ordered for their patients (Haga et al. 2010).

Vayena et al. (2014) assessed the attitudes of students from two Swiss universities and discovered that the majority of natural science students were interested in the uptake of direct to consumer genetic testing with the motivation of enhancing and contributing scientific data towards research and a keen interest in finding out their risks for genetic disorders (Vayena et al. 2014). She also established that 1.5% of the 1146 students had already undergone DTC genetic testing. The most frequent reason given by the students who were not interested in testing (41%) was a concern for results being positive for the predisposition of a disease. The majority of students who had a positive attitude were natural science students while the remainder were from humanities. Leightons, Valverde and Bernhardt's (2011) study provides evidence that the ability of an individual to correctly interpret a DTC genetic test result is reliant on their numeracy skills. This is due to the complexity of risk values associated with the genetic test results, where the numbers are representative of the associated risk (Leighton, Valverde and Bernhardt 2011). The consumer has trouble in interpreting the numerical value ascribed on their predisposition from a DTC test particularly in the absence of assistance from an appropriate medical professional.

When assessing the general publics' perceptions and understanding of DTC genetic test results in New Jersey, Leighton, Valverde and Bernhardt (2011) found that there was a significant

difference between the public and genetic counsellors in the interpretation of results relating to colorectal cancer, heart disease and skin cancer. The public was of the belief that there was no need for a genetic counsellor to assist in the interpretation of their genetic test results. Despite their belief that the interpretation of the genetic test results was easy, the majority misinterpreted the results (Leighton, Valverde and Bernhardt 2011).

A study conducted by Powell et al. in 2012, surveyed physicians' knowledge and attitudes regarding DTC genetic testing among primary health care providers in North Carolina and showed that only a minority of the respondents were aware of DTC genetic testing and only a few were willing to discuss DTC genetic testing with patients. From those who were aware of DTC genetic testing, only 40% believed that DTC genetic testing would be clinically useful.

Etchegary (2014) found that the public is more likely to order a DTC genetic test that is administered by a health care professional than a private company as they have concerns regarding the privacy of their medical information. These include:

- The public prefers tests of clinical utility, however there are some unacceptable uses for the uptake of genetic testing such as selection of new-born traits.
- There are both societal and individual concerns regarding the uptake of predictive genetic testing.
- There are racial differences in the attitudes of the public towards predictive genetic testing (Etchegary 2014).

2.7.4 Sociodemographic impact on the uptake of public health genomics

A study carried out in South Carolina evaluated the racial differences in attitudes towards personalised medicine among 190 Hispanic and non-Hispanic individuals (Diaz et al. 2014). Results showed that more non-Hispanic white participants were accepting of personalised medicine than non-Hispanic black participants who displayed concerns about the use of their genes including sharing of genetic information without consent, discrimination against them based on their genetic information, and lack of access as a result of the cost of the uptake of personalised medicine (Diaz et al. 2014).

A survey undertaken in the United States determined attitudes towards informed consent for genomic research (Valle-Mansilla et al. 2010). Results revealed that participants would give consent to participation but would not consent to research sponsored by industry (Valle-Mansilla et al. 2010). It is therefore vital to consider factors that influence patients to reject an

expansive informed consent for donation of samples for future genomic research (Valle-Mansilla et al. 2010).

A qualitative study undertaken in Amsterdam which explored women's attitudes towards genetic testing for breast cancer susceptibility revealed that women were positive towards breast cancer screening. However, screening was only offered based on age and susceptibility (Henneman et al. 2011). Similarly, in the Netherlands and other northern European countries, participation in screening for breast cancer was high given that it was organised as a public health initiative from the government. However, access was again dependent on age (Henneman et al. 2011). Participants in this study reported that while genetic screening for breast cancer gave them the confidence to be responsible for their health, they also felt that positive results would create a burden in their lives (Henneman et al. 2011). They agreed that women of all ages should be offered genetic testing irrespective of age and severity of predisposition (Henneman et al. 2011).

A longitudinal study carried out by the same researchers aimed to compare the public experiences, beliefs and expectations of genetic testing between 2002 and 2010 (Henneman et al. 2013). Over the eight-year period, awareness regarding genetic testing did not increase. However, genetic developments increased the expectations of the public, although there was an expression of concern about the disadvantage of genetic testing. This study also reported that younger respondents and those with tertiary education had fewer concerns regarding predictive genetic testing (Henneman et al. 2013).

2.8 Knowledge and attitudes of physicians towards the use of predictive genetic testing in practice

Marzuillo et al. (2013) assessed the knowledge, attitudes and behaviour of physicians regarding predictive genetic testing for breast and colorectal cancer among a random sample of Italian physicians (Marzuillo et al. 2013). Results showed a significant lack of knowledge among the physicians. Less than half of the physicians agreed with the importance of efficacy and cost-effectiveness in the adoption of predictive genetic testing (Marzuillo et al. 2013). Logistical regression analysis showed that education had a strong influence on the knowledge, attitudes and professional use of predictive genetic testing (OR = 12.65; 95% CI = 7.77 – 20.59). However, physicians were interested in specific training on genetic testing (Marzuillo et al. 2013).

Scheuner, Sieverding and Shekelle (2008) identified positive attitudes of physicians with respect to the perceived benefits of genomic testing. However, limitations such as the lack of understanding pertaining to genomic medicine which included a large gap in the knowledge of genomic medicine and genomic testing specifically for chronic diseases were identified Grant et al. (2009) conducted a national survey of general internists and endocrinologists in the U.S. to assess the perceptions of physicians regarding the utilisation of genomic testing for common chronic diseases such as diabetes (Grant et al. 2009).

Mainous et al. (2013) carried out a study in the U.S. to assess physicians' perceptions of genetic testing and integration into practice and found that most of the primary care and family physicians were of the opinion that genomic testing would be clinically beneficial in the next five to ten years (Mainous et al. 2013). Research in Australia reported that medical practitioners referred their patients for cancer genetic testing with the most referrals being made by breast/ovarian specialists followed by gastrointestinal specialists (Teng and Spielman 2014). There were indications of inappropriate referrals among doctors. However, many were willing to receive further information on cancer testing (Teng and Spielman 2014). This indicated a need for further training for correct referrals of patients to the relevant specialist (Teng and Spielman 2014).

2.9 PHG training

Lanuale et al. (2014) carried out a cross-sectional survey among 33 Italian public health post-graduate schools to determine the relevance and appropriateness of the presence of a Public Health Genomics course (Lanuale et al. 2014). The objective of this research was to evaluate the success of the PHG programme by establishing if medical students were aware of the use, interpretation and uptake of genetic testing in the medical field (Lanuale et al. 2014). The results showed that PHG courses in post-graduate public health schools were appropriate and relevant but further harmonisation of the training programmes for efficacy was recommended (Lanuale et al. 2014). Assessment of an online continuous professional development (CPD) programme revealed that an online genetics module proved to be a feasible, clinically acceptable method to improve the oncogenetics knowledge of medical practitioners. The researchers recommended that additional online genetics modules be developed to improve the knowledge of medical practitioners. Houwink et al. (2014) also state that the adoption of this educational technique has international reach and can be used to reach a larger audience.

In South Africa, the knowledge and perceptions of midwifery learners regarding genetics was investigated. The results revealed that genetics education is underrated in South Africa (Phaladi-Digamela 2014). A descriptive study conducted among advanced midwifery learners in South Africa revealed that advanced midwifery learners lack suitable genetic knowledge (Phaladi-Digamela, Mulaudzi and Maja 2014). This was attributed to the absence of a curriculum that requires an integration of adequate genetics in the advanced midwifery course. Currently Advanced Midwifery educators address genetics education at the discretion of the individual educator as there is a lack of curriculum framework surrounding the standardisation of genetics education at post-graduate nursing institutions in South Africa. Primary health care professionals lack a framework within the curriculum for standardised genetic education.

The introduction of early health education is expected to familiarise the public with genomics and this can also create a path for society to engage in and be a part of discussions regarding policy making in the future (Zusevics et al. 2014). Furthermore, the integration of PHG into health education could assist in encouraging end users to be critical of their decisions regarding the potential benefits and concerns surrounding the advent of PHG. In order to accelerate this Zusevics et al. (2014), PHG education needs to deliver on the following:

- Increase in the knowledge of end users of PHG.
- Contribute towards end users and among health science student's health literacy.
- Create a critical mindset among health science and medical students regarding the advent of new technologies for disease reduction.

2.10 Opinions from public health genomics end users

Gollust et al. (2015) surveyed the users of personalised genomics through an internet based survey regarding their enthusiasm, responsiveness to personalised medicine, perceptions of study risks and benefits and their intentions to share results with health care providers. The majority of respondents were personally motivated to know their disease risk in order to improve their health (Gollust et al. 2015). Although people from Europe and Northern America displayed a positive attitude towards genetic testing, their motivations for genetic testing was unclear (Etchegary 2014). In the USA and New Zealand people displayed a positive attitude towards predictive genetic testing which could have caused a psychological and behavioural impact based on the results received. Individuals may either change their behaviour to reduce their risk or they may go into depression and not want to make any lifestyle changes at all (Etchegary 2014).

2.11 Influence of religious beliefs on the uptake of public health genomics

A qualitative study in Nigeria confirmed that religious beliefs influenced participants' perceptions toward genomic testing with the majority of participants disclosing their fear of direct to consumer personal genomic testing and disclosing of their results to third parties (Fagbemiro and Adebamowo 2014).

South Africa has been identified as a country in transition with respect to genetic services (Kromberg, Sizer and Christianson 2013). Though there may be availability of genetic services, the number of professional genetic counsellors and the accessibility to genetic services are limited compared to other countries. Despite the introduction of a modern technology which is aimed at improving the morbidity, actual implementation remains a challenge. According to Kromberg, Sizer and Christianson (2013), the Health Professions Council of South Africa recognises genetic counselling as a registered health profession with formal post-graduate training at a masters' degree level. However, only four medical universities in the country have medical genetics professionals on their staff and the extent to which genetics is covered in the syllabus also varies (Kromberg, Sizer and Christianson 2013).

The development of medical genetic services is dependent on the knowledge and awareness among users. However, the genetic services that are available to the public at present can only meet 10% of the country's' genetic needs (this is based on an estimate of the calculation of the burden of disease in South Africa) (Kromberg, Sizer and Christianson 2013). It is evident that although there is a provision of genetic services for the predictive testing of non-communicable diseases, South Africa lacks adequate infrastructure to ensure the smooth delivery of genetic services. However, with the assistance of the relevant stakeholders, South Africa can be capacitated to broaden genetic services so that all aspects, including social to ethical considerations are adopted and applied.

2.12 Summary

It can be concluded that disease prevention is directly related to the education of health professionals (Wonkam, Njamnshi and Angwafo 2006). Studies conducted globally and locally reveal a common trend of misinterpretation, or inadequate knowledge pertaining to genomic medicine. According to Henneman et al. (2013), attitudes towards genetic testing also vary with age and gender, and someone who has more knowledge on genetic testing may not necessarily be more supportive of it. Increased knowledge may be interpreted as a reduced

perceived benefit from genomic testing (Henneman et al. 2013). Furthermore, based on literature, one can extrapolate that families, friends and the media can influence ones' perception and attitude towards predictive genetic testing.

Knowledge may not be the only factor which determines ones' attitude towards the uptake of predictive genetic testing. Research has shown that individuals in some countries preferred the use of DTC genetic testing that is offered online and excludes the services of a medical practitioner and a genetic counsellor making it much cheaper than when undergoing predictive genetic testing with medical professionals (Gollust et al. 2015).

Research also shows that people of colour are more fearful to undertake predictive genetic testing as they have the perception that it may result in discrimination. Individuals lacking relevant knowledge may display a negative opinion regarding its' impact in the health sector and in their own lives. While it is imperative to consider the ethical and social implications of the implementation of public health genomics, it is also vital to always inform individuals of both pros and cons prior to the introduction of a new technology.

There is a dearth of research in the South African context about the knowledge and perceptions of PHG from the general public. It is vital to obtain the opinion of the public specifically regarding non-communicable diseases as they are end users. De Villiers (2011) questions the PHG competence of family medical practitioners and recommends reviewing curriculum in medical schools to ensure the preparedness of doctors to understand clinical and practical aspects of genomics.

It is also essential that one identifies and establishes the level of knowledge and perceptions of public health genomics in context, as data has shown that each country varies in their level of knowledge and understanding of genomic medicine. Perceptions also vary according to their surroundings and what is most influential in the existing healthcare landscape. When the status quo is known regarding the level of knowledge and attitudes towards PHG, the general public can be protected and the medical fraternity educated to avoid the probability of ethical and social discrimination when predictive genetic testing is used.

CHAPTER 3: METHODOLOGY

3.1 Overview

This study assessed the knowledge, attitudes and practices of medical practitioners, medical students and the general public in KwaZulu-Natal (KZN). The fieldwork was carried out over a period of ten months and consisted of 3 points of data collection namely:

- Collection of data in the form of structured questionnaires from the general public which consisted of educators from five schools in and around Durban (Appendix A).
- Collection of data in the form of structured questionnaires from private medical practitioners within the South African Medical Association forum (Appendix B).
- Collection of data in the form of structured questionnaires from second year medical students attending the University of KwaZulu-Natal medical school (Appendix C).

3.2 Research design

A quantitative cross-sectional survey was implemented in the form of self-administered questionnaires. This type of study allowed for the identification of knowledge and attitudes of various medical doctors, second year medical students and educators representative of the general public, toward genomic medicine.

3.3 Study population of samples

The sample population consisted of three sample groups which were stratified related to objectives One, Two and Three.

Objective One: Ten teachers from each of the five schools in the Durban area were selected according to the inclusion and exclusion criteria to participate in the study. The total study sample was 50. Educators were representative of the general public as they are seen as individuals with tertiary education and are provided with medical aid and thus have the means to access genetic services.

Objective Two: Forty-five medical practitioners from SAMA (South African Medical Association), Ahmed Al-Kadi Hospital, Durban South Doctors Guild and Osindisweni Hospital. These were selected according to the inclusion and exclusion criteria.

Objective Three: Eighty students from the medical school in the University of KwaZulu-Natal were selected according to the exclusion and inclusion criteria.

3.4 Sampling strategy

Objective One:

Stratified sampling was used to recruit teachers who represented the public in this study to ensure equal representation from public and private schools. Hence, a random sample consisting of five schools within eThekwini was used to achieve the third objective.

Ten (10) teachers from five schools:

a. Columbia Primary School (Greenwood Park) – public school
b. Durban North College (Durban North) – public school
c. Orient Islamic School (Durban Central) – private school
d. Zenzelini Primary School (Verulam) – public school
e. Al Falaah Private School (Overport) – private school

The goal was ten teachers from each school (50). In total, 47 responded. This sample represented individuals with tertiary education qualification, and medical aid.

Inclusion Criteria:

- Teachers who are registered with South African Council of Educators (SACE).
- Teachers who have access to private medical aid.

Exclusion Criteria:

- Teachers who are not registered with SACE.
- Teachers who do not have access to private medical aid.
- Teachers who teach grade 12 as the basics of genetics are taught in the grade 12 natural science curricula.

Objective Two:

Creswell et al. (2012) refer to convenience sampling as the selection of participants within a population based on their ease of availability. For the purposes of this study, convenience sampling was used to achieve the first objective of this research.

This survey included the participation of 45 general medical practitioners from the South African Medical Association (SAMA), Ahmed Al-Kadi Hospital, Durban South Doctors Guild and Osindisweni hospital.

Inclusion criteria:

- Medical practitioners who are registered with the Health Professions Council of South Africa (HPCSA).
- Medical practitioners who have been practicing medicine for at least 2 years.

Exclusion Criteria

- Medical practitioners who are not registered with the Health Professions Council of South Africa (HPCSA).
- Medical practitioners practicing medicine for less than two years.

Objective Three:

Convenience sampling was used to recruit 80 students from the medical school (University of KwaZulu-Natal). Specifically, second year medical students who had not been exposed to any genetic modules were selected.

Inclusion Criteria:

- Students registered for MBChB at the University of KwaZulu-Natal Nelson R. Mandela School of Clinical Medicine.
- Second year students who had not yet been exposed to the genetic module in the curriculum.

Exclusion Criteria:

- Students who are not registered for their MBChB at the University of KwaZulu-Natal Nelson R. Mandela School of Clinical Medicine
- Students who had taken the genetics module in the curriculum.

3.5 Procedure for data collection

Objective Two

1. An appointment with the Director of South African Medical Association (SAMA) disclosing the objectives of the survey and requesting permission to hand out a letter of information (Appendix D), consent form (Appendix E) and a questionnaire to each participant before the commencement of the meeting was arranged.
2. Appropriate dates and times to access medical practitioners were identified. The researcher resolved not to impede the conference of private medical practitioners, therefore, the information letter, letter of consent and self-administered questionnaire was given before the conference.
3. The consent forms and questionnaires were collected after completion and placed into a sealed envelope.
4. Data was also collected from private medical practitioners from Ahmed Al-Kadi Hospital, Durban South Doctors Guild and Osindisweni hospital due to the sample size not being met at the SAMA conference.

Objective Three

1. An appointment was arranged with the Dean of the Nelson R. Mandela medical school in order to organise logistical procedures (date, time, location) of the study.
2. An appointment was made with the second-year lecturer/s disclosing the objectives of the survey and requesting permission to hand out a letter of information (Appendix D), a consent form (See Appendix E) and a questionnaire to participants.
3. Appropriate dates and times to access the medical students were identified. The intention of the interviewer was not to impede academic learning. Therefore, the information letters, letters of consent and self-administered questionnaires were handed out at the end of the lecture.
4. The consent forms and questionnaires were collected after completion and placed into an envelope that was sealed and labelled.

Objective One

1. A date and time were arranged with the Principal of each of the five schools in order to seek permission and organise logistical procedures of the study.

2. An appointment was made with educators disclosing the objectives of the survey and requesting permission to hand out a letter of information (See Appendix D), a consent form (See Appendix E) and a questionnaire to each participant.
3. Appropriate dates and times were identified to access the educators. The intention of the interviewer was to not hinder the educators in their responsibilities, therefore, the information letters, letters of consent and self-administered questionnaires were handed out after a staff school meeting.
4. The consent forms and questionnaires were collected after completion and placed into an envelope which was sealed and labelled.

3.5.1 Data collection

3.5.1.1 Measurement tool: Questionnaire development

Three structured questionnaires were designed by the researcher in order to gather data related to each objective of this study. The questionnaire was designed based on data gathered in the literature review and from previous studies conducted globally (De Vos 2011).

3.5.1.2 Focus group

Questionnaires were submitted to an expert focus group for feedback. The objective of a focus group is to encourage the members of the group to develop ideas surrounding the research question (Salant and Dillman 1994). Members of the group critically assessed the relevance of the questions in the questionnaire within the context of the research question and the objectives of this study. The focus group followed the guidelines as outlined by Silverman (2001). The focus group in this study consisted of the following members:

- The researcher
- A specialist in medical genomics.
- Peer representatives from Public Health.

Prior to commencing the focus group, the participants were required to read a Letter of Information (Appendix D) and sign a Confidentiality Statement (Appendix F), Code of Conduct Statement (Appendix G) and Informed Consent (Appendix E).

3.5.1.3 Pilot Study

A pilot study is a trial run of the larger study that is conducted in preparation for the study to determine the feasibility of a research tool (Trochim 2000). The aim of the pilot study in this context was to determine if the participants clearly understood the questionnaire in order to identify errors or ambiguity. This also allowed the researcher to identify possible problems in the conduct of this study.

All three questionnaires were piloted. The pilot study comprised representatives from the sampled population; three medical doctors, three medical students from fourth and fifth year, and three educators practicing in their field.

The objective of the pilot study determined whether the questions were answered efficiently as follows (Raad 2012).

- Are there any questions that are irrelevant or misleading?
- Are the questions appropriate for the individuals participating in the study?
- How long did it take to answer the questionnaire?
- How accurate is the information obtained by the questionnaire?
- Will the information the researcher collects enable her/him to use the questionnaire appropriately?
- How consistent is the information obtained by the questionnaire?

The objective of the pilot study found that the questionnaire was designed sufficiently to obtain information relevant for the study. The information obtained during the pilot study was found to be consistent and enabled the researcher to be able to utilise it for research purposes. There was no ambiguity identified and participants understood the questions and answered accordingly.

3.6 Validity and reliability

The reliability of an instrument indicates that if the same instrument is used at different times, or administered to various subjects from the same population, the findings should be the same. Reliability can be defined as the extent to which a measuring instrument is repeatable and consistent (Creswell et al. 2012). Validity can be defined as the extent to which the instrument measures what it is supposed to measure (Creswell et al. 2012).

The pilot study carried out in this study ensured the reliability of the sampling tool (questionnaires) and a focus group was used to determine the validity of the measuring tool (questionnaires). A reliability coefficient of 0.60 or higher is considered as "acceptable" for a newly developed construct. The reliability score (Cronbach's Alpha) for knowledge (0.61) and attitude (0.64) indicated an acceptable, consistent scoring for the knowledge and attitude sections of the questionnaires.

3.7 Data management and analysis

All questionnaires that were completed in full by the participants were entered using double entry and cleaned using Microsoft Excel 2013. STATA (version 12) was used and SPSS (version 25.0) was used for univariate, bivariate analysis. A p-value of < 0.05 was considered as statistically significant. Descriptive and frequency analysis using mean, standard deviation and range was used for quantitative variables. Knowledge and attitude responses of participants were stratified by gender, race and for medical practitioners – practice type. These were represented in the form of stacked bar charts. Outcome variables were described with the use of relative frequency, cross tabulations and bivariate analysis. Bivariate correlations using Spearman's rho test was conducted to identify significant associations with knowledge and attitudes of participants towards public health genomics. Principal Component Analysis (PCA) was conducted on knowledge and attitude sections of questionnaires from all study groups to find associations with variables in the dataset based on eigen values generated. The range of eigen values determined the variation of associations between knowledge and attitude variables. Scoring scales were used to determine the level of knowledge and type of attitude participants had towards predictive genetic testing. Knowledge levels were divided into three categories – excellent (if participant scored between 32 and 44 points), adequate (if participants scored between 31 and 24 points) and poor (if participants scored 24 points and below). All knowledge-based questions answered correctly were given a point, while incorrect answers were scored as 'zero'. The same criteria applied for scoring of attitudes of participants. Where the response of participant was positive, a point was given and for a negative answer, no point was given. Participants scoring between 33 and 22 points were categorised with a positive attitude. Participants scoring with points below 21 were identified as having a negative attitude towards predictive genetic testing.

3.8 Ethical considerations

- This study was approved by the Durban University of Technology's Institutional Research and Ethics Committee (IREC) (Ethical clearance number IREC 085/16) (Appendix H).
- Permission for implementation of the study was sought from the following relevant authorities:
  - KwaZulu-Natal Department of Education (Appendix I)
  - Registrar of the University of KwaZulu-Natal (Appendix J and Appendix K).
  - School principals from the five schools being sampled.
- Confidentiality of all participants was maintained, and informed consent was administered to those willing to participate in the study.
- All information concerning the study participants was and will be kept confidential.
- Study participants are entitled to privacy and had the option to withdraw from the study at any time without consequence.

CHAPTER 4: RESULTS

4.1 Introduction

This chapter presents the results from the questionnaires in this study. The questionnaire was distributed to three sample populations, namely: medical students, medical practitioners, general public. The results will present descriptive statistics in the form of graphs, cross tabulations and other figures. A total of 45 questionnaires were completed by the medical practitioners, 79 questionnaires by the medical students, and 47 questionnaires were completed by the general public. Two questionnaires from the general public sample were discarded as they were not completed or completed incorrectly.

Table 4.1: Demographic characteristics of general public, medical practitioners and medical students (n = 170)

Characteristic	n (%)
General Public (n = 45)	
Age (mean, SD)	39.3 (11.30)
Gender	
Male	4 (8.70)
female	42 (91.30)
Race	
African	9 (19.6)
White	10 (21.7)
Indian	27 (58.7)
Education	
University	42 (95.5)
National Qualification Level 6 (advanced certificates)	2 (4.5)
Medical Practitioners (n = 45)	
Age (mean, SD)	46.79 (14.65)
Gender	
Male	31 (68.9)
female	14 (31.1)
Race	
White	3 (6.7)
African	6 (13.3)
Indian	34 (75.6)
coloured	1 (2.2)
Practice Type	

Private	14 (31.1)
Government	17 (37.8)
Public	6 (13.3)
Other	4 (8.9)
Number of years in practice (mean, SD)	22. (14.6)
Medical students (n = 79)	
Age (mean, SD)	20.22 (2.76)
Gender	
Male	28 (35.4)
female	51 (64.6)

There were 170 participants (n = 170) in this study. The demographic characteristics of the study sample population from all sample groups are presented in Table 4.1. The mean age of general public was 39.30 years (SD $\pm$ 11.30), whereas the mean age for medical practitioners was 46.79 years (SD $\pm$ 14.65). There were more female participants among the general public (91.30%) and the medical students (64.6%). Most of the study participants were of Indian race. Approximately 37.8% of the medical practitioners practised in government health care facilities.

4.2 General public

The questionnaire was divided into three sections in terms of biographical data and Likert scale responses related knowledge and attitude towards genetic testing for diseases. Table 4.2 shows the frequency distribution for knowledge questions. The majority of the participants knew that genetic testing is offered in South Africa (53%), however only 24% of the respondents knew where to access a genetic test in KZN. Most respondents disagreed that genetic testing can be used to prevent HIV, AIDS and TB, whereas 43.5% of respondents indicated that genetic testing can be useful in the prevention of non-communicable diseases such as diabetes and cancer. Forty percent of respondents indicated that they did not know what to do after receiving their genetic test results.

Table 4.2 and Figure 4.1 depict the difference in male and female responses pertaining to their knowledge on genetics. Forty-seven percent of females indicated that they agree that genetic testing can be used to prevent diseases whereas 50% of males disagreed with this statement. More females than males knew where to have a genetic test done in KZN. Fifty percent of males and 31% of females were unaware that genetic testing was offered in South Africa. More

males (75%) than females (61%) agreed that genetic testing can be used to diagnose genetic conditions and treat them and can be helpful in determining the correct medication.

Table 4.2: Table 4.2.1 Knowledge of general public towards genetic testing (n = 45)

	Strongly Disagree n (%)	Disagree n (%)	Agree n (%)	Strongly Agree n (%)	p – value
Genetic testing can be used to prevent diseases such as diabetes, cancer.	0 (0.0)	5(10.9)	20 (43.5)	21 (45.7)	0.005
Genetic testing can be used to prevent HIV, AIDS, TB.	9 (19.6)	45.7	8 (17.4)	8 (17.4)	0.015
Genetic testing can be used to determine future susceptibility to certain diseases.	0 (0.0)	3 (6.5)	25 (54.3)	18 (39.1)	0.000
I know what to do after I get my genetic test results back.	4 (8.9)	18 (40)	17 (37.8)	6 (13.3)	0.003
Genetic testing is being offered in South Africa.	1 (2.2)	16 (35.6)	24 (53.3)	4 (8.9)	0.000
I know where to have a genetic test done in KwaZulu-Natal.	11 (24.4)	20 (44.4)	12 (26.7)	2 (4.4)	0.002
Having a genetic test is valid and accurate.	0 (0.0)	12 (27.3)	27 (61.4)	5 (11.4)	0.000
There are few ethical guidelines for human genetic tests in South Africa and these guidelines protect us.	2 (4.5)	9 (20.5)	24 (54.5)	9 (20.5)	0.000
There are no laws in South Africa for the protection of personal genetic information.	0 (0.0)	10(23.3)	25 (58.1)	8 (18.6)	0.002
Genetic testing can be used to also find genetic conditions and treat them.	0 (0.0)	1 (2.2)	28 (62.2)	16 (35.6)	0.000
Genetic testing is useful in helping to use the right medication for treatment.	1 (2.2)	1 (2.2)	29 (64.4)	14 (31.1)	0.000

*$p \leq 0.05$ was considered statistically significant

Figure 4.2 represents knowledge levels of the general public stratified by race. Forty-eight percent of Indians strongly agreed that genetic testing can be used to prevent diseases. Fifty-five percent of Africans and 40% of whites agreed with the same. More Africans (77%) than Indians (46.2%) and whites (50%) agreed that genetic testing is being offered in South Africa. All three race groups revealed that they do not know where to access a genetic test in KZN. Eighty-seven percent of the African race group agreed that having a genetic test is valid and accurate. Sixty-two percent of the African race group agreed with the statement that there are a few ethical guidelines for human genetic testing in South Africa and that these guidelines protect us.

Table 4.3 shows participant attitude towards genetic testing. It can be seen that 46.7% of the sample felt that it was important for the community to know about genetic testing. However, 59.1% of respondents felt that they would be discriminated against if they had to undertake genetic testing. Despite the potential for discrimination, 64% of respondents indicated that the benefits of genetic testing outweigh the disadvantages. The majority of the respondents (50%) indicated that they would not object to their genetic data being used for research purposes. However, 44.4% felt that the use of their genetic data for research purposes would create a cause for concern if used without their consent.

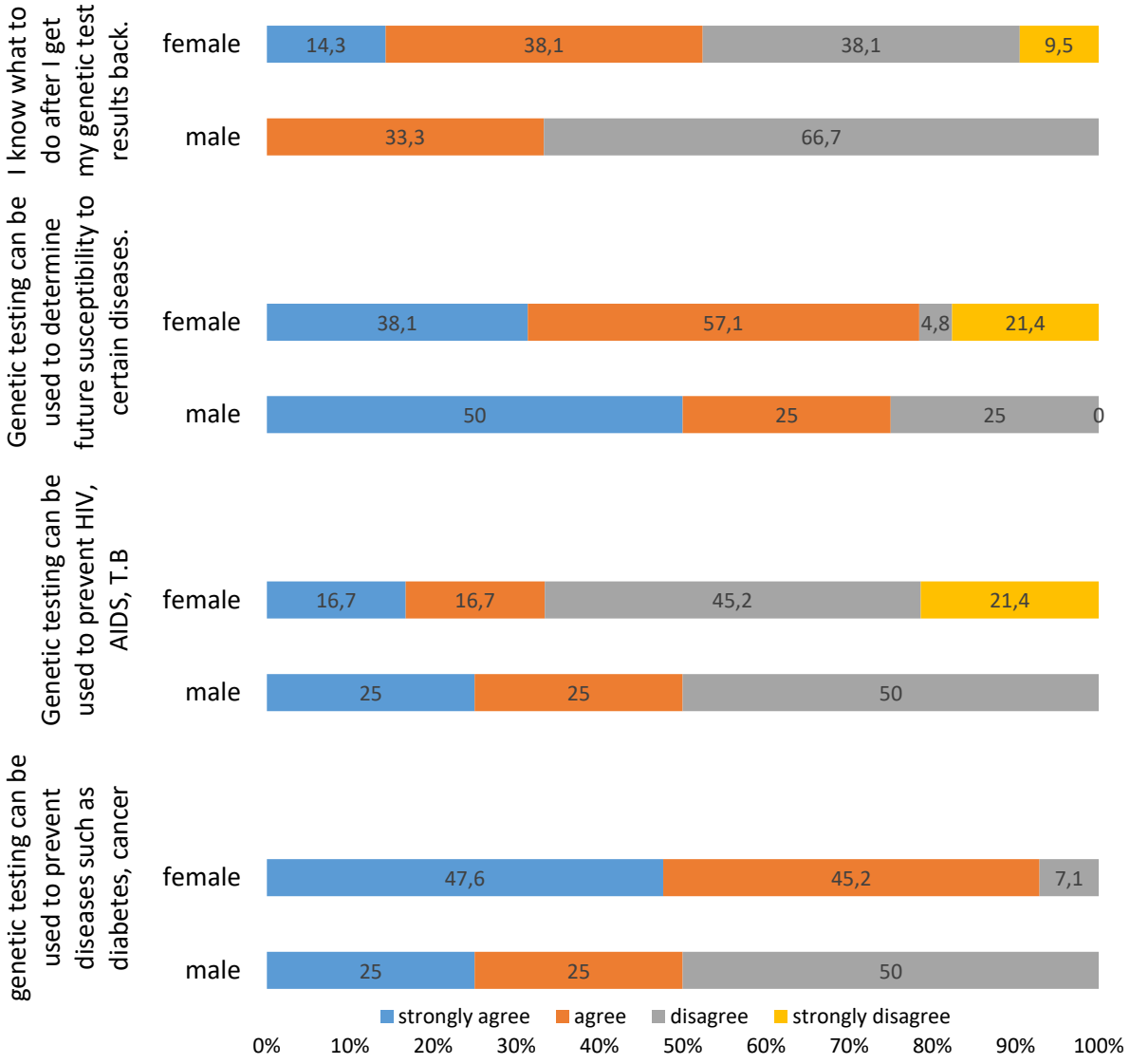

Figure 4.1: Knowledge of general public towards genetic testing stratified by gender (n = 47) – part 1

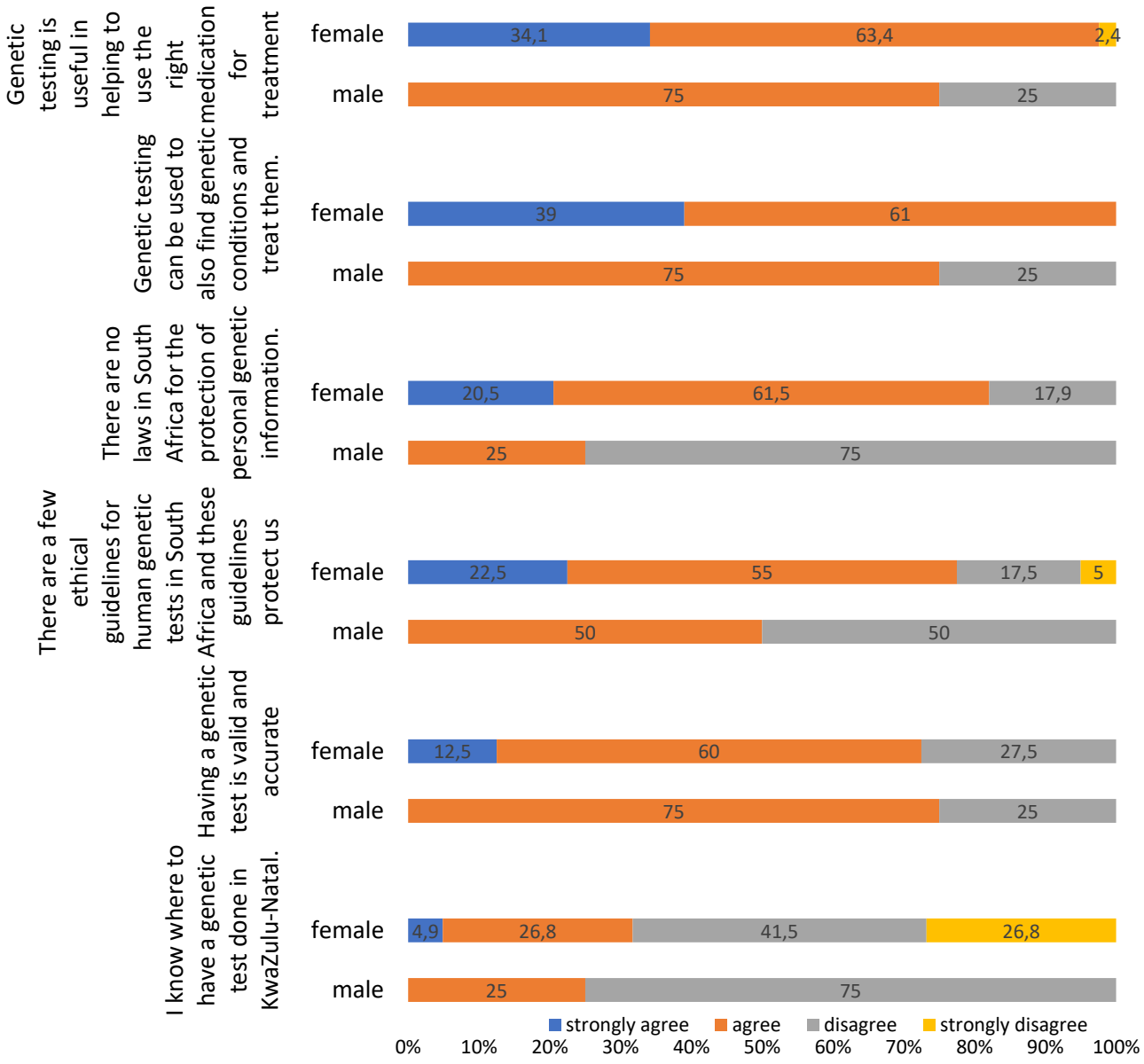

Figure 4.1: Knowledge of general public towards genetic testing stratified by gender (n = 47) – part 2

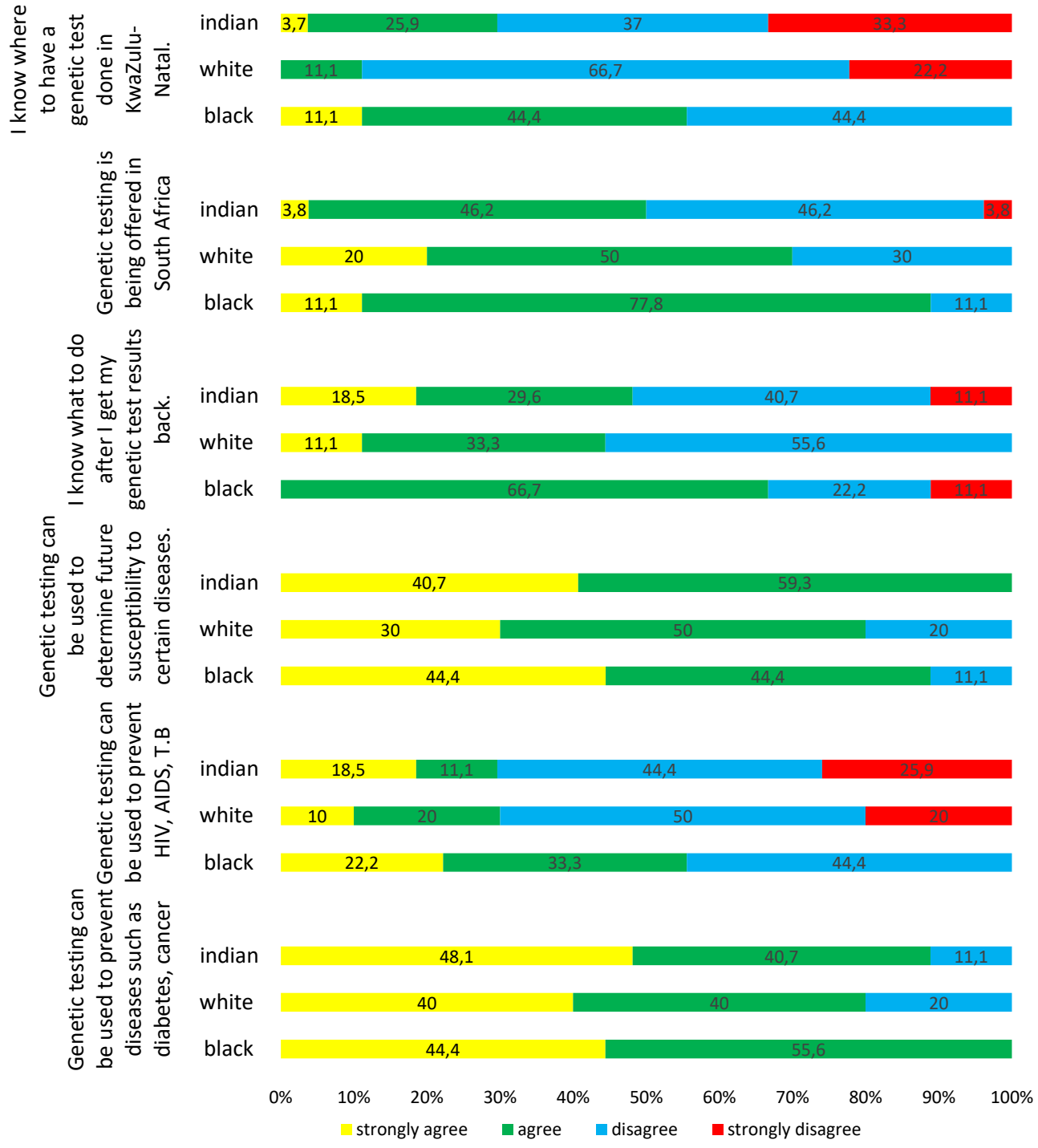

Figure 4.2: Knowledge of general public towards genetic testing stratified by race (n = 47) – part 1

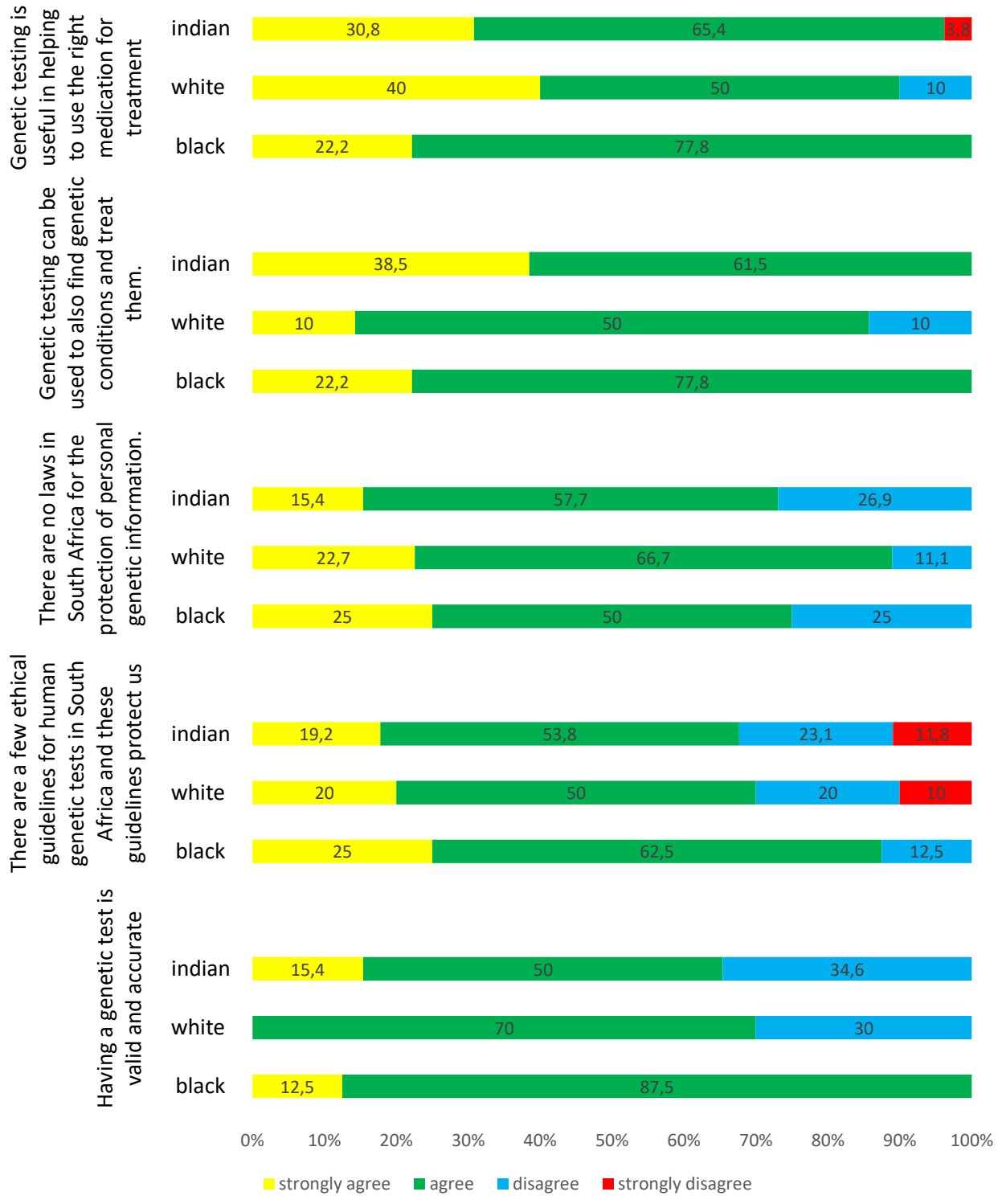

Figure 4.2: Knowledge of general public towards genetic testing stratified by race (n = 47) – part 2

Table 4.3: Attitude of general public towards genetic testing (n = 47)

	Strongly Disagree	Disagree	Agree	Strongly Agree	Chi Square p – value
	n (%)	n (%)	n (%)	n (%)	n (%)
Genetic testing is an important topic for the community to know about.	1 (2.2)	1 (2.2)	22 (48.9)	21 (46.7)	0.000
Genetic testing will not be too expensive to use.	0 (0.0)	10 (23.3)	28 (65.1)	5 (11.6)	0.000
I would like to find out if I am at risk for any chronic disease.	1 (2.2)	5 (11.1)	16 (35.6)	23 (51.1)	0.000
I will not be worried about what my genetic test results will be like if I had to have a test done.	1 (2.3)	10 (22.7)	26 (59.1)	7 (15.9)	0.000
If my genetic test result is positive for a disease, it will not cause me to be stressed.	1 (2.2)	9 (20.0)	27 (60.0)	8 (17.8)	0.000
I feel genetic testing has more benefits than disadvantages.	1 (2.2)	3 (6.7)	29 (64.4)	12 (26.7)	0.000
I am not concerned about my genetic data being used for further studies without my consent.	5 (11.1)	13 (28.9)	20 (44.4)	7 (15.6)	0.007
I would like for my genetic data to be used in scientific research.	7 (15.9)	12 (27.3)	22 (50.0)	3 (6.8)	0.000
I would like to learn more about genetic testing.	0 (0.0)	3 (6.8)	22 (50.0)	19 (43.2)	0.001
I will not be discriminated against if my genetic test results are positive.	9 (20.5)	26 (59.1)	8 (18.2)	1 (2.3)	0.000

*$p \leq 0.05$ was considered statistically significant

Figure 4.3 reveals the attitudes of males and females towards genetic testing. Both males and females agreed that genetic testing is an important topic. More males (75%) than females (57%) felt that they would not be concerned about their genetic test results should they have had the test done. This correlates with most males indicating that they would not be stressed if they received a result denoting increased disease risk. Only half of all participants indicated that they would not be averse to the use of their genetic data in scientific research. It is important to note that 100% of male participants and 55% of female participants were concerned about potential discrimination linked to test results.

Figure 4.4 shows that more Africans (77%) than whites (55%) and Indians (64%) agreed that genetic testing will not be too expensive to use. More Indians (53%) than whites (50%) and Africans (44%) strongly agreed that they would want to know if they are at risk for any chronic disease. All three race groups revealed their agreement that genetic testing has more benefits than disadvantages. All three race groups indicated that they would like to learn more about genetic testing.

4.2.1 Knowledge and attitude scores of the general public towards genetic testing

Scoring for knowledge questions were broken down into three categories, namely excellent, adequate and poor to identify the knowledge levels (Table 4.4). A similar scoring system was used for attitudes. If the response was linked to a positive attitude the score was higher. Overall the knowledge levels of the general public were adequate, and 89% of respondents displayed a positive attitude towards genetic testing.

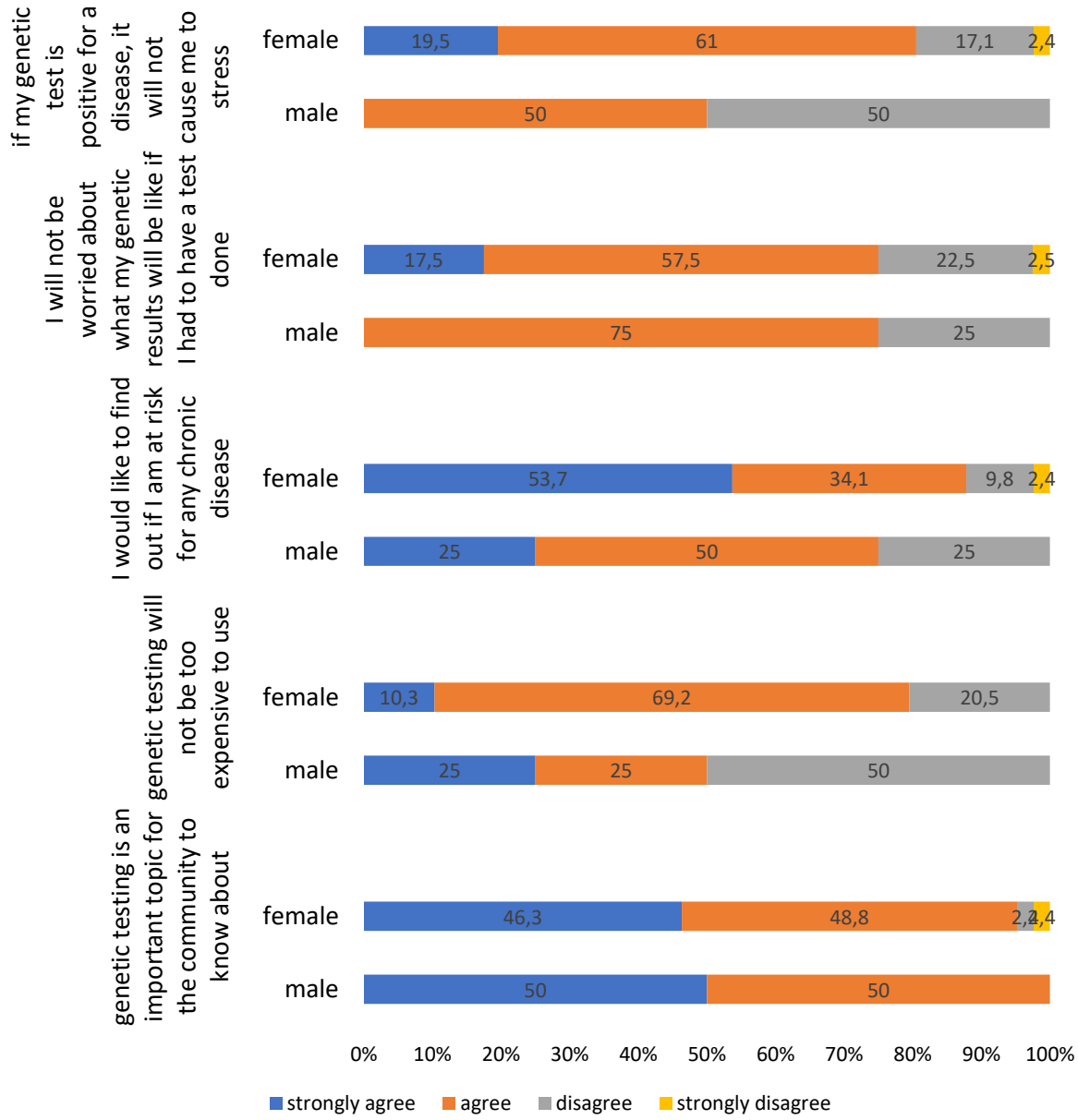

Figure 4.3: Attitudes of general public towards genetic testing stratified by gender (n = 47) – part 1

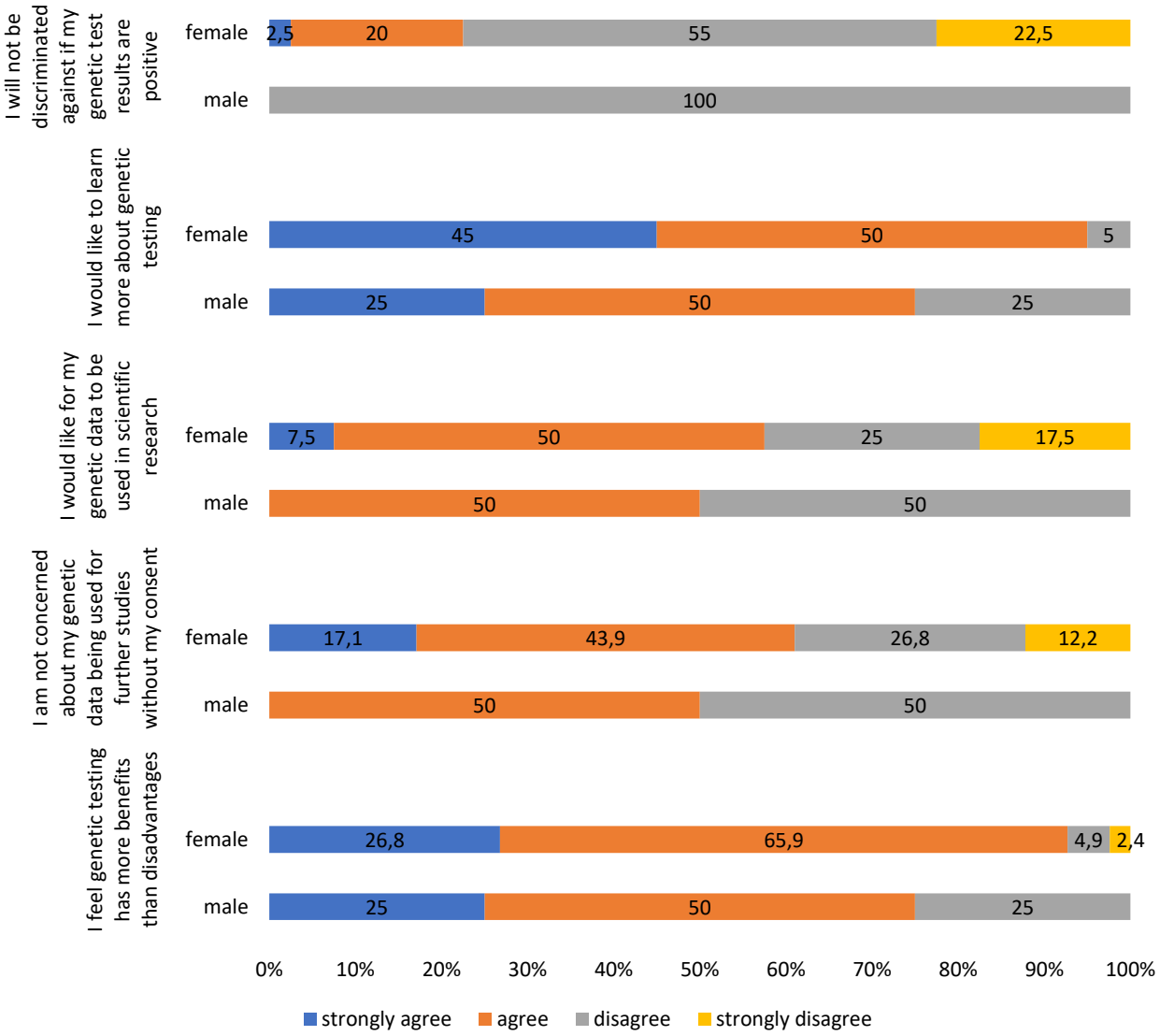

Figure 4.3: Attitudes of general public towards genetic testing stratified by gender (n = 47) – part 2

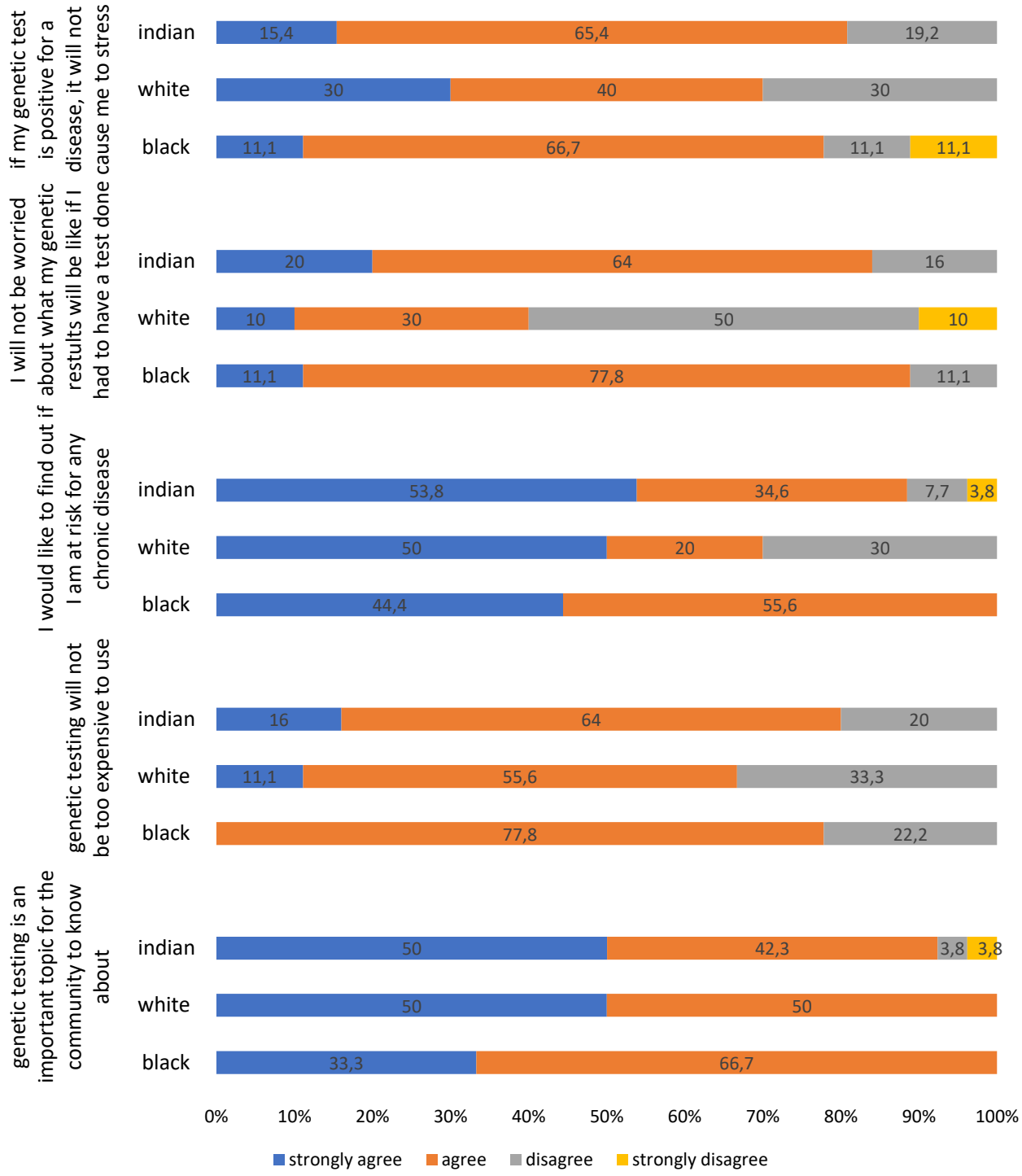

Figure 4.4: Attitudes of general public towards genetic testing stratified by race (n = 47) – part 1

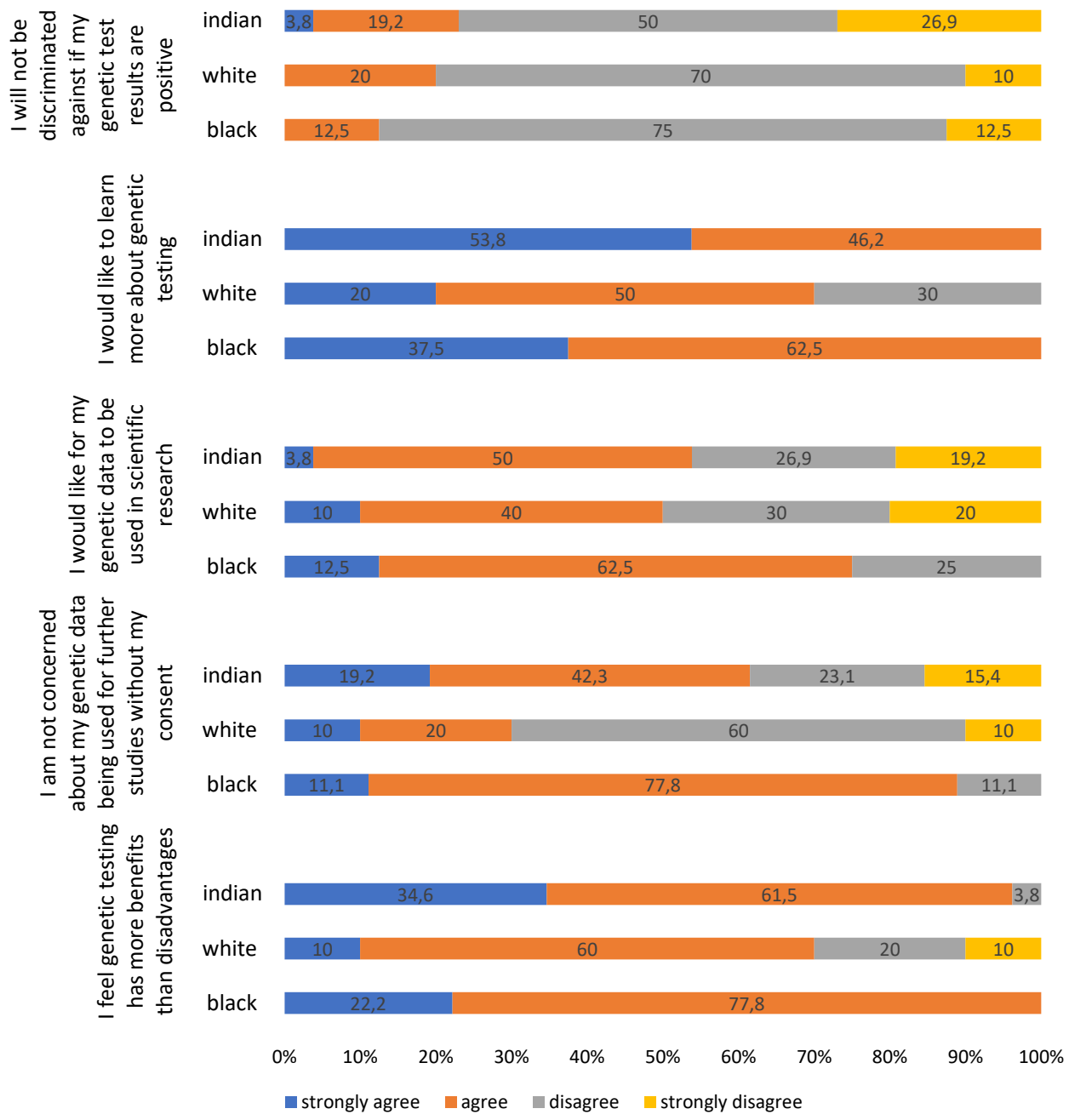

Figure 4.4: Attitudes of general public towards genetic testing stratified by race (n = 47) – part 2

Table 4.4: Knowledge and attitude scores of general public towards genetic testing (n = 47)

Scoring Scale for knowledge	n (%)
Excellent 44 – 32 points	9 (4.23)
Adequate 31 – 24 points	36 (76)
Poor 24 points and below	1 (0.47)
Scoring scale for attitudes	
Positive attitude 33 – 22 points	42 (89)
Negative attitude 21 points and below	4 (8.5)

Bivariate correlation was performed on ordinal data for the general public to determine possible relationships between variables (Table 4.5)

The correlation value between "I know where to have a genetic test done in KwaZulu-Natal" and "Genetic testing is being offered in South Africa" was (r = 0.46; p = 0.002). This suggests that if respondents knew that genetic testing is offered in South Africa, they were more likely to know where to access it in KZN. However, a negative correlation (r = -410; p = 0.006) indicates that as much as respondents were aware of where to have a genetic test conducted, they were not keen on knowing their risk for any chronic disease. A strong correlation value of (r = 0.807; p = 0.00) in response to the statements "genetic testing can be used to also find genetic conditions and treat them" and "genetic testing is useful in helping to use the right medication for treatment" revealed that respondents were aware that genetic testing not only assisted in diagnosis but was also useful in guiding therapy. A negative correlation (r = -646; p = 0.00) between the statements "there are a few ethical guidelines for human genetic tests in South Africa and these guidelines protect us" and "I will not be discriminated against if my genetic test results are positive" indicates that respondents did not feel protected by the current ethical guidelines in place with regard to human genetic testing. This is linked with the positive correlation between "there are a few ethical guidelines for human genetic tests in South Africa and these guidelines protect us" and "there are no laws in South Africa for the protection of personal genetic information." The positive correlation value of (r = 0.523; p = 0.00) between "I feel genetic testing has more benefits than disadvantages" and "I would like to learn more

about genetic testing" reveals the positive attitudes that respondents have towards genetic testing.

Principal Component Analysis (PCA) was conducted to evaluate associations among variables. The eigenvalues are a measure of their association with the variances in the dataset. Factor analysis retained 10 factors with knowledge variables, with 4 of them having an eigen value ≥ 1 (Table4.6). Table 4.6 shows that 10 knowledge variables were loaded for factor analysis and the results retained four factors. Each factor was given a designation based on the patterns observed. Four knowledge variables loaded strongly against disease prevention which indicates that the general public respondents were aware of the main use for predictive genetic testing. Three knowledge variables loaded strongly against the lack of guidelines and regulations. This meant that responses of participants were aligned to the concern for the lack of a legal framework with respect to genetic testing. There was a high factor loading for disease prevention as the eigen value is 3.32. One statement had a factor loading of 0.929 for prevention of communicable diseases. In terms of being knowledgeable about genetic testing, this high factor loading revealed that the respondents were aware that genetic testing ultimately used for diagnosis of genetic disorders can be used for the prevention of communicable diseases.

Table 4.5: Bivariate correlations for general public on genetic testing (n = 47)

	Genetic testing can be used to prevent diseases such as diabetes, cancer.	Genetic testing can be used to prevent HIV, AIDS, T.B.	Genetic testing can be used to determine future susceptibility to certain diseases.	I know what to do after I get my genetic test results back.	Genetic testing is being offered in South Africa.	I know where to have a genetic test done in KwaZulu-Natal.	Having a genetic test is valid and accurate.	There are few ethical guidelines for human genetic tests in South Africa and these guidelines protect us.	There are no laws in South Africa for the protection of personal genetic information.	Genetic testing can be used to also find genetic conditions and treat them.	Genetic testing is useful in helping to use the right medication for treatment.	Genetic testing will not be too expensive to use.	I would like to find out if I am at risk for any chronic disease.	I will not be worried about what my genetic test results will be like if I had to have a test done.	I feel genetic testing has more benefits than disadvantages.	I am not concerned about my genetic data being used for further studies without my consent.	I would like for my genetic data to be used in scientific research.
Genetic testing can be used to determine future susceptibility to certain diseases.	.429**	0.058	1.000														
I know what to do after I get my genetic test results back.	-0.236	-0.169	-.301*	1.000													
	0.119	0.268	0.044														
	45	45	45	45													
Genetic testing is being offered in South Africa.	0.013	-0.031	0.135	-.416**	1.000												
	0.934	0.840	0.375	0.005													
	45	45	45	44	45												
I know where to have a genetic test done in KwaZulu-Natal.	-0.075	0.114	-0.061	-.331*	.464**	1.000											
	0.624	0.457	0.690	0.028	0.002												
	45	45	45	44	44	45											
Having a genetic test is valid and accurate.	.306*	0.127	.343*	-0.279	0.055	0.140	1.000										
	0.044	0.412	0.022	0.070	0.726	0.369											
	44	44	44	43	43	43	44										
There are few ethical guidelines for human genetic tests in South Africa and these guidelines protect us.	0.206	0.074	0.265	-0.149	0.007	-0.046	.386*	1.000									
	0.179	0.631	0.082	0.340	0.967	0.769	0.010										
	44	44	44	43	43	43	43	44									
There are no laws in South Africa for the protection of personal genetic information.	0.096	-0.106	-0.021	-0.047	0.283	-0.130	0.173	.583**	1.000								
	0.539	0.497	0.896	0.768	0.070	0.405	0.273	0.000									
	43	43	43	42	42	43	42	43	43								
Genetic testing can be used to also find genetic conditions and treat them.	.352*	-0.249	.350*	-0.016	0.087	-0.130	.443**	.406**	.457**	1.000							
	0.018	0.099	0.019	0.918	0.574	0.400	0.003	0.006	0.002								
	45	45	45	44	44	44	44	44	43	45							
Genetic testing is useful in helping to use the right medication for treatment.	.302*	-0.040	0.186	0.123	-0.087	-0.215	.400**	.454**	.372*	.807**	1.000						
	0.044	0.795	0.221	0.427	0.575	0.162	0.007	0.002	0.014	0.000							
	45	45	45	44	44	44	44	44	43	45	45						
Genetic testing is an important topic for the community to know about.	0.193	0.063	0.247	0.073	-0.097	-0.122	.318*	0.247	0.087	.307*	.357*						
	0.204	0.681	0.101	0.637	0.532	0.431	0.035	0.106	0.578	0.040	0.016						
	45	45	45	44	44	44	44	44	43	45	45						
Genetic testing will not be too expensive to use.	-0.045	0.016	-0.034	0.092	0.025	-0.106	-0.124	0.254	0.176	0.098	0.205	1.000					
	0.773	0.918	0.828	0.564	0.876	0.498	0.433	0.105	0.266	0.531	0.187						
	43	43	43	42	42	43	42	42	42	43	43	43					
I would like to find out if I am at risk for any chronic disease.	0.157	0.184	0.207	-0.019	-0.114	-.410**	0.192	.367*	0.235	.339*	.428**	.338*	1.000				
	0.303	0.228	0.172	0.904	0.459	0.006	0.213	0.014	0.130	0.023	0.003	0.027					
	45	45	45	44	44	44	44	44	43	45	45	43	45				
I will not be worried about what my genetic test results will be like if I had to have a test done.	-0.043	-0.004	0.166	-0.009	0.234	0.104	0.110	-0.019	-0.024	0.214	0.213	0.106	0.296	1.000			
	0.780	0.981	0.280	0.954	0.130	0.505	0.483	0.906	0.879	0.163	0.165	0.504	0.051				
	44	44	44	43	43	43	43	43	42	44	44	42	44	44			
If my genetic test result is positive for a disease, it will not cause me to be stressed.	0.086	-.395**	0.113	0.249	0.061	-0.257	-0.267	-0.142	0.081	0.286	0.206	0.144	-0.018	0.083			
	0.573	0.007	0.458	0.103	0.696	0.092	0.080	0.358	0.605	0.057	0.174	0.356	0.906	0.590			
	45	45	45	44	44	44	44	44	43	45	45	43	45	44			
I feel genetic testing has more benefits than disadvantages.	.307*	-0.055	0.190	-0.225	-0.077	-.353*	.348*	.378*	0.280	0.238	0.282	.360*	.422**	-0.015	1.000		
	0.040	0.720	0.211	0.142	0.619	0.019	0.021	0.012	0.069	0.115	0.061	0.018	0.004	0.925			
	45	45	45	44	44	44	44	44	43	45	45	43	45	44	45		
I am not concerned about my genetic data being used for further studies without my consent.	0.005	.404**	0.051	0.155	-0.190	0.015	0.036	-0.199	-0.188	0.052	0.214	-0.093	0.123	.378*	-0.077	1.000	
	0.976	0.006	0.738	0.315	0.217	0.923	0.815	0.196	0.228	0.734	0.158	0.554	0.423	0.011	0.614		
	45	45	45	44	44	44	44	44	43	45	45	43	45	44	45	45	
I would like for my genetic data to be used in scientific research.	0.205	0.030	0.183	-0.044	-0.236	-0.161	.396**	0.252	0.160	0.278	0.203	0.116	0.244	-0.277	.508**	-0.124	1.000
	0.181	0.849	0.235	0.781	0.127	0.302	0.009	0.098	0.305	0.068	0.186	0.463	0.110	0.072	0.000	0.423	
	44	44	44	43	43	43	43	44	43	44	44	42	44	43	44	44	44
I would like to learn more about genetic testing.	0.204	-0.038	0.046	-0.035	-0.047	-0.068	0.255	0.232	0.155	.476**	.477**	0.299	.463**	0.249	.523**	0.237	0.278
	0.185	0.807	0.767	0.821	0.763	0.667	0.099	0.130	0.320	0.001	0.001	0.054	0.002	0.107	0.000	0.121	0.068
	44	44	44	43	43	43	43	44	43	44	44	42	44	43	44	44	44
I will not be discriminated against if my genetic test results are positive.	-.301*	0.055	-0.221	0.280	0.016	-0.032	-.486**	-.646**	-.352*	-.356*	-.330*	0.138	-0.170	0.060	-.303*	.327*	-.370*
	0.047	0.721	0.149	0.069	0.920	0.836	0.001	0.000	0.021	0.018	0.029	0.385	0.271	0.702	0.046	0.030	0.013
	44	44	44	43	43	43	43	44	43	44	44	42	44	43	44	44	44

All significant relationships are indicated by a * or ** (see Appendix M for larger image)

Table 4.6: Rotated Component Matrix – knowledge factors for general public retained by factor analysis

	Disease Prevention	**Lack of guidelines & regulations**	**Availability & access to genetic testing**	**Prevention of communicable diseases**
Genetic testing can be used to determine future susceptibility to certain diseases.	0.826	-	-	-
Genetic testing can be used to also find genetic conditions and treat them.	0.721	-	-	-
Genetic testing can be used to prevent diseases such as diabetes, cancer.	0.705	-	-	-
Having a genetic test is valid and accurate.	0.585	-	-	-
Genetic testing can be used to prevent HIV, AIDS, T.B.	-	-	-	0.929
Genetic testing is being offered in South Africa.	-	-	0.835	-
I know where to have a genetic test done in KwaZulu-Natal.	-	-	0.816	-
There are few ethical guidelines for human genetic tests in South Africa and these guidelines protect us.	-	0.857	-	-
There are no laws in South Africa for the protection of personal genetic information.	-	0.802	-	-
Genetic testing is useful in helping to use the right medication for treatment.	-	0.667	-	-
Eigen Value	3.32	1.51	1.41	1.02
% of Variance	33.17	15.11	14.13	10.24
Cumulative %	33.17	48.28	62.40	72.64
Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser Normalisation.				
a. Rotation converged in 5 iterations.				

Table 4.7: Rotated Component Matrix – attitude factors for general public retained by factor analysis

	Willingness to use predictive genetic testing	Confidence in the use of predictive genetic testing	Emotional and mental attitude towards predictive genetic testing	Importance of public to know about genetic testing
Genetic testing is an important topic for the community to know about.	-	-	-	0.897
I would like to learn more about genetic testing.	0.761	-	-	-
I would like to find out if I am at risk for any chronic disease.	0.733	-	-	-
I would like for my genetic data to be used in scientific research.	0.549	-	-	-
Genetic testing will not be too expensive to use.	0.529	-	-	-
I am not concerned about my genetic data being used for further studies without my consent.	-	0.766	-	-
I will not be worried about what my genetic test results will be like if I had to have a test done.	-	0.755	-	-
If my genetic test result is positive for a disease, it will not cause me to be stressed.	-	-	0.732	-
I will not be discriminated against if my genetic test results are positive.	-	-	0.667	-
Eigen value	2.69	1.58	1.37	1.01
% of Variance	26.98	15.84	13.760	10.12
Cumulative %	26.98	42.82	56.58	66.70

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalisation.

a. Rotation converged in 5 iterations.

Table 4.7 shows that nine attitude variables yielded four factors which included willingness to use predictive testing, confidence in use of predictive genetic testing, emotional and mental attitude towards genetic testing and the importance of public knowledge of genetic testing. The factor loading for "willingness to use predictive genetic testing" was high as four positive attitude variables loaded strongly (eigen value = 2.69). Two attitude variables loaded strongly against "confidence in use of predictive genetic testing" and "emotional and mental attitude towards predictive genetic testing."

4.3 Medical practitioners

Knowledge of medical practitioner respondents towards predictive genetic testing is shown in Table 4.8. Most respondents (73%) were aware of genetic testing, however only 50% were aware of it being offered in SA. Almost all of the respondents (93%) agreed that there is a need for genetic counsellors, while 43% indicated that the use of predictive genetic testing in the clinical and public health field does not need to take into account the social ethical and legal implications with respect to patients. The majority of respondents (74%) indicated that they were not exposed to cancer genetic testing during their undergraduate training. Half of the respondents agreed that the uptake of predictive genetic testing would alleviate the burden of disease when used in conjunction with the NHI.

Figure 4.5 shows the knowledge of respondents stratified by gender. Both males and females were aware of predictive genetic testing being offered in South Africa. Among the male respondents, 60% strongly agreed that predictive genetic testing assists in preventing chronic diseases in comparison to 21.4% of respondents. Figure 4.6 shows the knowledge of respondents stratified by race. Only three race groups (African, Indian, white) indicated that they have had exposure to genetic testing when in medical school. All races groups strongly agreed that predictive genetic testing prevents chronic diseases. Three out of four race groups agreed that there is no need to consider the social, ethical and legal implications of genetic testing. Many whites and Indians did not agree that genetic testing can assist in health promotion which in turn can positively impact the NHI. Figure 4.7 stratifies the knowledge of respondents by practice type. Almost 68% of respondents who worked in a public hospital strongly agreed that exposure to various factors can influence a patient's risk of disease.

Table 4.8: Knowledge levels of medical practitioners towards genetic testing (n = 45)

	Strongly Disagree	Disagree	Agree	Strongly Agree	p-value
	n (%)	n (%)	n (%)	n (%)	
Performing genetics should be associated with genetic testing	0 (0)	0 (0)	12 (26.7)	33 (73.3)	0.002
Genetic testing can be used to identify a patient's susceptibility towards a genetic disorder and NCD	0 (0)	1 (2.3)	16 (36.4)	27 (61.4)	0.000
The clinical use of a predictive genetic test is to improve the health status of the patient	1 (2.2)	1 (2.2)	19 (42.2)	24 (53.3)	0.000
Exposures to various factors such as socioeconomic status, lifestyle and environment can influence a patient's risk of disease due to their predisposition	0 (0)	4 (8.9)	17 (37.8)	24 (53.3)	0.001
There are not many ethical guidelines in South Africa which govern the use of predictive genetic testing among patients	1 (2.3)	7 (15.9)	21 (47.7)	15 (34.1)	0.000
Predictive genetic tests are valid and reliable as long as a specific genetic characteristic I identified accurately in the laboratory	0 (0)	3 (6.8)	22 (50.0)	19 (43.2)	0.001
There are not many laws in place in SA which protects the patient's personal genetic information	1 (2.3)	9 (20.5)	18 (40.9)	16 (36.4)	0.001
Predictive genetic testing is being offered to individuals in SA	3 (6.8)	19 (43.2)	17 (38.6)	5 (11.4)	0.000
I have had exposure to cancer genetic testing during my undergraduate training	12 (27.9)	20 (46.5)	9 (20.9)	2 (4.7)	0.001
Genetic counsellors are needed for patients to consult with once they have their genetic test results	1 (2.2)	2 (4.4)	18 (40.0)	24 (53.3)	0.000
The use of predictive genetic testing in clinical and public health practice does not need to take into account the legal, ethical and social implications	4 (9.1)	8 (18.2)	13 (29.5)	19 (43.2)	0.010
Predictive genetic testing can contribute positively towards health promotion and disease prevention which can assist in the launch of the NHI	0 (0)	6 (13.6)	23 (52.3)	15 (34.1)	0.007
Guidelines from the DOH is needed for the appropriate use of predictive genetic testing	0 (0)	2 (4.5)	18 (40.9)	24 (54.5)	0.000
Predictive genetic tests increase prevention opportunities for chronic diseases	0 (0)	3 (6.8)	20 (45.5)	21 (47.7)	0.001

*$p \leq 0.05$ was considered statistically significant

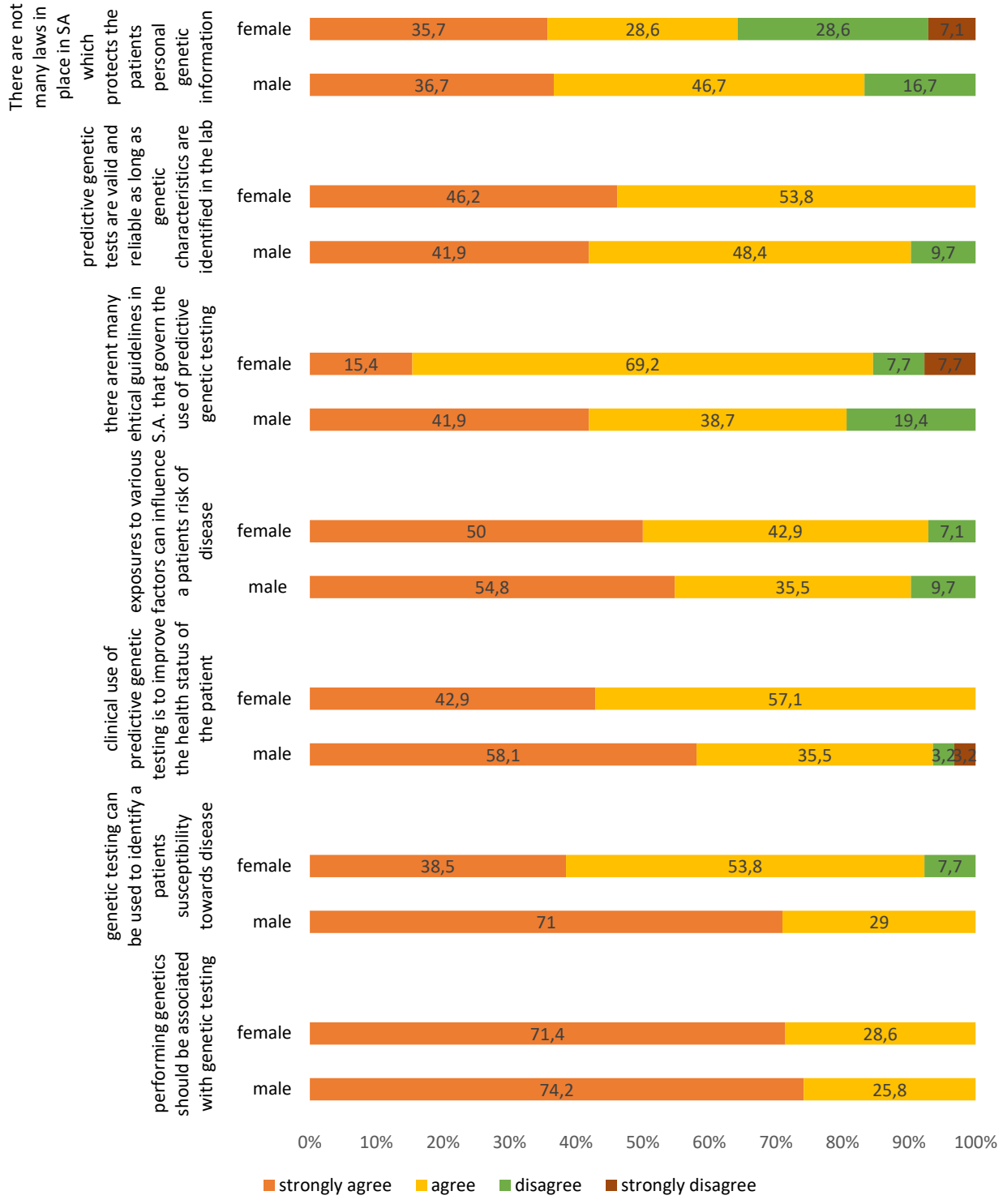

Figure 4.5: Knowledge of medical practitioners on genetic testing stratified by gender (n = 45) – part 1

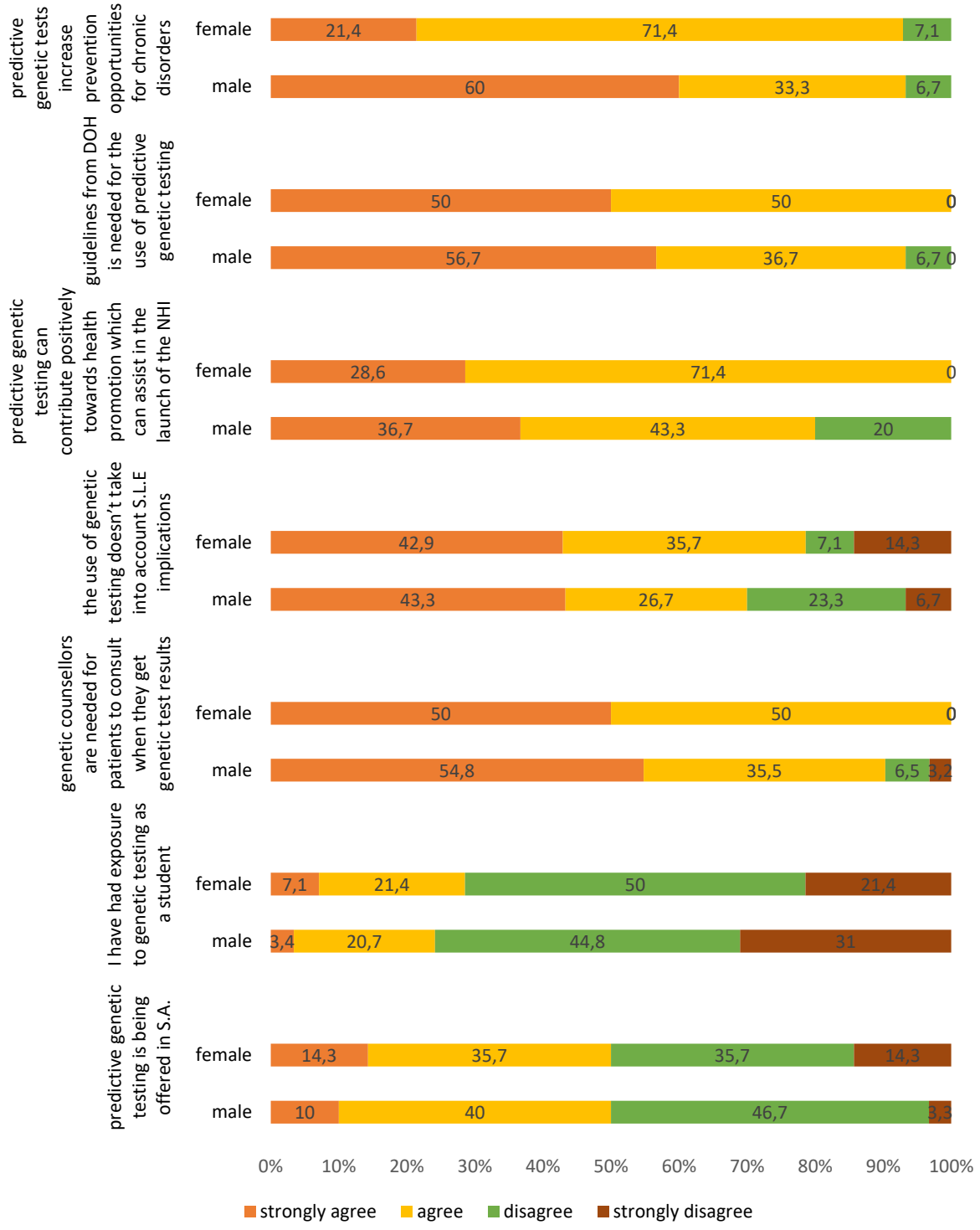

Figure 4.5: Knowledge of medical practitioners on genetic testing stratified by gender (n = 45) – part 2

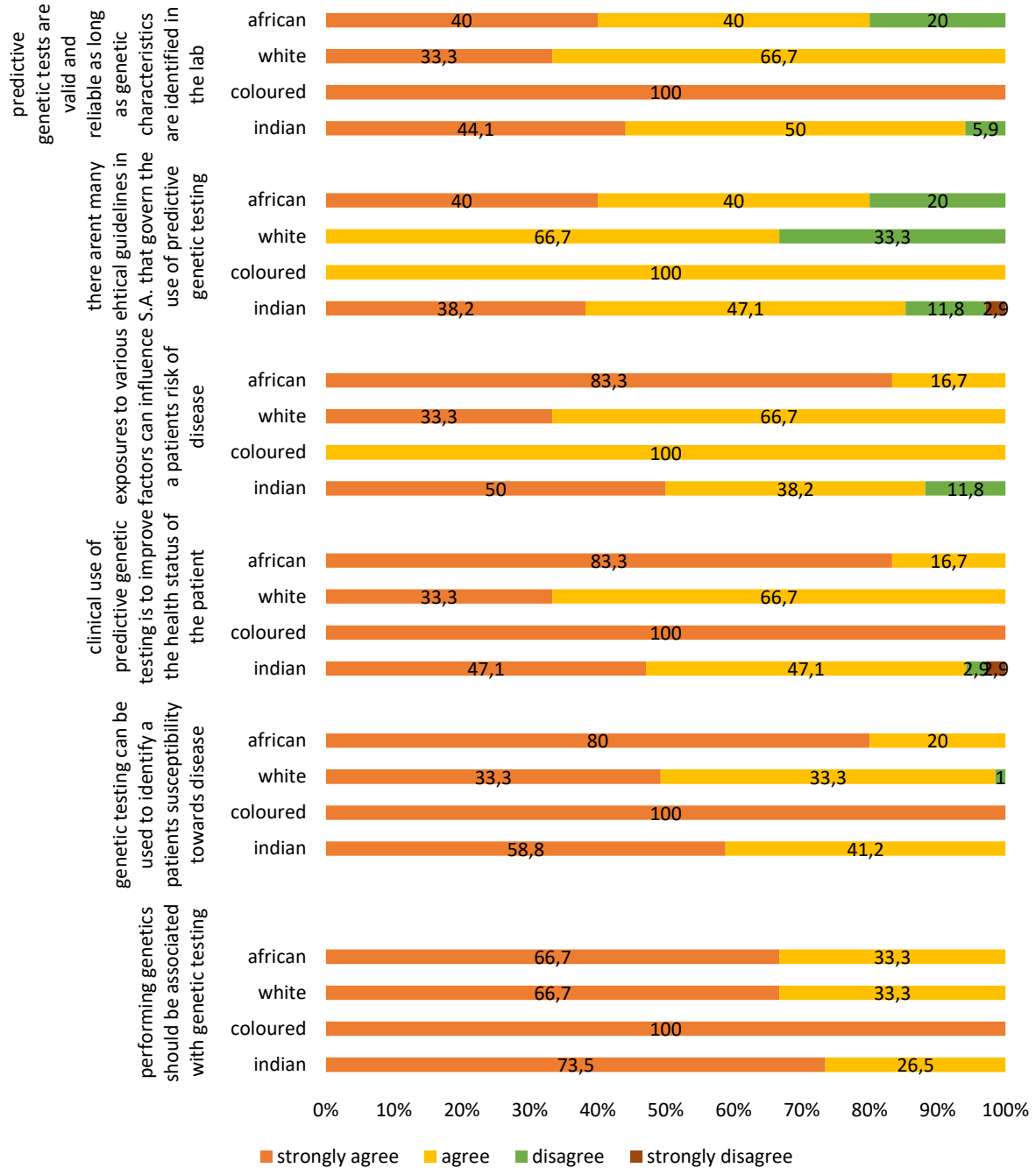

Figure 4.6: Knowledge of Medical Practitioners on genetic testing stratified by race (n = 45) – part 1

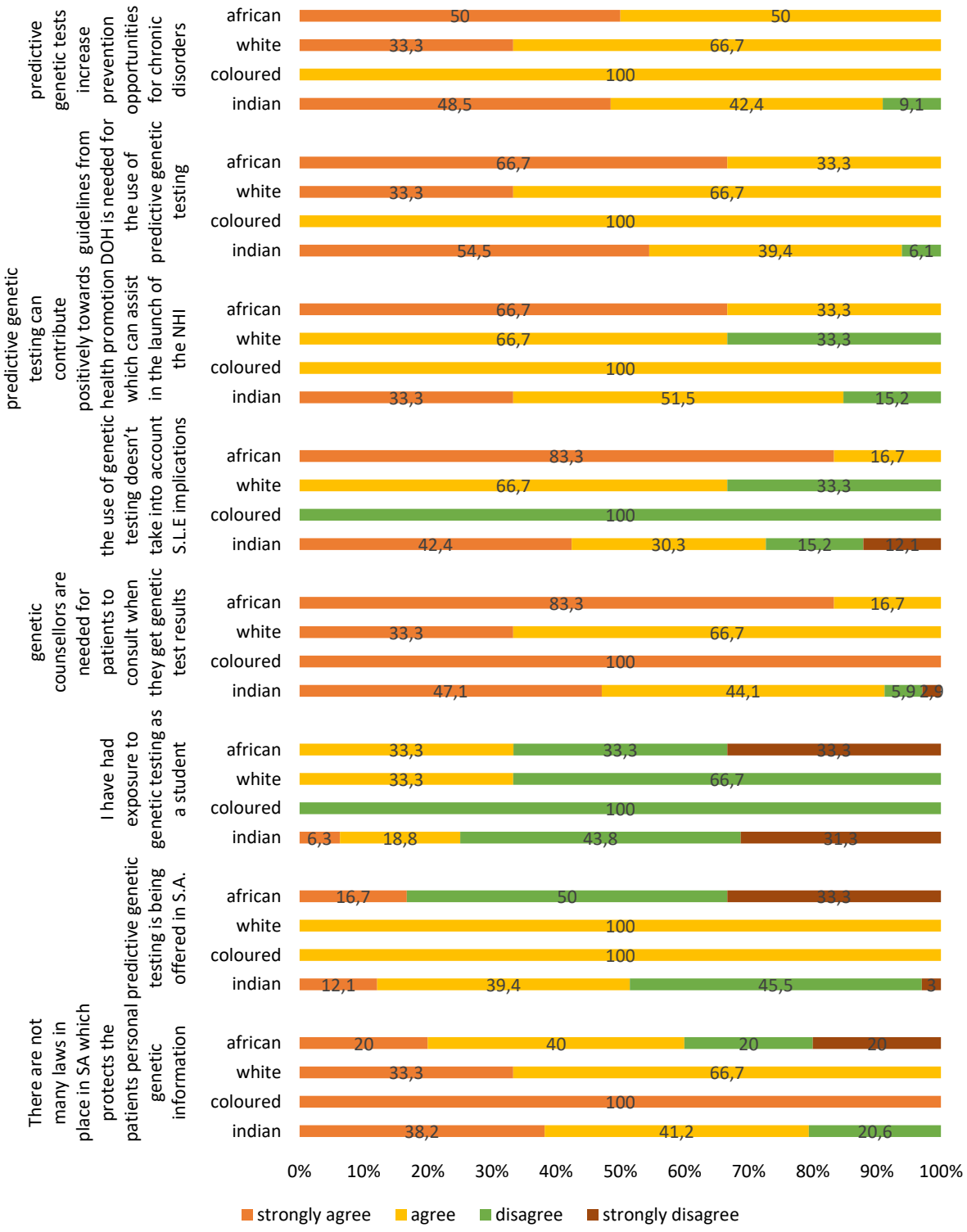

Figure 4.6: Knowledge of medical practitioners on genetic testing stratified by race (n = 45) – part 2

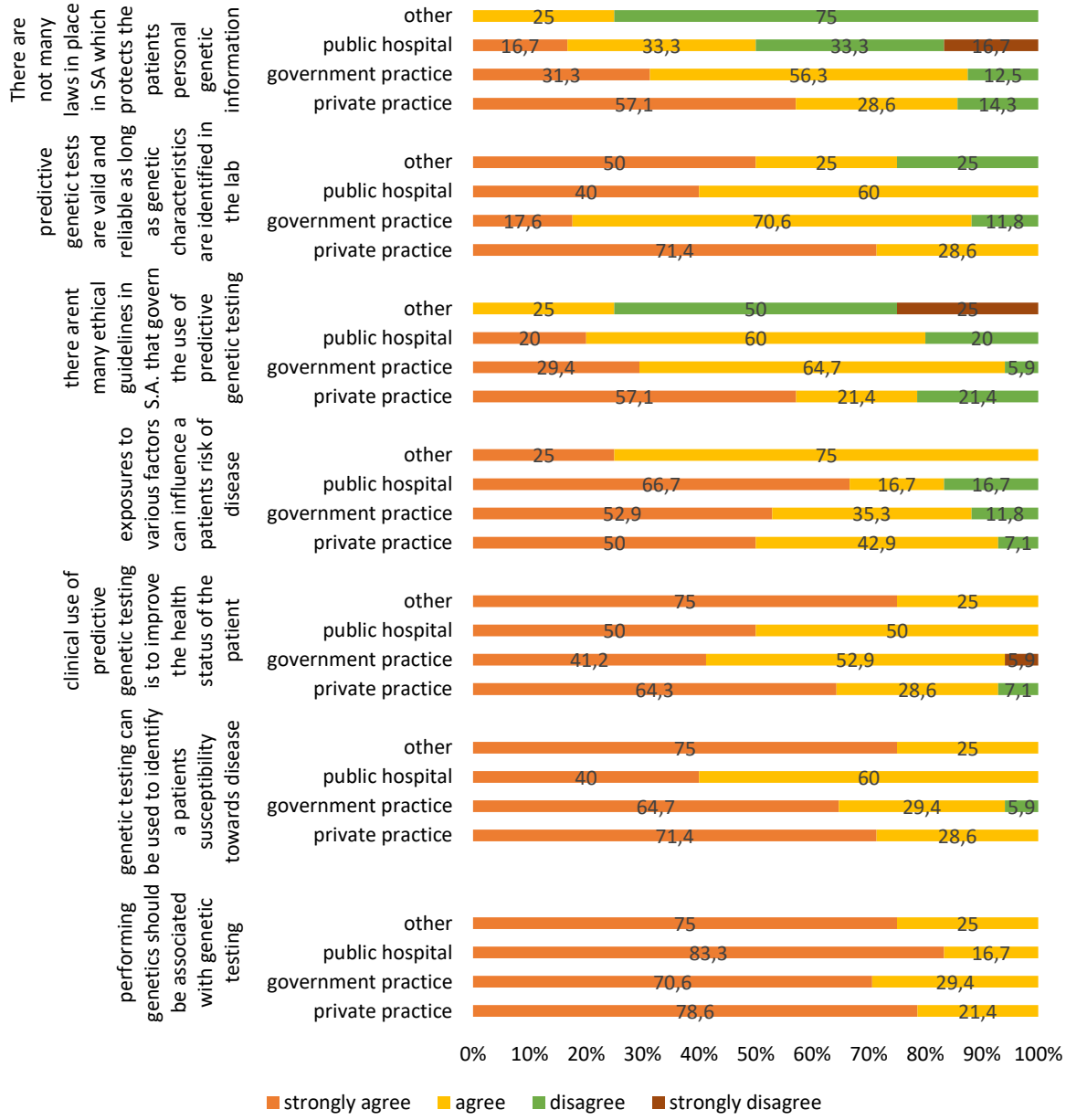

Figure 4.7: Knowledge of medical practitioners on genetic testing stratified by practice type (n = 45) – part 1

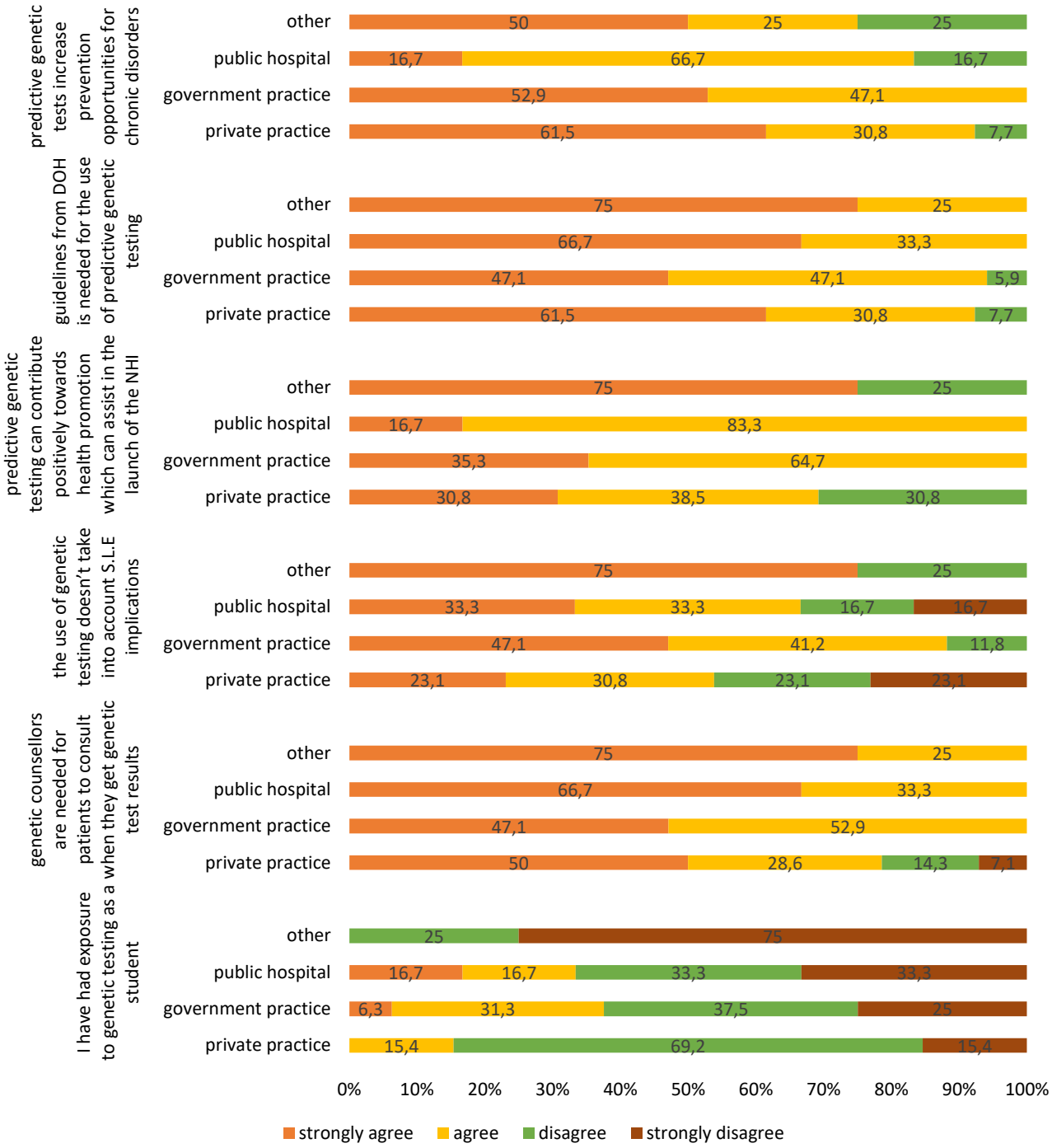

Figure 4.7: Knowledge of medical practitioners on genetic testing stratified by practice type (n = 45) – part 2

Table 4.9: Attitudes of Medical Practitioners towards predictive genetic testing (n = 45)

	Strongly Disagree	Disagree	Agree	Strongly Agree	p-value
	n (%)	n (%)	n (%)	n (%)	
I will use predictive genetic testing in diagnosis and treatment of patients	0 (0)	9 (20.9)	22 (51.2)	12 (27.9)	0.039
I have started using predictive genetic testing for diagnosis and treatment of patients	10 (25.0)	20 (50.0)	8 (20.0)	2 (5.0)	0.001
Predictive genetic tests should only be introduced to clinical and public health practice only if it is proven to be cost-effective in SA	5 (11.6)	11 (25.6)	17 (39.5)	10 (23.3)	0.080
Medical and health practitioners require training on predictive genetic testing/genomic medicine	0 (0)	2 (4.4)	16 (35.6)	27 (60.0)	0.000

*$p \leq 0.05$ was considered statistically significant

Attitudes of medical practitioner respondents towards predictive genetic testing is shown in Table 4.9. Most respondents (95.6%) agreed that both medical and health practitioners require training on predictive genetic testing. Twenty-five percent of respondents indicated that they were presently using genetic testing in their practice. The majority of respondents (62.8%) felt that genetic testing should only be introduced if it is proven to be cost-effective in South Africa. Twenty percent of respondents reported that they would not use genetic testing in diagnoses and treatment of patients.

Figure 4.8 displays results of attitudes of medical practitioner respondents stratified by gender. Seventy-one percent (71%) of male respondents felt that medical and health practitioners need to be trained in genetic testing. More male than female respondents have started using genetic testing in diagnosis and treatment of patients. More female respondents (69%) were keen on using genetic testing in the diagnosis and treatment of patients, than male respondents (26.7%). Figure 4.9 represents the attitudes of respondents stratified by race. All race groups indicated that they would use genetic testing in their treatment of patients. Only 20% and 24.2% of African and Indian respondents respectively indicated that they would not use genetic testing.

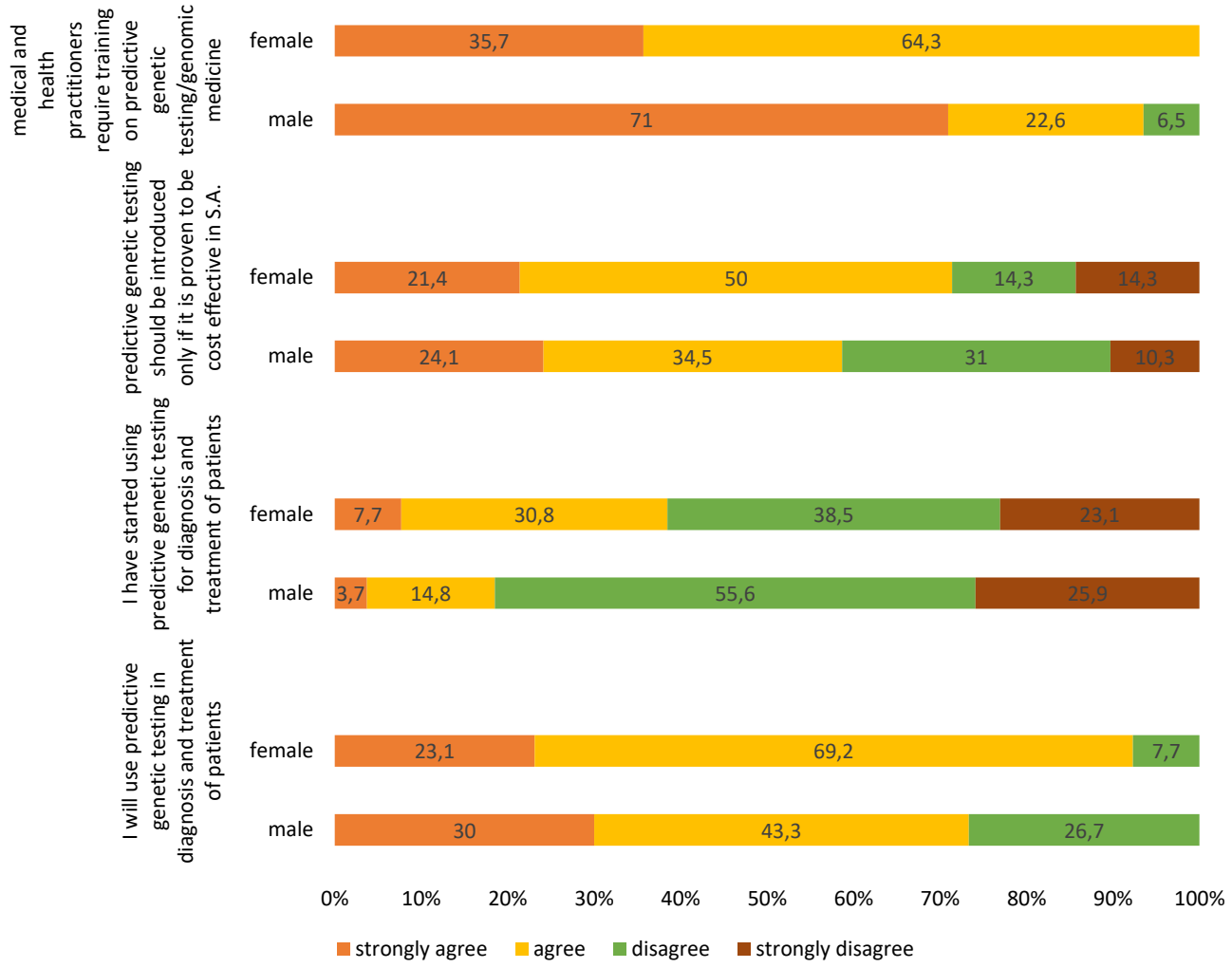

Figure 4.8: Attitudes of medical practitioners towards genetic testing stratified by gender (n = 45)

Figure 4.10 stratifies attitudes of medical practitioner respondents by practice type. Respondents from public, government and private practice supported the use of genetic testing in their field of practice. Respondents from private practice (41.7%) and government practice (33.3%) reported that genetic testing should not be used in South Africa unless it is cost-effective.

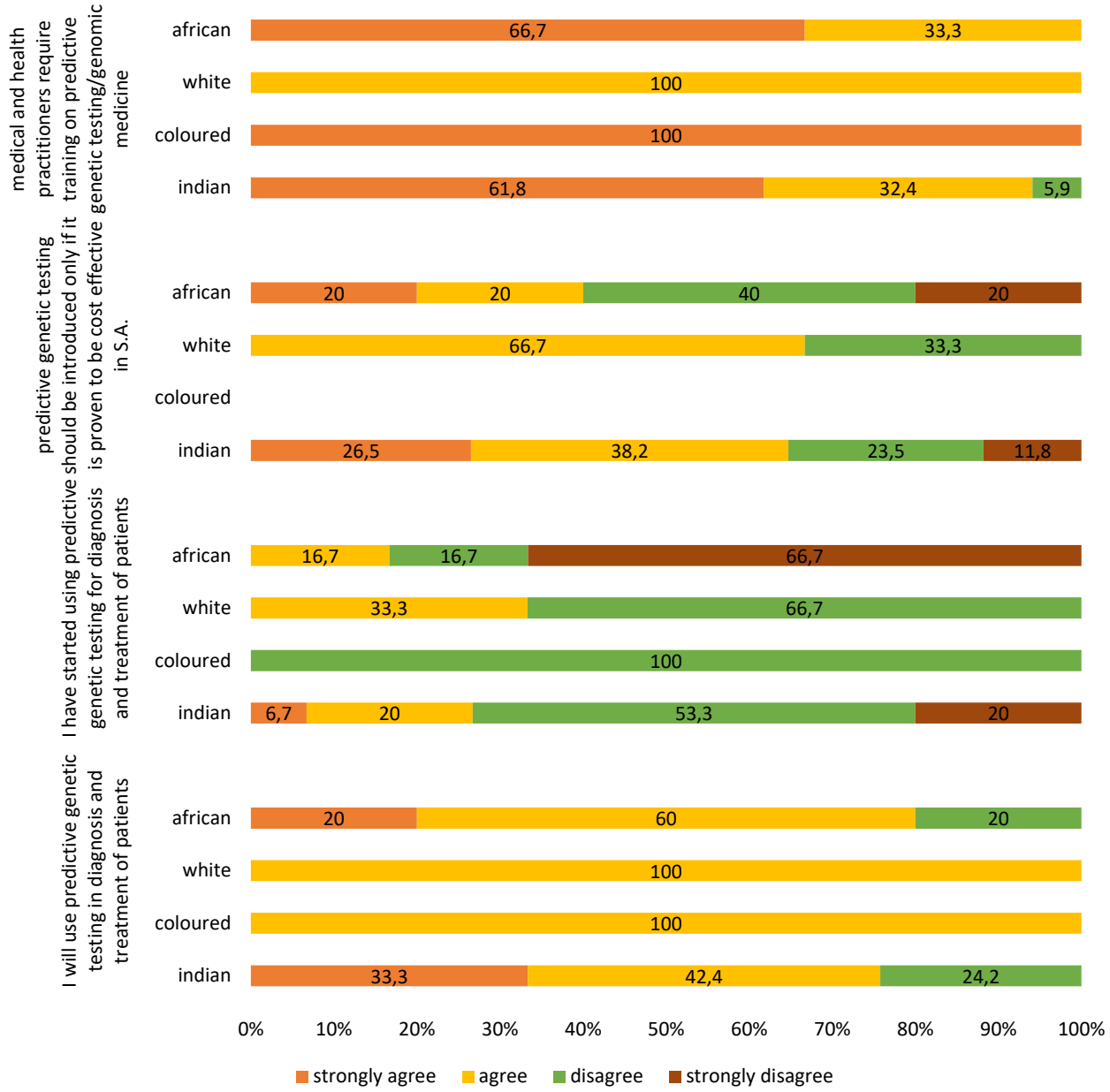

Figure 4.9: Attitudes of medical practitioners towards genetic testing stratified by race (n = 45)

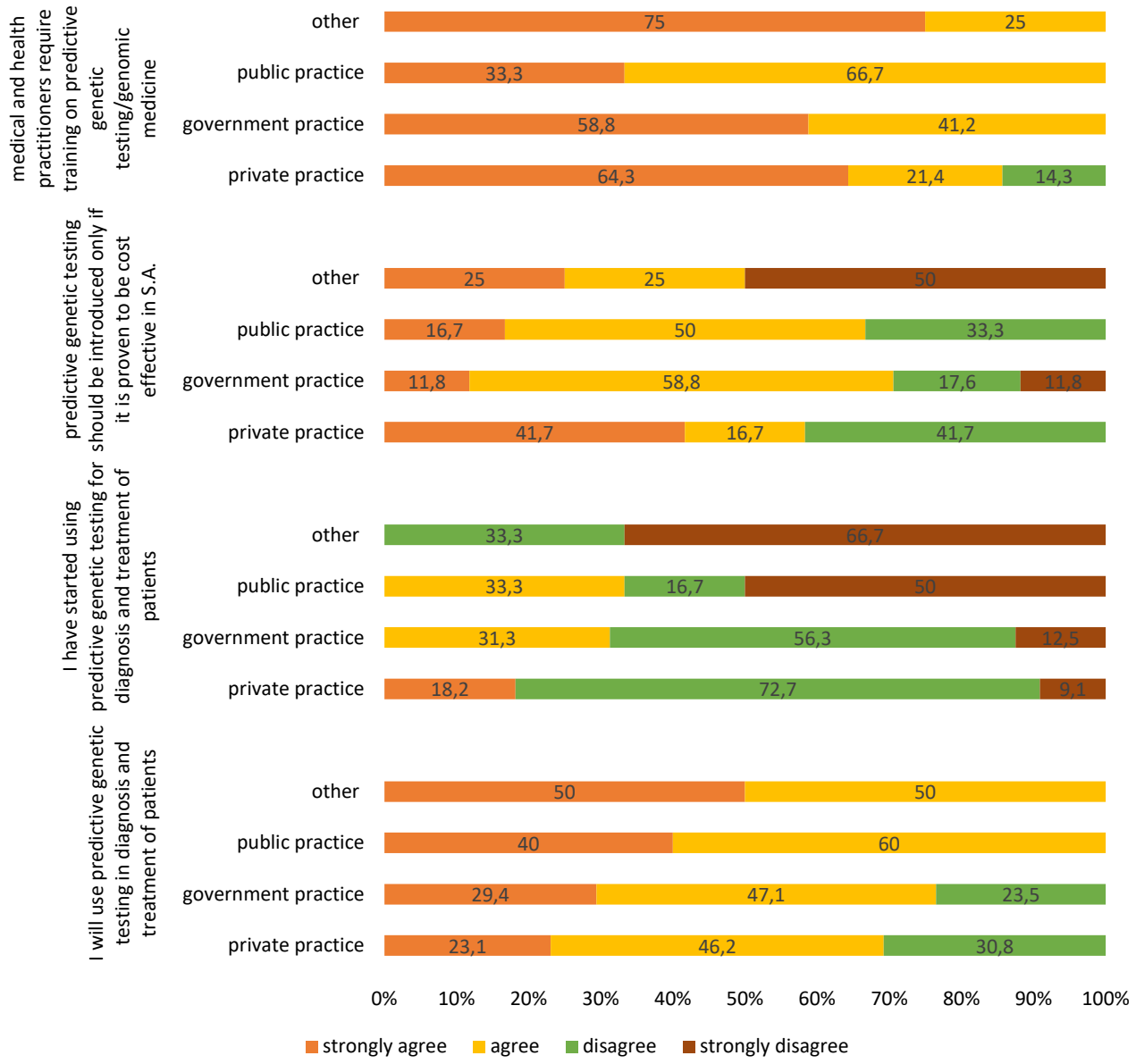

Figure 4.10: Attitudes of medical practitioners towards genetic testing stratified by practice type (n = 45)

4.3.1 Knowledge and attitude scores of medical practitioners on predictive genetic testing

Table 4.10: Knowledge and attitude scores of medical practitioners towards genetic testing (n = 45)

Scoring Scale for knowledge	**n (%)**
Excellent	
44 – 32 points	**35 (77.8)**
Adequate	
31 – 24 points	**10 (22)**
Poor	
24 points and below	**0**
Scoring Scale for attitudes	
Positive attitude	
33 – 22 points	**37 (82)**
Negative attitude	
21 points and below	**8 (17.8)**

Table 4.10 shows the knowledge and attitude scores for medical practitioner respondents towards genetic testing. The scoring scale has been generated on a points basis, where a point was allocated for a correct answer in the knowledge section and a point allocated for each positive response in the attitude section. Overall, 77.8% of respondents have an excellent knowledge and understanding of genetics and 82.2% of respondents have a positive attitude towards the use of genetic testing.

Table 4.11: Bivariate correlations for medical practitioners on predictive genetic testing (n = 45)

Correlations

			Performing genetics should be associated with genetic testing	Genetic testing can be used to identify a patient's susceptibility towards a genetic disorder and NCD	The clinical use of a predictive genetic test is to improve the health status of the patient	Exposures to various factors such as socioeconomic status, lifestyle and environment can influence a patient's risk of disease due to their predisposition	There are not many ethical guidelines in South Africa which govern the use of predictive genetic testing among patients	Predictive genetic tests are valid and reliable as long as a specific genetic characteristic I identified accurately in the laboratory	There are not many laws in place in SA which protects the patients personal genetic information	Predictive genetic testing is being offered to individuals in SA	I have had exposure to cancer genetic testing during my undergraduate training	Genetic counsellors are needed for patients to consult with once they have their genetic test results	The use of predictive genetic testing in clinical and public health practice does not need to take into account the legal, ethical and social implications	Predictive genetic testing can contribute positively towards health promotion and disease prevention which can assist in the launch of the NHI	Guidelines from the DOH is needed for the appropriate use of predictive genetic testing	Predictive genetic tests increase prevention opportunities for chronic diseases	I will use predictive genetic testing in diagnosis and treatment of patients	I have started using predictive genetic testing for diagnosis and treatment of patients	Predictive genetic tests should only be introduced to clinical and public health practice only if it is proven to be cost-effective in SA	Medical and health practitioners require training on predictive genetic testing/genomic medicine
Spearman's rho	Performing genetics should be associated with genetic testing	Correlation C	1.000																		
		Sig. (2-tailed)																			
		N	45																		
	Genetic testing can be used to identify a patient's susceptibility towards a genetic disorder and NCD	Correlation C	.636**	1.000																	
		Sig. (2-tailed)	0.000																		
		N	44	44																	
	The clinical use of a predictive genetic test is to improve the health status of the patient	Correlation C	.530**	.695**	1.000																
		Sig. (2-tailed)	0.000	0.000																	
		N	45	44	45																
	Exposures to various factors such as socioeconomic status, lifestyle and environment can influence a patient's risk of disease due to their predisposition	Correlation C	.345*	.466**	.443**	1.000															
		Sig. (2-tailed)	0.020	0.001	0.002																
		N	45	44	45	45															
	There are not many ethical guidelines in South Africa which govern the use of predictive genetic testing among patients	Correlation C	-0.131	0.011	0.038	0.254	1.000														
		Sig. (2-tailed)	0.397	0.943	0.806	0.097															
		N	44	44	44	44	44														
	Predictive genetic tests are valid and reliable as long as a specific genetic characteristic I identified accurately in the laboratory	Correlation C	.304*	0.279	.448**	.403**	.304*	1.000													
		Sig. (2-tailed)	0.045	0.067	0.002	0.007	0.045														
		N	44	44	44	44	44	44													
	There are not many laws in place in SA which protects the patients personal genetic information	Correlation C	0.110	0.255	0.094	.382*	.391**	0.289	1.000												
		Sig. (2-tailed)	0.479	0.099	0.545	0.010	0.010	0.060													
		N	44	43	44	44	43	43	44												
	Predictive genetic testing is being offered to individuals in SA	Correlation C	0.016	0.037	0.062	0.198	.401**	0.285	.458**	1.000											
		Sig. (2-tailed)	0.920	0.816	0.689	0.197	0.008	0.064	0.002												
		N	44	43	44	44	43	43	43	44											
	I have had exposure to cancer genetic testing during my undergraduate training	Correlation C	-0.012	-0.104	-0.290	0.042	0.038	-0.268	0.030	0.197	1.000										
		Sig. (2-tailed)	0.942	0.514	0.059	0.791	0.809	0.086	0.849	0.205											
		N	43	42	43	43	42	42	42	43	43										
	Genetic counsellors are needed for patients to consult with once they have their genetic test results	Correlation C	.502**	0.295	.319*	0.088	-0.102	0.147	-0.130	-0.086	-0.097	1.000									
		Sig. (2-tailed)	0.000	0.052	0.033	0.567	0.511	0.341	0.400	0.578	0.537										
		N	45	44	45	45	44	44	44	44	43	45									
	The use of predictive genetic testing in clinical and public health practice does not need to take into account the legal, ethical and social implications	Correlation C	0.167	0.267	0.238	0.081	-0.271	-0.287	-0.050	-0.191	-0.184	0.156	1.000								
		Sig. (2-tailed)	0.279	0.083	0.120	0.602	0.078	0.062	0.748	0.214	0.238	0.311									
		N	44	43	44	44	43	43	43	44	43	44	44								
	Predictive genetic testing can contribute positively towards health promotion and disease prevention which can assist in the launch of the NHI	Correlation C	.339*	.439**	.522**	0.226	0.111	0.066	-0.028	0.056	-0.099	.580**	.456**	1.000							
		Sig. (2-tailed)	0.025	0.003	0.000	0.141	0.478	0.675	0.858	0.720	0.527	0.000	0.002								
		N	44	43	44	44	43	43	43	44	43	44	44	44							
	Guidelines from the DOH is needed for the appropriate use of predictive genetic testing	Correlation C	.518**	.515**	.456**	.322*	-0.127	.314*	0.101	0.069	-0.219	.617**	.338*	.595**	1.000						
		Sig. (2-tailed)	0.000	0.000	0.002	0.033	0.418	0.040	0.518	0.655	0.158	0.000	0.025	0.000							
		N	44	43	44	44	43	43	43	44	43	44	44	44	44						
	Predictive genetic tests increase prevention opportunities for chronic diseases	Correlation C	.470**	.676**	.514**	.394**	0.050	0.232	.352*	0.294	-0.248	.396**	.305*	.528**	.743**	1.000					
		Sig. (2-tailed)	0.001	0.000	0.000	0.008	0.751	0.135	0.021	0.052	0.109	0.008	0.044	0.000	0.000						
		N	44	43	44	44	43	43	43	44	43	44	44	44	44	44					
	I will use predictive genetic testing in diagnosis and treatment of patients	Correlation C	.442**	.350*	.501**	0.092	-0.082	.305*	-0.224	0.037	-0.244	.333*	.308*	.352*	.537**	.347*	1.000				
		Sig. (2-tailed)	0.003	0.021	0.001	0.556	0.603	0.047	0.153	0.812	0.120	0.029	0.045	0.021	0.000	0.023					
		N	43	43	43	43	43	43	42	43	42	43	43	43	43	43	43				
	I have started using predictive genetic testing for diagnosis and treatment of patients	Correlation C	-0.063	-0.021	0.115	-0.020	0.074	0.041	0.130	.419**	0.119	-.451**	-0.074	-0.066	-0.175	0.116	0.180	1.000			
		Sig. (2-tailed)	0.699	0.900	0.481	0.902	0.656	0.804	0.429	0.007	0.464	0.004	0.648	0.687	0.280	0.478	0.272				
		N	40	39	40	40	39	39	39	40	40	40	40	40	40	40	39	40			
	Predictive genetic tests should only be introduced to clinical and public health practice only if it is proven to be cost-effective in SA	Correlation C	0.077	0.018	0.197	0.053	0.121	0.107	0.237	0.149	0.000	-0.110	-0.304	-0.043	0.018	0.193	0.003	0.304	1.000		
		Sig. (2-tailed)	0.625	0.909	0.205	0.736	0.445	0.499	0.130	0.347	0.999	0.481	0.051	0.787	0.912	0.220	0.986	0.064			
		N	43	42	43	43	42	42	42	42	41	43	42	42	42	42	41	38	43		
	Medical and health practitioners require training on predictive genetic testing/genomic medicine	Correlation C	.425**	.505**	.312*	0.152	-0.121	0.043	0.161	-0.041	-0.100	.529**	0.209	.407**	.415**	.535**	0.175	-0.070	0.023	1.000	
		Sig. (2-tailed)	0.004	0.000	0.037	0.318	0.433	0.779	0.295	0.789	0.522	0.000	0.173	0.006	0.005	0.000	0.262	0.670	0.886		
		N	45	44	45	45	44	44	44	44	43	45	44	44	44	44	43	40	43	45	

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

All significant relationships are indicated by a * or ** (see Appendix N for larger image)

Bivariate correlation was conducted on ordinal data of the medical practitioner respondents to observe relationships between variables (Table 4.11). The correlation value between "the clinical use of a predictive genetic test is to improve the health status of the patient" and "performing genetics should be associated with genetic testing" was (r = 0.530; p = 0.00). This is also linked to "genetic testing can be used to identify a patient's susceptibility towards a genetic disorder and NCD" respectively. A value of (r = -0.287; p = 0.062) shows an inversely proportional relationship between "The use of predictive genetic testing in clinical and public health practice does not need to take into account the legal, ethical and social implications" and "predictive genetic tests are valid and reliable as long as a specific genetic characteristic is identified accurately in the laboratory". This shows that as long as predictive genetic tests are valid and reliable, respondents would still use them despite the possibility of ethical, legal and social implications. "I will use predictive genetic testing in diagnosis and treatment of patients" and "guidelines from the DOH is needed for the appropriate use of predictive genetic testing" has a correlation value of (r = 0.537; p = 0.00)). This indicates that respondents are willing to use genetic testing in their practice and are willing to be capacitated regarding the legal and ethical framework that governs the use of genetic testing from the Department of Health.

Principle Component Analysis for Medical Practitioners

Table 4.12: Rotated Component Matrix – knowledge factors of medical practitioners retained by factor analysis -Positive factors of using predictive genetic testing

	Positive factors of using predictive genetic testing	Existing limitations in genetic testing	Lack of legislation for genetic testing in S.A.
Genetic testing can be used to identify a patient's susceptibility towards a genetic disorder and NCD	0.858	-	-
Performing genetics should be associated with genetic testing	0.689	-	-
Predictive genetic tests increase prevention opportunities for chronic diseases	0.682	-	-
The clinical use of a predictive genetic test is to improve the health status of the patient	0.671	-	-
Exposures to various factors such as socioeconomic status, lifestyle and environment can influence a patient's risk of disease due to their predisposition	0.619	-	-
Predictive genetic testing is being offered to individuals in SA	-	-	0.798
There are not many ethical guidelines in South Africa which govern the use of predictive genetic testing among patients		-	0.787
There are not many laws in place in SA which protects the patient's personal genetic information	-	-	0.716
Genetic counsellors are needed for patients to consult with once they have their genetic test results	-	0.871	-
Predictive genetic testing can contribute positively towards health promotion and disease prevention which can assist in the launch of the NHI	-	0.786	-
Guidelines from the DOH is needed for the appropriate use of predictive genetic testing	-	0.651	-
Eigen value	4.00	2.11	1.18
% of Variance	36.44	19.18	10.77
Cumulative %	36.44	55.62	66.39

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalisation.

a. Rotation converged in 6 iterations.

Table 4.13: Rotated Component Matrix – attitude factors of medical practitioners retained by factor analysis - benefits of predictive genetic testing

	Benefits of predictive genetic testing	Acknowledgement for need of training for predictive genetic testing
I will use predictive genetic testing in diagnosis and treatment of patients	-	0.793
I have started using predictive genetic testing for diagnosis and treatment of patients	0.832	-
Predictive genetic tests should only be introduced to clinical and public health practice only if it is proven to be cost-effective in SA	0.765	-
Medical and health practitioners require training on predictive genetic testing/genomic medicine	-	0.749
Eigen value	1.36	1.21
% of Variance	34.01	30.19
Cumulative %	34.01	64.21

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalisation.
a. Rotation converged in 3 iterations.

PCA was used to identify similar patterns in the responses of medical practitioner respondents in relation to questions based on knowledge. Factor analysis retained three factors on knowledge from eleven variables. All three factors have an eigen value ≥ 1 (Table 4.12). Five variables relating to knowledge and awareness of genetic testing had a high factor loading ranging from 0.619 to 0.858 (eigen value = 4). Three knowledge variables loaded strongly on a factor of limitations that currently exist in genetics. Positive factors of using predictive genetic testing had a significantly high factor loading. This was suggestive of respondents acknowledging the benefits of using genetic testing. With reference to existing limitations in genetic testing, an eigen value of 2.11 with three knowledge variables loading against this factor, indicating that respondents were aware of the challenges that are experienced with the use of genetic testing. One of these limitations is the lack of legislation for the use of genetic testing in S.A. and it is a component that three knowledge variables loaded against strongly. Respondents were aware of the need for more legislation to govern the use of genetic testing in South Africa.

Table 4.13 shows results of PCA conducted for the attitudes of the medical practitioner. Respondents. Two factors relating to attitude variables loaded strongly against the factor of benefits of predictive genetic testing. A strong factor loading of 0.832 and 0.765 confirmed

that respondents were aware of the benefits of using predictive genetic testing in their practice. Two attitude variables loaded strongly against the factor of acknowledgement for the need of training for predictive genetic testing. Both factors had an eigen value of ≥1.

4.4 Medical students

Table 4.14 presents responses to Likert scale questions in response to knowledge questions. There was a variance in the views of the medical student respondents towards predictive genetic testing. Seventy-five percent (75%) of respondents indicated that genetic counsellors are needed for patients to consult with once results are received. Fifty-five percent of respondents were aware of predictive genetic testing being offered in South Africa, and 73% of respondents reported that the use of genetic testing needs to consider ethical, legal and social implications of the users.

Figure 4.11 depicts the responses of male and female respondents to knowledge related questions. Most males (63%) and females (75.5%) felt that there were laws in South Africa that does protect the personal genetic information of patients. Sixty percent (60%) of female respondents felt that genetic tests are not valid and reliable, while 30% of male respondents shared the same views. Both male and female respondents agreed that external factors such as environment and lifestyle may affect the patients' predisposition towards diagnosis of genetic disorders.

Table 4.15 shows that 69.6% of respondents agreed that medical and health students require practical training on the use of genetic testing. The majority of respondents agreed that they would use predictive genetic testing once in practice. They also felt that the curriculum should be extended to provide adequate training to respondents regarding genetic testing. Twenty-seven percent of medical students felt that predictive genetic testing should only be used in South Africa if it is cost effective.

Figure 4.12 displays the attitudes of respondents stratified by gender. Seventy-six percent of female medical students felt that there is a need for the Department of Health in South Africa to create guidelines to assist in the use of genetic testing. Fifty-seven percent of male students indicated that they would not use predictive genetic testing when they are qualified.

Table 4.14: Knowledge levels of medical students towards predictive genetic testing (n = 79)

	Strongly Disagree	Disagree	Agree	Strongly Agree	p-value
	n (%)	n (%)	n (%)	n (%)	
Performing genetic tests should be associated with genetic counselling	1 (1.3)	1 (1.3)	18 (22.8)	59 (74.7)	0.000
Genetic testing can be used to identify a patients' susceptibility towards a genetic disorder and a non-communicable disease	0	0	23 (29.1)	56 (70.9)	0.000
The clinical use of a predictive genetic test is to ultimately improve the health status of the patient	0	5 (6.3)	36 (45.6)	38 (48.1)	0.000
Exposure to various factors such as socioeconomic status, lifestyle and environment can influence a patient's risk of disease due to their genetic predisposition	3 (3.9)	10 (13)	32 (41.6)	32 (41.6)	0.000
There are ethical guidelines in South Africa which govern the use of predictive genetic testing among patients	0	2 (2.6)	36 (46.8)	39 (50.6)	0.000
Predictive genetic tests are valid and reliable as long as a specific genetic characteristic is identified accurately in the laboratory	0	5 (6.4)	46 (59)	27 (34.6)	0.000
There are laws in place in South Africa which protects the patients' personal genetic information	1 (1.3)	2 (2.6)	19 (25)	54 (71.1)	0.000
Predictive genetic testing is being offered to individuals in South Africa	6 (7.9)	16 (21.1)	42 (55.3)	12 (15.8)	0.000
The use of predictive genetic testing in clinical and public health practice does not need to take into account the legal, ethical and social implications	57 (73.1)	17 (21.8)	2 (2.6)	2 (2.6)	0.000
Predictive genetic testing can contribute positively towards health promotion and disease prevention which can assist in the launch of NHI	2 (2.5)	2 (2.5)	27 (34.2)	48 (60.8)	0.000
Predictive genetic tests increase prevention opportunities for chronic diseases	0	9 (11.4)	28 (35.4)	42 (53.2)	0.000
I have had exposure to cancer genetic testing during my undergraduate training	50 (64.1)	22 (28.2)	4 (5.1)	2 (2.6)	0.000
Genetic counsellors are needed for patients to consult with once they have their genetic test results	1 (1.3)	3 (3.8)	15 (19.2)	59 (75.6)	0.000

*$p \leq 0.005$ was considered statistically significant

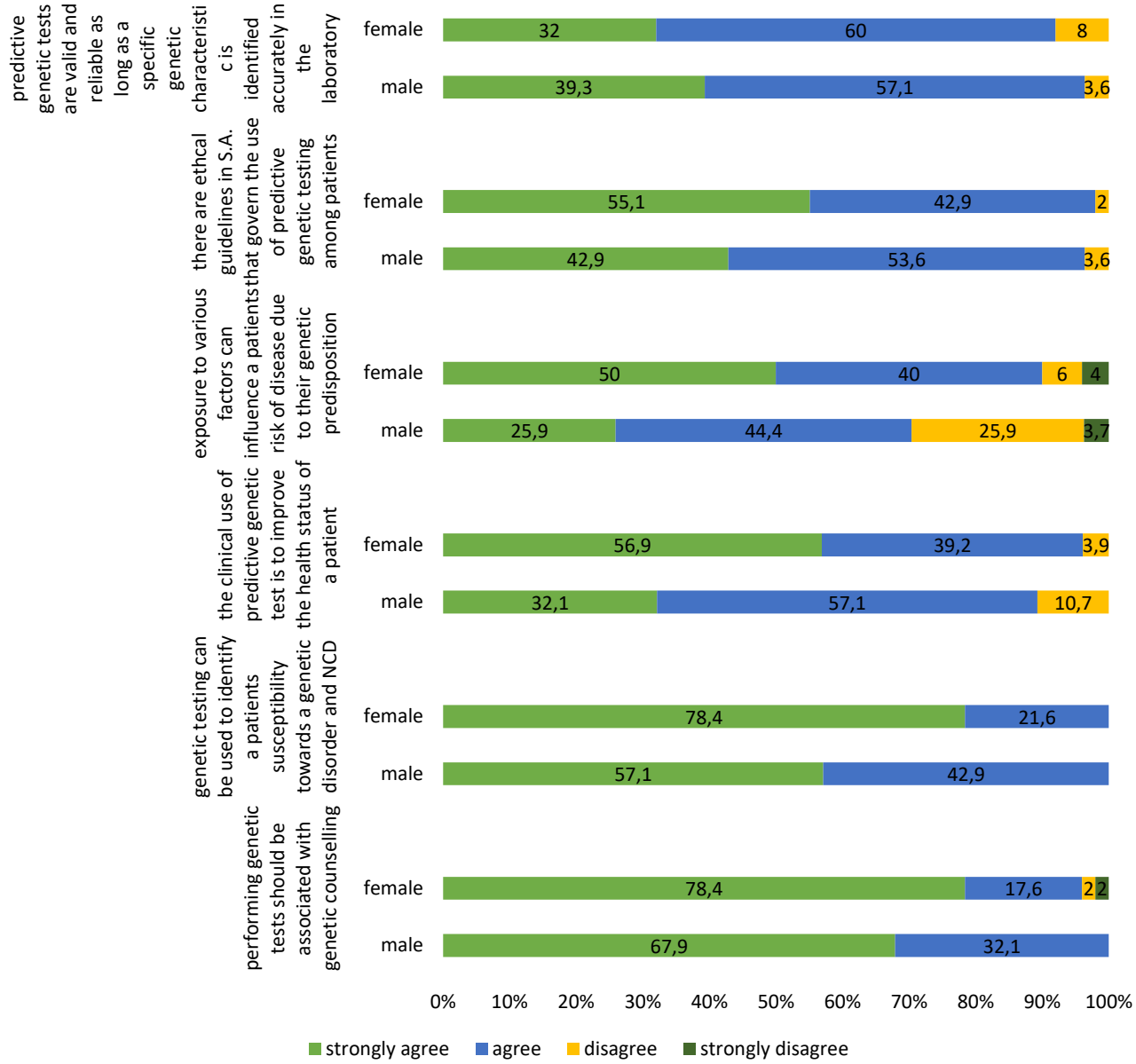

Figure 4.11: Knowledge of medical students on genetic testing stratified by gender (n = 79) – part 1

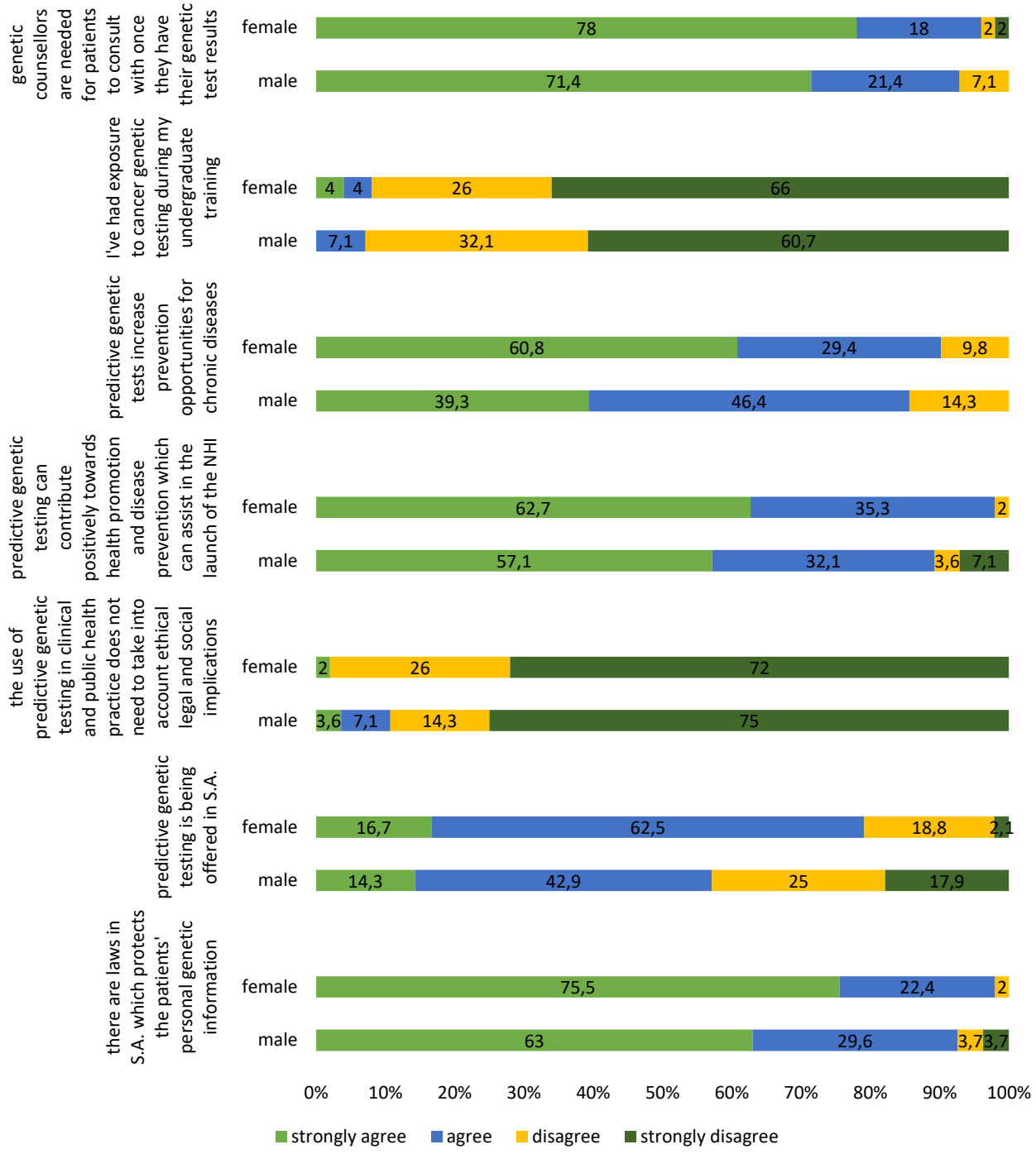

Figure 4.11: Knowledge of medical students on genetic testing stratified by gender (n = 79) – part 2

Table 4.15: Attitudes of Medical Students towards predictive genetic testing (n = 79)

	Strongly Disagree	Disagree	Agree	Strongly Agree	p-value
	n (%)	n (%)	n (%)	n (%)	
I will use predictive genetic testing in diagnosis and treatment of patients when I qualify as a medical practitioner	1 (1.3)	4 (5.1)	40 (51.3)	33 (42.3)	0.000
The curriculum needs to be extended to capacitate the medical students regarding predictive genetic testing	6 (7.6)	6 (7.6)	34 (43.0)	33 (41.8)	0.000
Guidelines from the department of health needs to be developed for the appropriate use of predictive genetic testing	0	0	27 (34.2)	52 (65.8)	0.005
Predictive genetic tests should not be introduced to clinical and public health practice unless it is proven to be cost effective in South Africa	6 (7.6)	22 (27.8)	37 (46.8)	14 (17.7)	0.000
Medical and health students require practical training on predictive genetic testing/genomic medicine	0	0	24 (30.4)	55 (69.6)	0.000

*$p \leq 0.05$ was considered statistically significant

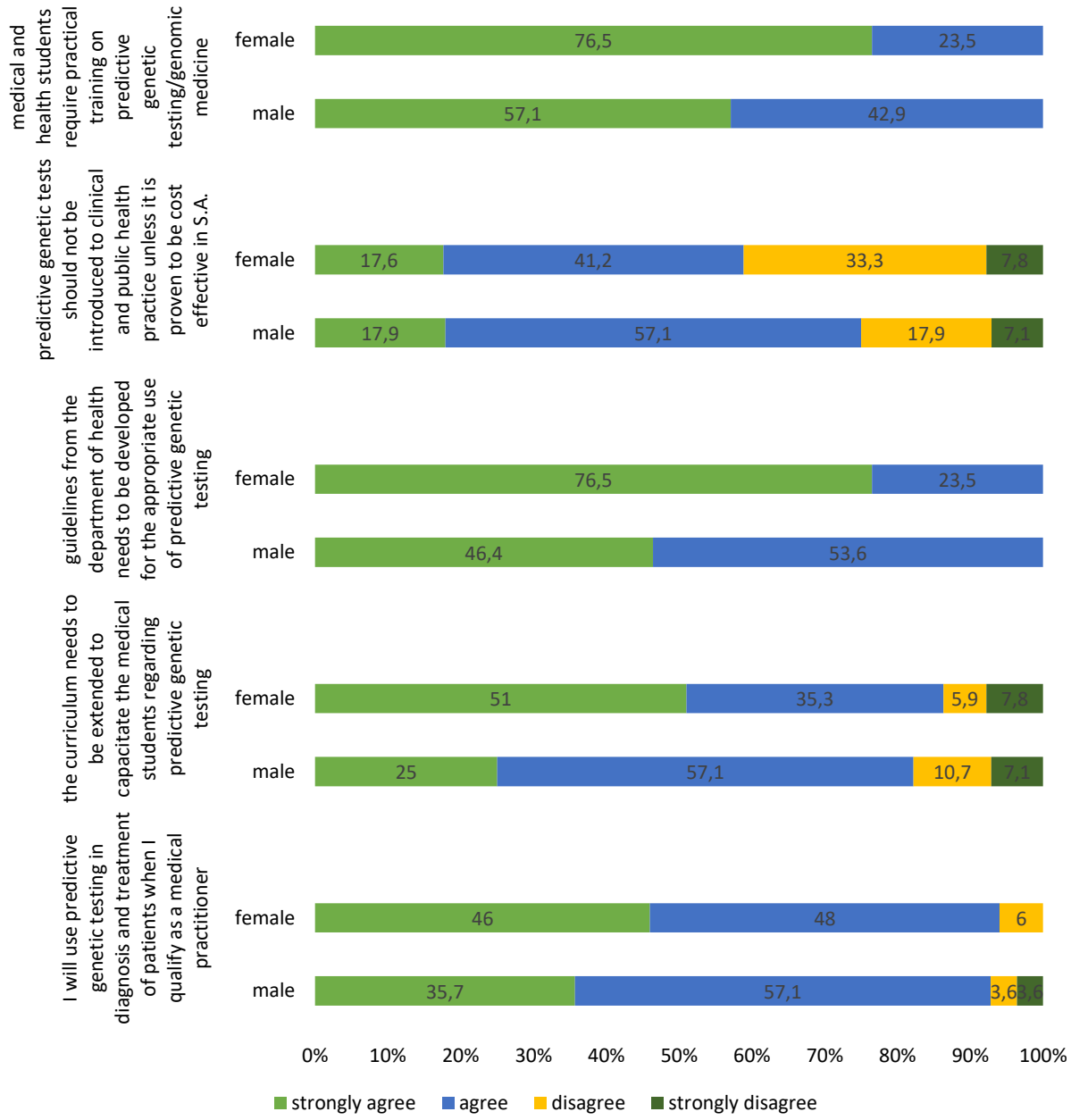

Figure 4.12: Attitude of medical students towards genetic testing stratified by gender (n = 79)

4.4.1 Knowledge and attitude scores of medical students on predictive genetic testing

Knowledge and attitude scores of medical student respondents are represented in Table 4.16 The same criteria that was used for medical practitioner sample and the general public sample was used for the medical student sample.

Table 4.16: Knowledge and attitude scores of medical students towards genetic testing (n = 79)

Scoring Scale for knowledge	**n (%)**
Excellent	
44 – 32 points	**25 (32.9)**
Adequate	
31 – 24 points	**53 (67.1)**
Poor	
24 points and below	**0**
Scoring Scale for attitudes	
Positive attitude	
33 – 22 points	**17 (21.5)**
Negative attitude	
21 points and below	**62 (78.5)**

The majority of medical student respondents (67.1%) had an adequate knowledge of genetic testing, whereas 32.9% of respondents had an excellent level of knowledge. There were no respondents with a poor knowledge of genetic testing. The majority of respondents (78.5%) had a negative attitude towards predictive genetic testing. Only 21.5% of respondents had a positive attitude.

Table 4.17: Bivariate Correlations for medical students (n = 79)

Correlations

			Performing genetic tests should be associated with genetic counselling	Genetic testing can be used to identify a patients' susceptibility towards a genetic disorder and a non-communicable disease	The clinical use of a predictive genetic test is to ultimately improve the health status of the patient	Exposure to various factors such as socioeconomic status, lifestyle and environment can influence a patients risk of disease due to their genetic predisposition	There are ethical guidelines in South Africa which govern the use of predictive genetic testing among patients	Predictive genetic tests are valid and reliable as long as a specific genetic characteristic is identified accurately in the laboratory	There are laws in place in South Africa which protects the patients' personal genetic information	Predictive genetic testing is being offered to individuals in South Africa	The use of predictive genetic testing in clinical and public health practice does not need to take into account the legal, ethical and social implications	Predictive genetic testing can contribute positively towards health promotion and disease prevention which can assist in the launch of NHI	Predictive genetic tests increase prevention opportunities for chronic diseases	I have had exposure to cancer genetic testing during my undergraduate training	Genetic counsellors are needed for patients to consult with once they have their genetic test results	I will use predictive genetic testing in diagnosis and treatment of patients when I qualify as a medical practitioner	The curriculum should be extended to capacitate the medical students regarding predictive genetic testing	Guidelines from the department of health is needed for the appropriate use of predictive genetic testing	Predictive genetic tests should only be introduced to clinical and public health practice only if it is proven to be cost effective in South Africa	Medical and health students require practical training on predictive genetic testing/genomic medicine
Spearman's	Performing genetic tests should be associated with genetic counselling	Correlation	1.000																			
		Sig. (2-tailed)																				
		N	79																			
	Genetic testing can be used to identify a patients' susceptibility towards a genetic disorder and a non-communicable disease	Correlation	0.188	1.000																		
		Sig. (2-taile	0.097																			
		N	79	79																		
	The clinical use of a predictive genetic test is to ultimately improve the health status of the patient	Correlation	0.131	.272*	1.000																	
		Sig. (2-taile	0.251	0.015																		
		N	79	79	79																	
	Exposure to various factors such as socioeconomic status, lifestyle and environment can influence a patients risk of disease due to their genetic	Correlation	0.057	0.166	.356**	1.000																
		Sig. (2-taile	0.623	0.148	0.001																	
		N	77	77	77	77																
	There are ethical guidelines in South Africa which govern the use of predictive genetic testing among patients	Correlation	0.089	0.158	.334**	0.226	1.000															
		Sig. (2-taile	0.441	0.170	0.003	0.051																
		N	77	77	77	75	77															
	Predictive genetic tests are valid and reliable as long as a specific genetic characteristic is identified accurately in the laboratory	Correlation	.278*	.243*	.253*	0.167	0.124	1.000														
		Sig. (2-taile	0.014	0.032	0.025	0.149	0.284															
		N	78	78	78	76	76	78														
	There are laws in place in South Africa which protects the patients' personal genetic information	Correlation	0.006	.226*	.447**	.326**	.385**	.238*	1.000													
		Sig. (2-taile	0.959	0.050	0.000	0.005	0.001	0.040														
		N	76	76	76	74	75	75	76													
	Predictive genetic testing is being offered to individuals in South Africa	Correlation	.290*	0.196	0.176	0.182	0.125	.326**	0.018	1.000												
		Sig. (2-taile	0.011	0.089	0.128	0.122	0.286	0.004	0.878													
		N	76	76	76	74	75	75	74	76												
	The use of predictive genetic testing in clinical and public health practice does not need to take into account the legal, ethical and social implications	Correlation	0.110	-0.047	-0.069	-0.060	0.008	0.028	-0.035	0.223	1.000											
		Sig. (2-taile	0.336	0.684	0.549	0.605	0.948	0.810	0.765	0.053												
		N	78	78	78	76	77	77	76	76	78											
	Predictive genetic testing can contribute positively towards health promotion and disease prevention which can assist in the launch of NHI	Correlation	0.106	.287*	.319**	.471**	.247*	.404**	.377**	0.043	-0.137	1.000										
		Sig. (2-taile	0.352	0.010	0.004	0.000	0.030	0.000	0.001	0.711	0.233											
		N	79	79	79	77	77	78	76	76	78	79										
	Predictive genetic tests increase prevention opportunities for chronic diseases	Correlation	0.130	.430**	0.112	0.196	0.120	.364**	0.099	.299**	-0.015	.383**	1.000									
		Sig. (2-taile	0.254	0.000	0.324	0.087	0.300	0.001	0.396	0.009	0.897	0.001										
		N	79	79	79	77	77	78	76	76	78	79	79									
	I have had exposure to cancer genetic testing during my undergraduate training	Correlation	0.107	-0.022	-0.080	-0.135	-0.216	0.027	-0.108	0.048	.229*	-0.193	-0.158	1.000								
		Sig. (2-taile	0.352	0.847	0.487	0.245	0.061	0.813	0.355	0.680	0.045	0.091	0.168									
		N	78	78	78	76	76	77	75	75	77	78	78	78								
	Genetic counsellors are needed for patients to consult with once they have their genetic test results	Correlation	0.108	.283*	0.121	0.067	0.177	.262*	.427**	0.091	-0.203	.346**	0.204	-.289*	1.000							
		Sig. (2-taile	0.346	0.012	0.292	0.566	0.125	0.021	0.000	0.438	0.076	0.002	0.073	0.010								
		N	78	78	78	76	76	77	75	75	77	78	78	78	78							
	I will use predictive genetic testing in diagnosis and treatment of patients when I qualify as a medical practitioner	Correlation	0.147	.313**	.250*	.286*	.258*	.343**	.251*	.516**	0.116	.353**	0.220	-0.126	.238*	1.000						
		Sig. (2-taile	0.199	0.005	0.028	0.012	0.024	0.002	0.030	0.000	0.314	0.002	0.052	0.274	0.037							
		N	78	78	78	76	76	77	75	76	77	78	78	77	77	78						
	The curriculum should be extended to capacitate the medical students regarding predictive genetic testing	Correlation	0.164	0.184	0.200	.299**	.254*	.394**	0.132	0.218	-0.140	.370**	.288*	-0.066	.320**	.414**	1.000					
		Sig. (2-taile	0.149	0.105	0.077	0.008	0.026	0.000	0.257	0.058	0.221	0.001	0.010	0.569	0.004	0.000						
		N	79	79	79	77	77	78	76	76	78	79	79	78	78	78	79					
	Guidelines from the department of health is needed for the appropriate use of predictive genetic testing	Correlation	-0.001	0.126	0.175	.327**	.255*	.314**	.322**	.323**	-0.066	.390**	.404**	-.354**	0.196	.247*	.222*	1.000				
		Sig. (2-taile	0.995	0.270	0.124	0.004	0.025	0.005	0.005	0.004	0.569	0.000	0.000	0.001	0.086	0.029	0.049					
		N	79	79	79	77	77	78	76	76	78	79	79	78	78	78	79	79				
	Predictive genetic tests should only be introduced to clinical and public health practice only if it is proven to be cost effective in South Africa	Correlation	0.103	-0.085	-0.089	0.073	0.035	0.184	0.063	0.079	0.039	0.101	0.069	0.070	0.183	.236*	.245*	-0.098	1.000			
		Sig. (2-taile	0.368	0.459	0.437	0.529	0.762	0.107	0.589	0.496	0.736	0.377	0.545	0.541	0.110	0.037	0.030	0.391				
		N	79	79	79	77	77	78	76	76	78	79	79	78	78	78	79	79	79			
	Medical and health students require practical training on predictive genetic testing/genomic medicine	Correlation	0.170	0.122	.319**	0.095	0.156	.225*	.323**	0.116	-0.119	.309**	.300**	-.302**	.234*	.381**	.450**	.452**	0.083	1.000		
		Sig. (2-taile	0.134	0.284	0.004	0.413	0.176	0.048	0.004	0.320	0.301	0.006	0.007	0.007	0.039	0.001	0.000	0.000	0.465			
		N	79	79	79	77	77	78	76	76	78	79	79	78	78	78	79	79	79	79		

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

All significant relationships are indicated by a * or ** (see Appendix O for larger image)

Bivariate correlation was performed (Table 4.17) on ordinal data of medical student respondents to look for potential relationships between variables. The correlation value between “medical and health students require practical training on predictive genetic testing/genomic medicine” and “Guidelines from the department of health is needed for the appropriate use of predictive genetic testing” is ($r = 0.45$; $p = 0.00$). Medical students agreed that training in predictive genetic testing should be conducted in conjunction with guidelines given by the Department of Health in South Africa. However, an inversely proportional relationship ($r = -0.12$; $p = 0.30$) between “medical and health students require practical training on predictive genetic testing/genomic medicine” and “the use of predictive genetic testing in clinical and public health practice does not need to take into account the legal, ethical and social implications” represents the existing gap regarding the lack of training on genetic testing. A positive correlation ($r = 0.43$; $p = 0.00$) between “genetic counsellors are needed for patients to consult with once they have their genetic test results” and “there are laws in place in South Africa which protects the patients' personal genetic information” shows that the respondents felt that laws need to be in place for the correct counselling services to be provided by the genetic counsellors in order to protect the patients’ personal genetic information.

PCA analysis yielded five factors from 12 knowledge variables (Table 4.18). Eigen values greater than 1 have loaded strongly against knowledge variables. Awareness of the use of genetic testing yielded a strong eigen value of 3.27. which indicated that respondents were knowledgeable about genetic testing being offered in South Africa and that genetic testing is used to prevent disease. The understanding of need for legislative framework had a high factor loading ranging from 0.824 to 0.549. Respondents were aware that guidelines should be in place to regulate the use of predictive genetic testing to protect patient interest and confidentiality. Benefits of genetic testing relating to improving health status had a factor loading of two knowledge variables indicating that respondents agreed that the use of genetic testing could contribute positively towards disease prevention and encourage health promotion. Two variables loaded strongly against the factor of correct use of genetic testing. Respondents felt that genetic counsellors are needed to facilitate the process of patients receiving their genetic results.

Table 4.18: Rotated Component Matrix – Knowledge factors of medical students retained by factor analysis

	Awareness of the use of genetic testing	Understanding of need for legislative framework	Benefits of genetic testing	Correct use of genetic testing	Exposure to cancer genetic testing
Predictive genetic testing is being offered to individuals in South Africa	0.804	-	-	-	-
Performing genetic tests should be associated with genetic counselling	0.650	-	-	-	-
Genetic counsellors are needed for patients to consult with once they have their genetic test results	-	-	-	0.853	-
Genetic testing can be used to identify a patients' susceptibility towards a genetic disorder and a non-communicable disease	-	-	-	0.483	-
There are ethical guidelines in South Africa which govern the use of predictive genetic testing among patients	-	0.824	-	-	-
The clinical use of a predictive genetic test is to ultimately improve the health status of the patient	-	0.760	-	-	-
Exposure to various factors such as socioeconomic status, lifestyle and environment can influence a patient's risk of disease due to their genetic predisposition	-	-	0.824	-	-
There are laws in place in South Africa which protects the patients' personal genetic information	-	0.549	-	-	-
Predictive genetic tests are valid and reliable as long as a specific genetic characteristic is identified accurately in the laboratory	0.575	-	-	-	-
Predictive genetic tests increase prevention opportunities for chronic diseases	0.566	-	-	-	-
Predictive genetic testing can contribute positively towards health promotion and disease prevention which can assist in the launch of NHI	-	-	0.693	-	-
I have had exposure to cancer genetic testing during my undergraduate training	-	-	-	-	0.882
Eigen value	3.27	1.57	1.39	1.06	1.02
% of Variance	27.32	13.10	11.61	8.84	8.52
Cumulative %	27.32	40.43	52.04	60.89	69.42

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalisation

a. Rotation converged in 8 iterations

Table 4.19 displays the common trends observed among the attitudes of medical student respondents towards predictive genetic testing. Factor analysis retained two factors on attitudes having an eigen value of ≥ 1. Medical students showed willingness to use predictive genetic testing in their field of practice once graduated but required practical training. The factor loading for the need for training on genetic testing is high.

Table 4.19: Rotated Component Matrix – Attitude factors of medical students retained by factor analysis

	Opinions of genetic testing	**Need for training on genetic testing**
The curriculum should be extended to capacitate the medical students regarding predictive genetic testing	0.728	-
Predictive genetic tests should only be introduced to clinical and public health practice only if it is proven to be cost effective in South Africa	0.719	-0.378
I will use predictive genetic testing in diagnosis and treatment of patients when I qualify as a medical practitioner	0.661	0.291
Guidelines from the department of health is needed for the appropriate use of predictive genetic testing	-0.025	0.838
Medical and health students require practical training on predictive genetic testing/genomic medicine	0.369	0.738
Eigen value	1.95	1.21
% of Variance	39.14	24.25
Cumulative %	39.14	63.40

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalisation

a. Rotation converged in 3 iterations.

4.5 Comparison of knowledge and attitude scores for all sample groups (n=170)

Knowledge levels were divided into three categories – excellent (if participant scored between 32 and 44 points), adequate (if participants scored between 31 and 24 points) and poor (if participants scored 24 points and below). All knowledge-based questions answered correctly were given a point. The same criteria applied for scoring of attitudes of participants. Where the response of participant was positive, a point was given and for a negative answer, no point was given. Participants scoring between 33 and 22 points were categorised with a positive attitude. Participants scoring with points below 21 were identified to have a negative attitude towards predictive genetic testing.

Table 4.20 reveals the overall level of knowledge from all three sample groups. Medical practitioners have the highest level of excellent knowledge pertaining to predictive genetic testing with a score of 77.8% followed by medical students with a knowledge score of 32.9%. The general public were perceived to have an adequate knowledge of predictive genetic testing.

Table 4.21 shows the overall attitude of all three sample populations. Medical practitioners and the general public have a positive attitude towards predictive genetic testing, compared to the medical students who have a negative attitude towards predictive genetic testing.

Table 4.20: Table of knowledge scores stratified by medical students, medical practitioners and the general public (n = 170)

Sample Population	Poor n (%)	Adequate n (%)	Excellent n (%)
Medical Students	0	53 (67.1)	25 (32.9)
Medical Practitioners	0	10 (22.2)	35 (77.8)
General Public	1 (0.47)	36 (76)	9 (4.23)

Table 4.21: Attitude scores stratified by medical students, medical practitioners and the general public (n = 170)

Sample Population	Positive Attitude n (%)	Negative Attitude n (%)
Medical students	17 (21.5)	62 (78.5)
Medical practitioners	37 (82.2)	8 (17.8)
General Public	44 (93.5)	3 (4.3)

CHAPTER 5: DISCUSSION

The introduction of predictive genetic testing by private medical insurance in South Africa has made genetic testing services available to the public. However, there is limited research in the South African context to establish the current status of the potential users and advocates for genetic testing. The aim of this quantitative KAP study was to determine the knowledge, attitudes and perceptions of medical practitioners, the general public and medical students towards public health genomics. It was vital to invite the participation of those who had access to predictive genetic testing and those who could advocate for such medical technology to be used. Contrary to other research conducted in various countries, we found that in this study, medical students were not keen on adopting the use of predictive genetic testing once they qualified as medical practitioners. Medical practitioners were keen on using predictive genetic testing and some reported the use of this technology in their practice. Only 18% of medical practitioners (18%) using genetic testing were from private practice which could be attributed to more patients undergoing genetic screening for cancer and other genetic disorders at government health care facilities. The potential users of predictive genetic testing were positive in their attitude towards the uptake of genetic testing. Fourteen respondents from the general public were aware of where to have a genetic test done in the KZN region.

Knowledge, attitudes and perceptions of medical practitioners in this study towards the uptake of genomic medicine in their practice was overall positive. The results of this study are in agreement with existing literature, where favourable attitudes to the use of genomic medicine in practice have been identified (Ikeda 2008; Teng and Spielman 2014; Grant et al. 2009; Scheuner, Sieverding and Shekelle 2008). Irrespective of the rating of their knowledge of genomic medicine, medical practitioners felt that the benefits of using predictive genetic testing outweighed the disadvantages. Despite the positive attitude towards the use of predictive genetic testing in their practice, medical practitioners acknowledged that they were limited in their use of this type of technology and required training to be capacitated regarding predictive genetic testing. The majority of practitioners indicated that they would use genetic testing in the diagnosis and treatment of patients which suggests a positive attitude. This is consistent with a study that was conducted in Italy where the medical fraternity acknowledged the benefits of predictive genetic testing despite their limited knowledge (Marzuillo et al. 2013). Academic staff, primary health care practitioners and family physicians had a positive attitude towards

genomic medicine and believed that it would be clinically beneficial (Mainous et al. 2013). In Japan, surveyed medical practitioners from 29 to 69 years displayed positive attitudes towards genomic medicine (Ikeda 2008), including those who had been practicing medicine for approximately 30 years. Studies also reveal that the number of years in practice, knowledge, and age of the medical practitioner influences one's attitude towards genomic medicine (Ikeda 2008). In this study, the mean age for medical practitioners was 46.79 and the years of experience/in practice was 22 years (Table 4.1). Most respondents were in practice for approximately 22 years. Increased work experience in practice may improve patient understanding and promote exploration of new medical technology to improve the quality of health care. Grant et al. (2009) assessed the perceptions of endocrinologists in the U.S. regarding the use of genomic medicine and found that most of the medical specialists were keen on the use of this technology and had a positive view despite their limited knowledge of genomic medicine.

Sufficient knowledge among medical practitioners is necessary to facilitate the use of genomic medicine with patients. In this study, 80% of the respondents displayed an adequate level of knowledge of predictive genetic testing and were aware of the services available with 2.2% having a poor knowledge of services available. Phaladi-Digamela, Mulaudzi and Maja (2014) state that sufficient knowledge is vital as it assists health professionals to evaluate, diagnose and prevent genetic diseases. Although 77.8% of our sample of medical practitioners were rated with an excellent knowledge of genomic medicine, this knowledge was attributed to self-learning rather than specific training. Most medical practitioners from both the public and private sector, revealed that they either attended conferences, workshops, or completed online courses in order to familiarise themselves with and have an understanding of genomic medicine. One could also assume that the lack of information on predictive genetic testing within the medical framework among undergraduate students could also be a contributing factor towards the second-year medical students having a negative attitude towards predictive genetic testing in this study. The existence of gaps within the educational framework could be a contributing factor towards the majority of medical practitioners not practicing predictive genetic testing. This could be resultant of medical practitioners not being exposed to training hence they would not want to compromise the diagnosis and treatment of their patients. In this study, bivariate correlations between variables showed a positive relationship ($r = 0.46$; $p = 0.002$) on the knowledge of medical practitioners in regard to the paucity of legislation for governing the use of predictive genetic testing. Medical practitioners were aware of the correct

application of genetic testing and that it is being offered in South Africa. Furthermore, PCA conducted for knowledge variables loaded a factor (eigen value = 2.11) for medical practitioners having a knowledge of the existing limitations that exist in the use of predictive genetic testing. Research conducted abroad has shown that the uptake of online and post-graduate courses within the medical fraternity show that there is uniformity in the curriculum regarding genomic medicine and this has an impact on the delivery of genetic services, as one requires the skill-set and a thorough understanding of genomic medicine prior to implementing it in the field (Houwink et al. 2014). More than 50% of medical practitioners indicated that they were not exposed to genetics during their undergraduate studies. Furthermore, 33% of those who indicated that they did not have exposure are currently practicing in the public health sector. In this study, there were medical practitioners in private practice who indicated that they have adopted the use of predictive genetic testing.

More than 50% of medical practitioners in this study indicated that training on the correct application of genetic testing is necessary for the effective use of predictive genetic testing. The interpretation of genetic results and the required post-results counselling is a challenge. Fifty-seven percent of medical practitioners from private practice and 29.4% from government practice felt that there are insufficient ethical guidelines and legislation governing the use of predictive genetic testing. Medical practitioners were aware of the possibility of patients being discriminated against and their test results being used for research purposes without consent. This necessitates the development of ethical and legal guidelines for medical practitioners when consulting with patients in South Africa.

In this study, scoring for attitudes revealed that 78.5% of second year medical students had a negative attitude towards genomic medicine. Students did not support the use of genomic medicine and once they are qualified they do not intend on using predictive genetic medicine in practice. However, there is no statistical difference or correlation among gender and attitudes of respondents. When PCA was conducted for attitude variables, it was found that medical students felt that there was a need for additional training among qualified medical and health care practitioners regarding the correct use of predictive genetic testing. They noted existing limitations legally and educationally in the use of genetic testing. This shows that medical students were sceptical regarding the use of new medical technology as they took into consideration all aspects of using a new form of medical technology. However, one could also determine that medical students do not have exposure in the field as they are undergraduate students. They have not seen the emotional and mental strain patients experience when

diagnosed with a disease, therefore they are not willing to risk practicing predictive genetic testing. However, in this study, more than 50% of students felt that genetic testing should be implemented in South Africa, if it is proven to be cost effective. The costs to patients accompanied by a lack of legal and educational framework surrounding genetic testing may hinder successful implementation of this technology.

Research carried out in Italy among 33 public health postgraduate schools showed that medical students were aware of the use, interpretation and uptake of genetic testing in the medical field (Lanuale et al. 2014). Students registered for these post graduate public health courses showed a positive attitude towards genomic medicine and they were keen on including it in their practice. It is interesting to note that the positive attitude was reported from postgraduate and not undergraduate students, which may be related to their experience in the field and their interest in reducing the burden of disease. There could be a possibility that once undergraduate students in this study have been exposed to the genetic module, their perception and attitude towards genetic testing could possibly change based on a deeper understanding of the role of genetics in disease management. In this study, more female students than male students were knowledgeable about the use of predictive genetic testing. Results of this study also indicate that more female students were likely to implement predictive genetic testing in their practice once they qualified compared to male students. Contrary to expected results, one could attribute their excellent and adequate knowledge scores of 67% and 33% respectively to them having prior knowledge of genetics as a result of the high school education curriculum. The natural science module accommodates the inclusion of genomes and baseline genetics in the CAPS curriculum for Life Sciences.

Bivariate correlations revealed that the medical student respondents were aware of patients' need for genetic counsellors. These respondents were aware that the uptake of genetic testing as a medical practitioner involved other trained healthcare specialists, knowing that there is a responsibility for accuracy in a diagnosis which determines the patient's predisposition towards diagnosis of a genetic disease. A negative correlation between variables for medical students ($r = -0.119$; $p = 0.30$) showed that having knowledge about genetic testing and knowing the potential benefits it may have on patients does not necessarily mean that all students would be keen on adopting the technology once qualified. PCA was carried out among knowledge variables for medical students and it was found that while medical students understood the main use of predictive genetic testing (eigen value = 3.27), they highlighted the need for legislative framework in South Africa regarding the use of genetic testing.

When the knowledge, attitudes and perceptions of midwifery learners were investigated regarding the uptake of predictive genetic testing in South Africa, the limited knowledge of the learners towards predictive genetic testing suggested a need for a revised curriculum framework (Phaladi-Digamela, Mulaudzi and Maja 2014). The results of the study showed that there was no correlation between attitudes and perceptions of learners and their knowledge levels. The need for a modified standardised genomic education framework in tertiary institutions is evident. Based on the self-administered questionnaire given to the medical students, it was found that 67.1% of the second year medical students in that study had an adequate level of knowledge regarding genomic medicine whereas only 32.9% of the students in this study had an excellent level of knowledge towards genomic medicine prior to being taught genetics. The results show a satisfactory level of knowledge among the medical students, especially considering that it was prior to exposure to the genetics module.

Education has a strong influence on one's knowledge and attitudes towards predictive genetic testing. This was concluded from a study by Marzuillo et al. (2013), where the knowledge, attitudes and behaviour of physicians with respect to predictive genetic testing were assessed. This is consistent with our findings with medical students. It is important to note that at the point of administering the questionnaire, the second year medical students were not yet taught the genetics module, and they were not yet exposed to practicing in the field where the need for predictive genetic testing is considered in assisting with diagnosis of diseases.

Research has been conducted to investigate the attitudes and knowledge of the general public towards predictive genetic testing (Gollust et al. 2015). The assessment of knowledge of available services in other countries revealed that most of the public either did not know much about predictive genetic testing or they had a misinterpretation of the use of technology. In contrast to these reports, the results of this study revealed that almost 60% of the general public were aware of predictive genetic testing being offered in South Africa. However, only 24% of the general public was knowledgeable of the facilities available to have this type of testing done.

The more knowledgeable the public was about genetic testing being offered in South Africa, the more likely they were to access it ($r = 0.47$; $p = 0.02$). The curiosity of the respondents led them to want to know more about genetic testing, resulting in them enquiring about genetics independently, rather than waiting for someone to educate them on the use of predictive genetic testing. However, not all respondents were keen on knowing the risk of contracting a disease.

This could be attributed to the lack of ethical guidelines and regulatory framework for use of genetic testing. In South Africa, the uptake of genetic testing for non-communicable diseases is mainly from the private health care sector. Public health care sectors probably involve genetic testing mainly for oncology and prenatal purposes. This means that the use of predictive genetic testing for non-communicable diseases is still in its infancy in the public health sector. It is also important to note that the general public representatives in this study all had access to private medical aid. PCA showed that the public was well-versed regarding the lack of guidelines that exist in the use of genetic testing from a user perspective. They were well-informed regarding the gap that exists and that potential users of genetic testing are concerned about their protection of privacy. To assist the general public to know more about predictive genetic testing, students from the Witwatersrand University in South Africa have developed a genetics app designed to create awareness and educate the community at large about genetics (University of the Witwatersrand 2019). This is a major leap in developing the knowledge of the South African population regarding genetics, as this app will increase the level of knowledge among those who are interested in genetics and could play a vital role in educating individuals about the fundamentals of genetics prior to undergoing genetic testing. This app can be developed to include information about genetic testing to create awareness among South Africans of genetic screening.

The launch of predictive genetic testing has raised expectation that people are able to act upon a possibility of having a disease before they can be clinically diagnosed with it. However, there are factors which can influence their perception regarding use. A study conducted in the United Kingdom revealed that the general public displayed a positive attitude towards the uptake of predictive genetic testing; however, once the cost of this service was factored in, only one in twenty of the total sample population of 4050 participants were keen (Cherkas et al. 2010). The results of this current study show that participants had a positive attitude towards the uptake of predictive genetic testing despite the potential costs. This means that the general public are willing to pay the price to identify predisposition for disease.

Once users are aware of their disposition after genetic screening they should be advised on behaviour modification and lifestyle changes. This means that in order to reduce the onset of disease or to avoid contraction of the disease entirely, users should be counselled on adaptation of diet to the needs of their body make-up (Grant et al. 2019). Examples of this could be to refrain from consuming alcohol or smoking or changing their work or residential environment if exposed to factors there that contribute towards disease predisposition.

In this study, the African race group was found to be more accepting of the use of genetic testing. It should be noted that this race group was previously unable to access adequate health care making them more accommodating towards the use of this technology to improve their quality of life.

PCA was conducted for attitude variables, and a common thread of willingness to use genetic testing was observed. There are social, ethical and legal implications that can affect the mental and emotional well-being of the potential users of genetic testing. It can be ascertained that although respondents want to use genetic testing to help diagnose predispositions for a disease, they are also fearful of the possibility of discrimination. For example, if an individual wanted to apply for a job which requires pre-employment screening, the question arises as to whether their genetic test results would be made available for the potential employer to view, or whether they be allowed to keep that information as private, because such information should not be used as a form of discrimination for employment. One can agree that it is vital for the public and private health sector to come together to provide a uniform service and provide legal input regarding the development of a context, or a platform strong enough for the advocacy of genomic medicine. This could allay the fears of the general public as results of this study show that they are willing to use genetic testing but are concerned about the existing information and legal gaps that surround this technology.

Females formed the majority of the public sample population in this study (91.3%) and they displayed a keen interest in wanting to know more about predictive genetic testing. This correlates with a study undertaken in Amsterdam where attitudes were explored towards genetic testing (Henneman et al. 2011). More female respondents were interested in knowing more about predictive genetic testing. Media coverage of health conditions among celebrities may also influence uptake for screening. It could be ascertained that females were interested in predictive genetic testing as a result of celebrity influence. For example, when actress Angeline Jolie disclosed her positive results after genetic screening for BRAC 1 / BRAC 2 and had a double mastectomy, research conducted in North Carolina showed that more than 50% of women, after hearing of this news, intended undergoing the same genetic screening (Roberts and Dusetzina 2017). Women in particular may have an increased interest in knowing their predisposition for contracting genetic disorders such as breast and cervical cancers. Age may also influence attitude and older women may be more accepting of predictive genetic testing (Henneman et al. 2011).

There is limited research with respect to the knowledge, attitudes and perceptions of users and supporters of genetic testing in the South African context from a patient and provider perspective. In order to control the burden of disease from non-communicable diseases such as diabetes and cancer, the use of this technology as a short term investment will result in long term rewards. Overall, the potential users, advocates and potential advocates of genetic testing were aware that there is a lack of ethical guidelines and regulations governing the use of predictive genetic testing. The need for training and specialisation was highlighted by both medical practitioners and medical students. However, the lack of legislation and training did not deter the medical practitioners from wanting to adopt the use of predictive genetic testing in practice. In contrast, medical students were more cautious about using it in practice when qualified. This could be due to them not having exposure to the field and associating predictive genetic testing with increased cost. The general public, however, indicated that they would support predictive genetic testing as an option despite the possible costs. It is important to consider alternative solutions for disease prevention and not depend on curative strategies only. When National Health Insurance is implemented, the reduction in the incidence of disease would assist in reducing overall costs as the inclusion of genetic services within the NHI system would function at a preventative measure rather than a curative measure for disease. Such testing could encourage adaptation to healthier lifestyles once an individual's predisposition for a disease is identified.

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

Medical practitioners displayed a good knowledge and positive attitude towards genomic medicine, whereas medical students presented the same but did not have a positive attitude towards the uptake of genetic testing as potential advocates. Medical students indicated that they would not want to implement predictive genetic testing when they qualify. The general public displayed a positive attitude towards the uptake of predictive genetic testing and were keen on learning more about this technology.

The following limitations existed in the study:

- Convenience sampling was used, thus resulting in skewed data of sample representation of the general public and medical practitioners. There were more female respondents than male respondents from the general public, and more male than female respondents from the medical practitioners.
- All questionnaires designed differed in their content as relevant to each group, therefore a thorough cross evaluation of all three sample groups could not be conducted.
- The general public was representative of those who have private medical aid/medical insurance and those who have had tertiary education.

The following recommendations can be made:

- Tertiary institutions can adapt undergraduate and post-graduate curriculum to make provision for a uniform module on genetics that would be extended not only to medical and health care students but offered to qualified practitioners for continuous professional development (CPD) training.
- Tertiary institutions, health professions councils, and the National Department of Health can also develop courses for medical and health care practitioners to attend to be educated on predictive genetic testing to create more confidence in the use of predictive genetic testing, and CPD points can be awarded for attendance. These workshops can be based on the practice of genetic testing within the legal framework of South Africa.

- Relevant stakeholders from academia, private and public health sectors can form a forum whereby legislation is developed for the user, adopter and researcher for the use of predictive genetic testing.
- Awareness should be created on various media platforms for the public to be informed about predictive genetic testing in South Africa.

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APPENDICES

APPENDIX A: QUESTIONNAIRE – GENERAL PUBLIC

QUESTIONNAIRE: GENERAL PUBLIC

Knowledge, attitudes and perceptions of Genomic Medicine among medical students, private medical practitioners and the general public in Durban, KwaZulu-Natal

Predictive genetic testing and genomic medicine in this context refers to testing for non-communicable diseases such as diabetes and cancer

All information obtained from this questionnaire will remain anonymous once the questionnaire is returned.

Please fill in spaces where your input is needed and tick the options that might apply to you. Please answer all questions to the best of your ability.

SECTION 1: DEMOGRAPHICS

1.1. Age: (in years)

_____

1.2. Gender

☐ Male ☐ Female ☐ Other

1.3. Race

☐ Black ☐ White ☐ Coloured ☐ Indian ☐ Other

1.4. Highest level of education

☐ No formal education ☐ Primary School ☐ High School ☐ Matric
☐ University
☐ NQF ☐ N2/N3 ☐ Other (Specify)

SECTION B: KNOWLEDGE & ATTITUDES ON GENOMIC MEDICINE

No.	Statement	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
1.	Genetic testing can be used to prevent diseases such as diabetes, cancer.				
2.	Genetic testing can be used to prevent HIV, AIDS, T.B.				
3.	Genetic testing can be used to determine future susceptibility to certain diseases.				
4.	Genetic testing is an important topic for the community to know about.				
5.	Genetic testing will be too expensive to use.				
6.	I would like to find out if I am at risk for any chronic disease.				
7.	I would will be worried about what my genetic test results will be like if I had to have a test done.				
8.	If my genetic test result is positive for a disease, it will cause me to be stressed.				
9.	I am not sure of what to do after I get my genetic test results back.				
10.	Genetic testing is being offered in South Africa.				
11.	I feel genetic testing has more benefits than disadvantages.				
12.	I know where to have a genetic test done in KwaZulu-Natal.				
13.	I am concerned about my genetic data being used for further studies without my consent.				

14.	Having a genetic test is valid and accurate.				
15.	I would like for my genetic data to be used in scientific research.				
16.	There are ethical guidelines for human genetic tests in South Africa and these guidelines protect us.				
17.	There is a law in South Africa for the protection of personal genetic information.				
18.	Genetic testing can be used to also find genetic conditions and treat them.				
19.	Genetic testing is useful in helping to use the right medication for treatment.				
20.	I would like to learn more about genetic testing.				
21.	I will be discriminated against if my genetic test results are positive.				

22. Is there a facility in KwaZulu-Natal that offers predictive genetic testing? If yes, please provide the suburb it is located in.

_____
_____
_____
_____

23. On a scale from 1 to 5, how confident are you in your knowledge of genetics?

NOT CONFIDENT	1	
SLIGHTLY CONFIDENT	2	
SOMEWHAT CONFIDENT	3	
CONFIDENT	4	
VERY CONFIDENT	5	

24. Has your medical aid offered or mentioned predictive genetic testing to you?

☐ Yes ☐ No ☐ Other

THANK YOU FOR ANSWERING ALL QUESTIONS!!!

APPENDIX B: QUESTIONNAIRE – MEDICAL PRACTITIONERS

QUESTIONNAIRE: MEDICAL PRACTITIONERS

Knowledge, attitudes and perceptions of Genomic Medicine among medical students, private medical practitioners and the general public in Durban, KwaZulu-Natal

Please note that all the information obtained from this questionnaire will remain anonymous once the questionnaire is returned. Predictive genetic testing/genomic medicine in this survey is within the context of non-communicable diseases like cancer, diabetes, among other disorders based on the genes of the patients

Please fill in spaces where your input is needed and tick the options that might apply to you. Please answer all questions to the best of your ability.

SECTION A: DEMOGRAPHICS

1.1. Age: (in years)

_____

1.2. Gender

☐ Male ☐ Female ☐ Other

1.3. Race

☐ Black ☐ White ☐ Coloured ☐ Indian ☐ Other

1.4. ☐ Private practice ☐ Government practice ☐ Public clinic

☐ Public hospital ☐ Other

1.5. Is there any further training apart from MBCHB?

_____
_____
_____
_____
_____
_____
_____
_____

1.6. Are there any specialist field/fields you are practicing in?

_____
_____
_____
_____

1.7. Number of years in experience as a doctor

_____

1.8. How do you keep up to date with information related to your profession?

_____
_____
_____
_____
_____

SECTION B: KNOWLEDGE & ATTITUDES ON GENOMIC MEDICINE

No.	STATEMENT	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
1.	Performing genetic tests should be associated with genetic counselling.				
2.	Genetic testing can be used to identify a patients' susceptibility towards a genetic disorder and a non-communicable disease.				
3.	The clinical use of a predictive genetic test is to ultimately improve the health status of the patient.				
4.	Exposures to various factors such as socioeconomic status, lifestyle and environment can influence a patients' risk of disease due to their genetic predisposition.				
5.	There are Ethical guidelines in South Africa which govern the use of predictive genetic testing among patients.				
6.	Predictive genetic tests are valid and reliable as long as a specific genetic characteristic is identified accurately in the laboratory.				
7.	There are laws in place in South Africa which protects the patients' personal genetic				

	information.				
8.	Predictive genetic testing is being offered to individuals in South Africa.				
9.	I will use predictive genetic testing in diagnosis and treatment of patients.				
10.	I have started using predictive genetic testing for diagnosis and treatment of patients.				
11.	The use of predictive genetic testing in clinical and public health practice does not need to take into account the legal, ethical and social implications.				
12.	Predictive genetic testing can contribute positively towards health promotion and disease prevention which can assist in the launching of the National Health Insurance (NHI).				
13.	Guidelines from the department of Health is needed for the appropriate use of predictive genetic testing.				
14.	Predictive genetic tests increase prevention opportunities for chronic diseases.				
15.	Predictive genetic tests should only be introduced to clinical and public health practice only if it is proven to be cost-effective in South Africa.				
16.	I have had exposure to cancer genetic testing during my undergraduate training.				
17.	Genetic counsellors are				

	needed for patients to consult with once they have their genetic test results.				
18.	Medical and health practitioners require training on predictive genetic testing/genomic medicine.				

19. Is there a facility in KwaZulu-Natal that offers predictive genetic testing? If yes, please state which suburb it is located in.

_____
_____
_____

20. On a scale from 1 – 5, how confident are you in your knowledge of genetics?

NOT CONFIDENT - 1 1	
SLIGHTLY CONFIDENT - 2 2	
SOMEWHAT CONFIDENT - 3	
CONFIDENT - 4	
VERY CONFIDENT - 5	

THANK YOU FOR ANSWERING ALL QUESTIONS!!!

APPENDIX C: QUESTIONNAIRE – MEDICAL STUDENTS

QUESTIONNAIRE: MEDICAL STUDENTS

Knowledge, attitudes and perceptions of Genomic Medicine among medical students, private medical practitioners and the general public in Durban, KwaZulu-Natal

Please note that all the information obtained from this questionnaire will remain anonymous once the questionnaire is returned. Predictive genetic testing/genomic medicine in this survey is within the context of non-communicable diseases like cancer, diabetes, among other disorders based on the genes of the patients

Please fill in spaces where your input is needed and tick the options that might apply to you. Please answer all questions to the best of your ability.

SECTION A: DEMOGRAPHICS

1.1. Age: (in years)

_____

1.2. Gender

☐ Male ☐ Female ☐ Other

SECTION B: KNOWLEDGE & ATTITUDES ON GENOMIC MEDICINE

No.	STATEMENT	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
1.	Performing genetic tests should be associated with genetic counselling.				
2.	Genetic testing can be used to identify a patients' susceptibility towards a genetic disorder and a non-communicable disease.				
3.	The clinical use of a predictive genetic test is to ultimately improve the health status of the patient.				
4.	Exposures to various factors such as				

	socioeconomic status, lifestyle and environment can influence a patients' risk of disease due to their genetic predisposition.				
5.	There are Ethical guidelines in South Africa which govern the use of predictive genetic testing among patients.				
6.	Predictive genetic tests are valid and reliable as long as a specific genetic characteristic is identified accurately in the laboratory.				
7.	There are laws in place in South Africa which protects the patients' personal genetic information.				
8.	Predictive genetic testing is being offered to individuals in South Africa.				
9.	I will use predictive genetic testing in diagnosis and treatment of patients when I qualify as a medical practitioner.				
10.	The curriculum should be extended to capacitate the medical students regarding predictive genetic testing.				
11.	The use of predictive genetic testing in clinical and public health practice does not need to take into account the legal, ethical and social implications.				

12.	Predictive genetic testing can contribute positively towards health promotion and disease prevention which can assist in the launching of the National Health Insurance (NHI).				
13.	Guidelines from the department of Health is needed for the appropriate use of predictive genetic testing.				
14.	Predictive genetic tests increase prevention opportunities for chronic diseases.				
15.	Predictive genetic tests should only be introduced to clinical and public health practice only if it is proven to be cost-effective in South Africa.				
16.	I have had exposure to cancer genetic testing during my undergraduate training.				
17.	Genetic counsellors are needed for patients to consult with once they have their genetic test results.				
18.	Medical and health students require practical training on predictive genetic testing/genomic medicine.				

19. Is there a facility in KwaZulu-Natal that offers predictive genetic testing? If yes, please state which suburb it is located in.

_____

_____

20. On a scale from 1 – 5, how confident are you in your knowledge of genetics?

NOT CONFIDENT	1	
SLIGHTLY CONFIDENT	2	
SOMEWHAT CONFIDENT	3	
CONFIDENT	4	
VERY CONFIDENT	5	

APPENDIX D: INFORMATION LETTER

APPENDIX F

DUT DURBAN UNIVERSITY OF TECHNOLOGY — INSTITUTIONAL RESEARCH ETHICS COMMITTEE

Letter of Information for Participation in Research

Hello, welcome to my study and thank you for taking time to participate!

Title of the Research Study: Knowledge, attitudes and perceptions of medical practitioners, medical students and the general public towards genomic medicine in KwaZulu-Natal South Africa.

Principal Investigator/s/researcher:
Levani Naidoo, BTech: Environmental Health

Co-Investigator/s/supervisor/s:
Professor P. Reddy (Phd)
Professor Colleen Aldous (Phd)

Brief Introduction and Purpose of the Study:
Predictive genetic testing has been made available to individuals who have medical aid. However, it is important for those who decide to have these tests done to know how these tests can have an impact on their lives. Educating individuals on a way forward regarding genetic testing can only be done once the amount of knowledge, and their attitudes towards genetic testing is known. Therefore, the purpose of this study is to identify your attitude and knowledge towards predictive genetic testing.

Outline of the Procedures: It would be great if you could sign the informed consent that will be handed to you after reading this letter. Thereafter, you may fill out the questionnaire to the best of your ability. When you have completed it, you may hand it in to the individual who is collecting it.

Risks or Discomforts to the Participant: There will be no risks or any discomfort to the participant, as this is a survey being filled out.

Benefits: The results will be published and you, the participants can view it on the DUT repository. These results will also assist South Africans in which direction to steer in when it comes to predictive genetic testing.

Reason why the Participant May Be Withdrawn from the Study: Only if you, the participant chooses to withdraw from the study then you will not participate.

Remuneration: There is no remuneration for this study.

Costs of the Study: There are no costs involved to you, the participant in participating in this study

Confidentiality: The participants' name and surname will not be requested for. All information given by you, the participant will be used only for research purposes.

Research-related Injury: There will be no compensation in the event of a research injury.

Persons to Contact in the Event of Any Problems or Queries:

Please contact the researcher (tel no.031-322 1743), my supervisor (tel no.031-373 2696) or the Institutional Research Ethics Administrator on 031 373 2900. Complaints can be reported to the Director: Research and Postgraduate Support, Prof S Moyo on 031 373 2577

APPENDIX E: INFORMED CONSENT FORM

INFORMED CONSENT

Statement of Agreement to Participate in the Research Study: Knowledge, attitudes and perceptions of medical practitioners, medical students and the general public towards genomic medicine in KwaZulu-Natal South Africa

- I hereby confirm that I have been informed by the researcher, Levani Naidoo, about the nature, conduct, benefits and risks of this study - Research Ethics Clearance Number: 085/16,
- I have also received, read and understood the above written information (Participant Letter of Information) regarding the study.
- I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by the researcher.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.
- I understand that significant new findings developed during the course of this research which may relate to my participation will be made available to me.

Full Name of Participant	**Date**	**Time**	**Signature / Right Thumbprint**

I, Levani Naidoo herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

Levani Naidoo **Full Name of Researcher**	**Date**	**Signature**
Full Name of Witness (If applicable)	**Date**	**Signature**

Page 1 of 2

Full Name of Legal Guardian (If applicable) **Date** **Signature**

Please note the following:

Research details must be provided in a clear, simple and culturally appropriate manner and prospective participants should be helped to arrive at an informed decision by use of appropriate language (grade 10 level - use Flesch Reading Ease Scores on Microsoft Word), selecting of a non-threatening environment for interaction and the availability of peer counseling (Department of Health, 2004)

If the potential participant is unable to read/illiterate, then a right thumb print is required and an impartial witness, who is literate and knows the participant e.g. parent, sibling, friend, pastor, etc. should verify in writing, duly signed that informed verbal consent was obtained (Department of Health, 2004).

If anyone makes a mistake completing this document e.g. wrong date or spelling mistake a new document has to be completed. The incomplete original document has to be kept in the participant file and not thrown away and copies thereof must be issued to the participant.

References:

Department of Health: 2004. *Ethics in Health Research: Principles, Structures and Processes* http://www.doh.gov.za/docs/factsheets/guidelines/ethnics/

Department of Health. 2006. *South African Good Clinical Practice Guidelines*. 2nd Ed. Available at: http://www.nhrec.org.za/?page_id=14

APPENDIX F: CONFIDENTIALITY STATEMENT – FOCUS GROUP

IMPORTANT NOTICE:

THIS FORM IS TO BE READ AND FILLED IN BY EVERY MEMBER PARTICIPATING IN THE FOCUS GROUP, PRIOR TO THE FOCUS GROUP MEETING COMMENCING

CONFIDENTIALITY STATEMENT – FOCUS GROUP

DECLARATION

1. All information contained in the research documents and any information discussed during the focus group meeting will be kept private and confidential. This is specifically binding to any information that may identify any of the participants in the research process.

2. The returned questionnaires will be coded and kept anonymous in the research process.

3. None of the information from this focus group will be made public in terms of a journal publication, which will not identify the participants of this research in any way.

Once this form has been read and agreed to, please fill in the appropriate information in the table provided on the following page and sign to acknowledge the agreement.

Page **1** of **2**

Dear Focus Group member Please Complete:

Name:	Surname:	Signature:

Researcher's Name: _____ Signature: _____

Supervisor's Name: _____ Signature: _____

APPENDIX G: CODE OF CONDUCT – FOCUS GROUP

CODE OF CONDUCT

This form is required to be completed by every member of the Focus group prior to commencement of the focus group meeting.

As a member of this committee I agree to abide by the following conditions:

1. All information contained in the research documents and any information discussed during the focus group meeting will be kept confidential and private. This is specifically binding to any information that may identify any of the participants in the research process.

2. None of the information shall be communicated to any other individual or organisation outside of this specific focus group as to the decisions of this focus group.

3. The information from this focus group will be made public in terms of a journal publication, which will in no way identify any participants of this research

Member Represents	Member's Name	Signature	Contact Details

Page **1** of **1**

APPENDIX H: IREC RESEARCH APPROVAL

Institutional Research Ethics Committee
Faculty of Health Sciences
Room MS 49, Mansfield School Site
Gate 8, Ritson Campus
Durban University of Technology

P O Box 1334, Durban, South Africa, 4001

Tel: 031 373 2900
Fax: 031 373 2407
Email: lavishad@dut.ac.za
http://www.dut.ac.za/research/institutional_research_ethics

www.dut.ac.za

17 November 2016

IREC Reference Number: **REC 91/16**

Ms L Naidoo
P O Box 40235
Redhill
Durban
4071

Dear Ms Naidoo

Knowledge, attitudes and perceptions of Genomic Medicine among medical students, private medical practitioners and the general public in eThekwini, KwaZulu-Natal

The Institutional Research Ethics Committee acknowledges receipt of your notification regarding the piloting of your data collection tool.

Kindly ensure that participants used for the pilot study are not part of the main study.

In addition, the IREC acknowledges receipt of your gatekeeper permission letters.

Please note that FULL APPROVAL is granted to your research proposal. You may proceed with data collection.

Yours Sincerely,

Professor J K Adam
Chairperson: IREC

DUT DURBAN UNIVERSITY OF TECHNOLOGY
2016 -11- 17
INSITUTUTIONAL RESEARCH ETHICS COMMITTEE
P O BOX 1334 DURBAN 4000 SOUTH AFRICA

APPENDIX I: DEPARTMENT OF EDUCATION PERMISSION TO CONDUCT RESEARCH

education

Department:
Education
PROVINCE OF KWAZULU-NATAL

Enquiries: Phindile Duma Tel: 033 392 1004 Ref.:2/4/8/912

Miss L Naidoo
PO Box 1995
Pietermaritzburg
3200

Dear Miss Naidoo

PERMISSION TO CONDUCT RESEARCH IN THE KZN DoE INSTITUTIONS

Your application to conduct research entitled: **"KNOWLEDGE, ATTITUDES AND PERCEPTIONS OF GENOMIC MEDICINE AMONG MEDICAL STUDENTS, PRIVATE MEDICAL PRACTITIONERS AND THE GENERAL PUBLIC IN ETHEKWINI, KWAZULU-NATAL"**, in the KwaZulu-Natal Department of Education Institutions has been approved. The conditions of the approval are as follows:

1. The researcher will make all the arrangements concerning the research and interviews.
2. The researcher must ensure that Educator and learning programmes are not interrupted.
3. Interviews are not conducted during the time of writing examinations in schools.
4. Learners, Educators, Schools and Institutions are not identifiable in any way from the results of the research.
5. A copy of this letter is submitted to District Managers, Principals and Heads of Institutions where the Intended research and interviews are to be conducted.
6. The period of investigation is limited to the period from 23 September 2016 to 26 March 2018.
7. Your research and interviews will be limited to the schools you have proposed and approved by the Head of Department. Please note that Principals, Educators, Departmental Officials and Learners are under no obligation to participate or assist you in your investigation.
8. Should you wish to extend the period of your survey at the school(s), please contact Miss Connie Kehologile at the contact numbers below
9. Upon completion of the research, a brief summary of the findings, recommendations or a full report / dissertation / thesis must be submitted to the research office of the Department. Please address it to The Office of the HOD, Private Bag X9137, Pietermaritzburg, 3200.
10. Please note that your research and interviews will be limited to schools and institutions in KwaZulu-Natal Department of Education.

(Please see list of Schools attached)

Adv. MS Masuku
Acting Head of Department: Education
Date: 26 September 2016

...Championing Quality Education - Creating and Securing a Brighter Future

KWAZULU-NATAL DEPARTMENT OF EDUCATION
Postal Address: Private Bag X9137 • Pietermaritzburg • 3200 • Republic of South Africa
Physical Address: 247 Burger Street • Anton Lembede Building • Pietermaritzburg • 3201
Tel.: +27 33 392 1004/41 • **Fax.:** +27 033 392 1203• **Email:**
Facebook: KZNDOE....Twitter: @DBE_KZN....Instagram: kzn_education....Youtube:kzndoe
Web:www.kzneducation.gov.za

Application for Permission to Conduct Research in KwaZulu Natal Department of Education Institutions

1. Applicants Details

Title: Prof / Dr / Rev / Mr / Mrs / Miss / Ms Surname: NAIDOO

Name(s) Of Applicant(s): LEVANI Email: levnaidoo@gmail.com

Tel No: 031-5693472 Fax: Cell: 0605080896

Postal Address: P.O. Box 40235 REDHILL

DURBAN 4051

2. Proposed Research Title:

KNOWLEDGE, ATTITUDES AND PERCEPTIONS OF GENOMIC MEDICINE AMONG MEDICAL STUDENTS, PRIVATE MEDICAL PRACTITIONERS AND THE GENERAL PUBLIC IN eTHEKWINI, KWAZULU-NATAL

3. Have you applied for permission to conduct this research or any other research within the KZNDoE institutions?

Yes	No

If "yes", please state reference Number:

4. Is the proposed research part of a tertiary qualification?

~~Yes~~	No

If "yes"

Name of tertiary institution: DURBAN UNIVERSITY OF TECHNOLOGY

Faculty and or School: FACULTY OF HEALTH SCIENCES

Qualification: MHSc: ENVIRONMENTAL HEALTH

Name of Supervisor: PROF. P. REDDY **Supervisors Signature**

If "no", state purpose of research:

5. **Briefly state the Research Background** PUBLIC HEALTH GENOMICS IS A FIELD CONCERNED WITH THE EFFECTIVE TRANSLATION OF GENOME BASED KNOWLEDGE & TECHNOLOGIES FOR THE IMPROVEMENT OF HEALTH AMONG PEOPLE. IN SOUTH AFRICA, MEDICAL SCHEMES ARE INTRODUCING THE MEDICAL REPORTING OF GENES IN THE FORM OF PREDICTIVE GENETIC TESTING, TO IDENTIFY ONES' PREDISPOSITION TOWARDS CHRONIC DISEASES IN THE FUTURE. RESEARCH RESULTS OF KNOWLEDGE AND PERCEPTIONS OF PUBLIC HEALTH GENOMICS AMONG THE HEALTH FRATERNITY AND THE GENERAL PUBLIC ARE SIMILAR ABROAD. HOWEVER, IT CAN BE ASCERTAINED THAT NOT MUCH RESEARCH PERTAINING TO THE GENERAL PUBLIC IN LIGHT OF THIS TOPIC, HAS BEEN CONDUCTED SPECIFICALLY IN SOUTH AFRICA.

6. **What is the main research question(s) :**
TO DETERMINE AND DOCUMENT THE KNOWLEDGE, ATTITUDES AND PERCEPTIONS OF MEDICAL STUDENTS, PRIVATE MEDICAL PRACTITIONERS AND THE GENERAL PUBLIC (EDUCATORS) TOWARDS GENOMIC MEDICINE.

7. **Methodology including sampling procedures and the people to be included in the sample:**
A QUANTITATIVE STUDY CONSISTING OF 10 EDUCATORS FROM EACH OF THE FIVE SCHOOLS WILL BE GIVEN AN INFORMED CONSENT FORM, LETTER OF INFORMATION & QUESTIONNAIRE ONCE ARRANGEMENTS HAVE BEEN MADE WITH THE PRINCIPAL OF EACH SCHOOL, OF A DATE AND TIME MOST CONVENIENT WITHOUT DISTURBING THE NORMAL SCHOOL PROGRAMME. EDUCATORS MUST BE REGISTERED WITH SACE, HAVE MEDICAL AID, AND NOT BE TEACHING GRADE 12.

8. **What contribution will the proposed study make to the education, health, safety, welfare of the learners and to the education system as a whole?:**

UPDATE OF EDUCATORS REGARDING THE ADVANCING OF GENOMIC / GENETIC TECHNOLOGY, WHICH CAN THEN BE IMPARTED TO STUDENTS FOR AWARENESS AND EDUCATIONAL PURPOSES REGARDING THEIR HEALTH.

KZN Department of Education Schools or Institutions from which sample will be drawn – If the list is long please attach at the end of the form

1. COLUMBIA PRIMARY SCHOOL.		
2. DURBAN NORTH COLLEGE		
3. ZENZELINI PRIMARY SCHOOL		
4. AVOCA SECONDARY SCHOOL		
5. ORIENT ISLAMIC SCHOOL		

9. **Research data collection instruments**: *(Note: a list and only a brief description is required here - the actual instruments must be attached)*:

1. ONE QUESTIONNAIRE CONSISTING OF 4 PAGES TO IDENTIFY THE KNOWLEDGE, ATTITUDES AND PERCEPTIONS OF TEACHERS TOWARDS PREDICTIVE GENETIC TESTING.
2. INFORMED CONSENT FORM.
3. LETTER OF INFORMATION.

10. Procedure for obtaining consent of participants and where appropriate parents or guardians:

PARTICIPANTS WILL BE GIVEN AN INFORMED CONSENT FORM TO READ AND SIGN AS ACKNOWLEDGEMENT OF PARTICIPATION IF THEY ARE WILLING TO PARTICIPATE.

11. Procedure to maintain confidentiality (if applicable):

THE PARTICIPANTS' NAME AND SURNAME WILL NOT BE REQUESTED FOR ON THE SURVEY. ALL INFORMATION GIVEN BY THE PARTICIPANT WILL BE USED FOR RESEARCH PURPOSES ONLY.

12. Questions or issues with the potential to be intrusive, upsetting or incriminating to participants (if applicable): N/A.

13. Additional support available to participants in the event of disturbance resulting from intrusive questions or issues (if applicable): N/A.

14. Research Timelines : RESEARCH TO BE COMPLETED AND SUBMITTED BY THE YEAR 2017.

15. Declaration

I hereby agree to comply with the relevant ethical conduct to ensure that participants' privacy and the confidentiality of records and other critical information.

I LEVANI NAIDOO **declare that the above information is true and correct**

13/09/2016

Signature of Applicant **Date**

16. Agreement to provide and to grant the KwaZulu Natal Department of Education the right to publish a summary of the report.

I/We agree to provide the KwaZulu Natal Department of Education with a copy of any report or dissertation written on the basis of information gained through the research activities described in this application.

I/We grant the KwaZulu Natal Department of Education the right to publish an edited summary of this report or dissertation using the print or electronic media.

Signature of Applicant(s) **Date**

Return a completed form to:
PHILISWA NDLOVU
Office of the Head of Department; KwaZulu Natal Department of Education

Hand Delivered:
Anton Lembede Building; 247 Burger Street; PIETERMARITZBURG
Or
Ordinary Mail
Private Bag X9137; Pietermaritzburg; 3200
Or
Email

APPENDIX J: UKZN PERMISSION LETTER

APPENDIX P

DUT DURBAN UNIVERSITY OF TECHNOLOGY

Dear Registrar of UKZN

I am a student (20900135) from the Durban University of Technology currently pursuing Masters in Health Science: Environmental Health in the form of research and humbly request your assistance.

Rationale for study: South African insurers are introducing medical reporting of genes to patients for the provision of genomic information in the form of predictive genetic testing which can offer individualized risk assessment to mitigate chronic diseases among individuals. Research results of knowledge and perceptions of public health genomics among the health fraternity and the general public in different parts of the world are similar. However, it can be ascertained that not much research has been conducted pertaining to the knowledge and attitudes of the general public specifically to predictive genetic testing for chronic diseases, as much focus and emphasis has been placed on neonatal genetic testing. In studies pertaining to genetic testing for chronic diseases, the level of knowledge contrasts and perceptions are based on personal opinions and attitudes of individuals. To this end, perceptions, attitudes and knowledge regarding PHG, specifically predictive genetic testing for chronic diseases among the general public has not been investigated specifically in South Africa.

Title of Research: Knowledge, attitudes and perceptions of Genomic Medicine among medical students, private medical practitioners and the general public in eThekwini, KwaZulu-Natal.

Aims/Purpose of study: To determine and document the knowledge, attitudes and perceptions of medical students, private medical practitioners and the general public towards genomic medicine.

For the attainment of knowledge, attitudes and perceptions of medical students, I require authorisation and access to carry out research in the form of a validated questionnaire to 25 second year and 25 fifth year medical students at UKZN. I will briefly discuss the research and thereafter a letter of information, informed consents and the questionnaires will be handed out for willing students to participate. The questionnaire will take approximately 15 minutes to complete followed by collection of respective documents.

Students will not be required to disclose their identity on the questionnaires. All data collected will be treated confidentially and utilised for research purposes only. Participants will remain anonymous in the research.

I have received an acknowledgment of receipt of application for ethical approval (Reference number: REC 91/16 assigned to my proposal) and my proposal is currently in the process of undergoing ethical approval.

Should you have any queries or require more information please feel free to contact myself or my supervisor Professor P. Reddy.

Thanking you sincerely

.....

Researcher: Levani Naidoo

(060-508 0896)

.....

Supervisor: Professor P. Reddy

(031-373 2808

APPENDIX K: UKZN ACKNOWLEDGEMENT LETTER

UNIVERSITY OF
KWAZULU-NATAL
INYUVESI
YAKWAZULU-NATALI

RESEARCH OFFICE
BIOMEDICAL RESEARCH ETHICS ADMINISTRATION
Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 260-4609
Email: BREC@ukzn.ac.z
Website:

10 November 2016

Ms Levani Naidoo (20900135)
Durban University of Technology
Department of Community Health Studies

Dear Ms Naidoo

Re: Request for Reciprocity (IREC085/16)
Study Title: "Knowledge, attitudes and perceptions of Genomic Medicine among medical students, private medical practitioners and the general public in eThekwini, KwaZulu-Natal"

I wish to advise that your letter dated 01 November 2016 to the Chair of the Biomedical Research Ethics Committee (BREC) requesting reciprocity for the above study refers.

The chair has granted reciprocity to the Durban University of Technology's ethics approval (Ethics Ref# IREC085/16). The permission letter from the Registrar of the University of KwaZulu-Natal has been noted by BREC.

This approval will be noted at the next Biomedical Research Ethics Committee meeting to be held on 13 December 2016.

Yours sincerely

PROFESSOR JOYCE TSOKA-GWEGWENI
Chair: Biomedical Research Ethics Committee

c: Prof P Reddy: supervisor (PoovieR@dut.ac.za)
Prof C Aldous: co-supervisor (Aldousc@ukzn.ac.za)

APPENDIX L: EDITING CERTIFICATE

DR RICHARD STEELE
BA, HDE, MTech(Hom)
HOMEOPATH
Registration No. A07309 HM
Practice No. 0807524
Freelance academic editor
Associate member: Professional Editors' Guild, South Africa

110 Cato Road
Glenwood, Durban 4001
031-201-6508/082-928-6208
Fax 031-201-4989
Postal: P.O. Box 30043, Mayville 4058
Email: rsteele@vodamail.co.za

EDITING CERTIFICATE

Re: **Levani Naidoo**
Master's dissertation: **Knowledge, attitudes and perceptions of Genomic Medicine among medical students, private medical practitioners and the general public in eThekwini, KwaZulu-Natal**

I confirm that I have edited this dissertation and the references for clarity, language and layout. I returned the document to the author with track changes so correct implementation of the changes and clarifications requested in the text and references is the responsibility of the author. I am a freelance editor specialising in proofreading and editing academic documents. My original tertiary degree which I obtained at the University of Cape Town was a B.A. with English as a major and I went on to complete an H.D.E. (P.G.) Sec. with English as my teaching subject. I obtained a distinction for my M.Tech. dissertation in the Department of Homeopathy at Technikon Natal in 1999 (now the Durban University of Technology). During my 13 years as a part-time lecturer in the Department of Homoeopathy at the Durban University of Technology I supervised numerous Master's degree dissertations.

Dr Richard Steele
20 July 2019
per email

APPENDIX M: BIVARIATE CORRELATIONS FOR GENERAL PUBLIC

	Genetic testing can be used to prevent diseases such as diabetes, cancer.	Genetic testing can be used to prevent HIV, AIDS, T.B.	Genetic testing can be used to determine future susceptibility to certain diseases.	I know what to do after I get my genetic test results back.	Genetic testing is being offered in South Africa.	I know where to have a genetic test done in KwaZulu-Natal.	Having a genetic test is valid and accurate.	There are few ethical guidelines for human genetic tests in South Africa and these guidelines protect us.	There are no laws in South Africa for the protection of personal genetic information.	Genetic testing can be used to also find genetic conditions and treat them.	Genetic testing is useful in helping to use the right medication for treatment.	Genetic testing will not be too expensive to use.	I would like to find out if I am at risk for any chronic disease.	I will not be worried about what my genetic test results will be like if I had to have a test done.	I feel genetic testing has more benefits than disadvantages.	I am not concerned about my genetic data being used for further studies without my consent.	I would like for my genetic data to be used in scientific research.
Genetic testing can be used to determine future susceptibility to certain diseases.	.429*	0.058	1.000														
I know what to do after I get my genetic test results back.	-0.226	-0.159	-.309*	1.000													
	0.119	0.298	0.044														
	45	45	45	45													
Genetic testing is being offered in South Africa.	0.013	-0.031	0.126	-.418**	1.000												
	0.934	0.840	0.375	0.005													
	45	45	45	44	45												
I know where to have a genetic test done in KwaZulu-Natal.	-0.079	0.114	-0.091	-.335*	.466**	1.000											
	0.624	0.457	0.550	0.028	0.002												
	45	45	45	44	44	45											
Having a genetic test is valid and accurate.	.306*	0.127	.345*	-0.279	0.055	0.140	1.000										
	0.044	0.412	0.022	0.070	0.725	0.359											
	44	44	44	43	43	43	44										
There are few ethical guidelines for human genetic tests in South Africa and these guidelines protect us.	0.206	0.074	0.268	-0.149	0.007	-0.046	.308*	1.000									
	0.179	0.631	0.082	0.340	0.967	0.769	0.010										
	44	44	44	43	43	43	43	44									
There are no laws in South Africa for the protection of personal genetic information.	0.096	-0.106	-0.021	-0.047	0.263	-0.150	0.173	.669**	1.000								
	0.539	0.497	0.896	0.768	0.070	0.406	0.273	0.000									
	43	43	43	42	42	43	42	43	43								
Genetic testing can be used to also find genetic conditions and treat them.	.382*	-0.249	.380*	-0.015	0.087	-0.150	.440**	.400**	.497**	1.000							
	0.010	0.099	0.010	0.918	0.574	0.400	0.003	0.008	0.002								
	45	45	45	44	44	44	44	44	43	45							
Genetic testing is useful in helping to use the right medication for treatment.	.382*	-0.040	0.188	0.123	-0.087	-0.215	.460**	.464**	.372*	.357*	1.000						
	0.044	0.795	0.221	0.427	0.573	0.162	0.007	0.002	0.014	0.000							
	45	45	45	44	44	44	44	44	43	45	45						
Genetic testing is an important topic for the community to know about.	0.193	0.063	0.247	0.073	-0.097	-0.122	.318*	0.247	0.087	.307*	.357*						
	0.204	0.681	0.101	0.637	0.522	0.431	0.035	0.106	0.578	0.040	0.016						
	45	45	45	44	44	44	44	44	43	45	45						
Genetic testing will not be too expensive to use.	-0.048	0.016	-0.034	0.060	0.035	-0.106	-0.124	0.254	0.178	0.098	0.205	1.000					
	0.773	0.918	0.828	0.564	0.579	0.498	0.433	0.105	0.256	0.531	0.187						
	43	43	43	42	42	43	42	42	42	43	43	43					
I would like to find out if I am at risk for any chronic disease.	0.157	0.184	0.237	-0.019	-0.114	-.410**	0.192	.307*	0.258	.338*	.429**	.338*	1.000				
	0.303	0.228	0.172	0.904	0.459	0.006	0.213	0.014	0.130	0.023	0.003	0.027					
	45	45	45	44	44	44	44	44	43	45	45	43	45				
I will not be worried about what my genetic test results will be like if I had to have a test done.	-0.043	-0.004	0.188	-0.009	0.254	0.104	0.110	-0.019	-0.024	0.214	0.213	0.108	0.266	1.000			
	0.780	0.981	0.220	0.954	0.100	0.505	0.483	0.906	0.879	0.165	0.165	0.504	0.081				
	44	44	44	43	43	43	43	43	42	44	44	42	44	44			
If my genetic test result is positive for a disease, it will not cause me to be stressed.	0.095	-.386**	0.110	0.269	0.091	-0.257	-0.257	-0.142	0.091	0.269	0.205	0.144	-0.018	0.093			
	0.573	0.007	0.468	0.100	0.556	0.092	0.093	0.358	0.606	0.057	0.174	0.356	0.906	0.550			
	45	45	45	44	44	44	44	44	43	45	45	43	45	44			
I feel genetic testing has more benefits than disadvantages.	.307*	-0.055	0.190	-0.225	-0.077	-.365*	.368*	.378*	0.260	0.239	0.202	.368*	.452**	-0.215	1.000		
	0.040	0.720	0.211	0.142	0.619	0.019	0.021	0.012	0.089	0.115	0.051	0.016	0.004	0.025			
	45	45	45	44	44	44	44	44	43	45	45	43	45	44	45		
I am not concerned about my genetic data being used for further studies without my consent.	0.005	.464**	0.091	0.155	-0.120	0.015	0.036	-0.199	-0.188	0.052	0.214	-0.092	0.123	.378*	-0.077	1.000	
	0.976	0.006	0.738	0.315	0.217	0.923	0.815	0.196	0.228	0.734	0.150	0.554	0.423	0.011	0.614		
	45	45	45	44	44	44	44	44	43	45	45	43	45	44	45	45	
I would like for my genetic data to be used in scientific research.	0.205	0.000	0.185	-0.044	-0.236	-0.151	.396**	0.252	0.160	0.276	0.205	0.116	0.244	-0.277	.508**	-0.124	1.000
	0.181	0.949	0.228	0.781	0.127	0.302	0.009	0.098	0.305	0.069	0.185	0.463	0.110	0.072	0.000	0.423	
	44	44	44	43	43	43	43	44	43	44	44	42	44	43	44	44	44
I would like to learn more about genetic testing.	0.204	-0.038	0.048	-0.036	-0.047	-0.068	0.256	0.232	0.155	.478**	.477**	0.269	.485**	0.249	.522**	0.237	0.276
	0.185	0.807	0.757	0.821	0.763	0.657	0.099	0.130	0.320	0.001	0.001	0.084	0.002	0.107	0.000	0.121	0.068
	44	44	44	43	43	43	43	44	43	44	44	42	44	43	44	44	44
I will not be discriminated against if my genetic test results are positive.	-.307*	0.055	-0.221	0.200	0.016	-0.052	-.486**	-.646**	-.382*	-.366*	-.330*	0.158	-0.170	0.060	-.308*	.322*	-.370*
	0.047	0.721	0.149	0.059	0.920	0.736	0.001	0.000	0.021	0.016	0.029	0.309	0.271	0.702	0.046	0.030	0.013
	44	44	44	43	43	43	43	44	43	44	44	42	44	43	44	44	44

APPENDIX N: BIVARIATE CORRELATIONS FOR MEDICAL PRACTITIONERS

Correlations

		Performing genetics should be associated with genetic testing	Genetic testing can be used to identify a patient's susceptibility towards a genetic disorder and NCD	The clinical use of a predictive genetic test is to improve the health status of the patient	Exposure to various factors such as socioeconomic status, lifestyle and environment can influence a patient's risk of disease due to their predisposition	There are not many ethical guidelines in South Africa which govern the use of predictive genetic testing among patients	Predictive genetic tests are valid and reliable as long as a specific genetic characteristic is identified accurately in the laboratory	There are not many laws in place in SA which protects the patients personal genetic information	Predictive genetic testing is being offered to individuals in SA	I have had exposure to cancer genetic testing during my undergraduate training	Genetic counsellors are needed for patients to consult with once they have their genetic test results	The use of predictive genetic testing in clinical and public health practice does not need to take into account the legal, ethical and social implications	Predictive genetic testing can contribute positively towards health promotion and disease prevention which can assist in the launch of the NHI	Guidelines from the DOH is needed for the appropriate use of predictive genetic testing	Predictive genetic tests increase prevention opportunities for chronic diseases	I will use predictive genetic testing in diagnosis and treatment of patients	I have started using predictive genetic testing for diagnosis and treatment of patients	Predictive genetic tests should only be introduced to clinical and public health practice only if it is proven to be cost-effective in SA	Medical and health practitioners require training on predictive genetic testing/genomic medicine
Performing genetics should be associated with genetic testing	Correlation C	1.000																	
	Sig. (2-tailed)																		
	N	45																	
Genetic testing can be used to identify a patient's susceptibility towards a genetic disorder and NCD	Correlation C	.538**	1.000																
	Sig. (2-tailed)	0.000																	
	N	44	44																
The clinical use of a predictive genetic test is to improve the health status of the patient	Correlation C	.538**	.695**	1.000															
	Sig. (2-tailed)	0.000	0.000																
	N	45	44	45															
Exposure to various factors such as socioeconomic status, lifestyle and environment can influence a patient's risk of disease due to their predisposition	Correlation C	.346*	.469**	.443**	1.000														
	Sig. (2-tailed)	0.020	0.001	0.002															
	N	45	44	45	45														
There are not many ethical guidelines in South Africa which govern the use of predictive genetic testing among patients	Correlation C	-0.131	0.011	0.038	0.254	1.000													
	Sig. (2-tailed)	0.397	0.943	0.808	0.097														
	N	44	44	44	44	44													
Predictive genetic tests are valid and reliable as long as a specific genetic characteristic is identified accurately in the laboratory	Correlation C	.308*	0.279	.448**	.403**	.304*	1.000												
	Sig. (2-tailed)	0.045	0.067	0.002	0.007	0.045													
	N	44	44	44	44	44	44												
There are not many laws in place in SA which protects the patients personal genetic information	Correlation C	0.110	0.255	0.094	.352*	.391**	0.259	1.000											
	Sig. (2-tailed)	0.479	0.098	0.545	0.010	0.010	0.093												
	N	44	43	44	44	43	43	44											
Predictive genetic testing is being offered to individuals in SA	Correlation C	0.016	0.037	0.092	0.190	.401**	0.255	.458**	1.000										
	Sig. (2-tailed)	0.920	0.816	0.558	0.197	0.008	0.094	0.002											
	N	44	43	44	44	43	43	43	44										
I have had exposure to cancer genetic testing during my undergraduate training	Correlation C	-0.012	-0.104	-0.200	0.002	0.030	-0.268	0.220	0.157	1.000									
	Sig. (2-tailed)	0.942	0.514	0.195	0.791	0.839	0.088	0.160	0.305										
	N	43	42	43	43	43	43	43	43	43									
Genetic counsellors are needed for patients to consult with once they have their genetic test results	Correlation C	.502**	0.255	.315*	0.268	-0.102	0.147	-0.139	-0.088	-0.097	1.000								
	Sig. (2-tailed)	0.000	0.052	0.033	0.167	0.511	0.341	0.400	0.570	0.537									
	N	45	44	45	45	44	44	44	44	43	45								
The use of predictive genetic testing in clinical and public health practice does not need to take into account the legal, ethical and social implications	Correlation C	0.167	0.267	0.238	0.281	-0.271	-0.287	-0.050	-0.151	-0.184	0.158	1.000							
	Sig. (2-tailed)	0.279	0.083	0.120	0.062	0.078	0.062	0.748	0.214	0.238	0.311								
	N	44	43	44	44	43	43	43	44	43	44	44							
Predictive genetic testing can contribute positively towards health promotion and disease prevention which can assist in the launch of the NHI	Correlation C	.338*	.459**	.503**	0.259	0.111	0.068	-0.028	0.056	-0.089	.590**	.466**	1.000						
	Sig. (2-tailed)	0.025	0.003	0.000	0.141	0.479	0.675	0.858	0.720	0.572	0.000	0.002							
	N	44	43	44	44	43	43	43	44	43	44	44	44						
Guidelines from the DOH is needed for the appropriate use of predictive genetic testing	Correlation C	.538**	.535**	.456**	.322*	-0.137	.314*	0.101	0.069	-0.219	.617**	.338*	.556**	1.000					
	Sig. (2-tailed)	0.000	0.000	0.002	0.033	0.418	0.040	0.518	0.655	0.158	0.000	0.025	0.000						
	N	44	43	44	44	43	43	43	44	43	44	44	44	44					
Predictive genetic tests increase prevention opportunities for chronic diseases	Correlation C	.435**	.529**	.514**	.384**	0.050	0.222	.352*	0.294	-0.248	.396**	.335*	.528**	.745**	1.000				
	Sig. (2-tailed)	0.001	0.000	0.000	0.009	0.751	0.135	0.021	0.052	0.109	0.008	0.044	0.000	0.000					
	N	44	43	44	44	43	43	43	44	43	44	44	44	44	44				
I will use predictive genetic testing in diagnosis and treatment of patients	Correlation C	.440**	.350*	.501**	0.280	-0.062	.305*	-0.234	0.037	-0.244	.332*	.306*	.352*	.533**	.347*	1.000			
	Sig. (2-tailed)	0.003	0.021	0.001	0.066	0.693	0.047	0.153	0.812	0.128	0.029	0.045	0.021	0.000	0.023				
	N	43	43	43	43	43	43	43	43	43	43	43	43	43	43	43			
I have started using predictive genetic testing for diagnosis and treatment of patients	Correlation C	-0.053	-0.021	0.115	-0.020	0.074	0.041	0.100	.469**	0.115	-.491**	-0.074	-0.066	-0.175	0.115	0.150	1.000		
	Sig. (2-tailed)	0.658	0.900	0.481	0.900	0.656	0.804	0.529	0.007	0.469	0.004	0.648	0.687	0.260	0.479	0.372			
	N	40	39	40	40	39	39	39	40	40	40	40	40	40	40	39	40		
Predictive genetic tests should only be introduced to clinical and public health practice only if it is proven to be cost-effective in SA	Correlation C	0.077	0.018	0.197	0.053	0.121	0.107	0.227	0.149	0.000	-0.110	-0.204	-0.040	0.015	0.153	0.003	0.304	1.000	
	Sig. (2-tailed)	0.625	0.905	0.235	0.736	0.446	0.499	0.150	0.347	0.998	0.491	0.051	0.797	0.912	0.220	0.986	0.059		
	N	43	42	43	43	42	43	43	42	41	43	42	42	42	42	41	38	43	
Medical and health practitioners require training on predictive genetic testing/genomic medicine	Correlation C	.425**	.505**	.312*	0.157	-0.121	0.043	0.161	-0.041	-0.180	.525**	0.288	.487**	.416**	.535**	0.175	-0.070	0.223	1.000
	Sig. (2-tailed)	0.004	0.000	0.037	0.318	0.433	0.779	0.295	0.789	0.522	0.000	0.173	0.000	0.005	0.000	0.282	0.670	0.566	
	N	45	44	45	45	44	44	44	44	43	45	44	44	44	44	43	40	43	45

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

APPENDIX O: BIVARIATE CORRELATIONS FOR MEDICAL STUDENTS

Correlations

		Performing genetic tests should be associated with genetic counselling	Genetic testing can be used to identify a patients' susceptibility towards a genetic disorder and a non-communicable disease	The clinical use of a predictive genetic test is to ultimately improve the health status of the patient	Exposure to various factors such as socioeconomic status, lifestyle and environment can influence a patients risk of disease due to their genetic predisposition	There are ethical guidelines in South Africa which govern the use of predictive genetic testing among patients	Predictive genetic tests are valid and reliable as long as a specific genetic characteristic is identified accurately in the laboratory	There are laws in place in South Africa which protects the patients' personal genetic information	Predictive genetic testing is being offered to individuals in South Africa	The use of predictive genetic testing in clinical and public health practice does not need to take into account the legal, ethical and social implications	Predictive genetic testing can contribute positively towards health promotion and disease prevention which can assist in the launch of NHI	Predictive genetic tests increase prevention opportunities for chronic diseases	I have had exposure to cancer genetic testing during my undergraduate training	Genetic counsellors are needed for patients to consult with once they have their genetic test results	I will use predictive genetic testing in diagnosis and treatment of patients when I qualify as a medical practitioner	The curriculum should be extended to capacitate the medical students regarding predictive genetic testing	Guidelines from the department of health is needed for the appropriate use of predictive genetic testing	Predictive genetic tests should only be introduced to clinical and public health practice only if it is proven to be cost effective in South Africa	Medical and health students require practical training on predictive genetic testing/genomic medicine
Spearman's																			
Performing genetic tests should be associated with genetic counselling	Correlation	1.000																	
	Sig. (2-tailed)																		
	N	79																	
Genetic testing can be used to identify a patients' susceptibility towards a genetic disorder and a non-communicable disease	Correlation	0.188	1.000																
	Sig. (2-tailed	0.097																	
	N	79	79																
The clinical use of a predictive genetic test is to ultimately improve the health status of the patient	Correlation	0.131	.272*	1.000															
	Sig. (2-tailed	0.251	0.015																
	N	79	79	79															
Exposure to various factors such as socioeconomic status, lifestyle and environment can influence a patients risk of disease due to their genetic	Correlation	0.057	0.188	.356**	1.000														
	Sig. (2-tailed	0.623	0.148	0.001															
	N	77	77	77	77														
There are ethical guidelines in South Africa which govern the use of predictive genetic testing among patients	Correlation	0.089	0.158	.334**	0.228	1.000													
	Sig. (2-tailed	0.441	0.170	0.003	0.051														
	N	77	77	77	75	77													
Predictive genetic tests are valid and reliable as long as a specific genetic characteristic is identified accurately in the laboratory	Correlation	.276*	.245*	.255*	0.167	0.124	1.000												
	Sig. (2-tailed	0.014	0.032	0.025	0.149	0.284													
	N	78	78	78	76	76	78												
There are laws in place in South Africa which protects the patients' personal genetic information	Correlation	0.008	.229*	.447**	.329**	.385**	.238*	1.000											
	Sig. (2-tailed	0.959	0.050	0.000	0.005	0.001	0.040												
	N	78	78	78	74	75	75	78											
Predictive genetic testing is being offered to individuals in South Africa	Correlation	.290*	0.196	0.176	0.182	0.125	.329**	0.018	1.000										
	Sig. (2-tailed	0.011	0.089	0.128	0.122	0.286	0.004	0.878											
	N	78	78	78	74	75	75	74	78										
The use of predictive genetic testing in clinical and public health practice does not need to take into account the legal, ethical and social implications	Correlation	0.110	-0.047	-0.069	-0.090	0.008	0.026	-0.035	0.223	1.000									
	Sig. (2-tailed	0.336	0.684	0.549	0.505	0.948	0.810	0.765	0.053										
	N	78	78	78	76	77	77	78	78	78									
Predictive genetic testing can contribute positively towards health promotion and disease prevention which can assist in the launch of NHI	Correlation	0.108	.267*	.318**	.471**	.247*	.404**	.377**	0.043	-0.137	1.000								
	Sig. (2-tailed	0.352	0.010	0.004	0.000	0.030	0.000	0.001	0.711	0.233									
	N	79	79	79	77	77	78	78	78	78	79								
Predictive genetic tests increase prevention opportunities for chronic diseases	Correlation	0.130	.426**	0.112	0.198	0.120	.364**	0.099	.286*	-0.075	.382**	1.000							
	Sig. (2-tailed	0.254	0.000	0.334	0.087	0.300	0.001	0.396	0.009	0.517	0.001								
	N	79	79	79	77	77	78	78	78	78	79	79							
I have had exposure to cancer genetic testing during my undergraduate training	Correlation	0.107	-0.022	-0.080	-0.135	-0.216	0.037	-0.108	0.048	.228*	-0.193	-0.158	1.000						
	Sig. (2-tailed	0.352	0.847	0.487	0.245	0.061	0.613	0.355	0.680	0.045	0.091	0.168							
	N	78	78	78	76	76	77	75	75	77	78	78	78						
Genetic counsellors are needed for patients to consult with once they have their genetic test results	Correlation	0.108	.260*	0.121	0.087	0.177	.352**	.427**	0.201	-0.203	.346**	0.204	-.269*	1.000					
	Sig. (2-tailed	0.346	0.012	0.292	0.566	0.125	0.021	0.000	0.438	0.076	0.002	0.073	0.018						
	N	78	78	78	76	76	77	75	75	77	78	78	78	78					
I will use predictive genetic testing in diagnosis and treatment of patients when I qualify as a medical practitioner	Correlation	0.147	.313**	.250*	.288*	.258*	.340**	.251*	.516**	0.116	.352**	0.220	-0.128	.238*	1.000				
	Sig. (2-tailed	0.199	0.005	0.028	0.012	0.024	0.002	0.030	0.000	0.314	0.002	0.052	0.274	0.037					
	N	78	78	78	76	76	77	75	75	77	78	78	77	77	78				
The curriculum should be extended to capacitate the medical students regarding predictive genetic testing	Correlation	0.158	0.184	0.200	.288*	.254*	.384**	0.132	0.218	-0.140	.370**	.288*	-0.098	.320**	.414**	1.000			
	Sig. (2-tailed	0.149	0.105	0.077	0.008	0.035	0.000	0.257	0.058	0.231	0.001	0.010	0.569	0.004	0.000				
	N	79	79	79	77	77	78	78	78	78	79	79	78	78	78	79			
Guidelines from the department of health is needed for the appropriate use of predictive genetic testing	Correlation	-0.001	0.126	0.175	.327**	.255*	.314**	.322**	.323**	-0.058	.380**	.404**	-.354**	0.196	.349**	.222*	1.000		
	Sig. (2-tailed	0.995	0.270	0.124	0.004	0.025	0.005	0.005	0.004	0.569	0.000	0.000	0.001	0.088	0.029	0.049			
	N	79	79	79	77	77	78	78	78	78	79	79	78	78	78	79	79		
Predictive genetic tests should only be introduced to clinical and public health practice only if it is proven to be cost effective in South Africa	Correlation	0.103	-0.065	-0.089	0.073	0.035	0.184	0.063	0.079	0.039	0.101	0.069	0.070	0.183	.236*	.245*	-0.098	1.000	
	Sig. (2-tailed	0.368	0.569	0.437	0.529	0.762	0.107	0.589	0.496	0.736	0.377	0.545	0.541	0.110	0.037	0.030	0.391		
	N	79	79	79	77	77	78	78	78	78	79	79	78	78	78	79	79	79	
Medical and health students require practical training on predictive genetic testing/genomic medicine	Correlation	0.110	0.122	.318**	0.095	0.156	.225*	.323**	0.115	-0.119	.309**	.308**	-.302**	.234*	.281*	.456**	.462**	0.093	1.000
	Sig. (2-tailed	0.134	0.284	0.004	0.413	0.175	0.048	0.004	0.320	0.301	0.006	0.007	0.007	0.039	0.001	0.000	0.000	0.405	
	N	79	79	79	77	77	78	78	78	78	79	79	78	78	78	79	79	79	79

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).